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# Understanding patients' experiences of the wish to hasten death: an updated and expanded systematic review and meta-ethnography

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## Title page

**Title:** Understanding patients' experiences of the wish to hasten death: an updated and expanded systematic review and meta-ethnography

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## Abstract

**Objectives**: Patients with advanced disease sometimes express a wish to hasten death (WTHD). In 2012 we published a systematic review and meta-ethnography of qualitative studies examining the experience and meaning of this phenomenon. Since then, new studies eligible for inclusion have been reported, including in Europe, a region not previously featured, and specifically in countries with different legal frameworks for euthanasia and assisted suicide. The aim of the present study was to update our previous review by including new research and to conduct a new analysis of available data on this topic.

**Setting**: Eligible studies originated from Australia, Canada, China, Germany, The Netherlands, Switzerland, Thailand, and USA.

**Participants**: Studies of patients with life-threatening conditions that had expressed the WTHD.

**Design**: The search strategy combined subject terms with free-text searching of PubMed MEDLINE, Web of Science, CINAHL and PsycInfo. The qualitative synthesis followed the methodology described by Noblit and Hare, using the “adding to and revising the original” model for updating a meta-ethnography, proposed by France et al. Quality assessment was done using the Critical Appraisal Skills Programme checklist.

**Results**: 14 studies involving 255 participants with life-threatening illnesses were identified. Five themes emerged from the analysis: suffering (overarching theme), reasons for and meanings and functions of the WTHD, and the experience of a timeline towards dying and death. In the context of advanced disease, the WTHD emerges as a reaction to physical, psychological, social and existential suffering, all of which impacts on the patient’s sense of self, of dignity and meaning in life.

**Conclusions**: The WTHD can hold different meanings for each individual; serving functions other than to communicate a genuine wish to die. Understanding the reasons for, and meanings and functions of, the WTHD is crucial for drawing up and implementing care plans to meet the needs of individual patients.

## Strengths and limitations of this study

- This updated review and synthesis of the published literature on the WTHD has brought a more detailed understanding of the phenomenon.
- Fourteen studies were identified, including 255 participants.
- Included studies originate from Australia, Canada, China, Germany, Switzerland, Thailand, The Netherlands and the USA.
- The study exemplifies a new approach to the updating of syntheses of qualitative research.
- The research objectives of some studies only touched indirectly upon the phenomenon.
- Not having access to the original interviews limits the available data.

# Understanding patients' experiences of the wish to hasten death: an updated and expanded systematic review and meta-ethnography

## INTRODUCTION

Few issues in modern society generate as much controversy as euthanasia, and assisted suicide (EAS) among people facing an advanced illness. Across the world, opinions, and attitudes towards this issue differ widely. Debate, however, often centres around the implications for society or the existing legal framework. What is often overlooked is the common thread that links all those persons who contemplate ending their life: the desire to die or to hasten their death. Why do some patients with advanced disease wish to hasten their death? What meaning does this wish hold for them? What is the experience of a person who feels such a wish? To what extent do commonalities exist among those who come to feel this wish?

Although the desire to die has traditionally been seen to result from physical suffering, research suggests that this explanation is reductionist (1), and that such a wish must be understood in the context of patient experience. Thus, while cross-sectional studies offer valuable information about what may trigger a wish to hasten death (WTHD), the fluctuating, ambivalent, subjective, and complex nature of such wishes requires a more detailed examination of patients' experiences.

Several qualitative studies have explored the WTHD in patients with advanced disease highlighting the important role played by psychosocial, and existential/spiritual factors, alongside physical symptoms (2,3). Thus, factors such as loss of self, loss of the sense of dignity, loss of autonomy, fear about the future, fear of suffering, and fear of being a burden to others are reported among the main triggers of a WTHD.

Interpretative analysis of the WTHD suggests that, in addition to these potential motivations, attention must focus on the meanings, functions, and intentions that underlie the expression of a WTHD. Thus, if we are to understand what patients actually mean when they say that they ‘no longer wish to live in this way’ we must explore their personal history, attitudes, beliefs, and thoughts. Furthermore, it is important not to confuse, for example, a wish to die in someone who is not considering actually hastening his/her death with a will to die in someone who takes action towards dying (4).

In 2012 our group published a systematic review, and interpretative synthesis (5) of then-published qualitative studies of the WTHD in seeking to understand the experience of patients with serious or incurable illness who expressed such a wish. The synthesis included studies conducted in Canada (1,6), Australia (2), China (7), and the USA (8). At that time, however, no such studies were identified from European countries.

Five years on, the subsequent publication of qualitative studies of the WTHD, among similar patient groups, and in different contexts to those featured in our earlier synthesis, justifies the need for an updated systematic review. In addition, the possibility of including studies from European countries in which EAS have been decriminalised (4,9–11) enables us to explore the extent to which different legal contexts influence the expression of a WTHD. The aim of the present study was therefore to provide an updated review of knowledge regarding the WTHD in patients with advanced disease or life-threatening illness, taking into account possible contextual differences.

# METHODS

This systematic review, and interpretative synthesis updates our previous synthesis (5) that included studies from 2001 to January 2010. In seeking to incorporate recent research within the synthesis, we extended our bibliographic search to cover the period from December 2000 to January 2016. The update employs Noblit and Hare's (12) meta-ethnography method, the aim of which is "to compare, re-interpret, and synthesise the findings (i.e. authors' concepts, and themes) of separate qualitative studies to arrive at an exhaustive description of the range, nature, and variety of patients' experiences" (13). This method was chosen given its widespread use in health-related research (14).

France et al. (15) propose various models for updating meta-ethnographies, using the analogy of house-building. This review applies the model they refer to as 'extending and renovating the original house' (i.e. adding to and revising an existing meta-ethnography). France et al. (15) outline potential advantages of using this model: the output forms a single coherent model or set of findings, rather than two, increasing its potential usefulness; it can lead to new conceptual insights; and it allows for innovation within the updated analysis/synthesis, while making efficient use of resources expended on the original meta-ethnography.

## Data sources and search strategy

In seeking recent clinical evidence about the WTHD we revised our original search strategy to optimise the trade-off between sensitivity, and specificity (see Table-S1). Relevant MeSH, and free-text terms were identified, and combined. The strategy was run in PubMed, CINAHL, Web of Science, and PsycINFO with the terminology being adapted to each database.

A filter for qualitative studies was used in PubMed (16), CINAHL (17), and PsycINFO (18). The qualitative PubMed filter was adapted to the specific language used by Web of Science.

### Inclusion and exclusion criteria

To be included, papers had to report primary qualitative studies (i.e. studies using recognised methods of both qualitative data collection, and qualitative data analysis) written in English, and focusing on the expression of the WTHD in patients with life-threatening conditions. Paediatric populations were excluded, as were studies focusing on older populations in the absence of advanced disease.

One researcher carried out the systematic literature search, which was verified by another researcher. Screening involved selection of retrieved citations by title, abstract, and full text. The entire sample was double-reviewed. Disagreements were resolved by discussion within the research team. Figure 1 shows the PRISMA flowchart for the selection of studies.

**Figure 1**. PRISMA flow diagram for study selection.

### Critical appraisal

Included studies were assessed for methodological quality, and rigour using Critical Appraisal Skills Programme (CASP) guidelines for qualitative studies (19) (Table-S2). No studies were excluded from this review based on their quality.

### Data analysis and synthesis

The synthesis followed the seven steps proposed by Noblit and Hare (12).

Supplementary Table-S3 juxtaposes the steps from the previous, and the updated meta-ethnography, and supplementary Table-S4 shows the comparison of yield between the original review, and the updated review. Atlas.ti 7 software was used to code, and memo significant statements to facilitate comparison of the themes, and categories obtained by each researcher.

## RESULTS

Fourteen articles were included in the updated meta-ethnography [seven from the original synthesis (2001-January 2010) plus seven additional recent studies (2010-February 2016)] (Table 1). Of the seven new studies included, six were conducted in European settings (4,9–11,20,21), and one in Asia (22).

Three studies used grounded theory (1,6,20), with a further study using a modified approach (21). One was a mixed-method study (2), from which only the qualitative results were included in the present analysis. One study reported using a phenomenological approach (23), and three a combination of phenomenological, and hermeneutical methods (4,7,11). A hermeneutical-ethical approach was applied in one study (10). The design of one qualitative study was unclear (not specified) (22). Most studies used in-depth or semi-structured interviews to collect data, except for one that used narrative interviews (10). Sample sizes ranged from 2 to 35 participants, yielding a total sample of 255 patients (excluding the relatives interviewed in one study (24)). The majority of studies aimed to explore the WTHD as expressed by patients with advanced disease. Only two studies had the main objective of describing suffering (9,22).

| Source paper | Country | Participants | Setting | Country's legislation on euthanasia and AS |
|---|---|---|---|---|
| Lavery et al. (1) | Canada | 31 men; 1 woman with HIV/AIDS | HIV Ontario Observational Database | Neither euthanasia nor AS are legal |
| Kelly et al. (2) | Australia | 30 terminally ill cancer patients | Inpatient hospice unit and home PC service | |
| Coyle and Sculco | USA | 7 terminally ill cancer | Pain and PC unit in an | |

| | | | | |
|---|---|---|---|---|
| (23) | | patients | urban cancer research centre | |
| Mak and Elwyn (7) | China | 6 patients | 26-bed hospice in China. | |
| Pearlman et al. (24) | USA | 35 patients | Patient advocacy organizations that counsel persons interested in AS, hospices and grief counsellors | AS legal since 2009. At the time of the study, AS had yet to be decriminalised |
| Schroepfer (8) | | 18 terminally ill elders | 2 PC programmes, 2 hospital outpatient clinics and 6 hospices | Neither euthanasia nor AS are legal |
| Nissim et al. (6) | Canada | 27 ambulatory cancer patients | Outpatient clinics at a large cancer centre | |
| Stiel et al. (20) | Germany | 10 inpatients and 2 outpatients of PMD | PMD of 3 university hospitals | |
| Dees et al. (9) | The Netherlands | 31 patients with different diagnoses | Support and Consultation on Euthanasia in The Netherlands network; hospice, hospital and nursing home | Euthanasia and AS legal since 2009 |
| Ohnsorge et al. (10) | Switzerland | 2 women with terminal cancer, and caregivers | PC hospice | AS legal since 1942 |
| Ohnsorge et al. (11) | | 30 terminally ill cancer inpatients/outpatients, and their caregivers/relatives | Hospice, a PC ward in the oncology department of a general hospital & an ambulatory PC service | |
| Ohnsorge et al. (4) | | 30 terminally ill cancer inpatients/outpatients, and their caregivers/relatives | Hospice, a PC ward in the oncology department of a general hospital & an ambulatory PC service | |
| Nilmanat et al. (22) | Thailand | 11 women & 4 men with terminal cancer and short life expectancy | Public health service for cancer treatment | Neither euthanasia nor AS are legal |
| Pestinger et al. (21) | Germany | 10 inpatients and 2 outpatients of PMD | PMD of 3 university hospitals | |

*PMD: Palliative Medicine Department

*PC: Palliative Care

**Table 1.** Characteristics of the studies included in the present review

## Description of themes

Five main themes emerged from the analysis of the WTHD expressed by patients with advanced disease: *suffering*, which appeared as an overarching theme; *reasons* for the WTHD; *meanings* of the WTHD; *functions* of the WTHD; and *lived experience of a timeline toward dying and death*. Supplementary Table-S5 shows the most representative statements for each theme together with its corresponding sub-themes.

The greater detail offered by the seven recent studies enabled the six themes from our previous meta-ethnography (5) to be subsumed under new, broader categories, without substantially changing their content (Table 2). One new theme emerged from the present analysis: *lived experience of a timeline toward dying and death.* Table 3 shows which themes, and sub-themes were present in each included study.

| **Themes from the original meta-ethnography** (5) | **Themes in the updated meta-ethnography** | |
|---|---|---|
| WTHD in response to physical/psychological/spiritual suffering | Reasons for the WTHD | Suffering |
| Loss of self | | |
| Fear | | |
| WTHD as a desire to live but 'not in this way' | Meanings of the WTHD | |
| WTHD as a way of ending suffering | | |
| WTHD as a kind of control over life: 'to have an ace up one's sleeve just in case' | Functions of the WTHD | |
| | Lived experience of a timeline toward dying and death | |

**Table 2.** Reclassification of themes from the original meta-ethnography in the present, updated meta-ethnography

| | Lavery et al. (1) | Kelly et al. (2) | Coyle and Sculco (23) | Mak and Elwyn (7) | Pearlman et al. (24) | Schroepfer (8) | Nissim et al. (6) | Stiel et al. (20) | Dees et al. (9) | Ohnsorge et al. (10) | Ohnsorge et al. (11) | Ohnsorge et al. (4) | Nilmanat et al. (22) | Pestinger et al. (21) |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| Suffering | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ |
| Reasons for the WTHD | | | | | | | | | | | | | | |
| Physical factors | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ |
| Psychological factors | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ | - | ✓ | - | ✓ | ✓ | ✓ | ✓ |
| Social factors | ✓ | ✓ | ✓ | ✓ | ✓ | - | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ |
| Loss of self | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ |
| Meanings of the WTHD | | | | | | | | | | | | | | |
| Cry for help | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ | - | ✓ | - | ✓ | ✓ | ✓ | - |
| To end suffering | ✓ | - | ✓ | ✓ | ✓ | ✓ | ✓ | - | ✓ | - | ✓ | ✓ | ✓ | ✓ |
| To spare others from the burden of oneself | ✓ | ✓ | ✓ | ✓ | ✓ | - | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ | - |
| To preserve self-determination to the very end | ✓ | - | ✓ | ✓ | ✓ | ✓ | ✓ | - | ✓ | - | ✓ | ✓ | ✓ | ✓ |
| Will to live but not in this way | | - | ✓ | ✓ | ✓ | ✓ | ✓ | - | ✓ | ✓ | ✓ | ✓ | ✓ | - |
| Functions of the WTHD | | | | | | | | | | | | | | |
| WTHD as a means of communicating | | - | ✓ | - | - | - | - | - | - | - | - | ✓ | - | - |
| WTHD as a form of control | ✓ | - | ✓ | ✓ | ✓ | ✓ | ✓ | - | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ |
| Lived experience of a timeline toward dying and death | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ |

**Table 3.** Themes and sub-themes present in each of the studies included in this review

### 1. Suffering

*Suffering* emerged as an overarching theme, confirming that the WTHD in people with advanced disease cannot be understood without taking their suffering into account. As a theme, suffering referred not only to physical distress (especially pain) but also to psychological, social or existential aspects. Thus, suffering was a complex, and multidimensional phenomenon affecting the whole person, having physical repercussions, and impacting both on their identity, and their relationships with all aspects of their immediate environment. Suffering was a common denominator for understanding the other four themes: *reasons, meanings, functions,* and *lived experience of a timeline toward dying and death.*

> "To have pain and also breathlessness, that would be terrible and so much suffering. My breathing is suffering and this affects my appetite. So many kinds of suffering… The social situation is suffering…" (7).

### 2. Reasons for the WTHD

This theme refers to the factors or rational motivations that led to a WTHD being expressed. As in our previous review (5), the WTHD emerged as a complex reaction to suffering that was related to all dimensions of personhood. Our analysis indicated that the theme *reasons* could be broken down into four sub-themes: *physical, psychological/emotional* and *social factors*, and the *loss of self.*

#### Physical factors

In all the studies reviewed, *physical factors* (symptoms) were a key issue leading to the WTHD. Participants particularly emphasised a loss of function, and pain, although aspects such as fatigue, dyspnoea, incontinence, and cognitive impairments were also mentioned as producing considerable distress (1,4,9,24).

Most participants referred to the loss of physical function; their illness prevented them from doing the things they once did, stripping them of their independence: “I lost my dignity, lying in bed in diapers, I am no longer the independent person I used to be” (9). The loss of function was also linked to a diminished quality of life.

Many patients described severe, and unbearable pain as a factor that triggered a WTHD. Pain “affected the wholeness of their beings” (22), and their lived experience: “pain affects everything. It makes you tired. It affects how you can eat. It affects other people, and the fact is that even if you try to hide it, you can’t. […] pain takes that life out of you”. Some patients experienced intense, and uncontrollable pain, but stated that were it not for this they would want to go on living: “It is torturous... thinking when I am going to die to escape from this suffering. But when I am not in pain, I want to live. When the symptoms disappear, I want to continue living, as I do not want to depart from my loved ones” (22). Likewise, some participants (9) stated that their request for euthanasia stemmed from the continuous pain they suffered. In many cases, they feared becoming a burden on others, and making them suffer. For others, however, it was linked to a loss of control over their illness (due to ineffective medical treatment), and to a feeling of helplessness, to the sense that nothing could remedy their situation.

**Psychological/emotional factors**

This sub-theme comprised two categories: *fear,* and *hopelessness*. Fear was expressed in most interview studies, encapsulating fear due to uncertainty, fear about future suffering, and fear of the dying process.

Fear due to uncertainty was linked to inadequate knowledge about prognosis, and to not knowing what lay ahead. In most cases, fear was associated with a loss of control over bodily functions, and over one's life and circumstances, as well as with physical, and functional decline, and the thought of becoming a burden on family.

Many patients, aware of their progressive deterioration, foresaw a death that would be painful both for them, and their relatives, and hence they experienced a fear about future suffering. The experience of pain, and distress, combined with a loss of function, led some to expect an unbearable suffering 'worse than death itself' (9,21,24,23). In some interviews, pain or suffering was explicitly mentioned as "the biggest fear" (23). Some reported that they would rather die than suffer further pain of the kind they had already experienced.

The fear of the dying process resulted from patients' expectation that they would be unable to express their needs, wishes or problems due to frailty or cognitive impairment (21). This fear was linked to not knowing whether the future would be marked by intense suffering.

The sense of hopelessness felt by patients was associated with the progressive nature of their illness, a process that would lead inevitably to death, and about which nothing could be done: "You lie in bed and none of the normal functions come back. They will never come back and it will only get worse" (9). Some patients said they felt mentally exhausted, and tired of fighting their illness. One of the interviewees described his illness as "the end of many dreams for plans […] the end of it all. There's no future really" (25).

**Social factors**

For many, *social factors*, such as being a burden on others, making loved ones suffer, or being dependent, and in need of help, were another cause of suffering, and a reason for expressing the WTHD. The idea of causing others to suffer frequently caused patients themselves to suffer. For some, observing their own deterioration, and the impact of this on loved ones, was more difficult to bear than their own suffering.

Related to loss of function was increased dependency on others resulting from a deteriorating state. In some cases this dependency left many patients “at the mercy of others” (9), and feeling useless. Participants complained about needing to be fed, washed or dressed by others (1,7): “It’s horrible […] the whole situation. […] Not being able to get out of it, and every morning the same thing: waking up, being washed, lying there till the evening, the same pain” (4). For those who had been highly independent prior to their illness, or who had a high level of professional responsibility at work, the change in role (i.e. to dependency, and vulnerability) impacted enormously on their way of life, with some finding this difficult to accept.

Some patients said that they felt devalued, and treated as if they were no longer a person. Thus, further suffering, and a loss of self-esteem could be caused by health professionals failing to respond to their needs, to convey empathy, and a comforting attitude, or to respect their treatment choices (4).

“Just one sentence can hurt me, making things even worse… Really bad… When I need someone to help me, they just hurt my self-esteem […] I was right but they said I was wrong... What was worst was that I had to admit to being wrong and agree with them” (7).

### Loss of self

Many participants attributed the WTHD to a perceived loss of self or of identity, due to the impact of their illness on their life. Physical, psychological, and social factors (suffering; dependency; loss of control, both mentally, and physically; loss of self-esteem; or feeling a burden on others, etc.) combined to severely undermine their self-image, their sense of who they were: “she was going to lose significant ability to be the person she was” (24). Some studies referred to the loss of self as a loss of the essence, loss of personality, loss of the sense of dignity (24) or destruction of the self (23). When participants felt vulnerable, looked down on or inferior with respect to others, then the loss of self was heightened. In some cases, this led the individual to feel a loss of community (1), that is, a loss of close personal relationships accompanied by feelings of isolation, and a lack of understanding.

Many patients described the experience of being devalued or treated as an object, as well as the feeling of having lost control over oneself, and of being forced into a situation that went against all they considered to be important, as losing their sense of dignity. Some situations  -especially those that drew attention to their loss of control, and independence, notably in hospital settings- were perceived by interviewees as demeaning, leading them to being felt treated as objects or patients rather than as individuals (1,24).

Some patients did not wish to succumb to a situation over which they had little control, and thus the WTHD emerged in response to a perceived lack of purpose or meaning in life: “I’m just saying to myself when I go to sleep, ‘Just let me die.’ I don’t want to have to wake up and face this. […] I have nothing to live for, absolutely nothing. There’s nothing coming up in my life that I am living towards, and if there was it would be so terrible because it probably wouldn't happen" (6). For patients such as this, losing what made life worthwhile, and relevant strips them of the will to live. This loss of self is associated with a broader series of losses (of quality of life, of autonomy, of the ability to perform daily life activities, etc.), such that illness is experienced as progressive loss that will cease only in death.

### 3. Meanings of the WTHD

Our analysis suggested that the meanings attributed by patients to the WTHD could be categorised into five sub-themes.

#### Cry for help

As a result of their suffering, many participants expressed the need for immediate action to put an end to their torture, to the misery of the current situation (23). In some cases this involved an explicit request for help -whether from professionals or someone close to them- in coping with all they were going through. For other patients, the cry of despair was the result of their suffering, and the difficulty of accepting their illness, an aspect revealed in the rhetorical questions that are sometimes posed: 'Why me?' or 'Why do I have to go through this?' (22,23).

#### To end suffering

Death was sometimes described as preferable to suffering, or as the lesser of two evils (4) ("I don't want to go through the dying process so I'll kill myself" (23)). Here, the WTHD becomes synonymous with not wanting to suffer any more, and the desired death is seen as a release ("a vehicle to just, just stop my life" (23)), as a way of putting an end to loneliness, fear, dependence, pain, hopelessness, and the feeling that life is no longer enjoyable (8), or as a means of limiting disintegration, and loss of self (1).

### To spare others from the burden of oneself

Advanced illness, and its consequences (i.e. suffering, loss of independence, the need for help from others) led some people to state that they would rather die than be a burden to their loved ones, or see them suffer: “No matter how much they love you, you are always a burden. You automatically become a burden to everyone…” (6); “When I know that my life has become a burden to my loved ones, I would rather die” (22). The WTHD can thus represent the desire to spare others from suffering, a gesture of altruism (23).

### To preserve self-determination to the very end

The WTHD was also seen as a way of preserving self-determination, autonomy or control through to the very end of life. For some patients, the possibility of putting an end to their life, and of exerting some control, became more important as they began to lose more of their capacities.

“I will do things my way and to hell with everything and everybody else. Nobody is going to talk me in or out of a darn thing…. What will be, will be; but will be, will be done my way. I will always be in control” (24).

“I am in control of this body […] I will do whatever I want to with it” (24).

“I would like to bring about my own death” (11).

### Will to live, but not in this way

The WTHD also emerged, somewhat paradoxically, as an expression of “the will to live, but not in this way”. For some people, not being able to do the things that brought meaning, and value to their life was a reason to wish for its end. Many patients mentioned activities that made life worth living (e.g. creative activities, reading, driving, or enjoying time spent with family, and friends), and they felt convinced that when they could no longer do any of those things, their life would be meaningless, and they wouldn't want to live anymore (24). Some participants referred explicitly to the paradox of a will to live but not in this way, acknowledging, for example, that they experienced a wish to die at the same time as undergoing active anti-cancer treatment (10).

## 4. Functions of the WTHD

Analysis of the reviewed studies suggested that the WTHD can serve two possible purposes or functions: *a means of communicating,* and *a form of control.*

### WTHD as a means of communicating

Although many participants did not refer to this aspect explicitly, the expression of a WTHD served to communicate feelings, thoughts, and wishes. In the context of extreme suffering it represented a 'cry for help'. In some studies patients used the WTHD to voice concerns about death, and illness (4,23). One patient spoke about how difficult it was to talk about death with her husband, adding that the verbalisation of her WTHD had opened a way into this topic (4).

### WTHD as a form of control

For some patients, having a sense of their own personal agency brought some relief from present suffering. In this respect, the WTHD was equated with maintaining some control over their life, and of avoiding further suffering. In some cases, this control was expressed through hypothetical plans about how they would end their life if things deteriorated. Coyle and Sculco (23) refer to this projection into the future as the 'if-then' scenario: if my illness progresses, and I can no longer bear to suffer, then I will put an end to my life. In countries where euthanasia or assisted suicide are legal, this notion of 'having a plan' implied making contact with organisations, or professionals that supported such practices (1,4,9,24).

### 5. Lived experience of a timeline toward dying and death

The experience of a WTHD was also associated with the sense that time was running out. The anticipation of imminent death, and an awareness of the finality of life brought more suffering, and disquiet, and it was in this context that, paradoxically, the idea of hastening one's death came to be seen as a way of putting an end to suffering. Some participants described how they had had to give up the usual things they did (4,24). Such inactivity left them feeling that all they could do was wait as time itself appeared to slow: "waiting and waiting, too often, extended, prolonged, so long, on and on, it should be over, limited, until the last moment, and from one second to another" (21).

For some people, their WTHD fluctuated over time. In these cases, the wish to live might become stronger as reasons why the person had wished to die became less prominent (e.g. their physical pain lessened). However, the balance could then tip the other way depending on their circumstances, such that, at times, a wish to die, and a wish to live might both be present.

## DISCUSSION

Five years on from our previous meta-ethnography the inclusion, and analysis of seven additional studies has brought greater understanding of the WTHD. Using an approach that France et al. (15) refer to as 'extending and renovating the house' the inclusion of recent literature has enabled us to reclassify categories from our original synthesis into a new set of themes. The new analysis also yielded an additional theme not present in the earlier review. Statements from participants in the additional studies, as well as theorisation proposed by study authors, were key to this reconceptualization.

Our findings indicate that the primary, overarching theme for an understanding of the WTHD in patients with advanced disease is suffering. This extends to different dimensions of their personhood, and thus may involve physical, social, psychological/emotional, and/or spiritual/existential suffering. Many patients referred to the deep impact of this suffering on their sense of self or identity, as well as on their immediate surroundings, and their ways of coping with life. These findings are consistent with a recent international expert consensus statement, which defined the WTHD as “a reaction to suffering, in the context of a life-threatening condition, from which the patient can see no way out other than to accelerate his or her death” (26).

Although suffering emerged as the common theme underlying the experience of the WTHD, one participant in the study by Ohnsorge et al. (4) stated that she was not suffering, but because she knew that she would die soon, she wanted death to come faster (without actually having the WTHD). While this is the only case we identified where a WTHD was expressed outside a context of suffering, we do not rule out the possibility that other similar cases may exist. Just as for some patients death was seen as release from their illness, the patient referred to above seems to have gained some relief from the knowledge that her illness was progressing, and that death was imminent.

The second theme, reasons, captures how a WTHD can represent a response to physical, psychological/emotional, and social factors in the context of intense suffering, and a perceived loss of self. Although physical pain was for many years considered the primary cause of the WTHD, studies conducted since the late 1990s offer a more complex view (27). Thus, while several authors report a close relationship between the WTHD and, for example, greater functional impairment, and dependency (28,29), there is evidence to suggest that psychological, and emotional factors play an important role in the emergence of such a wish (3,5,27). In terms of a person's subjective experience, it is not possible to separate physical symptoms, and functional impairment from the impact they have on the person's relationship to his or her surroundings, and the psychological or existential suffering that results. Indeed, physical pain, and loss of functionality are inextricably linked with all other aspects of the self, and as such they may, for example, lead to feelings of hopelessness making it difficult for the patient with advanced disease to find meaning in life. This multifaceted suffering, which cannot be reduced to its constituent parts, exemplifies what Cicely Saunders (30) referred to as 'total pain'. Some participants felt that were it not for their physical pain they would not wish to die. However, other statements made by patients indicate that the experience of pain cannot be understood in isolation from its impact on the person's psychological and emotional state and their relationship with the immediate environment. These apparent contradictions may reflect how researchers have explored or assessed pain in this context, since instruments used in cross-sectional studies are unable to capture the full intensity and experiential impact, with qualitative research offering a more nuanced holistic account of the experience of pain.

Although depression is reportedly associated with the WTHD (31,32), this aspect was not directly assessed by any of the included studies. However, three studies (24,23,25) referred to the need to address depression, especially in patients who express a WTHD.

While the authors of the included studies identify diverse reasons for the WTHD, these are, in fact, inter-related. In some cases it is difficult to differentiate the physical, psychological, emotional, social, and existential dimensions of patients' experience. Thus, for example, although aspects such as meaning in life or loss of the sense of dignity are often described as psychological/emotional/existential issues, in our analysis they relate to the sub-theme of *loss of self*, in other words, a loss of identity that covers all dimensions of personhood.

The third theme that emerged from our synthesis was *meanings*. Identifying the meanings the WTHD may have (other than simply a desire to die) is crucial for understanding the complex and dynamic nature of this phenomenon. Some studies point out how the WTHD can fluctuate over time (33,34), such that an individual may experience contradictory wishes (7,10,23). Such cases highlight the need for caution when exploring the meanings that a given individual may attribute to the expression of a WTHD. Furthermore, although the meanings identified in this updated review were derived from the statements made by participants, the meaning of a WTHD may also be influenced by the values and moral understanding of patients (10,35). In this respect, it is important to explore the cultural and personal background of a patient who expresses a WTHD so as to be able to properly contextualise what is being expressed.

The fourth theme, functions, considers the WTHD as a means of communicating and as a form of control. All the studies revealed that the WTHD served to express more than just a desire to die. The communicative function of the WTHD was clear in some cases, in strengthening family ties and highlighting how important the care and presence of loved ones was to the patient. Involving relatives in decision-making meant that responsibilities were shared and helped ensure, to some extent, that the patient would not be abandoned to their fate. Occasionally, the expression of a WTHD was used to make relatives, friends or professionals feel that they should do more for the patient, or to obtain personal gain. In the majority of cases, however, the expression of a WTHD was a way of communicating the extent of suffering (23).

The WTHD as a form of control featured in our previous meta-ethnography. For this update, however, our analysis paid closer attention to the legal context, especially in countries in which euthanasia or AS has been decriminalised. Of the 14 studies, six (4,8–11,24) refer explicitly to physicians or organisations that could provide support to persons interested in euthanasia or AS. Making contact with right-to-die organisations was seen as the final act of control available to someone with a terminal illness. Some patients who expressed this desire for control ended up dying through the administration of lethal drugs (9,24). In countries where such practices remain illegal, patients alluded to hypothetical plans in which the possibility of suicide was contemplated. Such plans appeared to generate a sense of control and of relief among patients (without the irreversibility associated with euthanasia or AS). Once again, the primary motive for such control was the wish to put an end to suffering. In sum, the existence of legislation that permits euthanasia or AS can influence decision-making for advanced patients at the end of life (4).

The final theme, *lived experience of a timeline toward dying and death*, contextualises patients' statements within a temporal framework. The experience of time only appeared explicitly (i.e. as a theme identified in the data analysis) in one study (21). However, when patients in other studies spoke of their experience of progressive deterioration, fear, anguish, hopelessness, and loss of control, etc. they made implicit reference to their life past, present, and future. This temporal aspect of the WTHD, captured only in qualitative studies, highlights the importance of a more detailed exploration of patients' experience when seeking to address their doubts, and concerns.

## Strengths and limitations

This updated review and synthesis of the published literature on the WTHD has brought a more detailed understanding of the phenomenon. For the present qualitative analysis, two researchers (ARP and ABo) joined two authors from the previous meta-ethnography (CMR, ABa), and this triangulation of researchers (36) injected a fresh perspective. Inclusion of studies from countries beyond those from the earlier meta-ethnography (specifically, Germany, The Netherlands, Switzerland, and Thailand) increases the transferability of results. So far, we have been unable to identify published studies of the WTHD in Africa, South America, and the Middle East. As in our previous review, we achieved data saturation in the present study. Only one new theme ('lived experience of a timeline towards dying and death') was identified, a theme already implicit in the earlier meta-ethnography. Other themes that emerged encapsulated previously identified themes, which were here reclassified, and reconceptualised.

One limitation of the present study concerns the difficulty of synthesising findings from primary qualitative studies. Not all studies used the same conceptualisation of the WTHD, and the research objectives of some studies only touched indirectly upon the phenomenon. Likewise, not having access to the original interviews limits the available data.

### Implications for practice and future research

The WTHD is a complex phenomenon to which various reasons, meanings, and functions may be attributed. This highlights the need for professionals to be trained so that they can respond to and understand the impact of a life-threatening illness on the individual. Furthermore, an understanding of the factors that can trigger a WTHD may help to prevent its emergence.

It has recently been suggested (29) that proactively asking patients about a potential WTHD could be beneficial. Further studies are required to explore this strategy. Given that social factors contribute to the emergence of a WTHD, future research should explore how the expression of a WTHD is experienced by the person's relatives, and what meanings it may have for them. Systematic guidelines regarding the WTHD are needed to help health care professionals respond adequately to the needs of these patients.

