



'Ambivalence' at the end of life: How to understand patients' wishes ethically

Nursing Ethics
19(5) 629–641
© The Author(s) 2012
Reprints and permission:
sagepub.co.uk/journalsPermissions.nav
10.1177/0969733011436206
nej.sagepub.com


Kathrin Ohnsorge

University of Basel, Switzerland

Heike R Gudat Keller

Hospice Arlesheim, Switzerland

Guy AM Widdershoven

VU University Medical Center, The Netherlands

Christoph Rehmann-Sutter

University of Lübeck, Germany

Abstract

Health-care professionals in end-of-life care are frequently confronted with patients who seem to be 'ambivalent' about treatment decisions, especially if they express a wish to die. This article investigates this phenomenon by analysing two case stories based on narrative interviews with two patients and their caregivers. First, we argue that a respectful approach to patients requires acknowledging that coexistence of opposing wishes can be part of authentic, multi-layered experiences and moral understandings at the end of life. Second, caregivers need to understand when contradictory statements point to tensions in a patient's moral experience that require support. Third, caregivers should be careful not to negatively label or even pathologize seemingly contradictory patient statements.

Keywords

Ambivalence, end of life, identity, narratives, patients' experience, wish to die

Introduction

Frequently, patients at the end of their lives express seemingly contradictory feelings, expectations or preferences with regard to their illness and their death. Palliative care professionals and families often find themselves confronted with patients who on one day hold something as important, while the next proclaim to be in favour of its opposite. This might be especially true if patients state that they wish to die. Nurses as well as physicians might be perplexed by palliative care patients expressing a wish to die, while asking for 'everything curative to be done'. If others cannot reasonably decode these opposing statements, there is likely to be confusion or irritation in the caring relationship. Sick people might be perceived to be 'ambivalent' or 'inconsistent' in their wishes or preferences.

Corresponding author: Kathrin Ohnsorge, Institute for Biomedical Ethics, University of Basel, Missionsstrasse 24, 4055 Basel, Switzerland
Email: kathrin.ohnsorge@unibas.ch

This article investigates these seemingly contradictory normative statements by patients in communication with others, from a hermeneutical-ethical perspective. We understand 'normative statements' as statements that directly or indirectly include moral claims regarding oneself or others. We will argue that these 'seemingly contradictory' patient statements can frequently be seen as 'naturally' belonging to the process of meaning making and negotiation about normative claims that happen on a personal level as well as in interactions with others. From a hermeneutical perspective, ambiguity and multi-layered meaning belong basically to the nature of personal meaning and moral understanding.¹ But we also want to show that there can be moments when contradictory statements become problematic in a personal life history and might indicate the need for further examination and deliberation.

This hypothesis emerged from the analysis of a series of empirical case studies in the context of a larger interview study (for the methodology see Table 1). Here we will focus on two case examples from this larger study: the stories of two women, Anna and Carola (pseudonyms), who suffer from terminal cancer and are both aware of their imminent death. Both inpatients of a hospice, they experience contradictory feelings and wishes regarding their life and their dying. In both cases, the caregivers, especially the nurses, are aware of these tensions and have various reactions towards them.

We hope with this article to contribute to a more careful and reflective practice of understanding patients' experiences and meaning making at the end of life and nurses' role in this practice.

Theoretical background

Clinical experience⁵ and empirical studies in end-of-life care^{6,7} have shown that many patients react with fluctuating behaviour to their illness and physical state, often oscillating rather than showing clear-cut preferences. A large number of studies, for example, observe the phenomenon of shifting patient attitudes and preferences regarding life-sustaining treatments as expressed in advanced directives.^{6,8-11} Some studies report oscillating preferences among dying patients towards a possible wish to die.¹²⁻¹⁵ Only very few authors indicate possible ways of dealing with these shifts in patients' attitude,^{7,16} although several authors state the need for further and more detailed research on this phenomenon.^{14,17}

In fact, in the literature, we can find very few investigations into the actual moral world of patients and what they experience when they express what seem from outside to be 'oscillating preferences'. An exception is the study of Sissel Johansen and colleagues,¹⁴ in which they show that wishes for euthanasia or physician-assisted suicide are generally characterized by a 'fluctuating, ambivalent, hypothetical and future oriented' nature. In their discussion, they suggest that the reason for this may be a series of strong emotions such as

fear of future pain, and a longing for a release from both physical and mental suffering. Love and commitments to loved ones, will to live, and hopes for the future are, on the other hand, emotions that run counter to such considerations.¹⁴

Johansen and colleagues emphasize the need for further empirical and reflective investigation of this phenomenon. This is what this article aims to provide.

