

# Attitudes towards, and wishes for, euthanasia in advanced cancer patients at a palliative medicine unit

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**Background:** Most studies on attitudes towards euthanasia and physician-assisted suicide (PAS) have been conducted in healthy populations. The aim of this study is to explore and describe attitudes towards, and wishes for, euthanasia/PAS in cancer patients with short life expectancy. **Method:** Semi-structured interviews with 18 cancer patients with a life expectancy of less than nine months. All patients were recruited from an inpatient palliative medicine unit. **Results:** Patients holding a positive attitude towards euthanasia/PAS do not necessarily want euthanasia/PAS for themselves. Wishes are different from requests for euthanasia/PAS. Fear of future pain and a painful death were the main reasons given for a possible wish for euthanasia/PAS. Worries about minimal quality of life and lack of hope also contributed to such thoughts. Wishes for euthanasia/PAS were hypothetical; they were future oriented and with a prerequisite that intense pain, lack of quality of life and/or hope had to be present. Additionally, wishes were fluctuating and ambivalent. **Conclusion:** The wish to die in these patients does not seem to be constant. Rather, this wish is more appropriately seen as an ambivalent and fluctuating mental 'solution' for the future. Health care providers should be aware of this when responding to utterances regarding euthanasia/PAS. *Palliative Medicine* 2005; **19**: 454–460

**Key words:** cancer; desire for death; euthanasia; palliative care; physician-assisted suicide (PAS), terminal illness

## Introduction

Both debate and research on euthanasia and physician-assisted suicide (PAS) have been sparked by the legalization of PAS in Oregon, US in 1997,<sup>1</sup> legalization of euthanasia and PAS in the Netherlands and legalization of euthanasia in Belgium in 2002.<sup>2,3</sup> In the near future, the House of Lords will consider a bill on assisted dying for the terminally ill in the UK. Furthermore, the council of Europe is now in the process of addressing the issue of the relationship between national euthanasia legalization and the European Convention on Human Rights. Against this backdrop, knowledge of how patients relate to euthanasia/PAS is highly relevant for health care professionals, lawmakers and the public. There exist, however, some shortcomings within this area of research. Most studies on attitudes towards euthanasia/PAS have focused almost exclusively on health care providers' attitudes and less on the attitudes of the seriously

ill.<sup>4–11</sup> Further, many studies employ vague and inappropriate definitions and descriptions of end-of-life acts, with increased risk of misunderstanding questions posed and thus making interpretations of the findings difficult.<sup>12</sup> In addition, nearly all studies that investigate patients' attitudes towards euthanasia/PAS fail to address the very concept 'attitude'. Neither the denotation nor the predictive power of attitudes has been questioned. Attitudes are held to be more or less rational evaluations of objects, and are important in the psychological process of guiding our thoughts, feelings and behaviour.<sup>13</sup>

It is worth noticing that in the Netherlands, whose history of euthanasia practice dates back at least to the 1973 court ruling in the Postma case,<sup>14</sup> there has never been any patient-centred research on the euthanasia/PAS issue.<sup>15</sup> The Dutch experience is portrayed in large scale studies – performed in 1990, 1995 and 2001 – with physicians' reports and retrospective accounts of their patients' reasons for requesting euthanasia or PAS.<sup>16–18</sup> Few qualitative, in-depth studies on how seriously ill patients relate to euthanasia/PAS have been conducted. A recent study found that patients with 'high wish for

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hastened death' had, according to the authors, greater 'concerns' with symptoms and suffering, and perceived themselves to be a burden.<sup>19</sup> The concepts used in this study are, however, somewhat vague and comparisons with the results of other studies can be limited. Kuuppelomaki<sup>7</sup> found that hopelessness, uncontrollable pain, and the right to self-determination were the main reasons for approving of 'active euthanasia'. No distinction was, however, made between different response groups (patients, family, physicians) when listing the findings, which makes it impossible to draw conclusions regarding patients' attitudes. Wilson *et al.* found that nearly 50% of 70 terminally ill cancer patients stated a possible future interest in euthanasia/PAS, especially if pain and symptoms were to become intolerable.<sup>20</sup> Clinical experience and research suggest that depression and fear of future pain are the most important factors associated with interest for hastened death and/or request for euthanasia/PAS.<sup>20-24</sup> In the literature, however, the emphasis has been on the frequency at which patients do consider euthanasia/PAS and on related explanatory factors, such as depression and hopelessness. In-depth analysis of the nature of attitudes and wishes, and on the complex, psychological processes of considering euthanasia/PAS among terminally ill cancer patients, are limited in the literature.

