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Dying is never beautiful, but there are beautiful moments: qualitative interviews with those affected on the subject of 'good dying'

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ABSTRACT

The concept of the good death has been widely considered. However, the perspectives of those affected have not received sufficient attention. In our empirical study, we conducted interviews with 32 people who were confronted with dying; these people were either terminally ill, elderly or else were bereaved carers. The findings show that for this group of people, dying is not just a physical process, but also a psychological, social and spiritual one. From the perspective of those affected, dying is never beautiful, in particular because of the associated pain and suffering. At the same time, people confronted with dying do experience beautiful moments. In the stories they tell of these beautiful moments, it is a beauty emanating from a sense of elevated emotion – of moral emotion – rather than any aesthetic beauty. We conclude that good care of the dying enables beautiful moments and creates reflective spaces for those affected to express what beauty means to them. We show that the public discourse differs significantly from the perspective of those affected and more efforts need to be made to include their voices.

KEYWORDS

Good dying; good death; beautiful dying; qualitative interviews; palliative care; hospice

Introduction

The concept of the good death has been widely considered (e.g. Becker et al., 2017; Cottrell & Duggleby, 2016; Field & Cassel, 1997; Kellehear, 2016; Lang, 2020; Lang et al., 2022; Masson, 2002; McNamara, 2004; Walters, 2004). It has been investigated in empirical, qualitative ways (e.g. Adesina et al., 2016; Becker et al., 2017; Caswell & O'Connor, 2019; Young et al., 2017) and also quantitatively (Gibson et al., 2008; Bennett & Proudfoot, 2016). Other authors have examined good death from theoretical or else normative perspectives (Field & Cassel, 1997; Zimmermann, 2012). The concept of the good death is bound up

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inextricably with normative expectations (Goldsteen et al., 2006), however the normative perspective has been criticised as imposing on carers the sense that they need to put the patient under a degree of pressure to die the 'right' way (Cottrell & Duggleby, 2016; Hart et al., 1998).

It has been said that there is no such thing as a good death, only a 'good enough' one (Masson, 2002; McNamara, 2004), as the preferences of the dying often have to be reconciled to the limited resources available. Other studies have set out a variety of ways of achieving a good death: describing it for example, as planned, peaceful and dignified (Cottrell & Duggleby, 2016) or as associated with dignity and 'personhood' (Chochinov et al., 2015). Regarding place of death, a good death is linked in the imagination with dying at home (Cottrell & Duggleby, 2016; Gomes et al., 2013; Gott et al., 2004).

Most of the literature is at variance with the perspectives of professionals, predominantly those of professional carers (Krikorian et al., 2020; Lang, 2020). Only rarely do we find research that focuses on the perspectives of patients, where patients' notions of a good death are described as individual, unique and varied (Payne et al., 1996, Clarke, Seymour 2010; Caswell & O'Connor, 2019; Krikorian et al., 2020). In exploring the reasons for the scarcity of studies into the perspectives of patients and informal carers, it is sometimes argued that those affected are in too vulnerable a state to be able to talk about death and dying. The opposite is in fact the case, as Bloomer et al. (2018) show in a review article: the dying appreciate the opportunity to participate in research, particularly if they feel their contribution may help others (Gysels et al., 2008). Bloomer et al. (2018) conclude that it is unethical to deny dying persons the opportunity to participate in research, as it denies them their right to autonomy.

In the present study, we aim to contribute to filling this gap by exploring the concept of good dying from the perspective of those affected, i.e. terminally-ill or elderly people and informal carers who have accompanied someone on their end-of-life journey.

We are focusing here on the concept of good *dying* rather than good *death*, acknowledging the social, psychological and spiritual elements of the dying process (Kellehear, 2014) and dying as socially constructed (Van Brussel & Carpentier, 2014).

Material and methods

The aim of the study has been to understand what 'good dying' means when viewed in the light of the experiences of people who are confronted with dying, whether they are terminally ill, whether they are close to dying due to very old age, or because they have been the informal caregiver of a dying person. We strove to answer the question: What does 'good dying' mean from the perspective of those affected by dying?

Design

We chose a qualitative approach, as this enabled us to explore patients' and informal carers' reasoning in depth, using semi-structured interviews thematically focused on 'good dying'. We used the Problem-Centred Interview method (Witzel, 2000), which is halfway between the purely narrative approach and the thematically-guided interview. Narratives were generated inductively but deductive questions were also asked. The interviews were performed with the use of an interview guide that the researchers

NARRATIVE BEGINNING

What was on your mind when you were asked to give an interview on the subject of 'good dying'?

What made you agree to the interview?