To investigate what patients actually experience when expressing contradictory wishes, we follow a hermeneutical approach. Hermeneutics suggests that what we experience is essentially structured through our interpretations of the world and the meaning we give to it. This interpretive process of meaning making is based on non-cognitive as well as cognitive pre-understandings of everyday life, which do not necessarily have to be articulated and are not always accessible to reflection but that are the starting and reference point for our rational knowledge about the world.^{18,19} We come to make sense of ourselves and the world we live in, by embedding what we experience into stories.²⁰⁻²² In these stories, we give meaning to our experiences

Table 1. Terminally ill patients' wish to die. The attitudes and concerns of patients with incurable cancer towards the end of life and dying

Main research question	What do terminally ill patients mean when they express a wish to die?
Interviews	Semi-structured interviews of 1 hour with patients and families; 20 minutes with caregivers; tape-recorded and transcribed in full.
Number of case studies	Thirty case studies (one case study consists of one to two patient interviews, one family member, one nurse, one physician). The combination of these interviews enabled us to analyse the meaning of the death wishes and the interactions surrounding them more in depth.
Overall number of interviews	N = 116
Sampling	All patients, their families and caregivers from one hospice and one hospital palliative care ward during the study period 2008–2011 that met the inclusion criteria.
Inclusion/exclusion criteria	Inclusion: patients with incurable cancer (palliative situation), already informed about the incurability of their disease, willingness to participate, physicians' OK for being interviewed, and sufficient language skills. Exclusion: cognitive impairment of a degree and kind that is incompatible with the interview.
Method	A combination of Grounded Theory ² and Interpretive Phenomenological Analysis. ³
Data analysis	Continuous analysis during the interview period. An initial close independent reading of transcripts by three researchers was followed by a deliberation between these researchers about their interpretations for each separate case study. This led to a list of emerging themes for each case study (higher-order themes with several sub-themes). Cluster of case studies and the interpretations of the main researchers were regularly discussed in whole research group meetings (including the group of interviewers who also read the transcripts) (= independent audit). This led to a continuous refinement of the list of emerging themes as well as to an adaptation of the interview questions. Finally, a combined list of genuine 'emerging themes' (arising from the analytical process) and 'set themes' (initially defined research questions) was established, which supported the final data analysis and ethical discussion. ⁴
Cases presented in this article	The case of Anna corresponds to P6, the case of Carola corresponds to P2 in our larger interview study. Names and ages are changed to safeguard confidentiality.
Overall results	See forthcoming publications.
Research ethics approval	From the Ethikkommission beider Basel (Ethics Commission of Both Basel).

and generate a meaningful relationship between different aspects of our experience. The stories we tell about our lives contribute to our sense of identity. These stories do not always necessarily represent a person's entire world view but are more frequently fragments of one's understanding of the world.^{23,24} Stories are usually *reflective*: experiences become rational-conscious experience through articulation and interpretation, but they are also *performative* as the new interpretations that happen in story-telling influence again the ways we relate to things, and they are often *evaluative* in a moral sense, as they contain moral judgements about what is personally held to be important or valuable, unjust, humiliating or shaming.²⁵

Looking at what patients care about in terms of 'narratives' and not only – as happens most frequently in bioethics and palliative care – in terms of 'preferences' enables us to see how meaning is personally attributed, and the moral reasoning that persons hold when they express certain preferences. For the American philosopher Margaret Walker, personal identities are narratively constructed, as we both define and constitute our moral identities through interpretive, narrative activity.²⁰ This constitutive process is the outcome of interactions with others and includes their judgements, ideas, expectations, the way they perceive or react

to what we say or the assumptions we have about what they might believe.²³ The way patients talk about what is important to them also includes in this sense what their surroundings or the persons they talk to (caregivers, families, friends) suggest, the ideas they pursue (or are believed to pursue), how they react to them or what they assume to be morally or rationally permissible. Consequently, the process of understanding the story of the other is, from a hermeneutical perspective, not simply a neutral act of listening or observing. Every time we listen to and interpret somebody's story we are drawing upon (mostly implicit) assumptions about what we ourselves hold to be significant. This becomes important when looking at the assumed 'ambivalence' of others, as we have to ask how to locate this assumption within the interaction between persons.

We understand 'ambivalence' in this context as to have mixed feelings or contradicting ideas about a decision to be taken in end-of-life care or about the coming end of life itself. In our data, the term appeared in several caregivers' statements when they described how they saw their patient. It has, however, not been used by the study patients themselves. We acknowledge that there is a large psychological discussion on this issue.^{16,26} Here, we shall discuss the phenomenon of 'ambivalence' from a moral perspective.

