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A Qualitative Study of Dying Patients in a Danish Hospice

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Abstract

Research suggests that addressing dying patients' existential concerns can improve their quality of life. We aimed to illuminate dying patients' existential concerns about the impending death through a descriptive analysis of semistructured interviews with 17 patients in Danish hospices. The main findings demonstrated how the patients faced the imminent death without being anxious of death but sorrowful about leaving life. Some patients expressed that they avoided thinking about death. They wished to focus on positive aspects in their daily life. We argue that the patients' existential concerns could not be fully captured by Yalom's existential psychology or by Kübler-Ross's theory about death stages. Patients' complex concerns could be more fully explained taking an outset in Heidegger's phenomenological thinking.

Keywords

patient perspectives, life-threatening diseases, support, afterlife, daily living, end of life

Introduction

Several studies have revealed that life-threatening disease leads to an intensification of existential concerns. These concerns are intensified as the likelihood of death increases.¹⁻³ Different studies emphasize that existential concerns of palliative patients are not being dealt with adequately in the health care system.^{2,4-10} Research suggests that support focusing on existential concerns may help patients with cancer and their relatives to cope with death and thereby improve quality of life in the palliative phase.^{1,11-14} Furthermore, lack of knowledge about patients' existential concerns can contribute to uncertainty about how to best support the patients.^{13,15} In Denmark, national surveys have investigated the quality of palliative care most often using a quantitative approach.¹⁶ Using a qualitative approach would gain insight into context, culture, and palliative practices as experienced by the patients.¹⁶ Furthermore, Denmark is known for its secularism.¹⁷ As opposed to many other cultures, Danes believe in a very subjective and individual way and do not share a common cultural understanding about death and afterlife.^{18,19} Therefore, it might be difficult to transfer research results on existential concerns about death conducted in more religious societies.^{20,21}

The term existential concern is very broad. Existential concerns are discussed in a stricter philosophical sense within the philosophical movement of existentialism by philosophers such as Kierkegaard,²² Heidegger,²³ and Sartre.²⁴ Existentialism deals with questions of life, its origin, and its conditions, given that all humans share some common basic existential conditions unaffiliated with the individual's own existential

explanatory model.²⁵ Although many attempts have been made to define existential conditions, there is no single commonly accepted definition. The American existential psychiatrist Irvin Yalom offers 1 way of categorizing existential domains.²⁶ He identifies 4 recurrent basic conditions that always challenge human existence: (1) that we all must die, (2) that we all are alone in critical moments, (3) that we have the freedom to choose our lives, and (4) that we are struggling to make sense of the world. This article will focus on the first domain "That we all must die" to explore palliative patients' existential concerns about death when the patient is in the last stage of the palliative period where active treatment has been stopped and the patient is dying.

Different theoretical models on death and dying involving patients' emotions and ways of coping have been proposed during the last decades.²⁷⁻³¹ Apart from the American psychiatrist Elisabeth Kübler-Ross's work, earlier studies are primarily based on the perspective of health care professionals.³¹ In the 1960s, Elisabeth Kübler-Ross²⁷ attempted to provide the terminally ill with a voice. Using information from more than 200 clinical interviews with American terminal patients, Kübler-

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Ross revealed a trend in emotions over time which enabled her to formulate a model of coping with death including 5 interdependent emotional stages: denial, anger, bargaining, depression, and acceptance. This model has become a widely accepted way to study death and dying and is often referred to as the “Five Stages of Grief.”^{25,32} However, questions have been raised about the adequacy and validity of this model due to the absence of any description of study sample or definitions used.^{25,30,31} One of the most important points of criticism concerns that the 5-stage theory is a mechanistic approach with the dying person moving through the universal stages.³¹

Different quantitative studies have been conducted regarding dying patients and death anxiety.³³⁻³⁶ These studies indicate that death anxiety is common among patients with terminal cancer but not universal as anxiety depends on other factors than illness severity. These studies do not point out the complexity of the patients’ thoughts and feelings about death or how they manage their concerns about death. Some qualitative studies^{32,37,38} focusing on the concerns of dying patients have been conducted. In 2012, Renz et al³² performed a study using participant observations to explore mode of perception of dying patients and deeper reasons for anxiety and existential suffering. The study revealed that few (14%) patients had a fear of death but many (35%/50%) expressed fears of pain and powerlessness. Furthermore, this study demonstrated that for many dying patients accepting illness or dying was crucial in the transition to death.

