



Dealing With Temporality in Patients With Life-Limiting Disease: An International Qualitative Study

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Abstract

The prospect of death influences people's thoughts about and how they deal with their remaining time. We aimed to understand whether patients with progressive, life-limiting diseases are oriented in the past, present, or future and how they deal with temporality. We conducted 57 in-depth interviews with end-of-life patients in 10 countries using thematic analysis at three levels (i.e., locally in three countries, with codes shared in the three-country subgroup, and in all 10 countries with a codebook that we developed). We found that the patients' thoughts were oriented toward all three time levels (i.e., past, present, and future). Complementing these levels, we identified another, namely, the future after death. Each time level included patients actively and passively dealing with their thoughts. Past themes were *remorse and regret*, *nostalgia*, and *coming to terms with past choices*; present themes were *feeling grateful for being alive*, *a time for farewells*, and *living for the day*; future themes were *worries about the future*, *to miss out*, *hope*, *ideas about death and dying*, and *planning the near future*; and future after death themes were *not being there*, *worries about loved ones*, and *preparations for a future after death*. A *changed view on lifetime* and *avoidance of thinking about a certain time level* related to several time levels, while *desire to die* fluctuated between levels and between acting on and feeling about it. *Living for the day*, *worries about the future*, and *worries about the well-being of loved ones* were common themes in all countries.

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Introduction

The definition of time has occupied mankind for centuries from different perspectives. The ancient Greeks already established a division of time into two dimensions, namely, time and timing, in their mythology of Chronos and Kairos (Roscher, 1884–1890, 1890–1894). In modern philosophy, time is also divided into different dimensions: time made and defined by man; clock time or external time that is objectively represented; and time as perceived by the person—an embodied, lived time, experiential time, or temporality (Caldas & Berterö, 2012; Heidegger, 2008; Hinck, 2007; Lövgren et al., 2010). In sociology, Norbert Elias explored behavior in relation to time throughout history and marveled at how a highly abstract concept such as time, in terms of philosophy and physics, can significantly influence social life (Elias, 1992). Even Dame Cicely Saunders, founder of the hospice movement, has referred to this dichotomy when she stated that the meaning of palliative care is to add life to patients' days, not days to their lives.

In the (medical) care setting, external—chronological—time is primarily considered, mostly the scarcity of time in (medical) care or the amount of time the patient has left after a severe diagnosis. Health care professionals are known to mostly operate within the realm of chronological time, such as routines and tasks following clock time, whereas the patient is located in their own time, their temporality, which is rooted in existential experience. By acknowledging the patient's thoughts about their past as well as their thoughts about their disease in the present and future, health care professionals can work with that patient's temporality (Caldas & Berterö, 2012).

Less is known about which level of time—past, present, or future—patients mostly live in and the way they deal with said levels. One's limited time and finitude are crucial psychological subjects (Kukla et al., 2022). The basis for providing good care at the end of a patient's life is a deep understanding of their overall situation; therefore, acquiring insights into how patients deal with their temporality at the end of life may be helpful for ensuring holistic care.

In this article, we use the phenomenological term temporality to highlight the link between being and time, thus underlining the subjectivity and inseparability of both, and include the past, present, and future (Heidegger, 2008; Kupke, 2011). There are different approaches for dealing with temporality. A phenomenological approach that consists of “affectedness” and “cognition” connects

sensing to the present, while understanding—based on our (cultural) knowledge—can also occur in reflections about times other than the present (Ellingsen et al., 2015; Heidegger, 2008; van Laarhoven et al., 2011). Dealing with temporality may result in coping, a complex approach that involves the development of problem-, emotion-, and meaning-focused strategies,¹ which include memories, daydreams, and fantasies (Folkman, 2022; Sand et al., 2009).

Most relevant studies have focused on patients with cancer or cancer survivors in a small national sample to approach the topic of temporality. Authors have found that patients with advanced cancer focus on the present (van Laarhoven et al., 2011), have an increased awareness of time (Rasmussen & Elverdam, 2007), describe having a time perception changed to a day-to-day basis (Rovers et al., 2019), and like to spend their daily lives performing familiar routines (La Cour et al., 2009). One study focused on patients with neurological diseases and created the concept of existential loss (of past skills, embodiment, spatiality, and future disease; Harris, 2015). Another study conducted with oldest-old people defined their time in relationships with much younger others and described their plans for the present and future; the author did not find a dominant time period (Hinck, 2007). Nevertheless, a variety of progressive, life-limiting diseases as well as different settings and cultures have not been considered in the available studies about patients' perceptions of temporality. Our study fills this gap by widening the perspective to patients receiving end-of-life care, independently of underlying diseases, care settings, and cultural backgrounds.

Method

This qualitative study was part of the larger iLIVE project that aimed to acquire insights into the expectations, concerns, and preferences of patients with progressing, life-limiting diseases (Yildiz et al., 2022). The study was conducted in accordance with the Declaration of Helsinki (World Medical Association, 2013). It was approved by the relevant Ethics Committees of all participating countries and registered in the Clinical Trials Register (#NCT04271085).