## CONCLUSIONS

The WTHD in patients with advanced disease cannot be understood outside the context of their suffering, a prerequisite for its emergence in this population. However, every expression of a WTHD will have associated reasons (the whys) and functions (for what purpose), and its meaning may vary by cultural background and lived experience, to not necessarily be synonymous with a genuine desire to die. In countries where EAS have been decriminalised, the expression of a WTHD may be seen as a way to end suffering. All these aspects underline the need to explore the reasons, meanings, and functions that a person attributes to such a wish, as only by doing so will we be able to understand his or her experience and develop appropriate individualised care plans.

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### Contributions

Contributors ARP and CMR designed the study. ARP and CMR collected data and conducted data analysis. ARP and CMR wrote the manuscript. ABa and ABo made substantial contributions to the identification of relevant literature, the interpretation of findings and were involved in drafting the manuscript and revising it critically. All authors gave final approval to this manuscript.

### Competing interest

The authors declare no conflict of interest.

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## Data sharing statement

All data supporting this study are provided as supplementary information accompanying this paper. Further information can be obtained from the corresponding author.

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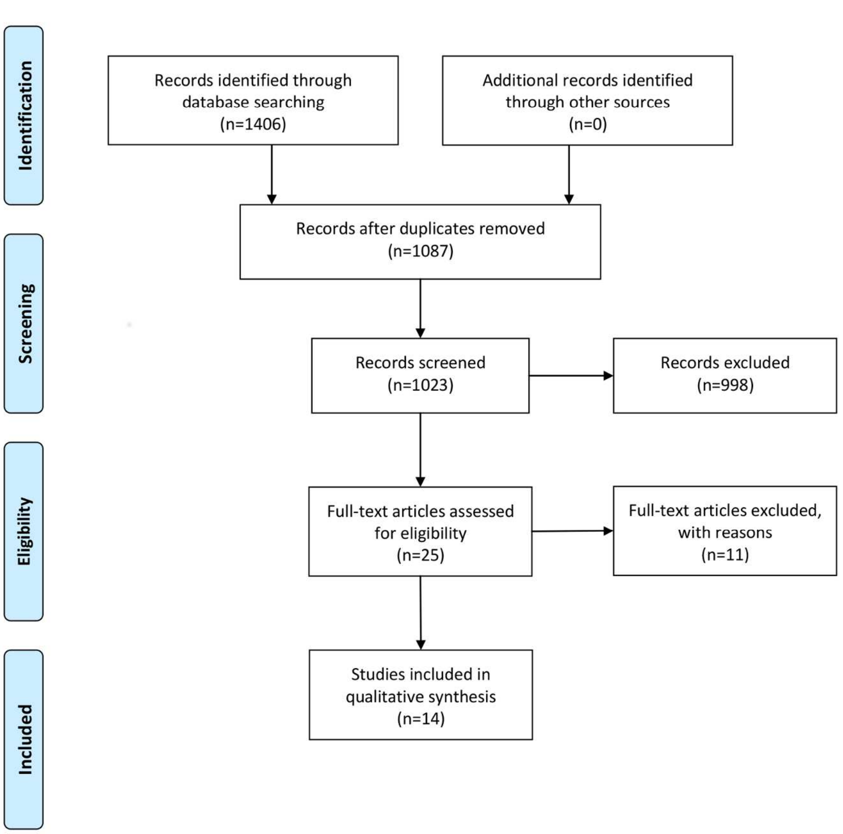

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Figure 1. Flowchart of the selection of the studies

173x146mm (300 x 300 DPI)

# SUPPLEMENTARY FILES

**Table-S1.** Final database search strategy.

| | |
|---|---|
| 1 | desire to hasten death |
| 2 | wish to hasten death |
| 3 | euthanasia [Mesh] |
| 4 | suicide, assisted [Mesh] |
| 5 | end of life decisions |
| 6 | wish to die |
| 7 | 1 or 2 or 3 or 4 or 5 or 6 |
| 9 | palliative care |
| 10 | end of life care |
| 11 | end of life |
| 12 | 9 or 10 |
| 13 | chronic disease |
| 14 | chronic illness |
| 15 | advanced disease |
| 16 | advanced illness |
| 17 | advanced cancer |
| 18 | life limiting illness |
| 19 | terminally ill |
| 20 | life threatening illness |
| 21 | life threatening condition |
| 22 | 13 or 14 or 15 or 16 or 17 or 18 or 19 or 20 or 21 |
| 23 | Qualitative Pubmed or CINAHL filter |
| 25 | 7 and 12 and 22 |
| 26 | 25 and 23 |
| 27 | 26 not (child*) or (pediatr*) |

**Table-S2.** Methodological quality of included studies, assessed using CASP criteria: qualitative research checklist

| **Reporting Criteria (CASP)** | **N (n=14)** | **References of studies reporting each criterion** |
|---|---|---|
| **1) Was there a clear statement of the aims of the research?**<br>**Consider:** (Yes // No // Comments)<br>- What the goal of the research was | 14 | Coyle & Sculco 2004; Dees et al. 2011; Kelly et al. 2002; Mak & Elwin 2005; Lavery et al. 2001; Nilmanat et al. 2010; Nissim et al. 2009; Ohnsorge et al. 2012; Ohnsorge et al. 2014a; Ohnsorge et al. 2014b; Pearlman et al. 2005; Pestinger et al. 2015; Schroepfer 2006; Stiel et al. 2010 |
| – Why it is important | 14 | Coyle & Sculco 2004; Dees et al. 2011; Kelly et al. 2002; Mak & Elwin 2005; Lavery et al. 2001; Nilmanat et al. 2010; Nissim et al. 2009; Ohnsorge et al. 2012; Ohnsorge et al. 2014a; Ohnsorge et al. 2014b; Pearlman et al. 2005; Pestinger et al. 2015; Schroepfer 2006; Stiel et al. 2010 |
| – Its relevance | 14 | Coyle & Sculco 2004; Dees et al. 2011; Kelly et al. 2002; Mak & Elwin 2005; Lavery et al. 2001; Nilmanat et al. 2010; Nissim et al. 2009; Ohnsorge et al. 2012; Ohnsorge et al. 2014a; Ohnsorge et al. 2014b; Pearlman et al. 2005; Pestinger et al. 2015; |

| | | |
|---|---|---|
| | | Schroepfer 2006; Stiel et al. 2010 |
| **2) Is a qualitative methodology appropriate? Consider:**<br>– If the research seeks to interpret or illuminate the actions and/or subjective experiences of research participants | 14 | Coyle & Sculco 2004; Dees et al. 2011; Kelly et al. 2002; Mak & Elwin 2005; Lavery et al. 2001; Nilmanat et al. 2010; Nissim et al. 2009; Ohnsorge et al. 2012; Ohnsorge et al. 2014a; Ohnsorge et al. 2014b; Pearlman et al. 2005; Pestinger et al. 2015; Schroepfer 2006; Stiel et al. 2010 |
| **3) Was the research design appropriate to address the aims of the research? Consider:**<br>– If the researcher has justified the research design (e.g. have they discussed how they decided which methods to use?) | 12 | Coyle & Sculco 2004; Dees et al. 2011; Mak & Elwin 2005; Lavery et al. 2001; Nilmanat et al. 2010; Nissim et al. 2009; Ohnsorge et al. 2014a; Ohnsorge et al. 2014b; Pearlman et al. 2005; Pestinger et al. 2015; Schroepfer 2006; Stiel et al. 2010 |
| **4) Was the recruitment strategy appropriate to the aims of the research? Consider:**<br>-If the researcher has explained how the participants were selected | 13 | Coyle & Sculco 2004; Dees et al. 2011; Kelly et al. 2002; Mak & Elwin 2005; Lavery et al. 2001; Nilmanat et al. 2010; Nissim et al. 2009; Ohnsorge et al. 2014a; Ohnsorge et al. 2014b; Pearlman et al. 2005; Pestinger et al. 2015; Schroepfer 2006; Stiel et al. 2010 |
| – If they explained why the participants they selected were the most appropriate to provide access to the type of knowledge sought by the study | 13 | Coyle & Sculco 2004; Dees et al. 2011; Kelly et al. 2002; Mak & Elwin 2005; Lavery et al. 2001; Nilmanat et al. 2010; Nissim et al. 2009; Ohnsorge et al. 2014a; Ohnsorge et al. 2014b; Pearlman et al. 2005; Pestinger et al. 2015; Schroepfer 2006; Stiel et al. 2010 |
| – If there are any discussions around recruitment (e.g. why some people chose not to take part) | 11 | Coyle & Sculco 2004; Dees et al. 2011; Kelly et al. 2002; Mak & Elwin 2005; Lavery et al. 2001; Nilmanat et al. 2010; Nissim et al. 2009; Ohnsorge et al. 2014a; Pearlman et al. 2005; Pestinger et al. 2015; Schroepfer 2006 |
| **5) Were the data collected in a way that addressed the research issue? Consider:**<br>- If the setting for data collection was justified | 14 | Coyle & Sculco 2004; Dees et al. 2011; Kelly et al. 2002; Mak & Elwin 2005; Lavery et al. 2001; Nilmanat et al. 2010; Nissim et al. 2009; Ohnsorge et al. 2012; Ohnsorge et al. 2014a; Ohnsorge et al. 2014b; Pearlman et al. 2005; Pestinger et al. 2015; Schroepfer 2006; Stiel et al. 2010 |
| – If it is clear how data were collected (e.g. focus group, semi-structured interview, etc.) | 13 | Coyle & Sculco 2004; Dees et al. 2011; Kelly et al. 2002; Mak & Elwin 2005; Lavery et al. 2001; Nilmanat et al. 2010; Nissim et al. 2009; Ohnsorge et al. 2012; Ohnsorge et al. 2014a; Ohnsorge et al. 2014b; Pearlman et al. 2005; Pestinger et al. 2015; Schroepfer 2006 |
| – If the researcher has justified the methods chosen | 7 | Dees et al. 2011; Mak & Elwin 2005; Nissim et al. 2009; Ohnsorge et al. 2014a; Pestinger et al. 2015; Schroepfer 2006; Stiel et al. 2010 |
| – If the researcher has made the methods explicit (e.g. for interview method, is there an indication of how interviews were conducted, did they use a topic guide?) | 11 | Coyle & Sculco 2004; Dees et al. 2011; Mak & Elwin 2005; Lavery et al. 2001; Nilmanat et al. 2010; Nissim et al. 2009; Ohnsorge et al. 2012; Ohnsorge et al. 2014a; Ohnsorge et al. 2014b; Pestinger et al. 2015; Schroepfer 2006 |
| – If methods were modified during the study. If so, has the researcher explained how and why? | 2 | Pestinger et al. 2015; Stiel et al. 2010 |
| – If the form of data is clear (e.g. tape recordings, video material, notes, etc.) | 14 | Coyle & Sculco 2004; Dees et al. 2011; Kelly et al. 2002; Mak & Elwin 2005; Lavery et al. 2001; Nilmanat et al. 2010; Nissim et al. 2009; Ohnsorge et al. 2012; Ohnsorge et al. 2014a; Ohnsorge et al. 2014b; Pearlman et al. 2005; Pestinger et al. 2015; Schroepfer 2006; Stiel et al. 2010 |
| – If the researcher has discussed saturation of data. | 10 | Dees et al. 2011; Kelly et al. 2002; Lavery et al. 2001; Pearlman et al. 2005; Nissim et al. 2009; Ohnsorge et al. 2014a; Ohnsorge et al. 2014b; Pestinger et al. 2015; Schroepfer 2006; Stiel et al. 2010 |
| **6) Has the relationship between researcher and participants been adequately considered? Consider whether it is clear:**<br>-If the researcher critically examined their own role, potential bias and influence during: | 2 | Mak & Elwin 2005; Nissim et al. 2009 |

| | | |
|---|---|---|
| formulation of research questions | 3 | Coyle & Sculco 2004; Lavery et al. 2001; Nissim et al. 2009 |
| data collection, including sample recruitment and choice of location | 5 | Coyle & Sculco 2004; Lavery et al. 2001; Mak & Elwin 2005; Nissim et al. 2009; Schroepfer 2006 |
| - How the researcher responded to events during the study and whether they considered the implications of any changes in the research design | - | - |
| **7) Have ethical issues been taken into consideration? Consider:**<br>– If there are sufficient details of how the research was explained to participants for the reader to assess whether ethical standards were maintained | 13 | Coyle & Sculco 2004; Dees et al. 2011; Kelly et al. 2002; Mak & Elwin 2005; Lavery et al. 2001; Nilmanat et al. 2010; Nissim et al. 2009; Ohnsorge et al. 2012; Ohnsorge et al. 2014a; Ohnsorge et al. 2014b; Pearlman et al. 2005; Pestinger et al. 2015; Stiel et al. 2010 |
| – If the researcher has discussed issues raised by the study (e.g. issues around informed consent or confidentiality or how they have handled the effects of the study on the participants during and after the study) | - | - |
| – If approval has been sought from the ethics committee | 14 | Coyle & Sculco 2004; Dees et al. 2011; Kelly et al. 2002; Mak & Elwin 2005; Lavery et al. 2001; Nilmanat et al. 2010; Nissim et al. 2009; Ohnsorge et al. 2012; Ohnsorge et al. 2014a; Ohnsorge et al. 2014b; Pearlman et al. 2005; Pestinger et al. 2015; Schroepfer 2006; Stiel et al. 2010 |
| **8) Was the data analysis sufficiently rigorous? Consider:**<br>– If there is an in-depth description of the analysis process | 12 | Coyle & Sculco 2004; Dees et al. 2011; Mak & Elwin 2005; Nilmanat et al. 2010; Nissim et al. 2009; Ohnsorge et al. 2012; Ohnsorge et al. 2014a; Ohnsorge et al. 2014b; Pearlman et al. 2005; Pestinger et al. 2015; Schroepfer 2006; Stiel et al. 2010 |
| – If thematic analysis is used. If so, is it clear how the categories/themes were derived from the data? | 12 | Coyle & Sculco 2004; Dees et al. 2011; Mak & Elwin 2005; Lavery et al. 2001; Nilmanat et al. 2010; Nissim et al. 2009; Ohnsorge et al. 2012; Ohnsorge et al. 2014a; Ohnsorge et al. 2014b; Pearlman et al. 2005; Pestinger et al. 2015; Schroepfer 2006 |
| – Whether the researcher explains how the data presented were selected from the original sample to demonstrate the analysis process | 6 | Coyle & Sculco 2004; Dees et al. 2011; Lavery et al. 2001; Mak & Elwin 2005; Pestinger et al. 2015; Stiel et al. 2010 |
| – If sufficient data are presented to support the findings | 12 | Coyle & Sculco 2004; Dees et al. 2011; Kelly et al. 2002; Mak & Elwin 2005; Lavery et al. 2001; Nilmanat et al. 2010; Nissim et al. 2009; Ohnsorge et al. 2014a; Ohnsorge et al. 2014b; Pearlman et al. 2005; Pestinger et al. 2015; Schroepfer 2006 |
| – To what extent contradictory data are taken into account | 1 | Ohnsorge et al. 2012 |
| – Whether the researcher critically examined their own role, potential bias and influence during analysis and selection of data for presentation | - | - |
| **9) Is there a clear statement of findings? Consider:**<br>– If the findings are explicit | 14 | Coyle & Sculco 2004; Dees et al. 2011; Kelly et al. 2002; Mak & Elwin 2005; Lavery et al. 2001; Nilmanat et al. 2010; Nissim et al. 2009; Ohnsorge et al. 2012; Ohnsorge et al. 2014a; Ohnsorge et al. 2014b; Pearlman et al. 2005; Pestinger et al. 2015; Schroepfer 2006; Stiel et al. 2010 |
| – If there is adequate discussion of the evidence both for and against the researcher's arguments | 9 | Lavery et al. 2001; Coyle & Sculco 2004; Schroepfer 2006; Nissim et al. 2009; Dees et al. 2011; Ohnsorge et al. 2012;Ohnsorge et al. 2014a; Ohnsorge et al. 2014b; Pestinger et al. 2015 |
| – If the researcher has discussed the credibility of their findings (e.g. triangulation, respondent validation, more than one analyst) | 10 | Coyle & Sculco 2004; Dees et al. 2011; Lavery et al. 2001; Nilmanat et al. 2010; Nissim et al. 2009; Ohnsorge et al. 2012;Ohnsorge et al. 2014a; Ohnsorge et al. 2014b; Pestinger et al. 2015; Schroepfer 2006 |
| – If the findings are discussed in relation to the original research questions | 14 | Coyle & Sculco 2004; Dees et al. 2011; Kelly et al. 2002; Mak & Elwin 2005; Lavery et al. 2001; Nilmanat et al. 2010; Nissim et al. 2009; Ohnsorge et al. 2012; Ohnsorge et al. 2014a; Ohnsorge et al. 2014b; Pearlman et al. 2005; Pestinger et al. 2015; Schroepfer 2006; Stiel et al. 2010 |

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| **10 How valuable is the research? Consider:**<br>– If the researcher discusses the contribution the study makes to existing knowledge or understanding (e.g. do they consider the findings in relation to current practice or policy, or relevant research-based literature?) | 13 | Coyle & Sculco 2004; Dees et al. 2011; Kelly et al. 2002; Mak & Elwin 2005; Lavery et al. 2001; Nilmanat et al. 2010; Nissim et al. 2009; Ohnsorge et al. 2012; Ohnsorge et al. 2014a; Ohnsorge et al. 2014b; Pearlman et al. 2005; Pestinger et al. 2015; Schroepfer 2006 |
| – If they identify new areas where research is necessary | 13 | Coyle & Sculco 2004; Dees et al. 2011; Kelly et al. 2002; Mak & Elwin 2005; Lavery et al. 2001; Nilmanat et al. 2010; Nissim et al. 2009; Ohnsorge et al. 2012; Ohnsorge et al. 2014a; Ohnsorge et al. 2014b; Pearlman et al. 2005; Pestinger et al. 2015; Schroepfer 2006 |
| – If the researchers have discussed whether or how the findings can be transferred to other populations or considered other ways the research may be used | 8 | Coyle & Sculco 2004; Dees et al. 2011; Lavery et al. 2001; Nilmanat et al. 2010; Nissim et al. 2009; Ohnsorge et al. 2012; Pearlman et al. 2005;Schroepfer 2006 |

**Table-S3.** The seven stages of meta-ethnography, summarising what each step entailed in the previous and the present review

| **Noblit and Hare's 7 steps** (12) | **What each step entailed in our original meta-ethnography** (5) | **What each step entailed in the present, updated meta-ethnography** |
|---|---|---|
| 1. "Getting started" (the topic focus) | To analyse the meaning of and motivation for the WTHD in patients with chronic illness or advanced disease. | To analyse the WTHD in patients with chronic illness, advanced disease or life-threatening illness. |
| 2. Deciding what is relevant to the initial interest | Design a search strategy to identify qualitative studies (December 2000-November 2009). | Design of a revised optimal search strategy. For inclusion: qualitative studies (December 2000-January 2016). Studies from original meta-ethnography and from update to be integrated. |
| 3. Reading the studies | Generate list of key concepts to identify common and disparate concepts and themes, both within and across studies. Findings from the research reports divided into text units coded by words, sentences or paragraphs, according to content. Codes grouped into themes to define characteristics or different dimensions of the phenomenon studied. | Generate list of key metaphors using Atlas.ti software to identify common and disparate concepts and themes, within and across studies. No distinction to be made during reading and analysis between previously reviewed and new studies. Findings from research reports to be handled in same way as for the original meta-ethnography. |
| 4. Determining how studies are related | Directly compare concepts from primary studies using reciprocal translations (generating metaphors to express similarities between study findings). | Directly compare concepts from primary studies using reciprocal translations (as for the original meta-ethnography). |
| 5. Translating the studies into one another | Having identified main concepts from each study, search for their presence or absence in all the studies. Comparison to begin with themes identified in the earliest published article and to proceed in chronological order of publication. Translate themes to the whole sample and to each individual study. | Having identified concepts from each study, search for the presence or absence of main concepts in all studies. Comparison again to follow chronological order. Translate themes to the whole sample and to each individual study. During the analysis, return to the original themes, comparing them with the new themes that emerge. Themes emerging from the update can confirm or broaden the original themes, or constitute new themes. |
| 6. Synthesising translations | Bring together translated concepts within a synthesis, starting from identified themes, and match them with their respective quotations, resulting in themes within final synthesis. Finally, derive explanatory model. | Bring together expanded number of translated concepts within an expanded final synthesis. Concepts can confirm original translated concepts, but might also lead to new explanatory model. |

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| 7. Expressing the synthesis | Express synthesis as themes with an accompanying narrative in a scientific journal. | Again, express synthesis as themes with an accompanying narrative for submission to a scientific journal. |

**Table-S4.** Comparison of yield between Original Review and Updated Review

| **Noblit and Hare's 7 steps** (12) | **Original Review** | **Updated Review** |
|---|---|---|
| 1. "Getting started" (the topic focus) | 7 studies (December 2000-November 2009) | 14 studies: 7 original + 7 new studies (December 2000-January 2016) |
| 2. Deciding what is relevant to the initial interest | | |
| 3. Reading the studies | | |
| 4. Determining how studies are related | 10 translated concepts | 25 translated concepts |
| 5. Translating the studies into one another | | |
| 6. Synthesising translations | 6 themes | 5 themes |
| 7. Expressing the synthesis | Explanatory model | New explanatory model |

**Table-S5.** Classification of verbatim statements from the studies by theme and sub-theme

| **Themes and subthemes** | **Related themes** |
|---|---|
| **1. Reasons for the WTHD** | |
| **1.1 Physical factors** | |
| "Um, the ability to perform simple things like, you know, going to the bathroom on your own and not through a bag, um, breathing with your own lungs, not dependent upon a machine to keep the body parts functioning, um being able to do anything, I mean as long as you can think then you can live, but if you can't [sic] no longer even formulate a thought due to dementia or you know the ravages of the disease. You know, if you were to stand there in your former self, would you want to see yourself in that position? I know I wouldn't. You get to the point where there's no return, you know, I can understand somebody saying, well geez, you know, like I used to be somebody, but now, like I mean, you know, I'm no better than like a doll, somebody has to dress me and feed me and I guess it's uh, I don't know how to explain it, really" (1). | Dependency<br>Progressive physical deterioration<br>Loss of function<br>Loss of the self<br>Loss of the sense of dignity |
| "… If I'm going to be rolling around in my own faeces because I have no control, then forget it" (1). | Loss of function<br>Loss of control |
| "You turn them over, they're in pain. They're going to shit themselves, they're going to piss themselves, they're going to lie there and have someone do all their bodily functions and just, they're going to suffer the whole time, they're going to be no happiness, they're going to go down to 60-70 pounds, they're just going to, their whole last weeks of life is just going to be in pain and agony and people coming in, people being upset, them being upset" (1). | Loss of function<br>Anticipation of future suffering |
| ''I can't move, just lie here... feeling like a vegetable… a useless person... needing people to feed me" (7). | Loss of function<br>Loss of independence<br>Dependency<br>Loss of value |

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| "But really yes, to see a man, who only exists of pain, who maybe is cognitively impaired and isn't able to participate actively in life, this man, who only lies in bed, not noticing his surroundings…" (21). | Suffering<br>Loss of function<br>Loss of daily life activities |
| "I say: I have made my decision. I don't want you to treat me any longer. Someone says, now you are probably too weak for chemo. I say: if I'm not too weak and they want to give me chemo, I will refuse it, because in the little time that is left to me I want quality of life, not quantity of life. I decided that a year ago: if this were to overcome me, then that's what I would choose" (9). | Loss of quality of life<br>Desire for control over life |
| "If you get cancer, you'll get pain. Cancer is a painful disease. It'll just get more and more painful" (7). | Progressive physical deterioration<br>Suffering<br>Lived experience of time |
| "Whether it gets better or not, it's destined. I'll wait to die. There's no way out even if the pain returns. It'll come when it may. I'll just go along with the pain and die. Nothing would help" (7). | Pain<br>Suffering<br>WTHD as unbearable situation with no other way out |
| "The side effects of the treatment are unacceptable… the Prednisone destroys you. For example, it destroys your muscles. My thighs are so weak I can't get up from the floor, and I don't have the energy to exercise. The whole thing is a vicious circle… My face… looks like a melon… I look like a frog in heat" (24). | Progressive physical deterioration<br>Loss of function |
| "… the terrible weakness and the nausea and just not feeling like you can do anything... And it's kind of like goals that I actually have or things that I want to accomplish are slowly being taken away… it's kind of like the realm of the possible… is shrinking" (24). | Progressive physical deterioration<br>Lived experience of time (there is no future)<br>Losses |
| "The pain could happen immediately or it could happen an hour or two later. And then I have to see about seeing [my provider] again. It is a treadmill that I'm on; I can't get off of it, and I've had it. And I can't live this anymore" (24). | Suffering<br>Unbearable suffering with no other way out |
| "Well, the pain that I had before with the rheumatoid arthritis I knew that I could handle—... But this pain that I have, I'm not sure—I can't get rid of it with the pain medicine always... To give me enough to keep that pain under control, they'd have to put me out, and I don't want my son to have to take care of a bed patient" (24). | Not wanting to be a burden<br>Unbearable suffering with no other way out |
| "I have fecal incontinence. I can no longer swallow and in hot weather I really envy people who can drink" (9). | Loss of physical functions<br>Loss of control |
| "The way to my bed is endless and finally I get there. It takes a lot of energy, but once I'm in bed, it takes an hour just to gather my strength again" (9). | Loss of function<br>Physical deterioration<br>Losses |
| "I am in pain all the time, I am in pain at night, I wake up with pain and I go to bed with pain. If they could take away half my pain I wouldn't be thinking about euthanasia" (9). | Pain<br>Suffering<br>Will to live but not in this way<br>Hastened death as a way of ending suffering |
| "I was simply nauseous and my energy was just running out. And I said that I wished that, just for a short period of time, I could eat normally and not have to fight to keep it down and that I wanted to have a little more energy. Then I stopped the chemo and indeed I had that improvement" (9). | Consequences of the medical treatment |
| "Yes, I could not tell it, because I have just no pain now. That's maybe less [the idea that her illness should proceed faster]. If I had pain now or so, then I would say: immediately. But then… I will have to wait. That's not my business. That's God's business" (10) | Pain as mediator of the WTHD<br>Ambivalence<br>Wish to live but not in this way |

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| P: "It's horrible, I can tell you. It's horrible. […] the whole situation. I: The situation. Not being able to get out of it. P: Not being able to get out of it, and every morning the same thing: waking up, being washed, lying there till the evening, the same pain" (4) | Dependency<br>Suffering<br>WTHD: unbearable situation with no way out (other than death)<br>Despair |
| "I sit back and I say, 'since I'm already dying, and since I'm already gone, lost my energy. Why? Why do I also have to take these disgusting pills?' and it seems that every day there's something more, something more disgusting" (6). | |
| **1.2 Psychological factors** | |
| "... the end of many dreams for, plans, complete halt to things I was doing, want to do. The biggest thing is the weakness, which I absolutely hate, not being able to do things, to realise that this is virtually the end of it all. There's no future really. You can't plan anything" (2). | Hopelessness<br>Physical deterioration<br>Limitation of activities<br>Loss of function<br>Lived experience of time |
| "Sometimes I start yelling at my shrink that this is horrible, that why don't I die right now?...Why do I have to live through this?" (23) | Fear of the dying process<br>Unbearable suffering |
| "I don't want to undergo that [expletive] feeling of helplessness, that there's not a [expletive] thing that I or anyone else can do" (23). | Helplessness |
| ''I just don't want to be in so much suffering... to endure these psychological effects" (7). | Suffering |
| "Not much hope, nor would there be any miracles… You doctors can't help when the patients deteriorate and then drop dead…" (7). | Progressive physical deterioration<br>Hopelessness<br>Lived experience of time |
| "Someone with a tube sticking up the bottom, a tube sticking into the nostrils, another somewhere else. I mean, what for? Can you save them?" (7). | Hopelessness<br>Loss of meaning |
| "I asked the doctor, 'Doctor, do people with cancer get a lot of pain?' He answered, 'In the majority they do.' Then I asked, 'Is it possible not to be like that?' He answered, 'Possible, I suppose.' Ah…" (7). | Fear of suffering |
| "Some don't have loved ones around. They have nobody to care for them. Others have relatives but they don't care… I only have one daughter. If she doesn't help, who is going to help?... So miserable that I cannot express in words (7). | Hopelessness<br>Fear about the future<br>Lack of social support |
| "My first husband, he suffered a long time. He had on those machines, and I used to say, 'God,' I said, 'don't let me go under those machines" (8) | Fear of suffering |
| "I never thought about giving up but my fear was that I didn't know much about cancer. There are so many people that linger, and I was afraid that I could not cope. I know I will die, but I don't want to be lingering and suffering and people around me to suffer with me. So I thought, 'I will go for a swim' and I don't know how to swim or I would go to a place like Holland. I just don't want to be lingering, like people that can hardly talk and are really suffering and I don't want to do that. It's the only thing that makes me feel a little bit emotional. I don't want to deal with it so I think I would speed up things myself. I don't want to be lingering here in palliative care, lying day and day, slowly dying. Oh no, I don't want to do that. So, suicide is a way of exiting. I don't want to talk about that because I like life and I have lots to live for, but if I come to the point when I am too weak to do anything, then I don't want to stay" (6). | Anticipation of future suffering<br>Progressive physical deterioration<br>Not wanting to be a burden<br>WTHD as a way of ending suffering<br>WTHD so as to spare others from burden<br>Having a plan<br>Will to live but not in this way |
| "It is such an aggressive form of cancer. I saw all my energy going down the drain- what I could still do last week I can't do at all now. I really enjoyed my life, but now I have just to wait and see how things go and what death will look like" (9). | Hopelessness<br>Suffering<br>Will to live but not in this way |
| **1.3 Social factors** | |

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| "I think it's very important for every single person to feel that they belong, and, and that they fit in a community, in a city, in a country, in a world, ah, in nature. The, the ah, and I think when we no longer feel that you have these linkages, and that the linkages are valued for everything that you're connected with, whether it, you know, family or friends or, you know, associates, or whatever, and your community, and city and all the rest of. Once the once, once you perceive that, that your relationships, all the links with, with other living things have deteriorated, and then, and they're not valued, then you've lost face. Dignity, then, has for me, has an awful lot to do with face" (1). | Loss of community<br>Loss of the sense of dignity<br>Disintegration |
| "No matter how much they love you, you are always a burden. You automatically become a burden to everyone. Even to your own missus" (2). | Being a burden |
| "After a while, your family, who you love so dearly, will remember you as a washed-out role model… It will remind them of what they have to go through, the lack of strength, the weakness, and so forth" (23) | Not wanting to be a burden<br>Fear of losing one's own value in the eyes of others<br>Loss of the self |
| "For them to see me in pain is suffering. To see family rushing around is so suffering… That makes me suffer. They spend a lot of money… I fear the rushing around would make her [wife] ill, burdening her" (7). | Suffering<br>Not wanting to make others suffer |
| "In the future when I can't manage, I would feel very bothersome and very suffering as if I'm really burdening them. I'm afraid of having others to serve me" (7). | Anticipation of future suffering<br>Physical deterioration |
| "I've experienced such incredible pain over the last little while and more in the last week. Such incredible pain that it made me think that death is preferable to this. I'll sit there for 2 hours in terrible pain. Such pain where I can't yawn even, and I get only half a yawn and my whole insides turn and waiting for the medication to start to work. I'd love to have 48 hours let's say, I'd love to have this weekend where I could plan to have a nice weekend and have no pain. I'd love to do that and it doesn't happen, and the pain affects everything. It makes you tired. It affects how you can eat. It affects your mood. It affects other people, and the fact is that even if you try to hide it, you can't. So that's hard, and I know it's gonna get worse, so that's hard too. It's great to be alive, and pain takes that life out of you, and to sit there for 2 hours with a blanket around you just shivering, with no solution, is really hard" (6). | Pain (affects everything)<br>Hastened death as a way of ending suffering<br>Suffering as something worse than death<br>Wish to live but not in this way<br>Anticipation of future suffering |
| " …that others are not affected by watching someone else wasting away for 2 month, willing to die and willing to die, but he does not. That is difficult for the family members" (20). | Not wanting to make others suffer |
| "I want to present myself as being as normal as possible, but everybody notices it: I stumble and I am slow and that is just not me because I always was a nimble girl" (9). | Loss of functions |
| "I am burdened myself, I am such a burden to others; I want to end this" (4). | Hastened death as a way of ending suffering<br>Not wanting to be a burden |
| "I am not used to somebody helping me. This I feel is tantalizing, this is no life" (21). | Dependency<br>Loss of control<br>Loss of value of life |
| "Not wanting to be seen by those that love me as this skin-and-bone frail, demented person. In other words, I don't want that image of me for me, and I don't want that image to be kind of a last image that my daughters and loved ones have of me. And that's just a dignity issue" (21). | Loss of the sense of dignity<br>Loss of the self |
| **1.4 Self - Identity - Losses** | |
| "I'm not comfortable, and I can't do anything, so as far as I'm concerned in quality of life I'm not living; I'm existing as a dependent non-person. I've lost, in effect, my essence" (24) | Loss of quality of life<br>Loss of independency |
| "I think passively sitting in my own garden, sitting on my own deck, would still be preferable to, to, to death. Quality of life, the concept of quality of life is shifted. I can live with an inactive life... and I'd still fight a bit to gain incrementally" (23). | Loss of function<br>Loss of quality of life<br>Ambivalence: wish to live and wish to die |