The present study aims at exploring and describing attitudes towards, and wishes for, euthanasia/PAS in a small group of advanced cancer patients at a palliative medicine unit. The predictive value of attitudes, and possible meanings of wishes, are explored. Possible psychological processes and relations between attitudes, wishes, and requests are preliminarily and theoretically examined.

## Method

### Sample

Eighteen advanced cancer patients, hospitalized at the Palliative Medicine Unit, Department of Oncology and Radiotherapy, University Hospital of Trondheim, Norway, were consecutively included. Mean age was 63 years (range: 38-83). Eight women and ten men with the following diagnoses were included: lung cancer ( $n=2$ ); prostate cancer ( $n=5$ ); gastrointestinal cancer ( $n=5$ ); breast cancer ( $n=2$ ); head and neck cancer ( $n=2$ ) and unknown primary cancer ( $n=2$ ). Time span between the initial diagnosis and the interview varied from two months to eight and a half years. Survival from the time of the interview varied from three days to nearly nine months. An attempt was made to achieve variation with regard to sex, age and expected survival time.

Eligible patients had to suffer from terminal cancer, have a short life expectancy (<9 months) and be

cognitively intact. The attending physician estimated life expectancy based upon clinical experience. All patients were fully aware of their disease and its prognosis. Patients with known previous or present psychiatric diagnosis were not approached. The attending physician was responsible for determining which patients to approach for participation. This was a two step process: initially, patients were given an oral orientation about the study, and only later were they presented with the written informed consent form. An estimated sample size of 25 respondents was set, according to customary standard within qualitative methodology. In our study, sampling stopped when no new analytical insights were forthcoming and conceptual saturation was reached. This occurred at  $n=18$ .

### Data collection

A specially trained interviewer (research nurse) carried out all interviews using an interview guide containing eight issues, each with several sub-questions (Table A1, Appendix). The interviewer did not work at the clinical ward, nor had any other contact with the patients except for the purpose of the present study. It was explained in great detail what is meant by 'euthanasia' and 'physician-assisted suicide', in accordance with the following definitions: 'a doctor intentionally killing a person by the administration of drugs, at that person's voluntary and competent request' and 'a doctor intentionally helping a person to commit suicide by providing drugs for self-administration, at that person's voluntary and competent request' respectively.<sup>25</sup> However, to avoid negative feelings towards euthanasia/PAS, thus aiming at reducing bias, we omitted the morally contested words 'killing' and 'suicide'. In their place, we employed expressions like: 'Have you ever *wished* for a *physician to release you from lifelend your life* by lethal injection?' (see Appendix). The interviews were scheduled for a maximum of 45 minutes and were recorded and transcribed ahead of interpretation. The interviewer revisited the patients the day after the interview, and they were offered follow-up conversation with doctors, nurses, a chaplain or others if needed (it never occurred).

The Regional Committee for Medical Research Ethics approved the study. Prior to participation, all patients gave written informed consent.

### Interpretation

Interpretation and analysis were performed according to 'grounded theory' within qualitative methodology.<sup>26</sup>

Interpretation started by listening to the recorded material. Important information regarding the patients' mood and way of using their voice to express their utterances was noted, in order to be able to 'read between the lines'.

As a next step, interpretation at a micro level was undertaken. This implies interpreting phrase by phrase, sometimes including word-by-word interpretation. The aim is to obtain a comprehensive pool of concepts and meanings, and to make the researcher aware of the multiple interpretations that may exist for each phrase when carrying out the remaining analysis. This stage of the analysis was performed for each respondent until no new concepts or new analytical insights were forthcoming.

After all interviews had been interpreted and analysed, an inter-case analysis was carried out by comparing all interviews. The purpose of this approach is to grasp the predominant concepts in the material. These concepts are then categorized according to their cumulative frequency within and between the interviews.

Throughout the entire analysis, the aim is to label and conceptualize themes that derive from the data material. An important tool is to ask questions that stimulate discovery of properties, dimensions and consequences of the phenomena/concepts derived. By asking such questions, the goal is to increase the explanatory power of the final concepts. The last stage of the analysis is to compare and group together the central concepts, in search of patterns and possible relationships between the central concepts.

To reduce a potential interpretation bias, two investigators reviewed all transcripts, and the interpretations/analyses were discussed. Few divergences appeared.

