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ORIGINAL ARTICLE

A good death from the perspective of palliative cancer patients

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Abstract
Purpose Although previous research has indicated some recurrent themes and similarities between what patients from different cultures regard as a good death, the concept is complex and there is lack of studies from the Nordic countries. The aim of this study was to explore the perception of a good death in dying cancer patients in Sweden.
Methods Interviews were conducted with 66 adult patients with cancer in the palliative phase who were recruited from home care and hospital care. Interviews were analysed using qualitative content analysis.
Results Participants viewed death as a process. A good death was associated with living with the prospect of imminent death, preparing for death and dying comfortably, e.g., dying quickly, with independence, with minimised suffering and with social relations intact. Some were comforted by their belief that death is predetermined. Others felt uneasy as they considered death an end to existence. Past experiences of the death of others influenced participants' views of a good death.
Conclusions Healthcare staff caring for palliative patients should consider asking them to describe what they consider a good death in order to identify goals for care. Exploring patients' personal experience of death and dying can help address their fears as death approaches.

Keywords Palliative care · Qualitative research · Good death · Attitude to death · End-of-life care · Quality of death

Background

Death fascinates us and most of us hope for a good death. Yet what is a good death? Previous studies of what constitutes a good death have shown that the concept is complex, and that a good death cannot easily be defined in general terms [1–16]. There may be major differences between the views of what patients and healthcare staff perceive as a good death [1, 2]. However, there are some recurrent themes in terms of what would be considered a good death from the perspective of patients suffering from terminal diseases. These include pain and symptom management [2–11]; preparation for death [1, 3–7, 9–12]; moment of death [1, 4, 5, 7, 8], such as sense of readiness, having experienced a meaningful life, state of one's choice and avoiding inappropriate prolongation of dying; feeling a sense of completion [1, 3, 4, 6, 7, 9, 11]; decisions about treatment preferences [1, 4–7, 9–11], such as having these preferences in writing and naming someone to make decisions in the event of own inability; the importance of family [1, 3, 5–11] and being treated as a "whole person" [4–7, 9–11].

Moreover, several studies have shown that, in comparing the attributes of a good death in different societies, there are many similarities between cultures which seem very far apart.

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People in Southern Ghana regard a "peaceful death" as a good death categorised in five aspects; a *social* aspect (where the patient is at peace with others, and vice versa), a *psychological* or *spiritual* aspect (where the patient is at peace with his/her own life and soul), a *time* aspect (dying in the fullness of time) and a *spatial* aspect (dying at home, surrounded by relatives) [17]. According to the author, these aspects would also contribute to a good death in his own culture (the Netherlands).

Although there are some recurrent themes and similarities between what patients from different cultures regard as a good death, authors have pointed out the importance for healthcare providers of an individualised approach for each patient, rather than focusing on preferences based on radical or ethnic stereotypes [18].

There are no previous studies of what terminally ill cancer patients in Sweden consider a good death. Therefore, the aim of this study was to explore the perception of a good death in dying cancer patients in Sweden.

Material and methods

The study was initiated in 1997 through interviews with patients suffering from cancer in the palliative phase. Questions were asked about life and death, communication, support, cancer care and euthanasia. The project was restarted in 2007 with additional interviews applying the same interview focus. Results from the project have been published on the topic of euthanasia [19, 20]. In 2014, a secondary analysis of the 66 interviews was conducted with focus on the topic of a good death.

Participants and interviews

Participants were recruited by staff in five different units in two county councils, and participants were selected through maximum variation sampling [19, 20]. In total, 66 participants were interviewed (*n* 54 in 1997–1998; *n* 12 in 2007). Two senior physicians performed the interviews (in 1997–1998 a specialist in oncology; in 2007 a specialist in geriatrics and palliative medicine (the third author). None of the interviewers was involved in the informants' medical care.

The study was approved by the regional board of ethics. The interviews consisted of open questions on the topics mentioned above, and clarifying questions were asked [21] to make sure there were no obscurities regarding the statements of the participants. Each interview was digitally recorded and then transcribed.

Analysis

The interviews were analysed using inductive qualitative content analyses, and no predetermined categories or themes were used [22–24]. Coding and development of the preliminary categories were mainly done by the first and third author. These tentative categories were discussed by the two researchers and revised. The categories were then validated by the second authors as part of the reflexivity process by supplementing and contesting each other's readings and preunderstandings [24, 25]. The researchers also made a qualitative comparison between the interviews made in 1997–1998 and 2007 respectively, using the categories that had emerged in the qualitative content analysis.

Results

An overview of the characteristics of the 66 participants is presented in Table 1.