FURTHER QUESTIONSSelf-determination and dependence

What is your life like right now?

How important is self-determination to you? How much can you determine yourself? Who will help you to achieve this?

Who's opinion carries particular weight and why?

With whom do you discuss decisions? In your world, who and what has an important meaning, who is missing?

Wishes and support

What do you need? What would you like?

What is helpful? What is hindering? Which persons were/are supportive for you?

What makes a good life for you now in this difficult situation?

What's on your mind right now? What are you thinking about at the moment?

Resource question

What gives strength? Courage? Hope?

Feelings and emotions

What is the predominant feeling?

What is the strongest feeling in your current situation?

What outrages you in the current situation?

CONCLUDING QUESTIONS

If you look into the future, what is important for you?

What would you wish for yourself and others?

Figure 1. The interview guide.

developed as a team and tested in the initial interviews. After five interviews, the interviewers met and discussed the effectiveness of the initial narration-generating question as given in the interview guide. In the original version, we had decided upon 'Please tell me about your situation'. However, as the question did not generate narratives in the desired way, we exchanged it for the 'What was on your mind when you were asked to give an interview on the subject of 'good dying'? What made you agree to the interview?'; this made the beginning of the interview easier comfortable for both participant and interviewer. [Figure 1](#) shows the final version of our interview guide.

Access to the field; sampling criteria

We used a purposeful sampling strategy and strove for maximum variation (Patton, 2002) in order to ensure that the interviewees differed from each other according to a set of demographic criteria, as shown in [Table 1](#).

The initial contact with patients and informal carers was made through gatekeepers, i.e. professional staff mainly in management positions. The organisations were: two hospices providing in-patient and home care services, one palliative care ward in a regional hospital, two nursing homes and one support organisation for patients with Alzheimer's disease. In our research, we included patients with palliative care needs,

Table 1. Sociodemographic characteristics of interviewees.

Gender	Female	Male	
Age	21 Range 44–99 years	11 Average 75 years	
Province	Vienna 6	Carinthia 12	Tyrol 14
Size of community	Metropolitan (> 1 million inhabitants) 6	City (< 200.000 inhabitants) 19	Small town/village (< 10.000 inhabitants) 7
Primary perspective	Patient 12	Relative 20	
Place of care of the patient	At home 9	Nursing home 16	Hospital 7

whose death would not come as a surprise in the foreseeable future; and informal caregivers, who are accompanying or have accompanied a close relative at the end of life, whose death occurred at least three months ago.

As we felt that we had insufficient insight in the recruiting process performed by the gatekeepers, we decided to assess it. Once all of the interviews had been accomplished, we gathered the gatekeepers in three group discussions and asked them to say what their considerations had been. For the gatekeepers it was of utmost importance that the interviews were tolerable for the interviewees and that they received something back from the conversations. They selected people whom they considered to be resilient, whose state of health was a relatively stable and who were comfortable with the topic. The gatekeepers also explicitly assigned participants to us whom they thought would benefit by talking with us.

Thirty-two participants consented to take part in our research. Two of the interviews involved couples, resulting in 30 interviews in total. The sociodemographic characteristics of the research participants are displayed in [Table 1](#).

One noteworthy fact is that women predominated. The ages of the interviewees varied widely: the youngest was 44 years old and the oldest 99; the average age was 75. There was a wide scattering both in terms of province and size of municipality. We conducted more interviews with informal carers (20) than with patients (12), although it was not always possible to clearly separate the two, because of the leaky nature of the boundary between the groups: some of the seriously ill or elderly people had had experience of being informal carers and the informal carers also tended to reflect on their own dying. We have therefore refrained from analysing the perspectives separately and thus have not compared the two. There is some evidence of concordance between the perspectives (Davis et al., 2019), although other researchers identify differing perspectives (Masson, 2002) and yet others emphasise that the perspective of the relative cannot stand in for that of the patient, particularly when it comes to studying people with dementia (Murphy et al., 2015).

The interview recordings are between 33 and 97 minutes long. Some conversations continued after recording ceased and in some cases lasted up to three hours, depending on the extent to which the interviewee felt the need to talk.

Performing the interviews

The interviews took place at locations chosen by the interviewees: at home, in an in-patient setting, at the university or in the office of the hospice organisation. All research participants provided written, informed consent and were asked to renew their consent at the onset of the interview. The interviews were conducted by seven interviewers (four female and three male). All interviewers were researchers with several years of research and/or professional experience in the field of death and dying and come from a broad range of disciplines.

The research received approval from the Ethics Committee of the University of Vienna, reference number 00255.