Accordingly, neither theories about death nor previous research seems to give sufficient answers to what dying patients think about and how they manage their imminent death. If the existential care should be optimized, further research aiming at investigating the complexity of the dying patients’ concerns is crucial.

This study presents findings from a larger qualitative study conducted at Danish hospices about existential concerns among patients with terminal cancer and their relatives. The aim was to illuminate the complexity of the patients’ existential concerns about death through a descriptive analysis of interviews with patients.

Methods

The study was conducted in 2011 (by the first author). The study material included 38 days (approximately 7 hours a day) of participant observations in 3 Danish hospices and semistructured interviews with 17 patients and 9 relatives. The empirical data presented in this article are primarily based on the interviews with patients. Participant observations were important for gaining knowledge of the participants and the context.

Participants

Participants were selected in close cooperation with the hospice staff. The participants were 11 women and 6 men between 40 and 85 years of age (mean age was 62 years). The patients all had a cancer diagnosis except 2. Participants represented

Table 1. Participant Distribution of Gender and Diagnosis.

Informant	Gender	Diagnosis
1	M	Cancer of the intestines
2	F	Diverse metastases to the bones
3	M	Lung cancer
4	F	Cancer of the intestines
5	M	Cancer in the pancreas
6	F	Cancer of the intestines
7	F	Breast cancer
8	F	Noncancer
9	F	Breast cancer
10	F	Cervical cancer
11	M	Cancer in tongue and throat
12	F	Cervical cancer
13	F	Cancer in liver
14	F	Ventricular cancer
15	F	Breast cancer
16	M	Lung cancer
17	M	Noncancer

Abbreviations: M, male; F, female.

variation in gender, age, social status, religious, faith, and diagnosis (Table 1). Participants’ survival ranged from a few days to a few months from time of inclusion into the study.

Setting and Context

The 3 participating Danish hospices were different according to architecture, size, and geographical location. The first hospice opened in 2007 in a new building with room for 15 patients and it is beautifully situated outside a provincial town. The modern architecture focuses on space and light and has a view of the sea. The second hospice is centrally located in a provincial town in an older building, formerly used as a hospital. This hospice opened in 1994 and has room for 12 patients. The hospice has old furniture and a cozy atmosphere. The third hospice is a part of a deaconess foundation. It opened in 1992 and is situated in the outskirts of Copenhagen with room for 24 patients. This hospice is simple with small rooms and shared bathrooms. The variation in hospice settings entailed that the participants had dissimilar experiences leading to variations in the empirical data.³⁹

In all hospices, there was a tradition of lighting candles for the patient who died with a nameplate added. The candles were placed in the corridors, which meant that patients, relatives, and staff would always be aware of the patient who died. Only occasionally no candles were lit; usually there was 1 and sometimes 2 or 3 candles lit. For the participant observer, these candles were the first to notice when arriving to the hospice. The confrontation with the presence of death became even more inevitable when the undertaker arrived to take away the deceased patient placed in a coffin in the deceased patient’s room. Coffins were rolled back and forth in the hospice hallways, sometimes accompanied by mourning relatives. Patients in the hallways or living rooms would typically be confronted with death in the meeting with these coffins.

Table 2. Examples of Interview Questions and Partial Answers Regarding Death.

Why did you choose to stay at a hospice?	Well, I did because—that—here they are experts in helping people who are going to die. (P1)
What do you think of when you are laying here in bed?	I'm not thinking about anything much at all—just that when I am about to die, then it should be without too much pain, and the last time should be in a way that we can stand it—us—those who are closest to me—and it shall be with dignity. (P1)
What do you think about death? Are you afraid of dying?	Of course I'm sad about leaving this—I don't think I am ready yet—eh—but you have to deal with it—I won't say that I'm depressed exactly, but of course a kind of sadness comes to me . . . But then—I do not believe in heaven and life and uh, of course—oh—am I—oh—both curious and a little—fearful of death, but I do not believe that—that it leads to something that hurts—I think oh actually, it is—it's a relief in a good way. (P12)
What do you think will happen after death?	I have such a eh private composite faith model . . . a kind of culture Christian, a little Buddhism, kind of an idea that souls don't die . . . you have a bit of a life-cycle . . . Yes, where people start as a childlike soul and are going to be a more mature soul and eh getting wiser and wiser and mature until you get to that stage where you are going to be a little gaga and then go back to childhood again . . . it is such a cycle for a soul that gives me meaning to think about. (P15)
Is it important for you to create a kind of memory? If yes, how do you do that?	What I think most of is that I want to write some letters to my children—I have—I have a need to tell them some things, but I'm doing whatever I can to tell them verbally, but I think that it might be nice for them to also have it in writing (P17)

