

Access to formal dementia care

Citation for published version (APA):

Kerpershoek, L. L. (2018). *Access to formal dementia care: A European perspective*. [Doctoral Thesis, Maastricht University]. Maastricht University. <https://doi.org/10.26481/dis.20181207lk>

Document status and date:

Published: 01/01/2018

DOI:

[10.26481/dis.20181207lk](https://doi.org/10.26481/dis.20181207lk)

Document Version:

Publisher's PDF, also known as Version of record

Please check the document version of this publication:

- A submitted manuscript is the version of the article upon submission and before peer-review. There can be important differences between the submitted version and the official published version of record. People interested in the research are advised to contact the author for the final version of the publication, or visit the DOI to the publisher's website.
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Access to formal dementia care

A European perspective



Liselot Kerpershoek

Access to formal dementia care

A European perspective

Lise Lotte Kerpershoek, Maastricht 2018

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Cover:	Alfred Rotteveel
Layout:	Mike van Herp
Printing:	Gildeprint
ISBN:	978-94-9301-491-6

Access to formal dementia care

A European perspective

PROEFSCHRIFT

Ter verkrijging van de graad van doctor aan de Universiteit Maastricht, op gezag van de Rector Magnificus, Prof. dr. Rianne M. Letschert, volgens het besluit van het College van Decanen, in het openbaar te verdedigen op vrijdag
7 december 2018 om 12:00

door

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Geboren op 5 oktober 1988 te Heerlen

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The research described in this thesis was performed at the Department of Psychiatry and Neuropsychology, School for Mental Health and Neuroscience, Maastricht University, Alzheimer Center Limburg, Maastricht, The Netherlands and was sponsored by Alzheimer Nederland.

Printing of this thesis was kindly supported by Alzheimer Nederland.



*“All we have to decide is what to do
with the time that is given to us”*

(J.R.R. Tolkien)

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General introduction

| 1

Living at home with dementia

Dementia has a major impact on a person's life, affecting not only cognitive abilities, but also activities of daily living. Many countries pursue health policies aimed at empowering people with dementia to live at home as long as possible, while being offered a variety of community and social care services. Most people prefer to stay in their homes because they believe they will be able to maintain the integrity of their social network [1] and enjoy a higher quality of life [2]. In addition, living at home is encouraged due to economic advantages: institutionalization is the main health care cost-driver for elderly [3] and people with dementia in particular [4]. In the beginning of the dementia process the majority of this group is offered support and care by informal caregivers, such as family or friends [5] [6]. When needs increase and informal care alone may not suffice, care from health and social care agencies in the community may be required. Previous studies indicated that the use of these services might postpone the need for institutionalization, such as nursing home or care home placement [7].

Mismatch between needs and service use

There is a broad range of formal care services to be offered, but we know from previous research that one third of people with dementia and their informal caregivers often do not use these services [8]. Why do people fail to use formal care services? Reasons vary from a lack of knowledge about the availability of services, services not being of the right type, refusal of the person with dementia, previous negative experiences with health care services, beliefs about the quality of services, experiencing stigma, and the consideration that services are not needed yet [6, 8-11]. In a recent review Phillipson et al. described that the majority of people with dementia and their informal caregivers experience difficulties in finding access to formal care services, and that received care is often not of the right type [9].

Informal care

In the decision-making process with regard to dementia care, not only factors related to the person with dementia are relevant, but also characteristics of the informal caregivers. When considering older people with dementia, research indicates that their informal caregivers provide around 75% of care at home, including help with personal care and instrumental activities of daily living [12]. During the provision of caregiving, there are amongst other differences in need for support from formal care services [12]. Additional differences between caregivers exist regarding relationship, age, gender and coping strategies. In a previous study caregiver profiles have been established [13] encompassing not only caregiver characteristics, but also characteristics of the person with dementia. Subjective as well as objective burden is included in these profiles, where the first one refers to how the caregiving tasks are experienced, and the latter to the amount of time spent on caregiving tasks [14].

Profiles [13] are mainly distinguished by age, caregiver relationship and experienced strain. Considering all these different factors within a profile may be useful for predicting service use, as well as for monitoring of the caregivers' well-being.

Equity and the Andersen model

Across countries and health care systems it is widely accepted that there should be equity of access to services [15] [16] with equal access for those with equal needs. Reasons for inequality could arise from differences in availability, quality, costs and information for different population groups [17]. To summarize, there is a variety of factors influencing the process of accessing formal care. A model that aims to combine this variety of factors is the Andersen Behavioural Model of Health Service Use. The model integrates predisposing, enabling factors and need factors to explain service use [18], and accordingly it can indicate inequity in access to care. Equitable access occurs when need and enabling factors such as disease severity and waiting lists determine realized access. Inequitable access is said to occur if predisposing factors such as gender, age or education contribute significantly to use of formal care, after controlling for need and enabling factors. The Andersen model is widely used in health care research, [19] and has for example been used previously to predict home care utilization in elderly [20]. However, the model has not yet been applied to determine equity in dementia care in Europe.

Actifcare

Actifcare builds on a previous EC 7th Frameworkproject project called Right Time Place Care [21] and is funded by the Joint Programme Neurodegenerative Disease (JPND) Research programme. JPND is the largest global research initiative whose aim is to tackle the challenge of neurodegenerative diseases. The overall aim of the European Actifcare project was to optimize access to care for community-dwelling people with dementia and their informal carers by finding the best match between care needs and the use of care. In addition, we aimed at determining equity in access to care across Europe. Actifcare focused on access to home- and community-based dementia care for people in the middle stages of dementia. A variety of research methods was used, such as literature reviews, focus groups, expert interviews, cost-consequence analyses and a cohort study. The studies conducted in this thesis were part of the Actifcare cohort study [22].

Aim of the thesis

The general aim of this thesis is to investigate the access to and use of formal dementia care services for those living in Europe. Predictors of service use will be investigated, as well as experiences and attitudes of people with dementia and their informal carers.

In this thesis the following research questions are addressed:

- 1) Which needs do home-dwelling people with dementia and their caregivers experience when formal care is not yet accessed? (chapter 3)
- 2) Is there equity in access to formal dementia care in Europe? (chapter 4)
- 3) How do people experience the access to and use of formal care? (chapter 5&6)
- 4) Can caregiver profiles predict the use of formal care services? (chapter 7)

Outline of the thesis

In **Chapter 2** an overview of the design of the Actifcare study is presented.

Chapter 3 describes the needs and quality of life of people with middle-stage dementia and their informal carers, during a phase in which no formal care is used yet.

Chapter 4 presents an analysis to determine equity in access to formal dementia care in Europe, with use of the Andersen Behavioural Model of Health Service Use.

In **Chapter 5** a qualitative study is presented, in which we delved deeper into the experiences and attitudes of people with dementia and their informal carers towards the access to and use of formal care services.

In **Chapter 6** experiences of caregivers regarding timeliness, access and satisfaction of formal care use are described.

In **Chapter 7** caregiver profiles are used to predict formal care use. In addition, the use of non-personal and supportive services is investigated as a predictor of formal care.

In **Chapter 8** the overall results are discussed, as well as the clinical (and scientific) implications and recommendations for future research.

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Chapter 1: General introduction

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Access to timely formal dementia care in Europe:
protocol of the Actifcare
(ACces to timely Formal Care) study



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Abstract

Background: Previous findings indicate that people with dementia and their informal carers experience difficulties accessing and using formal care services due to a mismatch between needs and service use. This mismatch causes overall dissatisfaction and is a waste of the scarce financial care resources. This article presents the background and methods of the Actifcare (ACcess to Timely Formal Care) project. This is a European study aiming at best-practice development in finding timely access to formal care for community-dwelling people with dementia and their informal carers. There are five main objectives: 1) Explore predisposing and enabling factors associated with the use of formal care, 2) Explore the association between the use of formal care, needs and quality of life and 3) Compare these across European countries, 4) Understand the costs and consequences of formal care services utilization in people with unmet needs, 5) Determine the major costs and quality of life drivers and their relationship with formal care services across European countries.

Methods: In a longitudinal cohort study conducted in eight European countries approximately 450 people with dementia and informal carers will be assessed three times in one year (baseline, 6 and 12 months). In this year we will closely monitor the process of finding access to formal care. Data on service use, quality of life and needs will be collected.

Discussion: The results of Actifcare are expected to reveal best-practices in organizing formal care. Knowledge about enabling and predisposing factors regarding access to care services, as well as its costs and consequences, can advance the state of the art in health systems research into pathways to dementia care, in order to benefit people with dementia and their informal carers.

Introduction

Approximately sixty percent of persons with dementia live at home. They have an increased need of care as the disease progresses. In many countries people with dementia are encouraged to live at home as long as possible, as it is assumed that quality of life is better at home than in institutions and this could also decrease the financial burden of dementia [1]. Several national and international organizations such as Alzheimer's Disease International (ADI) and Alzheimer Europe, have adopted strategies to promote timely recognition of dementia (European Parliament 2011, [2]). A timely diagnosis is regarded as necessary to enable improvements in dementia care. It allows stakeholders to collaborate in making important decisions regarding post-diagnostic care. Timely access to dementia care services is considered crucial to reduce health care costs e.g., to increase the quality of life for patients, to reduce informal caregiver burden, and by better coordinating nursing home placement [3]. 'Timely' is preferred to 'early' in this context, emphasizing that it is personally tailored and aimed at reducing both the risk of overtreatment as well as undertreatment.

Previous findings indicate that people with dementia and their informal carers experience difficulties accessing and working with community care services, even when having a diagnosis of dementia [4, 5]. This can put increasing pressure on them, which might lead to admission to a residential home simply because the appropriate support is not in place [6]. If such a mismatch between needs and service use occurs there is overall dissatisfaction for the service user and a waste of the scarce financial care resources. In these times where the financial burden of dementia should be decreased by encouraging people with dementia to live at home as long as possible, other efforts to restrain budget are of interest too. Economic evaluation of formal care service use is thus a crucial task. Factors that influence the access to and use of formal care can be explored with the Behavioural Model of Health Service Use by Anderson and colleagues [7] (see figure 1). This model describes predisposing and enabling factors in relation to needs and service use. The main deduction is that before services are being used, various factors positively influence patients and their informal carers to use services (predisposing variables), while other factors enable service use (enabling factors), and other variables determine the need for care (need variables). Predisposing variables include demographics (age, gender, marital status), socio-structural variables such as education and ethnicity, and health beliefs for example about disease and care. Enabling factors are resources either supporting or impeding service use (waiting lists, health insurance coverage). Need variables consist of the impairments that require service, e.g. type of illness. The relation between these variables is complex, and could change during the progress of dementia, as needs are constantly changing [8].

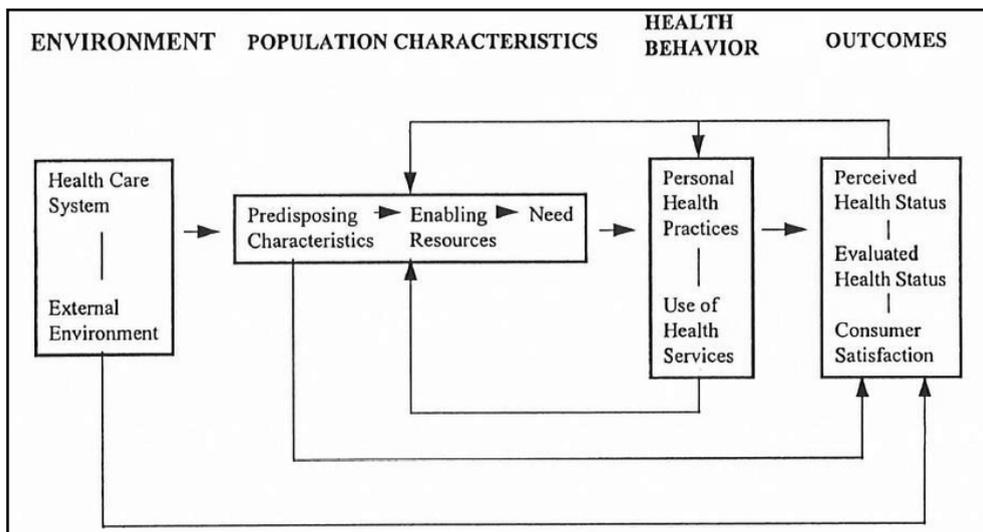


Figure 1: Anderson Behavioural Model of Health Service Use [9].

The Anderson model can be used to understand access to and use of services by identifying associations between service use and a broad spectrum of predisposing and enabling variables, while controlling for need. The differences between countries regarding equity in which services are accessed and delivered have not yet been studied, despite the critical nature of this information for understanding the current health care systems. Well-organized access to formal care is especially important in the middle stage of dementia, as increased care is needed in this stage.

The Actifcare (Access to timely formal care) study focuses on this middle stage of dementia, which makes it innovative in contrast to previous dementia studies that have focused predominantly on early or later stages. Actifcare builds on a previous EC 7th Frameworkproject project called Right Time Place Care (RTCP) [10] and focuses on people who are not using formal care, but are most likely to start in the near future. This enables a specific evaluation of the process of accessing formal care.

This protocol focuses on the part of the Actifcare study that aims to increase our understanding of why people with dementia and their informal carers use, or fail to use formal care services across Europe, and how the use of formal care is experienced. In Actifcare formal care includes home nursing care, day care service, community or long-term medical care, nursing and social care structures. It excludes domestic home help, housekeepers, volunteers, support groups, transport services and meal programs. The present state of the art concerning access to timely formal care for people with dementia and their informal carers will be envisioned. We want to explore the reasons behind (non)-use of formal care by learning from experiences of people with dementia and their informal carers. Through

different methods of data collection we aim to identify best-practice strategies regarding access to formal care for this vulnerable group. We will also use our large international database to validate some new measures during this study. Knowledge about enabling and predisposing factors regarding access to care services as well as its costs and consequences can advance the state of the art in health systems research into pathways to dementia care, in order to benefit people with dementia and their informal carers.

The main objectives are the following:

- 1) Exploring the predisposing and enabling factors that are associated with the use of formal care services;
- 2) Exploring the association between the use of formal care, needs and quality of life in people with dementia and their informal carers;
- 3) Comparing these across different European countries;
- 4) Understanding the costs and consequences of formal care services utilization in people with unmet needs in Europe;
- 5) Determining the major costs and quality of life drivers and the relation with formal care services across European countries;
- 6) Validation of the relatively new ICECAP-O instrument and the CarerQol instrument for the assessment of quality of life in relation to the timing of formal care in Europe;

Methods

Overall methodology

To achieve these objectives a longitudinal cohort of patients will be recruited in eight countries. Themes, which are obtained in focus groups and expert interviews preceding this longitudinal study, will form the basis for in-depth semi-structured interviews

Design

A prospective cohort study design is adopted and is conducted in eight European countries (Germany, Netherlands, Sweden, Norway, Ireland, United Kingdom, Portugal and Italy). Baseline assessments started in November 2014 and follow-up measurements are planned after 6 and 12 months. Last patient out is expected in June 2016.

Participants

The study aims to assess 480 dyads (60 per country) representing a cohort of community-dwelling people with dementia and their informal carers. Due to the exploratory nature of this study no power calculation is necessary. Eligibility criteria are described in table 1. Participation is restricted to mentally competent people with dementia. Only people with dementia and their carers who provided informed consent participate. The carer and the person with dementia both sign a separate informed consent form, after they had sufficient

time to read the form and ask questions if needed. Participants are recruited from various settings, e.g. general practices, memory clinics, casemanagers and community mental health teams. In addition advertisements are placed in local and various national newspapers.

Measures

Table 2 summarizes the outcome measures, which were selected through careful consideration of psychometric properties and clinical utility. Questionnaires that were not available in all languages were translated and back translated via a translation protocol to ensure validity.

Table 1: Eligibility criteria for dyad selection

Inclusion criteria
- The patient has a diagnosis of dementia meeting DSM IV TR criteria following an assessment by a clinical professional.
- The person with dementia has a Clinical Dementia Rating indicating mild or moderate degree of dementia (i.e. scores 1 or 2) or scores 24 or less on the MMSE.
- The patient is not receiving regular assistance from a paid worker with personal care, on account of his/her dementia, such as help with dressing/undressing; washing/ bathing/ showering; toileting; feeding/drinking; taking medication. (Note: ‘regular’ is defined as at least once per week; ‘paid worker’ includes those paid by health and social care services and those paid direct by the person and his/her family).
- A professional judges that additional assistance with personal care is likely to be considered / required within one year.
- The person with dementia has a carer who is able and willing to participate and is in contact at least once per week. The carer does not have to be residing with the carer, they could be a relative, friend or neighbour in regular contact.
Exclusion criteria
- The person with dementia or their carer is not able to complete the assessments due to communication/ language/ hearing/ understanding/ literacy problems that cannot be compensated for.
- The person with dementia or their carer has a terminal condition or comorbidities (including long-standing severe mental illness) contributing to a significant level of disability
- The person with dementia or their carer has a life-long learning disability or severe physical impairment that would prevent them from being able to complete the assessments.
- The person with dementia resides in a care home or nursing home or has been resident in a care home or nursing home (e.g. for respite) during the previous six months.
- The person with dementia has a diagnosis of alcohol-related dementia or of Huntington’s disease.

Main outcomes

One of the main objectives in Actifcare concerns met and unmet needs. These will be assessed with the Camberwell Assessment of Need for the Elderly (CANE), a tool especially designed to combine opinions regarding needs from people with dementia, informal carers and professionals [11]. The Resource Utilisation in Dementia instrument (RUD) measures service use, and will be completed by the researcher based on information provided by the carer. With the RUD we can obtain information regarding medical resources and informal care resource use. [12] A service use checklist was constructed with input from all participating countries to provide more information on the (non)-use of services and the reasons behind this.

Measures for people with dementia

Measures for people with dementia include a range of quality of life scales. The Quality of Life- Alzheimer's Disease scale (QOL-AD) is a reliable and valid scale for people with dementia with a Mini Mental State Examination (MMSE) score above 10 [13]; the same accounts for the DEMQOL. Both the QOL-AD and DEMQOL have a proxy-report version as well [14]. The ICECAP-O is a generic instrument that measures capabilities with preference-based tariffs applicable in health-economic evaluation. This promising tool is expected to more sensitively capture changes resulting from the use of formal care services in the middle stage of dementia than the EuroQol [15]. Health-related quality of life scales will also be administered. The EuroQol-5D has been validated in a number of European countries in and in the dementia population. It consists of five items and a people with mild to moderate dementia and it assesses the subjective perceptions and experiences of people with dementia [14]. In addition cognitive functioning is assessed with the Mini Mental State Examination (MMSE) [16], and the quality of the relationship with the informal carer with the Positive Affect Index (PAI) [17].

Measures for the informal carers

There are several measures for the informal carer regarding quality of life (EQ-5D-5L, CarerQol, ICECAP-O). The Care related quality of life scale (CarerQol) was developed (along the lines of the EuroQol instrument) to measure the impact of informal care by assessing happiness and describing the most important burden dimensions. This promising instrument will be applied and validated in the participating European countries [18, 19]. Anxiety and depression will be measured with the 14 item Hamilton Anxiety and Depression Scale (HADS) [20]. Perseverance time is measured with a single simple estimate of how long the informal carer can continue in this way if the situation remains unchanged. In addition, caregiving-related stress and social network is assessed with the Relative Stress Scale (RSS) [21] and the Lubben social network scale (LSNS-6) [22]. These measures are important as they give us a broad insight on different aspects of life of the informal carer. Information

regarding internal and external locus of control (Locus of Control of Behaviour Scale) and sense of coherence are also assessed (SOC-13)[23] [24]. The carer will also provide information regarding the persons' with dementia functional abilities. The Instrumental Activities of Daily living (IADL) scale provides us with specific information on daily living skills while the Physical Self-Maintenance Scale (PSMS) gives information about physical abilities [25]. Neuropsychiatric symptoms are assessed with the Neuropsychiatric Inventory (NPI-Q), as these influence caregiver burden [26]. Quality of life will be assessed with several measures similar to those administered with the people with dementia (QOL-AD, EQ-5D-5L, ICECAP-O) along with the DEMQOL-U proxy which is specifically designed for carers to rate quality of life for the people with dementia [14].

Table 2. Measurement instruments

Measurement instruments		
Variable	Measure	Assessed by
People with dementia		
Socio-demographics	Datasheet*	PwD
Cognition	MMSE	PwD
Service use	Checklist	PwD/CG
Personal and social resources	RUD	CG
Quality of life	QOL-AD	PwD
Health-related quality of life	EQ-5D-5L	PwD
Quality of life of PwD	DEMQOL-U-Proxy	CG
	DEMQOL-U	PwD
	QOL-AD	CG
	EQ-5D-5L	CG
Quality of relationship	PAI	PwD
Capability	ICECAP-O	PwD
(un)met needs	CANE	PwD, CG, In
Neuropsychiatric symptoms	NPI-Q	CG
Severity of dementia	CDR	In
Comorbidity	Charlson Index	In
Activities of daily life	IADL	CG
	PSMS	
Informal carers		
Social isolation	LSNS-6	CG
Quality of relationship	PAI	CG
Quality of life	CarerQol-7D	CG
Health related quality of life	EQ-5D-5L	CG
Anxiety and depression	HADS	CG
Perseverance time	Single question	CG
Stress	RSS	CG
Capability	ICECAP-O	CG
Control	Locus of control*	CG
Sense of coherence	SOC-13	CG
Personal and social resources	RUD	CG

Pwd: people with dementia, CG: informal carers, In: interviewer. Measures which are only assessed at baseline are marked with an *.

Additional measures

Comorbidities will be assessed with the Charlson Comorbidity Index, to control for service use for causes other than dementia [27]. Severity of dementia will be assessed with the Clinical Dementia Rating (CDR) [28]. People with dementia and carers will also complete a short questionnaire on socio-demographic information (age, gender, ethnicity, education, occupation, living situation).

Procedures cohort study

At baseline, at 6 months follow-up and at 12-months follow-up all questionnaires will be administered in the hospital or at home to ensure that participants are in a comfortable environment. The visit can be shortened or split in two to reduce the burden for the participants. All researchers involved have been trained in administering the different questionnaires and have clinical experience. In a purposively sampled subgroup of n=10 per country, in-depth semi-structured interviews will be conducted at 12-months follow-up ensuring inclusion of both dyads using formal care services and dyads not using formal care services. The content of the interview is developed from the outcome of a literature review and focus groups. Themes that will be discussed are e.g. attitude towards dementia, cooperation with healthcare professionals, joint decision making of the informal carer and the person with dementia regarding service use. The interviews will be tape-recorded and transcribed verbatim for analysis. Data triangulation through verification by two researchers will be used to ensure the trustworthiness of the data analysis.

Statistical analyses

Group characteristics per individual country will be calculated with proportions or means. Group comparisons will be performed with Chi square tests for categorical variables and t-tests for continuous variables. Transcultural differences are a specific area of interest. To ensure valid comparison of service use among countries direct standardizations will be carried out (using the entire pooled sample as the external standard population) for the effects of age group, gender, educational level, dementia diagnosis and severity. The relationship between predisposing factors, enabling factors and use of formal care services will be explored with a multi-level analysis. Cross level effect modification (e.g. living in a specific country/ country cluster modifies the effect of individual characteristics on service use) will be examined to identify ecological effects. To assess the potential inequity with which services are accessed and delivered, the associations between service use and predisposing and enabling variables will be controlled for needs. Multiple regression analysis will be used to explore the relationship between service use, met and unmet needs (independent variables) and quality of life of the people with dementia and informal carer (dependent variables).

Discussion

The current study focuses on middle stage dementia, and explores the association between the use of formal care, needs and quality of life in people with dementia and their informal carers in eight European countries. This paper describes the research protocol of the cohort study. The Actifcare projects aims to increase our understanding of why people with dementia and their informal carers use, or fail to use formal care services across Europe, and how the use of formal care is experienced.

The strengths of this cohort study are the overall size, where patient inclusion in different countries enables cross-country comparison. The fact that participants are included across different parts of Europe ensures diversity in the group, which enables us to investigate contextual differences. Measurements are assessed at three different time points; in this way we can follow patients and their carers throughout the trajectory in which formal care is initiated. One of the potential limitations is selection bias; those people who refuse service use are not likely to take part in a study concerning needs and service use, as they refuse all types of interference. It would be interesting to hear the rationale behind decisions from these people with dementia.

With the input of people with dementia, their informal carers and professionals we can develop formal care strategies, and combine these with information on cost-efficiency across Europe. This information will help us develop best-practice strategies to improve effectiveness and efficiency of access to European dementia care systems. We will reach a consensus regarding recommendations across countries, and create country-specific recommendations for the implementation of best practice strategies. Once the project ends and recommendations are developed, we will disseminate these results to a wide audience through different methods. The target audience is health care professionals, national health services, the general public, patient advocacy groups and dementia researchers.

A Consortium and Advisory board of expertise has been set up, representing different professional disciplines; several representatives of the project are closely related to national political boards as well as to institutions and political boards of the European Union. This will additionally facilitate widespread dissemination of results. The results will be available after the end of the cohort study in June 2016.

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Needs and quality of life of people with middle-stage dementia and their family carers when informal care alone may not suffice:

Findings of the European Actifcare study

3

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Abstract

Objective: During middle-stage dementia, formal care services are often introduced to augment the support of family and friends. The Actifcare (Access to timely formal care) study investigated the domains and level of needs of people with dementia and their families during the phase in which formal care is being considered, and it also examined whether higher need levels are related to lower quality of life.

Methods: From eight European countries (The Netherlands, Germany, United Kingdom, Sweden, Norway, Ireland, Portugal and Italy), a total of 451 people with mild to moderate dementia who were not receiving formal care and their carers participated. Demographic data were collected, and needs were measured with the Camberwell Assessment of Need for the Elderly. Quality of life (QOL) was measured with the QOL-AD, and carer quality of life was measured with the CarerQol. The relationship between needs and QOL was analysed with multiple regression analyses.

Results: Needs were primarily expressed in the domains of psychological distress, day-time activities, company and information. People with dementia rated their unmet needs significantly lower than their carers: the mean number of self-rated unmet needs was 0.95, whereas the mean proxy ratings were 1.66. For met needs, the self-rated mean was 5.5 and was 8 when proxy-rated. The level of needs reported was negatively associated with QOL: for both the person with dementia and the carer, QOL decreased as the number of needs increased.

Conclusion: The study results show that informal carers reported almost twice as many needs as people with dementia. Our cohort consisted of community-dwelling people with dementia who did not yet use formal care, and for whom the informal carer provides most of the care. This might have an influence on quality of life due to its inverse relationship with needs (for the person with dementia and informal carer). The domains in which needs are expressed should therefore be the primary focus for interventions to support QOL in community-dwelling people with dementia and their carers. In addition, the perspectives of people with dementia are informative in addition to those of their carers when identifying and addressing needs.

Introduction

Dementia has a major impact on a person's life. It leads to difficulties in different domains, such as self-care, meaningful activities and social contacts. Thus, people with dementia and their informal carers experience a wide range of needs that are subject to change as the disease progresses. Unmet needs can be defined as those needs in a particular area of an individual's life in which insufficient or inadequate support is provided or appropriate support is unavailable [1]. For met needs, sufficient and adequate support is available through either informal or formal care.

A number of studies have investigated these needs from various perspectives [2, 3], [4-6]. The needs of people with dementia are often measured using proxy-ratings [1]. Few studies have incorporated the self-rated needs of people with dementia. It is important to be aware of the subjective needs of people with dementia to provide more appropriate person-centered care. In terms of needs assessment, there are often discrepancies in perspectives. Typically, people with dementia report a significantly lower number of (unmet) needs than their caregivers. The reasons for this discrepancy could be lack of awareness of difficulties, lack of knowledge about the existence of services, barriers to accessing services and unsatisfactory service offerings [4, 5, 7]. A review of the literature investigating self-rated needs found that the domains in which needs are expressed by people with early to moderate dementia are related to their well-being and not to instrumental activities [1]. For example, needs were reported in the areas of receiving respect from others and needing to find a way to cope with their situations. Other studies have indicated the needs expressed by community-dwelling people with dementia in the areas of psychological distress, daytime activities and company [3]. Previous studies have generally focused on a broad range of dementia severity or on people with young onset dementia. In the Actifcare study, our focus was on a group of people that could be said to be in the middle-stage of dementia, in that it was considered that they were likely to start using formal care in the near future. Investigating this group is important because it allows us to focus on the specific needs of individuals who are potentially in transition from informal care exclusively to a combination of formal and informal care; it is in particular in the middle stage, that people with dementia are likely to have increasing care demands due to disease progression. The focus on people who do not use formal care but only rely on informal care does not imply that they do not have (unmet) needs. However, thus far, their needs have predominantly been addressed through informal care. Studies have shown that providing care influences the life of a carer to a large extent, with consequences that include depression, physical illness, and poor quality of life [8]. Informal carers of people with dementia are at increased risk of feeling socially isolated and financially burdened [9, 10]. This finding is particularly true for carers co-resident with the person with dementia, where informal carers typically provide many hours of care, often increasing as the disease progresses.

In the present study, we expected to find that people with middle-stage dementia and their

informal carers who do not yet use formal care do experience met and unmet needs. We hypothesized that for people with dementia and their informal carers, higher levels of met and unmet needs are reflected in lower quality of life ratings compared to those who express fewer needs.

We aimed (1) to describe the domains and level of needs in a group of people with middle stage dementia and their informal carers who do not yet use formal care and (2) to describe the relationship of needs and quality of life from different perspectives (i.e., self- and proxy-rated).

Methods

Study design and participants

The data considered in this paper are baseline data from the European prospective cohort study Actifcare (Access to timely formal care). In this study, 451 dyads of community-dwelling people with dementia and their caregivers were followed for one year, and data were collected about service use, needs, quality of life (QOL) and several other domains. People were included with (1) mild to moderate dementia determined by their specialist, according to the DSM-IV-TR criteria (2) an informal carer who was in close contact with the person with dementia at least once a week (3) no use of formal care yet at baseline, defined as home nursing care, day care service (including help with personal care), community or long-term medical care, nursing and social care structures. It did not include domestic home help, housekeepers, volunteers, support groups, transport services and meal programs. For all included dyads (4) formal care was expected to be necessary within one year based on the expert opinion of a clinician. Participants were recruited from various settings such as general practitioners, memory clinic and community mental health teams. In addition participants were recruited via advertisements that were placed in local and national newspapers. The complete design of the Actifcare study has been described elsewhere in detail [11].

Data collection and assessments

Ethical permission was obtained in all countries separately. Written informed consent was obtained from both the person with dementia and caregiver according to the national procedures in each country. Demographic information and service use details were collected, and two trained researchers administered a wide range of scales. The visit lasted approximately 90 minutes.

Needs assessments

The needs of people with dementia were measured with the Camberwell Assessment of Need for the Elderly (CANE) [12] This comprehensive interview-based questionnaire is designed to map the needs and amount of help (received and needed) for older people. Twenty-four areas are covered, and these areas can be subdivided into three main domains:

psychological, physical, and environmental. With this instrument, needs are identified as being absent (score 0), met (score 1), or unmet (score 2). If a need is rated as met, one must indicate which type of care (i.e., informal or formal care) ensures that the need is met. The instrument has good reliability and validity [13]. In this study, the person with dementia, the informal carer, and a trained researcher completed the CANE at baseline. The trained researcher made an estimation based on all available information from extensive interviews with both the people with dementia and their carers, including the CANE ratings of each participant. In these analyses, we considered all three perspectives in order to make best use of the available information. For the analyses in this study, we used the total number of needs (both met and unmet), since both indicate situations that require care. Having a need, either met or unmet, could signal that care is necessary.

Quality of life assessment

Quality of life was measured with the Quality of Life-Alzheimer's Disease Scale (QOL-AD), which was self-rated by the person with dementia and proxy-rated by the informal caregiver. The scale is designed for dementia and covers thirteen domains: physical health, energy, mood, living situation, memory, family, marriage, friends, chores, fun, money, self and life overall. All domains are scored on a four-point Likert scale (poor, fair, good, excellent), in which higher scores indicate higher QOL (ranging from 16-52). The scale has good validity and reliability [14]. To measure QOL of the carer, the CarerQol was used. This scale was developed to measure the impact of providing informal care [15]. It consists of seven items that are scored on a three-point scale (no, some, many); these answers are combined to form a sum score. In addition, there is a VAS-scale in which the informal carer indicates on a scale from zero to ten how happy he/she is at the moment. We used the sum- and VAS-scores for our analyses.

Statistical analysis

Proportions or means were calculated as descriptors and used to determine the number of met and unmet needs. Linear regression analysis was performed to assess the relationship between carer QOL and needs, and the CarerQol sum score and CarerQol VAS were dependent variables. The independent variables were the sum of needs from the informal carer perspective scored on the CANE. In addition, linear regression analyses were performed to assess the relationship between QOL and needs for the person with dementia, with the QOL-AD as dependent variable, and the self-rated sum of needs as independent variable. We used the backward method in regression, with a cut-off score of $p=0.10$. In stepwise regression analysis, the backward method is recommended over the forward method because it decreases the chance of creating a suppressor effect; this process ensures that a predictor is significant merely when another variable is held constant [16]. The demographic variables (gender, age, education) and living situation (living together with the person with

dementia) were covariates. In cases of missing values, we used a different method for each questionnaire. For the QOL-AD, CarerQol and CANE, if at least 80 % of the items were present, we rescaled the score (total score divided by the number of available items, multiplied by maximum number of items). SPSS version 24 was used to perform the analyses.