Data Collection

The study was conducted in the following 10 countries: Argentina (ARG), Germany (GER), Iceland (ICE),

Table 1. Inclusion and Exclusion Criteria.

| Inclusion Criteria | Exclusion Criteria |
|--|---|
| 18 years of age or older | Unable to provide informed consent |
| Attending physician would not be surprised if the patient were to die within 6 months | Incapable of filling in questionnaires in the country's main language or in English |
| In case of uncertainty about Surprise Question: at least one Supportive and Palliative Care Indicator Tool (SPICT) indicator | |
| Awareness that recovery is unlikely | |
| Written informed consent to participate | |

Norway (NO), Spain (SPA), Slovenia (SLO), Sweden (SWE), Switzerland (CH), the Netherlands (NL), and the United Kingdom (UK). The data were collected from February 2020 to January 2022.

The interview guide was developed by the Slovenian team. It comprised seven topics, namely, perception of illness, family, communication, environmental control, social organization and values, time orientation, and emotional and physical pain. These topics have been recognized as relevant at the end of life by the Transcultural Assessment Model and ABCD model and have been used as a basis (Newman Giger & Davidhizar, 2002; Srivastava, 2008). The main question related to time was as follows: "When people are seriously ill, some mostly think about the future, some mostly think about the past, and some think about the present. What about you? Where are your thoughts mostly oriented now?" The following three additional prompts were used: "What is your first thought in the morning?"; "Do you think about death?"; and "Has time become more valuable for you?" To ensure a common basis for all of the researchers, the Slovenian team developed an interview manual and conducted an online training session for all researchers that lasted 2 hr. The session aimed to harmonize the researchers' interview styles and procedures.

To find eligible patients, we asked hospital, hospice, palliative home care, and nursing home physicians to answer the modified Surprise Question (SQ; White et al., 2017) for adult patients by asking whether they would be surprised if a patient was to die within the next 6 months. If their answer was "no," then the patient met the main inclusion criterion. If physicians were unsure about the SQ, then we used the Supportive and Palliative Care Indicator Tool (SPICT; Highet et al., 2014), which consists of general and specific indicators for palliative care, and identified patients with at least one indicator. We also asked about the information given to the patients regarding their disease and whether the physician thought that the patients were aware of the unlikelihood of their recovery. If a patient fulfilled all of the inclusion criteria and met none of the exclusion criteria (Table 1), then we asked him or her to participate. Each patient was provided written informed consent prior to being enrolled in the study.

Next, each patient decided the time and place for their interview—either in the patient's home or their room at the institution where he/she was staying at the time (hospital, retirement and care home, or hospice), whichever the patient felt provided sufficient privacy for discussing end-of-life topics. Due to the sudden impact of the COVID-19 pandemic, five of the 57 interviews were conducted by telephone and one by video call. Therefore, we added a question that asked for these patients' views on their interview being held by telephone or video instead of face to face.

The interviewers were researchers with interdisciplinary backgrounds (e.g., psychology, nursing, medicine, public health, or social research methodology). Hence, the research team had a variety of perspectives on the subject, which enabled high reflexivity. Most interviews were conducted one-on-one, but in five cases, a relative, another patient, and/or a nurse were present in the room for some time during the interview, but they did not actively participate. Demographic data were collected from each patient before or after the interview. The interviewers took field notes in English immediately after the interviews, reflecting their impressions and providing additional information for the data analyses. In addition, except for Norway and the United Kingdom, summaries of the main topics of each interview were written in English because interviews and/or transcripts could not be read by each researcher in the original language. We used the Digital Research Environment (DRE) platform to guarantee all researchers' access to relevant documents and ensure easy and safe international collaboration.

Data Sample

For maximum variation sampling, we included patients who were considered to have a life expectancy of 6 months or less, regardless of disease, care setting, or treatment. However, we aimed for an even gender distribution in the sample (Table 2). We recruited patients in the following settings: (1) in hospitals and hospices associated with the study institutions and (2) in nursing homes and other hospices and hospitals that were willing to participate in the study. Within the hospitals, several

Table 2. Characteristics of the Participants.

| | N |
|-------------------------------|----|
| Total sample | 57 |
| Gender | |
| Male | 32 |
| Female | 25 |
| Under 65 | 16 |
| Over 65 | 37 |
| Exactly 65 | 3 |
| Missing | 1 |
| Living situation | |
| Alone | 11 |
| With spouse | 26 |
| With spouse and children <18 | 4 |
| With children <18 | 2 |
| With other adult(s) | 5 |
| In an institution | 8 |
| Other | 0 |
| Missing | 1 |
| Education | |
| Primary school | 3 |
| Secondary school | 20 |
| Tertiary vocational education | 10 |
| University | 20 |
| Other | 3 |
| Missing | 1 |
| Main diagnosis | |
| Cancer | 46 |
| Non-cancer | 9 |
| Cardiovascular disease | 1 |
| Neurological disease | 3 |
| Pulmonary disease | 2 |
| Frailty due to old age | 0 |
| Other | 3 |
| Missing | 2 |
| Focus of treatment | |
| Curing illness | 2 |
| Prolonging life | 8 |
| Supportive/palliative care | 39 |
| Other | 0 |
| Missing | 8 |
| Comorbidity | |
| None | 19 |
| One | 13 |
| Two | 7 |
| Three or more | 11 |
| Missing | 7 |

wards were involved—such as oncological, geriatric, and palliative care wards—as well as palliative home care services in some countries. The included patients had a mean Karnofsky performance status of 50, which meant that they required considerable assistance and frequent medical care (Karnofsky et al., 1948).

The main diagnosis, focus of treatment, comorbidity, and Karnofsky performance status were stated by the attending physician.