Interviews

The interview guide was inspired by 2 earlier studies: A pilot study⁴⁰ conducted in 2009 and a matrix model about existential meaning making.²¹ Furthermore, an exhaustive literature review about existential concerns and Yalom's 4 existential basic conditions²⁶ were used to construct an interview guide with primarily open-ended questions⁴¹ (Table 2).

The interviews took place in the patient's room at the hospice. The patient and the interviewer were alone during the interview except once (interview where the wife was sleeping in a bed beside). The interviews lasted from 15 to 64 minutes depending on the patients' condition; the average length of the interview was 40 minutes. All interviews except 1 were digitally recorded and transcribed verbatim by the first author.

In addition, participant observations including conversation with patients, relatives, and hospice staff were used to give insight into the setting, context, and atmosphere influencing the patients' daily lives. Participant observations took place in different areas of the hospices such as the patient rooms, dining room, music therapy room, and etc. and at all hours of the day except late at night. During the stay, the observations were documented in a notebook, typed up every evening, and supplemented with the observer's reflections.

Analysis

Four stages were used in the analysis, and a qualitative description approach was used in the first 3 stages of analysis.^{39,42} As proposed by Milne et al,^{42,43} following this analytical process we enhanced rigor by focusing on the following strategies: (1) authenticity, the analysis was close to the data and the participants' point of view, (2) credibility, capturing, and portraying a true insider perspective, (3) criticality, reflection on the critical appraisal applied to every research decision, and (4) integrity, reflecting on researcher bias conducted as an

ongoing reflection and self-reflection of the researcher's dual role as a researcher and an interviewer both in the generation of data and in the process of analyzing data.

First, all transcripts were read several times to get an overall impression of the data material before the initial coding.⁴⁴ Second, all meaningful text units according to concerns about the imminent death were identified and coded. Third, these text units were grouped into themes. Seven themes emerged directly from the empirical data in an attempt to make a straight descriptive summary of the data content.³⁹ At the fourth stage of analysis, a theoretical frame⁴⁵ with inspiration from the American psychologist Jerome Bruner's ideas about how a story constructs 2 landscapes⁴⁵ was chosen and applied to structure the themes into relevant categories. Consensus on themes and main categories was reached between the 2 authors through thorough discussions of the initial coding.

Ethics

The participants received written and oral information about the project and were given time to consider participation before verbal consent was obtained. Participants were assured that any information would be treated confidentially and reported anonymously. Written information about the research project and the first author's presence as a field observer at the hospice was placed on a notice board where everyone could read it.

The research project complied with Danish legislation on ethics and qualitative research and was registered at The Danish Data Protection Agency (J.no. 2010-41-5647).

Exploring this highly sensitive and complex research area entailed substantial ethical responsibility during the data collection. It was crucial for the first author to constantly taking individual considerations according to both the participants' physical abilities and their psychological vulnerability. This was done in close cooperation with the hospice nurses and included their assessment according to the participants'

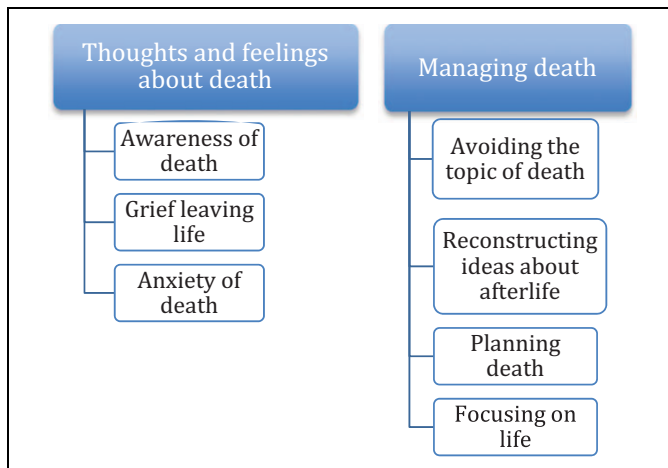


Figure 1. The 2 categories with a total of 7 themes.

