INTERNATIONAL CONFERENCE YOUNG ONSET DEMENTIA

Building Bridges
Research - Practice - Care

18 &19 September 2024
Odisee University of Applied Sciences
Brussels, Belgium

Book of Abstracts

Odisee
UNIVERSITY OF APPLIED SCIENCES

YOUNG-D

Co-funded by
the European Union

Preface

Dear participant of the conference,

The research group '***Active neighbourhoods and lifestyle interventions***' of the **Odisee University of Applied Sciences** welcomes you to the first International Conference on **Young Onset Dementia**, organised in Brussels in 2024.

During this conference we aim to bridge the gap between researchers, professionals, caregivers and practitioners involved and interested in **Young Onset Dementia**.

We thank all keynotes, authors and participants for their contributions. Together with inspiring keynotes and presentations from academia, care practices and (local) policies, we are reassured the program covers a broad range in order to bridge the gap between these different worlds.

We hope this conference offers you a unique opportunity to share your knowledge, current research and projects, to exchange experiences and to work together towards better care for people with **Young Onset Dementia** and their carers. This conference was co-funded by the Eramus+ program.

On behalf of the conference organising team, we wish all conference participants an inspiring and interactive event in Brussels.

Dr. Julie Vanderlinden

Research Lead YOUNG-D, Coordinator of the Research group Active neighbourhoods and lifestyle interventions, Odisee University of Applied Sciences

Sophie Dohogne

Researcher YOUNG-D

Liza Much

Researcher YOUNG-D

September, 2024, Brussels

EU Erasmus+ Consortium

This EU research consortium consists out of **7 different partners** from **4 different EU countries.**

Belgium

Odisee University of Applied Sciences

Familiezorg Oost-Vlaanderen

The Netherlands

Hanze University of Applied Sciences

Interzorg Nieuw-Graswijk

Denmark

Aarhus Kommune

SOSU Østjylland

Germany

Ostfalia Hochschule für Angewandte Wissenschaften

Scientific program

Day 1: 18 September 2024		
Hour	**Content**	**Speaker**
9.30-10.00	**Welcome with coffee/tea**	
10.00-10.10	**Opening and welcome words**	**Dr. Julie Vanderlinden** Research Lead YOUNG-D, Active neighborhoods and lifestyle interventions, Odisee University of Applied Sciences, Belgium
10.10-10.55	**Key note 1** **Young dementia: with the courage of an explorer**	**Jurn Verschraegen** Director Centre of Expertise on Dementia Flanders, Belgium
10.55-11.10	**Short Break**	
11.10-12.45	**Content session 1: Diagnosis, needs and care organisation**	
	1.1 The pre-diagnostic phase of young-onset dementia: a scoping review	**Charles David** Department of Psychiatry and Neuropsychology / Alzheimer Centre Limburg, Mental Health and Neuroscience Institute, Maastricht University, The Netherlands
	1.2 How to organize Advance Care Planning in Young-Onset Dementia: a scoping review in young and middle-aged adults with serious and chronic illnesses	**Lise Vandaele** University of Groningen, University Medical Center Groningen, Department of Geriatric Medicine, Groningen, The Netherlands, Alzheimer Center Groningen, Groningen, The Netherlands.
	1.3 A scoping review of psychosocial needs and requirements in people with Young Onset Dementia (student project)	**Emma-Louise Meuris** Student Psychosocial gerontology, Active neighborhoods and lifestyle interventions, Odisee University of Applied Sciences
	1.4 Incidence of behaviors adversely affecting intake of food and fluids is higher in persons with Young Onset Dementia compared to late onset dementia	**Eline Van Buuren** Department of Primary and Community Care, Radboud university medical center, Nijmegen, The Netherlands
	Questions-panel	
12.45-13.30	**LUNCH**	

13.30-14.45	**Content session 2: Analogue and digital tools to support people with Young Onset Dementia with emotions and sleep**	
	2.1 Coping with emotional stress and sleep problems in people with young-onset dementia: European co-creation and implementation of the YOUNG-D behavioural program and e-learning	**Sophie Dohogne** Researcher YOUNG-D, Active neighborhoods and lifestyle interventions, Odisee University of Applied Sciences, Belgium
	2.2 Trainers Perspectives on YOUNG-D program (student project)	**Bea Dijkman** Lecturer Hanze University of Applied Sciences Groningen, School of Nursing, The Netherlands
	2.3 How to design a digital application for people with Young Onset Dementia	**Davy De Winne** Researcher YOUNG-D, User experience, Odisee University of Applied Sciences, Belgium
	Questions-panel	
14.45-15.15	**BREAK**	
15.15-16.50	**Content session 3: People with Young Onset Dementia and their families**	
	3.1 Comprehensive Care and Support for Young-Onset dementia: A Client and family-Centered Approach	**Evy Van Handenhove** Familiezorg Oost-Vlaanderen, Belgium
	3.2 ‘Pampering weekend’ for children of a parent with young-onset dementia	**Tine Kenens** Alzheimer Liga, Belgium
	3.3 Creating support and awareness for young dementia	**Lydie Amici** Collectif Auguste et les autres: Alzheimer Jeunes, Belgium
	3.4 Sexuality in young onset dementia: A new conceptual framework and preliminary findings of a qualitative study	**Frauke Claes** Institute for Family and Sexuality Studies, Department of Neurosciences, Faculty of Medicine, KU Leuven, Belgium
	Questions-panel	
16.50	**Networking drink**	
18.00	**Closure of Day 1**	

Day 2: 19 september 2024

Hour	Content	Speaker
9.30-10.00	**Welcome with coffee/tea**	
10.00-10.45	**Key note 2:** **Building bridges between research, practice and policy in young-onset dementia**	**Dr. Christian Bakker** Healthcare psychologist and program leader of the young-onset dementia research program at the department of Primary and Community Care of the Radboud University Medical Centre in Nijmegen, the Netherlands
10.45-11.00	**Short Break**	
11.00-12.15	**Content session 4: People with Young Onset Dementia: Care, Work and Policy**	
	4.1 Interzorg	**Marijke Scheper, Marjon Caneel-Boerhof** Interzorg, The Netherlands
	4.2 Young Onset Dementia in the Workplace	**Sara Vandenwyngaerden** Regional center of expertise for dementia Memo, Belgium **Anouck De Bruijn** Regional center of expertise for dementia Orion & PGN, Belgium
	4.3 Aalst, dementia-friendly city	**Lore Robeyns** Social policy, Stad Aalst, Belgium
	Questions-panel	
12.15-13.00	**LUNCH**	
13.00-14.15	**Content session 5: People with Young Onset Dementia in the residential setting**	
	5.1 Approach and Experiences in a Unit (Saliehof) for Individuals with Young-Onset Dementia	**Gert-Jan Andries** Zorgband Leie&Schelde, Belgium
	5.2 A qualitative research study on the freedom of action of persons with young dementia in residential elderly care: creating a place/space for human flourishing	**Laurine Bourgonjon** Zorgband Leie&Schelde, Belgium

	5.3 Survival and Determinants of Mortality in Nursing Home Residents with Young Onset Dementia: Insights from BEYOnD and Care4Youngdem	**Jasper Maters** Department of Primary and Community Care, Radboud university medical center, Nijmegen, the Netherlands
	Questions-panel	
14.15-14.35	**BREAK**	
14.35-15.45	**Content session 6: Daily activities and leisure time for people with Young Onset Dementia**	
	6.1 Improving integrated care and support in young-onset dementia using participatory action research	**Sophie Van Westendorp** Department of Primary and Community Care, Radboud University Medical Center, Nijmegen, the Netherlands
	6.2 'Het Ventiel' – Buddy project for and with people with Young Onset Dementia	**Gudrun Callewaert** Het Ventiel, Belgium
	6.3 Enabling volunteering opportunities for persons with Young Onset Dementia in Flanders. The co-creational development of a toolbox and inspirational guidebook	**Elise Cornelis** Research and Innovation Centre for Health and Care, Artevelde University of Applied Sciences, Ghent (Belgium)
	Questions-panel	
15.45	**Closing words and networking drink**	**Dr. Julie Vanderlinden** Research Lead YOUNG-D, Active neighborhoods and lifestyle interventions, Odisee University of Applied Sciences, Belgium
18.00	**Closure of day 2**	

Keynote Speakers

Keynote 1: 18 September 2024

Young dementia: with the courage of an explorer

Jurn Verschraegen

Director Centre of Expertise on Dementia Flanders, Belgium

We welcome you to this first international conference on young onset dementia. We hope that you will be joining us for the conference that is held as a vital gathering of minds and hearts.