Results

Table 1: Group characteristics (N=451)

Person with dementia	
Male (n, %)	207 (46)
Age (mean, range, SD)	77.4 (47 – 92) 7.9
Education (mean years, SD)	9.8, 4.5
Marital status (n, %)	
Married	310 (68)
Widowed	109 (24)
Single	8 (2)
Other	24 (6)
Living together with carer (n, %)	325 (72)
Dementia type (n, %)	
Alzheimer’s Disease	218 (49)
Vascular dementia	52 (12)
Mixed dementia	56 (12)
Lewy body dementia	6 (1)
Other	119 (26)
CDR sum of boxes (mean, range, SD)	7.1 (2-16) 2.4
Caregiver	
Male (n, %)	151 (33)
Age (mean, range, SD)	66.4 (25 - 92) 13.3
Range	
Education (mean years, SD)	11.91, 4.4
Marital status (n, %)	
Married	363 (80)
Widowed	10 (2)
Single	31 (7)
Other	47 (11)
Caregiver relation (n, %)	
Spouse	271 (60)
Child	137 (30)
Other	43 (10)

PwD: person with dementia. CDR: clinical dementia rating scale

A total of 451 dyads participated in the study. The characteristics of the people with dementia and their caregivers are summarized in Table 1. Among the people with dementia nearly half (48 %) were diagnosed with Alzheimer’s Disease. The majority (78 %) had a CDR score of 1, and 72 % lived together with a carer. Most of the caregivers were female (66 %), and the majority had a spousal relationship (60 %).

Table 2: Questionnaire scores (N=451)

CarerQol sum (mean, range, SD)	9.42, [0-13], 0.2
CarerQol VAS (mean, range, SD)	6.37, [0-10], 1.9
Sum of met needs (mean, range)	
pwd	5.58, [0 - 18], 3.2
carer	8.03, [0 - 18], 3.2
trained researcher	8.15, [0 - 19], 3.3
Sum of unmet needs (mean, range)	
pwd	0.95, [0 - 10], 1.4
carer	1.69, [0 - 13], 1.9
trained researcher	1.87, [0 - 17], 2.0
Total needs (mean, range, SD)	
pwd	6.11, [0-22], 3.5
carer	9.52, [0-19], 3.5
trained researcher	9.69, [0-20], 3.7

CarerQol: Carer Quality of Life. PwD: person with dementia; VAS: visual analogue scale

Aim 1: Different perspectives on (un) met needs

People with dementia reported the most unmet needs in the domains of company (15%), information (13%) and daytime activities (9%), as shown in figure 1. The caregivers reported unmet needs more frequently compared with the people with dementia; however, the needs were in the same domains: company (24%), information (10%) and daytime activities (28%). In addition, the caregivers noted unmet needs in the domains of psychological distress (12%) and benefits (11%), as shown in figure 2. The researchers rated the unmet needs slightly higher than the caregivers (in similar domains): company (28%), information (13%), daytime activities (29%), psychological distress (14%) and benefits (10%), as shown in figure 3. Analysis of the number total needs showed a significant difference between perspectives: ($t=18.1, p=.000$) when comparing people with dementia to carers, and ($t=-19.5, p=.000$) when comparing people with dementia to trained researchers. The mean number of self-re

ported unmet needs rated by the person with dementia was 0.95; it was 1.66 when rated by the informal caregiver and 1.85 when rated by the trained researcher. For met needs, the people with dementia rated a mean of 5.5 met needs, while the carer and trained researcher rated an average of 8 met needs.

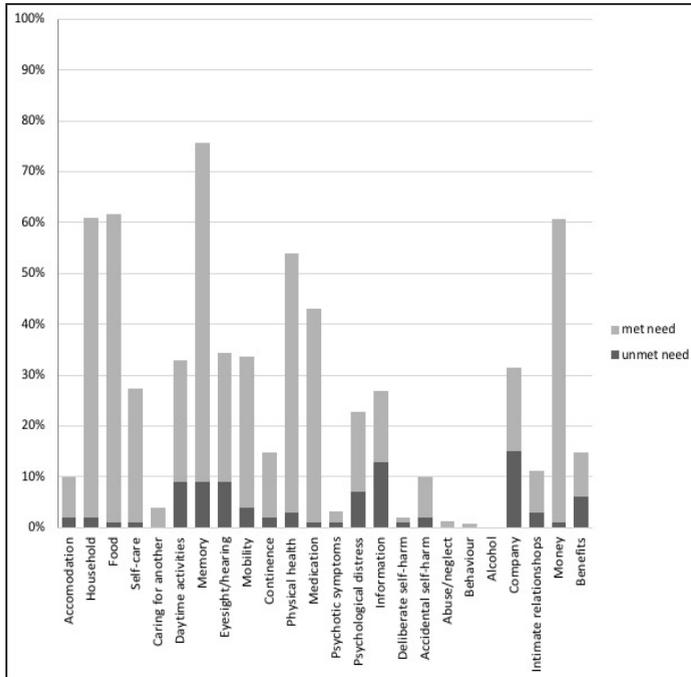


Figure 1: (Un)met needs rated by the people with dementia

Chapter 3: Needs and quality of life

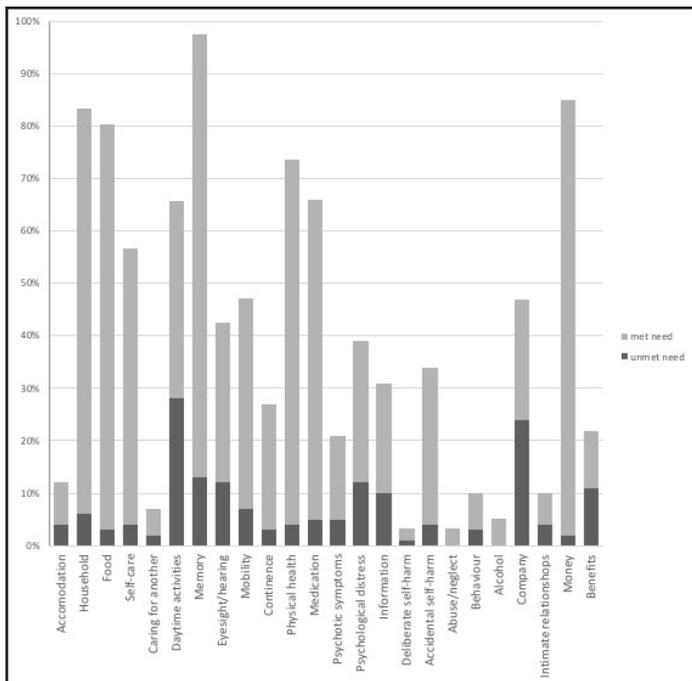


Figure 2: (Un)met needs rated by the caregivers

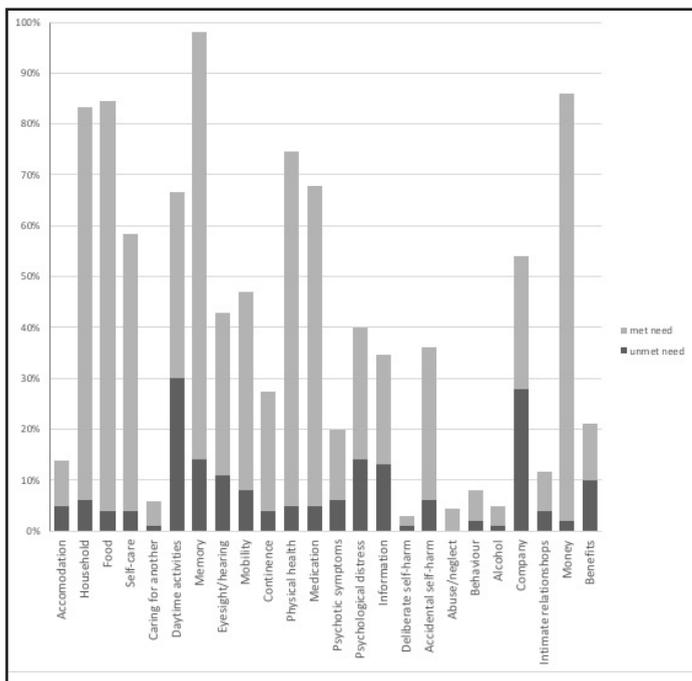


Figure 3: (Un)met needs rated by the trained researcher

Aim 2: Investigating the relationship between needs and QOL

Quality of life of people with dementia

In the linear backward regression analysis with the self-rated QOL-AD as the dependent variable, the only significant independent variable remaining in the final model was the self-rated sum of needs and education, in which QOL and needs were significantly related in a negative manner, while education was positively related. This implies that QOL decreases as the number of needs increase, and QOL is increased if the number of years of education is higher. When the dependent variable was proxy-rated QOL, the self-rated sum of needs was also significantly correlated in a negative manner, as well as the CDR sum of boxes. Covariate education was also significant in a positive direction, as well as gender (being female). The other covariates were not significant (age, living situation). This implies that QOL decreases as the number of needs and disease severity increase. In addition, QOL is increased for females, and if the number of years of education is higher. The results can be found in table 3.

Table 3: Final regression models for QOL-AD, only displaying the independent variables remaining after the backward selection procedure.

	QOL-AD self		QOL-AD proxy	
	Coefficient	p-value	Coefficient	p-value
Needs (self-rated)	-.482	.000	-.289	.000
Gender	*	*	1.317	0.22
Education	.445	.000	.409	.000
CDR	*	*	-.405	.001

Care-related Quality of life of the carer

Linear backward regression analysis assessing the relationship between carer QOL and needs, with the CarerQol sum as the dependent variable, showed that the only significant independent variable remaining in the final model was the sum of needs rated by the carer. Care-related QOL and needs were negatively associated, which means that the care-related QOL decreased as the sum of needs increased. None of the covariates (i.e., carer age, gender, education and living situation) were significant. In linear backward regression analysis, with CarerQol VAS as the dependent variable, the sum of needs rated by the carer was again a significant independent variable. This means that participants rate their QOL lower if the sum of needs is higher. The covariate living situation was also associated with carer QOL; if an informal carer lived with the person with dementia, the carer QOL was lower. None of the other covariates (carer age, gender, education) were significant. The results are shown in table 4.

Table 4: Final regression models for the CarerQol sum and VAS, only displaying the independent variables remaining after the backward selection procedure.

	CarerQol sum		CarerQol VAS	
	Coefficient	p-value	Coefficient	p-value
Needs (carer)	-.012	.000	-.120	.000
Living situation	*	*	-.467	0.20

Discussion

This study investigated needs from different rating perspectives in a sample of people with dementia and informal carers who do not yet use formal care but are expected to do so within one year. This study design allowed us to examine the domains and level of needs during the phase in which informal care may need to be supplemented by formal care, thereby providing important insight into how we can support this group of people who find themselves at a tipping point in their caregiving situations.

Aim 1: Different perspectives on (un)met needs

Overall, the people with dementia reported fewer needs than the informal carers and researchers. This finding aligns with that of a previous study and might be explained by the will to remain autonomous, a feeling that makes a person trivialize their needs assessments [5]. Acknowledging and reporting needs might be related to the willingness to engage in professional care. The difference in perspective of the person with dementia and the carer may in addition lead to conflicts in decision-making regarding the acceptance of care. Professionals should pay more attention to and be trained in dealing with these decisional conflicts [17].

The fact that people with dementia indicated a lower number of needs might also be due to a lack of insight, as insight seems to be related to disease severity in dementia patients, which declines as the disease progresses [18]. However, different studies report conflicting findings about changes in awareness in people with dementia and the relation with change in other cognitive and psychosocial variables [19]. Helping people with dementia at an early stage of the disease to gain insight into their needs could help them seek support earlier. This should however be carried out carefully in an individually tailored manner as awareness is related to personality [20].

The domains in which (un)met needs most frequently occurred aligned with those reported by previous studies of community-dwelling people with dementia [1, 3, 4]: psychological distress, daytime activities and company. In addition, we found a large number of unmet needs in the area of information, which aligned with our qualitative findings (to be published) and those of previous studies [21]. The amount of information about available services is not sufficient, likely leading to non-use of services, as depicted by lower QOL scores. Informa-

tion is a need that could be easily met, particularly at the phase in which people are starting to use formal care. Information should be particularly tailored to an individual's needs and wishes and must fit the stage of the disease (Stephan et al., 2017, under review). The fact that people experience this need should raise concern in the current health care system and requires more attention. From all three perspectives 'company' is the largest unmet need. From the literature it is well-known that loneliness has a negative influence on one's overall health [22], and that feelings of loneliness can even predict dementia onset [23]. This emphasizes the importance of social interventions. Meeting needs concerning company is important for an additional reason: in the current healthcare system the social network is increasingly involved in providing care[24]. Investing in a solid and reliable social network is thus important both to decrease loneliness and to expand your care network.

Aim 2: Investigating the relation between needs and QOL

When considering the reported met needs in our sample, they were predominantly met by informal care, as no formal care was used by our sample population. Previous studies have shown that as a primary caregiver, providing care is emotionally challenging and leads to being prone to depression, social isolation and physical complaints [25] [8]. In our sample, there was indeed a significant relationship between the sum of met and unmet needs and care-related QOL. As the number of needs increased, care-related QOL (the sum- and VAS-score) decreased. In addition, the VAS score was lower when the informal carer lived with the person he/she was caring for. This finding might be related to the increased number of hours of informal care when you co-resident [26, 27].

In this cohort, we also found a significant negative relationship between the needs and QOL of the person with dementia. The results are aligned with those from previous studies [2, 28] that found that higher QOL in the person with dementia was related to a lower number of unmet needs. From a psychosocial point of view, our aim should always be to increase quality of life. If this can be done by ensuring that a person's needs are met or by diminishing needs, this should be our focus. Ways of meeting needs in this sample are ensuring that the needs for daytime activities, company and information are fulfilled in a timely manner. This could be achieved by informing informal carers about their options and helping them find tailored solutions.

Limitations and strengths

One of the limitations in this design is selection bias; the people who refuse service use are not likely to participate in a study concerning needs and service use, as they might refuse all types of interference. In addition, unravelling the relationship between needs and QOL is, of course, a more complex task than our relatively simple model can perform. Including predictors, such as depressed mood, quality of relationship and self-concept, in the model might account for a large percentage of the variance [29]. This complexity will be investigated with the longitudinal data of this cohort. The strengths of this study are the size and variability of the cohort, as it represents people from eight European countries.

Conclusion

The study results show that informal carers reported almost twice as many needs as people with dementia, which is in line with previous research. These differences in perspective may lead to conflicts in decision-making regarding accepting care. Professionals should pay more attention to and be trained in dealing with these decisional conflicts.

As our large European cohort consists of community-dwelling people with dementia who do not yet use formal care, the informal carer provides most of the care. We found that this might have an influence on quality of life because QOL decreased as needs increased (for both the person with dementia and informal carer). This specific group is an important target for future research, as the amount of people with dementia will increase, and the demand for caregivers to provide care at home will increase accordingly. Improving information provision and promoting social interventions are important future research directions. In the follow-up of this study, we will delve deeper into the relationship between needs and QOL and investigate other predictors that could be targets for intervention.

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Is there equity in initial access to formal dementia care
in Europe?

The Andersen Model applied to the Actifcare cohort

4

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European Journal of Ageing, under revision

Abstract

Background: In the current study the Anderson model is used to determine equitable access to dementia care in Europe. Predisposing, enabling and need variables were investigated to find out whether there is equitable access to dementia-specific formal care services.

Methods: 451 People with middle-stage dementia and their informal carers from eight European countries were included. At baseline, there was no use of formal care yet, but people were expected to start using formal care within the next year. Logistic regressions were carried out with one of the four clusters of service use as dependent variables (home social care, home personal care, day care, admission). The independent variables (predisposing, enabling and need variables) were added to the regression in blocks.

Results: The most occurring significant predictors for the different care clusters are disease severity, a higher sum of (un)met needs, hours spent on informal care, living alone, age, region of residence, and gender.

Discussion: The Andersen model can be applied to dementia care, and for this cohort it provided the insight that besides need factors the predisposing variables region of residence, gender and age do play a role in finding access to care. In addition, it showed us that the numbers of hours spent on informal care, living alone, needs and disease severity are important predictors. Health care professionals should pay attention to these predisposing factors to ensure that they don't serve as barriers for those in need for care.

Introduction

Dementia has a major influence on a person's life, affecting not only cognitive abilities, but also activities of daily living. As the condition progresses an increasing amount of care and support is needed, typically commencing with care from family and friends [1], often described as 'informal care'. When informal care alone may not suffice, care from health and social care agencies ('formal care') in the community may be required and might postpone the need for institutionalization, such as nursing home or care home placement. For example, the use of in-home help (personal care and companionship) early in the dementia process may delay institutionalization [2].

Another reason for promoting the use of community care at home is the fact that admission to a hospital or to long-term care is currently the main cost-driver of health care for people older than 65 years in general [3] and for people with dementia in particular [4]. Accordingly, in current health care systems governments promote living at home as long as possible, with the use of formal care services. The World Health Organization defines home as 'a place of emotional and physical associations, memories and comfort' [5]. It is, in line with the current health care perspective, the preferred place to care for a person with dementia. Moreover, most people prefer to stay in their homes because they believe they will be able to maintain the integrity of their social network [6] and enjoy a higher quality of life [7]. However, a literature review showed that one third of informal carers of people with dementia does not make use of community services [8]. Reasons for non-use of services vary from the consideration that services are not needed, to a lack of awareness or refusal of the care recipient. In a recent review Phillipson et al. describe that the majority of people with dementia and their informal carers experience difficulties in finding access to formal care services. When care is received, often it is not of the right type [9].

It is widely accepted across many health care systems that there should be equity of access to services [10] [11] with equal access for those with equal needs. Possible reasons for inequality arise from differences in availability, quality, costs and information for different population groups [12]. A recent research project encompassing the Netherlands, Germany, Italy, Belgium, Finland and Iceland (Assessing Needs of Care In European Nations) reported that there is low equity in access to home health care services for older people in Italy and Finland [3]. When looking at overall healthcare for older people in Europe, approximately 50-75% of all formal long-term care is delivered at home [3]. There are major differences in how care is subsidized, organized and delivered. This is similar for dementia-specific care. The recent 'European Dementia Monitor' showed differences on a financial, organizational and practical level across Europe regarding access to dementia care and treatment leading to inequality [13]. Reports from WHO [14] and Alzheimer's Disease International (ADI) have shown a great and unequal distribution of dementia care resources worldwide [15]. This emphasizes the importance of identifying factors that can facilitate or hamper access

to formal care. A variety of factors can influence the process of accessing formal care. A model that considers this mix of factors is the Andersen Behavioural Model of Health Service Use. The model identifies predisposing, enabling factors and need factors to explain service use [16], and can indicate inequity in access to care. Predisposing factors include demographic information, such as age or level of education. Enabling factors include variables that either facilitate or hamper access to care such as travelling distance to a care facility or waiting lists. Need factors express the perceived and evaluated need of persons, based on their mental and physical condition.

Using the Andersen model, analyses can indicate inequity in access to care, while controlling for other relevant factors. The actual use of formal care can also be described as realized access [17]. Equitable access is said to occur when need and enabling factors such as disease severity and waiting lists determine realized access. Inequitable access is said to occur if predisposing factors such as gender, social economic status or education contribute significantly to use of formal care, after controlling for need and enabling factors. The Andersen model is widely used in health care research [18], and has for example been used previously to study home care utilization in elderly [19].

In the current European Actifcare study access to care is assessed using the Andersen model. People with dementia and their informal carers from eight European countries (the Netherlands, Germany, United Kingdom, Ireland, Sweden, Norway, Italy and Portugal) were followed for 1 year during which a transition to formal care was considered likely. By means of a set of questionnaires we were able to map a number of predisposing, enabling and need predictors of formal care use. These predictors were investigated to find out whether there is equitable access to dementia-specific formal care services in Europe. Results will identify which specific factors should be a target for interventions to improve access.

Data and methods

Study design and participants

Study data were collected as part of a European prospective cohort study: Access to Timely Formal Care (Actifcare). The design has been described elsewhere in detail [20] [21]. In total 451 dyads of community-dwelling people with dementia and their informal carers are included. Eligibility criteria at entry to the study were: (1) a diagnosis of dementia according to DSM-IV-TR criteria, (2) either a CDR score of 1 (mild dementia) or 2 (moderate dementia) {Holstein, 1975 #21}[22] or an MMSE score lower than 25 [23] (3) an informal carer in contact with the person with dementia at least once a week, (4) a professional judgement that additional assistance with personal care is likely within one year, (5) no terminal condition or comorbidities, and (6) no care home or nursing home residence within the last 6 months. At baseline, the participants had yet to use formal care support, involving personal care from a paid worker, in relation to the dementia. In the Actifcare cohort study formal care was operationalized as home nursing care, day care services, community or long-term medical

care and social care structures. It did not include day care received solely for social purposes, domestic home help, housekeepers, volunteers, support groups, transport services and meal programs. Written informed consent was obtained from both the person with dementia and the carer according to the national procedure in each country.

Measurements

Measurements were scheduled at baseline (T₀), six (T₁) and twelve (T₂) months. Comprehensive assessments were conducted [20].

The variables in our analyses were divided into three groups according to the Andersen Model: predisposing, enabling and need variables.

Predisposing variables

For both the informal carer and the care recipient, demographic characteristics recorded were age, gender, social economic status and years of education. Social economic status was generated by an occupation coding system with five classes (1= Higher managerial, administrative and professional occupations, 2= Intermediate occupations, 3=Small employers and own account workers, 4=Lower supervisory and technical occupations, 5=Semi-routine and routine occupations. In addition, region of residence was reported, where Norway and Sweden were classified as ' North', while Ireland, United Kingdom, Germany and the Netherlands were ' Middle' regions. Portugal and Italy were classified as ' South'. This classification was based on similarities in health care systems and culture.

Enabling variables

Informal care was reflected by the number of informal carers and the number of hours spent on informal care by the main carer. Both these variables were derived from the Resource Utilization in Dementia scale (RUD) [24], which is designed to measure informal and formal care use. An important demographic variable that may relate to service use is living situation. Several studies have shown that if a person with dementia lives together with their carer(s), they are less likely to use services [25, 26].

Need variables

Disease severity

To measure disease severity two variables were used: severity of dementia impairment and daily functioning. Severity of dementia impairment was measured with the Clinical Dementia Rating (CDR) [22], where we used the sum of boxes instead of the total score, since the sum of boxes gives a more fine-grained representation of cognition and functioning. It also has an increased range of values, and offers the opportunity to treat the data as interval instead of ordinal variables. In addition the MMSE scale was used, which is a scale with a range from 0-30, where lower scores indicate higher cognitive impairment [27]. To measure daily functioning the Instrumental Activities of Daily Life (IADL) and Physical Self Maintenance Scale (PSMS) [28] were used. The IADL scale consists of 8 items providing information about performance on daily activities such as shopping and handling money. The 6-item PSMS focuses on self care abilities such as washing and walking. For both scales a higher score indicates worse functioning.

Needs

Needs were assessed by the Camberwell Assessment of Need for the Elderly (CANE), which is a semi-structured interview tool concerning (un)met needs in 24 areas. Needs in medical, psychological and social areas are covered in the questions. In this study, the scale was rated using both the perspective of the person with dementia and the informal carer, as well as the interpretation by the researcher while keeping in mind the different opinions that were gathered. A need was considered met if it is provided for, either by informal or formal care [29]. In this study, we used the number of met and the number of unmet needs rated by the researcher.

Behavioural problems

Behavioural problems were assessed with the short version of the Neuropsychiatric Inventory Questionnaire (NPI-Q), which is a structured interview tool. Information on 12 neuropsychiatric symptoms was gathered; delusions, hallucinations, agitation/aggression, dysphoria, anxiety, euphoria, apathy, disinhibition, irritability/lability, aberrant motor behaviour, night time behaviour disturbances and eating abnormalities. Higher scores indicate the presence of more behavioural symptoms.

Service use

Service use was administered with a specifically for this study constructed service use checklist, which consisted of approximately 22-26 items (differed by availability per country). Usage of each service was recorded at each assessment point. Four clusters of formal care services were created in which a distinction was made between services which provided support for the person with dementia and carer at home, but which were focused on

providing company and activity (social activities), and those services providing personal care e.g. help with washing and dressing for the person with dementia at home. The clusters were: 1) help at home (social), 2) help at home (personal care), 3) day care, 4) admission to nursing home, care home, long-term admission to hospital due to dementia. Next, we dichotomized usage on each cluster as positive if any of the services within a cluster at any of the two follow-up time points was utilized.

Statistical analyses

Group characteristics were described using descriptive statistics. Logistic regression analyses were carried out with each of the four clusters of service use as dependent variable (home social care, home personal care, day care, admission). The independent variables were added to the regression in blocks: firstly, a block with all needs variables, secondly a block with enabling variables, and lastly a block with predisposing variables. This method is commonly used in analyses based on the Andersen model. Within each block, backward regression was used to keep all variables with $p \leq 0.10$, before continuing with the next block.

Results

Table 1: Characteristics at baseline grouped according to Andersen's behavioural model
(n= 451)

Predisposing variables	
PwD male (n, %)	207 (46)
PwD age (mean, SD)	77.8 (7.9)
Range	[47-92]
PwD education (mean years, SD)	9.8 (4.5)
PwD Social economic status (n, %)	Class 1: 109(24) Class 2: 62 (14) Class 3: 48 (10) Class 4: 28 (6) Class 5: 126 (28) Missing: 84 (18)
Dementia type (n, %)	
Alzheimer's Disease	218 (49)
Vascular dementia	52 (11)
Mixed dementia	56 (12)
Lewy body dementia	6 (1)
Unknown/Other	117 (27)
IC male (n,%)	151 (33)
IC age (mean, SD)	66.4 (13.2)
Range	[25-92]
IC education (mean years, SD)	11.9 (4.4)
IC Social economic status (n,%)	Class 1: 99 (22) Class 2: 60 (13) Class 3: 41 (9) Class 4: 6 (1) Class 5: 55 (12) Missing: 196 (43)
Region (n, %)	
North	110 (24)
Middle	222 (48)
South	119 (26)

Table continues on the next page

Enabling factors	
Living alone (n, %)	127 (28)
Number of informal carers (mean, SD)	1.1 (1.2)
Hours of informal care per month (mean, SD, range)	98.9 (93.2) 0-570
Need factors	
CDR sum of boxes (mean, range)	7.1 (2-16)
MMSE score 0-30 (mean, SD)	19 (4.9)
CANE unmet needs (mean, range)	1.87 (0-17)
CANE met needs (mean, range)	8.2 (0-19)
NPI (mean, range)	7.8 (0-30)

Pwd= person with dementia, IC= informal carer, CDR = clinical dementia rating, MMSE= mini mental state examination, CANE= Camberwell assessment of need for the elderly, NPI = Neuropsychiatric Inventory

A total of 451 dyads participated in the study. The group characteristics are summarized in Table 1. Among the people with dementia 48% were diagnosed with Alzheimer's Disease. The majority (78%) had a CDR score of 1. The percentages of service use uptake can be found in table 2.

Table 2: numbers and percentages of service use uptake for each care cluster

	Service use at either follow-up
Home social care	33 (8.3%)
Home personal care	51 (11.3%)
Day care	42 (9.3%)
Admission	50 (11.1%)

Predictors of home social care at T1 or T2 are presented in table 3. A higher CDR score, a higher sum of met needs, more hours spent on informal care at baseline and living alone at baseline significantly predicted the use of home social care at T1 or T2. None of the predisposing variables added significantly to the prediction.

Table 3: Significant baseline predictors of home social care at T1 or T2 in backward logistic regression

Block	Variable	B
Needs	CDR	1.13 (1.01-1.27)**
	Met needs	1.12 (1.02-1.23)**
Enabling	Living together	.44 (.23-.85)**
	IC hours	1.01 (1.00-1.01)*

CDR = clinical dementia rating, IC= informal carer. Odd's Ratio (lower CI-upper CI 95%), *p-value<0.01, ** p-value < 0.05

Predictors of home personal care at T1 or T2 are presented in table 4. A higher CDR score, a higher sum of unmet needs, more hours spent on informal care at baseline and living alone at baseline significantly predicted the use of home personal care at T1 or T2. The predisposing variable age of the person with dementia was significantly associated with service uptake in a positive direction. In addition, living in the North of Europe is significantly associated with the use of home personal care, in comparison to living in the South.

Table 4: Significant predictors of home personal care at T1 or T2 in backward logistic regression

Block	Variable	B
Needs	CDR	1.16 (1.04-1.29)**
	Unmet needs	1.25 (1.09-1.42)*
Enabling	Living together	.29 (.16-.52)*
	IC hours	1.00(1.00-1.01)**
Predisposing	Pwd age	1.07 (1.00-1.14)**
	Region South vs North	.13 (.03-.66)**

CDR = clinical dementia rating, IC= informal carer, Pwd= person with dementia. Odd's Ratio (lower CI-upper CI 95%),*p-value<0.01, ** p-value < 0.05

For day care, a higher sum of met needs, living alone at baseline and being a female informal carer predicts use at T1 or T2 (see table 5). In addition, living in the North of Europe is significantly associated with the use of day care, in comparison to living in the South or the Middle.

Table 5: Significant predictors of day care at T1 or T2 in backward logistic regression

Block	Variable	B
Needs	Met needs	1.13 (1.05-1.22)**
Enabling	Living together	.51 (.30-.87)**
Predisposing	Gender IC (being female)	5.1 (1.27-20.79)**
	Region South vs North	.06 (.01-.30)*
	Region Middle vs North	.53 (.16-.77)**

IC= informal carer. Odd's Ratio (lower CI-upper CI 95%), *p-value<0.01, ** p-value < 0.05

As shown in table 6, a higher CDR score, more hours spent on informal care at baseline and being a male person with dementia significantly predict admission to a nursing home, care home, long-term admission to hospital due to dementia at T1 or T2. Living in the North of Europe is significantly associated with admission, in comparison to living in the South or the Middle.

Table 6: Significant predictors of admission at T1 or T2 in backward logistic regression

Block	Variable	B
Needs	CDR	1.25 (1.12-1.41)*
Enabling	IC hours	1.00 (1.00-1.01)**
Predisposing	Gender pwd (being female)	.17 (.04-.70)**
	Region South vs North	.18 (.04-.91)**
	Region Middle vs North	.37 (.16-.89)**

CDR = clinical dementia rating, IC= informal carer, Pwd= person with dementia. Odd's Ratio (lower CI-upper CI 95%), *p-value<0.01, ** p-value < 0.05

Discussion

This study examines factors associated with access to formal care for people with dementia and their informal carers, based on the Andersen's framework, which can be used to determine equity regarding access to care. The longitudinal study design allowed us to investigate a variety of factors in relation to service use uptake after one year in a group who had yet to use formal dementia care at baseline, but who were anticipated to do so within that year. According to the Andersen model, access to care is considered equitable if it is predicted by enabling and need factors, and not by predisposing factors [17]. In our cohort, the major predictors for service use were indeed need factors, namely met or unmet needs as measured by the CANE and disease severity reflected by a higher CDR sum of boxes. This is an indication for equity in access to care.

There were also enabling factors predicting care use in most of the clusters. The first one was a higher number of hours spent by the informal caregiver on care tasks. There are complex interactions between informal and formal care, and studies on this subject are scarce [30]. Previous studies have shown that spousal caregivers often express reluctance to start using formal care because they perceive their tasks as a moral obligation [31]. Previous studies have found comparable results, with associations between a higher amount of caregiving hours and subsequent institutionalisation [6]. A logical explanation here could be that a more hours spent indicates a necessity for more care due to disease severity. This seems to be in line with a review investigating the burden of caregivers of people with dementia, which reported that objective burden significantly increases with growing disease severity [32].

The enabling factor 'living alone' predicted three subtypes of care (home social care, home personal care and day care), which is in line with previous research [33], where people with dementia who were living alone were more likely to receive home help with everyday tasks and meals on wheels. In absence of an informal caregiver living with the person with dementia, the need for help might be more urgent. 'Living alone' was not a predictor for admission due to dementia in our cohort, which is not in line with previous studies [34, 35]. A possible explanation for this is that the percentage of people who were admitted to a nursing/ care home in our cohort is rather low, since the follow-up period was only one year. The fact that both 'living alone' and 'more hours spent on informal care' significantly predicted the majority of care clusters is remarkable, as they seemingly contradict each other. The latter is much more likely to occur in a co-habiting scenario. Apparently, there seem to be two different pathways that can lead to breakdown of care at home. On the one hand the absence of an informal carer can lead to the necessity of formal care, while on the other hand formal care can be needed to supplement informal care if disease severity increases. There were also predisposing factors significantly predicting access to subtypes of care. A higher age of the person with dementia was related to home personal care uptake. This might partly be explained by the fact that frailty increases with age and dependence and

the need for support with self-care increases accordingly [36]. Although we asked about services related to the person's dementia, the complexity of interactions between cognitive and physical impairment makes it difficult to delineate services that are intended to meet needs arising from co-morbid physical health problems from those arising from dementia. In addition, this finding might reflect a difficulty in finding a way to care for older people.

Day care was started earlier where there was a female primary caregiver and admission was used earlier when the person with dementia was male. Our results are consistent with a systematic review by Luppá et al. which found that being a male PwD is a predictor for institutionalization [6]. However, in a different review no significant gender differences were found [34]. It is therefore difficult to find an explanation for these results without taking into account the whole range of variables that may differ between studies.

