PHD THESIS

The Dementia Carer assessment of support Needs Tool - Development of a questionnaire to assess the support needs of carers to people with dementia

Trine Holt Clemmensen

Department of Sports Science and Clinical Biomechanics, University of Southern Denmark

Health Sciences Research Centre, UCL University College

2020

PhD Thesis

The Dementia Carer assessment of support Needs Tool - Development of a questionnaire to assess the support needs of carers to people with dementia

Trine Holt Clemmensen, PhD student, MHSc, Senior lecturer, physiotherapist

Health Sciences Research Centre, UCL University College, DK

Department of Sports Science and Clinical Biomechanics, University of Southern Denmark

Correspondence: Trine Holt Clemmensen, thcl@ucl.dk, Phone +45 51 15 81 96

Supervisors

Henrik Hein Lauridsen, Associate professor, PhD, MSc

Clinical Biomechanics Research Unit, Department of Sports Science and Clinical Biomechanics, University of Southern Denmark

Hanne Kaae Kristensen, Professor, Docent, PhD, Occupational Therapist

Health Sciences Research Centre, UCL University College, DK

Research Unit for Rehabilitation, Department of Clinical Research, University of Southern Denmark

Karen Andersen-Ranberg, Clinical professor, PhD, MD

Geriatric Research Unit, Department of Clinical Research, University of Southern Denmark

Official opponents

Kjeld Andersen, Professor, PhD

Research Unit of Clinical Alcohol Research, BRIDGE, Brain Research - Inter-Disciplinary Guided Excellence, University of Southern Denmark, DK

Hanne-Mette Ochsner Ridder, Professor, PhD

Department of Communication and Psychology, The Faculty of Humanities, Aalborg University, DK

Jan Oyebode, Professor, PhD

The Centre for Applied Dementia Studies, Faculty of Health Studies, University of Bradford, UK

Table of contents

1 Preface 6
  1.1 Acknowledgements 6
2 List of original papers 8
3 Financial disclosure 8
4 List of tables and figures 9
5 List of appendices....................10
6 List of abbreviations 11
7 Definitions 12
8 Summary in English 13
9 Summary in Danish 15
10 Overall structure 17
11 Background 18
  11.1 Impact of dementia 18
    11.1.1 Dementia worldwide 18
    11.1.2 Dementia in Denmark 18
    11.1.3 Person with dementia 19
  11.2 Carers of a person with dementia 19
    11.2.1 Who are the carers? 19
    11.2.2 Costs of dementia....................20
    11.2.3 Impact on informal carers 20
    11.2.4 Supportive interventions....................22
    11.2.5 Carers' support needs 23
  11.3 Needs assessment instruments....................25
    11.3.1 The rehabilitation process as a model for needs assessment 26
12 Aim 28
  12.1 Objectives....................28
13 Overview of design....................28
14 Study 1 30
  14.1 Method study 1 30
    14.1.1 Study design 30
    14.1.2 Search strategy....................30
    14.1.3 Study selection 30
    14.1.4 Charting the data....................30

14.1.5 Synthesis of results 31
14.2 Summary of results Study 1 33
14.2.1 Selection and characteristics of included studies 33
14.2.2 Mapping of carers' support needs 34
14.2.3 Synthesis of carers' support needs 34
15 Study 2 35
15.1 Method Study 2 35
15.1.1 Study design 35
15.1.2 Participants 36
15.1.3 Data collection 37
15.1.4 Data analysis 39
15.1.5 Ethical considerations 40
15.2 Summary of results Study 2 41
16 Study 3 43
16.1 Method Study 3 43
16.1.1 Study design 43
16.1.2 Conceptual model 43
16.1.3 Development process 44
16.1.4 Item generation 44
16.1.5 Pilot-testing 45
16.1.6 Field-testing 48
16.2 Summary of results Study 3 52
16.2.1 Item generation 52
16.2.2 Pilot test 1 53
16.2.3 Pilot test 2 53
16.2.4 Pilot test 3 54
16.2.5 Field-test 54
17 Discussion 58
17.1 Carers' support needs 58
17.1.1 Identifying carers' support needs 59
17.1.2 The complexity of carers' support needs 60
17.2 Development of a PROM for carers 61
17.2.1 How DeCANT assesses support needs 63
17.2.2 Using DeCANT in health and social care 64

17.3 Overall methodological considerations 66
17.4 Strengths and limitations of Study 1 67
17.5 Strengths and limitations of Study 2 67
17.6 Strengths and limitations of Study 3 69
17.7 Ethical considerations 71
18 Conclusion 71
19 Future implications and areas of development 72
20 References 74
21 Appendices 88
22 Original papers 110

1 Preface

Early in my career when working as a physiotherapist in primary care, it was my experience that carers were overlooked when planning rehabilitative interventions for dementia. Nevertheless, carers are important collaborators and they play an important role in the joint effort to maintain the well-being of people with dementia. Since commencing this PhD project, I have come across different opinions about whether or not focusing on supportive interventions for carers makes sense. Some think that it involves a risk of creating unintended illness in carers, whereas others think that it is a timely initiative. It has been an interesting journey, and I have learned a lot from different professional views. I have also learned that my own clinical practice has been biased by my professional values and the dementia services available, despite being familiar with rehabilitation theory and practice.

Developing an instrument to assess carers' support needs comprises several steps. When starting out on this project, four studies were planned: to define the construct to be measured, to develop items and response options, to pilot and field-test the instrument and to evaluate its measurement properties. However, the evaluation of measurement properties, including examination of the construct validity and test-retest reliability, are not included in this thesis. Due to unforeseen challenges in recruiting participants, data were collected too late for me to analyse and report. However, survey data have been collected on 200 carers and 125 carers, respectively, regarding construct validity and test-retest reliability. The results from analysing these data will be written up in an article as soon as possible, as they may contribute important information in order to implement the new instrument in everyday health and social care.

1.1 Acknowledgements

First of all, I would like to thank my supervisors Henrik, Hanne and Karen for always being willing to discuss issues related to the PhD project. Each has contributed to my ability to undertake this work, and they are strong role models for how to do high quality research.

Also, I would like to thank my employer, UCL University College's Health Sciences Research Center and the Department of Physiotherapy, for co-funding this project and making it possible for me to have taken this journey. My motivation for engaging in research was, first and foremost, a desire to create knowledge that would be helpful in day-to day practice and to strengthen interdisciplinary collaboration in dementia care. With a holistic approach, I hope to develop new ways to involve carers and recipients of care to increase the focus on their rights to decide their own care needs.

Along my journey I have been privileged to get help from informal dementia carers and competent professionals in research as well as health and social care. Without the hours spent sparring with them, this project would not be as relevant for current practice. I would like to thank Statistician Jens Søndergaard Jensen, Aarhus University Hospital; Language Consultant Suzanne Capell, Australia; Psychologist Susanne Bollerup Overgaard; Dementia Coordinator Tine Kjeldsen, Sønderborg Kommune; and all of the contact people in the municipalities of Aarhus, Hedensted, Middelfart, Næstved, Odense, Svendborg, Sønderborg and at the Dementia Clinic at Odense University Hospital for their engagement in helping me to develop the DeCANT.

I would like to thank all my fellow PhD colleagues, especially Kamilla Kielsgaard and Laila Busted, who have shared sorrows and joys on our common journeys. I am also grateful to all of my colleagues and managers at UCL and SDU, who have always been supportive of me.

Last but not least, I want to pass on a special thanks to my husband and children, my parents and my sister. This journey would not have made any sense without you: Thank you!

2 List of original papers

Paper I:

Clemmensen TH, Lauridsen HH, Andersen-Ranberg K, Kristensen HK. Carers' support needs when caring for a person with dementia - A scoping literature review. Scandinavian Journal of Caring Sciences (in review)

Paper II:

Clemmensen TH, Lauridsen HH, Andersen-Ranberg K, Kristensen HK. 'I know his needs better than my own' – carers' support needs when caring for a person with dementia. Scandinavian Journal of Caring Sciences (first published: 15 May 2020).

Paper III:

Clemmensen TH, Kristensen HK, Andersen-Ranberg K, Lauridsen HH. Development and Field-testing of the Dementia Carer Assessment of Support Needs Tool (DeCANT). International Psychogeriatrics (in review)

3 Financial disclosure

This PhD project is funded by UCL University College Denmark, The Danish Association of Physiotherapists and The Danish Alzheimer's Association.

4 List of tables and figures

Table 1 Overview of studies, objectives, design, methods and conclusion in this thesis

Table 2 Inclusion and exclusion criteria used in study selection

Table 3 Inclusion criteria for participants in Study 2

Table 4 Categorisation matrix used for coding of data in the cognitive interviews with carers

Table 5 Hypothesised models in the confirmatory factor analysis of DeCANT

Table 6 Characteristics of expert panel participants for the Content Validity Index (CVI)

Table 7 Characteristics of participants in cognitive interviews

Table 8 Characteristics of participants in pilot test of electronic distribution

Table 9 Demographic characteristics of participants in the field-testing phase (n=301)

Table 10 Characteristics of non-respondents in the field-test (n=133)

Table 11 CFA fit indices for the analysed models, (n=298)

Table 12 Factor loadings of items in the three hypothesised models

Figure 1 Model of different ways of expressing needs inspired by Bradshaw (7)

Figure 2 Illustration of the rehabilitation process inspired by Wade (84)

Figure 3 Illustration of the six steps when developing a PROM inspired by de Vet (2)

Figure 4 Overview of study objectives, methods and results in the thesis

Figure 5 Flowchart of information through the phases of the scoping review

Figure 6 Illustration of the four main categories of key concepts of carers' support needs and the interaction between them (Paper I).

Figure 7 Sub, generic and main categories of carers' support needs identified in focus groups and individual interviews with carers and professionals in Study 2 (see Paper II)

Figure 8 Linking main and generic categories found in Study 2 to the ICF framework (Paper II)

Figure 9 Conceptual model to understand how different aspects of support needs are related. Model inspired by Engel (85).

Figure 10 Overview of the various steps of evaluation and adaptation when developing the DeCANT

5 List of appendices

Appendix 1 Interview guide used in focus groups in Study 2

Appendix 2 Interview guide used in individual interviews Study 2

Appendix 3 Examples of text cards used in interviews Study 2

Appendix 4 Information letter to participants Study 2

Appendix 5 The ICF model (3)

Appendix 6 Presentation of items in the DeCANT field-testing version (42 items)

Appendix 7 Item generation flow table

Appendix 8 DeCANT final version consisting of 25 items in Danish and English

Appendix 9 Using and scoring manual for The Dementia Carer Assessment of Support Needs Tool (DeCANT) in Danish and English

6 List of abbreviations

AD	Alzheimer’s disease
Barthel-20	Barthel-20 index
CANE	The Camberwell Assessment of Need for the Elderly scale
CareNap-D	The Care Needs assessment pack for Dementia
CFA	Confirmatory Factor Analysis
CNA-D	Carer’s Needs Assessment for Dementia
CFI	The Comparative Fit index
CVI	Content Validity Index
DeCANT	The Dementia Carer Assessment of support Needs Tool
Df	Degrees of freedom
DIF	Differential Item Functioning
EFA	Exploratory Factor Analysis
FTD	Frontotemporal Dementia
ICF	The International Classification of Functioning, Disability and Health
I-CVI	Item content validity index
JHDCNA	Johns Hopkins Dementia Care Needs Assessment
JPND	The EU Joint Programme – Neurodegenerative Disease Research
LBD	Lewy Body Dementia
NPI-Q	The Neuropsychiatric Inventory - Questionnaire
PROM	Patient-Reported Outcome Measure
RMSEA	The root mean square error of approximation
SD	Standard deviation
SF-12	The 12-item Short Form Health Survey
S-CVI	Scale level content validity index
SSCQ	The Short Sense of Competence Questionnaire
TLI	The Tucker-Lewis index
WLSMV	Weighted Least Square Mean and Variance
WRMR	Weighted root mean residual

7 Definitions

Carer	A person who helps a family member, spouse/partner or friend who has a need for personal and/or practical assistance. The assistance provided is motivated by a personal connection rather than financial compensation (1).
Construct	The terminology used for the concept to be measured with an instrument. If a construct contains multiple aspects, they should all be measured (2).
Functioning	An overall term containing all aspects of a person's body functions, activities and participation including personal and environmental factors (3).
Holistic	An approach that acknowledges all factors relevant to a person's health (4).
Person-centred	A health care approach that seeks to establish meaningful partnerships with the person who needs help by emphasising communication and sharing power and responsibility (5).
Psychometric	A scientific discipline to develop and evaluate measurements of high methodological quality using various measurement theories and methods (2).
Rehabilitation	A goal-oriented and time-limited collaborative process between a citizen, his/her relatives and professionals with the aim of maintaining, restoring or preventing limitations to physical, psychological and/or social functioning for the citizen to achieve independence and a meaningful life. The process takes the citizen's whole situation into consideration and interventions should be coordinated and evidence-based (6).
Support need	An abstract social concept that relates to services to help a person in need. Support needs are expressed in different ways, which should be taken into consideration when clarifying what might help (7).
Health and well-being	"Health is a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity" (8).

8 Summary in English

Dementia is a progressive disease that affects cognitive functioning and interferes with a person's ability to manage activities of daily living (ADL). Living with dementia is associated with complex needs and people with dementia often depend on informal care provided by family and friends. An informal carer (hereafter called 'carer') is defined as a person who helps a family member, spouse/partner or friend in need of personal and/or practical assistance. The carer is motivated by his/her personal connection rather than financial compensation. The prevalence of people with dementia is increasing and the costs of formal care are high. The carers' role is essential to provide supplementary informal care to ensure the health and well-being of people with dementia. However, caring for a person may jeopardise carers' own health and well-being. Compared with non-dementia carers, caring for a person with dementia is associated with reduced well-being, more physical and mental disability and increased risk of mortality.

Several supportive interventions exist, but no clear intervention strategies to support carers are recommended. In Denmark, supportive services are offered in most municipalities. Nevertheless, carers express a lack of support and they frequently find it difficult to manage the carer role. New methods to address carers' support needs are therefore called for.

No psychometric robust instrument exists to systematically assess dementia carers' support needs. However, several carer instruments do exist, but these instruments do not cover the complexity of carers' support needs. A framework allowing different ways of expressing support needs is Bradshaw's taxonomy of needs. This classification of needs makes it possible to recognise and give priority to the various ways carers may express their support needs. Identifying what might actually help may be a novel way of supporting the health and well-being of carers while providing essential care to people with dementia.

Therefore, the aim of this PhD study was to develop a questionnaire to assess the support needs of carers when caring for a person with dementia - The Dementia Carer Assessment of support Needs Tool (DeCANT). The PhD study used a mixed-method approach following the six steps for developing a patient-reported outcome measure (PROM) as described by De Vet et al. (2011). Three studies were conducted with the objectives to: 1) map knowledge on carers' support needs and to synthesise knowledge on key concepts of carers' support needs, 2) clarify the specific support needs of carers when caring for a person with dementia, and 3) develop items for a questionnaire to assess carers' support needs and to test its structural validity.

Mapping and synthesising of knowledge on carers' support needs resulted in four overarching key concepts of carers' support needs, and that carers' support needs originate from the different perspectives of the

carer, the person cared for, and the interaction between them. In clarifying the construct of carers' support needs, four main categories of carers' support needs were found. Findings underlined that carers' support needs are complex and relate to the temporal, physical, social and personal context of caring. Also, carers have support needs of their own, regardless of the relationship with the person with dementia, their severity of dementia or care setting. To illustrate the multi-dimensionality of support needs, the categories were linked to the ICF framework, which is a well-known framework to structure complex information on an individual's health and well-being. Through iterative pilot and field-testing, a 25-item questionnaire, the DeCANT, was developed. Investigation among the target population of carers demonstrated satisfying content (including face) validity of DeCANT, and the CFA showed a moderate fit to a four-factor model based on the ICF. The DeCANT has been developed in a Danish context and is considered ready for implementation among relevant professionals in Danish municipalities. However, further documentation of its measurement properties is recommended.

9 Summary in Danish

Demens er en neurodegenerativ lidelse, der påvirker kognitive funktioner og evnen til at klare dagligdags aktiviteter (ADL). Mennesker med demens har ofte komplekse behov og er afhængige af hjælp og omsorg fra pårørende. Betegnelsen 'pårørende' anvendes i dette studie for et familiemedlem, ægtefælle/partner eller ven, som giver praktisk hjælp og/eller personlig omsorg i hverdagen til en nærtstående med demens. Den pårørende hjælper ud fra personlig motivation og ikke økonomisk belønning. Antallet af mennesker med demens er stigende, og udgifter til pleje og omsorg er høj. Pårørende har derfor en central rolle i at hjælpe med til at sikre mennesker med demens' sundhed og trivsel. At være pårørende kan dog være svært. Pårørende til mennesker med demens er i større risiko for psykisk og fysisk sygdom og har øget dødelighed sammenlignet med pårørende til mennesker med andre kroniske lidelser.

De fleste kommuner i Danmark har allerede tilbud om støtte til pårørende i en eller anden form, men der er ikke nogen klare anbefalinger til, hvordan støtte til pårørende tilrettelægges. Samtidig udtrykker pårørende, at de ofte mangler hjælp og støtte i hverdagen. Der er derfor brug for nye måder til at hjælpe og støtte pårørende i deres rolle som omsorgsgiver.

Der findes intet solidt spørgeskema til systematisk vurdering af pårørendes behov for hjælp og støtte. Flere spørgeskemaer til pårørende findes dog, men de afdækker ikke kompleksiteten af den hjælp og støtte, som pårørende til mennesker med demens har. Bradshaw's taksonomi inddeler forskellige måder, hvorpå behov kan komme til udtryk. Inddelingen gør det muligt at genkende, når pårørende giver udtryk for deres behov for hjælp og støtte. En ny måde at støtte pårørende til mennesker med demens kan derfor være at identificere det, som pårørende selv mener, kan hjælpe og støtte.

Formålet med dette ph.d. studie var derfor at udvikle et spørgeskema til at vurdere behov for hjælp og støtte hos pårørende, som giver praktisk hjælp eller personlig omsorg til et menneske med demens - The Dementia Carer Assessment of support Needs Tool (DeCANT). En mixed-method tilgang blev anvendt, og De Vet et al.'s (2011) seks trin for udvikling af et patientrapporteret spørgeskema (PROM) blev fulgt. Tre studier med følgende formål blev gennemført: 1) at kortlægge og syntetisere viden om de opfattelser, der er af pårørendes behov for hjælp og støtte, 2) at klarlægge de særlige behov for hjælp og støtte, som pårørende til et menneske med demens har, og 3) at udvikle spørgsmål til et spørgeskema til vurdering af pårørendes behov for hjælp og støtte samt undersøge spørgeskemaets strukturelle validitet.

Syntesen af viden om behov resulterede i fire overordnede opfattelser, der beskriver pårørendes behov for hjælp og støtte. Syntesen viste også, hvordan pårørendes behov udspringer fra tre positioner: den pårørende, mennesket med demens og interaktionen mellem de to parter. Klarlægningen af pårørendes særlige behov for hjælp og støtte viste, at pårørendes behov kan inddeles i fire overordnede kategorier: hverdagsliv, fokus på dem selv, trivsel i hverdagen og interaktion med omgivelserne. Kompleksiteten af pårørendes behov blev tydeliggjort af, at de identificerede behov relaterede til både den tidsmæssige, fysiske, sociale og personlige kontekst. Desuden viste resultaterne, at pårørende havde behov for hjælp og støtte uafhængigt af relationen til mennesket med demens, sværhedsgrad af demens eller om omsorg blev givet i eget hjem/plejebolig. For at illustrere, at pårørendes behov for hjælp og støtte er multidimensionelle, blev behovskategorierne koblet til ICF, som er en velkendt måde at strukturere komplekse oplysninger om individuel sundhed og trivsel. Et spørgeskema med 25 spørgsmål, DeCANT, blev udviklet gennem iterative pilot- og field-tests. Undersøgelse blandt pårørende viste tilfredsstillende indholdsvaliditet af DeCANT, og CFA viste at en fire-faktor model baseret på ICF passede i tilstrækkelig grad. DeCANT er udviklet i en dansk kontekst og vil kunne anvendes af relevante fagpersoner i de danske kommuner. Der er brug for fortsat dokumentation af DeCANT's måleegenskaber.

10 Overall structure

This thesis consists of three studies with three associated papers. The studies will be referred to with the Arabic numerals 1-3 and the papers with the roman numerals I-III. Study 1 is a scoping review of the literature to give an overview of carers' support needs (Paper I). Study 2 is a qualitative study using focus groups and individual interviews to clarify categories of carers' support needs (Paper II). In Study 3, knowledge from the previous two studies was used to generate items for a questionnaire, and a survey design was used to field-test this new instrument (Paper III). The writing of this thesis used a structure where the methods and results for each study are presented separately. In Table 1, an overview of the three studies' objectives, design, methods and conclusion is provided.

Table 1 Overview of studies, objectives, design, methods and conclusion in this thesis

Study (Paper)	**Objectives**	**Study design**	**Methods**	**Conclusion**
1 (I)	To map knowledge on carers' support needs and to synthesise knowledge on key concepts of carers' support needs	Review using a scoping review methodology	Four databases were searched using predefined inclusion criteria. The search included quantitative and qualitative studies and primary and secondary literature. Inductive content analysis was used to synthesise findings.	Synthesis of the search revealed four overarching categories of key concepts of carers' support needs related to: 1) the carer as a person, 2) managing being a carer, 3) providing care and 4) knowledge of dementia. Carers' support needs arose from the perspectives of the carer, the person cared for and the interaction between them.
2 (II)	To clarify the specific support needs of carers of a person with dementia	Qualitative study using focus groups and individual interviews	Purposeful sampling of carers and professionals were used. Three focus groups with carers (n=18) and two focus groups with professionals (n=13) were conducted followed by five individual interviews with carers. Results from Study 1 informed the interview guide. Inductive content analyses were used to clarify carers' support needs.	Four main categories of carers' support needs were clarified: 1) Daily life when caring for a person with dementia, 2) Focus on themselves, 3) Maintaining own well-being and 4) Communicating and interacting with surroundings. Linking of categories to the ICF were possible.
3 (III)	To develop items for a questionnaire to assess carers' support needs and to test the structural validity of items	Psychometric study using a combination of an interview and a survey design	Generation, pilot and field-testing of items were carried out using: Content Validity Index in an expert panel (n=8), cognitive interviews with carers (n=12), electronic testing of digital feasibility of the questionnaire (n=10), and field-testing of the new questionnaire among carers (n=301) using Confirmatory Factor Analyses. Results from Studies 1 and 2 informed item generation and results from Study 2 were used to hypothesise models for testing structural validity.	Initially 63 items were generated. Iterative evaluation and adaptation resulted in a 25-item version of The Dementia Carer Assessment of Support Needs tool. Testing of structural validity demonstrated a moderate fit to a four-factor model based on the ICF.

11 Background

The purpose of this PhD thesis was to investigate the support needs of informal carers (hereafter referred to as 'carers') when caring for a person with dementia. As well as the person with dementia, carers have a need for support when a loved one gets a dementia diagnosis (9,10). In this thesis, a carer is defined as a person who helps a family member, spouse/partner or friend who has a need for personal and/or practical assistance. Further, the assistance provided by the carer is motivated by a personal connection rather than financial compensation (1). The carer's role is essential to enable a person with dementia to have a meaningful life. However, caring for a person with dementia has several implications, which may jeopardise a carer's health, well-being and ability to live their own life. The various aspects of caring for a person with dementia will be explained in this thesis.

11.1 Impact of dementia

11.1.1 Dementia worldwide

Dementia represents a global health challenge. The number of people living with dementia is expected to increase in the years to come due to increased life expectancy in the older population in low, middle and high-income countries, and because age itself constitutes a risk of developing dementia. The prevalence of dementia is approximately 7.5% in the population above 65 years (11). Although a decrease of incidence has been seen in the last decade in high income countries, prevalence has increased (12). One reason for this may be that people are diagnosed earlier or live longer with a dementia disease (12), thus extending the time people with dementia may need care.

11.1.2 Dementia in Denmark

In Denmark, 89,000 people are estimated to live with dementia (13), however only 36,000 people are registered with a dementia diagnosis. This indicates a lack in the health care system to identify and diagnose people living with dementia, and subsequently provide the needed day to day care and support to both people with dementia and their carers. As a part of the Danish Action Plan on Dementia, the goal is that more people should be examined for dementia and that 80% of those affected should receive a specific diagnosis (10). In Denmark, the responsibility for diagnostics and treatment of dementia is placed on specialised units in the secondary health care system (14). However, general practitioners have a particular responsibility for performing a preliminary examination and referring patients to specialised units and following up on a plan for treatment. Primary health care providers have the responsibility for the day to day care of people with dementia, which involves a multidisciplinary approach by various professionals, e.g. medical practitioners, nurses, neuropsychologists, occupational therapists and physiotherapists, to perform the complex tasks of treatment, care and support (14). Unique to the Danish context is the function of a dementia coordinator, who enables coherent care and support to both people with dementia and their carers in almost all municipalities. The dementia coordinator acts as a link between sectors and care services, as a counselor to people with dementia and their carers, and as a teacher in dementia knowledge to professionals and carers (15). Furthermore, as a part of the Danish Action Plan on Dementia, counselling centres have been established across the country in recent years to provide anonymous counselling and peer to peer support (16). Despite the efforts to increase focus on diagnostics, treatment, care and support, Danish carers express a lack of supportive services for both carers and the person cared for (17).

11.1.3 Person with dementia

Dementia is a progressive disease that affects cognitive functioning and interferes with a person's ability to manage activities of daily living (ADL) due to e.g. loss of memory, challenges in planning, changed behaviour and ultimately impaired mobility and physical functioning (9,18,19). Dementia is an umbrella term comprising several types, with Alzheimer's being the most frequent type accounting for 62% of all cases (20). Any type of dementia leaves the affected person in a vulnerable position requiring informal and formal care. Also, people with dementia are more likely to have comorbid conditions that are not attended to (21). In the early stages, people with dementia have a need to feel respected and to learn how to cope with their cognitive disabilities as well as to accept their situation (22,23). In the middle and later stages, people with dementia have an increasing need for support with ADL, thus implicating a need for formal care services and potentially residential/nursing home care (24). In addition, people living with dementia express that a good relationship with family and friends and a supportive social network are important throughout all stages (25).

11.2 Carers of a person with dementia

11.2.1 Who are the carers?

In Denmark, it is estimated that 400,000 family members or other closely connected people provide unpaid care for a person with dementia living either in their own home or at a nursing home (26). With more than 46.8 million people living with dementia worldwide, the number of carers is likely to approach equivalently high numbers (11). The population of carers comprises various types of carers with different relationships to the person with dementia, such as spouse, child, parent, neighbour and friends of all ages, sex and religious beliefs (27). Although more women than men are diagnosed with dementia, more women commit themselves to the role of carer (26,27). One reason for this may be that women in general take on the caring role in a family. Most carers have a family relationship to the person cared for, and a large proportion of carers are adult children (26). Also, the greatest majority of carers are below the age of 65 years and almost half have an upper secondary education or higher (28).

In many cases, people with dementia rely on more than one carer (27,29). Also, carers themselves may rely on other carers to reduce the burden of caring (30). When asked, carers give three overall reasons for providing care: they wish to give the person with dementia the chance to stay at home, they live close by the person with dementia, and they feel obliged to care (28).

11.2.2 Costs of dementia

Living with dementia is associated with complex needs requiring a range of health and social care services (9) both informal and formal. The global costs of dementia care are expected to increase from US$818 billion in 2015 to US$ 2 trillion in 2030 (11). One estimate is that informal care provided by carers contribute the equivalent of 40.4% of all the actual costs of dementia (11). On average, carers contribute 6 hours of informal care per day, including both assistance with ADL and supervision (31). This is an important unpaid contribution, because hospital and residential/nursing care are far more expensive than home care (32), and initiatives to prolong the time living at home is desirable to reduce costs (33). Most people with dementia live in their own home (31), and research shows that meeting the support needs of both people with dementia and their carers may prolong this time (34). In the years to come, such a preventive strategy may help to lessen the costs of formal care.

The conditions for carers in high income countries (HIC) compared to low income countries (LIC) are very different. Formal care constitutes a higher proportion of total care in HIC, and carers in HIC are faced with significantly different challenges than carers in LIC, where less formal care is provided (11). In the future, the proportion of formal care provided is expected to increase in HIC which will increase pressure on health and social care systems (11). In addition, demographic changes will cause the old age-dependency ratio to increase (35) meaning that fewer people in the working age group will be supporting the many more older people, thereby creating a greater burden to support this aging population. Already, the costs of dementia are overwhelming, and without the informal care provided by carers, the health and social care systems could be undermined. The focus of this thesis is limited to the context of carers in HIC, with Denmark as a starting context/point for how to support carers in providing essential care to people with dementia.

11.2.3 Impact on informal carers

Carers of people with dementia form a heterogeneous group. Informal carers are defined by their personal motivation to help the person rather than by the type or amount of care they provide. This implies that caring is not just to provide assistance to perform ADL tasks; caring is also to provide emotional support to the person with dementia to help them maintain their personal integrity and to enable participation in social activities (27).

Carers are often divided into groups such as spousal carer or adult child carer (36,37). Aside from spousal and child carers, other types of carers should be kept in mind, such as friend, neighbour, parent, grandchild and niece (27). However, these types of carers represent a smaller proportion of all carers and are seldom investigated alone. Being a spousal carer often means that the carer has lived with the person with dementia for many years and that caring is a natural part of the relationship (38). However, spousal carers are often of older age and experience decreased functioning or disabilities themselves, and their physical and mental health are more likely to be compromised (39). Child carers, on the other hand, may take on the caring role out of a sense of duty (40), while at the same time being accountable to an employer and a family of their own (27). This may cause emotional stress and feelings of inadequacy in child carers (41,42), and it has been argued that the specific relationship with the person with dementia affects the experience of caring (43,44). Child carers report more burden in general, while spousal carers report more grief with advancing disease (43,45). However, regardless of the relationship, all carers describe caring as burdensome, and not one type of carer can claim to be more burdened than another.

Compared with other groups of carers not caring for a person with dementia, caring for a person with dementia is associated with poorer well-being, more physical and mental disability and increased risk of mortality (46,47). A probable reason is the person with dementia’s loss in judgment and ability to communicate and understand (27,47). As symptoms progress, carers try to cope with symptoms worsening and help the person manage loss in judgment and ability to communicate. Further, dementia may affect the personality and behaviour of the person with dementia, which may cause excessive emotional stress and depression among carers (41,47). Aggressive behaviour, in particular, has been shown to cause stress and feelings of burden among carers (48).

The challenging situation of having to cope with exacerbated symptoms for many years affects a carer’s own life, as they continuously have to manage caring while dealing with their own issues in life (32). Also, carers have to take on new responsibilities and adjust to a new role (49). When living together, carers may feel isolated due to the difficulties experienced by the person with dementia to participate in social activities (41,50) or because the person with dementia needs supervision around the clock (51). Carers may also neglect their own needs with the consequence of ignoring their own health (29). Especially carers who live at some geographic distance have difficulties finding enough time, and the caring role inflicts disruptions to their employment and causes increased anxiety (19,52).

Carers also have positive experiences when caring for the person with dementia. Finding meaning in caring and maintaining a high quality relationship has been shown to give a less burdensome caring role (53). Also, the complexity of positive and negative aspects of caring is underscored by the fact that a large amount of time spent caring does not necessarily indicate the experience is a burden (31). Carers often describe the caring role as important, and they find it natural for them to help a loved one (31). Therefore, caring may be a source of personal satisfaction and carers with a familial relationship have been reported to find more satisfaction in the caring role (54). Consequently, not all carers experience emotional stress and feelings of burden. The difficult but important task is to identify the carers that do and to offer appropriate support.

11.2.4 Supportive interventions

Several interventions to support carers exist and have been evaluated, but no clear intervention strategies can be recommended (45,55,56). Existing interventions primarily include psychosocial interventions such as group-based psychoeducation, cognitive-behavioural therapy or group-based support and counselling (55). Other supportive interventions consist of respite care, home support and care coordination (57). These studies often only report on depression and emotional stressors as primary outcomes of the intervention (45). However, none of the studies provides sufficient evidence to conclude on the effectiveness of the supportive interventions. One plausible explanation is the lack of appropriate outcome measures and constructs being measured, as qualitative data demonstrate more positive evaluation of interventions (58,59) suggesting that some positive aspects of the intervention are not currently being measured. Although some studies show promising results of effective carer interventions, they do not necessarily cause carers to utilise the supportive services available, because many carers do not accept the help when offered (60). A study showed that even though carer support was offered, 73% of carers did not participate in support groups and 79% did not use respite services (61). However, counselling services are more often utilised than respite care (60). In Denmark, psychoeducation and counselling for carers are recommended by the clinical guidelines and most municipalities offer some kind of supportive services (62,63). Nevertheless, carers express a lack of support and find it difficult managing the carer role (26,64). In particular, carers, who are currently employed, report caring affecting their work life, and 26% stopped working due to caring responsibilities (26). Carers often feel overlooked and are at a loss as to how to make everything work (17). A more systematic approach is called for when offering supportive interventions, and professionals have to focus on what carers want instead of relying on a one-size-fits-all approach and what support is readily available (45).

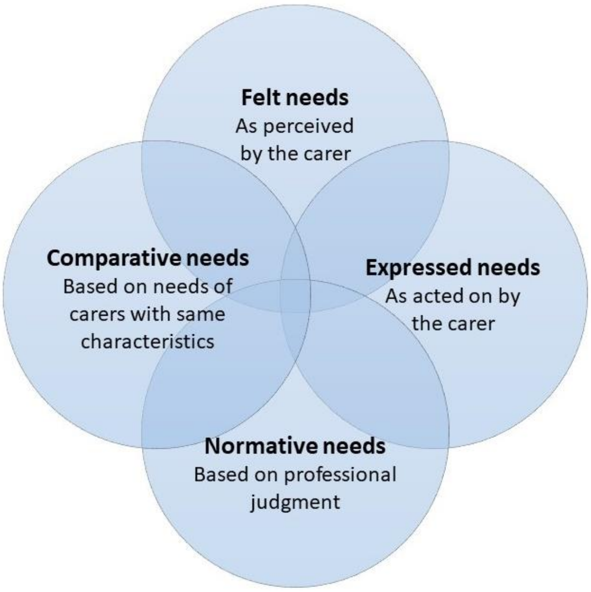
Before commencing supportive interventions, professionals have to ask the simple question “What do carers need?” before deciding on relevant goals for intervention (45). For example, if the professional’s goal for intervention is focusing on reducing emotional stress, and carers do not have a need for this, the intervention will be ineffective. In dementia care, a focus is already on person-centered care (65), however, this approach is less prevalent among professionals in health and social care in relation to carers. Applying a person-centered approach would seem obvious when developing effective intervention strategies for carers (45). Person-centered care is a holistic approach, and committing to this also in relation to carers could assist professionals to target interventions in accordance with carers' needs, enabling the development of a trusting collaboration to support carers in their important role caring for the person with dementia (5).

11.2.5 Carers' support needs

No clear definition of the construct of carers' support needs exists (66). However, several studies describe these needs (67,68). In a review investigating carers' support needs, more than half of the studies described carers' need for psychoeducation and coping strategies (67). Also, formal support and respite care were identified as frequent support needs (67). In another review, peer support and attending support groups to share information along with emotional support to manage fear, anxiety and stress were emphasised (68). Need for support from friends, family, or health, social and volunteer services to address carers' own health needs has been described as central (68). Overall, many similarities in carers' support needs are seen across various carer types such as spouses, children and friends. However, differences in carers' support needs often exist. Spousal carers have been seen to have more difficulties acknowledging their support needs, whereas adult child carers may more likely feel overwhelmed by the caring role and have extra mental health needs and need for information on disease progression (42,69). Nevertheless, both spousal and adult child carers ask for support on how to manage behavioural changes (36,69,70) and express a need for support to adapt to the changed relationship with the person with dementia (36,69). Further to this, spouses focus on loss of mutuality and intimacy in their relationship (36), whereas child carers focus on role reversal when taking care of their parent (69). Gender differences have also been reported where female carers report higher levels of burden (39), and female carers may have more need for support to learn effective coping strategies than male carers (71). However, a qualitative study investigating male spousal carers showed that caution should be exercised towards gendered assumptions, because male spouses' support needs rely on individual experience of their caring role in daily life (72). These divergent results indicate that prior judgment based on assumptions in relation to carer type may cause unnecessary constraints when addressing carers' support needs.

A complication in understanding carers' support needs is that needs may change over time (25,73) depending on the rate of progression in dementia and how carers adjust to the caring role (29). Understanding the construct of support needs should therefore embrace this temporal variability in addition to the issue that carers may only be able to recognise their needs retrospectively (74). Therefore, carers may not be able to articulate their need for support when asked. A framework facilitating different ways of expressing support needs is Bradshaw's taxonomy of needs (7,75). This classification of needs makes it possible to recognise and give priority to the various ways of expressing support needs (see Figure 1). Firstly, a 'felt' need is what carers want in their minds and their actual need for support, even though their wants may be affected by their individual perceptions. Secondly, 'expressed' needs convey the felt needs that carers are able to articulate, turning the need into a demand. Thirdly, 'normative' needs represent professional knowledge and depend on professional judgement of what is needed and valued in the society at a given time. Normative needs therefore change as knowledge develops. Lastly, 'comparative' needs arise based on what other people with the same characteristics may need. Comparative needs underlie any standardisation of health and social care and influence normative needs, because authorities use the characteristics of people previously in need to develop a practice to identify those in future need of services (7). The different expression of needs constitutes an overall perception that enables identification of needs in total. Classifying needs in this way entails that several perspectives should be considered when identifying carers' support needs and what might help. The effectiveness of supportive interventions is not clear cut, and perhaps this is due to the lack of addressing carers' individual perceptions, professional knowledge, common practice, services available and values in society before initiating support (45,76). However, as carers report having unmet needs (64,68,77), assessment of needs at present may be too focused on services available and professional judgement rather than what carers are able to express as their needs. Novel methods to address carers' needs are therefore required.

Figure 1 Model of different ways of expressing needs inspired by Bradshaw (7)



11.3 Needs assessment instruments

No psychometric robust self-administered instrument exists to assess dementia carers' support needs in a comprehensive manner in a daily health and social care context (66,73,78). A Patient-Reported Outcome Measure (PROM) is used to obtain information directly from a person without interpretation by a professional. PROMs are suitable to measure elements dependent on personal judgement to achieve physical, psychological and social well-being (2). Developing and using high quality PROMs in health and social care is a way to avoid trivialising the personal view and empowering people by acknowledging the importance of aspects that are not objectively measured. This also entails involving the PROM's target population in the development process (2). A review (78) focusing on existing dementia carers' needs assessment instruments found 36 instruments of which only one had been validated: the Carer's Needs Assessment for Dementia (CNA-D) (79). Yet, the CNA-D is developed for use in research and relies on a one-hour interview conducted by a professional and is therefore not feasible for use in daily health and social care. Novais et al. conclude that it is necessary to develop a validated instrument to assess the met and unmet needs of carers. Such an instrument should include multiple dimensions of needs and be applicable during the entire progression of dementia (78).

A more recent review identified four instruments measuring one or multiple aspects of carers' needs (66): The Camberwell Assessment of Need for the Elderly scale (CANE) (80), the Johns Hopkins Dementia Care Needs Assessment (JHDCNA) (81), the Care Needs assessment pack for Dementia (CareNap-D) (82) and CNA-D. However, these instruments rely on professional rating, and two instruments (CANE and CareNap-D) primarily assess the needs of the person with dementia. Also, the JHDCNA has not been psychometrically tested. In summary, Bangerter et al. found that theoretical conceptualisation of carers' needs was lacking in instrument development and that more attention should be given to developing a needs typology or specific categories for carers to enable development of instruments reflecting the complexity of carers' needs (66). In addition, the EU Joint Programme – Neurodegenerative Disease Research (JPND) does not recommend any existing instruments (83). The authors recommend developing a new instrument based on a conceptual model of the construct to be measured in collaboration with the target population and that the instrument should be self-completed. Also, the complexity of the construct should be reflected in questions including both positive and negative aspects of caring.