The qualitative analysis showed that in this study, the participants mainly viewed death *as a process* rather than an event. The interviews included many different descriptions of what constitutes a good death in dying cancer patients, and the analysis generated four main categories describing a good death: *living with the prospect of imminent death, preparing for death, dying comfortably* and *on being dead* (Fig. 1). *Past experiences* of the death of others influenced participants' views of a good death. When results from the two data collection periods were qualitatively compared, no change in content was found over time regarding what constitutes a good death.

Living with the prospect of imminent death

In the face of death, the participants' view of life was affected. Many of them expressed a change of perspective on life since they had been diagnosed with a terminal disease, such as an increased focus on love and affection for family and friends, attaching greater importance to letting go of grudges and not blaming others for their disease and impending death, an increased sense of living for the moment, liberation from fears and sometimes also greater happiness.

> "*Maybe, it's become even more important to live after I became ill, if you look at it that way. I think you, what shall I say, every morning when you wake up, you wake up in a much better way than before, if you understand the spirit of what I'm saying […] Yes, maybe you live for the moment in a better way now than … Many people never live for the moment. They always go on planning ahead what they will do next week or in two weeks, but you must not forget about now. That's where you should be.*" (Man, 61 years old, kidney cancer)

Participants expressed the importance of leading a meaningful life as death approached. Several participants described the importance of having projects which gave them a sense of meaning and normality, despite the fact that they knew they

Table 1 Demographics and characteristics of study sample. Participants total $n = 66$ (in 1997–1998 $n = 54$ and in 2007 $n = 12$)

Age mean (range)		64.7 years (30–90)
Gender men/women (*n*)		44% (29)/56% (37)
Cohabitant/living alone (*n*)		52% (34)/48% (32)
Having children yes/no (*n*)		83% (55)/17% (11)
Having religious faith (*n*)		21% (14)
Diagnosis: malignancy (*n*)	Digestive organs	30% (20)
	Female genital organs	17% (11)
	Lymphoid or haematopoietic system	14% (9)
	Respiratory tract	12% (8)
	Breast	12% (8)
	Urinary tract	5% (3)
	Various (skin, central nervous system, male genital organs, unspecified)	10% (7)
Time from cancer diagnosis to interview	<3 months	9% (6)
	4–12 months	33% (22)
	>1 year	58% (38)
Time from interview to death	<1 month	12% (8)
	1–3 months	30% (20)
	4–12 months	27% (18)
	>1 year	30% (20)
Type of care when interviewed	Oncological outpatient clinic	35% (23)
	Palliative care ward (hospice)	35% (23)
	Palliative home care	30% (20)
Ongoing palliative oncological treatment		12% (8)

were seriously ill and were about to die. If life no longer had meaning, several participants indicated that they would prefer their disease to progress quickly, and that they were afraid of being kept alive after they could no longer enjoy their lives.

"*I reckon a short and exciting and interesting life is much, much more precious than a long, meaningless life. That's my opinion.*" (Man, 76 years old, lung cancer)

