

"Together we understand,
Together we support"

Odisee
DE CO-HOGESCHOOL

A needs-based approach to psychosocial care for people with young onset dementia in (semi)residential settings

Emma-Louise Meuris and Julie Vanderlinden
Odisee University of Applied Sciences, Brussels, Belgium

Background & aims

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

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

Care guide

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

- Understanding YOD
- Psychosocial needs of people with YOD
- Communication and contact with people with YOD
- Support with sleep, stress and anxiety in people with YOD
- Age-appropriate and meaningful activities for YOD
- Network support
- Care provision for people with YOD in Flanders

Results Quantitative research

Knowledge and experience

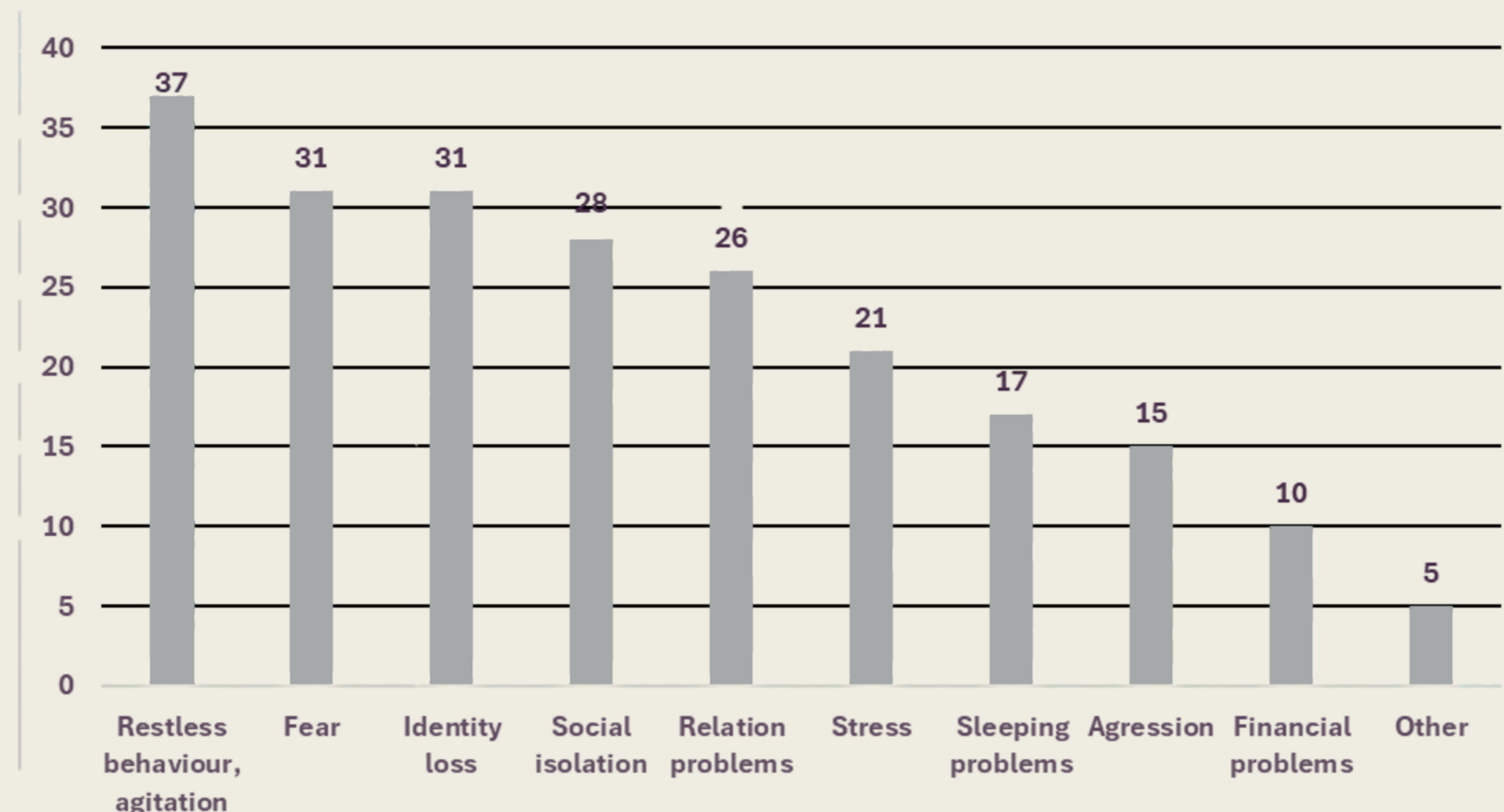
The majority of all caregivers don't have additional training, but indicate a need for further/specialised training