Data Analysis

Mean interview length was 55 min (range: 23–140 min). The interviews were pseudonymized and transcribed verbatim in all countries except Switzerland; the Swiss researchers used the original audio material for the analysis. We analyzed the overall data set inductively and deductively at several levels. Given that we had a large research team with professionals from several countries and interviews conducted in several languages, we focused on shared meaning and similarities rather than on differences between countries. To interpret the highly complex data set, we required a structuring yet flexible method with interpretation options; therefore, we employed codebook thematic analysis. As thematic analysis is itself a rather flexible and fluid method, we used the six steps of thematic analysis as a guideline in the overall process (Braun & Clarke, 2013, 2023), which we adapted by working with levels of analysis during the process.

First, a subgroup that consisted of researchers from Argentina, Spain, and Germany familiarized themselves with the respective local data and then performed inductive data coding of local interviews in their language. This first phase included 20 interviews. The researchers coded the answers to the questions concerning time in the interview guide as well as any responses that dealt with our research question, since reflections on temporality and time levels were present throughout the entire interview. In addition, valuable contextual information from field notes enriched the local analytical process, which led to a reflection of the social context of the interview.

Second, local codes were shared within the subgroup in English. We created overall codes close to the patient's words; moreover, we also began to generate initial candidate themes.

Third, the first author concentrated the codes and candidate themes to develop an initial codebook that consisted of the first set of candidate themes for the different time levels. The first author then distributed this codebook to all researchers of the participating countries as a shared document. Using this codebook, the local research teams in each participating country analyzed the local interviews deductively. They added additional inductive codes whenever a code did not fit a candidate theme. The researchers proposed and reviewed the candidate themes and added one or several representative quote(s) in English for each existing candidate theme. The shared document ensured that each researcher had access to the themes and quotes from each country, thereby allowing the possibility to compare and reflect upon the data collaboratively.

In a video meeting, representatives from each country discussed quotes with overlapping themes or quotes that

were not understandable without the interview context. Moreover, the representatives approved the decision to concentrate and refine the analysis for even higher-level themes with a higher abstraction level.

In a critical friends meeting in Cologne, 11 researchers spot-checked the finalized concentrated and refined themes with corresponding quotes. They also discussed additional possibilities for classification within the time levels by finding clusters of commonalities and differences (e.g., focus on death vs. focus on life) that did not apply for every time level (e.g., focus on death vs. life was apparent in the present and future but not at other time levels). The iterative process from this starting point and further reflection on the overall themes allowed us to classify themes of active and passive dealing with temporality, which encompassed all time levels. Because all forms of coping imply dealing with a subject, but dealing is not always coping (thoughts can “just happen” and have an influence without patients actively dealing with them), we deemed it more appropriate to use the term “dealing” rather than “coping” for analyzing and discussing the themes.

Findings

Patients were oriented in all time levels specified in the interview guide—past, present, and future; however, they also thought about a future in which they had already died. Although the patient’s own temporality ends with death, their thoughts about this time occur in the present; therefore, we argue that the time after death can still be included in this framework. Because the themes related to

the future after death were very different from those related to the future where the patients believed they would still be alive, we classified it as a new time level (Figure 1).

When we compared all time levels, another pattern emerged that could be best described as a dichotomy of (active) attitudes and (passive) feelings of the patients thinking about a certain time level (Figure 1). The patients indicated passive dealing with temporality when they described thoughts that came to mind about a time level. Active dealing provided explanations for their thoughts or allowed them to express an inner discussion or even use a strategy for dealing with the situation. A dichotomy in this case should not serve as model of strict delimitation of one mode from another but rather as a possible existence of two ways for dealing within the same time level. A person does not think solely in an active or passive mode at one time level; rather, one may demonstrate a fluctuating mode.

Evaluating the Past

A life review evaluating the past was common when the patients described their thoughts about their past, which revealed two sides. On the one hand, there was a passive dealing with the past, where patients felt trapped in negative feelings about this time level. On the other hand, thoughts about the past could actively be used to create positive feelings for the present.

For thoughts about the past, some patients described experiencing feelings of *remorse and regret* about life and/or health decisions. In hindsight, a typical view was

