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ORIGINAL ARTICLE

Issues of “life” and “death” for patients receiving palliative care—comments when confronted with a research tool

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Abstract

Purpose To be able to study the desire for hastened death (DhD) in patients receiving palliative care, research tools reflecting the thoughts of patients are needed. In order to better understand what issues of “life” and “death” mean to patients receiving palliative care in Germany, we analysed their spontaneous comments during a validation study of the German version of the Schedule of Attitudes Towards Hastened Death.

Method Field notes and transcripts of 39 interviews were analysed by thematic analysis.

Results Field notes from 32 patients were related to differentiating either an acute or a non-acute DhD. Furthermore, the patients’ comments were categorized and the distribution of codes analysed, leading to three types of comments: (a) longing for life excluding a hastened death, (b) wanting to live on, but perceiving death as an option, and (c) longing for death, but struggling for life.

Conclusion The existing construct of an increased DhD may benefit from a further differentiation between “non-acute” and “acute.” In addition, it could be helpful to conceptualize “will to live” and “desire for death” not as polarities from one dimension (two sides of the same coin), but to think them as two independent dimensions.

Keywords Desire for hastened death · Wish to die · Will to live

Introduction

Patients in palliative care who “want to die” represent a clinical and ethical challenge. The wish to die is conceptualized under different terms and definitions, e.g., as “desire for hastened death,” “wish to die,” or “desire to die.” These terms address different aspects and intensities of a wish to die [1].

Once a desire for hastening death is known, palliative care interventions have to manage the tightrope walk of not prolonging suffering and enabling a more or less natural dying process. Reducing suffering may lead to a reduced desire to die, and this might strengthen the patients’ will “to live the dying phase.” Despite the clinical relevance, few studies have examined these issues directly in patients receiving palliative care. Studies so far tend to distinguish between a “desire to die” [2] or “desire for hastened death” (DhD) [3] on one side and the “will to live” on the other [4].

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In many patients, this wish to die is hypothetical and may be fluctuating [1, 5]. Palliative care interventions with emphasis on listening play an important role in influencing this wish. The "will to live" also fluctuates, with similar variables identified as for DhD [6].

How the issues of "life" and "death," however, relate to each other in patients, and how and why patients' wish to die may change over time is basically unknown so far. Qualitatively, only one study found an expressed DhD as a possible manifestation of the will to live [7]. Quantitatively, measuring both a statistically significant but weak correlation was identified [6], suggesting that these two issues are not simply inversely correlated.

An effective research tool, in order to be clinically relevant, should as much as possible reflect patients' thoughts on these issues. The Schedule of Attitudes Towards Hastened Death (SAHD) is such an instrument derived from patients' comments [3]. The SAHD—a 20-item scale (with yes/no response)—was developed in the USA and validated for cancer and AIDS patients [3, 8, 9]. As the only self-administered questionnaire for DhD, it has been used in studies to find predictors of DhD [10, 11]. A Greek version has been also validated, with similar psychometric properties as the original version [12]. In order to see how the questions of the SAHD relate to the clinical situation and to develop a better understanding of what issues of "life" and "death" mean to patients receiving palliative care in Germany, we analysed the spontaneous comments of patients when confronted with the SAHD questions, during a validation study of the German version (SAHD-D).

Methods

In the context of an ongoing validation study of the German version of the questionnaire SAHD-D, field notes of spontaneous comments made by interviewed patients receiving palliative care were recorded by the interviewer.

This study was part of an "ABC" (Aachen, Bonn, and Cologne) research project on end-of-life issues [13, 14]. Formal inclusion criteria for this study were (a) inpatient treatment on a palliative care unit, (b) fluent in German language, (c) clinical situation adequate for the interview, (d) Mini Mental Status Examination score of ≥21, and (e) informed oral or written consent. The study protocol consisted of (a) "Mini Mental Status Examination", (b) Hospital Anxiety and Depression Scale [15], (c) European Organization for Research and Treatment of Cancer Quality of Life Questionnaire C15 PAL [16], and (d) the SAHD-D (to be validated). The interview was conducted within the first 5 days after admission. Ethics committee's approval was obtained in all three sites—Aachen, Bonn, and Cologne (number 06-208).