Your unwavering dedication to those affected by young onset dementia inspires us all and here we will learn from each other and share good practices.

When you are faced with a diagnosis of dementia at a young age, you are at a stage of life when you do not expect it. You are still working, your children still need attention and financially you are struggling to pay for care and support in addition to your mortgage. Flanders has some particularly wonderful initiatives for people with young onset dementia. Many of them were created by people who have been confronted with it themselves.

During these two days of conference, we hope to feel the pulse of those dealing with the issue.

I myself had the honor of organising two wonderful expeditions with the Brain Adventure Team. I learnt from their agility, their willpower and, above all, their positive outlook. The participants and their family caregivers were one with their 'companions'. Strong together.

Meanwhile, the Flemish government has already chosen to pay extra attention to this specific group, inspired by the voice of many of them.

This conference is a testament to our shared commitment to improving care and support for young individuals facing this condition.

Together, we will explore innovative strategies, share knowledge, and build a stronger community of support.

Thank you for your compassion, expertise, and tireless efforts. Let’s make this conference a beacon of hope and progress.

Keynote 2: 19 September 2024

Building bridges between research, practice and policy in young-onset dementia

Prof. dr. Christian Bakker - Professor of care and support in young-onset dementia
UKON / Department of primary and community care, Radboud university medical center / Radboudumc Alzheimercenter / Young-onset Dementia Knowledge Center

Young-onset dementia profoundly affects how people live their lives. Research should address those things that are important to people living with young-onset dementia and to people involved in their care, both family carers as well as healthcare professionals. The development and evaluation of psychosocial interventions addressing the specific care and support needs in young-onset dementia and the exploration of how these can best be integrated into the care system is essential to support people living with young-onset dementia. In his talk Christian Bakker will discuss what lessons have been learned in the last two decades in the Netherlands with establishing an infrastructure that allows to build bridges between research, clinical practice and policy in young-onset dementia.

Abstracts

September 18, 2024

Content session 1: Diagnosis and care

1.1 The pre-diagnostic phase of young-onset dementia: a scoping review

Charles David MSc[a], Stevie Hendriks PhD[a], Line Damsgaard MD[b], Prof. Sebastian Köhler PhD[a], Prof. Marjolein de Vugt PhD[a]

[a] Department of Psychiatry and Neuropsychology / Alzheimer Centre Limburg, Mental Health and Neuroscience Institute, Maastricht University, The Netherlands
[b] Danish Dementia Research Centre, Department of Neurology, Copenhagen University Hospital – Rigshospitalet, Copenhagen, Denmark

Background and aims

Dementia before the age of 65 is called young-onset dementia (YOD) and affects about 3.9 million people worldwide (1). Heterogeneity in underlying etiologies lead to clinical variability of first symptoms, which can include cognitive decline, behavioural changes, and language impairment (2). Younger onset age and prevalence of non-cognitive symptoms poses challenges in recognizing YOD by clinicians, often leading to a diagnostic delay of 4-5 years (3). Recognizing prodromal symptoms is vital for early YOD diagnosis and to facilitate access to appropriate services and informal care arrangements. Therefore, this review aims to gain insights into the pre-diagnostic phase of YOD by exploring available literature on presenting symptoms and the factors aiding to a timely diagnosis of YOD.

Methods

A literature search was done across PubMed, Embase, Web of Science, and PsychInfo. Two independent reviewers screened 4,403 titles/abstracts, followed by a full-text review of 556 articles. A standardized data extraction form was used to report findings on time to diagnosis, prodromal symptoms, barriers, and facilitators to diagnosis amongst others. Review reporting adheres to PRISMA-ScR guidelines.

Results

We included 266 studies out of which time to diagnosis was mentioned in 45 studies and ranged from 1 to 15 years. We categorized early symptoms into cognitive, affective, behavioural, vascular, gait, changes in weight or appetite, social and symptoms affecting daily functioning. Prevailing early symptoms reported in 103 studies, were forgetfulness, apathy, depression, learning difficulties, problems with speech, mistakes at work and self-neglect. Common barriers to timely YOD diagnosis included lack of knowledge about YOD among clinicians, people with YOD and their caregivers, misdiagnosis, misattribution, and denial of symptoms while facilitators for early diagnosis were YOD dedicated diagnostic services, timely referrals, and persistence of follow up in the diagnostic process.

Implications for practice and future perspectives

This review shows the diversity of first symptoms of YOD and identified several barriers and facilitators for timely diagnosing YOD. This information can be used in future research and clinical practice to improve the diagnostic trajectory for people with YOD.

Key references

[1] Hendriks S, Peetoom K, Bakker C, van der Flier WM, Papma JM, Koopmans R, et al. Global Prevalence of Young-Onset Dementia. JAMA Neurol. 2021 Sep;78(9):1–11.

[2] Hendriks S, Peetoom K, Tange H, van Bokhoven MA, van der Flier WM, Bakker C, et al. Pre-Diagnostic Symptoms of Young-Onset Dementia in the General Practice up to Five Years Before Diagnosis. J Alzheimers Dis. 2022 Jun 28;88(1):229–39.

[3] Chiari A, Tondelli M, Galli C, Carbone C, Fiondella L, Salemme S, et al. How long does it take to diagnose young-onset dementia? A comparison with late-onset dementia. Neurol Sci. 2022 Aug 1;43(8):4729–34.

1.2 How to organize Advance Care Planning in Young-Onset Dementia: a scoping review in young and middle-aged adults with serious and chronic illnesses

Lise vandaele1,2, Marlise E.A. van Eersel1,2, Karin M. Vermeulen1,3, Pauline de Graeff1 , Barbara C. van Munster1,2

1. University of Groningen, University Medical Center Groningen, Department of Geriatric Medicine Groningen, The Netherlands.
2. Alzheimer Center Groningen, Groningen, The Netherlands.
3. University of Groningen, University Medical Center Groningen, Department of Epidemiology

Background and aims

Advance care planning (ACP) in dementia may be a desirable process for discussing preferences regarding future care [1,2]. Extensive studies have been conducted on ACP in older patients with dementia, yet there is little knowledge regarding ACP in people with young-onset dementia (YOD) [3]. Patients with YOD may have different needs and preferences [2]. Insights can be gained from applying ACP to other serious and chronic illnesses. The objective of this review is to evaluate the process of ACP in young and middle-aged individuals with serious and chronic illnesses to ascertain its applicability in patients with YOD.

Methods

A systematic search was conducted in PubMed, EMBASE, and CINAHL for qualitative and quantitative studies. The search covered the concepts: 'advance care planning', 'population', and 'diseases. One screener conducted title/abstract-screening using AS Review, and two screeners independently performed the full-text screening. The data will be extracted according to the following themes: "How ACP is applied," "When ACP is applied," "By whom ACP is applied," and "Which topics are discussed."

Preliminary results

The search yielded 1.691 unique abstracts, of which 227 relevant full texts. ACP was performed in varied population with various illnesses, including dementia, cancer and heart failure. Different interventions are available for the discussion of ACP. The optimal timing for initiating ACP should be immediately following diagnosis, although it was recognized that patients should be afforded sufficient time to process the diagnosis. It is recommended that a physician should be responsible for initiating ACP. The desired topics of ACP can be divided into two categories: medical topics (e.g., euthanasia, home care) and non-medical topics (e.g., financial wills, religious and spiritual topics).

Discussion

ACP in young and middle-aged people with serious and chronic illnesses can be applied in YOD. However, ACP should be applied earlier, as cognitive decline affects future decision-making capacity.

Implications for practice and future perspectives

Based on the results of this review, these new insights are applicable in the care for adults with YOD.