## Results

### Attitudes

Respondents holding a positive attitude towards euthanasia/PAS differed according to how the attitudes were arrived at: those who had made up their mind prior to, and independently of, the illness; and those who became in favour of euthanasia/PAS after becoming ill, due to a severe symptom burden, and especially because of pain. Fear of future pain, and/or poor quality of life, were the most commonly cited arguments for holding a positive attitude towards euthanasia/PAS. What was held to be the individuals' right to choose when the suffering should end was an argument for euthanasia/PAS. Mostly religious and ethical arguments were given among respondents being against euthanasia/PAS, e.g., the wrongdoing of taking life.

### Wishes

A frequent finding was that patients uttered the possibility of wishing euthanasia/PAS. However, in so far as they had wishes for euthanasia/PAS, these were always oriented towards the future, as a hypothetical possibility.

No one expressed a wish for euthanasia/PAS at the time of the interview.

It is a little bit too early. My consciousness is not impaired yet, and I have no pain (No. 11).

Such thoughts and wishes fluctuated over time:

No, not today. But a few days ago I might have had another opinion (No. 6).

The way I feel right now, I want to live for a day or two. When you become more ill again, then... (No. 10).

These wishes thus appeared to be fluctuating and ambivalent in nature, as is further illustrated:

'There are big ups and downs. Some days, I just want to disappear. There have been several times that I have felt I wanted help to do that. But at other times, all this changes'. Interviewer (I): 'Have you ever thought about taking your own life?' Patient (P): 'Never'. I: 'You have never had any concrete wishes to get help from a doctor?' P: 'Yes, I have, but you know, when you arrive at the situation and face the reality, I don't think I would have done it anyway. You want to postpone' (No. 6).

Characteristics of the wish are summarized in Table 1.

### Factors reported to influence possible wishes for euthanasia/PAS to appear

Four major reasons were reported to be determining factors in so far as the appearance of wishes for euthanasia/PAS are concerned; fear of future pain; previous or present pain experiences; worries about future lack of quality of life; and worries about future lack of hope.

*Fear of pain.* A distinctive aspect of the data material was the patients' concern about pain.

... it is the pain that I am most afraid of, because I don't want to live with pain. My only hope is to have no pain (No. 11).

Worries and anxieties about the future were closely linked to pain. Previous experiences of pain seemed to cause fear of repetitive pain attacks in the future.

**Table 1** Factors influencing the wish for euthanasia/PAS to appear and main characteristics of the wish

Influencing factors for the wish to appear	Characteristics of the wish
Fear of future pain and a painful death	Future oriented
Previous or present pain experiences	Hypothetical/conditioned
Worries about lack of quality of life	Fluctuating
Worries about lack of hope	Ambivalent

The way I feel today, I am not considering requesting [euthanasia/PAS]. But if I get pain and become really ill, I could consider it (No. 3).

Mental images and ideas about possible future pain, derived from earlier experiences with friends, family, and from TV images, caused a similar fear.

*Pain experiences.* The informants reported that their will to live diminished when the pain became 'unbearable'. When pain occupied all their attention, life itself became pain. This was experienced as a life without meaning and worth, and a wish for euthanasia/PAS could appear.

However, as soon as the pain was alleviated, the wish for euthanasia/PAS disappeared.

[when the pain is alleviated] then I want to live a little bit longer. (No. 10).

Hence, the wish for euthanasia/PAS was not a constant, but appeared to fluctuate with the level of pain.

*Worries about lack of quality of life.* Also perceived quality of life was closely related to, and determined by, pain experiences.

[Quality of life is now] that the pain eases somewhat, that it is alleviated. There is nothing else left of value. Now, I think it is so nice just to feel no pain. Only then I think life is worth living (No. 6).

Receiving alleviating pain management while hospitalized at the palliative medicine unit was cited by many as an important contributor to their quality of life. Additionally, the feeling of safety as an inpatient at this medical unit, as well as the attention and concern from the personnel were of great importance.

*Worries about lack of hope.* Despite their terminal condition, most patients expressed hope for the future. Hope seems to have a major influence on the will to live and seems to prevent patients from wanting to die:

I choose to believe that I will attend [my daughter's confirmation]. I am clinging to this hope (No. 13).