It has been widely acknowledged that researchers in the field of death studies have to cope with both their own emotional responses and those of the interviewees (Borgstrom & Ellis, 2017; Hockey, 2007; Woodthorpe, 2009), although the researcher's emotions are all too often ignored (Cain, 2012). The interview process included several opportunities for reflection. In a preparatory workshop, the researchers exchanged experiences, expectations and fears. As the interviews were performed in three different Austrian provinces, a great deal of travelling was involved. Although each interview was conducted by a single interviewer, we made the decision to travel in pairs, which allowed us to prepare for, and reflect on, the interviews with a fellow interviewer. To further give structure to the reflection process, as well as to enable us to inform the project lead if the need to talk arose, we agreed to write personal reflective field notes. We began the process of analysis after the first five interviews and started each analysis workshop with an opportunity for the interviewers to share their experiences and feelings.

Borgstrom and Ellis (2017) flag up the emotional labour linked to research into death, dying and bereavement and encourage the cultivation of 'a community of support', leading to a

more nuanced understanding of how the researcher's own emotions become an integral part of analytical processes and knowledge production. (p. 95)

Methodologically, we felt encouraged to make our researcher-self visible and our experiences during the interviews plausible.

Data analysis

We transcribed the interviews verbatim and assigned a pseudonym rather than a number to each interviewee in order to respect their personhood. The data was coded in German and translated for the purposes of publication. The interviewers coded the transcripts individually. We took care that no interviewer coded an interview that they had themselves conducted. In order to introduce an external perspective, three additional researchers who had not conducted any interviews coded interviews and participated in the analysis workshops. All interviews were transcribed by the same student, who participated in the last analysis workshop and added her insights to that analysis. In the following findings section the numbers after participant names represent line numbers from the transcript.

Using thematic analysis, each interview was analysed in isolation by at least two researchers (Braun & Clarke, 2006). We coded the interviews inductively and undertook five analysis workshops in which the analysing researchers met, exchanged initial insights into the coding process and agreed on the level of code abstraction. The project leader and coordinator merged codes into overarching themes and compiled a coding guide that was then used by everyone involved in the analysis (Schmidt, 2007). We discussed the relationships between the different themes and between themes and codes and generated several versions of a thematic map before deciding on a final version.

All authors participated either in the generation of the data or in the analytical and interpretative discussions and all authors contributed to the manuscript.

Findings

We conducted and analysed qualitative interviews with 32 people confronted with dying either as patients or as bereaved informal carers. We examined the key issues that dominated their accounts when asked what ‘good dying’ meant to them. We found 16 overarching themes in total, covering a wide range of topics, as shown in Figure 2. The first version of our thematic map has already been published in German (Heimerl & Egger, 2021). Three overarching themes – ‘dying is never beautiful’, ‘beautiful moments’ and ‘care networks’ – were of particular significance to the interviewees as well as to us researchers.

The participants explained in their accounts that social networks are more important to them than places of death. They told stories about family, professional and civil society networks that gained in importance as death approached. We have published our findings on the theme of ‘care networks’ in German (Egger et al., 2019).

<p>Dying is never beautiful</p> <ul style="list-style-type: none"> Enduring pain and suffering Bodily <p>Beautiful and enjoyable moments</p> <ul style="list-style-type: none"> Beautiful and elevating Enjoying life Living everyday life <p>Caring network</p> <ul style="list-style-type: none"> Familial Professional Civil society Between loneliness and being alone Place of death <p>Biography</p> <ul style="list-style-type: none"> Conflict and reconciliation Self-reproach Near death <p>Autonomy and self-determination</p> <ul style="list-style-type: none"> Self-determination Autonomy Making decisions (surrender) Safeguarding 	<p>Needs of the dying</p> <ul style="list-style-type: none"> Needs of the relatives <p>Time to recognise</p> <ul style="list-style-type: none"> Plain speaking, communication Open conversations about illness and dying Letting go Philosophical questions and thoughts <p>Dementia</p> <ul style="list-style-type: none"> Incurable dementia Alzheimer's Eating Dealing with people with dementia <p>Quality of care</p> <ul style="list-style-type: none"> End-of-life care <p>Wishes to die</p> <ul style="list-style-type: none"> Exit (Swiss Euthanasia Association) <p>Letting go and saying goodbye</p> <ul style="list-style-type: none"> Rest/restlessness Being allowed to die Redemption Farewell 	<p>Images of the end of life and coming to terms with dying</p> <ul style="list-style-type: none"> Concluding something/being at peace Conditions of good dying Concept of dying, death and the hereafter Experiencing dying <p>Spirituality</p> <ul style="list-style-type: none"> Faith and religion Metaphysical <p>Financial</p> <ul style="list-style-type: none"> Making money with hope Pocket money and medicines Pharmaceutical industry <p>Artefacts</p> <ul style="list-style-type: none"> Things/artefacts/objects Question about places and things <p>Feedback on the interview and motivation to participate</p> <ul style="list-style-type: none"> Help The interview itself Wishes for the future Motivation for the interview
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Figure 2. Thematic map – Overview.