Analysis

The two cases we present here were selected because the nurses, or members of the health-care team, including the nurses, described the patient as 'ambivalent'. However, we believe them to be exemplary of what patients and their caregivers can experience, since the notion of 'ambivalence' appears in related ways also elsewhere in our sample of 30 case studies (more publications to follow).²⁷ The analysis of the narratives resulted in several higher order themes. The main theme of the article, 'ambivalence towards dying', was one of several higher order themes. Other themes will be reported elsewhere.

In our analysis, the higher order theme 'ambivalence towards dying' emerged out of several sub-themes that we want to describe here for each patient narrative. First, the two patients have different wishes or expectations regarding their own death. To explain these wishes they invoke different frameworks of meaning that contribute to their sense of identity. Second, these wishes provoked reactions and interpretations in the caregivers that led them to see the patient as 'ambivalent'. Third, the expectations and roles that people attribute to each other in interactions are closely linked to the fact that someone might be perceived to be 'ambivalent'.

Anna

Different frameworks of meaning. Anna came to the hospice after she decided against further diagnostics to clarify the malignancy of a tumour in the abdomen and an operation recommended by the physicians in the clinic. In the hospice, it was agreed, together with her and her family, that she would be treated with a palliative comfort therapy. In the hospice, where we interviewed her, Anna stuck to her decision against further diagnostics and therapy. She felt prepared for death and confirmed repeatedly that she wanted to let 'things run as they run'.

I let it go now. I have lived like this myself, and just as it comes, I tell myself, yes! Well, I am ready to, yes!

Anna argues that she personally does not want to undergo an operation because she fears that the outcome might not be positive. But she also mentions that at 80 she does not feel socially obliged to do so. Her acceptance of her condition arises from her sense of a long and fully lived life that seems to enable her to accept whatever might happen in future.

In the interview, Anna introduces next her joy and curiosity about life after death. Several times, she confirms that she is looking forward to her existence after being diseased and she explains this through her explicit spiritual beliefs:

Interviewer: So, you are looking forward to it, to the other that is coming then.

P: Yes! Yes. Of that I have no fear. Maybe of the dying, yes when you don't know what will happen to you. But after death? To that I can look forward. I read so much about it and . . . yes and it shall continue.

She describes then that this 'looking forward' to death was not so much a desire to end her existence, which she had always enjoyed, as much as the happiness about going to 'another level' of existence. The data reveal that her strong spiritual appraisal lets her see her death as an inevitable passage to another form of existence to which she is looking forward. Her spiritual conviction of the continuity of existence represents a strong evaluative framework, within which she interprets her current condition and treatment decisions.

But Anna's identity relies – as for most of us – on more than one evaluative framework. In her ideas about her body and about medicine, Anna also invokes a naturalistic framework of meaning. In the interview, Anna reports that she is reluctant to take medication, as she believes the body has, in principle, the force to heal itself:

And then I always had a little bit this aversion to medication. I always said: 'Yes, medication, it always shifts the symptoms'. You have to look for the cause, to look for the cause of why it is like this.

However, she also explains that in some situations medicine might help:

P: Yes, I see it a little differently now. That when I really cannot move myself anymore, the fact that then my pill helps can also be of help.

I 2: And that you are also allowed to take them?

P: I'm no longer so extremely against pills. They are also necessary. But, simply I do not want to overdo it.

In this excerpt, she seems to say that she has had a change in her ideas about medication: from a rather strict reliance on the healing force of the human body to a more tolerant position that allows her to accept medication under certain conditions.

'The patient shows an impressive ambivalence'. To the hospice workers, Anna gave the impression of being cheerful, filled with equanimity and certain about what she wanted. Nevertheless, in the following weeks, the health-care team in the hospice experienced some difficulties due to her seemingly contradictory statements. In front of the health-care team, she stated that she was prepared for death and that she did not want any further diagnosis or curative treatment. But when it came to medical decisions at critical moments, it was not clear for the health-care team what she really wanted. The physician we interviewed reported that on several occasions, Anna was not against further curative therapy that was proposed to her. On two occasions, she accepted antibiotics against an infection causing a heart insufficiency. One of the hospice physicians concluded from this that the patient showed an 'impressive ambivalence'. In the medical charts, he wrote about the patient:

Next to the wish for being burden-free and for having strength in good times, she has the wish to take no further medicines and to be able to die soon . . . If she experiences burdens, she wants help (life) – if help lies in

medication, she doesn't want to have medication, but prefers to die. This ambivalence is for the patient, the relatives and us [the health care team] a big problem. (Medical Chart Notes)

On the other hand, some nurses perceived the patient to really want to die. During hygiene care, Anna shared much of her life philosophy with the nurses. Several times she stated that she had enough of life, that she would be prepared for death and that she did not see any sense in a life in which she was a burden to others, even though she felt very well cared for in the hospice. Her physician said in the interview:

The nurses have often heard or noticed that she said: 'I actually want to die. It's actually enough now'. And they have said: 'She wants us to stop'.