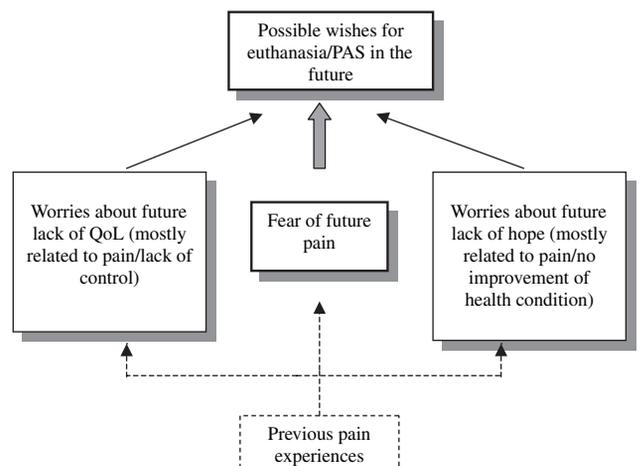
I hope to survive this [relapse] too, to get a few more years to live. You have to live in hope, right? (No. 18).

Hope was something that could be directed towards the next appointment with the doctor, towards the possibility of getting better, or the hope that one would enjoy an acceptable quality of life. To many patients, hope was equal to pain alleviation.

## Discussion

This was an exploratory, descriptive study of how terminally ill cancer patients relate to the issue of euthanasia/PAS generally (attitudes) and personally (wishes). An important finding is that *fear* of future pain, rather than actual, perceived pain, was the predominant motivation for a *possible* future wish for euthanasia/PAS. This lends support in previous findings/interpretations.<sup>4,7,21,22</sup> Pain was also of major importance for perceived meaning of, and quality of, life, as well as influenced hopes for the future (see Figure 1). An interesting and, to our knowledge, new documentation is the clear discrepancy between attitudes, wishes and requests, and what seems to be the characteristics and nature of wishing euthanasia/PAS, i.e., ambivalent, fluctuating and hypothetical.

This is a poorly explored area and qualitative designs are best suited for such purposes. Although our sample is relatively small, the aim of 'grounded theory' is to generate conceptual categories and explore possible relations or theories concerning the issue under investigation. Research on a group of patients with so-called 'short life expectancy' faces considerable challenges. For a doctor to determine the exact survival time is impossible. In our sample there is variability in time of survival after the interview. This might represent a limitation to the findings' validity. One might argue that people having few days to live have other opinions and desires than a person having some months to live. Furthermore, respondents may be reluctant to speak freely about an illegal act, and there is the potential taboo of discussing end-of-life issues. Another venture, which holds for all studies regarding attitudes, public opinion polls, and decision making, is the pitfall that the wording of questions posed can bias



**Figure 1** The interwoven and interacting structure of factors influencing wishes for euthanasia/PAS to appear.

the results. For these reasons, it is important to continue exploring the theme with different approaches to compare the findings.

Our findings emphasize the need for increased awareness of the use, and denotation, of the concept 'attitude' when designing studies and reporting result. The fact that a seriously ill patient is in favour of euthanasia/PAS does not, according to our results, signify that the person wants to request it, has personal wishes for it, or wants it legalized. Erroneous inferences are not uncommon, as illustrated in the following quote:

Surveys of attitudes of patients to euthanasia and PAS highlight the small proportion of patients who seriously consider such action [...].<sup>27</sup>

Attitude theory offers a theoretical framework for understanding our, and similar, findings. An attitude is commonly regarded as a rational evaluation of objects, and of other people's opinions of the same object.<sup>13</sup> As mentioned, erroneous inferences concerning attitudes are not uncommon. The predictive power of attitudes is limited according to several factors, such as emotions and whether one finds oneself able to accomplish the act in question.<sup>13</sup> There is obviously a wide spectre of conflicting and strong emotions among terminally ill patients: considering euthanasia/PAS may be associated with feelings such as fear of future pain, and a longing for a release from both physical and mental suffering. Love and commitments to loved ones, will to live, and hopes for the future are, on the other hand, emotions that run counter to such considerations. Such emotions may explain the fluctuating and ambivalent nature of wishing euthanasia/PAS in our sample.

When assessing attitudes, one is also interested in whether these are strong or weak, something that contributes significantly to the predictive power of attitudes. 'Attitude strength' is defined in terms of degree of resistance to change and stability over time.<sup>28</sup> When these elements are absent, the attitude is qualified as weak. Both attitudes and wishes in our sample appeared unstable – sometimes even during the interview – and can thus be considered weak. 'Attitude ambivalence' is defined as the effect of conflict between positive and negative evaluations of an object.<sup>29</sup> That is, individuals may hold both positive and negative attitudes towards the same object simultaneously. This ambivalence is found in our sample; at the same time as patients are considering euthanasia/PAS, they are postponing or rejecting the idea. Several psychological dimensions fluctuate as death approaches: fluctuations between hope/despair, certainty/uncertainty and will to live/wish to die.<sup>30,31</sup> The fact that a wish to die here and now was absent in our sample, despite previous, and possible future, considerations of euthanasia/PAS, thus substanti-

ates the apparent fluctuating and ambivalent nature of such wishes. Such ambivalence lends support in previous findings.<sup>5,23</sup>

