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The individual and societal economic consequences of young onset dementia: A rapid review.

Presentation by Dr Kiera Kenny, Lancaster University

What is a rapid review?

A rapid review is a type of research synthesis that summarises **existing evidence** in a shorter timeframe than a traditional systematic review.

It uses streamlined methods, such as
> searching fewer databases
> limiting the date range
> having one reviewer screen studies with checks

...to produce timely evidence for decision-makers while still following transparent and systematic principles.

Introduction

- Young-onset dementia affects ~ 70,800 people in the UK (Dementia UK, 2024).
- It can affect the life course of individuals at a time of peak socio-economic and professional productivity
- Employment is often one of the first areas of life affected by young-onset dementia, with significant financial consequences for both individuals and their families (Kilty et al., 2023)
- Whilst a person diagnosed may continue working, leaving paid employment early is common – this may be voluntary or involuntary
- Most research on dementia focuses on economic impacts of **late-onset dementia** (Cantarero-Prieto et al., 2020; Meijer et al., 2022; Ruiz-Adame, 2022).

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When cognitive decline occurs during working life, it can affect:

Health & well-being

Job/career

Finances

Housing

Bills

Dependents

(Kandiah et al. 2016; Bayly et al. 2021; Hirano et al. 2021; Mayrhofer et al. 2021; Knight and Pepper 2024)

And many other aspects of life!

Aims & Research Questions

Aim:

To examine the data from current research on the economic consequences of young-onset dementia on individuals, households, and the wider economy.

Research Questions:

1. What are the economic and financial consequences of young-onset dementia for individuals and their households?
2. What are the wider societal and public-sector economic consequences associated with young-onset dementia?

Methods

Inclusion criteria

- **Population**: Young-onset dementia
- **Concept**: Economic consequences related to young-onset dementia
- **Context:** English language published between 2016-2026

Search strategy

- Three databases: Medline, Econlit and Scopus
- Three reviewers

Data synthesis

- Parallel synthesis convergent design (Hong et al. 2017)

Patient and public involvement

- The WWDN stakeholder and lived experience group were consulted on the research review topics, aims and designs
- A member with lived experience of young-onset dementia is contributing to the write-up to help ensure it reflects authentic lived experience perspectives.

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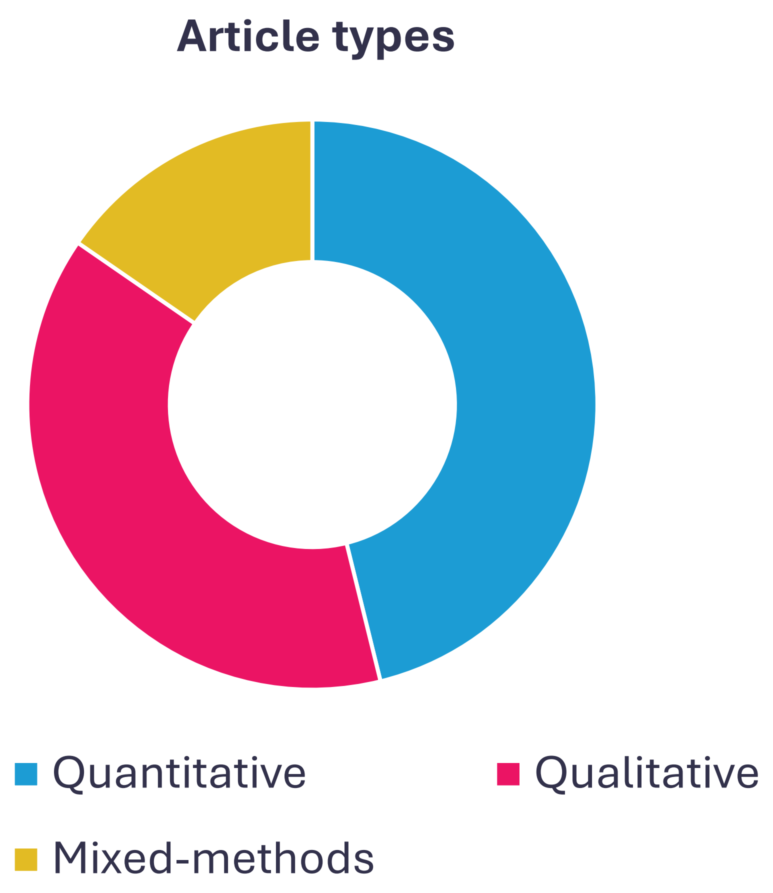
Results

> 1513 articles were retrieved (Medline = 1332, EconLit = 55, Scopus = 126)
> 13 articles were included in the synthesis