According to the physician, the nurses concluded that Anna wished to die and that she did not want to be treated any longer. Among the health-care team, there was increasing confusion about what Anna actually wanted.

'My wishes are actually in balance'. In the interview with us, Anna indeed describes that she has two different desires: one to be able to walk again and to live on her own again and the other to be able to die.

P: That is exactly the contradiction! Either going home and being able to walk or . . . simply starting the journey . . . Yes, on the one hand I want to go home and on the other hand, I think: Yes, now I just would be ready. Why not? But there is somebody else deciding. The time is not yet here, it seems.

I 1: And yet you also want to go home.

P: I would like to go home, yes! This, yes. But not now, like this. Then I would rather prefer to continue over there and shht . . . [movement with the hand towards the ceiling].

I 2: How do you experience this contradiction, on the one hand the thought, which seems to make you happy, of really going home, really being back in your apartment, but also the other thought, of going to another level, both . . . ?

P: Both are actually in balance.

I 2: And yet you say that is a contradiction? Where does that lead? What is that?

P: When I always speak about going home and say . . . that is a contradiction? I don't know, yes, but that nobody knows when the time is coming.

In this interview extract, Anna expresses that she sees in herself a logical contradiction with regard to wishing both to go back to her own apartment and to pass to 'another level of existence'. However, Anna acknowledges both desires. Apparently, even though she experiences a logical contradiction she does not seem to experience a conflict. For her sense of identity, it does not seem a problem that both sets of values (belonging to two different frameworks of meaning) exist alongside each other.

Her daughter, who had a close relationship with her mother, interpreted her two wishes as both equally present, as 'wanting to die and still holding onto life'. However, she did not believe that her mother experienced a conflict. She talked about her mother's two wishes as a 'contradiction' or as 'resistances', but she did not feel her to be in conflict with or suffer from them.

Normative expectations and roles. For the physician, whom we interviewed and who cared most closely for Anna, the conflict in the team came less from Anna's different wishes than from different types of

communication Anna had with the different team members. While she talked openly to the nurses, she met the physicians always with great respect and would accept what was proposed to her rather than sharing her personal ideas with the physicians:

She reminds me of many elderly, who, who . . . how should I say, place their life in the hands of the physicians with a lot of confidence. And then even make an exact distinction: the physician decides, the nurse is caring for me.

This physician noticed that Anna got stressed when involved in treatment decisions or asked about her preferences too explicitly. The physician believed that some of the nurses attributed a more active part in decision making to Anna, expecting her to express with her statements (such as ‘However, I want to die. It is actually enough now. I’m prepared now.’) a wish to die that she wants to see enacted. The physician herself did not agree with that. To clarify, the physician went several times together with the nurses to ask Anna how she really felt. She then gave a totally different, more content impression. The physician said

And from this some nurses interpreted outside the room, that there is a conflict [in her]. But personally, I do not think she seriously had a conflict. She simply had a different concept from what we are used to.

Carola

Different frameworks of meaning. Carola, a 75-year-old woman, came to the hospice after the diagnosis of a brain tumour. As her brother recently died of the same sort of tumour, she decided to not undergo further diagnostics and therapy. After the death of her husband 7 years ago, she lived alone. She had no children but was well integrated in the neighbourhood, where she – as she says – cared as much as she could for the people around her:

I always worked, always have done and also always helped and . . . And so I always [went round] with cakes and things, and coffee, or they came to me, drinking coffee. I simply have been there for everybody all the time. Also telephonically. So many people call me and say: ‘I will miss you’ – my telephone calls always, where I gave people courage and everything, and helped and such. Have always helped, whenever it’s been possible.

This quote reveals how much ‘helping’ and caring for others are part of a set of values that contribute essentially to Carola’s self-understanding.

Carola describes herself as a firm Catholic believer. This fundamentally colours her ideas about life and death and gives her a certain acceptance when dealing with things as they might come. She meets life with humour and even reports difficult moments with laughter and a certain distanced irony. She says she could accept dying as part of what God has foreseen. In the interview with us, she reports in lively images that she hopes that in the moment of death her husband will come and reach out his hand to help her to go to ‘the other side’. But she does not deny that she is also afraid, especially of being declared dead while still alive.

However, Carola expresses a strong desire to die. The analysis shows that during the 1 h of interview, Carola claimed no less than five times that she would continuously pray to God that she could die now. The only reason that she gives for this during the entire interview is because she does not want to be a burden to others any longer.