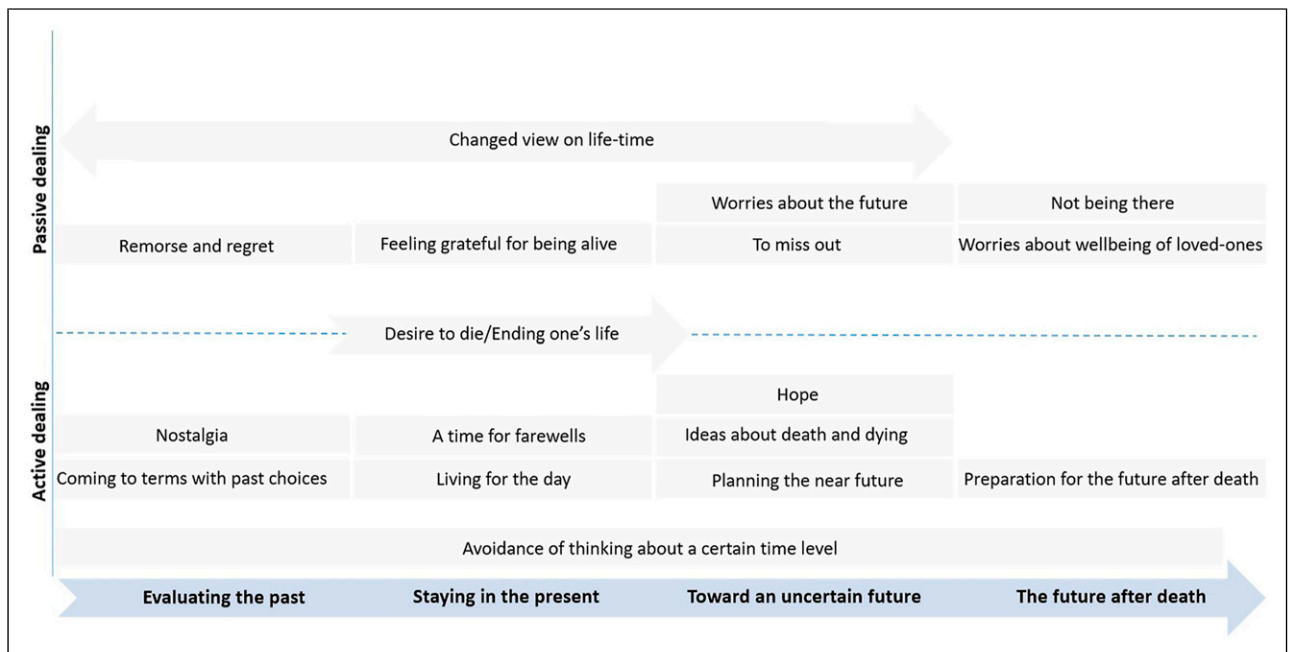


Figure 1. The themes of each time level separated into active and passive dealing.

the doubt—and self-accusation—that another decision could have resulted in a happier life. One patient said the following:

I've been thinking a lot about the past, why I didn't do this or that. Because I didn't really want to live in [REGION], I wanted to move back, but I was too much of a coward and didn't do it. So, then I wonder why I didn't do it. (SWE_P01_F_B)²

Moreover, the patients described feeling *nostalgia*, which was connected with pleasant memories, such as positive experiences, such as traveling and moments they shared with people with whom they were close. In general, the feeling of nostalgia that enabled them to actively revive positive memories seemed to provide comfort and was experienced as a mental resource:

But I've traveled a lot, I've traveled a lot here in Europe and we've been to Africa and Asia and Australia and. So we've seen most of it so it's nothing we're really. So that's the kind of thing you sit and think about how much you've experienced anyway and it's kind of a form of comfort too. (SWE_P05_M_B)

When thinking about the past, several patients reached a moment of inner discussion that ended in satisfaction about their living, which assisted them with *coming to terms with past choices*. One patient stated the following: “[S]ometimes, I also think ‘phew, what could you have done differently!’ and then I said ‘no, I have gone THIS way now!’” (GER_P03_F_B).

By contrast, one patient did not express satisfaction about her past choices. Instead, she reflected on those choices and demonstrated kindness and forgiveness toward herself. In addition, she generalized her mode of thinking to express that making bad choices is part of human behavior. She stated the following:

About the past. Yes, that you could also have done things differently, but then it is too late. [...] No, we [my husband and I] don't regret the way things went but somewhere along the line I think we [people] all have the feeling that if I hadn't done this better or done that better in certain moments, what I have chosen to do and not done. But that is so complex, you can't keep blaming yourself for that. (NL_P05_F_B)

Staying in the Present

Many patients mentioned staying in the present when they described positive feelings that arose (passively). Other explanations or descriptions concerned how patients actively handled the present situation.

Although struggling with symptoms and physical challenges, *feeling grateful for being alive* was a part of some patients being in the present with their thoughts,

manifesting the desire to enjoy life and live more every day—despite facing an approaching death—as a sometimes unexpected, yet joyful, gift. One patient stated the following: “I have to be grateful that although this is happening to me, I am still alive one more day” (ARG_P02_M_A).

However, the present was connected with a narrow perspective on the future; therefore, there was *a time for farewells* to personal things, people, or a working body mentioned in anticipation of the approaching death. Related to their deteriorating health situation, patients' comparisons with earlier times created an air of wistfulness toward the present. They recognized a change in their health that they had to reluctantly accept. This view indicates how the disease had changed the patient's body over time as part of a process, as well as a time point, at which this was noticeable for the patient as a farewell. One patient stated the following: “Sometimes, when you notice, ‘THIS doesn't work or then THAT wears off’. With the disease, something is constantly wearing off. It's not as if you were like that from now on, but you say goodbye all the time” (GER_P04_F_A).

Furthermore, there were several shades in saying farewell, such as being able to (finally) let go of material things in a confident way or feeling closure. However, this was also characterized by elements of stress in seeing as many people as possible, balancing the will to say farewell with the little time the patient had left and their frailty due to their deteriorating health.

Patients from all countries agreed to intentionally *live for the day* with a focus on the present, some with a more pragmatic view—namely, to live in the present because they did not know how long the future would last. The patients considered it a logical consequence that they would use the present as a trusted anchor to focus on more short-term outcomes because long-term goals seemed unachievable. One patient stated the following: “Now that I have been diagnosed with recurrence, I think that the present moment makes much more sense” (ARG_P04_F_A).

Other patients lived more in the present with the aim of enjoying the moment. They had a mindful attitude to live more consciously each day, focusing on everything that happens in the moment and leaving everything else behind. One patient stated the following: “The past is over, and the future is yet to come. I try to live just one day at a time as every day comes” (ICE_P05_F_B).