The SAHD-D was scored by the interviewer (JW); the questions were asked and recorded without active delay. However, reactions and open comments by the patients were recorded as field notes (FN). These field notes (A, B, or C stands for the cities where the interviews were conducted) were originally planned to serve as a memory hook, following the request of the ethics committee that the interviewer should give feedback to the team on any features that request an intervention or support of any kind. The interviewer noticed difficulties in answering the questions of the instruments and wrote down these patient induced comments. After interviewing 36 patients, we decided to additionally record and transcribe three interviews (T for recorded and transcribed interviews). Interviews and field notes were transcribed and analysed thematically [17]. The qualitative data analysis package MAXQDA was used for the initial stages of coding. Due to the restricted nature of our data, we chose a strongly explorative and hypotheses-generating approach.

Following this approach for data analysis, initially field notes (FN=field notes) from 12 interviews and—where existing—their transcripts (T=transcript), were coded openly by an independent researcher (MG), producing a list of inductive codes representing manifest and latent themes. The analysis was carried out on case and not on item level, i.e., data from one interview were analysed as a whole. One of the reasons for this procedure was that the authors of the instrument could show a unidimensional structure so that comments can stand for more than one question. After this case-based analysis, the different cases were compared for similarities and differences in codes, generating a "code tree" or system of categorisation. The remaining 27 interviews were coded accordingly and the system modified by new codes if necessary, refining the "code tree" continuously during the allocation process. Among the categories, a constant comparison was performed between the interviews [18]. Out of the categorical system that identified ten main categories found (see "Results"), we focused further analysis on the two core categories "life" and "death/dying." This research interest was triggered by the impression of the interviewer that there were repeated difficulties in answering the items of the questionnaire SAHD-D, which are focused on life and death. Furthermore, because of the nature of a validation study, these categories had to be addressed in order to understand how well the questionnaire fits German patients. Interviews were additionally analysed for emergent patterns across the categories [19, 20] to detect common characteristics of patients and their attitude toward life and death.

The structure of codes and the identification of patterns across categories, on the basis of the existing data, was discussed with another qualitative working researcher (UK) and, where necessary, refined.

Results

Field notes of interviews of the first 39 patients of the validation study were analysed. Of these, 28 (72%) were female and 11 (28%) male. Median age was 63 (range, 42–86). All patients suffered from progressive cancer. The most frequent diagnoses were related to the breast or female genitals (40%), the digestive system (23%), and the respiratory tract (18%). For 29%, a poor functional status [Eastern Cooperative Oncology Group (ECOG) 3 and 4] was reported, 51% had a good to moderate functional status (ECOG 0–2), while in 20%, the functional status was not documented.

Ten main categories were identified, which, to some degree, mirror the topics of the test battery as "treatment," "illness," "time," "sense," "life," and "death/dying," but some go beyond these such as "interpersonal relationships," "identity," and "desire to share experience" (Table 1). Of these, we analysed in depth the categories "life" and "death/dying."

A mapping of the corresponding subcategories and first hints from the interviews about how they may be linked is shown in Fig. 1.

Categories of comments

The comments could be grouped into the following possible scenarios (Fig. 1):

EITHER hastened death is not an option by principle attitude (n=6):

- "No, I would not end my life … and then I was so down, I came off the rails. This was … but even then, I would not have ended my life" (T-C158)
- "That is rubbish"—as an answer to the item *I hope my disease will progress rapidly because I would prefer to die, rather than continue living with this illness* (FN-C90)

OR hastened death generally may be taken into account (n=14).

