The intentions in wishes to die: analysis and a typology - a report of 30 qualitative case studies with terminally ill cancer patients in palliative care

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Abstract

Objective: To investigate the variations in and intentions of wishes to die (WTD) of palliative care cancer patients.

Methods: 30 terminally ill cancer patients, their caregivers and relatives in a hospice, an oncology palliative care ward of a general hospital, and an outpatient palliative care service. 116 semi-structured qualitative interviews analysed by a combined approach using Grounded Theory and Interpretive Phenomenological Analysis.

Results: A WTD is dynamic and interactive. Its subjective phenomenology can be described by three aspects: intentions, motivations and interactions. In this article we present a typology of the possible intentions. We identified nine different (ideal) types of intentions that WTD statements might have, other than wishing to live and accepting death. Many WTD statements do not imply a desire to hasten death. The intentions of statements differ according to whether a WTD is related to as imaginary or as an action. Often WTD statements contain several partial wishes, which can be in tension with each other and form a dynamic, sometimes unstable equilibrium.

Conclusions: Terminally ill persons’ WTD statements differ in their intention, and deeper knowledge about these differences is ethically relevant.

Introduction

It is not uncommon that patients facing incurable cancer enter into an interior dialogue about their wishes for life and death and may develop a wish to die (WTD) (Chochinov et al. 1995). In some patients the WTD may persist even with access to palliative care (Arnold et al. 2004). Talking with patients about their WTD is perceived by caregivers as challenging and is therefore often avoided (Kohlwes et al. 2001). There is awareness today that a superficial understanding of a WTD carries the risk of either taking a WTD statement at face value or medicalizing it. Both can lead to suboptimal palliative care, disrespect, and the risk of abandoning the patient (Hudson et al. 2006 a and b). Health professionals are therefore ethically obliged to adequately address patients’ WTD statements and to understand the meaning of a WTD in a patient’s life (Ohnsorge et al. 2014).

Research has been undertaken to better understand the phenomenon of a WTD in terminally ill patients (literature overview in appendix I). Earlier studies, mainly based on quantitative methods, reported a multifactorial aetiology and an association between a WTD and depression and hopelessness (Brown et al. 1989; Breitbart et al. 1996; Ganzini et al. 1998; Chochinov et al. 1998; Seal 1994; Emmanuel 2002; Schneidermann 1999/2000; Back et al. 1996; Cavalieri et al. 2002; Ferrand et al. 2012; Filiberti et al. 2001; Ganzini 2002; Kissane et al. 1998; Volker 2001; Suarez-Almazor et al. 2002). After 2000 some qualitative studies investigated the experience of dying patients with a WTD prospectively from a first-person perspective, confirming the multifactorial aetiology (Wilson et al. 2000; Lavery 2001; Kelly et al. 2002; Mak and Elwyn 2005; Coyle and Sculco 2005; Pearlmann et al. 2005; Johansen et al. 2005; Schroepfer 2006).

Many questions remain unanswered. Most studies included patients with an explicit WTD or wish to hasten death. Less is known about the attitudes and views of patients not making WTD statements (Hudson et al. 2006b). Studies did not clearly differentiate between a general WTD, a wish to hasten death, and requests for assisted suicide or euthanasia (Stiel et al. 2010; Montforte-Royo et al. 2010). Thus, results are difficult to compare (Montforte-Royo et al. 2010 and 2012). More insight is needed into the subjective structure of the WTD, its longitudinal development and the constitutive role of relevant others, in particular relatives and caregivers.

We undertook a qualitative interview study with 30 palliative cancer patients, their caregivers and their relatives to investigate the subjective structure of WTD statements, including its temporal development and social relatedness. The main findings concern the general phenomenological structure of WTD, seen through WTD statements. Data analysis revealed that WTD statements were composed of three constitutive elements: (1) different types of intentions a WTD can have; this describes what a person wishes for when expressing a WTD, (2) underlying or overt motivations for a WTD; why a WTD is present, and (3) social interactions in which a WTD is expressed and understood. This paper describes findings about the first element, “intentions”. We investigate the question of what a person with a WTD wishes for, or the variations a WTD can assume.
We used a qualitative research methodology, which combines phenomenological and hermeneutic approaches, and is inspired by Interpretive Phenomenological Analysis (IPA) (Smith et al. 2009) and Grounded Theory (GT) (Corbin and Strauss 2008; Charmaz 2006). The idiographic approach of IPA enables in-depth investigation of how patients make sense of their personal experiences and the meanings they personally attribute to them. The study design was prospective and focused on first-person perspectives. We interpreted interviews with 30 patients, their caregivers and relatives (116 interviews total: inpatients in a hospice and a palliative care ward within the oncology department of a general hospital, and outpatients in a palliative care service, all in the region of Basel, Switzerland).