Toward an Uncertain Future

A common description of uncertainty and limited time remaining led to (passive) thoughts of concerns about the time level. Patients also described an active and intentional thinking mode in which they imagined scenarios or planned.

In most countries, *worries about the future* indicated that patients were concerned about the outcome of practical issues, such as a change in the care setting in the future and the burden on their families. Worries regarding the fear of complications of their health situation or being a burden themselves both revealed the fear of losing independency and control. One patient stated the following: “I am concerned about these little things that I’m sorting out right now. Oxygen, how to improve my breathing, in what shape I will be, how many meters I’ll be able to walk” (SLO_P04_M_B).

Another shared aspect that indicated loss of control was vast uncertainty about the effect of treatment, the time required for therapy, and the time left in general, which made it difficult to make plans or even think about the future. One patient stated the following: “I can think little about the future, because I don’t even know how long it will last” (SPA_P04_M_B).

Moreover, because the illness would lead to health deterioration, projects would not be possible in the future for most patients. They were going *to miss out* on activities such as traveling, and they experienced this as a loss of the future, which in this context can be understood not as a loss of time, such as hours, but rather as a loss of being in time. The essence is how the time was to be used and what was then taken away from the patient. This dealing with temporality was expressed either through acceptance or disappointment and anger associated with a feeling of being robbed of the future. One patient stated the following: “Obviously, I’m gutted to have my future taken away from me, you know; we had all these plans [...] and I know none of that’s going to happen” (UK_P02_F_B).

Nevertheless, patients experienced *hope* for the future—hope that they would be able to live longer or even be cured and also, by contrast, hope for a peaceful death, which mostly included release from pain. One Spanish patient expressed that hope was keeping him alive. In his case, hope had the effect of easing his mental suffering when he thought about what the future might hold. He stated the following:

If I knew that my end would be with suffering, I would be very worried, I would throw myself out of the window, I understand and I hope that my end will be without suffering; that is the most important thing. (SPA_P04_M_B)

Ideas of death and dying concerned how one’s own dying process would depend on one’s disease and one’s knowledge of body functions. Knowledge and information about how one’s life was going to end seemed to sooth the patients’ fear of the dying process. Some patients indicated a vague, some a strong conviction to know when the time had come. *Ideas about death and dying* also included the wish to or ideals of

dying well, such as dying peacefully in one’s sleep after having said goodbye to everyone or surrounded by one’s loved ones. Some ideas depended on spirituality, expressed by the belief in an afterlife, which provided comfort and a perspective for time after death. Questioning an afterlife or being convinced of its nonexistence went together with death as the end of physical suffering. Experiences, such as getting in touch with the dying process of others, could offer comfort and an idea of one’s own dying situation as well as relieved the fear of dying. One patient stated the following:

I’ll tell you a, a nice story that was about my dad in the first place. He was cared for at home. I was called down a couple of days before he died because you knew that now it was close. And then at the moment of death he says “Marguerites.” You know, Daisy by another name. And that’s what he liked so much. And then you got the idea that, alright, he had some kind of beauty experience. (SWE_P03_M_B)

Furthermore, several patients mentioned actively making *plans for the near future*, such as working on one’s personality, visiting loved ones, being creative, or pursuing one’s hobbies. Although the patients’ plans might exceed their capacities, the urge to be active and achieve small goals was important for spending their remaining time well. One patient stated the following:

But I also think about what I can still do in general, so, I take on a little too much sometimes. You can also see this, I had planned to repair all my watches, now the whole tool is lying around here. And there are other things that I want to do somehow, PC-wise and so on. (GER_P01_M_A)

The Future After Death

Similar to the other time levels, the future after death holds passive and active features, such as describing concerns and acting on them. When thinking about the time after they have died, patients from many countries mentioned themselves *not being there* in the future, which they described as an intangible and overwhelming phenomenon. One patient stated the following: “In the present, everything is fine, but when something comes up, some situation is going to happen in the future, that’s when I think, ‘Eh ... I’m not going to be there’” (ARG_P03_F_A).

Even finding expressions for the time after one has died did not seem feasible, and it was less a description of what might be—only individual patients spoke about spiritual aspects such as an afterlife after death—than an expression of absence. On the one hand, it was associated with a hurtful feeling of not experiencing things, feeling left out, or being disconnected from others. One patient stated the following: “It’s hard to imagine that I won’t be around this time next year. Very hard. And that I won’t see my

grandchildren grow up, and all that sort of thing” (UK_P02_F_B).

Another painful thought was the idea of someone else taking one’s place representing the loss of control by *not being there* to interfere with the invasion of one’s privacy after one’s death. One patient stated the following:

Men get a new partner quickly. He can’t be on his own, it feels like, and that’s really annoying! Someone will come in and rummage through my things and so. I think it’s disgusting! That someone else comes into my house and takes over my clothes and stuff. (SWE_P01_F_B)

On the other hand, *not being there* described leaving a legacy—to still be there in a way—even after one’s death. The thought of living continuing in the next generation serves as a comfort and a substitute for an afterlife. One patient stated the following:

Well it’s that I have support around me, my wife and my children and grandchildren. And if we’re going to talk about the fact that there will be nothing more after death, there will be something left after me here anyway that. A little bit anyway. (SWE_P05_M_B)

Not being there also raised the question of how a person would be remembered after death. This represents part of wanting to leave a legacy, but it also indicates a helplessness to want to be remembered in a chosen way after death. However, the person cannot influence this process. One patient stated the following: “That image . . . What will they have remaining of their grandfather? What image will remain? And that’s the image I don’t want to remain, the image of the old, older man, the one who can’t talk, who can’t walk” (ARG_P06_M_B).

