

MISDIAGNOSIS OF DEMENTIA: FINDINGS FROM A RECENT SYSTEMATIC REVIEW

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YOD Webinar July 2024

WHAT ARE INEQUALITIES IN DEMENTIA?



COVID-19 SNAPSHOT



Reduced social care service utilisation in dementia linked to poorer mental health

UNIVERSITY OF LIVERPOOL | Heseltine Institute for Public Policy, Practice and Place | LIVERPOOL CITY REGION

Responding to COVID-19 in the Liverpool City Region

COVID-19 and Social Care: The Impact of the Pandemic on People with Dementia and Carers
Dr Clarissa Giebel

Policy Briefing 030 | November 2020

UNIVERSITY OF LIVERPOOL | Heseltine Institute for Public Policy, Practice and Place | LIVERPOOL CITY REGION

Care home practices, mental health and staff support

Learnings from the pandemic and lessons for future policy

Dr Clarissa Giebel and Dr Kerry Hanna

Policy Briefing 2(04) | November 2021



TASKFORCE

Survey and consensus meetings

- 49 academics, people with dementia, carers
- 10 country-survey (Belgium, Denmark, Germany, Greece, Ireland, Italy, Poland, Malta, Netherlands, UK)
- 5-country consensus meetings (Germany, Ireland, Italy, Poland, UK)





**Regional
variation**

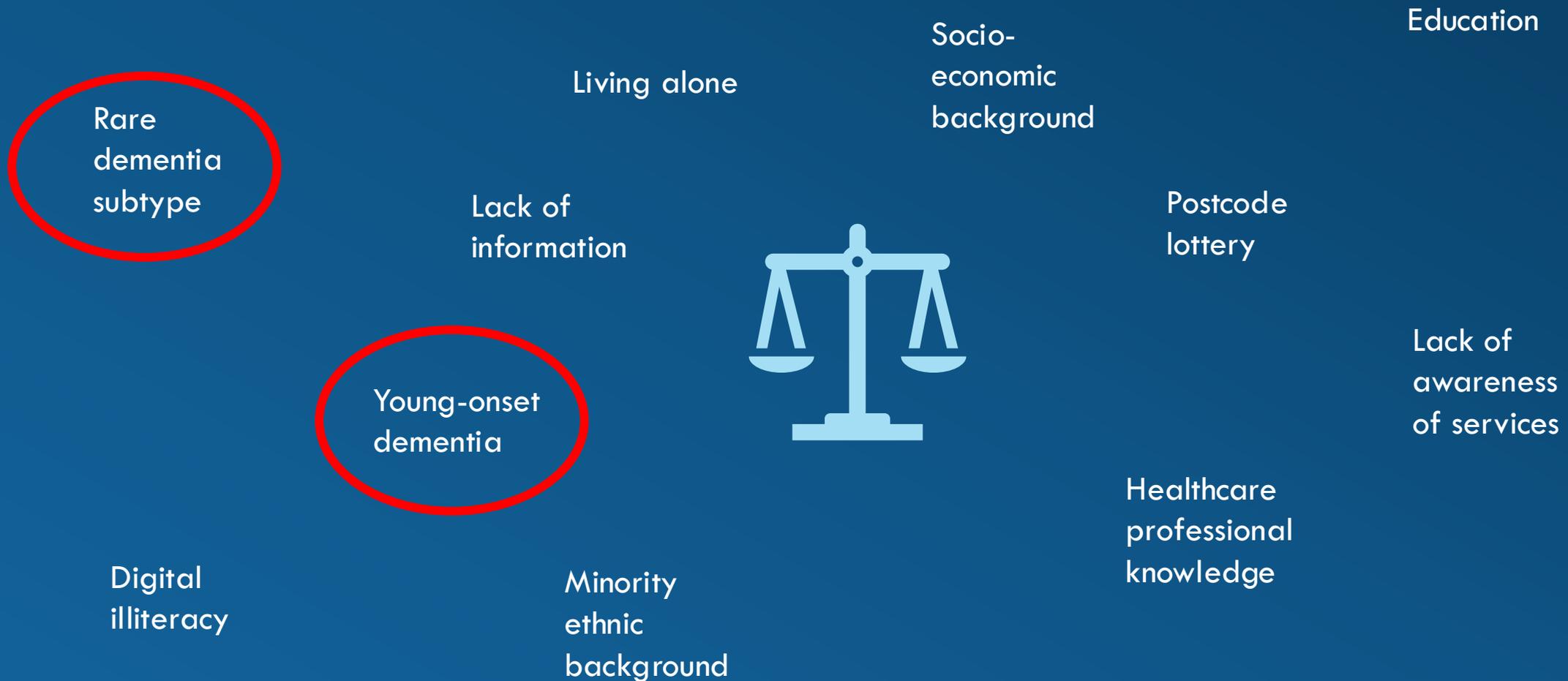
Increasing access to
a dementia diagnosis



**CORRECT
AND TIMELY
DIAGNOSIS**



WHAT ARE INEQUALITIES IN DEMENTIA?



DEMENTIA

Dementia is an umbrella term that describes a collection of symptoms that are caused by disorders affecting the brain. It is not one specific disease. Dementia affects thinking, behaviour and the ability to perform every day tasks, and brain function is affected enough to interfere with the person's normal social or working life. The most common type of dementia is Alzheimer's disease.

