



Leiden University  
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## Elderly people. Values and wishes.

### Dementia and self-determination

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# Themes

- Dementia and identity
- Values and wishes
- Involvement of loved ones
- Shifting interests and decisions concerning the future
- Merits of early diagnosis





# What is important in the later phases of life? Values of elderly people

## Modern care for the elderly

- Autonomy: you need to be in charge of what happens to you
- Stay at home as long as possible; at home is best
- Any care that is needed, you arrange yourself (informal care)



## Wishes in this phase of life

- Old age is a blessing but can also be a burden
- Ailments of old age
- Enjoy life to the max
- But also: what is going to happen?
  - It is hard to think about the future
  - Threatening future scenarios



## Identity and old age

- Illness is experienced as a threat and erosion of self
  - Not being viewed as oneself but as 'a person with such and such a disease'
- This applies even more to an affliction like dementia
  - Changes in character
  - Changes in social behaviour
  - Shift in relationships
  - Breach with one's former life



## Identity and biography

- Desire for a cohesive life story
- Narrative identity
  - Who one is, is also determined by what one lived through and what one is living through
- The narrative identity of a person is per definition a changing, historical narrative

Ricoeur: “Demander la question ‘Qui?’ c’est demander l’histoire d’une vie.”

- Social identity
  - Who one is, is also defined by one’s social context
  - One’s social context contributes to the maintenance of one’s identity

## Study of Informal caregiving

*“From ‘helping to decide’ towards ‘deciding on behalf’”*

Funded through the National Care for the Elderly Programme

Moral problems of informal caregivers in the care for home dwelling elderly people with and without dementia

- Interviews with older persons and their informal caregiver (but separately)
- Questionnaire sent out to 6000 informal caregivers
  - Which problems are you faced with?
  - How hard are those problems?





## Two central statements of elderly people

“The most important thing is, that I am not alone. That there are people who look after me. I am very grateful for that.”

“I find it hard to ask for help. They have their own lives to live.”



## Perspective of care receiving elderly people

- Wish to grow old within the context of family
- Loneliness is one of the greatest fears
- Independence is greatly valued
- Being in charge is both considered desirable and a burden
- Longing for the proximity of loved ones
  - Fear of overtaxing them
  - Irritation because of their interference in one's affairs
- Greatest worry: to be left alone





# Family involvement and self-determination

## Social identity and autonomy

In our study...

- People define their interests and values in the context of their social identity
- However, these were people being looked after by informal caregivers (mostly partners and family)
- Modern care for the elderly: organize your care principally within your own social circle

But also:

- Autonomy is not an isolated capacity but is partially shaped by relations with others
- Important decisions are often made together
- When incompetent to decide, we expect family to be able to act as surrogate decision makers

# Self determination

“Autonomy”

“Being in charge of what happens to one”

- But how to do that?
- Is it possible to be in charge of what is going to happen in one’s future?
- How do wishes of different phases of life compare to new situations?
- Does it help to know which scenario applies to one’s future self, even if there is nothing one can do to change it?
- What role may family members play, esp. in the case of incompetence?

## Family and self-determination

Family members are expected to decide on behalf of the elderly person who is incompetent to decide

- Surrogate decision making
  - Carry out the elderly person's wishes
  - "Do what he would have done"
  - Surrogacy as 'delegated self-determination'

## Surrogate decision making

- 74% of informal caregivers states they think to know largely what the elderly person would want to happen
- 60,6 % of informal caregivers think it is pretty clear who should have the role of surrogate decision maker, even though is has not been discussed
- But 97% of informal caregivers admits never to have discussed what the elderly person would want to happen in future medical situations.

Van Bruggen S et al. (2016): Problems experienced by informal caregivers with older care recipients with and without cognitive impairment, Home Health Care Services Quarterly, DOI: 10.1080/01621424.2016.1145166



# Mr Fisher 1

Mr Fisher, 82, widower, 2 sons

- Recently admitted to a nursing home because of the untenable situation at home
- Alzheimer's disease, strongly progressive
- Former professor of social sciences
- Well-adjusted to nursing home life, loved classical music sessions, loves the meals (especially meat dishes)





## Mr Fisher 2

Sons: “This is not who our father was! Our father was a principled vegetarian. Please don’t serve him any meat any more, only vegetarian dishes!”

So now Mr Fisher tries to steal the meatballs from his neighbour’s plate.



## Mr Fisher 3

- Should Mr Fisher be allowed to eat meat because he likes it?
- Should Mr Fisher be a vegetarian because he chose to be so in his former life?
- Whose wishes prevail: those of Mr Fisher then or those of Mr Fisher now?
- Must he eat vegetarian food because of himself or because of his sons?



# What is good for the incompetent patient?

Different perspectives:

- Relatives and loved ones: historical view  
(fitting with the duties as a conscientious surrogate decision maker)
- Professional caregivers: a-historical view  
the patient now as the recipient of care

## Nuffield Council on Bioethics, UK: Dementia 2009

- Autonomy interests and well-being interests
- Both are expressions of the one person's autonomy
- Well-being preferences should be taken into account (though not simply take automatic precedence)
- “Neither past nor present can automatically take precedence, but the relative strength of the person's wishes, the degree of importance of the decision, and the amount of distress being caused should all be important factors to consider.”

## So, in the case of Mr Fisher...

- Having been a principled vegetarian is significant
- Still being recognized by his sons as the man that he was, is important too
- Having positive experiences now that he is demented, adds to his current quality of life
- Search for solution to do justice to both:
  - Meat substitutes
  - Tasty vegetarian food
  - Perhaps not just for him but occasionally also for his neighbours



# Merits of early diagnosis

## Is knowledge always a blessing?

- Knowledge may be a burden (bleak future, nothing can be done about it)
- Knowledge may help understand what is happening anyway (relief, explanation)
- Knowledge may create the opportunity to be prepared



# Merits of early diagnosis

For the person herself:

- In time to think about and discuss what one would want to happen
  - What is really important to me?
- In time to determine who is to decide
  - Who do I trust to represent me?

For the loved ones and family

- In time to become familiar with the elderly person's views
- In time to divide the tasks and be prepared

For the professional care givers

- Start up the process of regular discussions about what is important to the elderly person
- Help patient and family to be prepared





# Concluding remarks



- Essential values for elderly people: to stay in a relationship with significant others
- If the aim is to maintain a good quality of life for people with dementia, then professional care efforts should be aimed at sustaining the social context
  - Support of the informal caregivers
  - Helping them to recognize how important this relationship is, also when things change due to the illness



This does not necessarily mean

- Keeping the person with dementia at home at all costs
- Letting the family members do all the work

What it means is that people should get support

- To find ways to have a social life together
- To find a balance between involvement and upholding one's own life
- To rest assured that they are inextricably linked (and to help maintain these links)



## Questions?

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