Key references

[1] Van Rickstal, R., et al. (2022). "A qualitative study with people with young-onset dementia and their family caregivers on advance care planning: A holistic, flexible, and relational approach is recommended." Palliat Med 36(6): 964-975.

[2] Van Rickstal, R., et al. (2019). "Limited engagement in, yet clear preferences for advance care planning in young-onset dementia: An exploratory interview-study with family caregivers." Palliat Med 33(9): 1166-1175.

[3] Koopmans, R. T., et al. (2015). "Palliative Care in People With Young-Onset Dementia (YOD): An Undiscovered Area!" J Am Med Dir Assoc 16(12): 1008-1009.

1.3 A scoping review of psychosocial needs and requirements in people with Young Onset Dementia (student project)

Emma-Louise Meuris, Julie Vanderlinden

Research group Active Neighborhoods and lifestyle intervention, Psychosocial gerontology, Odisee University of Applied Sciences, Brussels (Belgium)

Background and aims

In various countries, age-specific care and support for people with young-onset dementia is (still) not available. In Flanders, there are several initiatives for individuals with young-onset dementia, but they often have a limited capacity or they are geographically difficult to reach. However, in recent years, there has been increasing awareness among health care organizations, health professionals, researchers, and policy makers that individuals with young-onset dementia have specific psychosocial needs related to the life stage in which they receive the diagnosis of young-onset dementia. These psychosocial needs of individuals with young-onset dementia differ from those diagnosed with late onset dementia.

This scoping review is part of a broader research project which has the goal to map psychosocial needs of people with young-onset dementia and to identify existing good practices and interventions in the current care for people with young-onset dementia that aim to meet these psychosocial needs.

The aims of this scoping review were:

- To investigate the psychosocial needs of people with young-onset dementia in care.
- To identify the obstacles in the current care for people with young-onset dementia.
- To search for psychosocial interventions for people with young-onset dementia.

Methods

The search for literature began in January 2024. For this review, various databases were consulted Limo Libis, Google Scholar and PubMed. The search terms were: young onset dementia, participation, daycare, elderly, activities, engagement, psychosocial needs and occupation. Twelve scientific articles with average to good quality were included in this review. The main inclusion criteria were: studies targeting individuals with young-onset dementia and studies that report the psychosocial needs of individuals with young-onset dementia. The main exclusion criteria were: studies older than 10 years.

Results

Young-onset dementia has a psychosocial impact on daily life of people with young-onset dementia and their relatives. It is important for caregivers to consider the various losses that individuals with young-onset dementia experience. These include physical loss (motor and cognitive), loss of autonomy and societal roles, and loss of social contacts. Based on these loss processes, the needs of individuals with young-onset dementia were identified, yielding the following results:

- Remaining Engaged: It is important to stay involved in activities, which can be achieved through household tasks, work, or other leisure activities [1].
- Adapted Environment: Individuals with young-onset dementia often receive care in facilities for the elderly, where they may feel different and lack connection. An adapted environment is crucial [2].
- Flexible Care: The need for flexible care that is adapted to the individual's (changing)needs.
- Competences of care professionals: Ensuring that care professionals are well-trained and competent in handling the specific needs of young-onset dementia [3].
- Information Needs: Providing adequate information to both the individuals with young-onset dementia and their relatives [3].

Various interventions for individuals with young-onset dementia were reported, including: voluntary work, Post-diagnostic care, Physical (outdoor) activities, Psychosocial support and guidance.

Discussion

The literature review indicates that individuals with young-onset dementia have unique psychosocial needs that differ from people with late onset dementia. People with young-onset dementia have a strong need to maintain independence, engage in meaningful social interactions, and participate in significant activities. There is a clear demand for specialized care and activities tailored to the psychosocial needs of individuals with young-onset dementia.

This scoping review shows that activities such as gardening, volunteering, physical exercise, and participating in activities with peers have positive effects on self-esteem, anxiety reduction, a sense of usefulness, and overall well-being in individuals with young-onset dementia. The results from the review as well as next steps in this research project will be discussed.

Implications for practice and future perspectives

There are several important future perspectives that need to be considered:

- There is a need for specialized and individualized approaches that address the psychosocial needs of people with young-onset dementia.
- As the prevalence of young-onset dementia is expected to increase, there will be a need for more facilities and resources for both individuals with young-onset dementia and their social environment
- Individuals with young-onset dementia often receive semi-residential care in settings for older adults where age-appropriate activities for younger people with dementia isn’t always available nor provided.

Key references

[1] Couzner, L., Day, S., Draper, B., Withall, A., Laver, K. E., Eccleston, C., Elliott, K.-E., McInerney, F., & Cations, M. (2022). What do health professionals need to know about young onset dementia? An international Delphi consensus study. BMC Health Services Research, 22, 14. https://doi.org/10.1186/s12913-021-07411-2

[2] Millenaar, J. K., Bakker, C., Koopmans, R. T. C. M., Verhey, F. R. J., Kurz, A., & de Vugt, M. E. (2016). The care needs and experiences with the use of services of people with young-onset dementia and their caregivers: A systematic review. International Journal of Geriatric Psychiatry, 31(12), 1261-1276. https://doi.org/10.1002/gps.4502

[3] Van Vliet, D. van, Persoon, A., Bakker, C., Koopmans, R. T. C. M., Vugt, M. E. de, Bielderman, A., & Gerritsen, D. L. (2017). Feeling useful and engaged in daily life: Exploring the experiences of people with young-onset dementia. International Psychogeriatrics, 29(11), 1889-1898. https://doi.org/10.1017/S1041610217001314

1.4 Incidence of behaviors adversely affecting intake of food and fluids is higher in persons with Young Onset Dementia compared to late onset dementia

Eline van Buuren (1,2,3), Jenny T. van der Steen (1,3,4,5), Marieke Perry (1,3,6), Raymond T.C.M. Koopmans (1,2,3), Christian Bakker (1,3,7)

1 *Department of Primary and Community Care, Radboud university medical center, Nijmegen, The Netherlands.*
1 *'Joachim en Anna' center for Specialized Geriatric Care, De Waalboog, Nijmegen, The Netherlands.*
2 *Radboudumc Alzheimer Center, Nijmegen, The Netherlands.*
3 *Department of Public Health and Primary Care, Leiden University Medical Center, Leiden, The Netherlands.*
4 *Cicely Saunders Institute, King's College London, United Kingdom.*
5 *General Medical Practice, Velp, The Netherlands.*
6 *Groenhuysen Center for Geriatric Care, Roosendaal, The Netherlands.*

Background and aims

People with dementia may develop behavioral problems that affect the intake of food and fluids. This includes (non) verbal refusal, such as pushing cutlery or an assisting person away [1, 2]. This in turn can lead to malnutrition, dehydration, and an increased mortality risk. These situations have a profound impact on (informal) caregivers [3]. We aimed at assessing the incidence of these behaviors in nursing home residents with late onset dementia (LOD) and young onset dementia (YOD).

Methods

A prospective cohort study was performed with a 12-month follow-up, monitoring 36 dementia special care units comprising 424 care beds. Each month the total number of residents at risk was registered to calculate the denominator. The numerator was the number of incident cases during follow-up. Cases had to meet the inclusion criteria of a diagnosis of dementia, presence of one or more symptoms of behavioral problems, occurrence of behaviors at least twice weekly, and consequences such as weight loss or dehydration.

Results

Among 40 reported cases, 16 were included, resulting in an incidence rate of 32/1000 person-years. The incidence rate was higher in people with YOD (45/1000 person-years) than in LOD (26/1000 personyears). In all cases there were at least two behavioral symptoms, of which 'turning his/her head away', 'pushes cutlery/crockery/food/nurse away', and 'stands up from the chair or leaves the table' were reported most often. Comfort care was the goal in all cases.

Implications for practice and future perspectives

The incidence of behaviors that adversely affect the intake of food and fluids in this study was low. However, a higher incidence was found in residents with YOD. This may imply young residents are more at risk of developing these behaviors. The low numbers may indicate that caregivers in long-term care facilities are able to effectively or pro-actively manage such situations.

