

Mobility of people with dementia in public space - ethical aspects of participatory research

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Background

- Around 130.000 people with dementia live in Austria
- 80% are living at home
- Persons with dementia and their relatives undergo a progressive process of withdrawing from various social activities
- This is accompanied by a reduction of their mobility in public space
- Mobility as core factor influencing social participation of people with dementia.
- Little is known of how people with dementia experience accessibility in public space in Austria.
- Austrian dementia strategy (2015) aims at social inclusion

Key data of the project

- Duration: Sept. 2016 - Dez. 2018
- Projectpartners:
 - Institute for Palliative Care und Organisational Ethics, IFF Vienna, University of Klagenfurt (project lead)
 - B-NK Büro für nachhaltige Kompetenz
 - CS Caritas Socialis
 - Wiener Linien (public transport operator of Vienna)
- The project is funded by the Austrian Research Promoting Agency (FFG) with resources by the Austrian Ministry for Transport, Innovation and Technology (BMVIT)

Aims of the project

To contribute to a broader knowledge base of mobility in public space - with a focus on public transport - of people with dementia the study aims at

- Talking with people with early dementia about their experiences and discover factors that promote or hinder the mobility in public areas
- Conducting client-centered usability studies with already existing technical support systems focusing on public transport
- Formulating of recommendations for relevant stakeholders.

Methodological Approach

Based on a participatory qualitative approach (Hockley et al 2013, Alzheimer Europe 2011), the research project uses

- Narrative interviews (24)
- Participant observation (15)
- Usability tests (15)

Overall 27 persons with dementia participated in data collection

- Focus groups (3): professionals, relatives and stakeholders

Ethical issues within the research process

- Ethical questions deal with “care ethics” as well as with “principle ethics”
 - Coping with vulnerability, emotions within research and relational autonomy are core aspects
 - Person-centered communication: Validation after Naomi Feil
- Especially within early phases of dementia, diagnosis can have effects of stigma and shame
 - Talking about “dementia”
 - Questions of informed consent: process consent
- “Othering” (de Beauvoir, Spivak):
 - How do “we” as researchers address “people with dementia”?

Thank you very much for your attention!



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