

## 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
<b>1) Was there a clear statement of the aims of the research? Consider:</b> (Yes // No // Comments) - What the goal of the research was	14	(1–14)
- Why it is important	14	(1–14)
- Its relevance	14	(1–14)
<b>2) Is a qualitative methodology appropriate? Consider:</b> - If the research seeks to interpret or illuminate the actions and/or subjective experiences of research participants	14	(1–14)
<b>3) Was the research design appropriate to address the aims of the research? Consider:</b> - 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)
<b>4) Was the recruitment strategy appropriate to the aims of the research? Consider:</b> -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)
<b>5) Were the data collected in a way that addressed the research issue? Consider:</b> - 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)
<b>6) Has the relationship between researcher and participants been adequately considered? Consider whether it is clear:</b> -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	-	-
<b>7) Have ethical issues been taken into consideration? Consider:</b> - 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)
<b>8) Was the data analysis sufficiently rigorous? Consider:</b> - 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	-	-
<b>9) Is there a clear statement of findings? Consider:</b>		(1-14)
- If the findings are explicit	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)
<b>10 How valuable is the research? Consider:</b>	13	(1-9,11-14)
- 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?)		
- 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

<b>Noblit and Hare's 7 steps (15)</b>	<b>What each step entailed in our original meta-ethnography (16)</b>	<b>What each step entailed in the present, updated meta-ethnography</b>
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-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
<b>1. Reasons for the WTHD</b>	
<b>1.1 Physical factors</b>	
"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 Progressive deterioration Loss of function Loss of the self 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 Loss of control

<p>“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).</p>	<p>Loss of function Anticipation of future suffering Not wanting to make others suffer</p>
<p>“I can't move, just lie here... feeling like a vegetable... a useless person... needing people to feed me” (4).</p>	<p>Loss of function Loss of independence Dependency Loss of value</p>
<p>“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).</p>	<p>Suffering Loss of physical function and cognitive impairment Loss of daily life activities Loss of value</p>
<p>“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).</p>	<p>Loss of quality of life Desire for control over life</p>
<p>“If you get cancer, you'll get pain. Cancer is a painful disease. It'll just get more and more painful” (4).</p>	<p>Progressive deterioration Suffering Lived experience of time Anticipation of future suffering</p>
<p>“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).</p>	<p>Pain Suffering Hopelessness WTHD as unbearable situation with no other way out</p>
<p>“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).</p>	<p>Progressive deterioration Loss of function Loss of image: shame</p>
<p>“... 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).</p>	<p>Progressive deterioration Lived experience of time (there is no future) Hopelessness Losses</p>
<p>“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).</p>	<p>Anticipation of future suffering Unbearable suffering with no other way out</p>
<p>“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).</p>	<p>Not wanting to be a burden Unbearable suffering with no other way out</p>
<p>“I have fecal incontinence. I can no longer swallow and in hot weather I really envy people who can drink” (9).</p>	<p>Loss of physical functions Loss of control Loss of the sense of dignity: shame</p>
<p>“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).</p>	<p>Loss of function Progressive deterioration Losses</p>

<p>“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).</p>	<p>Pain Suffering Will to live but not in this way Hastened death as a way of ending suffering</p>
<p>“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).</p>	<p>Consequences of the medical treatment</p>
<p>“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).</p>	<p>Pain as <i>mediator</i> of the WTHD Ambivalence Wish to live but not in this way</p>
<p>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).</p>	<p>Dependency Suffering WTHD: unbearable situation with no way out (other than death) Despair</p>
<p>“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).</p>	<p>Hopelessness Tired of fighting</p>
<p><b>1.2 Psychological factors</b></p>	
<p>“... 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).</p>	<p>Hopelessness Progressive deterioration Limitation of activities Loss of function Lived experience of time</p>
<p>“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)</p>	<p>Fear of the dying process Unbearable suffering Loss of meaning</p>
<p>“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).</p>	<p>Helplessness Hopelessness</p>
<p>“I just don’t want to be in so much suffering... to endure these psychological effects” (4).</p>	<p>Suffering</p>
<p>“Not much hope, nor would there be any miracles... You doctors can’t help when the patients deteriorate and then drop dead...” (4).</p>	<p>Progressive deterioration Hopelessness</p>
<p>“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).</p>	<p>Hopelessness Loss of meaning</p>
<p>“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).</p>	<p>Fear of suffering</p>
<p>“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).</p>	<p>Hopelessness Fear about the future Lack of social support</p>
<p>“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)</p>	<p>Fear of suffering</p>