I always pray that I can release people, eh, that I can free them of a burden, release the others also. That I do not always have to rely on help, I want . . . My whole life, I only worked and always took care of [others] myself . . . Then after this it’s simply difficult, if you always have to have other people. That you have to be a burden . . . That I’ve never liked.

This interview extract shows that her wish to die is clearly linked to her feeling of dependency and her fear of being a burden to others. But it also gives evidence of how much she seems to experience a breakdown of her narrative about herself – the narrative of being a person who actively cares for others and is also appreciated for that by others.

Carola reported that on some nights, she wished that it would be over soon. But when we asked her in the interview whether she ever wished her illness to proceed faster than it did, she experienced difficulties in answering, which might seem astonishing after her frequent statements about her desire to die:

Yes, I could not tell it, because I have just no pain now. That's maybe less [the idea that her illness should proceed faster]. If I had pain now or so, then I would say: immediately. But then . . . I will have to wait. That's not my business. That's God's business.

'*She really has two sides*'. The nurse who cared for her could mostly understand her, but she also thought that Carola was somehow 'ambivalent'. She noticed that Carola talked significantly often about her wish to die.

She said this again and again . . . several times a day: 'Well, it is time to go now, well now the time has come for me, well now I can leave, yes now I can . . .'

But the way Carola talked about her wish to die did not convince the nurse. She believed Carola's statements to be 'set phrases' and assumed a misfit between what Carola was saying and what she was maybe thinking. She also suggested that it was not always clear to her how to interpret Carola's laughter: as 'true cheerfulness' or as 'a hidden fear'? She saw this laughter, therefore, as rather 'double edged' and believed overall that Carola had two sides:

She always talked about that, that she wants to go now [to die now], but what she radiated, was something different. Somehow this didn't fit. As also her laughter . . . I believe, she really has two sides.

Normative expectations and roles. The nurse noticed that Carola, who during most of her life had cared for others herself, now had difficulty in accepting the care of others. Especially difficult for her was to accept the hygiene care of intimate parts of her body. And it was mostly on these occasions that she expressed her wish to die:

Well yes, it would be better I would die now, what you have to do here with me. [In quotation of the nurse.]

The nurse reflects also on the way Carola presents herself during their encounters:

She also somehow needs people to like her, to come to her, to be a good, a lovable patient, to whom you like to come. So she doesn't want to be a burden under any circumstances.

Discussion

A close reading of the patients' narratives shows that their statements about dying are embedded in more general frameworks of meaning within their personal narratives and how these wishes or expectations contribute to or conflict with the patients' sense of identity. The analysis also illuminates how much the description of somebody being 'ambivalent' is a result of social interactions and interpretations between caregivers

and patients and can both hinder or support such interactions. These two aspects – patients' self-understanding and understanding of others – are in a hermeneutical sense always intertwined.

Seemingly contradictory moral ideas

Anna presents herself as somebody who is self-reflective, deeply interested in spirituality and nature and has generally an accepting attitude towards life and death. Her moral beliefs are informed not only by her strong spiritual convictions but also by her ideas about the healing force of the body and her beliefs about the physician's authority to take the lead in treatment decisions. These ideas influence not only her choices (i.e. to accept medication if it gives her quality of life) but also her attitude to participate in treatment decisions (i.e. leaving the details of the treatment decisions to the physicians).

Anna herself is aware that she has two opposing wishes (to be able to walk again and to be able to die) but does not view herself as being in conflict because of them. Even though she herself calls it a 'contradiction', she experiences these two wishes or storylines as equally meaningful without finding herself in conflict.

Carola presents herself as a lovable, humorous and cheerful person who has always actively cared for others around her. Her nurse sees her partly as 'ambivalent' because Carola expresses so explicitly her wish to die soon, while on the other hand she 'appears not really convincing in that'. Like Anna, Carola also tells two different stories. On the one hand, her firm Catholic beliefs give her an accepting, sometimes even humorous attitude towards dying ('You know what: ask me afterwards!'). Death in this story is something that she can accept as the will of God, as part of human existence on earth that comes to its natural end. For this reason, she also says that she does not wish her sickness to proceed faster than it does. On the other hand, she also tells the story that she desperately wishes to die soon. She confirms this by saying that she prays for death to come. This wish is embedded in the story about her suffering from feeling dependent and receiving care, especially care for the most intimate parts of her body. She not only experiences shame but also feels that her self-image of being independent and caring for others is turned upside down.

