

Socio-economic predictors of formal dementia care with dementia

No registrations found.

Ethical review	Positive opinion
Status	Recruitment stopped
Health condition type	-
Study type	Observational non invasive

Summary

ID

NL-OMON29398

Source

Nationaal Trial Register

Brief title

SEFDEM

Health condition

Any type of dementia

Sponsors and support

Primary sponsor: University of Liverpool, Maastricht University

Source(s) of monetary or material Support: This study is supported by an Alzheimer's Society Knowledge Exchange Fellowship awarded to the lead applicant Clarissa Giebel (Award Number: 471) in 2019, and is part-funded by The National Institute for Health Research Collaboration for Leadership in Applied Health Research and Care North West Coast (NIHR CLAHRC NWC). There is no funding for the part of the study that is carried out by Maastricht University.

Intervention

Outcome measures

Primary outcome

Secondary outcome

Well-being

Study description

Background summary

Background: People from disadvantaged backgrounds often experience difficulties in accessing and using health care services. Often, this is linked to health illiteracy, as people from disadvantaged backgrounds may struggle obtaining and understanding basic health information. So, it may be difficult for people from disadvantaged backgrounds to access formal dementia care when needed. Whilst research has looked at access to formal dementia care, little evidence exists on how health inequalities and health illiteracy might affect using formal dementia care.

Method: Data will be collected in England and in the Netherlands. This study comprises of two projects. Project 1 is a questionnaire for informal carers of people with dementia, which will be handed out to them via memory clinics at NHS Trusts across the North West Coast region, via the ENRICH and Join Dementia Research network, and via support groups from dementia Carers UK. Similar methodologies will be employed in the Netherlands, where questionnaires will be handed out via long-term care providers (e.g. community nurses and case managers) memory clinics, nursing homes and organisations such as the Alzheimer café. National ethical approval will be sought separately. The questionnaires asks information about their basic demographics, the person they care for with dementia, and his/her formal dementia care utilisation and health care utilisation. Completed questionnaires can then be returned via free post envelopes. Project 2 involves 20 semi-structured interviews with people with dementia and their informal carers to explore their experiences of trying to and accessing and utilising formal dementia care services in England, and 20 in the Netherlands. Recruitment for this project will be similar to the questionnaire project.

Analysis: It is anticipated to receive back 500 carer questionnaires. Findings will be analysed through frequency analysis, bivariate correlation analysis, and multiple regression (a) to explore how formal dementia care receipt varies between people with dementia from disadvantaged and advantaged backgrounds, and to compare between England and the Netherlands; and (b) to explore to what extent socio-economic factors predict formal dementia care. Data from the interviews will be analysed using thematic analysis.

Potential implications: Findings from this study will help to understand how socio-economic factors might hinder people with dementia and their carers in accessing and utilising formal dementia care services, and understand any national variations between England and the Netherlands. Subsequently, it could be possible to address some of these barriers through

interventions, to enable people from any background, whether disadvantaged or advantaged, to access the right dementia care they need at the right time.

Study objective

People from more disadvantaged backgrounds face barriers in accessing post-diagnostic dementia care.

Study design

Single point in time

Intervention

The current study is not an intervention study. Participants will be asked to fill in a questionnaire about the topic, or to participate in a semi-structured interview.

Contacts

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Eligibility criteria

Inclusion criteria

- Carer of a person with any stage and type of dementia
- 18 years or older

Exclusion criteria

No exclusion criteria

Study design

Design

Study type:	Observational non invasive
Intervention model:	Other
Allocation:	Non controlled trial
Masking:	Open (masking not used)
Control:	N/A , unknown

Recruitment

NL	
Recruitment status:	Recruitment stopped
Start date (anticipated):	02-09-2019
Enrollment:	500
Type:	Actual

IPD sharing statement

Plan to share IPD: No

Ethics review

Positive opinion	
Date:	29-07-2019
Application type:	First submission

Study registrations

Followed up by the following (possibly more current) registration

No registrations found.

Other (possibly less up-to-date) registrations in this register

No registrations found.

In other registers

Register	ID
NTR-new	NL7912
Other	METC Z : METCZ20190089

Study results

Summary results

Giebel, C.; Robertson, S.; Beaulen, A.; Zwakhalen, S.; Allen, D.; Verbeek, H. "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, 12233. <https://doi.org/10.3390/ijerph182212233>