<p>“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).</p>	<p>Anticipation of future suffering Progressive deterioration Not wanting to be a burden WTHD as a way of ending suffering WTHD so as to spare others from burden Having a plan Will to live but not in this way</p>
<p>“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).</p>	<p>Hopelessness Suffering Will to live but not in this way</p>
<p><b>1.3 Social factors</b></p>	
<p>“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).</p>	<p>Loss of community Loss of the sense of dignity Disintegration Loss of value</p>
<p>“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).</p>	<p>Being a burden</p>
<p>“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).</p>	<p>Not wanting to be a burden Fear of losing one’s own value/dignity in the eyes of others Loss of the self</p>
<p>“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).</p>	<p>Suffering Not wanting to make others suffer</p>
<p>“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).</p>	<p>Anticipation of future suffering Progressive deterioration Not wanting to be a burden</p>
<p>“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).</p>	<p>Pain (affects everything) Hastened death as a way of ending suffering Suffering as something worse than death Wish to live but not in this way Anticipation of future suffering</p>
<p>“...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).</p>	<p>Not wanting to make others suffer</p>
<p>“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).</p>	<p>Loss of functions Fear of losing one’s own value/dignity in the eyes of others</p>

<p>"I am burdened myself, I am such a burden to others; I want to end this" (12).</p>	<p>Hastened death as a way of ending suffering Not wanting to be a burden</p>
<p>"I am not used to somebody helping me. This I feel is tantalizing, this is no life" (14).</p>	<p>Dependency Loss of control Loss of value of life</p>
<p>"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).</p>	<p>Loss of the sense of dignity Loss of the self Fear of losing one's own value/dignity in the eyes of others Loss of image: shame Anticipation of cognitive impairment</p>
<p><b>1.4 Self - Identity - Losses</b></p>	
<p>"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)</p>	<p>Loss of quality of life Loss of independency Loss of the self Loss of daily life activities</p>
<p>"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).</p>	<p>Loss of function Loss of quality of life Ambivalence: wish to live and wish to die</p>
<p>"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).</p>	<p>Losing Anticipation of future suffering Loss of control Loss of independence Loss of meaning in life Loss of daily life activities</p>
<p>"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).</p>	<p>Limitation of activities Loss of function WTHD maintaining meaningful activities</p>
<p>"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).</p>	<p>Loss of value Loss of will to live Helplessness</p>
<p>"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)</p>	<p>Hopelessness Despair Loss of meaning in life Loss of will to live</p>
<p>"When I'm in pain, it is not so much the pain, it's the loss of control and the helplessness" (7).</p>	<p>Desire for control over life Helplessness</p>
<p>"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).</p>	<p>Progressive deterioration Loss of the self</p>
<p>"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).</p>	<p>Progressive deterioration Hopelessness Loss of the sense of dignity Loss of will to live Hastened death as a way of ending suffering</p>
<p>"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).</p>	<p>Pain Progressive deterioration Loss of self Not wanting to make others suffer</p>

<p>“...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).</p>	<p>Loss of meaning in life Loss of will to live</p>
<p>“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).</p>	<p>Hopelessness Loss of meaning Limitation of activities Loss of function</p>
<p>“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).</p>	<p>Hopelessness Loss of will to live WTHD maintaining meaningful activities</p>
<p>“I lost my dignity, lying in bed in diapers, I am no longer the independent person I used to be” (9).</p>	<p>Loss of function Loss of independence Loss of the sense of dignity Loss of self</p>
<p>“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).</p>	<p>Loss of activities (that make life enjoyable) Loss of value Loss of will to live Loss of life’s worth WTHD maintaining meaningful activities</p>
<p>“Activities with friends not possible—and indeed activities outside or with the family, I would say, meanwhile completely passed away” (14).</p>	<p>Limitation of activities</p>
<p>“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).</p>	<p>Loss of control Loss of the sense of dignity Loss of self-worth Loss of will to live</p>
<p>“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).</p>	<p>Loss of control Loss of the sense of dignity Loss of self-worth Loss of will to live WTHD as a way of self-preservation</p>
<p><b>2. Suffering</b></p>	
<p>“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).</p>	<p>Physical factors</p>
<p>“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).</p>	<p>Anticipation of a painful death Fear of suffering</p>
<p>“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).</p>	<p>Suffering Unbearable situation with no other way out</p>
<p><b>3. Meanings of the WTHD</b></p>	
<p><b>3.1 Cry for helping</b></p>	
<p>“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).</p>	<p>Suffering Loss of meaning Hopelessness</p>