physical and psychological conditions the day the first author was introduced to the participant and again at the day the interview was conducted. The first author constantly used her experience as a nurse to observe whether the participant showed any sign of fatigue or was too emotionally affected. If a participant seemed tired, the first author offered to stop the interview. If the participant was crying or seemed to be otherwise affected, the first author asked if he/she wanted to change the subject or stop the interview. Moreover, participants were encouraged to talk with the chaplain or a nurse after the interviews.

Results

The analysis of interviews resulted in 7 themes and 2 overall categories: “Thoughts and feelings about death” and “Managing death” (Figure 1). Inspired by Bruner,⁴⁵ the themes emerging from the interviews were analyzed as stories that constructed 2 landscapes—one of consciousness and one of action. The themes demonstrated how the stories mediated between an inner world of thoughts and feelings and a world of actions. The actions originated from the participants’ actual situation as dying and were understood as the way the participants managed their thoughts and feelings about death. It is, however, important to emphasize that this distinction was a construction made by the authors.

Thoughts and Feelings About Death

The analysis revealed 3 main themes of thoughts and feelings related to the imminent death: (1) awareness of death, (2) grief leaving life, and (3) anxiety of death.

Awareness of death. Both observations and interviews showed how death was always present at the hospice. All participants were aware that the hospice typically was the place where life ends. Staying at a hospice was in that way associated with death.

P10: I’ve seen some coffins being driven out of here . . . and that’s the way I’m going—I’ve actually got used to it . . . yes—I’m fully aware of what is going to happen.

Furthermore, some patients articulated that they appreciated that death was forthcoming as a consequence of their disease.

P 17: Things are as they are—what happens, happens . . . Yes, that’s it . . . Yes somehow there’s not so much to do, because there are—the disease is what it is . . . and then of course it’s also a joy and a peace today, to learn and to say: well, I’m sick and I must die—and eh I have experienced many good things.

Almost all participants had in that way realized that they were going to die shortly. Although the patients were facing death, several expressed that they hoped for more time before death would occur.

Only 1 participant expressed that she expected to be cured. She had a terminal diagnosis, but, was, contrary to the other participants, still getting life-prolonging treatment and she was staying at the hospice to recover after this treatment.

Grief leaving life. Several participants expressed their sadness about leaving life and that they were not ready to die.

I: When did you realize that there was nothing more to do?

P7: “14 days ago—but I knew it . . . because I assessed it myself . . . It doesn’t come as a surprise, but I’m sorry about it . . . I’m really sad—really sad.”

P12: “Of course I’m sad about leaving this—I don’t think I am ready yet—eh—but you have to deal with it—I won’t say that I’m depressed exactly, but of course a kind of sadness comes to me—and it can come suddenly—it can come when you have a visit and you are talking about something, that’s important to you.”

For some women, grief was linked to concerns about leaving their children or grandchildren. These women told how they were thinking more at the children’s situation than their own and that they worried a lot about how the children would be able to handle the future without their mother or grandmother.

P9: I had to look after them (her grandchildren) (crying) . . . So the thought that they’re going to lose me . . . I’ve had a good life, so it’s more them, I think of—that they have to do without me.

The interviews demonstrated that the participants grieved over and ruminated about what and whom they left when they were gone. They were facing death but they were very sorrowful about dying.

Anxiety of death. Anxiety turned out to be a complex term and the participants’ stories showed how this term had to be divided into 2 understandings: anxiety of death as a final state and fear of the death process. During the interviews, most of the participants were asked whether they were anxious about dying,

which the majority denied with a short answer “no.” Most often the participants expressed it like this:

I: Do you fear dying?

P17: No—no I’ve no thoughts about that—not about the moment of death.

Others did not express whether they were anxious about death. Only 1 participant expressed a kind of fearfulness of death as the end of life:

P12: I do not believe in heaven and life and uh, of course—oh—am I—oh—both curious and a little—fearful of death, but I do not believe that—that it leads to something that hurts—I think oh actually, it is—it’s a relief in a good way.