As the Andersen model states, it is undesirable that predisposing factors predict care use, as they cannot be subject to change. Gender and age do seem to play a role in equitable access to care, but the explanatory mechanism for this deserves further attention. The predisposing factors education and social economic status were not hindering or facilitating access to dementia care in this cohort. This is not in line with recent findings, in which a clear difference between countries was established in (amongst others) availability and affordability of care. In a large study into medical care, inequity was found in nearly half of the Economic Cooperation and Development (OECD) countries. This was the case for visits to a physician, where richer patients found easier access to care, especially in Mexico, the US, Finland, Portugal and Sweden [37]. In addition, people with a higher social economic status were more likely to visit a specialist. The fact that we did not find inequity due to social economic status might be because we focused solely on dementia care and on countries that are all part of Western Europe. In addition, this finding could be partly explained by the relation between region and social economic status.

Lastly, we studied the effect of region of residence in this cohort. People with dementia who were living in the North of Europe find easier access to care, which is in line with previous findings. Recently, in 'The European Dementia Monitor', the highest ranked country was also a Northern European country, namely Finland. Shortly after Finland, the Middle European countries followed (United Kingdom, the Netherlands and Germany) [13]. In a different study, Southern European countries had a 5.0-fold lower chance of complementing informal with formal care. The authors suggested that culture (including the representation of family caregiving as a moral obligation) likely played a role in their results. In addition they found that people from Denmark or the Netherlands have a 2.4-fold greater chance of complementing informal with formal care in contrast to other Middle European countries [31]. This might partly be explained by the larger availability of care in Northern versus Southern countries [38].

The Andersen model is useful, but the accompanying analyses bring along limitations. In future studies additions can be made to the model e.g. in terms of additional factors or interactions in order to reveal the complex pathways of access to care. A limitation of this study is that the follow-up period was relatively short, which likely led to a low proportion of service uptake. We are now extending the follow-up period to assess more closely at when care transitions take place and which factors predict these transitions.

For this cohort, the Andersen model provided the insight that besides need factors the predisposing factors region of residence, gender and age do play a role in finding access to care. In addition, it showed us that more hours spent on informal care, living alone, needs and disease severity are important predictors. Health care professionals should pay attention to these predisposing factors to ensure that these do not act as barriers for those in need for care.

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Optimizing access to care: qualitative findings
from the Actifcare study

| 5

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Abstract

Objectives: This paper reports on qualitative data from the Actifcare study investigating experiences, attitudes, barriers and facilitators concerning access to and use of formal care.

Methods: A total of 85 semi-structured in-depth interviews were conducted in eight European countries. Results were analysed with a deductive content analysis, first within country, and then integrated in a cross-national analysis.

Results: Overall, analysis of the in-depth interviews revealed two major themes with five subcategories. The results can be summarized in an optimal pathway for access to dementia care. This pathway includes fixed factors such as disease-related factors and system-related factors. In addition there are personal factors that are subject to change such as attitudes towards care. An important finding consisted of the necessity of having sufficient information about the disease and available care, and having a key contact person to guide you through the process of finding suitable care while monitoring your needs. In addition, it is important to involve your social network as they can take on caregiving tasks. It is helpful to have a diagnosis (in most countries). Concerning decision-making, the person closest to the person with dementia is in the majority of cases the one who makes the ultimate decision to access and use services and he/she should therefore be supported in this process.

Conclusion: These results provide insight into the factors that influence the pathway to formal care use, and help professionals to enhance access to formal dementia care by focusing on factors that can be modified.

Introduction

Dementia is a progressive syndrome, with symptoms affecting cognition, behaviour, and the ability to carry out activities of daily living. As the disease progresses an increasing amount of care is needed. In current society the use of home care for people with dementia is encouraged. In an ideal situation for society, needs would first be covered by informal care, until formal community services become necessary [2], and it will then complement informal care. There are several services that can be offered at home, such as help with personal care, day care, or nursing care. These types of services are considered formal care services. Regarding access to care, barriers have been defined in different ways [3]. They can be structural, relational, psychological or cultural. Structural barriers concern the characteristics of services, such as organization, location or type. Relational barriers are concerned with interpersonal factors, such as difficulties in communication or conflicts within the family, while psychological barriers are concerned with intrapersonal factors, such as attitudes or psychological processes. Cultural barriers encompass social attitudes, as well as norms and values shared by a community or group [3].

Previous research has shown that people often do not use the amount and type of services that they objectively need [4]. Different barriers have been described, but peculiarly, many carers mention that they do not use services because they simply feel it is not necessary [3]. This is however often regretted in later stages, where carers indicate that they would now prefer to have used services in an earlier stage, also known as the early stage needs paradox [5]. Another reason for non-use is experiencing difficulties in accessing suitable services. People trying to access formal care experience this process as difficult and time-consuming [6]. Informal carers express the need for better advice and support in this process of accessing formal care. In a society where it is encouraged to live in the community as long as possible, it is important that there are as few barriers as possible in accessing care.

The Actifcare study (ACcess to Timely Formal Care) focused on access to home- and community-based dementia care, for people in the middle stages of dementia. Various research methods were used, such as literature reviews, focus groups, expert interviews, cost-consequence analyses and a cohort study [7]. The current individual interviews with people with dementia and their informal carers build on the results of the cohort study and of the focus groups [8] and aim to provide a more detailed and in-depth insight into people's motives, experiences and considerations towards access to care in an explorative manner. To cover a broad spectrum of experiences a sample was selected in which some had accessed services and some had not. Accordingly we aim to describe in more detail the optimal circumstances for timely access to care.

Methods

As part of the Actifcare project qualitative in-depth interviews were conducted in eight European countries. This study has been described elsewhere in detail [7] [9]. The Actifcare cohort consists of 451 community-dwelling dyads of people with middle-stage dementia (mean age: 77.8, mean Mini Mental State Examination (MMSE) score: 19 and their informal carers (mean age: 66.4). At baseline, the dyads did not use formal care yet, but they were expected, based on clinical judgement, to start using formal care within the next year. The complete in- and exclusion criteria are described in the design paper [7]. The definition of formal care used in Actifcare includes home nursing care, day care service, community or long-term medical care, nursing and social care structures. It excludes domestic home help, housekeepers, volunteers, support groups, transport services and meal programs. In the quantitative part of the study data were collected about service use, needs, quality of life and various other variables at baseline, six months and twelve months follow-up.

Study participants

In each country the research group was asked to select ten dyads, as we aimed to include N=80 interviews in total. A purposive sampling selection procedure was used, to ensure a diverse sample regarding care use, gender, age and education. Half of the sample represented people who started using formal care, and half of the sample did not start using formal care (yet). Interviewing both these groups allowed us to include a broad range of attitudes, opinions and experiences.

Procedure

The interviews took place after the last follow-up (12 months) assessment. The semi-structured interviews were conducted either at the researchers' site or at the participants' home, depending on what was preferred by the participants. All interviews were audio recorded and transcribed verbatim for analysis purposes. Interviewers were members of the Actifcare research group of each country, who were acquainted with the participants due to previous assessments in the cohort study. Their backgrounds are amongst others research nurses, psychologists or physicians.

Interview guide

The German research group developed an interview guide (see Appendix 1) in close cooperation with all partners. The interview guide was built upon the outcomes of the focus groups conducted earlier in the project with people with dementia, informal carers, and healthcare professionals [8]. The interview topics were attitudes towards services, care and personal experienced facilitators and barriers to access. Specific questions were formulated based on the outcomes of the focus group analyses that showed that ‘Receiving the diagnosis’, ‘Attitudes towards formal care’, ‘Tension between independence and acceptance of care’, ‘Exchanging views within the family’, and ‘Cooperation with health care professionals’ were important and deserved further exploration in the individual interviews.

Data analysis

First, each country transcribed their own interviews verbatim and analysed them following a deductive qualitative content analysis method. Each country reported their themes, categories and quotes translated to English. Second, the Dutch research group carried out a cross-national comparison of these translated documents, to reveal differences and similarities across the findings. Each country then carefully checked this analysis to guarantee that no information was misinterpreted. Throughout this process all national research groups collaborated closely.

Results

Participants

A total of 85 in-depth interviews were conducted between January and July 2016 (see table 1). In the majority of the interviews informal carers participated on their own; in some of the interviews the person with dementia also participated, depending on their own wish. Some of the interviews were carried out with only the person with dementia. The interviews lasted on average 35,8 minutes. The mean age of the interviewed people with dementia was 79.1 and of the informal carers 66.2. Of the people with dementia 44% were male, while 28.6 % of the informal carers were male. The dyad relations were as follows: 60.7 spouse or partner, 35.7% child and 3.6% other relatives.

Table 1: number of interviews

Country	NL	DE	UK	SE	NO	IE	IT	PT
Total # dyads	10	11	10	10	10	10	12	12

Overall, analysis of the in-depth interviews revealed two major themes with five subcategories. These categories are visualized in a pathway showing optimal access to care, as depicted in figure 1. In the following paragraphs the categories are described in-depth with accompanying illustrating quotes. Each quote is labelled with a code referring to the country (NL=the Netherlands, DE=Germany, UK= United Kingdom, IE= Ireland, NW= Norway, SE=Sweden, PT= Portugal, IT=Italy), and it states whether the quote derived from a (non)-formal care user.

Theme 1) Conditions to enhance access:

- 1) Personal
- 2) Diagnosis & post-diagnostic support
- 3) System/process

Theme 2) Decision-making

- 1) Decisional conflicts
- 2) Involvement of others

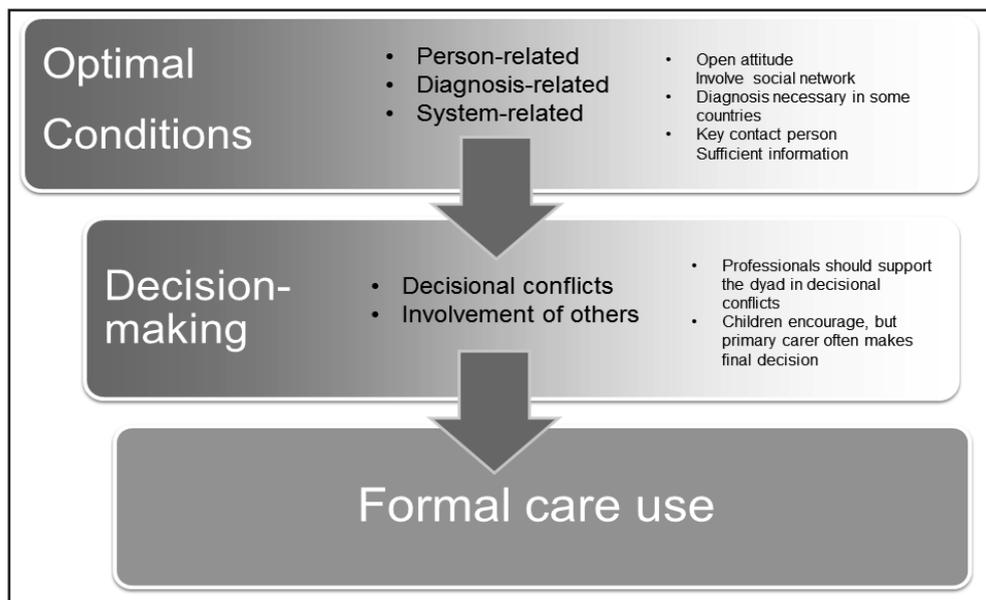


Figure 1: An optimal pathway for finding access to care

The results can be summarized in a pathway, representing the optimal conditions for access to care. Overall, there are fixed factors that cannot be changed, such as disease-related factors and system-related factors. In addition, there are personal factors that are subject to change such as attitudes. To enhance optimal access to care, the most important factors are described below.

Theme 1) Conditions to enhance access: Personal factors

Attitude and need for care

The majority of the carers reported having an open attitude towards receiving care, as long as the request for care is 'justified', and care is appropriate for the perceived need. Those who did not yet use formal care indicated that changes in health of either themselves or the person with dementia would be a reason to start using care.

Having an open attitude functions as a facilitator in accessing formal care. Carers reported that a good insight into the disease fosters an open attitude. There might be some initial embarrassment in relation to personal care. This was mainly related to the influence on privacy. Only a few participants reported a feeling of shame.

"It is a privilege; I see it as a privilege that you can receive care. You have to accept it in my opinion and don't think: I can do this all on my own, because at some point you cannot do that anymore. It might work for two weeks, but no longer." (NL, Formal care use, Carer)

Using a certain type of care might make it easier to accept other types of care, as a gradual build up is reported as helpful. For instance, if people made use of meals on wheels services, the threshold to start using personal care, for example, was lowered.

In the post-diagnostic period carers felt that accepting services at an early stage would have a negative impact on the person with dementia's independence and self-esteem. However, independence might also be enhanced because of socialization and increased motivation through engagement in activities. For carers the use of formal care could enhance their independence, giving more time for their personal activities and social life.

Besides (changes in) attitudes, other reasons to start using formal care were reported in relation to an increase in disease severity or occurrence of crisis situation. Alleviating strain and carer burden was mentioned often, as well as the feeling of 'now it is necessary', and therefore it is justified.

"What I think is important is that the request is justified, I have a reason to ask for this, if there is the chance to have it, it is welcomed." (IT, Formal care use, Person with dementia)

Other reasons to postpone the use of care were the person with dementia refusing formal care, not being emotionally ready as a carer, or experiencing a sense of guilt or shame towards the person you are caring for, since you have to admit that you can not provide all care alone. The main reason that came forward was that as a carer, you try to maintain autonomy and do not want to resign your care tasks (IE, NL, NO, SE, PT). Some carers indicated that only now that care was in place, they realized how they themselves were

struggling to manage caring for the person even when they had initially felt reluctant to accept support. Another reason to postpone care was the availability of a large social network and therefore plenty of people to turn to for help (IE, NL). Several carers underscore that because of their good health and ability to help they did not need assistance yet.

“I’d like to do it alone for as long as I can. This is important for my husband too, because I’m the key contact person for him.” (DE, No formal care use, Carer)

Theme 1) Conditions to enhance access: Diagnosis & post-diagnostic support

Overall, there were ambiguous responses concerning this topic within and between countries. Some carers said that it is not necessary to have a diagnosis to access care (DE, NO, NL, SE, IT). In PT one carer even suggested that having a diagnosis would impede access to day care or nursing homes.

“I felt that the diagnosis would have been an exclusion criteria.” (PT, Formal care use, Carer)

Some carers thought that a diagnosis would be a precondition for receiving care (IT, DE, IE, NO, SE). Even if it might not be a precondition, it served sometimes as a facilitator, as it provides you with an incentive to look for help.

In some countries carers mentioned that care was offered immediately after the diagnosis (NL, NO, UK), in either a direct way or an indirect way in offering help when this will be necessary. There was however no structured approach in which information or care was offered, while carers indicated that good information post-diagnosis could postpone the need for care. Some participants stated that they were guided towards post-diagnostic care by health and social care professionals. Other participants indicated that they did not receive any practical advice following the diagnosis that would have helped them, and reported that advice was now merely focused on medical needs.

“In this disease, no one cares to support the family. The carer does not exist. The neurologist only told me that this tends to get worse and worse [referring to the dementia progression]. Besides medication, the doctor said there was nothing else to do (...).” (IT, No formal care use, Carer)

“Nobody sort of sat you down and said, “Well this is what’s going to happen.” No, I didn’t find him (General Practitioner) helpful.” (IE, No formal care use, Carer)

THEME 1) Conditions to enhance access: System-related factors

Barriers and facilitators

Overall, the most often reported barrier was a lack of knowledge and information. Adequate information about dementia and about available resources is necessary. Carers indicated that it is essential that you search pro-actively yourself if insufficient information is provided.

“There would be a huge crowd of us that would much prefer to see a simple little leaflet put in the bag and find it there that night, not think well I must turn on the computer and remember what button to press to get into dementia.” (IE, No formal care use, Person with dementia)

“I missed a list where I could find exactly written which services I could have had access to.” (IT, Formal care use, Carer)

Having an assigned key contact person who you can approach for questions and concerns was mentioned as an important facilitator. It was reported that it is confusing if there are too many different professionals involved, and that knowing whom to turn to is a relief.

“These people keep coming and ringing up- I’m getting confused. So many people ringing you, I get confused about who I’m talking to sometimes.” (UK, Formal care use, Carer)

Other important characteristics of health care professionals were that they should be easy to reach and have dementia-specific skills and knowledge. Where they do not have the skills or knowledge to cope with a certain situation, it is important that they are able to refer adequately. If services are not tailored to the individual’s situation, this is experienced as a barrier and could lead to rejection of further use of formal care. Everyone has different backgrounds and individual preferences so e.g. day care programs that are well suited for older people may not be suited for people with young onset dementia. Day care should also fit one’s interests. Carers indicate that it is helpful to have a sense of control over the timing and nature of the help you receive, for example being able to indicate the timeslots during the week that are best suited. It is also helpful when formal care is gradually built up so people can get used to it. Another reported barrier in some countries was costs: a lack of financial support would lead to non-use of services. People are often entitled to receiving financial compensation for services but they are unaware of this.

“We did not access other care services besides day center because it was very expensive.” (PT, Formal care use, Carer)

THEME 2) Decision-making: Decisional conflicts

The majority of carers indicated that the involvement of the person with dementia in the decision-making process concerning care use depends on levels of awareness of difficulties. If the person with dementia lacked awareness, it was difficult for the carer to ignore their reluctance: most carers indicated they would consult with the person with dementia and never force them to accept an offer of provision of formal care if they did not want to. Caregivers often experienced difficulties in exchanging views with the person with dementia on care needs due to communication difficulties. Several 'solutions' to be able to discuss the need for care came forward; the one that was named most often was 'telling little white lies', and motivating or convincing.

"We did say to him, "you're going to a special hotel where they'll help you get well"; perhaps that was not being honest but I think it helped him." (UK, Formal care use, Carer)

THEME 2) Decision-making: Involvement of others

For a significant number of participating dyads other family members are involved in the decision-making process regarding the use of formal care. Children are often the ones who encourage their parents to look for help in the first place and offer emotional and practical support. Formal care use is facilitated when children who are consulted have similar views regarding care. Decisions to take up formal care were however often made by the dyad prior to consultation with the children. On the other hand, some carers do not wish to involve their children in the caregiving process and decisions about the situation of care. In this regard the carer that is closest to the person with dementia is the most important one in the decision-making process.

"At the present time, my mother is the one who has the last word since she is the one who lives with dad." (IT, No formal care use, Carer)

Discussion

For this qualitative study, interviews were conducted with people with dementia and their carers, to explore their attitudes and experiences concerning access to formal care. The results indicate a complex interplay of factors in the process of finding access to care including personal, diagnosis-related, system-related and relational factors. It is important to receive sufficient information, to have a key contact person who guides you in the process of finding and accessing formal care, to have an open attitude, and to be supported in the decision-making process as it is difficult for the primary carer to deal with this on his/her own. These factors can be summarized in an optimal pathway for access to care.

Theme 1: Conditions to enhance access

Concerning personal factors, it is helpful to have an open attitude towards formal care, and to feel that it is justified to make use of formal care services. The latter might be related to a lack of understanding of how different services suit different stages of dementia, which makes service use feel unjustified. This finding supports previous research, where stigmatic beliefs and feelings of shame regarding using services were reported as potential barriers [10]. In the current sample, few people reported a shameful attitude, which might however have been due to our sample. Those who are willing to participate in research and share their views are less likely to express shame. Focus groups that were previously conducted within the Actifcare study revealed that people with dementia still experience stigma related to dementia, and that they perceived receiving formal care as a threat to their independence rather than as a measure to maintain independence and support living at home. This was reported as one of the reasons to postpone formal care [8]. In the current in-depth interviews participants were asked whether formal care influences the ability to stay independent, but the answers remained unclear and ambiguous. Overall, it should be clarified that there are a wide range of services, and that some can be geared towards the earlier post-diagnostic stages (these enhance independence and autonomy) while others are more suited to later stages of the condition and if introduced too early, they could create excess disability. In addition, governments and local institutions should pay attention to reducing stigma by increasing awareness with, for example, awareness campaigns and promotion of dementia friendly communities.

In most countries interviewees reported that it is helpful to have a dementia diagnosis while trying to access care. However, in Portugal the feeling was reported that a diagnosis might also impede the access, and it was sometimes concealed while applying for care. This specific barrier may be related to a lack of dementia-specific community formal services, and of staff that is trained specifically for dementia care. The country of residence therefore determines if a dementia diagnosis is necessary for accessing care. Nevertheless, participants reported that having a diagnosis does provide an incentive to seek help.

The results showed that having a key contact person to guide and support those living with dementia is very helpful. This supports previous research, where a specific contact person was identified as a marker of best practice [11] ([12] [8]). Another crucial element to optimize access to care is to receive adequate information about dementia and about available resources immediately after the diagnosis. This has also been well established in previous research: providing information post-diagnosis can delay institutionalization [11] and serves as a facilitator in help-seeking [10] [13]. Families should also be made aware of any financial assistance that may be available in each country, as expected high costs can serve as a barrier in decision-making about care. Carers advised that it was important to be pro-active in

looking for information and services. Being more pro-active might however be more difficult for the current older generation, as (online) information may be difficult to access for them. Participants expressed the wish that health care professionals should have dementia-specific knowledge and skills. Jansen et al. found that home care providers themselves reported the importance of dementia-training and certificates, as this would lead to higher-quality care and higher retention rates of personnel [12]. If health care professionals do not possess the necessary skills or knowledge, it is important to refer adequately.

We found that it is important to involve your social network, as they can assist with care tasks. Previous research has shown that informal carers often feel reluctant to ask their social network for support [14]. Health care professionals should pay attention to help carers to motivate and mobilize their social network and decrease barriers to ask for support, for example through family meetings.

Theme 2: Decision-making

Concerning decision-making, we found that involvement of others beyond the immediate dyad was helpful in some instances, but was not a major influence. Children often play an encouraging role, trying to persuade the parents to take up services. The person closest to the person with dementia is the most important one in decision-making; this person is often the partner or spouse. Decision-making is often gradually taken over, from everyday small decisions to major decisions concerning e.g. service use [15]. As cognitive functioning decreases, there is a shift for informal carers from supported or shared decision-making to substitute decision-making [16]: this is a gradual process. A phenomenological study found that all participating dyads shifted to a state of substitute decision-making, but in most cases they tried to maintain the autonomy of the person with dementia for as long as possible [15]. Since this is a complex process that should be attended with care, healthcare professionals should be equipped to support the person closest to the person with dementia and to be a mediator between the carer and the person with dementia.

The main outcome of a previous focus group study was that needs of the person with dementia and the informal caregivers should be balanced, a so-called dyadic focus. On the caregivers' side there is a need for support and knowledge, while on the person with dementia's side one should take the need for integrity into account [11]. It is important that people with dementia retain a sense of autonomy by being able to participate in everyday decisions [16]. This can for example be established with shared decision-making, where all individual needs are taken into account. These situations become most complex if the person with dementia refuses care due to a lack of awareness; it is then important that the carer is supported by a health care professional that understands these fragile processes. These professionals could benefit from training in motivational interviewing, which is an interaction-method aimed at assisting behavioural change. The goal of motivational interviewing is to ensure that intrinsic motivation is increased in order for behavioural change to

come from within as opposed to extrinsically [17, 18]. This method is already widely used in relation to other diseases (alcohol and drug abuse, diabetes, overall treatment adherence) [17] and could be useful in relation to formal care decision-making as well, as the motivation to start using formal care should come from within.

There are some methodological strengths and limitations to be discussed. Within the Actifcare cohort we were able to interview an international and diverse group, which enabled us to compare experiences across countries. Another strength of this design is that in the majority of the interviews the person with dementia was also included, in addition to the informal caregiver. The interview questions were based on the outcomes of previously held focus groups, to ensure current relevance of each topic. One of the methodological limitations is that it was not possible to interview until data saturation was reached. A sample size of 10 per country was defined 'a priori' to take into account time restrictions and schedules. In addition, we were not in all cases able to interview the dyad both together and separately, and we do feel that in some cases participants did not speak freely while being interviewed together.

Clinical implications

These results have several clinical implications. Health care professionals should pay attention to factors that are modifiable during the process of finding access to care. In addition, tailored advice should be given, and health care professionals should act as a mediator in dyads' decision-making process, and support them with techniques such as motivational interviewing and family meetings.

Conclusion

Based on the outcomes of 85 in-depth interviews across Europe we summarize the factors for optimal access to care in a positive pathway. Results showed the importance of having an open attitude regarding dementia care services, to be informed sufficiently regarding dementia and care options and to have a key contact person who is easy to reach and guides people with dementia and their carers during the disease process while monitoring the different needs. In addition, it is important to involve and mobilize one's social network as this decreases the necessity for formal care. In most countries it was helpful to have a diagnosis. A lack of financial support, not knowing one's rights concerning financial compensation, and services that are not tailored to one's needs were amongst others mentioned as barriers. Children often encourage taking steps towards care, but the primary carer (often partner/spouse) often makes the final decision. Health care professionals should support the dyad in decision-making and with decisional conflicts. This study provided in-depth insight into people's motives, experiences and considerations with regard to access to dementia care that can help health care professionals and policy makers to optimize timely access to care across Europe.

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Appendix 1: Interview guide

The following themes are based on the findings of the focus group interviews. They have been developed by the German working group.

A: Receiving the diagnosis

Introduction: you received a dementia diagnosis: that must have been an emotional and difficult time. We are interested if this diagnosis has ‘helped’ you as well, namely with finding access to care.

Has/ have initiated formal care	Has/ have NOT initiated formal care
<p><u>Main question</u></p> <p>A1. Did receiving a dementia diagnosis influence the process of access to care?</p>	
<p><u>Questions (for further exploration)</u></p> <p>A1.1 Was disclosure/receiving of the diagnosis followed by guidance or support?</p> <p>A1.2 Were you satisfied or dissatisfied with this situation (i.e. with (not) receiving guidance or support after the diagnosis) ?(please elaborate).</p> <p>A1.3 Do you think a dementia diagnosis is necessary for access to formal dementia care?</p>	<p><u>Questions (for further exploration)</u></p> <p>A1.1 Was disclosure/receiving of the diagnosis followed by guidance or support?</p> <p>A1.2 Were you satisfied or dissatisfied with this situation (i.e. with (not) receiving guidance or support after the diagnosis) ?(please elaborate).</p> <p>A1.3 Do you think a dementia diagnosis is necessary for access to formal dementia care?</p>

B and C: Attitude towards formal care (meaning of formal care)

Introduction: we are interested in your experiences with regard to asking for and receiving care.

Has/ have initiated formal care	Has/ have NOT initiated formal care
<p><u>Main question</u></p> <p><i>B1. What is your attitude towards receiving (formal) dementia care or asking for it? (we are interested in both opinions of pwd and carer).</i></p> <p><i>B1.1 Do you feel embarrassed/have scruples or is it easy for you?</i></p> <p><u>Questions (for further exploration)</u></p> <p><i>B2.1 How do you feel that you (pwd) / your husband/wife is using (fill out this information based on FU2)? Explore opinions / reasons!</i></p> <p><i>B2.2 How do you feel about other people knowing that you make use of formal care?</i></p>	<p><u>Main question</u></p> <p><i>B1. What is your attitude towards receiving (formal) dementia care or asking for it? (we are interested in both opinions of pwd and carer).</i></p> <p><i>B2.3 Have you considered a time in the future where you would start using care, (and what would make the difference?)</i></p> <p><i>What type of circumstances can you imagine which would lead to service use in the future?</i></p>
Has/ have initiated formal care	Has/ have NOT initiated formal care
<p><i>C1.1 Does it influence your ability to stay independent?</i></p> <p><u>Questions (for further exploration)</u></p> <p><i>C1.1 Did you experience formal care as a limitation or as an enhancement of your independence?</i></p>	<p><i>C1.1 Would receiving services influence your ability to stay independent?</i></p>

D: Exchanging views within the family - Influence on joint decision making?

Has/ have initiated formal care	Has/ have NOT initiated formal care
<p><u>Main question</u></p> <p>D1. Do you (carer and PwD) share similar views on initiating or accepting help?(explore what these views are)</p> <p><u>Questions (for further exploration)</u></p> <p>D1.1 Is there someone else in the family (e.g. children) who play a role in this decision making?</p> <p>D1.2 Is this a topic that you can easily discuss with each other? (explore!)</p> <p>What does a conversation like this look like, is it emotional, does it take long, who takes the lead, do you need to make an effort to convince the other person?</p> <p>D1.3 How do you deal with dissimilarities?</p>	<p><u>Main question</u></p> <p>D1. Do you (carer and PwD) share similar views on initiating or accepting help?(explore what these views are)</p> <p><u>Questions (for further exploration)</u></p> <p>D1.1 Is there someone else in the family (e.g. children) who play a role in this decision making?</p> <p>D1.2 Is this a topic that you can easily discuss with each other? (explore!)</p> <p>What does a conversation like this look like, is it emotional, does it take long, who takes the lead, do you need to make an effort to convince the other person?</p> <p>D1.3 How do you deal with dissimilarities?</p> <p>D1.4 Was it a joint decision to start using formal care?</p>

E: Cooperation with healthcare professionals (focus on facilitating aspects) joint decision making

Has/ have initiated formal care	Has/ have NOT initiated formal care
<p><u>Main question</u></p> <p><i>E1. How do you experience the cooperation with your health care professionals in the process of access to care? (explore!)</i></p> <p><u>Questions (for further exploration)</u></p> <p><i>E1.1 What difficulties did you experience? Did you miss anything?</i></p> <p><i>E1.2 What helped you or would have helped you in this process?</i></p> <p><i>E1.3 Is there any advice that you would give to the professionals regarding the process of (finding) access to care?</i></p> <p><i>E1.4 Is there any advice you could give to other carers and people with dementia regarding the process of (finding) access to care?</i></p>	<p><i>E1.3 Is there any advice that you would give to the professionals regarding the process of (finding) access to care?</i></p> <p><i>E1.4 Is there any advice you could give to other carers and people with dementia regarding the process of (finding) access to care?</i></p>

Carers' experiences of timely access to and use of dementia care services in eight European countries

| 6

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Submitted

Abstract

Background: Timely access to care services is crucial to support people with dementia and their carers to live well. Understanding experiences of service use and reasons for non-use is of key importance when aiming to support people with dementia and their informal carers as best as possible.

Methods: 390 informal carers of people with dementia completed semi-structured interviews about their experiences of either accessing or not using formal care services in the 'Access to Timely Formal Care' (Actifcare) project. Participant responses were summarised by research teams, using content analysis participant answers were categorised into clusters and frequencies calculated.

Results: 42.3 per cent of participants reported service use and 57.7 per cent reported no service use. For participants using services 72.8 per cent reported timely access and for those not using services 67.2 per cent felt satisfied with this decision. However, 27.2 per cent of those using services reported access at the wrong time and 32.8 per cent not using services reported feeling dissatisfied or mixed feelings about not accessing services. Reasons given for using or not using services included responding to changes, considered need or perceived suitability of services, opportunities for use and practicalities of services. Facilitators and barriers to service use included supportive professionals, speed of the process, participant's proactive attitude, GP help, information, social network support, bureaucracy and finances. Knowing someone in the service was a facilitator, whereas refusal, knowing the care service and communication between services were considered barriers to service use.

Conclusion: To achieve timely support, simplified pathways to use of formal dementia care services are needed for easier understanding. Healthcare professionals can play a key role in increasing awareness and opportunities for service access. More information about services is required and the lack of services tailored towards the psychosocial needs of people with dementia should be addressed.

Introduction

Dementia is considered to be one of the largest global challenges the public health and social care sectors face today [1] and with increasing numbers of informal carers worldwide providing care [2], it is critical that supportive services receive increased priority. A global action plan [3] and increasing numbers of countries developing dementia strategies indicates the international realisation of the growing impact of dementia. As part of the global action plan, the World Health Organisation [3] envisions people with dementia and their carers receiving the care and support they need to be able to lead a life that they feel is meaningful. To achieve this ambition, it is important that we optimise services offering care and support by listening to the perspectives of people with dementia and their informal carers to understand their experiences with these services.

There has been great interest in healthcare service use and factors predicting use for some time. The Andersen behavioural model of health service use is frequently utilised to describe the complex relationship between environmental factors, population characteristics and health behaviours when accounting for use of services [4]. Despite the increase in numbers of people affected, and presumably demand for care services, reports of those services that are available being under-utilised are common, with many barriers that prevent help-seeking for people with dementia having been identified [5] [6-8]. Carers often perceive themselves as managing and therefore “services are not needed”, others are “reluctant to use services” even if they are struggling to manage. Some carers are willing to use services but the “service characteristics” are not suitable for them and many carers simply “do not know about services” [6]. Furthermore, the literature suggests that spouses might be most reluctant to use services [7] or that some carers do not identify themselves as carers [6, 9, 10]; they consider their role part of their duty as a family member and therefore are reluctant to use services [6, 11, 12]. A lack of information was frequently reported as a barrier to service use [13] [11, 14], whereas past positive encounters and supportive professionals providing information and help facilitated service access [11, 14].

Family carers require more information and support [15], especially from their General Practitioners (GP) [16-18], in particular when acknowledging that as the severity of dementia progresses service use is more likely to be required [19]. The literature suggests that carers might be more accepting of services with more flexibility and personalised support [14, 15] and it is recognised that providing access to services tailored to individual needs is essential to support the physical, mental and social demands of a caregiving role [3]. Health care professionals can play an important role in empowering people with dementia and their carers by ensuring that they are aware of what options are available to them [15, 20]. Even when satisfaction with service use is reported, a need remains for clearer care pathways and management to improve appropriate and timely interventions [21].