- "Finally, doubts still remain whether I am authorised to end my life" (FN-C16)
- As an answer to the item *I am seriously considering asking my doctor for help ending my life*: "Sometimes I do, but he is not allowed to do so anyway." (FN-C138)

Of those patients who do take DhD into account,

1. Some may decide to see hastened death not as an option for them (n=3),
    - Is laughing—"I sometimes say so, but I'd never do it" (FN-B34)
2. Others keep the option open that, in case of a hypothetic future deterioration, it could again be taken into account (n=16).
    - "I would not say I would like to die, but I keep it at the back of my mind" (FN-C89)
    - "In principle I can imagine this, but at the moment it is not necessary yet" (FN-C19)
3. Others think about how to accomplish hastened death (n=11).
    - "She says that she had been already thinking of suicide via drugs, that she had planned it, but finally she was lacking the power and courage to do it" (FN-C18)
    - "I looked into the work of "Dignitas"/ found the documents from the internet" (FN-C77)
    - "I have already asked several physicians at different times for help in ending my life" (FN-B91)

Moreover, some patients (n=11) were even considering the possibilities to put the DhD into practice. Two participants decided for life, three were in favour of following through with death, and from the data for the remaining six, intention was unclear.

Differentiation of desire for hastened death

Our data suggest that the desire for hastened death can be further differentiated between an acute and a non-acute desire. Thirty-two out of 39 patients felt they had to clarify some of the SAHD-D questions during the interview, whether their answers refer to

(a) The actual situation:

- "[Dying] is the only possibility that I still have" (FN-C18)
- "If I could, I would do it [ending my life if it becomes unbearable]" (FN-C18)

Table 1 Main categories and number of interviews in which the category was identified

Interpersonal relationships	4
Identity	10
Care/treatment	22
Illness	16
Time	38
Meaning	9
Life	27
Death/dying	38
Desire to communicate	2
Feedback interview	38

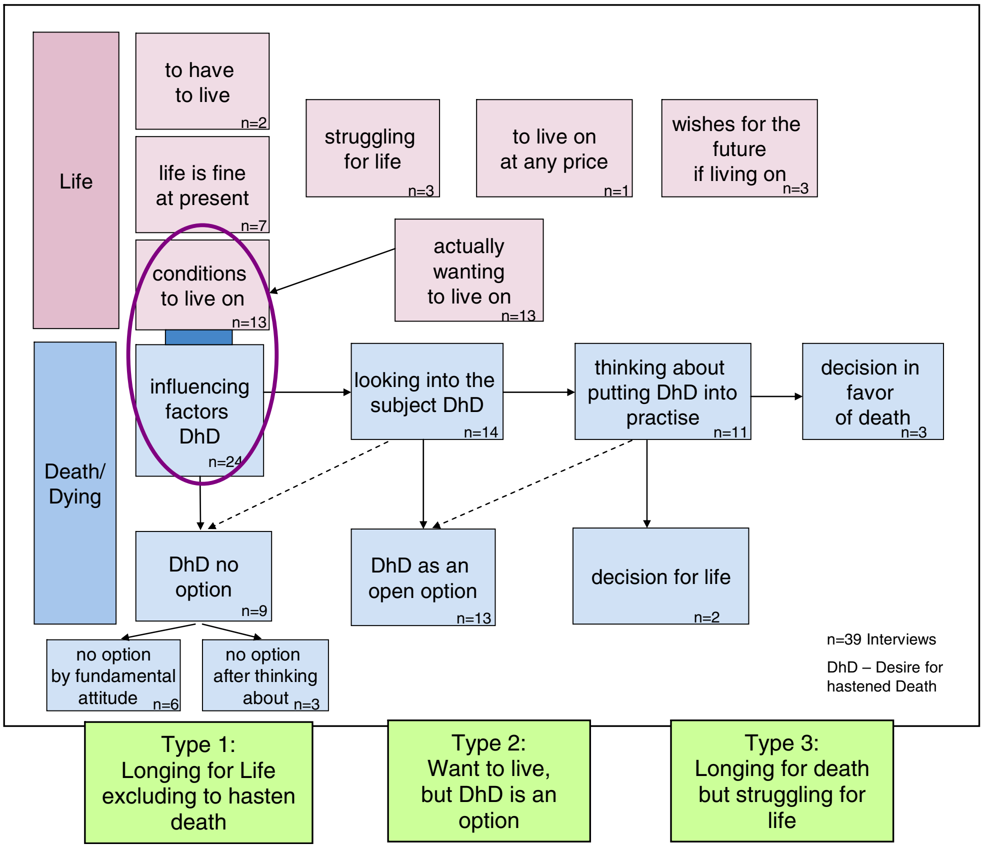

Fig. 1 Mapping of subcategories and conjunctions of patients' comments in the main category of "to live on" and "desire for hastened death"