A few of the participants expressed concerns of death related to symptoms according to the process of death. This concern was related to both physical symptoms such as pain and to a fear of psychical changes in their last time.

P1: When I’m about to die, then it should be without too much pain, and then the last time should be in a way that we can bear. It has to be in a way where I don’t lie down like a vegetable that can’t be contacted and have no views about anything.

Hence, the analysis demonstrated that anxiousness about the forthcoming death as a final state of life did not seem to be present for most of the participants or at least it was not something they would talk about in the interview. The fear concerning death according to the way they were going to die was expressed by a few as something they were wondering about. Table 3 provides a brief overview of participants’ answers related to the theme anxiety of death.

Managing Death

Four main themes emerged addressing managing death: (1) avoiding the topic of death, (2) reconstructing ideas about afterlife, (3) planning death, and (4) focusing on life.

Avoiding the topic of death. During the interviews, the participants were asked what they thought about their situation. Several told that they did not wonder much at all and especially not about death. For some participants, it was a very conscious strategy to avoid thinking about death:

I: What do you think of?

P8: At any rate I don’t think about dying...it’s pushed away...yes, it is placed—it’s clarified...it’s how it is, and when it comes, then, that’s the way it is.

P9: The doctor said yesterday that I had to take one day at a time—because tomorrow I can be gone—he did not say that exactly, but that’s what he meant—so you have just to take one day at a time and I have done so...I won’t worry about it. I don’t want to worry about what may happen tomorrow and what can happen in the next

three days—I simply will not spend my time on that—it may happen that it comes to mind.”

Others expressed how they preferred not to talk about death. For instance, 1 participant (P10) refused to talk with the interviewer about death. In the field observations, it was found that she also had refused to talk about death with the health care professionals. Another participant told that her imminent death was a private matter, which she wouldn’t talk with too many about. One participant told how she was upset about the way the health care professionals focused on talking about dying:

P13: And it had also been written in my record that I haven’t realized it—but it’s bullshit—it’s just because I’m not crying...I just don’t want to go that way—and I just want to live normally—I do know that I can die from it—I know with cancer—I know it all, but why should we talk about IT all time...I’m saying that I can defeat it...no—I’ve damn realized it—I just don’t want to plod around in it.

In this way, the interviews showed how most of the participants more or less intentionally attempted not to think about or talk about their imminent death. Some did not have the energy to think about death, others wished to focus on other aspects of their life, and avoiding the topic of death was an intended strategy for many.

Reconstructing ideas about afterlife. When asked about thoughts concerning death, the participants expressed how they were managing the imminent death by reconstructing or trying to reconstruct ideas about what happened after death. These ideas were reconstructed on the basis of the participants’ faith and their previous ideological and cultural meaning making. The reconstruction of ideas about afterlife was hence understood as a way of managing the current situation where the participants realized death. The ideas about afterlife were very individual, but most imagined something transcendent and anticipated that something good would happen:

P12: I don’t think that it (death)...that it brings something that hurts...I think eh actual I think it is...it is a kind of liberation in a good way...now I am scientifically trained eh...so for me it has always been a thought about energy, you know...well you arise from some great energy and then you return to that energy again...if some soul is going to be involved somewhere...it...it is difficult to say...you don’t know.

P15: “I have such a eh private composite faith model...a kind of traditional culture Christian, a little Buddhism, kind of an idea that souls don’t die...you have a bit of a life-cycle...Yes, where people start as a childlike soul and are going to be a more mature soul and eh getting wiser and wiser and mature until you get to that stage where you are going to be a little gaga and then go back to childhood again...it is such a cycle for a soul that makes sense to me.”

A single participant believed in and hoped for Heaven in a traditional Christian way:

Table 3. The Participants' Faith, Ideas about Afterlife, and Anxiety of Death.

Participant	Faith	Believing in afterlife	Anxiety of death
1	Unsure about her faith	In doubt	Fear the way of dying
2	Christian	Something good	Unknown
3	Atheist	Nothing	No
4	Christian	Something good	No
5	Christian	Something good	No
6	Unsure—angry with God	In doubt	Not expressed
7	Christian—angry with God	In doubt	Fear the way of dying
8	Unsure about faith	Something	No
9	Unsure—angry with God	Won't think about it	No
10	Unsure about her faith	Something good	Fear the way of dying
11	Christian	?	Not expressed
12	Christian	Private imagination about humans being energy	A little fearful
13	Atheist	Won't think about it	Not expressed
14	Unsure about her faith	Something	Not expressed
15	Private mixed faith model	Souls have a life cycle	Not expressed
16	Unsure about his faith	Something	No
17	Christian	Heaven	No

P17: My partner always says that we are going to meet in Heaven, so that I hope of course . . . and when God has created such a fine world and a fine day that we live in, why shouldn't he create something after . . . so that is actually what I choose to believe in.

