

Essay/Personal Reflection

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Balancing burden and benefit: Reflecting on interviews with individuals nearing the end of their lives

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Conducting interviews in the field of end-of-life care usually involves discussing sensitive topics that are “laden with emotion or which inspire feeling of awe or dread” (Lee 1993). The benefits of research within this area must outweigh the risk of eventually burdening the participants, who may be emotionally vulnerable due to existential issues when nearing the end of their lives (Breitbart et al. 2004; Neimeyer et al. 2011). Consequently, health-care professionals, relatives, and next of kin try to avoid sources of unnecessary psychological distress and may limit or prevent access to eligible participants for research participation (Kars et al. 2016; Sharkey et al. 2010). This process is known as gatekeeping and can be mitigated if gatekeepers are involved in decision-making processes and can thus exert influence and ensure credibility and validity of the research procedure (Seidman 2013). Thus, gatekeepers play a protective role, and it becomes relevant to explore whether people nearing the end of life experience burden during research interviews or if such interviews can have positive effects (Dempsey et al. 2016).

In the context of a dissertation project focusing on confronting one’s own end of life when nearing death due to age or disease, I conducted semi-structured interviews with 21 individuals aged 80 and over or with life-limiting diseases (Kukla et al. 2022). I would like to report on remarkable experiences during data collection, highlighting the significance of collecting data from first-order perspectives to understand the needs and wishes at the end of life, as well as the potential additional benefits of self-reflection and reordering of thoughts. In the following, I summarize experiences related to establishing contact, conducting interviews, and the shared effects of the conversation.

- (1) Encountering participants: To create a comfortable atmosphere for the conversation, I prioritized relationship-building and engaged in nonhierarchical discussions by sharing personal experiences and valuing the participants’ stories and insights. In most cases, a sense of closeness was established within the first 10 minutes, providing a solid foundation for the interview about one’s own end of life. The participants appeared at ease and some even initiated the research interview by inquiring about my objectives and how they could assist. Furthermore, I emphasized that participants were in control of deciding when to take breaks, when to end the interview, and how to best address their needs.
- (2) Conducting the interview: In some interviews, I played a minimal role in guiding the conversation as participants had already shared extensive content. In other cases, I posed several questions to delve deeper into the subject matter. It was easy for me to maintain a researcher’s role with empathetic distance. At the end of one interview, a participant spontaneously hugged me, which I allowed at the moment, but I refrained from further physical contact. While some participants became emotional during the interviews, all chose to continue, and none required the aftercare offer.
- (3) Effects of the conversations: The emotional intensity of the conversations varied. Some remained relatively superficial, while others were highly emotionally charged. The interview guide did not specifically inquire about direct effects, but some participants reported on how they felt afterward (Kukla et al. 2022): You start telling stories (Interview 10: pos. 153), *I am enjoying this with the two of us, though I didn’t expected it* (Interview 17: pos. 208), *I liven up when I face someone like you to talk to* (Interview 7: pos. 130). One participant mentioned the opportunity for action resulting from the interview: *Maybe the interview is encouraging action* (Interview 16: pos.153). The interviews appeared to have a therapeutic effect, allowing participants to relive emotions, reflect on past experiences, and re-evaluate their lives. A compassionate and empathetic conversation can encourage storytelling and can even result in a changed sense of self (Clyne et al. 2019; Dempsey et al. 2016; Kruizinga et al. 2018). Almost all participants felt much closer after the interview, and some even commented on their sense of closeness, with one participant stating: *You feel like a friend after the interview* (Interview 7: pos. 108), and another expressing:

[...] my daughter would not see me like you see me now (cries)
(Interview 5: pos. 102).

In conclusion, based on these experiences, it can be summarized that no negative effects were reported but rather positive effects were observed in interviews conducted in the field of end-of-life care, which had beneficial effects on measures of comfort. It is assumed that the power of storytelling may enable the people to construct or reconstruct their framework of meaning in life (Kruizinga et al. 2016). End-of-life interviews appear to initiate reflective processes and pave the way for life reflection. Considering the vulnerability of the participants when planning and conducting interviews is crucial to prevent harm, but qualitative research may also be empowering for participants (Gysels et al. 2008).

Therefore, this personal reflection can serve as a plea for sensitive interviewing and as a gate-opener for the potential inclusion of people nearing the end of their lives. It is not about disregarding the reasons for gatekeeping, as they may be justified and essential, but rather about encouraging potential gatekeepers to engage in reflective and individual decision-making processes.

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