Often, the timing of service intervention is reactive to a sudden change in the situation of the carer or the person with dementia, which results in a formal care intervention occurring

in a crisis situation [22]. In contrast, formal care interventions in a timely fashion might assist in preventing future crises. To enable a more proactive and needs driven approach to service use, a European research collaboration on the Access to Timely Formal Care (Actifcare) project across Germany (DE), Ireland (IE), Italy (IT), The Netherlands (NL), Norway (NO), Portugal (PT), Sweden (SE), and the United Kingdom (UK) aimed to better understand experiences of service use and explore facilitating factors that enabled service access as well as reasons for not using services for people with dementia and their carers in Europe. This large-scale project employed a mixed methods approach utilising a broad range of research methodology, including the interviews with family carers that form the basis for this report. This study aims to explore timely access of formal care services for people with dementia. The current paper reports the perspectives of carers of people with dementia from the cohort study of the Actifcare project, describing experiences of service (non)-use. We addressed the following specific research question: ‘What experiences do carers of people with dementia have with regard to timely access to formal dementia care services, and what were their views on facilitators/ barriers to use of services?’

Methods

Sample

Participants in the Actifcare project were people meeting the diagnostic criteria for dementia outlined by the DSM IV TR, with a Clinical Dementia Rating (CDR) score of one or two or a Mini-Mental State Examination (MMSE) score ≤ 24 indicating mild to moderate dementia. For each person with dementia an informal carer participated, who had contact with the person with dementia at least once a week, and in this paper it is the carers perspective that is reported. For detailed inclusion and exclusion criteria of the Actifcare study, please see the project protocol reported by Kerpershoek et al. [23].

Procedure

In the Actifcare cohort study participant dyads were interviewed at baseline, six months and twelve months. At all stages participants’ service use was recorded using a ‘service use checklist’ developed for this project [23]. To expand further on this record of service use, the final follow-up included a semi-structured interview to retrospectively explore experiences of service (non)-use over the year. A proportion of the interviews were conducted jointly with the dyad, while others were conducted separately. In each dyad interview, the carer’s perspective was specifically recorded. As the extent of information provided by people with dementia proved more limited than that from the carer’s viewpoint, this paper focuses specifically on the carers’ perspective. The interview questions included descriptive, exploratory and open-ended questions about service use. Interviews were audio-recorded for note taking purposes, and the data includes verbatim descriptions or annotations of services, as well as the researchers’ summary of carers’ responses.

Analysis

Content analysis [24] descriptively explored common experiences of (non)-use of services and identified frequencies of occurrence. The interview responses were collated into an excel database with responses categorised into separate spreadsheets containing either participants that were receiving services or those that were not using services. Although within the Actifcare project, the primary focus has been on formal care services involving personal care for the person with dementia, for the purposes of the current analysis, a broader definition of care was used in order to capture the wide range of experiences of services discussed in the carer interviews. Participants accessing any formal care services in relation to dementia, including home nursing and other home services, day care, nursing home, hospital, supportive services and (non-) pharmacological interventions were considered to be using services. Services were grouped to include a range of different types of services accessed which is recommended for better understanding of reasons for service (non) use [25].

The first and second authors (HJ and LK) reviewed the data to cluster participant answers and generated categories that described the experiences of services being reported and whether they were positive or negative. A proportion of responses were independently categorised and any disagreements were resolved by a third author (BW). The clusters of answers described the types of services accessed, service timeliness, reasons for (non)-use of services, satisfaction with service access or no access, and factors considered to facilitate or hinder service access. Once the authors were satisfied with the robustness of the descriptive categories, frequencies were calculated with SPSS Version 22.

Table 1. Carers' relationships to the person with dementia and reports of service use

Carer relation	NL	DE	UK	SE	NO	IE	PT	IT	Males	Females	Total
Carers reporting service use											
Spouse/ partner	9	26	18	8	17	11	4	7	33	67	100
Child	2	7	5	10	6	8	4	8	10	40	50
Other	0	3	1	5	2	2	1	1	1	14	15
Total	11/ 36	36/ 54	24/ 56	23/ 45	25/ 50	21/ 40	9/ 57	16/ 52	44	121	165
Carers reporting no service use											
Spouse/ partner	23	16	27	17	19	10	29	10	61	90	151
Child	2	2	5	5	6	8	15	23	20	46	66
Other	0	0	0	0	0	1	4	3	0	8	8
Total	25/ 36	18/ 54	32/ 56	22/ 45	25/ 50	19/ 40	48/ 57	36/ 52	81	144	225

Results

This paper reports findings from 390 interviews in total, of which 36 were completed in the Netherlands (NL), 54 in Germany (DE), 56 in the United Kingdom (UK), 45 in Sweden (SE), 50 in Norway (NO), 40 in Ireland (IE), 57 in Portugal (PT), and 52 in Italy (IT).

The relationships of the carer to the person with dementia included 251 (64.4%) spouses and partners, 116 (29.7%) children, and 23 (5.9%) other relationships (son/daughter-in-law, sibling, other relative, friend, or neighbour). Overall, 42.3 per cent of participants reported service use (see Table 1).

The range of service use reported was clustered into seven categories: (a) 'Supportive services' which involved services that were initiated following diagnosis to provide support for the person with dementia or their carer. This included the memory clinic, mental health support, Alzheimer's cafes, and social support groups for people with dementia or carers. (b) 'Home Social' involved services that were designed to provide company or social activities for the person at home, such as sitting services. (c) 'Home Personal' involved services that were designed to support personal care needs whilst at home, these included community carers providing support with washing, dressing, assisting with eating or physiotherapy for gait movement problems. (d) 'Day Care' included all attendance (inclusive of respite) at a Day Care Centre. (e) 'Admission' included all admissions (including respite) to nursing home, care home, and long-term hospital stays. (f) 'Home Services' involved domestic and

maintenance services that occurred at the persons home that were taken up due to the person's dementia, including gardening or cleaning services, adaptations to the home, meals on wheels (companies delivering food), and medication delivery to the person's home (not involving administering medication). (g) '(Non)- Pharmacological Interventions' involved both medication for the person's memory or psychosocial interventions for people with dementia including Cognitive Stimulation Therapy (CST) and cognitive training combined with exercise. 153 participants reported the types of services they were accessing, various combinations of services were accessed which are reflected in the total figures (see Table 2).

Table 2. Types of services accessed

Types of Service	NL (11)	DE (36)	UK (24)	SE (23)	NO (25)	IE (21)	PT (9)	IT (16)	Total N = 153 (12 missing data)
Supportive services	6	9	13	0	2	3	1	9	43 (28.1%)
Home Social	4	12	2	0	0	3	1	8	30 (19.6%)
Home Personal	3	7	10	9	9	15	3	6	62 (40.5%)
Daycare	2	7	9	7	8	10	5	1	49 (32.0%)
Admission	3	1	7	10	11	4	3	1	40 (26.1%)
Home Services	1	2	6	11	6	1	3	1	31 (20.3%)
(Non)- Pharmacological Interventions	6	3	1	7	1	0	1	1	20 (13.1%)

The timeliness of access to formal dementia care services

Responses of 147 participants who elaborated on their use of services indicated that the majority (107 - 72.8%) considered that they had accessed services on time, whilst 4 (2.7%) indicated that they had accessed services too early, 32 (21.8%) too late and 4 (2.7%) reported mixed feelings of some timely access and other services being accessed either too late or too early. Amongst the majority of carers that considered services to be 'timely' a range of experiences were described, including services becoming available when the condition worsened or when there was an unexpected crisis. However, even when access was considered 'timely' some carers were still dissatisfied.

“The worsening of [person with dementia’s] condition was very sudden so everything has been done very quickly and at the right time.” (Timely service access/ IT carer).

“It was at the right time. Although it happened very suddenly because of the unexpected hospitalisation.” (Timely service access/ UK carer).

“Yes, but there should be more information available about what supports and services there are and how to access them.” (Timely Service access/ IE carer).

The few carers that considered service access to be ‘too early’ mostly related this to care home entry and the carer’s feelings of regret or guilt, or being guided by professionals.

“At the time it felt like the timing was right. But with what we now know, we would do things differently.” (Service access too early/ NO carer).

“Initially felt it was too soon for [person with dementia] to attend respite and day care services- other patients there were more dependent. Encouraged to stick with it by the doctor.” (Service access too early/ IE carer).

Amongst the carers that considered service access ‘too late’ a range of experiences were outlined. These included accessing care following concerns arising during crisis, a lack of awareness and a lack of support resulting in service access ‘too late’.

“May have been beneficial if received care a bit sooner. Only accessed care after crisis situation- was worried that things would deteriorate rapidly.” (Service access too late/ IE carer).

“If we had been more aware of what was available then services might have been accessed sooner, instead we were left alone to struggle and had to find help privately ourselves.” (Service access too late/ UK carer).

“I should have looked earlier, but she [person with dementia] rejects it.” (Service access too late/ DE carer).

“Too late. GP should have helped more. The difference the support makes is huge. Things were very bad before the support started and it need not have become that bad.” (Service access too late/ IE carer).

The carers also described the challenge of finding services themselves and the difficulty in receiving the level of support required. Moreover, the slow process was also reported as a reason for late support.

“Possibly a little late but it is difficult to find services on your own.” (Service access too late/ UK carer).

“Too difficult to get. Basically you have to be on the phone crying to get it, even if the public health nurse requests 20 hours (she did this 3 times), you still only get 6. Getting any kinds of needs review takes 6 months, this is too long as huge amounts of change can happen in this timeframe.” (Service access too late/ IE carer).

“Support came too late; merely due to the fact that it took a long time before the diagnosis.” (Service access too late/ NL carer).

Although only a small number of carers reported ‘mixed feelings’, this did serve to highlight that the perception of timeliness differed by service type.

“Memory clinic and day care were on time. Support group was too early.” (mixed service access/ NL carer).

“Time was right, but it was not the right service at the right moment for my husband.” (mixed service access/ DE carer).

Interestingly there were very few reports of other services such as home personal care and day care being initiated before admission. Of those admitted during the year none reported receiving a combination of both home personal care and day care, and only 5/61 (8.1%) had received home personal care and 3/45 (6.6%) had received day care.

Satisfaction with service use

For those participants accessing formal care services, 144 participants elaborated on their answers when asked to what extent they were satisfied with the formal care they were using. Responses included 98 (68.1%) participants reporting feeling satisfied with the services they were accessing, 17 (11.8%) reported feeling dissatisfied with the services they were accessing and 29 (20.1%) reported mixed feelings of satisfaction, being happy with some services but not with others.

Of those participants who were not accessing care services, 122 participants elaborated on whether they thought that formal care should have been introduced. Two thirds of participants 82 (67.2%) were satisfied that care had not been introduced. A small proportion 21 (17.2%) was dissatisfied with their situation and felt that formal care should have been introduced. The remaining participants 19 (15.6%) reported mixed feelings that some services should have been introduced but not others, or were satisfied with some aspects of not accessing formal care services but not with every aspect of their situation.

A variety of explanations were given for their satisfaction with not using services, such as the consideration that services were not necessary or needed yet, often because the carer considered they were coping, or they expressed a preference not to use formal care despite challenges.

“[Carer is] capable to take care of [Person with Dementia] and would not change anything.” (Satisfied with no service use/ notes on PT carer interview)

“[the person with dementia] is better with his family.” (Satisfied with no service use/ PT carer).

The proportion of participants that reported that they were dissatisfied with not accessing services, indicated a range of experiences from difficulty in coping or accepting services, to a lack of information and awareness.

“Not at all satisfied, formal care should have been introduced long ago, but [her husband] refuses.” (Dissatisfied with no service use/ SE carer).

“Not satisfied, not been given any information about services and we’re unaware of what services are available.” (Dissatisfied with no service use/ UK carer).

The remaining mixed feelings appeared to reflect either internal or external conflicts or a resilience involving coping and proactive awareness of support.

“Currently don’t feel formal care services are needed as [carer] is managing well. However [carer] is looking into support groups for both [person with dementia] and [carer] as feels this might be of help.” (Mixed feelings about no service use/ notes on UK carer interview).

Reasons for service use

Of the 165 participants who had accessed services over the year, 150 were able to specify reasons why they sought formal care. Often, there were multiple reasons, relating either to the person with dementia, the carer or both. A number of carers cited changes in the person with dementia including cognitive (21.3% of carers) or behavioural changes (10%). The potential of services to meet the individual needs of the person using formal care was also frequently reported; these included physical (34.7%), emotional (18.7%) and social (9.3%) needs. In some cases, formal care was accessed when it was considered no longer possible to cope without a service (16.6%) or the opportunity to take up services arose (12.7%), (see Figure 1).

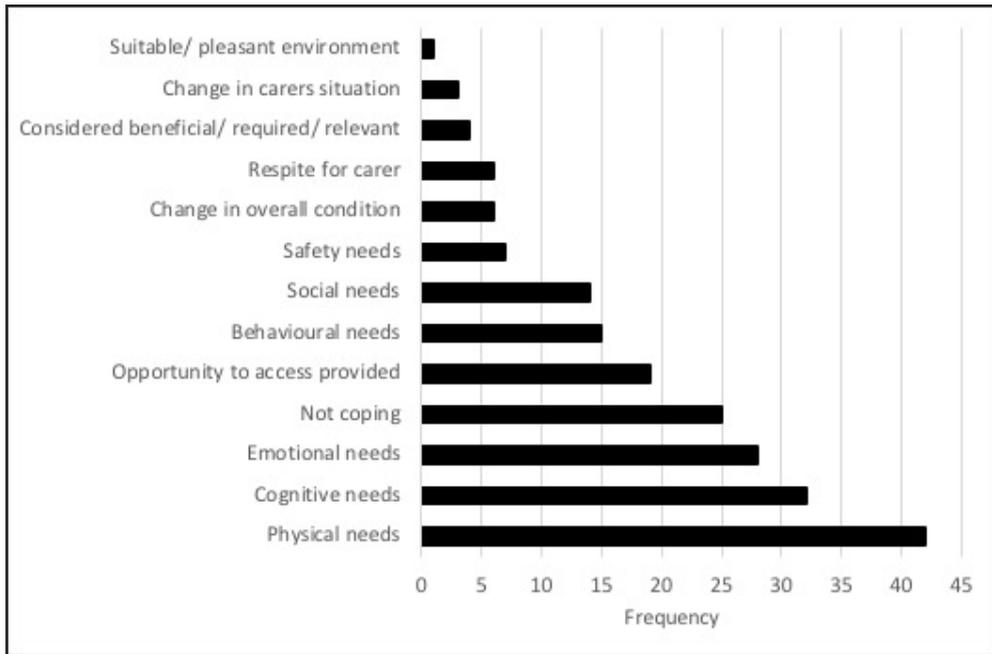


Figure 1. Reasons why participants using services accessed formal care

Reasons for non-use of services

Of the 225 participants not using any services over the previous 12-month period, 198 participants specified reasons for not using formal care. Participants provided multiple reasons for non-use of services that related either to the person with dementia, the carer, or practical and service provision issues. The most common reason for not accessing services was the perception of them as not necessary yet (71.7% of carers). Other frequent reasons given included either the person with dementia (19.2% of carers) or their carer (11.1%) refusing to use a service. Less frequently reported reasons included a lack of awareness of available care services (5.1%), or the informal carer (12.6%) or their social support network being considered able to provide support (4.0%), negating the need for a formal care service. Very few carers reported not using services because they were considered not useful or worthwhile (2.5%), unsuitable (1%) or because of logistical problems (1%). Only one carer reported disagreements within the family, or placement on a waiting list hindering service access (see Figure 2).

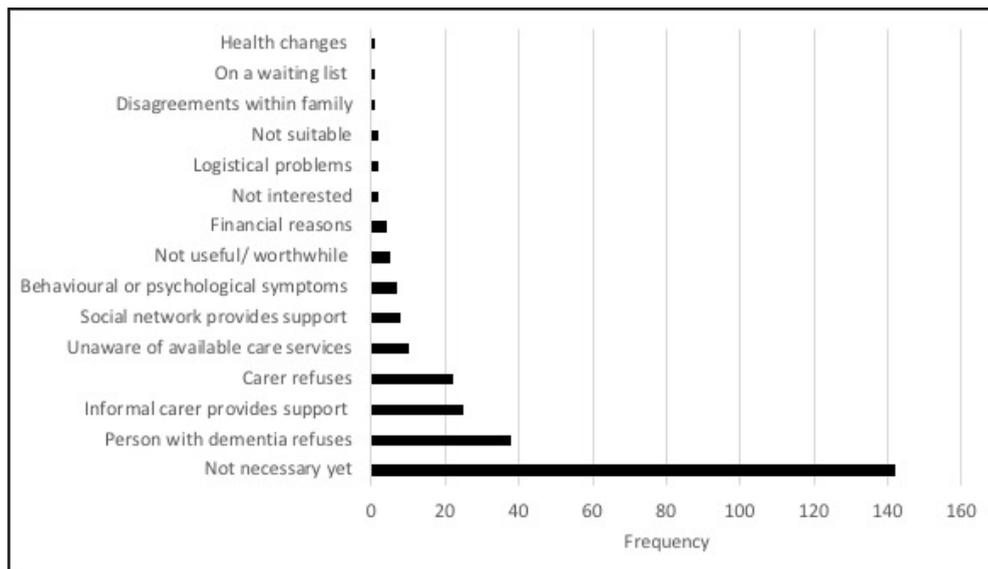


Figure 2. Reasons why participants not using services did not access formal care

Facilitators and Barriers to service use

For all 390 participants, factors that were considered either facilitators or barriers to service use ranged from characteristics of the services and professionals involved, to personal attributes and situational factors related to the individuals. The main aspects outlined included whether they experienced supportive professionals (25.6%), the speed of the process (8.7%), whether they had a helpful GP (8.5%), or the dyad’s own proactive attitude (8.2%); for example whether they investigated service availability for themselves rather than depending on professionals. Furthermore, participants reported that information (or lack thereof) (7.9%) could both facilitate or hinder service access. This included participants’ discussing the amount of available information and the quality or appropriateness of information in relation to their particular situation or about a specific service (see Figure 3).

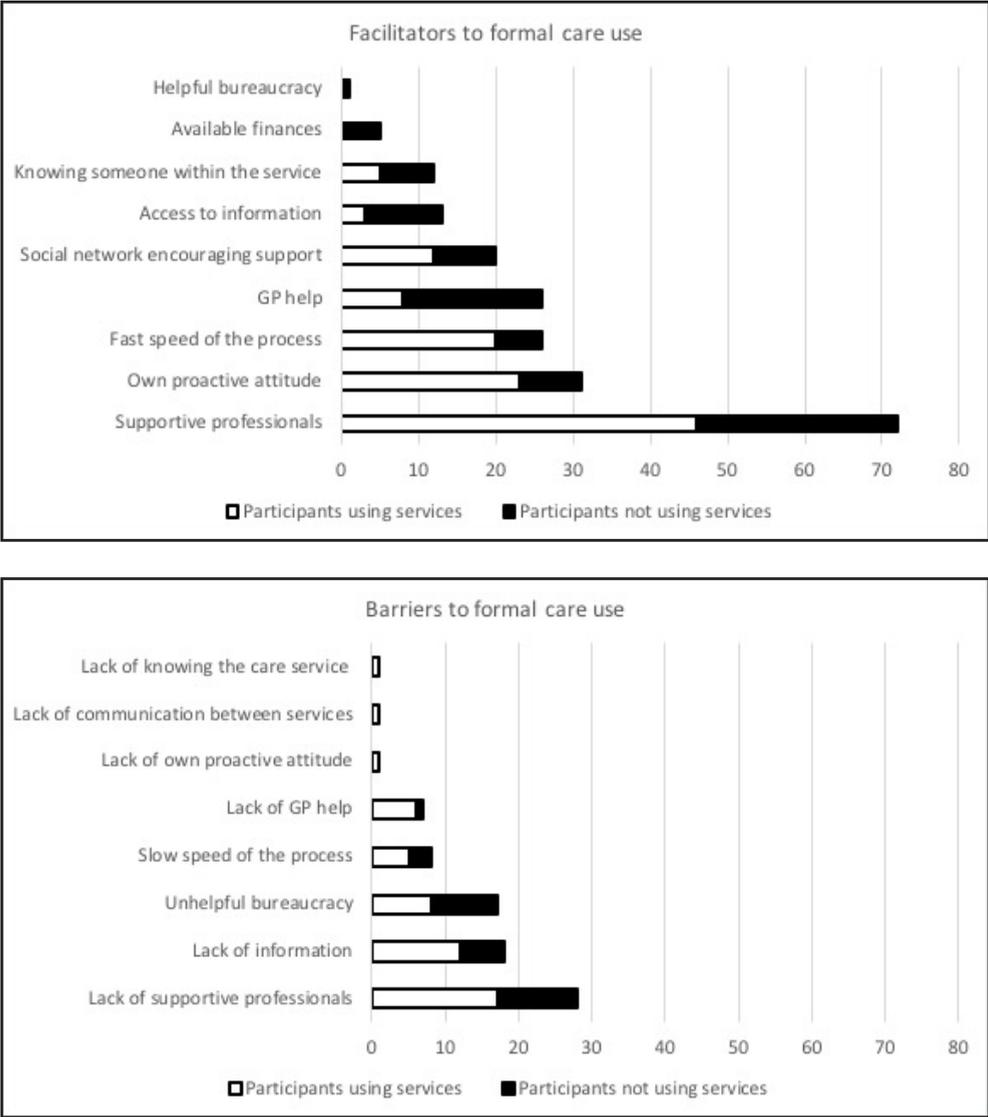


Figure 3: Factors considered facilitators or barriers to service use.

Discussion

To the best of our knowledge, this is the largest European study that has investigated timely service access by people with dementia and their carers. This study recruited participants that had not yet accessed formal care services at baseline but were expected to transition into service- use over a 12- month period. However, the majority of participants (56.8%) did not start to use services during this year.

The majority of participants in this study reported timely access of services or satisfaction with not using services. However, some carers reported that they had accessed services at the wrong time or were dissatisfied with not using services. The positive experiences reported by the majority of carers in this European sample appears to be an unusual finding in the literature. The barriers reported in this study are in line with previous research reporting barriers to service use [6, 14, 16, 18]. This highlights the need to further refine the process of introducing formal care, to improve timely care and satisfaction with decisions of service use.

In this cohort study, most of the services were accessed to provide personal care at home or to meet physical needs, while only a limited number of services were used for companionship or social activities at home. This suggests the range of service provision requires expansion to include more services for higher-level social needs, particularly within the persons' own home in the community. These findings reflect the continued predominance of the medical model view of dementia with a primary focus on meeting physical care needs almost to the exclusion of all other needs. This is in line with previous research, establishing that services meeting social needs are often under-represented or lacking [26], although the need for a biopsychosocial approach to care, that moves beyond only addressing medical needs, is recognised by political decision makers and stakeholders across Europe [27]. Explorations of admission, and reports of use of home personal and day care services indicated that over 75 per cent of those admitted did not report use of alternative services such as daycare or personal care at home. Furthermore, none of the participants reporting accessing a combination of daycare and home personal care services went on to admission in the 12-month period of this study. This is an interesting finding that might indicate that such a 'community care package' might prevent long-term care admission. This would support the 'balance of care' notion that suggests enhanced community services could support people appropriately at home avoiding residential or hospital placement [28]. Further research is needed to determine whether this finding was simply a reflection of where this sample were in relation to their journey with dementia, or whether indeed the right combination of community care services is able to reduce the likelihood of long-term care admission. Many of the reasons outlined for accessing services support the suggestion in previous research of the increased likelihood of service use with dementia progression [19] and service uptake during crisis situations [22, 29]. An interesting finding of the current study was how access was frequently described as opportunistic: services were taken up as the opportunity

was presented to participants. This suggests that although carers do not or are not able to proactively seek services, they are open to service use when the possibility is presented to them. This novel finding might be considered fitting when considered within the context of research reporting challenges faced in help seeking [8].

The reasons provided for not using services support previous research reporting no need for services or reluctance to use services [6, 12] and a preference for specifically tailored services [16]. Our results are consistent with research describing factors that prevent help seeking, such as a lack of sufficient information and knowledge of services [6, 11, 13, 14, 16, 18]. Surprisingly, the results provide only very limited support for previous research describing logistical challenges [16, 30] and a sense of withdrawal or resignation to the situation and low expectations [31]. This might be a reflection of this sample's considerable contentment with service (non) use or perhaps attitudes to service use are changing. Furthermore, the long process of applying to access services [6] was reported in this sample, in addition to the suggestion that a faster process can facilitate service use. Our findings on reasons for service use are in line with research suggesting the likelihood of service use increases when carers are no longer able to cope alone without support [18] or where there have been positive previous experiences facilitating service access and increased familiarity [14]. It was clear that many preferred to seek support from close relatives and trusted primary healthcare professionals [8]. Our findings also support research advocating a collaborative partnership between carers and healthcare professionals to support the care of people with dementia [15, 32, 33] and highlight the important support role of front line healthcare professionals [8, 14, 16]. It is interesting to note that the only care professional explicitly referred to by participants was the GP. This might be considered problematic due to the various constraints of primary care provision [34-36] and highlights the need for a specialist key contact person in dementia care [11, 22].

Overall, there is a need to improve access to services. A proactive attitude of those using services is a facilitator to service access, however this would not be needed if there was more easily obtainable service information. The perception of services is of key importance [15], and increased familiarity was considered beneficial. Services could, perhaps consider offering trial sessions for individuals to discover the service and become more familiar to enable an informed decision of whether to take up a service. The findings in this study support recommendations for tailored services with more flexibility [11, 16]. Services might consider reflecting on the suitability and need of a service to allow for adaptation and improvements to match individuals more appropriately. If the perceived value of services can be improved through better information and exposure then this might facilitate timely access of services and reduce reactive uptake during crisis situations.

The findings from this study also highlight the need to accept that many people with dementia and their carers do not feel the need of support from services. It is important to recognise the value of autonomy [37] and respect decisions of whether or not to use formal

care services. Regardless of diagnosis, every person experiencing dementia is an individual and not all services are suitable nor required, but when they are, it is important for this transition into service use to be made as easy as possible. The experiences of timely access and use of dementia care services reported here indicate a positive outlook, suggesting that many people with dementia and their carers in Europe experience both timely access and satisfaction with their (non)-use of services. However, the findings also highlight the need for continual developments for improved experiences for the substantial minority who are less satisfied.

A limitation of the current study might be that the presence of people with dementia in many of the interviews has constrained the ability of the carers to communicate openly. Furthermore, it is important to recognise that this paper presents data from the carers' perspective only and is limited to the 12-month period. Although at times the carers' answers suggested a joint representation, the researchers could only assume this to be an accurate view of the carer, regardless of any suggestion that the carer was able to answer on behalf of the person with dementia. The researchers had planned to collect more extensive data from the perspective of the person with dementia but particularly in cases where the person with dementia was in the more advanced stages, this proved challenging. The experiences presented in this study are informative for both service providers and those considering accessing dementia care services. There is a need for more large-scale studies on service utilisation among carers of people with dementia (Robinson Robinson, Buckwalter and Reed 2005) to build on these findings and develop empirically based interventions and improve practice.

Conclusion

These results highlight that timing remains essential for appropriate formal care service use. There is a need for more simplified service access pathways that are easier for carers to understand, and that consider the difficult balance between planning ahead to avoid crisis situations and preventative strategies. Barriers preventing service access must be addressed and insights into facilitators embraced. These findings can help service providers and health and social care professionals to empower people with dementia and their carers to make informed decisions about service use to enable satisfaction with appropriate and timely support.

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Do caregiver profiles predict the use of
dementia care services?
Findings from the Actifcare study

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Aging & Mental Health, under revision

Abstract

Objectives: Previously developed dementia caregiver profiles defined by caregiver age and burden, have been associated with caregiver quality of life, depression and perseverance time. The current aim was to investigate whether these caregiver profiles could predict subsequent service use. In addition, non-personal (e.g. meals on wheels) and supportive services (e.g. Alzheimer café) in early dementia were investigated as predictors.

Methods: A total of 451 dyads of people with dementia and their informal caregivers from eight European countries were followed for one year. People were included if they did not use formal (personal) care but were expected to do so within 1 year. Logistic regression analyses were used with four clusters of service use as dependent variables (home social care, home personal care, day care and admission). The independent variables were caregiver profiles, and non-personal and supportive services at baseline.

Results: Caregiver profiles were significant predictors of service use: those experiencing high strain were more likely to use formal care. The use of low-intensity, less intrusive services at baseline significantly predicted the use of home personal care and admission at follow-up. The use of day care at follow-up was predicted by the baseline use of supportive services.

Conclusion: Caregiver profiles are valuable predictors for service use: this knowledge can aid professionals in ensuring optimal access to services, which is important for maintaining independence at home. In addition, the use of supportive and less intrusive, non-personal services in the early stages of dementia is to be advised.

Introduction

Many countries pursue health care policies aimed at enabling people with dementia to live at home for as long as possible, while being offered a wide range of community and social care services. The majority of people with dementia currently receive care and support from informal caregivers [1]. They are often spouses or partners who are of a similar age and who often have health problems themselves. At some point in the disease, when needs of the person with dementia can no longer be met with informal care alone, formal care services become necessary [2]: a combination of these two types of care occurs more often when the amount of needs is higher [3]. Yet, previous studies indicate that formal dementia services are not being accessed as much as needed [4-6], and are used less frequently compared to people requiring care due to other conditions [7]. There is a tendency for people with dementia to use medical services more often than community services [8] while at the same time expressing the need and preference for community and social services [9, 10]. Health and social care policy tends to encourage people with dementia to live at home for as long as possible, but this can only be realized if informal care is supplemented with appropriate formal care. It is therefore important for governments to understand the reasons behind the (non)-use of formal care services and the associated social and economic consequences of this (non)-use [2]. So far, reported reasons for the non-use of care services include refusal of the person with dementia, a lack of knowledge about available services, services not being of the right type, and the consideration that care is not yet necessary [1, 4, 5]. In addition, stigma, norms about being responsible for caregiving as a family, and negative experiences with previous health care services were found to play a role in non-use [11]. Recent years have seen the development of a range of services that offer support to people with dementia and caregivers, such as Alzheimer cafes, support groups and befriending services. It is unclear whether these low intensity, less intrusive services help to break down some of the barriers to more intensive service use noted: previous qualitative Actifcare results do indicate that this is the case [9].

When considering care (non)-use, there seems to be a complex interplay between factors related to the person with dementia and to the informal caregiver [12]. In a previous article based on the Actifcare baseline data [12] five different caregiver profiles were established (Older Low Strain, Older Intermediate Strain, Older High Strain, Younger Low Strain, Younger High Strain) following a latent class analysis. These profiles included characteristics of the person with dementia and the informal caregiver, in an attempt to summarize the complex interaction between them. Subjective as well as objective burden was also included, where subjective burden is reflected by caregiving-related stress, and objective burden by more time spent with the person with dementia in a care-giving role [13]. The higher strain profiles were characterized by lower cognitive functioning and more behavioural and psychological symptoms of the person with dementia. Interestingly, objective burden was highest in the Older Intermediate Strain group, but subjective burden was low: apparently these

caregivers are more resilient and maintain good adjustment in dealing with more severe problems. The low strain profiles were associated with higher caregiver quality of life and a longer perseverance time (perceived ability to continue providing care at home), while the high strain profiles were associated with more depressive symptoms [12]. Since these caregiver profiles encompass a broad range of variables reflecting the complex interplay of several relevant factors of the person with dementia and informal caregivers, they may have utility in exploring the use of formal dementia care services. If caregiver profiles could predict service use, this may aid professionals in ensuring optimal access to services that are important for maintaining independence at home. The profiles were previously validated against baseline measures of caregiver quality of life, depression and perseverance time, so it would be informative to determine whether these other variables add to the prediction of later service use. Since reluctance of the person with dementia is one of the reasons cited for non-use of services [4], leading to potential conflict between caregiver and person with dementia, the quality of relationship between caregiver and person with dementia may also be relevant. It is also associated with caregiver stress [14], and may add further to the prediction of later service use.

Accordingly, our research questions are as follows:

- 1) Can caregiver profiles in dementia predict the use of formal care services?
- 2) Do caregiver depression and anxiety, perseverance time, caregiver quality of life and relationship quality add to this prediction?
- 3) Does the use of low-intensity and less intrusive non-personal and supportive services at baseline predict the use of formal care services?

Methods

Study design and participants

The Actifcare study (ACcess to TImely Formal Care) investigated access to home- and community-based dementia care for people with mild to moderate dementia in eight European countries (The Netherlands, Germany, United Kingdom, Sweden, Norway, Ireland, Italy and Portugal). A wide range of research methods were used, such as literature reviews, focus groups, and expert interviews [15]. In addition, a prospective one-year cohort study was carried out in which people with dementia and their informal caregivers were followed and interviewed about topics including their needs, service use and quality of life. People with mild to moderate dementia according to DSM-IV-TR criteria were included, defined as having a CDR score of 1 or 2 [16] or an MMSE score lower than 25 [17], together with an informal caregiver who was in contact with the person with dementia at least once a week. At baseline, the participants were not using formal care for personal care on account of their dementia. Formal care is defined within Actifcare as home nursing care, day care services, community or long-term medical care, nursing and social care structures that involve care

from a paid worker. It does not include domestic home help, housekeepers, volunteers, support groups, transport services and meal programs. It was anticipated that participant dyads would start using formal care within one year, based on expert opinion. The complete design and in- and exclusion criteria of the Actifcare study have been described elsewhere [15].

Data collection and measurements

Written informed consent was obtained from the person with dementia and the informal caregiver according to the national procedure in each country. Measurements were scheduled at baseline, and after six (FU1) and 12 (FU2) months. A variety of questionnaires were administered, in addition to the collection of demographic information and details on service use.

