

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

Kathrin Ohnsorge, Heike R Gudat Keller, Guy AM Widdershoven,
Christoph Rehmann-Sutter

Nursing Ethics 19(5), 2012, 629-641

Heike R Gudat Keller – leitende Ärztin am Hospiz im Park, Arlesheim (bei Basel)

Christoph Rehmann-Sutter – Institut für Medizingeschichte und Wissenschaftsforschung der
Universität Lübeck (Norddeutschland)

Helmut Hofbauer

Study design

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

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 criteria: Patients with incurable cancer, already informed, willing to participate, without cognitive impairment

Method: A combination of **Grounded Theory** and **Interpretative Phenomenological Analysis**

Funding

The study was supported by

- **Oncosuisse/Foundation Cancer Research (grant number 01960-10-2006)**
- the **Gottfried and Julia Bangerther-Thyner-Stiftung**
- and the **Foundation of the Hospice Arlesheim**

Whose problem?

It's a problem of nurses and physicians:

„**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.“ (p. 629)

Anna

Age: **80 years**

Diagnosis: **Tumour of the abdomen** – Anna decided against further diagnostics and against an operation.

Anna

Different frameworks of meaning

1st framework of meaning:

Her strong spiritual beliefs: joy and curiosity about life after death

2nd framework of meaning:

Naturalistic framework: Anna's ideas about her body and about medicine. She is reluctant about medication, as she believes her body has the force to heal itself.

Anna

Communication

She shares her ideas with the **nurses**, and accepts what is proposed to her by the **physicians**.

Anna talks openly to nurses, but meets physicians with great respect.

→ Only the **nurses** know about her 2nd framework of meaning.

Anna

My wishes are actually in balance

Two different desires: One to be able to walk again and be able to live on her own again and the other to be able to die.

Even though she experiences a logical contradiction she does not seem to experience a conflict.

Anna

Impression of ‚ambivalence‘

One of the hospice **physicians** concluded that the patient showed an ‚impressive ambivalence‘.

On the other hand, some **nurses** perceived the patient to really want to die. Among the health-care team, there was an increasing confusion about what Anna actually wanted.

Apparently, even though Anna experiences a logical contradiction she does **not** seem to experience a **conflict**.

Carola

Age: **75 years**

Diagnosis: **brain tumour.**

Her brother recently died of the same tumour → she decided not to undergo further diagnostics and therapy.

Carola

After the death of her husband 7 years ago, **Carola lived alone.**

She had no children, but lived in a **well-integrated neighbourhood**, where she cared for and helped other people around her.

‚Helping‘ and ‚caring for others‘ – values that contribute to **Carola’s self-understanding.**

‚Being a burden to others‘ = **breakdown of her narrative about herself.**

She wants to die because she is **‚a burden to others‘.**

Carola

Different frameworks of meaning

1st framework of meaning:

Religious framework: death is something that she can accept as **the will of God**; for that reason she does not want her sickness to proceed faster than it does.

2nd framework of meaning:

Framework of her self-definition as active, helping person: she expresses very often her wish to die soon; she does that because she **suffers from feeling dependent** and receiving care.

Results

Different frameworks of meaning

The patients' statements about dying are **embedded** in more general frameworks of meaning within their personal narratives

The description of somebody being 'ambivalent' is a **result** of social interactions and interpretations between caregivers and patients. (= is an interpretative **construction**)

Anna seems to have **no problem** with the existence of both of her frameworks of meaning.

Carola experiences the **breakdown of one of them**: social recognition as a caring person

Conclusions

Bioethicist Hilde Lindemann: **personal identities** are constituted **by many stories** – by a ‚cluster of identity-constituting stories‘.

A respectful response to patients like **Anna**:

might include **recognizing and valuing the different frames of meaning** supporting a person's sense of identity.

A respectful response to patients like **Carola**:

But seemingly contradictory statements might indeed point to tensions in a patient's moral experience – as in **Carola's** case. One can ask whether it might be possible to **help her to view her situation differently**.