Inclusion / exclusion criteria: We decided not to limit the sample to patients who had expressed a desire to die, because we assumed there was a possibility of unexpressed WTD in some patients. We included only patients (i) with incurable cancer in (ii) a palliative situation (characterized by limited anti-tumour treatment, predominant use of palliative measures, and limited life expectancy), who (iii) had been informed that their disease was incurable, who (iv) were cognitively in a condition to be interviewed, (v) whose primary physician had agreed to their enrolment in the study, and who (vi) consented to participate. Informed consent also covered the disclosure of patients’ medical records and the possibility for interviews with relatives and caregivers.

Participants were interviewed face to face at a location of their choice; for most patients this was the place of medical care. Patients and relatives were interviewed by two trained interviewers who were not involved in patient care or treatment. The interview team consisted of one bioethicist, one art therapist in palliative care, two palliative care nurses, and one pastoral care worker. Interviews lasted between 30 and 90 minutes. Nurses and physicians were interviewed for about 20 to 60 minutes. Interviews were semi-structured, starting with a schedule (see appendix II) and probing important topics as they arose. If possible, we interviewed the patient multiple times, with intervals adapted to the disease trajectory. The median interval between the final interview and a patient’s death was 22.5 days (range 5-237 days, with 2 patients not included who were considered to be not in a terminal state when they entered the study and who were still alive at the end of the study). Periodically, the interview guide was refined on the basis of emerging themes. The interpretations of clusters of cases were discussed at group meetings, which included the interviewers as well.

We believe that theoretical saturation was achieved with regard to the research question posed in this paper: intentions of the WTD.

**Definitions**

The term ‘wish’ generally refers to a hope or a desire for something to happen. A ‘wish to die’ can be defined as the inclination for death to come; a ‘wish to live’ is an inclination for life to continue. A wish to hasten death is the desire to act in such a way that life will end sooner. Wishes are inner attitudes, which can be expressed either in words or by nonverbal signs, or can remain unexpressed. WTD statements are the lingual utterances, which might not cover all actual wishes.

We use the term ‘intention’ in a broader sense to capture what it is that a person wishes to happen, or what the wish is aiming at. This is the ‘what’ of a wish (what is wished for), as opposed to the ‘why’: why something is wished for (explanation, aetiology).

**Findings**

A typology of intentions about dying was generated on the basis of the complete case studies, integrating the interviews with family and professional caregivers as well (Table 1).

**Wish to live.** In 12 patients, the wish to live was prevalent. However, only 5 of them denied any wish to die at any time during the course of their disease. Others had a predominant wish to live, but also had other ideas or experienced shifting or ambivalent feelings. One patient said that she recovered her wish to live after a period of dominating ideas about hastening death and an attempted suicide.

**Acceptance of dying.** In between the categories of wishing to live and wishing to die were statements expressing the mere acceptence of dying, which cannot be categorized as a wish. Acceptance describes an affirmative attitude towards dying in the near future without positively wishing for it.
Wish to die. Data analysis revealed nine different intentions that patients were pursuing when expressing a WTD. In general we saw that: 1. Patients who expressed a WTD did not necessarily express a wish to hasten death as well. 2. Many participants spoke about their WTD as an \textit{imagination} they had about dying. Other participants spoke about their WTD relating it to \textit{actions} that lead to dying, including expressing an active request. We found it useful to distinguish between a \textit{wish} in a narrower sense, as an intention that is directed towards an idea or an imagination, and a \textit{will} as an intention that is directed to actions that lead to death (Bloch 1959, pp. 49-52). 3. We can differentiate three groups: participants who express a WTD with no idea of hastening death, those who consider a hastened death without undertaking actions that would lead to it, and those who act towards it (‘will’).

