

Intentions in wishes to die: analysis and a typology – A report of 30 qualitative case studies of 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: Thirty 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 semistructured qualitative interviews analyzed 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.

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Received: 4 June 2013

Revised: 26 February 2014

Accepted: 26 February 2014

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) [1]. In some patients, the WTD may persist even with access to palliative care [2]. Talking with patients about their WTD is perceived by caregivers as challenging and is therefore often avoided [3]. 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 [4,5]. Health professionals are therefore ethically obliged to adequately address patients' WTD statements and to understand the meaning of a WTD in a patients' life [6].

Research has been undertaken to better understand the phenomenon of a WTD in terminally ill patients (literature overview in Appendix A). Earlier studies, mainly based on quantitative methods, reported a multifactorial etiology and an association between a WTD and depression and hopelessness [7–21]. After 2000, some qualitative studies investigated the experience of dying patients with a WTD prospectively from a first-person perspective, confirming the multifactorial etiology [22–29].

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 [5]. Studies did not clearly differentiate between a general WTD, a wish to hasten death, and requests for assisted suicide or euthanasia [30,31]. Thus, results are difficult to compare [31,32]. 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. (For findings on motivations and relational aspects see [6]; on the perception of ambivalence, see [33].)

Methods

A more detailed section about the methodology of this study is available in Appendix B (Supporting Information). We used a qualitative research methodology, which combines phenomenological and hermeneutic approaches, and is inspired by Interpretive Phenomenological Analysis [34] and Grounded Theory [35,36]. The idiographic approach of Interpretive Phenomenological Analysis 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 antitumor 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 min. Nurses and physicians were interviewed for about 20–60 min. Interviews were semistructured, starting with a schedule (Appendix B) 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 two 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 the experience gained from the interviews. All interviews were audio-recorded and

fully transcribed using simple verbatim transcription rules. The analysis and interpretation was based on the transcripts in the original language.

Transcripts were continuously analyzed during the interview period. After initial independent coding of the transcripts by each of the authors, the coding and interpretation of all interviews belonging to one case unit were discussed by the three authors for each patient story. For each patient story, we interpreted the patients' interviews together with those of the relatives and healthcare givers. The triangulation of the patients' interviews with those of relatives and professional caregivers served to give a richer and more rigorous interpretation of patients' statements. Apart from the 'set themes' (stemming from the initial research questions) in the interview schedule, we searched for and characterized 'emerging themes'. After 14 interviews, a provisional list of set and emerging themes was compiled, which was then used to support further data analysis (see Appendix E). 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 'WTD' 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).

Results

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; all supportive quotes can be found in Appendix C; patient characteristics in Appendix D).

Wish to live

In 12 patients, the *wish to live* was prevalent. However, only five of them denied any WTD 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

Table 1. Intentions toward 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 toward dying (such as suicide or assisted dying)

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 *acceptance* of dying, which cannot be categorized as a wish. Acceptance describes an affirmative attitude toward 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 observed: (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 *imagination* they had about dying. Other participants spoke about their WTD relating it to *actions* that lead to dying, including expressing an active request. We found it useful to distinguish between a *wish* in a narrower sense, as an intention that is directed toward an idea or an imagination, and a *will* as an intention that is directed to actions that lead to death [cf. 37, pp 49-52]. (3) We can differentiate between 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. *Looking forward to dying.* These patients explicitly wished for death to come while nevertheless retaining a positive attitude toward 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. *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. *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 WTD (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. *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. *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. *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. *Explicit request.* This category included those who explicitly asked for any sort of aid in dying.
8. *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. Whereas 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. *Acting toward dying.* Still other patients were engaged in a process that could hasten death, such as suicide, or a legal form of assisted dying.

Multiple coexisting wishes

Most statements of the WTD 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 [33]. 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.

Evolution of wishes to die 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 1 day to the next, depending on the situation (see quote of P20, Appendix C, “Evolution over time” in the Supporting Information).

We cannot suggest a linear temporal model of intentions toward dying. Quite the contrary: some patients shifted or jumped from one type to another and could do this in both directions. And some types of wishes, even contradictory ones, can coexist. There is certainly no single linear process from ‘acceptance’ through a ‘WTD’ 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 ‘WTD’. 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 toward 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 the following: (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 conceptualization of WTD statements as requested by the authors of [5,31,32]. (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 [12]. (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 toward dying' adopted by 96 terminally ill elderly people [29]. 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 [38].

Variation in degrees of concreteness of WTD has been observed in several studies using different quantitative approaches [1,2]. 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 [39], which presupposes 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 Schedule of Attitudes toward Hastening Death 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.* [28]. 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 might provide 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 patients' subjective experience. The fact that WTD statements sometimes fluctuate does not justify seeing them as 'inauthentic'. On the other hand, WTD statements should never 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 moral understandings, relationships and the overall life narrative of the patient. This cannot be performed 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-centered 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, 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.

Acknowledgements

We thank the participating patients and families for sharing their intimate concerns, experience and time, when time was actually short. We also thank the participating healthcare workers of the institutions involved, Jackie Leach Scully and Guy Withershoven for their helpful suggestions, and Monica Buckland for revising the English text. The study was funded by Oncosuisse (grant 01960-10-2006), and the Gottfried und Julia Bangerter-Rhyner-Stiftung; the pilot study was funded by the Förderstiftung HOSPIZ IM PARK and the Freiwillige Akademische Gesellschaft Basel.

Conflict of interest

H. G. is head physician at the Hospiz im Park Arlesheim. She was interviewed about some of her patients in her position as physician. In these cases she did not take part in the data interpretation.

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Supporting information

Additional supporting information may be found in the online version of this article at the publisher's web site.