Socio-economic predictors of formal dementia care with dementia

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

Ethische beoordeling	Positief advies
Status	Werving gestopt
Type aandoening	-
Onderzoekstype	Observationeel onderzoek, zonder invasieve metingen

Samenvatting

ID

NL-OMON29398

Bron
Nationaal Trial Register

Verkorte titel
SEFDEM

Aandoening

Any type of dementia

Ondersteuning

Primaire sponsor: University of Liverpool, Maastricht University
Overige ondersteuning: 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.

Onderzoeksproduct en/of interventie

Uitkomstmaten

Primaire uitkomstmaten

Toelichting onderzoek

Achtergrond van het onderzoek

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.

Doel van het onderzoek

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

Onderzoeksopzet

Single point in time

Onderzoeksproduct en/of interventie

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.

Contactpersonen

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Deelname eisen

Belangrijkste voorwaarden om deel te mogen nemen (Inclusiecriteria)

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

Belangrijkste redenen om niet deel te kunnen nemen

(Exclusiecriteria)

No exclusion criteria

Onderzoeksopzet

Opzet

Type:	Observationeel onderzoek, zonder invasieve metingen
Onderzoeksmodel:	Anders
Toewijzing:	N.v.t. / één studie arm
Blindering:	Open / niet geblindeerd
Controle:	N.v.t. / onbekend

Deelname

Nederland

Status:	Werving gestopt
(Verwachte) startdatum:	02-09-2019
Aantal proefpersonen:	500
Type:	Werkelijke startdatum

Voornemen beschikbaar stellen Individuele Patiënten Data (IPD)

Wordt de data na het onderzoek gedeeld: Nee

Ethische beoordeling

Positief advies

Datum:	29-07-2019
Soort:	Eerste indiening

Registraties

Opgevolgd door onderstaande (mogelijk meer actuele) registratie

Geen registraties gevonden.

Andere (mogelijk minder actuele) registraties in dit register

Geen registraties gevonden.

In overige registers

Register	ID
NTR-new	NL7912
Ander register	METC Z : METCZ20190089

Resultaten

Samenvatting resultaten

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