

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

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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

- 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’.

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