<p>“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).</p>	<p>Pain Loss of independence (not being able to perform activities of daily life) Not wanting to be a burden Loss of life’s worth Suffering as something worse than death WTHD: unbearable situation with no way out (other than death) Despair</p>
<p>“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).</p>	<p>Despair Suffering Loss of life’s worth Loss of meaning WTHD: unbearable situation with no way out (other than death)</p>
<p>“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).</p>	<p>Disintegration Unbearable situation with no way out other than death (end suffering) Loss of life’s worth</p>
<p><b>3.2 Unbearable situation with no way out other than death (end suffering)</b></p>	
<p>“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).</p>	<p>Hastened death as a way of ending suffering Suffering as something worse than death Despair Pain Suffering</p>
<p>“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).</p>	<p>Suffering Hopelessness Loss of meaning</p>
<p>“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).</p>	<p>Fear of suffering Loss of will to live</p>
<p>“I can’t bear the dying process so I’ll short circuit it by dying” (3).</p>	<p>Fear of the dying process</p>
<p>“If the pain gets worse, then I want to be dead” (3).</p>	<p>Anticipation of future suffering Suffering as something worse than death Despair</p>
<p>“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).</p>	<p>Anticipation of future suffering Pain Desire for control over life Fear of the dying process Despair</p>
<p>“... 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).</p>	<p>Autonomy Desire for control over life</p>
<p>“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).</p>	<p>Progressive deterioration Dependency Loss of the self Fear of losing one’s own value/dignity in the eyes of others: shame</p>

<b>3.3 To spare others from the burden of oneself</b>	
“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 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 Fear of suffering Not wanting to be a burden 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 Not wanting to make others suffer 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 Not wanting to be a burden Suffering as something worse than death WTHD: unbearable situation with no way out (other than death) 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
<b>3.4 To preserve self-determination in the last moments of life</b>	
“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 Desire for control over life Hastened death as a way of ending suffering Having a plan Suffering as something worse than death 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 Desire for control over life Wish to live but not in this way
<b>3.5 Will to live but not in this way</b>	
“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 <i>mediator</i> of the WTHD 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 Having control
<b>4. Functions of the WTHD</b>	
<b>4.1 WTHD as a means of communication</b>	
“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
<b>4.2 WTHD as a form of control - Having a plan – Just in case / avoiding suffering (future)</b>	
“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 Desire for control over life Hastened death as a way of ending suffering "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 WTHD as a way of sparing others from burden 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 Loss of independence Desire for control over life Loss of the self Loss of the sense of dignity 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 Desire for control over life Hastened death as a way of ending suffering 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 Ultimate control

<p>“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).</p>	<p>Desire for control over life Fear of a painful death</p>
<p>“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).</p>	<p>Hastened death as a way of ending suffering Suffering as something worse than death WTHD: unbearable situation with no way out (other than death) "If then"</p>
<p>“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).</p>	<p>Hastened death as a way of ending suffering Suffering as something worse than death WTHD: unbearable situation with no way out (other than death)</p>
<p>“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).</p>	<p>"If then"</p>
<p>“[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).</p>	<p>WTHD: unbearable situation with no way out (other than death)</p>
<p><b>5. Lived experience of timeline toward dying and death</b></p>	
<p>“I just want to get it over with... Tomorrow is the same thing, the same thing” (6).</p>	<p>Despair Suffering Tiredness Hopelessness</p>
<p><b>5.1 Anticipation of a painful death or agony</b></p>	
<p>“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 by 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).</p>	<p>Progressive deterioration Anticipation of a painful death Uncertainty</p>
<p>“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).</p>	<p>Anticipation of future suffering Progressive deterioration Fear of suffering</p>
<p>“I am not afraid about death. I am only afraid of an agonizing death. Taking too much time” (14).</p>	<p>Anticipation of a painful death Fear of the dying process Suffering as something worse than death</p>
<p>“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).</p>	<p>Fear of suffering Fear of the dying process</p>
<p><b>5.2 Progressive deterioration</b></p>	
<p>“This sort of disease ultimately leads to death. I have to walk that path” (4).</p>	
<p>“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).</p>	<p>Loss of function</p>

“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
<b>5.3 Uncertainty</b>	
“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
<b>5.4 Ambivalence</b>	
“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 WTHD as a will to live

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