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| "Finally the illness that dominates everything will wipe out all life has to offer me, what I feared most is exactly what will happen to me. I won't belong anymore, the emptiness of existence, the lack of independence, being unable to do things myself, being at the mercy of others whom I will have to beg to do the things I need in a way that's suitable for me" (9). | Losing<br>Anticipation of future suffering<br>Loss of control<br>Loss of independence<br>Loss of meaning in life |
| "I just can't do what I used to. Um, I can't go out, I can't go to the store… I can't write a check for nothing. I, it's just a lot of things… Oh, I hate it" (8). | Limitation of activities<br>Loss of function<br>WTHD maintaining meaningful activities |
| "There's not any good reason for me to go on living. Nobody really needs me… I'm really not serving any purpose. If you don't, aren't needed by anybody, you kind of have a different feeling about life" (8). | Loss of value<br>Loss of will to live |
| ''I'm just saying to myself when I go to sleep, 'Just let me die.' I don't want to have to wake up and face this. Honestly I just pray that I would just die in my sleep. I have nothing to live for, absolutely nothing. There's nothing coming up in my life that I am living towards, and if there was it would be so terrible because it probably wouldn't happen" (6) | Hopelessness<br>Despair<br>Loss of meaning in life<br>Loss of will to live |
| "When I'm in pain, it is not so much the pain, it's the loss of control and the helplessness" (6). | Desire for control over life<br>Helplessness |
| "The energy that I have always had, the positive (energy), that has made me as a person… but exactly this is getting less and less at the moment" (6). | Progressive physical deterioration |
| "The past few days even the news doesn't interest me anymore, I have less interest in the outside world. My brain no longer works and to me that is a part of human dignity and of unbearable suffering. I want to function normally and if I can't do that" (9).. | Progressive physical deterioration<br>Loss of the sense of dignity<br>Loss of will to live<br>Hastened death as a way of ending suffering |
| "I have become so weak because of the pain. I can't walk anymore, I can't eat anymore. My children have suffered enough. I don't want them to go through this again. Everybody has to lose their parents someday anyway" (9). | Pain<br>Being a burden |
| "…claustrophobia of my existence. To put it simply, it is insight without perspective. Never in my life have I felt any love. If there had been some warmth and love and safety, I could have grown" (9). | Loss of meaning in life<br>Loss of will to live |
| "I can't drive anymore. I loved to paint and draw, but I can't do that either anymore. Everything I enjoyed is gone. And then, my sight became worse" (9). | Loss of meaning<br>Limitation of activities<br>Loss of function |
| "I'm not interested at all anymore, I just lie here and what's the point? There isn't any. I no longer read. Not books, not newspapers. I have CDs and the Walkman right here. Well, I've listened to, um, two CDs and that's enough. And yet I really loved music, but it's all over. I'm just not interested anymore…" (9). | Loss of will to live<br>WTHD maintaining meaningful activities |
| "I lost my dignity, lying in bed in diapers, I am no longer the independent person I used to be" (9). | Loss of function<br>Loss of independence<br>Loss of the sense of dignity |
| "And I don't feel this is a life for me [pause], carrying on living like this. That's why [pause] um, I am [pause] very – how should I put it, so you understand me – I'm on the road, on the move a lot and [pause] then I thought, if I can't live like before, life has no value, does it? And [pause] I drove my car a lot, and I can't do that anymore either. […] Yes, did a lot of travelling. […] I feel my life isn't worth anything at all any more, if I just lie here and wait" (4). | Loss of activities (that make life enjoyable)<br>Loss of value<br>Loss of will to live<br>Loss of life's worth<br>WTHD maintaining meaningful activities |
| "Activities with friends not possible—and indeed activities outside or with the family, I would say, meanwhile completely passed away" (21). | Limitation of activities |
| "You've become a bag of potatoes to be moved from spot to spot, to be rushed back and forth from the hospital, to be carried to your doctors' appointments or wheeled in a wheelchair, and it really does take away any self-worth, any dignity, or any will to continue to live" (1). | Loss of control<br>Loss of the sense of dignity<br>Loss of self-worth<br>Loss of will to live |

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| “Oh, it’s the dignity and wholeness of my body, as well as spirit. And, it is, it’s cruel too for others to have to do this when there’s no end in sight, other than death. To just, to clean me up. I just don’t want that ...Dignity is that I have control over my body, when, when, not, not a virus that is going to take my life. I’m the one who’s going to decide when my life will end, not a virus, and not with great pain. Not anything else other than in, in my control. It is my control, my choice to do” (1). | Loss of control<br>Loss of the sense of dignity<br>Loss of self-worth<br>Loss of will to live<br>WTHD as a way of self-preservation |
| **2. Suffering** | |
| “To have pain and also breathlessness, that would be really terrible and so much suffering. My breathing is suffering and this affects my appetite. So many kinds of suffering… The social situation is suffering...” (7). | Physical factors |
| “I’ve seen other patients yelling in pain and they were suffering... so intolerable... Just to hear them was very suffering... It must have been so unbearable to have to yell like that. If they could endure it, they wouldn’t have yelled.” (7). | Anticipation of a painful death<br>Fear of suffering |
| “I just don’t want to endure these psychological effects. . . So much suffering. . . I have had the pain for four years... So many psychological effects… How can I bear it?” (7). | Suffering<br>Unbearable situation with no other way out |
| **3. Meanings of the WTHD** | |
| **3.1 Cry for helping** | |
| “Why do I have to go through this? Why can’t I just die right now?” and, “When I pray, I use [sic] to feel the power of God on me. . . . Now I sometimes feel as though I am talking to the air” (23). | Suffering |
| “When I was in excruciating pain … sometimes, I wanted to grab a knife and stab myself, and cut it [pain/cancer] out. I felt angry…why I am suffering so? I did not know what to do or how to deal with it. I could not work, so my life was no longer worth living. Continuing to live would only bring more suffering… I could not look after myself. I made [Buddhist] merits in the morning, offered food to monks. I prayed every day. I prayed to have the day, during which I was no longer able to perform my daily activities, as my last day of life… I prayed to die so that my suffering could end. I did not want to be fed by my children and grandchildren. Just let me die” (22). | Pain<br>Loss of independence (not being able to perform activities of daily life)<br>Not wanting to be a burden<br>Loss of life’s worth<br>Suffering as something worse than death<br>WTHD: unbearable situation with no way out (other than death)<br>Despair |
| “I suffer so much that I can’t recall when life was lovely and happy. My life is hell. My life is inhuman. I have such deep pain inside” (9). | Despair<br>Suffering<br>Loss of life’s worth<br>WTHD: unbearable situation with no way out (other than death) |
| “Then all the red lights started flashing for me, because it was in your head, wasn’t it. Then I thought: No! No, just no. Now I’ve simply had enough. […] I’ve tortured myself enough; I don’t want to torture myself anymore” (4). | Disintegration<br>Hastened death as a way of ending suffering<br>Loss of life’s worth |
| **3.2 Unbearable situation with no way out other than death (end suffering)** | |
| “There were many times when I was in such pain and such misery. I said, let me go... Finished... no more of this torture” " (23). | Hastened death as a way of ending suffering<br>Suffering as something worse than death<br>Despair |
| “I feel, deep inside, I don’t want to feel hurting [sic]… that I want to end this… I ask God why he don’t take me, why I suffer so much” (23). | |
| “Pain is my biggest fear. It puts me in a darkness and a lack of will to go forward and a desire to die... The pain wants me to have a vehicle to just, just stop my life” (23). | Fear of suffering |
| “I can’t bear the dying process so I’ll short circuit it by dying" (23). | Fear<br>Suffering |

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| "If the pain gets worse, then I want to be dead" (23). | Anticipation of future suffering<br>Suffering as something worse than death<br>Despair |
| "If I had to go through [an acute episode of shortness of breath] again, I would throw myself in front of a subway train. I am not going through that again" (23). | Anticipation of future suffering<br>Desire for control over life<br>Fear of the dying process<br>Despair |
| "... it should be up to me to decide… when I've had enough suffering... One of my landmarks, if I'm at the point where all I can do is lie on a bed all day long, then to me that's probably not living anymore" (24) | Autonomy<br>Desire for control over life |
| "I'm inconveniencing. I'm still inconveniencing other people who look after me and stuff like that. I don't want to be like that. I wouldn't, I wouldn't. No, I'd rather die" (1). | Progressive physical deterioration<br>Dependency<br>Loss of the self |
| **3.3 To spare others from the burden of oneself** | |
| "There have been times I've felt so much a burden on my family that maybe it is best for me to die just to relieve them of going through the terminal phase of my disease" " (23). | Being a burden<br>Altruism |
| "All of a sudden, it dawned on me that there was no solution, and if there was no solution to my cancer, then why was I hanging around? I got thinking about death as a practical matter. Why hang around and cause a lot of people a lot of grief?" " (23). | Not wanting to be a burden |
| "[T]here's no question about wanting to make provisions for a hastened death should conditions become so unbearable. I want to spare my family as much of that grief as I can… [My mother] died of cancer, and we were constantly frustrated by not being able to do anything for her… And just watched her waste away. And what a terrible way to go" (24). | Loss of control |
| "I hope everyone can accept it… Most important is that my family wouldn't be heartbroken. If there were no suffering. I would like to see them for longer" (7). | Fear of suffering<br>Not wanting to make others suffer<br>Wish to live but not in this way |
| "That is somehow a vicious circle. If my wife sees me having a hard time, she is suffering from that. And then, when I see my wife suffering in extreme, and then I am in a bad shape, because after all, it is my fault" (20). | Not wanting to be a burden |
| "When I know that my life has become a burden to my loved ones, I would rather die. I think of death as a way to release me from this frustration" (22) | WTHD as a way of ending suffering<br>Not wanting to be a burden<br>Suffering as something worse than death<br>WTHD: unbearable situation with no way out (other than death)<br>Despair |
| "I always pray that I can release people, eh, that I can free them of a burden, release the others also. That I do not always have to rely on help, I want… My whole life, I only worked and always took care of [others] myself… Then after this it's simply difficult, if you always have to have other people. That you have to be a burden…That I've never like" (10). | Not wanting to be a burden |
| "I would like to go. You see, I want to let people off the hook. I don't, I don't like it that they always have to… they all have a life too and I don't want to, that I… well" (4). | Not wanting to be a burden |
| "I can't just walk away like that. One time you think, 'I might as well give up.' But that's easy for me, but not easy for them [family]. There are other people [to consider]" (6). | |
| **3.4 To preserve self-determination in the last moments of life** | |

| | |
|---|---|
| "I immediately turned to the option of Exit [pause], because I said I'd like to have this option whatever happens. If things become unbearable for me for some reason, but I'm still not dying, then I'd like to be able to grant myself my own death. And I saw to everything, so that it's ready, that I have the prescription, and talked to those people. They're quasi on call now. […] This is really only about ending a situation that has become unbearable, and not having to rely on either being hit by another stroke or some doctor being understanding after all. I want to be able to keep this in my own hands for when the moment comes. I was a very self-determined person all my life, and that's very important to me" (4). | Anticipation of a painful death<br>Desire for control over life<br>Hastened death as a way of ending suffering<br>Having a plan<br>Suffering as something worse than death<br>WTHD as a form of control |
| ''I have no desire to commit suicide, but I have no desire to take it out of my hands either" (6). | Autonomy<br>Desire for control over life<br>Wish to live but not in this way |
| **3.5 Will to live but not in this way** | |
| "See, there's a problem while planning or pursuing your death… On the one hand, I am saying all these things, and, on the other hand, I am going down for radiation" (23). | |
| "Wish to live but can't live; wish to die but can't die" (7). | Suffering |
| "It is torturous… thinking when I am going to die to escape from this suffering. But when I am not in pain, I want to live. When the symptoms disappear, I want to continue living, as I do not want to depart from my loved ones. Actually, I do not want to be parted [die]… when I do not experience any symptom. But when I suffer the symptoms, I again wish to die to escape the suffering" (22). | Pain as full mediator<br>Hastened death as a way of ending suffering |
| "No, not at this moment, but on those days when I am so miserably sick" (11). | Suffering<br>Pain<br>Having control |
| **4. Functions of the WTHD** | |
| **4.1 WTHD as a means of communication** | |
| "So I was glad that I could talk to him [husband] about it [WTHD]. Actually I was the only one, I was able to communicate that and [pause] just be able to let go of the thought, rather than letting it eat into you. Whether you then do it or not is actually secondary. It's bad for people if they can't say to anyone: you know, I have thoughts like this sometimes. So I really am glad that I was able to discuss it with him [husband], it did me good as well" (4). | Family reinforcement |
| **4.2 Family reinforcement** | |
| "I shared that I wouldn't do it until we discussed it together… She didn't have to worry about me taking the pills… It wasn't fair to them... It would leave them wondering, did they do, you know, contribute to it, did they do all they could... And I want them to feel comfortable that they've done everything" (23). | Manipulation |
| "I've also said these tongue-in-cheek things: so, now I'm starting to collect pills. Yes. And then the people concerned, the ones you say that to, they're shocked, and yet it was said tongue-in-cheek. I: To test their reaction. P: Yes, perhaps sometimes a bit of deliberate provocation" (4). | Expression of the WTHD so as to observe people's reaction |
| **4.3 WTHD as a form of control - Having a plan – Just in case / avoiding suffering (future)** | |
| "EXIT would really just be there for an emergency, and not because that's what I'd wish. That would only be if I felt I couldn't get back off this track [...] If it gets that hard, and I don't know how to put on my socks or I'm so dead sick that I think: for Heaven's sake huuh… then I would wish for it to end, just to be relieved, just that it ends. […] Yes, it's rather just being set free from this state" (4). | Anticipation of future suffering<br>Desire for control over life<br>Hastened death as a way of ending suffering<br>"If then" |
| "Yes, I have thought many times, I want to get somebody from EXIT, I also registered at Dignitas, because I thought: 'Yes, well, if it's so unbearable that, that everybody around me has to hold their nose [due to tumour ulceration and smell]. That was the worst, I think, then I wanted to break off the exercise'" (11). | Anticipation of future suffering<br>WTHD as a way of sparing others from burden<br>Hastened death as a way of ending suffering |

| | |
|---|---|
| Participant: "Oh, it's the dignity and wholeness of my body, as well as spirit. And, it is, it's cruel too for others to have to do this when there's no end in sight, other than death. To just, to clean me up. I just don't want that ...Dignity is that I have control over my body, when, when, not, not a virus that is going to take my life. I'm the one who's going to decide when my life will end, not a virus, and not with great pain. Not anything else other than in, in my control. It is my control, my choice to do" (1). | Loss of control<br>Loss of independence<br>Desire for control over life<br>Loss of the self<br>Loss of the sense of dignity |
| "…and then this sleepiness and so on, and then at some point at the back of your mind you say: well, how long am I supposed to put up with this? And then it occurs to you: well, you don't have to, you can get out of it any time. But it's more of a reassurance […] It's a reserve (4). | Loss of function<br>Desire for control over life<br>Hastened death as a way of ending suffering |
| "I will do things my way and the hell with everything and everybody else. Nobody is going to talk me in or out of a darn thing... what will be, will be; but what will be, will be done my way. I will always be in control" (24). | Desire for control over life |
| "I just feel sometimes as though cancer is, uh, an opponent. And, it seems to me, it says to itself, 'I am in control of this body. This is mine, I will do whatever I want to with it" (8). | Desire for control over life<br>Ultimate control |
| "I have considered, I do like this physician-assisted suicide. With the assistance of a doctor, so you won't have a, a, messy death… and they [doctors] have said that any time I'm going to want to, it's up to me. That's right. I'm very glad about it. Yeah" (8). | Desire for control over life<br>Fear of a painful death |
| "But it [WTD] is a ray of hope. You can say, if nothing works anymore and things are only getting worse, then you'd still have some way of shortening it" (4). | Hastened death as a way of ending suffering<br>Suffering as something worse than death<br>WTHD: unbearable situation with no way out (other than death)<br>"If then" |
| "When I feel very, very, very wretched, this thought always returns: If you can't bear it any more, you can actually cut it short. Right at the last I just could [pause]… if it's even worse than it is now" (4). | Hastened death as a way of ending suffering<br>Suffering as something worse than death<br>WTHD: unbearable situation with no way out (other than death) |
| "If I would have such a pill in some drawer or the other, and I could take it on my own when I would have the feeling that nothing goes any more, then I would feel considerably better" (21). | |
| "[When metastasis was diagnosed] I immediately set about the option of Exit … because I said, I would like to have this possibility in any case. If for any reason it becomes unbearable for me, but I'm still not dying, then I would like to bring about my own death. And I saw to it all, that it was ready, that I had the prescription, and I talked to these people. That's sort of there on demand now" (11). | WTHD: unbearable situation with no way out (other than death) |
| **5. Lived experience of timeline toward dying and death** | |
| "I just want to get it over with… Tomorrow is the same thing, the same thing" (8). | Despair<br>Suffering<br>Tiredness |
| **5.1 Anticipation of a painful death or agony** | |
| "AIDS, that's probably -seeing as I'm 41- that's probably what I'm going to die of. That is going to be a very painful death. It is painful, I've seen it. It's painful, it's sad, it's lonely in a way, that you can be surrounded be all the loving people on your life, but you, it's lonely because you're gradually rotting away, your flesh is rotting, I hope to God in a way that your mind is rotting with it, because then you become totally, you don't know what's going on" (1). | Progressive physical deterioration<br>Anticipation of a painful death |

| | |
|---|---|
| "It'll be extremely terrible. It'll be coming up from here, coming up from there, just everywhere. I mean the complications and that would give me so much pain and suffering. I anticipate the future would be like this. Very severe, very scary when I think about it" (7). | Anticipation of future suffering<br>Progressive physical deterioration<br>Fear of suffering |
| "I am not afraid about death. I am only afraid of an agonizing death. Taking too much time" (21). | Anticipation of a painful death<br>Fear of the dying process<br>Suffering as something worse than death |
| "I, I fear some of the, uh, some of the physical stress that may come in the course of my dying. Nobody chooses to die little by little. At least, I can't visualize that" (8). | Fear of suffering<br>Fear of the dying process |
| **5.2 Progressive physical deterioration** | |
| "This sort of disease ultimately leads to death. I have to walk that path" (7). | |
| "You lie on a bed and none of the normal functions come back. They will never come back and it will only get worse" (9). | Loss of function |
| "And I would not want to go through this as a daughter (of a patient). Sit down every day and watch how somebody is running towards death, lying there and finally waiting to be released" (21). | Not wanting to lose one's own value in the eyes of others |
| **5.3 Uncertainty** | |
| "I haven't been in hospital before. I wouldn't know the facts. I haven't been ill before" (7). | Fear |
| "Yes, and that is this uncertainty. You can plan nothing and, let me say, only on short notice, for very short distances" (21). | Loss of control |
| **5.4 Ambivalence** | |
| "The goal is now to die… I'm using my flexibility not to devote my time toward how I am going to die and praying, etc. I'm using my flexibility in time management to do things that the living do, not the dying." (23). | Ambivalence<br>WTHD as a will to live |

# PRISMA 2009 Checklist

| Section/topic | # | Checklist item | Reported on page # |
|---|---|---|---|
| **TITLE** | | | |
| Title | 1 | Identify the report as a systematic review, meta-analysis, or both. | Page 1 |
| **ABSTRACT** | | | |
| Structured summary | 2 | Provide a structured summary including, as applicable: background; objectives; data sources; study eligibility criteria, participants, and interventions; study appraisal and synthesis methods; results; limitations; conclusions and implications of key findings; systematic review registration number. | Page 2 |
| **INTRODUCTION** | | | |
| Rationale | 3 | Describe the rationale for the review in the context of what is already known. | Page 4 |
| Objectives | 4 | Provide an explicit statement of questions being addressed with reference to participants, interventions, comparisons, outcomes, and study design (PICOS). | Page 4 |
| **METHODS** | | | |
| Protocol and registration | 5 | Indicate if a review protocol exists, if and where it can be accessed (e.g., Web address), and, if available, provide registration information including registration number. | N/A |
| Eligibility criteria | 6 | Specify study characteristics (e.g., PICOS, length of follow-up) and report characteristics (e.g., years considered, language, publication status) used as criteria for eligibility, giving rationale. | Page 6 |
| Information sources | 7 | Describe all information sources (e.g., databases with dates of coverage, contact with study authors to identify additional studies) in the search and date last searched. | Pages from 5 to 7 |
| Search | 8 | Present full electronic search strategy for at least one database, including any limits used, such that it could be repeated. | Pages 5 and 6 |
| Study selection | 9 | State the process for selecting studies (i.e., screening, eligibility, included in systematic review, and, if applicable, included in the meta-analysis). | Page 6 |
| Data collection process | 10 | Describe method of data extraction from reports (e.g., piloted forms, independently, in duplicate) and any processes for obtaining and confirming data from investigators. | Page 6 |
| Data items | 11 | List and define all variables for which data were sought (e.g., PICOS, funding sources) and any assumptions and simplifications made. | NA |
| Risk of bias in individual studies | 12 | Describe methods used for assessing risk of bias of individual studies (including specification of whether this was done at the study or outcome level), and how this information is to be used in any data synthesis. | NA |
| Summary measures | 13 | State the principal summary measures (e.g., risk ratio, difference in means). | NA |
| Synthesis of results | 14 | Describe the methods of handling data and combining results of studies, if done, including measures of consistency (e.g., $I^2$) for each meta-analysis. | NA |

# PRISMA 2009 Checklist

| Section/topic | # | Checklist item | Reported on page # |
|---|---|---|---|
| Risk of bias across studies | 15 | Specify any assessment of risk of bias that may affect the cumulative evidence (e.g., publication bias, selective reporting within studies). | NA |
| Additional analyses | 16 | Describe methods of additional analyses (e.g., sensitivity or subgroup analyses, meta-regression), if done, indicating which were pre-specified. | NA |
| **RESULTS** | | | |
| Study selection | 17 | Give numbers of studies screened, assessed for eligibility, and included in the review, with reasons for exclusions at each stage, ideally with a flow diagram. | Pages 5 and 6 |
| Study characteristics | 18 | For each study, present characteristics for which data were extracted (e.g., study size, PICOS, follow-up period) and provide the citations. | Pages 7 and 8 |
| Risk of bias within studies | 19 | Present data on risk of bias of each study and, if available, any outcome level assessment (see item 12). | NA |
| Results of individual studies | 20 | For all outcomes considered (benefits or harms), present, for each study: (a) simple summary data for each intervention group (b) effect estimates and confidence intervals, ideally with a forest plot. | NA |
| Synthesis of results | 21 | Present results of each meta-analysis done, including confidence intervals and measures of consistency. | NA |
| Risk of bias across studies | 22 | Present results of any assessment of risk of bias across studies (see Item 15). | NA |
| Additional analysis | 23 | Give results of additional analyses, if done (e.g., sensitivity or subgroup analyses, meta-regression [see Item 16]). | NA |
| **DISCUSSION** | | | |
| Summary of evidence | 24 | Summarize the main findings including the strength of evidence for each main outcome; consider their relevance to key groups (e.g., healthcare providers, users, and policy makers). | Pages 23 and 24 |
| Limitations | 25 | Discuss limitations at study and outcome level (e.g., risk of bias), and at review-level (e.g., incomplete retrieval of identified research, reporting bias). | Pages 22 and 23 |
| Conclusions | 26 | Provide a general interpretation of the results in the context of other evidence, and implications for future research. | Page 24 |
| **FUNDING** | | | |
| Funding | 27 | Describe sources of funding for the systematic review and other support (e.g., supply of data); role of funders for the systematic review. | Pages 24 and 25 |

*From:* Moher D, Liberati A, Tetzlaff J, Altman DG, The PRISMA Group (2009). Preferred Reporting Items for Systematic Reviews and Meta-Analyses: The PRISMA Statement. PLoS Med 6(7): e1000097. doi:10.1371/journal.pmed1000097

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# Understanding patients' experiences of the wish to hasten death: an updated and expanded systematic review and meta-ethnography

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**Title page**

# **Title:** Understanding patients' experiences of the wish to hasten death: an updated and expanded systematic review and meta-ethnography

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## Abstract

**Objectives**: Patients with advanced disease sometimes express a wish to hasten death (WTHD). In 2012 we published a systematic review and meta-ethnography of qualitative studies examining the experience and meaning of this phenomenon. Since then, new studies eligible for inclusion have been reported, including in Europe, a region not previously featured, and specifically in countries with different legal frameworks for euthanasia and assisted suicide. The aim of the present study was to update our previous review by including new research and to conduct a new analysis of available data on this topic.

**Setting**: Eligible studies originated from Australia, Canada, China, Germany, The Netherlands, Switzerland, Thailand, and USA.

**Participants**: Studies of patients with life-threatening conditions that had expressed the WTHD.

**Design**: The search strategy combined subject terms with free-text searching of PubMed MEDLINE, Web of Science, CINAHL and PsycInfo. The qualitative synthesis followed the methodology described by Noblit and Hare, using the “adding to and revising the original” model for updating a meta-ethnography, proposed by France et al. Quality assessment was done using the Critical Appraisal Skills Programme checklist.

**Results**: 14 studies involving 255 participants with life-threatening illnesses were identified. Five themes emerged from the analysis: suffering (overarching theme), reasons for and meanings and functions of the WTHD, and the experience of a timeline towards dying and death. In the context of advanced disease, the WTHD emerges as a reaction to physical, psychological, social and existential suffering, all of which impacts on the patient’s sense of self, of dignity and meaning in life.

**Conclusions**: The WTHD can hold different meanings for each individual; serving functions other than to communicate a genuine wish to die. Understanding the reasons for, and meanings and functions of, the WTHD is crucial for drawing up and implementing care plans to meet the needs of individual patients.

### Strengths and limitations of this study

- This updated review and synthesis of the published literature on the WTHD offers a more nuanced understanding of the phenomenon.
- The review provides meta-ethnographic analysis of 14 studies which recorded, the experiences of 255 participants from different cultural backgrounds including Australia, Canada, China, Germany, Switzerland, Thailand, The Netherlands and the USA.
- This synthesis highlights suffering as an overarching theme and includes physical, psychological, social or existential factors.
- The synthesis exemplifies a new approach to the updating of syntheses of qualitative research.
- Included studies offer different conceptualizations of the WTHD with the research objectives of some studies only touching indirectly upon the phenomenon.

# Understanding patients' experiences of the wish to hasten death: an updated and expanded systematic review and meta-ethnography

## INTRODUCTION

Few issues in modern society generate as much controversy as euthanasia, and assisted suicide (EAS) among people facing an advanced illness. Across the world, opinions, and attitudes towards this issue differ widely. Debate, however, often centres around the implications for society or the existing legal framework. What is often overlooked is the common thread that links all those persons who contemplate ending their life: the desire to die or to hasten their death. Why do some patients with advanced disease wish to hasten their death? What meaning does this wish hold for them? What is the experience of a person who feels such a wish? To what extent do commonalities exist among those who come to feel this wish?

Although the desire to die has traditionally been seen to result from physical suffering, research suggests that this explanation is reductionist (1), and that such a wish must be understood in the context of patient experience. Thus, while cross-sectional studies offer valuable information about what may trigger a wish to ~~hasten death~~ die, the fluctuating, ambivalent, subjective, and complex nature of such wishes requires a more detailed examination of patients' experiences.

Several qualitative studies have explored the wish to die in patients with advanced disease highlighting the important role played by psychosocial, and existential/spiritual factors, alongside physical symptoms (2,3). Thus, factors such as loss of self, loss of the sense of dignity, loss of autonomy, fear about the future, fear of suffering, and fear of being a burden to others are reported among the main triggers of a wish to hasten death (WTHD). Interpretative analysis of the WTHD suggests that, in addition to these potential motivations, attention must focus on the meanings, functions, and intentions that underlie the expression of a WTHD. Thus, if we are to understand what patients actually mean when they say that they ‘no longer wish to live in this way’ we must explore their personal history, attitudes, beliefs, and thoughts. Furthermore, it is important not to confuse, for example, a wish to die in someone who is not considering actually hastening his/her death with a will to die in someone who takes action towards dying (4).

In 2012 our group published a systematic review, and interpretative synthesis (5) of then-published qualitative studies of the WTHD in seeking to understand the experience of patients with serious or incurable illness who expressed such a wish. The synthesis included studies conducted in Canada (1,6), Australia (2), China (7), and the USA (8). At that time, however, no such studies were identified from European countries.

Five years on, the subsequent publication of qualitative studies of the WTHD, among similar patient groups, and in different contexts to those featured in our earlier synthesis, justifies the need for an updated systematic review. In addition, the possibility of including studies from European countries in which EAS have been decriminalised (4,9–11) enables us to explore the extent to which different legal contexts influence the expression of a WTHD. The aim of the present study was therefore to provide an updated review of knowledge regarding the WTHD (understood here as any expression of the desire to die in patients affected by a life threatening condition), taking into account possible contextual differences.

## METHODS

This systematic review, and interpretative synthesis updates our previous synthesis (5) that included studies from 2001 to January 2010. In seeking to incorporate recent research within the synthesis, we extended our bibliographic search to cover the period from December 2000 to January 2016. The update employs Noblit and Hare's (12) meta-ethnography method, the aim of which is "to compare, re-interpret, and synthesise the findings (i.e. authors' concepts, and themes) of separate qualitative studies to arrive at an exhaustive description of the range, nature, and variety of patients' experiences" (13). This method was chosen given its widespread use in health-related research (14).

France et al. (15) propose various models for updating meta-ethnographies, using the analogy of house-building. This review applies the model they refer to as 'extending and renovating the original house' (i.e. adding to and revising an existing meta-ethnography). France et al. (15) outline potential advantages of using this model: the output forms a single coherent model or set of findings, rather than two, increasing its potential usefulness; it can lead to new conceptual insights; and it allows for innovation within the updated analysis/synthesis, while making efficient use of resources expended on the original meta-ethnography.

### Data sources and search strategy

In seeking recent clinical evidence about the WTHD we revised our original search strategy to optimise the trade-off between sensitivity, and specificity (see Table-S1). Relevant MeSH, and free-text terms were identified, and combined. The strategy was run in PubMed, CINAHL, Web of Science, and PsycINFO with the terminology being adapted to each database.

A filter for qualitative studies was used in PubMed (16), CINAHL (17), and PsycINFO (18). The qualitative PubMed filter was adapted to the specific language used by Web of Science.

### Inclusion and exclusion criteria

To be included, papers had to report primary qualitative studies (i.e. studies using recognised methods of both qualitative data collection, and qualitative data analysis) written in English, and focusing on the expression of the WTHD in patients with life-threatening conditions. Paediatric populations were excluded, as were studies focusing on older populations in the absence of advanced disease.

One researcher carried out the systematic literature search, which was verified by another researcher. Screening involved selection of retrieved citations by title, abstract, and full text. The entire sample was double-reviewed. Disagreements were resolved by discussion within the research team. Figure 1 shows the PRISMA flowchart for the selection of studies.

**Figure 1**. PRISMA flow diagram for study selection.

### Critical appraisal

Included studies were assessed for methodological quality, and rigour using Critical Appraisal Skills Programme (CASP) guidelines for qualitative studies (19) (Table-S2). No studies were excluded from this review based on their quality.

### Data analysis and synthesis

The synthesis followed the seven steps proposed by Noblit and Hare (12) as follows:

1) Definition of the research question: What is the experience of the wish to hasten death expressed by people with advanced illness?

2) A literature search for references to studies for inclusion in the synthesis.

3) Reading the studies in order to identify key and secondary concepts in each of them.

4) Determining how the studies are related. To this end we created a chart showing the categories that emerged from the studies (more descriptive level), and this served as the basis for abstracting themes and sub-themes from each study (more abstract levels that encapsulate the categories found in the different studies).

5) To perform translation across studies, in other words, to ‘deconstruct’ the studies, identifying different metaphors or concepts on the basis of words or statements in the original articles.

6) These translations were synthesized, to generate different levels of themes, sub-themes and final categories.

7) Presentation of the synthesis of the studies included, thus giving rise to a global understanding of the phenomenon and a response to the research question posed at the outset.

Supplementary Table-S3 juxtaposes the steps from the previous, and the updated meta-ethnography, and supplementary Table-S4 shows the comparison of yield between the original review, and the updated review. Atlas.ti 7 software was used to code, and memo significant statements to facilitate comparison of the themes, and categories obtained by each researcher.

## RESULTS

Fourteen articles were included in the updated meta-ethnography [seven from the original synthesis (2001-January 2010) plus seven additional recent studies (2010-February 2016)] (Table 1). Of the seven new studies included, six were conducted in European settings (4,9–11,20,21), and one in Asia (22).

