Exploring perspectives of young onset dementia caregivers

Joany Millenaar
Young Onset Dementia (YOD)

Dementia diagnosis < 65 years

- Specific issues related to a younger age
- Services for dementia in general often designed for the elderly
- Are the needs of people with YOD and their informal caregivers met?

PO3.21.
Alexander Kurz
Methods

18 interviews with YOD caregivers: selected by number of unmet needs (CANE)

Social
Physical
Psychological
Environmental

high amount of unmet needs

no unmet needs

Transcription of the interviews entered into Atlas.ti: inductive content analysis
Results

- Mean age: 58.7, SD 8.4
- Gender: 9 male, 9 female
- Diagnosis:
  - 8 Alzheimer’s disease
  - 3 Fronto-temporal dementia
  - 3 Vascular dementia
  - 2 Lewy Body
  - 2 Mixed dementia (AD/VD)
- Relationship:
  - 14 partners
  - 2 children
  - 2 friends
Results

Six themes

1. Acceptance of the diagnosis
2. Perception of the relationship
3. Role adaptation
4. Availability of services and tailored care
5. Support system and communication
6. Awareness and acceptance in the person with dementia
1. Acceptance of the diagnosis

- Clarity
- Adaptation
- Adjusting expectations

“If they would not have found anything, then there was no hope for me to continue, it was unbearable at the moment. The diagnosis was the final missing piece of the puzzle.”

“Your whole life changes, it is all different. But that does not mean it is not good. You have to see the pleasant side of things.”
Results

Caregivers with high amount of unmet needs:
- Uncertainties about diagnosis
- Focus on what could have been

Acceptance: allows to focus on the positive instead of experienced losses
Results

2. Perception of the relationship

- Caregivers miss their partner
- Decreasing intimacy and reciprocity
- Changes in original role division

Carers without needs: important to find a new balance, focus on the positive

More difficult in carers with unmet needs:

“It is a constant battle; you are not on the same level anymore”.

“I start to realise that we’ve had 25 good years but that there are bad years ahead of us”.
Results

3. Role adaptation

Unmet needs
- Difficult to find balance between being a caregiver and other roles
- Avoid situations
- Worry
- Afraid to ask for help

No needs
- Determine boundaries
- Look for possibilities
- High sense of competence
- Live in the moment
- Ask for help
Results

3. Role adaptation

### Unmet needs
- Difficult to find balance between being a caregiver and other roles
- Avoid situations
- Worry
- Afraid to ask for help

### No needs
- Determine boundaries
- Look for possibilities
- High sense of competence
- Live in the moment
- **(Ask for help)**
4. Availability of appropriate services

“The biggest problem for all of us is to find our way. There is no instruction manual.”
Results

5. Social support

- Importance of open communication
- Friends and family know what is going on so they are able to provide help
Results

High unmet needs
- Not a lot of support from friends and family
- Feel like they were on their own
Results

6. Awareness and acceptance in the person with dementia

- Reluctance to accept help
- Not comfortable with day care

You see I don’t have Alzheimer’s!
He always tries to prove himself when he is with others
Discussion

Caregivers without unmet needs:

- Accept their new role as caregiver
- Adjust their expectations
- Focus on possibilities and positive aspects
- Have more social support
- Know where to ask for help
- Openly communicate about experienced problems
- Are able to determine boundaries
- Ask for help when necessary

Support early on is necessary
Thank you!

joany.millenaar@maastrichtuniversity.nl