Key references

[1] Chen H, Li C, Wang J, Fei Y, Min M, Zhao Y, Shan EF, Yin YH, Liu CY, Li XW (2023) Non-pharmacological interventions for feeding and eating disorders in persons with dementia: systematic review and evidence summary. J Alzheimers Dis, 1-22.

[2] Liu W, Perkhounkova Y, Williams K, Batchelor M, Hein M (2022) Mealtime nonverbal behaviors in nursing home staff and residents with dementia: Behavioral analyses of videotaped observations. Geriatr Nurs 44, 112-124.

[3] Jung D, Lee K, De Gagne JC, Lee M, Lee H, Yoo L, Won S, Choi E (2021) Eating Difficulties among Older Adults with Dementia in Long-Term Care Facilities: A Scoping Review. Int J Environ Res Public Health 18, 1-16.

Content session 2: Analogue and digital tools to support people with Young Onset Dementia with emotions and sleep

2.1 Coping with emotional stress and sleep problems in people with young-onset dementia: European co-creation and implementation of the YOUNG-D behavioural program and e-learning

Julie Vanderlinden (1, 2), Sophie Dohogne (1), Liza Musch (1,2)

1. *Research group active neighborhoods and lifestyle interventions, department of Health Care (Odisee University of Applied Sciences)*
2. *Pain in Motion Research Group, Department of Physiotherapy, Human Physiology and Anatomy, Faculty of Physical Education and Physiotherapy, Vrije Universiteit Brussel, 1000 Brussels, Belgium*

Background

When dementia starts prior to the age of 65 years, the symptoms often progress faster than in late onset dementia (diagnosis >65 years). Young onset dementia (YOD) often goes along with increased stress and sleep problems, which affects quality of life. Relaxation exercises such as breathing and mindfulness have been described to help cope with these psychosocial challenges. However, caregivers don't always know how to handle emotional distress and questions regarding relaxation or sleep problems when they occur during their caregiving for people with YOD. Furthermore, caregivers don't always feel skilled or secure to offer these relaxation exercises to people with YOD.

Methods

A 6-week behavioral program (JONG-D) was developed and tested by researchers at Odisee University of Applied Sciences (Brussels, Belgium) in co-creation with YOD care providers in Flanders. This program was intended for people with YOD to provide tools and coping mechanisms regarding stress and sleep management. After a pilot of this program in four day care centers, the researchers from Odisee University of Applied sciences expanded the JONG-D program in co-creation with practical and educational partners from The Netherlands, Denmark and Germany in to an integral YOUNG-D program. In a further stage, this co-created YOUNG-D program has been implemented in three settings for YOD (residential, semi-residential and outpatient). A YOUNG-D trainers' manual was developed for professional caregivers. Based on this YOUNG-D program, an e-learning was also developed to help caregivers and students gain insight in the possibilities of breathing and mindfulness techniques as tools to cope with emotional distress and sleep problems in YOD. This project received co-funding of the EU Erasmus+ program.

Results and conclusions

This European co-creative project resulted in a more tailormade YOUNG-D program to reduce emotional stress and sleep problems in people with YOD. An e-learning was developed to help caregivers and students understand the interplay between YOD and feelings, emotions and sleep as well as the application of relaxation techniques such as breathing and mindfulness in YOD. The presentation will provide an insight in perspectives and experiences of trainers and people with YOD in the YOUNG-D program as well as avenues for future research and collaboration.

2.2 Trainers Perspectives on YOUNG-D program: Evaluation of a behavioural program for people with early onset dementia in order to cope with anxiety, stress and sleep problems

Bea Dijkman, Ellis van Ark, Amber Niestijl
Hanze University of Applied Sciences Groningen, School of Nursing

Background

Early onset dementia (EOD) presents unique challenges, particularly in managing anxiety, stress, and sleep disturbances. Within the Young-D project, the project partners developed workshop programme for people with EOD, with the aim to address these issues. The Young-D programme was piloted in three healthcare organisations, one in Belgium, one in the Netherlands and one in Denmark. All trainers were experienced with the target group and familiar with the program participants. Gaining an understanding of their perspectives and experiences can offer valuable insights into the effectiveness of the interventions and highlight areas for improvement.

Methods

This study employed semi-structured, qualitative in-depth interviews with trainers from the Young-D program. The interviews were conducted by two nursing students during a research semester at the end of their Bachelor of Nursing program at Hanze University of Applied Sciences Groningen in the Netherlands. The interviews were conducted using a pre-drafted interview guide, and all interviews were transcribed. The qualitative data were analyzed using a deductive thematic analysis approach.

Results

Ultimately, four of the five trainers were interviewed. All trainers emphasized that their experience with people with EOD was essential for the success of the sessions. Building a relationship of trust with clients was crucial, as good group dynamics enhance interaction.

Although the trainer's manual contains a wealth of information, some trainers found it confusing and felt it lacked practical details. The freedom to tailor sessions to the needs of the group was highly appreciated, despite the time-consuming preparation involved. The use of various materials and a positive environment contributed positively to the sessions. Evaluating the program with participants proved challenging due to clients' memory problems and limited recollection of the sessions. The trainers recommend closer collaboration with informal caregivers to improve the program's effectiveness for people with EOD.

Conclusion

The trainers' experiences with the YOUNG-D program were generally positive. However, they emphasized the importance of adapting various elements of the program to achieve greater success in the interventions. The findings suggest that improving the manual, providing additional training, and fostering closer collaboration with informal caregivers are crucial steps to enhance the feasibility and usability of the YOUNG-D program.

Recommendations

It is recommended to maintain the flexibility to adjust the Young-D program to the specific situations and characteristics of the target group. Additionally, the program trainer manual should be clarified and supplemented with important guidelines, advice, and practical tips. It is crucial to adjust the sleep session and develop closer collaboration with informal caregivers and other healthcare providers to ensure continuity of care and better evaluate the interventions' impact on people with EOD.

Further research is recommended to explore the benefits of these types of programs and non-pharmaceutical interventions for people with EOD and their informal caregivers, and to identify best practices for implementation.

2.3 How to design a digital application for people with Young Onset Dementia

Davy De Winne, Rutger De Wilde
User experience design Research, Odisee University of Applied Sciences

Background

Designing and developing a digital application begins with understanding the needs of your users. Conducting user research with individuals diagnosed with young onset dementia (YOD) presents unique challenges and opportunities when interviewing or testing with participants. This presentation explores the methodology, findings, and practical insights gained from the process of developing a digital application aimed at supporting these individuals.

Methods

We discuss tailored approaches to user interviews, including the use of simplified language or symbols and strategies for maintaining engagement despite cognitive fluctuations. We also emphasize how we report the results to our co-researchers and other stakeholders to validate the findings.

Results

The presentation covers the specific challenges encountered during user testing of the prototype, such as empathizing with scenarios, accommodating physical impairments, and ensuring a stress-free testing environment.

Conclusions

Key findings highlight the necessity of flexible testing protocols, the value of iterative feedback loops, and the importance of involving caregivers and family members in the research process. By sharing our experiences and strategies, we aim to equip researchers with the tools to effectively engage with and design digital applications for individuals with young onset dementia, ultimately fostering more inclusive and supportive digital solutions.

Content session 3: People with Young Onset Dementia: care, work and policy

3.1 Comprehensive Care and Support for Young-Onset Dementia: A Client and family-Centered Approach

Evy Van Handenhoven, Laure Vervaet
Familiezorg O.Vl. – Belgium

Background and aims

Familiezorg offers family care support for all life stages and care needs. We provide tailored care packages and advice, keeping the user central. Our services include care advice and case management, promoting broad access to family care for those with a care indication. We provide family care for various target groups. One of these groups includes people with young-onset dementia.

Since 2016, Familiezorg has been offering specialized care for young people with dementia. The aim is to provide tailored and focused support that emphasizes the abilities of individuals with young-onset dementia while also supporting their families and caregivers. This is achieved through small-scale day centers and comprehensive care guidance.