(b) A later time under certain conditions (non-acute–hypothetical):

- "Maybe in the future. At the moment life is in the focus" (FN-C101)
- "Later yes, not yet now. Only if it becomes serious" (FN-C138)

or

(c) To a more general or fundamental attitude (non-acute – fundamental):

- "In principal I can imagine this but at the moment it is not necessary yet" (FN-C19)
- "Generally, this would be an option" (FN-C129)

All patients who leave DhD as an open option have, in this sense, a non-acute DhD.

Desire for death and wish to live—one or two dimensions?

The distribution of codes of different interviews across the categories led to first hints about *three possible decision types* using comments from 17 patients who spontaneously gave enough information on this topic (Fig. 1):

Type 1 Longing for life excluding hastened death

Patients whose comments fell into this type state that they want to live on, some at any price, and do not want to die (*n*=4; C2, C99, C158, and A80). They appear to have a particularly strong bond to life. They could not name possible promoting factors for developing a desire for hastened death. The subcategory "to live on at any price" is only found here, whereas "struggling for life" can also be seen in type 3.

"I do not want to die yet at all. […] But I did not, I never had a thought about dying or something like that." (T-C158)

- "It is my fate. I'd never had the courage to do it. I look forward to every day, even when I cannot really look forward to my future. I cling too much to life." (FN-C2)

Type 2 Wanting to live on, but perceiving death as an option

The majority of the interviews could be allocated to this type (*n*=9; C19, C77, C92, C101, C106, C138, C190, C188, and A60). The patients definitely want to live on, but still consider a hastened death as a potential option for them. These patients contributed essentially to the list of possible promoting factors for a desire for hastened death (Table 2), as they could imagine putting it eventually into action. Table 2 illustrates that some points, like the absence or presence of pain or close relationships with loved ones, are intertwined to both categories: the wish to live and the desire for hastened death. Nevertheless, the influencing factors for DhD are more diverse and differentiated than the mentioned conditions for living on.

Some of the patients in this type of comments, despite wanting to live, have actively sought information on possible ways to end their lives. Nevertheless, they do not pursue this thought further, but keep it as an option.

- One patient (C188) reported that she wanted to die earlier in her disease course ("I know this feeling when you only want to die and the others will be better off. You have to die right now and the others can go on living better. This urgent feeling I know very well. This I don't have now anymore"). She decided now for life ("I know that I in this concern made another decision than some time before"). Nevertheless, she admits that dying in *this moment* does not yet seem the best way to end her life, implying it could seem so later.

Type 3 Longing for death but struggling for life

In this group (n=4; A51, B91, C18, and C139), the patients "want to die," and this wish is acute and not hypothetical. Despite the strong desire to die, a perception of life as being a present and the struggle for life is still evident in this patient group.

- One patient (C139) has a strong wish for living ("'I want to live, oh Lord'—begins to cry"), but to the question whether he would end his life when his illness becomes unbearable, he answers "if somebody gave me something and told me 'here—in two seconds', I would try it" (FN-C139).
- Another patient (B91) admits he had already asked several physicians several times for help in ending his life (FN-B91).

Discussion

The spontaneous comments of patients receiving palliative care regarding the issues of "life" and "death" during a validation study of the German version of the SAHD raised the following issues.

First, some patients saw their DhD as a "hypothetical possibility" under certain conditions for the future, when pain or emotional suffering would become unbearable. This supports earlier data, such as results from semistructured interviews in 18 cancer patients, in whom wishes for euthanasia and physician-assisted suicide were found to be hypothetical [5]. This may be interpreted as a coping strategy of keeping control [5]. Therefore, the existing construct of an increased DhD may benefit from a further differentiation between "non-acute" and "acute." It seems possible that non-acute DhDs can be different in character. Therefore, there might be a fundamental attitude supporting euthanasia or physician-assisted suicide on the one hand and a hypothetical DhD bound on certain conditions on the other hand. In few patients, this DhD is, however, more acute, leading the patients to wish to put it into action [21]. Whether and how both these possibilities overlap is unknown so far.