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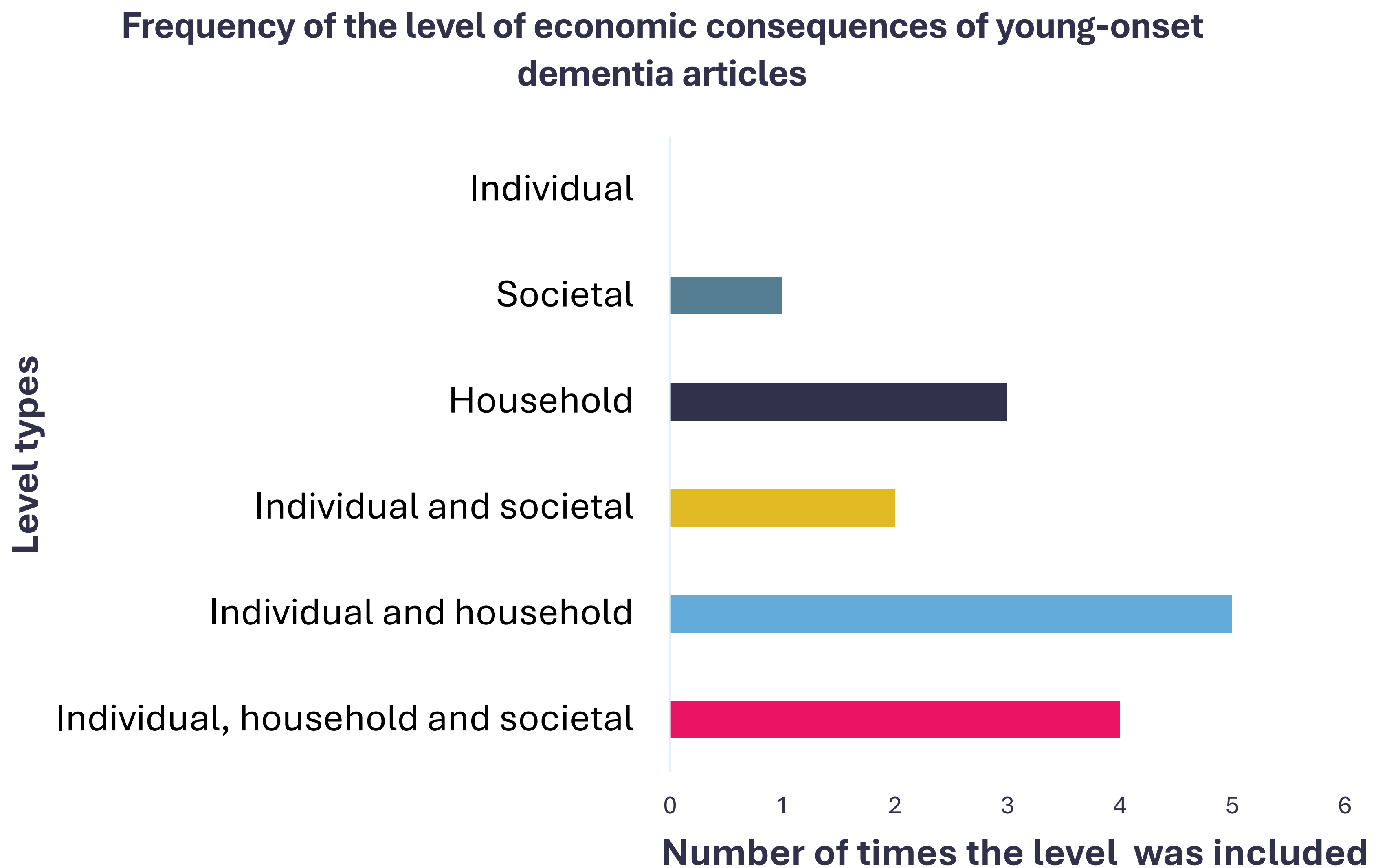

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Some key extracted data

- In an employee cohort - 1-year job loss rate for participants with early onset dementia (EOD) was 14.0% and 7.3% for participants without EOD. In the family member cohort, 1-year job loss rate for supporters - family members was 7.8% and without EOD = 6.5% (Sakata and Okumura, 2017).

- ~£1.2 billion total annual cost of young-onset dementia in England (Wittenberg et al., 2019).

- The top three cost contributors associated with young-onset dementia was: productivity loss (68.5% of the total annual cost), informal care (14.3%) and home care (6.5%) (Kandiah et al. 2016).

- ~ 25% of family carers reported finances as an unmet need (Helvik et al., 2024).

- Accessing welfare support to mitigate some of the financial strain was described as a complex process (Mayrhofer et al., 2021)

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Preliminary findings

Employment disruption and income loss

Household role reconfiguration and economic adaptation

Household financial strain and cost burden

Long-term financial insecurity

Increased service use and associated costs

Welfare system and structural barriers

Conclusion

There are profound economic consequences associated with young onset dementia at the individual and household level.

Although the data shows an increased need for service usage, associated costs and welfare, less is known about the broader, public economic consequences.

Early diagnosis and robust social support systems are vital to mitigate the financial challenges faced by individuals with dementia under age 65 (Bagnasco et al. 2025).

Employment, economic, and social supports are needed for people living with young-onset dementia and their family (Hirano et al. 2021).

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Thank you

www.workingwithdementia.org

k.kenny1@lancaster.ac.uk

Linked In: Kiera Kenny and
Working with Dementia Network Plus