A limited number of studies have used the term 'wish' but without defining or discussing the concept and its denotation.<sup>19,32–34</sup> Our findings reveal what seems to be characteristics of wishing euthanasia/PAS; fluctuation and ambivalence, hypothetical and future oriented. Given this ambivalent nature it is permissible to presume that this wish reflects other meanings than a genuine desire to die. Rather it might represent a need to control pain, feelings of hopelessness, and/or a way to cope with the fear of suffering unbearable pain. Viewed as a coping strategy, it is here hypothesized that such wishes may generate an experience of a private, inner freedom of choice of action, of having an option, i.e., the option of requesting euthanasia/PAS. Furthermore, it may represent a kind of emergency plan, a possible future 'solution' or way out. Such wishes may thus have a positive psychological impact in the sense that they create a feeling of control and consolation. The hypothesis that such wishes may actually represent a coping strategy should be further explored in future research.

An important learning process took place in these patients when they experienced that intense pain could be alleviated. Many patients knew little about modern pain treatment prior to hospitalisation at the Palliative Medicine Unit. Such lack of knowledge may have several, unfavourable effects. As noticed, the interviews revealed that hope very often amounts to the hope of reduced pain. When patients do not know what advanced pain management can do for them, the hope of getting satisfactory pain relief is correspondingly absent. Hopelessness is thus one possible consequence of poor information, and thoughts about euthanasia/PAS might occur.<sup>6,21,23,28,29</sup> Another consequence might be feelings of insecurity and lack of control. Fear of uncontrollable pain and a corresponding wish for euthanasia/PAS could thus partly be rooted in insufficient patient information. By increasing patients' knowledge of medical treatment, their sense of security and control may increase too. This could then have a direct effect on thoughts about euthanasia/PAS.

The individual's right to choose when and how to die is found to be an important reason for favouring euthanasia/PAS.<sup>7,20</sup> In our sample, this argument was given by those who had a positive, general attitude towards euthanasia/PAS. However, when asked to state reasons for having personal wishes for euthanasia/PAS, no one emphasized the right to self-determination. An adjacent explanation is that 'the right to choose' is a reason given for having a general attitude. When wishing euthanasia/PAS it is but a premise, rather than a motivation or reason.

## Clinical implications

As far as future clinical interventions are concerned, it is not only depression that needs to be identified and treated. Hopelessness, and the identification of what factors cause this feeling, should be addressed in order to reduce patients' interest in euthanasia/PAS.

In a broader sense, the results of the present study highlight the importance of proper communication between doctor and patient during end-of-life care and that the physician possesses the required skills to establish such communication. Given the many possible meanings of a wish for euthanasia/PAS, it is crucial that the doctor listens empathetically to the patient and tries to get hold of what she knows, believes, and feels, in order to identify what her statements are based upon – and what they signify. Premature conclusions about the meaning of patients' considerations of euthanasia/PAS can have grave consequences. The obvious and most dangerous scenario is the doctor who responds to patients' wishes for euthanasia/PAS as if they were actual requests. Alternatively, responding to such wishes as merely expressions of depression might lead to inadequate interventions (e.g., with antidepressants) and possibly further reinforce the patients' feelings of hopelessness. The patient may also see such a response in the doctor as a violation of his autonomy – or as a lack of respect for his decision-making capacities.

Because of the irrevocable nature of euthanasia/PAS, it is of great importance that health care workers are aware of the apparent ambivalent nature of wishes for euthanasia/PAS. A wish for euthanasia/PAS may be something completely different from a request for it.

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## Appendix

**Table A1** Themes and questions from the interview guide

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1. The patients' understanding of the concept 'help in dying', and the public debate concerning euthanasia and PAS.
    - 5 sub-questions
  2. Life at present/right now
    - 10 sub-questions
  3. Life as ill up until this point/this moment
    - 12 sub-questions
  4. Life before you fell ill – and at the time you became ill
    - 6 sub-questions
  5. Active help in dying in relation to health care personnel – and in relation to other patients
    - 11 sub-questions
  6. Active help in dying in relation to family/next-of-kin
    - 8 sub-questions
  7. Life henceforward/ahead
    - 4 sub-questions
  8. The patient's experience of being interviewed about active help in dying
    - 3 sub-questions
  9. Closure
-