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

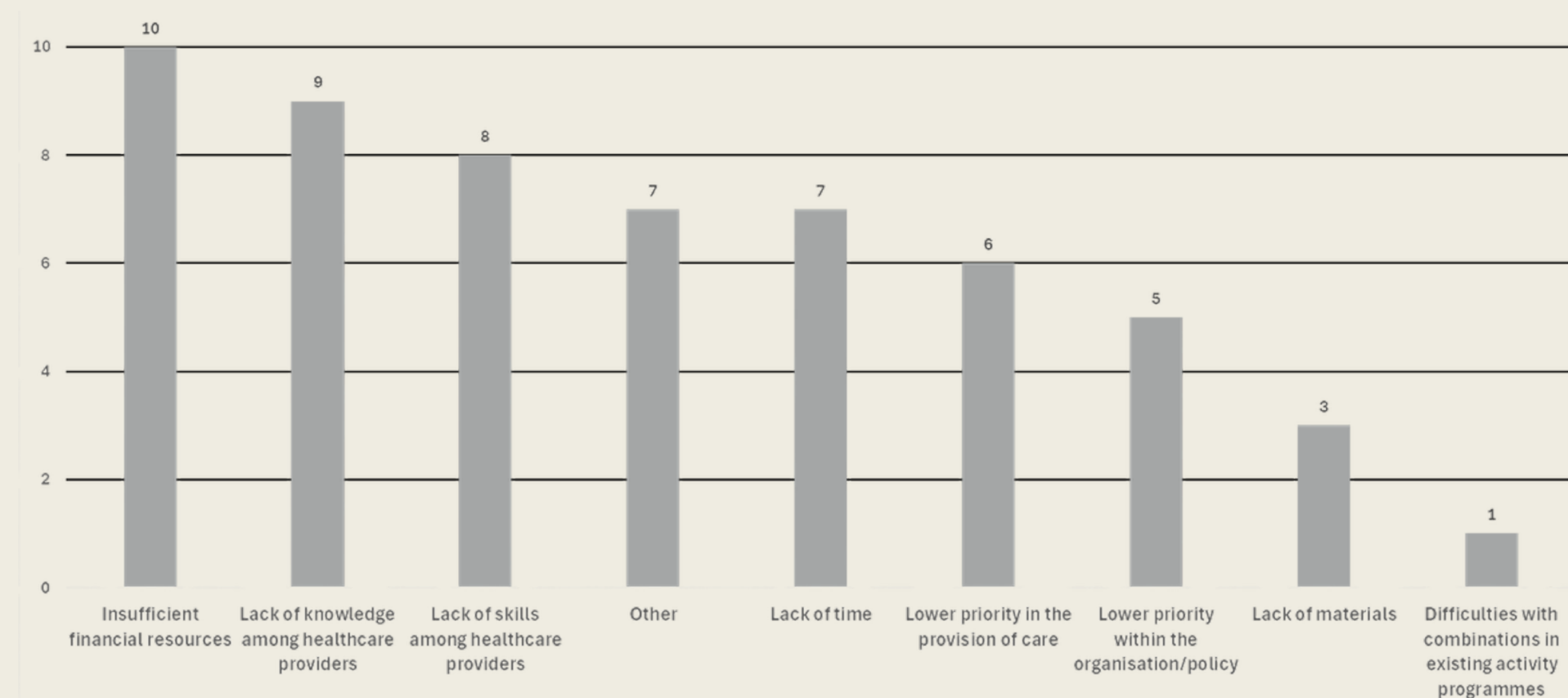
Young-onset dementia and late-onset dementia

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

Psychosocial challenges and needs



Barriers to organise activities tailored to people with YOD



Results Qualitative research

Psychosocial needs

Care

- The majority of all caregivers indicated that they had not followed any additional training
- Need for further/specialised training

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 impact the 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

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.

Further validation of this care guide in practice is needed

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.

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



Conclusions

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