Other participants expressed that they were very unsure or skeptical according to their ideas about afterlife. Some expressed a wish to believe that there would be "something":

P7: Well, that (thoughts about afterlife) is something my mind is full of at the moment, and it is probably why I am so sad, because I . . . I do not . . . after all I think that there will be nothing after—and other times I think, I hope that there will be something . . . you can believe but you cannot be absolutely sure.

One participant, who had articulated a purely atheistic approach (P3), did not express any ideas about anything transcendent afterlife. He was convinced that death was nothingness and he rejected at the same time to be afraid of death.

P3: There is a big dark hole . . . there is for sure a big dark hole.

The interviews demonstrated that most of the participants had reconstructed specific ideas or were searching for ideas about afterlife. Those ideas were something the participants had created individually and could talk about. The ideas were very subjective but they seemed to be a way of managing death in a kind of positive way, which might imply that death was less fearful. Although the ideas were very different, none of the participants expressed a fear about what would happen; on the contrary the ideas were positive. There was no clear associations or patterns between the participants' faith, their ideas about an afterlife, or their anxiety of death (Table 3).

Planning death. The majority of the participants expressed that they had planned practical aspects related to their own death. Most had together with their relatives planned where they

should be buried, which hymns should be song, maybe what kind of flowers that should adorn the coffin, or who should participate at the funeral.

Similarly, a few participants had planned who should be present and together with them at the time of dying:

P12: My son and my grandchildren and my daughter-in-law and then two friends, who are my trio, and they shall also be with me in my last moments. I also have an outer circle of ten friends, who comes now and then, but they do not come so close to me . . . eh they are more excluded when I come to the stage where we would say that I'm terminal.

Several of the participants had written letters or diaries to their children or grandchildren. Some had a focus on clearing up in their homes or manage any financial issues before death and some focused on issues related to inheritance:

P3: I have written diaries for them (his children) and so on and that is what I have done . . . they must be there when I die . . . I have also had plenty of time—so in that way I feel privileged . . . I feel privileged in that way . . . to have the opportunity to give them that.

According to the interviews, it was obvious that planning death was something most of the participants spend time on and could talk with their relatives, the nurses, and the chaplain about. The participants' descriptions of how they planned death appeared as a way to control specific aspects of their imminent death.

Focusing on living. Almost all participants expressed a deep gratitude and joy of the way they could live at the hospice through their last time. To stay at the hospice entailed that the participants experienced a basic peace of mind according to the professional handling of the needs that might arise in relation to the death process. The participants expressed in different ways

how they could hand over the responsibility for their own situation to the hospice staff. That gave them an opportunity to focus on living:

P3: Well, they've got care here at the hospice that allows me to function—I couldn't without... yes, because I have this belief in the hospice... it's home care and nursing education—and to give away the responsibility to them.

At the same time, the participants experienced that the health care staff provided empathic care and treated them with respect. Hospice architecture and aesthetics, the opportunity to have dinner together with the health care professionals or to look at a beautiful view were additional elements, which created an opportunity for the participants to experience that they could enjoy life.

P5: But you know what—when you walk through the door (at hospice), so you can feel the spirit and when you get to know the nurses who are here, so you feel all the time that they put their hearts into their work and it should be experienced—they are so damn sweet and nice and helpful. Never a bad word no matter what happens. We look forward to every day now—it's important—I had not imagined... I can push the bed and then I can lie down and look out over the sea... I think it's so beautiful... and being together down there (in the dining room)—when one can be allowed to eat with all the others and with the nurses, with the whole staff—it would not happen in a hospital.

Several of the participants' stories and field notes from participant observations demonstrated that the participants focused on and talked about positive aspects of life as being together with family, listening to music, watching television, enjoying a meal, having a spa bath, and so on. Focusing on these activities in their daily life seemed to create meaning for the participants even in the situations where they were facing death.