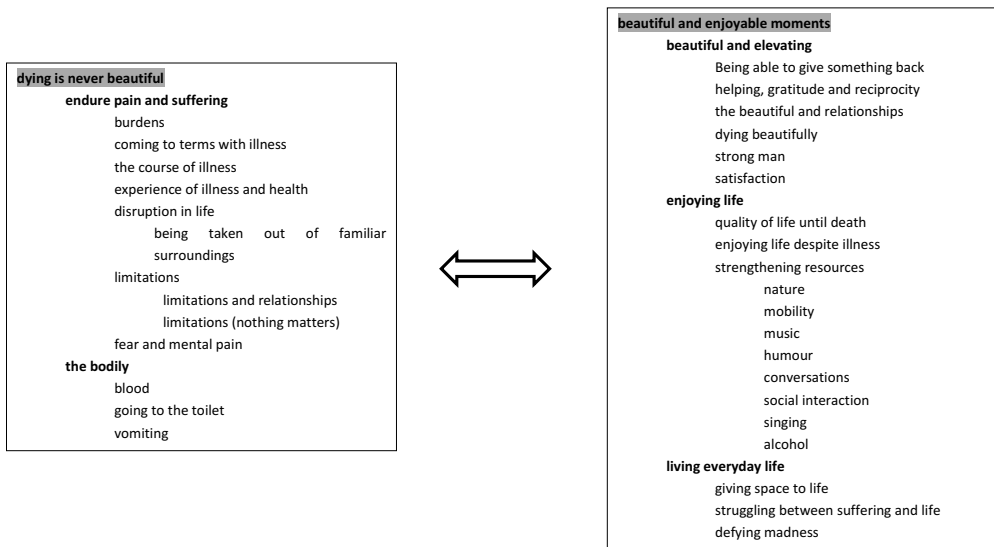


Figure 3. Thematic map of the themes ‘dying is never beautiful’ and ‘beautiful and enjoyable moments’.

Each main theme consisted of several codes; those pertaining to ‘dying is never beautiful’ and ‘beautiful and enjoyable moments’ are displayed in [Figure 3](#).

Dying is never beautiful

The accounts often started with statements to the effect that dying ‘is not good’ or ‘is never beautiful’, followed by stories about the difficult aspects of dying. A patient on a palliative ward suffering from advanced cancer summed it up briefly:

May I tell you something? There is no such thing as a good death.(Wolfgang Strasser, 894)

When someone is facing death, inquiring about ‘good dying’ sometimes elicits an angry reaction that, while directed at the researcher, in fact concerns the interviewee’s overall condition:

My God, what’s the point of asking me that when I’m lying here dying? I’m lying here waiting to snuff it. I’m going to snuff it really soon, aren’t I? What is it you want me to imagine? I’m not a dreamer ... I know what I’ve got - I know I’ve got you-know-what. (Herwig Achatz, 506-509)

Wanting to contemplate ‘good dying’ is framed as naïve (‘I’m not a dreamer’), because the reality of being at the end of one’s life is harsh. How did dying and death emerge as ‘not beautiful’ in the interviewees’ narratives? Those affected spoke about the need to endure pain and suffering and about the burdens and difficulties of coming to terms with illness.

Disruption of social roles and meaning

Dying is of course always connected to living, until the moment of death. For example, one interviewee experienced his life as having been full of deprivation; he felt that his life's balance sheet was decidedly negative and that his end of life was now marked by pain that was difficult to control. He was our first interviewee, was seriously ill with cancer and a patient on a palliative ward

Men, human beings, are strongest on their own, because then they don't have to be considerate towards other people. These days, as soon as you have to be considerate towards anyone, especially when you're ill ... (Herwig Achatz, 87-89)

Terminal illness is challenging his traditional and biographical role and perception of himself as a 'strong man' and thus evinces anger. His physical deterioration and declining abilities are accompanied by a perceived loss of autonomy that does not align with his customary role in the world. Throughout the interview, he linked his present situation to his difficult life of hard graft and made it clear that he could not see anything positive about his situation and survived by just living from day to day.