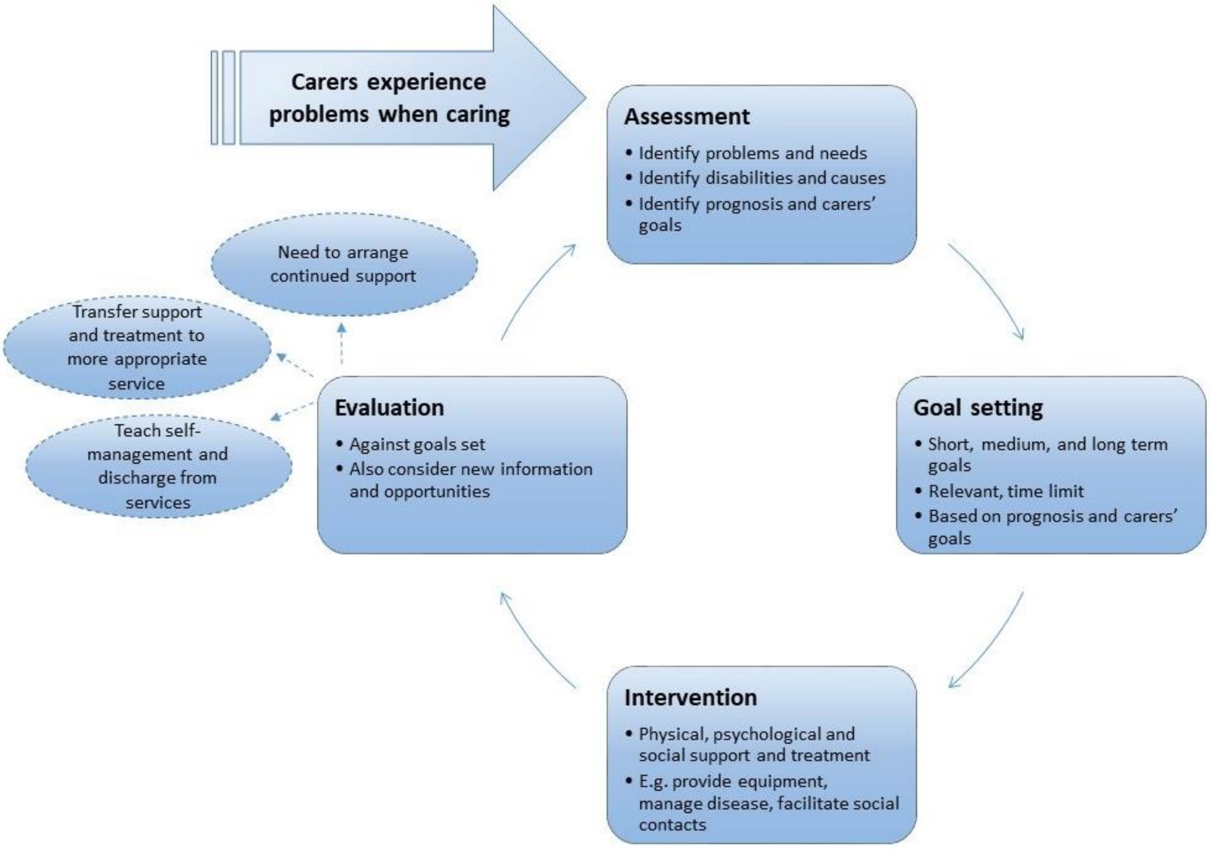
In summary, the literature clearly suggests the need for developing a self-administered instrument to assess carers' support needs that can be used throughout the progression of the disease in the person with dementia. In the development, the target population should be involved, and focus should be on applying a conceptual model that reflects the complexity of caring.

11.3.1 The rehabilitation process as a model for needs assessment

When conceptualising needs assessment, the rehabilitation process accommodates the interaction between assessment, goal-setting, intervention and evaluation (84) (Figure 2). The process describes and guides how it is possible for professionals to help solve complex problems which are characterised by multiple factors influencing the problem and interacting in various ways (84). The rehabilitation process is subjected to the biopsychosocial model that recognises a person's problems in relation to the physical, psychological and social context and the individual's personality (85,86). The model was intended as an alternative to the biomedical model, instead assuming a holistic approach which included all aspects in a person's daily life when providing health care. The most recent version of the model reflects a person-centered approach considering the individual's personality and life situation. Further, the model attributes meaning to the person's interaction with the physical environment and social relationships. It also recognises that participation is the highest level of functioning in daily life, referring to a person's social role or status (86).

When developing an instrument to assess carers' support needs, the rehabilitation process explains how assessment of carers' complex needs for support may be used when planning health and social care. Assessment of carers' support needs should identify problems important to them considering their personality and life situation. Using the biopsychosocial model, all conditions that may increase or decrease success of the rehabilitation process should be identified (6). Based on carers' own wishes and resources, short-, medium-, and long-term goals are set in collaboration with professionals depending on what is possible. Interventions are developed to fulfill the various goals and may entail support and treatment in relation to context, potential impairments and participation. Completing the rehabilitation process, evaluation of goal fulfillment is important to determine if continued support is needed.

Figure 2 Illustration of the rehabilitation process inspired by Wade (84)



Developing an assessment instrument based on the described rehabilitation process may offer an innovative way for professionals to support carers in health and social care. Although no clear organisation of supportive services exists, using a systematic approach to involving carers by first identifying support needs, setting goals and timeframes before offering support, could be a sustainable way to offer person-centred and targeted interventions and organise responsibilities among professionals (86). Identifying support needs is not enough. Funding of supportive services in the primary and secondary health-care sectors as well as the civil society are necessary to ensure the health and well-being of carers and people with dementia (9). If successful assessment of carers' support needs are implemented, this may be the first step in improving outcomes of the carer and the person cared for (86), thus decreasing the growing costs of dementia care.

12 Aim

The aim of this study was to develop a questionnaire to assess the support needs of carers when caring for a person with dementia - The Dementia Carer Assessment of support Needs Tool (DeCANT).

12.1 Objectives

The objectives of the study were threefold:

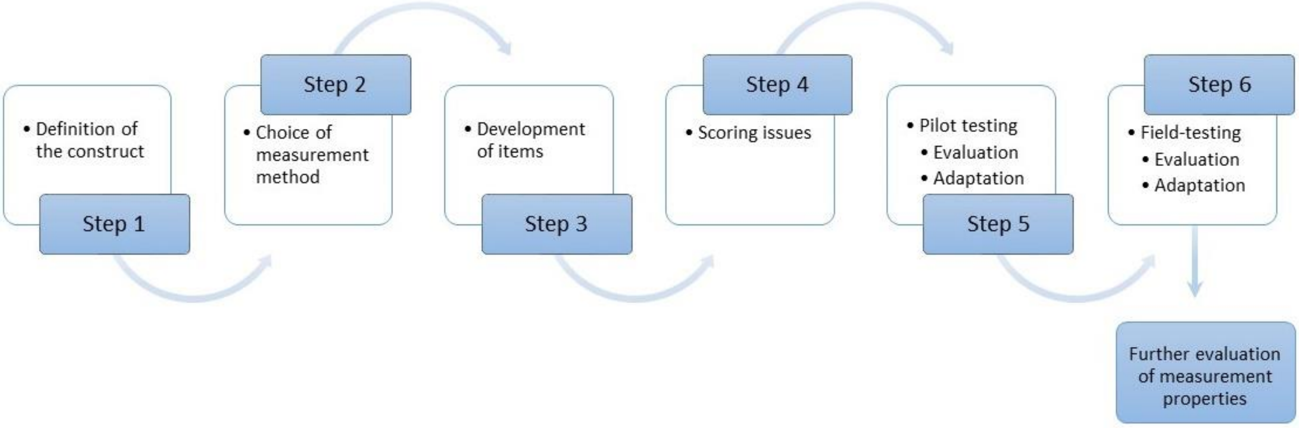
1) To map knowledge on carers' support needs and to synthesise knowledge on key concepts of carers' support needs (Paper I)
2) To clarify the specific support needs of carers when caring for a person with dementia (Paper II)
3) To develop items for a questionnaire to assess carers' support needs and to test the structural validity of these items (Paper III)

13 Overview of design

A PROM distinguishes itself by collecting information directly from the person of interest without interpretation by a professional (2,87). It is important when using a PROM to decide whether it is intended for generic or disease-specific use. The advantage of a generic measure is that it can be used in any population. However, caring for a person with dementia has been shown to cause more strain than caring for people with other chronic diseases (88), and the specific aspects of carers' support needs can only be addressed by a disease-specific measure (87).

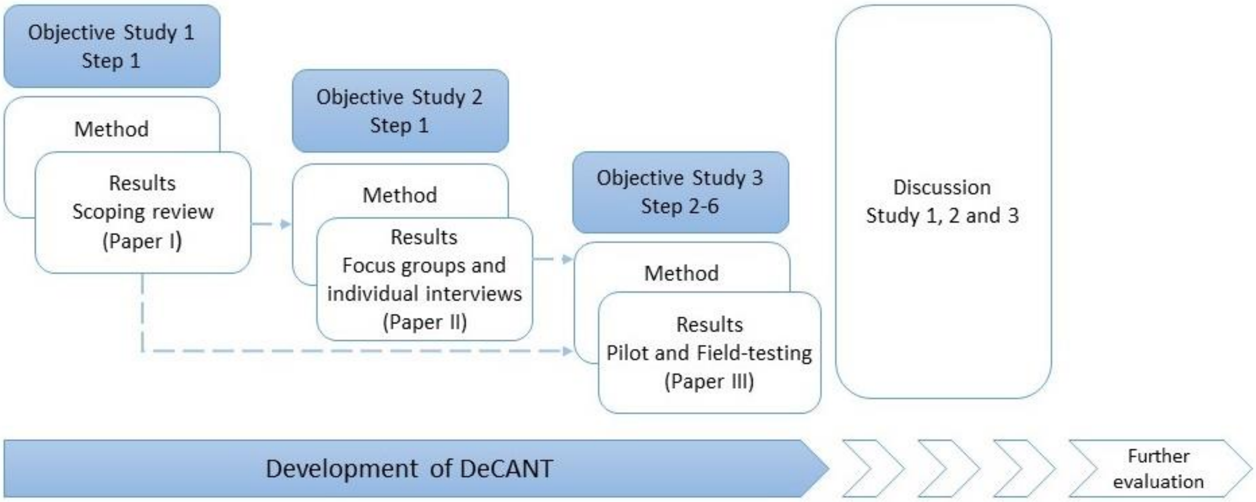
The overall design of this study follows the six steps for developing a PROM as illustrated in Figure 3 (2). The process is iterative with continuous evaluation and adaptation. The first step starts with defining the construct of what you want to measure. When a construct has multiple aspects, a conceptual model that describes this multi-dimensionality is necessary. Also, defining the target population is important. The second step consists of choosing a measurement method, e.g. questionnaire, depending on how information is best obtained regarding the construct to be measured. The third step involves selection and formulation of items. Information on the construct to be measured is gathered through investigation of existing literature and the target population. In the fourth step, the scoring of items needs to be considered and also how to express the scores as a scale, index or profile. The fifth step involves several steps of pilot-testing the PROM among experts and the target population. Continuous evaluation and adjustments are made by using various data collection methods to ensure comprehensibility, completeness and relevance of the PROM. Lastly, the sixth step consists of a larger scale field-testing of the PROM among the target population. In case pilot or field-testing demonstrates that the PROM is unsatisfactory regarding measuring the construct of interest, further testing should be conducted (2).

Figure 3 Illustration of the six steps when developing a PROM inspired by de Vet (2)



To ensure clarity, this thesis is structured by presenting the objectives, methods and results for each Study 1-3 consecutively, because Studies 2 and 3 depend on the results of the previous study. The objectives of the first and second studies address the first step of the process to develop a PROM. Thorough investigation of the construct to be measured is conducted to ensure a solid foundation for assessment of carers' support needs. The objective of the third study addresses the second to sixth steps of developing a PROM. Although, the methods and results are presented in a linear manner, an iterative process took place throughout all steps in relation to answering the aim of the entire thesis: to develop a questionnaire. Figure 4 depicts the structure of this thesis divided into three studies with their respective objectives and produced papers, followed by a coherent discussion of all results.

Figure 4 Overview of study objectives, methods and results in the thesis



14 Study 1

The objective of the first study was to map knowledge on carers' support needs and to synthesise knowledge on key concepts of carers' support needs (Paper I).

14.1 Method study 1

14.1.1 Study design

A literature review using the methodology of a scoping review as described by Levac et al. was conducted to investigate the construct of carers' support needs (89).

14.1.2 Search strategy

To obtain an overview of carers' support needs, a broad search of the literature was done by searching four databases of research literature within health and social care: PsycINFO via EBSCO, CINAHL Complete, PubMed via MEDLINE and EMBASE via Ovid. Three overall search terms were used representing carers, dementia and support needs (See Table 1 Paper I for an example of a search in a database). The search included quantitative and qualitative studies, primary and secondary literature, reports, conference abstracts, etc. providing information on carers' support needs from the carer's perspective. The search was performed from January 2007 to October 2019 and limited to English, Danish, Norwegian and Swedish languages (Paper I).

14.1.3 Study selection

Initially, titles and abstracts were screened for eligibility. Potentially eligible studies were reviewed as full text. At all stages, two reviewers decided on study inclusion eligibility criteria described in Table 2. A third reviewer was consulted if disagreements arose (Paper I).

Table 2 Inclusion and exclusion criteria used in study selection

Inclusion criteria	Express carers' support needs of people >18 years old when caring for a person with dementia or other dementia-related diseases	Focus on carers' own needs and not the needs of the person with dementia	Information on support needs comes from carers themselves	Reflects support needs when living in a culture with health and social care comparable with high-income countries
Exclusion criteria	Only describes the experience of caring	Evaluates the effect of carer interventions		

14.1.4 Charting the data

To extract data, a matrix with the following variables was used: author, publication type, year of publication, place of origin, carer type, design/data collection method, setting, diagnosis, extent of progression of dementia and type of interpretation used in data analysis. Variables were chosen to provide sufficient information on included studies and characteristics important to the caring role. Studies have shown that setting and relationship to the person with dementia affects carers' experience of burden and thus may be important when identifying carers' support needs (19,47). Combined with this, progression of dementia has been shown to have an impact on carers' level of burden due to the person with dementia's degree of dependency and need for supervision (19). Also, the type of dementia may be important to acknowledge, because disruptive behaviour is prominent in some types of dementias, e.g. frontotemporal dementia, and has been associated with a perceived increase in level of burden (47). Further, socioeconomic and cultural context (31,67) may affect carers' support needs, because level of service differs among countries. The 'type of interpretation' variable was used to identify carers' support needs in the included studies regardless of manifest or latent interpretation of data. Results based on a manifest interpretation of support needs include studies directly asking about support needs, whereas results based on latent interpretation include studies where the results have been subjected to interpretation of the underlying meaning to estimate carers' support needs (90).

The matrix was tested on three studies before use to ensure its relevance, and two reviewers independently extracted data. Extraction of data was continuously discussed, and studies were consecutively excluded if identification of non-adherence to eligibility criteria was determined (See Appendix 1 in Paper I).

14.1.5 Synthesis of results

Extracted data were synthesised using inductive content analysis (91) because it enables condensation of the broad information in the studies into categories that describe content in common (90). An inductive approach was chosen because no clear overview of carers' support needs exist, thus the purpose of the analysis was to move from specific information in the studies to more general information on carers' support needs by combining information into a larger whole (91,92). The inductive content analysis involved three phases: preparation, organising and reporting.

14.1.5.1 Preparation phase

All material was read to make sense of the data and to identify units of meaning for analysis. A unit could be a word, sentence or a portion of text on a page. However, due to the large quantity of information after retrieval of articles to be included in the analysis, a primary focus on units of meaning in the results and discussion sections was applied.

14.1.5.2 Organising phase

Firstly, to organise the open coding of data, categories were created using NVIVO 11 (http://www.qsrinternational.com/nvivo/nvivo-products/nvivo-11-for-windows) by giving meaningful units a heading when reading the text (91). While reading the text material, as many headings as necessary were generated and categories arose spontaneously, because the same headings were applicable to describe information contained in several meaningful units. Secondly, categories were created by grouping the headings of the meaningful units into higher order categories that described data belonging to the same category, which indicated a comparison with other categories in the data to describe different aspects of carers' support needs. When grouping units into higher order categories, interpretation of data was continuously undertaken. Lastly, abstraction was conducted as a process by combining categories into sub-categories followed by grouping these into generic categories and lastly into main categories. Each category was named using content-specific words, and the abstraction process ended when further grouping of categories was not possible (see Table 3 Paper I). The steps of creating categories and abstraction were carried out by continuous discussion between researchers in the research team.

14.1.5.3 Reporting phase

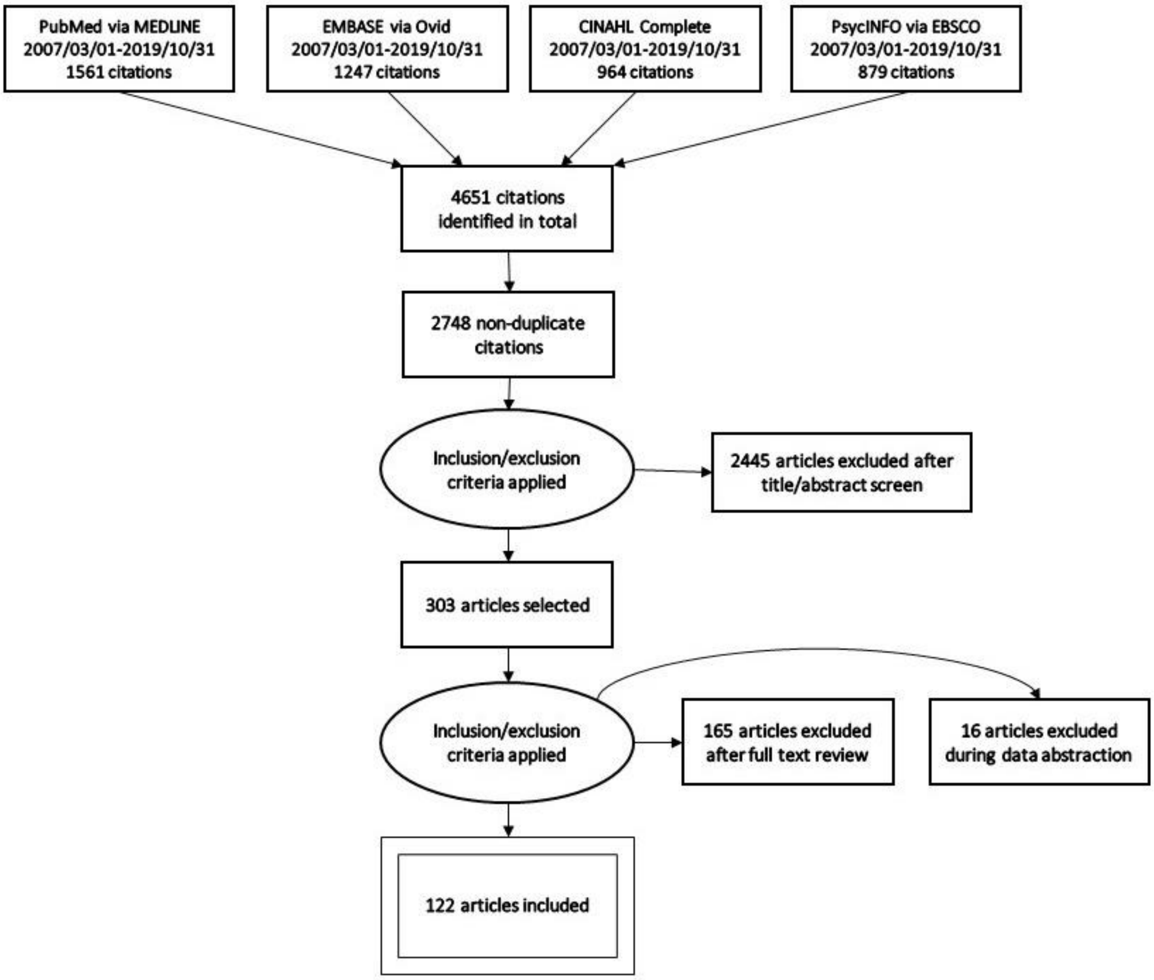
The results of the analysis were presented as a figure to provide an overview of the main categories identified describing key concepts of carers' support needs (Figure 6). This figure enables an immediate overview of the results. When reporting the analysis process, trustworthiness was important. Therefore, a table illustrating the link between results and data was made to describe the process of generating categories (see Table 3 Paper I). Also, citations from the original data in the included studies were used when describing the meaning of the created main categories.

14.2 Summary of results Study 1

14.2.1 Selection and characteristics of included studies

A total of 2748 studies were identified in the search after removal of duplicates. After screening titles and abstracts, 303 studies were included for full text reading, and 122 studies were included in the final analysis (Figure 5).

Figure 5 Flowchart of information through the phases of the scoping review



Most of the included studies were primary literature with 61 studies using focus groups or individual interviews, 35 studies using a survey design with questionnaires, and 8 studies using a mixed methods design. Eighteen studies were secondary literature using a literature review design. The origins of included studies were high income countries, with most studies representing European (n=52) and North American (n=39) countries. Asian countries (n=10) and Australia (n=13) were also represented.

14.2.2 Mapping of carers' support needs

A variety of support needs were identified, with the most frequently reported need being information on dementia. Also, mental health support was frequently reported. All studies reported more than one support need, illustrating the complexity of carers' support needs.

14.2.3 Synthesis of carers' support needs

The inductive analysis of included studies revealed four main categories of key concepts of support needs. Synthesising the results showed that an interaction of needs arising in the context of the carer as opposed to the context of the person cared for seems to be present. This may be important when understanding the complexity of carers' support needs, because the full extent of carers' needs for support may only be identified when acknowledging the needs arising from both perspectives and in the interaction between them (Figure 6). The four main categories of carers' support needs are briefly described below:

1. Support needs related to the carer as a person

Carers in general state that they pay only little attention to their own needs. However, carers also express a need for mental, physical and social support for themselves without considering the needs of the person with dementia.

2. Support needs related to managing being a carer

Carers describe a need for support to learn how to manage the caring role. For instance, learning how to use problem-solving strategies to avoid conflicts in day-to-day care was described as an important area for support.

3. Support needs related to providing care

Despite carers' commitment to caring, carers have a need for supportive services and knowledge about how to access these. Collaboration with professionals was often requested as well as a need for support with financial issues.

4. Support needs related to knowledge of dementia

Carers expressed a need for information and knowledge of dementia throughout the progression of dementia. Timing of this information was emphasised.

Figure 6 Illustration of the four main categories of key concepts of carers' support needs and the interaction between them (Paper I).

These four categories were consistent across carer types and care settings, but not associated with the degree of dependency of the person cared for nor the cultural and socioeconomic context. For further elaboration of results, see Paper I.

15 Study 2

The objective of the second study was to clarify the specific support needs of carers when caring for a person with dementia (Paper II).

15.1 Method Study 2

15.1.1 Study design

The findings from Study 1 indicated that carers' support needs were dependent on the context of caring. Therefore, a qualitative approach based on interpretative epistemology was used to investigate the construct of support needs, because this approach does not dictate finding an absolute truth (93). The study was designed to empirically describe the phenomenon in a pragmatic way (Cooper and Endacott, 2007) by asking carers and professionals directly about their understandings of carers' support needs. This design was chosen as previous studies suggest that carers' support needs may be viewed differently from the perspective of carers versus professionals (94,95). Carers find it difficult to articulate their own needs (75) and professionals have a tendency to identify carers' support needs in relation to the needs of the person with dementia (96) and their own professional knowledge (7). Thus, the perspectives of carers and professionals complement each other when seeking clarity on carers' support needs. The sequence of conducting the interviews in this study was carefully considered to allow the perspectives of carers and professionals to support each other in the data collection process. First, focus groups with professionals were conducted, and second, focus groups with carers were conducted, allowing carers to reflect upon the perspectives articulated by the professionals and to authenticate their relevance. Last, individual interviews were conducted to enable investigation of the more personal and sensitive experiences relevant to support needs.

A rigorous process of collecting and analysing data to answer the research question is described in the following.

15.1.2 Participants

To ensure identification and selection of participants with knowledge and experience of the phenomenon, purposeful sampling was used (97). To obtain an information-rich range in variation of participants, predefined inclusion criteria had to be decided from the beginning. Knowledge gained from mapping and synthesising literature of carers' support needs in Study 1 was used to decide the inclusion criteria for the current study (see Table 3). Hence, recruitment was conducted in one rural and one urban municipality in Denmark. Including participants from both rural and urban settings was important because carers' support needs may be influenced by accessibility to services and availability of specialist providers of health and social care (98). Alongside recruiting participants based on experience of the phenomenon, purposeful sampling constitutes a pragmatic recruitment strategy that takes into consideration availability and willingness of participants who are able to reflect and express themselves (97).

Table 3 Inclusion criteria for participants in Study 2

Interview type	Inclusion criteria
Focus groups, professionals	Working in dementia social care or health care
Focus groups, carers **Individual interviews, carers**	≥ 18 years, provides help on a regular basis because of a personal relationship rather than financial compensation to a closely related person who has received a dementia diagnosis, able to communicate in Danish

15.1.2.1 Criteria for carers

Variation was sought among carers with respect to the following criteria: sex, co-habitation, progression of dementia and relationship to the person with dementia. These criteria were chosen based on previous studies indicate their importance (53,99,100). In particular, carers feeling isolated due to high dependency or supervision of the person with dementia has shown to be important of carers' experience of support needs (101). Also, relationship quality may be important for carer motivation, and spouses have been seen to experience higher relationship quality and find more meaning in the caring role than other carers (44). Carers were recruited by key professionals in each municipality. This strategy was chosen to promote a heterogeneous composition of participants, and because these professionals were in a unique position to engage carers who may not have volunteered on their own. An example of this is carers of a person with dementia in the later stages of the disease who could be assumed to have less energy to participate in research. Therefore, key professionals were asked to prioritise recruitment of carers who may not volunteer by themselves.

15.1.2.2 Criteria for professionals

Diversity was also sought regarding experience and educational background among professionals. Various professions are represented in dementia care with educational backgrounds ranging from upper secondary school to a Master's degree (15,60). The level of education and specialisation within dementia care may affect the quality of care and support provided by professionals (60). The different educational experience and clinical expertise and knowledge may impact professionals' views on carers' support needs.

15.1.3 Data collection

15.1.3.1 Settings

Several factors were considered to ensure the best set-up for conducting the interviews, as carers may find themselves in a vulnerable position, and professionals may be hesitant to compromise themselves in front of unknown colleagues or a superior.

Focus groups were held in local meeting facilities in each municipality. Accessibility for participants was important, so carers were offered financial compensation for transportation to guarantee their opportunity to participate. For professionals, reducing time spent on transportation was important given their busy schedules. The focus groups lasted a maximum of 2 hours, which allowed enough time to welcome people and for a discussion to evolve naturally without a feeling of time pressure. Coffee, tea and cake were offered to create a welcoming and relaxed environment. An experienced moderator (THC) and co-moderator (HKK) conducted the focus groups. The moderator's role was to facilitate the discussion and make sure that all participants' voices were heard (102). The role of the co-moderator was to observe the discussion, take notes and follow up on issues that were passed over too lightly.

In the individual interviews, participants had the choice of the interview being conducted in their own home or at a local meeting facility. They were given this choice to ensure a feeling of safety in the interview setting, because taking part in an individual interview may feel intimidating for some. Interviews were conducted by the PhD student (THC). All interviews were recorded and transcribed verbatim afterwards.

15.1.3.2 Focus groups

The composition of groups was important. To enable a good group dynamic, eight participants were preferred (102,103). However, as few as five participants were deemed enough to constitute a focus group, as a smaller group rather than a larger group can sometimes lead to intense involvement and contribute to unique knowledge (103). At least two focus groups of professionals and carers were required to adequately sample the complexity of carers' support needs, respectively. To ensure healthy functioning of the groups and a reasonable comparison of issues raised by participants, some segmenting of the group of carers was necessary to achieve homogeneity (103). Carers' ability to see resemblance to their daily life when caring for a person with dementia was chosen as an important criterion, and carers were categorised based on whether or not they co-habitated with the person with dementia. The daily life of a carer living with a person with dementia has obvious restrictions, and carers may more easily recognise themselves in a person living a life resembling theirs.

The strategy of purposive sampling was used for recruitment of carers and professionals, who were unfamiliar with one another. This was desired as participants may feel anonymous and speak freely when thinking that the information shared is kept confidential from colleagues, family and friends (103).

15.1.3.3 Individual interviews

Carers in the individual interviews were identified to complement carer participants in the focus groups. Therefore, interview participants were recruited after completion of the focus groups. Also, carers reluctant to participate in focus groups were given the opportunity to give expression to their experience of carers' support needs in interviews which ensured more intimate surroundings (102). The adequate number of participants was determined by a repeated process of reflections: first, does preliminary analysis of focus groups provide sufficient variation of carers' experience of their support needs to answer the research question? Second, do individual interviews contribute as much variation as expected after conducting the first three interviews? Due to the specific sampling strategy and that the interviewer was experienced in achieving a well-focused interview with a good dialogue, a provisional number of five to ten participants was assumed to be enough. However, before finalising the data collection, a preliminary analysis was undertaken to consider if the data from the interviews showed adequate relevance and depth for the research question (104).

15.1.3.4 Interview guide

An interview guide was produced to ensure richness and consistency in the data collection across all interviews. The guide functioned as a memory aid that was organised around key topics assisting the moderator to facilitate a discussion (103). Through brain-storming (102), the PhD student along with one co-supervisor (HKK) formed ideas for how to organise the interviews, so that the guide could be used in the context of focus groups and individual interviews (see interview guide in Appendix 1 and Appendix 2). The guide was organised into three sections. Firstly, an introductory question where participants were asked to present themselves. Secondly, to enrich the discussion in the interviews, an activity of sorting and choosing text cards most important to each participant was chosen (103,105) and thirdly, a final question to close the discussion and to give the moderator a sense of what was most important in the discussion.

The text cards used for discussion of key topics were developed based on the results of the scoping review in Study 1 (Paper I). This review of existing knowledge of carers' support needs provided an overview of important topics that should be explored in the interviews. Sixteen cards were produced in accordance with the generic categories synthesised in Study 1 (see Table 3 Paper I) including four blank cards to encourage participants to generate new topics for discussion (see Appendix 3 for examples of text cards). In the activity part of the interview, participants were given 8 minutes to go through the topics described on the text cards, remove the cards not important to them and to choose the cards representing the topics most important to them. Afterwards, participants were given the chance to elaborate on their choices. In the focus groups, the moderator invited participants to engage in the discussion and speak their mind or comment on the other participants' choices. In the individual interviews, the interviewer facilitated discussion by asking carers to reflect on multiple perspectives of their choices.

15.1.4 Data analysis

Inductive content analysis (91) was used to clarify the specific support needs of carers. This method made it possible to condense the various statements of support needs into content-related categories. Choosing this approach allows a broad description of the phenomenon of carers' support needs. Also, no specific theory describes carers' support needs, and an inductive approach allows for a combination of specific data into a general statement. Due to the overall aim of developing a questionnaire to assess carers' support needs, manifest interpretation of the content was chosen (90). To generate items in a questionnaire, a clear description of the construct to be measured is necessary (2) and preferably, items should be phrased using the target population's own words. By using manifest interpretation, it was possible to stay very close to the transcribed text and to describe what carers and professionals actually said about support needs (106). When performing inductive content analysis, several phases are undertaken, which are described below.

15.1.4.1 Preparation

The transcribed material of all focus groups and individual interviews was chosen as the unit of analysis. A thorough reading of all the material to become familiar with the content initiated the groundwork for conducting the subsequent phases in the analysis process (91,106).

15.1.4.2 Organising

In this phase, open coding, creating categories and abstraction were conducted (91) using NVIVO 11 (http://www.qsrinternational.com/nvivo/nvivo-products/nvivo-11-for-windows) to help organise the data. Firstly, open coding was done by identifying units of meaning in the text and providing them with a heading that intuitively described the unit (106). This process was undertaken repeatedly, because as coding progressed, new details in the text were recognised, thus calling for an examination of the text more than once. Secondly, categories were created by grouping higher orders of headings. When grouping content, patterns across all of the material were sought (91), and all data had to fit into at least one group and no data were allowed to fit under more than one heading (106). Thirdly, abstraction was conducted by generating sub, generic and main categories describing carers' support needs (for an example of the abstraction process, see Table 2, Paper II). Sub-categories were created based on the grouped content and further grouped into generic, and finally main, categories. Abstraction continued until additional grouping of content no longer made sense and would have detracted from the meaning of the specific category (107). The organising phase was conducted in discussion with the main supervisor (HHL) and co-supervisor (HKK), although only the PhD student took part in the open coding.

15.1.4.3 Reporting

Presenting the results of the content analysis depends on the depth of interpretation of the data (106). Summarising the results of the manifest content analysis should explain the categories of support needs at a descriptive level, using quotations from the data material (91). Also, an easy overview in tabular form of the sub, generic and main categories should be presented (Figure 7) (106).

15.1.5 Ethical considerations

The study complied with the General Data Protection Regulations and was registered with the Danish Data Protection Agency (2015-57-0016-020a). The study followed the principles of the Declaration of Helsinki (108), however in agreement with Danish law, no ethics approval was required (109). All participants gave their informed written consent and all information was stored in a secure locker or server, and will be destroyed when the study is finished.

When interviewing carers and professionals, special consideration was given to ensuring the anonymity of the people spoken about by the participants. Further, in the focus group and interview situations, it was likely that sensitive information could be shared about a person not present, who would not be in a position to speak for themselves. Therefore, a respectful and well-intentioned tone was asked of all participants at the beginning of the interviews and especially in the focus groups, with participants being reminded of this if the tone changed.

An important consideration before conducting the interviews was that topics might appear about carers' support that participants had not thought of before or been able to express. The process of reflection might also cause carers to subsequently request additional care and support from professionals that service providers could not fulfil. Therefore, participants were informed when consenting to participate that the aim of this study was only to gather information on carers' support needs to help improve services for carers in the future (see information letter to participants Appendix 4).

15.2 Summary of results Study 2

A total of 23 carers and 13 professionals participated in focus groups and individual interviews. For more specific details on participants, see Table 3 in Paper II. Inductive content analysis resulted in four main categories that clarify carers' support needs. An overview of the abstraction process from sub- and generic categories into main categories can be seen in Figure 7. Below, the main categories are described briefly.

1. Carers' support needs in daily life when caring for a person with dementia

Carers described a need for support to manage issues of care in daily life, especially adjusting to the person with dementia needing formal care and their journey of finding ways to ensure the well-being of the person with dementia. Also, carers needed continuous knowledge on how to care for the person with dementia.

2. Carers' support needs to focus on themselves

Carers needed support to realise they had their own needs and they needed someone to force them into talking about difficult issues, otherwise they would be left alone to deal with these.

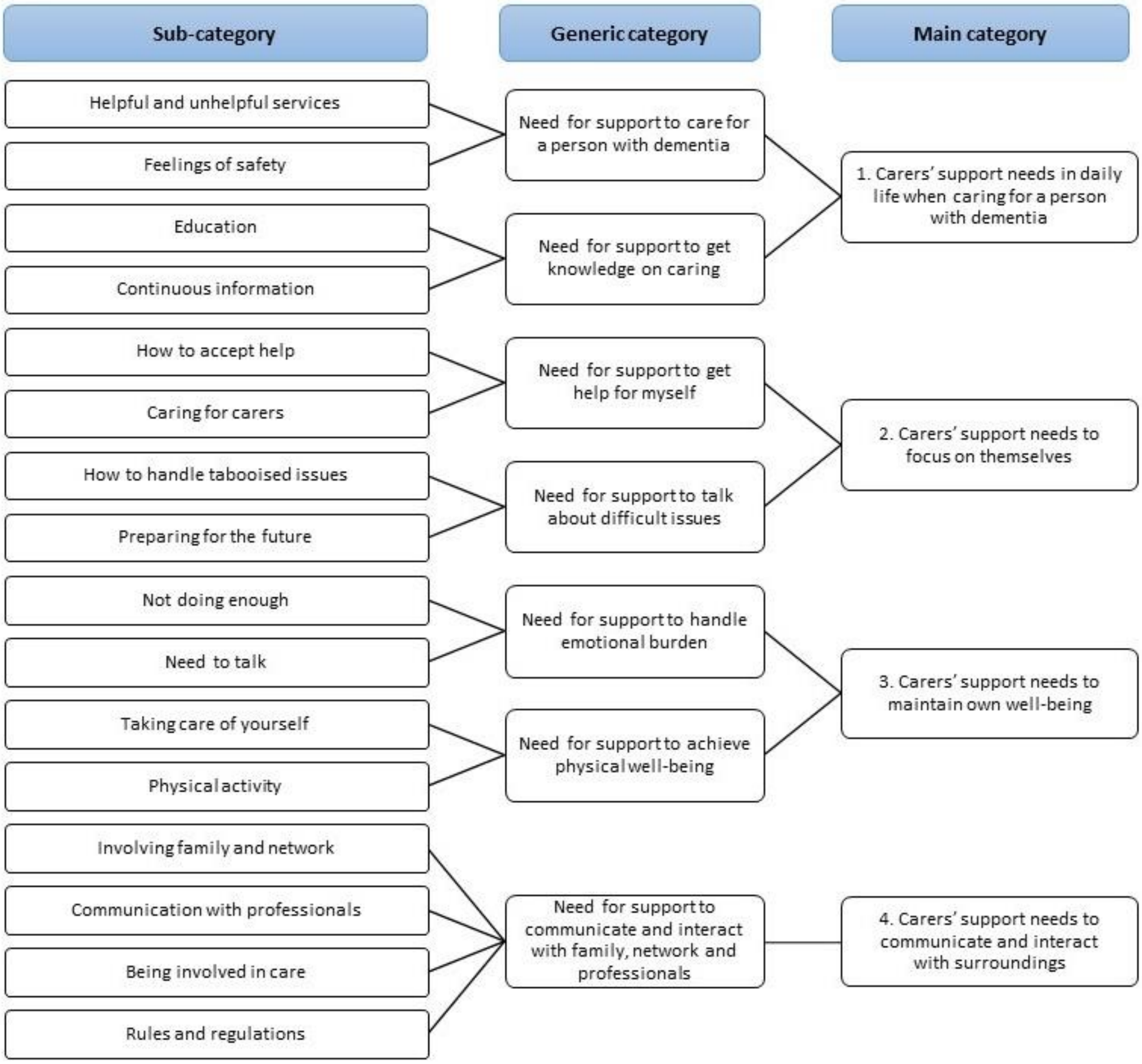
3. Carers' support needs to maintain own well-being

Carers needed support to focus on positive experiences. They needed support to organise activities to maintain a good relationship with the person with dementia and initiate activities focusing on their own emotional and physical well-being.

4. Carers' support needs to communicate and interact with the surroundings

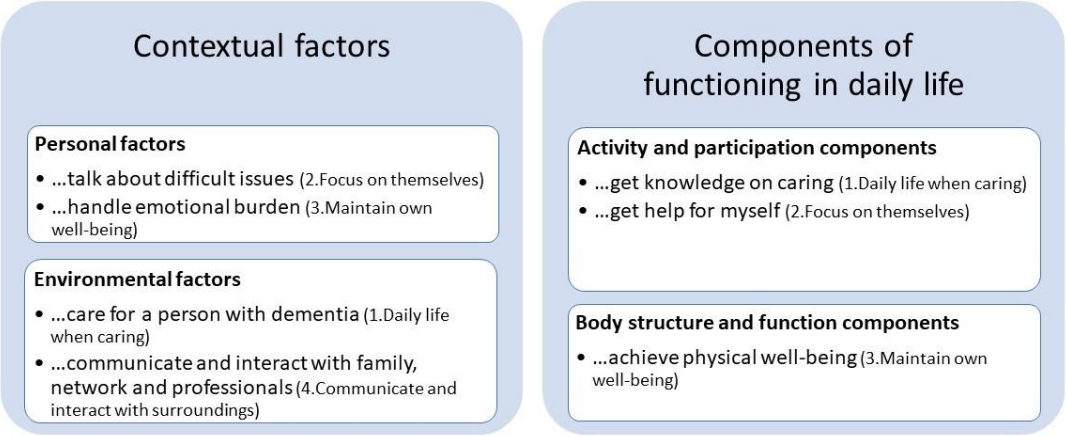
Carers expressed a need for support from close family and friends, especially to be reassured regarding decisions made about the person with dementia. Also, communication and accessibility of professionals was important for carers to feel supported in the caring role.

