Advance research directives for dementia research
What do affected people think?
A German interview study

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Dementia Prediction and Risk Reduction:
Socio-cultural Insights, Ethical Reflections and Future Developments
Background

• Research with persons with dementia
  • Important to better understand causes of dementia and to develop more effective diagnostics, therapies, and risk reducing measures
  • Difficulties due to cognitive decline in the course of dementia and potential lack of (full) capacity
  • International legal standard including consent of legal representative has flaws (Kim et al. 2013; Wendler 2011; Livingston 2010)

• Advance research directives (ARDs) can give competent individuals opportunity to express preferences for research participation for later stage of incapacity (Andorno et al. 2016; Jongsma & van de Vathorst 2015)
  • Despite regulated use in some countries, uptake remains considerably low (Ries et al. 2020; Bravo 2016; Muthappan 2005)
German (legal) context and need for empirical study

• Nov. 2016: Changes to the German Medicinal Products Act (MPA)
  - Research with “group benefit”
  - Condition: Drafting of ARD

• Little knowledge about perspectives of those affected

• Our study: Focus on how people with subjective or mild cognitive impairment assess the introduction of ARDs
Methods

• Semi-structured interviews: 24 persons with cognitive impairment (SCI/MCI)
  (1) How do you assess the introduction of ARDs?
  (2) Should anyone besides you be involved in drafting an ARD?
  (3) What is a good time to draft an ARD?
  (4) What would assist you in drafting an ARD?

• Participants:
  – aged between 45 and 85 years
  – even distribution of gender

• Interviews lasted between 16 and 80 minutes; Ø42 minutes
• Thematic content analysis assisted by the scientific software Atlas.ti™
Results:
a) General Attitudes

- Positive attitudes towards ARDs
  - Instrument for making own decisions regarding consenting to or vetoing research participation
  - Importance of helping others by participating in research / value of scientific research
- Negative or ambivalent attitudes due to difficulty of making anticipated decisions
Results:
b) Necessary Conditions

Who should be involved?
- Ability to fill out ARD own their own
- Desire to discuss with a clinician
- Researchers conducting specific research
- Children/partners

When is a good time?
- When one is still healthy
- Shortly after receiving diagnosis / at time of diagnosis
- Necessity to make information more widely available

What preconditions should be fulfilled by health providers?
- Trust building / no conflict of interest
- Sufficient time and medical expertise
- Combination of template and safeguarding through representative
Results:

c) Remaining Worries

• Fear of not being able to withdraw from research
• Fear of abuse in research or of insufficient protection through ARDs
• Concern whether physicians and other staff will be trained sufficiently to deal with ARDs
Practical recommendations

• Need for expertise and training of treating physicians concerning dementia research
• Need for time to talk about anticipated course of the disease and its implications
• Need for development of standardized template with space for individualized wishes and adaptations
• Need for additional safeguards to be in place
• Need for spread of information on ARDs and provision of practical support
• Need for studies testing motivational approaches taking cultural differences into account
Thank you!

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References


## Participant demographics

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