Anna and Carola present two different storylines with regard to their death. At first glance, these storylines seem to be at least logically contradictory. However, on closer inspection, they are well situated in larger frames of values that these women care for equally in their lives and that both contribute to their identity. But while Anna seems to have no problems with the existence of both, Carola seems to experience a breakdown of one of the frameworks of meaning that most contributes to her sense of identity: social recognition as a caring person.

Hermeneutics acknowledges that the experience of multi-layered, seemingly contradictory meanings can be intrinsically part of personal moral experience, as it can characterize the process of negotiating personal meanings.²⁸ What often seems to others illogical, contradictory or at least difficult to understand, might be triggered by the interaction between different stories told by the same person about what she or he equally cares for.

The narrative bioethicist Hilde Lindemann holds that personal identities are not constituted by only a single story but by many stories. She assumes, therefore, that the 'cluster of identity-constituting stories' will most probably not present a linear structure or 'any particular form at all'.²³ This implies that the cluster of narratives necessarily contains inconsistencies, fractions or ambiguities that do not make the overall experience purely contingent.²⁹ She argues that sometimes only the coexistence of different personal stories can really represent the entire complexity of one's personal moral experience. A respectful response to patients like Anna might include recognizing and valuing the different frames of meaning supporting a person's sense of identity.

On the other hand, one should not be naïve about contradictory statements. Seemingly contradictory statements may indeed point to tensions in a patient's moral experience. For Carola, her idea of being a burden to others makes her so desperate as to frequently express a wish to die. While one has to take this wish

within her story as authentic, one can ask whether it might be possible to help her to view her situation differently. In fact, her nurse reported that when she started to talk openly with Carola about her ideas of being a burden, Carola relaxed 'and then, as the case may be, the wish to die recedes a bit'. Through this deliberative approach, the nurse could successfully challenge Carola's moral views about responsibilities, independency and identities.

Interactions around 'ambivalence'

The cases of Anna and Carola show that our narratives are constituted not only by what we care for but also by the narratives of others, by the features of our lives that they care most about, by how they perceive us to be or by what we presume they perceive us to be.²³ Carola's sense of identity is based on her perception that others always saw her as a person taking care of other people. Her current situation of dependency shatters her narrative about herself. She also suffers from thinking others could perceive her as a burden and preferring or 'deserving better lives without her'.

The case of Anna shows that understanding each other in social interactions is everything but a neutral act. Her caregivers were apparently troubled by her statements. They interpreted what Anna said as contradictory and assumed that she was in conflict. But there were also different interpretations of her ideas within the team. While one of the physicians believed that Anna wanted at least in part to go on with curative treatment, some nurses believed that Anna clearly asked them to let her die. In consequence, most of the team perceived her not to be consistent but rather ambivalent in her preferences.

In the interview with us, Anna reported her strong spiritual ideas that conditioned the way she evaluated her current situation and her death. The interviews with the hospice team revealed that these were not known to them. It might also be assumed that the hospice team was not aware of her naturalistic ideas about the healing force of the human body and her reluctance to use medication. This missing information on the part of the hospice team might explain why they had difficulties in interpreting the way Anna was stating her preferences regarding medication and the way she was talking about her dying.

Confusion also arose because Anna presented herself differently to the physicians and the nurses. As the physician describes it, Anna's case reveals different normative ideas about roles and different attributions of responsibilities that influence communication between the health-care team and the patient. Anna's communication style reflected her normative ideas, which were opposed to the normative expectations of the second physician and of the nurses, who were very aware of the fact that patients nowadays want to be informed and actively take part in decisions. These preconceptions might have made it harder for them to understand the way of decision making that Anna preferred, and the roles and responsibilities that she attributed to the people around her.

One obvious limitation of this article is that it only discusses two singular cases. From this base, no generalizations about who experiences ambivalence under which circumstances should be made. We do not claim these cases to be representative. The cases have been selected from a larger database for being particularly pertinent and illuminating for the topic of ambivalence. The case study approach, as we use it here, has, however, the strength that the phenomenon of ambivalence in the proper experience of the patient can be meaningfully reconstructed and understood in some detail. Second, as Paley²² has stressed, stories, in particular formalized stories with a 'teleogenic plot', can be seen as speech acts with a perlocutionary force, designed to provoke a certain effect on the recipient. This refers to the content and to the form of a story, which is told to somebody with an intention. With her narration, Carola, for example, might have provoked caregivers' reassurance that she is not a burden to them. In our article, we do not deny these aspects of performativity; however, we assume that it indeed makes sense to listen to the patients' narrations without doubting their authenticity.