First of all, ... what is there to describe? ... You can't describe it. Every day is a new day, a new experience. I have to experience every day afresh, every day I have to cope with my pain, with my condition, and make the best of it. (Herwig Achatz, 102-105)

In these interviews, dying was described in negative terms because it disrupts one's position in society, because it questions life's meaning and one's role in the world and takes away one's autonomy.

Leaving family behind

The informal carers emphasised the burden that caring for a terminally ill person involves. Speaking as someone who cared for her husband as he was dying, one interviewee was convinced that there was no such thing as beautiful dying; she emphasised this several times:

I don't know that there's anything to say about dying beautifully? It isn't beautiful (. . .) I don't think there's any such thing as a beautiful death. I don't reckon there is. Because, because, even if the person affected slips away peacefully, let's say, it's never beautiful for the people left behind. (Waltraud Maier, 3746; 3490-3499)

Here, in viewing dying as 'not beautiful', it is not just about the person dying, but also about the relatives: those who are left behind. While dying may, for the person dying, involve peacefully slipping into death, those 'left behind' may make a different emotional appraisal, because they have lost an important person in their lives.

Physical pain and symptoms

The absence of beauty is especially apparent in accounts of symptoms and pain, including breathlessness and fatigue. In the interviews, this was expressed by describing the parts of the body which are painful, or else the body as a whole:

But other than that - you - I'm just a ball of pain, really. A lot of pain. My neck hurts and everything. My whole body's a ... ball of pain. My joints, well, I've done a lot of manual work, a lot of cleaning all over the place. And as a child, I don't think I got enough to eat really. And during the war I was always starving. (Erika Graf, 1178-1189)

or by describing one's reduced or complete lack of ability to carry out everyday tasks such as going to the bathroom:

And nowadays I've got to the point where, if I need to go to the loo, I can't even get there by myself, . . . I need a wheeler and I have to stop pretty much every three or four meters because I just don't have enough puff. (Hermann Schmidt, 240-242)

The pain as described in the narratives is often a physical one, expressed as actual suffering and disgust relating to a loss of control over one's own body or its degeneration. Although the participants did not express it this way, it could also be interpreted as existential pain in the face of impending death. In one of our interviews, the physical experience was particularly prominent. Ms. Zimmermann lived at home and had advanced cancer. She struggled to find the right words to talk about the vaginal bleeding that she experienced after the menopause, the first physical sign of her cancer:

And then I said, I had to . . . think it through. I was really confused and upset . . . I really went through a lot, and I said: "I've got this thing." (Roswitha Zimmermann, 1864-1866)

The confusion, the suffering, and the indescribable 'thing' point at a certain speechlessness in face of a diagnosis that the person cannot accept. Later in the interview, she associated the shame and fear with the physical symptoms of her cancer, which in turn resulted in her speechlessness.

Some things in the physical realm emerge not from the transcripts but can nevertheless be heard in the recording. For example, during the analysis process, one of the interviewers tells the others that the participant vomited several times during the interview. This can be inferred from the text passage which follows, where the vomiting has been replaced by [. . .]:

It'll only be some water again in any case, or now and then some wine, but when it's wine, I'll only swallow a bit, I'll have a little taste. It tastes really, really wonderful. [. . .] I swallow some but then right away, "whoosh", [. . .] it comes straight back up again. (Wolfgang Strasser, 118-127)

It was not merely the participants who were speechless from time to time. When faced with the symptoms exhibited by the dying, we as researchers had to suppress our automatic responses in order to be able to accept this very human and not at all beautiful aspect of dying.

'Isn't it beautiful?' Beautiful and enjoyable moments during the dying process

Although in many respects, dying is 'never beautiful', our analysis reveals that those who are terminally ill and their carers both report experiencing beautiful and enjoyable moments. Those affected address beauty in the dying process when they speak of reciprocity, of the possibility of 'giving something back', of showing gratitude. They talk about the beauty in their relationships, about the beauty of being a strong man, of being satisfied or even in some way happy. This was the case for Wolfgang Strasser, who first of all talked about there being no good way of dying and about the pain, but concluded by saying that he was happy:

May I tell you something? There's no such thing as a "good death". There's only the hope of not wasting away like a, . . . racked with pain and everything, until the devil finally gets you (. . .) Anyway, I've got this thing, my pain pump. It turns on automatically every so often, every quarter of an hour . . . Suits me. I don't have any pain; I can have a drink . . . So, you could say I'm "happy." (Wolfgang Strasser, 894-940)

While the notion that there is no such thing as 'no good dying' pervaded Wolfgang Strasser's narrative, he still found some things in life to enjoy, with the help of technology such as his analgesic pump or in sipping his favourite drink. In this as in other instances, good and bad dying are closely linked in the narrative; beautiful moments can be experienced even within a situation that is assessed as being 'bad' overall.