1 \textit{Looking forward to dying}. These patients explicitly wished for death to come while nevertheless retaining a positive attitude towards life. The two patients in this group held strong religious beliefs. Their WTD consisted in looking forward to a less burdensome existence in the afterlife.

2 \textit{Hoping that dying happens more quickly}. Some patients expressed a WTD that was about the dying process to be shortened. Others reported that they experienced this specific wish only in acute moments of crisis.

3 \textit{Desiring to die (but hastening death is not considered)}. Some patients expressed a strong desire to die, but for moral or other reasons rejected the idea of hastening death. These patients differed from the first subgroup in that they had a strong wish to die (more than simply looking forward to it), and from the second in that what desired was the end of their existence now in the present situation and not only the dying process to happen faster.

4 \textit{Hypothetically considering hastening death}: Relatively frequently patients considered hastening death in a hypothetical, future-oriented sense, and only under certain conditions. To some of these patients it was important that they were members of one of the Swiss organizations that provide suicide assistance.

5 \textit{Actually considering hastening death, but at the moment (for moral or other reasons) it is not an option}. One patient said that he desired something that would accelerate his dying, but excluded suicide as an option for him because years ago, his son had committed suicide and this was terrible for the family. He wished for palliative sedation, believing it to be a possible means of accelerating the dying process without socially qualifying as suicide.

6 \textit{Actually considering hastening death, hastening death is a (moral) option}. Other patients made it clear that hastening death was also a realistic option. But for various reasons, at this point in time they had not (yet) talked to others or made an explicit request. These wishes differed from (4) in that hastening death is being considered in the present. And they differ from (5) in that these patients have no other reason strong enough to outweigh their wish to hasten death. But they are still in a phase of imagining and reflecting on it.

7 \textit{Explicit request}. This category included those who explicitly asked for any sort of aid in dying.

8 \textit{Refusing life-sustaining support (such as food or treatments) with the intention of hastening death}. Some patients in our study opted to refuse life-prolonging treatment or care, not just to preserve their quality of life, but with the explicit intention of dying sooner. While other patients usually refused life-sustaining treatments when they accepted that they were in the last phase of life, the patients in this group explicitly did this with the intention of speeding up the dying process.

9 \textit{Acting towards dying}. Still other patients were engaged in a process that could hasten death, such as suicide, or a legal form of assisted dying.

\textbf{Multiple coexisting wishes}

Most statements of the wish to die and the wish to live contained multiple partial, sometimes even contradictory wishes that were continuously evaluated against each other. The prioritisation of these wishes could change over time, due to an inner progress of thinking or to the changing conditions of the disease and/or care. Wishes were represented in narratives that could run in parallel and were not always integrated into one coherent desire.

The resulting unstable equilibrium captured the inherent ambivalence of the experience of the life situation near death (Ohnsorge et al. 2012). However, this does not mean that a WTD is per se volatile. Eight out of our 30 study patients held on to a WTD statement throughout the accessible time period before and after the interviews, and made no statement that abrogated or suspended their WTD, even transiently.

\textbf{Evolution of WTD over time}

Frequently, patients reported that their main preferences shifted over the course of time, sometimes showing dramatic changes from an explicit desire to hasten death to a newly experienced wish to live. Most strikingly, patients experienced several thoughts and wishes concomitantly, with one of these currently prevailing, but the balance of their wishes could shift—sometimes from one day to the next, depending on the situation (see quote of P20, Appendix III, Evolution over time).
We cannot suggest a linear temporal model of intentions towards dying. Quite the contrary: some patients shifted or jumped from one type to another, and could do in both directions. And some types of wishes, even contradictory ones, can coexist. There is certainly no single linear process from “acceptance” through a “wish to die” to the “will to die”. The process can also take the reverse direction. But as mentioned, this does not mean that patients’ wishes were generally unstable or that a ‘will to die’ can never be called ‘persisting’.

In clinical settings, we observed smooth transitions between “wish” and “will”, which may make some distinctions in the model difficult to apply. The options of acting – defining a “will” – may be constrained by frailty, immobility, depression, or dementia. The reasons behind a “will to die” might also be susceptible to modification when the situation changes.