Figure 7 Sub, generic and main categories of carers' support needs identified in focus groups and individual interviews with carers and professionals in Study 2 (see Paper II)



To reflect on whether the identified needs provide a comprehensive description of carers' support needs including the complexity implied by the results of Study 1, the International Classification of Functioning, Disability and Health (ICF) (3) founded in the biopsychosocial model (86) was used. The ICF framework categorises physical, psychological and social aspects of health and functioning (110,111), and explains an interaction between components of functioning and contextual factors (the ICF model can be seen in Appendix 5). Linking the categories found in this study to the ICF was possible (see Figure 8), which may suggest that categories could be used as a comprehensive conceptual framework when developing items in an instrument to assess carers' support needs. For further elaboration of the results, see Paper II.

Figure 8 Linking main and generic categories found in Study 2 to the ICF framework (Paper II)



16 Study 3

The objective of the third study was to develop items in a questionnaire to assess carers' support needs and to test the structural validity of the questionnaire (Paper III).

16.1 Method Study 3

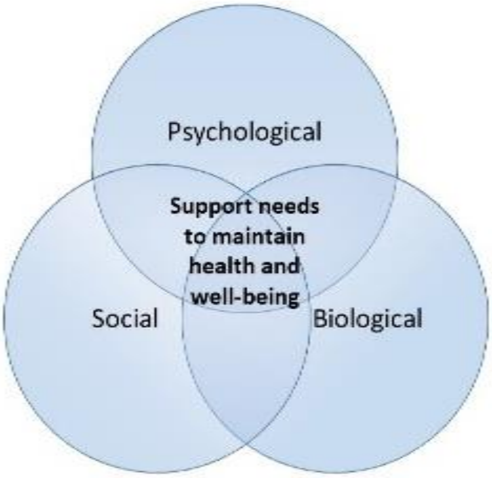
16.1.1 Study design

This study used a PROM development design, combining quantitative and qualitative methods to ensure high quality of the developed questionnaire's measurement properties (2).

16.1.2 Conceptual model

The biopsychosocial model was used as a theoretical model to describe carers' support needs consisting of physical, psychological and social aspects (85). The biopsychosocial model has a systemic approach which entails recognising the specific support need as part of a larger whole of various problems affecting a person's need for support in order to maintain physical, psychological and social well-being and health (112).

Figure 9 Conceptual model to understand how different aspects of support needs are related. Model inspired by Engel (85).

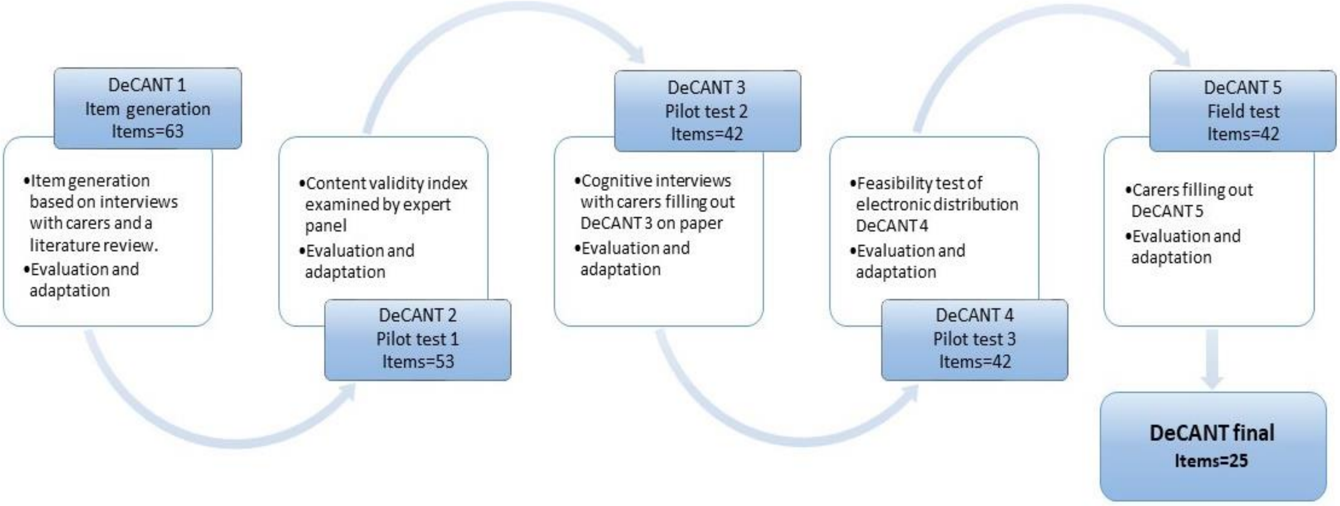


Also, this conceptual model defines that the construct to be measured is multi-dimensional and support needs are reflected in the items (2).

16.1.3 Development process

Developing an instrument based on this conceptual model was an iterative process, because evaluation and adaptation of items were ongoing. The developmental steps have been described by de Vet et al. (see Figure 3) (2), and the methods used in Study 3 follow these recommendations. To give an overview of the various steps of development, Figure 10 presents the different versions of DeCANT in connection with the different methods used for evaluation and adaptation.

Figure 10 Overview of the various steps of evaluation and adaptation when developing the DeCANT



16.1.4 Item generation

Items were generated based on knowledge of carers' support needs identified in the scoping review in Study 1 and interviews with carers and professionals in Study 2. Information on carers' support needs from existing questionnaires was also included. The process started with formulating questions covering the support needs identified in sub-categories in Study 2 (see Figure 7). This process was chosen to allow the subjective view of carers' support needs to be reflected as much as possible in the items. After this process, results of the scoping review were scrutinised to check whether any important topics were left out. Also, items in existing instruments were evaluated to ensure coverage of the developed items. Existing instruments on carers' needs were identified through searching the literature in the electronic databases: CINAHL Complete, PubMed via MEDLINE and EMBASE via Ovid and a hand search of governmental and special interest organisations' publications, emphasising results and recommendations from systematic reviews already conducted in the past 5 years.

After developing the initial item pool, these were discussed in the project team consisting of the PhD student (THC) and her supervisors (HHL, HKK, KAR). The supervisors were given the opportunity to comment on items in writing before meeting to discuss comprehensiveness, relevance and comprehensibility. Only items reaching consensus were retained, and ambiguous items were clarified.

Item formulation was targeted at the carer population, reflecting the words used by the carers and avoiding professional language (2,113). The same introductory phrase and response options were used for all items. Considering the setting for use, items had to be formulated in a way that would be acceptable to professionals too, especially considering that response options should provide information that may inform assessment of carers' needs for supportive services. An ordinal scale of categories was therefore considered useful to capture both the individual experience and a rating of severity (2). Assuming multi-dimensionality of the instrument to be developed, only a profile of carers' support needs summing one score per dimension would be appropriate, due to the choice of using an ordinal scale.

16.1.5 Pilot-testing

Pilot-testing entails testing comprehensibility, relevance and acceptability of the new instrument among the target population. Feasibility as to the difficulty and length of the questionnaire should also be tested (2). Pilot-testing provides important information to identify aspects that need adjusting in the questionnaire to ensure that it will be applicable in health and social care contexts.

16.1.5.1 Pilot test 1: Expert panel

The first draft of DeCANT was tested using the content validity index (CVI) by asking an expert panel to evaluate relevance, comprehensiveness and comprehensibility (114,115). This evaluation provides information which can be used to reduce the number and adjust formulation of items. Also, information on feasibility in the settings for use is possible.

16.1.5.1.1 Settings

Representing as many perspectives as possible, participants were sought from among informal dementia carers and professionals in both primary and secondary health care, nongovernmental organisations. Carers with particular interest in reflecting on their carer role were sought from the participants in Study 2. Professionals were considered experts within their field, working with specific problems related to dementia health and social care, including collaboration with carers. Experts with different professional backgrounds were desirable in order to get a variety of perspectives on carers' support needs.

16.1.5.1.2 Participants

A pragmatic approach was undertaken to recruit experts from the networks of the PhD student and supervisors. A minimum of three and up to 10 experts are recommended to be recruited based on specific criteria about who qualifies as an expert or member of the expert panel (115). Four categories of experts were identified, and at least one participant representing each expert category was required. Criteria for each category were:

- Informal dementia carers: A person who provides help on a regular basis because of a personal relationship rather than financial compensation to a person with dementia, able to communicate in Danish, and >18 years old.

- Nongovernmental organisations: An experienced specialist who works to protect the interests and rights of people with dementia and their carers.

- Primary health care: A professional attending to the health needs of people with dementia and carers through promotive, protective, preventive, curative, rehabilitative and palliative efforts in the local setting of a municipality (116).

- Secondary health care: A professional attending to the specialised health needs of people with dementia and carers in the setting of a dementia outpatient clinic or hospital (117).

16.1.5.1.3 Data collection

An email was sent to each expert encouraging them to give suggestions for improvement. The experts evaluated relevance, comprehensiveness and comprehensibility of the items on a scale ranging from 1='Not relevant' to 4='Highly relevant' (118,119) independently.

16.1.5.1.4 Analysis

Experts' scores for each item were dichotomised as relevant (ratings 3-4) or not relevant (ratings 1-2). An Item content validity index (I-CVI) was calculated for each item by summing the dichotomised scores. The proportion of experts in agreement was calculated and kappa statistics were used to measure agreement (118). Criteria for evaluation of agreement followed the recommendations of Fleiss et al. (120). Items with kappa below 0.75 were considered for removal or adjustment (also see Paper III).

16.1.5.2 Pilot test 2: Target population

Cognitive interviews were used to test how the target population responded to DeCANT and if any adjustments were necessary, as seen from the personal and subjective perspective of carers (114).

16.1.5.2.1 Settings

All participants were recruited through key professionals in primary and secondary health care who had a professional relationship with the person cared for. Carers were therefore known to the system because of the person with dementia.

16.1.5.2.2 Participants

Purposive sampling (97,121) of carers was used based on the same criteria as for carers in Study 2. A minimum of ten participants was necessary to be able to interpret on face and content validity (114).

16.1.5.2.3 Data collection

Interviews were conducted using a combination of verbal probing and Think-Aloud method (2,114). Participants were asked to think aloud while filling out DeCANT. The interviewer was not allowed to comment or help. Probing questions were subsequently asked regarding comprehensibility, relevance, completeness, acceptability and feasibility. A semi-structured interview guide was prepared to ensure that specific issues were talked about e.g. if the introduction was relevant and comprehensible and if some words were too technical/professional. At this point in the development process, it was also possible to investigate the meaning of any discrepancies between the findings in the scoping review in Study 1 and the focus groups and individual interviews in Study 2 regarding comprehensiveness of the items. All interviews were audio-recorded.

16.1.5.2.4 Analysis

Interpretation of the data was carried out using deductive content analysis (90,91). Using a deductive approach entailed categorisation of collected data into predefined categories to investigate face and content validity of DeCANT. A categorisation matrix (see Table 4) was developed to code the data based on the key elements of content validity (122). Only content fitting the matrix was included in the analysis (91).

Table 4 Categorisation matrix used for coding of data in the cognitive interviews with carers

	Comprehensibility	**Relevance**	**Comprehensiveness**
What do carers think is important to ensure that DeCANT is an adequate reflection of carers' support needs?			

Based on the results of the deductive analysis, items were adjusted in discussion between the PhD student and her supervisors. Emphasis was put on carer's personal and subjective views of what was important.

16.1.5.2.5 Ethical considerations

All interviews were carried out by an experienced interviewer (THC) in the safe environment of their homes. Also, the interviewer made sure that carers knew whom to contact if questions arose as a result of the interview. Interviews were conducted according to the Declaration of Helsinki (108), and participants gave their informed written consent before participating. Data collection and management were conducted in accordance with the General Data Protection Regulations and registered at the Danish Data Protection Agency (2015-57-0016-020a). In agreement with Danish law, no ethics approval was required (109).

16.1.5.3 Pilot test 3: Electronic distribution

A third pilot test was conducted to ensure feasibility of electronic distribution, because DeCANT was only tested on paper in Pilot Test 2. Distribution of DeCANT using an electronic platform will become relevant in the following field-test study requiring a larger sample. Also, it may be relevant when used in future health and social care due to its ease of use.

16.1.5.3.1 Settings

Electronic pilot-testing was conducted in the general population to investigate whether it was feasible to fill in DeCANT in digital form using various private electronic devices such as smart phones, tablets and computers.

16.1.5.3.2 Participants

Purposeful sampling (97,121) (resembling convenience sampling) in the PhD student's network was conducted, representing different types of digital users based on the following criteria: age range (young to old), educational background (short to long) and use of electronic device (smart phone, tablet or computer). A minimum of 10 tests was desirable to be able to identify any technical challenges or issues of comprehension.

16.1.5.3.3 Data collection

An email with a link to DeCANT in digital form was sent using REDCap electronic data capture hosted by the Odense Patient data Explorative Network (OPEN), Odense University Hospital, Odense, Denmark (123,124). Participants were given written instructions to fill in DeCANT and comment in free text their thoughts on its comprehensibility and feasibility. If participants expressed any problems, a follow-up telephone interview was conducted.

16.1.5.3.4 Analysis

Registration of successful responses were tracked and frequency distribution was calculated. Qualitative analysis of written comments was conducted following the same rigorous data analysis process as described in Pilot Test 2 (91). Findings pointing to needed adjustments of DeCANT were implemented before field-testing.

16.1.6 Field-testing

Based on evaluation and adjustment of DeCANT in the previous pilot tests, a field-test was carried out to reduce the number of items and to examine structural validity of the instrument.

16.1.6.1.1 Settings

The field-test was carried out with carers of a person with dementia across several municipalities in Denmark in association with a broad range of primary and secondary health and social care services, as well as carers with no association with formal care. Therefore, carers, both known and unknown to the health and social care system, were included.

16.1.6.1.2 Participants

An *a priori* sample size for the factor analysis was determined based on a recommendation of seven cases per item and a minimum of 100 participants (2). A strategy of purposeful sampling (97,121) was used to achieve a heterogeneous composition of carers. The inclusion criteria were the same as for carers in Study 2 and Pilot Test 2. Carers were recruited by key professionals in nine municipalities and one dementia clinic at a hospital. Also, social media were used to connect with carers outside the formal care system.

16.1.6.1.3 Data collection

All participants were given information about the survey by telephone or email. Each participant could choose between answering the survey by mail or email. Paper-based surveys were managed manually by the PhD student and a research assistant. Participants were contacted by email or telephone after 4 to 6 weeks if a response was not received. REDCap electronic data capture hosted by OPEN, Odense University Hospital, Odense, Denmark (123,124) was used for distribution of the survey in digital form, data management, and entry of data in both paper and digital form.

16.1.6.1.3.1 Instruments

DeCANT was distributed in a 42-item version (see Appendix 6). Items were organised into four domains as described in the results section of Study 2 measuring support needs in relation to 1) Carers' support needs in daily life when caring for a person with dementia, 2) Carers' support needs to focus on themselves, 3) Carers' support needs to maintain own well-being and 4) Carers' support needs to communicate and interact with the surroundings (Paper II). Items within each domain were scored on an ordinal scale of '*No'* representing the value 0, '*Yes, a little more'* representing the value 1, '*Yes, quite a bit more'* representing the value 2 and '*Yes, very much more'* representing the value 3.

Information on participant characteristics relevant to describe the context of caring were collected in relation to the carer and the person cared for. Therefore, background characteristics on carers such as age, sex, relationship with the person with dementia, educational background, employment, and cohabitation status were registered. Also, information on type of dementia, time of diagnosis and use of formal services in the person cared for were registered.

*The 12-item Short Form Health Surve*y (SF-12) was used to measure carers' general health and well-being. The SF-12 was chosen because it is a short and frequently used instrument in health care research and has been validated for use in a Danish context (125). It consists of eight domains measuring physical functioning, physical role, bodily pain, general health, vitality, social functioning, emotional role, and mental health. A summary of physical (PCS) and mental health (MCS) components can be calculated as T-scores ranging from 0-100 with 100 reflecting better health.

The Barthel-20 Index (Barthel-20) (126) was used to screen the person with dementia's self-care and mobility skills in ADL by carers' proxy response. Barthel-20 consists of 10 items, it is easy to administer and has been used widely as a clinical measure of disability (127). It is scored on a 0-20 scale with 20 demonstrating high independence in ADL. Although, Barthel-20 has not been specifically developed for people with cognitive impairment, it has previously been used for proxy rating of self-care and mobility in dementia research (127,128). Also, Barthel-20 has previously been used in Danish health care setting similar to the context of this study (129).

The Neuropsychiatric Inventory (NPI-Q) is used to measure cognitive and functional decline in a person with dementia. The NPI-Q has been developed for use in clinical practice of dementia to assess neuropsychiatric symptoms and caregiver distress (130), and has been validated for use in a Danish context (131). The NPI-Q consists of 10 items asking about the person with dementia's neuropsychiatric symptoms and carers had to first rate the severity of symptoms and next their own distress caused by that. Severity is scored from 0-36 with 36 as high severity. Distress is scored from 0-60 with 60 as high distress.

Both Barthel-20 and NPI-Q contain questions using technical health terms such as 'klysma' in Danish meaning laxative in English or 'agitation' in Danish meaning the same in English. However, these words are not commonly used in the Danish language. Therefore, a pilot test of these questionnaires was conducted in a small sample of five Danish carers using a convenience sampling strategy. Carers filled in Barthel-20 and NPI-Q and were interviewed afterwards about comprehension and if any problems presented. Findings demonstrated that only a few words needed to be explained, because the context of questions using technical terms was self-explanatory.

16.1.6.1.4 Data analysis

16.1.6.1.4.1 Descriptive statistics

Statistical analyses of participant characteristics were carried out with a descriptive purpose. Frequencies, frequency distributions, mean, median, standard deviation (SD) and interquartile range were calculated for categorical and numerical variables.

16.1.6.1.4.2 Item score distribution

To evaluate information quality, item score distribution of response frequencies was inspected at an item level. Items with a large proportion of participants choosing the same response option were considered for redundancy, because this may suggest less discriminative power (2).

16.1.6.1.4.3 Partial inter-item correlation

To promote retention of unambiguous items, partial inter-item correlations were investigated. Even though correlation between items was expected in a reflective model, partial correlation should be avoided (2,132). Item pairs with partial correlation above 0.3 were inspected (133,134), and items were removed if content was overlapping.

16.1.6.1.4.4 Confirmatory Factor Analysis

To examine structural validity of DeCANT, a total of three four-factor models were hypothesised using confirmatory factor analysis.

16.1.6.1.4.4.1 Model 1

Four main categories of carers' support needs derived through inductive analysis in Study 2 were used to hypothesise a four-factor model: Factor 1) Communicating and interacting with surroundings, Factor 2) Daily life when caring for a person with dementia, Factor 3) Maintaining own well-being and Factor 4) Focusing on themselves (see Table 5).

16.1.6.1.4.4.2 Model 2

As suggested in Study 2, the International Classification of Functioning (ICF) (3) was used as a framework to hypothesise a four-factor model. Using linking rules described by Cieza et al. (111), items were categorised into a first-level ICF category: Factor 1) Environmental factors, Factor 2) Activity and participation component, Factor 3) Personal factors, and Factor 4) Body structure and function component (see Table 5). Three experienced researchers (including the PhD student THC and supervisor HKK) in using the ICF as a theoretical framework to organise information on physical, biological and social aspect of an individual's health and well-being, independently coded items to the ICF. Coding was not concluded until consensus was reached.

16.1.6.1.4.4.3 Model 3

A predefined theoretical framework describing dimensionality of carers' support needs could likely be a stronger model from the beginning when performing CFA (2). Further, in Classical Test Theory, local independence is implicitly assumed (135). Consequently, an inaccurate model may be hypothesised, and it was checked if the assumption of local independence was fulfilled. If it was not, the corresponding items were allowed to correlate to take this local dependence into account, resulting in a third model (see Table 5).

Table 5 Hypothesised models in the confirmatory factor analysis of DeCANT

	Factor 1	Factor 2	Factor 3	Factor 4
Model 1: based on four main categories derived in Study 2	i33, i37, i38, i41, i42	i1, i3, i4, i6, i9	i22, i23, i24, i26, i27, i28, i30, i31, i32	i12, i13, i16, i18, i19, i21
Model 2: Based on the ICF framework	i1, i21, i22, i26, i33, i37, i38, i41, i42	i3, i4, i6, i23, i28, i30, i31, i32	i9, i12, i13, i27	i16, i18, i19, i24
Model 3: Post hoc analysis of Model 2	i1*^{1}, i21, i22*^{1}, i26, i33, i37, i38, i41*^{2}, i42*^{2}	i3, i4, i6, i23, i28, i30, i31, i32	i9, i12, i13, i27	i16*^{3,4}, i18*^{3}, i19*^{4}, i24

Note Three models were hypothesised in the field-test. Model 1 is based on a framework of support needs derived from inductive analysis. Model 2 is based on linking items to the ICF framework. Model 3 is based on post hoc analysis of Model 2 including four instances of possible local dependence between items marked with *accompanied by a number to demonstrate that correlation between these specific items was allowed in the hypothesised Model 3: Post hoc analysis of Model 2.

To assess the fit of the hypothesised model, Weighted Least Square Mean and Variance (WLSMV) estimation (136) was used in CFA, because all items were categorical. To evaluate goodness of fit of the models to the data, the following five criteria were used: the chi-squared test ($\chi 2$) including degrees of freedom (df) and p-values, the weighted root mean residual (WRMR), the root mean square error of approximation (RMSEA), the Tucker-Lewis index (TLI) and the Comparative Fit index (CFI) (137). Schreiber et al.'s guidelines to indicate a close model fit for categorical data were followed: $\chi 2$ with non-significant p-values, WRMR < 0.90, RMSEA < 0.06, TLI > 0.95, CFI> 0.95 (137). Local dependence was examined by calculating partial correlations (138). The same criterion, as with the previous examination of partial inter-item correlations of partial correlation between item pairs exceeding 0.3, was used to indicate possible local dependence (133). Also, modification indices and standardised residuals were looked at to see if any improvements to the estimated model were indicated (113,137). Data were analysed with Stata 15 IC (StataCorp, College Station, TX, USA), RUMM2030 (RuMM Laboratory P/L, Duncraig WA, Australia) and Mplus version 7.0 (136).

16.2 Summary of results Study 3

16.2.1 Item generation

An initial item pool of 63 items was generated based on knowledge of carers' support needs identified in Study 1, Study 2 and existing carer instruments (CNA-D, CANE, JHDCNA, CareNap-D). Considering the importance of a person-centered approach to understand carers' support needs, knowledge from interviews guided the phrasing and structure of items.

Items were discussed in the project team where consensus was sought as to which items should be retained, revised or removed. Examples of issues discussed for adjustment were: harmonising of concepts used e.g. care worker (in Danish: fagperson) or professional (in Danish: professionel), avoid negatively charged words such as burden (in Danish: belastning) and replace technical terms such as communicate (in Danish: kommunikere) with speak (in Danish: tale). As a result of the discussion, 10 items were removed because several items asked about the same support need e.g. the item ‘Do you have a need for support to get respite from everyday caring?’ was similar to the item ‘Do you have a need for support to get a day off?’. Thus, a pool of 53 items were left for further testing. See Appendix 7 for a full overview of the item generation process. In addition to the project team’s discussion of language, a language expert was consulted to ensure correct grammar and unambiguous use of language in items.

Along with item generation, an introduction to guide carers filling in DeCANT was produced. Emphasis was put on the introduction being short, the purpose of DeCANT explained, and how questions should be answered. Also, response categories in an ordinal scale were developed. The categories were ‘*No (not relevant/ need met*’, ‘*Yes, a little more*’, ‘*Yes, quite a bit more*’ and ‘*Yes, very much more*’.

16.2.2 Pilot test 1

Eight experts contributed to CVI testing of DeCANT (Table 6). Following discussion in the project team, 11 items were removed based on experts’ comments and I-CVIs resulting in kappa below 0.75. For further elaboration, see Paper III and Appendix 1 in Paper III.

Table 6 Characteristics of expert panel participants for the Content Validity Index (CVI)

Participants	**Sex**	**Care setting**
Carer to a wife with Alzheimer’s	Male	Home-dwelling
Consultant	Female	Non-Governmental Organisation in dementia care
Nurse	female	Primary care
Psychologist	female	Primary care
Physiotherapist	Female	Primary care
Nurse	Female	Hospital
Doctor	Male	Hospital
Occupational therapist	Female	Researcher in dementia care

16.2.3 Pilot test 2

Based on cognitive interviews with 12 carers of people with dementia (Table 7), the remaining 42 items were evaluated and wording of items was adjusted to their preferences to ensure comprehensibility (see Appendix 7). Participants did not think any items were redundant or that any items were missing. In fact, carers independently expressed that items represented important support needs, demonstrating a high degree of relevance and completeness of the items. Further, they expressed that DeCANT should only be administered if professionals were to follow up on identified support needs, because of thought-provoking and sensitive content in items (for details, see Paper III).

Table 7 Characteristics of participants in cognitive interviews

Relation to the person with dementia	Residence of the person with dementia	Sex	Age	Education
Brother	Living at home	Male	55	Secondary education
Brother	Nursing home	Male	59	Secondary education
Daughter	Nursing home	Female	42	Higher education
Daughter	Nursing home	Female	69	Higher education
Daughter	Deceased	Female	35	Secondary education
Husband	Nursing home	Male	79	Higher education
Wife	Living at home	Female	70	Secondary education
Wife	Living at home	Female	67	Elementary education
Wife	Nursing home	Female	72	Higher education
Wife	Nursing home	Female	77	Elementary education
Wife	Deceased	Female	73	Secondary education
Ex wife	Living at home	Female	56	Higher education

16.2.4 Pilot test 3

Electronic testing of DeCANT in digital form was conducted using 10 different devices by seven participants (Table 8). Having to fill in DeCANT as a self-reported instrument in digital form did not cause any problems. Some participants pointed out that it was helpful that a warning was given when a response was missed. This was especially useful when using a device with a small screen, because they had to scroll through the page. The digital layout did not cause any problems when using DeCANT on different devices.

Table 8 Characteristics of participants in pilot test of electronic distribution

Type of electronic device	Sex	Age	Education	Carer (Yes/No)
Computer	Male	52	Higher education	No
Computer	Female	69	Secondary education	No
Computer	Male	56	Higher education	Yes
Tablet	Male	72	Secondary education	No
Tablet and computer	Male	39	Higher education	Yes
Computer and smart phone	Male	64	Higher education	Yes
Computer and smart phone	Female	40	Higher education	Yes

16.2.5 Field-test

16.2.5.1 Descriptive statistics

In total, 434 carers were contacted by email or telephone and invited to participate. Three hundred and one carers filled in the survey, giving a response rate of 69%. Data were collected from February 1st 2018 to October 31st 2018. Most respondents were female (78.41%), not co-habitating with the person with dementia (55.81%) and had a family relationship with the person cared for (95%) (Table 9). Regarding non-respondents, only contact information was available to describe this population (Table 10). Thus, 28.57 % of non-respondents were male, which resembles the frequency distribution of sex in the population of respondents (Table 9). However, when conducting random checks by calling or emailing non-respondents asking why they did not participate, the following reasons were mentioned: I have forgotten it, I have been busy at work, I do not have the energy, or the person with dementia had deceased.

Table 9 Demographic characteristics of participants in the field-testing phase (n=301)

Variable		
Sex (female), n (%)	236	(78.41)
Age (years), mean (min-max)	61,7	(23-95)
Relation to person with dementia, N (%)		
Spouse/partner	161	(53.67)
Child	123	(41.00)
Sibling	2	(0.67)
Other	14	(4.67)
Education, n (%)		
Elementary education	21	(7.22)
Secondary education	112	(38.49)
Higher education	139	(47.77)
Other	19	(6.53)
Employment, n (%)		
Paid employment	121	(40.88)
Unemployed/retired	161	(54.39)
Other (e.g. sick leave)	14	(4.73)
Residential care status, n (%)		
Co-resident with person with dementia	128	(42.52)
Resides away from person with dementia	168	(55.81)
Living in the same municipality, n (%)		
Same municipality	212	(70.90)
Different municipalities	87	(29.10)
SF-12 carer, mean (SD)		
Physical health component	49.49	(11.29)
Mental health component	44.43	(12.59)
Diagnosis of person with dementia, n (%)		
Alzheimer's	198	(67.35)
Frontotemporal dementia	17	(5.78)
Lewy Body dementia	14	(4.76)
Vascular dementia	13	(4.42)
Mixed dementia diagnosis	14	(4.76)
Other	23	(7.82)
Don't know	15	(5.10)
Barthel-20 person with dementia, median (IQR*)	18	(6)
NPI-Q, median (IQR)		
Severity	6	(7)
Distress	7	(10)
Impact of dementia rated by carer, n (%)		
None	3	(1.01)
Low	34	(11.45)
Moderate	153	(51.52)
Severe	100	(33.67)
Don't know	7	(2.36)

* IQR, interquartile range

Table 10 Characteristics of non-respondents in the field-test (n=133)

Variable		
Place of recruitment, n (%)		
Aarhus	3	(2,26)
Danish Alzheimer Association	1	(0,75)
Hedensted	1	(0,75)
Langeland	0	(0,00)
Middelfart	11	(8,27)
Næstved	2	(1,50)
Odense	24	(18,05)
Social media	45	(33,83)
Svendborg	13	(9,77)
Sønderborg	16	(12,03)
Varde	0	(0,75)
Sex, n (%)		
Male	38	(28,57)
Female	95	(71,43)

16.2.5.2 Item score distribution

In general, all response categories were used and only up to three responses were missing per item (see Table 2 in Paper III). A right-skewed distribution of responses was seen in most items indicating that the support need was small, not relevant or it had already been met. However, three items (i24, i29, i39) had items of participants choosing the same response two out of three times resulting in a very large right-skewed distribution.

16.2.5.3 Partial Inter-Item Correlation

Forty-one item pairs had high partial inter-item correlation (>0.3). In combination with findings from cognitive interviews and examination of item score distribution, this information was used to evaluate items and ensure each item provided important information on carers' support needs. Consequently, 17 items were removed (i2, i5, i7, i8, i10, i11, i14, i15, i17, i29, i25, i29, i34, i35, i36, i39 and i40) resulting in a 25-item version of DeCANT.

16.2.5.4 Confirmatory Factor Analysis

CFA was used to investigate factor structure of DeCANT. Fit indices of Models 1 and 2 both suggest a moderate fit to each hypothesised four-factor model (see Table 11). Post hoc analysis of Model 2 using test for possible local dependence revealed that this was present for four item pairs (i1 and i22, i16 and 18, i16 and i19, i41 and i42). Therefore, these items were allowed to correlate in Model 3. Compared to Models 1 and 2, Model 3 demonstrated some improvement in all fit indices (see Table 11). Factor loadings ranged between 0.502 and 0.870 (Model 1), 0.467 and 0.922 (Model 2) and 0.467 and 0.909 (Model 3) (see Table 12). Inspection of modification indices and standardised residuals did not give rise to any adjustments of the analysed models. For further elaboration of results of CFA, see Paper III.

Table 11 CFA fit indices for the analysed models, (n=298)

	Chi-squared (χ^2)	Degrees of Freedom	P-Value	RMSEA (90% C.I.)	Probability RMSEA <= .05	CFI	TLI	WRMR
Model 1: Four factor model based on inductive categories	833.447	269	<0.001	0.083 (0.077-0.090)	0.000	0.934	0.927	1.342
Model 2: Four factor model based on ICF framework	851.985	270	<0.001	0.084 (0.078-0.091)	0.000	0.932	0.925	1.393
Model 3: Post hoc analysis of Model 2	775.170	266	<0.001	0.073 (0.068- 0.079)	0.000	0.946	0.938	1.265

Table 12 Factor loadings of items in the three hypothesised models

Model 1: Four-factor model based on inductive categories			**Model 2: Four-factor model based on ICF framework**			**Model 3: Post hoc analysis of Model 2**		
	Item	**Factor loading**		**Item**	**Factor loading**		**Item**	**Factor loading**
Factor 1	i1	0.792	**Factor 1**	i1	0.774	**Factor 1**	i1	0.751
	i3	0.502		i21	0.774		i21	0.770
	i4	0.711		i22	0.767		i22	0.743
	i6	0.724		i26	0.670		i26	0.667
	i9	0.675		i33	0.710		i33	0.705
Factor 2	i12	0.755		i37	0.664		i37	0.660
	i13	0.870		i38	0.639		i38	0.636
	i16	0.833		i41	0.696		i41	0.662
	i18	0.834		i42	0.598		i42	0.542
	i19	0.824	**Factor 2**	i3	0.467	**Factor 2**	i3	0.467
	i21	0.748		i4	0.664		i4	0.664
Factor 3	i22	0.733		i6	0.673		i6	0.673
	i23	0.809		i23	0.807		i23	0.807
	i24	0.697		i28	0.759		i28	0.759
	i26	0.637		i30	0.690		i30	0.690
	i27	0.817		i31	0.808		i31	0.808
	i28	0.761		i32	0.715		i32	0.715
	i30	0.693	**Factor 3**	i9	0.634	**Factor 3**	i9	0.635
	i31	0.810		i12	0.743		i12	0.743
	i32	0.718		i13	0.859		i13	0.859
Factor 4	i33	0.799		i27	0.818		i27	0.818
	i37	0.745	**Factor 4**	i16	0.922	**Factor 4**	i16	0.909
	i38	0.719		i18	0.865		i18	0.859
	i41	0.791		i19	0.854		i19	0.845
	i42	0.673		i24	0.746		i24	0.743

17 Discussion

A questionnaire - the Dementia Carer Assessment of support Needs Tool (DeCANT) - to assess the support needed by carers of people with dementia was developed with specific focus on content and structural validity. The DeCANT was developed based on three studies in this thesis. For this discussion, firstly, a brief summary of the results of Studies 1-3 is presented. Secondly, the results are discussed with a focus on how to acquire a better understanding of carers' support needs and how to enable assessment of these. Lastly, overall methodological considerations are presented and the strengths and limitations of each study are discussed.

In Study 1, a scoping review revealed much knowledge about carers' support needs, which was produced using various methodologies and levels of interpretation of data. This indicates that a comprehensive overview of carers' support needs is possible to achieve. A synthesis of knowledge demonstrated four overarching categories of support needs important to carers, originating from either the perspective of the carer or the person cared for. The results of Study 1 were used to plan data collection in Study 2 and develop and test the questionnaire in Study 3.

In Study 2, interviews with carers and professionals showed that carers' support needs emerge in the context of caring and were independent of the relationship between the carer and the person with dementia, and the carer's cohabitation status and sex. Four main categories of carers' support needs were clarified, and it was possible to link these categories to the ICF framework, which explains the interaction between physical, psychological and social components of caring and contextual factors. The results of this study were therefore used in Study 3 to generate items and to hypothesise models for structuring items in a questionnaire to assess carers' support needs.

In Study 3, an initial pool of 63 items was generated in discussion between the PhD student and her supervisors, based on the results of Studies 1 and 2 and existing carer instruments. Iterative pilot and field-testing among carers and professionals resulted in a 25-item version of DeCANT. Testing for structural validity showed a moderate fit of a hypothesised four-factor model based on the ICF framework.

17.1 Carers' support needs

A clear definition of the construct of carers' support needs does not exist. However, several studies have investigated and explained carers' support needs, and a comprehensive overview of carers' support needs may be within reach, because identified support needs are similar across settings, carer types and dementia diagnosis (Paper I). To understand the construct of support needs, Bradshaw's theoretical framework has been used in this thesis to clarify different ways of expressing need for support (7). Within this framework, it is recognised that carers' and professionals' understanding of support needs may differ. To develop a definition of carers' support needs usable in dementia care, integrating different perspectives of needs is therefore preferable. Three positions of support needs were suggested: the carer, the person with dementia and the interaction between them (Paper I). Professionals may be more prepared to identify these needs in relation to the person with dementia due to their normative thinking of needs and context of dementia care (7). A mismatch between the supportive services offered by professionals, and the support needed by carers thus exists. Furthermore, even when supportive services are offered, carers often do not utilise these, because they fail to meet carers' individual demands for support (139). A demand can be seen as carers' expressing their felt needs (7). In contrast, supplied services are more likely to be based on a comparison of what carers in a similar situation have needed in combination with professionals' normative judgement of what is needed (75). If professionals are not mindful of this mismatch, effective supportive services may not be achievable (139,140). However, a needs assessment is not easily undertaken, because a universal definition of carers' support needs does not exist. To assess carers' support needs though, it may be useful to identify support needs based on what might actually help the carer in the specific context of caring. Therefore, to enable targeted supportive services, a needs assessment has to reflect a joint understanding of carers' support needs that incorporates carers' subjective felt and expressed needs, the context of caring, as well as professionals' objective normative and comparative assumptions of needs.

17.1.1 Identifying carers' support needs

Carers express having support needs of their own, but they have difficulty realising it. Carers neglect their own health and well-being, because they are so caught up in caring for the person with dementia (Paper I, Paper II). Similar to this finding, another study explained that carers' lack of self-care can be linked to their inability to articulate their felt needs, and, thus, state their demands for support (75). Also, a study of carers' needs suggests that carers experience a needs paradox especially in the early stages of dementia (74). Carers with a low acceptance of the impact of the disease may experience more negative emotions in the day-to-day interaction with the person with dementia. Low acceptance manifests in carers not acknowledging their need for support, which may cause those most in need of support not asking for help. Interestingly, the results of the field-test supports this. Fifty-two percent of carers answered 'yes' to having a need for support to ask for help for themselves (i13), and 53.4 % of carers answered 'yes' to needing support to accept supportive services for themselves (i15) (Paper III). Combining the findings of Studies 1-3 demonstrated the necessity of systematic needs assessment among carers to redeem the full potential of carers' contribution to ensuring the health and well-being of the person with dementia without doing so at the expense of carers' health and well-being.

Carers having support needs of their own yet, at the same time, finding it hard to express these needs, reflects the complexity of assessing support needs. It indicates that the full extent of carers' need for support may only be identified when acknowledging that support needs arise from several perspectives: the needs of carers themselves, the needs of the person with dementia and needs that emerge in the interaction between them (Paper I). The reciprocity of needs between the person with dementia and the carer has been identified before (141). It may be explained by carers' need for feeling connected with the person with dementia and those around them, as well as a protection of their social roles (142). Also, carers' support needs arising from the perspective of the person cared for may be elucidated by carers' need to keep the person with dementia both physically and psychologically safe (141). Findings in Study 2 echo this need of keeping the person with dementia safe and making sure that he/she is offered appropriate activities. In addition, emphasising support needs arising from the position of carers themselves is necessary, because carers often have to balance a hectic daily life managing both the caring role and coping with their own issues associated with family and work (143,144). Some carers are more resourceful, and carers' capacity for being optimistic, accepting and communicating positively have proven important for carers' ability to adapt to changes and cope with the burden of caring (145). When assessing carers' support needs, it is therefore important that a person-centred approach, incorporating carers' personal needs and the context of caring, is used in order to appreciate the full extent of support needs.

17.1.2 The complexity of carers' support needs

Assuming a holistic understanding of health and well-being, as founded in the biopsychosocial model, is a way of incorporating a person-centred approach to identifying carers' support needs (5,86,146). Individual carers have their own strengths and resources based on their unique experiences, values and motivations (147). Therefore, carers' need for support depends on their individual situation and specific physical and social context of caring. The complexity of carers' support needs indicates that carers' support needs consist of physical, psychological and social components to maintain daily functioning in addition to environmental and personal factors influencing the health and well-being of the carer (Paper II). Assessment of carers' unique problems and needs should therefore precede any supportive interventions (84) in combination with identifying barriers to, and facilitators of, carers' ability to ask for help and the mismatch between supportive services offered and carers' need for support (139).

In general, support needs identified in Studies 1 and 2 and the content of existing instruments measuring carers' needs were found to be overlapping. When generating items in DeCANT, items had to be exhaustive of all support needs to make sure that the questionnaire was measuring the full extent of carers' support needs (2). Initially, 63 items were generated, representing all support needs identified with respect to including the positions of needs originating from carers themselves, the person with dementia and the interaction between them. To investigate if the needs identified actually contained the complexity of assessing carers' support needs, the ICF was used as a comprehensive framework to which all items were linked (111). Linking of items demonstrated that all components to maintain functioning in daily life and contextual factors were included (3). Although, the ICF has been developed as a classification system on which assessment tools with a person-centred approach may be based, it has limitations. Personal contextual factors have not yet been classified, because social and cultural differences make it difficult to reach scientific consensus on coding of content (148).This means that linking of items to personal factors is dependent on interpretation of the team coding the content of the items. In this thesis, the linking of items to personal factors has been straightforward, because the description in the ICF regarding what is contained in the personal factors was sufficient to conclude linking of items (147). Apart from this limitation, the ICF is considered a strong theoretical framework, and it is used worldwide as a common language to organise complex information on physical, psychological and social aspects of individuals' problems and needs (86).