Beautiful moments

Even Waltraud Maier, for whom dying is never beautiful, thought that there were in fact some beautiful moments during the time she looked after her dying husband.

During those two years, he did occasionally have some very good times. Despite everything . . . Trips to the lake or going out for a good meal or something. Going out for a beer somewhere. (Waltraud Maier, 3194-3293)

These beautiful moments are to be found when one leaves one's home (or hospital room) and experiences different surroundings, by leaving the environment that is associated with one's final illness and end-of-life care. However, they can also happen in simpler ways, such as enjoying good food or even just by looking out of the window and taking pleasure in the scenery.

An older man touched us with a story about a conversation that he had with his wife shortly before her death:

May I tell you, may I tell you something . . . about my wife? The lovely thing that happened was that, before she went into the hospice, she was sitting up in bed on a beautiful autumn day. It's sad, you know, when you know that it's . . . she's going to leave you. And outside you can see nature in all its glory . . . and she sat up and said: 'We don't actually know which of us will go first'. And I said: "No, Anna, we don't. And she said: 'But if I go first . . . and you follow me' and then her eyes lit up and she said: 'then I'll run to meet you'. Isn't that beautiful? (Anton Riegler, 315-366)

Here, the beauty comes not only from one's surrounding (the 'beautiful autumn day'), but also from the metaphysical, spiritual idea expressed at that moment of being together for eternity. It is a moment of togetherness and of trust in the permanence of the couple's romantic bond with each another. The close, warm relationship has beauty for Mr. Riegler.

One couple experienced a particular moment at the point of her mother's death which they described as 'beautiful'. In their words, it is something 'beautiful and wonderful' to have the privilege of caring for someone. They described the ritual of letting a soul go as being especially beautiful:

It was so beautiful. After Mom left, we opened the door, the balcony door. it was so beautiful to be able to let her soul go. It was so beautiful. (Karin and Andreas Neubauer, 962-965)

In the last moments of life, as the soul leaves the body, some research participants reported experiences beyond the physical; experiences which could be categorised as metaphysical. Elfriede Koller described a vision she had when her mother was dying:

And then suddenly I see this blue, blue figure coming out of her head, right? And then behind her, on the wall, suddenly a shining, yellow-white . . . crack opened up, you know? And . . . it got bigger and bigger and . . . then it was somehow like this, this, this giant tunnel or something . . . A beautiful, circular area, yellowy-white, really dazzling. And in it, these figures were floating: And then the blue figure went into it. And I had this feeling that she was going to leave now. That really felt like a gift, for me. (Elfriede Koller, 1935-1979)

After a long and intense relationship with her mother, Mrs. Koller felt that the beauty of the vision she had had when her mother's soul was leaving her body was a gift. In both interviews, the process of dying was described as a long one with ups and downs, with the last hours described as peaceful and the very moment when the soul left the body as being beautiful.

Paula Jäger told us that the moment of saying goodbye to her mother after she had died had beauty:

I went in at eight in the morning with the clothes and then I . . . she was still in the room and I said: "I can't go in. I can't go in." I said that a few times, but the head nurse knew that I did want to, and she said I should go in, and there was my mother lying in the room . . . with a white sheet over her and a bunch of tulips in her hand and she looked really beautiful. There she was with her pointy nose and she was so beautiful. (Paula Jäger, 731-738)

Even if the interviewees described difficult aspects of and moments in their relationships with the deceased loved ones that they had cared for, the dying process itself is connected with beautiful moments. For some, the beautiful moments happen only at the very end.

Enjoy each day 'as if it were the last'

Beyond experiencing individual moments that it is possible to enjoy, there is a sense in the interviews of a broader idea of finding joy during the time that remains. Many of the interviewees were seriously ill and suffering from pain or other distressing symptoms, yet they spoke of enjoyment:

Stay positive and . . . live every day as if it were your last and enjoy life. How you do that, everyone needs to work out for themselves. I don't think you can ask for much more than that. (Paul Vogl, 779-823)

There are also enjoyable moments in the life of the interviewee below, who was living at home and suffering from advanced cancer. He was a man for whom self-determination was very important. Even now that his life was coming to an end, there were pleasurable moments, where being outdoors and experiencing nature played a major role:

I am not preparing myself all that much for what's coming. I'm enjoying life. The spring, and the good weather. That gives me strength, unimaginable, unimaginable strength. (Rudolf Haas, 238-242)

It is almost as if enjoying every single day might be able to put off the day of dying:

Today was a beautiful day, so that's . . . you can't die on a day like this. You just can't. (Rudolf Haas, 422-428)

Feeling a connection with nature makes the end of life beautiful for Jutta Ebner, too, who was very old, suffering from cancer and had moved to a nursing home a few months previously. She was bedbound but still enjoyed the beautiful view through her window

And of course, the beautiful view. I just look out and enjoy the beautiful . . . surroundings. The mountains and so on. (Jutta Ebner, 453; 713-720)

Quality of life is also mentioned in conversations on the subject of ‘good dying’. For Barbara Fischer – an elderly woman living alone – maintaining her quality of life is of utmost importance. She explained that for her, quality of life is about more than just going for a walk. There were many ways in which she could contribute to her own quality of life:

Quality of life isn’t only about things like for example, the fact that I go for a walk every day, I was out and about at seven a.m. again this morning. It’s not just about things like that, but about other things that you can take pleasure in, too. A good book, if your eyesight will still allow you to read, listening to beautiful music. The little pleasures in life. (Barbara Fischer, 143-147)

The interviewer asked her whether her thoughts about her quality of life had anything to do with dying and she affirmed:

Yes, and I hope it’ll stay that way. I have this idea that, that I’ll continue to be able to do these things, but I don’t know if that’s true. I don’t know. I hope I’ll be lucky enough to be given this gift. (Barbara Fischer, 149-159)

Music and singing provided some of the interviewees with enjoyable moments. Siegfried Pfeifer had recently lost his father. Although his narratives tended to be on an abstract level – relatively unemotional with few illustrations – he was fairly specific about the beautiful moments at the end of his father’s life:

At the very end, music was very, very important to him. So we, that’s why he was, it wasn’t just because that was where the stereo was, but we, we made sure he had access to his classical music, right up to the end . . . because it meant a lot to him. (Siegfried Pfeifer, 956-959)

For Wolfgang Strasser, who had advanced cancer and could hardly swallow, alcohol had always been an important part of life. Now that he was on the palliative ward, he was given frozen cubes of alcohol that he could allow to melt in his mouth, and this gave him great pleasure:

I used to drink an awful lot. Letting it melt in your mouth is like having your birthday and Christmas all rolled into one. (Wolfgang Strasser, 148-160)

Living an enjoyable life, enjoying life right to the end, is an important concern for people who are dying. Because time is limited and one’s physical capabilities are deteriorating, what is really important in life becomes increasingly evident to those affected. It is about finding a balance between the closeness of death and the beautiful and enjoyable things in life.

Being able to live a normal life

We heard from the research participants that good dying is about creating a daily routine despite the fact that death is ever-present: an everyday life consisting of washing clothes, baking cakes, knitting and going for walks.

I can walk and knit and read, play solitaire . . . or listen to the radio, watch TV. Or cassettes and CDs. (Jutta Ebner, 704-711)

A daily routine is important, even if the severe disease and the burden of symptoms often make it impossible for the patients to foresee how the day will turn out:

Then I went home. I hung up some laundry again and just messed about. Did lots of little things. Several packages arrived, but well, my days aren't planned out or structured. Whatever happens, happens. (Rudolf Haas, 452-460)

Good dying also includes being able to go to beautiful places without needing any help to do so. Barbara Fischer, for example, emphasised that mobility was an expression of autonomy, and that this contributed to her quality of life:

When I leave the nursing home, I say to myself: "See, now you can get into the car, you're still able to use your brain when you're driving and your feet too."(. . .) Driving a car is an act of freedom. (Barbara Fischer, 507-518)

Beauty emerges in those parts of the interviewees' accounts in which they are able to maintain a sense of a 'normal' life; one where their identity is preserved. By keeping going they find meaning in their everyday habits and things that, while 'ordinary', distract them from the finite nature of their lives and those facets of the end of life which are less than beautiful.

Discussion

Those affected provided insights into the process of dying from their own individual perspectives. They communicated to us that the process is not only physical, but also psychological, social and spiritual. When analysing the interviews, we noticed that those features of the end of life which are 'good' are repeatedly described using the adjective 'beautiful'. Previous academic work has dealt with different aspects of beautiful dying and death (Ariés, 2008; McInerney, 2007; Song, 2015; Wilches-Gutiérrez et al., 2012). In her work on approaching death from the perspective of aesthetic experience, Song (2015) concludes

If we could change our final life journey into a beautiful garden with an aesthetic vision, then death to us is no longer a horrible experience but a pleasant, natural and beautiful one. (p. 111)

Our analysis of the interviews has given us the insight that those affected are not talking about the aesthetic dimension when they speak of beauty. In their 'beautiful stories', it is a moral emotion which resonates and which elevates the mind. Haidt (2003) describes the moral emotional 'elevation' as a positive emotion capable of 'uplift[ing] and transform[ing] people' (p. 275). Elevation has also been defined as an emotional reaction to acts of moral beauty (Pohling & Diessner, 2016; Turner & Stets, 2006). In many of the narratives and in many ways, our interviewees describe elevating feelings that are connected to their experience of dying and death.