Discussion

We have proposed a data-saturated map of different possible intentions about dying. The analysis revealed that patients’ wishes with regard to their own death were frequently not static, nor could they always be unambiguously classified as the ‘wish to live’ or ‘wish to die’. Rather, they were dynamic and composed of different, sometimes conflicting partial wishes, which were represented in storylines that were continuously evaluated against each other. WTD and wishes to live were rooted in a complex and dynamic process of coming to terms with the situation at the end of life.

Even if patients express a strong WTD, they might not be thinking about hastening death, but expressing their desire that their life should come to its natural end. The choice of intentions was strongly connected to the patients’ moral considerations about others involved or affected by the patient’s attitude towards dying.

Among those who experience a wish to hasten death the WTD varies in concreteness, from hypothetical, future-oriented wishes to considerations about hastening death as a real option. Some wishes are even more concrete but linked to an action. Our data suggest that at least some patients’ WTD had a tendency to move from weaker to stronger or to more action-oriented inclinations. However, in other patients, wishes were dynamic, running in both directions or existing in parallel.

Some patients expressed their WTD over a longer period. We defined it as a “longer” period if it remained stable from the time before the interview and persisted over the observation time up to death. However, in some patients a long-lasting and apparently consolidated WTD altered substantially when the care setting changed. The definition of constancy of WTD statements seems difficult and definitely requires more research, especially as it is used in a normative and legal context.

The strengths of our study lie in (a) its prospective approach, that allows a detailed analysis of first-person accounts and provides insight into the personal experience and subjective evaluation of a WTD. (b) As we interviewed people on average 23 days before death, the data report on WTD statements in a situation of relative proximity to death.

(c) The quality of the subjective patients’ accounts has been supported by triangulation with interviews with relatives and professional caregivers, as well as clinical records. (d) The results give an empirically grounded contribution to the conceptualisation of WTD statements as requested by (Hudson et al. 2006b; Montforte-Royo et al. 2010 and 2012). (e) The hermeneutic approach enables us to elaborate the complex and fluctuating nature of WTD statements. However, our study does have limitations: (1) The small number of 30 cases does not allow quantitative generalizations. (2) As 19 patients were not able to attend a follow-up interview, longitudinal information has been limited. Patients reported to us about the evolution of their wish to live or to die through the lens of their current perspective. More longitudinal research is needed to investigate the real-time evolution of patients’ intentions. (3) The sample of patients with access to specialized palliative care and hospice care is not representative of the whole population. (4) The inclusion of patients in the study depended on physicians’ judgment. This inclusion criterion may have caused a selection bias but was justified to protect particularly vulnerable patients from burdening themselves by volunteering for the study and is part of good practice in palliative care research (Emmanuel 2002). (5) Data provide access to patients’ wishes only via their subjective explanations at the time of the interviews.

Our results confirm the findings of other studies. Schroepfer found six distinct ‘mind frames towards dying’ adopted by 96 terminally ill elderly people (Schroepfer 2006). Our data confirm that a WTD can express different intentions and that not every WTD is a wish to hasten death. However, we found more differences within her categories: for example, her category of “ready, accepting, and wishing for death” contains our intention types 1, 2 and 3; her “considering and has specific plan” contains our intention types 4–9. Nissim’s three types of wishes to hasten death, however intuitively appealing (WTD as hypothetical exit plan, expression of despair, or manifestation of letting go) do not sufficiently differentiate between intentions to die and motivations, nor between acceptance and wishing (Nissim et al. 2009).

Variation in degrees of concreteness of WTD has been observed in several studies using different quantitative approaches (Chocharin et al 1995; Arnold et al. 2004). Our results however challenge the idea that a WTD can have a ‘degree’ that could be quantified. The most commonly used scale is the Schedule of Attitudes toward Hastening Death (SAHD) (Rosenfeld et al. 2000), which presumes a coherent intensity scale of a WTD (low, moderate, high) and excludes the possibility that different types of WTD may be incommensurable. Based on our results, the SAHD approach is significantly lacking in the awareness of the essential differences between types of a WTD and of their temporal coexistence.