Measures for people with dementia

Two scales measured cognitive functioning: the Mini Mental State Examination (MMSE) [17] and the researcher-rated Clinical Dementia Rating [16], of which the sum of boxes was used instead of the total score. Behavioural and psychological symptoms were assessed with the Neuropsychiatric Inventory Questionnaire, NPI-Q, in which the informal caregiver provided information on twelve neuropsychiatric symptoms of the person with dementia [18].

Measures for informal caregivers

The extent of informal caregiving was measured with the Resource Utilization in Dementia scale (RUD), an instrument developed to reflect both formal and informal care use [19]. The number of hours spent on informal caregiving on personal and instrumental activities of daily living was collected. Stress related to caregiving was measured with the Relatives' Stress Scale (RSS) [20], in which different patterns of distress are measured [21]. Perseverance time was measured with a single simple estimate of how long the informal caregiver considered he/she could continue in this way if the situation remained unchanged, with response options from 1 'less than one week' to 6 'more than two years'. Two scales were administered to investigate informal caregiver attributes: The Sense of Coherence Scale, 13 item version (SOC-13) and the Locus of Control Behaviour Scale (LOC). The SOC-13 indicates to what extent a person experiences life to be comprehensible, manageable and meaningful. It is not necessarily a stable trait as it has been described to increase with age [22]. The LOC assesses whether someone perceives life events as being under personal control or as being attributable to external sources [23]. The Hospital Anxiety and Depression Scale (HADS) was used to measure depressive and anxious symptoms. The scale provides separate scores for depression and anxiety, where a score of zero indicates the absence, and a score of 21 indicates the presence of depressive or anxious symptoms [24]. Caregiving related quality of life was measured with the Care-related Quality of life scale (CarerQoI). The scale consists of

7 items, and a visual analogue scale (CarerQol-VAS) [25]. The Positive Affect Index (PAI) was used to measure the person with dementia's and the caregiver's view of their relationship quality [26]. It consists of five items, where a higher total score (range 5 to 30) indicates a better relationship quality.

Caregiver profiles

Caregiver profiles were established in a previous study [12] with a latent class analysis, combining both baseline characteristics of the person with dementia and the informal caregiver. Five profiles were identified reflecting demographics of the informal caregiver, and the subjective and objective burden: younger caregivers experiencing low strain; younger caregivers experiencing high strain; older caregivers experiencing low strain; older caregivers experiencing high strain; and a cluster of older caregivers providing support to people with dementia with a high level of needs, but reporting comparatively low strain, described as the older intermediate strain group.

Service use

Information concerning the person with dementia's service use was collected with a checklist, constructed for the Actifcare study. It comprised 22-26 items to reflect different service constellations in each country, and was administered at each assessment (baseline, FU1, FU2). Checklist items in all countries were combined into four clusters: 1) help at home (social), 2) help at home (personal care), 3) day care, 4) admission to nursing or care home or long-term admission to hospital due to dementia (see appendix for details). The development process for these clusters has been described in more detail elsewhere [27]. Next, scores were dichotomized for each cluster to reflect use at either of the two follow-up points. An extra cluster was created to describe non-personal services used at baseline that might facilitate access to formal care. This cluster includes meals on wheels, domestic services, help at home (social) and day care (without personal care). In addition, a cluster with supportive services was created, consisting of support groups, training sessions for the carer, individual or dyadic support and the Alzheimer café.

Statistical analyses

Frequency distributions were calculated to describe service use and group characteristics at baseline. Separate automated logistic regressions were carried out for the four service use clusters, with a dichotomous dependent variable (service use yes/no). The five caregiver profiles were transformed to dummy codes, where the 'Old low strain' group was the reference group. In addition, CarerQol-sum and VAS, carer depression and anxiety, perseverance time on a continuous scale, and relationship quality were used as independent variables. Finally, dichotomous scores of personal and supportive service use at baseline were investigated as independent variables in separate logistics regression analyses.

Results

Group characteristics are displayed in table 1. At baseline, 451 dyads were included in the study. At FU1 422 dyads still participated, and at FU2 339 dyads, which reflects a loss to follow up of 25% after one year. All those who completed at least FU1 were included in the regression analyses. The majority of the dyads were living together and had a spousal relationship. Participants were reasonably evenly distributed across the five caregiver profiles, but the largest group was the Older Low Strain.

Table 1: Sample characteristics (N=451) at baseline

Person with dementia	
Male (n, %)	207 (46%)
Age (mean, [range], SD)	77.4 [47 – 92] 7.9
Education (mean years, SD)	9.8, 4.5
Marital status (n, %)	
Married	310 (68%)
Widowed	109 (24%)
Single	8 (2%)
Other	24 (6%)
Living together with carer (n, %)	325 (72%)
Dementia type (n, %)	
Alzheimer’s Disease	218 (49%)
Vascular dementia	52 (12%)
Mixed dementia	56 (12%)
Lewy body dementia	6 (1%)
Other/unknown	119 (26%)
CDR sum of boxes (mean, [range], SD)	7.1 [2-16] 2.4
Caregiver	
Male (n, %)	151 (33%)
Age (mean, range, SD)	66.4 (25 - 92) 13.3
Range	
Education (mean years, SD)	11.9, 4.4
Marital status (n, %)	
Married	363 (80%)
Widowed	10 (2%)
Single	31 (7%)
Other	47 (11%)
Caregiver relation (n, %)	
Spouse	271 (60%)
Child	137 (30%)
Other	43 (10%)
Caregiver profiles	
Older High Strain (n, %)	88 (20%)
Younger High Strain (n, %)	62 (14%)
Older Low Strain (n, %)	106 (23%)
Younger Low Strain (n, %)	100 (22%)
Older Intermediate Strain (n, %)	95 (21%)

PwD: person with dementia. CDR: clinical dementia rating scale

Table 2 displays the percentages of service use at baseline and at follow-up across the different caregiver profiles. The use of home personal care and admission at baseline reflect care that was needed for reasons other than the person's dementia; the use of day care reflects use of a service not including personal care. Percentages of service use are the lowest in the low strain profiles.

Table 2: Service use distribution across caregiver profiles, % (n)

Baseline (n=451)						
	Home social	Home personal	Day care	Admission	Non-personal services*	Supportive services*
Older high strain	5% (4)	6% (5)	16% (14)	0	21% (30)	23% (30)
Younger high strain	13% (8)	11% (7)	11% (7)	0	16% (22)	14% (18)
Older low strain	6% (6)	4% (4)	8% (8)	<1% (1)	12% (17)	16% (20)
Younger low strain	11% (11)	7% (7)	20% (20)	0	31% (44)	14% (18)
Older intermediate strain	13% (12)	3% (3)	24% (23)	0	19% (27)	33% (43)
Follow-up 1 and/or 2 (n=370)						
	Home social	Home personal	Daycare	Admission		
Older high strain	21% (14)	26% (17)	30% (20)	21% (14)		
Younger high strain	33% (14)	28% (13)	28% (12)	23% (9)		
Older low strain	10% (9)	7% (6)	15% (14)	8% (7)		
Younger low strain	16% (13)	33% (28)	39% (32)	17% (15)		
Older intermediate strain	22% (16)	31% (23)	38% (30)	30% (22)		

Percentages (N),* only used as baseline variables

Outcomes of the logistic regressions investigating the relationship between caregiver profiles and care use are presented in table 3. In relation to home social care, the chances of care use were higher for the intermediate and high strain profiles than for the low strain profiles. Participants in the Younger High Strain group were most likely to use home social care. All four groups had a higher chance of using home personal care in comparison to the Older Low Strain group. The Older Intermediate Strain, the Older High Strain and the Young Low Strain groups were more likely to use day care. Lastly, the people with dementia from all groups except for the Young Low Strain group had a higher chance of admission when compared with the Older Low Strain group.

CarerQol, HADS depression and anxiety scores, perseverance time and relationship quality were subsequently added in a block to each of the logistic regressions to investigate whether these added value to the prediction (see table 4). The p-value in table 4 indicates the significance of the dummy set of the 5 caregiver profiles. For both home personal care and admission, the predictors showed significant results, where the probability of using home personal care was higher for those caregivers with a lower quality of life and lower anxiety scores. A lower relationship quality as rated by the informal caregiver significantly predicted the use of day care, and the probability of admission was higher for those with a lower perseverance time.

Table 3: Caregiver profiles as predictors for each of the 4 types of care use

	Home social	Home personal	Day care	Admission
Young low strain	1.7 (0.7-4.4)	7.3(2.8-18.6)**	3.7(1.8-7.5)**	2.5(0.9-6.5)
Young high strain	4.5(1.8-11.5)**	5.7 (2-16.3)**	2.3(0.9-5.4)	3.5(1.2-10.3)**
Old intermediate strain	2.6(1.1-6.3)**	6.4(2.5-16.8)**	3.6(1.7-7.4)**	3.1(2.1-13.1)**
Old high strain	2.5(1-6.1)	5.1(1.8-13.6)**	5.2(1.2-5.6)**	3.1(1.2-8.2)**

Reference dummy: 'Old Low strain'. Odd's Ratio (lower CI-upper CI 95%), ** p-value < 0.05

Table 4: effects of CarerQol, HADS depression and anxiety scores, perseverance time and relationship quality on the relation between caregiver profiles and service use, in addition to caregiver profile.

	Home social	Home personal	Day care	Admission
Caregiver profile		**	**	**
HADS-Anxiety	1.0 (0.9-1.1)	0.9 (0.8-1)**	0.9 (0.9-1)	0.9(0.9-1.1)
HADS-Depression	1.0 (.865-1.1)	0.9 (.830-1.1)	1 (0.9-1.1)	0.0 (0.8-1)
Perseverance time	0.9 (0.7-1.3)	0.8 (0.6-1)	1.1 (0.8-1.4)	0.6 (0.4-0.8)**
PAI PWD-rated	1.1 (0.9-1.2)	0.9 (0.8-1)	1 (1-1.1)	1 (0.9-1.1)
PAI IC-rated	0.9 (0.9-1)	1 (0.9-1.1)	0.9 (0.9-1)**	1 (0.9-1.1)
CarerQol-sum	1 (0.9-1.2)	0.9 (0.7-1)**	1 (0.9-1.1)	1(0.8-1.1)

Odd's Ratio (lower CI-upper CI 95%). PWD: person with dementia IC: informal caregiver, HADS: Hospital Anxiety and Depression Scale PAI: positive affect index, ** p-value < 0.05

Table 5 shows the relationship between baseline care use and formal care use at either FU 1 or 2. This was investigated with two independent variables: supportive services at baseline and non-personal service use at baseline (meals on wheels, domestic services, home social and day care without personal care). Non-personal service use at baseline significantly predicted the use of 2 out of 4 formal care types at FU1/2. Using supportive services at baseline significantly predicted the use of day care at FU1/2, but not home personal care or admission.

Table 5: Service use at baseline and supportive services predicting formal care use at FU1/2

	Home personal care	Day care	Admission
Non-personal service use at baseline	4.9 (2.9-8.4)**	0.9 (0.6-1.6)	2.4 (1.4-5.2)**
Supportive services	1.5 (0.9-2.6)	2.5 (1.6-4.1)**	1.4 (0.8-2.6)

Odd's Ratio (lower CI-upper CI 95%), ** p-value < 0.05

Discussion

The challenge of understanding the factors that influence the take-up of formal care arises from the complex interplay between the characteristics of the services and of those using them. The latter may differ in relationship, disease severity, coping mechanisms, health problems amongst other factors [28]. By using caregiver profiles, we tried to encompass as many characteristics as possible in a simple typology, and have identified important differences in service use between these five types of caregiving contexts.

For home social care, the probability of using services is higher for the intermediate and high strain profiles compared to the low strain profiles. Participants in the Younger High Strain group were most likely to use home social care. This could be explained by the fact that the majority of young caregivers are often employed children with obligations towards their own families [29]. This leaves them little time to provide social company in a situation where this is needed, so formal care becomes a necessity. This also supports previous research, which indicated a higher amount of social care use by people with dementia who live alone [27]. The use of home personal care is much higher in all four groups compared to the reference (Older Low Strain) group. This could partly be explained by higher levels of objective and subjective burden, leading to increased needs regarding activities of daily living (ADL). The finding that service use in the younger age profiles is so high could be due to living arrangement: children who are living apart from their parents are not able to provide continuous care. This supports previous research that found that those with dementia living alone have an increased chance of using meals on wheels and help at home with ADL [30]. In addition, younger caregivers may have easier access to information about available services through on-line resources, for example.

The Older Intermediate Strain and the Older High Strain group were more likely to use day care. This was also the case for the Young Low Strain group. Here caregivers were often employed children with less time to provide help with day-to-day activities. The fact that the Young High Strain group did not have a higher chance of day care use could probably be explained by the relatively high number of admissions in this group at follow-up. Lastly, people with dementia from all intermediate and high strain groups had a higher chance of admission in comparison to the low strain groups. The need for admission may simply have been absent in these groups with a relatively low objective burden, which is supported by previous research [13, 31, 32].

The Older Intermediate Strain group has a distinctive profile in which the objective burden is the highest but the subjective burden is relatively low. These resilient caregivers seem to have found successful coping strategies. This supports previous reviews which have indicated that there is no association between dementia severity and subjective burden, since this relationship is more strongly influenced by coping styles and social support [13]. The Older Intermediate Strain group also has the highest percentage of supportive service use at baseline, which could reflect a proactive attitude and active help-seeking. Overall, averaging

across the different types of services at follow-up this group has the highest level of service use: a low subjective burden does not necessarily entail that no services are sought. For this group, service use may have been largely driven by the severity of the difficulties faced (with twice as many of this group having moderate or severe dementia (39%) compared with the older high strain group (19%), rather than by their difficulties in coping with or managing the emotional impact of their situation.

The two low strain groups have in common at baseline [12] low levels of relative stress, higher levels of sense of coherence and a more internal locus of control, together with a higher proportion of care recipients with mild dementia and less neuropsychiatric symptoms. This profile, for both age groups, appears, over a 12-month period, to be associated with less risk of admission, and lower up-take of home social care. However, the older low strain group make less use of home personal care and day care. This may be attributed to the older caregivers being much more likely to be living with the person with dementia (100% vs. 13.1%) [11].

As the previously established caregiver profiles were shown to be associated with caregiver quality of life, depression, and perseverance time, we were interested in investigating whether these measures influence the relation between formal care use and being a certain type of caregiver. The probability of using home personal care was increased for those caregivers with lower anxiety scores and a lower quality of life. These results are difficult to interpret: perhaps anxious caregivers show avoidant behaviour and may have anxious feelings about allowing someone in to their home to provide personal care, and therefore not look for it proactively. Those with less anxious symptoms could be more likely to initiate help-seeking. On the other hand, it seems reasonable that, a caregiver with a high quality of life might not feel the need to have additional potentially intrusive help at home. The probability of using day care was increased in those cases where the caregiver rated the relationship quality lower, which could be explained by the dyad wanting more time apart, or by tension in the home situation. This tension could arise if the couple is struggling to cope with the fact that the dementia is impacting not only both individuals, but also their relationship [33]. In addition, when relationship quality is higher the caregiver might be better able to fulfil needs concerned with daytime activities themselves. Regarding admission, results showed that a lower perseverance time adds to the prediction. This can logically be explained in terms of the question being asked (If the care situation remains as it is now, how long will you be able to carry on giving care?). It appears that caregivers' reports of their ability to carry on were a good indicator of what transpired.

Using low-intensity, less intrusive services at baseline (meals on wheels, domestic care, home social and day care without personal care) significantly predicted the use of home personal care and admission at follow-up. From previous qualitative results of the Actifcare study [9] [10], it was found that a gradual build up in care use is important to improve access to services. Starting with more accessible services such as domestic help or meals on

wheels might lower the threshold to start using services involving personal care, and may help people with dementia to overcome reluctance to accept help from those outside the family. This was also reported in previous research [34] [35] suggesting that even though people with dementia and informal caregivers express reluctance, service use in the early stages can have favourable consequences.

In addition, the use of day care at follow-up was predicted by the use of supportive services (support groups, training session, individual/dyadic support, Alzheimer cafe). There seem to be different mechanisms at work here. Information about available formal care is often provided as part of supportive services; for example, there is often contact with peers who share their experiences and knowledge. Given that a lack of knowledge has been reported as an important barrier in accessing formal care, these findings emphasize the need for information provision in the early stages of help-seeking [4, 11, 36].

These analyses have some limitations. The trajectory over a one-year follow-up period may not be the same as that over a longer period of time. Although being on the verge of needing formal care services was an inclusion criterion, this was based on the expert opinion of a clinician and for various reasons, many dyads did not in fact take up additional services during the year. The service use variable is itself quite general, reflecting use at either follow-up point, and not taking into account differences in timing of the service uptake, the extent or intensity of service use, or any change in circumstances leading to it. Therefore, future studies could consider looking at characteristics and timing of service use into more detail. The caregiver profiles could be validated in other samples, perhaps with greater numbers of younger caregivers, given that only 2 clusters emerged for younger caregivers, compared with 3 for older caregivers. However, our results do help validate patterns of caregiving contexts that may have clinical utility.

Conclusion

The different established caregiver profiles [12] have demonstrated their predictive value when examining dementia care use. The profiles include a broad range of information relating to the person with dementia and the informal caregiver, and therefore can provide useful information for professionals. These results suggest that some caregiver groups need more guidance in finding optimal access to formal care to ensure maintenance of independence in their home situation. Also, it seems important for clinicians to apply a more systemic approach, focusing on the relationship of the person with dementia and their spouse. In addition, the use of supportive and less intrusive, non-personal services in the early stages of dementia is recommended, as they could both provide information and lower the threshold to use more formal care in later stages. These findings could feed an intervention in which supportive services are introduced in an early stage, to investigate whether this indeed improves access to care.

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General introduction

| 8

Introduction

The aim of this thesis was to investigate the access to and use of formal dementia care services for community-dwelling people with dementia and their informal carers living in Europe. The relationship between specific care needs and quality of life is described in chapter 3. In addition, we determined whether there is equity in access to dementia care across Europe (chapter 4). Experiences concerning access to and use of formal care is described (chapter 5&6). Lastly, the usefulness of caregiver profiles as predictors for formal care use was investigated (chapter 7). In this last chapter an overview of the main findings is presented, as well as methodological considerations. In addition, implications for clinical practice and directions for future research are addressed.

Main findings

1. Which needs do home-dwelling people with dementia and their caregivers experience when formal care is not yet in place? (chapter 3)

Selecting a group of community-dwelling people with dementia and their caregivers who did not use formal care yet, but were expected to do so within the next year, allowed us to examine the domains and severity of needs in this specific phase. Informal carers reported almost twice as many needs as people with dementia, which supports previous research [1]. These differences in perspective may lead to conflicts within the dyad regarding the necessity and acceptance of care resulting in challenging situations for professionals. As needs increased, reported quality of life decreased for both the person with dementia and the informal carer [2]. This emphasizes the importance of meeting needs from early in the disease progress onwards, and to keep assessing needs on a regular basis. The highest numbers of needs were reported in the domains of psychological distress, daytime activities, company and information, which is in line with previous findings [3, 4], and with findings from studies regarding young onset dementia [5].

2. Is there equity to formal dementia care in Europe? (chapter 4)

The Andersen Behavioural Model of Health Service Use has been used extensively to predict all kinds of service use [6]. The model can indicate equity in access to care, by assessing the role of predisposing, enabling and need variables [7]. If predisposing variables such as gender, age and education, predict service use, this is an indicator for inequity in access. We found that the major drivers for service use were needs, disease severity and a high amount of hours spent on informal care. Living arrangement was a significant predictor as well, where formal care is commenced earlier if the person with dementia is living alone. In absence of a co-resident informal carer, the need for formal care might become more urgent. While analysing region of residence it became apparent that those living in the North of Europe find easier access to care compared to those dyads in the South or Middle of Europe.

This could be explained by a larger availability of care [8] and by the role of culture, where family caregiving is seen as a moral obligation in Southern countries [9]. The predisposing variables gender and age significantly predicted some types of care use, where a higher age of the person with dementia was related to personal home care. Concerning gender, day care was used more in the presence of a female primary caregiver, and admission was used more if the person with dementia was male. Previous studies generated contradictory findings, so the role of gender remains ambiguous [10, 11]. Overall, we could not conclude that there is inequity access to all types of dementia care, but gender and age do play a role in finding access to some subtypes of care.

3. How do people experience the access to and use of formal care? (chapter 5&6)

In chapter 5 a qualitative study was presented, in which we delved deeper into the experiences and attitudes of people with dementia and their informal carers towards the access to and use of formal care services. They expressed the necessity for having both sufficient information and a key contact person to guide them while monitoring their needs. In some countries this is more in place than others, such as case managers (NL) or dementia advisors (NO). Besides having a key contact person, it is important to involve your social network as they can take on caregiving tasks. Having a solid social network was also reported as one of the main reasons for the non-use of formal care. When being interviewed about needs, people with dementia report more social needs than needs in physical domains. Concerning decision-making, the person closest to the person with dementia is the one who makes the ultimate decision in the majority of cases, and should therefore be supported by health care professionals in this decision-making process. Dyads indicated that conflicts can easily arise, and that these are difficult to be dealt with by professionals.

In chapter 6 experiences of caregivers regarding timeliness, access and satisfaction of formal care use were described. Overall, people reported that care was offered in a timely manner, and that they were satisfied about the process of accessing care. Also in these semi-structured interviews, dyads emphasized the important role of healthcare professionals in increasing awareness and opportunities for service access. If the perceived value of services can be improved through better information and exposure this might facilitate timely access of services and reduce reactive uptake during crisis situations [12].

4. Are caregiver profiles useful predictors for formal care use? (chapter 7)

The challenge of understanding all factors that influence the uptake of formal care arises from the complex interplay between the characteristics of the services and the individuals involved. By using caregiver profiles, we tried to encompass as many characteristics as possible, such as disease severity, behavioural problems, age, caregiver burden and caregiver stress. Five profiles were revealed with a latent class analysis: Younger Low Strain, Younger High Strain, Older Low Strain, Older Intermediate Strain and Older High Strain [13].

An interesting group that appears to have found successful coping strategies is the Older Intermediate Strain group, in which the objective burden is the highest, but the subjective reported burden is relatively low. These caregivers are more likely to use supportive services at baseline, and they have the highest numbers of service use after one year. Overall, the high strain caregiver groups as well as the younger caregiver groups use more formal care. The latter can be explained by a parent-child relationship, in which the child is often still employed and lacks time to provide full-time care for their parent. These results suggest that some caregiver groups need more guidance in finding optimal access to formal care to ensure maintenance of independence in their home situation.

The use of low-intensity less intrusive services early in the dementia process was significantly associated with the use of home personal care and admission after one year. This supports previous Actifcare findings [14], where a gradual build-up of care is favoured. The use of supportive services such as support groups or Alzheimer cafes was significantly associated with the use of day care after one year, which could be explained by information provision and contact with peers at these types of services.

Methodological considerations

This thesis has several methodological strengths and limitations, which will be discussed below.

Strengths

A variety of research methods was used in the study, creating a unique dataset: literature reviews, focus groups, expert interviews, cost-consequence analyses and a cohort study. Access to care was therefore studied from different angles, encompassing barriers and facilitators, quality of life, costs and predicting factors. This enabled us to provide well-founded input for clinical practice.

Within the Actifcare study, our focus was on a specific group of community-dwelling people with mild to moderate dementia that were, at baseline, not yet using any formal care on account of their dementia. Part of the inclusion criteria was that they were expected to start using formal care in the next year. This enabled us to investigate dyads who were potentially in transition from informal care exclusively to a combination of formal and informal care, allowing us to explore (potential barriers in) access to formal care. This is, to the best of our knowledge, the first international study considering this specific group. The cohort covers a large number of participants from eight European countries, resulting in a heterogeneous sample. In addition, participation of countries in North-, Middle- and South- Europe enabled a large cross-country comparison, and allowed us to learn from other healthcare policies and cultures.

Another strength of the Actifcare cohort study is the use of a mixed methods approach, with both quantitative and qualitative measures, exploring the perspectives of the per-

son with the dementia as well as their informal caregiver. Measurements took place in a well-structured manner with intervals of six months, and included a self-rated and proxy-rated version in the majority of the questionnaires. Investigating both perspectives is especially valuable in research concerned with care needs and experiences. The qualitative data provided more in-depth insights into the experiences and attitudes of the dyads, enabling us to answer questions arising from the quantitative analyses.

Limitations

There are also some limitations that have to be considered. First of all, one of the potential limitations is selection bias. People who refuse services are not likely to take part in a study concerning needs and service use, as they prefer no interference. This is unfortunate, as it would be interesting to include this specific group as well, to explore their attitudes regarding support. In addition, people with dementia without a primary informal caregiver with whom they were in regular contact could not be included due to our inclusion criteria. However, it might have been valuable to gather information about the care pathways of those without a social network.

Second of all, one of the inclusion criteria of the Actifcare cohort study was that people were expected to start using formal care within the next year. However, the numbers of service use uptake were smaller than expected, probably because the study period may have been too short. As we were limited by the current design of the study, the follow-up period was extended with assessments at 36, 48 and 60 months. During these assessments (taking place in the Netherlands, Norway, Sweden, Italy and Portugal) via telephone, we will gather information about the current living situation, service use and informal care, aiming to provide a complete picture of the pathways and access to formal care.

Third of all, there were differences in recruitment of dyads between countries, where some countries only approached dyads in the hospital, while others recruited mainly via general practitioners and community mental health teams. This may have led to differences between countries in our sample. However, the heterogeneity of this sample represents the diversity of the normal population of people with dementia and their caregivers throughout Europe.

Clinical implications

The findings of this cohort study have several implications for clinical practice. Besides the cohort study described in this thesis, other research methods were used within the Actifcare project, such as literature reviews, focus groups and expert interviews. Based on all Actifcare findings, 23 best practice recommendations have been developed by means of a Delphi consensus panel. The recommendations are concerned with enhancing access to care, enhancing the use of care, and with factors that facilitate access or use indirectly [15] [16].

The key recommendation was to have one appointed proactive contact person, whom they can contact when they are in need or when they need specific information. This was not only firmly expressed by the dyads in our cohort study, but also resulted clearly from other parts of Actifcare such as the expert interviews and focus groups [17] [18]. People with dementia and their informal caregivers indicated that it is confusing to have so many different people to turn to, and the abundance of different health care professionals with different specializations has the undesired effect that dyads did not know who to address. This finding supports previous research [19] indicating that having a specific contact person is an indicator for best practice.

We are fully aware that this recommendation has been suggested before, but the availability of a key contact person has varied to a great extent in the last years. This could be due to economic motives, but also due to policy-related motives. Across European countries there is a large variation in the way the role of the contact person was operationalized, and there is an urgent need to empower their skills and competencies. In contrast to general beliefs dyads also experience the lack of a key contact person in the Netherlands, where some of these tasks are embodied by the casemanager. In Norway some of these tasks are carried out by a so-called dementia advisor, but in the majority of European countries this function, and in particular the continuity of this function is lacking.

Key contact person

One of the main clinical implications of this thesis therefore pertains implementing the function of a key contact person. Merely availability of a contact person is not sufficient, as the focus should be on their tasks and competences. Below, we will point out which tasks should be carried out by an appointed contact person.

Tasks of the key contact person

Support during decision-making

Findings from chapter 3, as well as previous research [1] indicate differences in needs assessment between people with dementia and their informal caregiver. The latter expresses almost twice as many needs as the person with dementia. It seems that people with dementia experience less needs, which may cause tension at home and consequently leads to conflicts. These discrepancies can form an obstacle in decision-making concerning service use. Health care professionals have the difficult task to try to take into account both opinions in the search for the most fitting solution. Accordingly, health care professionals are advised to follow training such as conversation techniques or motivational interviewing. Motivational interviewing is an interaction-method aimed at assisting behavioural change.

The goal of motivational interviewing is to ensure that intrinsic motivation is increased in order for behavioural change to come from within as opposed to extrinsically [20, 21]. This has proven to be an effective method in a wide range of other clinical pictures (diabetes, alcohol abuse) and in overall treatment adherence [21].

Advise supportive services in the early stages

Results from chapter 7 indicate that it is important to use supportive services in the early stages of dementia, as this paves the way to other types of support such as day care. In the context of these supportive services, information is provided and peers share their experiences, which might change one's attitude towards care, and as such can be useful in decreasing barriers. This can be related to the finding that the preference of a gradual build-up of services was expressed by dyads [14], as this allowed them to slowly get used to the idea of relinquishing care, and in allowing a stranger into their home. Overall, the use of supportive and less intrusive, non-personal services in the early stages of dementia is to be advised, as these offer information as well as lower the threshold to use more formal care in later stages and possibly delay nursing home placement. These findings can be linked to the needs paradox [22], in which caregivers in later stages retrospectively stress the importance of accepting care early on in the disease process, while yet rejecting it in the early stages. This underlines the importance of offering early support with a positive focus, aimed at facilitating the adaptation process. The support and information that is offered should be adapted to specific needs in the early stages, and should not have a stigmatizing character. Since the focus in our Western society lies on remaining autonomous for as long as possible, this may deter dyads as they feel that it is expected of them to remain independent as long as possible. This stresses the need for a personal and proactive approach, and for trustworthy contact persons and healthcare professionals who can convey the importance of accepting care in the early stages to be able to live at home as long as possible. This could amongst others be obtained with motivational interviewing training as discussed above. In addition, health care professionals indicated in a focus group study they use several approaches to develop a bond of trust, such as keeping regular contact, continuity of staff, apply shared decision-making and a gradual build-up of support [18].

Offer personalized information

Both from chapter 5 and 6 and from other Actifcare results [17, 18] it was shown that dyads experience an overall lack of information. In the post-diagnostic stage mainly medical information was provided, while people expressed the need for practical advice. Up to date information about the availability of services in their region was lacking as well, and dyads were often not aware of their prospects and possibilities. This stresses the need for personalized information, not only regarding the dementia, but also regarding services adjusted to one's needs.

Care needs of people with young onset dementia are for example very different from those with late onset dementia [23]. Besides, needs are subject to change throughout the disease, which emphasizes the importance for regular needs assessment [24]. One of the tasks of the contact person could therefore be to regularly assess (changes in) the dyads' needs, to proactively monitor these needs closely, and to offer personalized information accordingly.

Invest in a social network

In Chapter 2, one of the most frequently mentioned unmet need was expressed in the domain of company. Results of the in-depth interviews in chapter 5 indicate that it is important for a dyad to have a reliable social network. Having a social network was also mentioned as one of the main reasons for the non-use of formal care, as friends or family can take on caregiving tasks. In addition, it decreases feelings of loneliness. However, a previous study reported that there is a mismatch between supply and demand of support of the social network, as there are both barriers to ask for as well as to offer support [25]. The dyad may experience a barrier to reach out due to stigma around dementia, and due to their wish to remain autonomous. The contact person could try to convey to the dyad that open communication is crucial, and that the social network often wants to offer help but does not know how to approach this. Those without a social network should be monitored more closely, as they have less resources to rely on and are more likely to have unfulfilled care needs as the dementia progresses.

Overall, many of the tasks described above could be carried out by an appointed contact person, in order to guide the dyad along the path from diagnosis onwards. In case of absence of a contact person, these tasks should be referred to other health care professionals with a coordinating role who are involved with the dyad.

Future research directions

The results of this thesis have important implications for future research. We established the importance of and need for a continuous key contact person. Specific recommendations were developed to equip them with the appropriate resources and competences, in order to enhance equity in access to care. To investigate whether these recommendations result in better access to care, studies are warranted to explore the training and efficacy of a key contact person in multiple countries, to allow cross-country comparison.

In the Netherlands, these tasks could for example be carried out by the so-called casemanager. Casemanagement is a form of long-term guidance for community-dwelling dyads, and it is offered in many ways, where differences can be found in e.g. the type of tasks and the degree of collaboration with other professionals. In many studies the effect of casemanagement has been evaluated [26].

When two types of casemanagement were compared to a group receiving no such support, the latter reports more (un)met care needs and a lower quality of life [26]. Previous studies have also shown that the use of a casemanager can lower care costs for informal care and day care on the long term [27]. In the Netherlands, up until now it is not financed nor offered in a continuous manner.

The discussion concerning casemanagement can be linked to our own results showing that dyads prefer a gradual build-up of services, and that the use of supportive services early on ameliorates access to care. This highlights the importance for future research to focus on the effect of person-centered support in the early stages, as this may eventually decrease care costs, increase quality of life and improve access to care.

Conclusion

The findings presented in this thesis provide a unique insight into the experiences of people with dementia and their informal caregivers while accessing formal dementia care services. We have described the role of barriers and facilitators in this process, and have found relevant predictors for equity in access to care across Europe. Attention should be paid to vulnerable dyads without a social network, and the use of supportive services should be advised in the early stages of the dementia. Dyads expressed the need for a continuous key contact person to guide them throughout the disease process. The Actifcare results are translated into best practice recommendations, and inform health care professionals and health care systems which steps to take to enhance the access to and use of formal dementia care services.

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Addendum

Summary
Samenvatting
Knowledge valorization
Dankwoord
Thesis defences from MHeNs
List of publications
Curriculum Vitae

Summary

Many countries pursue health policies aimed at empowering people with dementia to live at home as long as possible, while being offered a variety of community and social care services. In the beginning of the dementia process the majority of this group is offered support and care by informal caregivers, such as family or friends. When needs increase and informal care alone may not suffice, care from health and social care agencies in the community may be required. There is a broad range of formal care services to be offered, but we know from previous research that one third of people with dementia and their informal caregivers often do not use these services. In addition, the majority of people with dementia and their informal caregivers experience difficulties in finding access to formal care services, and they indicate that received care is often not of the right type. The general aim of this thesis was to investigate the access to and use of formal dementia care services for those living in Europe. Predictors of service use were investigated, as well as experiences and attitudes of people with dementia and their informal carers.