Methods

Familiezorg operates four day centers, each accommodating up to eight people with young-onset dementia daily. The care teams focus on social interaction, activation, and enjoyable activities, emphasizing what the visitors can still do. The small-scale, homely setting ensures personal attention and customized care. Additionally, care guidance is provided to families and caregivers, offering support in the home situation, advice on managing behavioral changes, and emotional support. The dementia process is closely monitored in collaboration with the involved family. This is achieved through regular phone contacts, informal meetings, home visits, afternoon discussions with caregivers, and joint activities.

Additionally, we aim to participate in projects to further expand our knowledge and vision. One of these projects is Young D, through which we, together with international partners, created a practical guide on stress, anxiety, and sleep disorders in young people with dementia. The developed methodologies and activities on these topics are regularly applied in our day centers.

Results

The small-scale approach and client-centered vision have proven effective in providing focused attention and customized care. Visitors benefit from activities that highlight their abilities, while families and caregivers receive valuable support and guidance. This approach helps in managing the dementia process and planning for future care needs.

Implications for practice and future perspectives

The client-centered and small-scale approach of Familiezorg highlights the importance of personalized care and building trust-based relationships in dementia care. This model can serve as a valuable example for other care providers. Future perspectives include further specializing the range of activities offered in the day centers and improving our supportive care guidance service for families and caregivers, to ensure and further enhance comprehensive and accessible care for people with young-onset dementia.

3.2 ‘Pampering weekend’ for children of a parent with young-onset dementia

Tine Kenens

Alzheimer’s Association Flanders

Background and aims

Since 2021, Alzheimer’s Association Flanders has organized a Summer Camp for children of a parent with young-onset dementia in Houthulst, West Flanders. In 2024 the weekend gets a new name, chosen by the target group: ‘pampering weekend’. This event is offered free of charge to the target group: school-going or studying children of a parent with young-onset dementia aged between 8 and 25 years. The ‘healthy parent’ can also join us. The goal of the pampering weekend is to provide a safe haven for young people struggling with questions about how to cope with the changes their parent is undergoing due to young-onset dementia.

Methods

Workshops, activities, and in-depth conversations help them not only understand themselves better but also find their place within a community of peers. The young participants and their healthy parents will connect with peers, receive information about young-onset dementia, and gain numerous tips and insights to help them manage their daily lives. The process is guided by counselors and psychologists with experience regarding (young-onset) dementia and group dynamics.

Results

Participant quotes: "Here, we can just 'be' without having to explain anything. We understand each other without many words because we all go through the same experiences. Dementia affects us too, but it's not always easy to talk about it with others. Here, we can," many young people agreed in unison. During the summer camp, heartwarming moments were shared, unique stories exchanged, and valuable friendships forged

Discussion

Despite the heartwarming stories and the enthusiasm of the participants, as well as the growing recognition of the weekend, it remains challenging to reach families with a parent with young-onset dementia or to convince them to overcome the barrier to participate.

Implications for practice and future perspectives

An exponential growth in the number of participants and activities is a promising vision for the future, along with expanding our services to include the 'older' group of children with a parent with young-onset dementia.

3.3 Creating support and awareness for young dementia

Lydie Amici
Collectif Auguste et les autres, Belgium

Background and aims

In 2020, an unsuccessful search for a place to live for a 49-year-old person with early-onset dementia and high dependency, resulted in the finding of a total lack of policy towards young dementia in Brussels and in Wallonia. An expansion of the research territory highlighted a disparity between the federated entities. More precisely, between the North and the South of the country. Another observation was the absence of a clear and proper guideline[1] for care of young dementia. There is no national epidemiological [2] monitoring of young dementia in Belgium.

Moreover, isolation was a common feeling among families encountered, as no association seemed to exist to exchange experience, provide support and advocate[3] towards public authorities, the scientific world, and those in the field.

Methods

The Collectif Auguste et les autres was created in September 2021. It was a spontaneous reaction. A name, a movement to allow the early dementia community to be visible. In November 2022, a participatory research carried out with Esenca, an association for the defense of people with disabilities, made it possible to objectivize the existence of unmet needs of people with early dementia in Belgium (Brussels and Wallonia). In April 2023, several concerned families joined the Collective project, which acquired legal status.

Results

The formation of an association affirmed the existence of a need for representation, and the recognition of specific difficulties linked to early dementia.

The creation of the association allowed several professionals to express, indeed the lack of specific support for early dementia. The association also allows to formulate clear demands in terms of care pathways.

Discussion

The Collective now fulfills missions for people with early dementia, including leisure activities to break isolation. Connection and support.

The identification of such a group in the French-speaking Belgium makes it possible to request a place at the table in discussions on the development of a care pathway such as the KCE 2023-51 (HSR) study.

Implications for practice and future perspectives

Field work aimed at future professionals has begun and must be developed. The creation of an association helps to express demands and make them visible and legitimate. The aim of the Collectif is to work and exchange with Dutch associations.

3.4 Sexuality in young onset dementia: A new conceptual framework and preliminary findings of a qualitative study

Frauke Claes (1), Mathieu Vandenbulcke (2), Paul Enzlin (1)

1. Institute for Family and Sexuality Studies, Department of Neurosciences, Faculty of Medicine, KU Leuven, Belgium;
2. Department of Geriatric Psychiatry, University Hospitals Leuven, Belgium

Background

Young onset dementia (YOD), i.e., dementia with symptom onset before the age of 65, affects not only the individual but also their partner and broader social context. The condition can put a strain on several aspects of the partner relationship, including intimacy and sexuality [1]. It has been shown that in cases of YOD,the partner often assumes the role of primary caregiver, leading to a shift in roles and potentially a decline in sexual connection [1]. Maintaining positive relational and sexual experiences is, however, important to secure and enhance the quality of life for both the person with YOD and their partner [2]. As in the absence of a curative treatment, treatments aim to optimize their quality of life, it seems that addressing relational and sexual challenges should be a crucial component of dementia care.

Methods

A comprehensive narrative literature review was performed using data bases such as PubMed and PsycINFO, with search terms related to dementia and sexuality. Insights from this review informed the development of a new conceptual framework [3]. This presentation introduces the framework with a particular focus on its application to YOD along with some preliminary findings from a small-scale qualitative interview study (n=6) that aimed to explore the relational and sexual experiences of partners of persons with YOD.

Results

The literature review emphasized the importance of adopting a longitudinal, multi-actor perspective to understand how the (sexual) relationship of couples living with (young onset) dementia regularly needs to be renegotiated as the condition progresses. The review resulted in a conceptual framework showing the impact of (young onset) dementia on a sexual relationship between partners, and the increasing involvement of various actors in managing this aspect across the premorbid, preclinical, and clinical phase. Each phase presents unique challenges that may affect the expression of sexuality within the relationship. These challenges appear to be more significant in couples facing dementia at a younger age, as sexuality may at younger age still play a more central role in their identity. With the progression of the condition, and the consequent increasing involvement of healthcare providers and family members in the sexual decision-making of couples, the need for sexual renegotiation remains ongoing. The framework advocates that all involved actors should adopt a sex-positive, person-centered approach with special attention to the sexual autonomy of persons with (young onset) dementia.

Conclusion

This new conceptual framework, along with some preliminary findings, contributes to the underexplored domain of (sexual) relationships in YOD. Further research on this topic is essential to enhance clinicians' understanding of the relational and sexual impact of YOD, ultimately guiding the development of tailored, person-centered care that respects the sexual needs of confronted couples.

Key references

[1] Holdsworth, K., & McCabe, M. (2018). The impact of younger-onset dementia on relationships, intimacy, and sexuality in midlife couples: A systematic review. International Psychogeriatrics, 30(1), 15-29.

[2] Youell, J. (2015). Enabling sexual expression in people with dementia. Nursing Standard, 30(15), 43–48.

[3] Claes, F., & Enzlin, P. (2023). Dementia and sexuality: A story of continued renegotiation. The Gerontologist, 63(2), 308-317.