Our findings confirm the dynamic character of the WTD, similarly to Johansen et al. (2005). However, we did not observe the hypothetical or future-oriented nature of the WTD in all patients; some of our participants had very concrete and present-oriented ideas about dying, others expressed a request or undertook actions to end their
lives. Our typology of intentions provides an opportunity to study the stability-fluctuation continuum on the temporal axis in more detail.

**Implications for practice, policy and research.** The findings of our study and other similar ones can be useful in refining the communication skills of professional caregivers. WTD statements may be a normal (i.e. not pathological) response to impending death. Caregivers should understand patients’ expressions of a WTD as reflections of different elements of a complex and dynamic constellation of intentions and meanings, and should be hesitant to label patients as ‘contradictory’ or ‘depressive’. WTD statements can be occasions to probe and better understand the patient’s subjective experience. The fact that WTD statements sometimes fluctuate does not justify seeing them as ‘in-authentic’. On the other hand, WTD statements should not be taken at face value without appreciating their deeper intentional content. To respond adequately to a WTD statement, it needs to be understood within the overall life narrative of the patient. This cannot be done from an objective external perspective, but only through a process of dialogue with the patient.

Without precise knowledge of what is wished for by the speaker, and why it is wished for, there is a risk of drawing the wrong conclusions from WTD statements or from the statistics about them. An in-depth exploration of each patient’s WTD in clinical care is therefore an ethical requirement.

**Conclusions**

Patient-centred treatment and care planning can be improved by deepening the understanding of a WTD. Terminally ill patients’ WTD have to be understood as complex and dynamic statements composed of different, sometimes conflicting partial wishes that express intimate concerns of palliative patients, and which should in any case be taken seriously. We propose that a WTD should be understood as a responsive and agential space, within which internal and external negotiations interact, conflicting values and aims are continuously valued and weighed against each other, and the patient, relatives and multiple caregivers are involved.

**References**


**Table 1: Intentions towards dying**

Patients’ statements expressing their wishes about the end of their life can fall into one or more of the following categories:

**Wish to live**

**Acceptance of dying**

**Wish to die**

*Not considering hastening death*
1. Looking forward to dying
2. Hoping that dying happens more quickly
3. Desiring to die (but hastening death is not considered)

*Considering hastening death*
4. Hypothetically considering hastening death (in future, if certain things happen)
5. Actually considering hastening death, but at the moment (for moral or other reasons) it is not an option
6. Actually considering hastening death, hastening death is a (moral) option

*Will to die*
7. Explicit request
8. Refusing life-sustaining support (such as food or treatments) with the intention of hastening death
9. Acting towards dying (such as suicide or assisted dying)
APPENDIX

APPENDIX I: REVIEW OF LITERATURE
In the 1980s and 1990s, studies of patients with cancer, HIV or ALS predominantly focused on the association between a WTD and depression or hopelessness (Brown et al. 1989; Breitbart et al. 1996; Ganzini et al. 1998; Chochinov et al. 1998). Studies were conducted using large patient numbers (N=100-378), but the self-report questionnaires used did not allow in-depth insight into the patients’ narratives, attitudes, considerations or medical situation, nor their psychosocial or spiritual backgrounds. Only Chochinov et al. explored the patients’ perspectives using short semi-structured interviews (1995). They found an occasional WTD in 44.5% and a serious and pervasive desire to die in 8.5% out of 200 cancer patients, half of them with manifest depression, some of them with pain or social isolation. Studies based on retrospective data, and/or information from relatives (Seal 1994; Emmanuel 2002) or healthcare workers, (Arnold et al. 2004; Schneidemann 1999/2000; Back et al. 1996; Cavalieri et al. 2002; Ferrand et al. 2012; Filiberti et al. 2001; Ganzini 2002; Kissane et al. 1998; Volker 2001) underlined the multifactorial aetiology of WTD statements.