Conclusions

What we know from each other as patients, families, clinicians or bioethicists is the result of interpretation and interaction. Sometimes, we share similar stories about how we perceive things to be. But sometimes, others construct very different stories, with different plots, based on different values or (moral) preconceptions. The aim of hermeneutics is not to say which one of these stories is right but to create insight into how acts of interpretation can be realized, how stories themselves represent acts of interpretation and how different stories can conflict, but also to interact and enrich each other. Having insight into the patients' and team members' interpretation can help to create a better base for negotiation about moral motives and claims, enlarging individuals' own viewpoints and hopefully coming to a shared understanding or – where this is not possible – gaining more insight, and with this more tolerance, regarding positions that differ from one's own. A hermeneutic approach to ethics is essentially aimed at moral learning.

Illness or dying narratives can tell of disrupted and chaotic experiences that might not to be brought into a 'coherent whole' and might be uncomfortable to hear or not easy to understand.¹ An ethical approach to patients' reflexivity and agency requires us to not only honour chaotic experiences as they are but also to understand when support is needed.

We have tried to demonstrate how the expression of contradictory normative ideas, which in contexts of care are sometimes classified as 'ambivalent', rather than being a sign of inconsistency or confusion can be part of finding words for one's multi-layered experiences and multiple moral understandings in an authentic way. Fractures within or logical contradictions between different storylines are not necessarily signs of a personal conflict.³⁰ In fact, 'inconsistencies' are generally part of everyday storytelling.²³ In narrative theory, it has been noticed that these fractures are under-investigated. There is a tendency in narrative research in palliative care to 'smooth out the inconsistencies and the flux of narrated experience'.¹⁷ The findings documented here might serve as an antidote against this tendency.

For nurses, and for all health-care practitioners, it is important to reflect on the complexity of communication. Especially, there is a need for understanding one's own role in interpreting communications about others' agency. Perceiving somebody's expressions as 'ambivalent' might indicate that the other person experiences tensions. In that case, good health care requires us to be responsive to the needs of the patient. What patients would then need from caregivers could include (a) being recognized as living in this situation and (b) receiving support and time to find the most sensible and responsible course of action.

However, the perception of somebody as 'ambivalent' or 'inconsistent' might also result from misunderstandings in communication or lack of knowledge due to personal pre-understandings or pre-judgements that hinder a better understanding or due to missing information about what the patient experiences about his or her world view or values. Therefore, we should be careful not to negatively label or even pathologize seemingly contradictory patient behaviour or statements. This is especially important as the relations between caregivers and care receivers are *per se* characterized by asymmetric power differentials and dependency. A respectful approach to patients implies that we embrace rather than suppress³¹ the contradictions we observe in patients when they think about specific interventions at the end of their lives and acknowledge that seemingly contradictory ways of reflection can function as a tool to attain more balanced choices.

Acknowledgements

We are deeply grateful to all patients, families and caregivers who participated in the interviews for their openness and generosity in sharing their experience. Thanks to the interviewer team: Lucia Stäubli, Heidi Gass, Settimio Monteverde, Georg Gusewski, Rita Hutchinson and Franziska Boinay.

Funding

This study was supported by Oncosuisse/Foundation Cancer Research (grant number 01960-10-2006), by the Gottfried und Julia Bangerter-Rhyner-Stiftung and the Foundation of the Hospice Arlesheim.

Conflict of interest

Heike R Gudat Keller is head physician at the Hospice Arlesheim. She gave interviews for some patients in her position as physician. In these cases she did not take part in the data interpretation.