Content session 4: People with Young Onset Dementia and their families

4.1 Interzorg

4.2 Young Onset Dementia in the Workplace

Anouck de Bruijn, Sara Vandenwyngaerden
Regionaal Expertisecentrum Dementie (ECD) Orion ism PGN, Belgium and Regionaal Expertisecentrum Dementie Memo, Belgium

Background and aims

Young-Onset Dementia (YOD) symptoms are often present in the workplace. This has an impact on the employee, but also on the colleagues, managers and the relatives. This project aims to provide support and information to all parties involved.

Methods

Different questions received at the ECDs (Center for Expertise in Dementia) formed a starting point for this project, after which several interviews with different parties (people with YOD, informal caregivers, employers and different labor services such as occupational physicians and human resources departments but also neurologists and psychologists) were conducted. Work experiences and support needs were identified and discussed from different perspectives. A standard literature review completed our preparatory work.

Results

There is a clear need in Belgium for more clear-cut and summarized information on this topic from the various parties involved. A 56p brochure was created, summarizing information, support options and experiences for the 3 target audiences. The first draft document was shared with an extensive review group. All feedback was incorporated. The final brochure will be released at the end of 2024.

Discussion

The findings highlighted a strong need for more support tools, information and guidance for all parties involved. Next to this, a question for more collaboration across different services and a more positive approach towards working post YOD-diagnosis arose.

Implications for practice and future perspectives

Our aim is to address the different needs detected with this first brochure on this topic in Belgium. As it is the first one, we would like to receive feedback and questions. The main goal is to achieve more options and a more positive approach towards people with YOD in the workplace.

Key references

[1] Evans, D. M. (2019). An exploration of the impact of younger-onset dementia on employment. Dementia (London, England), 18(1), 262–281. https://doi.org/10.1177/1471301216668661

[2] Janssens, A., & de Vugt, M. (reds.) (2020). Dementie op jonge leeftijd. Leuven: LannooCampus.

[3] Ritchie, L., Egdell, V., Danson, M. J., Cook, M. L. H., Stavert, J., & Tolson, D. (2020). Dementia, work and employability: Using the capability approach to understand the employability potential for people living with dementia. Work, Employment & Society: A Journal of the British Sociological Association, 36(4), 591–609.

4.3 Aalst, dementia-friendly city

Lore Robeyns
Social policy, City of Aalst, Belgium

Background and aims

The Flemish government created the Flemish dementia plan (2021-2025), based on input from various focus groups with approximately 60 stakeholders. The city of Aalst translated this Flemish dementia plan to the local context of Aalst. This was developed with local stakeholders (residential care centers, local officials with expertise in healthcare and elderly policy, associations for informal caregivers) and experts such as the Alzheimer Liga Flanders and the Regional dementia expertise center.

This resulted in the 'Dementia action plan 2024-2025, Aalst, dementia-friendly city'. With this plan we work towards a dementia-friendly city through various objectives during a two-year period.

1. Objective 1: We promote a healthy lifestyle among our citizens (aged 40 and over) to prevent dementia.
2. Objective 2: We create broader social awareness on dementia
3. Objective 3: We provide high-quality and accessible service for people with dementia and their context (caregivers, family,...).
4. Objective 4: We promote and improve the existing services and support for people with dementia and their caregivers.

Specifically for people with Young Onset Dementia the city will:

1. Organize leisure activities for them and their families/caregivers.
    - Local partners make an agreement with the city. They are committed to organize activities for people with dementia and people with young onset dementia.
    - The city supports communication about the activities and offers a financial contribution for the organizational costs.
    - Conclusion after the first two activities: it appears to be a challenge to reach people with young onset dementia living at home and to get them to participate in activities.

2. Look into the needs of young caregivers and possibilities of support.
    - Bachelor students from the local University of Applied Sciences (Odisee) will investigate this in the scope of their bachelor thesis. First, they will map the needs of young caregivers (of children and teenagers with a parent or grandparent with (young onset) dementia. Second, the students will examine opportunities for support that meet the needs of these young informal caregivers.

3. The city of Aalst will map the local opportunities that can support people with dementia, people with young onset dementia and their caregivers.

Methods

We work to achieve our objectives through collaborations with local actors and services.

Implications for practice and future perspectives

The dementia action plan 2024-2025 will be evaluated at the end of 2025. Depending on the decisions taken by the new city council, the dementia action plan can be continued after 2025.

Content session 5: People with Young Onset Dementia in the residential setting

5.1 Approach and Experiences in a Unit (Saliehof) for Individuals with Young-Onset Dementia

Gert-Jan Andries
Zorgband Leie&Schelde - Belgium

At Saliehof, our goal is to provide a warm, homelike environment for individuals with young-onset dementia. Our approach is based on respecting the individuality and autonomy of our residents. We never force participation in activities; instead, we encourage individuals to take part in a range of opportunities that enhance and enrich their daily lives.

Our care is focused on engaging with residents both in groups and individually, ensuring that everyone receives the attention and support they need. By balancing structured and spontaneous activities, we aim to maintain a sense of routine and comfort.

We have been operating for four years now, and during this time, our vision has evolved. Initially, the focus was mainly on fixed programs and activities, but through experience and feedback from residents and their families, we have learned to work more flexibly and person-centered. A significant change in our vision came from the realization that the residents who come to us often require more intensive care than we initially expected. Additionally, we have faced increased and varied forms of aggression, unlike what we previously encountered with our older residents. This adjustment has enabled us to better meet the diverse needs of our residents, helping them feel more at ease and at home.

At Saliehof, we aim to be more than a care facility; we want to be a home where residents feel safe and loved, and where they can participate in life at their own pace and in their own way.

Moving forward, we aim to further refine our approach by integrating even more personalized care strategies and continuing to foster a supportive, homelike environment. Additionally, we recognize the need for ongoing professional development to enhance our staff's ability to meet the evolving needs of our residents effectively. By sharing our experiences and insights, we hope to contribute to the broader understanding and improvement of care for individuals with dementia, both within our facility and beyond.

5.2 A qualitative research study on the freedom of action of persons with young dementia in residential elderly care: creating a place/space for human flourishing

Laurine Bourgonjon (1), Matthias Remmery (2), Toon Benoot (3), Els Vervloesem (4), Griet Roets (5)

1. Zorgband Leie & Schelde, Belgium;
2. Ghent University, Belgium

Background and aims

As a response to the worldwide ageing megatrend, international research, policy and practice are focusing on concepts as ageing in place. The shift from formal to self- and informal care entails a problematic dichotomy between independent and dependent elderly people, who end up in residential elderly care as a 'last resort' that is heavily under pressure. This presentation is based on a study in the department of an elderly care facility in Flanders, which focus on the experiences of people with young dementia. From a socio-spatial theoretical perspective, we examine how both professional and spatial paradigms foster or inhibit the freedom of action and autonomy of people with young dementia.

Methods

A triangulation of qualitative research methods was used: (1) ethnographic observations within the department for people with young dementia, (2) the mapping of wander- and walklines of the residents with young dementia, and (3) a focus group with the professionals working in the department.

Results

The article discusses five key findings: (1) the entrance as a space where restrictions influence the balance between freedom and safety, (2) the living room as a space where chaos can also be a frequent structuring element, (3) the bedroom as a space at the intersection between personal and communal, (4) the hallway as a space not enough responding to the moving and sensory dynamics of the people with young dementia and (5) the environment as a space to engage the relationship between the inside facility and outside world.

Discussion

The findings show that the professional and organisational policy play a major role in changing standardised action patterns and establishing new socio-spatial circumstances in elderly care facilities. The creation of an open and safe environment can be experienced as a space for human flourishing, as it strengthens the freedom of action of people with young dementia.

Implications for practice and future perspectives

Understanding socio-spatial dimensions within residential environments remains significantly undeveloped. More research is needed on the socio-spatial transformation of elderly care facilities towards a place where residents enjoy living, staff enjoy working and a diversity of people enjoy living together.

