

Advance research directives for dementia research

What do affected people think?
A German interview study

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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 demential 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



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Motivations for people with cognitive

impairment to complete an advance research directive – a qualitative interview Karin Jongsma 12*†, Silke Schicktanz and Katrin Radenbach

Background: Research with persons with dementia is important to better understand the causes of dementia and to double more affording diagnostics thoronics and mention managiness. Advance Descarch Directions (ADDS) to develop more effective diagnostics, therapies, and preventive measures. Advance Research Directives (ARDs) have been suggested as a possible solution to include persons with dementia in research in an ethically sound have been suggested as a possible solution to include persons with dementia in research in an ethically sound way. Little is known about how people, especially those affected by cognitive impairment, understand and regard

way. Little is known about now people, especially those affected by cognitive impairment, understand and regard the use of ARDs, as empirical studies are mainly conducted with healthy, non-cognitively impaired, participants. Methods: This qualitative study, a sub-study of a larger study on the evaluation of ARDs in the context of dementia

methods: This qualitative study, a sub-study of a larger study on the evaluation of Philos in the context of demention of demention of the context of demention of demen Results: Our results indicate that most participants consider ARDs a valuable tool for allowing them to make their Kesurs: Our results indicate that most participants consider ARDs a valuable tool for allowing them to make to draft an ARD when they are still healthy or soon after the diagnosis of cognitive impairment. Participants suggested that the completion of ARDs can be advanced with the provision of practical support and increased dissemination of information on ARDs in society.

Conclusion: Persons with subjective or mild cognitive impairment (SCVMCI) suggested several motivating factors Conclusion: Persons with subjective or mild cognitive impairment (SCVVVICI) suggested several motivating factors and concerns for completing an ARD. Clinicians need to be trained to accommodate patients' needs for sufficient and concerns for completing an ARD. Conscious need to be trained to accommodate patients needs for sufficient an ARD. As such tosted templates are consorted not not not available this addresses the unions pood for and adequate information, Furthermore, a standardised, partly pre-formulated template could be neighbor for the standardised and standardised templates are currently not yet available, this addresses the urgent need for more

Keywords: Dementia, Alzheimer's disease, Advance directives, Research participation, Ethics

Thank you!

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Participant demographics

Characteristic	No.
Gender	
Male	11
Female	13
Prefer not to say	0
Age in years	
<60	10
60-74	9
>74	5
Educational level	
High school/practical education	18
College	2
Postgraduate education	4
Diagnosis	
MCI	8
SCI	11
Prefer not to share/not sure	5