Data from the Actifcare (Access to timely formal care) study was used. A general introduction, the study rationale and research questions are discussed in the introduction of this thesis (Chapter 1).

In Chapter 2 the rationale and design of the Actifcare study is presented. This longitudinal one-year cohort study was carried out in eight European countries (The Netherlands, Germany, United Kingdom, Ireland, Sweden, Norway, Portugal, Italy). The study included people with mild-moderate dementia and their informal caregivers, with measurements at baseline, six months and after one year. People were followed in the process of accessing formal care, and data was gathered on amongst others, service use, needs and quality of life. In addition, in-depth interviews were carried out to investigate experiences and attitudes concerning accessing formal care.

In Chapter 3 we investigated the domains and level of needs of people with dementia and their families during the phase in which formal care is being considered, and we examined whether higher need levels are related to lower quality of life. Needs were primarily expressed in the domains of psychological distress, daytime activities, company and information. In addition, the results show that informal carers reported almost twice as many needs as people with dementia. Our cohort consisted of community-dwelling people with dementia who did not yet use formal care, and for whom the informal carer provides most of the care. We were interested in seeing whether this was reflected by a lower quality of life. As needs increased, reported quality of life decreased for both the person with dementia and the informal carer.

Chapter 4 is concerned with the Andersen Behavioural Model of Health Service Use. With this model equity in access to dementia care can be indicated, by assessing the role of predisposing, enabling and need variables. If predisposing variables such as gender, age and education, predict service use, this is an indicator for inequity in access. We found that the major drivers for service use were a higher number of needs, increased disease severity and a higher amount of hours spent on informal care. Living arrangement was a significant predictor as well, where formal care is commenced earlier if the person with dementia is living alone. A higher age of the person with dementia was related to the uptake of personal care at home. Those living in the North of Europe found easier access to care compared to those dyads in the South or Middle of Europe. Concerning gender, day care was used more in the presence of a female primary caregiver, and admission was used more if the person with dementia was male. Overall, we could not conclude that there is inequity in access to all types of dementia care, but gender and age do play a role in finding access to some subtypes of care.

In chapter 5 a qualitative study was presented, in which we delved deeper into the experiences and attitudes of people with dementia and their informal carers towards the access to and use of formal care services. They expressed the necessity for having both sufficient information and a key contact person to guide them while monitoring their needs. Besides having a key contact person, it is important to involve your social network as they can take on caregiving tasks. Having a solid social network was also reported as one of the main reasons for the non-use of formal care. When being interviewed about needs, people with dementia report more social needs than needs in physical domains. Concerning decision-making, the person closest to the person with dementia is the one who makes the ultimate decision in the majority of cases. Dyads indicated that conflicts can easily arise, and that these are difficult to be dealt with by professionals.

In chapter 6 experiences of caregivers regarding timeliness, access and satisfaction of formal care use were described. Participant responses were summarized using content analysis. Then, answers were categorized into clusters and frequencies were calculated. Overall, people reported that care was offered in a timely manner, and that they were satisfied about the process of accessing care. Dyads emphasized the important role of healthcare professionals in increasing awareness and opportunities for service access. If the perceived value of services can be improved through better information and exposure this might facilitate timely access of services and reduce reactive uptake during crisis situation.

Summary

In Chapter 7 caregiver profiles were investigated, in which as many characteristics as possible were encompassed, such as disease severity, behavioural problems, age, caregiver burden and caregiver stress. In a previous Actifcare publication, five profiles were revealed with a latent class analysis: Younger Low Strain, Younger High Strain, Older Low Strain, Older Intermediate Strain and Older High Strain. An interesting group that appears to have found successful coping strategies is the Older Intermediate Strain group, in which the objective burden is the highest, but the subjective reported burden is relatively low. These caregivers are more likely to use supportive services at baseline, and they have the highest numbers of service use after one year. Overall, the high strain caregiver groups as well as the younger caregiver groups use more formal care. These results suggest that some caregiver groups need more guidance in finding optimal access to formal care to ensure maintenance of independence in their home situation. The use of low-intensity less intrusive services early in the dementia process was significantly associated with the use of home personal care and admission after one year. The use of supportive services such as support groups or Alzheimer cafes was significantly associated with the use of day care after one year, which could be explained by information provision and contact with peers at these types of services.

Chapter 8 provided a discussion of the main findings together with methodological considerations. In addition, clinical implications of the results in this thesis are presented, with recommendations for future research.

Samenvatting

In veel landen wordt een zorgbeleid nagestreefd waarin mensen met dementie worden ondersteund om zo lang mogelijk thuis te wonen, waarbij ze verschillende types zorg thuis krijgen aangeboden. In de vroege fase van dementie krijgt de meerderheid van deze groep hulp aangeboden in de vorm van mantelzorg, door bijvoorbeeld familie of vrienden. Wanneer het aantal behoeftes toeneemt en enkel mantelzorg niet meer genoeg is kan hulp vanuit zorgorganisaties in de gemeente worden ingeschakeld. Het zorgaanbod is breed, maar we weten uit eerder onderzoek dat één derde van de mensen met dementie en hun mantelzorgers dit soort zorg niet inschakelt. Daarnaast ervaart de meerderheid moeilijkheden met het vinden van toegang tot formele zorg, en ze geven aan dat de zorg vaak niet goed bij de behoeften aansluit. Het doel van dit proefschrift is om de toegang tot en het gebruik van formele dementiezorg te onderzoeken voor hen die in Europa wonen. Voorspellers van zorggebruik worden onderzocht, en ervaringen van mensen met dementie en hun mantelzorgers omtrent zorggebruik worden beschreven. Daarvoor is data van het Actifcare (Access to timely formal care) onderzoek gebruikt. Een algemene introductie, de aanleiding van het onderzoek en de onderzoeksvragen worden toegelicht in hoofdstuk 1.

In hoofdstuk 2 wordt de aanleiding en het design van de Actifcare studie toegelicht. Dit longitudinale 1-jaar durende onderzoek is uitgevoerd in acht Europese landen (Nederland, Duitsland, Engeland, Ierland, Zweden, Noorwegen, Portugal en Italië). Mensen met milde tot matige dementie zijn bezocht op baseline, na zes maanden en na twaalf maanden, waarbij een heel aantal vragenlijsten werd afgenomen. Mensen werden gevolgd in het proces van toegang vinden tot formele zorg, en we hebben onder andere informatie verzameld over zorggebruik, behoeftes en kwaliteit van leven. Daarnaast zijn er diepte-interviews afgenomen om meer te weten te komen over ervaringen met en attitudes tegenover toegang vinden tot formele zorg.

In hoofdstuk 3 hebben we de aantallen en soorten behoeftes van mensen met dementie en hun voornaamste mantelzorgers onderzocht, in een fase waarin formele zorg werd overwogen. Daarnaast hebben we onderzocht of een hoger aantal behoeftes geassocieerd is met een lagere kwaliteit van leven. Behoeftes werden vooral geuit in de domeinen psychische nood, dagbesteding, gezelschap en informatie. Daarnaast zagen we dat mantelzorgers twee keer zoveel behoeftes rapporteerden als de personen met dementie. Ons cohort bestaat uit mensen met dementie die thuis wonen, en die op baseline nog geen formele zorg gebruiken. De zorg die wordt verleend wordt dus met name door de voornaamste mantelzorgers ingevuld. We hebben onderzocht of dit werd weerspiegeld door een lagere kwaliteit van leven van de mantelzorgers. De resultaten laten zien dat kwaliteit van leven lager was voor de persoon met dementie en de mantelzorgers zodra het aantal behoeftes toenam.

In hoofdstuk 4 staat het Andersen Behavioural Model of Health Service Use centraal. Met dit model kan gelijkheid in toegang tot zorg worden bepaald, door de invloed te berekenen van predisponerende, faciliterende, en behoefte-gerelateerde factoren. Als predisponerende factoren zoals geslacht, leeftijd, of opleiding zorggebruik voorspellen, dan betekent dit dat er ongelijke toegang tot zorg is. We hebben gevonden dat een hoger aantal behoeftes, hogere ziekte-ernst en een hoger aantal uren besteed aan informele zorg significante voorspellers zijn van zorggebruik. Daarnaast werd er eerder formele zorg gebruikt wanneer de persoon met dementie alleen woont. Persoonlijke thuiszorg werd eerder ingeschakeld wanneer de persoon met dementie ouder is. Mensen die in het noorden van Europa wonen gebruiken meer zorg in vergelijking met mensen die in het zuiden of midden van Europa wonen. Wanneer we kijken naar de rol van geslacht, dan zien we dat dagopvang meer werd gebruikt wanneer de mantelzorger vrouw is, en dat er eerder tot opname wordt overgegaan wanneer de persoon met dementie man is. Over het algemeen konden we niet concluderen dat er ongelijke toegang is tot dementiezorg, maar dat geslacht en leeftijd wel een rol spelen in het vinden van toegang tot bepaalde soorten zorg.

In hoofdstuk 5 worden de resultaten van een kwalitatieve diepte-interview studie beschreven. Hierin hebben we onder andere de attitudes van mensen met dementie en mantelzorgers tegenover zorggebruik geëxploreerd. Participanten benadrukten het belang van voldoende informatie krijgen, en van één aangewezen contactpersoon die hen begeleidt en behoeftes regelmatig peilt. Daarnaast is het van belang om je sociale netwerk te betrekken omdat zij kunnen helpen met verschillende taken. Het hebben van een sterk sociaal netwerk werd ook genoemd als één van de redenen om geen formele zorg te gebruiken. Mensen met dementie geven zelf aan dat ze meer sociale behoeftes ervaren dan fysieke behoeftes. Omtrent besluitvorming geven mantelzorgers aan dat de persoon die het dichtst bij de persoon met dementie staat vaak de uiteindelijke beslissing maakt. Ook geven ze aan dat er gemakkelijk conflicten kunnen ontstaan tussen de mantelzorger en de persoon met dementie, en dat het voor zorgprofessionals moeilijk is om met dit soort conflicten om te gaan.

In hoofdstuk 6 worden de ervaringen van mantelzorgers beschreven omtrent het vinden van (tijdige) toegang tot zorg, en omtrent tevredenheid met zorggebruik. In gestructureerde interviews werden deze onderwerpen besproken. Over het algemeen rapporteerden participanten dat zorg werd aangeboden op een tijdige manier, en dat ze tevreden waren over het proces van toegang vinden tot zorg. Dyades benadrukten het belang van de rol van zorgprofessionals in het wijzen op en het aanbieden van services. Als het belang van zorggebruik beter kan worden overgebracht door middel van betere informatie dan zou dit tijdige toegang tot zorg kunnen faciliteren.

Samenvatting

In hoofdstuk 7 staan mantelzorgers centraal. In deze profielen zijn verschillende kenmerken opgenomen, zoals ziekte ernst, gedragsproblemen, en door de mantelzorgers ervaren belasting en stress. In een eerdere Actifcare publicatie zijn vijf mantelzorgers profielen gedefinieerd door middel van een latente klasse analyse: Jonger Lage belasting, Jonger Hoge belasting, Ouder Lage belasting, Ouder Gemiddelde belasting en Ouder Hoge belasting. Een interessante groep die een succesvolle coping strategie gevonden lijkt te hebben is de Ouder Gemiddelde belasting groep, waarin de objectieve belasting het hoogst is, maar de subjectieve belasting het laagste. Deze mantelzorgers gebruikten meer ondersteunende hulp op baseline, en hadden het hoogste percentage zorggebruik na een jaar. Over het algemeen gebruikten de groepen met hoge belasting en de jongere mantelzorgers groepen meer formele zorg. Deze resultaten suggereren dat sommige mantelzorgers meer ondersteuning nodig hebben in het vinden van de optimale toegang tot formele zorg zodat ze hun onafhankelijkheid thuis zo lang mogelijk kunnen handhaven.

Het gebruik van minder intensieve en ingrijpende zorg (zoals tafeltje dekje) in de vroege fase van dementie was significant geassocieerd met het gebruik van persoonlijke thuiszorg en opname na één jaar. Het gebruik van ondersteunende hulp zoals praatgroepen en Alzheimer cafés was significant geassocieerd met het gebruik van dagopvang na één jaar. Dit kan worden verklaard door het contact met lotgenoten en het verschaffen van informatie aldaar.

In hoofdstuk 8 worden de resultaten samengevat en worden de methodologische aspecten besproken. Ook is er hier aandacht voor de implicaties van de bevindingen voor de klinische praktijk en voor aanbevelingen voor toekomstig onderzoek.

Knowledge Valorization

Societal relevance

Currently, 47 million people worldwide live with dementia. Due to the fact that the population is aging these numbers are expected to double within the next 30 years. This will have great economic consequences as public health care costs will increase accordingly. In a response, the World Health Organization has recently highlighted dementia as a global public health priority.

In absence of a cure for dementia, the optimization of care is crucial. In this context, an early diagnosis is important as it opens the door to care and treatment, and as such can help people with dementia and their informal caregivers to take control of their lives. Many countries in Europe have adopted strategies to foster timely recognition of dementia. Besides timely recognition, timely access to dementia care services is important. Despite these strategies, people with dementia and their informal caregivers are often not satisfied with the type, quality and timing of care that is offered. The majority of people with dementia live at home with the support of informal care. When the dementia progresses and needs increase, this might need to be complemented with formal care at home.

Living at home with the use of informal and formal care is encouraged because of the economic advantages: institutionalization is the main health care cost-driver for elderly, and for people with dementia in particular. With the postponement of nursing home placement, health care costs could be reduced to a great extent. In addition, crisis situations can be prevented as people are monitored more closely at home. Therefore, it is of crucial importance that people can easily find their way to formal care.

Target groups

The findings presented in this thesis are relevant for people with dementia and their informal carers as well as for health care professionals and (inter)national policy makers.

Many countries are adopting strategies to ensure that people with dementia can live at home as long as possible with the right type of care. In this way, they can maintain their integrity and independence at home, and enjoy a higher quality of life. Within the Actifcare project, best practice recommendations have been developed based on all study outcomes. These best practice recommendations are of importance for policy makers and national decision makers who are in the process of reforming their health and social systems. There would not only be societal but also economic benefits if access to formal care would be optimized, and if people are enabled to live in their homes longer with a higher quality of life.

The findings of the Actifcare study are also important for people with dementia and their informal caregivers. They have been involved to a large extent in the cohort study and the in-depth interviews, and have shared their experiences and attitudes with us. Based on these, we described the optimal access to care. Moreover people with dementia and their informal caregivers would benefit from the implementation of the developed best practice recommendations. If recommendations concerned with for example a specific dementia training for health care personnel or better psychoeducation after a diagnosis would be implemented, this would have a direct positive effect for care users.

Lastly, our findings are of interest to health care professionals. In the list of best practice recommendations, there are very specific recommendations for the training and education of dementia health care professionals. There is for example a detailed description of the competences and skills that a key contact person should be enabled with. In addition, we provide advice for creating the optimal circumstances for overall access to dementia care, which is useful for professionals to ensure that they can provide care which is easy accessible, personal and tailored to needs.

Activities and products

Next to the cohort study presented in this thesis, a multitude of other research methods have been used. Literature reviews have been conducted and expert interviews were carried out with policy makers, health care professionals, health care insurers and clinicians. Besides, focus groups were organized with people with dementia, informal caregivers and health care professionals. Based on all Actifcare findings, 23 best practice recommendations have been developed by means of a Delphi consensus panel. The recommendations are concerned with enhancing access to care, enhancing the use of care, and with factors that facilitate access or use indirectly. To enhance access, it is recommended that each person with dementia is appointed a contact person with defined competencies and tasks. The contact person should establish contact proactively as soon possible in the disease process, provide individualized information about available services, assess needs regularly and facilitates access to services. To enhance use, measures are described as to how services can be made attractive so people would want to use them. Recommended enabling factors that can facilitate access or use indirectly are for instance training of health care personnel, including the general practitioner, and raising awareness about dementia through the educational system and mass media.

Each Actifcare country hosted a national meeting to present and discuss these best practice recommendations. Attendees for this meeting were government agencies, policy makers, researchers, healthcare providers and insurers, primary care organizations, dementia organizations (e.g. Alzheimer societies), and experts by experience (i.e. people with dementia and their family carers). The aims were to discuss the implementation, to propose a prioritized list of the recommendations that have not already been implemented and to describe action points that should be executed to implement them. Each country was free to design the meeting according to its own views, for example, a World Café Method was used in the Netherlands. In all countries the discussion was semi-structured and the facilitators aimed to address questions regarding the importance of the best practice recommendations in each country. They can be integrated in existing European health and social care systems in order to enable national decision makers to base their decisions on the best knowledge available when they reform the organization of dementia care.

Innovation

Actifcare was the first large European longitudinal cohort study to investigate access to formal dementia care for community-dwelling people with mild to moderate dementia. The variety of research methods enabled us to cover a wide range of opinions and experiences. The Actifcare Best Practice Recommendations represent a step forward from describing barriers to access by suggesting practical measures to overcome the barriers, based on the existing knowledge. The key recommendation was to have one appointed proactive contact person, whom they can contact when they are in need or when they need specific information. This was not only firmly expressed by the dyads in our cohort study, but also resulted clearly from the Actifcare expert interviews and focus groups. People with dementia and their informal caregivers indicated that it is confusing to have so many different people to turn to, and the abundance of different health care professionals with different specializations has the undesired effect that dyads did not know who to address.

We are aware that this recommendation has been suggested before, but the availability of a key contact person has varied to a great extent in the last years. This could be due to economic motives, but also due to policy-related motives. Across European countries there is a large variation in the way the role of the contact person was operationalized, and there is an urgent need to empower their skills and competencies. In contrast to general beliefs dyads also experience the lack of a key contact person in the Netherlands, where some of these tasks are embodied by the casemanager. In Norway some of these tasks are carried out by a so-called dementia advisor, but in the majority of European countries this function, and in particular the continuity of this function is lacking.

Implementation

Participants of the Actifcare study were updated about the study progress and the results through newsletters. Newspaper articles were published in several countries as well, not only to recruit participants but also to inform about the results. Besides, updates and publications were placed on the website (www.actifcare.eu). Once the results were available, a motion graphic was developed with a voice over for each Actifcare country to summarize the project and the results in a captivating way. In addition, results have been presented at a variety of national and international congresses and symposia with poster and oral presentations. The best practice recommendations generated through this project were presented on national meetings to facilitate implementation. Finally, national institutions, such as Alzheimer Nederland in the Netherlands, will be used to disseminate our scientific findings and accompanying clinical implications.

Dankwoord

Een klein beetje trots ben ik toch wel, nu ik dit boekje voor me zie liggen met mijn eigen naam erop. Ik heb me heel lang niet kunnen voorstellen dat dat echt zou gaan gebeuren, maar nu is het zover: ik ben dr. !

Dit had ik in mijn eentje nooit kunnen doen, dus er zijn een hoop mensen die ik graag wil bedanken:

Op de eerste plaats wil ik alle deelnemers van het Actifcare onderzoek bedanken: bedankt voor jullie gastvrijheid, alle kopjes thee en koekjes, jullie openheid, en voor de mooie inzichten en die jullie mij gegeven hebben. Door jullie te leren kennen kwamen de resultaten van het onderzoek voor mij tot leven, en realiseerde ik me steeds opnieuw waarom dit soort onderzoek belangrijk is.

Daarnaast wil ik mijn promotieteam bestaande uit Frans Verhey, Marjolein de Vugt, Claire Wolfs en Bob Woods bedanken.

Frans, we hebben heel wat uren besteed aan Actifcare overleggen, en jouw enthousiasme over deze mooie studie werkte aanstekelijk. Ook wist jij altijd de juiste vragen te stellen waardoor ik kritisch heb leren nadenken. Onze overleggen op vrijdagmiddag begonnen steevast met wat leuke anekdotes, en ook tijdens de Actifcare-reisjes en de vele Actifcare diners was het altijd heel gezellig!

Marjolein, ik ben altijd onder de indruk van jouw vaardigheid om onderzoeksresultaten te verwoorden op een mooie en treffende manier, en van hoe jij altijd een link weet te leggen met de praktijk. In de laatste weken voor de deadline van mijn proefschrift hebben we veel samen overlegd en had je altijd een goeie peptalk klaar. Dankjewel voor het meedenken en voor de ruimte die je me gegeven hebt om klinische ervaring op te doen!

Lieve Claire, wat heb ik mij vaak gelukkig geprezen met jou als co-promotor! Je maakte altijd tijd, en had altijd aandacht en interesse. Ik heb veel van je geleerd, en hecht veel waarde aan jouw inzichten. Ook hebben we vaak gelachen, zoals op het moment dat we ervan overtuigd waren dat onze benzine bijna op was onderweg naar Brescia of toen we hotelkamers kregen in Stockholm die groter waren dan mijn eigen appartement (inclusief vergaderruimte erbij!)

Dear Bob, thank you very much for your guidance during my PhD. Our Skype meetings and e-mail conversations have been so valuable, as well as your feedback on my articles (and thank you for responding so quickly even when there were so many articles to comment on in the final months!) The way you look at data and results, and how you can link this to daily life is inspiring!

Dear Actifcare colleagues, it has been such a pleasure working with you! Everyone was dedicated and worked hard to establish this rich set of data: I think it is fair to say that we can be proud of ourselves. Thank you for your help and patience as co-authors. Our half yearly meetings were always a lot of fun, ranging from wine tastings in Italy to eating in the same restaurant that Justin Bieber visited in Norway, it just kept getting better and better! A special thanks to Hannah for our collaboration on quite a difficult article! I enjoyed working with you. Janne and Mona, you deserve a big thank you as well- I really enjoyed sitting next to you during all our Actifcare dinners and meeting each other at conferences to share Wilhelmina peppermints.

Zonder alle liefvallige onderzoeksassistenten was het nooit gelukt om al onze deelnemers thuis te bezoeken. Niky, Niels, Rebecca en Claudia: Jullie hebben samen bergen werk verzet en zijn afgereisd naar de meest afgelegen Limburgse plekjes met de meest gekke OV-verbindingen om deelnemers te bezoeken: duizendmaal dank.

Mijn proefschrift was pas helemaal af toen er zo'n mooie kaft voor werd gemaakt: Dankjewel oom Alfred! Balen voor de Kerpershoekjes dat alle creativiteit aan de andere kant van de familie is terecht gekomen, maar gelukkig helpen jullie ons altijd graag. Mike, ik wil jou ook bedanken voor de mooie opmaak van mijn boek en voor de gezellige Skype-overleggen, dat was best een baitje fijn! Sowieso dat de prijs voor beste medewerker van de maand naar jou gaat!

Wanneer thuis werken verstandiger is omdat het op kantoor zo gezellig is weet je dat je op een goede afdeling werkt! Ik heb een ontzettend fijne tijd gehad met een heleboel leuke collega's: een paar daarvan wil ik er in het bijzonder bedanken:

Paranimfjes!

Allerliefste Anja: jij bent misschien nog wel het allerleukste dat deze PhD heeft opgeleverd; zonder jou was dit echt 337 keer minder leuk geweest. Wat een heerlijke humor heb jij, en wat een onzinnige gesprekken kunnen wij voeren. Daarnaast konden we ook onze problemen bespreken en was jij er eigenlijk altijd. Zelfs als we enorm vervelende draken waren konden we nog steeds om én met elkaar nog lachen. Hoe hard ze ook hebben geprobeerd om ons op de afdeling in andere kamers neer te zetten, het is toch mooi gelukt om tot het einde binnen een straal van twee meter naast elkaar te zitten, lekker puh!

Allerliefste Joan, mijn pocket full of sunshine. Met jou is het altijd fijn: je hebt de gave om me heel erg gerust te stellen en om me heel erg aan het lachen te maken. Daarnaast is het heel fijn om met jou te genieten van culinaire hoogstandjes, speciaalbiertjes, feestjes en prachtige selfies. Zelfs als we fietsend door de stromende regen in Rotterdam op zoek zijn naar een feestje kunnen we nog steeds lachen; dit is maar voor weinig mensen weggelegd lijkt mij zo. Ik hoop dat we nog heel lang vriendinnetjes blijven, zelfs nu we out-of-office-chicks zijn!

De andere twee office chicks verdienen ook een dankwoordje: Lieve Liz, you fabulous mama! Wat heb ik genoten van alle koffiemomentjes, Eftelingtripjes (en daar samen een appje proberen te formuleren, is het nou Hi, Hey, of toch beter Hoi?) Dankjewel voor alle gezelligheid. Lieve Roosje, ook jij was er altijd, en was altijd in voor een koffietje of een knuffel: ik hoop dat onze etentjes en pretparkbezoeken een traditie worden die we doorzetten totdat we allemaal echt out-of-office chicks zijn!

Roomies! Niels, wat ben jij een fijne en lieve roomie geweest. Je bent áltijd behulpzaam, geïnteresseerd, altijd in voor een sessie galgje of brainstormen over dilemma's op dinsdag: wat hebben wij samen veel gelachen! Niet alleen op kantoor, maar ook tijdens onze leuke huisbezoeken en Actifcare reisjes: huisbezoeken nabespreken bij de gouverneur, wine tastings met kaas in Italië, samen nerveus zijn voor onze presentaties en elkaar peptalks geven: Dankjewel! Ik ga je wijze uitspraken en onze koffietjes missen.

Dankwoord

Leonie, toen jij ook nog onze roomie werd was het helemaal compleet. Bij jou kan ik altijd terecht voor wijsheden en knuffels, wát een mooi mens ben jij. Samen feesten na een paar flesjes Leffe Blond is iets waar we goed in zijn, net als prosecco drinken in Florence, en peanutbutterballs eten in Amerika: dankjewel voor al die fijne momenten!

Science club, mede feestbeesten: Lieve Olin, ik ken maar weinig mensen die zo goed een mop kunnen vertellen als jij; dankjewel voor al het lachen samen, de koffiemomentjes, de feestjes samen, en met als hoogtepunt de USA reis: kortom: ook nuchter durf ik te zeggen dat jij een fijne toevoeging aan mijn leven bent.

Annemarie, bedankt voor jouw hartverwarmende en aanstekelijke lach (en je niesjes, GEZONDHEID) die je door de muur heen hoort. Oh, en wat is het fijn om samen met jou te en je complexlachje feesten!

Lieve Bert, dankjewel voor het delen van alle mooie gedichtjes, je mooie grapjes (op een schaal van nul tot...), voor het delen van waanzinnige schijfjes en voor het tonen van je epische drum 'n bass moves! Ook heb je mijn meest favoriete stelling verzonnen, waarvoor een klein bedankje toch ook wel op z'n plaats is.

Even later werd dit clubje tot een hoger level getild tot Irrelevant; dit is zeker geen irrelevante uitbreiding geweest! (zien jullie dat het woord nu al 2 keer in m'n proefschrift staat?) eierballen eten in Grunn, gezapige bingo-avondjes, kaasplankjes en complexe Black Box stories ontrafelen. Jullie zijn leuk!

Lieve kleine Linda, ookal spelen we intussen niet meer met de B en laten we onze konijnen niet meer uit in jouw achtertuin, toch blijf jij voor mij altijd kleine Linda. Wat fijn dat we van bijna-buren in de Belvauer nog steeds bijna-buren zijn gebleven op de afdeling, met altijd tijd voor een knuffel en een koffietje tussendoor. Ik hoop dat we onze samen uit-eten traditie zullen voortzetten tot we heel oud en grijs zijn!

Lieve Elles; wij kunnen elkaar nu al een heel aantal jaar, waarin ik altijd een beetje bang werd van hoeveel jij werkte ;) we hebben samen heel wat uren op kantoor, bij cursussen (vooraan het lunchbuffet uiteraard), en in Coffeelovers tentjes doorgebracht. Zomaar een aantal hoogtepuntjes: jouw paranimf zijn op die bijzondere dag, cheesecake eten in Florence, nog een keer cheesecake eten in Florence, truffelpasta eten in Florence, eten bij Gusto...wat is het fijn om vriendinnen te zijn met iemand die net zo blij van eten kan worden als ik!

Lieve Niky, we leerden elkaar kennen als stagiaires, en daarna heb je mijn leven een héel stuk fijner gemaakt als onderzoeksassistent - telefoontjes plegen, planningen maken, 578 keer ID-nummers op boekjes schrijven, huisbezoeken afleggen (die waren samen toch echt het leukst!). De laatste jaren was het heel fijn dat we nog steeds dicht bij elkaar in de buurt zaten, om samen te kunnen lachen en huilen, koffie te leuten, en te Gouverneur daten uiteraard. Ik vind je lief!

Ron, zonder jouw hulp bij statistiek was het waarschijnlijk alleen bij descriptives draaien gebleven! Je kritische vragen en nieuwsgierigheid hebben mij ontzettend geholpen: ik hoop dat ik genoeg repen Tony heb kunnen aanslepen om mijn dankbaarheid te tonen.

Kay -Jij bent nog steeds dezelfde Kay gebleven als tijdens de geschiedenislessen tussen Babs en mij in, alleen ben je nu nóg slimmer! Ron&Nico, dankjewel voor de hulp tijdens alle

paniekmomenten waarop mijn laptop niet deed wat ik wilde, en voor het helpen opzetten van filmmaker, superhandig! Danielle, bedankt voor al je hulp en al je interesse, fijn dat ik altijd bij je binnen kon lopen. Els, ook jij bedankt voor al je hulp en vriendelijkheid. Lieve vrienden en vriendinnen, zonder jullie waren de afgelopen vier jaar ook een stuk minder mooi geweest:

Mijn studententijd (en nee, nu ben ik écht geen student meer) begon in het gezelschap van Diez D'oro: dankjulliewel voor alle fijne avondjes, voor alle Koko feestjes, en voor de fijne reünietjes die we nu nog steeds hebben. Diez D'oro Actief: wij hebben het nog lang volgehouden met z'n drie! Reni, wat ben jij een fijn mens: altijd opgewekt en geïnteresseerd, en altijd in voor een grapje. Juul boft maar met zo'n mama! Lieve Ine, wij hebben samen ongeveer 20973 uur op de bank doorgebracht, en minstens zoveel uren geappt, samen gegeten, of Rodenbach gedronken in Knokke. Wat is het fijn om zo'n buurmeisje gehad te hebben tijdens al die jaren als student, dankjewel!

Lieve Kyra, hoe ver we ook uit elkaar wonen (Spanje, Utrecht, of om de hoek) we zijn altijd buurvrouwen gebleven. Wat hebben wij samen veel meegemaakt: van samen turnen in de slaapkamer en gazpacho maken van met de hand gepelde tomaten (TOEN) tot mojito's drinken in Praag met een verzwikte enkel en dansen op festivals (NU). Zullen we dit blijven doen tot we heel oude buurvrouwen zijn? Ripiditulakis repeed!

Lieve Bitje: we spelen al lang we niet meer buiten, trappen geen miertjes meer dood, en ik doe niet meer zo bazig tegen jou (nee bier!), toch hebben we nog altijd een bijzondere vriendschap waar ik veel waarde aan hecht. I never let go!

Lieve Chrissie en Ilse, mede-peanutbutterlovers- dankjewel voor alle uren op UCM in the common room, voor alle broodjes bij Something Good, voor alle Double Trouble en Alla avondjes, voor alle tripjes die we daarna samen gemaakt hebben, en voor jullie oneindige interesse: jullie zijn zo slim en knuffelbaar en lief!

Lieve Anna, ik weet nog precies wanneer ik jou voor het eerst zag op het schoolplein van Rolduc, en dat ik toen meteen dacht: wow, zij is leuk! Dit denk ik eigenlijk elke keer weer opnieuw als ik je zie, of als ik weer een lief kaartje in mijn brievenbus heb, of een lief appje. Een aantal hoogtepuntjes: onze Nieuw-Zeeland reis, de slappe lach op het strand in Tel-Aviv, het mooie-mannen-poortje, Sziget, samen chocoladeperenoten eten met Kate Nash, zingend en luchtgitaar spelend door de kamer heen springen (of mocht ik dat niet verder vertellen?) Love you An!

Heeeeeeeeeeeeeeeeeeeee Babsie, ook jou ken ik al zo lang: we hebben hele schriften naar elkaar volgeschreven, hele kletsen gepraat op school en dan thuis snel verder msn-en: we zijn gelukkig nog steeds niet uitgepraat! Ik ken maar weinig mensen die zo hard werken mét plezier: ik bewonder jou om je ambitie, en bovenal om je hilarische humor. Niemand zal ons (helaas) ooit zo grappig vinden als wijzelf. Pinkie!

Dankwoord

Lieve Antje, jij was altijd al belangrijk voor mij, maar dit afgelopen jaar werd dat ongeveer verviëfdubbeld: onze appjes, facetimesessietjes, reisjes, motiverende instagram-posts en gedichtjes waren heerlijk. Ook heb ik erg genoten van ons gevraagd en ongevraagd advies aan elkaar, waarbij we er dan toch standaard voor kozen om het compleet tegenovergesteld te doen... dat kan je vast alleen maar pikken van elkaar als je zoveel van elkaar houdt! Antje, you're my person!

Liefste apies, wat is het fijn om twee oudere zussen te hebben om tegenop te kijken en om tegenaan te kruipen.