17.2 Development of a PROM for carers

Since 2006, several international initiatives have been taken to promote the prioritisation of dementia as a public health priority (149,150). An increasing number of countries are developing national dementia strategies to organise treatment, care and support of people with dementia and their carers (9). Furthermore, more research has been initiated, and global coordination of research activities is an important part of advancing knowledge to help solve the global and local impact of dementia (151). In 2015, the JPND Research Strategy (152) conducted a comprehensive review of the literature on dementia outcome measures, but no instruments to assess carers' support needs have been recommended (83). This PhD project emerges from this context with the aim of developing a PROM to assess carers' support needs. Since then, other research projects have dealt with developing high quality PROMs regarding carers' need for support. However, these instruments have either a specific focus on dementia carers' quality of life (153,154) or on how to identify carers' needs for dementia-related services with respect to the unmet needs of the person with dementia (155). However, the content of items developed for these PROMs resembles the content of items in DeCANT (Paper III), underpinning the specific purpose of identifying dementia carers' support needs. For example, DeCANT i12 (see Appendix 6) about feeling appreciated resembles Oyebode et al.'s '*Most people around me recognise what I do as a carer*' (154), and DeCANT i21 (see Appendix 6) about preparing for deterioration of the person cared for resembles Brown et al.'s question '*I worry about how I will be able to cope emotionally as the dementia gets worse in the future*' (153). Unique to DeCANT when assessing carers' support needs is the dire consequences of the neurodegenerative progression of symptoms in the person cared for that carers have to deal with (27).

Besides witnessing cognitive, social and physical deterioration of the person cared for, carers often have to cope with the gradual loss of a loved one at the same time as they experience other losses such as loss of personal freedom, role identity, health and well-being (156,157). Compared to carers of people with other terminal illnesses, carers of a person with dementia experience more anticipatory grief (158), emphasising the importance of a dementia-specific PROM to assess carers' support needs. Developing a dementia-specific PROM to assess carers' support needs could be a way of empowering carers by giving their voice priority (68,78) and to avoid the mismatch seen between carers' unique demands and the supportive interventions on offer (139).

When developing a PROM to assess carers' support needs, the target group should be carefully considered. At the beginning of this PhD project, a decision was made that the questionnaire should be developed for use across a heterogeneous group of carers including those with varying types of relationships with the person needing care and for all stages of the dementia. The definition of carers presented at the beginning of this thesis reflects this broad definition of carers, and the inclusion criteria when recruiting carers in Studies 1-3 also contain this heterogeneity. That choice of definition was important, because a simplified assumption that one carer can provide the majority of informal care required is often made (30,159). However, due to changes in family structures and values over the past decades, taking on the carer role has increasingly become an active choice and priority (160). Today, it is common that several carers of a person with dementia share the responsibility of providing informal care (30). Dividing carers into groups according to relationship they have with the person in care e.g. spouses or adult children, may not be appropriate. This would assume that in all cases of people with dementia, one or the other type of carer has the primary caring role, without acknowledging that more than one carer in the family/network takes on the role (30). The roles of all carers are equally important, and they experience their own unique problems and needs throughout the progression of the dementia (29). Nonetheless, the results of Studies 1 and 2 affirmed that the majority of carers expressed support needs in common, regardless of their relationship with the person with dementia and the progression of the disease (Paper I, Paper II). However, being a spousal carer often means having had an intimate relationship for many years (38), and spouses may have a greater need for emotional support to preserve a feeling of mutuality with the person with dementia (Paper I). In addition to this, spousal carers may have more need for practical support due to older age and the likelihood of compromised health (39). Developing a questionnaire for a heterogeneous group of carers does not exclude assessment of spousal carers' special needs. The DeCANT has been developed so that all identified needs are included, and the iterative process of testing and validating items has been a structured way of ensuring this. Also, response categories have been developed specifically to accommodate when a carer might find an item irrelevant, and non-spousal carers therefore have the opportunity to skip that item e.g. i32 '*Do you have a need for support to talk to someone about intimacy?*' or i30 '*Do you have a need for support to create nice experiences together with the person with dementia?*'

Importantly, when developing a PROM to assess carers' support needs is the finding that carers' needs change over time in relation to the context of caring, which is influenced by the cognitive, physical and social decline of the person with dementia. Carers have to adapt continuously to the changing circumstances of their own life and their caring responsibilities (Paper II), and a needs assessment has to incorporate this. Carers expressed difficulties with knowing whom to contact when needs emerge (Paper I), and this was supported by carers often expressing that the provision of information would have been of use much earlier (Paper II). Carers' changing needs are also highlighted in a review that demonstrates the importance of carers adapting to new management strategies throughout the progression of dementia to facilitate successful coping in the caring role (161). Needs assessment therefore has to be undertaken regularly to meet carers' demands.

17.2.1 How DeCANT assesses support needs

The final version of DeCANT consists of 25 items (Paper III). Results of Studies 1 and 2 showed that the construct of carers' support needs is multi-dimensional, as was to be expected due to its complexity (Papers I and II). A structure with four dimensions was hypothesised and confirmatory procedures determined that DeCANT had a moderate fit to this model (Paper III). This holistic and multi-dimensional structure makes DeCANT practical for use in health and social care to facilitate dialogue between carers and professionals. It provides a systematic way of assessing carers' support needs and enables professionals to develop targeted supportive interventions and assist in developing care strategies that meet the needs of both the carers and the people cared for (94,144).

The four subscales of DeCANT represent four dimensions incorporating different origins of support needs and their interaction (Papers I and II). Therefore, each subscale contains this complexity (see Appendix 8 with the final version of DeCANT). For example, the subscale called 'Focus on you' in the final version of DeCANT, which is coded under personal factors within the ICF framework has one item, which originates from the person with dementia: '*Do you have a need for support to manage the person with dementia's lack of disease awareness*'. Another item originates from carers themselves: '*Do you have a need for support to ask for help for yourself*', and two items arise in the interaction between the carer and the person cared for: '*Do you have a need for support to feel appreciated in what you are doing for the person with dementia*' and '*Do you have a need for support to feel confident in the caring role'*. Developing DeCANT iteratively has made it possible to develop a conceptual framework that specifically incorporates both the complexity of origin and the multi-dimensionality of carers' support needs. Existing carers' needs assessment instruments have failed to include this process (66), and DeCANT is therefore the first of its kind to adapt to a truly person-centred and comprehensive approach when assessing carers' need for support.

17.2.2 Using DeCANT in health and social care

When developing DeCANT, the starting point was ‘why even bother developing a new PROM’ and what would that mean for its future prospects. Carers and professionals have searched for a more systematic way of identifying carers’ support needs (17,45), and a person-centred way of assessing support needs may help implementation and effectiveness of targeted supportive carer interventions (5). The findings of Studies 1, 2 and 3 indicate that DeCANT is a feasible instrument for the assessment of carers’ support needs using a self-administered questionnaire that includes the multi-dimensionality and the different origins of support needs as well as their dynamic interaction. The suggested areas for use are: to focus on carers’ support needs to improve their health and well-being and, by extension, those of the person being cared for; to identify carers’ support needs to enable timely supportive interventions; and as an outcome measure, to evaluate and describe carers’ support needs in general to create or improve supportive interventions (Paper III). When using DeCANT, the included instructions should enable carers to fill out the questionnaire without assistance from a professional. However, to clarify the areas for use and explain how to administer and score DeCANT, a user manual has been produced (See Appendix 9). In this manual, the target population, background and settings for application have been described along with a scoring manual. Due to its sensitive content, an important aspect of using DeCANT is that carers may develop expectations about the provision of supportive interventions, which service providers cannot meet. Professionals are therefore advised to be cautious when using DeCANT if supportive interventions cannot be initiated, and carers should be made aware of this.

DeCANT has been designed to enable the development of an individual profile of carers’ support needs and can be used to prioritise carers’ resources when offering supportive interventions (Paper III). A sum score for each of the four subscales is calculated by summing all items within a subscale (for further elaboration of scoring issues, see Using and scoring manual in Appendix 9). Sum scores range between: factor 1) 0-24 (eight items), factor 2) 0-12 (four items), factor 3) 0-12 (four items) and factor 4) 0-27 (nine items). A higher score represents more need for support. Even so, a dialogue between the carer and the professional, who will use the assessment to identify needed supportive services, is necessary to elaborate the true expression of carers’ felt needs. Calculating a sum score means losing the information of the underlying content in items (2), and it is therefore recommended that these scores are only used to evaluate changes in support needs using the rehabilitation process as a model for implementation of supportive interventions. In everyday health and social care, the brief nature of DeCANT therefore makes it easy to facilitate a dialogue based on the response of the specific item without calculating sum scores.

As a way of implementing DeCANT in everyday health and social care, it could be argued that the rehabilitation process is a suitable model for the collaborative work between carers and professionals (84).

In this process, carers' physical, psychological and social problems and needs can be assessed using DeCANT to inform person-centred and relevant goal-setting before deciding supportive interventions. As part of the rehabilitation process, DeCANT can also be used to evaluate interventions against set goals to determine if continued support is necessary. Using this model to facilitate a dialogue, regular assessment of carers' support needs comes naturally. In Study 2, carers' constantly changing needs due to the context of caring was identified as important in needs assessment. Responding to the temporal context of needs, using the rehabilitation process when implementing DeCANT, may be a way of supporting this. Aside from monitoring carers' individual need for support, using DeCANT regularly could also be a way to make sure that relevant services are available and to monitor the effectiveness of supportive interventions initiated on the basis of a person-centred approach.

Further, DeCANT is developed in a Danish context, which may resemble dementia care settings in other HIC. The caring role in HIC is different from the caring role in LIC, because a higher proportion of formal care is provided in HIC (31). However, cross-cultural validity in different nationalities, ethnic groups or minorities has not been investigated. Looking critically at items in DeCANT, it is possible that the content reflects the societal context and living standards in Denmark where a high proportion of formal care is provided (162). For example, the item, '*Do you have a need for support to involve family/network in tasks or decision-making in relation to the person with dementia*' (i38) may be the result of carers living in a Danish culture with high living standards. In Denmark, people live comfortable, supported lives in small families, and people are accustomed to the welfare state looking after the weak and the elderly. When caring for a person with dementia, carers are confronted with the unusual situation of involving the larger family/network in tasks that normally lie within the private sphere of an individual (29). However, this way of living to some extent resembles other HIC, and in particular, the Scandinavian countries with cultural values and health care systems very similar to those in the Danish context (163). Furthermore, familial attitudes towards the caring role may also have importance as to whether carers find it hard to involve family/network in tasks that assist the person with dementia (164,165). Familial attitudes of how the caring role is perceived may especially differ among ethnic minority carers in Denmark and other HIC. Involving family/close network in caring is more common among carers from ethnic minorities (166) and caring is commonly perceived as a virtue or religious duty (164,167). Nevertheless, a shift in perception of the caring role can be seen among ethnic minority carers as traditional family roles change due to the influence of women entering the job market (165). This shift in traditional family roles may impact whether DeCANT is appropriate for use among ethnic minorities in a Danish context. However, DeCANT has not been validated among ethnic minorities, so it is unknown if it would be of use in that context.

17.3 Overall methodological considerations

When developing a PROM to assess carers' support needs, the most important measurement property is that the content of the questionnaire reflects the construct of interest (122). When using a PROM, the subjective view of the person of interest is emphasised as opposed to the objective view of professionals (168). However, the usefulness of a PROM depends on its measurement properties, and a PROM of unknown or poor quality is likely to provide useless or wrong information (169). Following the six steps for developing high quality PROMs (2), the strong conceptual model of the biopsychosocial model has guided investigation of the multi-dimensional aspects of carers' support needs to enable development of an assessment instrument that is understood by carers as intended. However, it could be argued that linking together assessment of carers' support needs to a model of health and disability is inappropriate, because caring is neither a disease nor a certain status of health. In response to this, the biopsychosocial model is relevant in relation to carers' support needs, because it allows for explaining disability as a state of not feeling well rather than a definite diagnosis. Within the traditional biomedical understanding, diagnostic criteria define a disease, which makes it difficult to explain why some people with a diagnosis feel well and have no need for intervention, whereas others without a diagnosis may feel sick and in need of help (85). Using the biopsychosocial model as a conceptual model is a way of acknowledging the complexity of both caring for people with dementia and the biopsychosocial support needs of carers (86).

An issue for existing carer needs assessment instruments is the lack of psychometric testing of robustness (66,73,78). As a strength, face and content validity of DeCANT were tested by experts and representatives from the target population and were shown to be satisfactory (Paper III) (2,170). Throughout pilot testing, carers and experts agreed that items were relevant and comprehensive, and comments were primarily addressed to the rephrasing and redundancy of items (Paper III). Further, structural validity of DeCANT was investigated using CFA (Paper III). Though only a moderate fit to a four-factor model based on the ICF framework was found, when judging the fit of items to a model, the likelihood of its applicability in actual practice is important. The strength of choosing the ICF is that it is a well-known framework to structure complex information on an individual's health and well-being in everyday health and social care including physical, psychological and social aspects of functioning (147). Also, throughout the six steps of developing DeCANT, feasibility has been an important aspect. The design and sampling of participants were carried out in settings similar to the settings where DeCANT could be used (2). Furthermore, feasibility was considered when defining the construct to be measured, because both the target population and the professionals, who are likely to implement DeCANT in their clinical practice, were involved. Though initial testing of the measurement properties of DeCANT have been proven to be sound, further testing of measurement properties, such as reliability and hypotheses-testing for construct validity, are needed.

As a limitation to the design of the three studies, very different methodologies have been used in order to answer the research questions, which may pose a risk of reduced methodological rigour, because it is a lot for one researcher to become specialised in within the scope of this project. Therefore, the research team, consisting of the PhD student and supervisors, have carefully been put together to ensure expertise in all of the methodologies used. However, due to the many steps in developing a questionnaire, choices made regarding sampling of participants in particular may have been influenced by prioritising the use of resources. Nevertheless, recommendations for developing a questionnaire have been adhered to (2,171).

17.4 Strengths and limitations of Study 1

A strength of the scoping review design in Study 1 was the inclusive search strategy used, integrating studies involving qualitative, quantitative and mixed methods data collection approaches, which provide a comprehensive overview of carers' support needs (89). Further strengths of the study were that selection of studies and data analysis were carried out in joint discussion with researchers in the research team, and that inductive content analysis was conducted in addition to mapping the literature (89,172).

A limitation of the selection of studies is that no quality appraisal was carried out, which may compromise the trustworthiness of the findings in Study 1. However, quality appraisal is not required in a scoping review, and the lack of an appraisal tool covering the range of studies included questions if comparable quality assessment across diverse study designs is possible (89). Another limitation was that the charting of data and subsequent synthesis contained a great amount of data (122 studies). A risk of overlooking some details may have been present. However, to safeguard credibility in the reinterpretation of the data, the team approach in the research process was designed to consider this by researchers discussing how to use the inclusion criteria and create the categories. Including the large amount of data may have made the comprehensive description of carers' support needs possible, which was helpful when refining the research question and planning data collection for Study 2 to further clarify the concept of carers' support needs.

17.5 Strengths and limitations of Study 2

A strength in Study 2 is that a heterogeneous group of participants was recruited, which emphasised the objective of a comprehensive clarification of support needs of various types of carers. Nevertheless, two out of three carers were female and half of the carers had a spousal relationship with the person with dementia (Paper II). A plausible reason for this high proportion of female carers is that women more often take on the caring role (26,27). Also, one reason for the high participation of spousal carers may be that some types of carers are more difficult to recruit. Adult child carers are more likely to have other responsibilities (27), making it difficult to find time to participate in research.

Another strength of the study is that careful consideration was given to the order of conducting focus groups with professionals before carers, and scheduling focus groups before individual interviews. Organising data collection in this way allowed exploration of the phenomenon of interest more deeply, which may enable saturation (173). Though criteria for saturation were not clearly defined from the beginning (104), the recruitment strategy attempted maximum variation among carers regarding sex, cohabitation, progression of dementia and relationship with the person with dementia, which to some degree may indicate that a nuanced and full understanding of the phenomenon of interest was possible. Also, support for saturation having been achieved is that the same codes emerged over and over again across the sources in the data analysis (174).

A limitation of Study 2 involved focus groups combining carers and professionals and individual interviews with carers as a means of data source triangulation (173). Combining data sources raises the question of how to weight data from the different sources, as trustworthiness of the results may have been affected, because separate analyses and synthesis of data sources were not carried out (173). To remedy this, we considered all statements from participants equally, and great efforts were made to ensure that participants from all focus groups and individual interviews were represented.

Another limitation of the data analysis in Study 2 was that a very descriptive type of manifest interpretation of data was carried out (91,107), which may appear superficial. The reason for choosing this approach was that the descriptive clarification of carers' support needs would lead to a comprehensive conceptual framework for generating items in DeCANT in Study 3. However, this type of manifest interpretation is vulnerable to excessive interpretation, and congruence between the degree of interpretation and level of abstraction was carefully considered to ensure credibility of findings (90). Therefore, the abstraction process was carried out focusing on creating exhaustive and mutually exclusive categories. Also, as a way of displaying credibility, examples of the abstraction process and quotations from the participants have been presented for the reader to judge the authenticity of findings on their own (see Table 2 Paper II) (90). Further, a limitation of the data analysis is that only similarities were looked for, because the aim of the study focused on clarification of carers' support needs in a comprehensive way, thus not focusing on differences between carers' and professionals' views. Exploring discrepancies in carers' and professionals' views could have revealed relevant information about what should be given special attention when facilitating a dialogue to improve their collaborative work. However, looking into how to improve communication was not the objective of this study, although this would be a relevant area of research when implementing an assessment instrument of carers' support needs in health and social care. Also, if analysis of the data had shown conflicting views on carers' support needs, it would most likely have appeared in the analysis process as the inductive approach allowed for this to emerge (91,107). Transferability of the results may be limited to dementia carers in a Danish context. However, to enhance trustworthiness of the findings, the group of participants have been carefully selected to represent multiple types of carers and they have been described for the reader to be able to decide if the categories of carers' support needs apply in other contexts (107,175).

17.6 Strengths and limitations of Study 3

A strength when developing DeCANT was that items were generated through creative and iterative discussions between the PhD student and supervisors to further clarify the construct to be measured (2). Items were therefore formulated based on a thorough investigation of carers' support needs, emphasising wordings used by carers. However, an even more involving way of doing this could have been engaging carers to participate in these discussions as an expert monitoring group to increase the presence of the carers' voice when formulating items. In present-day research, methods to increase patient and public involvement in dementia research are iteratively developed (176), which corresponds to the person-centred approach used in this PhD project.

The methodology of using multiple pilot tests with different sampling criteria for the participants is considered a strength (2,113,171). Also considered a strength is that feasibility has been taken into consideration when evaluating and adjusting DeCANT in settings similar to those where it is likely to be used (2). Another strength regarding participants is that the composition of carers in the field-test to some extent shows heterogeneity. Although more female (78.41 %) than male carers participated, a large proportion of non-spousal carers were represented (46.33 %) including both co-residing (42.52 %) and non-residing carers who were caring for people with varying dementia diagnoses and severity. When testing structural validity of DeCANT, the sample may therefore be representative of many types of carers in different caring contexts, which implies usefulness of DeCANT in both home care and residential care contexts. Further, a sample size of 301 carers complying with the *a priori* sample size and the high response rate (69%) in the field-test is considered a strength (2,177). However, for CFA, a larger participant/ item ratio of at least 10 participants per item is preferred (113). Therefore, the sample may be too small to obtain stable factor loadings and low measurement errors and future research to replicate DeCANT's factor structure in similar populations should be carried out (113).

A limitation of Pilot Test 1 is that only one round of CVI testing was carried out (115). Adjustment of items after the first round would have allowed for a second round of panel testing. As a result of this, calculating a scale-CVI (S-CVI) containing the total information about each item's performance would have made it possible to evaluate the overall content validity of the instrument (118). Nevertheless, calculating a S-CVI in addition to the I-CVIs may had been an inappropriate way of demonstrating content validity of DeCANT, because DeCANT is not a unidimensional scale.

In Pilot Test 2, a limitation is that only 12 interviews were conducted compared to the 15-30 interviews recommended for evaluating content validity (2,114). The results may therefore not provide a sufficient evaluation of content validity. Nevertheless, in the interviews conducted, a comprehensive approach to evaluating items was chosen to gain a deeper understanding of carers' perspectives on content validity (2,114). Fewer interviews were therefore carried out, because more data do not necessarily provide better information (173).

Creating a profile of carers' support needs by summing the scores of items within each subscale was chosen as a way to summarise responses in DeCANT. Although, this is recommended when dealing with a multi-dimensional scale (2), a total score for statistical purposes could provide an easy way of summarising responses, especially if DeCANT is to be used in research to evaluate supportive interventions for carers with a person-centred approach. This however, would not be appropriate, because too much information would be lost summing the scores of different dimensions of the construct to be measured, and assessment of support needs using DeCANT would not be valid. Also, DeCANT is developed for use in everyday health and social care, and a total score would not help express individual carers' need for support.

A limitation to examining the factor structure of DeCANT is that the models hypothesised are solely based on the conceptual frameworks suggested in Study 2. Using Exploratory Factor Analysis (EFA) could have pointed towards an alternative factorial structure of DeCANT (2,113), which could have provided a better fitting EFA-based model. However, to perform EFA in this study, a larger sample size would have been necessary (178). Also, an EFA-based model would most likely not be as strong a model to describe the multi-dimensionality of carers' support needs, because dimensionality would be determined by statistical analysis without including a deeper understanding of the construct to be measured (2). Further, an EFA-model would be very sensitive to the data quality of the sample, depending on strong primary factor loadings and few cross-loadings in factors, which is hard to obtain in empirical research (178). Therefore, in this study, it was prioritised to perform CFA to investigate structural validity of DeCANT using a theory-based conceptual framework for in-depth investigation of the construct to be measured. This choice of approach enhances the possibility of truly incorporating the multi-dimensionality of carers' complex support needs in temporal, physical, social and personal contexts of caring.

17.7 Ethical considerations

An ethical point requiring special attention is that assessment of carers' support needs may be a way of directing focus away from the person with dementia. Caring is not a condition in itself, however, the consequences of performing the caring role may affect one's health and well-being. Preventive and health promoting initiatives can be equally important to treatment of a condition (6). Development of the DeCANT is therefore thought of as a supplement to dementia care supporting carers in their caring role while acknowledging the interdependent relationship between carers and the person cared for (179,180).

To avoid carers having unmet expectations of supportive interventions following participation in this research project, personal contact with all participants was prioritised. Participants were given written and verbal information about the purpose of the project, and they were informed as to whom to contact if questions arose before or after participation. In a few instances, carers contacted the dementia coordinator or the PhD student to ask for help in where to find supportive services.

Assessing carers' support needs may mean that some positive aspects of caring are neglected. In recent years, it has been suggested that giving attention to positive experiences of caring may increase carers' health and well-being (181). In addition to the biopsychosocial and person-centred approach, a human rights approach could help shift the focus from the burden of caring to empowering carers and people with dementia to live their lives with a similar quality to other people (182). When generating items in DeCANT, the positive aspects of caring have not deliberately been delved into, and further research should investigate if DeCANT neglects the positive aspects of caring when assessing carers' needs for support.

18 Conclusion

In conclusion, the Dementia Carer Assessment of support Needs Tool (DeCANT) has been developed in a six-step process using a mixed-method design. It has been shown that carers have support needs of their own regardless of the relationship they have with the person with dementia, their severity of dementia or caring context (i.e. home or nursing home). Also, the results suggest that carers' support needs are multi-dimensional comprising physical, psychological, social components of functioning and personal and environmental factors.

The synthesis of knowledge on carers' support needs revealed four overarching key concepts of carers' support needs originating from either the perspective of the carer, the person cared for, or the interaction between them. These different positions of support needs underline the complexity of carers' support needs.

The comprehensive overview of the multi-dimensional construct of carers' support needs constituted an important basis for in-depth clarification of carers' specific support needs. The result was four main categories of carers' support needs as seen from the perspectives of both carers and professionals, thereby combining felt, expressed, normative and comparative needs for support. The categories were linked to the ICF framework, which incorporates the multi-dimensionality of support needs in relation to the interaction between carers and the person cared for and the temporal, physical, social and personal context of caring.

Based on this clarification of support needs, the DeCANT was developed and tested through an iterative process of pilot and field-testing. DeCANT demonstrated satisfying content validity, and testing of its structural validity showed a satisfactory fit to a four-factor model based on a well-known conceptual framework that incorporates the complexity of carers' support needs, which makes DeCANT practical for use in everyday health and social care. The DeCANT has been developed in a Danish dementia care context and is considered ready for implementation by relevant professionals in Danish municipalities.

19 Future implications and areas of development

The development of an instrument to assess carers' support needs may provide a systematic way of facilitating dialogue between carers and professionals to enable targeted supportive interventions for the benefit of both carers and the person cared for. As implementing systematic assessment of carers' support needs is a complex process, future research should investigate how implementation of DeCANT in health and social care is possible. Using methods of involving and engaging both carers and professionals would be necessary to ensure successful implementation (176,183). Also, using the rehabilitation process as a model for the collaboration could be fruitful to achieve high quality in dementia care while protecting the health and well-being of both carers and people with dementia (84), and presumably also reduce the growing costs of dementia care (86).

Along with implementing DeCANT in day-to-day health and social care, further investigations are necessary to document the measurement properties not investigated in the current study. However, investigation of an instrument is time-consuming and resource-consuming. A fourth study with a focus on further validation was originally planned to investigate test-retest reliability and construct validity of DeCANT (2). Baseline and 2-4-week follow-up data have already been collected in a population of carers using inclusion criteria and methods similar to data collection in the field-test study. However, these data are yet to be analysed.

Hypothesis-testing based on formulation of how the association is between item and sum scores of DeCANT and scores of instruments of similar constructs is planned. This will provide information to discuss and conclude on the construct validity of DeCANT (2). As part of the hypothesis-testing, selecting instruments reflecting a similar construct is important. Using the recommendations from JPND (83), the NPI-Q (131) and the Short Sense of Competence Questionnaire (SSCQ) (184) were selected as instruments to reflect similar constructs with regard to carers' distress and carers' feelings of capability to care for the person with dementia. However, the SSCQ has not been translated into Danish, and as a part of preparing for the fourth study, a structured process of cross-cultural adaptation of the SSCQ was carried out following the process described by Beaton et al. (185).

Also, based on the collection of data, test-retesting of DeCANT to demonstrate reliability of repeated measurements over time is planned using the intraclass correlation coefficient (ICC) (2,1) (186). Internal consistency to clarify the relationship between items in the multi-dimensional instrument will also be calculated (2). Further research into the robustness of DeCANT is important, because only an assessment instrument of high quality should be implemented in everyday health and social care.

Differential Item Functioning (DIF) is a feature that might be relevant to investigate further. Looking at DIF makes it possible to evaluate if sub-groups, e.g. males, females, children or spouses, respond differently to the level of support needs when comparing carers in the heterogeneous target population. DIF may lead to a systematic error in the DeCANT where sub-groups of carers perceive an item differently, which may cause uncertainty if the item performs differently in the different sub-groups (2).

Finally, a future area for research is to evaluate DeCANT's generalisability and measurement properties in other countries with different languages and health care systems (187). Translation into Scandinavian languages and Dutch could be natural first steps (170,185), because the dementia care contexts in these countries resemble the Danish context (99,188).

20 References

(1) Medical directorate and Nursing directorate. NHS England's commitment to carers. NHS England.May 2014.

(2) de Vet HC, Terwee CB, Mokkink LB, Knol DL. Measurement in Medicine: A Practical Guide. 1st ed. Cambridge: Cambridge University Press; 2011. doi:10.1017/CBO9780511996214.

(3) World Health Organization. ICF - International classification of functioning, disability and health. 2001:299 s.

(4) Holistic health care—what is it, and how can we achieve it? Nuffield Orthopaedic Centre's Annual General Meeting, Oxford, UK; 2009.

(5) Sharma T, Bamford M, Dodman D. Person-centred care: an overview of reviews. Contemp Nurse 2015 Oct-Dec;51(2-3):107-120. doi:10.1080/10376178.2016.1150192.

(6) Marselisborgcentret, Rehabiliteringsforum Danmark. Rehabilitering i Danmark: hvidbog om rehabiliteringsbegrebet. Århus: Marselisborgcentret; 2004.

(7) Bradshaw J. Taxonomy of social need. In: McLachlan G, editor. Problems and progress in medical care : essays on current research. 7th ed. London: Oxford University Press; 1972. p. 71-82.

(8) WHO International Health Conference. Constitution of the World Health Organization. 1946. Bull World Health Organ 2002;80(12):983-984.

(9) World Health Organization. Global action plan on the public health response to dementia 2017–2025. : World Health Organization; 2017.

(10) Sundheds- og Ældreministeriet. Et trygt og værdigt liv med demens - National demenshandlingsplan 2025. 2017.

(11) Prince M, Guerchet MM, Ali GC, Wu Y, Prina M. World Alzheimer Report 2015 - The Global Impact of Dementia: An analysis of prevalence, incidence, cost and trends. : Alzheimer's Disease International; 2015.

(12) Taudorf L, Nørgaard A, Islamoska S, Jørgensen K, Laursen TM, Waldemar G. Declining incidence of dementia: A national registry-based study over 20 years. Alzheimer's & Dementia 2019;15(11):1383-1391. doi:10.1016/j.jalz.2019.07.006.

(13) Nationalt Videncenter for Demens. Forekomst af demens i Danmark. 2019; Available at: http://www.videnscenterfordemens.dk/statistik/forekomst-af-demens-i-danmark/. Accessed 04/16, 2020.

(14) Sundhedsstyrelsen. Anbefalinger til organisering af udrednings- og behandlingsenheder for demens. 2017 30.05.2017.

(15) Sundhedsstyrelsen. Demenskoordinatorfunktioner og -kompetencer. 2018 9.9.2018.

(16) Sundhedsstyrelsen. Evaluering af puljen ”Rådgivningsog aktivitetscentre for mennesker med demens og deres pårørende, herunder yngre med demens”. 2019.

(17) Sundhedsstyrelsen. Evaluering af de regionale forløbsprogrammer og samarbejdsaftaler for patienter med demens. 2017 18.12.2017.

(18) Wortmann M. World alzheimer report 2013 on long-term care. Alzheimer's Dementia 2014;10:P597-P598. doi:10.1016/j.jalz.2014.05.1002.

(19) Alzheimer's Association, Thies W, Bleiler L. 2013 Alzheimer's disease facts and figures. Alzheimer's & dementia 2013;9(2):208-245. doi:10.1016/j.jalz.2013.02.003.

(20) Prince M, Knapp M, Guerchet M, McCrone P, Prina M, Comas-Herrera A, Wittenberg R, Adelaja B, Hu B, King D. Dementia UK: Second edition – Overview. 2nd ed. London: Alzheimer’s Society; 2014.

(21) Bunn F, Burn AM, Goodman C, Rait G, Norton S, Robinson L, Schoeman J, Brayne C. Comorbidity and dementia: a scoping review of the literature. BMC Med 2014 Oct 31;12:192-014-0192-4. doi:10.1186/s12916-014-0192-4.

(22) Van Der Roest, Henriëtte G, Meiland FJ, Maroccini R, Comijs HC, Jonker C, Dröes R. Subjective needs of people with dementia: a review of the literature. Int Psychogeriatr 2007;19(3):559-592. doi:10.1017/S1041610206004716.

(23) Kristensen HK, Peoples H. Experiences related to quality of life in people with dementia living in institutional settings–A meta-aggregation. British Journal of Occupational Therapy 2020;83(3):145-161. doi:10.1177/0308022619879080.

(24) Prince M, Comas-Herrera A, Knapp M, Guerchet M, Karagiannidou M. World Alzheimer report 2016: improving healthcare for people living with dementia: coverage, quality and costs now and in the future. 2016.

(25) Morrisby C, Joosten A, Ciccarelli M. Needs of people with dementia and their spousal carers: A study of those living in the community. Australas J Ageing 2019 06;38(2):e43-e49. doi:10.1111/ajag.12609.

(26) Alzheimerforeningen. Livet med demens. Rapport om en spørgeskemaundersøgelse blandt pårørende til demenspatienter i Danmark. 2018;February.

(27) Alzheimer's Association. 2019 Alzheimer's disease facts and figures. Alzheimer's & Dementia 2019;15(3):321-387. doi:10.1016/j.jalz.2019.01.010.

(28) Alzheimer’s Disease International. World Alzheimer Report 2019: Attitudes to dementia. 2019.

(29) Clemmensen TH, Busted LM, Søborg J, Bruun P. The family’s experience and perception of phases and roles in the progression of dementia: An explorative, interview-based study. Dementia 2019;18(2):490-513. doi:10.1177/1471301216682602.

(30) Liu H, Fang B, Chan J, Chen G. The relationship between comorbidities in dementia patients and burden on adult–child primary caregivers: Does having a secondary caregiver matter? International journal of mental health nursing 2019;28(6):1306-1317. doi:10.1111/inm.12640.

(31) Wimo A, Gauthier S, Prince M. Global estimates of informal care. 2018.

(32) Alzheimer's Association. 2018 Alzheimer's disease facts and figures. Alzheimer's & Dementia 2018;14(3):367-429. doi:10.1016/j.jalz.2018.02.001.

(33) Mittelman MS, Haley WE, Clay OJ, Roth DL. Improving caregiver well-being delays nursing home placement of patients with Alzheimer disease. Neurology 2006 Nov 14;67(9):1592-1599. doi:10.1212/01.wnl.0000242727.81172.91.

(34) Gaugler JE, Kane RL, Kane RA, Newcomer R. Unmet care needs and key outcomes in dementia. J Am Geriatr Soc 2005 Dec;53(12):2098-2105. doi:10.1111/j.1532-5415.2005.00495.x.

(35) Muszyńska MM, Rau R. The old-age healthy dependency ratio in Europe. Journal of population ageing 2012;5(3):151-162. doi:10.1007/s12062-012-9068-6.

(36) Pozzebon M, Douglas J, Ames D. Spouses' experience of living with a partner diagnosed with a dementia: a synthesis of the qualitative research. Int Psychogeriatr 2016 Apr;28(4):537-556. doi:10.1017/S1041610215002239.

(37) Tatangelo G, McCabe M, Macleod A, Konis A. I just can't please them all and stay sane: Adult child caregivers' experiences of family dynamics in care-giving for a parent with dementia in Australia. Health Soc Care Community 2018 May;26(3):e370-e377. doi:10.1111/hsc.12534.

(38) Hellström I, Nolan M, Lundh U. Sustaining `couplehood': Spouses' strategies for living positively with dementia. Dementia 2007 08/01; 2019/12;6(3):383-409. doi:10.1177/1471301207081571.

(39) Chiao CY, Wu HS, Hsiao CY. Caregiver burden for informal caregivers of patients with dementia: A systematic review. Int Nurs Rev 2015 Sep;62(3):340-350. doi:10.1111/inr.12194.

(40) Eifert EK, Adams R, Dudley W, Perko M. Family caregiver identity: A literature review. American Journal of Health Education 2015;46(6):357-367. doi:10.1080/19325037.2015.1099482.

(41) Alzheimer's Association. 2014 Alzheimer's disease facts and figures. Alzheimer's & Dementia 2014;10(2):e47-e92. doi:10.1016/j.jalz.2014.02.001.

(42) Tatangelo G, McCabe M, Macleod A, You E. "I just don't focus on my needs." The unmet health needs of partner and offspring caregivers of people with dementia: A qualitative study. Int J Nurs Stud 2018 Jan;77:8-14. doi:10.1016/j.ijnurstu.2017.09.011.

(43) Rigby T, Ashwill RT, Johnson DK, Galvin JE. Differences in the experience of caregiving between spouse and adult child caregivers in dementia with Lewy Bodies. Innovation in aging 2019;3(3):igz027. doi:10.1093/geroni/igz027.

(44) Quinn C, Clare L, McGuinness T, Woods RT. The impact of relationships, motivations, and meanings on dementia caregiving outcomes. Int Psychogeriatr 2012;24(11):1816-1826. doi:10.1017/S1041610212000889.

(45) Zarit SH. Past is prologue: how to advance caregiver interventions. Aging Ment Health 2018 Jun;22(6):717-722. doi:10.1080/13607863.2017.1328482.

(46) Pinquart M, Sorensen S. Correlates of physical health of informal caregivers: a meta-analysis. J Gerontol B Psychol Sci Soc Sci 2007 Mar;62(2):P126-37. doi:10.1093/geronb/62.2.P126.

(47) Cheng ST. Dementia Caregiver Burden: a Research Update and Critical Analysis. Curr Psychiatry Rep 2017 Aug 10;19(9):64-017-0818-2. doi:10.1007/s11920-017-0818-2.

(48) Ornstein K, Gaugler JE. The problem with “problem behaviors”: a systematic review of the association between individual patient behavioral and psychological symptoms and caregiver depression and burden within the dementia patient–caregiver dyad. Int Psychogeriatr 2012;24(10):1536-1552. doi:10.1017/S1041610212000737.

(49) Lee K, Puga F, Pickering CEZ, Masoud SS, White CL. Transitioning into the caregiver role following a diagnosis of Alzheimer's disease or related dementia: A scoping review. Int J Nurs Stud 2019 08;96:119-131. doi:10.1016/j.ijnurstu.2019.02.007.

(50) Afram B, Verbeek H, Bleijlevens MH, Hamers JP. Needs of informal caregivers during transition from home towards institutional care in dementia: a systematic review of qualitative studies. Int Psychogeriatr 2015 Jun;27(6):891-902. doi:10.1017/S1041610214002154.

(51) Haro J, Kahle-Wrobleski K, Bruno G, Belger M, Dell’Agnello G, Dodel R, Jones R, Reed C, Vellas B, Wimo A. Analysis of burden in caregivers of people with Alzheimer’s disease using self-report and supervision hours. J Nutr Health Aging 2014;18(7):677-684. doi:10.1007/s12603-014-0500-x.

(52) Cagle JG, Munn JC. Long-distance caregiving: a systematic review of the literature. Journal of gerontological social work 2012;55(8):682-707. doi:10.1080/01634372.2012.703763.

(53) Quinn C, Clare L, Woods RT. Balancing needs: the role of motivations, meanings and relationship dynamics in the experience of informal caregivers of people with dementia. Dementia 2015 Mar;14(2):220-237. doi:10.1177/1471301213495863.

(54) de Labra C, Millan-Calenti JC, Bujan A, Nunez-Naveira L, Jensen AM, Peersen MC, Mojs E, Samborski W, Maseda A. Predictors of caregiving satisfaction in informal caregivers of people with dementia. Arch Gerontol Geriatr 2015 May-Jun;60(3):380-388. doi:10.1016/j.archger.2015.03.002.

(55) Clarkson P, Hughes J, Xie C, Larbey M, Roe B, Giebel CM, Jolley D, Challis D, HoSt-D (Home Support in Dementia) Programme Management Group. Overview of systematic reviews: Effective home support in dementia care, components and impacts—Stage 1, psychosocial interventions for dementia. J Adv Nurs 2017;73(12):2845-2863. doi:10.1111/jan.13362.

(56) Sundhedsstyrelsen. National klinisk retningslinje for udredning og behandling af demens. 2013.

(57) Clarkson P, Hughes J, Roe B, Giebel CM, Jolley D, Poland F, Abendstern M, Chester H, Challis D. Systematic review: Effective home support in dementia care, components and impacts–Stage 2, effectiveness of home support interventions. J Adv Nurs 2018;74(3):507-527. doi:10.1111/jan.13460.

(58) Dam AE, de Vugt ME, Klinkenberg IP, Verhey FR, van Boxtel MP. A systematic review of social support interventions for caregivers of people with dementia: are they doing what they promise? Maturitas 2016;85:117-130. doi:10.1016/j.maturitas.2015.12.008.

(59) Thompson CA, Spilsbury K, Hall J, Birks Y, Barnes C, Adamson J. Systematic review of information and support interventions for caregivers of people with dementia. BMC geriatrics 2007;7(1):18. doi:10.1186/1471-2318-7-18.