In every country, an important theme was *worries about the well-being of loved ones* after dying. The patients reported that they were more worried about their loved ones than themselves. Dying seemed to be easier to bear than the pain of their loved ones’ grief, which reveals a high level of empathy. It also suggests an ability to change perspective even in an existential situation, in which it would be understandable to focus on the self. One patient stated the following:

I feel it is easier to be the patient. It is so hard to be the relative because the patient, as me, just goes or dies or however that is but they are left behind and that’s what I feel is difficult. (ICE_P02_F_A)

In addition, patients’ worries did not only concern the grief of their loved ones but also the changes associated with the loss, the perceived helplessness of their loved ones after their death, and the despair of not being able to

help in everyday situations. One patient stated the following:

Yes, I think about death. Not for myself, that I want to die, that I will come to some kind of an end. But I am constantly thinking, how will it go with the others? Because I’m used to deciding, helping, so I’m more concerned about whether my wife will be able to cope. (NO_P02_M_B)

Moreover, *worries about loved ones* could be seen as a driver for *preparations for the future after death*. This refers to finding practical preparations to facilitate their loved ones’ future without them. One patient stated the following: “I’ve been in the process for half a year of teaching her on my computer and all the things she needs to know should I be gone” (GER_10_M_B, hospital).

In addition, the patients thought about funeral wishes, financial and personal legacy matters, and how to organize these matters to ease their loved ones’ handling of their death. On the one hand, this focus represented personal closure by getting everything in order before one’s death. On the other hand, as previously mentioned, the change in perspective and consideration of the feelings of the bereaved were of the utmost importance for these decisions.

I think, what’s going to happen to my apartment? They would have to clear out my apartment afterwards, clear out my stuff, so to speak. It’s still such a strange idea, when you have to clear out your father’s stuff, I can imagine. Whether one would have to dispose of certain things beforehand or say certain things beforehand, you can have that then or that’s for you. (CH_P02_M_B)

Beyond a Time Level

Three themes were not limited to one time level; rather, they described a broader and/or not defined timespan.

A *changed view on lifetime* related to either the past or the future compared with the present. All statements concerning a changed view on one’s lifetime were expressed in a positive manner, involving dealing with daily situations with a more positive attitude than before. A Swiss patient provided a possible explanation for this change, where knowing of one’s limited lifetime seemed to lead to a greater awareness of the small things, expressed in a timespan as small as moments. He stated the following: “I’ve really had some good moments now with colleagues, in my hobby or in my job. You actually enjoy it even more then. It makes you much more aware of yourself. One lives it then more intensively actually” (CH_P02_M_B).

Furthermore, the patients perceived experiences and their remaining time as more valuable. However, recognizing a shorter (life)time forced the patients to focus on

what was most important to them. In the following quote, one patient indicated a shift of distributing time along with changed preferences, and she had articulated this change in her will to spend her remaining time with her family:

For example, I used to be in a choir. And those people are also all very sympathetic towards me, they shower me with attention, but I find that just too much. I don't need all that anymore. I'd rather just have family. So I do want to spend my time with what has real emotional value for me. (NL_P05_F_B)

The remarks on *desire to die* greatly fluctuated across time orientations. This phenomenon is represented by one German patient's quote, which included the past ("for years"), the future ("tomorrow"), as well as the present ("I wouldn't be"). To leave a loved one behind was seen as an obstacle and a reason not to turn the idea of ending her life into reality. The patient stated the following: "I've been having suicidal thoughts for years I think, so I don't want to kill myself tomorrow but the thought is kind of always there and I'm actually convinced if my husband was no more I wouldn't be either" (GER_P08_F_B).

Moreover, some patients held onto the possibility of ending their life as an option for the future, which was mostly dependent on their health and care situation influencing their will to live. Many of the patients indicated that if their symptom burden were to increase or their required care exceeded their imagined capacities of their family carers, they would wish to die soon. Some patients perceived a lack of control over the time of their death and having to wait for death as an emotional burden that they wanted to actively get rid of by making plans to no longer take their medications. Beyond this, the social situation influenced the time point at which the patients questioned (the quality of) life itself. Some patients described dealing with it in a passive manner, without knowing how this situation could be helped. One patient stated the following:

I've got nothing to live for. I've got no family. I've got no—well, I've got quite a few acquaintances. And what else is there in life? I can't see anything, and like just now out of the blue I suddenly get vomiting or something like that. Now if I was at home on my own, I know I have carers four times a day, but if I was on my own this morning and it just come like that, what could I do then? (UK_P04_F_B)

Some patients also expressed the *avoidance of thinking about a certain time level*, so that they would not experience negative emotions about it. This served to not have to relive bad memories from the past, blank out the actual situation in the present, not imagine negative scenarios for

the future, or push away thoughts of death and ideas about what happens after. One patient stated the following:

In a months' time I may not be walking or be able to stand at all. I might have lost my swallow but equally in a months' time I might be just as I am today so for me there isn't any point looking that far ahead particularly not unless there's a reason to do so. (UK_P0_F_A)

Discussion

We investigated how end-of-life patients dealt with temporality at different time levels—evaluating the past, staying in the present, looking toward an uncertain future, and considering a future after death—as well as themes that went beyond the aforementioned time levels.