Key references

[1] Hawkins, R. J., Prashar, A., Lusambili, A., Ellard, D & Godfrey M. (2018). ‘If they don't use it, they lose it’: how organisational structures and practices shape residents’ physical movement in care home settings. Ageing and Society, 38(9), 1817-1842. https://doi.org/10.1017/S0144686X17000290

[2] Schiettecat, T., Campens, J., Roets, G., De Witte, N., Lesseliers, J. & Goethals, I. (2023). Care and support for older people with intellectual disabilities beyond the pursuit of ageing ‘in place’: towards constructing a space to be(long). European Journal of Social Work. https://doi.org/10.1080/13691457.2023.2257004

[3] Anand, J. C., Donnelly, S., Milne, A., Nelson-Becker, H., Vingare, E-L., Deusdad, B., Cellini, G., Kinni, R-L. & Pregno, C. (2022). The covid-19 pandemic and care homes for older people in Europe - deaths, damage and violations of human rights. European Journal of Social Work, 25(5). https://doi.org/10.1080/13691457.2021.1954886

5.3 Survival and Determinants of Mortality in Nursing Home Residents with Young Onset Dementia: Insights from BEYOnD and Care4Youngdem

Jasper Maters, MD(1) (2), Jenny T. van der Steen, MSc, PhD, FGSA (1) (2) (3), Marjolein E. de Vugt, MSc, (4), Ans Mulders, MD, PhD(5), Christian Bakker, MSc, PhD(1) (2) (6), and Raymond T.C.M. Koopmans MD, PhD(1) (2) (7)

1. *Department of Primary and Community Care, Radboud university medical center, Nijmegen, the Netherlands.*
2. *Radboudumc Alzheimer Center, Nijmegen, the Netherlands.*
3. *Department of Public Health and Primary Care, University Medical Center Leiden, Leiden, the Netherlands.*
4. *Alzheimer Center Limburg, Mental Health and Neuroscience research institute, Maastricht University Medical Center, Maastricht, the Netherlands*
5. *Thebe, Center for Geriatric Care, Tilburg, the Netherlands.*
6. *Groenhuysen, Center for Geriatric Care, Roosendaal, the Netherlands*
7. *Joachim en Anna, Center for Specialized Geriatric Care, Nijmegen, the Netherlands.*

Background and aim

Young Onset Dementia (YOD) is associated with a reduced life expectancy. However, studies concerning survival in people with YOD are sparse and there are no studies reporting about survival after admission to a nursing home. Our aim was to examine survival time, determinants of survival and causes of death in nursing home residents with YOD.

Methods

Survival data were obtained from the BEYOnD- and Care4Youngdem-study. Both studies provided samples from YOD special care units. Residents were followed until death or census date. Causes of death were retrieved from medical records and surveys. Kaplan-Meier curves were plotted to analyze survival times after diagnosis and admission. Cox proportional hazards regression models were composed to investigate determinants of survival, including sex, age, severity and type of dementia, and comorbidities. Finally, the hazard ratio (HR) of the independent determinants in the combined samples were assessed.

Results

138 (73.8%) residents of the BEYOnD-sample and 121 (58.8%) residents of the Care4Youngdemsample died during follow-up. Median survival time after diagnosis was 9.0 (95% CI 7.8-10.2) and 8.1 (95% CI 7.1-9.0) years in BEYOnD and Care4Youngdem, respectively. Median survival time after admission was 6.3 (95% CI 5.3-7.2) and 4.9 (95% CI 4.3-5.5) years. Survival times did not differ significantly between the cohorts. Type and severity of dementia were found to be associated with mortality. The most common primary causes of death were dehydration/cachexia (29.9%) and respiratory infection (24.1%).

Discussion

Our study shows a longer survival of YOD patients living in long term care facilities compared to studies in residents with late onset dementia.

Implications for practice and future perspectives

Survival data of YOD patients may be relevant in the context of prognostication and thereby advance care planning. Future studies could focus on predictors of survival time after admission in order to develop a prediction tool.

Content session 6: Daily activities and leisure time for people with Young Onset Dementia

6.1 Improving integrated care and support in young-onset dementia using participatory action research

Sophie van Westendorp MSc(a), Cynthia Hofman PhD (b) , Paula Gerring(b) , the YOD-included consortium, Christian Bakker PhD (a, c, d) , Prof. Raymond Koopmans PhD (a, c, e, f)

(a) Department of Primary and Community Care, Radboud University Medical Center, Nijmegen, the Netherlands
(b) Vilans, National Center of Expertise for Long-term Care, Utrecht, the Netherlands
(c) Radboudumc Alzheimer Center, Radboud University Medical Center, Nijmegen, the Netherlands
(d) Groenhuysen, Center for Specialized Geriatric Care, Roosendaal, the Netherlands
(e) Young-onset Dementia Knowledge Center, Amersfoort, the Netherlands.
(f) De Waalboog "Joachim and Anna", Center for Specialized Geriatric Care, Nijmegen, the Netherlands.

Background and aims

Currently, people living with young-onset dementia (YOD) often do not have access to age-appropriate services and support [1,2]. This study aims at increasing access to care and support for YOD by improving integrated care and support through Participatory Action Research (PAR). PAR is an effective, valuable research method for addressing complex social dilemmas [3]. This method ensures us to achieve two goals: (1) making a sustainable and effective improvement in integrated care and support by addressing related dilemmas (action); and (2) evaluating the process of performing PAR in two different Dutch Dementia Networks (DDN) (research). Our study is part of the YOD-INCLUDED project.

Methods

To improve integrated care and support in young-onset dementia we collaborated with key stakeholders to perform PAR in one regional DDN and one superregional DDN, which is a partnership of four regional DDNs in the Netherlands. A PAR cycle consists of seven phases. We will perform multiple PAR cycles per network, addressing different dilemmas in each cycle. After each phase, we reflect on our actions as researchers and with all stakeholders per DDN. By critical reflection we can identify (in)effective actions and make adjustments for the next iterative loop. This study has been reviewed and deemed non-WMO obligatory by the Medical Ethics Committee.

Results

(Preliminary) insights will be shared on 1) lessons and experiences in performing PAR in DDNs at different levels, and 2) insights in exploring initial dilemmas such as organising daily activities for YOD in a superregional DDN.
Implications for practice and future perspectives

This is the first study in which PAR has been conducted on this scale with DDNs. The lessons and experiences gathered about the PAR process will be included in a toolbox for other DDNs to improve their integrated care and support. Furthermore, it will lead to better access to age-appropriate services and support by addressing the dilemmas.

Key references

[1] Giebel, C., et al., "Nobody Seems to Know Where to Even Turn To": Barriers in Accessing and Utilising Dementia Care Services in England and The Netherlands. Int J Environ Res Public Health, 2021. 18(22).

[2] Mayrhofer, A., et al., Age-appropriate services for people diagnosed with young onset dementia (YOD): a systematic review. Aging Ment Health, 2018. 22(8): p. 927-935.

[3] Cornish, F., et al., Participatory action research. Nature Reviews Methods Primers, 2023. 3(1): p. 34.

6.2 ‘Het Ventiel’ – Buddy project for and with people with Young Onset Dementia

Gudrun Callewaert
Het Ventiel - Belgium

Background

Het Ventiel (The Valve) was founded by Gudrun Callewaert when her spouse (50) was affected by frontotemporal dementia. Participating at a project with the intention breaking the taboo surrounding early-onset dementia by cycling up Mount Ventoux, they discovered that so much is still possible. He was no longer able do a lot of things, but there he reached the top of Mont Ventoux. It gave his confidence and self-esteem a huge boost. The warm connection with his 3 fellow-participants did him the world of good. She also felt that meeting other partners who understood what they were going through was an enriching experience. That was how *Het Ventiel* was born. With a valve, you can breathe new air into a deflated tyre and you can let some air back out when the terrain gets a bit harder. That is what the project sets out to do for people with dementia and the people around them.

Aims

- Integrating in society
- Counteracting isolation and increasing self esteem
- Giving an energy boost
- Encouraging and/or restoring the contact with family, neighbours, friends and colleagues
- Showing people with dementia that they are not alone
- Increasing self-esteem and sense of self-worth in people with dementia
- Making people with dementia experience that they still have opportunities
- Making people with dementia feel that they can still mean something to others
- Giving a clear voice to a group of people that is not always recognised by healthcare professionals and seeing them as a group with possibilities
- Changing the stigma surrounding dementia into a balanced view
- Encouraging people with dementia to make their voice heard and to show their desires, abilities, feelings, obstacles and needs in terms of support
- Giving carers some breathing space by offering relief and by making them experience all the things that are still possible
- Offering understanding and support to carers by getting them in touch with others who are going through the same experience
- Making an impact on the environment and society as a whole: sharing experiences in terms of dementia presents it as a subject of discussion
- Transferring acquired insights in modern dementia care truly focusing on the participation of people with dementia themselves.