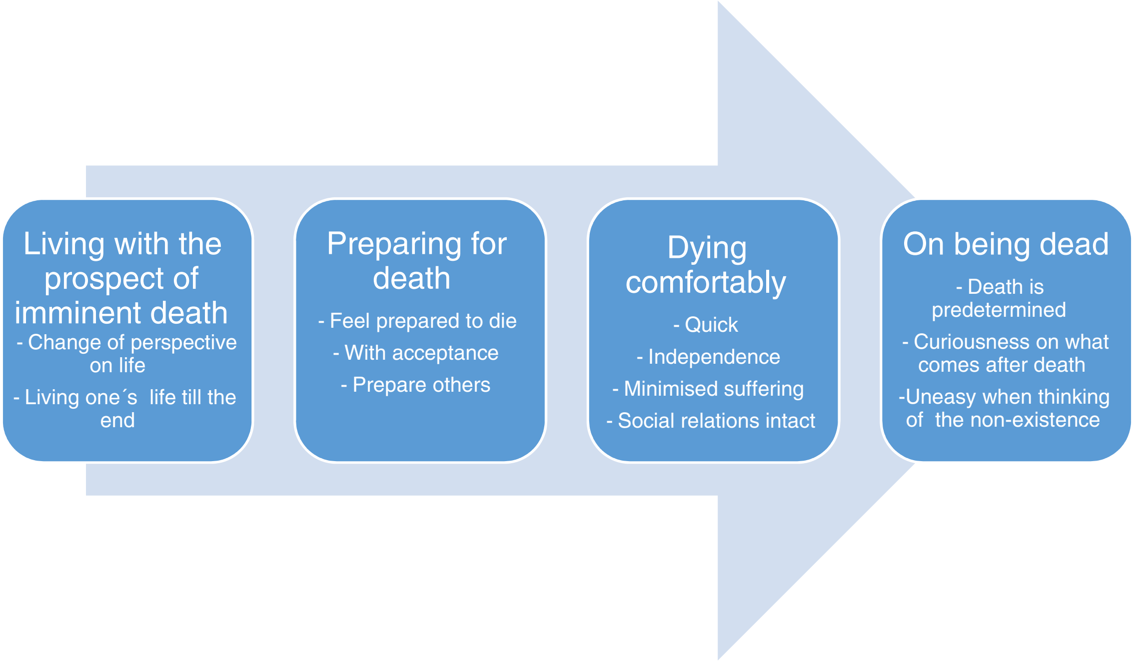

Fig. 1 Main categories describing a good death

Preparing for death

Many participants expressed the importance of preparing for death, which could include saying good-bye to their loved ones, completing unfinished business, such as making funeral arrangements, sorting out financial affairs and writing down specific requests, preparing others for their death and gradually accepting their own death. Knowing about their impending death could provide time to plan for dying and for putting things in order, to minimise the burden on loved ones after they pass away.

> "*…Then I have made some preparations. I have made a will and left descriptions of how I want it to be, and economic matters, which magazine subscriptions have to be cancelled, and electricity and phone and all those things.*" (Man, 77 years old, lymphoma)

Although preparing for death was expressed as something important by many of the participants, some who had not accepted it, and for whom thinking of their impending death was associated with great discomfort such as leaving their children behind, described difficulties in preparing for death.

> [On talking to someone about the impending death] "*No, because I am not sure about how I would like to die. I put it off until later. I actually don't want to die …*" (Man, 59 years old, carcinoid of the gastrointestinal tract)

Dying comfortably

Participants expressed how their death could be a good one in terms of dying comfortably. The descriptions included the moment and place of death, the presence of others and decisions about treatment.

Quick

Several participants mentioned their fear that their death would be prolonged. Instead, they were hoping it would happen quickly. A prolonged death was associated with suffering, not only for the patient, but also for the loved ones. Several participants explicitly expressed their wish not to prolong life, but to allow death to take its natural course.

> [On dying] "*Yes, if I could choose, it's clear. Yes, I would walk out into the forest to do something, maybe to search for a Christmas tree, or to have a look to see where the rabbit was sitting. [There he dies.] And they would have to come and search for me out there, and carry me home […]. It couldn't be much better. And that, I know … I have got so many examples of people who literally suffered to death in bed or in a wheelchair. Compared to just falling down and dying. There's no question what I'd choose …*" (Man 81 years old, rectal cancer)

Independence

The physical, psychological and social aspects of independence were valued by many participants. Many expressed their fear of "being a package", thereby totally losing control and autonomy, and becoming dependent on others. Some participants could not even think of dying anywhere except in their homes. Others wanted to go into hospital at the very end, mainly to spare the family suffering, and for fear of being a burden on them during the process of dying:

> "*And so we'll see. It's absolutely impossible to say. I don't know if I can stay at home to die. Of course I want it to be that way. But I don't want my children to take time off work to be at home. I mean, they've got their hands full …*" (Woman, 81 years old, cancer of the gall bladder)

Autonomy was often mentioned as an important attribute of a good death. This included patients' involvement in decisions at the end of life. Some participants had written living wills to make sure that the very end would be as good as possible. Many participants were comfortable with and trusted their care providers, while others' experiences of "bad deaths" implied that they were worried about their own death.

> "*I wouldn't call it a living-will. I just call it* "*my will*". *I have written down that I don't want any help or prolonged time when life is coming to an end. Not in any way. Just the opposite.*" (Man, 64 years old, cancer of the kidney)

Minimised suffering

Several participants associated a good death and dying comfortably with freedom from pain and other types of discomfort, such as anxiety. Many participants expressed confidence in the healthcare system and trusted that they would receive treatment to avoid suffering during the process of dying. In the case of other participants, past experience of the death of a friend or family member with inadequately controlled symptoms influenced their views of a good death. Others mentioned a fear of suffering, a term which implied different aspects of discomfort for the patients themselves, but also in terms of their surroundings. For a few, the meaning of suffering involved the fact that dying meant leaving their children.

> "*Yes, a good death for me is, maybe firstly avoiding pain, because when you're in pain, severe pain, which I understand is reality for many of us, then you probably can't experience internal peace or calm either, I suppose …*" (Woman, 80 years old, cancer of the urinary tract)

Social relations intact

Many participants noted that an important criterion of a good death involved the presence of their loved ones, such as family members. For some participants, the presence or proximity of family was considered important throughout the process of dying.