Three studies used grounded theory (1,6,20), with a further study using a modified approach (21). One was a mixed-method study (2), from which only the qualitative results were included in the present analysis. One study reported using a phenomenological approach (2), and three a combination of phenomenological, and hermeneutical methods (4,7,11). A hermeneutical-ethical approach was applied in one study (10). The design of one qualitative study was unclear (not specified) (22). Most studies used in-depth or semi-structured interviews to collect data, except for one that used narrative interviews (10). Sample sizes ranged from 2 to 35 participants, yielding a total sample of 255 patients (excluding the relatives interviewed in one study (23)). The majority of studies aimed to explore the WTHD as expressed by patients with advanced disease. Only two studies had the main objective of describing suffering (9,22).

| Source paper | Country | Participants | Setting | Country’s legislation on euthanasia and AS |
|---|---|---|---|---|
| Lavery et al. (1) | Canada | 31 men; 1 woman with HIV/AIDS | HIV Ontario Observational Database | Neither euthanasia nor AS are legal |
| Kelly et al. (2) | Australia | 30 terminally ill cancer patients | Inpatient hospice unit and home PC service | |
| Coyle and Sculco (24) | USA | 7 terminally ill cancer patients | Pain and PC unit in an urban cancer research centre | |
| Mak and Elwyn (7) | China | 6 patients | 26-bed hospice in China. | |
| Pearlman et al. (23) | USA | 35 patients | Patient advocacy organizations that counsel persons interested in AS, hospices and grief counsellors | AS legal since 2009. At the time of the study, AS had yet to be decriminalised |
| Schroepfer (8) | | 18 terminally ill elders | 2 PC programmes, 2 hospital outpatient clinics and 6 hospices | Neither euthanasia nor AS are legal |
| Nissim et al. (6) | Canada | 27 ambulatory cancer patients | Outpatient clinics at a large cancer centre | |
| Stiel et al. (20) | Germany | 10 inpatients and 2 outpatients of PMD | PMD of 3 university hospitals | |

| | | | | |
|---|---|---|---|---|
| Dees et al. (9) | The Netherlands | 31 patients with different diagnoses | Support and Consultation on Euthanasia in The Netherlands network; hospice, hospital and nursing home | Euthanasia and AS legal since 2009 |
| Ohnsorge et al. (10) | Switzerland | 2 women with terminal cancer, and caregivers | PC hospice | AS legal since 1942 |
| Ohnsorge et al. (11) | | 30 terminally ill cancer inpatients/outpatients, and their caregivers/relatives | Hospice, a PC ward in the oncology department of a general hospital & an ambulatory PC service | |
| Ohnsorge et al. (4) | | 30 terminally ill cancer inpatients/outpatients, and their caregivers/relatives | Hospice, a PC ward in the oncology department of a general hospital & an ambulatory PC service | |
| Nilmanat et al. (22) | Thailand | 11 women & 4 men with terminal cancer and short life expectancy | Public health service for cancer treatment | Neither euthanasia nor AS are legal |
| Pestinger et al. (21) | Germany | 10 inpatients and 2 outpatients of PMD | PMD of 3 university hospitals | |

*PMD: Palliative Medicine Department
*PC: Palliative Care
**Table 1.** Characteristics of the studies included in the present review

## Description of themes

Five main themes emerged from the analysis of the WTHD expressed by patients with advanced disease: *suffering*, which appeared as an overarching theme; *reasons* for the WTHD; *meanings* of the WTHD; *functions* of the WTHD; and *lived experience of a timeline toward dying and death*. Supplementary Table-S5 shows the most representative statements for each theme together with its corresponding sub-themes.

The greater detail offered by the seven recent studies enabled the six themes from our previous meta-ethnography (5) to be subsumed under new, broader categories, without substantially changing their content (Table 2). One new theme emerged from the present analysis: *lived experience of a timeline toward dying and death.* Table 3 shows which themes, and sub-themes were present in each included study.

| **Themes from the original meta-ethnography** (5) | **Themes in the updated meta-ethnography** | |
|---|---|---|
| WTHD in response to physical/psychological/spiritual suffering | Reasons for the WTHD | Suffering |
| Loss of self | | |
| Fear | | |
| WTHD as a desire to live but ‘not in this way’ | Meanings of the WTHD | |

| | | |
|---|---|---|
| WTHD as a way of ending suffering | | |
| WTHD as a kind of control over life: ‘to have an ace up one’s sleeve just in case’ | Functions of the WTHD | |
| | Lived experience of a timeline toward dying and death | |

**Table 2.** Reclassification of themes from the original meta-ethnography in the present, updated meta-ethnography

| | Lavery et al. (1) | Kelly et al. (2) | Coyle and Sculco (24) | Mak and Elwyn (7) | Pearlman et al. (23) | Schroepfer (8) | Nissim et al. (6) | Stiel et al. (20) | Dees et al. (9) | Ohnsorge et al. (10) | Ohnsorge et al. (11) | Ohnsorge et al. (4) | Nilmanat et al. (22) | Pestinger et al. (21) |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| Suffering | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ |
| Reasons for the WTHD | | | | | | | | | | | | | | |
| Physical factors | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ |
| Psychological factors | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ | - | ✓ | - | ✓ | ✓ | ✓ | ✓ |
| Social factors | ✓ | ✓ | ✓ | ✓ | ✓ | - | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ |
| Loss of self | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ |
| Meanings of the WTHD | | | | | | | | | | | | | | |
| Cry for help | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ | - | ✓ | - | ✓ | ✓ | ✓ | - |
| To end suffering | ✓ | - | ✓ | ✓ | ✓ | ✓ | ✓ | - | ✓ | - | ✓ | ✓ | ✓ | ✓ |
| To spare others from the burden of oneself | ✓ | ✓ | ✓ | ✓ | ✓ | - | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ | - |
| To preserve self-determination to the very end | ✓ | - | ✓ | ✓ | ✓ | ✓ | ✓ | - | ✓ | - | ✓ | ✓ | ✓ | ✓ |
| Will to live but not in this way | | - | ✓ | ✓ | ✓ | ✓ | ✓ | - | ✓ | ✓ | ✓ | ✓ | ✓ | - |
| Functions of the WTHD | | | | | | | | | | | | | | |
| WTHD as a means of communicating | | - | ✓ | - | - | - | - | - | - | - | - | ✓ | - | - |
| WTHD as a form of control | ✓ | - | ✓ | ✓ | ✓ | ✓ | ✓ | - | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ |
| Lived experience of a timeline toward dying and death | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ |

**Table 3.** Themes and sub-themes present in each of the studies included in this review

## 1. Suffering

*Suffering* emerged as an overarching theme, confirming that the WTHD in people with advanced disease cannot be understood without taking their suffering into account. As a theme, suffering referred not only to physical distress (especially pain) but also to psychological, social or existential aspects. Thus, suffering was a complex, and multidimensional phenomenon affecting the whole person, having physical repercussions, and impacting both on their identity, and their relationships with all aspects of their immediate environment. Suffering was a common denominator for understanding the other four themes: *reasons, meanings, functions,* and *lived experience of a timeline toward dying and death.*

> "To have pain and also breathlessness, that would be terrible and so much suffering. My breathing is suffering and this affects my appetite. So many kinds of suffering… The social situation is suffering…" (7).

### 2. Reasons for the WTHD

This theme refers to the factors or rational motivations that led to a WTHD being expressed. As in our previous review (5), the WTHD emerged as a complex reaction to suffering that was related to all dimensions of personhood. Our analysis indicated that the theme *reasons* could be broken down into four sub-themes: *physical, psychological/emotional* and *social factors*, and the *loss of self*.

#### Physical factors

In all the studies reviewed, *physical factors* (symptoms) were a key issue leading to the WTHD. Participants particularly emphasised a loss of function, and pain, although aspects such as fatigue, dyspnoea, incontinence, and cognitive impairments were also mentioned as producing considerable distress (1,4,9,23).

Most participants referred to the loss of physical function; their illness prevented them from doing the things they once did, stripping them of their independence: "I lost my dignity, lying in bed in diapers, I am no longer the independent person I used to be" (9). The loss of function was also linked to a diminished quality of life.

Many patients described severe, and unbearable pain as a factor that triggered a WTHD. Pain “affected the wholeness of their beings” (22), and their lived experience: “pain affects everything. It makes you tired. It affects how you can eat. It affects other people, and the fact is that even if you try to hide it, you can’t. […] pain takes that life out of you”. Some patients experienced intense, and uncontrollable pain, but stated that were it not for this they would want to go on living: “It is torturous... thinking when I am going to die to escape from this suffering. But when I am not in pain, I want to live. When the symptoms disappear, I want to continue living, as I do not want to depart from my loved ones” (22). Likewise, some participants (9) stated that their request for euthanasia stemmed from the continuous pain they suffered. In many cases, they feared becoming a burden on others, and making them suffer. For others, however, it was linked to a loss of control over their illness (due to ineffective medical treatment), and to a feeling of helplessness, to the sense that nothing could remedy their situation.

### Psychological/emotional factors

This sub-theme comprised two categories: *fear,* and *hopelessness*. Fear was expressed in most interview studies, encapsulating fear due to uncertainty, fear about future suffering, and fear of the dying process.

Fear due to uncertainty was linked to inadequate knowledge about prognosis, and to not knowing what lay ahead. In most cases, fear was associated with a loss of control over bodily functions, and over one’s life and circumstances, as well as with physical, and functional decline, and the thought of becoming a burden on family.

Many patients, aware of their progressive deterioration, foresaw a death that would be painful both for them, and their relatives, and hence they experienced a fear about future suffering. The experience of pain, and distress, combined with a loss of function, led some to expect an unbearable suffering 'worse than death itself' (9,21,23,24). In some interviews, pain or suffering was explicitly mentioned as "the biggest fear" (24). Some reported that they would rather die than suffer further pain of the kind they had already experienced.

The fear of the dying process resulted from patients' expectation that they would be unable to express their needs, wishes or problems due to frailty or cognitive impairment (21). This fear was linked to not knowing whether the future would be marked by intense suffering.

The sense of hopelessness felt by patients was associated with the progressive nature of their illness, a process that would lead inevitably to death, and about which nothing could be done: "You lie in bed and none of the normal functions come back. They will never come back and it will only get worse" (9). Some patients said they felt mentally exhausted, and tired of fighting their illness. One of the interviewees described his illness as "the end of many dreams for plans […] the end of it all. There's no future really" (2).

## Social factors

For many, *social factors*, such as being a burden on others, making loved ones suffer, or being dependent, and in need of help, were another cause of suffering, and a reason for expressing the WTHD. The idea of causing others to suffer frequently caused patients themselves to suffer. For some, observing their own deterioration, and the impact of this on loved ones, was more difficult to bear than their own suffering.

Related to loss of function was increased dependency on others resulting from a deteriorating state. In some cases this dependency left many patients "at the mercy of others" (9), and feeling useless. Participants complained about needing to be fed, washed or dressed by others (1,7): "It's horrible […] the whole situation. […] Not being able to get out of it, and every morning the same thing: waking up, being washed, lying there till the evening, the same pain" (4). For those who had been highly independent prior to their illness, or who had a high level of professional responsibility at work, the change in role (i.e. to dependency, and vulnerability) impacted enormously on their way of life, with some finding this difficult to accept.

Some patients said that they felt devalued, and treated as if they were no longer a person. Thus, further suffering, and a loss of self-esteem could be caused by health professionals failing to respond to their needs, to convey empathy, and a comforting attitude, or to respect their treatment choices (4).

"Just one sentence can hurt me, making things even worse… Really bad… When I need someone to help me, they just hurt my self-esteem […] I was right but they said I was wrong... What was worst was that I had to admit to being wrong and agree with them" (7).

**Loss of self**

Many participants attributed the WTHD to a perceived loss of self or of identity, due to the impact of their illness on their life. Physical, psychological, and social factors (suffering; dependency; loss of control, both mentally, and physically; loss of self-esteem; or feeling a burden on others, etc.) combined to severely undermine their self-image, their sense of who they were: "she was going to lose significant ability to be the person she was" (23). Some studies referred to the loss of self as a loss of the essence, loss of personality, loss of the sense of dignity (23) or destruction of the self (24). When participants felt vulnerable, looked down on or inferior with respect to others, then the loss of self was heightened. In some cases, this led the individual to feel a loss of community (1), that is, a loss of close personal relationships accompanied by feelings of isolation, and a lack of understanding.

Many patients described the experience of being devalued or treated as an object, as well as the feeling of having lost control over oneself, and of being forced into a situation that went against all they considered to be important, as losing their sense of dignity. Some situations -especially those that drew attention to their loss of control, and independence, notably in hospital settings- were perceived by interviewees as demeaning, leading them to being felt treated as objects or patients rather than as individuals (1,23).

Some patients did not wish to succumb to a situation over which they had little control, and thus the WTHD emerged in response to a perceived lack of purpose or meaning in life: “I’m just saying to myself when I go to sleep, ‘Just let me die.’ I don’t want to have to wake up and face this. […] I have nothing to live for, absolutely nothing. There’s nothing coming up in my life that I am living towards, and if there was it would be so terrible because it probably wouldn’t happen” (6). For patients such as this, losing what made life worthwhile, and relevant strips them of the will to live. This loss of self is associated with a broader series of losses (of quality of life, of autonomy, of the ability to perform daily life activities, etc.), such that illness is experienced as progressive loss that will cease only in death.

## 3. Meanings of the WTHD

Our analysis suggested that the meanings attributed by patients to the WTHD could be categorised into five sub-themes.

### Cry for help

As a result of their suffering, many participants expressed the need for immediate action to put an end to their torture, to the misery of the current situation (24). In some cases this involved an explicit request for help -whether from professionals or someone close to them- in coping with all they were going through. For other patients, the cry of despair was the result of their suffering, and the difficulty of accepting their illness, an aspect revealed in the rhetorical questions that are sometimes posed: ‘Why me?’ or ‘Why do I have to go through this?’ (22,24).

### To end suffering

Death was sometimes described as preferable to suffering, or as the lesser of two evils (4) (“I don’t want to go through the dying process so I’ll kill myself” (24)). Here, the WTHD becomes synonymous with not wanting to suffer any more, and the desired death is seen as a release (“a vehicle to just, just stop my life” (24)), as a way of putting an end to loneliness, fear, dependence, pain, hopelessness, and the feeling that life is no longer enjoyable (8), or as a means of limiting disintegration, and loss of self (1).

### To spare others from the burden of oneself

Advanced illness, and its consequences (i.e. suffering, loss of independence, the need for help from others) led some people to state that they would rather die than be a burden to their loved ones, or see them suffer: “No matter how much they love you, you are always a burden. You automatically become a burden to everyone…” (6); “When I know that my life has become a burden to my loved ones, I would rather die” (22). The WTHD can thus represent the desire to spare others from suffering, a gesture of altruism (24).

### To preserve self-determination to the very end

The WTHD was also seen as a way of preserving self-determination, autonomy or control through to the very end of life. For some patients, the possibility of putting an end to their life, and of exerting some control, became more important as they began to lose more of their capacities.

"I will do things my way and to hell with everything and everybody else. Nobody is going to talk me in or out of a darn thing…. What will be, will be; but will be, will be done my way. I will always be in control" (23).

"I am in control of this body […] I will do whatever I want to with it" (23).

"I would like to bring about my own death" (11).

### Will to live, but not in this way

The WTHD also emerged, somewhat paradoxically, as an expression of "the will to live, but not in this way". For some people, not being able to do the things that brought meaning, and value to their life was a reason to wish for its end. Many patients mentioned activities that made life worth living (e.g. creative activities, reading, driving, or enjoying time spent with family, and friends), and they felt convinced that when they could no longer do any of those things, their life would be meaningless, and they wouldn't want to live anymore (23). Some participants referred explicitly to the paradox of a will to live but not in this way, acknowledging, for example, that they experienced a wish to die at the same time as undergoing active anti-cancer treatment (10).

## 4. Functions of the WTHD

Analysis of the reviewed studies suggested that the WTHD can serve two possible purposes or functions: *a means of communicating,* and *a form of control.*

### WTHD as a means of communicating

Although many participants did not refer to this aspect explicitly, the expression of a WTHD served to communicate feelings, thoughts, and wishes. In the context of extreme suffering it represented a 'cry for help'. In some studies patients used the WTHD to voice concerns about death, and illness (4,24). One patient spoke about how difficult it was to talk about death with her husband, adding that the verbalisation of her WTHD had opened a way into this topic (4).

### WTHD as a form of control

For some patients, having a sense of their own personal agency brought some relief from present suffering. In this respect, the WTHD was equated with maintaining some control over their life, and of avoiding further suffering. In some cases, this control was expressed through hypothetical plans about how they would end their life if things deteriorated. Coyle and Sculco (24) refer to this projection into the future as the 'if-then' scenario: if my illness progresses, and I can no longer bear to suffer, then I will put an end to my life. In countries where euthanasia or assisted suicide are legal, this notion of 'having a plan' implied making contact with organisations, or professionals that supported such practices (1,4,9,23).

### 5. Lived experience of a timeline toward dying and death

The experience of a WTHD was also associated with the sense that time was running out. The anticipation of imminent death, and an awareness of the finality of life brought more suffering, and disquiet, and it was in this context that, paradoxically, the idea of hastening one’s death came to be seen as a way of putting an end to suffering. Some participants described how they had had to give up the usual things they did (4,23). Such inactivity left them feeling that all they could do was wait as time itself appeared to slow: “waiting and waiting, too often, extended, prolonged, so long, on and on, it should be over, limited, until the last moment, and from one second to another” (21).

For some people, their WTHD fluctuated over time. In these cases, the wish to live might become stronger as reasons why the person had wished to die became less prominent (e.g. their physical pain lessened). However, the balance could then tip the other way depending on their circumstances, such that, at times, a wish to die, and a wish to live might both be present.

## DISCUSSION

Five years on from our previous meta-ethnography the inclusion, and analysis of seven additional studies has brought greater understanding of the WTHD. Using an approach that France et al. (15) refer to as ‘extending and renovating the house’ the inclusion of recent literature has enabled us to reclassify categories from our original synthesis into a new set of themes. The new analysis also yielded an additional theme not present in the earlier review. Statements from participants in the additional studies, as well as theorisation proposed by study authors, were key to this reconceptualization.

Our findings indicate that the primary, overarching theme for an understanding of the WTHD in patients with advanced disease is suffering. This extends to different dimensions of their personhood, and thus may involve physical, social, psychological/emotional, and/or spiritual/existential suffering. Many patients referred to the deep impact of this suffering on their sense of self or identity, as well as on their immediate surroundings, and their ways of coping with life. These findings are consistent with a recent international expert consensus statement, which defined the WTHD as “a reaction to suffering, in the context of a life-threatening condition, from which the patient can see no way out other than to accelerate his or her death” (25).

Although suffering emerged as the common theme underlying the experience of the WTHD, one participant in the study by Ohnsorge et al. (4) stated that she was not suffering, but because she knew that she would die soon, she wanted death to come faster (without actually having the WTHD). While this is the only case we identified where a WTHD was expressed outside a context of suffering, we do not rule out the possibility that other similar cases may exist. Just as for some patients death was seen as release from their illness, the patient referred to above seems to have gained some relief from the knowledge that her illness was progressing, and that death was imminent.

The second theme, reasons, captures how a WTHD can represent a response to physical, psychological/emotional, and social factors in the context of intense suffering, and a perceived loss of self. Although physical pain was for many years considered the primary cause of the WTHD, studies conducted since the late 1990s offer a more complex view (26). Thus, while several authors report a close relationship between the WTHD and, for example, greater functional impairment, and dependency (27,28), there is evidence to suggest that psychological, and emotional factors play an important role in the emergence of such a wish (3,5,26). In terms of a person’s subjective experience, it is not possible to separate physical symptoms, and functional impairment from the impact they have on the person’s relationship to his or her surroundings, and the psychological or existential suffering that results. Indeed, physical pain, and loss of functionality are inextricably linked with all other aspects of the self, and as such they may, for example, lead to feelings of hopelessness and helplessness making it difficult for the patient with advanced disease to find meaning in life. This multifaceted suffering, which cannot be reduced to its constituent parts, exemplifies what Cicely Saunders (29) referred to as 'total pain'. Some participants felt that were it not for their physical pain they would not wish to die. However, other statements made by patients indicate that the experience of pain cannot be understood in isolation from its impact on the person's psychological and emotional state and their relationship with the immediate environment. These apparent contradictions may reflect how researchers have explored or assessed pain in this context, since instruments used in cross-sectional studies are unable to capture the full intensity and experiential impact, with qualitative research offering a more nuanced holistic account of the experience of pain.

In our synthesis psychological factors are prominent as triggers of the WTHD. Quantitative studies, assessing psychological factors related to the WTHD, could add valuable, complementary information to the findings of the qualitative studies. Depression, for example, has been widely reported as a mediating factor for the WTHD (30,31). In a study by Breitbart et al. (30) it was observed that patients who presented the desire to die were four times more likely to be depressed than those who did not. In another study, Akechi et al. (31) showed that, of a sample of 1721 patients, 220 were diagnosed with major depression and that 51.4% of these had suicidal ideation.

In this synthesis, only three of the 14 included studies (2,23,24) directly referred to the need to address depression. However, in the light of our analysis of study data, clear symptoms of depression can be detected: loss of interest or pleasure in usual activities, loss of energy, feelings of worthlessness, self-reproach, fearfulness, pessimism, recurrent thoughts of death (32).

Similarly, it is important to explore and evaluate hopelessness, helplessness, purposelessness, etc., recurrent states for those who experience the WTHD, as demonstrated by the majority of the participants in our analysis.

Another factor linked to the emergence of the WTHD is demoralization syndrome which can be clinically differentiated from depression and is a powerful mediator of the WTHD in these patients (33,34). Three studies included in this synthesis refer to demoralization (2,4,9). The fact that participants presented hopelessness, loss of meaning and purpose, sense of helplessness, social isolation and lack of support among other findings (35) could be symptomatic of demoralization syndrome, at least in some of the sample. This finding is especially relevant for clinicians, who could implement measures for its detection and treatment (36).

Another aspect that was prominent in our synthesis was that many patients referred to the fear of future physical symptoms or future suffering rather than actual current physical symptoms. Our analysis identified that many patients had already experienced episodes of acute poor symptom control with past experience leading them to be fearful when anticipating the future process. In this way, we can further confirm an overlap between physical or psychological factors. Furthermore, we can see how the symptom picture offers a basis for the psychological response to the situation being encountered: in this case, through fear.

While the authors of the included studies identify diverse reasons for the WTHD, these are, in fact, inter-related. In some cases it is difficult to differentiate the physical, psychological, emotional, social, and existential dimensions of patients' experience. Thus, for example, although aspects such as meaning in life or loss of the sense of dignity are often described as psychological/emotional/existential issues, in our analysis they relate to the sub-theme of *loss of self*, in other words, a loss of identity that covers all dimensions of personhood.

The concept of dignity in the context of patients with advanced illnesses is crucial because it resolves the inevitable difficulty in trying to delineate physical from psychological suffering. It allows us to understand that patients perceive suffering and simultaneously attribute meaning to their experience. Dignity has been defined as an intrinsic and absolute quality of human beings, which can be perceived as a sense of identity, in relations to physical, psychological, spiritual and social factors mediated by illness (37). The perception of personal dignity, understood as how a person perceives themselves in the light of suffering, the loss of functionality, changes in physical image etc., along with the emotional impact of experiencing illness, holds special relevance. In this sense, dignity encompasses very different aspects from loss of the sense of dignity mediated by the loss of functionality (loss of bodily function, cognitive impairment, loss of value of life, loss of quality of life) through to dignity understood as personal identity (loss of self-worth, loss of image, loss of self-esteem, loss of social identity: fear of being vulnerable, shame) (37–41).

The third theme that emerged from our synthesis was *meanings*. Identifying the meanings the WTHD may hold (other than simply a desire to die) is crucial for understanding the complex and dynamic nature of this phenomenon. Some studies point out how the WTHD can fluctuate over time (42,43), such that an individual may experience contradictory wishes (7,10,24). Such cases highlight the need for caution when exploring the meanings that a given individual may attribute to the expression of a WTHD. Furthermore, although the meanings identified in this updated review were derived from the statements made by participants, the meaning of a WTHD may also be influenced by the values and moral understanding of patients (10,44). In this respect, it is important to explore the cultural and personal background of a patient who expresses a WTHD so as to be able to properly contextualise what is being expressed.

The fourth theme, functions, considers the WTHD as a means of communicating and as a form of control. All the studies revealed that the WTHD served to express more than just a desire to die. The communicative function of the WTHD was clear in some cases, in strengthening family ties and highlighting how important the care and presence of loved ones was to the patient. In some way, the WTHD is also experienced as a way of reducing the burden on family members and of saving them from experiencing a protracted process before death (4,23). Involving relatives in decision-making meant that responsibilities were shared and helped ensure, to some extent, that the patient would not be abandoned to their fate. Occasionally, the expression of a WTHD was used to make relatives, friends or professionals feel that they should do more for the patient, or to obtain personal gain. In the majority of cases, however, the expression of a WTHD was a way of communicating the extent of suffering (24).

The WTHD as a form of control featured in our previous meta-ethnography. For this update, however, our analysis paid closer attention to the legal context, especially in countries in which euthanasia or AS has been decriminalised. Of the 14 studies, six (4,8–11,23) refer explicitly to physicians or organisations that could provide support to persons interested in euthanasia or AS. Making contact with right-to-die organisations was seen as the final act of control available to someone with a terminal illness. Some patients who expressed this desire for control ended up dying through the administration of lethal drugs (9,23). In countries where such practices remain illegal, patients alluded to hypothetical plans in which the possibility of suicide was contemplated. Such plans appeared to generate a sense of control and of relief among patients (without the irreversibility associated with euthanasia or AS). Once again, the primary motive for such control was the wish to put an end to suffering. In sum, the existence of legislation that permits euthanasia or AS can influence decision-making for advanced patients at the end of life (4).

The final theme, *lived experience of a timeline toward dying and death*, contextualises patients' statements within a temporal framework. The experience of time only appeared explicitly (i.e. as a theme identified in the data analysis) in one study (21). However, when patients in other studies spoke of their experience of progressive deterioration, fear, anguish, hopelessness, and loss of control, etc. they made implicit reference to their life past, present, and future. This temporal aspect of the WTHD, captured not only in qualitative studies (45), highlights the importance of a more detailed exploration of patients' experience when seeking to address their doubts, and concerns.

## Strengths and limitations

This updated review and synthesis of the published literature on the WTHD has brought a more detailed understanding of the phenomenon. For the present qualitative analysis, two researchers (ARP and ABo) joined two authors from the previous meta-ethnography (CMR, ABa), and this triangulation of researchers (46) injected a fresh perspective. Inclusion of studies from countries beyond those from the earlier meta-ethnography (specifically, Germany, The Netherlands, Switzerland, and Thailand) increases the transferability of results. So far, we have been unable to identify published studies of the WTHD in Africa, South America, and the Middle East. As in our previous review, we achieved data saturation in the present study. Only one new theme ('lived experience of a timeline towards dying and death') was identified, a theme already implicit in the earlier meta-ethnography. Other themes that emerged encapsulated previously identified themes, which were here reclassified, and reconceptualised.

One limitation of the present study concerns the difficulty of synthesising findings from primary qualitative studies. Not all studies used the same conceptualisation of the WTHD, and the research objectives of some studies only touched indirectly upon the phenomenon. Likewise, not having access to the original interviews limits the available data.

**Implications for practice and future research**

The WTHD is a complex phenomenon to which various reasons, meanings, and functions may be attributed. This highlights the need for professionals to be trained so that they can respond to and understand the impact of a life-threatening illness on the individual. Furthermore, an understanding of the factors that can trigger a WTHD may help to prevent its emergence. From a quantitative perspective, many studies have linked the emergence of the WTHD with the aforementioned factors. Some of these even analyse predictors of the WTHD (28,33,47,48). For example, Rodin et al. (49) used a structural equation model to support the view that depression, hopelessness, and the desire for hastened death represent final common pathways of distress determined by multiple risk and protective factors. Vehling et al. (48), using a similar methodology, showed that loss of dignity partially explains the positive association between the number of physical problems and demoralization in cancer patients. Robinson et al. (33) suggest that depressive symptoms, loss of meaning and purpose, loss of control, and low self-worth are relevant psychological mechanisms that probably contribute to the development of a desire to hasten death in palliative care patients. Recently, Guerrero-Torrelles et al. (50) show a model whereby meaning in life (specifically in the sense of diminished meaning) and, to a lesser extent, depression have a mediator effect on the relationship between physical impairment and the WTHD in patients with advanced cancer. Nevertheless, the large majority of quantitative studies have cross-sectional designs, which limits the possibility of establishing causality, as well as only studying variables that could be quantified. In this sense, qualitative studies offer a more in-depth study of the phenomenon as a whole.

It has recently been suggested (28) that proactively asking patients about a potential WTHD could be beneficial. Further studies are required to explore this strategy. Given that social factors contribute to the emergence of a WTHD, future research should explore how the expression of a WTHD is experienced by the person's relatives, and what meanings it may have for them. Systematic guidelines regarding the WTHD are needed to help health care professionals respond adequately to the needs of these patients.

## CONCLUSIONS

The WTHD in patients with advanced disease cannot be understood outside the context of their suffering, a prerequisite for its emergence in this population. However, every expression of a WTHD will have associated reasons (the whys) and functions (for what purpose), and its meaning may vary by cultural background and lived experience, to not necessarily be synonymous with a genuine desire to die. In countries where EAS have been decriminalised, the expression of a WTHD may be seen as a way to end suffering. All these aspects underline the need to explore the reasons, meanings, and functions that a person attributes to such a wish, as only by doing so will we be able to understand his or her experience and develop appropriate individualised care plans.

## Figure legend

Figure 1. PRISMA flow diagram for study selection.

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### Contributions

Contributors CMR and ABa designed the study. CMR collected data. ARP and CMR conducted data analysis. ARP, CMR and ABa wrote the manuscript. ABa and ABo made substantial contributions to the identification of relevant literature, the interpretation of findings and were involved in drafting the manuscript and revising it critically. All authors gave final approval to this manuscript.

### Competing interest

The authors declare no conflict of interest.

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### Data sharing statement

All data supporting this study are provided as supplementary information accompanying this paper. Further information can be obtained from the corresponding author.

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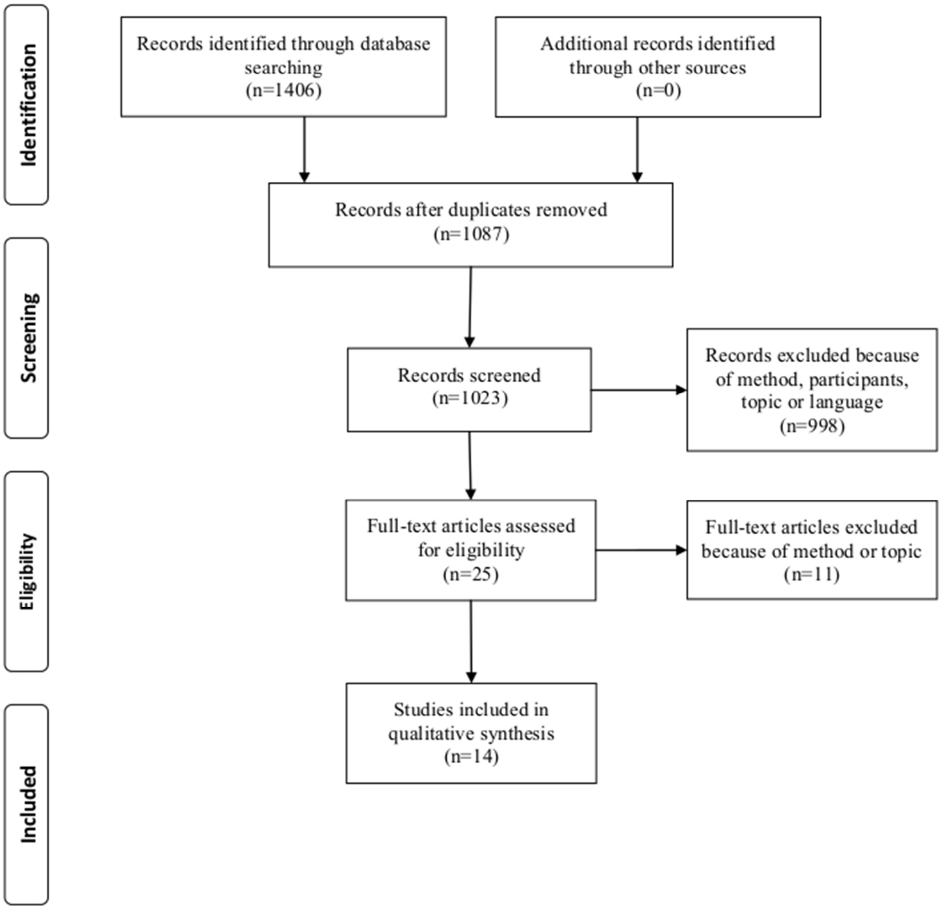

Figure 1. PRISMA flow diagram for study selection.

