

Influences of “family” on the meaning of end-of-life decision making for patients in palliative care

From individual autonomy to responsibility in relationships

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1. Introduction / Research Question

The Global Atlas of Palliative Care at the End of Life (WHO)¹ estimates that over 20 million people are in need of palliative care every year. Studies have shown that family plays an important role in the care of terminally ill patients – as well as in the decision making involved.² Yet little is known about exactly **how family influences the meaning of end-of-life decision making for patients in palliative care**. To learn more about family influences, we conducted a **qualitative pilot study** – focussing on decisions about **life-sustaining measures in advance directives (AD)**.

2. Method

- 6 cases fusing semi-structured interviews with a **terminally ill patient, a family member, an attending physician and a nurse**
- conducted in the palliative care ward at the university clinic (UKSH) in Lübeck, Germany in January/February 2016
- data is being analysed using Interpretative Phenomenological Analysis (IPA)³
- we followed Kristjanson's⁴ suggestion “to permit patients and their family members to self-define [family]” (Kristjanson et al., 2004, 360)

Patient 1: 50 year old female nurse separated (friendly relationship), 1 foster son (age 8)

- diagnosis: metastatic lung cancer (first diagnosed in November 2015)
- **rejection of all life-sustaining measures** in AD (December 2015)
- current treatment: palliative chemotherapy and radiation + pain management

Patient 3: 55 year old female dental assistant married, 2 sons (age 20 and 24)

- diagnosis: colon carcinoma (first diagnosed in 2012)
- **rejection of all life-sustaining measures** in AD (2013, renewed in 2016)
- current treatment: pain management + fluids for relief

Here we present first results based on the analysis of **two cases**:

3. Results: Emerging Themes

(“family”-linked themes underlined)

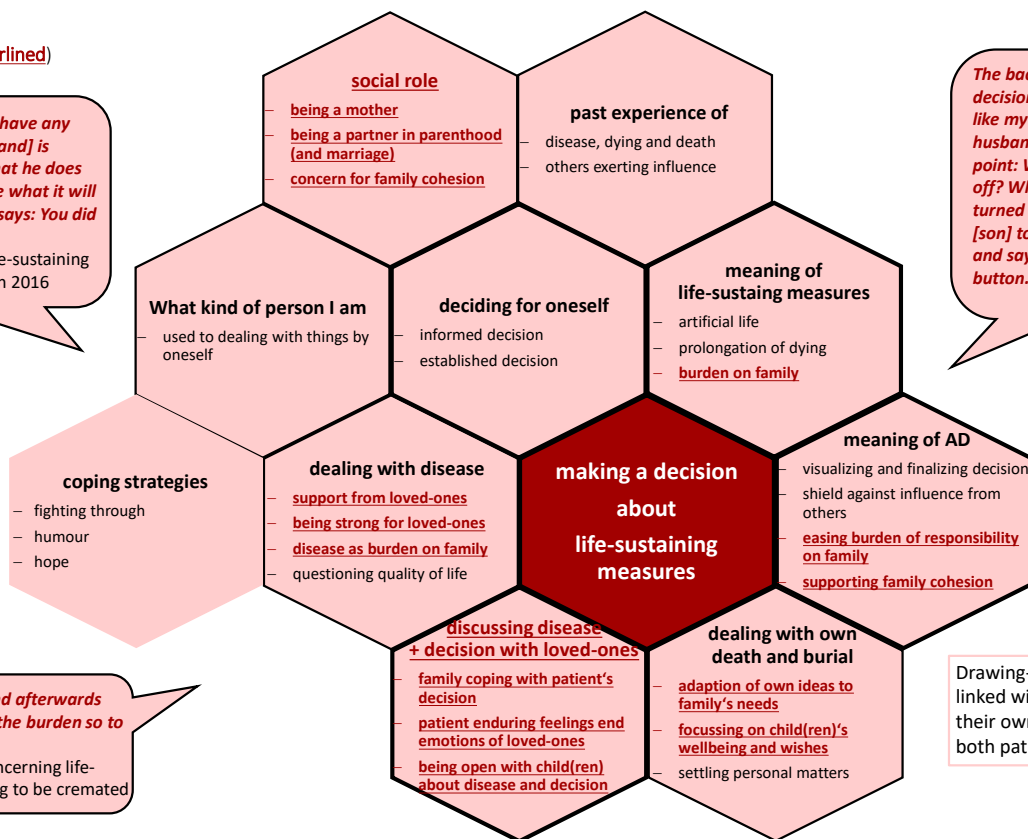
Because I was ready to say: I don't have any strength left anymore. Lukas [husband] is shocked – of course. But he says, that he does understand. He just cannot imagine what it will be like...afterwards, alone...but he says: You did fight after all.

P3 on her decision to reject all life-sustaining measures in renewal of AD in 2016

In both cases the patients emphasized that the decision about life-sustaining measures was as entirely their own.

No, that was always clear for me and afterwards [after death] I don't care. But now the burden so to speak is taken from the family.

P3 about making a decision concerning life-sustaining measures and her wanting to be cremated



The background of this decision was, well, I wouldn't like my sister, my mother, my husband to fight at some point: What are we turning off? What are we having turned off? I don't want Leon [son] to someday stand there and say: Papa pressed the off button.

P1 on her AD

Drawing-up an AD was closely linked with thoughts about their own death and burial for both patients.

4. Discussion

- Results illustrate how family affects the meaning of end-of-life decision making in various ways – even if there is no active influence.
- We believe the influences of family can best be captured with the concept of **caring responsibility** – referring not only to the patient's caring for her family (being closely linked to her social role) but also to her expressed responsibility to care.
- This is compatible with the concept of relational autonomy that originated in feminist ethics⁵. Westlund⁶ has suggested defining relational autonomy as self-responsibility in terms of a “commitment to certain values [...] for which [a person] holds [oneself] responsible” (Westlund, 2009, 30). As the results uncover, taking care for their loved-ones can indeed be a value for which patients hold themselves responsible – being consistent with an autonomous decision.
- The findings support the critique that the Western autonomy paradigm in medical decision making ignores the reality of the patient being part of a family^{7,8} and considers her as an “essentially lonely soul without personal ties” (Verkerk, 2014, 2).
- It also emphasizes the importance of taking a closer look at relationships and responsibility within, when trying to gain a better understanding of decision making at the end-of-life.

5. Conclusion

The small size of the study means that further research is needed. Nevertheless, the idea of **caring responsibility** adds not only to the concept of relational autonomy and deepens the understanding of the **influence of family in end-of-life decision making**, it also offers a better **understanding of the decision making process** as a whole.