

Social Health in Young-Onset Dementia: Lived Experiences and Perceived Support Needs

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OLLSCOIL NA GAILLIMHE
UNIVERSITY OF GALWAY

Ziyue Wang, Andrew Hunter, Duygu Sezgin

School of Nursing, Midwifery & Evidence Science, University of Galway, Ireland



Our study highlighted priorities for action: 1) person-first dementia care, 2) practical employment & financial guidance and family-included support, 3) earlier post-diagnostic support pathways, 4) public awareness, including dementia inclusive community care and services; and 5) accessible, age-appropriate, and universal dementia care and support activities.

INTRODUCTION

Young-onset dementia (YOD) refers to dementia onset before age 65 ¹. It can disrupt employment, family responsibilities, and social participation at a life stage when people are often working, parenting, and socially active ²⁻⁴. Social frailty and social isolation are increasingly recognised as important social health issues ^{5, 6}. However, qualitative evidence describing how these challenges are experienced in YOD and what support people prioritise remain limited. This study explored lived experiences and perceived support needs related to social frailty and social isolation of people living with YOD.

METHODS

Qualitative descriptive design

Socially pre-frail

Socially frail

Socially isolated

Semi-structured interviews

UK flag

Ireland flag

Interviews were conducted between December 2024 and March 2025 via video or telephone, audio-recorded. Inductive thematic analysis was used to analyse the interview data.

RESULTS

Participants were aged 56-64 and living with YOD for between four and 10 years. Five themes and 13 subthemes were identified:

Persevering in independence and voice

Challenges to stability: employment, finance, and family

Impact on support: living with young-onset dementia and finding hope

Exclusion from inclusion: building a dementia-friendly environment

Gaps: limited support and challenges

"The Alzheimer's Society are supposed to be the biggest and the best. But they really talk to my wife, **not me.**"

CONCLUSIONS

People living with YOD experienced social frailty and social isolation through intersecting work, family, and stigma-related challenges and unequal access to suitable dementia supports and services.

Despite this, participants were actively looking for connections and advocacy for a more inclusive society.

These actions and interventions highlighted in our study should be co-produced with individuals living with YOD.

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CONTACT

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LinkedIn



Ziyue Wang:
z.wang17@universityofgalway.ie