More recent prospective qualitative studies using descriptive, discovery-orientated, face-to-face interviews have yielded deeper insight into patients’ perspectives, their attitudes and moral beliefs. Most studies focused on a multifactorial aetiology with physical symptoms (if well controlled) being less influential than psychosocial and existential-spiritual distress, such as depression, demoralization, hopelessness, spiritual abandonment, and fear of the future or of losing control and sense of self (Wilson et al. 2000; Lavery 2001; Kelly et al. 2002; Mak and Elwyn 2005; Coyle and Sculco 2005). Depression-related decisional incapacity when planning assisted suicide and highlighted the need to avoid a reductionist understanding of the role of psychiatric illness (Baruch et al. 2004). In several studies a significant number of patients perceived themselves to be a burden to others, or felt that death would be a gesture of altruism. The complex clinical, legal, and ethical questions raised within a deliberated public discussion on assisted suicide and euthanasia have been critically discussed (Suarez- Almazor, 2002; Wilson et al. 2002; Lavery 2001; Kelly et al. 2002; Mak and Elwyn 2005).

In addition to the questions mentioned in the introduction, the current state of research leaves open other questions as well. For example, reasons behind WTD statements may vary with disease trajectories, which are clearly different in cancer, HIV, frailty or neurodegenerative diseases. Attitudes towards and beliefs about WTD statements also exist against a defined sociocultural background. The results and conclusions of the mostly American and Canadian studies might be valid in other countries, but we do not know enough about the cultural dependency of attitudes to end-of-life to be sure.

APPENDIX II: METHODS

Rationale of the study design
The idiographic approach of IPA enables in-depth investigation of how patients make sense of their personal experiences and the meanings they personally attribute to them. GT enables analysis of the data on a higher sociological level of abstraction. This approach is conceived to be as open as possible to the participants’ subjective views and avoids moral judgments about controversial end-of-life practices. We used a prospective, first-person study-design to explore the topic. Such an approach has the advantage of studying in-depth the individual person’s thoughts, needs and actual experiences in the final phase of life, and therefore gives deeper insights into the subjective complexity and structure of individuals’ WTD than a cross-sectional study based on third person, retrospective accounts. Similar methodologies were tested in previous studies (Scully et al. 2004; Haines et al. 2008). Prior to the main study, the interview schedule was tested in a pilot study with 5 patients, their relatives and caregivers.

Sampling
Eight patients were interviewed more than once. With patient consent, in 18 cases we also interviewed one of the patient’s close relatives, indicated to us by the patient (in 4 cases there was no relative, in 5 cases interviewing relatives was refused by the patient, and in 3 cases declined by the relative). Informed patient consent was also obtained for the collection of medical documentation and for the interviews with healthcare professionals. In all cases the primary physician and one nurse with close patient contact were interviewed. In addition to idiographic data from the interviews, we systematically collected the medical records for each of the 30 patients. Patients were selected as far as possible by theoretical sampling, which was sometimes limited by factors of convenience due to the low number of cases that met all inclusion criteria. Case selection took place parallel with an ongoing interpretation process, as suggested in GT (Corbin and Strauss 2008).

Depression screening
Each patient was tested for depression (anamnesis and screening by Robinson’s mini-screen for depression (Robinson and Crawford 2005) and Beck-Depression Inventory in suspected depression (Beck and Kovacs 1979). Depression however was not an exclusion criterion. Three out of 30 patients suffered from depression, one of them borderline. At the time of the interview all depressive patients were on antidepressants. In no case did the patient’s decision-making capacity seem compromised by depression.
Informed consent

Patients were informed about the study by their physician, orally and in writing through an information brochure. Patients expressing interest were visited a number of days before the interview by the main interviewer or a member of the research team in order to introduce themselves, to clarify participant questions and to obtain written informed consent. Patients were also asked for consent for the interviews with relatives and professional caregivers. Strict confidentiality between interviews was guaranteed. For the interview with relatives, we asked the patients to indicate which of their relatives they wished to be interviewed. Informed patient consent was also obtained for the collection of information from medical records. Relatives and healthcare professionals were contacted by the research team, and signed informed consent forms before the start of the interview.

Interview Schedule

All interview questions were asked in such a way as to elicit personal meanings and moral understandings. The interview schedule contained a progression scale. Only participants who said things that could be related to a WTD were asked more specifically about their understandings of what they had said, about their perceptions of triggering or hindering factors, relational aspects, the importance of autonomy and spirituality, and also whether the permissive situation of organized assisted suicide in Switzerland influenced their attitude. The term “wish to die” was used only when introduced by the patient. The main part of the interview contained the questions given below. Their precise formulation and the sequence was carefully adapted to the individual interview situation with the specific aim of soliciting narrative accounts of the interviewees’ experiences and exploring personal meaning.

