

TAILORING PSYCHOSOCIAL CARE FOR YOUNG ONSET DEMENTIA (YOD) IN NURSING HOMES IN FLANDERS DEVELOPMENT OF A CARE GUIDE

"HOW CAN CENTRES AND CARE INSTITUTIONS IN A SEMI-RESIDENTIAL SETTING MEET THE PSYCHOSOCIAL NEEDS OF PEOPLE WITH YOD?"

1. BACKGROUND & AIMS

Background

People with YOD often receive care in a setting designed for older people. The lack of personalised care can lead to boredom and difficulties in participation. There is a need for more specialised care for people with YOD.

Aims

- Provide insight and inspiration for caregivers
- Develop a tool that can be used to provide care tailored to the psychosocial needs of people with YOD

2. METHODS

Mixed-method design

Quantitative research

- Online survey
- 25 formal caregivers
- 24 informal caregivers
- 2 people with YOD

Qualitative research

- Online interviews
- 3 formal caregivers
- 1 informal caregiver

4. CARE GUIDE

Development of a care guide aimed at caregivers responsible for the care of people with YOD

1 Understanding YOD



- What is YOD?
- Psychosocial impact of YOD
- Differences between YOD and LOD

2 Psychosocial needs of people with YOD

3 Communication and contact with people with YOD



- Tips for making contact
- Methods for making contact
- ...

4 Support with sleep, stress and anxiety in people with YOD



- Healthy sleep behaviours and sleep tips
- Mindfulness and relaxation exercises
- ...

5 Age-appropriate and meaningful activities for YOD



- Volunteering
- Outdoor activities
- ...

6 Network support



- Supporting family and friends
- Contact with peers
- Psycho-education

7 Care provision for people with YOD in Flanders

3. RESULTS

Quantitative research

Knowledge and experience

- The majority of all caregivers don't have additional training, but indicate a need for further/specialised training



1. Interaction with people with YOD
2. Support after diagnosis
3. Knowledge about types of (young-onset) dementia
4. Communication with family and informal caregivers

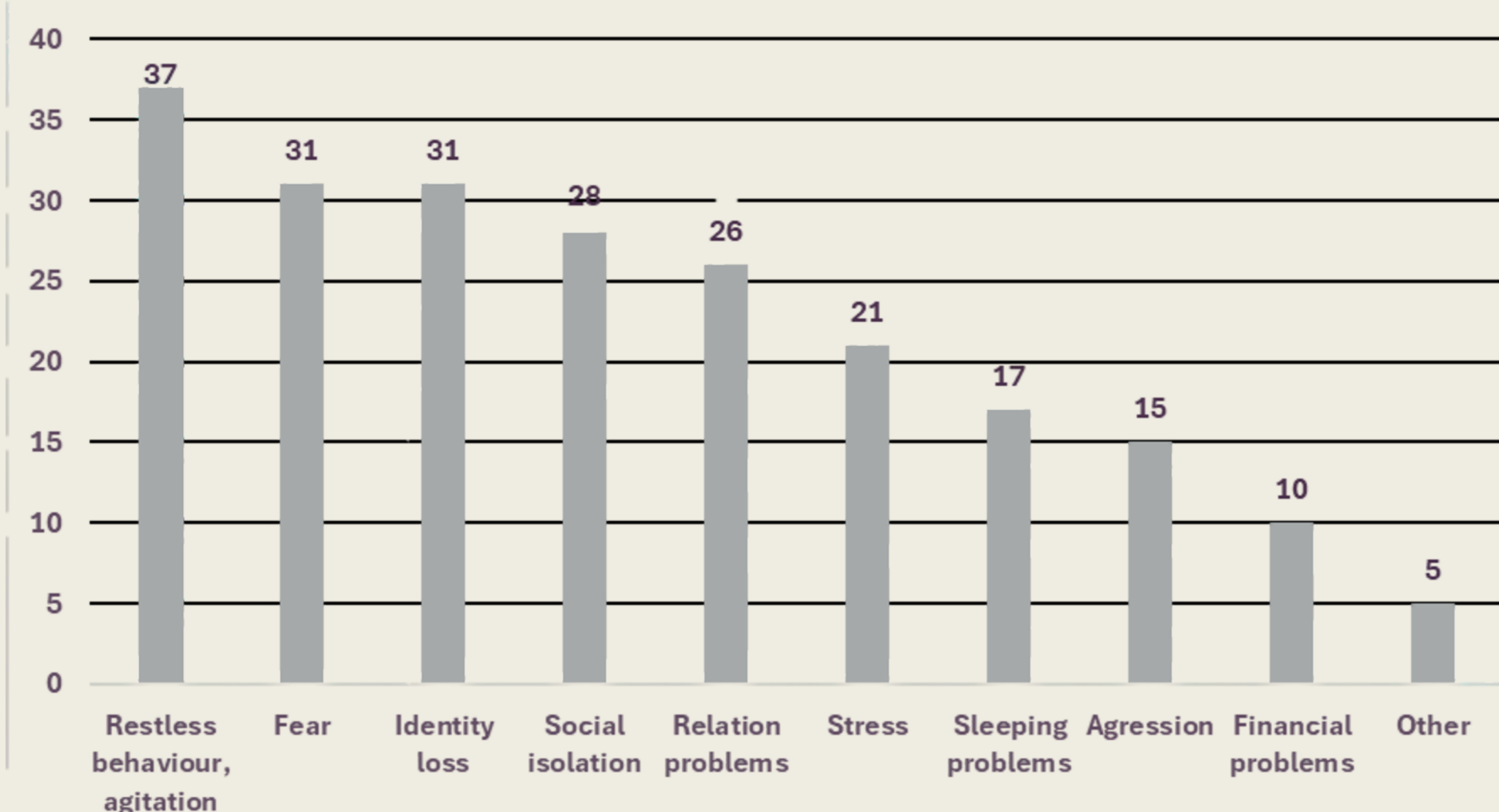
Young-onset dementia and late-onset dementia