63x60mm (300 x 300 DPI)

## SUPPLEMENTARY FILES

**Table-S1.** Final database search strategy.

| | |
|---|---|
| 1 | desire to hasten death |
| 2 | wish to hasten death |
| 3 | euthanasia [Mesh] |
| 4 | suicide, assisted [Mesh] |
| 5 | end of life decisions |
| 6 | wish to die |
| 7 | 1 or 2 or 3 or 4 or 5 or 6 |
| 9 | palliative care |
| 10 | end of life care |
| 11 | end of life |
| 12 | 9 or 10 |
| 13 | chronic disease |
| 14 | chronic illness |
| 15 | advanced disease |
| 16 | advanced illness |
| 17 | advanced cancer |
| 18 | life limiting illness |
| 19 | terminally ill |
| 20 | life threatening illness |
| 21 | life threatening condition |
| 22 | 13 or 14 or 15 or 16 or 17 or 18 or 19 or 20 or 21 |
| 23 | Qualitative Pubmed or CINAHL filter |
| 25 | 7 and 12 and 22 |
| 26 | 25 and 23 |
| 27 | 26 not (child*) or (pediatr*) |

**Table-S2.** Methodological quality of included studies, assessed using CASP criteria: qualitative research checklist

| Reporting Criteria (CASP) | N (n=14) | References of studies reporting each criterion |
|---|---|---|
| **1) Was there a clear statement of the aims of the research?**<br>**Consider:** (Yes // No // Comments)<br>- What the goal of the research was | 14 | (1–14) |
| – Why it is important | 14 | (1–14) |
| – Its relevance | 14 | (1–14) |
| **2) Is a qualitative methodology appropriate? Consider:**<br>– If the research seeks to interpret or illuminate the actions and/or subjective experiences of research participants | 14 | (1–14) |
| **3) Was the research design appropriate to address the aims of the research? Consider:**<br>– If the researcher has justified the research design (e.g. have they discussed how they decided which methods to use?) | 12 | (1,3–10,13,14) |
| **4) Was the recruitment strategy appropriate to the aims of the research? Consider:**<br>-If the researcher has explained how the participants were selected | 13 | (1–10,12–14) |
| – If they explained why the participants they selected were the most appropriate to provide access to the type of knowledge sought by the study | 13 | (1–10,12–14) |
| – If there are any discussions around recruitment (e.g. why some | 11 | (1–9,12,14) |

| | | |
|---|---|---|
| people chose not to take part) | | |
| **5) Were the data collected in a way that addressed the research issue? Consider:**<br>- If the setting for data collection was justified | 14 | (1–14) |
| – If it is clear how data were collected (e.g. focus group, semi-structured interview, etc.) | 13 | (1–9,11–14) |
| – If the researcher has justified the methods chosen | 7 | (4,6,7,9,10,13,14) |
| – If the researcher has made the methods explicit (e.g. for interview method, is there an indication of how interviews were conducted, did they use a topic guide?) | 11 | (1,3,4,6–9,11–14) |
| – If methods were modified during the study. If so, has the researcher explained how and why? | 2 | (10,14) |
| – If the form of data is clear (e.g. tape recordings, video material, notes, etc.) | 14 | (1–14) |
| – If the researcher has discussed saturation of data. | 10 | (1,2,5–7,9,10,12–14) |
| **6) Has the relationship between researcher and participants been adequately considered? Consider whether it is clear:**<br>-If the researcher critically examined their own role, potential bias and influence during: | 2 | (4,7) |
| formulation of research questions | 3 | (1,3,7) |
| data collection, including sample recruitment and choice of location | 5 | (1,3,4,6,7) |
| - How the researcher responded to events during the study and whether they considered the implications of any changes in the research design | - | - |
| **7) Have ethical issues been taken into consideration? Consider:**<br>– If there are sufficient details of how the research was explained to participants for the reader to assess whether ethical standards were maintained | 13 | (1–5,7–14) |
| – If the researcher has discussed issues raised by the study (e.g. issues around informed consent or confidentiality or how they have handled the effects of the study on the participants during and after the study) | - | - |
| – If approval has been sought from the ethics committee | 14 | (1–14) |
| **8) Was the data analysis sufficiently rigorous? Consider:**<br>– If there is an in-depth description of the analysis process | 12 | (3–14) |
| – If thematic analysis is used. If so, is it clear how the categories/themes were derived from the data? | 12 | (1,3–5,7–12,14) |
| – Whether the researcher explains how the data presented were selected from the original sample to demonstrate the analysis process | 6 | (1,3,4,9,10,14) |
| – If sufficient data are presented to support the findings | 12 | (1–8,10,12–14) |
| – To what extent contradictory data are taken into account | 1 | (11) |
| – Whether the researcher critically examined their own role, potential bias and influence during analysis and selection of data for presentation | - | - |
| **9) Is there a clear statement of findings? Consider:**<br>– If the findings are explicit | 14 | (1–14) |
| – If there is adequate discussion of the evidence both for and against the researcher's arguments | 9 | (1,3,6,7,9,11–14) |
| – If the researcher has discussed the credibility of their findings (e.g. triangulation, respondent validation, more than one analyst) | 10 | (1,3,6–9,11–14) |
| – If the findings are discussed in relation to the original research questions | 14 | (1–14) |
| **10 How valuable is the research? Consider:**<br>– If the researcher discusses the contribution the study makes to existing knowledge or understanding (e.g. do they consider the findings in relation to current practice or policy, or relevant research-based literature?) | 13 | (1–9,11–14) |
| – If they identify new areas where research is necessary | 13 | (1–9,11–14) |
| – If the researchers have discussed whether or how the findings can be transferred to other populations or considered other ways the research may be used | 8 | (1,3,5–9,11) |

**Table-S3.** The seven stages of meta-ethnography, summarising what each step entailed in the previous and the present review

| **Noblit and Hare's 7 steps** (15) | **What each step entailed in our original meta-ethnography** (16) | **What each step entailed in the present, updated meta-ethnography** |
|---|---|---|
| 1. "Getting started" (the topic focus) | To analyse the meaning of and motivation for the WTHD in patients with chronic illness or advanced disease. | To analyse the WTHD in patients with chronic illness, advanced disease or life-threatening illness. |
| 2. Deciding what is relevant to the initial interest | Design a search strategy to identify qualitative studies (December 2000-November 2009). | Design of a revised optimal search strategy. For inclusion: qualitative studies (December 2000-January 2016). Studies from original meta-ethnography and from update to be integrated. |
| 3. Reading the studies | Generate list of key concepts to identify common and disparate concepts and themes, both within and across studies. Findings from the research reports divided into text units coded by words, sentences or paragraphs, according to content. Codes grouped into themes to define characteristics or different dimensions of the phenomenon studied. | Generate list of key metaphors using Atlas.ti software to identify common and disparate concepts and themes, within and across studies. No distinction to be made during reading and analysis between previously reviewed and new studies. Findings from research reports to be handled in same way as for the original meta-ethnography. |
| 4. Determining how studies are related | Directly compare concepts from primary studies using reciprocal translations (generating metaphors to express similarities between study findings). | Directly compare concepts from primary studies using reciprocal translations (as for the original meta-ethnography). |
| 5. Translating the studies into one another | Having identified main concepts from each study, search for their presence or absence in all the studies. Comparison to begin with themes identified in the earliest published article and to proceed in chronological order of publication. Translate themes to the whole sample and to each individual study. | Having identified concepts from each study, search for the presence or absence of main concepts in all studies. Comparison again to follow chronological order. Translate themes to the whole sample and to each individual study. During the analysis, return to the original themes, comparing them with the new themes that emerge. Themes emerging from the update can confirm or broaden the original themes, or constitute new themes. |
| 6. Synthesising translations | Bring together translated concepts within a synthesis, starting from identified themes, and match them with their respective quotations, resulting in themes within final synthesis. Finally, derive explanatory model. | Bring together expanded number of translated concepts within an expanded final synthesis. Concepts can confirm original translated concepts, but might also lead to new explanatory model. |
| 7. Expressing the synthesis | Express synthesis as themes with an accompanying narrative in a scientific journal. | Again, express synthesis as themes with an accompanying narrative for submission to a scientific journal. |

**Table-S4.** Comparison of yield between Original Review and Updated Review

| **Noblit and Hare's 7 steps** (15) | **Original Review** | **Updated Review** |
|---|---|---|
| 1. "Getting started" (the topic focus) | 7 studies (December 2000-November 2009) | 14 studies: 7 original + 7 new studies (December 2000-January 2016) |
| 2. Deciding what is relevant to the initial interest | | |
| 3. Reading the studies | | |
| 4. Determining how studies are related | 10 translated concepts | 25 translated concepts |
| 5. Translating the studies into one another | | |

| | | |
|---|---|---|
| 6. Synthesising translations | 6 themes | 5 themes |
| 7. Expressing the synthesis | Explanatory model | New explanatory model |

**Table-S5.** Classification of verbatim statements from the studies by theme and sub-theme

| **Themes, subthemes and quotations** | **Some of the related themes** |
|---|---|
| **1. Reasons for the WTHD** | |
| **1.1 Physical factors** | |
| "Um, the ability to perform simple things like, you know, going to the bathroom on your own and not through a bag, um, breathing with your own lungs, not dependent upon a machine to keep the body parts functioning, um being able to do anything, I mean as long as you can think then you can live, but if you can't [sic] no longer even formulate a thought due to dementia or you know the ravages of the disease. You know, if you were to stand there in your former self, would you want to see yourself in that position? I know I wouldn't. You get to the point where there's no return, you know, I can understand somebody saying, well geez, you know, like I used to be somebody, but now, like I mean, you know, I'm no better than like a doll, somebody has to dress me and feed me and I guess it's uh, I don't know how to explain it, really" (1). | Dependency<br>Progressive deterioration<br>Loss of function<br>Loss of the self<br>Loss of the sense of dignity |
| "… If I'm going to be rolling around in my own faeces because I have no control, then forget it" (1). | Loss of function<br>Loss of control |
| "You turn them over, they're in pain. They're going to shit themselves, they're going to piss themselves, they're going to lie there and have someone do all their bodily functions and just, they're going to suffer the whole time, they're going to be no happiness, they're going to go down to 60-70 pounds, they're just going to, their whole last weeks of life is just going to be in pain and agony and people coming in, people being upset, them being upset" (1). | Loss of function<br>Anticipation of future suffering<br>Not wanting to make others suffer |
| "I can't move, just lie here... feeling like a vegetable… a useless person... needing people to feed me" (4). | Loss of function<br>Loss of independence<br>Dependency<br>Loss of value |
| "But really yes, to see a man, who only exists of pain, who maybe is cognitively impaired and isn't able to participate actively in life, this man, who only lies in bed, not noticing his surroundings…" (14). | Suffering<br>Loss of physical function and cognitive impairment<br>Loss of daily life activities<br>Loss of value |
| "I say: I have made my decision. I don't want you to treat me any longer. Someone says, now you are probably too weak for chemo. I say: if I'm not too weak and they want to give me chemo, I will refuse it, because in the little time that is left to me I want quality of life, not quantity of life. I decided that a year ago: if this were to overcome me, then that's what I would choose" (9). | Loss of quality of life<br>Desire for control over life |
| "If you get cancer, you'll get pain. Cancer is a painful disease. It'll just get more and more painful" (4). | Progressive deterioration<br>Suffering<br>Lived experience of time<br>Anticipation of future suffering |
| "Whether it gets better or not, it's destined. I'll wait to die. There's no way out even if the pain returns. It'll come when it may. I'll just go along with the pain and die. Nothing would help" (4). | Pain<br>Suffering<br>Hopelessness<br>WTHD as unbearable |

| | |
|---|---|
| | situation with no other way out |
| “The side effects of the treatment are unacceptable… the Prednisone destroys you. For example, it destroys your muscles. My thighs are so weak I can’t get up from the floor, and I don’t have the energy to exercise. The whole thing is a vicious circle… My face… looks like a melon… I look like a frog in heat” (5). | Progressive deterioration<br>Loss of function<br>Loss of image: shame |
| “... the terrible weakness and the nausea and just not feeling like you can do anything... And it’s kind of like goals that I actually have or things that I want to accomplish are slowly being taken away… it’s kind of like the realm of the possible… is shrinking” (5). | Progressive deterioration<br>Lived experience of time (there is no future)<br>Hopelessness<br>Losses |
| “The pain could happen immediately or it could happen an hour or two later. And then I have to see about seeing [my provider] again. It is a treadmill that I'm on; I can't get off of it, and I've had it. And I can't live this anymore” (5). | Anticipation of future suffering<br>Unbearable suffering with no other way out |
| “Well, the pain that I had before with the rheumatoid arthritis I knew that I could handle—... But this pain that I have, I’m not sure—I can’t get rid of it with the pain medicine always... To give me enough to keep that pain under control, they’d have to put me out, and I don’t want my son to have to take care of a bed patient” (5). | Not wanting to be a burden<br>Unbearable suffering with no other way out |
| “I have fecal incontinence. I can no longer swallow and in hot weather I really envy people who can drink” (9). | Loss of physical functions<br>Loss of control<br>Loss of the sense of dignity: shame |
| “The way to my bed is endless and finally I get there. It takes a lot of energy, but once I’m in bed, it takes an hour just to gather my strength again” (9). | Loss of function<br>Progressive deterioration<br>Losses |
| “I am in pain all the time, I am in pain at night, I wake up with pain and I go to bed with pain. If they could take away half my pain I wouldn’t be thinking about euthanasia” (9). | Pain<br>Suffering<br>Will to live but not in this way<br>Hastened death as a way of ending suffering |
| “I was simply nauseous and my energy was just running out. And I said that I wished that, just for a short period of time, I could eat normally and not have to fight to keep it down and that I wanted to have a little more energy. Then I stopped the chemo and indeed I had that improvement” (9). | Consequences of the medical treatment |
| “Yes, I could not tell it, because I have just no pain now. That’s maybe less [the idea that her illness should proceed faster]. If I had pain now or so, then I would say: immediately. But then… I will have to wait. That’s not my business. That’s God’s business” (11). | Pain as *mediator* of the WTHD<br>Ambivalence<br>Wish to live but not in this way |
| P: “It’s horrible, I can tell you. It’s horrible. […] the whole situation. I: The situation. Not being able to get out of it. P: Not being able to get out of it, and every morning the same thing: waking up, being washed, lying there till the evening, the same pain” (12). | Dependency<br>Suffering<br>WTHD: unbearable situation with no way out (other than death)<br>Despair |
| “I sit back and I say, ‘since I’m already dying, and since I’m already gone, lost my energy. Why? Why do I also have to take these disgusting pills?’ and it seems that every day there’s something more, something more disgusting” (7). | Hopelessness<br>Tired of fighting |
| **1.2 Psychological factors** | |

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| “... the end of many dreams for, plans, complete halt to things I was doing, want to do. The biggest thing is the weakness, which I absolutely hate, not being able to do things, to realise that this is virtually the end of it all. There’s no future really. You can’t plan anything” (17). | Hopelessness<br>Progressive deterioration<br>Limitation of activities<br>Loss of function<br>Lived experience of time |
| “Sometimes I start yelling at my shrink that this is horrible, that why don't I die right now?...Why do I have to live through this?” (3) | Fear of the dying process<br>Unbearable suffering<br>Loss of meaning |
| “I don’t want to undergo that [expletive] feeling of helplessness, that there’s not a [expletive] thing that I or anyone else can do” (3). | Helplessness<br>Hopelessness |
| “I just don’t want to be in so much suffering... to endure these psychological effects” (4). | Suffering |
| “Not much hope, nor would there be any miracles… You doctors can’t help when the patients deteriorate and then drop dead…” (4). | Progressive deterioration<br>Hopelessness |
| “Someone with a tube sticking up the bottom, a tube sticking into the nostrils, another somewhere else. I mean, what for? Can you save them?” (4). | Hopelessness<br>Loss of meaning |
| “I asked the doctor, ‘Doctor, do people with cancer get a lot of pain?’ He answered, ‘In the majority they do.’ Then I asked, ‘Is it possible not to be like that?’ He answered, ‘Possible, I suppose.’ Ah…” (4). | Fear of suffering |
| “Some don't have loved ones around. They have nobody to care for them. Others have relatives but they don't care… I only have one daughter. If she doesn't help, who is going to help?… So miserable that I cannot express in words” (4). | Hopelessness<br>Fear about the future<br>Lack of social support |
| “My first husband, he suffered a long time. He had on those machines, and I used to say, ‘God,’ I said, ‘don’t let me go under those machines” (6) | Fear of suffering |
| “I never thought about giving up but my fear was that I didn’t know much about cancer. There are so many people that linger, and I was afraid that I could not cope. I know I will die, but I don’t want to be lingering and suffering and people around me to suffer with me. So I thought, ‘I will go for a swim’ and I don’t know how to swim or I would go to a place like Holland. I just don’t want to be lingering, like people that can hardly talk and are really suffering and I don’t want to do that. It’s the only thing that makes me feel a little bit emotional. I don’t want to deal with it so I think I would speed up things myself. I don’t want to be lingering here in palliative care, lying day and day, slowly dying. Oh no, I don’t want to do that. So, suicide is a way of exiting. I don’t want to talk about that because I like life and I have lots to live for, but if I come to the point when I am too weak to do anything, then I don’t want to stay” (7). | Anticipation of future suffering<br>Progressive deterioration<br>Not wanting to be a burden<br>WTHD as a way of ending suffering<br>WTHD so as to spare others from burden<br>Having a plan<br>Will to live but not in this way |
| “It is such an aggressive form of cancer. I saw all my energy going down the drain-what I could still do last week I can’t do at all now. I really enjoyed my life, but now I have just to wait and see how things go and what death will look like” (9). | Hopelessness<br>Suffering<br>Will to live but not in this way |
| **1.3 Social factors** | |
| “I think it's very important for every single person to feel that they belong, and, and that they fit in a community, in a city, in a country, in a world, ah, in nature. The, the ah, and I think when we no longer feel that you have these linkages, and that the linkages are valued for everything that you're connected with, whether it, you know, family or friends or, you know, associates, or whatever, and your community, and city and all the rest of. Once the once, once you perceive that, that your relationships, all the links with, with other living things have deteriorated, and then, and they're not valued, then you've lost face. Dignity, then, has for me, has an awful lot to do with face” (1). | Loss of community<br>Loss of the sense of dignity<br>Disintegration<br>Loss of value |
| “No matter how much they love you, you are always a burden. You automatically become a burden to everyone. Even to your own missus” (17). | Being a burden |
| “After a while, your family, who you love so dearly, will remember you as a washed-out role model… It will remind them of what they have to go through, the lack of strength, the weakness, and so forth” (3). | Not wanting to be a burden<br>Fear of losing one’s own value/dignity in the eyes of others |

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| | Loss of the self |
| “For them to see me in pain is suffering. To see family rushing around is so suffering… That makes me suffer. They spend a lot of money… I fear the rushing around would make her [wife] ill, burdening her” (4). | Suffering<br>Not wanting to make others suffer |
| “In the future when I can't manage, I would feel very bothersome and very suffering as if I'm really burdening them. I'm afraid of having others to serve me” (4). | Anticipation of future suffering<br>Progressive deterioration<br>Not wanting to be a burden |
| “I’ve experienced such incredible pain over the last little while and more in the last week. Such incredible pain that it made me think that death is preferable to this. I’ll sit there for 2 hours in terrible pain. Such pain where I can’t yawn even, and I get only half a yawn and my whole insides turn and waiting for the medication to start to work. I’d love to have 48 hours let’s say, I’d love to have this weekend where I could plan to have a nice weekend and have no pain. I’d love to do that and it doesn’t happen, and the pain affects everything. It makes you tired. It affects how you can eat. It affects your mood. It affects other people, and the fact is that even if you try to hide it, you can’t. So that’s hard, and I know it’s gonna get worse, so that’s hard too. It’s great to be alive, and pain takes that life out of you, and to sit there for 2 hours with a blanket around you just shivering, with no solution, is really hard” (7). | Pain (affects everything)<br>Hastened death as a way of ending suffering<br>Suffering as something worse than death<br>Wish to live but not in this way<br>Anticipation of future suffering |
| “ …that others are not affected by watching someone else wasting away for 2 month, willing to die and willing to die, but he does not. That is difficult for the family members” (10). | Not wanting to make others suffer |
| “I want to present myself as being as normal as possible, but everybody notices it: I stumble and I am slow and that is just not me because I always was a nimble girl” (9). | Loss of functions<br>Fear of losing one’s own value/dignity in the eyes of others |
| “I am burdened myself, I am such a burden to others; I want to end this” (12). | Hastened death as a way of ending suffering<br>Not wanting to be a burden |
| “I am not used to somebody helping me. This I feel is tantalizing, this is no life” (14). | Dependency<br>Loss of control<br>Loss of value of life |
| “Not wanting to be seen by those that love me as this skin-and-bone frail, demented person. In other words, I don’t want that image of me for me, and I don’t want that image to be kind of a last image that my daughters and loved ones have of me. And that’s just a dignity issue” (14). | Loss of the sense of dignity<br>Loss of the self<br>Fear of losing one’s own value/dignity in the eyes of others<br>Loss of image: shame<br>Anticipation of cognitive impairment |
| **1.4 Self - Identity - Losses** | |
| “I’m not comfortable, and I can’t do anything, so as far as I’m concerned in quality of life I’m not living; I’m existing as a dependent non-person. I’ve lost, in effect, my essence” (5) | Loss of quality of life<br>Loss of independency<br>Loss of the self<br>Loss of daily life activities |
| “I think passively sitting in my own garden, sitting on my own deck, would still be preferable to, to, to death. Quality of life, the concept of quality of life is shifted. I can live with an inactive life... and I’d still fight a bit to gain incrementally” (3). | Loss of function<br>Loss of quality of life<br>Ambivalence: wish to live and wish to die |
| “Finally the illness that dominates everything will wipe out all life has to offer me, what I feared most is exactly what will happen to me. I won’t belong anymore, the emptiness of existence, the lack of independence, being unable to do things myself, being at the mercy of others whom I will have to beg to do the things I need in a way that’s suitable for me” (9). | Losing<br>Anticipation of future suffering<br>Loss of control<br>Loss of independence<br>Loss of meaning in life |

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| | Loss of daily life activities |
| "I just can't do what I used to. Um, I can't go out, I can't go to the store… I can't write a check for nothing. I, it's just a lot of things… Oh, I hate it" (6). | Limitation of activities<br>Loss of function<br>WTHD maintaining meaningful activities |
| "There's not any good reason for me to go on living. Nobody really needs me… I'm really not serving any purpose. If you don't, aren't needed by anybody, you kind of have a different feeling about life" (6). | Loss of value<br>Loss of will to live<br>Helplessness |
| "I'm just saying to myself when I go to sleep, 'Just let me die.' I don't want to have to wake up and face this. Honestly I just pray that I would just die in my sleep. I have nothing to live for, absolutely nothing. There's nothing coming up in my life that I am living towards, and if there was it would be so terrible because it probably wouldn't happen" (7) | Hopelessness<br>Despair<br>Loss of meaning in life<br>Loss of will to live |
| "When I'm in pain, it is not so much the pain, it's the loss of control and the helplessness" (7). | Desire for control over life<br>Helplessness |
| "The energy that I have always had, the positive (energy), that has made me as a person… but exactly this is getting less and less at the moment" (7). | Progressive deterioration<br>Loss of the self |
| "The past few days even the news doesn't interest me anymore, I have less interest in the outside world. My brain no longer works and to me that is a part of human dignity and of unbearable suffering. I want to function normally and if I can't do that" (9). | Progressive deterioration<br>Hopelessness<br>Loss of the sense of dignity<br>Loss of will to live<br>Hastened death as a way of ending suffering |
| "I have become so weak because of the pain. I can't walk anymore, I can't eat anymore. My children have suffered enough. I don't want them to go through this again. Everybody has to lose their parents someday anyway" (9). | Pain<br>Progressive deterioration<br>Loss of self<br>Not wanting to make others suffer |
| "…claustrophobia of my existence. To put it simply, it is insight without perspective. Never in my life have I felt any love. If there had been some warmth and love and safety, I could have grown" (9). | Loss of meaning in life<br>Loss of will to live |
| "I can't drive anymore. I loved to paint and draw, but I can't do that either anymore. Everything I enjoyed is gone. And then, my sight became worse" (9). | Hopelessness<br>Loss of meaning<br>Limitation of activities<br>Loss of function |
| "I'm not interested at all anymore, I just lie here and what's the point? There isn't any. I no longer read. Not books, not newspapers. I have CDs and the Walkman right here. Well, I've listened to, um, two CDs and that's enough. And yet I really loved music, but it's all over. I'm just not interested anymore…" (9). | Hopelessness<br>Loss of will to live<br>WTHD maintaining meaningful activities |
| "I lost my dignity, lying in bed in diapers, I am no longer the independent person I used to be" (9). | Loss of function<br>Loss of independence<br>Loss of the sense of dignity<br>Loss of self |
| "And I don't feel this is a life for me [pause], carrying on living like this. That's why [pause] um, I am [pause] very – how should I put it, so you understand me – I'm on the road, on the move a lot and [pause] then I thought, if I can't live like before, life has no value, does it? And [pause] I drove my car a lot, and I can't do that anymore either. […] Yes, did a lot of travelling. […] I feel my life isn't worth anything at all any more, if I just lie here and wait" (12). | Loss of activities (that make life enjoyable)<br>Loss of value<br>Loss of will to live<br>Loss of life's worth<br>WTHD maintaining meaningful activities |
| "Activities with friends not possible—and indeed activities outside or with the family, I would say, meanwhile completely passed away" (14). | Limitation of activities |
| "You've become a bag of potatoes to be moved from spot to spot, to be rushed back and forth from the hospital, to be carried to your doctors' appointments or wheeled in a wheelchair, and it really does take away any self-worth, any dignity, or any will to continue to live" (1). | Loss of control<br>Loss of the sense of dignity<br>Loss of self-worth<br>Loss of will to live |

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| "Oh, it's the dignity and wholeness of my body, as well as spirit. And, it is, it's cruel too for others to have to do this when there's no end in sight, other than death. To just, to clean me up. I just don't want that... Dignity is that I have control over my body, when, when, not, not a virus that is going to take my life. I'm the one who's going to decide when my life will end, not a virus, and not with great pain. Not anything else other than in, in my control. It is my control, my choice to do" (1). | Loss of control<br>Loss of the sense of dignity<br>Loss of self-worth<br>Loss of will to live<br>WTHD as a way of self-preservation |
| **2. Suffering** | |
| "To have pain and also breathlessness, that would be really terrible and so much suffering. My breathing is suffering and this affects my appetite. So many kinds of suffering… The social situation is suffering..." (4). | Physical factors |
| "I've seen other patients yelling in pain and they were suffering... so intolerable... Just to hear them was very suffering... It must have been so unbearable to have to yell like that. If they could endure it, they wouldn't have yelled" (4). | Anticipation of a painful death<br>Fear of suffering |
| "I just don't want to endure these psychological effects... So much suffering... I have had the pain for four years... So many psychological effects… How can I bear it?" (4). | Suffering<br>Unbearable situation with no other way out |
| **3. Meanings of the WTHD** | |
| **3.1 Cry for helping** | |
| "Why do I have to go through this? Why can't I just die right now?" and, "When I pray, I use [sic] to feel the power of God on me... Now I sometimes feel as though I am talking to the air" (3). | Suffering<br>Loss of meaning<br>Hopelessness |
| "When I was in excruciating pain… sometimes, I wanted to grab a knife and stab myself, and cut it [pain/cancer] out. I felt angry…why I am suffering so? I did not know what to do or how to deal with it. I could not work, so my life was no longer worth living. Continuing to live would only bring more suffering… I could not look after myself. I made [Buddhist] merits in the morning, offered food to monks. I prayed every day. I prayed to have the day, during which I was no longer able to perform my daily activities, as my last day of life… I prayed to die so that my suffering could end. I did not want to be fed by my children and grandchildren. Just let me die" (8). | Pain<br>Loss of independence (not being able to perform activities of daily life)<br>Not wanting to be a burden<br>Loss of life's worth<br>Suffering as something worse than death<br>WTHD: unbearable situation with no way out (other than death)<br>Despair |
| "I suffer so much that I can't recall when life was lovely and happy. My life is hell. My life is inhuman. I have such deep pain inside" (9). | Despair<br>Suffering<br>Loss of life's worth<br>Loss of meaning<br>WTHD: unbearable situation with no way out (other than death) |
| "Then all the red lights started flashing for me, because it was in your head, wasn't it. Then I thought: No! No, just no. Now I've simply had enough. […] I've tortured myself enough; I don't want to torture myself anymore" (12). | Disintegration<br>Unbearable situation with no way out other than death (end suffering)<br>Loss of life's worth |
| **3.2 Unbearable situation with no way out other than death (end suffering)** | |
| "There were many times when I was in such pain and such misery. I said, let me go... Finished... no more of this torture" (3). | Hastened death as a way of ending suffering<br>Suffering as something worse than death<br>Despair<br>Pain<br>Suffering |
| "I feel, deep inside, I don't want to feel hurting [sic]… that I want to end this… I ask God why he don't take me, why I suffer so much" (3). | Suffering<br>Hopelessness<br>Loss of meaning |

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| "Pain is my biggest fear. It puts me in a darkness and a lack of will to go forward and a desire to die... The pain wants me to have a vehicle to just, just stop my life" (3). | Fear of suffering<br>Loss of will to live |
| "I can't bear the dying process so I'll short circuit it by dying" (3). | Fear of the dying process |
| "If the pain gets worse, then I want to be dead" (3). | Anticipation of future suffering<br>Suffering as something worse than death<br>Despair |
| "If I had to go through [an acute episode of shortness of breath] again, I would throw myself in front of a subway train. I am not going through that again" (3). | Anticipation of future suffering<br>Pain<br>Desire for control over life<br>Fear of the dying process<br>Despair |
| "... it should be up to me to decide… when I've had enough suffering... One of my landmarks, if I'm at the point where all I can do is lie on a bed all day long, then to me that's probably not living anymore" (5). | Autonomy<br>Desire for control over life |
| "I'm inconveniencing. I'm still inconveniencing other people who look after me and stuff like that. I don't want to be like that. I wouldn't, I wouldn't. No, I'd rather die" (1). | Progressive deterioration<br>Dependency<br>Loss of the self<br>Fear of losing one's own value/dignity in the eyes of others: shame |
| **3.3 To spare others from the burden of oneself** | |
| "There have been times I've felt so much a burden on my family that maybe it is best for me to die just to relieve them of going through the terminal phase of my disease" (3). | Being a burden<br>WTHD as a form of altruism |
| "All of a sudden, it dawned on me that there was no solution, and if there was no solution to my cancer, then why was I hanging around? I got thinking about death as a practical matter. Why hang around and cause a lot of people a lot of grief?" (3). | Not wanting to be a burden |
| "[T]here's no question about wanting to make provisions for a hastened death should conditions become so unbearable. I want to spare my family as much of that grief as I can… [My mother] died of cancer, and we were constantly frustrated by not being able to do anything for her… And just watched her waste away. And what a terrible way to go" (5). | Loss of control<br>Fear of suffering<br>Not wanting to be a burden<br>Not wanting to make others suffer |
| "I hope everyone can accept it… Most important is that my family wouldn't be heartbroken. If there were no suffering. I would like to see them for longer" (4). | Fear of suffering<br>Not wanting to make others suffer<br>Wish to live but not in this way |
| "That is somehow a vicious circle. If my wife sees me having a hard time, she is suffering from that. And then, when I see my wife suffering in extreme, and then I am in a bad shape, because after all, it is my fault" (10). | Not wanting to be a burden |
| "When I know that my life has become a burden to my loved ones, I would rather die. I think of death as a way to release me from this frustration" (8). | WTHD as a way of ending suffering<br>Not wanting to be a burden<br>Suffering as something worse than death<br>WTHD: unbearable situation with no way out (other than death)<br>Despair |
| "I always pray that I can release people, eh, that I can free them of a burden, release the others also. That I do not always have to rely on help, I want… My whole life, I only worked and always took care of [others] myself… Then after this it's simply difficult, if you always have to have other people. That you have to be a burden…That I've never like" (11). | Not wanting to be a burden |