Discussion

The aim of the study was to illuminate the complexity of dying patients' concerns about their imminent death. The results showed how the participants' stories created a "landscape" of thoughts and feelings indicating that most of the participants realized that they were going to die. They seemed to be facing death without being anxious of death as the final state but some were afraid of the death process. Almost all participants expressed sorrow about leaving life. The results also demonstrated a varying and contradictory "landscape" in the way the participants managed their imminent death. They avoided thinking and talking about death and wished to talk about and focus on positive aspects in life. In an article concerning psychoanalytic reflections on mortality, Rodin and Zimmerman⁴⁶ described contradictory self-states of terminally ill patients facing death. They point out that these patients' desire to live may coexist with the increasing recognition that the end of life is approaching. These findings can be compared with our findings and show that even when persons are facing death, feeling

grief, and fear of physical suffering they can still be searching for meaning in their life.

Rodin and Zimmerman⁴⁶ also described how seriously ill patients could be in a relational dilemma. This dilemma existed between patient's need for intimacy and the threat of self-dissolution, brought by the intimacy, and their need for autonomy and the intersubjective isolation, ensued from the autonomy. The participants in the present study may have felt a similar tension when they seemed to push death away but at the same time tried to come to terms with death. They did not wish to think and talk about death; this can be understood as a need for emotional distance to reclaim their self and a way to sustain autonomy.⁴⁶ However, at the same time several participants had specific ideas about afterlife and had made accurate decisions about their funeral and other practical issues related to death. These decisions were often made together with other persons and thus demonstrated a need for proximity and emotional intensity. The oscillation between a desire for proximity and a need for autonomy might contribute to explain the participants contradictory managing.

The analysis of the interviews did not prepare a ground for claiming a potential interdependence or causality between the 2 overall categories, for instance that the participants avoid the fear of death by actively managing death. According to Kolva et al,³⁵ Wilson et al,⁴⁷ Renz et al,³² Rodin and Zimmermann,⁴⁶ the absence of anxiety of death is not unexpected. It was surprising that most of the participants in the present study expressed a belief in afterlife without being anxious about death, as Kolva et al³⁵ found a significant negative association between believing in afterlife and anxiety of death. The participants in the present study expressed positive ideas about afterlife and did not report any fearful conceptions about afterlife. This might explain the missing negative association between believing in afterlife and anxiety. That the participants reconstructed positive ideas about afterlife could be explained by the lack of tradition in religious believing in Denmark; instead Danes typically construct their own individual faith.¹⁷⁻¹⁹ However, the data material in the present study is too small to demonstrate a possible positive association between believing in afterlife and an absence of anxiety about death.

The different hospice contexts did not seem to impact on the participants' thoughts and feelings about death. A possible explanation is that all hospices confronted the participants with the presence of death during common traditions, for example, by lighting candles for the patients who died. Still, the differences between hospice facilities, architecture, and geographical location created different opportunities for reflecting the inner values of participants and their engagement in life. At 1 hospice, it was possible to enjoy the view of the sea; at another it was possible to walk in the garden and at the third participants could experience city life. Hospice facilities in this way created different possibilities for engaging in life; however, almost all participants were focused on life and living as a part of managing death.

According to the model of Kübler-Ross,²⁷ with the 5 interdependent emotional stages: denial, anger, bargaining,

depression, and acceptance, most of the participants in the present study would be expected to be in the last 2 stages. The participants were sad but most could still find pleasure and positive aspects in daily life at hospice and did not seem to be depressed. The stage of acceptance is according to Kübler-Ross characterized by being void of feelings and with no more energy to fight for life, with reduced interest in the outer world and a wish to be left in peace from the surroundings.²⁷ These characteristics were not found among participants in this study; the participants were facing death but still seemed interested in the surroundings with a wish to be involved in and enjoy their daily life. Hence, the results of this study did not seem to correspond with the theory of the “Five Stages of Grief.”