1. Have there been times in your life when you reconsidered your ideas about dying?
2. In the course of your illness, did you ever wish your disease to proceed more rapidly?
3. Can you imagine situations in which you would prefer not to continue living?
4. Have you ever thought of putting an end to your life?
5. If questions 2 or 4 were answered “yes”: Please explain briefly what you understand by “the wish to die”.
6. If questions 2 or 4 were answered “yes”: When did your wish to die first appear?
7. If questions 2 or 4 were answered “yes”: Why did you have this wish?
8. If questions 2 or 4 were answered “yes”: Did you ever talk to anyone about your wish to die?
9. If question 8 was answered “yes”: What reaction did you get?
10. If questions 2 or 4 were answered “yes”: Have you asked anyone to help you with this?
11. If question 10 was answered “yes”: What reaction did you get?
12. If questions 2 or 4 were answered “yes”: Why have you not done it? (or: What stopped you?)
13. In Switzerland, people who are terminally ill can take their own life with the help of a physician or an organization that provides assisted suicide. Could you tell us more about your ideas on that?
14. In cases of unbearable suffering, physicians are legally allowed to induce continuous sleep - so-called sedation - in a person. What do you think about this?
15. What kind of person were you before you got ill?
16. Is faith or spirituality important to you?
17. What significance/meaning do independence and self-determination have for you?
18. Do you have an advanced directive? If yes, what did it mean to you to write it?

The interviews with nurses, doctors and relatives, which took place shortly after the patient interview, centred on the experiences and ideas of the patient. Adapted schedules, based on the one above, were used in these interviews. We wanted to know how these groups saw the patient’s wishes regarding death, to what extent relatives and healthcare professionals were informed about these ideas, and what conversations, interactions or reactions were important with respect to a patient’s WTD statement.

For the present publication, selected interview quotes have been translated from German or Swiss-German dialect into English.

Analysis

The analysis revealed different ideal types of intentions towards dying (Table 1). We generated the findings by a comparative method (Smith et al. 2009; Charmaz 2006) using an inductive process, extrapolating patterns from individual case stories and comparing data with data, data with category, category with category, and category with concepts (Finlay 2009). Real manifestations that fall into these categories had of course many more nuances that cannot all be represented within an idealized scheme.

Ethics

We encouraged patients to interrupt or to postpone the interviews if they felt emotionally burdened or showed signs of tiredness. Patients and relatives were personally followed-up by the primary physician shortly after the interview and monitored for adverse effects (which were reported by only one patient-participant, who had been strongly affected by childhood memories). The study was approved by the Basel research ethics committee (Ethikkommission Beider Basel EKBB).
APPENDIX III: Supporting quotes

Wish to live

Many patients expressed a clear wish to live, as P14:
“Certainly there will be pleasant moments before death comes, therefore I want to experience them.”

Acceptance of dying

P7 said that her joy at being reunited with her deceased husband made her own death acceptable to her. P9 explained that her acceptance came from her sense of having concluded her life and from her faith in God:
“I reckon, I was neither asked whether I wanted to come [into the world] or not. [...] If I still had small children, it would be different. Then I would resist. But at 81 I’ve had my life.”

Wishes to die

1 Looking forward to dying
P6 held strong religious beliefs. She explained her WTD by a curiosity about life after death, and expressed a wish to experience it:
“Yes! Yes. Of that [death] I have no fear. Maybe of the dying, yes, when you don’t know what will happen to you. But after death? That I can look forward to. I read so much about it and... yes and it should continue. [...] I would like to go home [to her apartment], yes! But not like this. I’d rather carry on there [on another level of consciousness after death] und sss... [note: hand movement towards the ceiling]” (P6)

2 Hoping that dying happens more quickly
P5 reported that she repeatedly wished that her illness would progress more rapidly:
“Yes, [I hoped] that it is quick. I know how such a disease can go. [...] Then, oh for Heaven’s sake, instead of vegetating somewhere! [...] I simply hope that nature plays along and lets me go where it then goes.” (P5)

3 Desiring to die (but hastening death is not considered)
P17 wished for the end of her existence, not just for the dying process to happen faster: However, she held a WTD without a wish to hasten death:
“Above all, I want to go [to die], I want to go, I don’t want any more [to live...]. I am not nervous and I am not afraid, not at all, none of that. I am going just as I am going. [...] But you know, I lived in a high building. I could have gone to the 15th floor there, to the roof terrace and jumped off. But I think this is not digni-
7 Explicit request
P22’s nurse reported that the patient had asked her to give her “the injection” containing an overdose of morphine.