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| "I would like to go. You see, I want to let people off the hook. I don't, I don't like it that they always have to… they all have a life too and I don't want to, that I… well" (12). | Not wanting to be a burden |
| "I can't just walk away like that. One time you think, 'I might as well give up.' But that's easy for me, but not easy for them [family]. There are other people [to consider]" (7). | Not wanting to be a burden |
| **3.4 To preserve self-determination in the last moments of life** | |
| "I immediately turned to the option of Exit [pause], because I said I'd like to have this option whatever happens. If things become unbearable for me for some reason, but I'm still not dying, then I'd like to be able to grant myself my own death. And I saw to everything, so that it's ready, that I have the prescription, and talked to those people. They're quasi on call now. […] This is really only about ending a situation that has become unbearable, and not having to rely on either being hit by another stroke or some doctor being understanding after all. I want to be able to keep this in my own hands for when the moment comes. I was a very self-determined person all my life, and that's very important to me" (12). | Anticipation of a painful death<br>Desire for control over life<br>Hastened death as a way of ending suffering<br>Having a plan<br>Suffering as something worse than death<br>WTHD as a form of control |
| "I have no desire to commit suicide, but I have no desire to take it out of my hands either" (7). | Autonomy<br>Desire for control over life<br>Wish to live but not in this way |
| **3.5 Will to live but not in this way** | |
| "See, there's a problem while planning or pursuing your death… On the one hand, I am saying all these things, and, on the other hand, I am going down for radiation" (3). | |
| "Wish to live but can't live; wish to die but can't die" (4). | Suffering |
| "It is torturous… thinking when I am going to die to escape from this suffering. But when I am not in pain, I want to live. When the symptoms disappear, I want to continue living, as I do not want to depart from my loved ones. Actually, I do not want to be parted [die]… when I do not experience any symptom. But when I suffer the symptoms, I again wish to die to escape the suffering" (8). | Pain as *mediator* of the WTHD<br>Hastened death as a way of ending suffering |
| "No, not at this moment, but on those days when I am so miserably sick" (13). | Anticipation of future suffering and pain<br>Having control |
| **4. Functions of the WTHD** | |
| **4.1 WTHD as a means of communication** | |
| "So I was glad that I could talk to him [husband] about it [WTHD]. Actually I was the only one, I was able to communicate that and [pause] just be able to let go of the thought, rather than letting it eat into you. Whether you then do it or not is actually secondary. It's bad for people if they can't say to anyone: you know, I have thoughts like this sometimes. So I really am glad that I was able to discuss it with him [husband], it did me good as well" (12). | Family reinforcement |
| "I shared that I wouldn't do it until we discussed it together… She didn't have to worry about me taking the pills… It wasn't fair to them... It would leave them wondering, did they do, you know, contribute to it, did they do all they could... And I want them to feel comfortable that they've done everything" (3). | Manipulation |
| "I've also said these tongue-in-cheek things: so, now I'm starting to collect pills. Yes. And then the people concerned, the ones you say that to, they're shocked, and yet it was said tongue-in-cheek. I: To test their reaction. P: Yes, perhaps sometimes a bit of deliberate provocation" (12). | Expression of the WTHD so as to observe people's reaction |
| **4.2 WTHD as a form of control - Having a plan – Just in case / avoiding suffering (future)** | |
| "Exit would really just be there for an emergency, and not because that's what I'd wish. That would only be if I felt I couldn't get back off this track [...] If it gets that hard, and I don't know how to put on my socks or I'm so dead sick that I think: for Heaven's sake huuh… then I would wish for it to end, just to be relieved, just that it ends. […] Yes, it's rather just being set free from this state" (12). | Anticipation of future suffering<br>Desire for control over life<br>Hastened death as a way of ending suffering<br>"If then" |

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| “Yes, I have thought many times, I want to get somebody from Exit, I also registered at Dignitas, because I thought: 'Yes, well, if it’s so unbearable that, that everybody around me has to hold their nose [due to tumour ulceration and smell]. That was the worst, I think, then I wanted to break off the exercise” (13). | Anticipation of future suffering<br>WTHD as a way of sparing others from burden<br>Hastened death as a way of ending suffering |
| “Oh, it’s the dignity and wholeness of my body, as well as spirit. And, it is, it’s cruel too for others to have to do this when there’s no end in sight, other than death. To just, to clean me up. I just don’t want that... Dignity is that I have control over my body, when, when, not, not a virus that is going to take my life. I’m the one who’s going to decide when my life will end, not a virus, and not with great pain. Not anything else other than in, in my control. It is my control, my choice to do” (1). | Loss of control<br>Loss of independence<br>Desire for control over life<br>Loss of the self<br>Loss of the sense of dignity<br>Loss of meaning |
| “…and then this sleepiness and so on, and then at some point at the back of your mind you say: well, how long am I supposed to put up with this? And then it occurs to you: well, you don’t have to, you can get out of it any time. But it’s more of a reassurance […] It’s a reserve” (12). | Loss of function<br>Desire for control over life<br>Hastened death as a way of ending suffering<br>Hopelessness |
| “I will do things my way and the hell with everything and everybody else. Nobody is going to talk me in or out of a darn thing... what will be, will be; but what will be, will be done my way. I will always be in control” (5). | Desire for control over life |
| “I just feel sometimes as though cancer is, uh, an opponent. And, it seems to me, it says to itself, ‘I am in control of this body. This is mine, I will do whatever I want to with it” (6). | Desire for control over life<br>Ultimate control |
| “I have considered, I do like this physician-assisted suicide. With the assistance of a doctor, so you won’t have a, a, messy death… and they [doctors] have said that any time I’m going to want to, it’s up to me. That’s right. I’m very glad about it. Yeah” (6). | Desire for control over life<br>Fear of a painful death |
| “But it [WTD] is a ray of hope. You can say, if nothing works anymore and things are only getting worse, then you’d still have some way of shortening it” (12). | Hastened death as a way of ending suffering<br>Suffering as something worse than death<br>WTHD: unbearable situation with no way out (other than death)<br>"If then" |
| “When I feel very, very, very wretched, this thought always returns: If you can’t bear it any more, you can actually cut it short. Right at the last I just could [pause]… if it’s even worse than it is now” (12). | Hastened death as a way of ending suffering<br>Suffering as something worse than death<br>WTHD: unbearable situation with no way out (other than death) |
| “If I would have such a pill in some drawer or the other, and I could take it on my own when I would have the feeling that nothing goes any more, then I would feel considerably better” (14). | "If then" |
| “[When metastasis was diagnosed] I immediately set about the option of Exit… because I said, I would like to have this possibility in any case. If for any reason it becomes unbearable for me, but I’m still not dying, then I would like to bring about my own death. And I saw to it all, that it was ready, that I had the prescription, and I talked to these people. That’s sort of there on demand now” (13). | WTHD: unbearable situation with no way out (other than death) |
| **5. Lived experience of timeline toward dying and death** | |
| “I just want to get it over with… Tomorrow is the same thing, the same thing” (6). | Despair<br>Suffering<br>Tiredness<br>Hopelessness |
| **5.1 Anticipation of a painful death or agony** | |

| | |
|---|---|
| "AIDS, that's probably -seeing as I'm 41- that's probably what I'm going to die of. That is going to be a very painful death. It is painful, I've seen it. It's painful, it's sad, it's lonely in a way, that you can be surrounded be all the loving people on your life, but you, it's lonely because you're gradually rotting away, your flesh is rotting, I hope to God in a way that your mind is rotting with it, because then you become totally, you don't know what's going on" (1). | Progressive deterioration<br>Anticipation of a painful death<br>Uncertainty |
| "It'll be extremely terrible. It'll be coming up from here, coming up from there, just everywhere. I mean the complications and that would give me so much pain and suffering. I anticipate the future would be like this. Very severe, very scary when I think about it" (4). | Anticipation of future suffering<br>Progressive deterioration<br>Fear of suffering |
| "I am not afraid about death. I am only afraid of an agonizing death. Taking too much time" (14). | Anticipation of a painful death<br>Fear of the dying process<br>Suffering as something worse than death |
| "I, I fear some of the, uh, some of the physical stress that may come in the course of my dying. Nobody chooses to die little by little. At least, I can't visualize that" (6). | Fear of suffering<br>Fear of the dying process |
| **5.2 Progressive deterioration** | |
| "This sort of disease ultimately leads to death. I have to walk that path" (4). | |
| "You lie on a bed and none of the normal functions come back. They will never come back and it will only get worse" (9). | Loss of function |
| "And I would not want to go through this as a daughter (of a patient). Sit down every day and watch how somebody is running towards death, lying there and finally waiting to be released" (14). | Not wanting to lose one's own value in the eyes of others |
| **5.3 Uncertainty** | |
| "I haven't been in hospital before. I wouldn't know the facts. I haven't been ill before" (4). | Fear |
| "Yes, and that is this uncertainty. You can plan nothing and, let me say, only on short notice, for very short distances" (14). | Loss of control |
| **5.4 Ambivalence** | |
| "The goal is now to die… I'm using my flexibility not to devote my time toward how I am going to die and praying, etc. I'm using my flexibility in time management to do things that the living do, not the dying" (3). | Ambivalence<br>WTHD as a will to live |

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# PRISMA 2009 Checklist

| Section/topic | # | Checklist item | Reported on page # |
|---|---|---|---|
| **TITLE** | | | |
| Title | 1 | Identify the report as a systematic review, meta-analysis, or both. | Page 1 |
| **ABSTRACT** | | | |
| Structured summary | 2 | Provide a structured summary including, as applicable: background; objectives; data sources; study eligibility criteria, participants, and interventions; study appraisal and synthesis methods; results; limitations; conclusions and implications of key findings; systematic review registration number. | Page 2 |
| **INTRODUCTION** | | | |
| Rationale | 3 | Describe the rationale for the review in the context of what is already known. | Page 4 |
| Objectives | 4 | Provide an explicit statement of questions being addressed with reference to participants, interventions, comparisons, outcomes, and study design (PICOS). | Page 4 |
| **METHODS** | | | |
| Protocol and registration | 5 | Indicate if a review protocol exists, if and where it can be accessed (e.g., Web address), and, if available, provide registration information including registration number. | N/A |
| Eligibility criteria | 6 | Specify study characteristics (e.g., PICOS, length of follow-up) and report characteristics (e.g., years considered, language, publication status) used as criteria for eligibility, giving rationale. | Page 6 |
| Information sources | 7 | Describe all information sources (e.g., databases with dates of coverage, contact with study authors to identify additional studies) in the search and date last searched. | Pages from 5 to 7 |
| Search | 8 | Present full electronic search strategy for at least one database, including any limits used, such that it could be repeated. | Pages 5 and 6 |
| Study selection | 9 | State the process for selecting studies (i.e., screening, eligibility, included in systematic review, and, if applicable, included in the meta-analysis). | Page 6 |
| Data collection process | 10 | Describe method of data extraction from reports (e.g., piloted forms, independently, in duplicate) and any processes for obtaining and confirming data from investigators. | Page 6 |
| Data items | 11 | List and define all variables for which data were sought (e.g., PICOS, funding sources) and any assumptions and simplifications made. | NA |
| Risk of bias in individual studies | 12 | Describe methods used for assessing risk of bias of individual studies (including specification of whether this was done at the study or outcome level), and how this information is to be used in any data synthesis. | NA |
| Summary measures | 13 | State the principal summary measures (e.g., risk ratio, difference in means). | NA |
| Synthesis of results | 14 | Describe the methods of handling data and combining results of studies, if done, including measures of consistency (e.g., $I^2$) for each meta-analysis. | NA |

# PRISMA 2009 Checklist

| Section/topic | # | Checklist item | Reported on page # |
|---|---|---|---|
| Risk of bias across studies | 15 | Specify any assessment of risk of bias that may affect the cumulative evidence (e.g., publication bias, selective reporting within studies). | NA |
| Additional analyses | 16 | Describe methods of additional analyses (e.g., sensitivity or subgroup analyses, meta-regression), if done, indicating which were pre-specified. | NA |
| **RESULTS** | | | |
| Study selection | 17 | Give numbers of studies screened, assessed for eligibility, and included in the review, with reasons for exclusions at each stage, ideally with a flow diagram. | Pages 5 and 6 |
| Study characteristics | 18 | For each study, present characteristics for which data were extracted (e.g., study size, PICOS, follow-up period) and provide the citations. | Pages 7 and 8 |
| Risk of bias within studies | 19 | Present data on risk of bias of each study and, if available, any outcome level assessment (see item 12). | NA |
| Results of individual studies | 20 | For all outcomes considered (benefits or harms), present, for each study: (a) simple summary data for each intervention group (b) effect estimates and confidence intervals, ideally with a forest plot. | NA |
| Synthesis of results | 21 | Present results of each meta-analysis done, including confidence intervals and measures of consistency. | NA |
| Risk of bias across studies | 22 | Present results of any assessment of risk of bias across studies (see Item 15). | NA |
| Additional analysis | 23 | Give results of additional analyses, if done (e.g., sensitivity or subgroup analyses, meta-regression [see Item 16]). | NA |
| **DISCUSSION** | | | |
| Summary of evidence | 24 | Summarize the main findings including the strength of evidence for each main outcome; consider their relevance to key groups (e.g., healthcare providers, users, and policy makers). | Pages 23 and 24 |
| Limitations | 25 | Discuss limitations at study and outcome level (e.g., risk of bias), and at review-level (e.g., incomplete retrieval of identified research, reporting bias). | Pages 22 and 23 |
| Conclusions | 26 | Provide a general interpretation of the results in the context of other evidence, and implications for future research. | Page 24 |
| **FUNDING** | | | |
| Funding | 27 | Describe sources of funding for the systematic review and other support (e.g., supply of data); role of funders for the systematic review. | Pages 24 and 25 |

*From:* Moher D, Liberati A, Tetzlaff J, Altman DG, The PRISMA Group (2009). Preferred Reporting Items for Systematic Reviews and Meta-Analyses: The PRISMA Statement. PLoS Med 6(7): e1000097. doi:10.1371/journal.pmed1000097

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Page 2 of 2

BMJ Open

# Understanding patients' experiences of the wish to hasten death: an updated and expanded systematic review and meta-ethnography

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**Title page**

# **Title:** Understanding patients' experiences of the wish to hasten death: an updated and expanded systematic review and meta-ethnography

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## Abstract

**Objectives**: Patients with advanced disease sometimes express a wish to hasten death (WTHD). In 2012 we published a systematic review and meta-ethnography of qualitative studies examining the experience and meaning of this phenomenon. Since then, new studies eligible for inclusion have been reported, including in Europe, a region not previously featured, and specifically in countries with different legal frameworks for euthanasia and assisted suicide. The aim of the present study was to update our previous review by including new research and to conduct a new analysis of available data on this topic.

**Setting**: Eligible studies originated from Australia, Canada, China, Germany, The Netherlands, Switzerland, Thailand, and USA.

**Participants**: Studies of patients with life-threatening conditions that had expressed the WTHD.

**Design**: The search strategy combined subject terms with free-text searching of PubMed MEDLINE, Web of Science, CINAHL and PsycInfo. The qualitative synthesis followed the methodology described by Noblit and Hare, using the "adding to and revising the original" model for updating a meta-ethnography, proposed by France et al. Quality assessment was done using the Critical Appraisal Skills Programme checklist.

**Results**: 14 studies involving 255 participants with life-threatening illnesses were identified. Five themes emerged from the analysis: suffering (overarching theme), reasons for and meanings and functions of the WTHD, and the experience of a timeline towards dying and death. In the context of advanced disease, the WTHD emerges as a reaction to physical, psychological, social and existential suffering, all of which impacts on the patient's sense of self, of dignity and meaning in life.

**Conclusions**: The WTHD can hold different meanings for each individual; serving functions other than to communicate a genuine wish to die. Understanding the reasons for, and meanings and functions of, the WTHD is crucial for drawing up and implementing care plans to meet the needs of individual patients.

## Strengths and limitations of this study

- This updated review and synthesis of the published literature on the WTHD offers a more nuanced understanding of the phenomenon.
- The review provides meta-ethnographic analysis of 14 studies which recorded, the experiences of 255 participants from different cultural backgrounds including Australia, Canada, China, Germany, Switzerland, Thailand, The Netherlands and the USA.
- This synthesis highlights suffering as an overarching theme and includes physical, psychological, social or existential factors.
- The synthesis exemplifies a new approach to the updating of syntheses of qualitative research.
- Included studies offer different conceptualizations of the WTHD with the research objectives of some studies only touching indirectly upon the phenomenon.

# Understanding patients' experiences of the wish to hasten death: an updated and expanded systematic review and meta-ethnography

## INTRODUCTION

Few issues in modern society generate as much controversy as euthanasia, and assisted suicide (EAS) among people facing an advanced illness. Across the world, opinions, and attitudes towards this issue differ widely. Debate, however, often centres around the implications for society or the existing legal framework. What is often overlooked is the common thread that links all those persons who contemplate ending their life: the desire to die or to hasten their death. Why do some patients with advanced disease wish to hasten their death? What meaning does this wish hold for them? What is the experience of a person who feels such a wish? To what extent do commonalities exist among those who come to feel this wish?

Although the desire to die has traditionally been seen to result from physical suffering, research suggests that this explanation is reductionist (1), and that such a wish must be understood in the context of patient experience. Thus, while cross-sectional studies offer valuable information about what may trigger a wish to die, the fluctuating, ambivalent, subjective, and complex nature of such wishes requires a more detailed examination of patients' experiences.

Several qualitative studies have explored the wish to die in patients with advanced disease highlighting the important role played by psychosocial, and existential/spiritual factors, alongside physical symptoms (2,3). Thus, factors such as loss of self, loss of the sense of dignity, loss of autonomy, fear about the future, fear of suffering, and fear of being a burden to others are reported among the main triggers of a wish to hasten death (WTHD). Interpretative analysis of the WTHD suggests that, in addition to these potential motivations, attention must focus on the meanings, functions, and intentions that underlie the expression of a WTHD. Thus, if we are to understand what patients actually mean when they say that they ‘no longer wish to live in this way’ we must explore their personal history, attitudes, beliefs, and thoughts. Furthermore, it is important not to confuse, for example, a wish to die in someone who is not considering actually hastening his/her death with a will to die in someone who takes action towards dying (4).

In 2012 our group published a systematic review, and interpretative synthesis (5) of then-published qualitative studies of the WTHD in seeking to understand the experience of patients with serious or incurable illness who expressed such a wish. The synthesis included studies conducted in Canada (1,6), Australia (2), China (7), and the USA (8). At that time, however, no such studies were identified from European countries.

Five years on, the subsequent publication of qualitative studies of the WTHD, among similar patient groups, and in different contexts to those featured in our earlier synthesis, justifies the need for an updated systematic review. In addition, the possibility of including studies from European countries in which EAS have been decriminalised (4,9–11) enables us to explore the extent to which different legal contexts influence the expression of a WTHD. The aim of the present study was therefore to provide an updated review of knowledge regarding the WTHD (understood here as any expression of the desire to die in patients affected by a life threatening condition), taking into account possible contextual differences.

# METHODS

This systematic review, and interpretative synthesis updates our previous synthesis (5) that included studies from 2001 to January 2010. In seeking to incorporate recent research within the synthesis, we extended our bibliographic search to cover the period from December 2000 to January 2016. The update employs Noblit and Hare's (12) meta-ethnography method, the aim of which is "to compare, re-interpret, and synthesise the findings (i.e. authors' concepts, and themes) of separate qualitative studies to arrive at an exhaustive description of the range, nature, and variety of patients' experiences" (13). This method was chosen given its widespread use in health-related research (14).

France et al. (15) propose various models for updating meta-ethnographies, using the analogy of house-building. This review applies the model they refer to as 'extending and renovating the original house' (i.e. adding to and revising an existing meta-ethnography). France et al. (15) outline potential advantages of using this model: the output forms a single coherent model or set of findings, rather than two, increasing its potential usefulness; it can lead to new conceptual insights; and it allows for innovation within the updated analysis/synthesis, while making efficient use of resources expended on the original meta-ethnography.

## Data sources and search strategy

In seeking recent clinical evidence about the WTHD we revised our original search strategy to optimise the trade-off between sensitivity, and specificity (see Table 1). Relevant MeSH, and free-text terms were identified, and combined. The strategy was run in PubMed, CINAHL, Web of Science, and PsycINFO with the terminology being adapted to each database.

**Table 1.** Final database search strategy.

| | |
|---|---|
| 1 | desire to hasten death |
| 2 | wish to hasten death |
| 3 | euthanasia [Mesh] |
| 4 | suicide, assisted [Mesh] |
| 5 | end of life decisions |
| 6 | wish to die |
| 7 | 1 or 2 or 3 or 4 or 5 or 6 |
| 9 | palliative care |
| 10 | end of life care |
| 11 | end of life |
| 12 | 9 or 10 |
| 13 | chronic disease |
| 14 | chronic illness |
| 15 | advanced disease |
| 16 | advanced illness |
| 17 | advanced cancer |
| 18 | life limiting illness |
| 19 | terminally ill |
| 20 | life threatening illness |
| 21 | life threatening condition |
| 22 | 13 or 14 or 15 or 16 or 17 or 18 or 19 or 20 or 21 |
| 23 | Qualitative Pubmed or CINAHL filter |
| 25 | 7 and 12 and 22 |
| 26 | 25 and 23 |
| 27 | 26 not (child*) or (pediatr*) |

A filter for qualitative studies was used in PubMed (16), CINAHL (17), and PsycINFO (18). The qualitative PubMed filter was adapted to the specific language used by Web of Science.

## Inclusion and exclusion criteria

To be included, papers had to report primary qualitative studies (i.e. studies using recognised methods of both qualitative data collection, and qualitative data analysis) written in English, and focusing on the expression of the WTHD in patients with life-threatening conditions. Paediatric populations were excluded, as were studies focusing on older populations in the absence of advanced disease.

One researcher carried out the systematic literature search, which was verified by another researcher. Screening involved selection of retrieved citations by title, abstract, and full text. The entire sample was double-reviewed. Disagreements were resolved by discussion within the research team. Figure 1 shows the PRISMA flowchart for the selection of studies.

**Figure 1**. PRISMA flow diagram for study selection.

### Critical appraisal

Included studies were assessed for methodological quality, and rigour using Critical Appraisal Skills Programme (CASP) guidelines for qualitative studies (19) (supplementary Table-S1). No studies were excluded from this review based on their quality.

### Data analysis and synthesis

The synthesis followed the seven steps proposed by Noblit and Hare (12) as follows:

1) Definition of the research question: What is the experience of the wish to hasten death expressed by people with advanced illness?

2) A literature search for references to studies for inclusion in the synthesis.

3) Reading the studies in order to identify key and secondary concepts in each of them.

4) Determining how the studies are related. To this end we created a chart showing the categories that emerged from the studies (more descriptive level), and this served as the basis for abstracting themes and sub-themes from each study (more abstract levels that encapsulate the categories found in the different studies).

5) To perform translation across studies, in other words, to 'deconstruct' the studies, identifying different metaphors or concepts on the basis of words or statements in the original articles.

6) These translations were synthesized, to generate different levels of themes, sub-themes and final categories.

7) Presentation of the synthesis of the studies included, thus giving rise to a global understanding of the phenomenon and a response to the research question posed at the outset.

Supplementary Table-S2 juxtaposes the steps from the previous, and the updated meta-ethnography, and supplementary Table-S3 shows the comparison of yield between the original review, and the updated review. Atlas.ti 7 software was used to code, and memo significant statements to facilitate comparison of the themes, and categories obtained by each researcher.

## RESULTS

Fourteen articles were included in the updated meta-ethnography [seven from the original synthesis (2001-January 2010) plus seven additional recent studies (2010-February 2016)] (Table 2). Of the seven new studies included, six were conducted in European settings (4,9–11,20,21), and one in Asia (22).

Three studies used grounded theory (1,6,20), with a further study using a modified approach (21). One was a mixed-method study (2), from which only the qualitative results were included in the present analysis. One study reported using a phenomenological approach (2), and three a combination of phenomenological, and hermeneutical methods (4,7,11). A hermeneutical-ethical approach was applied in one study (10). The design of one qualitative study was unclear (not specified) (22). Most studies used in-depth or semi-structured interviews to collect data, except for one that used narrative interviews (10). Sample sizes ranged from 2 to 35 participants, yielding a total sample of 255 patients (excluding the relatives interviewed in one study (23)). The majority of studies aimed to explore the WTHD as expressed by patients with advanced disease. Only two studies had the main objective of describing suffering (9,22).

| Source paper | Country | Participants | Setting | Country's legislation on euthanasia and AS |
|---|---|---|---|---|
| Lavery et al. (1) | Canada | 31 men; 1 woman with HIV/AIDS | HIV Ontario Observational Database | Neither euthanasia nor AS are legal |
| Kelly et al. (2) | Australia | 30 terminally ill cancer patients | Inpatient hospice unit and home PC service | |
| Coyle and Sculco (24) | USA | 7 terminally ill cancer patients | Pain and PC unit in an urban cancer research centre | |
| Mak and Elwyn (7) | China | 6 patients | 26-bed hospice in China. | |
| Pearlman et al. (23) | USA | 35 patients | Patient advocacy organizations that counsel persons interested in AS, hospices and grief counsellors | AS legal since 2009. At the time of the study, AS had yet to be decriminalised |
| Schroepfer (8) | | 18 terminally ill elders | 2 PC programmes, 2 hospital outpatient clinics and 6 hospices | Neither euthanasia nor AS are legal |
| Nissim et al. (6) | Canada | 27 ambulatory cancer patients | Outpatient clinics at a large cancer centre | |
| Stiel et al. (20) | Germany | 10 inpatients and 2 outpatients of PMD | PMD of 3 university hospitals | |
| Dees et al. (9) | The Netherlands | 31 patients with different diagnoses | Support and Consultation on Euthanasia in The Netherlands network; hospice, hospital and nursing home | Euthanasia and AS legal since 2009 |
| Ohnsorge et al. (10) | Switzerland | 2 women with terminal cancer, and caregivers | PC hospice | AS legal since 1942 |
| Ohnsorge et al. (11) | | 30 terminally ill cancer inpatients/outpatients, and their caregivers/relatives | Hospice, a PC ward in the oncology department of a general hospital & an ambulatory PC service | |
| Ohnsorge et al. (4) | | 30 terminally ill cancer inpatients/outpatients, and their caregivers/relatives | Hospice, a PC ward in the oncology department of a general hospital & an ambulatory PC service | |
| Nilmanat et al. (22) | Thailand | 11 women & 4 men with terminal cancer and short life expectancy | Public health service for cancer treatment | Neither euthanasia nor AS are legal |
| Pestinger et al. (21) | Germany | 10 inpatients and 2 outpatients of PMD | PMD of 3 university hospitals | |

*PMD: Palliative Medicine Department
*PC: Palliative Care

**Table 2.** Characteristics of the studies included in the present review

## Description of themes

Five main themes emerged from the analysis of the WTHD expressed by patients with advanced disease: *suffering*, which appeared as an overarching theme; *reasons* for the WTHD; *meanings* of the WTHD; *functions* of the WTHD; and *lived experience of a timeline toward dying and death*. Supplementary Table-S4 shows the most representative statements for each theme together with its corresponding sub-themes.

The greater detail offered by the seven recent studies enabled the six themes from our previous meta-ethnography (5) to be subsumed under new, broader categories, without substantially changing their content (Table 3). One new theme emerged from the present analysis: *lived experience of a timeline toward dying and death.* Table 4 shows which themes, and sub-themes were present in each included study.

| **Themes from the original meta-ethnography** (5) | **Themes in the updated meta-ethnography** | |
|---|---|---|
| WTHD in response to physical/psychological/spiritual suffering | Reasons for the WTHD | Suffering |
| Loss of self | | |
| Fear | | |
| WTHD as a desire to live but ‘not in this way’ | Meanings of the WTHD | |
| WTHD as a way of ending suffering | | |
| WTHD as a kind of control over life: ‘to have an ace up one’s sleeve just in case’ | Functions of the WTHD | |
| | Lived experience of a timeline toward dying and death | |

**Table 3.** Reclassification of themes from the original meta-ethnography in the present, updated meta-ethnography

| | Lavery et al. (1) | Kelly et al. (2) | Coyle and Sculco (24) | Mak and Elwyn (7) | Pearlman et al. (23) | Schroepfer (8) | Nissim et al. (6) | Stiel et al. (20) | Dees et al. (9) | Ohnsorge et al. (10) | Ohnsorge et al. (11) | Ohnsorge et al. (4) | Nilmanat et al. (22) | Pestinger et al. (21) |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| Suffering | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ |
| Reasons for the WTHD | | | | | | | | | | | | | | |
| Physical factors | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ |
| Psychological factors | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ | - | ✓ | - | ✓ | ✓ | ✓ | ✓ |
| Social factors | ✓ | ✓ | ✓ | ✓ | ✓ | - | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ |
| Loss of self | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ |

| | | | | | | | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| Meanings of the WTHD | | | | | | | | | | | | | | |
| Cry for help | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ | - | ✓ | - | ✓ | ✓ | ✓ | - |
| To end suffering | ✓ | - | ✓ | ✓ | ✓ | ✓ | ✓ | - | ✓ | - | ✓ | ✓ | ✓ | ✓ |
| To spare others from the burden of oneself | ✓ | ✓ | ✓ | ✓ | ✓ | - | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ | - |
| To preserve self-determination to the very end | ✓ | - | ✓ | ✓ | ✓ | ✓ | ✓ | - | ✓ | - | ✓ | ✓ | ✓ | ✓ |
| Will to live but not in this way | | - | ✓ | ✓ | ✓ | ✓ | ✓ | - | ✓ | ✓ | ✓ | ✓ | ✓ | - |
| Functions of the WTHD | | | | | | | | | | | | | | |
| WTHD as a means of communicating | | - | ✓ | - | - | - | - | - | - | - | - | ✓ | - | - |
| WTHD as a form of control | ✓ | - | ✓ | ✓ | ✓ | ✓ | ✓ | - | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ |
| Lived experience of a timeline toward dying and death | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ |

**Table 4.** Themes and sub-themes present in each of the studies included in this review

## 1. Suffering

*Suffering* emerged as an overarching theme, confirming that the WTHD in people with advanced disease cannot be understood without taking their suffering into account. As a theme, suffering referred not only to physical distress (especially pain) but also to psychological, social or existential aspects. Thus, suffering was a complex, and multidimensional phenomenon affecting the whole person, having physical repercussions, and impacting both on their identity, and their relationships with all aspects of their immediate environment. Suffering was a common denominator for understanding the other four themes: *reasons, meanings, functions,* and *lived experience of a timeline toward dying and death.*

"To have pain and also breathlessness, that would be terrible and so much suffering. My breathing is suffering and this affects my appetite. So many kinds of suffering… The social situation is suffering…" (7).

## 2. Reasons for the WTHD

This theme refers to the factors or rational motivations that led to a WTHD being expressed. As in our previous review (5), the WTHD emerged as a complex reaction to suffering that was related to all dimensions of personhood. Our analysis indicated that the theme *reasons* could be broken down into four sub-themes: *physical, psychological/emotional* and *social factors*, and the *loss of self*.

## Physical factors

In all the studies reviewed, *physical factors* (symptoms) were a key issue leading to the WTHD. Participants particularly emphasised a loss of function, and pain, although aspects such as fatigue, dyspnoea, incontinence, and cognitive impairments were also mentioned as producing considerable distress (1,4,9,23).

Most participants referred to the loss of physical function; their illness prevented them from doing the things they once did, stripping them of their independence: "I lost my dignity, lying in bed in diapers, I am no longer the independent person I used to be" (9). The loss of function was also linked to a diminished quality of life.

Many patients described severe, and unbearable pain as a factor that triggered a WTHD. Pain "affected the wholeness of their beings" (22), and their lived experience: "pain affects everything. It makes you tired. It affects how you can eat. It affects other people, and the fact is that even if you try to hide it, you can't. […] pain takes that life out of you". Some patients experienced intense, and uncontrollable pain, but stated that were it not for this they would want to go on living: "It is torturous... thinking when I am going to die to escape from this suffering. But when I am not in pain, I want to live. When the symptoms disappear, I want to continue living, as I do not want to depart from my loved ones" (22). Likewise, some participants (9) stated that their request for euthanasia stemmed from the continuous pain they suffered. In many cases, they feared becoming a burden on others, and making them suffer. For others, however, it was linked to a loss of control over their illness (due to ineffective medical treatment), and to a feeling of helplessness, to the sense that nothing could remedy their situation.

**Psychological/emotional factors**

This sub-theme comprised two categories: *fear,* and *hopelessness*. Fear was expressed in most interview studies, encapsulating fear due to uncertainty, fear about future suffering, and fear of the dying process.

Fear due to uncertainty was linked to inadequate knowledge about prognosis, and to not knowing what lay ahead. In most cases, fear was associated with a loss of control over bodily functions, and over one’s life and circumstances, as well as with physical, and functional decline, and the thought of becoming a burden on family.

Many patients, aware of their progressive deterioration, foresaw a death that would be painful both for them, and their relatives, and hence they experienced a fear about future suffering. The experience of pain, and distress, combined with a loss of function, led some to expect an unbearable suffering ‘worse than death itself’ (9,21,23,24). In some interviews, pain or suffering was explicitly mentioned as “the biggest fear” (24). Some reported that they would rather die than suffer further pain of the kind they had already experienced.

The fear of the dying process resulted from patients’ expectation that they would be unable to express their needs, wishes or problems due to frailty or cognitive impairment (21). This fear was linked to not knowing whether the future would be marked by intense suffering.

The sense of hopelessness felt by patients was associated with the progressive nature of their illness, a process that would lead inevitably to death, and about which nothing could be done: "You lie in bed and none of the normal functions come back. They will never come back and it will only get worse" (9). Some patients said they felt mentally exhausted, and tired of fighting their illness. One of the interviewees described his illness as "the end of many dreams for plans […] the end of it all. There's no future really" (2).

## Social factors

For many, *social factors*, such as being a burden on others, making loved ones suffer, or being dependent, and in need of help, were another cause of suffering, and a reason for expressing the WTHD. The idea of causing others to suffer frequently caused patients themselves to suffer. For some, observing their own deterioration, and the impact of this on loved ones, was more difficult to bear than their own suffering.

Related to loss of function was increased dependency on others resulting from a deteriorating state. In some cases this dependency left many patients "at the mercy of others" (9), and feeling useless. Participants complained about needing to be fed, washed or dressed by others (1,7): "It's horrible […] the whole situation. […] Not being able to get out of it, and every morning the same thing: waking up, being washed, lying there till the evening, the same pain" (4). For those who had been highly independent prior to their illness, or who had a high level of professional responsibility at work, the change in role (i.e. to dependency, and vulnerability) impacted enormously on their way of life, with some finding this difficult to accept.

Some patients said that they felt devalued, and treated as if they were no longer a person. Thus, further suffering, and a loss of self-esteem could be caused by health professionals failing to respond to their needs, to convey empathy, and a comforting attitude, or to respect their treatment choices (4).