Conclusions

We argue that (p 629)

1. A respectful approach to patients requires **acknowledging that coexistence of opposing wishes** can be part of authentic, multi-layered experiences and moral understandings.
2. Caregivers need to **understand when contradictory statements point to tensions** in a patient's moral experience that require support (the case of Carola).
3. Caregivers should be careful **not to negatively label or even pathologize** seemingly contradictory patient statements.

Discussion

Obvious limitation of this article: it only discusses **two cases** → therefore **no generalizations** about who experiences ambivalences 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** has the strength that the phenomenon of ambivalence in the proper experience of the patient can be meaningfully reconstructed and **understood in some detail**.

→ **Lernen anhand von Beispielen.**

Discussion

Aim of hermeneutics – not to say which stories are right but to **create insight** into how acts of interpretation can be realized...(=into the different stories involved). Having insight can help to **create a better base for negotiation about moral motives** and claims, enlarging individuals' viewpoints and coming to a shared understanding.

More insight = more tolerance. A hermeneutic approach to ethics is essentially aimed at **moral learning.**

→ Towards the formation of **personal moral attitudes!**

Further articles by the same authors (on methodological issues)

- Christoph Rehmann-Sutter etc al.:
How to Relate the Empirical to the Normative. Towards a Phenomenologically Informed Hermeneutic Approach to Bioethics.

Cambridge Quarterly of Healthcare Ethics (2012), 21, 436-447.
- Kathrin Ohnsorge, Christoph Rehmann-Sutter:
“Menschen, die sterben möchten. Empirische Studien in der Palliativmedizin und ihre ethischen Implikationen“,

in: Annette Hilt/Isabella Jordan/Andreas Frewer (Hrsg.): *Endlichkeit, Medizin und Unsterblichkeit. Geschichte - Theorie - Ethik*. Franz Steiner Verlag, Stuttgart 2010. S. 249-270.

„Context of discovery“ und „context of justification“

Der logische Empirist [Hans Reichenbach](#) führte diese Unterscheidung 1938 ein.

Entdeckungszusammenhang: Reichenbach zufolge braucht der Wissenschaftsphilosoph bei der rationalen Rekonstruktion und der Erklärung von Wissenschaft singuläre und subjektive Einflüsse, denen ein Forscher ausgesetzt ist ([Entdeckungszusammenhang](#)), **nicht** zu berücksichtigen.

Begründungszusammenhang: **Alles, worauf es ankommt**, ist, wie der Wissenschaftler seine Behauptungen – normalerweise in der Form von mathematischen Gleichungen und mittels Logik – rechtfertigt ([Rechtfertigungszusammenhang](#), [Begründungszusammenhang](#), [Erklärungszusammenhang](#)).

http://de.wikipedia.org/wiki/Wissenschaftstheorie#.E2.80.9EContext_of_discovery.E2.80.9C_und_.E2.80.9Econtext_of_justification.E2.80.9C

Nomothetische vs. idiographische Forschung

Wilhelm Windelband (1894) unterschied zunächst Mathematik und Philosophie als rationale Wissenschaften von den Erfahrungswissenschaften. Letztere teilte er dann nochmal in die nomothetischen Naturwissenschaften und die idiographischen Geisteswissenschaften.^[1]

Nomothetisch (von griechisch *nomos*: 'Gesetz' und *thesis*: 'aufbauen') bezeichnet eine Forschungsrichtung, bei der das Ziel wissenschaftlicher Arbeit **allgemeingültige Gesetze** sind. Ihre Methoden sind experimentell, oft reduktionistisch, die erhobenen Daten quantitativ. Nomothetische Theorien abstrahieren von den Phänomenen. Diese Denkweise ist typisch für die Naturwissenschaften. **Idiographisch** (von griech. *idios*: 'eigen' und *graphein*: 'beschreiben') ist eine Forschungsrichtung, bei der das Ziel wissenschaftlicher Arbeit die umfassende Analyse **konkreter, also zeitlich und räumlich einzigartiger Gegenstände** ist. Ihr Hauptanwendungsbereich sind die Geisteswissenschaften.