References

1. Frank AW. *The wounded storyteller. Body, illness and ethics*. Chicago, IL: The University of Chicago Press, 1995.
2. Glaser BG and Strauss AL. *The discovery of grounded theory*. Chicago, IL: Aldine, 1967.
3. Smith J, Flowers P and Larkin M. *Interpretive phenomenological analysis. Theory, method and research*. Los Angeles, CA: SAGE, 2009.
4. Rehmann-Sutter C, Porz R and Scully JL. How to relate the empirical to the normative. Towards a phenomenologically-informed hermeneutic approach to bioethics. *Camb Q Healthc Ethics*, in press.
5. Arnold R. Ambivalence and ambiguity in hospitalized, critically ill patients and its relevance for palliative care. *J Palliat Med* 2000; 3: 17–22.
6. Fried TR, O’Leary J, Van Ness P, et al. Inconsistency over time in the preferences of older persons with advanced illness for life-sustaining treatment. *J Am Geriatr Soc* 2007; 55: 1007–1014.
7. Paterson BL. The shifting perspective model of chronic illness. *J Nurs Scholarsh* 2001; 1: 21–26.
8. Rosenfeld KE, Wenger NS, Phillips RS, et al. Factors associated with change in resuscitation preferences of seriously ill patients. The SUPPORT Investigators. Study to understand prognoses and preferences for outcomes and risks of treatments. *Arch Intern Med* 1996; 156: 1558–1564.
9. Carmel S and Mutran EJ. Stability of elderly persons’ expressed preferences regarding the use of life-sustaining treatments. *Soc Sci Med* 1999; 49(3): 303–311.
10. Straton JB, Wang NY, Meoni LA, et al. Physical functioning, depression, and preferences for treatment at the end of life: the Johns Hopkins Precursors Study. *J Am Geriatr Soc* 2004; 52: 577–582.
11. Wittink MN, Morales KH, Meoni LA, et al. Stability of preferences of end-of-life treatment after 3 years of follow-up. *Arch Intern Med* 2008; 168(19): 2125–2130.
12. Emanuel EF, Fairclough DL and Emanuel LL. Attitudes and desires related to euthanasia and physician-assisted suicide among terminally ill patients and their caregivers. *JAMA* 2000; 284: 2460–2468.
13. Chochinov HM, Wilson KG, Enns M, et al. Desire for death in the terminally ill. *Am J Psychiatry* 1995; 152: 1185–1191.
14. Johansen S, Hølen JC, Kaas S, et al. Attitudes towards, and wishes for, euthanasia in advanced cancer patients at a palliative medicine unit. *Palliat Med* 2005; 19: 454–460.
15. Chunlestskul K, Carlson L, Koopmans J, et al. Lived experiences of Canadian women with metastatic breast cancer in preparation for their death. Part II. *J Palliat Care* 2008; 24(1): 16–25.
16. Coyle N and Sculco L. Expressed desire for hastened death in seven patients living with advanced cancer: a phenomenologic inquiry. *Oncol Nurs Forum* 2004; 31(4): 699–706.
17. Gunaratnam Y. Narrative interviews and research. In: Gunaratnam Y and Oliviere D (eds) *Narrative and stories in health care. Illness stories and bereavement*. Oxford: Oxford University Press, 2009, pp.47–61.
18. Heidegger M. *Sein und Zeit*. Tübingen: Max Niemeyer Verlag, 1927.
19. Gadamer HG. *Wahrheit und Methode*. Tübingen: Mohr, 1960.
20. Walker MU. *Moral understandings: a feminist study in ethics*. 2nd ed. New York: Oxford University Press, 2007.
21. Taylor C. *The sources of the self: the making of modern identity*. Cambridge, MA: Harvard University Press, 1989.

22. Paley J. Narrative machinery. In: Gunaratnam Y and Oliviere D (eds) *Narrative stories in health care. Illness, dying, and bereavement*. Oxford: Oxford University Press, 2009, pp.17–32.
23. Lindemann NH. *Damaged identities, narrative repair*. New York: Cornell University Press, 2001.
24. Hardwig J. Autobiography, biography and narrative ethics. In: Lindemann NH (ed.) *Stories and their limits. Narrative approaches to bioethics*. New York: Routledge, 1997, pp.50–64.
25. Haker H. Narrative bioethik. In: Graumann S and Grüber K (eds) *Anerkennung, Ethik und Behinderung. Beiträge aus dem Institut Mensch Ethik und Wissenschaft*. Berlin: LIT Verlag Münster, 2005, Vol. 2, pp.113–132.
26. Waldvogel B. Ambivalenz. In: Mertens W and Waldvogel B (eds) *Handbuch der psychoanalytischen Grundbegriffe*. Stuttgart: Kohlhammer, 2008, pp.56–62.
27. Ohnsorge K and Rehmann-Sutter C. Menschen, die sterben möchten. Empirische Studien in der Palliativmedizin und ihre ethischen Implikationen. In: Hilt A, Jordan I and Frewer A (eds) *Endlichkeit, Medizin und Unsterblichkeit*. Stuttgart: Steiner, 2010, pp.249–270.
28. Widdershoven G. Interpretation and dialogue in hermeneutic ethics. In: Ashcroft R, Lucassen A, Parker M, et al. (eds) *Case analysis in clinical ethics*. Cambridge: Cambridge University Press, 2005, pp.57–75.
29. Widdershoven G. Identity and development. A narrative perspective. In: Bosma H, Graafsma T, Grotevant H, et al. (eds) *Identity and development: an interdisciplinary approach*. Thousand Oaks, CA: SAGE, 1994, Vol. 172, pp.3–117.
30. Larsen JT. Ambivalence. In: Baumeister RF and Vohs KD (eds) *Encyclopedia of social-psychology*. Thousand Oaks, CA: SAGE, 2007.
31. Parens E. Authenticity and ambivalence. Toward understanding the enhancement debate. *Hastings Cent Rep* 2005; 3: 34–41.