Lieve Lon: Samen bloemkool eten in de camper in Nieuw-zeeland (ik ga naar het straa-haad), Skydiven, Harry Potter sokken delen, veel te dure cocktails drinken in Florence, lelijke magneetjes kopen voor elkaar, Facetimen terwijl we stomme bekken naar elkaar trekken: ik word blij van jou! Wat is het fijn dat wij exact dezelfde slechte humor hebben, en exact dezelfde aanleg om prachtige selfies te maken: als ik slechte zin heb hoef ik alleen maar even door onze whatsapp-gesprekken heen te scrollen.

Lieve Lin: samen rocken bij Editors met een grijns van oor tot oor, dansen bij Kölsch tot in de late uurtjes, Koffiehuuske-momentjes, luchtgitaar spelen, gewoon met een theetje op de bank hangen en talloze bel-sessies vanuit de auto: van jou word ik al net zo blij! Wat is het fijn dat je weer gewoon binnen een straal van 40 kilometer woont en dat ik zo vaak op bezoek kan komen en gezinnetje kan spelen met jullie. Dankjewel voor al je goede advies: jij weet me altijd op te vrolijken!

En last but most important: papa en mama. Het is zo fijn om nog steeds thuis te kunnen komen wanneer ik daar zin in heb (voor wijze adviezen, om lasagne van mama te eten, voor een knuffel, om goeie wijn te drinken met papa en om gewoon tot rust te komen). Ik ben ontzettend dankbaar dat jullie zo'n fijn en warm nest hebben gecreëerd waar we steeds maar weer naartoe komen vliegen.

Thesis defences from MHeNS - School for Mental Health and Neuroscience

2013

Rob Havermans: Bipolar disorder in daily life; Mood and cortisol responses to naturally occurring events. Supervisor: Prof.dr. M. de Vries; Co-Supervisor: Dr. N. Nicolson.

Véronique Moers-Hornikx: Deep brain stimulation and the cerebellum. Supervisors: Prof.dr. J. Vles / Prof.dr. Y. Temel; Co-Supervisor: Dr. G. Hoogland.

Nicole Veldhorst-Janssen: Intranasal delivery of rapid acting drugs. Supervisors: Prof.dr. M. Marcus / Prof.dr. C. Neef; Co-Supervisor: Dr. P.H. van der Kuy.

Stéphanie Knippenberg: Vitamin D and Multiple Sclerosis: immunological and clinical outcome. Supervisor: Prof.dr. J. Cohen-Ter-vaert; Co-Supervisors: Dr. J. Damoiseaux / Dr. Y. Bols.

Erik D. Gommer: Dynamic Cerebral Autoregulation: from methodology towards clinical application. Supervisors: Prof.dr. W.H. Mess / Prof.dr. R.B. Panerai, UK; Co-Supervisor: Dr.ir. J.P.H. Reulen.

Olga A.H. Reneerkens: Can PDE inhibition improve cognition? Translational insights. Supervisor: Prof.dr. H.W.M. Steinbusch; Co-Supervisor: Dr. J. Prickaerts.

Lyzel S. Elias-Sonnenschein: Clinical and bio- marker correlates of genetic risk factors for Alzheimer's disease. Supervisor: Prof.dr. F.R.J. Verhey; Co-Supervisor: Dr. P.J. Visser.

Diego F. Mastroeni: Epigenetic Dysregulation and the Pathophysiology of Alzheimer's Disease. Supervisors: Prof.dr. H.W.M. Steinbusch / Prof.dr. P.D. Coleman, Sun City, Ari- zona; Co-Supervisors: Dr. B.P.F. Rutten / Dr. D.L.A. van den Hove.

Leonidas Chouliaras: Epigenetic Regulation in Aging and Alzheimer's disease: A translational perspective. Supervisor: Prof.dr. H.W.M. Steinbusch; Co-Supervisors: Dr. B.P.F. Rutten / Dr. D.L.A. van den Hove.

Liesbeth Knaepen: Perinatal events and altered pain sensitivity in later life. Supervisors: Prof.dr. E.A.J. Joosten / Prof.dr. D. Tibboel, EUR; Co-Supervisor: Dr. J. Patijn.

Marisela Martinez-Claros: Hippocampal plasticity and corticosterone: From dendrites to behaviour. Supervisor: Prof.dr. H.W.M. Steinbusch; Co-Supervisors: Dr. J.L. Pawluski / Dr. J. Prickaerts.

Marcus D. Lancé: A circle of improvement in bleeding management: from laboratory to clinic and back. Supervisors: Prof.dr. M.A.E. Marcu / Prof.dr. J.W.M. Heemsker; Co-Supervisor: Dr. Y.M.C. Henskens.

Hilde Braakman: Imaging the brain; neuronal correlates of cognitive impairment in children with frontal lobe epilepsy. Supervisors: Prof.dr. A.P. Aldenkamp / Prof.dr. J.S.H. Vles; Co-Supervisors: Dr.ir. W.H. Backes / Dr. P.A.M. Hofman.

Willem H. van Zwam: Aneurysmal subarach- noid hemorrhage: imaging strategies and cost- effectiveness aspects in diagnostic work-up and post-therapeutic follow-up. Supervisors: Prof.dr. J.T. Wilmink / Prof.dr. J.E. Wildberger; Co-Supervisor: Dr. P.A.M. Hofman.

Klara De Cort: The Pathogenesis of Panic Disorder. Supervisors: Prof.dr. I. Myin-Germeys / Prof.dr. E.J.L. Griez; Co-Supervisors: Dr. K.R.J. Schruers / Dr. I. Van Diest, Leuven.

Kim van Wijck: Mind the Gap; experimental studies on splanchnic hyperfusion and gastrointestinal integrity loss in man. Supervisors: Prof.dr. W.A. Buurman / Prof.dr. C.H.C. Dejong; Co-Supervisor: Dr. K. Lenaerts.

Yvette Roke: Antipsychotic-induced hyperprolactinemia in children and adolescents with mainly autism spectrum disorders. Prevalence, symptoms, clinical consequences and genetic risk factors. Supervisors: Prof. dr. P.N. van Harten / Prof.dr. J.K. Buitelaar (RUN); Co-Supervisor: Dr. A. Boot (UMCG).

Fleur Goezinne: Retinal detachment surgery: pre and postoperative prognostic factors. Supervisors: Prof.dr. F. Hendrikse / Prof.dr. C.A.B. Webers; Co-Supervisor: Dr. E.C. La Heij (Amsterdam).

Ralph L.J.G. Maassen: The Merits of Videolaryngoscopy during Glottic Visualisation for Endotracheal Intubation. Supervisors: Prof. dr. M. Marcus / Prof.dr. A. van Zundert (University of Queensland).

Maria J. de Sousa Guerreiro: The role of sensory modality in age-related distraction. Supervisor: Prof.dr. C.M. van Heugten; Co-Supervisor: Dr. P.W.M. van Gerven.

Ine Rayen: Effects of developmental oxetane exposure on neurobehavioral outcomes. Supervisor: Prof.dr. H.W.M. Steinbusch; Co-Supervisors: Dr. J.L. Pawluski / Dr. T.D. Charlier (Ohio University, USA).

Nynke M.G. Bodde: Psychogenic non-epileptic seizures; a separate disorder or part of a continuum? Supervisors: Prof.dr. R. van Oostenbrugge / Prof.dr. K. Vonck (UZ Gent); Co-Supervisors: Dr. R. Lazeron / Dr. A. de Louw (Epilepsiecentrum Kempenhaeghe, Heeze).

Alejandro M. Gomez: Novel strategies for making myasthenia less gravis: targeting plasma cells and the neuromuscular junction. Supervisor: Prof.dr. M.H. De Baets; Co-Supervisors: Dr. M. Losen / Dr. P. Martinez-Martinez.

Mohammad S. Rahnama'i: Prostaglandins and Phosphodiesterases in the Urinary Bladder Wall. Supervisors: Prof.dr. Ph. Van Kerrebroeck / Prof.dr. S. de Wachter (Universiteit Antwerpen); Co-Supervisor: Dr. G. van Koevringe.

Mariken B. de Koning: Studying biomarkers in populations at genetic and clinical high risk for psychosis. Supervisors: Prof.dr. T. Amelvoort / Prof.dr. J. Booij (AMC).

Fabien Boule: Epigenetic regulation of BDNF/TrkB signaling in the pathophysiology and treatment of mood disorders. Supervisors: Prof.dr. H.W.M. Steinbusch / Prof.dr. L. Lanfumey (Universiteit Parijs); Co-Supervisors: Dr. D. van den Hove / Dr. G. Kenis.

2014

Iris Nowak-Maes: Tinnitus; assessment of quality of life & cost-effectiveness. Supervisors: Prof.dr. M. Peters / Prof.dr. B. Kremer; Co-Supervisors: Dr. M. Joore / Dr. L. Anteunis.

Marjolein Huijts: Cognitive function in patients with cerebral small vessel disease. Supervisor: Prof.dr. R.J. van Oostenbrugge; Co-Supervisors: Dr. A.A. Duits / Dr. J. Staals.

Markus Gantert: Fetal inflammatory injury as origin of long term disease: Lessons from animal models. Supervisors: Prof.dr. B. Kramer / Prof.dr. L. Zimmermann; Co-Supervisor: Dr. A. Gavilanes.

Elke Kuypers: Fetal development after antenatal exposures: Chorioamnionitis and maternal glucocorticoids. Supervisors: Prof.dr. B.W. Kramer / Prof.dr. H.W. Steinbusch / Prof. dr. Suhas G. Kallapur (University of Cincinnati, Ohio, USA).

Pieter Kubben: Ultra low-field strength intraoperative MRI for Glioblastoma Surgery. Supervisor: Prof.dr. J.J. van Overbeeke; Co-Supervisor: Dr. H. van Santbrink.

Thesis defences from MHeNS

Laura Baijens: Surface electrical stimulation of the neck for oropharyngeal dysphagia in Parkinson's disease: therapeutic aspects and reliability of measurement. Supervisor: Prof.dr. B. Kremer; Co-Supervisor: Dr. R. Speyer, Townsville.

Janneke Hoeijmakers: Small fiber neuropathy and sodium channels; a paradigm shift. Supervisor: Prof.dr. R.J. van Oostenbrugge; Co-Supervisors: Dr. C.G. Faber / Dr. I.S.J. Merkies.

Stephanie Vos: The Role of biomarkers in preclinical and prodromal Alzheimer's disease. Supervisor: Prof.dr. F.R. Verhey; Co-Supervisor: Dr. P.J. Visser.

Muriël Doors: The Value of Optical Coherence Tomography in Anterior Segment Surgery. Supervisors: Prof.dr. R.M. Nuijts / Prof.dr. C.A. Webers; Co-Supervisor: Dr. T.T.J.M. Berendschot.

Anneke Maas: Sleep problems in individuals with genetic disorders associated with intellectual disability. Supervisors: Prof.dr. I. Curfs / Prof.dr. R. Didden

Sebastiaan van Gorp: Translational research on spinal cord injury and cell-based therapies; a focus on pain and sensorimotor disturbances. Supervisors: Prof.dr. B. Joosten / Prof.dr. M. van Kleef; Co-Supervisors: Dr. J. Patijn / Dr. R. Deumens, KU Leuven

Andrea Sannia: High risk newborns and brain biochemical monitoring. Supervisor: Prof.dr. J.S.H. Vles; Co-Supervisors: Dr. D. Gazzolo, Alessandria, Italy / Dr. A.W.D. Gavilanes.

Julie A.D.A. Dela Cruz: Dopamine mechanisms in learning and memory: Evidence from rodent studies. Supervisors: Prof.dr. H.W.M. Steinbusch / Prof.dr. R.J. Bodnar, New York; Co-Supervisor: Dr. B.P.F. Rutten

René Besseling: Brain wiring and neuronal dynamics; advances in MR imaging of focal epilepsy. Supervisors: Prof.dr. A.P. Aldenkamp / Prof.dr.ir. W.H. Backes; Co-Supervisor: dr. J.F.A. Jansen.

Maria Quint-Fens: Long-term care after stroke; development and evaluation of a longterm intervention in primary care. Supervisors: Prof.dr. J.F.M. Metsemakers / Prof.dr. C.M. van Heugten / Prof.dr. M. Limburg, Almere; Co-Supervisor: dr. G.H.M.I. Beusmans.

Veronique Moulart: Life after survival of a cardiac arrest; the heart of the matter. Supervisors: Prof.dr. J.A. Verbunt / Prof.dr. C.M. van Heugten / Prof.dr. D.T. Wade, Oxford, UK.

Feikje Smeets: The hallucinatory-delusional state: a crucial connection in the psychosis symptom network. Supervisor: Prof.dr. J. van Os; Co-Supervisor: Dr. T. Lataster.

Lies Clerx: Alzheimer's disease through the MR-eye; novel diagnostic markers and the road to clinical implementation". Supervisor: Prof.dr. F. Verhey; Co-Supervisors: Dr. P.J. Visser / P. Aalten.

Sonny Tan: The subthalamic nucleus in Parkinson's disease. Supervisors: Prof.dr. Y. Temel / Prof.dr. H.W.M. Steinbusch / Prof.dr. T. Sharp, Oxford, UK / Prof.dr. V. Visser-Vandewalle, Koln.

Koen van Boxem: The use of pulsed radiofrequency in the management of chronic lumbosacral radicular pain. Supervisors: Prof.dr. M. van Kleef / Prof.dr. E.A.J. Joosten; Co-Supervisor: Assoc. Prof.dr. J. van Zundert.

Jérôme Waterval: Hyperostosis cranialis interna. Supervisors: Prof.dr. J.J. Manni / Prof.dr. R.J. Stokroos.

Sylvie Kolfschoten-van der Kruijs: Psychogenic non-epileptic seizures; the identification of neurophysiological correlates. Supervisors: Prof.dr. A.P. Aldenkamp / Prof.dr. K.E.J. Vonck, Universiteit Gent; Co-Supervisors: Dr. J.F.A. Jansen / Dr. R.H.C. Lazon, Kempenhaeghe.

Wouter Pluijms: Spinal cord stimulation and pain relief in painful diabetic: polyneuropathy, a translational approach. Supervisors: Prof.dr. M. van Kleef / Prof.dr. E.A. Joosten; Co-supervisor: Dr. C.G. Faber.

Ron Handels: Health technology assessment of diagnostic strategies for Alzheimer's disease. Supervisors: Prof.dr. F.R.J. Verhey / Prof.dr. J.L. Severens (EUR); Co-Supervisor: Dr. M.A. Joore / Dr. C.A.G. Wolfs.

Evelyn Peelen: Regulatory T cells in the pathogenesis of Multiple Sclerosis: potential targets for vitamin D therapy. Supervisors: Prof.dr. R.M.M. Hupperts / Prof.dr. J.W. Cohen Tervaert; Co-Supervisor: Dr. J.G.M.C. Damoiseaux / Dr. M.M.G.L.Thewissen, Diepenbeek.

Reint Jellema: Cell-based therapy for hypoxic-ischemic injury in the preterm brain. Supervisors: Prof.dr. B.W.W. Kramer / Prof.dr. H.W.M. Steinbusch; Co-Supervisor: Dr. W.T.V. Germeeraad / Dr. P. Andriessen, Veldhoven.

Maria Wertli: Prognosis of Chronic Clinical Pain Conditions: The Example of Complex Regional Pain Syndrome 1 and Low Back Pain. Supervisors: Prof.dr. M. van Kleef; Co-Supervisor: Dr. F. Brunner, Zürich / Dr. R. Perez, VUmc.

Dagmar Zeef: An experimental model of Huntington's disease: Validation & Stimulation. Supervisors: Prof.dr. Y. Temel / Prof.dr. H.W.M. Steinbusch; Co-supervisor: Dr. A. Jahanshahi.

Jeroen Decoster: Breaking Down Schizophrenia into phenes, genes and environment. Supervisors: Prof.dr. I. Myin-Germeys / Prof.dr. M. De Hert, KU Leuven; Co-Supervisor: Dr. R. van Winkel.

Eaja Anindya Sekhar Mukherjee: Fetal Alcohol Spectrum Disorders: exploring prevention and management. Supervisor: Prof.dr. L.M.G. Curfs; Co-Supervisor: Prof. S. Hollins, St. George's University of London, UK.

Catherine van Zelst: Inside out; On stereotype awareness, childhood trauma and stigma in psychosis. Supervisors: Prof.dr. Ph. Delespaul / Prof.dr. J. van Os.

Ibrahim Tolga Binbay: Extended Psychosis Phenotype in the Wider Social Environment. Supervisor: Prof.dr. J. van Os; Co-Supervisor: Dr. M. Drukker.

Frank Van Dael: OCD matters in psychosis. Supervisors: Prof.dr. J. van Os / Prof.dr. I. Myin-Germeys.

Pamela Kleikers: NOXious oxidative stress: from head toe too and back. Supervisors: Prof.dr. H.H.H.W. Schmidt / Prof.dr. H.W.M. Steinbusch; Co-Supervisor: Dr. B. Janssen.

José Luis Gerardo Nava: In vitro assay systems in the development of therapeutic interventions strategies for neuroprotection and repair. Supervisors: Prof.dr.med. J. Weis / Prof.dr. H.W.M. Steinbusch; Co-Supervisor: Dr. G.A. Brook, RWTH Aachen.

Eva Bollen: Cyclic nucleotide signaling and plasticity. Supervisors: Prof.dr. H.W.M. Steinbusch / Prof.dr. R. D'Hooge, KU Leuven; Co-Supervisor: Dr. J. Prickaerts.

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Jessica A. Hartmann: A good laugh and a long sleep; Insights from prospective and ambulatory assessments about the importance of positive affect and sleep in mental health. Supervisor: Prof.dr. J. van Os; Co-Supervisors: C.J.P. Simons / Dr. M. Wichers.

Bart Ament: Frailty in old age; conceptualization and care innovations. Supervisors: Prof.dr. G.I.J.M. Kempen / Prof.dr. F.R.J. Verhey; Co-Supervisor: Dr. M.E. de Vugt.

Mayke Janssens: Exploring course and outcome across the psychosis-continuum. Supervisor: Prof.dr. I. Myin-Germeys; Co-Supervisor: Dr. T. Lataster.

Dennis M.J. Hernau: Dopayours is not dopamine: genetic, environmental and pathological variations in dopaminergic stress processing. Supervisor: Prof.dr. I. MyinGermeys; Co-Supervisors: Prof.dr. F.M. Mottaghy / Dr. D. Collip.

Ingrid M.H. Brands: The adaptation process after acquired brain injury Pieces of the puzzle. Supervisors: Prof. dr. C.M. van Heugten / Prof.dr. D.T. Wade, Oxford UK; Co-Supervisors: Dr. S.Z. Stapert / Dr. S. Köhler.

Francesco Riso: Urinary and salivary S100B monitoring in high risk infants. Supervisor: Prof.dr. J.S.H. Vles; Co-Supervisors: Dr. D. Gazzolo, Genoa,Italy / Dr. A.W.D. Gavilanes.

Alessandro Borghesi: Stem and Progenitor Cells in Preterm Infants: Role in the Pathogenesis and Potential for Therapy. Supervisor: Prof.dr. L. Zimmermann; Prof.dr. B. Kramer; Co-Supervisors: Dr. D. Gazzolo, Genoa,Italy / Dr. A.W.D. Gavilanes.

Claudia Menne-Lothmann: Affect dynamics; A focus on genes, stress, and an opportunity for change. Supervisor: Prof.dr. J. van Os; Co-Supervisors: Dr. M. Wichers / Dr. N. Jacobs.

Martine van Nierop: Surviving childhood new perspectives on the link between childhood trauma and psychosis. Supervisors: Prof.dr. I. Myin-Germeys / Prof.dr. J. van Os; Co-Supervisor: Dr. R. van Winkel.

Sylvia Klinkenberg: VNS in children; more than just seizure reduction. Supervisors: Prof.dr. J. Vles / Prof.dr. A. Aldenkamp; Co-Supervisor: Dr. H. Majoie.

Anouk Linssen: Considerations in designing an adult hearing screening programme. Supervisor: Prof.dr. B. Kremer; Co-Supervisors: Dr. L. Anteunis / Dr. M. Joore.

Janny Hof: Hearing loss in young children; challenges in assessment and intervention. Supervisors: Prof.dr. B. Kremer / Prof.dr. R. Stokroos / Prof.dr. P. van Dijk, RUG; Co-Supervisor: Dr. L. Antheunis.

Kimberly Cox-Limpens: Mechanisms of endogenous brain protection; Clues from the transcriptome. Supervisors: Prof.dr. J. Vles / Prof.dr. L. Zimmermann; Co-Supervisor: Dr. A. Gavilanes.

Els Vanhoutte: Peripheral Neuropathy outcome measures; Standardisation (PeriNomS) study part 2: Getting consensus. Supervisors: Prof.dr. C. Faber / Prof.dr. P. van Doorn; Co-Supervisor: Dr. I. Merkies, Spaarne ziekenhuis Hoofddorp.

Mayienne Bakkers: Small fibers, big troubles; diagnosis and implications of small fiber neuropathy. Supervisors: Prof.dr. C. Faber / Prof.dr. M. de Baets; Co-Supervisor: Dr. I. Merkies, Spaarne ziekenhuis Hoofddorp.

Ingrid Kramer: Zooming into the micro-level of experience: An approach for understanding and treating psychopathology. Supervisor: Prof.dr. J. van Os; Co-Supervisors: Dr. M. Wichers, UMC Groningen / Dr. C. Simons.

Esther Bouman: Risks and Benefits of Regional Anesthesia in the Perioperative Setting. Supervisors: Prof.dr. M. van Kleef / Prof.dr. M. Marcus, HMC, Qatar / Prof.dr. E. Joosten; Co-Supervisor: Dr. H. Gramke.

Mark Janssen: Selective stimulation of the subthalamic nucleus in Parkinson's disease; dream or near future. Supervisors: Prof.dr. Y. Temel / Prof.dr. V. Visser-Vandewalle, Keulen / Prof.dr. A. Benazzouz, Bordeaux, France.

Reina de Kinderen: Health Technology Assessment in Epilepsy; economic evaluations and preference studies. Supervisors: Prof.dr. S. Evers / Prof.dr. A. Aldenkamp; Co-Supervisor: Dr. H. Majoie / Dr. D. Postlart, GGZ O-Brabant.

Saskia Ebus: Interictal epileptiform activity as a marker for clinical outcome. Supervisors: Prof.dr. A. Aldenkamp / Prof.dr. J. Arends, TUE / Prof.dr. P. Boon, Universiteit Gent, België.

Inge Knuts: Experimental and clinical studies into determinants of panic severity. Supervisor: Prof.dr. I. Myin-Germeys; Co-Supervisor: Dr. K. Schruers; Influencing panic.

Nienke Tielemans: Proactive coping post stroke: The Restored4Stroke Self-Management study. Supervisors: Prof.dr. C. van Heugten / Prof.dr. J. Visser-Meily, UMC Utrecht; Co-Supervisor: Dr. V. Schepers, UMC Utrecht.

Tom van Zundert: Improvements Towards Safer Extraglottic Airway Devices. Supervisors: Prof.dr. A.E.M. Marcus / Prof.dr. W. Buhre / Prof.dr. J.R. Brimacombe, Queensland, Australia / Prof.dr. C.A. Hagberg.

Tijmen van Assen: Anterior Cutaneous Nerve Entrapment Syndrome Epidemiology and surgical management. Supervisors: Prof.dr. G.L. Beets / Prof.dr. M. van Kleef / Dr. R.M.H. Roumen / Dr. M.R.M. Scheltinga, MMC Veldhoven.

Rohit Shetty: Understanding the Clinical, Immunological and Genetic Molecular Mechanisms of Keratoconus. Supervisors: Prof.dr. R.M.M.A. Nuijts / Prof.dr. C.A.B. Webers.

Christine van der Leeuw: Blood, bones and brains; peripheral biological endophenotypes and their structural cerebral correlates in psychotic disorder. Supervisor: Prof.dr. J. van Os; Co-supervisor: Dr. M. Marcelis.

Sanne Peeters: The Idle Mind Never Rests; functional brain connectivity across the psychosis continuum. Supervisor: Prof.dr. J. van Os; Co-supervisor: dr. M. Marcelis.

Nick van Goethem: $\alpha 7$ nicotinic acetylcholine receptors and memory processes: mechanistic and behavioral studies. Supervisor: Prof.dr. H.W.M. Steinbusch; Cosupervisor: Dr. J. Prickaerts.

Nicole Leibold: A Breath of fear; a translational approach into the mechanisms of panic. Supervisor: Prof.dr. H.W.M. Steinbusch; Co-supervisors: Dr. K.R.J. Schruers / Dr. D.L.A. van den Hove.

Renske Hamel: The course of mild cognitive impairment and the role of comorbidity. Supervisor: Prof.dr. F.R.J. Verhey; Co-supervisors: Dr. I.H.G.B. Ramakers / Dr. P.J. Visser.

Lucia Speth: Effects of botulinum toxin A injections and bimanual task-oriented therapy on hand functions and bimanual activities in unilateral Cerebral Palsy. Supervisors: Prof.dr. J. Vles; Prof.dr. R. Smeets; Co-supervisor: Dr. Y. Janssen-Potten, Adelante Hoensbroek.

Yuan Tian: The effects of Lutein on the inflammatory pathways in age-related macular degeneration (AMD). Supervisors: Prof.dr. C. Webers; Prof.dr. A. Kijlstra, WUR; Cosupervisor: Dr. M. Spreuwenberg; Dr. H. Tange.

Peggy Spauwen: Cognition and Type 2 diabetes; the interplay of risk factors. Supervisors: Prof.dr. F. Verhey; Prof.dr. C. Stehouwer; Co-supervisor: Dr. M. van Boxtel

Marc Hilhorst: Crescentic glomerulonephritis in ANCA associated vasculitis. Supervisors: Prof.dr. J. Cohen-Tervaert; Co-supervisor: Dr. P. van Paassen.

Martin Gevonden: The odd one out: exploring the nature of the association between minority status and psychosis. Supervisors: Prof.dr. J-P. Selden; Prof.dr. J. Booij, Uva; Prof.dr. I. Myin-Germeys

Bart Biallosterski: Structural and functional aspects of sensory-motor Interaction in the urinary bladder. Supervisors: Prof.dr. Ph. Van Kerrebroeck; Prof.dr. S. De Wachter, UvAntwerpen; Co-supervisors: Dr. G. van Koeveeringe; Dr. M. Rahnama'i.

Thesis defences from MHeNS

Alexandra König: The use of information and communication technologies (ICT) for the assessment of patients with Alzheimer's Disease and related disorders. Supervisors: prof.dr. F. Verhey; prof.dr. Ph. Robert, Nice, Fr; Co-supervisors: dr. P. Aalten; dr. R. David, Nice, Fr.

Micheline Chenault: Assessing Readiness for Hearing Rehabilitation. Supervisors: prof.dr. M.P.F. Berger; prof. dr. B. Kremer; Co-supervisor: dr. L.J.C. Anteunis.

Anand Vinekar: Retinopathy of Prematurity. Recent advances in tele-medicine screening, risk factors and spectral domain optical coherence tomography imaging. Supervisor: prof.dr. C.A.B. Webers; Co-supervisor: dr. N.J. Bauer

Fleur van Dooren: Diabetes and Depression: exploring the Interface between Pathophysiological and Psychological factors. Supervisors: prof.dr. F.R.J. Verhey; prof.dr. J.K.L. Denollet, UvT; prof.dr. F. Pouwer, UvT; Co-supervisor: dr. M.T. Schram.

Gabriëlla Pons van Dijk: Taekwondo and physical fitness components in middle-aged healthy volunteers; the Sekwondo study. Supervisors: prof.dr. J. Lodder; prof.dr. H. Kingma; Co-supervisor: dr. A.F. Lenssen.

Yara Pujol López: Development and psychoneuroimmunological mechanisms in depression. Supervisor: prof. dr. H.W.M. Steinbusch; Co-supervisors: Dr. G. Kenis; Dr. D. van den Hove; Dr. Aye Mu Myint, München.

Romina Gentier: UBB+1; an important switch in the onset of Alzheimer's disease. Supervisors: Prof. H. Steinbusch; Prof. D. Hopkins; Co-supervisor: Dr. F. van Leeuwen.

Sanne Smeets: Insights into insight: studies on awareness of deficits after acquired brain injury. Supervisor: Prof. C. van Heugten; Prof. R. Ponds; Co-supervisor: Dr. I. Winkens.

Kim Beerhorst: Bone disease in chronic epilepsy: fit for a fracture. Supervisor: Prof. A. Aldenkamp; Prof. R. van Oostenbrugge; Co-supervisor: Dr. P. Verschuure.

Alex Zwanenburg: Cerebral and cardiac signal monitoring in fetal sheep with hypoxicischemic encephalopathy. Supervisor: Prof. T. Delhaas; Prof. B. Kramer; Co-supervisors: Dr. T. Wolfs; Dr. P. Andriessen, MMC.

Ismail Sinan Guloksuz: Biological mechanisms of environmental stressors in psychiatry. Supervisor: Prof. J. van Os; Co-supervisors: Dr. B. Rutten; Dr. M. Drukker.

Seyed Ehsan Pishva MD: Environmental Epigenetics in mental health and illness. Supervisor: Prof.dr. J. van Os; Co-supervisors: Dr. B.P.F. Rutten; Dr. G. Kenis.

Ankie Hamaekers: Rescue ventilation using expiratory ventilation assistance; innovating while clutching at straws. Supervisors: Prof.dr. W.F. Buhre; Prof.dr. M. van Kleef.

Rens Evers. 22q11.2 deletion syndrome: intelligence, psychopathology and neurochemistry at adult age. Supervisors: Prof.dr. L.M.G. Curfs; Prof.dr. T. v. Amelsvoort.

Sarah-Anna Heschem. Novel insights towards memory restoration. Supervisor: Prof.dr. Y. Temel; Co-supervisor: Dr. A. Blokland; Dr. A. Jahanshahi.

João P. da Costa Alvares Viegas Nunes. Insulin receptor sensitization improves affective pathology in various mouse models. Supervisor: Prof.dr. H.W.M. Steinbusch; Cosupervisors: Dr. K-P. Lesch; Dr. T. Strelakova; Dr.B.H. Cline, Oxford.

Yanny Ying-Yee Cheng. Clinical Outcomes After Innovative Lamellar Corneal Transplantation Surgery. Supervisor: Prof.dr. R.M.M.A. Nuijts; Co-supervisor: Dr. J.S.A.G. Schouten.

2016

Oliver Gerlach. Parkinson's disease, deterioration during hospitalization. Supervisor: Prof.dr. R. van Oostenbrugge; Co-supervisor: Dr. W. Weber.

Remo Arts. Intracochlear electrical stimulation to suppress tinnitus. Supervisor: Prof.dr. R.J. Stokroos; Co-supervisor: Dr. E.L.J. Georg.

Mitchel van Eeden. The €- Restore4stroke study: Economic evaluation of stroke care in the Netherlands. Supervisors: Prof.dr.mr. S.M.A.A. Evers; Prof.dr. C.M. v. Heugten; Co-supervisor: dr. G.A.P. van Mastrigt.

Pim Klarenbeek. Blood pressure and cerebral small vessel disease. Supervisor: Prof.dr. R.J. van Oostenbrugge; Co-supervisor: Dr. J. Staals.

Ramona Hohnen. Peripheral pharmacological targets to modify bladder contractility. Supervisor: Prof.dr. Ph.E.V. van Kerrebroeck; Co-supervisors: Dr. G.A. van Koeveringe; Dr. M.A. Sahnama'i; Dr. C. Meriaux.

Ersoy Kocabicak. Deep brain stimulation of the subthalamic nucleus: Clinical and scientific aspects. Supervisors: Prof.dr. Y. Temel; Prof.dr. K. van Overbeeke; Co-supervisor: Dr. A. Jahanshahi.

Sven Akkerman. Temporal aspects of cyclic messenger signaling in object recognition memory; a pharmacological approach. Supervisor: Prof.dr. H.W.M. Steinbusch; Co-supervisors: dr. J. Prickaerts; dr. A. Blokland.

Anja Moonen. Emotion and Cognition in Parkinson's disease; etiology and neurobiological mechanisms. Supervisor: Prof.dr. F.R.J. Verhey; Co-supervisor: dr. A.F.G. Leentjens.

Anna Schüth. Three-dimensional bladder tissue morphology. Supervisors: Prof.dr. G.A. van Koeveringe; Prof. dr. M. v. Zandvoort, Aachen; Prof.dr. Ph. V. Kerrebroeck.

Elisabeth van der Ven. Ethnic minority position as risk indicator for autismSpectrum and psychotic disorders. Supervisors: Prof.dr. J.P. Seltén; Prof.dr. J. van Os.

Zuzana Kasanova. Environmental reactivity for better or worse; The impact of stress and reward on neurochemistry, affect and behavior across the psychosis continuum. Supervisor: Prof.dr. I. Myin-Germeyns, KU Leuven/UM; Co-supervisor: dr. D. Collip.

Danielle Lambrechts. Ketogenic diet therapies; treatment for children and adults with refractory epilepsy. Supervisors: Prof.dr. H.J.M. Majoie; Prof.dr. J.S.H. Vles; Prof.dr. A.P. Aldenkamp; Co-supervisor: dr. A.J.A. de Louw, Kempenhaghe, Heeze.

Frank van Bussel. Advanced MRI in diabetes; cerebral biomarkers of cognitive decrements. Supervisors: Prof. dr.ir. W.H. Backes; Prof.dr. P.A.M. Hofman; Co-supervisor: dr. J.F.A. Jansen.

Lisa Schönfeldt. Neurostimulation to treat brain injury? Supervisors: Prof.dr. Y. Temel; Prof.dr. S. Hendrikx, Hasselt; Co-supervisor: dr. A. Jahanshahi.

