

Dying worlds – the perspectives of patients and relatives on ‘good dying’

Katharina Heimerl¹, Barbara Egger¹, Patrick Schuchter¹, Alexander Lang², Klaus Wegleitner⁴, Lukas Kaelin³, Elisabeth Frankus²

1 Institute for Palliative Care und Organisational Ethics, University of Klagenfurt, Vienna, Austria

2 Techno Science and Societal Transformation, Institute for Advanced Studies, Vienna, Austria

3 Institute for Practical Philosophy/Ethics, Catholic Private University Linz, Austria

4 Institute for Pastoral Theology, University of Graz, Austria

Background

In the last decades, the public attention for death and dying in Austria has increased. The public discourse is driven by professionals and experts demanding an extension of specialized palliative care and shaped by controversial discussions about euthanasia and assisted suicide. However, the different perspectives of patients and their relatives and their various ideas of ‘good dying’ are often underrepresented. To address this gap, we performed an exploratory qualitative research project.

Methods

	Relatives	Patients	Total
Women	15	6	21
Men	5	6	11
Interview partners	18	12	32
	Tyrol	Carinthia	Vienna
Interviews, n= 30	13	11	6

Table 1: Interview sample

We conducted 30 qualitative interviews with 32 interview partners (2 interviews with a couple). All persons were affected by dying and death, either as incurably ill patients, as very old persons, or as bereaved caregivers. We selected interview partners from three different states in Austria; theoretical sampling criteria included age, sex, community size, care settings and the difference patients/relatives. We developed an interview guide, recorded each interview and prepared observation and reflection notes. Audios were transcribed verbally and anonymized. We analyzed the interview transcripts individually and comparatively by single researchers and within team. We developed codes inductively out of the data and created a code map.

Findings

New themes of care, well-being and suffering at the end of life appear. The findings show that patients and relatives describe their ‘dying worlds’ in different yet very distinct ways. These ‘worlds’ differ from the conception of ‘places of death’ and include social relations and emotions. Of utmost importance for the ‘dying worlds’ are the individual care-networks, consisting among others of families, neighbors and professional carers.

„When he was diagnosed the neighbours were so important. We don’t usually spend so much time together, sometimes we drink a beer over the fence. But they helped me so much. In the night, when my husband died they all came over to my place and they comforted me.“ (Paula Jäger,¹ 731-739)

Even when exposed to the extraordinary situation of death and dying patients and relatives endeavor to establish a daily routine.

“Then I went home, I did the laundry and I rummaged about. A lot of small things. It’s not a planned, not a structured day. What will be will be.” (Rudolf Haas, 452-460)

The interview partners build their conception of good dying on their biography, some of them speak about enjoyment and about beauty.

„I don’t prepare for it so intensely. I enjoy life.“ (Rudolf Haas, 438)

„And this was so beautiful. You could – after mother was gone – you could open the door widely, the door to the balcony. You could let her soul leave so beautifully. So this was so beautiful“ (Karin und Andreas Neubauer, 962-965)

¹ all names are pseudonyms

CONCLUSION

- The perspectives of patients and relatives on ‘good dying’ are best described by the notion of ‘dying worlds’, they encompass social relations, care networks and individual emotions.
- The dying worlds of patients and relatives have their own characteristics and concepts which are distinct from professional discourses.
- Although the interview partners talk about suffering they also experience beauty at the end of their life or the life of their relatives.
- When we strive for enabling a dying process that respects the perspectives of those concerned as a public health priority, we have to consider the individual ‘dying worlds’.

Presented at the 10th Research Congress of the European Association for Palliative Care, 24 -2 6 May 2018, Bern, Switzerland

Funded by the Anniversary Fund of the Oesterreichische Nationalbank (OeNB), project nr. 17075

Acknowledgements

- We are grateful to the door openers for establishing contacts with our interview partners (see logos on the right side)
- Many thanks to all patients and relatives who agreed to participate in the research

Contact

Assoz. Prof.ⁱⁿ Dr.ⁱⁿ Katharina Heimerl
IFF-Palliative Care and Organizational Ethics
Schottenfeldgasse 29/4
1070 Wien, Austria
katharina.heimerl@aau.at