A life review of the past is common among patients at the end of their lives (Liu et al., 2023; Ng et al., 2022; Valdés-Stauber et al., 2021). In our study, the patients' thoughts about the past revealed two sides of a life review: on the one hand, there was remorse and regret, a feeling that appeared when thinking about the past, while on the other hand, the patients reported getting over these feelings while coming to terms with their life choices. Autobiographical reasoning, such as gaining insight or learning a lesson from life changes, is related to past-present self-continuity (Sedikides et al., 2023), and defining the (present) self through experience is consistent with a study with oldest-old people (Hinck, 2007).

Another way to think about the past is nostalgia, which is a social emotion for feeling close to others, reflecting a relation to others, finding meaning in the past for the present, and constructing patterns on how the past has influenced our present being (Sedikides et al., 2023). Our results confirmed the feelings of closeness but neither a finding of meaning nor the influence on the present. For the participants in our study, nostalgia served as a strategy for (actively) reviving positive memories and seeking comfort in the past, where one's health was still intact, which is in line with the phenomenological approach of seeing the past as "re-presented" to perceive it again in the present in an imaginative way (Husserl & Churchill, 1964).

In their thoughts about the present, the patients reported feeling grateful to be alive. The meaning of gratitude has been well described as a social emotion in relation to another person and is linked to subjective well-being (Asgeirsdottir et al., 2013; Liao & Weng, 2018). However, our results revealed a more universal gratitude that might subliminally also refer to the actions of others, but that mostly refer to a life experience—"just" to be alive—as was also demonstrated in a qualitative study that involved patients with dementia (Pearson et al., 2022).

Knowledge of the end of life as well as the loss of physical integrity urges patients to say farewell. The

patients mentioned not only saying farewell to people but also to abilities and material things. This view is in line with the study of Valdés-Stauber et al. (2021), who described biographical closure in the sense of an “anticipatory farewell to existence” as a coping process of the conscious mind, especially in dying people.

In a Swedish study with patients with lung cancer, a study of people approaching the end of life, and a qualitative study with oldest-old people, the authors highlighted the focus on the present as a way to cope with an uncertain future (Dönmez & Johnston, 2020; Hinck, 2007; Lövgren et al., 2010). This view is in line with our interviews, which indicated an either conscious or pragmatic way of living for the day, living life to the fullest to enjoy it as much as possible, and/or recognizing that, because the future is uncertain, focusing on the present day makes more sense. The day serves as a metaphor for the present, as a “closed and overlookable experience unit” (Fränkel, 1931) to which one can adapt. Arantzamendi et al. (2020) found that the reason to live in the moment was to focus on life, not on the illness, and to shift the patient’s attention to other things. Therefore, living for the day may serve as a strategy for gaining control over everything that the patient is still capable of despite the uncontrollable disease leading to a lack of energy and other physical limitations, as routines can represent security (Hinck, 2007; La Cour et al., 2009; Sand et al., 2009).

The future holds worries and uncertainties regarding how treatment and/or the care setting will work out as well as worries about burdening loved ones with physical and mental deterioration. This integral part of thinking about the future was also reported by patients with lung cancer in China (Zhang et al., 2022).

Inevitably, the certainty of death causes uncertainty regarding *how* a person is going to die (Harris, 2015). There are a variety of ideas about death and dying in the (near) future. A Danish study that explored the experience of meaning at the end of life revealed knowledge and comprehension about how the body functions as well as one’s own and others’ experiences (Viftrup et al., 2021). Both aspects may lead to comfort: patients may use their imagination as a strategy to prepare and gain a certain control over the uncertainty of dying by seeing death as redemption—as a wish for an afterlife or for the end of suffering.

Our participants also described missing out on events and things they would have loved to experience in the future. These feelings of loss of the future are in line with an English study with patients with motor neuron disease (Harris, 2015). By contrast, the patients talked about the anticipation of planned projects in the future. van Laarhoven et al. (2011) found that time dominance of the future appeared more in patients whose physical

integrity was not affected by the disease than in patients with advanced cancer. However, we found that most patients make plans, even if they are small and have to be readjusted, depending on the anticipated future health situation, as was also mentioned by oldest-old people (Hinck, 2007). Therefore, making plans for the future, comparable to living for the day in the present, may serve as a reassurance of possibilities, even when the body’s functions may be limited. These results are in line with those of Sand et al. (2009), who described the maintenance of the commitment and skills of patients receiving palliative care as a “useful source for coping,” protecting them from negative emotions to enable them adapt to the situation. Folkman (2022) highlighted the revision of goals to adapt to the new situation as meaning-focused coping, which leads people to gain back a sense of control.

Dying of an incurable disease in itself goes beyond the patient’s control. Hope appears in uncontrollable situations and is common when a future situation is uncertain (Folkman, 2022). The patients did not know how their symptoms would affect them. They expressed hope that their life would end well or that they would have more time than expected (or even hoped for a cure), which served to enable them to cope with this uncertainty by imagining. Our findings are in line with the study of Sand et al. (2009), who reported hope as coping in the sense of taming the thoughts of death.