When Yalom^{26,48} writes about anxiety of death, he refers to what he calls “the most central form of anxiety of death.” This concerns the anxiety of the personal annihilation—the not being. He does not in his material refer to the fear of what happens after death or to the fear of the death process itself. According to Yalom, anxiety of death is inevitable, but at the same it is essential for humans to assimilate death in life and hereby enrich life by living more purposefully and authentically without focusing on triviality. To assimilate death in life creates an existential awakening necessary for the dying person in order to obtain a good death. With an existential psychological approach with reference to Yalom, the absence of anxiety of death among the participants in the present study could be caused by the fact that they used different defense mechanisms against anxiety of death. Thus, most of the participants did not want to think or talk about death but wanted to focus on positive aspects of daily living. These actions can with this existential psychological approach be seen as a way the participants tried to keep a distance to the imminent death. They were trying to escape from death and used a defense mechanism called “specialness” (that does not happen to me) according to Yalom. If the participants in this way could avoid being confronted with their imminent death and instead focus on trivialities in daily life, they could ignore their pain, but according to Yalom, necessary anxiety of death. Likewise, the way participants created positive ideas about afterlife could, according to Yalom, describe the defense mechanism, which he calls “the belief in the great savior.” Yalom himself is not religious and views any religious conviction as a way of denying death as a final step. He does, however, accept that religious beliefs can relieve anxiety of death. The fact that the participants in the present study in such a clear way described how they were absolutely aware of their imminent death, and how some in a very intentional way avoided thinking about death, may demonstrate that this way of thinking and managing was not an unconscious strategy for all. In our study, the awareness and management of death were conscious for most and therefore in opposition to Yalom’s theory about defense mechanisms; this is in reference to Freudian arguments about defense mechanisms being unconscious. Furthermore, almost all participants had been planning practical aspects of their death. According to Yalom, these actions will inevitably lead to an existential awakening, because the actions will create considerations

about important existential issues such as: Who do I care for? Who is going to miss me? How do I want my family to remember me?

In summary, it appears that the participants’ concerns about death in the present study are not in line with Yalom’s theory. The participants seemed to have experienced an existential awakening in the way they were facing and planning death but they did not want to think about death and preferred to focus on positive and maybe trivial aspects of daily life.

Inspired by Danish research about “being” in everyday life^{49,50} based on Martin Heidegger⁵¹ phenomenological thinking, the results of the present study can be understood in another perspective, which can contribute to explore the contradictory “landscape” of managing. Findings from a study by la Cour and Hansen⁵⁰ about esthetic engagement among patients with advanced cancer⁵⁰ demonstrated how the suffering of pain and illness was identified as coexisting with an appreciation of life in the ongoing endeavor of making the best of the time left. This involved engaging in daily activities and esthetic enjoyments. People who were incurably ill might strive for a sense of authentic being through involvement that accorded with their inner priorities even when they negotiated the realities of imminent death and responded to everyday life. Their study indicated that it was not a matter of either inauthentic or authentic being but rather an oscillation between the 2 given that engagement in daily activities was essential to create meaning in life. The participants’ way of managing death in the present study can be comparable to this in the sense that participants choose when and how they should enter “the room of death.” They preferred to focus on meaningful activities in daily life at hospice but at the same time they tried to encompass death by planning it and reconstructing ideas of afterlife in accordance with their individual set of values.

Limitations

When using a qualitative approach with interviews, it is important to emphasize that the findings can only report what the participants wished and were able to express about their concerns to the interviewer. Concerning credibility where an insider perspective seeks to be captured and portrayed, a study based on semistructured interviews has some limitations. First of all the subjects “death and anxiety of death” may be very private and difficult subjects to talk about. The interviewer was a stranger and there was only 1 interview with each participant; this could indicate that the participants would not share their inner thoughts about these subjects. However, before the interviews were obtained, the interviewer had a kind of familiarity with most of the participants through informal conversations during the fieldwork. Furthermore, the participants had profound information about the nature of interview subjects prior to the interview, and they seemed to have an interest in and a wish to share their thoughts.

Second, the interviews were obtained in the middle of the day where participants generally felt most comfortable. The participants might have other feelings about anxiety of death

in the evening and at night where the surroundings are silent and the participants may have pain or feel lonely. This kind of anxiety was not directly expressed to the interviewer but could be more present than the results demonstrate.

We intended with this study to illuminate some aspects of how dying patients experience their imminent death by describing their existential concerns about death. The analysis demonstrated that patients' concerns were complex, contradictory, and possibly not suited to be captured by one single theory. An ongoing reflection including different theoretical perspectives seems important when providing existential support to dying patients.

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