- The majority of formal caregivers indicated that people with YOD come into contact with late-onset dementia (LOD)
- There are no difference in the activities provided for people with late-onset dementia and YOD in the current care

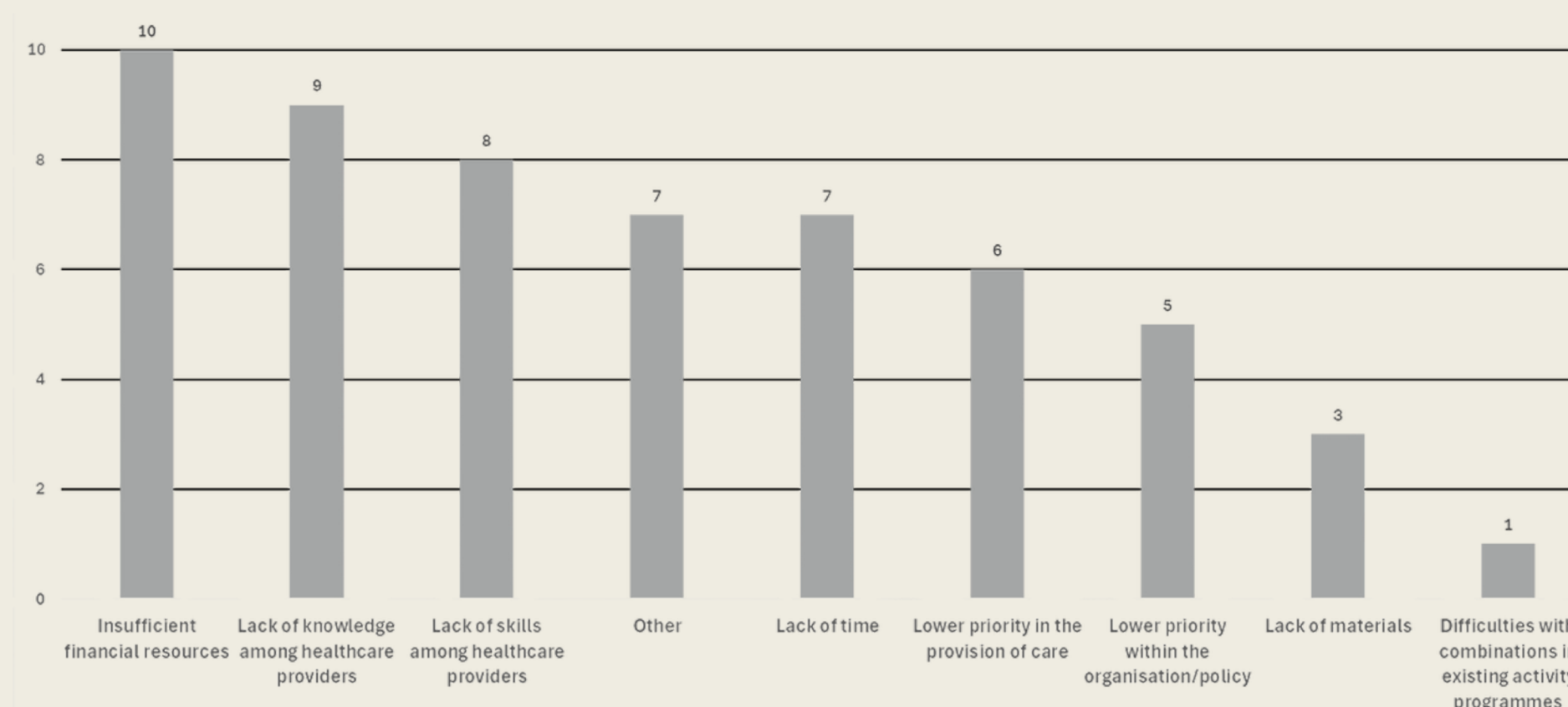
Activities

- The majority of formal caregivers indicated that they had a specific range of activities for people with YOD.

Psychosocial challenges and needs



Barriers to organise activities tailored to people with YOD



Qualitative research

Psychosocial needs

Care

- The majority of all caregivers indicated that they had not followed any additional training, but did indicate a need for further/specialised training
- Offering domestic tasks in residential care centres

Emotional and psychological aspects

- The importance of closeness, understanding and trust
- Room for fear, sadness and frustration
- Medication as a last resort for agitation

Differences between YOD and LOD

- The disease progresses more rapidly in YOD
- More language difficulties in YOD
- Greater need for a fixed structure for people with YOD

Activities

- No fixed activity calendar, activities based on needs and interests

Informal care and family involvement

- Family members are concerned about the reactions from those around them.
- Importance of family discussions with the person with YOD

Social network

Support for informal caregivers

- Caregivers can provide support throughout the process
- Organise opportunities where informal carers can meet each other

Broader social network

- Social network declines as the disease progresses
- Behavioural changes resulting from the disease can also have an impact on the declining social network

Care services

Access to care

- Neurologists play an important role in finding day care centres
- Geographically, it is often difficult to find the right care

