CARE PRACTICES THAT AIM TO ADDRESS THE PSYCHOSOCIAL NEEDS OF INDIVIDUALS WITH YOUNG ONSET DEMENTIA (YOD)

A SCOPING REVIEW

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1.Prevalence of YOD

Worldwide: 119,0/100.00 residents

Europe: 159,4/100.00 residents

Belgium : 2050 → 8.374 people with YOD

2. Psychosocial impact of YOD

Physical loss

The decline in physical and cognitive abilities causes feelings of confusion and confrontation. People with YOD are often still energetic individuals, so there is a fear of losing fitness and involvement in meaningful activities.

Loss of autonomy and roles in society

People with YOD experience fear of losing control, fear of losing their freedom and fear of losing choices. In addition, there is also fear of losing social roles. Roles such as being a(n) employee, parent, partner, etc. can suddenly diminish.

Loss of social contacts

A diagnosis of YOD has a major impact on the person with YOD but also on those around them. There are feelings of incomprehension or ignorance. Many social contacts are often lost during the course of the disease.

3. Psychosocial needs of people with YOD

Importance of staying involved

Research demonstrates the importance of remaining engaged in society. Activities in which talents and competencies can be utilised are important.

Important note: people with YOD are often overestimated in terms of their abilities. This is probably due to the difference between their physical appearance and their declining cognitive abilities.

Non-adapted environment

People with YOD may feel “different” when participating in activities with mainly older people. It is important that people with YOD can receive care in a familiar, age-adapted and safe environment.

Flexibility

Current care provision in the home setting and semi-residential facilities is usually on weekdays and during office hours. This is not always convenient for the informal cargiver.

Financial aspect

The (care) partner often has to increase working hours or stop working in order to provide financial support. This can lead to reduced access to services for people with YOD.

In Flanders, there are 200 beds specifically for people with YOD spread across 23 accredited residential care centres.
People with YOD can receive a discount on the invoice when they reside in one of these centres.

Competencies of caregivers

Formal caregivers are often not sufficiently informed or trained to provide care for people with YOD.

Need for information

After receiving a diagnosis of YOD, a process of adjustment follows. Families need information about the disease, treatment options, home modifications, etc. This information is often lacking after the diagnosis.

4. psychosocial interventions for people with YOD

Volunteering

Utilising skills and talents enables people with YOD to participate in society. Remaining engaged stimulates the preservation of autonomy, improves well-being and quality of life, and promotes physical abilities.

Post-diagnostic care for YOD

According to research, current services for individuals with YOD are often inadequate or geographically dispersed. Only a few countries have specific recommendations for post-diagnostic care.

Physical (outdoor) activities

Physical activities have numerous physical benefits. They are beneficial for muscle strength, coordination, overall fitness and well-being.

Psychosocial support and guidance

The presence of external support or guidance can be important in participating in the daily lives of people with YOD. It is important to organise purposeful and age-appropriate tasks with the necessary support and structure.

5. Conclusion

1. People with YOD require a specialised and individualised approach that meets their specific needs.
The current level of care is often not sufficiently adapted.

2. Access to (specialised care) for people with YOD is not always straightforward.
More facilities will need to be established and professionals will need to be trained to continue providing adequate care to this target group.

3. People with YOD in residential care often stay in care facilities tailored to older people, where their psychosocial needs are not always met. As a result, age-en needs-adapted activities are not always organised.

4. Organisations should have a specialised range of services for informal caregivers of people with YOD.
This can help support and educate informal caregivers.

JONG-D

Meuris, E. (2024). Een literatuurstudie naar de psychosociale noden van personen met jongdementie. Odisee University of Applied Sciences