(60) Lethin C, Leino-Kilpi H, Roe B, Soto MM, Saks K, Stephan A, Zwakhalen S, Zabalegui A, Karlsson S, RightTimePlaceCare Consortium. Formal support for informal caregivers to older persons with dementia through the course of the disease: an exploratory, cross-sectional study. BMC geriatrics 2016;16(1):32. doi:10.1186/s12877-016-0210-9.

(61) Robinson KM, Buckwalter K, Reed D. Differences between dementia caregivers who are users and nonusers of community services. Public Health Nurs 2013 Nov-Dec;30(6):501-510. doi:10.1111/phn.12041.

(62) Thuesen J, Kristensen F, Frausing S, Kruse ER. Rehabilitering ved demens i let til moderat grad. National kortlaegning af forståelser, indsatser og organisering i regioner og kommuner.Nyborg: REHPA Videncenter for Rehabilitering og Palliation 2018.

(63) Sundhedsstyrelsen. National klinisk retningslinje for udredning og behandling af demens. 2013.

(64) Socialstyrelsen. Undersøgelse af behov for afløsning og aflastning blandt pårørende til mennesker med en demenssygdom. 2013.

(65) Terkelsen AS, Petersen JV, Kristensen HK. Mapping empirical experiences of Tom Kitwood's framework of person-centred care for persons with dementia in institutional settings. A scoping review . Scand J Caring Sci 2020;34(1):6-22. doi:10.1111/scs.12709.

(66) Bangerter LR, Griffin JM, Zarit SH, Havyer R. Measuring the Needs of Family Caregivers of People With Dementia: An Assessment of Current Methodological Strategies and Key Recommendations. Journal of Applied Gerontology 2019 01 Sep 2019;38(9):1304-1318. doi:10.1177/0733464817705959.

(67) Queluz FN, Kervin E, Wozney L, Fancey P, McGrath PJ, Keefe J. Understanding the needs of caregivers of persons with dementia: a scoping review. Int Psychogeriatr 2019 Apr 10:1-18. doi:10.1017/S1041610219000243.

(68) McCabe M, You E, Tatangelo G. Hearing Their Voice: A Systematic Review of Dementia Family Caregivers' Needs. Gerontologist 2016 Oct;56(5):e70-88. doi:10.1093/geront/gnw078.

(69) Cova I, Travi N, Maggiore L, Cucumo V, Mariani C, Pomati S. What are the caregivers' needs on dementia care? An integrated qualitative and quantitative assessment. Neurol Sci 2018 Jun;39(6):1085-1091. doi:10.1007/s10072-018-3332-3.

(70) Tyrrell M., Fossum B., Skovdahl K., Religa D., Hilleras P. Living with a well-known stranger: Voices of family members to older persons with frontotemporal dementia. International journal of older people nursing 2019 02 Oct 2019:e12264. doi:10.1111/opn.12264.

(71) Pillemer S, Davis J, Tremont G. Gender effects on components of burden and depression among dementia caregivers. Aging & mental health 2018;22(9):1162-1167. doi:10.1080/13607863.2017.1337718.

(72) Hellstrom I, Hakanson C, Eriksson H, Sandberg J. Development of older men's caregiving roles for wives with dementia. Scand J Caring Sci 2017;31(4):957-964. doi:10.1111/scs.12419.

(73) Mansfield E, Boyes AW, Bryant J, Sanson-Fisher R. Quantifying the unmet needs of caregivers of people with dementia: a critical review of the quality of measures. Int J Geriatr Psychiatry 2017 Mar;32(3):274-287. doi:10.1002/gps.4642.

(74) Boots LM, Wolfs CA, Verhey FR, Kempen GI, de Vugt ME. Qualitative study on needs and wishes of early-stage dementia caregivers: the paradox between needing and accepting help. Int Psychogeriatr 2015 Jun;27(6):927-936. doi:10.1017/S1041610214002804.

(75) Stirling C, Andrews S, Croft T, Vickers J, Turner P, Robinson A. Measuring dementia carers' unmet need for services-an exploratory mixed method study. BMC Health Serv Res 2010 May 13;10:122-(1-10). doi:10.1186/1472-6963-10-122.

(76) Gaugler JE, Jutkowitz E, Shippee TP, Brasure M. Consistency of dementia caregiver intervention classification: an evidence-based synthesis. Int Psychogeriatr 2017;29(1):19-30. doi:10.1017/S1041610216001514.

(77) Handels RL, Sköldunger A, Bieber A, Edwards RT, Gonçalves-Pereira M, Hopper L, Irving K, Jelley H, Kerpershoek L, Marques MJ. Quality of life, care resource use, and costs of dementia in 8 European countries in a cross-sectional cohort of the actifcare study. J Alzheimer's Dis 2018;66(3):1027-1040. doi:10.3233/JAD-180275.

(78) Novais T, Dauphinot V, Krolak-Salmon P, Mouchoux C. How to explore the needs of informal caregivers of individuals with cognitive impairment in Alzheimer's disease or related diseases? A systematic review of quantitative and qualitative studies. BMC Geriatr 2017 Apr 17;17(1):86-(1-18). doi:10.1186/s12877-017-0481-9.

(79) Wancata J, Krautgartner M, Berner J, Alexandrowicz R, Unger A, Kaiser G, Marquart B, Weiss M. The Carers' Needs Assessment for Dementia (CNA-D): development, validity and reliability. Int Psychogeriatr 2005 Sep;17(3):393-406. doi:10.1017/S1041610205001699.

(80) Reynolds T, Thornicroft G, Abas M, Woods B, Hoe J, Leese M, Orrell M. Camberwell Assessment of Need for the Elderly (CANE). Development, validity and reliability. Br J Psychiatry 2000 May;176:444-452. doi:10.1192/bjp.176.5.444.

(81) Black B, Johnston D, Handel S, Morrison A, Robbins B, Rye R. Manual for the Johns Hopkins Dementia Care Needs Assessment (JHDCNA). Baltimore, MD 2008.

(82) McWalter G, Toner H, McWalter A, Eastwood J, Marshall M, Turvey T. A community needs assessment: the care needs assessment pack for dementia (CarenapD)--its development, reliability and validity. Int J Geriatr Psychiatry 1998 Jan;13(1):16-22. doi:10.1002/(SICI)1099-1166(199801)13:13.0.CO;2-N.

(83) Mountain G. Dementia Outcome Measures: Charting new territory Report of a JPND Working Group on Longitudinal Cohorts. 2015.

(84) Wade D. Rehabilitation–a new approach. Part three: the implications of the theories. Clinical Rehabilitation 2016;30(1):3-10. doi:10.1177/0269215515601176.

(85) Engel GL. The need for a new medical model: a challenge for biomedicine. Science 1977 Apr 8;196(4286):129-136. doi:10.1126/science.847460.

(86) Wade DT, Halligan PW. The biopsychosocial model of illness: a model whose time has come. Clin Rehabil 2017 Aug;31(8):995-1004. doi:10.1177/0269215517709890.

(87) McKenna SP. Measuring patient-reported outcomes: moving beyond misplaced common sense to hard science. BMC medicine 2011;9(1):86. doi:10.1186/1741-7015-9-86.

(88) Schulz R, Sherwood PR. Physical and mental health effects of family caregiving. Am J Nurs 2008 Sep;108(9 Suppl):23-27. doi:10.1097/01.NAJ.0000336406.45248.4c.

(89) Levac D, Colquhoun H, O'Brien KK. Scoping studies: advancing the methodology. Implement Sci 2010 Sep 20;5:69. doi:10.1186/1748-5908-5-69.

(90) Graneheim UH, Lindgren BM, Lundman B. Methodological challenges in qualitative content analysis: A discussion paper. Nurse Educ Today 2017 Sep;56:29-34. doi:10.1016/j.nedt.2017.06.002.

(91) Elo S, Kyngas H. The qualitative content analysis process. J Adv Nurs 2008 Apr;62(1):107-115. doi:10.1111/j.1365-2648.2007.04569.x.

(92) Krippendorff K. Content analysis: an introduction to its methodology. 3.th ed. London; Los Angeles: SAGE; 2013.

(93) Giacomini M. Theory matters in qualitative health research. In: Bourgeault I, Dingwall R, De Vries R, editors. The SAGE handbook of qualitative methods in health research
London: Sage; 2010. p. 125-156.

(94) Riffin C, Wolff JL, Estill M, Prabhu S, Pillemer KA. Caregiver Needs Assessment in Primary Care: Views of Clinicians, Staff, Patients, and Caregivers. J Am Geriatr Soc 2020. doi:10.1111/jgs.16401.

(95) Gridley K, Brooks J, Glendinning C. Good practice in social care: the views of people with severe and complex needs and those who support them. Health Soc Care Community 2014 Nov;22(6):588-597. doi:10.1111/hsc.12105.

(96) Connell CM, Janevic MR, Gallant MP. The costs of caring: impact of dementia on family caregivers. J Geriatr Psychiatry Neurol 2001;14(4):179-187. doi:10.1177/089198870101400403.

(97) Palinkas LA, Horwitz SM, Green CA, Wisdom JP, Duan N, Hoagwood K. Purposeful Sampling for Qualitative Data Collection and Analysis in Mixed Method Implementation Research. Adm Policy Ment Health 2015 Sep;42(5):533-544. doi:10.1007/s10488-013-0528-y.

(98) Bauer M, Fetherstonhaugh D, Blackberry I, Farmer J, Wilding C. Identifying support needs to improve rural dementia services for people with dementia and their carers: A consultation study in Victoria, Australia. Aust J Rural Health 2019 Feb;27(1):22-27. doi:10.1111/ajr.12444.

(99) Stephan A, Bieber A, Hopper L, Joyce R, Irving K, Zanetti O, Portolani E, Kerpershoek L, Verhey F, de Vugt M, Wolfs C, Eriksen S, Rosvik J, Marques MJ, Goncalves-Pereira M, Sjolund BM, Jelley H, Woods B, Meyer G, Actifcare Consortium. Barriers and facilitators to the access to and use of formal dementia care: findings of a focus group study with people with dementia, informal carers and health and social care professionals in eight European countries. BMC Geriatr 2018 Jun 4;18(1):131-(1-16). doi:10.1186/s12877-018-0816-1.

(100) Farina N, Page TE, Daley S, Brown A, Bowling A, Basset T, Livingston G, Knapp M, Murray J, Banerjee S. Factors associated with the quality of life of family carers of people with dementia: A systematic review. Alzheimers Dement 2017 May;13(5):572-581. doi:10.1016/j.jalz.2016.12.010.

(101) McCann TV, Bamberg J, McCann F. Family carers' experience of caring for an older parent with severe and persistent mental illness. Int J Ment Health Nurs 2015 06;24(3):203-212. doi:10.1111/inm.12135.

(102) Stalmeijer RE, Mcnaughton N, Van Mook WN. Using focus groups in medical education research: AMEE Guide No. 91. Med Teach 2014 Nov;36(11):923-939. doi:10.3109/0142159X.2014.917165.

(103) Hennink MM. International focus group research : a handbook for the health and social sciences. Cambridge: Cambridge University Press; 2007. doi:10.1017/CBO9780511619458.

(104) Malterud K, Siersma VD, Guassora AD. Sample size in qualitative interview studies: guided by information power. Qual Health Res 2016;26(13):1753-1760. doi:10.1177/1049732315617444.

(105) Colucci E. “Focus groups can be fun”: The use of activity-oriented questions in focus group discussions. Qual Health Res 2007;17(10):1422-1433. doi:10.1177/1049732307308129.

(106) Bengtsson M. How to plan and perform a qualitative study using content analysis. NursingPlus Open 2016;2:8-14. doi:10.1016/j.npls.2016.01.001.

(107) Graneheim UH, Lundman B. Qualitative content analysis in nursing research: concepts, procedures and measures to achieve trustworthiness. Nurse Educ Today 2004 Feb;24(2):105-112. doi:10.1016/j.nedt.2003.10.001.

(108) World Medical Association. World medical association declaration of Helsinki: Ethical principles for medical research involving human subjects. JAMA 2013 November 27;310(20):2191-2194. doi:10.1001/jama.2013.281053.

(109) Ministry of Health and the Elderly. Komitéloven. Bekendtgørelse af lov om videnskabsetisk behandling af sundhedsvidenskabelige forskningsprojekter. LBK nr. 1083 15/9/2017. Lovtidende A 2017 22-09-2017;LBK nr 1083 af 15/09/2017(European legislation identifier /eli/lta/2017/1083).

(110) Dean SG, Siegert RJ, Taylor WJ. Interprofessional rehabilitation: a person-centred approach. 1st ed. West Sussex, UK: John Wiley & Sons; 2012. doi:10.1002/9781118702741.

(111) Cieza A, Fayed N, Bickenbach J, Prodinger B. Refinements of the ICF Linking Rules to strengthen their potential for establishing comparability of health information. Disabil Rehabil 2016 Mar 17;41(5):1-10. doi:10.3109/09638288.2016.1145258.

(112) Wade D. Rehabilitation - a new approach. Part two: the underlying theories. Clin Rehabil 2015 Dec;29(12):1145-1154. doi:10.1177/0269215515601175.

(113) Boateng GO, Neilands TB, Frongillo EA, Melgar-Quinonez HR, Young SL. Best Practices for Developing and Validating Scales for Health, Social, and Behavioral Research: A Primer. Front Public Health 2018 Jun 11;6:149. doi:10.3389/fpubh.2018.00149.

(114) Artino AR,Jr, La Rochelle JS, Dezee KJ, Gehlbach H. Developing questionnaires for educational research: AMEE Guide No. 87. Med Teach 2014 Jun;36(6):463-474. doi:10.3109/0142159X.2014.889814.

(115) Polit DF, Beck CT. The content validity index: are you sure you know what's being reported? Critique and recommendations. Res Nurs Health 2006 Oct;29(5):489-497. doi:10.1002/nur.20147.

(116) World Health Organization. Primary health care. 2019; Available at: https://www.who.int/news-room/fact-sheets/detail/primary-health-care. Accessed 04/25, 2020.

(117) Burn AM, Fleming J, Brayne C, Fox C, Bunn F. Dementia case-finding in hospitals: a qualitative study exploring the views of healthcare professionals in English primary care and secondary care. BMJ Open 2018 Mar 17;8(3):e020521-2017-020521. doi:10.1136/bmjopen-2017-020521.

(118) Polit DF, Beck CT, Owen SV. Is the CVI an acceptable indicator of content validity? Appraisal and recommendations. Res Nurs Health 2007 Aug;30(4):459-467. doi:10.1002/nur.20199.

(119) Lynn MR. Determination and quantification of content validity. Nurs Res 1986;35(6):382-385. doi:10.1097/00006199-198611000-00017.

(120) Fleiss JL, Levin B, Paik MC. Statistical methods for rates and proportions. 3rd ed. New Jersey: John Wiley & Sons; 2003. doi:10.1002/0471445428.

(121) Bernard HR. Research methods in anthropology: Qualitative and quantitative approaches. 6th ed. Lanham: Rowman & Littlefield; 2017.

(122) Terwee CB, Prinsen CA, Chiarotto A, Westerman M, Patrick DL, Alonso J, Bouter LM, De Vet HC, Mokkink LB. COSMIN methodology for evaluating the content validity of patient-reported outcome measures: a Delphi study. Quality of Life Research 2018;27(5):1159-1170. doi:10.1007/s11136-018-1829-0.

(123) Harris PA, Taylor R, Thielke R, Payne J, Gonzalez N, Conde JG. Research electronic data capture (REDCap)—a metadata-driven methodology and workflow process for providing translational research informatics support. J Biomed Inform 2009;42(2):377-381. doi:10.1016/j.jbi.2008.08.010.

(124) Harris PA, Taylor R, Minor BL, Elliott V, Fernandez M, O'Neal L, McLeod L, Delacqua G, Delacqua F, Kirby J. The REDCap consortium: Building an international community of software platform partners. J Biomed Inform 2019;95:103208-(1-10). doi:10.1016/j.jbi.2019.103208.

(125) Christensen LN, Ehlers L, Larsen FB, Jensen MB. Validation of the 12 Item Short form Health Survey in a Sample from Region Central Jutland. Soc Indicators Res 2013;114(2):513-521. doi:10.1007/s11205-012-0159-9.

(126) Collin C, Wade D, Davies S, Horne V. The Barthel ADL Index: a reliability study. Int Disabil Stud 1988;10(2):61-63. doi:10.3109/09638288809164103.

(127) Sainsbury A, Seebass G, Bansal A, Young JB. Reliability of the Barthel Index when used with older people. Age Ageing 2005 May;34(3):228-232. doi:10.1093/ageing/afi063.

(128) Mangiaracina F, Meiland F, Kerkhof Y, Orrell M, Graff M, Dröes R. Self-management and social participation in community-dwelling people with mild dementia: a review of measuring instruments. Int Psychogeriatr 2019;31(9):1267-1285. doi:10.1017/S1041610218001709.

(129) Maribo T, Lauritsen J, Wæhrens EE, Poulsen I, Hesselbo B. Barthel indeks til vurdering af funktionsevne: Dansk konsensus om brug. Ugeskr Laeger 2006;168(34):2790-2792.

(130) Kaufer DI, Cummings JL, Ketchel P, Smith V, MacMillan A, Shelley T, Lopez OL, DeKosky ST. Validation of the NPI-Q, a brief clinical form of the Neuropsychiatric Inventory. J Neuropsychiatry Clin Neurosci 2000;12(2):233-239. doi:10.1176/jnp.12.2.233.

(131) Kørner A, Lauritzen L, Lolk A, Abelskov K, Christensen P, Nilsson FM. The Neuropsychiatric Inventory—NPI. Validation of the Danish version. Nordic journal of psychiatry 2008;62(6):481-485. doi:10.1080/08039480801985146.

(132) Marais I, Andrich D. Formalizing dimension and response violations of local independence in the unidimensional Rasch model. J Appl Meas 2008;9(3):200-215.

(133) van der Velde G, Beaton D, Hogg-Johnston S, Hurwitz E, Tennant A. Rasch analysis provides new insights into the measurement properties of the neck disability index. Arthritis Care & Research: Official Journal of the American College of Rheumatology 2009;61(4):544-551. doi:10.1002/art.24399.

(134) Lundgren Nilsson A, Tennant A. Past and present issues in Rasch analysis: the functional independence measure (FIM) revisited. J Rehabil Med 2011 Oct;43(10):884-891. doi:10.2340/16501977-0871.

(135) Henning G. Meanings and implications of the principle of local independence. Language testing 1989;6(1):95-108. doi:10.1177/026553228900600108.

(136) Muthén LK, Muthén BO. Mplus User’s Guide. 8th ed. Los Angeles, CA: Muthén & Muthén; 1998-2017.

(137) Schreiber JB, Nora A, Stage FK, Barlow EA, King J. Reporting Structural Equation Modeling and Confirmatory Factor Analysis Results: A Review. Journal of Educational Research 2006 2006-07-01;99(6):323-338. doi:10.3200/JOER.99.6.323-338.

(138) Greene WH. Econometric analysis. 8th ed. New York, NY: Pearson; 2018.

(139) Dam AEH, Boots LMM, van Boxtel MPJ, Verhey FRJ, de Vugt ME. A mismatch between supply and demand of social support in dementia care: a qualitative study on the perspectives of spousal caregivers and their social network members. Int Psychogeriatr 2018 Jun;30(6):881-892. doi:10.1017/S1041610217000898.

(140) Stirling C, Lloyd B, Scott J, Abbey J, Croft T, Robinson A. A qualitative study of professional and client perspectives on information flows and decision aid use. BMC Med Inform Decis Mak 2012 Mar 29;12:26-6947-12-26. doi:10.1186/1472-6947-12-26.

(141) Pini S, Ingleson E, Megson M, Clare L, Wright P, Oyebode JR. A Needs-led Framework for Understanding the Impact of Caring for a Family Member With Dementia. Gerontologist 2018 Mar 19;58(2):e68-e77. doi:10.1093/geront/gnx148.

(142) Scholzel-Dorenbos CJ, Meeuwsen EJ, Olde Rikkert MG. Integrating unmet needs into dementia health-related quality of life research and care: Introduction of the Hierarchy Model of Needs in Dementia. Aging Ment Health 2010 Jan;14(1):113-119. doi:10.1080/13607860903046495.

(143) Silva AL, Teixeira HJ, Teixeira MJC, Freitas S. The needs of informal caregivers of elderly people living at home: an integrative review. Scand J Caring Sci 2013;27(4):792-803. doi:10.1111/scs.12019.

(144) Akgun-Citak E, Attepe-Ozden S, Vaskelyte A, van Bruchem-Visser RL, Pompili S, Kav S, Acar S, Aksoydan E, Altintas A, Aytar A. Challenges and needs of informal caregivers in elderly care: Qualitative research in four European countries, the TRACE project. Arch Gerontol Geriatr 2020;87:103971. doi:10.1016/j.archger.2019.103971.

(145) Deist M, Greeff AP. Living with a parent with dementia: A family resilience study. Dementia 2017 01;16(1):126-141. doi:10.1177/1471301215621853.

(146) Clare L. Rehabilitation for people living with dementia: A practical framework of positive support. PLoS Med 2017 Mar 7;14(3):e1002245. doi:10.1371/journal.pmed.1002245.

(147) World Health Organization. How to use the ICF: A practical manual for using the International Classification of Functioning, Disability and Health (ICF). 2013;October.

(148) Simeonsson RJ, Lollar D, Björck-Åkesson E, Granlund M, Brown SC, Zhuoying Q, Gray D, Pan Y. ICF and ICF-CY lessons learned: Pandora’s box of personal factors. Disabil Rehabil 2014;36(25):2187-2194. doi:10.3109/09638288.2014.892638.

(149) Alzheimer Europe. Paris Declaration - 2006. 2015; Available at: https://www.alzheimer-europe.org/Policy/Paris-Declaration-2006. Accessed 03/31, 2020.

(150) Centers for Disease Control and Prevention, Alzheimer's Association. The Healthy Brain Initiative: a national public health road map to maintaining cognitive health. Chicago, IL: Alzheimer's Association 2007.

(151) Shah H, Albanese E, Duggan C, Rudan I, Langa KM, Carrillo MC, Chan KY, Joanette Y, Prince M, Rossor M. Research priorities to reduce the global burden of dementia by 2025. The Lancet Neurology 2016;15(12):1285-1294. doi:10.1016/S1474-4422(16)30235-6.

(152) JPND Research. The EU Joint Programme – Neurodegenerative Disease Research (JPND). 2019; Available at: https://www.neurodegenerationresearch.eu/about/. Accessed 05/01, 2020.

(153) Brown A, Page TE, Daley S, Farina N, Basset T, Livingston G, Budgett J, Gallaher L, Feeney Y, Murray J, Bowling A, Knapp M, Banerjee S. Measuring the quality of life of family carers of people with dementia: development and validation of C-DEMQOL. Qual Life Res 2019 Aug;28(8):2299-2310. doi:10.1007/s11136-019-02186-w.

(154) Oyebode JR, Pini S, Ingleson E, Megson M, Horton M, Clare L, Al-Janabi H, Brayne C, Wright P. Development of an Item Pool for a Needs-Based Measure of Quality of Life of Carers of a Family Member with Dementia. Patient 2019 Feb;12(1):125-136. doi:10.1007/s40271-018-0334-4.

(155) Borson S, Mobley P, Fernstrom K, Bingham P, Sadak T, Britt HR. Measuring caregiver activation to identify coaching and support needs: Extending MYLOH to advanced chronic illness. PLoS One 2018 Oct 11;13(10):e0205153. doi:10.1371/journal.pone.0205153.

(156) Cheung DSK, Ho KHM, Cheung TF, Lam SC, Tse MMY. Anticipatory grief of spousal and adult children caregivers of people with dementia. BMC Palliat Care 2018 Nov 20;17(1):124-018-0376-3. doi:10.1186/s12904-018-0376-3.

(157) Chan D, Livingston G, Jones L, Sampson EL. Grief reactions in dementia carers: a systematic review. Int J Geriatr Psychiatry 2013;28(1):1-17. doi:10.1002/gps.3795.

(158) Coelho A, de Brito M, Barbosa A. Caregiver anticipatory grief: phenomenology, assessment and clinical interventions. Curr Opin Support Palliat Care 2018 Mar;12(1):52-57. doi:10.1097/SPC.0000000000000321.

(159) Gaugler JE, Mendiondo M, Smith CD, Schmitt FA. Secondary dementia caregiving and its consequences. American Journal of Alzheimer's Disease & Other Dementias® 2003;18(5):300-308. doi:10.1177/153331750301800505.

(160) Moon H, Dilworth-Anderson P. Baby boomer caregiver and dementia caregiving: findings from the National Study of Caregiving. Age Ageing 2015 03;44(2):300-306. doi:ageing/afu119.

(161) Egilstrod B, Ravn MB, Petersen KS. Living with a partner with dementia: a systematic review and thematic synthesis of spouses' lived experiences of changes in their everyday lives. Aging Ment Health 2019 May;23(5):541-550. doi:10.1080/13607863.2018.1433634.

(162) Diderichsen F, Andersen I, Manuel C. Ulighed i Sundhed: årsager og indsatser. 1st ed. København: Sundhedsstyrelsen; 2011.

(163) Valkonen T, Vihriälä V editors. The Nordic model–challenged but capable of reform. TemaNord 2014: 531 ed. Copenhagen: Nordic Council; 2014. doi:10.6027/TN2014-531.

(164) Lawrence V, Murray J, Samsi K, Banerjee S. Attitudes and support needs of Black Caribbean, south Asian and White British carers of people with dementia in the UK. Br J Psychiatry 2008 Sep;193(3):240-246. doi:10.1192/bjp.bp.107.045187.

(165) Hossain MZ, Stores R, Hakak Y, Dewey A. Traditional Gender Roles and Effects of Dementia Caregiving within a South Asian Ethnic Group in England. Dement Geriatr Cogn Disord 2019;48(5-6):330-336. doi:10.1159/000506363.

(166) Nielsen TR, Nielsen DS, Waldemar G. Barriers to post-diagnostic care and support in minority ethnic communities: A survey of Danish primary care dementia coordinators. Dementia 2019 published online ahead of print, 2019 Jun 5:1-12. doi:10.1177/1471301219853945.

(167) Hossain M, Crossland J, Stores R, Dewey A, Hakak Y. Awareness and understanding of dementia in South Asians: A synthesis of qualitative evidence. Dementia 2018 published online ahead of print, 2018 Oct 8:1-33. doi:10.1177/1471301218800641.

(168) Fleischmann M, Vaughan B. The challenges and opportunities of using patient reported outcome measures (PROMs) in clinical practice. International Journal of Osteopathic Medicine 2018;28:56-61. doi:10.1016/j.ijosm.2018.03.003.

(169) Mokkink LB, De Vet HC, Prinsen CA, Patrick DL, Alonso J, Bouter LM, Terwee CB. COSMIN Risk of Bias checklist for systematic reviews of Patient-Reported Outcome Measures. Quality of Life Research 2018;27(5):1171-1179. doi:10.1007/s11136-017-1765-4.

(170) Mokkink LB, Terwee CB, Patrick DL, Alonso J, Stratford PW, Knol DL, Bouter LM, de Vet HC. The COSMIN checklist for assessing the methodological quality of studies on measurement properties of health status measurement instruments: an international Delphi study. Qual Life Res 2010 May;19(4):539-549. doi:10.1007/s11136-010-9606-8.

(171) Mokkink LB, Prinsen CA, Patrick DL, Alonso J, Bouter LM, De Vet H, Terwee CB. COSMIN Study Design checklist for Patient-reported outcome measurement instruments. COSMIN Study Design checklist for Patient-reported outcome measurement instruments 2019 July:1-32.

(172) Tricco AC, Lillie E, Zarin W, O'Brien KK, Colquhoun H, Levac D, Moher D, Peters MDJ, Horsley T, Weeks L, Hempel S, Akl EA, Chang C, McGowan J, Stewart L, Hartling L, Aldcroft A, Wilson MG, Garritty C, Lewin S, Godfrey CM, Macdonald MT, Langlois EV, Soares-Weiser K, Moriarty J, Clifford T, Tuncalp O, Straus SE. PRISMA Extension for Scoping Reviews (PRISMA-ScR): Checklist and Explanation. Ann Intern Med 2018 Oct 2;169(7):467-473. doi:10.7326/M18-0850.

(173) Carter N, Bryant-Lukosius D, DiCenso A, Blythe J, Neville AJ. The use of triangulation in qualitative research. Oncology nursing forum 2014;41(5). doi:10.1188/14.ONF.545-547.

(174) Saunders B, Sim J, Kingstone T, Baker S, Waterfield J, Bartlam B, Burroughs H, Jinks C. Saturation in qualitative research: exploring its conceptualization and operationalization. Quality & quantity 2018;52(4):1893-1907. doi:10.1007/s11135-017-0574-8.

(175) Elo S, Kääriäinen M, Kanste O, Pölkki T, Utriainen K, Kyngäs H. Qualitative content analysis: A focus on trustworthiness. SAGE open 2014;4(1):1-10. doi:10.1177/2158244014522633.

(176) Burton A, Ogden M, Cooper C. Planning and enabling meaningful patient and public involvement in dementia research. Current opinion in psychiatry 2019;32(6):557-562. doi:10.1097/YCO.0000000000000548.

(177) Sinkowitz-Cochran RL. Survey Design: To Ask or Not to Ask? That is the Question. Clin Infect Dis 2013 Apr;56(8):1159-1164. doi:10.1093/cid/cit005.

(178) Kyriazos TA. Applied psychometrics: sample size and sample power considerations in factor analysis (EFA, CFA) and SEM in general. Psychology 2018;9(08):2207. doi:10.4236/psych.2018.98126.

(179) Miller LM, Kaye JA, Lyons KS, Lee CS, Whitlatch CJ, Caserta MS. Well-being in dementia: a cross-sectional dyadic study of the impact of multiple dimensions of strain on persons living with dementia and their family care partners. Int Psychogeriatr 2019;31(5):617-626. doi:10.1017/S104161021800203X.

(180) McGovern J. Couple meaning-making and dementia: challenges to the deficit model. J Gerontol Soc Work 2011 Oct;54(7):678-690. doi:10.1080/01634372.2011.593021.

(181) Quinn C, Toms G. Influence of positive aspects of dementia caregiving on caregivers' well-being: A systematic review. Gerontologist 2019;59(5):e584-e596. doi:10.1093/geront/gny168.

(182) Rushford N, Harvey D. Dementia as a Disability and Human Rights Issue. Healthc Pap 2016;16(2):45-51. doi:10.12927/hcpap.2017.25003.

(183) Bethell J, Commisso E, Rostad HM, Puts M, Babineau J, Grinbergs-Saull A, Wighton MB, Hammel J, Doyle E, Nadeau S. Patient engagement in research related to dementia: a scoping review. Dementia 2018;17(8):944-975. doi:10.1177/1471301218789292.

(184) Vernooij-Dassen MJ, Felling AJ, Brummelkamp E, Dauzenberg MG, van den Bos GA, Grol R. Assessment of caregiver's competence in dealing with the burden of caregiving for a dementia patient: a Short Sense of Competence Questionnaire (SSCQ) suitable for clinical practice. J Am Geriatr Soc 1999 Feb;47(2):256-257. doi:10.1111/j.1532-5415.1999.tb04588.x.

(185) Beaton DE, Bombardier C, Guillemin F, Ferraz MB. Guidelines for the process of cross-cultural adaptation of self-report measures. Spine (Phila Pa 1976) 2000 Dec 15;25(24):3186-3191. doi:10.1097/00007632-200012150-00014.

(186) Koo TK, Li MY. A guideline of selecting and reporting intraclass correlation coefficients for reliability research. Journal of chiropractic medicine 2016;15(2):155-163. doi:10.1016/j.jcm.2016.02.012.

(187) Mokkink L, Terwee C, Patrick D, Alonso J, Stratford P, Knol D, Bouter L, De Vet H. International consensus on taxonomy, terminology, and definitions of measurement properties for health-related patient-reported outcomes: results of the COSMIN study. Journal of Clinical Epidemiology (accepted for publication) 2010. doi:10.1016/j.jclinepi.2010.02.006.

(188) UNECE Working Group on Ageing. The challenging roles of informal carers. Policy Brief on Ageing 2019 September;22.

21 Appendices

Appendix 1 Interview guide used in focus groups in Study 2

Briefing:

- Formål med studiet, hvem der indgår i samarbejdet, hvordan resultater vil blive anvendt.
- Definere vigtige begreber: fx hvem er pårørende, hvilke former for demens.
- Præsentation af forskere.
- Tak fordi de vil være med. Hvorfor er de blevet inviteret og sammensætning af gruppen.
- Forventninger til deltagerne ift. at have en åben dialog, egne holdninger, gerne forskellige synsvinkler, ingen forkerte svar.
- Hvordan interviewet vil forløbe (underskrive samtykke, udfylde personlig information, præsentation af alle, anvendelse af kort, generelle spørgsmål til gruppen, opsummering til sidst). Forklare ”regler” (fx kun tale en ad gangen, gerne markere, hvis samtalen tager en drejning vil jeg stoppe jer) og roller (moderator faciliterer samtale, hjælper kan stille opklarende spørgsmål/sikre at alt kommer med, men det er dem der skal snakke).
- Etik: frivilligt, informeret samtykke, lydoptagelse da det ikke er muligt at tage dækkende noter, fortroligt, opbevaring af data, hvor lang tid interviewet varer.

Discussion guide:

Personal information (is to be filled out at the same time as the informed consent), lave navneskilt	
Introduction (Optager tændes)	Professionelle: Lad os starte med at I hver især fortæller hvad I hedder, hvilken funktion du har i relation til pårørende til personer med demens og motivation for at være med i dag. Pårørende: Lad os starte med at I hver især fortæller hvad I hedder, hvilken relation du har til personen med demens og motivation for at være med i dag.
Group activity Ligge ud med kortene	Hver deltager får en bunke med kort med forskellige behov skrevet på + nogle blanke. 1. (lille forklaring om at pårørende kan opleve, at det er svært at få dækket egne behov: hvem spørger til mig?/ passe på mig selv – hvordan gør jeg det/ det ville jeg ønske jeg havde vidst) 2. Deltagerne skal udvælge de behov de synes er gældende for dem selv eller de pårørende de har mødt i deres arbejdsfunktion. Instruktion: ”I skal vælge de kort der omhandler behov I synes er vigtige for pårørendes hverdag. Kortene er skrevet i en jeg form, hvor det er set ud fra en pårørendes perspektiv. I får 5-7 min til dette. Efterfølgende starter vi med at jeg udvælger 2-3 af jer der begrunder hvilken/hvilke behov I synes er de vigtigste, hvor I andre kan byde ind undervejs ”. 3. Evt. en opsamling hvor de deltagere, der ikke har sagt så meget bliver inviteret til at supplere om de behov, de synes er vigtige.
Pause 10 min	
Key questions Hvad er svært	Opsamlende spørgsmål ud fra de behov der er nævnt i kort, hvor jeg skal sikre mig at vi er kommet rundt om de behov, der er nævnt i litteraturen eller i foregående interviews. Hvad gør det svært at være pårørende? Hvordan oplever bliver du/pårørende bliver mødt med forståelse fra omgivelser? Hvad har betydning i hverdagen i rollen som pårørende? Særlige emner: Tab/kunne give slip? At være mand versus kvinde? Geografi?

Hvad hjælper	Hvad hjælper dig/pårørende i hverdagen? Kan du give et eksempel på noget du har oplevet eller gjort, som har hjulpet? Er der noget du ville ønske du havde hjulpet en pårørende med eller vil gøre fremadrettet?
Timing	Er der nogen særlige tidspunkter hvor du oplever at pårørende kan have brug for hjælp? Hvordan oplever du at timing af hjælp og støtte gør det muligt at dække dine/pårørendes behov?
Tilgængelighed	Er der forskel på hvordan du/pårørende oplever at få hjælp – opsøgende versus bliver tilbudt hjælp (tilgængelighed)? Giv et eksempel hvor du har oplevet det, hvor ofte sker det?
Fremtid	Hvad vil du/pårørende gerne vil spørges ind til/have hjælp til (både bagudrettet og i fremtiden)?
Ending questions	Vi er ved at nå til vejs ende. Inden vi runder af vil jeg gerne høre jer om en sidste ting ift. hvis I kunne påvirke vores statsminister til at gøre noget, der kunne hjælpe til at støtte pårørende i at blive mødt i deres behov. Hvad skulle han gøre for dem? Er der andet I ønsker at tilføje inden vi slutter samtalen?
(Optager slukkes først når de begynder at rejse sig)	

Appendix 2 Interview guide used in individual interviews Study 2

Briefing:

- Formål med studiet, hvem der indgår i samarbejdet, hvordan resultater vil blive anvendt.
- Definere vigtige begreber: fx hvem er pårørende, hvilke former for demens.
- Præsentation af forsker.
- Tak fordi du vil være med.
- Forventninger til deltagen ift. at have en åben dialog, egne holdninger, ingen forkerte svar.
- Hvordan interviewet vil forløbe (underskrive samtykke, udfylde personlig information, anvendelse af kort, generelle spørgsmål, opsummering til sidst). Forklare ”regler” (fx hvis samtalen tager en drejning vil jeg stoppe dig) og roller (jeg har guide til at facilitere samtale, men det er dig der skal snakke).
- Etik: frivilligt, informeret samtykke, lydoptagelse da det ikke er muligt at tage dækkende noter, fortroligt, opbevaring af data, hvor lang tid interviewet varer.
- Debriefing: Tak og du velkommen til at kontakte mig, hvis der er spørgsmål.

Discussion guide:

Personal information (is to be filled out at the same time as the informed consent)	
Introduction (Optager tændes)	*Lad os starte med at du fortæller lidt om dig selv: hvilken relation du har til personen med demens og motivation for at være med i dag.*
Individual activity Ligge ud med kortene	Deltageren får en bunke med kort med forskellige behov skrevet på + nogle blanke. 1. (lille forklaring om at pårørende kan opleve, at det er svært at få dækket egne behov: hvem spørger til mig?/ passe på mig selv – hvordan gør jeg det/ det ville jeg ønske jeg havde vidst) 2. Deltageren skal udvælge de behov, som er gældende for dem. Instruktion: ”*Du skal vælge de kort der omhandler behov du synes er vigtige for dig i din hverdag. Du får 5-6 min til dette. Efterfølgende kan du begrunde hvilke behov du synes er de vigtigste*”.
Key questions	Opsamlende spørgsmål om der er behov som ikke er nævnt i kort, hvor jeg skal sikre mig at vi er kommet rundt om de behov, personen måtte have.
Hvad er svært	Hvad gør det svært for dig som pårørende? Hvad har betydning for dig i rollen som pårørende i hverdagen? Hvordan oplever du at blive mødt med forståelse fra omgivelser? Særlige emner: At kunne give slip? At være mand versus kvinde? Geografi?
Hvad hjælper	Hvad hjælper dig i hverdagen? Kan du give et eksempel på noget du har deltaget i eller nogen har gjort for dig som har hjulpet dig i din rolle som pårørende?
Timing	Er der nogen særlige tidspunkter hvor du oplever at have brug for hjælp? Hvordan oplever du at timing af hjælp og støtte har betydning?
Tilgængelighed	Er der forskel på hvordan du oplever at få hjælp – at du selv er opsøgende versus bliver tilbudt hjælp? Giv et eksempel på hvor du har oplevet det.