Implications for practice and future perspectives

The twinkle in the eye of people with young onset dementia is the clearest proof that the project works, although this is obviously not a tangible, scientifically proven result.

However, the improved scores on the Mini Mental State Examination are measurable. The scores of some participants of *Het Ventiel* went up by no less than 9 points in the MMSE. Such results cannot be matched by any acetylcholinesterase inhibitor.

By continuing to encourage people with young onset dementia, by keeping them active, by stimulating social interaction and by making them feel good, their functioning will improve rather than deteriorate. More and more neurologists are surprised by the project's extraordinary impact on their patients during check-ups and they encourage other people with young onset dementia to take part as well. 'I have a new medicine: *Het Ventiel*,' one of our participants reported to the consultant.

6.3 Enabling volunteering opportunities for persons with Young Onset Dementia in Flanders. The co-creational development of a toolbox and inspirational guidebook

Elise Cornelis (1,2), Hanne Bossuyt (2), Nadine Praet (2), Jolien Allart (1,2)

1. Research and Innovation Centre for Health and Care, Artevelde University of Applied Sciences, Voetweg 66, 9000 Ghent (Belgium)
2. Department of Occupational Therapy, Artevelde University of Applied Sciences, Voetweg 66, 9000 Ghent (Belgium)

Background and aims

Volunteering can enable persons with young onset dementia to remain socially connected, embedded within their communities and engaged in personally meaningful activities [1,2]. However, several barriers have been found and deprive the opportunities for persons with young onset dementia to access volunteering in Flanders. In order to lower the thresholds, this project explored what could support and enable persons with (young onset) dementia to access volunteering.

Methods

Based on the human-centred design process [3], this project identified experiences and good practices of persons with (young onset) dementia, their caregivers, healthcare professionals and non-profit organizations. Inspired by a positive appreciative, participatory and competence-based approach, two guided brainstorms and five co-creations sessions took place in order to develop tools which can enable volunteering opportunities for persons with (young onset) dementia in Flanders.

Results

This project developed a practical awareness-raising toolbox including (1) a form to identify individual interests, strengths and talents of persons with (young onset) dementia, (2) rethinking cards to counter stigma's and stereotypes, (3) puzzle-pieces to discuss six fundamental principles of age-friendly volunteering opportunities; flexibility, supportiveness, connectivity, appreciativeness, meaningfulness and focus on strengths. And (4) an inspirational guidebook with several testimonials of volunteers with (young onset) dementia and practical guidelines on how organizations can enable volunteering opportunities.

Implications for practice and future perspectives

The toolbox and inspirational guidebook provides practical guidance to enable accessible volunteering opportunities for persons with (young onset) dementia. Nevertheless, rethinking perceptions and stigma's about the volunteering opportunities of persons with (young onset) dementia is still necessary. An individually tailored,
appreciative approach for each person with (young onset) dementia is needed.

Key references

[1] Vincent RE, Ashworth R, Donaldson I, et al. (2024) Volunteering as Meaningful Activity for People Living with Young Onset Dementia: A Thematic 'Co-Analysis'. DOI: 10.20944/preprints202405.0114.v1

[2] Hackett RA, Steptoe A, Cadar D, Fancourt D (2019) Social Engagement Before And After Dementia Diagnosis In The English Longitudinal Study Of Ageing. Plos One 14(8): E0220195. Https://Doi.Org/10.1371/Journal.Pone.0220195.

[3] Hartung H, Rottenberg S. In: Human-Centred Design: Understanding Customers' Needs Through Discovery and Interviewing, 2019.

POSTERS

Life interrupted by young onset dementia and the loss and grief for everyone involved

Virginie Van Mol

Grief and loss counsellor- vzw Gewoon Leven, Belgium

Loss and grief are experiences that affect to everyone. Each person deals with them differently, and everyone has their own unique process. Often, grief is misunderstood and underrepresented. It is an emotion that many do not take the time to process, nor are they encouraged to do so.

When diagnosed with dementia, both the patient and their loved ones face significant loss, grief, and pain. This raises the question: how do you continue living with this prospect, and how can you find meaning together?

People with young onset dementia experience the continuous loss of abilities and more. The aspect of loss and grief in dementia is often insufficiently recognized, despite the ongoing desire for contact from everyone involved. Care partners can experience a loss of connection with their loved one, a loss of the loved one’s personality as they know it, and a loss of hopes and dreams. The experience of grieving before a death occurs is called anticipatory grief, and it can be an enormous burden for anyone impacted by young onset dementia.

Studies suggest that depressive symptoms in the early stages of dementia may reflect a grieving process related to an awareness of lost abilities. People living with late-stage dementia may express grief in ways that are perceived as agitation or anxiety. It is important to recognize this.

We also know that intentionally dealing with loss and grief can provide strength and opportunities for growth. Accepting a situation that includes dementia, which impacts every aspect of your life, may be challenging, but adapting to a new reality can open the door to meaningful new opportunities.

It is essential to develop effective grief interventions that can be implemented in both clinical and community settings. These interventions can reduce the emotional distress of people with young onset dementia and their caregivers to enhance their quality of life.

Investing in support groups, non-profit organizations, and workshops that provide local support, shared experiences, and specialized grief counseling is crucial. These resources connect people with dementia, caregivers, and family members. As Brené Brown wisely said, 'Connection is the energy that exists between people when they feel seen, heard, and valued.' This quote nicely sums up the profound impact of genuine connection in fostering empathy and resilience within care communities, supporting individuals through their grieving and loss process.

Building bridges between home care and (semi)residential care for people with young onset dementia regarding stress and sleep management (Connected Care)

Julie Vanderlinden (1,2), Liza Musch (1,2), Sophie Dohogne (1)

1. *Research group active neighborhoods and lifestyle interventions, department of Health Care (Odisee University of Applied Sciences)*
2. *Pain in Motion Research Group, Department of Physiotherapy, Human Physiology and Anatomy, Faculty of Physical Education and Physiotherapy, Vrije Universiteit Brussel, 1000 Brussels, Belgium*

Background

People with young onset dementia (YOD) have a preference to dwell in their own home setting until it remains no longer feasible or safe for themselves or for their relatives. People with YOD as well as their relatives often face emotional distress which go along with decreased sleep and a decrease in wellbeing for both parties. As a result of that, caregivers in the home care are often challenged in dealing with negative emotions, stress and sleep problems. Care organisations in the (semi)residential setting can play a role to help the caregivers in the home setting with these challenges. This project aims to connect competences between home setting and (semi)residential care setting within the scope of emotional distress and healthy sleep management in individuals with YOD.

Methods

In total, a consortium of 12 formal care organisations of which semi-residential (n=6) and residential care (n=6) are assessed on current competencies and needs to provide support in emotional stress and healthy sleep management in YOD. Furthermore, both formal home care organisations (n=4), informal caregivers (n=10) and people with YOD (n=10) will be assessed for existing needs in terms of experienced emotional distress and sleep challenges. Based on group interviews, a framework will be developed and provided.

Results and conclusions

This project aims to connect the care between (semi)residential care and home care for individuals with YOD. Based on the needs and competence assessment in caregivers for YOD with regard to emotional stress and healthy sleep management as well as the assessment of needs from the individuals with YOD and their informal caregivers, a framework 'connected care' will be developed. In order to transfer knowledge and skills in handling emotional stress and healthy sleep management between actors in different settings, a framework will be developed in order to connect both care settings.

Thank you for joining us during this international conference on Young Onset Dementia.

Interested in more information on the research conducted in Odisee University of Applied Sciences (Brussels) regarding **Young Onset Dementia** or interested to collaborate with us?

Access the info and contact details of the research team via the QR code:

YOUNG-D: English

YOUNG-D: Nederlands