What do people with dementia and their informal caregivers know about advance directives?

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Outline

- Advance directives and dementia
- Results of the interviews with
  - People with dementia in early stage
  - Informal caregivers
- Conclusion
Advance directives and dementia

- Support Autonomy
- Possibility to define how she/he would be treated in the case of dementia
- Question: What do people know about advance directives?
Results

- Survey in the European Metropol Region Nürnberg (Germany)
- Face-to-face-interviews with open and structured questions
- 52 persons with dementia in early stage (aged 53 to 92 years)
- 51 informal caregivers (aged 31 to 81 years)
Results

How do you got the information about advance directives?

- 34% not reported
- 17% family
- 14% doctor/hospital
- 10% internet
- 6% books/booklet
- 6% friends/fellows
- 5% personal contact to healthcare professionals
- 4% notary
- 4% journals/magazines
- 2% others (TV/radio, bank, hospice...)

EMERGING FIELDS INITIATIVE

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Results

Why did you write or would you write an advance directive?

- 22% to avoid undesired misery by therapies
- 22% possibility of self-determination
- 20% self-formation of the last chapter in life
- 19% to ease the burden for relatives
- 12% diagnosis dementia
- 5% others
Results

„Doctor is obligated to fulfill my advance directive“

People with dementia

- Yes: 31%
- No: 8%
- Don't know: 61%
- Not reported: 2%

Informal caregivers

- Yes: 14%
- No: 2%
- Don't know: 2%
- Not reported: 82%
Results

„Advance directives cannot be revoked“

People with dementia

Informal caregivers

- 62% yes
- 15% no
- 10% don't know
- 13% not reported

- 63% yes
- 19% no
- 14% don't know
- 4% not reported
Results

„Dementia specific terms are possible“

People with dementia       Informal caregivers

- 60% yes
- 19% no
- 19% don't know
- 2% not reported

- 61% yes
- 14% no
- 17% don't know
- 8% not reported
Conclusion

- People are not always sure about the possibilities and boundaries of advance directives

- More information and enlightenment is necessary to support the idea of advance directives
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