

Connected Care in Young-Onset Dementia

Bridging psychosocial expertise about anxiety, stress and sleep between (semi)residential and home settings

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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

- 8 focus groups with health care professionals
- 4 interviews with people with YOD
- 10 interviews with informal caregivers

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Next steps

- Disseminate framework
- Deliver training
- Foster and educate network

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Results

People with young onset dementia

- Frequently experience anxiety, stress, and sleep problems, especially in unfamiliar or overstimulating situations
- Structure, meaningful activities, emotional closeness, humor, and familiar people help reduce distress and promote calm

Informal caregivers

- Experience a high emotional and mental burden, including persistent stress & anxiety about the future, and disrupted sleep
- Express a strong need for practical guidance, recognition, respite, and support in managing anxiety and sleep problems

Healthcare professionals

- Recognize anxiety, stress, and sleep problems as core and ongoing challenges
- Emphasize the need for person-centered, non-pharmacological approaches, closer collaboration with the home context, and practice-oriented training and knowledge exchange.

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