

Bridging psycho-emotional care for young onset dementia (YOD)

A connected care approach for anxiety, stress and sleep problems

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Background

Young onset dementia (YOD) impacts various life domains causing anxiety, stress, and sleep disturbances

Current care systems often overlook these issues

Caregivers feel unprepared to address feelings of anxiety, distress and sleep problems

The aim is to bridge the expertise of (semi-)residential care with home care settings to better manage these problems in people with YOD and their informal caregivers

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Methods

- Identification of the gaps in (semi-)residential and home setting
- Detection of needs of people with YOD and their informal caregivers
- Analysis of the initiatives in the community

Mixed-methods approach

Qualitative focus groups, interviews and quantitative environmental analysis of community initiatives

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Next steps

- Finalise and analyse focus groups and interviews
- Initialise neighborhood analysis
- Development of framework and training
- Foster and educate network

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Results

- Focus groups (n=48)
- Interviews with people with YOD (n=3)
- Neighborhood analysis

Caregivers experiences

- Frequent sleep issues, anxiety and stress among YOD
- Staff shortages and time pressure

Knowledge gaps

- Limited understanding of lifestyle interventions, stress management and sleep strategies
- Existing training is often too general

Support needs

- Caregivers request hands-on training, case-based workshops, coaching in communication and more (time for) interdisciplinary collaboration
- Strong desire for better digital communication, shared care plans and home visits to build trust and ensure continuity between residential and home care

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