Second, the "will to live" may be present, despite a DhD in the same patient, at the same time. This is in contrast to the more intuitive starting point of understanding the construct "desire for hastened death" as including the will to live to be on the same dimension. This intuitive paradox has been described earlier in another qualitative study [7]. Therefore, it could be helpful to conceptualize "will to live" and "desire for death" not as the polarities from one dimension (two sides of the same coin) but to think of them as two independent dimensions. That would imply that asking for the will to live would not necessarily lead to gaining information about the desire to die, as it is not simply the opposite. In an earlier quantitative study, both constructs were measured by independent instruments, showing a significant but only moderate correlation ($r_s = -0.427$) [6]. If both these constructs were simply two sides of the same coin, the correlation could be expected to be much higher.

Third, how patients may change between the identified possible subcategories or types must be answered by longitudinal studies in the future. So far, it remains hypothetical that it is a process leading the patient from a first idea about ending one's life, considering this possibility more intensively, up to the implementation of the decision. Our data suggest that psychological models of intentional and volitional processes can be helpful to gain a deeper understanding of this phenomenon and develop corresponding interventions (e.g., [22]). Future research will benefit from using a more robust study design to confirm and further explore the findings of this study.

Consequently, validated research tools will be necessary in order to be able to use a change in attitude toward DhD or in the will to live as an outcome criterion for palliative care interventions [23]. An interdisciplinary approach of integrating and interrogating findings from suicidology and testing the feasibility of their instruments might be fruitful.

This study has its clear methodological limitations. Initially, the patients' comments were documented spontaneously, evolving in the process of the study, feeding back results important for the staff, and gathering interesting information that was unexpected. In order to neutralize a possible bias of the interviewer, the analysis of the field

Table 2 List of patients' comments on influencing factors, both hindering and promoting

Type	Category "death/dying"		Category "Life"
	Factors…	Conditions for wishing to live on	
	Hindering DhD	Promoting DhD	
1. Longing for life excluding hastened death	Lack of courage		No pain
2. Wanting to live on, but perceiving death as an option	Enjoying life	Persistent unbearable pain	No pain
	Lack of strength	Physical discomfort	Maintainance of present good state
	Close relationships	Being a burden	Feeling beloved
	Fear of death	Fear of suffocation	
	Self-managing of emotional distress	Psychological suffering	
	No allowance for ending one's life	Unbearable situation	
	Ending one's life as a defeat	Losses of abilities and meaning	
3. Longing for death but struggling for life	Helpful conversations	Last resort from emotional suffering	Contact to family
	Risk of failure when committing suicide	Suffering	Caring partnership
		Physical discomfort	Contact to family doctor
		(Untreatable) Pain	No pain
		Wish for a quick dying	Clarification and organization of further care
		Dependency on drugs	
		Fatigue	

notes was done by an independent researcher. By this, the individual perception of the interviewer could be reflected to some degree. To further control for a possible bias, an analysis of transcripts of some interviews was also performed. Nevertheless, due to the small number of audio-recorded and transcribed interviews, there is only limited control of the bias in recording field notes. Another limitation is that field notes sometimes are not sufficient enough to understand the position of the patient. Whether the types of comments identified in this study also reflect types of patients has to be confirmed or complemented, using a more rigorous methodological design.

The strengths of this study, however, are that all interviews and field notes were conducted by the same interviewer (JW), which guarantees a comparability of field notes. Participants were able to express their attitudes, thoughts and experiences, activated by the SAHD interview, on topics such as quality of life, anxiety, and depression, and hastened death. The interview itself confronted patients with their situation and gave them a place to speak about these issues, which potentially might underlie certain social taboos, maybe even on palliative care or hospice units. The SAHD interview gave room to these topics, to something patients had often thought but not spoken about earlier.

Conclusion

In patients receiving palliative care, a desire for hastened death may be subgrouped as "acute" and "non-acute," and it may be independent but interwoven with a "will to live." This has to be taken into account when caring for these patients and when developing clinically relevant research tools for studying further these issues.

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