Not being there is connected to a personal legacy and the question of how one will be remembered. It is also connected to the loss of control of what is happening when one is not there. The importance of leaving a legacy and how to be remembered in a good way is considered part of a “good death” (Hinck, 2007; Zaman et al., 2021). A lack of expressions for elaborating on not being there as an existential thought may be one reason for spiritual content rarely being apparent in this theme. Indeed, Viftrup et al. (2021) found that patients lacked the existential vernacular to express themselves.

When thinking about the future when they have already died, patients’ worries about their loved ones burdened some of them more than their own death, which is in line with a study that demonstrated significantly higher levels of altruistic preoccupation in patients at the end of their lives (Valdés-Stauber et al., 2021). Problem-focused coping refers to planful acting such as addressing the problem that causes distress (Folkman & Moskowitz, 2007). Consequently, the patients may view preparation for the future after their death as a strategy for lifting at least one aspect of the burden from their loved ones and for being able to support them after their death, which may cause them to feel relief.

In the interviews, some patients avoided thinking about a certain time level, be it the past connected with hurtful experiences, the present when connected with suffering,

or the future when avoiding thinking about death. Avoidance is a well-known coping strategy for preventing hurtful emotions. When considering the fear of death as an emotion that may consume their whole existence, patients prefer not to think about it (Sand et al., 2009). Therefore, stopping thinking makes patients feel in control of their thoughts.

The desire to die has been described as quite variable (Kremeike et al., 2022; van Loon, 1999). Hence, it is not a surprise that we confirmed that patients had different active or passive methods for dealing with this desire—such as postponing ending their lives into the future or just permitting thoughts about the desire to die or wishing to be dead soon, all of which are linked with the actual and anticipated future social and care situation.

A progressive, life-limiting disease comes with numerous changes that, as discussed previously, go beyond physical changes. The theme of *a changed view on life(time)* included all three time levels of existence. Because the patient would no longer exist, the future after death was not touched. Different from the theme of *coming to terms with past choices*, which composed of acceptance of past attitudes and may enter into past–present continuity (Sedikides et al., 2023), a changed view results in an epistemological discovery of meaning (Gijsberts et al., 2019; Zhang et al., 2022), with the reprioritization of time (Lövgren et al., 2010; Rasmussen & Elverdam, 2007). Time, like thought, is fleeting (Rasmussen & Elverdam, 2007). The patient may be in the present one moment or day but then lost in their thoughts about the past in the next moment or day. This phenomenon may be why we could not confirm temporal dominance, as described in other studies (van Laarhoven et al., 2011), in our interviews.

Strengths and Weaknesses

All of the studies that we found about temporality have focused on a specific setting or/and a certain region. A strength of the present study is that we included patients from 10 countries without restriction to diagnoses or specific care settings. We included in- and outpatients from hospitals (from palliative care and other wards), hospices, and retirement and care homes. Thus, our sample consisted of a wide spectrum of patients in the last months and weeks of their lives, reflecting the end-of-life reality in the best possible way. We interviewed patients in their preferred location, where they were most comfortable, thus allowing good privacy and perhaps leading to higher-quality material than interviews that only take place in hospitals.

Although our intention was to include patients regardless of their disease, we were only able to include a few patients with diseases other than cancer. Because

communication about the end of life mostly takes place with patients with cancer (Kasdorf et al., 2022), the nonidentification of end-of-life patients without cancer may explain the difference of including patients without cancer (16%) and patients with cancer in the sample. Moreover, most of the participating countries have a Western way of life, so future research is required in countries of the Global South.

Unfortunately, the vast majority of the interviews were conducted during the COVID-19 pandemic. Although it may not have interfered with our topic per se, it still altered how the interviews were conducted. In some countries, physical contact with the patients was not allowed or desired, so we conducted telephone, video, or face-to-face interviews depending on the country's regulations—which ranged from severe lockdowns to mild restrictions—and the patients' preferences. However, for interviews that were not face to face, we asked the patient how she/he felt about having the interview over the telephone or by video call. This question did not elicit negative comments.

Conclusion

The patients' thoughts were oriented toward all time levels: the past, present, future, and the future after death without time dominance. We identified three themes that were present in all countries, namely, living for the day, worries about the future, and worries about the well-being of loved ones, which suggests that these themes are important across cultures. We also found that patients had passive and active ways of dealing with thoughts, some of which we found to be coping strategies.

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Author Contributions

HKC, MB, and UL were responsible for the design of the study. MJ was responsible for methodology and coordination of the analysis. MJ, GHA, MB, HKC, DRFH, UL, EVM, BM, BHR, ER, VT, AH, VV, BY, SZ, JS, and RV contributed to the acquisition and/or analysis and/or interpretation of the data. MJ prepared and wrote the original draft. GHA, MB, HKC, DRFH, UL, EVM, BM, BHR, ER, VT, AH, VV, BY, SZ, JS, and RV reviewed and edited the manuscript. All authors have read and agreed to the published version of the manuscript.

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Ethical Statement

Ethical Approval

Our study was approved by all participating countries' Ethics Committees. All participants provided written informed consent prior to enrollment in the study.

iLIVE Consortium

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Notes

1. In stress and coping theory, emotion-focused coping refers to regulating distress with strategies such as seeking emotional support. Problem-focused coping refers to management of the problems causing the distress, like gathering information. Meaning-focused coping stresses the strategy of (positive) reappraisal of meaning in a given situation (Folkman, 2022; Folkman & Moskowitz, 2007).
2. The pseudonym consists of the country code, gender, and age (A for patients younger than 65 years and B for patients 65 years or older).

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