Fremtid	Hvad vil du gerne spørges om? Er der noget du ville ønske du havde fået hjælp til eller få hjælp til fremadrettet?
Ending questions	*Vi er ved at nå til vejs ende. Er der andet du ønsker at tilføje inden vi slutter samtalen?*
(Optager slukkes først når deltager rejser sig)	

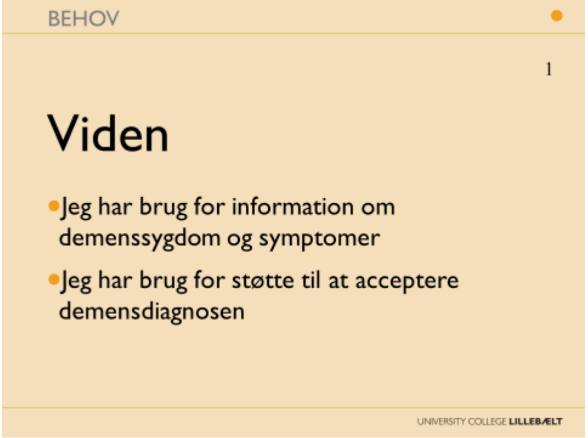
Appendix 3 Examples of text cards used in interviews Study 2

BEHOV

Økonomiske forhold

- Jeg har brug for hjælp til at klare økonomiske opgaver
- Jeg har brug for hjælp til at navigere i det offentlige system ift. økonomi

UNIVERSITY COLLEGE **LILLEBÆLT**



BEHOV

1

Viden

- Jeg har brug for information om demenssygdom og symptomer
- Jeg har brug for støtte til at acceptere demensdiagnosen

UNIVERSITY COLLEGE **LILLEBÆLT**

BEHOV

Fysiske forhold hos mig selv

- Jeg har brug for hjælp til at få hvilet ud og få søvn
- Jeg har brug for hjælp til at prioritere at tage vare på mit eget helbred

UNIVERSITY COLLEGE **LILLEBÆLT**

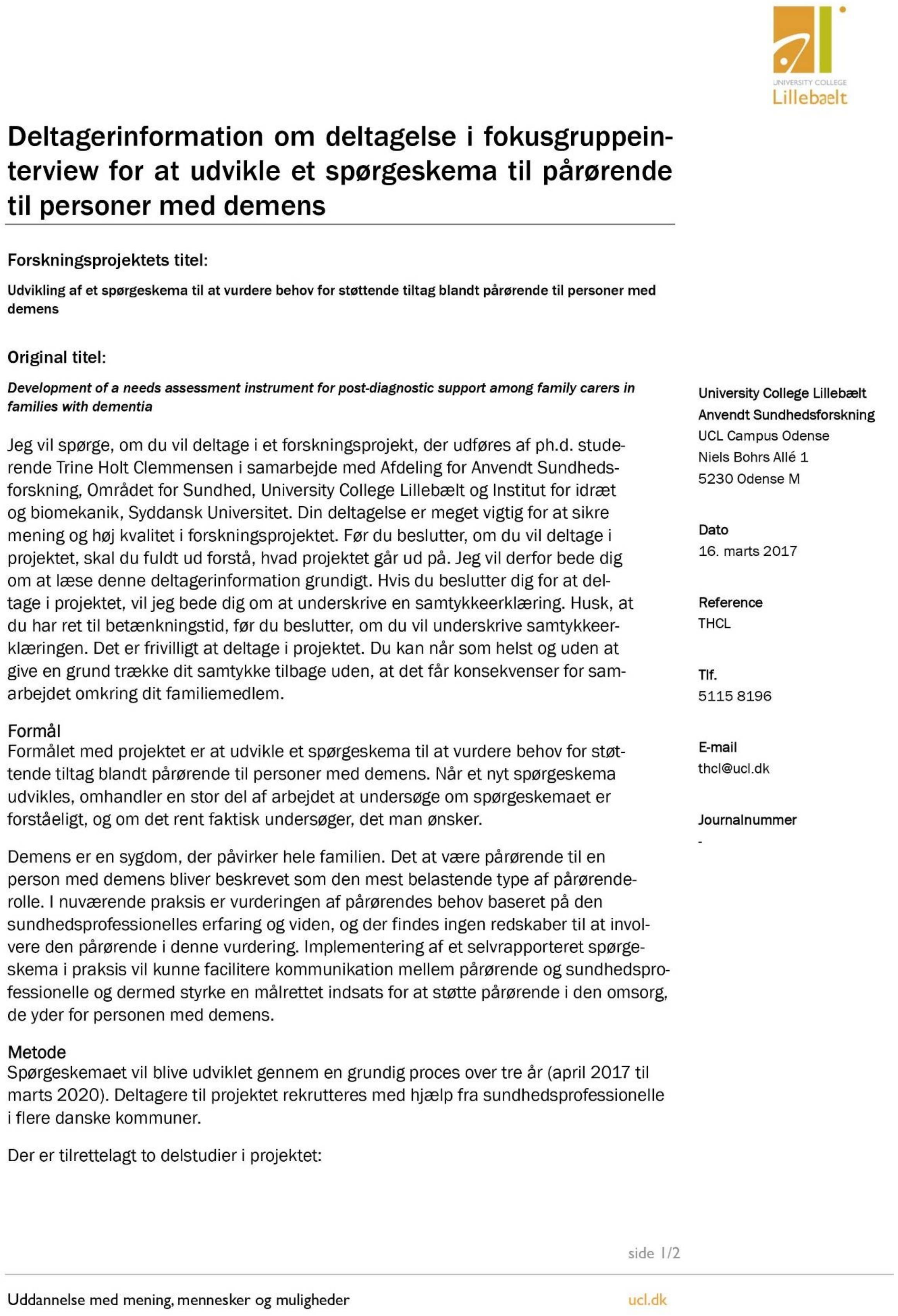
BEHOV

Bekymring

- Jeg har brug for støtte til at håndtere forandringerne i hverdagen
- Jeg har brug for hjælp til at håndtere de dilemmaer, der kan opstå

UNIVERSITY COLLEGE **LILLEBÆLT**

Appendix 4 Information letter to participants Study 2



UNIVERSITY COLLEGE
Lillebælt

Deltagerinformation om deltagelse i fokusgruppeinterview for at udvikle et spørgeskema til pårørende til personer med demens

Forskningsprojektets titel:

Udvikling af et spørgeskema til at vurdere behov for støttende tiltag blandt pårørende til personer med demens

Original titel:

Development of a needs assessment instrument for post-diagnostic support among family carers in families with dementia

University College Lillebælt
Anvendt Sundhedsforskning
UCL Campus Odense
Niels Bohrs Allé 1
5230 Odense M

Dato
16. marts 2017

Reference
THCL

Tlf.
5115 8196

E-mail
thcl@ucl.dk

Journalnummer
-

Jeg vil spørge, om du vil deltage i et forskningsprojekt, der udføres af ph.d. studerende Trine Holt Clemmensen i samarbejde med Afdeling for Anvendt Sundhedsforskning, Området for Sundhed, University College Lillebælt og Institut for idræt og biomekanik, Syddansk Universitet. Din deltagelse er meget vigtig for at sikre mening og høj kvalitet i forskningsprojektet. Før du beslutter, om du vil deltage i projektet, skal du fuldt ud forstå, hvad projektet går ud på. Jeg vil derfor bede dig om at læse denne deltagerinformation grundigt. Hvis du beslutter dig for at deltage i projektet, vil jeg bede dig om at underskrive en samtykkeerklæring. Husk, at du har ret til betænkningstid, før du beslutter, om du vil underskrive samtykkeerklæringen. Det er frivilligt at deltage i projektet. Du kan når som helst og uden at give en grund trække dit samtykke tilbage uden, at det får konsekvenser for samarbejdet omkring dit familiemedlem.

Formål

Formålet med projektet er at udvikle et spørgeskema til at vurdere behov for støttende tiltag blandt pårørende til personer med demens. Når et nyt spørgeskema udvikles, omhandler en stor del af arbejdet at undersøge om spørgeskemaet er forståeligt, og om det rent faktisk undersøger, det man ønsker.

Demens er en sygdom, der påvirker hele familien. Det at være pårørende til en person med demens bliver beskrevet som den mest belastende type af pårørenderolle. I nuværende praksis er vurderingen af pårørendes behov baseret på den sundhedsprofessionelles erfaring og viden, og der findes ingen redskaber til at involvere den pårørende i denne vurdering. Implementering af et selvrapporteret spørgeskema i praksis vil kunne facilitere kommunikation mellem pårørende og sundhedsprofessionelle og dermed styrke en målrettet indsats for at støtte pårørende i den omsorg, de yder for personen med demens.

Metode

Spørgeskemaet vil blive udviklet gennem en grundig proces over tre år (april 2017 til marts 2020). Deltagere til projektet rekrutteres med hjælp fra sundhedsprofessionelle i flere danske kommuner.

Der er tilrettelagt to delstudier i projektet:

side 1/2

Uddannelse med mening, mennesker og muligheder
ucl.dk

Studie 1: Udvikling af spørgeskema til at vurdere behov blandt pårørende til personer med demens – *The Dementia Carer Needs Assessment Questionnaire* (DCNAQ).

På baggrund af litteraturgennemgang og fokusgruppeinterview med ca. 24 pårørende til personer med demens samt ca. 16 sundhedsprofessionelle med tilknytning til familier med demens undersøges, hvilke behov for støttende tiltag pårørende har. Første version af spørgeskemaet afprøves blandt 270 pårørende til personer med demens for at afklare antal spørgsmål og undersøge gyldighed af spørgsmål (strukturel validitet).

Studie 2: Validering af spørgeskema (DCNAQ).

Den endelige version af spørgeskemaet (DCNAQ) testes for gyldighed (begrebsvaliditet), pålidelighed (reliabilitet) og mulighed for fortolkning.

Gyldighed undersøges ved, at 170 pårørende til personer med demens besvarer spørgeskemaet (DCNAQ), og besvarelser sammenholdes med tre allerede standardiserede spørgeskemaer, der afdækker helbreds- og livskvalitet blandt pårørende.

Pålidelighed undersøges ved, at 70 ud af de 170 pårørende besvarer spørgeskemaet (DCNAQ) igen efter to uger.

Fortolkning undersøges ved, at alle 170 pårørende igen efter tre måneder besvarer spørgeskemaet (DCNAQ) og de tre førnævnte standardiserede spørgeskemaer. Herudfra kan scorerne for spørgeskemaet (DCNAQ) sammenlignes, hvilket muliggør fortolkning.

Fokusgruppeinterview

Har du lyst til at deltage i et fokusgruppeinterview vil du blive inviteret til at deltage i et interview sammen med 7 andre pårørende til personer med demens. Interviewet varer i alt 1½ time og vil foregå i et lokale i din kommune. Tilstede vil være den projektansvarlige og en hjælper. Ved behov for transport vil jeg kunne dække dine udgifter til taxa/tog, blot du gemmer kvittering.

Interviewet vil omhandle din oplevelse af, hvordan det er at være pårørende til en person med demens og hvilke behov du har eller har oplevet at have undervejs i forløbet.

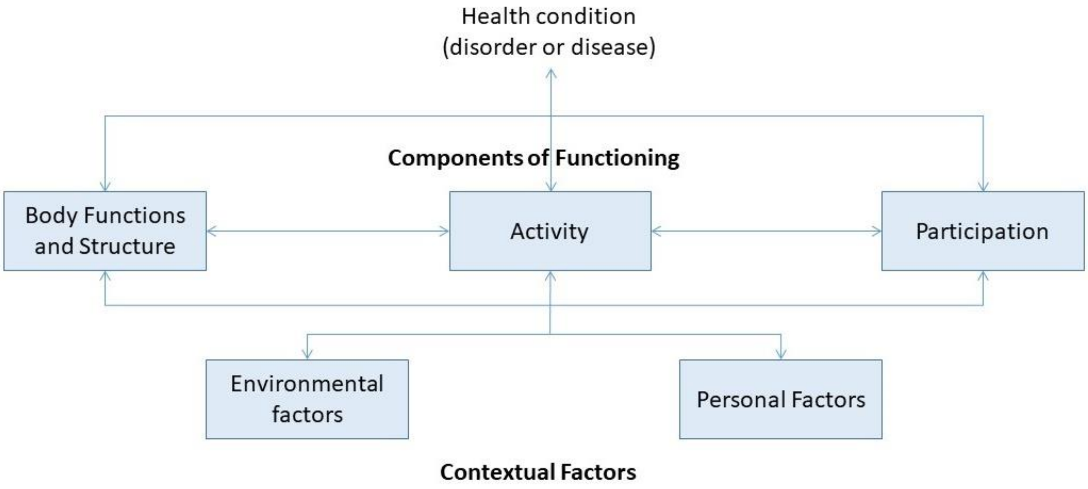
Interviewet vil blive optaget, så jeg senere kan nedskrive ordret, hvad du og de andre har fortalt i interviewet. Al materiale vil blive behandlet fortroligt og opbevaret aflåst og krypteret. Resultater vil i anonymiseret form blive offentliggjort i spørgeskemaet (DCNAQ), en rapport og i faglige tidsskrifter.

Jeg håber, at du med denne information har fået tilstrækkeligt indblik i, hvad det vil sige at deltage i projektet, og at du føler dig rustet til at tage beslutningen om din eventuelle deltagelse. Hvis du vil vide mere, er du meget velkommen til at kontakte projektansvarlig Trine Holt Clemmensen (telefon: 51 15 81 96, email: thcl@ucl.dk)

Med venlig hilsen

Trine Holt Clemmensen
ph.d. studerende

Appendix 5 The ICF model (3)



Appendix 6 Presentation of items in the DeCANT field-testing version (42 items)

Item# DeCANT version 5	42 item version of DeCANT used in the field-testing
Consider your present situation caring for the person with dementia. Do you have a need for support...	
Daily life when caring for a person with dementia	
i1	...to make sure that services targeted the person with dementia conform to your daily life?
i2	...for activities to the person with dementia
i3	...to manage everyday chores (e.g. dressing, cleaning, transportation)?
i4	...to maintain your social network?
i5	...to transportation of the person with dementia (e.g. to the GP, hairdresser etc.)?
i6	...to manage changed behaviour in the person with dementia (e.g. aggressive, restless or passive behaviour)?
i7	...to improve your communication skills in relation to the person with dementia?
i8	...to manage the person with dementia's loss of memory?
i9	...to manage person with dementia's lack of disease awareness?
i10	...to solve problems in everyday life with the person with dementia?
i11	...to get information on assistive aids (e.g. assistive technologies)?
Focusing on themselves	
i12	...to feel appreciated in what you are doing for the person with dementia?
i13	...to ask for help for yourself?
i14	...to get information on help and counselling for yourself?
i15	...to accept supportive services for yourself?
i16	...to cope with your own emotions (e.g. loss or grief)?
i17	...to cope with everyday worries?
i18	...to manage stress?
i19	...to deal with bad conscience or guilt?
i20	...to get information on challenges that may occur in the progression of dementia?
i21	...to prepare for deterioration of the situation (e.g. moving into nursing home)?
Maintaining own well-being	
i22	...to get respite from everyday caring?
i23	...to prioritise your own health?
i24	...to sleep better?
i25	...to get more time for yourself?
i26	...to get in contact with others in the same situation as you?
i27	...to feel confident in the caring role?
i28	...to make decisions regarding the person with dementia?
i29	...to maintain a good relationship with the person with dementia?
i30	...to create nice experiences together with the person with dementia?
i31	...to share the responsibility of caring with someone else?
i32	...to talk to someone about intimacy?

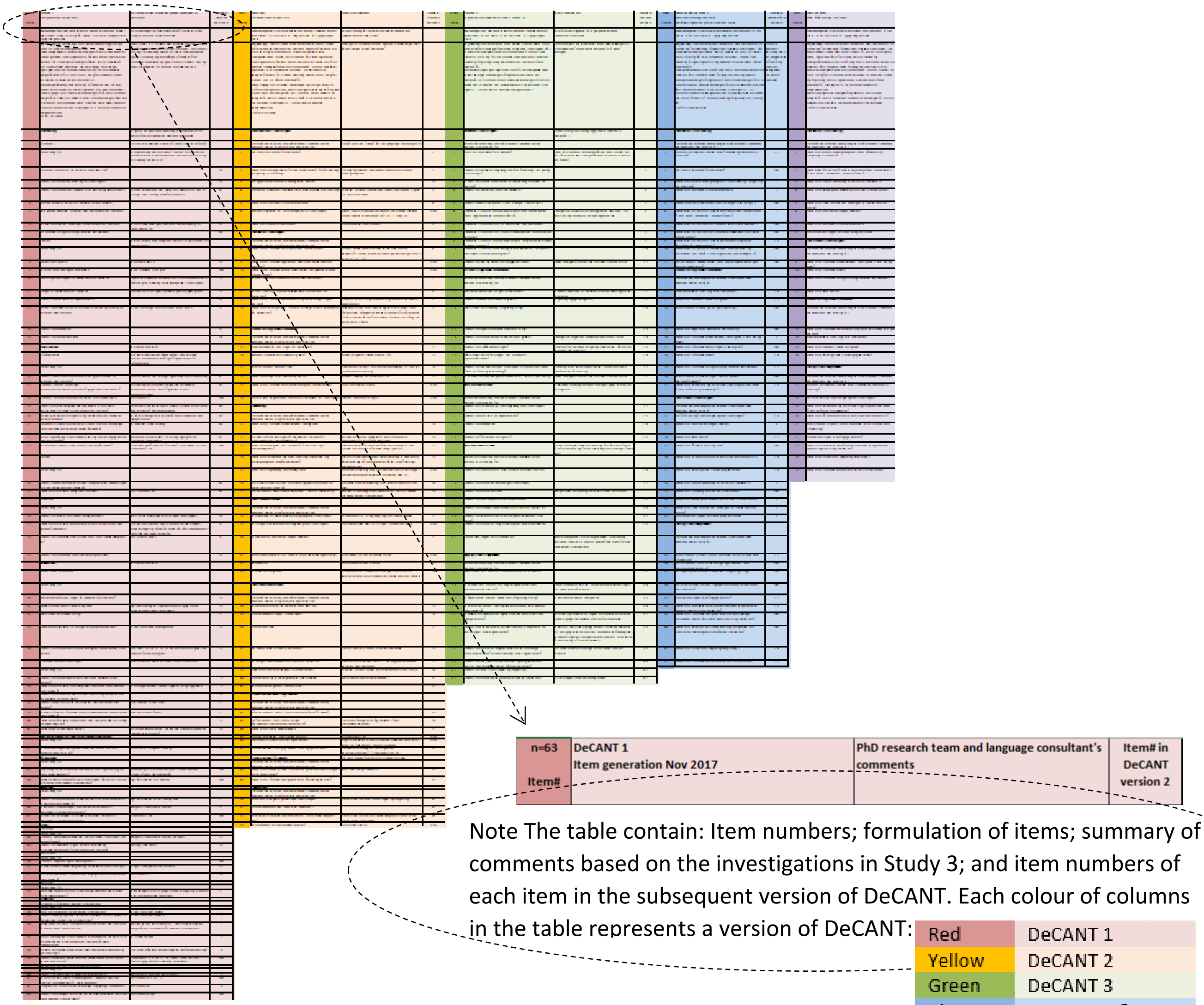
To be continued on next page...

Communicating and interacting with surroundings

i33	…to get information about who to contact for support?
i34	…to get information on what services professionals (e.g. nurse) may offer?
i35	...of professionals offering support to you?
i36	…to get information on the collaborative caring work in relation to the person with dementia?
i37	…to be involved in this collaborative caring work?
i38	…to involve family/network in tasks or decision making in relation to the person with dementia?
i39	…to deal with disagreements within the family/network in relation to the person with dementia?
i40	...to communicate with family/network and surroundings about how dementia affects the person with dementia?
i41	…to navigate rules and legislation?
i42	…to manage financial issues on behalf of the person with dementia?

Appendix 7 Item generation flow table

This table presents an overview of the item generation flow when developing DeCANT. First, a description of how to read the table is presented. Next, a small version of the item flow table is presented on the following 2 pages. Also, the table can be seen in full electronically, if you follow this link: http://filer.dcnaq.dk/Flow_DeCANT.xlsx



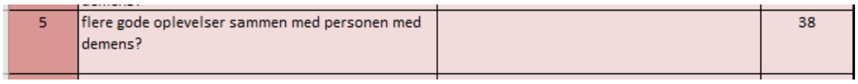
n=63 Item#	DeCANT 1 Item generation Nov 2017	PhD research team and language consultant's comments	Item# in DeCANT version 2

Note The table contain: Item numbers; formulation of items; summary of comments based on the investigations in Study 3; and item numbers of each item in the subsequent version of DeCANT. Each colour of columns in the table represents a version of DeCANT:

Red	DeCANT 1
Yellow	DeCANT 2
Green	DeCANT 3
Blue	DeCANT 4 & 5
Purple	DeCANT final

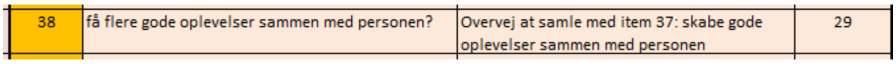
To demonstrate the item flow in the table, an example is shown below:

1. We look at **item 5** in DeCANT 1:



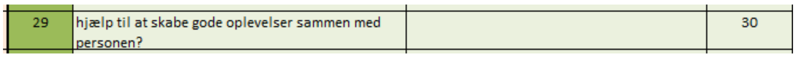
5	flere gode oplevelser sammen med personen med demens?		38

2. Go to item 38 in DeCANT 2:



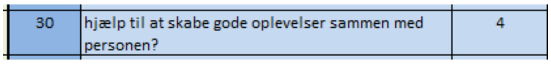
38	få flere gode oplevelser sammen med personen?	Overvej at samle med item 37: skabe gode oplevelser sammen med personen	29

3. Then go to item 29 in DeCANT 3:



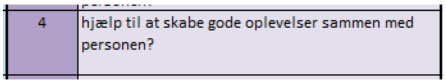
29	hjælp til at skabe gode oplevelser sammen med personen?		30

4. In DeCANT 4 & 5, the item number is 30:



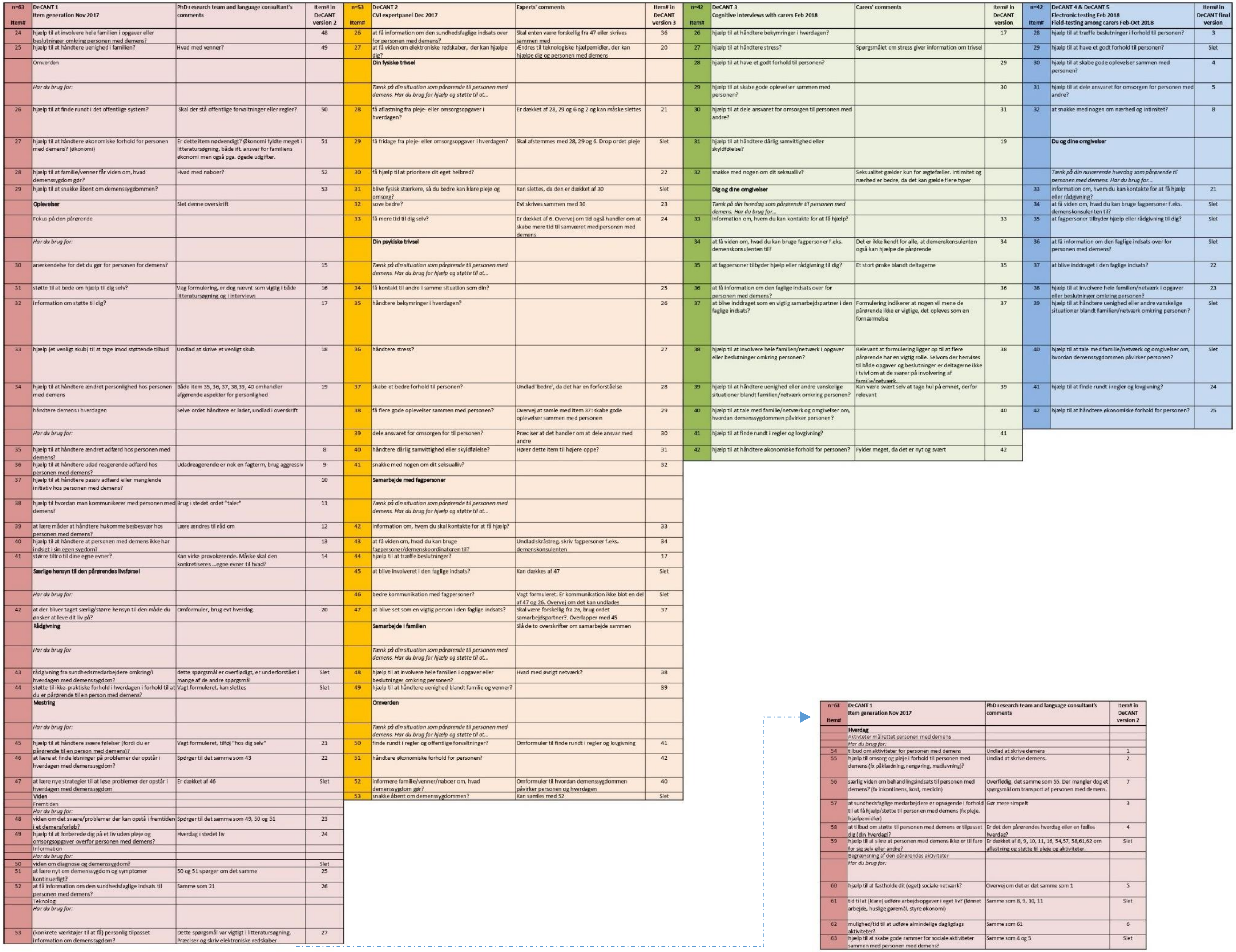
30	hjælp til at skabe gode oplevelser sammen med personen?	4

5. Finally, go to item 4 in DeCANT final:



4	hjælp til at skabe gode oplevelser sammen med personen?

n=63 Item#	DeCANT 1 Item generation Nov 2017	PhD research team and language consultant's comments	Item# in DeCANT version 2	n=53 Item#	DeCANT 2 CVI expertpanel Dec 2017	Experts' comments	Item# in DeCANT version 3	n=42 Item#	DeCANT 3 Cognitive interviews with carers Feb 2018	Carers' comments	Item# in DeCANT version 4 & 5	n=42 Item#	DeCANT 4 & DeCANT 5 Electronic testing Feb 2018 Field-testing among carers Feb-Oct 2018	Item# in DeCANT final version	n=25 Item#	DeCANT final After field-testing Jun 2020
	Svarkategorier: Nej (ikke relevant, behov er dækket, ønsker ikke hjælp), Ja jeg har brug for hjælp: Lidt mere, Meget mere, Rigtig meget mere	Kan svarkategorier forenkles mere? Overvej om der mangler at kunne svares ved ikke.			**Svarkategorier:** Nej (ikke relevant, behov er dækket, ønsker ikke hjælp), Ja, lidt mere, Ja, meget mere, Ja, rigtig meget mere	Brug skråstreg for at dele ikke relevant/behov er dækket/ønsker ikke hjælp			**Svarkategorier:** Nej (ikke relevant/behov er dækket/ønsker ikke hjælp), Ja, lidt mere, Ja, en del mere, Ja, rigtig meget mere	Forstår svarmuligheder. Bruger generelt ikke Nej=ønsker ikke hjælp			**Svarkategorier:** Nej (ikke relevant/behov er dækket), Ja, lidt mere, Ja, en del mere, Ja, rigtig meget mere			**Svarkategorier:** Nej (ikke relevant/behov er dækket), Ja, lidt mere, Ja, en del mere, Ja, rigtig meget mere
	Vejledning: Det er vigtigt, at du læser vejledning grundigt inden, du udfylder spørgeskemaet. Dette spørgeskema indeholder spørgemål om dine behov for hjælp og støtte i hverdagen som pårørende til en person med demens. Når du besvarer spørgsmålene, skal du tænke på, hvad du selv føler og mener. Det er vigtigt, at du tager udgangspunkt i din nuværende situation. Du skal besvare spørgsmålene ud fra, hvad du har brug for hjælp til ud over den støtte, du (eventuelt) allerede har. Læs spørgsmålet og sæt kryds i ét af felterne. Der må ikke sættes kryds mellem to svarmuligheder. Evt giv et eksempel. Det er vigtigt, at du besvarer alle spørgsmål. Hvis du synes et spørgsmål er svært at besvare eller, du synes spørgsmålet ikke er relevant, skal du sætte kryds i det felt, der passer bedst til din situation som helhed. Det tager ca. x minutter at besvare spørgeskemaet Tak for din hjælp!	Introducerer til, at afsenderen er bekendt med, at man som pårørende kan komme i den situation, at man selv har brug for hjælp og støtte. En mere anerkendende tilgang. Inddeling og rækkefølge af spørgsmål er vanskelig at overskue og giver ikke umiddelbar mening. Anvend kategorier fra induktiv analyse studie 2!			**Vejledning:** Det kan være en belastende situation at være pårørende til en person med demens, og som pårørende kan du have brug for støtte til at yde omsorg eller pleje. Spørgeskemaet handler om dit behov for hjælp og støtte i hverdagen som pårørende til en person med demens. Når du besvarer spørgsmålene, skal du tænke på, hvad du selv føler og mener i din nuværende situation. Du skal besvare spørgsmålene ud fra, hvilken hjælp og støtte du har brug for ud over den, du måske allerede får. Det er vigtigt, at du læser vejledningen grundigt, inden du udfylder spørgeskemaet. Besvar venligst alle spørgsmål og sæt kun ét kryds per spørgsmål. Har du svært ved at besvare et spørgsmål, skal du sætte kryds i det felt, der passer bedst til din situation. Det tager ca. 15 minutter at besvare spørgeskemaet. Tak for din hjælp!	Forslag til andre overskrifter og anden rækkefølge. Fjern så vidt muligt ordet "personen"			**Vejledning:** Som pårørende til en person med demens kan du have brug for hjælp og rådgivning til dig selv i hverdagen. Når du besvarer spørgsmålene, skal du tænke på, hvad du selv mener du har brug for i din nuværende situation ud over den hjælp og rådgivning du og personen med demens måske allerede får. Læs vejledningen grundigt inden du udfylder spørgeskemaet. Besvar venligst alle spørgsmål og sæt kun ét kryds per spørgsmål. Har du svært ved at besvare et spørgsmål, skal du sætte kryds i det felt, der pas-ser bedst til din situation. Det tager ca. 15 minutter at besvare spørgeskemaet.	Godt at vejledning forbereder én på svære spørgsmål. Tidsangivelsen "nuværende situation" må godt gentages			**Vejledning:** Som pårørende til en person med demens kan du have brug for hjælp og rådgivning til dig selv i hverdagen. Når du besvarer spørgsmålene, skal du tænke på, hvad du mener, at du har brug for i din nuværende situation, ud over den hjælp og rådgivning som du og personen med demens måske allerede får. Spørgsmålene kommer ind på ting, som det kan være svært at tale om, for at komme tæt på dig og din hverdag. Besvar venligst alle spørgsmål og sæt kun ét kryds per spørgsmål. Har du svært ved at besvare et spørgsmål, skal du sætte kryds i det felt, der passer bedst til din situation. Det tager ca. 15 minutter at besvare spørgeskemaet. Din besvarelse vil hjælpe med til at finde ud af, hvilken hjælp og rådgivning du har brug for. Tak for din besvarelse!	Kan tåle gennem-skrivning med tydelig-gørelse af formål og hvordan spørgeske-maet skal besvares.		**Vejledning:** Som pårørende til en person med demens kan du have brug for hjælp og rådgivning til dig selv i hverdagen. Din besvarelse vil være med til at finde ud af, om du har brug for hjælp, og hvilken form for hjælp der kan hjælpe dig. Spørgsmålene kommer ind på ting, som det kan være svært at tale om, for at komme tæt på dig og din hverdag. Når du besvarer spørgsmålene, skal du tænke på, hvad du mener, at du har brug for i din nuværende situation, ud over den hjælp og rådgivning som du og personen med demens måske allerede får. Det tager ca. 10 minutter at besvare spørgeskemaet. Besvar venligst alle spørgsmål og sæt kun ét kryds per spørgsmål. Har du svært ved at besvare et spørgsmål, skal du sætte kryds i det felt, der passer bedst til din situation. Tak for din besvarelse
	Belastning	Undgå at bruge ordet belastning, evt slet overskrift. Overskrifter skal generelt ændres og tilpasses			**Aktiviteter i hverdagen**				**Demens i hverdagen**	Overskrifter giver mening og guider én gennem spørgsmål			**Demens i din hverdag**			**Demens i din hverdag**
	Emotionel	Ændre til din psykiske trivsel, så det er lettere at forstå			*Tænk på din situation som pårørende til personen med demens. Har du brug for hjælp og støtte til at...*	Undgå at skrive "hjælp" for mange gange i et spørgsmål. Ordet "situation" er upersonligt			*Tænk på din hverdag som pårørende til personen med demens. Har du brug for...*				*Tænk på din nuværende hverdag som pårørende til personen med demens. Har du brug for...*			*Tænk på din nuværende hverdag som pårørende til personen med demens. Har du brug for...*
	Har du brug for:	Denne sætning bør udvides til "Tænk på din situation som pårørende til personen med demens. Har du brug for hjælp og støtte til at..."		1	tilbud om aktiviteter for personen?		1	1	tilbud om aktiviteter for personen?	Bliver forvirret over et spørgsmål der ikke handler om den pårørende selv. Spørgsmålet er relevant, men kan det flyttes?	2	1	at tilbud om støtte til personen er fleksible og tilpasset din hverdag?	17	1	hjælp til praktiske omsorgsopgaver(f.eks. påklædning, rengøring, transport)?
1	at snakke med andre i samme situation som din?		34	2	hjælp til omsorg og pleje i forhold til personen? (fx påklædning, rengøring, madlavning)	Omsorg og pleje er bedre beskrevet som praktiske omsorgsopgaver	2	2	hjælp til praktiske omsorgsopgaver (fx påklædning, rengøring, madlavning)?		3	2	tilbud om aktiviteter for personen?	Slet	2	hjælp eller råd om at håndtere ændret adfærd hospersonen (f.eks. vrede, rastløshed, passiv adfærd)?
2	hjælp til at håndtere bekymringer i hverdagen?		35	3	at fagpersoner tilbyder hjælp og/eller støtte?		35	3	at tilbud om støtte til personen er fleksible og tilpasset din hverdag?		1	3	hjælp til praktiske omsorgsopgaver (fx påklædning, rengøring, madlavning)?	1	3	hjælp til at træffe beslutninger i forhold til personen?
3	hjælp til at snakke med nogen om dit samliv (og seksualitet)?	Hvis det er sekualliv, der menes, så slet samliv. Det er for vagt. Det kan dog blive for snævert.	41	4	at tilbud om støtte til personen er bedre tilpasset din hverdag?	Præciser at det er fleksibilitet i tilbud der menes. Ligner 20, som kan slettes	3	4	hjælp til at fastholde dit sociale netværk?		4	4	hjælp til at fastholde dit sociale netværk?	7	4	hjælp til at skabe gode oplevelser sammen med personen?
4	at skabe et bedre forhold til personen med demens?		37	5	hjælp til at fastholde dit sociale netværk?		4	5	hjælp til kørsel af personen (f.eks. til læge, frisør el.lign)?		5	5	hjælp til kørsel af personen (f.eks. til læge, frisør el.lign.)?	Slet	5	hjælp til at dele ansvaret for omsorgen for personen med andre?
5	flere gode oplevelser sammen med personen med demens?		38	6	bedre muligheder for at udføre gøremål i hverdagen?	Det er uklart for eksperterne hvad der menes. Slettes, da det delvist er dækket ind af 2, 4, 7, 20 og 33	Slet	6	hjælp eller råd til at håndtere ændret adfærd hos personen (f.eks. aggressiv eller passiv adfærd)?	Deltagerne misforstår ordet aggressiv med vold. Ord som vred og rastløs kan de bedre genkende.	6	6	hjælp eller råd om at håndtere ændret adfærd hos personen (f.eks. vrede, rastløshed, passiv adfærd)?	2	6	hjælp til at prioritere dit eget helbred?
6	at dele ansvaret for omsorgen til personen med demens?	Det skal hele vejen igennem ikke hedde omsorg 'til', men omsorg 'for'	39	7	hjælp til transport af personen?	Giv eksempler på transport	5	7	hjælp eller råd til hvordan du bedst taler med personen?		7	7	hjælp eller råd om hvordan du bedst taler med personen?	Slet	7	hjælp til at fastholde dit sociale netværk?
7	at håndtere dårlig samvittighed eller skyldfølelse?		40		**Demens i hverdagen**			8	hjælp eller råd til hvordan hukommelsesbesvær håndteres hos personen?		8	8	hjælp eller råd om hvordan hukommelsesbesvær håndteres hos personen?	Slet	8	at snakke med nogen om nærhed og intimitet?
	Helbred	Helbred er ikke et let begreb at forstå, brug i stedet 'Din fysiske trivsel'			*Tænk på din situation som pårørende til personen med demens. Har du brug for hjælp og støtte til at...*			9	hjælp eller råd til at håndtere personens manglende forståelse for egen sygdom?		9	9	hjælp eller råd om at håndtere personens manglende forståelse for egen sygdom?	13		**Din trivsel i hverdagen**
	Har du brug for:			8	hjælp til at håndtere ændret adfærd hos personen?	Kan evt slettes eller sammenskrives med andre spørgsmål, da den er overordnet og bliver spurgt ind til i 9, 10, 11, 12, 13	6	10	hjælp eller råd til at finde løsninger på problemer, der opstår i hverdagen med demenssygdom?		10	10	hjælp eller råd om at finde løsninger på problemer og situationer, der opstår i hverdagen med demenssygdom?	Slet		*Tænk på din nuværende hverdag som pårørende til personen med demens. Har du brug for...*
8	mere tid til dig selv?	Det samme som 9	33	9	hjælp til at håndtere aggressiv adfærd hos personen med demens?		Slet	11	hjælp til at føle dig sikker i omsorgsgiverrollen?	Dette spørgsmål passer ikke sammen med de andre	27	11	at få viden om hjælpemidler (f.eks. teknologiske løsninger), der kan hjælpe dig?	Slet	9	hjælp til at håndtere svære følelser hos dig selv (f.eks. tab og sorg)?
9	tid til at dyrke dine egne interesser?	Slet, er dækket af 8 og 10	Slet	10	hjælp til at håndtere passiv adfærd eller manglende initiativ hos personen?		Slet		**Fokus på dig som pårørende**				**Fokus på dig som pårørende**		10	hjælp til at håndtere stress?
10	aflastning i hverdagen fra personen med demens?	9 og 10 er meget det samme. Kan man i stedet skrive få aflastning fra pleje- og omsorgsopgaver i hverdagen	28	11	råd om, hvordan du bedst taler til/med personen?		7		*Tænk på din hverdag som pårørende til personen med demens. Har du brug for...*				*Tænk på din nuværende hverdag som pårørende til personen med demens. Har du brug for...*		11	hjælp til at håndtere dårlig samvittighed eller skyldfølelse?
11	fridage fra personen med demens?	Præciser at få fridage fra pleje- og omsorgsopgaver	29	12	råd om, hvordan hukommelsesbesvær håndteres hos personen?		8	12	anerkendelse for det, du gør for personen?	Anerkendelse især fra personen med demens og andre pårørende	12	12	anerkendelse for det, du gør for personen?	14	12	hjælp til at sove bedre?
12	hjælp til at prioritere dit eget helbred?		30	13	hjælp til at håndtere personens manglende indsigt i egen sygdom?	Svært at forstå, brug i stedet manglende forståelse for egen sygdom	9	13	hjælp til at bede om hjælp til dig selv?	Et godt og vigtigt spørgsmål	13	13	hjælp til at bede om hjælp til dig selv?	15		**Fokus på dig som pårørende**
13	at blive fysisk stærkere til at kunne klare pleje og omsorg for personen med demens	Undlad at antage at man ikke er fysisk stærk	31	14	hjælp til at føle dig sikker i at klare omsorgs- eller plejeopgaver for personen?	Eksperter synes ikke dette spørgsmål er vigtigt, men flere studier påpeger dette som centralt for pårørende. Omformuleres så det fremhæves at det er tro på egne evner der er i fokus.	11	14	information om hjælp og rådgivning til dig?		14	14	information om hjælp og rådgivning til dig?	Slet		*Tænk på din nuværende hverdag som pårørende til personen med demens. Har du brug for...*
14	hjælp til at sove bedre?		32		**Fokus på dig som pårørende**			15	hjælp til at tage imod støttende tilbud til dig?		15	15	hjælp til at tage imod støttende tilbud til dig?	Slet	13	hjælp til at håndtere personens manglende forståelse for egen sygdom?
15	hjælp til at håndtere stress?		36		*Tænk på din situation som pårørende til personen med demens. Har du brug for hjælp og støtte til at...*			16	hjælp til at håndtere svære følelser hos dig selv?	Deltagerne vil gerne have eksempler sat på, fx tab.	16	16	hjælp til at håndtere svære følelser hos dig selv (f.eks. tab og sorg)?	9	14	anerkendelse for det, du gør for personen?
	Samarbejde	Slet denne overskrift		15	anerkendelse for det, du gør for personen?		12	17	hjælp til at træffe beslutninger ?	Uklart om det er beslutninger generelt eller i forhold til personen med demens.	28	17	hjælp til at håndtere bekymringer i hverdagen?	Slet	15	hjælp til at bede om hjælp til dig selv?
	Professionelle	Skriv samarbejde med fagpersoner, det er mere konkret. Konsekvensret brug af fagpersoner ift professionelle		16	støtte til at bede om hjælp til dig selv?	Ensret brugen af hjælp, støtte, råd	13	18	information om udfordringer, der kan opstå i sygdomsforløbet?		20	18	hjælp til at håndtere stress?	10	16	hjælp til at føle dig sikker i omsorgsgiverrollen?
	Har du brug for:			17	information om støtte til dig?	Overvej om 16 og 17 skal bytte rækkefølge. 15,16 og 17 kan flyttes til mestring	14	19	hjælp til at forberede dig på udviklingen af sygdomsforløbet (f.eks. indflytning i plejebolig)?	Udvikling er en forkert beskrivelse, da demens reelt medfører en forværring	21	19	hjælp til at håndtere dårlig samvittighed eller skyldfølelse?	11		**Du og dine omgivelser**
16	hjælp til hvem du skal kontakte for opgaver knyttet til personen med demens?	Evt skriv støtte. Der er to gange hjælp i samme sætning	42	18	hjælp til at tage imod støttende tilbud?	Kan evt dækkes ind under spml 16	15	20	at få viden om teknologiske hjælpemidler, der kan hjælpe dig?	Dette spørgsmål passer ikke sammen med de andre	11	20	information om udfordringer, der kan opstå i sygdomsforløbet?	Slet		*Tænk på din nuværende hverdag som pårørende til personen med demens. Har du brug for...*
17	viden om hvad du kan bruge demenskoordinatoren/sundhedsfaglige medarbejdere til?	Terminologi om sundhedfaglige medarbejdere, demenskoordinator eller fagpersoner skal konsekvensrettes	43	19	hjælp til at håndtere ændret personlighed hos personen?	Kan slås sammen med 8	slet		**Din fysiske trivsel**	Adskillelse i fysisk og psykisk trivsel gør ingen forskel for deltagerne		21	hjælp til at forberede dig på forværring af sygdomsforløbet (f.eks. indflytning i plejebolig)?	19	17	at tilbud om støtte til personen er fleksible og tilpasset din hverdag?
18	viden om hvad demenskoordinatoren kan hjælpe med?	Samme som 17	Slet	20	at der bliver taget større hensyn til dine ønsker for hverdagen?	Slettes. Dækket af 4 og 33	Slet		*Tænk på din hverdag som pårørende til personen med demens. Har du brug for...*				**Din trivsel i hverdagen**		18	at få aflastning fra omsorgsopgaver i hverdagen?
19	hjælp fra sundhedsfaglige medarbejdere til at træffe beslutninger relateret til personen med demens?	Skal omformuleres så det handler om hjælp til at træffe beslutninger på personens vegne	44		**Mestring**			21	hjælp til at få aflastning fra omsorgsopgaver i hverdagen?		22		*Tænk på din nuværende hverdag som pårørende til personen med demens. Har du brug for...*		19	hjælp til at forberede dig på forværring af sygdomsforløbet (f.eks. indflytning i plejebolig)?
20	at blive involveret i tiltag omkring personen med demens/i demensforløbet?	Gør formulering mere simpel fx blive involveret i den faglige indsats	45		*Tænk på din situation som pårørende til personen med demens. Har du brug for hjælp og støtte til at...*			22	hjælp til at prioritere dit eget helbred?		23	22	at få aflastning fra omsorgsopgaver i hverdagen?	18	20	hjælp til at få kontakt til andre i samme situation som din?
21	mere kommunikation med/information fra sundhedsfaglige medarbejdere vedrørende demensforløbet?	Gør pointen mere tydelig	46	21	hjælp til at håndtere svære følelser hos dig selv?		16	23	hjælp til at sove bedre?		24	23	hjælp til at prioritere dit eget helbred?	6	21	information om, hvem du kan kontakte for at få hjælp eller rådgivning?
22	at sundhedsfaglige medarbejdere ser dig som en vigtig person i demensforløbet?	Næsten det samme som 20, er dog vigtig for de pårørende i interviews	47	22	at lære at finde løsninger på problemer, der opstår i hverdagen med demenssygdom?	At lære er ny type spørgsmål. Bør måske være vejledning/råd til at finde løsninger	10	24	hjælp til at få mere tid til dig selv?		25	24	hjælp til at sove bedre?	12	22	at blive inddraget i den faglige indsats?
23	at der bliver lyttet til dine ønsker i demensforløbet?	Fra hvilken side? Internt i familien? Kan slettes, da den er dækket af 20	Slet	23	viden om problemer, der kan opstå i fremtiden pga. demenssygdom?	Slettes eller omformuleres så det er tydeligt at det handler om at kunne forberede sig i god tid.	18		**Din psykiske trivsel**	Hvordan adskiller psykisk trivsel sig fra afsnit om fokus på pårørende? Brug for en mere logisk placering af disse spml.		25	hjælp til at få mere tid til dig selv?	Slet	23	hjælp til at involvere hele familien/netværk i opgaver eller beslutninger omkring personen?
	Familien			24	hjælp til at forberede dig på en hverdag uden pleje- og omsorgsopgaver overfor personen?	Der skal arbejdes med denne formulering fx hjælp til at forberede dig på at sygdommen fører til indflytning i plejebolig/død	19		Tænk på din hverdag som pårørende til personen med demens. Har du brug for...			26	hjælp til at få kontakt til andre i samme situation som din?	20	24	hjælp til at finde rundt i regler og lovgivning?
	Har du brug for:			25	viden om diagnose og demenssygdom?	Evt omformulering: viden/information om udfordringer ved demenssygdom ellers slås sammen med 23	Slet	25	hjælp til at få kontakt til andre i samme situation som din?		26	27	hjælp til at føle dig sikker i omsorgsgiverrollen?	16	25	hjælp til at håndtere økonomiske forhold for personen?