“It was on my evening round when she spontaneously said to me that she has had enough. And then I asked her more in detail, what she meant by ‘enough’. Then she told me: I would like to die, and I would like it most that you give me the big injection of morphine, if this is possible.”

8 Refusing life-sustaining support (such as food or treatments) with the intention of hastening death
P21 discontinued steroids for intracranial pressure, assuming that death would come within a few days. P30 stopped eating in order to accelerate the dying process:

P: My niece came to visit me. She’s in the paraplegic [home]. She works there as a therapist. And of course she experiences a lot. And then she said to me: “I can give you some good advice. Stop eating and drinking! Or just carry on drinking.” She said. “I mean, if you have this tumour in your tummy, I wouldn’t do that any more.” [...] She said, you’re going to die, she told me right away. [...] Yes, that did me good. [...] Yes, that she’s so open and honest with me. [...] Yes, I thought, that’s the best thing!
I: And now you’ve done that?
P: I’ve done that now. I mean, I still drink a little.
I: But you don’t eat anything?
P: No, don’t eat anything any more.

9 Acting toward dying (such as suicide or assisted dying)
P32 attempted suicide with an overdose of sedatives, but failed. Other patients (P13, P29) undertook actions with the help of the organization EXIT to enable them to die (P29 contacted EXIT via her physician; P13 was in possession of a prescription for the lethal drug used by this organization):

“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”.

Evolution over time
P20’s nurse reported that the patient twice explicitly asked for euthanasia during her final weeks. The patient herself said that her wish for a hastened death was persistent and strong:

“It would be my dream that one could say, take this pill and you won’t wake up again tomorrow.”
But when asked during the interview, she said that ‘today’ it would not be what she wanted for herself:
“No, not at this moment, but on those days when I am so miserably sick.”
APPENDIX IV: Patient Characteristics

Number of patients asked for interview
Total 34, patients who refused 2 (speaking too burdensome), patients who accepted 32. Excluded after interview 2 (P23 non-cancer disease, P27 interviewer involved in patient care). Patient cases analysed 30, interviews analysed 116.

Characteristics of study patients (n=30)
Male 12, female 18, age 34-87 years (average 69.7 years, median 75 years).

Median interval between final interview and a patient’s death
22.5 days (range 5-237 days), with 2 patients not included who were palliative but not considered to be terminal when entering the study – and who were still alive at the end of the research period.

<table>
<thead>
<tr>
<th>Sex</th>
<th>Age</th>
<th>Primary tumour</th>
<th>Duration of disease (years)</th>
<th>Place of care at time of interview</th>
<th>Interval between final interview and death (days)</th>
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<tr>
<td>P1</td>
<td>M</td>
<td>68</td>
<td>Prostate</td>
<td>7</td>
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<td>Breast</td>
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<tr>
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<td>Ovary</td>
<td>8</td>
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</tbody>
</table>
APPENDIX IV: Set and emerging themes

The interview schedule included 12 set themes:

S1 subjective meaning of one’s dying
S2 time
S3 advance directives
S4 factors that trigger, influence or delay a wish to die
S5 image of body and self
S6 sedation
S7 how others are moved, touched or challenged by a wish to die
S8 significance and definition of a wish to die from the perspective of healthcare professionals and relatives
S9 thought construct ‘wish to die’
S10 breaks in the narration
S11 influence and significance of the Swiss regulation on and attitude towards assisted suicide to patient’s personal attitude
S12 SAHD

In the analysis of the data 9 more themes emerged:

E1 autonomy
E2 speechlessness
E3 ambivalence
E4 taking decisions regarding others
E5 ideas of a good death
E6 negotiating one’s dying
E7 the interview as intervention
E8 how patients perceive the doctors
E9 spiritual imagination