> [On a good death] "*Yes, to die at home, that is. Having your loved ones nearby. And everyone knows you're about to die, and is prepared for that …*" (Woman, 75 years old, breast cancer)

On being dead

Some participants were comforted by their belief that death is predetermined, and that after death there is something else. Some were curious to know what would happen, even though they were not religious, while others felt uncomfortable when they thought about their existence coming to an end after death.

> [Reflecting on death] "*… I feel like, for the sake of my children, clarifying that I am not afraid, and after death there is something else, and life goes on for them and for me. And we will meet again one day …*" (Woman, 75 years old, breast cancer)
> [Reflecting on death] "*… You don't want to be separated from your children … And I … like the moment of death. It might come later, but the moment of death doesn't scare me, I think. But that sense of not existing […] Not taking part. Not knowing what is happening to your children …*" (Woman, 43 years old, breast cancer)

Discussion

The results of this study bear some similarities to previous studies on the topic of a good death, for example by illuminating the importance of preparing for death, freedom from suffering and maintained autonomy through the dying trajectory [1–16]. The concept of a good death is highly individual and heterogenic, and the results once again show the complexity and great diversity involved.

One question in terms of discussing a good death involves whether dying is considered an event or a process. Some authors view death as an event, while others take the approach that it is a process [7, 16]. In this study, participants mainly took the view that death is a process, as they were discussing issues such as decision making at the end of life and preparation for dying. Several of the categories of a good death in this study involve patients' activities. These include *preparing for death*, such as saying good-bye to loved ones and completing unfinished business, and *independence*, as well as patients' *involvement in decisions* at the end of their life. These results support being open with patients, letting them know that death is approaching and thereby giving them the opportunity to be active during the process of dying, which may facilitate a good death.

Participants in this study valued autonomy and independence. Walter [26] suggests that postmodern society has adopted ideals of individualisation, autonomy and independence, and defines the postmodern death as one where it is important to individualise and to control dying according to the personal preferences of the dying individual [26, 27]. Even though "the self" is central in todays' society, during life as well as during the process of dying, healthcare staff often find it difficult to communicate with patients and their family members about impending death [28–30]. These difficulties could derive partly from a fear of aggravating symptoms such as anxiety and losing hope at the very end. However, Lundqvist et al. [31] showed that giving palliative cancer patients information about death as the end approached did not increase the anxiety or symptom burden, but was associated instead with improved care and conditions for a good death.

In this study, it was apparent that the patients' past personal experiences of the death of a friend or family member, where symptoms had been inadequately controlled or the process of dying had been prolonged, often contributed to shaping their fears as their own death approached, and influencing how they would like it to be. Some fears and concerns were based on irregularities from earlier treatment regimes, which no longer exist. Previous studies have shown that fear of future pain and suffering, as well as current experience, is a common argument for positive attitudes towards euthanasia [20, 32]. Therefore, in clinical practice, exploring patients' personal experiences of death and dying can help address realistic and unrealistic fears, e.g., by asking the patient "Have you ever experienced the illness and death of a family member or friend?" In a secular country like Sweden, the issue of what happens after death may also be important, not only to patients with a religious faith, but also to atheists. Concerns about the fact that they may not exist after death may contribute to anxiety, for example.

This study involved 66 participants, with great variation regarding types of cancer, age, education and proximity to death. A non-probability strategic sampling method was applied, with an underlying theoretical aim of achieving maximum variation. Therefore, the generalizability is limited [33].

The data were collected on two different occasions, which gave the researchers an opportunity to study whether the aspects had changed over time. When results from the two data collection periods were qualitatively compared, all four categories of what constitutes a good death were identified in the interviews performed in the two data collection periods respectively. Thus, no differences were found over time regarding the concept of a good death. The fact that three different researchers (of whom one researcher made the interviews on the second data collection occasion) were involved, providing an opportunity to validate the findings, could also be seen as analyst triangulation [34], therefore strengthening the results.

Clinical implications

The results of this study have implications for staff caring for patients suffering from terminal disease. To comply with the WHO definition of palliative care [35], healthcare needs to adopt a more individualised view on dying patients. Medical staff may require more training and practice in communicating with dying people about how they wish to live their last days. Clinicians involved with dying patients should consider their own preferences and views of a good death, and recognise that these values may not be shared by the patient they are caring for. Physicians, and all staff caring for palliative patients, should consider asking their patients to identify specific concerns about their impending death, and describe what they consider to be a good death. As given terms have different meanings for each person, patients should be asked to describe what a good death means to them personally. Different individuals' criteria for a good death are heterogenic and may also change over time. This requires good communication and sensitivity. Discovering what matters to each individual in the different stages of his or her disease is fundamental to ensuring a good death. Good communication with patients and their families, as well as between healthcare staff, is necessary for establishing the conditions for patients to experience a good death.

Compliance with ethical standards

Disclosure None.

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