Alzheimer's Disease

Alzheimer's disease is the most common type of dementia accounting for approximately 40-70 % of all dementias.

Vascular Dementias

Vascular dementia is the second most common type of dementia, accounting for approximately 15-25% of all dementias.

Lewy Body Dementia

Lewy Body dementia accounts for approximately 2-20% of all dementias.

Fronto Temporal Dementias

Fronto Temporal Dementia accounts for approximately 2-4% of all dementia.

Other Dementias

Include dementia associated with Parkinson's disease, Huntington's disease, head trauma, human immunodeficiency virus (HIV), alcohol related dementia, Crutzfeldt-Jakob Disease, corticobasal degeneration and progressive supranuclear palsy.

Kate Swaffer © 2016

SYSTEMATIC REVIEW

Databases: 8

Searches conducted: June 2023

Years published: since 2010

Focus: To synthesise evidence on misdiagnosis of dementia

4,314 titles
and abstracts
screened

97 full texts
read

20 included
(16 quant, 4
qual)



North America – 10 studies
Netherlands – 5
UK – 1
Germany – 1
Slovenia – 1
Spain – 1
Sweden - 1



Any dementia – 9 studies
FTD – 3
Alzheimer's – 1
FTD & Alzheimer's focus - 1
Lewy Body – 3
YOD - 3

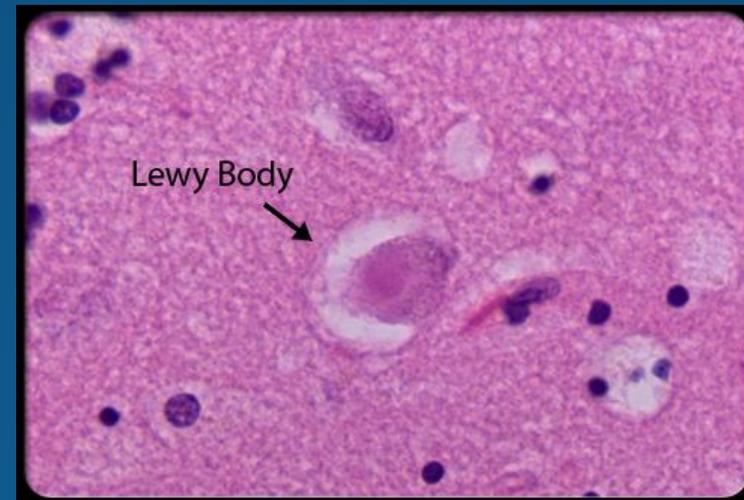
FACTORS ASSOCIATED WITH DELAYED OR MISDIAGNOSIS

- Ethnicity (*i.e. Lin et al., 2021*)
- Increased age – misdiagnosis (*2 US studies*)
- Worse cognitive status
- Multimorbidity, incl. depression and mood disorders (*i.e. Besser et al., 2020*)



- Focus on **FTD** → increased age, having a spousal carer, rural residence, presence of specific symptoms linked to correct diagnosis within 1 year
- *Barker et al. (2023)*: 50% received incorrect first diagnosis
- Receiving a diagnosis of **LBD** significantly delayed compared to other dementias (*Surendranathan et al., 2020*)

DIFFICULTIES RELATED TO THE DIAGNOSTIC PROCESS





ECONOMIC CONSEQUENCES

- 2 US studies
- Substantial cost implications (incl. extra inpatient days, outpatient visits, home health care, etc)
- Misdiagnosis via Medicare claims

EXPERIENCES OF OBTAINING A DEMENTIA DIAGNOSIS



Young onset dementia

- 45% misdiagnosis and inadequate help and misattribution of symptoms *Van Vliet et al. (2011)*
- Poor HC communication and lack of knowledge in recognising YOD symptoms *Novek et al. (2021), Hoppe et al. (2019), Van Vliet et al. (2011)*
- Limitations of diagnostic tests



STILL A LOT OF UNKNOWNNS...

Lack of focus on individual
subtypes

More cross-country evidence
needed

Greater focus on YOD

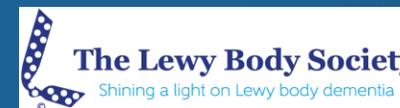
Economic impacts under-
investigated

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So what can we do?

1 solution to inequalities: Dementia Inequalities Game

Co-produced with 40 people with dementia, carers, H&SC professionals, Third Sector, academics





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ORIGINAL ARTICLE

WILEY

Co-producing a board game to learn and engage about dementia inequalities: First impacts on knowledge in the general population

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Abstract
Background: Receiving and accessing care after a diagnosis of dementia, both for the person and their carer, are fraught with inequalities. The aim of this public engagement activity was to co-produce a board game about dementia inequalities to facilitate learning, dialogue and educate about different barriers, and facilitators, to diagnosis and care and to test the game's impact on dementia knowledge with the general public.
Methods: Two virtual and two face-to-face workshops with people with dementia

- Significant improvements in knowledge in 312 students
- International adaptations so far in Ireland, Germany, Portugal

Dementia Inequalities Game

PRE-DIAGNOSIS

POST-DIAGNOSIS



<https://www.lewybody.org/shop/>



The Lewy Body Society

Shining a light on Lewy body dementia



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