n=63 Item#	DeCANT 1 Item generation Nov 2017	PhD research team and language consultant's comments	Item# in DeCANT version 2
24	hjælp til at involvere hele familien i opgaver eller beslutninger omkring personen med demens?		48
25	hjælp til at håndtere uenighed i familien?	Hvad med venner?	49
	Omverden		
	Har du brug for:		
26	hjælp til at finde rundt i det offentlige system?	Skal der stå offentlige forvaltninger eller regler?	50
27	hjælp til at håndtere økonomiske forhold for personen med demens? (økonomi)	Er dette item nødvendigt? Økonomi fyldte meget i litteratursøgning, både ift. ansvar for familiens økonomi men også pga. øgede udgifter.	51
28	hjælp til at familie/venner får viden om, hvad demenssygdom gør?	Hvad med naboer?	52
29	hjælp til at snakke åbent om demenssygdommen?		53
	Oplevelser	Slet denne overskrift	
	Fokus på den pårørende		
	Har du brug for:		
30	anerkendelse for det du gør for personen for demens?		15
31	støtte til at bede om hjælp til dig selv?	Vag formulering, er dog nævnt som vigtig i både litteratursøgning og i interviews	16
32	information om støtte til dig?		17
33	hjælp (et venligt skub) til at tage imod støttende tilbud	Undlad at skrive et venligt skub	18
34	hjælp til at håndtere ændret personlighed hos personen med demens	Både item 35, 36, 37, 38,39, 40 omhandler afgørende aspekter for personlighed	19
	håndtere demens i hverdagen	Selve ordet håndtere er ladet, undlad i overskrift	
	Har du brug for:		
35	hjælp til at håndtere ændret adfærd hos personen med demens?		8
36	hjælp til at håndtere udad reagerende adfærd hos personen med demens?	Udadreagerende er nok en fagterm, brug aggressiv	9
37	hjælp til at håndtere passiv adfærd eller manglende initiativ hos personen med demens?		10
38	hjælp til hvordan man kommunikerer med personen med demens?	Brug i stedet ordet "taler"	11
39	at lære måder at håndtere hukommelsesbesvær hos personen med demens?	Lære ændres til råd om	12
40	hjælp til at håndtere at personen med demens ikke har indsigt i sin egen sygdom?		13
41	større tiltro til dine egne evner?	Kan virke provokerende. Måske skal den konkretiseres ...egne evner til hvad?	14
	Særlige hensyn til den pårørendes livsførsel		
	Har du brug for:		
42	at der bliver taget særlig/større hensyn til den måde du ønsker at leve dit liv på?	Omformuler, brug evt hverdag.	20
	Rådgivning		
	Har du brug for		
43	rådgivning fra sundhedsmedarbejdere omkring/i hverdagen med demenssygdom?	dette spørgsmål er overflødigt, er underforstået i mange af de andre spørgsmål	Slet
44	støtte til ikke-praktiske forhold i hverdagen i forhold til at du er pårørende til en person med demens?	Vagt formuleret, kan slettes	Slet
	Mestring		
	Har du brug for:		
45	hjælp til at håndtere svære følelser (fordi du er pårørende til en person med demens)?	Vagt formuleret, tilføj "hos dig selv"	21
46	at lære at finde løsninger på problemer der opstår i hverdagen med demenssygdom?	Spørger til det samme som 43	22
47	at lære nye strategier til at løse problemer der opstår i hverdagen med demenssygdom	Er dækket af 46	Slet
	Viden		
	Fremtiden		
	Har du brug for:		
48	viden om det svære/problemer der kan opstå i fremtiden i et demensforløb?	Spørger til det samme som 49, 50 og 51	23
49	hjælp til at forberede dig på et liv uden pleje og omsorgsopgaver overfor personen med demens?	Hverdag i stedet liv	24
	Information		
	Har du brug for:		
50	viden om diagnose og demenssygdom?		Slet
51	at lære nyt om demenssygdom og symptomer kontinuerligt?	50 og 51 spørger om det samme	25
52	at få information om den sundhedsfaglige indsats til personen med demens?	Samme som 21	26
	Teknologi		
	Har du brug for:		
53	(konkrete værktøjer til at få) personlig tilpasset information om demenssygdom?	Dette spørgsmål var vigtigt i litteratursøgning. Præciser og skriv elektroniske redskaber	27

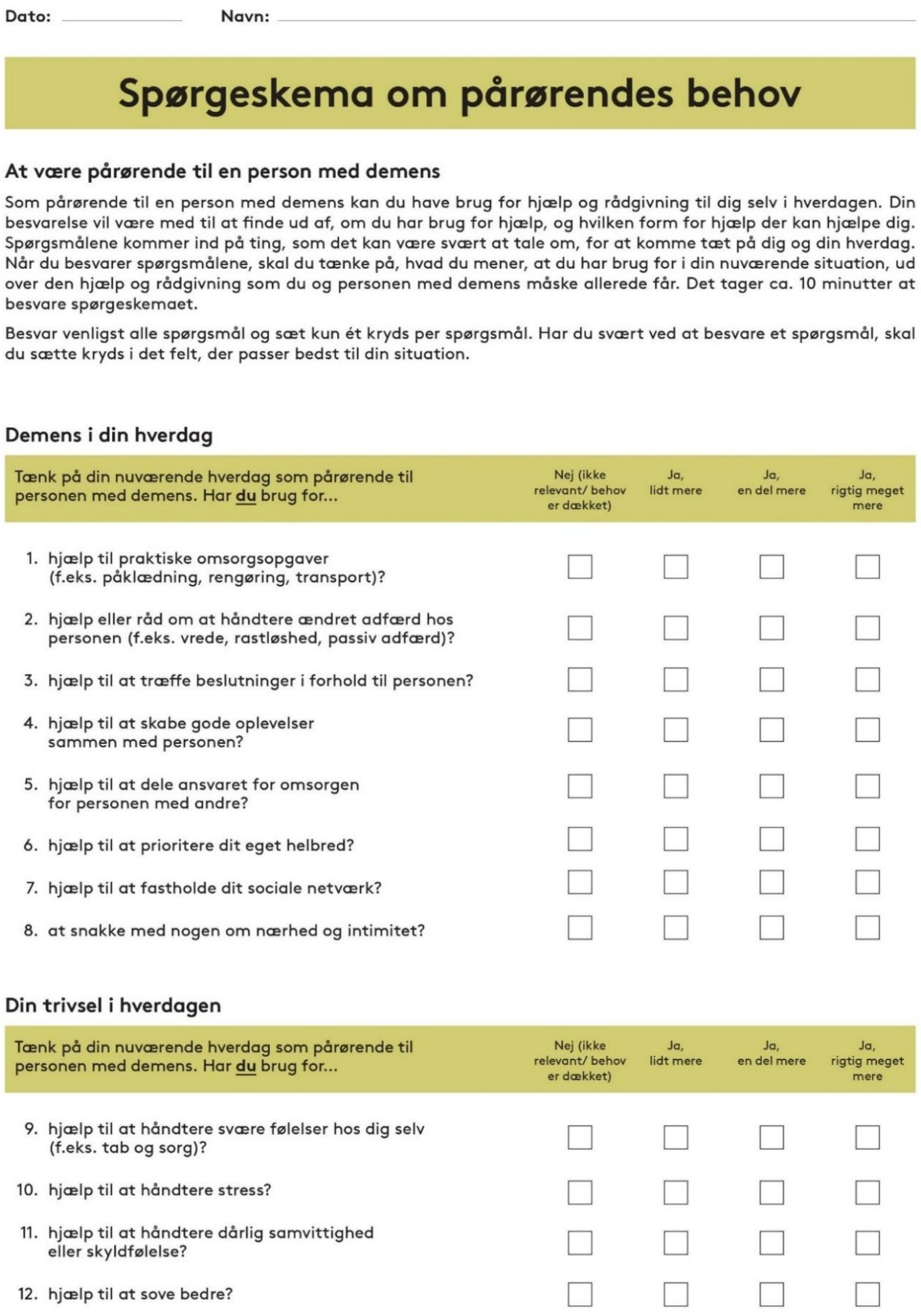
n=53 Item#	DeCANT 2 CVI expertpanel Dec 2017	Experts' comments	Item# in DeCANT version 3
26	at få information om den sundhedsfaglige indsats over for personen med demens?	Skal enten være forskellig fra 47 eller skrives sammen med	36
27	at få viden om elektroniske redskaber, der kan hjælpe dig?	Ændres til teknologiske hjælpemidler, der kan hjælpe dig og personen med demens	20
	Din fysiske trivsel		
	Tænk på din situation som pårørende til personen med demens. Har du brug for hjælp og støtte til at...		
28	få aflastning fra pleje- eller omsorgsopgaver i hverdagen?	Er dækket af 28, 29 og 6 og 2 og kan måske slettes	21
29	få fridage fra pleje- eller omsorgsopgaver i hverdagen?	Skal afstemmes med 28, 29 og 6. Drop ordet pleje	Slet
30	få hjælp til at prioritere dit eget helbred?		22
31	blive fysisk stærkere, så du bedre kan klare pleje og omsorg?	Kan slettes, da den er dækket af 30	Slet
32	sove bedre?	Evt skrives sammen med 30	23
33	få mere tid til dig selv?	Er dækket af 6. Overvej om tid også handler om at skabe mere tid til samværet med personen med demens	24
	Din psykiske trivsel		
	Tænk på din situation som pårørende til personen med demens. Har du brug for hjælp og støtte til at...		
34	få kontakt til andre i samme situation som din?		25
35	håndtere bekymringer i hverdagen?		26
36	håndtere stress?		27
37	skabe et bedre forhold til personen?	Undlad 'bedre', da det har en forforståelse	28
38	få flere gode oplevelser sammen med personen?	Overvej at samle med item 37: skabe gode oplevelser sammen med personen	29
39	dele ansvaret for omsorgen for til personen?	Præciser at det handler om at dele ansvar med andre	30
40	håndtere dårlig samvittighed eller skyldfølelse?	Hører dette item til højere oppe?	31
41	snakke med nogen om dit seksualliv?		32
	Samarbejde med fagpersoner		
	Tænk på din situation som pårørende til personen med demens. Har du brug for hjælp og støtte til at...		
42	information om, hvem du skal kontakte for at få hjælp?		33
43	at få viden om, hvad du kan bruge fagpersoner/demenskoordinatoren til?	Undlad skråstreg, skriv fagpersoner f.eks. demenskonsulenten	34
44	hjælp til at træffe beslutninger?		17
45	at blive involveret i den faglige indsats?	Kan dækkes af 47	Slet
46	bedre kommunikation med fagpersoner?	Vagt formuleret. Er kommunikation ikke blot en del af 47 og 26. Overvej om det kan undlades	Slet
47	at blive set som en vigtig person i den faglige indsats?	Skal være forskellig fra 26, brug ordet samarbejdspartner?. Overlapper med 45	37
	Samarbejde i familien	Slå de to overskrifter om samarbejde sammen	
	Tænk på din situation som pårørende til personen med demens. Har du brug for hjælp og støtte til at...		
48	hjælp til at involvere hele familien i opgaver eller beslutninger omkring personen?	Hvad med øvrigt netværk?	38
49	hjælp til at håndtere uenighed blandt familie og venner?		39
	Omverden		
	Tænk på din situation som pårørende til personen med demens. Har du brug for hjælp og støtte til at...		
50	finde rundt i regler og offentlige forvaltninger?	Omformuler til finde rundt i regler og lovgivning	41
51	håndtere økonomiske forhold for personen?		42
52	informere familie/venner/naboer om, hvad demenssygdom gør?	Omformuler til hvordan demenssygdommen påvirker personen og hverdagen	40
53	snakke åbent om demenssygdommen?	Kan samles med 52	Slet

n=42 Item#	DeCANT 3 Cognitive interviews with carers Feb 2018	Carers' comments	Item# in DeCANT version
26	hjælp til at håndtere bekymringer i hverdagen?		17
27	hjælp til at håndtere stress?	Spørgsmålet om stress giver information om trivsel	
28	hjælp til at have et godt forhold til personen?		29
29	hjælp til at skabe gode oplevelser sammen med personen?		30
30	hjælp til at dele ansvaret for omsorgen til personen med andre?		31
31	hjælp til at håndtere dårlig samvittighed eller skyldfølelse?		19
32	snakke med nogen om dit seksualliv?	Seksualitet gælder kun for ægtefæller. Intimitet og nærhed er bedre, da det kan gælde flere typer	
	Dig og dine omgivelser		
	Tænk på din hverdag som pårørende til personen med demens. Har du brug for...		
33	information om, hvem du kan kontakte for at få hjælp?		33
34	at få viden om, hvad du kan bruge fagpersoner f.eks. demenskonsulenten til?	Det er ikke kendt for alle, at demenskonsulenten også kan hjælpe de pårørende	34
35	at fagpersoner tilbyder hjælp eller rådgivning til dig?	Et stort ønske blandt deltagerne	35
36	at få information om den faglige indsats over for personen med demens?		36
37	at blive inddraget som en vigtig samarbejdspartner i den faglige indsats?	Formulering indikerer at nogen vil mene de pårørende ikke er vigtige, det opleves som en fornærmelse	37
38	hjælp til at involvere hele familien/netværk i opgaver eller beslutninger omkring personen?	Relevant at formulering ligger op til at flere pårørende har en vigtig rolle. Selvom der henvises til både opgaver og beslutninger er deltagerne ikke i tvivl om at de svarer på involvering af familie/netværk.	38
39	hjælp til at håndtere uenighed eller andre vanskelige situationer blandt familien/netværk omkring personen?	Kan være svært selv at tage hul på emnet, derfor relevant	39
40	hjælp til at tale med familie/netværk og omgivelser om, hvordan demenssygdommen påvirker personen?		40
41	hjælp til at finde rundt i regler og lovgivning?		41
42	hjælp til at håndtere økonomiske forhold for personen?	Fylder meget, da det er nyt og svært	42

n=42 Item#	DeCANT 4 & DeCANT 5 Electronic testing Feb 2018 Field-testing among carers Feb-Oct 2018	Item# in DeCANT final version
28	hjælp til at træffe beslutninger i forhold til personen?	3
29	hjælp til at have et godt forhold til personen?	Slet
30	hjælp til at skabe gode oplevelser sammen med personen?	4
31	hjælp til at dele ansvaret for omsorgen for personen med andre?	5
32	at snakke med nogen om nærhed og intimitet?	8
	Du og dine omgivelser	
	Tænk på din nuværende hverdag som pårørende til personen med demens. Har du brug for...	
33	information om, hvem du kan kontakte for at få hjælp eller rådgivning?	21
34	at få viden om, hvad du kan bruge fagpersoner f.eks. demenskonsulenten til?	Slet
35	at fagpersoner tilbyder hjælp eller rådgivning til dig?	Slet
36	at få information om den faglige indsats over for personen med demens?	Slet
37	at blive inddraget i den faglige indsats?	22
38	hjælp til at involvere hele familien/netværk i opgaver eller beslutninger omkring personen?	23
39	hjælp til at håndtere uenighed eller andre vanskelige situationer blandt familien/netværk omkring personen?	Slet
40	hjælp til at tale med familie/netværk og omgivelser om, hvordan demenssygdommen påvirker personen?	Slet
41	hjælp til at finde rundt i regler og lovgivning?	24
42	hjælp til at håndtere økonomiske forhold for personen?	25

n=63 Item#	DeCANT 1 Item generation Nov 2017	PhD research team and language consultant's comments	Item# in DeCANT version 2
	Hverdag		
	Aktivteter målrettet personen med demens		
	Har du brug for:		
54	tilbud om aktiviteter for personen med demens	Undlad at skrive demens	1
55	hjælp til omsorg og pleje i forhold til personen med demens (fx påklædning, rengøring, madlavning)?	Undlad at skrive demens.	2
56	særlig viden om behandlingsindsats til personen med demens? (fx inkontinens, kost, medicin)	Overflødig, det samme som 55. Der mangler dog et spørgsmål om transport af personen med demens.	7
57	at sundhedsfaglige medarbejdere er opsøgende i forhold til at få hjælp/støtte til personen med demens (fx pleje, hjælpemidler)	Gør mere simpelt	3
58	at tilbud om støtte til personen med demens er tilpasset dig (din hverdag)?	Er det den pårørendes hverdag eller en fælles hverdag?	4
59	hjælp til at sikre at personen med demens ikke er til fare for sig selv eller andre?	Er dækket af 8, 9, 10, 11, 16, 54,57, 58,61,62 om aflastning og støtte til pleje og aktiviteter.	Slet
	Begrænsning af den pårørendes aktiviteter		
	Har du brug for:		
60	hjælp til at fastholde dit (eget) sociale netværk?	Overvej om det er det samme som 1	5
61	tid til at (klare) udføre arbejdsopgaver i eget liv? (lønnet arbejde, huslige gøremål, styre økonomi)	Samme som 8, 9, 10, 11	Slet
62	mulighed/tid til at udføre almindelige dagligdags aktiviteter?	Samme som 61	6
63	hjælp til at skabe gode rammer for sociale aktiviteter sammen med personen med demens?	Samme som 4 og 5	Slet

Appendix 8 DeCANT final version consisting of 25 items in Danish and English



Dato: ______________ **Navn:** ______________________________________

Spørgeskema om pårørendes behov

At være pårørende til en person med demens

Som pårørende til en person med demens kan du have brug for hjælp og rådgivning til dig selv i hverdagen. Din besvarelse vil være med til at finde ud af, om du har brug for hjælp, og hvilken form for hjælp der kan hjælpe dig. Spørgsmålene kommer ind på ting, som det kan være svært at tale om, for at komme tæt på dig og din hverdag. Når du besvarer spørgsmålene, skal du tænke på, hvad du mener, at du har brug for i din nuværende situation, ud over den hjælp og rådgivning som du og personen med demens måske allerede får. Det tager ca. 10 minutter at besvare spørgeskemaet.

Besvar venligst alle spørgsmål og sæt kun ét kryds per spørgsmål. Har du svært ved at besvare et spørgsmål, skal du sætte kryds i det felt, der passer bedst til din situation.

Demens i din hverdag

Tænk på din nuværende hverdag som pårørende til personen med demens. Har **du** brug for...	Nej (ikke relevant/ behov er dækket)	Ja, lidt mere	Ja, en del mere	Ja, rigtig meget mere
1. hjælp til praktiske omsorgsopgaver (f.eks. påklædning, rengøring, transport)?	☐	☐	☐	☐
2. hjælp eller råd om at håndtere ændret adfærd hos personen (f.eks. vrede, rastløshed, passiv adfærd)?	☐	☐	☐	☐
3. hjælp til at træffe beslutninger i forhold til personen?	☐	☐	☐	☐
4. hjælp til at skabe gode oplevelser sammen med personen?	☐	☐	☐	☐
5. hjælp til at dele ansvaret for omsorgen for personen med andre?	☐	☐	☐	☐
6. hjælp til at prioritere dit eget helbred?	☐	☐	☐	☐
7. hjælp til at fastholde dit sociale netværk?	☐	☐	☐	☐
8. at snakke med nogen om nærhed og intimitet?	☐	☐	☐	☐

Din trivsel i hverdagen

Tænk på din nuværende hverdag som pårørende til personen med demens. Har **du** brug for...	Nej (ikke relevant/ behov er dækket)	Ja, lidt mere	Ja, en del mere	Ja, rigtig meget mere
9. hjælp til at håndtere svære følelser hos dig selv (f.eks. tab og sorg)?	☐	☐	☐	☐
10. hjælp til at håndtere stress?	☐	☐	☐	☐
11. hjælp til at håndtere dårlig samvittighed eller skyldfølelse?	☐	☐	☐	☐
12. hjælp til at sove bedre?	☐	☐	☐	☐

Fokus på dig som pårørende

Tænk på din nuværende hverdag som pårørende til personen med demens. Har **du** brug for...	Nej (ikke relevant/ behov er dækket)	Ja, lidt mere	Ja, en del mere	Ja, rigtig meget mere
13. hjælp til at håndtere personens manglende forståelse for egen sygdom?	☐	☐	☐	☐
14. anerkendelse for det, du gør for personen?	☐	☐	☐	☐
15. hjælp til at bede om hjælp til dig selv?	☐	☐	☐	☐
16. hjælp til at føle dig sikker i omsorgsgiverrollen?	☐	☐	☐	☐

Du og dine omgivelser

Tænk på din nuværende hverdag som pårørende til personen med demens. Har **du** brug for...	Nej (ikke relevant/ behov er dækket)	Ja, lidt mere	Ja, en del mere	Ja, rigtig meget mere
17. at tilbud om støtte til personen er fleksible og tilpasset din hverdag?	☐	☐	☐	☐
18. at få aflastning fra omsorgsopgaver i hverdagen?	☐	☐	☐	☐
19. hjælp til at forberede dig på forværring af sygdomsforløbet (f.eks. indflytning i plejebolig)?	☐	☐	☐	☐
20. hjælp til at få kontakt til andre i samme situation som din?	☐	☐	☐	☐
21. information om, hvem du kan kontakte for at få hjælp eller rådgivning?	☐	☐	☐	☐
22. at blive inddraget i den faglige indsats?	☐	☐	☐	☐
23. hjælp til at involvere hele familien/netværk i opgaver eller beslutninger omkring personen?	☐	☐	☐	☐
24. hjælp til at finde rundt i regler og lovgivning?	☐	☐	☐	☐
25. hjælp til at håndtere økonomiske forhold for personen?	☐	☐	☐	☐

Evt. kommentarer:

Tak for din besvarelse

DeCANT - The Dementia Carer Assessment of Support Needs Tool. Clemmensen T, Kristensen H, Andersen-Ranberg K og Lauridsen H (2020). Udgave juni 2020

Date: ______________ **Name:** ____

The Dementia Carer Assessment of support Needs Tool

Being a carer to a person with dementia

When caring for a person with dementia you may need help and support for yourself. Your answers will help to identify if you have a need for support, and what might help in your present situation. The questions may address topics sensitive to you. When answering questions you have to consider support needs aside from the support you and the person with dementia may already receive. Filling out the questionnaire takes about 10 minutes.

Please answer all of the questions, and tick only one response per question. If you find a question difficult to answer, you may choose the response most relevant to you.

Daily life when caring for a person with dementia

Consider your present situation caring for the person with dementia. Do <u>you</u> have a need for support…	No (not relevant/ need met)	Yes, a little more	Yes, quite a bit more	Yes, very much more
1. to manage everyday chores (e.g. dressing, cleaning, transportation)?	☐	☐	☐	☐
2. to maintain your social network?	☐	☐	☐	☐
3. to manage changed behaviour in the person with dementia (e.g. aggressive, restless or passive behaviour)?	☐	☐	☐	☐
4. to prioritise your own health?	☐	☐	☐	☐
5. to make decisions regarding the person with dementia?	☐	☐	☐	☐
6. to create nice experiences together with the person with dementia?	☐	☐	☐	☐
7. to share the responsibility of caring with someone else?	☐	☐	☐	☐
8. to talk to someone about intimacy?	☐	☐	☐	☐

Maintaining own well-being

Consider your present situation caring for the person with dementia. Do <u>you</u> have a need for support…	No (not relevant/ need met)	Yes, a little more	Yes, quite a bit more	Yes, very much more
9. to cope with your own emotions (e.g. loss or grief)?	☐	☐	☐	☐
10. to manage stress?	☐	☐	☐	☐
11. to deal with bad conscience or guilt?	☐	☐	☐	☐
12. to sleep better?	☐	☐	☐	☐

Focus on yourself

Consider your present situation caring for the person with dementia. Do you have a need for support…		No (not relevant/ need met)	Yes, a little more	Yes, quite a bit more	Yes, very much more
13.	to manage person with dementia's lack of disease awareness?	☐	☐	☐	☐
14.	to feel appreciated in what you are doing for the person with dementia?	☐	☐	☐	☐
15.	to ask for help for yourself?	☐	☐	☐	☐
16.	to feel confident in the caring role?	☐	☐	☐	☐

Communicating and interacting with surroundings

Consider your present situation caring for the person with dementia. Do you have a need for support…		No (not relevant/ need met)	Yes, a little more	Yes, quite a bit more	Yes, very much more
17.	to make sure that services targeted the person with dementia conform to your daily life?	☐	☐	☐	☐
18.	to prepare for deterioration of the situation (e.g. moving into nursing home)?	☐	☐	☐	☐
19.	to get respite from everyday caring?	☐	☐	☐	☐
20.	to get in contact with others in the same situation as you?	☐	☐	☐	☐
21.	to get information about who to contact for support?	☐	☐	☐	☐
22.	to be involved in this collaborative caring work?	☐	☐	☐	☐
23.	to involve family/network in tasks or decision making in relation to the person with dementia?	☐	☐	☐	☐
24.	to navigate rules and legislation?	☐	☐	☐	☐
25.	to manage financial issues on behalf of the person with dementia?	☐	☐	☐	☐

Comments:

____

____

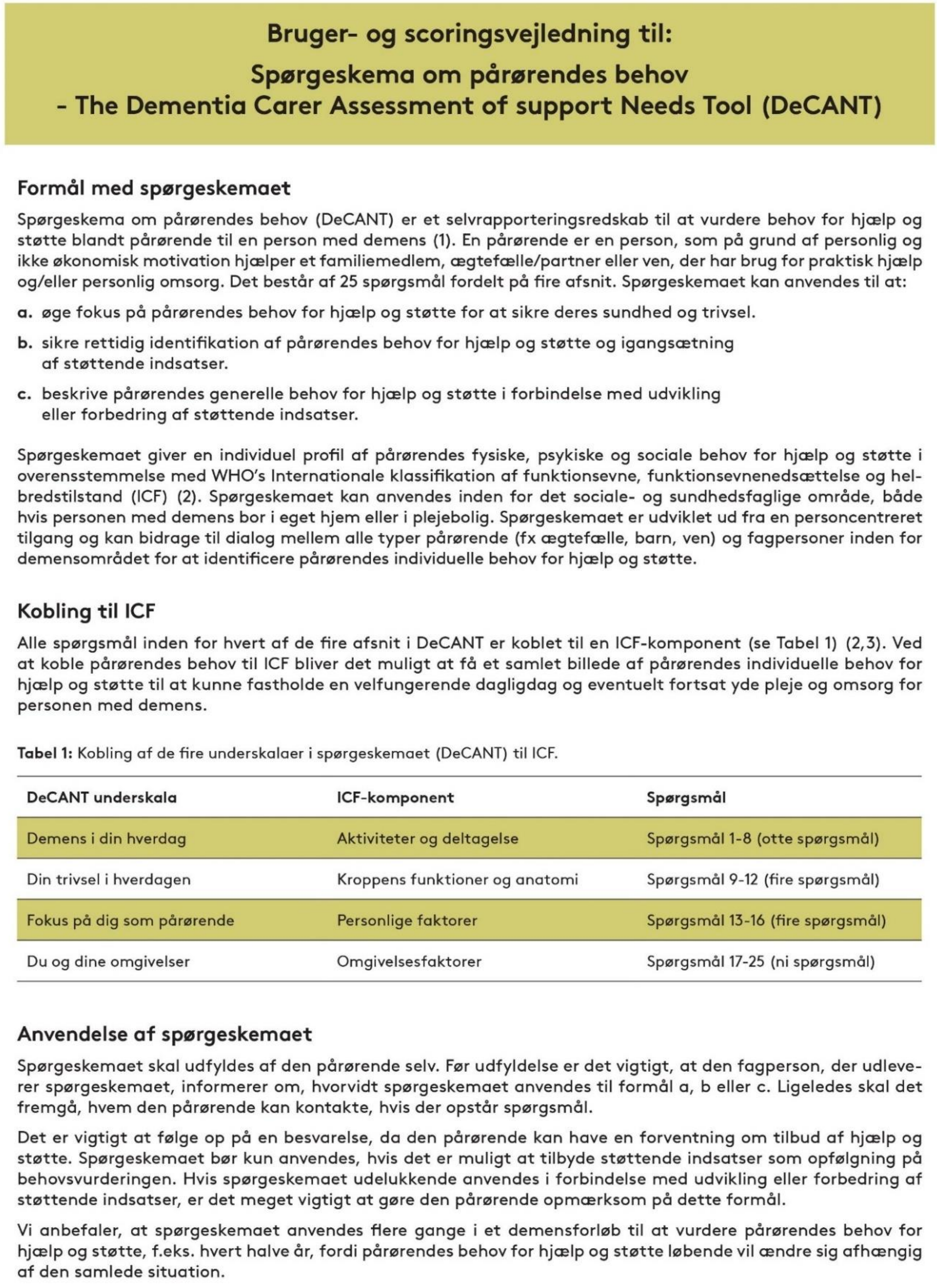
____

____

____

Thank you

Appendix 9 Using and scoring manual for The Dementia Carer Assessment of Support Needs Tool (DeCANT) in Danish and English



Bruger- og scoringsvejledning til:

Spørgeskema om pårørendes behov
- The Dementia Carer Assessment of support Needs Tool (DeCANT)

Formål med spørgeskemaet

Spørgeskema om pårørendes behov (DeCANT) er et selvrapporteringsredskab til at vurdere behov for hjælp og støtte blandt pårørende til en person med demens (1). En pårørende er en person, som på grund af personlig og ikke økonomisk motivation hjælper et familiemedlem, ægtefælle/partner eller ven, der har brug for praktisk hjælp og/eller personlig omsorg. Det består af 25 spørgsmål fordelt på fire afsnit. Spørgeskemaet kan anvendes til at:

a. øge fokus på pårørendes behov for hjælp og støtte for at sikre deres sundhed og trivsel.

b. sikre rettidig identifikation af pårørendes behov for hjælp og støtte og igangsætning af støttende indsatser.

c. beskrive pårørendes generelle behov for hjælp og støtte i forbindelse med udvikling eller forbedring af støttende indsatser.

Spørgeskemaet giver en individuel profil af pårørendes fysiske, psykiske og sociale behov for hjælp og støtte i overensstemmelse med WHO's Internationale klassifikation af funktionsevne, funktionsevnenedsættelse og helbredstilstand (ICF) (2). Spørgeskemaet kan anvendes inden for det sociale- og sundhedsfaglige område, både hvis personen med demens bor i eget hjem eller i plejebolig. Spørgeskemaet er udviklet ud fra en personcentreret tilgang og kan bidrage til dialog mellem alle typer pårørende (fx ægtefælle, barn, ven) og fagpersoner inden for demensområdet for at identificere pårørendes individuelle behov for hjælp og støtte.

Kobling til ICF

Alle spørgsmål inden for hvert af de fire afsnit i DeCANT er koblet til en ICF-komponent (se Tabel 1) (2,3). Ved at koble pårørendes behov til ICF bliver det muligt at få et samlet billede af pårørendes individuelle behov for hjælp og støtte til at kunne fastholde en velfungerende dagligdag og eventuelt fortsat yde pleje og omsorg for personen med demens.

Tabel 1: Kobling af de fire underskalaer i spørgeskemaet (DeCANT) til ICF.

DeCANT underskala	ICF-komponent	Spørgsmål
Demens i din hverdag	Aktiviteter og deltagelse	Spørgsmål 1-8 (otte spørgsmål)
Din trivsel i hverdagen	Kroppens funktioner og anatomi	Spørgsmål 9-12 (fire spørgsmål)
Fokus på dig som pårørende	Personlige faktorer	Spørgsmål 13-16 (fire spørgsmål)
Du og dine omgivelser	Omgivelsesfaktorer	Spørgsmål 17-25 (ni spørgsmål)

Anvendelse af spørgeskemaet

Spørgeskemaet skal udfyldes af den pårørende selv. Før udfyldelse er det vigtigt, at den fagperson, der udleverer spørgeskemaet, informerer om, hvorvidt spørgeskemaet anvendes til formål a, b eller c. Ligeledes skal det fremgå, hvem den pårørende kan kontakte, hvis der opstår spørgsmål.

Det er vigtigt at følge op på en besvarelse, da den pårørende kan have en forventning om tilbud af hjælp og støtte. Spørgeskemaet bør kun anvendes, hvis det er muligt at tilbyde støttende indsatser som opfølgning på behovsvurderingen. Hvis spørgeskemaet udelukkende anvendes i forbindelse med udvikling eller forbedring af støttende indsatser, er det meget vigtigt at gøre den pårørende opmærksom på dette formål.

Vi anbefaler, at spørgeskemaet anvendes flere gange i et demensforløb til at vurdere pårørendes behov for hjælp og støtte, f.eks. hvert halve år, fordi pårørendes behov for hjælp og støtte løbende vil ændre sig afhængig af den samlede situation.

Hvordan scores spørgeskemaet

Hvert spørgsmål kan scores ud fra den tilsvarende svarkategoris værdi. Scoring af svarkategorier og anbefalinger for tolkning af behov for hjælp og støtte er angivet i Tabel 2 herunder.

Beregning af en sumscore er ikke nødvendig ved anvendelse i daglig social- eller sundhedsfaglig praksis. Det er dog muligt at lave en profil af pårørendes behov for hjælp og støtte ved at beregne en sumscore for hver af de fire afsnit. En sumscore beregnes for hvert afsnit ved at lægge alle værdier for svarkategorierne sammen inden for et afsnit. En høj sumscore indikerer et stort behov for hjælp og støtte. Sumscore for hvert afsnit er vist i nedenstående Tabel 3.

Tabel 2: Scoring af DeCANT.

Svarkategori	Svarkategori værdi	Tolkning af scoring
Nej (ikke relevant/behov er dækket)	0	Handling er ikke nødvendig
Ja, lidt mere	1	Handling formodentlig ikke nødvendig
Ja, en del mere	2	Hjælp og støtte bør overvejes
Ja, rigtig meget mere	3	Hjælp og støtte er påkrævet

Tabel 3: Sumscore for hver af de fire afsnit i DeCANT

DeCANT afsnit	Sumscore interval	Spørgsmål
Demens i din hverdag	0-24	Spørgsmål 1-8 (otte spørgsmål)
Din trivsel i hverdagen	0-12	Spørgsmål 9-12 (fire spørgsmål)
Fokus på dig som pårørende	0-12	Spørgsmål 13-16 (fire spørgsmål)
Du og dine omgivelser	0-27	Spørgsmål 17-25 (ni spørgsmål)

Manglende svar

Hvis der er sat kryds uden for felterne, vælges det felt nærmest krydset. Hvis to felter er afkrydset, vælges det svar, der angiver det mindste behov for hjælp og støtte. For at kunne beregne sumscore for et afsnit må højst 25% af spørgsmålene mangle svar (Demens i din hverdag: 25% =2 spørgsmål, Din trivsel i hverdagen: 25%= 1 spørgsmål, Fokus på dig som pårørende: 25%= 1 spørgsmål, Du og dine omgivelser: 25%= 2 spørgsmål).

Litteraturliste

1) *Clemmensen TH, Kristensen HK, Andersen-Ranberg K, Lauridsen HH.*
Development and Field-testing of the Dementia Carer Assessment of Support Needs Tool (DeCANT). 2020.