“Just one sentence can hurt me, making things even worse… Really bad… When I need someone to help me, they just hurt my self-esteem […] I was right but they said I was wrong... What was worst was that I had to admit to being wrong and agree with them” (7).

**Loss of self**

Many participants attributed the WTHD to a perceived loss of self or of identity, due to the impact of their illness on their life. Physical, psychological, and social factors (suffering; dependency; loss of control, both mentally, and physically; loss of self-esteem; or feeling a burden on others, etc.) combined to severely undermine their self-image, their sense of who they were: “she was going to lose significant ability to be the person she was” (23). Some studies referred to the loss of self as a loss of the essence, loss of personality, loss of the sense of dignity (23) or destruction of the self (24). When participants felt vulnerable, looked down on or inferior with respect to others, then the loss of self was heightened. In some cases, this led the individual to feel a loss of community (1), that is, a loss of close personal relationships accompanied by feelings of isolation, and a lack of understanding.

Many patients described the experience of being devalued or treated as an object, as well as the feeling of having lost control over oneself, and of being forced into a situation that went against all they considered to be important, as losing their sense of dignity. Some situations -especially those that drew attention to their loss of control, and independence, notably in hospital settings- were perceived by interviewees as demeaning, leading them to being felt treated as objects or patients rather than as individuals (1,23).

Some patients did not wish to succumb to a situation over which they had little control, and thus the WTHD emerged in response to a perceived lack of purpose or meaning in life: “I’m just saying to myself when I go to sleep, ‘Just let me die.’ I don’t want to have to wake up and face this. […] I have nothing to live for, absolutely nothing. There’s nothing coming up in my life that I am living towards, and if there was it would be so terrible because it probably wouldn’t happen” (6). For patients such as this, losing what made life worthwhile, and relevant strips them of the will to live. This loss of self is associated with a broader series of losses (of quality of life, of autonomy, of the ability to perform daily life activities, etc.), such that illness is experienced as progressive loss that will cease only in death.

## 3. Meanings of the WTHD

Our analysis suggested that the meanings attributed by patients to the WTHD could be categorised into five sub-themes.

### Cry for help

As a result of their suffering, many participants expressed the need for immediate action to put an end to their torture, to the misery of the current situation (24). In some cases this involved an explicit request for help -whether from professionals or someone close to them- in coping with all they were going through. For other patients, the cry of despair was the result of their suffering, and the difficulty of accepting their illness, an aspect revealed in the rhetorical questions that are sometimes posed: ‘Why me?’ or ‘Why do I have to go through this?’ (22,24).

### To end suffering

Death was sometimes described as preferable to suffering, or as the lesser of two evils

(4) ("I don't want to go through the dying process so I'll kill myself" (24)). Here, the WTHD becomes synonymous with not wanting to suffer any more, and the desired death is seen as a release ("a vehicle to just, just stop my life" (24)), as a way of putting an end to loneliness, fear, dependence, pain, hopelessness, and the feeling that life is no longer enjoyable (8), or as a means of limiting disintegration, and loss of self (1).

### To spare others from the burden of oneself

Advanced illness, and its consequences (i.e. suffering, loss of independence, the need for help from others) led some people to state that they would rather die than be a burden to their loved ones, or see them suffer: "No matter how much they love you, you are always a burden. You automatically become a burden to everyone…" (6); "When I know that my life has become a burden to my loved ones, I would rather die" (22). The WTHD can thus represent the desire to spare others from suffering, a gesture of altruism (24).

### To preserve self-determination to the very end

The WTHD was also seen as a way of preserving self-determination, autonomy or control through to the very end of life. For some patients, the possibility of putting an end to their life, and of exerting some control, became more important as they began to lose more of their capacities.

"I will do things my way and to hell with everything and everybody else. Nobody is going to talk me in or out of a darn thing…. What will be, will be; but will be, will be done my way. I will always be in control" (23).

"I am in control of this body […] I will do whatever I want to with it" (23).

"I would like to bring about my own death" (11).

### Will to live, but not in this way

The WTHD also emerged, somewhat paradoxically, as an expression of "the will to live, but not in this way". For some people, not being able to do the things that brought meaning, and value to their life was a reason to wish for its end. Many patients mentioned activities that made life worth living (e.g. creative activities, reading, driving, or enjoying time spent with family, and friends), and they felt convinced that when they could no longer do any of those things, their life would be meaningless, and they wouldn't want to live anymore (23). Some participants referred explicitly to the paradox of a will to live but not in this way, acknowledging, for example, that they experienced a wish to die at the same time as undergoing active anti-cancer treatment (10).

## 4. Functions of the WTHD

Analysis of the reviewed studies suggested that the WTHD can serve two possible purposes or functions: *a means of communicating,* and *a form of control.*

### WTHD as a means of communicating

Although many participants did not refer to this aspect explicitly, the expression of a WTHD served to communicate feelings, thoughts, and wishes. In the context of extreme suffering it represented a 'cry for help'. In some studies patients used the WTHD to voice concerns about death, and illness (4,24). One patient spoke about how difficult it was to talk about death with her husband, adding that the verbalisation of her WTHD had opened a way into this topic (4).

### WTHD as a form of control

For some patients, having a sense of their own personal agency brought some relief from present suffering. In this respect, the WTHD was equated with maintaining some control over their life, and of avoiding further suffering. In some cases, this control was expressed through hypothetical plans about how they would end their life if things deteriorated. Coyle and Sculco (24) refer to this projection into the future as the 'if-then' scenario: if my illness progresses, and I can no longer bear to suffer, then I will put an end to my life. In countries where euthanasia or assisted suicide are legal, this notion of 'having a plan' implied making contact with organisations, or professionals that supported such practices (1,4,9,23).

### 5. Lived experience of a timeline toward dying and death

The experience of a WTHD was also associated with the sense that time was running out. The anticipation of imminent death, and an awareness of the finality of life brought more suffering, and disquiet, and it was in this context that, paradoxically, the idea of hastening one's death came to be seen as a way of putting an end to suffering. Some participants described how they had had to give up the usual things they did (4,23). Such inactivity left them feeling that all they could do was wait as time itself appeared to slow: "waiting and waiting, too often, extended, prolonged, so long, on and on, it should be over, limited, until the last moment, and from one second to another" (21).

For some people, their WTHD fluctuated over time. In these cases, the wish to live might become stronger as reasons why the person had wished to die became less prominent (e.g. their physical pain lessened). However, the balance could then tip the other way depending on their circumstances, such that, at times, a wish to die, and a wish to live might both be present.

## DISCUSSION

Five years on from our previous meta-ethnography the inclusion, and analysis of seven additional studies has brought greater understanding of the WTHD. Using an approach that France et al. (15) refer to as ‘extending and renovating the house’ the inclusion of recent literature has enabled us to reclassify categories from our original synthesis into a new set of themes. The new analysis also yielded an additional theme not present in the earlier review. Statements from participants in the additional studies, as well as theorisation proposed by study authors, were key to this reconceptualization.

Our findings indicate that the primary, overarching theme for an understanding of the WTHD in patients with advanced disease is suffering. This extends to different dimensions of their personhood, and thus may involve physical, social, psychological/emotional, and/or spiritual/existential suffering. Many patients referred to the deep impact of this suffering on their sense of self or identity, as well as on their immediate surroundings, and their ways of coping with life. These findings are consistent with a recent international expert consensus statement, which defined the WTHD as “a reaction to suffering, in the context of a life-threatening condition, from which the patient can see no way out other than to accelerate his or her death” (25).

Although suffering emerged as the common theme underlying the experience of the WTHD, one participant in the study by Ohnsorge et al. (4) stated that she was not suffering, but because she knew that she would die soon, she wanted death to come faster (without actually having the WTHD). While this is the only case we identified where a WTHD was expressed outside a context of suffering, we do not rule out the possibility that other similar cases may exist. Just as for some patients death was seen as release from their illness, the patient referred to above seems to have gained some relief from the knowledge that her illness was progressing, and that death was imminent.

The second theme, reasons, captures how a WTHD can represent a response to physical, psychological/emotional, and social factors in the context of intense suffering, and a perceived loss of self. Although physical pain was for many years considered the primary cause of the WTHD, studies conducted since the late 1990s offer a more complex view (26). Thus, while several authors report a close relationship between the WTHD and, for example, greater functional impairment, and dependency (27,28), there is evidence to suggest that psychological, and emotional factors play an important role in the emergence of such a wish (3,5,26). In terms of a person's subjective experience, it is not possible to separate physical symptoms, and functional impairment from the impact they have on the person's relationship to his or her surroundings, and the psychological or existential suffering that results. Indeed, physical pain, and loss of functionality are inextricably linked with all other aspects of the self, and as such they may, for example, lead to feelings of hopelessness and helplessness making it difficult for the patient with advanced disease to find meaning in life. This multifaceted suffering, which cannot be reduced to its constituent parts, exemplifies what Cicely Saunders (29) referred to as 'total pain'. Some participants felt that were it not for their physical pain they would not wish to die. However, other statements made by patients indicate that the experience of pain cannot be understood in isolation from its impact on the person's psychological and emotional state and their relationship with the immediate environment. These apparent contradictions may reflect how researchers have explored or assessed pain in this context, since instruments used in cross-sectional studies are unable to capture the full intensity and experiential impact, with qualitative research offering a more nuanced holistic account of the experience of pain.

In our synthesis psychological factors are prominent as triggers of the WTHD. Quantitative studies, assessing psychological factors related to the WTHD, could add valuable, complementary information to the findings of the qualitative studies. Depression, for example, has been widely reported as a mediating factor for the WTHD (30,31). In a study by Breitbart et al. (30) it was observed that patients who presented the desire to die were four times more likely to be depressed than those who did not. In another study, Akechi et al. (31) showed that, of a sample of 1721 patients, 220 were diagnosed with major depression and that 51.4% of these had suicidal ideation.

In this synthesis, only three of the 14 included studies (2,23,24) directly referred to the need to address depression. However, in the light of our analysis of study data, clear symptoms of depression can be detected: loss of interest or pleasure in usual activities, loss of energy, feelings of worthlessness, self-reproach, fearfulness, pessimism, recurrent thoughts of death (32).

Similarly, it is important to explore and evaluate hopelessness, helplessness, purposelessness, etc., recurrent states for those who experience the WTHD, as demonstrated by the majority of the participants in our analysis.

Another factor linked to the emergence of the WTHD is demoralization syndrome which can be clinically differentiated from depression and is a powerful mediator of the WTHD in these patients (33,34). Three studies included in this synthesis refer to demoralization (2,4,9). The fact that participants presented hopelessness, loss of meaning and purpose, sense of helplessness, social isolation and lack of support among other findings (35) could be symptomatic of demoralization syndrome, at least in some of the sample. This finding is especially relevant for clinicians, who could implement measures for its detection and treatment (36).

Another aspect that was prominent in our synthesis was that many patients referred to the fear of future physical symptoms or future suffering rather than actual current physical symptoms. Our analysis identified that many patients had already experienced episodes of acute poor symptom control with past experience leading them to be fearful when anticipating the future process. In this way, we can further confirm an overlap between physical or psychological factors. Furthermore, we can see how the symptom picture offers a basis for the psychological response to the situation being encountered: in this case, through fear.

While the authors of the included studies identify diverse reasons for the WTHD, these are, in fact, inter-related. In some cases it is difficult to differentiate the physical, psychological, emotional, social, and existential dimensions of patients' experience. Thus, for example, although aspects such as meaning in life or loss of the sense of dignity are often described as psychological/emotional/existential issues, in our analysis they relate to the sub-theme of *loss of self*, in other words, a loss of identity that covers all dimensions of personhood.

The concept of dignity in the context of patients with advanced illnesses is crucial because it resolves the inevitable difficulty in trying to delineate physical from psychological suffering. It allows us to understand that patients perceive suffering and simultaneously attribute meaning to their experience. Dignity has been defined as an intrinsic and absolute quality of human beings, which can be perceived as a sense of identity, in relations to physical, psychological, spiritual and social factors mediated by illness (37). The perception of personal dignity, understood as how a person perceives themselves in the light of suffering, the loss of functionality, changes in physical image etc., along with the emotional impact of experiencing illness, holds special relevance. In this sense, dignity encompasses very different aspects from loss of the sense of dignity mediated by the loss of functionality (loss of bodily function, cognitive impairment, loss of value of life, loss of quality of life) through to dignity understood as personal identity (loss of self-worth, loss of image, loss of self-esteem, loss of social identity: fear of being vulnerable, shame) (37–41).

The third theme that emerged from our synthesis was *meanings*. Identifying the meanings the WTHD may hold (other than simply a desire to die) is crucial for understanding the complex and dynamic nature of this phenomenon. Some studies point out how the WTHD can fluctuate over time (42,43), such that an individual may experience contradictory wishes (7,10,24). Such cases highlight the need for caution when exploring the meanings that a given individual may attribute to the expression of a WTHD. Furthermore, although the meanings identified in this updated review were derived from the statements made by participants, the meaning of a WTHD may also be influenced by the values and moral understanding of patients (10,44). In this respect, it is important to explore the cultural and personal background of a patient who expresses a WTHD so as to be able to properly contextualise what is being expressed.

The fourth theme, functions, considers the WTHD as a means of communicating and as a form of control. All the studies revealed that the WTHD served to express more than just a desire to die. The communicative function of the WTHD was clear in some cases, in strengthening family ties and highlighting how important the care and presence of loved ones was to the patient. In some way, the WTHD is also experienced as a way of reducing the burden on family members and of saving them from experiencing a protracted process before death (4,23). Involving relatives in decision-making meant that responsibilities were shared and helped ensure, to some extent, that the patient would not be abandoned to their fate. Occasionally, the expression of a WTHD was used to make relatives, friends or professionals feel that they should do more for the patient, or to obtain personal gain. In the majority of cases, however, the expression of a WTHD was a way of communicating the extent of suffering (24).

The WTHD as a form of control featured in our previous meta-ethnography. For this update, however, our analysis paid closer attention to the legal context, especially in countries in which euthanasia or AS has been decriminalised. Of the 14 studies, six (4,8–11,23) refer explicitly to physicians or organisations that could provide support to persons interested in euthanasia or AS. Making contact with right-to-die organisations was seen as the final act of control available to someone with a terminal illness. Some patients who expressed this desire for control ended up dying through the administration of lethal drugs (9,23). In countries where such practices remain illegal, patients alluded to hypothetical plans in which the possibility of suicide was contemplated. Such plans appeared to generate a sense of control and of relief among patients (without the irreversibility associated with euthanasia or AS). Once again, the primary motive for such control was the wish to put an end to suffering. In sum, the existence of legislation that permits euthanasia or AS can influence decision-making for advanced patients at the end of life (4).

The final theme, *lived experience of a timeline toward dying and death*, contextualises patients' statements within a temporal framework. The experience of time only appeared explicitly (i.e. as a theme identified in the data analysis) in one study (21). However, when patients in other studies spoke of their experience of progressive deterioration, fear, anguish, hopelessness, and loss of control, etc. they made implicit reference to their life past, present, and future. This temporal aspect of the WTHD, captured not only in qualitative studies (45), highlights the importance of a more detailed exploration of patients' experience when seeking to address their doubts, and concerns.

**Strengths and limitations**

This updated review and synthesis of the published literature on the WTHD has brought a more detailed understanding of the phenomenon. For the present qualitative analysis, two researchers (ARP and ABo) joined two authors from the previous meta-ethnography (CMR, ABa), and this triangulation of researchers (46) injected a fresh perspective. Inclusion of studies from countries beyond those from the earlier meta-ethnography (specifically, Germany, The Netherlands, Switzerland, and Thailand) increases the transferability of results. So far, we have been unable to identify published studies of the WTHD in Africa, South America, and the Middle East. As in our previous review, we achieved data saturation in the present study. Only one new theme ('lived experience of a timeline towards dying and death') was identified, a theme already implicit in the earlier meta-ethnography. Other themes that emerged encapsulated previously identified themes, which were here reclassified, and reconceptualised.

One limitation of the present study concerns the difficulty of synthesising findings from primary qualitative studies. Not all studies used the same conceptualisation of the WTHD, and the research objectives of some studies only touched indirectly upon the phenomenon. Likewise, not having access to the original interviews limits the available data.

The analysis necessary to reach a categorisation entails a somewhat forced disection. For example, the subthemes physical, psychological/emotional and social factors were treated independently in order to be able to analyse them in more depth. However, in the experience of illness, these factors, like the majority of those analysed, are interlinked and inseparable.

**Implications for practice and future research**

The WTHD is a complex phenomenon to which various reasons, meanings, and functions may be attributed. This highlights the need for professionals to be trained so that they can respond to and understand the impact of a life-threatening illness on the individual.

These findings can also provide a number of indicators for ways to improve the health care for patients at end of life as suggested in different studies: by focusing on understanding the source of suffering, by enhancing the experience of dignity (39,47–49) or meaning in life (50,51), or promoting therapeutic interventions to address demoralization (36).

Healthcare professionals have an important part to play; they are able to acknowledge the meaning of physical symptoms and physical suffering and the role of tending to family members and social factors (including available strategies to guide clinicians in caring for families of dying patients). What's more, the finding from our qualitative data offer a detailed insight into the fact that frequent symptoms and features of depression (hopelessness, helplessness, loss of self esteem and related sense of burden to others) have important clinical implications for the importance of identifying, assessing and effectively treating depression in this context.

Furthermore, an understanding of the factors that can trigger a WTHD may help to prevent its emergence. From a quantitative perspective, many studies have linked the emergence of the WTHD with the aforementioned factors. Some of these even analyse predictors of the WTHD (28,33,52,53). For example, Rodin et al. (54) used a structural equation model to support the view that depression, hopelessness, and the desire for hastened death represent final common pathways of distress determined by multiple risk and protective factors. Vehling et al. (53), using a similar methodology, showed that loss of dignity partially explains the positive association between the number of physical problems and demoralization in cancer patients. Robinson et al. (33) suggest that depressive symptoms, loss of meaning and purpose, loss of control, and low self-worth are relevant psychological mechanisms that probably contribute to the development of a desire to hasten death in palliative care patients. Recently, Guerrero-Torrelles et al. (55) show a model whereby meaning in life (specifically in the sense of diminished meaning) and, to a lesser extent, depression have a mediator effect on the relationship between physical impairment and the WTHD in patients with advanced cancer. Nevertheless, the large majority of quantitative studies have cross-sectional designs, which limits the possibility of establishing causality, as well as only studying variables that could be quantified. In this sense, qualitative studies offer a more in-depth study of the phenomenon as a whole.

It has recently been suggested (28) that proactively asking patients about a potential WTHD could be beneficial. Further studies are required to explore this strategy. Given that social factors contribute to the emergence of a WTHD, future research should explore how the expression of a WTHD is experienced by the person's relatives, and what meanings it may have for them. Systematic guidelines regarding the WTHD are needed to help health care professionals respond adequately to the needs of these patients.

## CONCLUSIONS

The WTHD in patients with advanced disease cannot be understood outside the context of their suffering, a prerequisite for its emergence in this population. However, every expression of a WTHD will have associated reasons (the whys) and functions (for what purpose), and its meaning may vary by cultural background and lived experience, to not necessarily be synonymous with a genuine desire to die. In countries where EAS have been decriminalised, the expression of a WTHD may be seen as a way to end suffering.

All these aspects underline the need to explore the reasons, meanings, and functions that a person attributes to such a wish, as only by doing so will we be able to understand his or her experience and develop appropriate individualised care plans.

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## Contributions

Contributors CMR and ABa designed the study. CMR collected data. ARP and CMR conducted data analysis. ARP, CMR and ABa wrote the manuscript. ABa and ABo made substantial contributions to the identification of relevant literature, the interpretation of findings and were involved in drafting the manuscript and revising it critically. All authors gave final approval to this manuscript.

## Competing interest

The authors declare no conflict of interest.

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## Data sharing statement

All data supporting this study are provided as supplementary information accompanying this paper. Further information can be obtained from the corresponding author.

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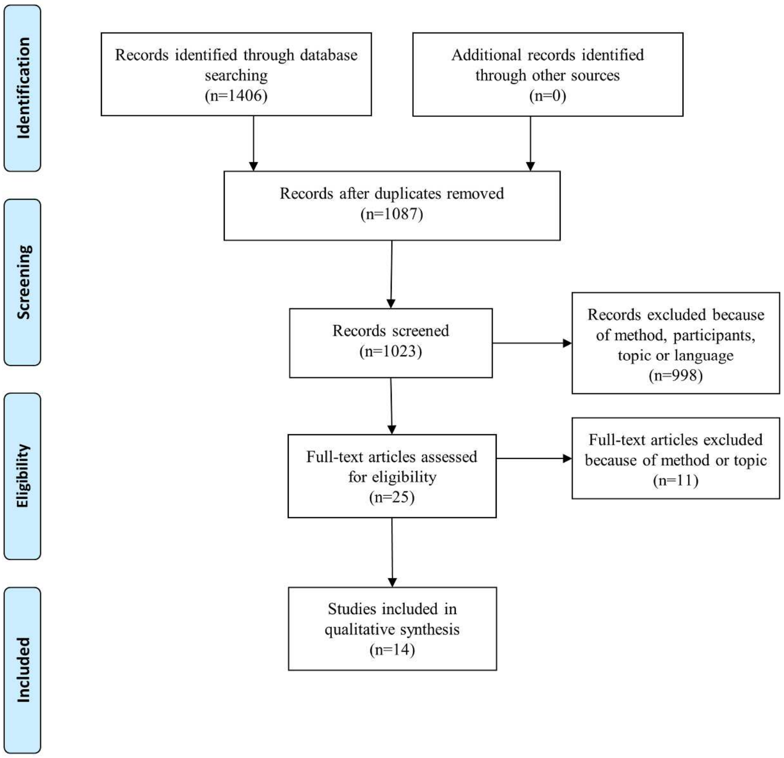

Figure 1. Flowchart of the selection of the studies

# SUPPLEMENTARY FILES

**Table-S1.** Methodological quality of included studies, assessed using CASP criteria: qualitative research checklist

| Reporting Criteria (CASP) | N (n=14) | References of studies reporting each criterion |
|---|---|---|
| **1) Was there a clear statement of the aims of the research? Consider:** (Yes // No // Comments)<br>- What the goal of the research was | 14 | (1–14) |
| – Why it is important | 14 | (1–14) |
| – Its relevance | 14 | (1–14) |
| **2) Is a qualitative methodology appropriate? Consider:**<br>– If the research seeks to interpret or illuminate the actions and/or subjective experiences of research participants | 14 | (1–14) |
| **3) Was the research design appropriate to address the aims of the research? Consider:**<br>– If the researcher has justified the research design (e.g. have they discussed how they decided which methods to use?) | 12 | (1,3–10,13,14) |
| **4) Was the recruitment strategy appropriate to the aims of the research? Consider:**<br>-If the researcher has explained how the participants were selected | 13 | (1–10,12–14) |
| – If they explained why the participants they selected were the most appropriate to provide access to the type of knowledge sought by the study | 13 | (1–10,12–14) |
| – If there are any discussions around recruitment (e.g. why some people chose not to take part) | 11 | (1–9,12,14) |
| **5) Were the data collected in a way that addressed the research issue? Consider:**<br>- If the setting for data collection was justified | 14 | (1–14) |
| – If it is clear how data were collected (e.g. focus group, semi-structured interview, etc.) | 13 | (1–9,11–14) |
| – If the researcher has justified the methods chosen | 7 | (4,6,7,9,10,13,14) |
| – If the researcher has made the methods explicit (e.g. for interview method, is there an indication of how interviews were conducted, did they use a topic guide?) | 11 | (1,3,4,6–9,11–14) |
| – If methods were modified during the study. If so, has the researcher explained how and why? | 2 | (10,14) |
| – If the form of data is clear (e.g. tape recordings, video material, notes, etc.) | 14 | (1–14) |
| – If the researcher has discussed saturation of data. | 10 | (1,2,5–7,9,10,12–14) |
| **6) Has the relationship between researcher and participants been adequately considered? Consider whether it is clear:**<br>-If the researcher critically examined their own role, potential bias and influence during: | 2 | (4,7) |
| formulation of research questions | 3 | (1,3,7) |
| data collection, including sample recruitment and choice of location | 5 | (1,3,4,6,7) |
| - How the researcher responded to events during the study and whether they considered the implications of any changes in the research design | - | - |
| **7) Have ethical issues been taken into consideration? Consider:**<br>– If there are sufficient details of how the research was explained to participants for the reader to assess whether ethical standards were maintained | 13 | (1–5,7–14) |
| – If the researcher has discussed issues raised by the study (e.g. issues around informed consent or confidentiality or how they have handled the effects of the study on the participants during and after the study) | - | - |
| – If approval has been sought from the ethics committee | 14 | (1–14) |
| **8) Was the data analysis sufficiently rigorous? Consider:**<br>– If there is an in-depth description of the analysis process | 12 | (3–14) |
| – If thematic analysis is used. If so, is it clear how the categories/themes were derived from the data? | 12 | (1,3–5,7–12,14) |

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| – Whether the researcher explains how the data presented were selected from the original sample to demonstrate the analysis process | 6 | (1,3,4,9,10,14) |
| – If sufficient data are presented to support the findings | 12 | (1–8,10,12–14) |
| – To what extent contradictory data are taken into account | 1 | (11) |
| – Whether the researcher critically examined their own role, potential bias and influence during analysis and selection of data for presentation | - | - |
| **9) Is there a clear statement of findings? Consider:**<br>– If the findings are explicit | 14 | (1–14) |
| – If there is adequate discussion of the evidence both for and against the researcher's arguments | 9 | (1,3,6,7,9,11–14) |
| – If the researcher has discussed the credibility of their findings (e.g. triangulation, respondent validation, more than one analyst) | 10 | (1,3,6–9,11–14) |
| – If the findings are discussed in relation to the original research questions | 14 | (1–14) |
| **10 How valuable is the research? Consider:**<br>– If the researcher discusses the contribution the study makes to existing knowledge or understanding (e.g. do they consider the findings in relation to current practice or policy, or relevant research-based literature?) | 13 | (1–9,11–14) |
| – If they identify new areas where research is necessary | 13 | (1–9,11–14) |
| – If the researchers have discussed whether or how the findings can be transferred to other populations or considered other ways the research may be used | 8 | (1,3,5–9,11) |

**Table-S2.** The seven stages of meta-ethnography, summarising what each step entailed in the previous and the present review

| **Noblit and Hare's 7 steps** (15) | **What each step entailed in our original meta-ethnography** (16) | **What each step entailed in the present, updated meta-ethnography** |
|---|---|---|
| 1. "Getting started" (the topic focus) | To analyse the meaning of and motivation for the WTHD in patients with chronic illness or advanced disease. | To analyse the WTHD in patients with chronic illness, advanced disease or life-threatening illness. |
| 2. Deciding what is relevant to the initial interest | Design a search strategy to identify qualitative studies (December 2000-November 2009). | Design of a revised optimal search strategy. For inclusion: qualitative studies (December 2000-January 2016). Studies from original meta-ethnography and from update to be integrated. |
| 3. Reading the studies | Generate list of key concepts to identify common and disparate concepts and themes, both within and across studies. Findings from the research reports divided into text units coded by words, sentences or paragraphs, according to content. Codes grouped into themes to define characteristics or different dimensions of the phenomenon studied. | Generate list of key metaphors using Atlas.ti software to identify common and disparate concepts and themes, within and across studies. No distinction to be made during reading and analysis between previously reviewed and new studies. Findings from research reports to be handled in same way as for the original meta-ethnography. |
| 4. Determining how studies are related | Directly compare concepts from primary studies using reciprocal translations (generating metaphors to express similarities between study findings). | Directly compare concepts from primary studies using reciprocal translations (as for the original meta-ethnography). |
| 5. Translating the studies into one another | Having identified main concepts from each study, search for their presence or absence in all the studies. Comparison to begin with themes identified in the earliest published article and to proceed in chronological order of publication. Translate themes to the whole sample and to each individual study. | Having identified concepts from each study, search for the presence or absence of main concepts in all studies. Comparison again to follow chronological order. Translate themes to the whole sample and to each individual study. During the analysis, return to the original themes, comparing them with the new themes that emerge. Themes emerging from the update can confirm or broaden the original themes, or constitute new themes. |

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| 6. Synthesising translations | Bring together translated concepts within a synthesis, starting from identified themes, and match them with their respective quotations, resulting in themes within final synthesis. Finally, derive explanatory model. | Bring together expanded number of translated concepts within an expanded final synthesis. Concepts can confirm original translated concepts, but might also lead to new explanatory model. |
| 7. Expressing the synthesis | Express synthesis as themes with an accompanying narrative in a scientific journal. | Again, express synthesis as themes with an accompanying narrative for submission to a scientific journal. |

**Table-S3.** Comparison of yield between Original Review and Updated Review

| **Noblit and Hare's 7 steps** (15) | **Original Review** | **Updated Review** |
|---|---|---|
| 1. "Getting started" (the topic focus) | 7 studies (December 2000-November 2009) | 14 studies: 7 original + 7 new studies (December 2000-January 2016) |
| 2. Deciding what is relevant to the initial interest | | |
| 3. Reading the studies | | |
| 4. Determining how studies are related | 10 translated concepts | 25 translated concepts |
| 5. Translating the studies into one another | | |
| 6. Synthesising translations | 6 themes | 5 themes |
| 7. Expressing the synthesis | Explanatory model | New explanatory model |

**Table-S4.** Classification of verbatim statements from the studies by theme and sub-theme

| **Themes, subthemes and quotations** | **Some of the related themes** |
|---|---|
| **1. Reasons for the WTHD** | |
| **1.1 Physical factors** | |
| "Um, the ability to perform simple things like, you know, going to the bathroom on your own and not through a bag, um, breathing with your own lungs, not dependent upon a machine to keep the body parts functioning, um being able to do anything, I mean as long as you can think then you can live, but if you can't [sic] no longer even formulate a thought due to dementia or you know the ravages of the disease. You know, if you were to stand there in your former self, would you want to see yourself in that position? I know I wouldn't. You get to the point where there's no return, you know, I can understand somebody saying, well geez, you know, like I used to be somebody, but now, like I mean, you know, I'm no better than like a doll, somebody has to dress me and feed me and I guess it's uh, I don't know how to explain it, really" (1). | Dependency<br>Progressive deterioration<br>Loss of function<br>Loss of the self<br>Loss of the sense of dignity |
| "… If I'm going to be rolling around in my own faeces because I have no control, then forget it" (1). | Loss of function<br>Loss of control |

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| “You turn them over, they're in pain. They're going to shit themselves, they're going to piss themselves, they're going to lie there and have someone do all their bodily functions and just, they're going to suffer the whole time, they're going to be no happiness, they're going to go down to 60-70 pounds, they're just going to, their whole last weeks of life is just going to be in pain and agony and people coming in, people being upset, them being upset” (1). | Loss of function<br>Anticipation of future suffering<br>Not wanting to make others suffer |
| “I can’t move, just lie here... feeling like a vegetable… a useless person... needing people to feed me” (4). | Loss of function<br>Loss of independence<br>Dependency<br>Loss of value |
| “But really yes, to see a man, who only exists of pain, who maybe is cognitively impaired and isn’t able to participate actively in life, this man, who only lies in bed, not noticing his surroundings…” (14). | Suffering<br>Loss of physical function and cognitive impairment<br>Loss of daily life activities<br>Loss of value |
| “I say: I have made my decision. I don’t want you to treat me any longer. Someone says, now you are probably too weak for chemo. I say: if I’m not too weak and they want to give me chemo, I will refuse it, because in the little time that is left to me I want quality of life, not quantity of life. I decided that a year ago: if this were to overcome me, then that’s what I would choose” (9). | Loss of quality of life<br>Desire for control over life |
| “If you get cancer, you’ll get pain. Cancer is a painful disease. It’ll just get more and more painful” (4). | Progressive deterioration<br>Suffering<br>Lived experience of time<br>Anticipation of future suffering |
| “Whether it gets better or not, it's destined. I'll wait to die. There's no way out even if the pain returns. It'll come when it may. I'll just go along with the pain and die. Nothing would help” (4). | Pain<br>Suffering<br>Hopelessness<br>WTHD as unbearable situation with no other way out |
| “The side effects of the treatment are unacceptable… the Prednisone destroys you. For example, it destroys your muscles. My thighs are so weak I can’t get up from the floor, and I don’t have the energy to exercise. The whole thing is a vicious circle… My face… looks like a melon… I look like a frog in heat” (5). | Progressive deterioration<br>Loss of function<br>Loss of image: shame |
| “... the terrible weakness and the nausea and just not feeling like you can do anything... And it’s kind of like goals that I actually have or things that I want to accomplish are slowly being taken away… it’s kind of like the realm of the possible… is shrinking” (5). | Progressive deterioration<br>Lived experience of time (there is no future)<br>Hopelessness<br>Losses |
| “The pain could happen immediately or it could happen an hour or two later. And then I have to see about seeing [my provider] again. It is a treadmill that I'm on; I can't get off of it, and I've had it. And I can't live this anymore” (5). | Anticipation of future suffering<br>Unbearable suffering with no other way out |
| “Well, the pain that I had before with the rheumatoid arthritis I knew that I could handle—... But this pain that I have, I’m not sure—I can’t get rid of it with the pain medicine always... To give me enough to keep that pain under control, they’d have to put me out, and I don’t want my son to have to take care of a bed patient” (5). | Not wanting to be a burden<br>Unbearable suffering with no other way out |
| “I have fecal incontinence. I can no longer swallow and in hot weather I really envy people who can drink” (9). | Loss of physical functions<br>Loss of control<br>Loss of the sense of dignity: shame |
| “The way to my bed is endless and finally I get there. It takes a lot of energy, but once I’m in bed, it takes an hour just to gather my strength again” (9). | Loss of function<br>Progressive deterioration<br>Losses |

