The Value of Privacy in Technical Assistance for People with **Dementia: an Empirically Informed Ethical Analysis** Eike Buhr & Mark Schweda

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Background

- Increasing use of technical assistance (TA) systems in the care and nursing of people with dementia.
- TA to increase user independence, self-efficacy and relieve caregiver burden
- Discussion in general care- and technology-ethical debate from the point of view of privacy

Problem and Questioning

- Privacy as the right to actively and consciously control one's own informational, local, and decisional concerns.
- Progression of cognitive impairment is associated with loss of ability to actively and consciously control
- How do people with dementia and family caregivers explicate the value of privacy in the context of TA?

Method

- Semistructured guided interviews with people with dementia and family caregivers (n=27).
- Representation of TA through illustrated case vignettes.
- Qualitative content analysis according to Mayring (2015)

"I could perhaps imagine something like that, but something like this [robot] not [...]. So when it gets to that point, then I would say, enough, now you're going to the old people's home." (Mr. A., person with dementia)

"So for me it would be important if it was my wife, right? [...] Or [...] I think it depends on the degree of the disease that you have, [...] where it is better that a doctor can locate you." (Mr. C., person with dementia)

local/ topological

informational

"On the one hand, we have finally reached the point with dementia that we [...] take the person [...] as he is and on the other hand, these assistance systems should then contribute to ensuring that everything somehow works out according to the rules at home, on one's own." (Mrs. M., relative)

"But [...] as long as the relatives can do that, it is [...] also a piece of intimacy [...] somewhere. It's easier when my mother [...] can rely on it that it stays in our circle." (Mrs. F., relative)

decisional



- Interpretation of privacy independent of autonomy by people with dementia and their family caregivers.
- Presence of TA as intrusion into local privacy in the sense of perception of one's own home
- Interference of TA in (everyday) action processes as a violation of decisional privacy independent of the presence of autonomy ability
- Emphasis on relational dimension of informational privacy: individual control less in focus than social and medical contextual conditions

Literature:

- Rössler, Beate (2001): Der Wert des Privaten. Frankfurt am Main: Suhrkamp.
- Evans, Joanna; Brown, Michael; Coughlan, Tim; Lawson, Glyn; Craven, Michael P. (2015): A Systematic Review of Dementia Focused Assistive Technology. In: Masaaki Kurosu (Hg.): Human-computer interaction. 17th international conference, HCI International 2015, Los Angeles, CA, USA, August 2-7, 2015; proceedings, Bd. 9170. Cham: Springer (Lecture notes in computer science Information systems and applications, incl. Internet/web, and HCI, 9170), S. 406-417.
- Mayring, Philipp (2015): Qualitative Inhaltsanalyse. Grundlagen und Techniken. Weinheim: Beltz



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