Building relationships of trust

- Working in small teams
- Getting to know each other well
- Going along with the rhythm of the person with YOD

5. DISCUSSION

There is a clear gap between the psychosocial needs of people with YOD and the current care provision. Although the importance of specialised care has been widely acknowledged, existing services remain insufficiently tailored to the specific psychosocial needs of this group.

Topics such as sexuality and intimacy, sleep and stress were addressed only briefly or explained in more detail. It is important to detect where this limited interest comes from.

Further validation of this care guide in practice is needed

6. CONCLUSION

There is a lack of specialised care for people with YOD. There is a need for more care based on empathy, flexibility and trust

There is a great need for emotional support and for emotions to be discussed openly. Feelings of fear, loss and incomprehension are difficult to express, which can lead to social isolation, stress or misunderstood behaviour

It is important to support the social network throughout the process. Case managers could be a great help here

Caregivers indicated that they had limited knowledge and/or training regarding the care of people with YOD. This deficiency may result in inadequate psychosocial care for people with YOD

Current care for people with YOD is often offered on a small scale: individual (home setting) or in small groups (day care setting), which is ideal for offering activities tailored to their needs and requirements

Further research is needed to better understand the current care provided to people with YOD, including its requirements, the needs of those affected, and the opportunities available within their immediate environment

Our project website and link to the developed guide for caregivers in YOD