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| "I am in pain all the time, I am in pain at night, I wake up with pain and I go to bed with pain. If they could take away half my pain I wouldn't be thinking about euthanasia" (9). | Pain<br>Suffering<br>Will to live but not in this way<br>Hastened death as a way of ending suffering |
| "I was simply nauseous and my energy was just running out. And I said that I wished that, just for a short period of time, I could eat normally and not have to fight to keep it down and that I wanted to have a little more energy. Then I stopped the chemo and indeed I had that improvement" (9). | Consequences of the medical treatment |
| "Yes, I could not tell it, because I have just no pain now. That's maybe less [the idea that her illness should proceed faster]. If I had pain now or so, then I would say: immediately. But then… I will have to wait. That's not my business. That's God's business" (11). | Pain as *mediator* of the WTHD<br>Ambivalence<br>Wish to live but not in this way |
| P: "It's horrible, I can tell you. It's horrible. […] the whole situation. I: The situation. Not being able to get out of it. P: Not being able to get out of it, and every morning the same thing: waking up, being washed, lying there till the evening, the same pain" (12). | Dependency<br>Suffering<br>WTHD: unbearable situation with no way out (other than death)<br>Despair |
| "I sit back and I say, 'since I'm already dying, and since I'm already gone, lost my energy. Why? Why do I also have to take these disgusting pills?' and it seems that every day there's something more, something more disgusting" (7). | Hopelessness<br>Tired of fighting |
| **1.2 Psychological factors** | |
| "... the end of many dreams for, plans, complete halt to things I was doing, want to do. The biggest thing is the weakness, which I absolutely hate, not being able to do things, to realise that this is virtually the end of it all. There's no future really. You can't plan anything" (17). | Hopelessness<br>Progressive deterioration<br>Limitation of activities<br>Loss of function<br>Lived experience of time |
| "Sometimes I start yelling at my shrink that this is horrible, that why don't I die right now?...Why do I have to live through this?" (3) | Fear of the dying process<br>Unbearable suffering<br>Loss of meaning |
| "I don't want to undergo that [expletive] feeling of helplessness, that there's not a [expletive] thing that I or anyone else can do" (3). | Helplessness<br>Hopelessness |
| "I just don't want to be in so much suffering... to endure these psychological effects" (4). | Suffering |
| "Not much hope, nor would there be any miracles… You doctors can't help when the patients deteriorate and then drop dead…" (4). | Progressive deterioration<br>Hopelessness |
| "Someone with a tube sticking up the bottom, a tube sticking into the nostrils, another somewhere else. I mean, what for? Can you save them?" (4). | Hopelessness<br>Loss of meaning |
| "I asked the doctor, 'Doctor, do people with cancer get a lot of pain?' He answered, 'In the majority they do.' Then I asked, 'Is it possible not to be like that?' He answered, 'Possible, I suppose.' Ah…" (4). | Fear of suffering |
| "Some don't have loved ones around. They have nobody to care for them. Others have relatives but they don't care… I only have one daughter. If she doesn't help, who is going to help?… So miserable that I cannot express in words" (4). | Hopelessness<br>Fear about the future<br>Lack of social support |
| "My first husband, he suffered a long time. He had on those machines, and I used to say, 'God,' I said, 'don't let me go under those machines" (6) | Fear of suffering |

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| "I never thought about giving up but my fear was that I didn't know much about cancer. There are so many people that linger, and I was afraid that I could not cope. I know I will die, but I don't want to be lingering and suffering and people around me to suffer with me. So I thought, 'I will go for a swim' and I don't know how to swim or I would go to a place like Holland. I just don't want to be lingering, like people that can hardly talk and are really suffering and I don't want to do that. It's the only thing that makes me feel a little bit emotional. I don't want to deal with it so I think I would speed up things myself. I don't want to be lingering here in palliative care, lying day and day, slowly dying. Oh no, I don't want to do that. So, suicide is a way of exiting. I don't want to talk about that because I like life and I have lots to live for, but if I come to the point when I am too weak to do anything, then I don't want to stay" (7). | Anticipation of future suffering<br>Progressive deterioration<br>Not wanting to be a burden<br>WTHD as a way of ending suffering<br>WTHD so as to spare others from burden<br>Having a plan<br>Will to live but not in this way |
| "It is such an aggressive form of cancer. I saw all my energy going down the drain- what I could still do last week I can't do at all now. I really enjoyed my life, but now I have just to wait and see how things go and what death will look like" (9). | Hopelessness<br>Suffering<br>Will to live but not in this way |
| **1.3 Social factors** | |
| "I think it's very important for every single person to feel that they belong, and, and that they fit in a community, in a city, in a country, in a world, ah, in nature. The, the ah, and I think when we no longer feel that you have these linkages, and that the linkages are valued for everything that you're connected with, whether it, you know, family or friends or, you know, associates, or whatever, and your community, and city and all the rest of. Once the once, once you perceive that, that your relationships, all the links with, with other living things have deteriorated, and then, and they're not valued, then you've lost face. Dignity, then, has for me, has an awful lot to do with face" (1). | Loss of community<br>Loss of the sense of dignity<br>Disintegration<br>Loss of value |
| "No matter how much they love you, you are always a burden. You automatically become a burden to everyone. Even to your own missus" (17). | Being a burden |
| "After a while, your family, who you love so dearly, will remember you as a washed-out role model… It will remind them of what they have to go through, the lack of strength, the weakness, and so forth" (3). | Not wanting to be a burden<br>Fear of losing one's own value/dignity in the eyes of others<br>Loss of the self |
| "For them to see me in pain is suffering. To see family rushing around is so suffering… That makes me suffer. They spend a lot of money… I fear the rushing around would make her [wife] ill, burdening her" (4). | Suffering<br>Not wanting to make others suffer |
| "In the future when I can't manage, I would feel very bothersome and very suffering as if I'm really burdening them. I'm afraid of having others to serve me" (4). | Anticipation of future suffering<br>Progressive deterioration<br>Not wanting to be a burden |
| "I've experienced such incredible pain over the last little while and more in the last week. Such incredible pain that it made me think that death is preferable to this. I'll sit there for 2 hours in terrible pain. Such pain where I can't yawn even, and I get only half a yawn and my whole insides turn and waiting for the medication to start to work. I'd love to have 48 hours let's say, I'd love to have this weekend where I could plan to have a nice weekend and have no pain. I'd love to do that and it doesn't happen, and the pain affects everything. It makes you tired. It affects how you can eat. It affects your mood. It affects other people, and the fact is that even if you try to hide it, you can't. So that's hard, and I know it's gonna get worse, so that's hard too. It's great to be alive, and pain takes that life out of you, and to sit there for 2 hours with a blanket around you just shivering, with no solution, is really hard" (7). | Pain (affects everything)<br>Hastened death as a way of ending suffering<br>Suffering as something worse than death<br>Wish to live but not in this way<br>Anticipation of future suffering |
| " …that others are not affected by watching someone else wasting away for 2 month, willing to die and willing to die, but he does not. That is difficult for the family members" (10). | Not wanting to make others suffer |
| "I want to present myself as being as normal as possible, but everybody notices it: I stumble and I am slow and that is just not me because I always was a nimble girl" (9). | Loss of functions<br>Fear of losing one's own value/dignity in the eyes of others |

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| "I am burdened myself, I am such a burden to others; I want to end this" (12). | Hastened death as a way of ending suffering<br>Not wanting to be a burden |
| "I am not used to somebody helping me. This I feel is tantalizing, this is no life" (14). | Dependency<br>Loss of control<br>Loss of value of life |
| "Not wanting to be seen by those that love me as this skin-and-bone frail, demented person. In other words, I don't want that image of me for me, and I don't want that image to be kind of a last image that my daughters and loved ones have of me. And that's just a dignity issue" (14). | Loss of the sense of dignity<br>Loss of the self<br>Fear of losing one's own value/dignity in the eyes of others<br>Loss of image: shame<br>Anticipation of cognitive impairment |
| **1.4 Self - Identity - Losses** | |
| "I'm not comfortable, and I can't do anything, so as far as I'm concerned in quality of life I'm not living; I'm existing as a dependent non-person. I've lost, in effect, my essence" (5) | Loss of quality of life<br>Loss of independency<br>Loss of the self<br>Loss of daily life activities |
| "I think passively sitting in my own garden, sitting on my own deck, would still be preferable to, to, to death. Quality of life, the concept of quality of life is shifted. I can live with an inactive life... and I'd still fight a bit to gain incrementally" (3). | Loss of function<br>Loss of quality of life<br>Ambivalence: wish to live and wish to die |
| "Finally the illness that dominates everything will wipe out all life has to offer me, what I feared most is exactly what will happen to me. I won't belong anymore, the emptiness of existence, the lack of independence, being unable to do things myself, being at the mercy of others whom I will have to beg to do the things I need in a way that's suitable for me" (9). | Losing<br>Anticipation of future suffering<br>Loss of control<br>Loss of independence<br>Loss of meaning in life<br>Loss of daily life activities |
| "I just can't do what I used to. Um, I can't go out, I can't go to the store… I can't write a check for nothing. I, it's just a lot of things… Oh, I hate it" (6). | Limitation of activities<br>Loss of function<br>WTHD maintaining meaningful activities |
| "There's not any good reason for me to go on living. Nobody really needs me… I'm really not serving any purpose. If you don't, aren't needed by anybody, you kind of have a different feeling about life" (6). | Loss of value<br>Loss of will to live<br>Helplessness |
| "I'm just saying to myself when I go to sleep, 'Just let me die.' I don't want to have to wake up and face this. Honestly I just pray that I would just die in my sleep. I have nothing to live for, absolutely nothing. There's nothing coming up in my life that I am living towards, and if there was it would be so terrible because it probably wouldn't happen" (7) | Hopelessness<br>Despair<br>Loss of meaning in life<br>Loss of will to live |
| "When I'm in pain, it is not so much the pain, it's the loss of control and the helplessness" (7). | Desire for control over life<br>Helplessness |
| "The energy that I have always had, the positive (energy), that has made me as a person… but exactly this is getting less and less at the moment" (7). | Progressive deterioration<br>Loss of the self |
| "The past few days even the news doesn't interest me anymore, I have less interest in the outside world. My brain no longer works and to me that is a part of human dignity and of unbearable suffering. I want to function normally and if I can't do that" (9). | Progressive deterioration<br>Hopelessness<br>Loss of the sense of dignity<br>Loss of will to live<br>Hastened death as a way of ending suffering |
| "I have become so weak because of the pain. I can't walk anymore, I can't eat anymore. My children have suffered enough. I don't want them to go through this again. Everybody has to lose their parents someday anyway" (9). | Pain<br>Progressive deterioration<br>Loss of self<br>Not wanting to make others suffer |

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| "…claustrophobia of my existence. To put it simply, it is insight without perspective. Never in my life have I felt any love. If there had been some warmth and love and safety, I could have grown" (9). | Loss of meaning in life<br>Loss of will to live |
| "I can't drive anymore. I loved to paint and draw, but I can't do that either anymore. Everything I enjoyed is gone. And then, my sight became worse" (9). | Hopelessness<br>Loss of meaning<br>Limitation of activities<br>Loss of function |
| "I'm not interested at all anymore, I just lie here and what's the point? There isn't any. I no longer read. Not books, not newspapers. I have CDs and the Walkman right here. Well, I've listened to, um, two CDs and that's enough. And yet I really loved music, but it's all over. I'm just not interested anymore…" (9). | Hopelessness<br>Loss of will to live<br>WTHD maintaining meaningful activities |
| "I lost my dignity, lying in bed in diapers, I am no longer the independent person I used to be" (9). | Loss of function<br>Loss of independence<br>Loss of the sense of dignity<br>Loss of self |
| "And I don't feel this is a life for me [pause], carrying on living like this. That's why [pause] um, I am [pause] very – how should I put it, so you understand me – I'm on the road, on the move a lot and [pause] then I thought, if I can't live like before, life has no value, does it? And [pause] I drove my car a lot, and I can't do that anymore either. […] Yes, did a lot of travelling. […] I feel my life isn't worth anything at all any more, if I just lie here and wait" (12). | Loss of activities (that make life enjoyable)<br>Loss of value<br>Loss of will to live<br>Loss of life's worth<br>WTHD maintaining meaningful activities |
| "Activities with friends not possible—and indeed activities outside or with the family, I would say, meanwhile completely passed away" (14). | Limitation of activities |
| "You've become a bag of potatoes to be moved from spot to spot, to be rushed back and forth from the hospital, to be carried to your doctors' appointments or wheeled in a wheelchair, and it really does take away any self-worth, any dignity, or any will to continue to live" (1). | Loss of control<br>Loss of the sense of dignity<br>Loss of self-worth<br>Loss of will to live |
| "Oh, it's the dignity and wholeness of my body, as well as spirit. And, it is, it's cruel too for others to have to do this when there's no end in sight, other than death. To just, to clean me up. I just don't want that... Dignity is that I have control over my body, when, when, not, not a virus that is going to take my life. I'm the one who's going to decide when my life will end, not a virus, and not with great pain. Not anything else other than in, in my control. It is my control, my choice to do" (1). | Loss of control<br>Loss of the sense of dignity<br>Loss of self-worth<br>Loss of will to live<br>WTHD as a way of self-preservation |
| **2. Suffering** | |
| "To have pain and also breathlessness, that would be really terrible and so much suffering. My breathing is suffering and this affects my appetite. So many kinds of suffering… The social situation is suffering..." (4). | Physical factors |
| "I've seen other patients yelling in pain and they were suffering... so intolerable... Just to hear them was very suffering... It must have been so unbearable to have to yell like that. If they could endure it, they wouldn't have yelled" (4). | Anticipation of a painful death<br>Fear of suffering |
| "I just don't want to endure these psychological effects... So much suffering... I have had the pain for four years... So many psychological effects… How can I bear it?" (4). | Suffering<br>Unbearable situation with no other way out |
| **3. Meanings of the WTHD** | |
| **3.1 Cry for helping** | |
| "Why do I have to go through this? Why can't I just die right now?" and, "When I pray, I use [sic] to feel the power of God on me... Now I sometimes feel as though I am talking to the air" (3). | Suffering<br>Loss of meaning<br>Hopelessness |

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| "When I was in excruciating pain… sometimes, I wanted to grab a knife and stab myself, and cut it [pain/cancer] out. I felt angry…why I am suffering so? I did not know what to do or how to deal with it. I could not work, so my life was no longer worth living. Continuing to live would only bring more suffering… I could not look after myself. I made [Buddhist] merits in the morning, offered food to monks. I prayed every day. I prayed to have the day, during which I was no longer able to perform my daily activities, as my last day of life… I prayed to die so that my suffering could end. I did not want to be fed by my children and grandchildren. Just let me die" (8). | Pain<br>Loss of independence (not being able to perform activities of daily life)<br>Not wanting to be a burden<br>Loss of life's worth<br>Suffering as something worse than death<br>WTHD: unbearable situation with no way out (other than death)<br>Despair |
| "I suffer so much that I can't recall when life was lovely and happy. My life is hell. My life is inhuman. I have such deep pain inside" (9). | Despair<br>Suffering<br>Loss of life's worth<br>Loss of meaning<br>WTHD: unbearable situation with no way out (other than death) |
| "Then all the red lights started flashing for me, because it was in your head, wasn't it. Then I thought: No! No, just no. Now I've simply had enough. […] I've tortured myself enough; I don't want to torture myself anymore" (12). | Disintegration<br>Unbearable situation with no way out other than death (end suffering)<br>Loss of life's worth |
| **3.2 Unbearable situation with no way out other than death (end suffering)** | |
| "There were many times when I was in such pain and such misery. I said, let me go... Finished... no more of this torture" (3). | Hastened death as a way of ending suffering<br>Suffering as something worse than death<br>Despair<br>Pain<br>Suffering |
| "I feel, deep inside, I don't want to feel hurting [sic]… that I want to end this… I ask God why he don't take me, why I suffer so much" (3). | Suffering<br>Hopelessness<br>Loss of meaning |
| "Pain is my biggest fear. It puts me in a darkness and a lack of will to go forward and a desire to die... The pain wants me to have a vehicle to just, just stop my life" (3). | Fear of suffering<br>Loss of will to live |
| "I can't bear the dying process so I'll short circuit it by dying" (3). | Fear of the dying process |
| "If the pain gets worse, then I want to be dead" (3). | Anticipation of future suffering<br>Suffering as something worse than death<br>Despair |
| "If I had to go through [an acute episode of shortness of breath] again, I would throw myself in front of a subway train. I am not going through that again" (3). | Anticipation of future suffering<br>Pain<br>Desire for control over life<br>Fear of the dying process<br>Despair |
| "... it should be up to me to decide… when I've had enough suffering... One of my landmarks, if I'm at the point where all I can do is lie on a bed all day long, then to me that's probably not living anymore" (5). | Autonomy<br>Desire for control over life |
| "I'm inconveniencing. I'm still inconveniencing other people who look after me and stuff like that. I don't want to be like that. I wouldn't, I wouldn't. No, I'd rather die" (1). | Progressive deterioration<br>Dependency<br>Loss of the self<br>Fear of losing one's own value/dignity in the eyes of others: shame |

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| **3.3 To spare others from the burden of oneself** | |
| "There have been times I've felt so much a burden on my family that maybe it is best for me to die just to relieve them of going through the terminal phase of my disease" (3). | Being a burden<br>WTHD as a form of altruism |
| "All of a sudden, it dawned on me that there was no solution, and if there was no solution to my cancer, then why was I hanging around? I got thinking about death as a practical matter. Why hang around and cause a lot of people a lot of grief?" (3). | Not wanting to be a burden |
| "[T]here's no question about wanting to make provisions for a hastened death should conditions become so unbearable. I want to spare my family as much of that grief as I can… [My mother] died of cancer, and we were constantly frustrated by not being able to do anything for her… And just watched her waste away. And what a terrible way to go" (5). | Loss of control<br>Fear of suffering<br>Not wanting to be a burden<br>Not wanting to make others suffer |
| "I hope everyone can accept it… Most important is that my family wouldn't be heartbroken. If there were no suffering. I would like to see them for longer" (4). | Fear of suffering<br>Not wanting to make others suffer<br>Wish to live but not in this way |
| "That is somehow a vicious circle. If my wife sees me having a hard time, she is suffering from that. And then, when I see my wife suffering in extreme, and then I am in a bad shape, because after all, it is my fault" (10). | Not wanting to be a burden |
| "When I know that my life has become a burden to my loved ones, I would rather die. I think of death as a way to release me from this frustration" (8). | WTHD as a way of ending suffering<br>Not wanting to be a burden<br>Suffering as something worse than death<br>WTHD: unbearable situation with no way out (other than death)<br>Despair |
| "I always pray that I can release people, eh, that I can free them of a burden, release the others also. That I do not always have to rely on help, I want… My whole life, I only worked and always took care of [others] myself… Then after this it's simply difficult, if you always have to have other people. That you have to be a burden…That I've never like" (11). | Not wanting to be a burden |
| "I would like to go. You see, I want to let people off the hook. I don't, I don't like it that they always have to… they all have a life too and I don't want to, that I… well" (12). | Not wanting to be a burden |
| "I can't just walk away like that. One time you think, 'I might as well give up.' But that's easy for me, but not easy for them [family]. There are other people [to consider]" (7). | Not wanting to be a burden |
| **3.4 To preserve self-determination in the last moments of life** | |
| "I immediately turned to the option of Exit [pause], because I said I'd like to have this option whatever happens. If things become unbearable for me for some reason, but I'm still not dying, then I'd like to be able to grant myself my own death. And I saw to everything, so that it's ready, that I have the prescription, and talked to those people. They're quasi on call now. […] This is really only about ending a situation that has become unbearable, and not having to rely on either being hit by another stroke or some doctor being understanding after all. I want to be able to keep this in my own hands for when the moment comes. I was a very self-determined person all my life, and that's very important to me" (12). | Anticipation of a painful death<br>Desire for control over life<br>Hastened death as a way of ending suffering<br>Having a plan<br>Suffering as something worse than death<br>WTHD as a form of control |
| "I have no desire to commit suicide, but I have no desire to take it out of my hands either" (7). | Autonomy<br>Desire for control over life<br>Wish to live but not in this way |
| **3.5 Will to live but not in this way** | |
| "See, there's a problem while planning or pursuing your death… On the one hand, I am saying all these things, and, on the other hand, I am going down for radiation" (3). | |

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| "Wish to live but can't live; wish to die but can't die" (4). | Suffering |
| "It is torturous… thinking when I am going to die to escape from this suffering. But when I am not in pain, I want to live. When the symptoms disappear, I want to continue living, as I do not want to depart from my loved ones. Actually, I do not want to be parted [die]… when I do not experience any symptom. But when I suffer the symptoms, I again wish to die to escape the suffering" (8). | Pain as *mediator* of the WTHD<br>Hastened death as a way of ending suffering |
| "No, not at this moment, but on those days when I am so miserably sick" (13). | Anticipation of future suffering and pain<br>Having control |
| **4. Functions of the WTHD** | |
| **4.1 WTHD as a means of communication** | |
| "So I was glad that I could talk to him [husband] about it [WTHD]. Actually I was the only one, I was able to communicate that and [pause] just be able to let go of the thought, rather than letting it eat into you. Whether you then do it or not is actually secondary. It's bad for people if they can't say to anyone: you know, I have thoughts like this sometimes. So I really am glad that I was able to discuss it with him [husband], it did me good as well" (12). | Family reinforcement |
| "I shared that I wouldn't do it until we discussed it together… She didn't have to worry about me taking the pills… It wasn't fair to them... It would leave them wondering, did they do, you know, contribute to it, did they do all they could... And I want them to feel comfortable that they've done everything" (3). | Manipulation |
| "I've also said these tongue-in-cheek things: so, now I'm starting to collect pills. Yes. And then the people concerned, the ones you say that to, they're shocked, and yet it was said tongue-in-cheek. I: To test their reaction. P: Yes, perhaps sometimes a bit of deliberate provocation" (12). | Expression of the WTHD so as to observe people's reaction |
| **4.2 WTHD as a form of control - Having a plan – Just in case / avoiding suffering (future)** | |
| "Exit would really just be there for an emergency, and not because that's what I'd wish. That would only be if I felt I couldn't get back off this track [...] If it gets that hard, and I don't know how to put on my socks or I'm so dead sick that I think: for Heaven's sake huuh… then I would wish for it to end, just to be relieved, just that it ends. […] Yes, it's rather just being set free from this state" (12). | Anticipation of future suffering<br>Desire for control over life<br>Hastened death as a way of ending suffering<br>"If then" |
| "Yes, I have thought many times, I want to get somebody from Exit, I also registered at Dignitas, because I thought: 'Yes, well, if it's so unbearable that, that everybody around me has to hold their nose [due to tumour ulceration and smell]. That was the worst, I think, then I wanted to break off the exercise" (13). | Anticipation of future suffering<br>WTHD as a way of sparing others from burden<br>Hastened death as a way of ending suffering |
| "Oh, it's the dignity and wholeness of my body, as well as spirit. And, it is, it's cruel too for others to have to do this when there's no end in sight, other than death. To just, to clean me up. I just don't want that... Dignity is that I have control over my body, when, when, not, not a virus that is going to take my life. I'm the one who's going to decide when my life will end, not a virus, and not with great pain. Not anything else other than in, in my control. It is my control, my choice to do" (1). | Loss of control<br>Loss of independence<br>Desire for control over life<br>Loss of the self<br>Loss of the sense of dignity<br>Loss of meaning |
| "…and then this sleepiness and so on, and then at some point at the back of your mind you say: well, how long am I supposed to put up with this? And then it occurs to you: well, you don't have to, you can get out of it any time. But it's more of a reassurance […] It's a reserve" (12). | Loss of function<br>Desire for control over life<br>Hastened death as a way of ending suffering<br>Hopelessness |
| "I will do things my way and the hell with everything and everybody else. Nobody is going to talk me in or out of a darn thing... what will be, will be; but what will be, will be done my way. I will always be in control" (5). | Desire for control over life |
| "I just feel sometimes as though cancer is, uh, an opponent. And, it seems to me, it says to itself, 'I am in control of this body. This is mine, I will do whatever I want to with it" (6). | Desire for control over life<br>Ultimate control |

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| “I have considered, I do like this physician-assisted suicide. With the assistance of a doctor, so you won’t have a, a, messy death… and they [doctors] have said that any time I’m going to want to, it’s up to me. That’s right. I’m very glad about it. Yeah” (6). | Desire for control over life<br>Fear of a painful death |
| “But it [WTD] is a ray of hope. You can say, if nothing works anymore and things are only getting worse, then you’d still have some way of shortening it” (12). | Hastened death as a way of ending suffering<br>Suffering as something worse than death<br>WTHD: unbearable situation with no way out (other than death)<br>"If then" |
| “When I feel very, very, very wretched, this thought always returns: If you can’t bear it any more, you can actually cut it short. Right at the last I just could [pause]… if it’s even worse than it is now” (12). | Hastened death as a way of ending suffering<br>Suffering as something worse than death<br>WTHD: unbearable situation with no way out (other than death) |
| “If I would have such a pill in some drawer or the other, and I could take it on my own when I would have the feeling that nothing goes any more, then I would feel considerably better” (14). | "If then" |
| “[When metastasis was diagnosed] I immediately set about the option of Exit… because I said, I would like to have this possibility in any case. If for any reason it becomes unbearable for me, but I’m still not dying, then I would like to bring about my own death. And I saw to it all, that it was ready, that I had the prescription, and I talked to these people. That’s sort of there on demand now” (13). | WTHD: unbearable situation with no way out (other than death) |
| **5. Lived experience of timeline toward dying and death** | |
| “I just want to get it over with… Tomorrow is the same thing, the same thing” (6). | Despair<br>Suffering<br>Tiredness<br>Hopelessness |
| **5.1 Anticipation of a painful death or agony** | |
| “AIDS, that's probably -seeing as I'm 41- that's probably what I'm going to die of. That is going to be a very painful death. It is painful, I've seen it. It's painful, it's sad, it's lonely in a way, that you can be surrounded be all the loving people on your life, but you, it's lonely because you're gradually rotting away, your flesh is rotting, I hope to God in a way that your mind is rotting with it, because then you become totally, you don't know what's going on” (1). | Progressive deterioration<br>Anticipation of a painful death<br>Uncertainty |
| “It’ll be extremely terrible. It’ll be coming up from here, coming up from there, just everywhere. I mean the complications and that would give me so much pain and suffering. I anticipate the future would be like this. Very severe, very scary when I think about it” (4). | Anticipation of future suffering<br>Progressive deterioration<br>Fear of suffering |
| “I am not afraid about death. I am only afraid of an agonizing death. Taking too much time” (14). | Anticipation of a painful death<br>Fear of the dying process<br>Suffering as something worse than death |
| “I, I fear some of the, uh, some of the physical stress that may come in the course of my dying. Nobody chooses to die little by little. At least, I can’t visualize that” (6). | Fear of suffering<br>Fear of the dying process |
| **5.2 Progressive deterioration** | |
| “This sort of disease ultimately leads to death. I have to walk that path” (4). | |
| “You lie on a bed and none of the normal functions come back. They will never come back and it will only get worse” (9). | Loss of function |

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| “And I would not want to go through this as a daughter (of a patient). Sit down every day and watch how somebody is running towards death, lying there and finally waiting to be released” (14). | Not wanting to lose one’s own value in the eyes of others |
| **5.3 Uncertainty** | |
| “I haven’t been in hospital before. I wouldn’t know the facts. I haven’t been ill before” (4). | Fear |
| “Yes, and that is this uncertainty. You can plan nothing and, let me say, only on short notice, for very short distances” (14). | Loss of control |
| **5.4 Ambivalence** | |
| “The goal is now to die… I’m using my flexibility not to devote my time toward how I am going to die and praying, etc. I’m using my flexibility in time management to do things that the living do, not the dying” (3). | Ambivalence<br>WTHD as a will to live |

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# PRISMA 2009 Checklist

| Section/topic | # | Checklist item | Reported on page # |
|---|---|---|---|
| **TITLE** | | | |
| Title | 1 | Identify the report as a systematic review, meta-analysis, or both. | Page 1 |
| **ABSTRACT** | | | |
| Structured summary | 2 | Provide a structured summary including, as applicable: background; objectives; data sources; study eligibility criteria, participants, and interventions; study appraisal and synthesis methods; results; limitations; conclusions and implications of key findings; systematic review registration number. | Page 2 |
| **INTRODUCTION** | | | |
| Rationale | 3 | Describe the rationale for the review in the context of what is already known. | Page 4 |
| Objectives | 4 | Provide an explicit statement of questions being addressed with reference to participants, interventions, comparisons, outcomes, and study design (PICOS). | Page 4 |
| **METHODS** | | | |
| Protocol and registration | 5 | Indicate if a review protocol exists, if and where it can be accessed (e.g., Web address), and, if available, provide registration information including registration number. | N/A |
| Eligibility criteria | 6 | Specify study characteristics (e.g., PICOS, length of follow-up) and report characteristics (e.g., years considered, language, publication status) used as criteria for eligibility, giving rationale. | Page 6 |
| Information sources | 7 | Describe all information sources (e.g., databases with dates of coverage, contact with study authors to identify additional studies) in the search and date last searched. | Pages from 5 to 7 |
| Search | 8 | Present full electronic search strategy for at least one database, including any limits used, such that it could be repeated. | Pages 5 and 6 |
| Study selection | 9 | State the process for selecting studies (i.e., screening, eligibility, included in systematic review, and, if applicable, included in the meta-analysis). | Page 6 |
| Data collection process | 10 | Describe method of data extraction from reports (e.g., piloted forms, independently, in duplicate) and any processes for obtaining and confirming data from investigators. | Page 6 |
| Data items | 11 | List and define all variables for which data were sought (e.g., PICOS, funding sources) and any assumptions and simplifications made. | NA |
| Risk of bias in individual studies | 12 | Describe methods used for assessing risk of bias of individual studies (including specification of whether this was done at the study or outcome level), and how this information is to be used in any data synthesis. | NA |
| Summary measures | 13 | State the principal summary measures (e.g., risk ratio, difference in means). | NA |
| Synthesis of results | 14 | Describe the methods of handling data and combining results of studies, if done, including measures of consistency (e.g., $I^2$) for each meta-analysis. | NA |

# PRISMA 2009 Checklist

| Section/topic | # | Checklist item | Reported on page # |
|---|---|---|---|
| Risk of bias across studies | 15 | Specify any assessment of risk of bias that may affect the cumulative evidence (e.g., publication bias, selective reporting within studies). | NA |
| Additional analyses | 16 | Describe methods of additional analyses (e.g., sensitivity or subgroup analyses, meta-regression), if done, indicating which were pre-specified. | NA |
| **RESULTS** | | | |
| Study selection | 17 | Give numbers of studies screened, assessed for eligibility, and included in the review, with reasons for exclusions at each stage, ideally with a flow diagram. | Pages 5 and 6 |
| Study characteristics | 18 | For each study, present characteristics for which data were extracted (e.g., study size, PICOS, follow-up period) and provide the citations. | Pages 7 and 8 |
| Risk of bias within studies | 19 | Present data on risk of bias of each study and, if available, any outcome level assessment (see item 12). | NA |
| Results of individual studies | 20 | For all outcomes considered (benefits or harms), present, for each study: (a) simple summary data for each intervention group (b) effect estimates and confidence intervals, ideally with a forest plot. | NA |
| Synthesis of results | 21 | Present results of each meta-analysis done, including confidence intervals and measures of consistency. | NA |
| Risk of bias across studies | 22 | Present results of any assessment of risk of bias across studies (see Item 15). | NA |
| Additional analysis | 23 | Give results of additional analyses, if done (e.g., sensitivity or subgroup analyses, meta-regression [see Item 16]). | NA |
| **DISCUSSION** | | | |
| Summary of evidence | 24 | Summarize the main findings including the strength of evidence for each main outcome; consider their relevance to key groups (e.g., healthcare providers, users, and policy makers). | Pages 23 and 24 |
| Limitations | 25 | Discuss limitations at study and outcome level (e.g., risk of bias), and at review-level (e.g., incomplete retrieval of identified research, reporting bias). | Pages 22 and 23 |
| Conclusions | 26 | Provide a general interpretation of the results in the context of other evidence, and implications for future research. | Page 24 |
| **FUNDING** | | | |
| Funding | 27 | Describe sources of funding for the systematic review and other support (e.g., supply of data); role of funders for the systematic review. | Pages 24 and 25 |

*From:* Moher D, Liberati A, Tetzlaff J, Altman DG, The PRISMA Group (2009). Preferred Reporting Items for Systematic Reviews and Meta-Analyses: The PRISMA Statement. PLoS Med 6(7): e1000097. doi:10.1371/journal.pmed1000097

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