Ambivalence at the end of life – how to understand patients’ wishes ethically

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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. We argue, first, that a respectful approach to patients requires acknowledging that co-existence 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.

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.

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 (Frank 1995). 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 in-patients 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.
**Table 1 Method**

<table>
<thead>
<tr>
<th>Main research question</th>
<th>What do terminally ill patients mean when they express a wish to die?</th>
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<tbody>
<tr>
<td>Interviews</td>
<td>Semi-structured interviews of 1 hour with patients and families; 20 minutes with caregivers; tape-recorded and transcribed in full.</td>
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<tr>
<td>Number of case studies</td>
<td>30 case studies (1 case study consists of 1-2 patient interviews, 1 family member, 1 nurse, 1 physician). The combination of these interviews enabled us to analyse the meaning of the death wishes and the interactions surrounding them more in depth.</td>
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<tr>
<td>Overall number of interviews</td>
<td>N = 116</td>
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<tr>
<td>Sampling</td>
<td>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.</td>
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<td>Inclusion/exclusion criteria</td>
<td>Inclusion: Patients with incurable cancer (palliative situation); already informed about the incurability of their disease; willingness to participate; physicians’ OK for being interviewed; sufficient language skills. Exclusion: Cognitive impairment of a degree and kind that is incompatible with the interview.</td>
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<tr>
<td>Method</td>
<td>A combination of Grounded Theory (Glaser and Strauss 1967) and Interpretive Phenomenological Analysis (Smith et al. 2009)</td>
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<tr>
<td>Data analysis</td>
<td>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 lead 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 lead 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 (Rehmann-Sutter et al. 2009).</td>
</tr>
<tr>
<td>Cases presented in this article</td>
<td>The case of Anna corresponds to P6, the case of Carola corresponds to P2 in our larger interview study. Names and age are changed to safeguard confidentiality.</td>
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<tr>
<td>Overall results</td>
<td>See forthcoming publications</td>
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<td>Research ethics approval</td>
<td>From the Ethics Commission of Both Basel</td>
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**Theoretical background**

Clinical experience (Arnold 2000) and empirical studies in end-of-life care (Paterson 2001; Fried et al. 2007) 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 (Fried et al. 2007; Rosenfeld et al. 1996; Carmel and Mutran 1999; Staton et al. 2004; Wittink et al. 2008). Some studies report oscillating preferences among dying patients towards a possible wish to die (Emmanuel et al. 2000; Chochinov 1995; Johansen 2005; Chunlekskul et al. 2008). Only very few authors indicate possible ways of dealing with these shifts in patients’ attitude (Paterson 2001; Coyle and Sculco 2004), although several authors state the need for further and more detailed research on this phenomenon (Johansen et al. 2005; Gunaratnam 2009).

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 (2005), 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.” (Johansen et al. 2005). 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 (Heidegger 1927; Gadamer 1960). We come to make sense of ourselves and the world we live in, by embedding what we experience into stories (Walker 2007; Taylor 1989; Paley 2009). In these stories we give meaning to our experiences, 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 (Lindemann Nelson 2001; Hardwig 1997). 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 (Haker 2005).

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 (Walker 2007). 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 (Lindemann Nelson 2001). 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 inexplicit) 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 (Coyle and Sculco 2004; Waldvogel 2008). 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 (Ohnsorge and Rehmann-Sutter 2010). 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 subthemes 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 I: 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 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.

“The patient shows an impressive ambivalence”

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 (Like: “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 tumor. 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 seven 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 one hour 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 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 radi-
ated, 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 ac-
cept 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 pa-
tient, 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 spiritual-
ity and nature, and has generally an accepting attitude towards life and death. Her
moral beliefs are informed 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 participating in
treatment decisions (i.e. leaving the details of the treatment decisions to the physi-
cians).

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 story
lines 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 “ap-
ppears not really convincing in that”. Like Anna also Carola tells two different stories.
On the one hand, her firm Catholic beliefs give her an accepting, sometimes even hu-
morous 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 de-
pendent and receiving care, especially care for the most intimate parts of her body. She
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 story lines with regard to their death. At first
.glance these story lines 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 break-
down of one of the frameworks of meaning that most contributes to her sense of iden-
tity: social recognition as a caring person.

Hermeneutics acknowledges that the experience of multi-layered, seemingly con-
tradictory meanings can be intrinsically part of personal moral experience, as it can
characterize the process of negotiating personal meanings (Widdershoven 2005).
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 (2001) 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”. This implies that the cluster of narratives nec-
essarily contains inconsistencies, fractions or ambiguities that do not make the over-all
experience purely contingent (Widdershoven 1994). She argues that sometimes only
the co-existence 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 naive 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 (Lindemann Nelson 2001). 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 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 Anna preferred, and the roles and responsibilities that she attributed to the people around her.

One obvious limitation of this paper 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 neither 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. Secondly, as Paley (2009) 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 paper we don’t 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 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 (Frank 1995). An ethical approach to patients’ reflexivity and agency requires us to 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 story lines are not necessarily signs of a personal conflict (Larsen 2007). In fact, “inconsistencies” are generally part of
everyday storytelling (Lindemann Nelson 2001). In narrative theory it has been noticed that the investigation of these fractures is under-investigated. There is a tendency in narrative research in palliative care to “smooth out the inconsistencies and the flux of narrated experience” (Gunaratnam 2009). 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 (i) being recognised as living in this situation, (ii) 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 prejudgements that hinder a better understanding, or due to missing information about what the patient experiences, about his or her worldview 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 care givers and care receivers are characterized by nature by asymmetric power differentials and dependency. A respectful approach to patients implies that we embrace rather than suppress (Parens 2005) 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.

References