Rianne Geerlings. Transition in patients with childhood-onset epilepsy; a long way to adulthood. Supervisor: Prof.dr. A.P. Aldenkamp; Co-supervisors: dr. A.J.A. de Louw, dr. L.M.C. Gottmer, Kempenhaeghe.

Nele Claes. B cells as multifactorial players in multiple sclerosis pathogenesis: insights from therapeutics. Supervisors: Prof.dr. V. Somers, Hasselt; Prof.dr. R. Hupperts Co-supervisors: Prof.dr. P. Stinissen, dr. J. Fraussen, Hasselt.

Olaf Schijns. Epilepsy surgery and biomarkers from history to molecular imaging. Supervisors: Prof.dr. J.J. van Overbeeke; Prof.dr. H. Clustermann, Aachen; Co-supervisors: dr. G. Hoogland; dr. M.J.P. v. Kroonenburgh.

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Thesis defences from MHeNS

Lizzy Boots. *Balanced and Prepared*; development and evaluation of a supportive ehealth intervention for caregivers of people with early-stage dementia. Supervisors: Prof.dr. F.R.J. Verhey; Prof.dr. G.I.J.M. Kempen; Co-supervisor: dr. M.E. de Vugt.

Wouter Donders. *Towards patient-specific (cerebro-) vascular model applications*. Supervisors: Prof.dr. T. Delhaas; Prof.dr.ir. F.N. van de Vosse, TUE; Co-supervisor: dr.ir. W. Huberts.

Sizzle Vanterpool. *The implications of intrauterine invasion by microbes for placental Pathology and the occurrence of adverse pregnancy outcomes*. Supervisor: Prof.dr. B.W. Kramer. Co-supervisors: dr. J.V. Been, Erasmus MC Rotterdam, dr. U von Rango.

Manuela Heins. *The Relationship between Social Adversity, Psychosis, and Depression across an Individual's Life Span*. Supervisor: Prof.dr. I. Myin-Germeys.

Christianus van Ganzewinkel. *NEONATAL PAIN; Out of Sight, Out of Mind?* Supervisor: Prof.dr. B.W.W. Kramer; Co-supervisor: dr. P. Andriessen, MMC Veldhoven.

Anne-Hilde Muris. *Hype or hope? Vitamin D in multiple sclerosis; A clinical and immunological perspective*. Supervisor: Prof.dr. R.M.M. Hupperts; Co-supervisor: dr. J.G.M.C. Damoiseaux.

Gerard Bode. *The link between ceramide transporters, innate Immunity and Alzheimer's disease*. Supervisor: Prof.dr. M.H.V. de Baets; Co-supervisors: dr. P. Martinez, dr. M. Losen.

Jo Stevens. *Advanced diagnostics and therapeutics for Alzheimer's disease*. Supervisor: Prof.dr. M. de Baets; Co-supervisors: dr. M. Losen, dr. P. Martinez-Martinez.

Rosan Luijckx. *Stress and pain in muscles and brain; developing psychophysiological paradigms to examine stress and pain interactions*. Supervisors: Prof.dr. J.J. van Os; Prof.dr.ir. H.J. Hermens, UT; Co-supervisor: dr. R. Lousberg.

M.C. Haanschoten. *Towards efficient cardiac surgery – the integrating role of anesthesiology and intensive care*. Supervisors: Prof. dr. W. Buhre; Prof. dr. A. van Zundert (Queensland); Co-supervisors: Dr. M.A. Soliman Hamad; Dr. A. van Straten (Catharina zkh.).

Harmen Jan van de Haar. *Microvascular and blood-brain barrier dysfunction in Alzheimer's disease*. Supervisor: Prof.dr.ir. W. Backes; Prof.dr. F. Verhey; Co-supervisor: Dr. J. Jansen; Dr.ir. M. v. Osch, LUMC.

Coenraad Itz. *Chronic low back pain, considerations about: Natural Course, Diagnosis, Interventional Treatment and Costs*. Supervisor: Prof.dr. M. van Kleef; Prof.dr. F. Huygen, EUR; Cosupervisor: Dr. B. Ramaekers.

Willemijn Jansen. *The Path of Alzheimer's disease: from neuropathology to clinic*. Supervisor: Prof.dr. F. Verhey; Co-supervisors: Dr. P.J. Visser; Dr. I. Ramakers.

Ligia dos Santos Mendes Lemes Soares. *Phosphodiesterase inhibitors: a potential therapeutic approach for ischemic cerebral injury*. Supervisor: Prof.dr. H.W.M. Steinbusch; Co-supervisors: Dr. R.M. Weffort de Oliveira, Brazil; Dr. J. Prickaerts

Martijn Broen. *Anxiety and depression in Parkinson's disease*. Supervisor: Prof.dr. R.J. van Oostenbrugge; Co-supervisors: Dr. A.F.G. Leentjens; Dr. M.L. Kuijf.

Sandra Schipper. *Extrasynaptic receptors as a treatment target in epilepsy*. Supervisor: Prof.dr. J.H.S. Vles; Co-supervisors: Dr. G. Hoogland; Dr. S. Klinkenberg; Dr. M.W. Aalbers, RUG.

João Casaca Carreira. *Making sense of Antisense Oligonucleotides Therapy in Experimental Huntington's disease*. Supervisor: Prof.dr. Y. Temel; Co-supervisors: Dr. A. Jahanshahi; Dr. W. van Roon-Mom, LUMC.

Dominique IJff. Trick or Treat? Cognitive side-effects of antiepileptic treatment. Supervisors: Prof.dr. A.P. Aldenkamp; Prof.dr. M. Majoie; Co-supervisors: Dr. J. Jansen; Dr. R. Lazeron, Kempenhaeghe.

Alfredo Ramirez. Neurogenetic approach in neurodegenerative disorders. Supervisors: Prof.dr. B.P.F. Rutten; Prof.dr. H.W.M. Steinbusch; Prof.dr. M.M. Nöthen, University of Bonn.

Nienke Visser. Toric Intraocular lenses in cataract surgery. Supervisor: Prof.dr. R.M.M.A. Nuijts; Co-supervisor: Dr. N.J.C. Bauer.

Jakob Burgstaller. Prognostic indicators for patients with degenerative lumbar spinal stenosis. Supervisor: Prof.dr. M. van Kleef; Co-supervisors: Dr. M.M. Wertli, University of Zurich; Dr. H.F. Gramke.

Mark van den Hurk. Neuronal Identity and Maturation: Insights from the Single-Cell Transcriptome. Supervisors: Prof.dr. H.W.M. Steinbusch; Prof.dr. B.P.F. Rutten; Cosupervisors: Dr. G. Kenis; Dr. C. Bardy, Adelaide.

Maria Nikiforou. Prenatal stress and the fetal gut. Potential interventions to prevent adverse outcomes. Supervisors: Prof.dr. B.W. Kramer; Prof.dr. H.W. Steinbusch; Cosupervisor: Dr. T.G. Wolfs.

Janneke Peijnenborgh. Assessment of cognition, time perception, and motivation in children. Supervisors: Prof.dr. J.S.H. Vles; Prof.dr. A.P. Aldenkamp; Co-supervisors: Dr. J. Hendriksen; Dr. P. Hurks.

Joany Millenaar. Young onset dementia; towards a better understanding of care needs and experiences. Supervisors: Prof.dr. F. Verhey; Prof.dr. R. Koopmans, RUN; Cosupervisors: Dr. M. de Vugt; Dr. C. Bakker, RUN.

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Adriana Smits. Perinatal factors and hearing outcome. Supervisors: Prof.dr. R.J. Stokroos; Prof.dr. B.W. Kramer; Prof.dr. B. Kremer.

Angela Bouwmans. Transcranial sonography in parkinsonian disorders: clear window or blurred vision. Supervisor: Prof.dr. W.H. Mess; Co-promotores: Dr. W.E.J. Weber; Dr. A.F.G. Leentjens.

Björn K. Stessel. Patient centred care after day surgery: scope for improvement. Supervisors: Prof.dr. W. Buhre; Prof.dr. B. Joosten. Co-supervisor: Dr. A.H. Gramke.

Jan Guy Bogaarts. Quantitative EEG and machine learning methods for the detection of epileptic seizures and cerebral asymmetry. Supervisor: Prof.dr. W.M. Mess; Co-supervisor: Dr.ir. J.P.H. Reulen; Dr.ir. E.D. Gommer.

Martin M. Müller. Pregnancy derived products for treatment of perinatal brain injuries. Supervisors: Prof.dr. B.W.W. Kramer; Prof.dr. D. Surbek, Bern; Co-supervisors: Dr. T. Wolfs; Dr. G. Gavilanes.

Daan Ophelders. Novel treatment strategies for the protection of the preterm brain; Rebalancing inflammation and regeneration. Supervisor: Prof.dr. B. Kramer; Co-supervisor: Dr. T. Wolfs; Dr. R. Jellema.

Rosalie van Knippenberg. Experience sampling in dementia care; an innovative intervention to support caregivers in daily life. Supervisors: Prof.dr. F. Verhey; Prof.dr. R. Ponds; Prof.dr. I. Myin-Germeys, KU Leuven; Co-supervisor: Dr. M. de Vugt.

Claudia Vingerhoets. Investigating neurobiological mechanisms underlying comorbid cognitive symptoms in psychosis and substance use. Supervisors: Prof.dr. T. van Amelsvoort; Prof.dr. J. Booij, UvA; Co-supervisor: Dr. O. Bloemen.

Dennis Oerlemans. Evolution of Neuromodulation for Lower Urinary Tract Dysfunction; Past, Present and Future. Supervisors: Prof.dr. Ph. van Kerrebroeck; Prof.dr. G. van Koeveeringe. Co-supervisors: Dr. E. Weil; Dr. T. Marcelissen.

Thesis defences from MHeNS

Marion Levy. Evaluation of BDNF/TrkB signaling as a common target in the treatment of major depression and Alzheimer's disease. Supervisors: Prof.dr. H. Steinbusch; Prof. L. Lanfumey, Université Paris Descartes, France. Co-supervisors: Dr. G. Kenis; Dr. D. van den Hove.

Patrick Domen. Stay connected: a family-based diffusion imaging study in psychotic disorder. Supervisor: Prof.dr. J. van Os. Co-supervisor: Dr. M. Marcelis.

Geor Bakker. Innovative Approaches to Understanding the Neurobiology of Psychosis. Supervisors: Prof.dr. T. van Amelsfoort; Prof.dr. J. Booij, UvA. Co-supervisor: dr. M. Caan, UvA; dr. O. Bloemen.

Wilma Boevink. HEE! Over Herstel, Empowerment en Ervaringsdeskundigheid in de psychiatrie. Supervisors: Prof.dr. J. van Os; Prof.dr. Ph. Delespaul. Co-supervisor: dr. H. Kroon.

Natalia Markova . Modified swim test as a mouse depression paradigm of enhanced Cognitive processing: the role of GSK3 β . Supervisor: Prof.dr. H. Steinbusch; Prof.dr. K-P. Lesch, University of Wuerzburg. Co-supervisor: Dr. T. Strekalova.

Merijn van de Laar. Individual differences in insomnia; implications of Psychological factors for diagnosis and treatment. Supervisor: Prof.dr. A. Aldenkamp; Prof.dr. D. Pevernagie, Universiteit Gent. Co-supervisor: Dr. S. Overeem, TUE.

Willem Buskermolen. If only I could tell ...; Measuring predictors for challenging behaviour in people with both intellectual disability and hearing impairment. Supervisor: Prof.dr. A. Aldenkamp. Co-supervisor: Dr. J. Hoekman, UL.

Kay Deckers. The role of lifestyle factors in primary prevention of dementia; an epidemiological perspective. Supervisor: Prof.dr. F. Verhey. Co-supervisor: Dr. M. van Boxtel; Dr. S. Köhler.

Brechje Dandachi-FitzGerald. Symptom validity in clinical assessments. Supervisors: Prof.dr. R. Ponds; Prof.dr. F. Verhey.

Maurice Theunissen. Understanding factors affecting postoperative Quality of Life. Supervisors: Prof.dr. M. Peters, Prof.dr. M. Marcus. Co-supervisor: Dr. H. Gramke.

Anna Cleutjens. COgnitive-Pulmonary Disease? Neuropsychological functioning in patients with COPD. Supervisors: Prof.dr. E. Wouters, Prof.dr. R. Ponds. Co-supervisors: Dr. D. Janssen, Horn, Dr. J. Dijkstra.

Laura Serpero. Next Generaton Biomarkers in Perinatal Medicine: S100B Protein. Supervisors: Prof.dr. D. Gazzalo, Alessandria, Italy; Prof.dr. B..W.W. Kramer. Co-supervisor: Dr. A.W.D. Gavilanes.

Alessandro Varrica. S100B Protein and Congenital Heart Diseases: Brain Aspects. Supervisors: Prof.dr. D. Gazzalo, Alessandria, Italy; Prof.dr. J.S.H. Vles; Prof.dr. L.J.I. Zimmermann. Co-supervisor: Dr. A.W.D. Gavilanes.

Pim R.A. Heckman. Targeting phosphodiesterase type 4 for improving cognitive frontostriatal function: a translational approach. Supervisor: Prof.dr. J.G. Ramaekers. Cosupervisors: Dr. J.H.H.J.. Prickaerts; Dr. A. Blokland.

Sven van Poucke. Platelets, form sample to big data; exploring granularity in platelet research. Supervisors: Prof.dr. M.A.E. Marcus; Prof.dr. W. Buhre. Co-supervisor: Dr. M. Lancé.

Désirée M.J. Vrijens. Dysfunctions of the Lower Urinary Tract and Affective Symptoms. Supervisors: Prof.dr. Ph.E.V. van Kerrebroeck; Prof.dr. G.A. van Koeveeringe. Cosupervisors: Dr. C. Leue.

Tamar van Veenendaal. Neurotransmitters & Networks. An MR view on epilepsy and antiepileptic drugs. Supervisors: Prof.dr.ir. W.H. Backes; Prof.dr. A.P. Aldenkamp. Cosupervisor: Dr. J.F.A. Jansen.

Evelien M. Barendse. Autism Spectrum Disorders in High functioning Adolescents; Diagnostic considerations (AHA). Supervisors: Prof.dr. A.P. Aldenkamp; Prof.dr. R.P.C. Kessels, Radboud University.

Roy Lardenoije. A venture into the epigenetics of aging and Alzheimer's Disease. Supervisors: Prof.dr. B.P.F. Rutten; Prof.dr. H.W.M. Steinbusch. Co-supervisors: Dr. D. van den Hove; Dr. C.A. Lemere, USA.

Charlotte L. Mentzel. The course recognition and treatment of movement disorders in severe mental illness. Supervisors: Prof.dr. P.N. van Harten; Prof.dr. M.A.J. de KoningTijssen, UMCG. Co-supervisor: Dr. P.R. Bakker.

Tim Batink. Third Wave Behaviour Therapy: Process Measures and Contextual Interventions. Supervisors: Prof.dr. F.P.M.L. Peeters; Prof.dr. J.J. van Os; Prof.dr. M.C. Wichers, UMC Groningen.

Kevin L.J. Rademakers. Detrusor Underactivity: From Theory To Clinical Assessment. Supervisors: Prof.dr. G.A. van Koeveinge; Prof.dr. Ph.E.V. van Kerrebroeck. Co-supervisor: Dr. M. Oelke.

Iris M.J. Lange. Should I stay or should I go? Brain mechanisms underlying fear and safety learning, and exposure therapy outcome. Supervisors: Prof.dr. K.R.J. Schruers; Prof.dr. T.A.M.J. van Amelsfoort. Co-supervisor: Dr. L. Goossens.

Ruben G.F. Hendriksen. Evidence for a dystrophin-associated encephalopathy in Duchenne Muscular Dystrophy. Supervisor: Prof.dr. J.S.H. Vles. Co-supervisors: Dr. G. Hoogland; Dr. M.W. Aalbers, UMC Groningen.

Michael Gofeld. Strengths and limitations of the lumbar spine ultrasound-guided interventions. Supervisor: Prof.dr. M. van Kleef. Co-supervisor: Dr. M. Sommer.

Willem A.R. Zwaans. Strategies for chronic inguinal pain. Supervisor: Prof.dr. M. van Kleef. Co-supervisors: Dr. R.H.M. Roumen; Dr. M.R.M. Scheltinga, MMC Veldhoven.

Linda M. Rolf. Mapping the effects of vitamin D in multiple sclerosis A 3D Perspective. Supervisor: Prof.dr. R.M.M. Hupperts. Co-supervisors: Dr. J.G.M.C. Damoiseaux; Dr. J.J.F.M. Smolders, CWZ Nijmegen.

Maarten van Beek. Spinal Cord Stimulation in Clinical and Experimental Painful Diabetic Polyneuropathy. Supervisors: Prof.dr. E.A. Joosten; Prof.dr. M. van Kleef. Cosupervisor: Dr. S.M.J. van Kuijk.

Melina Barkhuizen. Genetic and perinatal risk factors for movement disorders. Supervisors: prof.dr. B.W.W. Kramer, prof.dr. H.W.M. Steinbusch, Prof.dr. A.F. Grobler. Cosupervisor: dr. A.W.D.Gavilanes-Jimenez.

Renske Uiterwijk. Cognitive function and cerebral small vessel disease in hypertension. Supervisor: prof.dr. R.J. van Oostenbrugge. Co-supervisor: Dr. J.E.A. Staals.

Elles Douven. Depression and apathy after stroke. Supervisor: prof.dr. F.R.J. Verhey. Cosupervisors: Dr. P. Aalten, dr. J. Staals.

Mauro Pessia. Brain K+ Channels: from molecular and physiological features to autism spectrum disorder and intellectual disability. Supervisors: prof.dr. H.W.M. Steinbusch, prof.dr. M.B. Donati, It.

Carsten Leue. Hyperarousal in the Hospital and what to do about it: the MED-PSYCHNET - a transitional network approach fostering personalized care in psychosomatic medicine. Supervisors: Prof.dr. J. van Os, Prof. dr. A. Masclee. Co-supervisors: Dr. J. Strik, Dr. J. Kruiemel.

Andrea S. Herrera Soto. Aminochrome, an endotoxin for inducing a new rat model of Parkinson's Disease. Supervisor: prof.dr. H.W.M. Steinbusch. Co-supervisors: Prof.dr. Juan Segura-Aquilar; prof. G. Diaz-Veliz, Santiago of Chile

Thesis defences from MHeNS

Eline E.B. de Clerck. Ocular neurodegenerative changes and macular cysts in prediabetes and type 2 diabetes. Supervisors: Prof.dr. C.A.B. Webers, Prof.dr. C.D.A. Stehouwer. Co-supervisor: Dr. J.S.A.G. Schouten

Steven T.H. Honings. Exploring psychosis and multidirectional violence: a prospective study in the general population. Supervisor: Prof.dr. J. van Os. Co-supervisor: Dr. M. Drukker

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Sau May Wong. Advances in Microvasculair MRI Techniques: Breaking the Pathophysiological Barriers in Cerebral Small Vessel Disease. Supervisor: Prof.dr. W.H. Backes, Prof.dr. R.J. van Oostenbrugge. Co-supervisor: Dr. J.F.A. Jansen

Mark B.N. van Winkel. Lonely at heart and stressed in company of Others; the influence of daily life social experiences and emotions on depression. Supervisors: prof.dr. F. Peeters; prof.dr. I. Myin-Germeys, KU Leuven/UM; prof.dr. M. Wichers, UMC Groningen

Harsha Birur Laxmana Rao. Revisiting the vascular theory of glaucoma using optical coherence tomography angiography. Supervisors: prof.dr. C.A.B. Webers; prof.dr. R.N. Weinreb, University of California, San Diego

Babette L.R. Reijs. Cognitive correlates of cerebrospinal fluid biomarkers for Alzheimer's disease. Supervisor: prof.dr. F.R.J. Verhey. Co-supervisors: Dr. P.J. Visser; dr. I.H.G.B. Ramakers

Rachel Slangen. Spinal cord stimulation in painful diabetic peripheral Neuropathy. Clinical- and cost-effectiveness. Supervisors: prof.dr. M. van Kleef; Prof.dr. C. Dirksen; prof.dr. C. Faber

Ganne Chaitanya. Epilepsy: A network disorder. Supervisors: prof.dr. A.P. Aldenkamp; prof. P. Satishchandra, NIMHANS, Bangalore, India. Co-supervisors: Dr. J.F.A. Jansen; Dr. S. Zinger, TUE.

Sumitha Rajendrarao. New Insight into the Multifaceted Pathogenic Mechanisms of Sporadic Amyotrophic Lateral Sclerosis. Supervisors: prof.dr. B.W. Kamer; prof.dr. H.W. Steinbusch. Co-supervisor: prof. T.R. Raju, NIMHANS, Bangalore, India.

Suzanne Roggeveen. Interference of mobile phone with electrophysiology and emotions; results from short-term experimental studies. Supervisor: Prof.dr. J. van Os. Co-supervisor: Dr. R. Lousberg.

Matthias Walter. Multi-methodological approaches to investigate lower urinary tract function in health and disease. Supervisors: Prof.dr. Ph.E.V.A. van Kerrebroek; Prof.dr. G.A. van Koeveinge; Prof.dr. A. Curt, Zürich, CH.

Lalit Gupta. Inhomogeneities in spontaneous brain fluctuations. Supervisors: Prof.dr. W.H. Backes; Prof.dr. P.A.M. Hofman. Co-supervisor: Dr. J.F.A. Jansen.

Chaitra Jayadev. Impact of imaging the pediatric retina. Supervisor: Prof.dr. C.A.B. Webers. Co-supervisor: Dr. N.J.C. Bauer; Dr. A. Vinekar.

Annelie Klippel. Navigating through complexity; processes and mechanisms underlying the development of psychosis. Supervisors: Prof.dr. I. Myin-Germeys, KU-Leuven; Prof.dr. M.C. Wichers, UMC Groningen. Co-supervisor: Dr. U. Reininghaus.

Kürşat Altınbaş. Reconstructing The Diagnostic Framework of Bipolarity. Supervisor: Prof.dr. J. van Os. Co-supervisor: Dr. I.S. Gülöksüz.

Andrea J.R. Balthasar. Eyes of the needle; Spectral tissue sensing, an innovative technology for detecting various tissue types during percutaneous needle-based procedures in locoregional anesthesia and pain medicine. Supervisor: Prof.dr. M. van Kleef. Co-supervisor: Dr. G.-J. van Geffen, Radboud UMC Nijmegen.

Walmari Pilz. Shedding light on oropharyngeal dysphagia in myotonic dystrophy type 1. Supervisor: Prof.dr. B. Kremer. Co-supervisors: Dr. L.W.J. Baijens; Dr. V. Lima Passos.

Nynke J. van den Hoogen. Repetitive painful procedures in the neonate: Treatment and adult pain sensitivity. Supervisors: Prof.dr. E.A.J. Joosten, Prof.dr. D. Tibboel, Erasmus MC-Sophia, Rotterdam. Co-supervisor: Dr. J. Patijn.

Carlota Mestres Gonzalvo. Medication optimisation; Methodological aspects and new strategies. Supervisors: Prof.dr. F.R.J. Verhey, Prof.dr. P.H.M. van der Kuy, Erasmus MC Rotterdam. Co-supervisors: Dr. R. Janknegt, Zuyderland MC.

Carolin Hoffmann. The Brain under Attack: Autoantibodies in Psychotic Disorders. Supervisors: Prof.dr. P. Martinez, Prof.dr. B. Rutten, Prof.dr. J. van Os, UU/UM.

Jindra M. Bakker. On the bumpy road of happiness: Mechanisms of daily life reward processing and how it can be changed. Supervisors: Prof.dr. M. Wichers, UMC Groningen, Prof.dr. I. Myin-Germeys, KU Leuven/UM. Co-supervisor: Dr. L. Goossens.

Marasha-Fiona de Jong. Between mood and matter; studies on the interface between mood disorders and physical conditions. Supervisor: Prof.dr. F.P.M.L. Peeters. Cosupervisors: Prof.dr. Mischoulon.

Anouk Smeets. New insights in deep brain stimulation for Tourette syndrome. Supervisor: Prof.dr. Y. Temel. Co-supervisors: Dr. L. Ackermans, Dr. A.A. Duits, de. A.F.G. Leentjens.

Margaretha Skowron. Cisplatin resistance in urothelial carcinoma; Understanding and targeting inherent and acquired mechanisms. Supervisors: Prof.dr. G.A. van Koeveringe, Prof.dr. P. Albers, Heinrich-Heine Univ. Düsseldorf. Co-supervisors: Dr. J.G.H. van Roermund, Dr. A. Romano.

Thierry Mentzel. Capturing the cacophony of movement. Supervisors: Prof.dr. P.N. van Harten, Prof.dr. H.A.M. Daanen, VUA. Co-supervisor: Dr.mr. O.J.N. Bloemen, GGZ Hilversum/UM.

Petronella de Meij. Quality indicators for the assessment of pain clinic care: A step forward? Quality from professionals and pain patients' perspective (QiPPP). Supervisors: Prof.dr. G.D.E.M. van der Weijden, Prof.dr. M. v. Kleef. Co-supervisor: Dr. A.J.A. Köke.

Thomas Vaessen. Stress sensitivity in psychosis: assessment, mechanism & intervention. Supervisor: Prof.dr. I. Myin-Germeys, KU Leuven/UM.

Yori van der Steen. Dissecting the psychosis continuum; risk factors along the pathway from experiences to disorder. Supervisor: Prof.dr. I. Myin-Germeys, KU Leuven/UM, Prof.dr. R. van Winkel, KU Leuven.

Aryo Zare. Unveiling the sensory connections between the bladder and the brain that involve the periaqueductal gray matter. Supervisor: Prof.dr. G.A. van Koeveringe; Cosupervisor: Dr. A. Jahanshahi.

Magdalena Weidner. Brain serotonin throughout development – for better and for worse. Supervisors: Prof. dr. H.W.M. Steinbusch, Prof.dr. K.P. Lesch, JM.Univ. Würzburg. Cosupervisor: Dr. D.L.A. van den Hove.

Catherine Vossen. Cortical processing of pain; the role of habituation. Supervisors: Prof.dr. E.A. Joosten, Prof. dr. J. van Os, UU/UM. Co-supervisor: Dr. R. Lousberg.

Whitney Freeze. Microvascular contributions to dementia; Exploring the role of bloodbrain barrier leakage in cerebral small vessel disease and Alzheimer disease. Supervisors: Prof.dr. F.R.J. Verhey, Prof.dr.ir. W.H. Backes. Co-supervisor: Dr. H.I.L. Jacobs.

Thesis defences from MHeNS

Simone Schüller. Characterization of Stem and Immune Cell Ontogeny to Inform Prevention and Treatment of Infections in Preterm Newborns. Supervisors: Prof.dr. B.W.W. Kramer, Prof.dr.med. A. Berger, Wien. Co-supervisor: Dr. E. Villamor.

Michael J. Kemna. Predicting relapses in ANCA associated vasculitis. Supervisor: Prof.dr. J.W. Cohen Tervaert. Co-supervisors: Dr. J. Damoiseaux, Dr. P. van Paassen.

Artemis Iatrou. Epigenetics in mental and neurodegenerative disorders. Supervisor: Prof.dr. B.P.F. Rutten. Co-supervisors: Dr. D.L.A. van den Hove, Dr. G. Kenis.

Laura Wielders. Prevention & Treatment of Cystoid Macular Edema after Cataract Surgery. Supervisor: Prof. dr. R.M.M. Nuijts. Co-supervisors: Dr. J.S.A.G. Schouten, CWZ Nijmegen, Dr. B. Winkens.

Daisy Hoofwijk. The way to understanding Chronic Postsurgical Pain; From clinical and psychological predictors to incorporating genetics. Supervisor: Prof.dr. W.F.F.A. Buhre; Prof.dr. E.A.J. Joosten; Co-Supervisor: dr. H.-F. Gramke; dr. A.A.A. Fiddlers.

Loes Leenen. Self-management in Epilepsy; The Goal is: "Live with a Z(s)mile. Supervisors: Prof.dr. H.J.M. Majoie; Prof.dr.mr. S.M.A.A. Evers; Prof.dr. C.M. van Heugten.

Chiara Peila. 'Effects of Pasteurization and Refrigerated Storage on Human Milk Neurobiomarkers Concentrations. Supervisors: Prof.dr. D. Gazzallo, Alessandria, It./MUMC+; Prof.dr. G. Visser, UU; Prof.dr. E. Bertino, Alessandria, It.

Raymond van de Berg. The Vestibular Implant: Feasibility in humans. Supervisor: Prof.dr. H. Kingma; Co-supervisor: dr. J.-P. Guyot, Université de Genève, CH.

Nils Guinand. The Vestibular Implant: a more stable horizon for patients with a bilateral vestibular deficit? Supervisors: prof.dr. H. Kingma; Prof.dr. J.-P. Guyot, Université de Genève, CH.

Jasper Smit. Exploring deep brain stimulation as a treatment for tinnitus. Supervisors: Prof.dr. R.J. Stokroos; Prof.dr. Y. Temel; Co-supervisor: dr. Jahanshahianvar.

Bindu Paravil Sankaran. Brain MRI in Mitochondrial Disorders: Correlating the Phenotype with Genotype. Supervisor: Prof.dr. H. Smeets; Prof.dr. A. Taly, NIMHANS, Bangalore, India.

List of publications

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Kerpershoek, L., de Vugt, M., Wolfs, C., Jelley, H., Orrell, M., Woods, B., Stephan, A., Bieber, A., Meyer, G., Engedal, K., Selbaek, G., Handels, R., Wimo, A., Hopper, L., Irving, K., Marques, M., Gonçalves-Pereira, M., Portolani, E., Zanetti, O., Verhey, F. and the Actifcare consortium (2016). Access to timely formal dementia care in Europe: protocol of the Actifcare (ACcess to Timely Formal Care) study. *BMC health services research*, 16(1), 423.

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Bieber, A., Stephan, A., Verbeek, H., Verhey, F., **Kerpershoek, L.**, Wolfs, C., de Vugt, M., Woods, R.T., Røsvik, J., Selbaek, G., Sjölund, B.M., Wimo, A., Hopper, L., Irving, K., Marques, M., Gonçalves-Pereira, M., Portolani, E., Zanetti, O. & Meyer, G. (2017). Access to community care for people with dementia and their informal carers : Case vignettes for a European comparison of structures and common pathways to formal care. *Zeitschrift für Gerontologie und Geriatrie*, 1-7.

Janssen, E.P.C.J., de Vugt, M., Köhler, S., Wolfs, C., **Kerpershoek, L.**, Handels, R.L.H., Orrell, M., Woods, B., Jelley, H., Stephan, A., Bieber, A., Meyer, G., Engedal, K., Selbaek, G., Wimo, A., Irving, K., Hopper, L., Marques, M., Gonçalves-Pereira, M., Portolani, E., Zanetti, O., & Verhey, F.R. (2017). Caregiver profiles in dementia related to quality of life, depression and perseverance time in the European Actifcare study: the importance of social health, *Aging & Mental Health*; 21: 49-57

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Jelley, H., **Kerpershoek, L.**, Woods, B., Wolfs, C., de Vugt, M., Bieber, A., Stephan, A., Meyer, G., Michelet, M., Selbaek, G., Sjølund B., Sköldunger, A., Hopper, L., Irving, K., Marques, M., Balsinha, C., Gonçalves-Pereira, M., Portolani, E., Zanetti, O., Verhey, F., Carers experiences of timely access and use of dementia care services in 8 European countries. 2018 (Submitted)

Curriculum Vitae

Liselot Kerpershoek werd geboren in Heerlen op 5 oktober 1988 en groeide op in Landgraaf. Nadat ze haar gymnasium diploma behaalde op College Rolduc ging ze een paar maanden op reis naar Nieuw-Zeeland en Australie voordat ze aan haar bachelor op University College Maastricht begon. In 2012 begon ze met de tweejarige onderzoeksmaster Psychopathologie; als onderdeel hiervan volgde ze een onderzoeksstage op de afdeling Psychiatrie en Neuropsychologie van de Universiteit Maastricht. Ook liep ze een klinische stage op de geheugenpoli in het Maastricht Universitair Medisch Centrum (MUMC+), waar ze haar psychodiagnostiek basisregistratie behaalde (BAPD). Nadat ze haar Master in Cognitieve en Klinische Neurowetenschappen behaalde, bleef ze werken op dezelfde afdeling als PhD-kandidaat onder supervisie van Prof. Marjolein de Vugt, Prof. Verhey, Dr. Wolfs en Prof. Woods. Dit resulteerde in het onderzoek beschreven in dit proefschrift. Liselot werkt momenteel als post-doc onderzoeker op de afdeling Psychiatrie en Neuropsychologie van de Universiteit van Maastricht en Alzheimer Centrum Limburg.

Liselot Kerpershoek was born on October 5th 1988 in Heerlen and grew up in Landgraaf. After graduating from College Rolduc in 2007 she travelled to New-Zealand and Australia, and afterwards started with her bachelor at University College Maastricht. In 2012 she started her two-year Research Master Psychopathology, for which she performed a research internship at the Department of Psychiatry and Neuropsychology of the Maastricht University. She also performed a clinical internship at Maastricht University Medical Centre (MUMC+) and acquired her psychodiagnostics registration (BAPD). After she received her Master of Cognitive and Clinical Neuroscience, she remained to work at the same department as a PhD candidate, under supervision of Prof. de Vugt, Prof. Verhey, Dr. Wolfs and Prof. Woods. This resulted in the work described in this thesis. Currently, Liselot works as a postdoctoral researcher.