In this paper, we have shown how those affected by dying assess it in an ambivalent way: never beautiful on the one hand, but as including beautiful moments on the other. The interviewees connect dying with pain and suffering, and with bodily symptoms which act as a burden, deteriorating abilities that act as hurdles, and the inevitability of leaving behind grieving relatives. Many interviews begin with a description of the bitterness of

dying, of pain, distressing symptoms and deeply-felt grief and loss. Despite this, the accounts speak of beauty and even joy at the end of life. It is often not until later on in the interviews that interviewees speak of beautiful and enjoyable moments, of sucking on the frozen cube of a favourite drink, of enjoying the beautiful weather or remembering beautiful situations with the loved ones they have lost. To live a full and enjoyable life, to enjoy life to the end, is a common desire among dying people, as has also been shown in earlier work (Kellehear, 2014). Precisely because there is an awareness that time is limited, one's understanding of time becomes more immediate and real (Ellingsen et al., 2015).

There is a tension in the participants' descriptions of 'good dying' between the idea that 'dying is never beautiful' and the fact that 'beautiful and enjoyable moments' do occur at the end of life. The responses seem contradictory, at first glance. Is dying beautiful or not? Our analysis shows that both are possible at the same time. This reminds us of Masson's (2002) study of patients and relatives. Participants acknowledged that tensions and paradoxes are in the very nature of dying: What may be or may have been good for the dying or deceased person, may not be what the relatives want. It feels important to emphasise the ambivalent character of end-of-life experiences. In raising the question, 'Is there such a thing as a good death?' Walters (2004) suggests,

that thinking about good death should be broadened to accept the struggle with which many people face their death. (p. 404)

In a way, our research turns the relationship around: despite the pain, suffering and physical decay, those affected tell of beautiful moments.

Between 2014 and 2015 the Austrian Parliament held an Enquete Commission entitled *Dignity at the End of Life*. Lang (2020) has analysed 15 documents produced by the Commission and 58 written statements made to the Commission by the public. He concludes that the public debate in Austria is dominated by three themes: (1) a view of dying as a long and painful process undergone by old or ill people; (2) the need for institutionalisation for terminally ill people so that pain and other symptoms may be properly controlled; and (3) normative opinions about voluntary euthanasia and assisted suicide. The latter issue has received attention in recent months as a result of the Austrian Constitutional Court's lifting of the ban on assisted suicide (Frühwald et al., 2021). Contrary to this trend in the Austrian public debate, good end-of-life care – according to Kellehear (2016) – requires much greater attention to the needs of elderly and terminally ill people, as well as to the social process and the better embedding of dying into society; but above all to the perspectives and viewpoints of those directly affected. Just as Kellehear (2016) says, the Austrian public discourse, too, has not paid enough attention to the perspectives of those directly affected.

Limitations

The majority of our gatekeepers were working in specialised palliative care. This is due to the fact that we have a long history of collaboration with this field. As discussed in the Methods section, the gatekeepers chose research participants whom they considered to be physically and emotionally resilient. Some voices are missing, for example, those who withdrew from the study and those who were not able to articulate their views, such as those with dementia. It has been argued that greater attention is needed into what 'good

death' means to people living in different types of social settings (Burles et al., 2016). Marginalised groups, such as people with disabilities, prisoners, homeless people and people with a migration background did not have their say in our interviews. Including these groups and using a more diverse range of gatekeepers might have resulted in differences in the research outcome.

Conclusion

Dying people and people who had cared for a dying person gave us insights into their ideas about 'good dying'. It became clear that the process of dying has not only a physical, but also a psychological, a social and a spiritual dimension. For those affected, dying is never beautiful, but there are beautiful moments that are linked to elevating moral emotions. We conclude that an important element of good care for the dying should be to make beautiful moments possible. This requires reflective spaces for those affected to state their wishes and express what they consider a beautiful moment to look like.

Our study shows that the views of those affected differ significantly from those we hear in the public discourse. We conclude that the public debate on 'good dying' should give a voice to those affected: to terminally-ill and elderly people and to their informal carers. The academic discourse can make a contribution by differentiating between various perspectives and by researching the points of view of those concerned.

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