2) *World Health Organization. ICF - International classification of functioning, disability and health. 2001:299*

3) *Cieza A, Fayed N, Bickenbach J, Prodinger B. Refinements of the ICF Linking Rules to strengthen*
their potential for establishing comparability of health information. Disabil Rehabil 2016 Mar 17;41(5):1-10.

Using and scoring manual for:
The Dementia Carer Assessment of support Needs Tool (DeCANT)

Purpose of DeCANT

The Dementia Carer Assessment of support Needs Tool (DeCANT) is a self-administered instrument for carers, aimed at assessing their support needs when caring for a person with dementia (1). A carer is any person who helps a family member, spouse/partner or friend in need of personal and/or practical assistance out of personal motivation rather than financial compensation. It consists of 25 items distributed on four subscales. DeCANT can be used to:

a. focus on the carer's support needs in order to improve their health and well-being.

b. identify the carer's support needs in order to enable timely supportive interventions.

c. describe the carer's support needs in general in order to create or improve supportive interventions.

The DeCANT provides an individual profile of the carer's physical, psychological and social support needs in correspondence with WHOs International Classification of Functioning, Disability and Health (ICF) (2). With the purpose of supporting carers in their caring role, this instrument is developed for use in health and social care to enable person-centred assessment of the carer's support needs as well as to facilitate dialogue between carers and professionals. The DeCANT is suitable for all carers in both home care and residential care settings.

Linking DeCANT to ICF

Each item within the four DeCANT subscales is linked to a first level ICF category (see Table 1) (2,3). Linking support needs to an ICF category can be used to target individual support needs to maintain or improve a carer's functioning in daily life when providing essential care to a person with dementia.

Table 1: Linking of the four subscales in DeCANT to the ICF.

DeCANT subscale	ICF first level category	Items
Daily life when caring	Activity and participation component	Item 1-8 (eight items)
Your well-being	Body structures and functions component	Item 9-12 (four items)
Focus on yourself	Personal factors	Item 13-16 (four items)
Your surroundings	Environmental factors	Item 17-25 (nine items)

How to use DeCANT

The DeCANT is a self-administered instrument for carers to fill out on their own. When administering DeCANT, the person responsible for handing out the instrument, should carefully instruct the carer on the purpose of using DeCANT in the specific context (a, b or c) and who to contact if questions arise.

It is very important that a dialogue takes place following scoring of DeCANT. Due to its sensitive content, carers may develop expectations about supportive interventions. DeCANT should therefore only be administered if supportive interventions can be initiated. In case DeCANT is applied solely to create or improve supportive interventions, it is important that the carer has been informed of this purpose of use. We recommend regular utilization of DeCANT, e.g. every six months, as support needs change concurrently within the context of caring.

How to score DeCANT

Scoring each item with a value for the response categories is enough to carry out an individual assessment of support needs. Scoring values and our recommendations for interpretation of support needs are shown in Table 2 below.

When used in day-to-day health and social care, calculation of sum scores are not necessary. However, a profile of the carer's support needs can easily be calculated on the basis of the four subscales. Subscale scores are calculated by summing the value of response categories for all items within a subscale. A higher score represents more need for support. The subscale scores are shown in

Table ***3*** below.

Table 2: Scoring of DeCANT.

Response category	Scoring value	Interpretation of score
No (not relevant/met need)	0	No action is necessary
Yes, a little more	1	Probably no action necessary
Yes, quite a bit more	2	Supportive interventions should be considered
Yes, very much more	3	Supportive interventions are necessary

Table 3: Sumscore for each subscale in DeCANT.

DeCANT subscale	Subscale score range	Items
Daily life when caring	0-24	Item 1-8 (eight items)
Your well-being	0-12	Item 9-12 (four items)
Focus on yourself	0-12	Item 13-16 (four items)
Your surroundings	0-27	Item 17-25 (nine items)

Missing data

If an answer is checked outside the boxes, the box closest to is chosen. If two boxes are checked, the answer that indicates less support need is chosen. If more than 25% of a subscale's items are omitted, a subscale score cannot be calculated (Daily life when caring: 25% = 2 items, Your well-being: 25%= 1 item, Focus on yourself: 25%= 1 item, Your surroundings: 25%= 2 items).

References

1) Clemmensen TH, Kristensen HK, Andersen-Ranberg K, Lauridsen HH. Development and Field-testing of the Dementia Carer Assessment of Support Needs Tool (DeCANT) 2020.

2) World Health Organization. ICF - International classification of functioning, disability and health. 2001:299.

3) Cieza A, Fayed N, Bickenbach J, Prodinger B. Refinements of the ICF Linking Rules to strengthen their potential for establishing comparability of health information. Disabil Rehabil 2016 Mar 17;41(5):1-10.

22 Original papers

Paper I

Carers' support needs when caring for a person with dementia - A scoping literature review

Original article

Informal carers’ support needs when caring for a person with dementia - A scoping literature review

Trine Holt Clemmensen, M.H.Sc.[1, 2], Henrik Hein Lauridsen, Ph.D., Assoc.Prof.[2], Karen Andersen-Ranberg, Ph.D., Clin.Prof.[3, 4], Hanne Kaae Kristensen, Ph.D., Prof. [1, 4]

1 Health Sciences Research Centre, UCL University College, Denmark. 2 Department of Sports Science and Clinical Biomechanics, University of Southern Denmark, Denmark. 3 Department of Public Health, University of Southern Denmark, Denmark. 4 Department of Clinical Research, University of Southern Denmark, Denmark.

Corresponding author: Trine Holt Clemmensen, Niels Bohrs Allé 1, 5230 Odense M, Denmark. Email address: thcl@ucl.dk orcid.org/0000-0002-6080-8883

Abstract

Background: Informal carers of people with dementia report having unmet needs for support and few supportive interventions have been shown to be effective. There is a need to develop needs assessment instruments and supportive interventions with a holistic and person-centered approach to meet the various and complex needs of carers. The aim of this study was to provide an overview of carers’ support needs when caring for people with dementia with the objectives to map and synthesise knowledge on key concepts of carers’ support needs.

Methods: A scoping review methodology was used. A literature search was conducted in PsycINFO, CINAHL, PubMed and EMBASE between January 2007 and October 2019. Three authors independently selected articles meeting the inclusion criteria and data were extracted using a matrix developed for that purpose. Inductive content analysis was used to synthesise key concepts of carers’ support needs.

Results: The search identified 2748 articles after removing duplicates and 122 articles were included in the mapping of carers’ support needs. Synthesising carers’ support needs indicated that the full extent of support needs emerges in the interaction between the carer and the person cared for, and that it is possible to categorise support needs into four key concepts related to: 1) the carer as a person, 2) managing being a carer, 3) providing care, and 4) knowledge of dementia.

Conclusion: The findings of this study help to map a framework describing carers’ support needs that may guide the development of future needs assessment instruments and supportive interventions.

Keywords

Alzheimer’s, caregiving, carer, dementia, mapping, scoping literature review, support needs

Background

Informal carers’ (hereafter carers) involvement in dementia care is crucial for the requisite care and well-being of people with dementia (1). However, caring for a person with dementia is associated with increased physical and mental illness (2) and financial costs (3). Recognising carers’ support needs is therefore important from both an individual and a societal perspective if the need for care among the growing population of people with dementia is to be met (4). Consequently, providing appropriate support to carers is essential, because they provide most of the care (5).

Carers’ well-being is affected by physical and mental stressors when caring for people with dementia, and their health is reported to be more affected than those caring for people with any other type of chronic illness (6). Moreover, the role of caring may be burdensome and lonely. Notably, a lack of knowledge of dementia in society and the disruptive behaviour that may follow a dementia diagnosis can often lead to stigmatisation (1) and social exclusion (7). This social exclusion adds to the burden many carers experience (8). Furthermore, carers describe neglecting their own needs, jeopardising their own well-being (9) and finding it difficult to express their own needs (10), because they are so committed to caring for the person with dementia. To understand the concept of needs, Maslow’s Theory of Human Motivation suggests that satisfying different types of needs is what makes human beings thrive (11). The concept of need is defined as physical, mental or social shortcomings interacting with each other (11). Carers report having unmet support needs (12), which may be due to the individual nature of their needs, but also that interventions are not targeted to those individual needs. Given the importance of the carers’ role in the care of people with dementia, research on carers’ support needs is important to develop needs assessment instruments and supportive interventions. A few interventions for carers, such as psychoeducation and support groups, have been shown to be effective (13). Person-centered care is a recognised holistic approach to dementia care (14,15), and professionals and stakeholders worldwide are committed to this (1). However, in health and social care, a person-centered approach for carers is not self-evident, even though empowerment and shared responsibility are as equally important to carers as they are to people with dementia. There is no clear definition of collaborative person-centered care by carers of people with dementia, but general characteristics of person-centered care, such as “getting to know the person”, “sufficient communication” and “trust and respect”, have been applied to the collaboration between carers and professionals throughout the progression of dementia (16). The potential of this approach lies in creating individual and targeted efforts that meet carers' support needs when continually providing important care.

To enable identification of carers' individual support needs, a mapping of existing research has contributed to an overview (17) and basis for future person-centered interventions. Further to that, other reviews have provided knowledge about carers' needs, but with a limited focus on specific types of needs (18), dementia diagnosis (19), temporal progression of dementia (20) or study design (21). Conducting a review with a broad scope that explores existing knowledge of carers' support needs with a person-centered approach renders the possibility of getting a complete overview of the current extensive but considerably fragmented body of knowledge.

The aim of this scoping review was to provide an overview of carers' support needs when caring for a person with dementia. The objectives were to map existing knowledge of carers' support needs and to synthesise the knowledge on key concepts of carers' support needs. The principal question of this scoping review was: *What is known in the existing literature about carers' support needs when caring for a person with dementia?*

Methods

A scoping review methodology designed by Levac et al. (17) was adopted to give an overview of carers' support needs when caring for a person with dementia. A scoping review is appropriate when conducting a knowledge synthesis of key concepts within an area of diverse evidence (22). A recommended framework of six stages was used in the conduct of this study (17): Stage 1) Identifying the research question, Stage 2) Identifying relevant studies, Stage 3) Selecting the studies, Stage 4) Charting the data, Stage 5) Collating, summarising, and reporting the results, and Stage 6) Consultation, the last stage being optional and not applied in this study.

Search strategy

A literature search with a broad scope and a narrow search strategy was conducted in four databases: PsycINFO via EBSCO, CINAHL Complete, PubMed via MEDLINE and EMBASE via Ovid. The search was limited to identifying articles published between January 2007 and October 2019 to ensure that support needs reflected current representations of society and demographic development in dementia diseases. The start date was chosen because several international initiatives were taken around this time, promoting the prioritization of dementia as a public health priority and the development of national dementia strategies, including those about people with dementia and their informal carers (23,24). The search was limited to English, Danish, Norwegian and Swedish languages. Search terms were identified based on the current literature and by consulting a librarian. See an example of the search in the database below (Table 1).

Table 1 Example of electronic search in Cinahl COMPLETE

Date of search: November 8th 2019

Search: (Carer OR Relative OR Family OR Spouse OR Child OR Caregiver) AND (Dementia OR Alzheimer's OR Neurodegenerative disease) AND (Support AND Needs)

Filters: Publication date from 2007/01/01 to 2019/10/31; Danish; English; Norwegian; Swedish

Study selection

The process for selecting articles followed the guideline of Levac et al. (17). Articles retrieved from each database were imported into RefWorks reference management software and duplicates were removed. Three authors independently screened articles for eligibility using inclusion and exclusion criteria, firstly by reading the title and abstract, and secondly by reading the full text articles. The first author (THC) screened all articles, a second author screened one-third (HHL) and a third author, two-thirds (HKK) of the articles. Inclusion criteria for articles were:

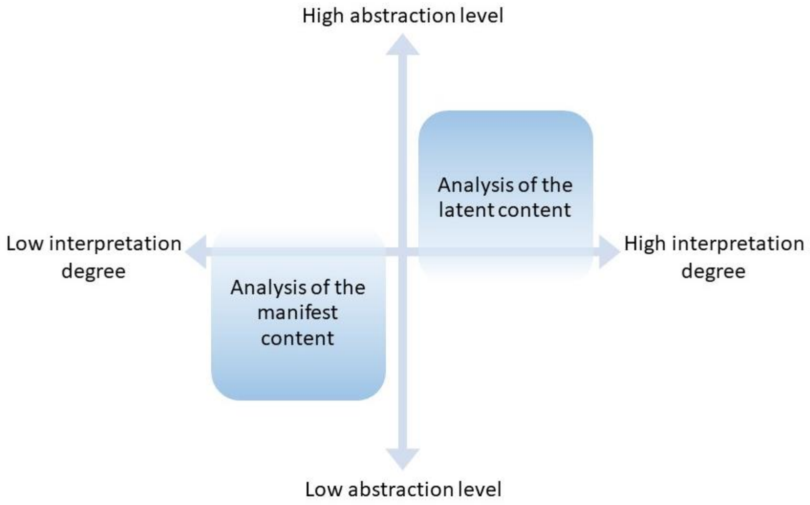
- They contained information about adult carers' support needs when caring for a person with dementia, those needs having been stated by carers themselves and not professionals,
- The stated support needs focused on carers' own needs and not the needs of the person with dementia, and
- These support needs reflected those of carers living in conditions representative of the culture, health and social care provided in high-income countries.

Broad inclusion criteria regarding publication type and data collection methods were chosen. However, articles were excluded if they only described the experience of caring or evaluated the effect of carer interventions. If there was any disagreement between authors, consensus was reached by the first author (THC) conferring with either of the two above-mentioned co-authors (HHL, HKK). According to the methodology used and the exploratory nature of a scoping review, no quality assessment was conducted (17).

Data charting and synthesis

A matrix of data variables to describe the articles identified for this study was developed (Appendix 1). The data included author, publication type, year of publication, place of origin, sample, design/data collection method, setting, diagnosis of the person cared for and extent of progression of dementia. In addition, a model of how to interpret content was used before data extraction (see Figure 1). The model enabled identification of support needs regardless of whether or not the support needs had their origin in manifest or latent interpretation of content (25). Manifest content comprised description of support needs with a low degree of interpretation such as survey and interview data of carers directly expressing their needs for support. In contrast, latent content included description of support needs with a high degree of interpretation of data, such as interviews with carers revealing that they experience various problems in relation to caring, which indicated the need for support. The matrix was tested before data extraction and discussed by two of the authors (THC and HKK).

Figure 1 Two-dimensional model of approaches when analysing data in relation to abstraction level and interpretation degree (25)



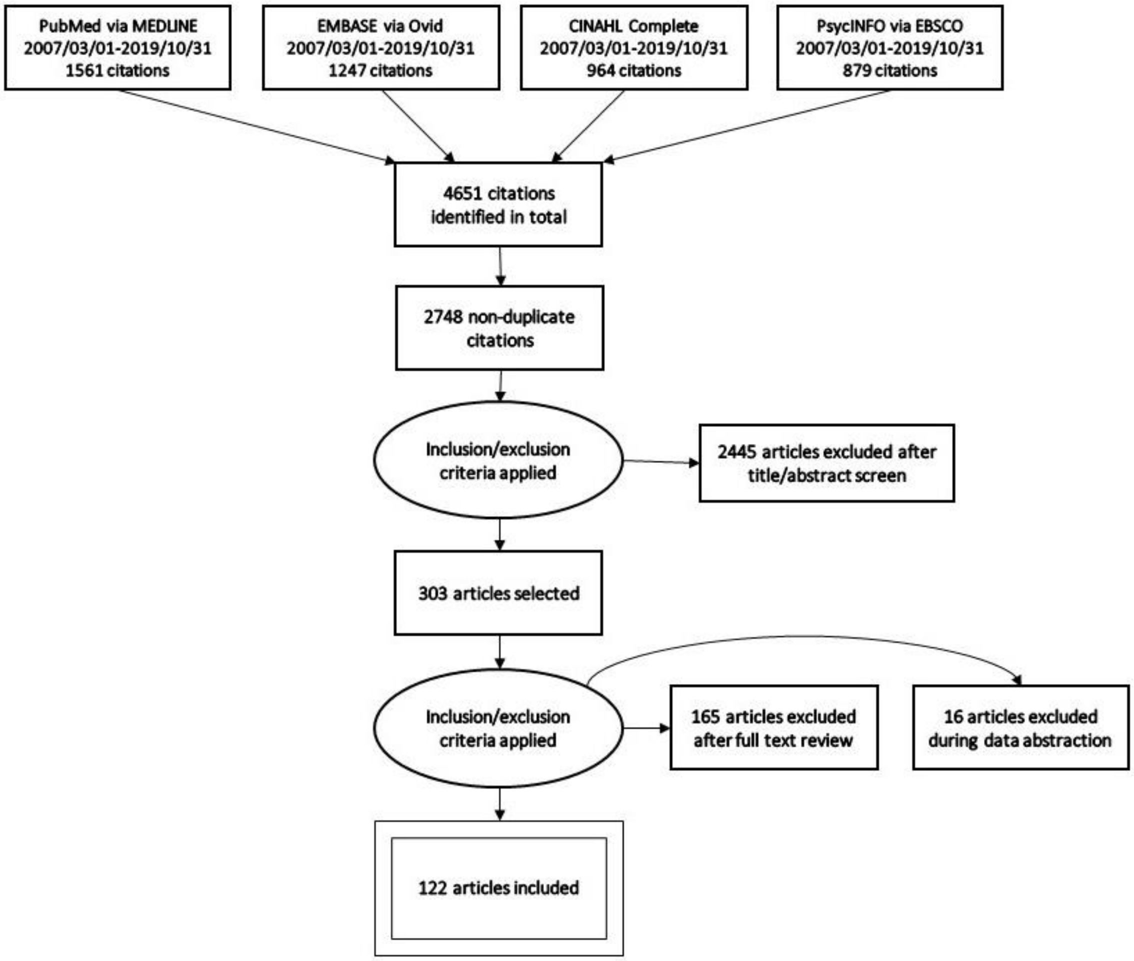
To extract data, the first author (THC) and one of the two co-authors (HKK or HHL) independently extracted findings of carers' support needs from reading the full text articles (Appendix 1). Inductive content analysis was used to synthesise the extracted data (26) and involved three stages: open coding, creating categories, and abstracting. Discussion between the authors (THC, HKK, and HHL) occurred at all stages to achieve consensus on creating categories and abstracting.

Results

Summary of identified articles

The search identified 4651 articles, with 2748 left after removing duplicates. Using eligibility criteria for screening titles and abstracts, 303 articles were selected for full text review. One hundred and twenty-two articles were included for data extraction after full-text review (Figure 2). Full text articles were primarily excluded if they only described the experience of caring. Overall, each of the included articles identified more than one support need and a summary of all articles is provided in Appendix 1.

Figure 2 Flowchart of information through the phases of the scoping review (PRISMA flowchart)



Further, characteristics of the included articles are reported in Table 2. Only studies clearly stating caring for a person with a diagnosis of a dementia disease were included; however the severity of dementia for the person cared for was not reported in most of the studies (n=84). Also, the care setting was not clearly described in 48 of the included articles. Those that were described were home care, institutional care, hospitalisation or a combination (see Table 2).

A great variety of publication types were represented in the included articles, with 90 journal articles, 26 conference abstracts, 5 dissertations and 1 book chapter. Data were mostly collected through interviews (n=61), either individual qualitative interviews or focus groups, or questionnaires (n=35). Other data collection methods were reviews (n=18) and mixed methods (n=8). Methods for interpretation of data varied in the included articles. Approximately half of the articles (n=63) identified the latent content of support needs by interpreting the underlying meaning of data in the study. The other half (n=59) identified the manifest content of support needs based on an evident interpretation and clear alignment of the data with a specific research aim being to describe carers' support needs when caring (see Table 2). Therefore, the results of this scoping review are based on high degrees of interpretation as well as more descriptive presentations of the data.

Table 2 Characteristics of the included articles (n=122)

		Number of articles
Publication type	Article	90
	Conference abstract	26
	Dissertation	5
	Chapter in book	1
Place of origin	Asian countries	10
	Australia	13
	Canada	11
	Scandinavia	9
	South America	1
	Southern Europe	8
	UK	17
	USA	35
	Western Europe	18
Sample	Informal carers	94
	Informal/formal carers	4
	Informal carers/person with dementia	21
	Informal/formal carers/person with dementia	3
Design/data collection method	Interview	61
	Questionnaire	35
	Review	18
	Mixed methods	8
Setting	Home care	45
	Institutional care	7
	Hospitalisation	3
	Home care/institutional care	19
	Unknown	48
Diagnosis of the person cared for	Dementia, unspecified	91
	Alzheimer's	7
	Frontotemporal dementia	8
	Lewy Body dementia	2
	Early onset dementia	7
	Dementia and other diseases	7
Progression of dementia	Early stage	3
	Moderate stage	4
	Advanced stage	13
	Several stages	18
	Unknown	84
Manifest or latent interpretation of support needs	Manifest	59
	Latent	63

Synthesis of knowledge on key concepts of carers' support needs

During the open coding of data, 54 subcategories of carers' support needs were identified. Through an abstraction process, the identified subcategories of support needs were categorised into 12 generic categories and subsequently into four main categories of key concepts. The process revealed that support needs were dependent on the context of origin, some originating from the carers themselves and others from the people with dementia (Figure 3). The different contexts of identified support needs are equally important, but analysis suggests that the full extent of needs arises in the interaction between the context of the carer and the person being cared for. For a complete overview of categorisation of articles into main and generic categories identified in the inductive analysis, see Table 3. The four main categories: 1) Support needs related to the carer as a person, 2) Support needs related to managing being a carer, 3) Support needs related to providing care and 4) Support needs related to knowledge of dementia, will be presented below.

Figure 3 Illustration of the interaction between the four main categories of key concepts of carers' support needs derived from the inductive analysis due to the context of the origin of needs

Table 3. Data extraction matrix of identified carer support needs in the included articles (n=122)

Main category	Generic category	Sub category	Articles	# of articles
1. Support needs related to the carer as a person	Emotional support	1. Social support	(20,35,71,83,86,88,90,91,100,103-108)	15
		2. Need for sharing experiences	(29,30,32-34,44,59,60,82,87,109-112)	15
		3. Mental (health) support	(21,27,28,31,32,39,46-49,55,57,58,66,67,69,76,82,83,88,89,91,100,104,108,113-122)	38
		4. Isolation	(29,41,123)	3
		5. Feelings of loss	(47,52,124)	3
		6. Preparedness for death	(36,43,51,74,121,125-127)	7
		7. Interconnectedness and mutuality	(38-40,54,56,68,70,109,128,129)	10
	Physical health support	8. Health issues	(32,41-43,56,58,108,128)	8
		9. Self-care	(21,28,32,35,39,44,47,55,69,78,102,129-131)	15
		10. Sleep	(69,70,83)	3
	Special considerations	11. Cultural issues	(38,118)	2
		12. Young carers	(29,85,111,118,132)	5
		13. Female and male carers react differently to the carer role	(27,117)	2
		14. Children and spouses react differently to the carer role	(31,38,124)	3
2. Support needs related to managing being a carer	Conflicts	15. Decision-making	(36,38,51,107,121,133,134)	7
		16. Worrying about the future	(32,85,134,135)	4
		17. Problem-solving	(20,45-48,57)	6
		18. Family involvement	(20,35,43,46,52,53,64,113,115,118,126,127,131,136,137)	14
		19. Societal understanding	(49,69,86,107,138)	5
		20. Keeping up appearances	(38,138,139)	3
	Management of carer role	21. Role adjustment	(47,54-56,70,124,128)	7
		22. Appraisal of caring role	(35,110,122,140)	4
		23. Carer self-efficacy	(45,90,100,123,141,142)	6
		24. Management of changed behaviour	(27,31,34,37,38,43,46,58-60,65,77,81,84,110,112,122,127,137,138,143)	21
		25. Some dementia diagnoses are more demanding	(30,36,37,41,50)	5
3. Support needs related to providing care	Legal and financial issues	26. Legal support	(31,44,69,71,80,81,127)	7
		27. Financial issues	(28,44,49,53,61,66,69,71,80,86,118,142,144)	13
		28. Financial support for costs	(35,60,64,69,80-82,119,138)	9

		29. How to navigate the system	(51,60,61)	3
	Professional care	30. Practical care support	(21,64,65,81,86,91,114,116,117,119,126,129,131,144)	14
		31. Respite	(21,41,48,55,60,62,66-68,71,83,90,111,116,122,123,127,129,131)	19
		32. Safety and high-quality care	(38,51,52,62,77,116,123,145)	8
		33. Specific caring tasks (e.g. skin care, nutrition)	(42,55,89,100,112,115,119,139,141,143,146,147)	13
		34. Community care services	(41,46,55,65,67,69,70,82,86,144)	10
		35. Assistive technologies and Information and Communication Technology (ICT) tools	(38,49,59,78,79,103,119,122,145)	9
		36. Flexible services	(55,66,70-73,77,111,148)	9
	Services offered to carers	37. Difficulties asking for help	(63,118,146)	3
		38. How to access help	(28,31,36,43,60-62,71,85,102,105,117,118,127,132,142)	16
		39. Early post diagnostic support	(66,85,140,142)	4
		40. Lack of services to carers	(29,54,148,149)	4
	Specific needs of the person with dementia	41. Person with dementia's unmet needs	(31,67,74,105,109,123,148,150,151)	9
		42. Transportation	(65,77,113,149)	4
		43. Neuropsychiatric symptoms	(21,31,38,44,57,60,62,70,88,114,115,146)	12
	Collaboration with health professionals	44. Involvement in care	(20,34,48,52,66,73,74,76,77,90,91,104,121,137,140,143,152,153)	18
		45. Collaboration with the general practitioner	(117,152)	2
		46. Coordination of professional support	(31,47,73,106,116)	4
4. Support needs related to knowledge of dementia	Knowledge on dementia	47. Information on the disease and understanding of symptoms	(20,21,27,30,33,34,37,41,43-47,49,50,57,58,60,69,70,76,77,81,83,84,86,89-91,99,100,105,106,110,112,127,132,135,138,141,142,144,153)	40
		48. Knowledge of prognosis	(28,31,51,73,77,78,84,85,120)	9
		49. Information and communication technologies to distribute knowledge	(50,59,137,154)	4
		50. Acceptance of diagnosis	(54,124)	2
	Demands on daily life coming from outside the carer themselves	51. Distribution of tasks in daily life	(47)	1
		52. Timing of support	(28,33,47,73,87,99,104,130,150)	9
		53. Work-related issues	(20)	
		54. Carers' needs associated with person with dementia's needs	(47,88-90)	4

Note: The terms Main category, Generic category and Sub category refer to the content analysis, where the content in each category is a result of the process of open coding, creating categories and abstracting.

Main category 1: Support needs related to the carer as a person

In general, the studies identified in the search describe a lack of focus on carers' personal needs regardless of the needs of the person cared for (see Table 3). Carers express a need for emotional support based on their mental, physical or social concerns. Although the need for mental (health) support was prominent, most studies were unclear on the definition of mental support. Two studies described mental support as helping to cope with feelings such as guilt and stigma (27) or to reduce the stress from caregiving (28). Another example of emotional support was the need for sharing experiences with others in the same situation. Carers described feeling neglected by their surroundings and meeting with like-minded people made them feel they were not alone (29-31). The context of sharing experiences could be professionally initiated or coincidental (32-34). Another example is carers describing a social support need from families and friends to take interest in care-giving (20). Feeling that people close by know and understand the situation was seen to be especially helpful. A carer stated: "*I work and have my family to talk to so that's good and (my) family helps me by talking to them and by better understanding my worries. (Interviewee 3)*" (35). Also, carers of a person with early-onset dementia (EOD) expressed additional need for support from their surroundings because holding a full-time job made it difficult for them to manage their caring role satisfactorily (29,36,37).

In relation to social support needs, the analyses identified an emotional support need to preserve carers' feelings of interconnectedness and mutuality with the person with dementia. This was especially the case for spouses (38,39). Carers needed support to maintain continuity in their relationship by enabling the sharing of mutual moments and structuring visits within residential care facilities (40).

Throughout several studies, carers expressed a need for support to address their own physical health, and carers were reluctant to seek assistance (41,42). A carer described the lack of self-care: *''You don't look at yourself anymore . . . that is why it is very important to [take] care of yourself, because there comes a point where you live only for the [person] and then he is no longer here."* (43). Subsequently, carers realised that they had to take care of themselves, but no one had helped them in doing so (44).

Main category 2: Support needs related to managing being a carer

In the included articles, carers described a need for support to manage the carer role (see Table 3). Carers expressed a support need to learn how to solve problems in a constructive manner when conflicts arose in the day-to-day relationship with the person with dementia (45,46). A carer stated: *"Every day brings something new and the things that you think you have figured out . . . aren't what you think they are . . . how do you deal* *with those things?"*(43). Carers experienced a need for support when dealing, for example, with changed behaviour in the person with dementia (47) and needed help developing problem-solving strategies to avoid stressful conflicts with the person with dementia (43,48). Carers of a person with fronto-temporal dementia (FTD) in particular, reported having a need for support to manage behavioural changes (30,49,50).

Another pertinent issue was the need for support to involve family or friends in shared decision-making (20,51). Carers experienced damaged relationships because of disagreements, and in some instances, they needed help from outside to enable family involvement or to mediate conflicting opinions (20,52,53).

Furthermore, carers described a support need to adjust to their new role (47,54,55). Some carers had to learn new household skills and others had to adapt to a relationship that was never going to be the same (54,56). A mediating factor of carers' degree of support needs was if they were able to find positive meaning in taking on the caring role (55) and they received positive feedback from family, professionals or the person cared for (35). A carer said: *"The good thing is that my mum is contented when she has a good day. She is very appreciative of what I do. . . . She can't help me at all. The fact that she's appreciative is great. (Interviewee 13)"* (35).

Several studies described carers having a need for support to learn communication skills or new coping strategies (20,57,58). Carers needed support to communicate with the person with dementia regardless of cognitive decline (20), and carers found both structured training and less structured support groups helpful (47,59).

Main category 3: Support needs related to providing care

In general, carers had a need for support to provide care (see Table 3). Carers needed help to find out how to access services targeted at themselves or the person cared for (60-62). Carers also described having support needs additional to the services provided (31). As an extension of this, carers described a fear to burden other people (63), making their support need for where to seek help even more important.

Receiving professional care (21,64,65) and respite care (66-68) were perceived as vital support needs. Carers asked for respite through access to both day and night care programs to manage the many tasks of caring (69-71). Flexible respite services were especially essential for carers (72,73). A carer stated: *"I would have liked some days at the day care centres to be a little longer because if I, for instance, go out to have lunch with my nieces, they like to eat at 13.30, not at 12. As my husband comes home at half past two, I am in a bit of a hurry, you see (spouse, 11)."* (55). Carers expressed that services were not appropriate to their situation (36), suggesting a need for an individual assessment of support. To enable correct assessment of carers' support needs, the identified studies pointed towards enhancing collaboration with professionals (20,74). Good collaboration is described as frequent communication and outreaching professionals who inform carers of care and treatment plans, which enable carers' involvement in care (21,75-77). One particular identified topic was carers' need for assistive technologies or information and communication technology (ICT) tools to enable easy access to professional or peer support, education and training when providing care (59,78,79).

Furthermore, carers struggled with legal and financial issues and expressed a need for professional support. Some studies described carers' need for legal support regarding completing a will, appointing a power of attorney or drawing up a living will (80,81). Other studies described carers' need for financial support to make financial decisions, secure financial stability or to cover costs of e.g. medication (53,69,82). Worrying over financial issues was described by carers as something taking up a lot of their strength and causing a sense of burden (69,70,83).

Main category 4: Support needs related to knowledge of dementia

Knowledge of dementia was identified as an important area of need for additional support (see Table 3). Carers described a support need as help to understand and learn about dementia throughout the progression of the disease (84,85) and also to explain challenging behaviour (20,86). Some carers found educational courses and communication technologies helpful while others had a need for personally targeted information (43,86,87). Some studies also emphasised that carers' knowledge of support available and timing of support provision were determinative for carers utilising services (60,77,80,87). Unfortunately, carers experienced that support may not be available when needed. A carer stated: *"The community centre has 51 families waiting for services in our area. I feel fortunate for the help I get [30 min/week] when I think about that (CG #28)."* (28).

Lastly, four studies described that carers' support needs seems to be associated with the level of unmet needs of the person with dementia (47,88-90).

Discussion

This scoping review provides an overview of existing knowledge including the characteristics and results of a heterogeneous sample of studies and study designs that describe carers' support needs. Our results show that they emerge from two overall positions: that of the carer and that of the person cared for. The most common support needs identified were carers' need for emotional support and knowledge about dementia. Further, the synthesis of carers' support needs indicated categorisation of support needs into four key concepts: 1) Support needs related to the carer as a person, 2) Support needs related to managing being a carer, 3) Support needs related to providing care, and 4) Support needs related to knowledge about dementia.

Unique to our study was the combining of medical, emotional, physical, social and financial perspectives when mapping carers' extensive support needs across a wide range of carer types, care settings, care trajectories and study designs. Other reviews (21,91) mapping carers' support needs identified many of the same issues, but did not have the same holistic approach. Though the studies included in our review investigate carers' support needs via various approaches, they actually describe many of the same needs. This indicates that a comprehensive and holistic overview of carers' support needs is within reach, because carers express the same needs despite different situations and care trajectories. This is a noteworthy finding considering dementia carers' difficulty in expressing their own needs (9,10). The similarities in support needs are an important finding, because this may serve as groundwork for a conceptual framework to develop needs assessment instruments and supportive interventions (92). In addition, none of the included studies have applied a specific holistic and person-centered approach (14) when describing and interpreting carers' support needs. Existing knowledge relies on one-sided biomedical or psychological professional models to identify carers' support needs. Consequently, there is a remarkable lack of including the carer perspective genuinely when understanding carers' support needs, implying that research exploring carers' support needs is needed in the future using a person-centered approach.

An important step towards developing a conceptual framework of carers' support needs is to have a well-defined understanding of support needs as a construct, because characteristics of support needs in themselves are not observable (92). Using content analysis to synthesise the identified support needs of carers, we proposed four categories of key concepts. In line with findings of previous reviews (21,91), the categories contained support needs regarding knowledge of dementia, professional and social support, and support to maintain self-care. However, unique to our results is the identification of two overall positions of support needs originating from carers themselves and the person cared for (Figure 3). Support needs originating from carers comprise the identity, coping strategies and personal beliefs of the carer, whereas support needs originating from the person with dementia concern necessary actions and considerations when consenting to the requirements of care. Recognising both positions is important, but even more important is recognising their interaction to grasp the full extent of carers' support needs. As an example, the identified key concepts related to the carer as a person contain the need for emotional support. In other studies, emotional support is described as being connected to a feeling of burden (93,94). Our results suggest that carers' need for emotional support is also connected to the carer as a person and how affected the personal relationship is to the person with dementia, and not just to the feeling of burden due to carrying out caring tasks. Using a person-centered approach, the significance of carers' interaction with the person with dementia may be explained by support needs arising in the temporal physical and social context of caring (95). Carers dependent on identity and personal experience continuously have to adjust behaviour accordingly. Evaluating carers' burden on the basis of the physical caring context defined by the need for care of the person with dementia is therefore a simplified way to understand carers' need for emotional support, because social context and the carer as a person are as important as the physical context. Also, the challenge of constantly adjusting to the physical and social context may require a high level of personal motivation to continue caring (96). Focusing on personal motivation for adjusting to context is essential (16), and carers' support needs may actually be more dependent on their own motivation in the caring situation than on the strain of managing actual caring tasks (11,97,98). This new understanding of needs arising in a constant interaction between the carer and the person being cared for may be essential to address individual needs for support.

When using a person-centered approach, the temporal nature of the physical and social context imply that needs change over time (95). Carers, due to context, may have all of their needs met, but over time, new needs may arise due to the progression of dementia and high demands on carers' own perseverance and motivation. Analysis of the included studies identified that carers do not know who to contact when needs emerge and how to 'navigate the system' (43,60,61). This indicates a need for regularly adjusted and timely support, which may be difficult to comply with, because carers may only realise their needs in retrospect (99). One solution could be systematic and regular assessment of carers' support needs (100,101). At present, no psychometrically robust instrument to assess carers' support needs exists, and future research should focus on the development and validation of such a tool (12,91,100).

Strength and limitations

The main strength of this review is its inclusivity of studies. It integrates different data collection strategies to embrace a comprehensive understanding of carers' support needs. A quality assessment of the included studies has not been conducted, which may reduce the quality and credibility of our conclusions. However, using a scoping review method does not include quality assessment (17), which therefore includes knowledge outside the traditional academic publishing channels, which supports the broad scope of our study.

A limitation of the search strategy is the inclusion of studies that only reflect carers' needs when living in a culture comparable to the health and social care context of high-income countries. Consequently, the results of our study do not offer insight into carers' support needs when living in low-income countries. It is also possible that value-based support needs related to cultural minorities living in high-income countries have been overlooked (102).

Finally, the time limit of the search poses a risk of missing relevant information because articles published before January 2007 were excluded. However, including more than just primary articles in our review most likely ensured that earlier important knowledge was included.

Conclusion

The results of this scoping review provide a broad and promising framework comprising four key concepts of carers' support needs related to: 1) The carer as a person, 2) Managing being a carer, 3) Providing care, and 4) Knowledge of dementia. Understanding carers' support needs with a person-centered approach is important when developing and planning interventions to support carers who care for a person with dementia. Especially combining the large body of knowledge of carers' support needs makes way for a new understanding of support needs dependent on context and interaction between the carer and the person with dementia, which may be essential when assessing carers' current and individual support needs in the future.

Ethics approval

No approval was needed.

Declaration of Conflicting Interest

No conflict of interest to declare.

Acknowledgements and Funding

The Health Sciences Research Centre at UCL University College Denmark; The Danish Alzheimer Association; and The Association of Danish Physiotherapists supported this work.

References

(1) World Health Organization. Global action plan on the public health response to dementia 2017–2025. 2017.

(2) Farina N, Page TE, Daley S, Brown A, Bowling A, Basset T, et al. Factors associated with the quality of life of family carers of people with dementia: A systematic review. Alzheimers Dement 2017 May;13(5):572-581.

(3) Michalowsky B, Flessa S, Eichler T, Hertel J, Dreier A, Zwingmann I, et al. Healthcare utilization and costs in primary care patients with dementia: baseline results of the DelpHi-trial. The European Journal of Health Economics 2018 Jan;19(1):87-102.

(4) Prince M, Bryce R, Albanese E, Wimo A, Ribeiro W, Ferri CP. The global prevalence of dementia: a systematic review and metaanalysis. Alzheimer's & Dementia 2013;9(1):63-75. e2.

(5) Prince M, Guerchet MM, Ali GC, Wu Y, Prina M. World Alzheimer Report 2015 - The Global Impact of Dementia: An analysis of prevalence, incidence, cost and trends. : Alzheimer's Disease International; 2015.

(6) Schulz R, Sherwood PR. Physical and mental health effects of family caregiving. Am J Nurs 2008 Sep;108(9 Suppl):23-27.

(7) Greenwood N, Mezey G, Smith R. Social exclusion in adult informal carers: A systematic narrative review of the experiences of informal carers of people with dementia and mental illness. Maturitas 2018 Jun;112:39-45.

(8) Chiao CY, Wu HS, Hsiao CY. Caregiver burden for informal caregivers of patients with dementia: A systematic review. Int Nurs Rev 2015 Sep;62(3):340-350.

(9) Boots LM, Wolfs CA, Verhey FR, Kempen GI, de Vugt ME. Qualitative study on needs and wishes of early-stage dementia caregivers: the paradox between needing and accepting help. Int Psychogeriatr 2015 Jun;27(6):927-936.

(10) Stirling C, Andrews S, Croft T, Vickers J, Turner P, Robinson A. Measuring dementia carers' unmet need for services-an exploratory mixed method study. BMC Health Serv Res 2010 May 13;10:122-(1-10).

(11) Maslow AH. A theory of human motivation. Psychological Review 1943;50(4):370-396.

(12) Mansfield E, Boyes AW, Bryant J, Sanson-Fisher R. Quantifying the unmet needs of caregivers of people with dementia: a critical review of the quality of measures. Int J Geriatr Psychiatry 2017 Mar;32(3):274-287.

(13) Dickinson C, Dow J, Gibson G, Hayes L, Robalino S, Robinson L. Psychosocial intervention for carers of people with dementia: What components are most effective and when? A systematic review of systematic reviews. Int Psychogeriatr 2017 Jan;29(1):31-31-43.

(14) Terkelsen AS, Petersen JV, Kristensen HK. Mapping empirical experiences of Tom Kitwood's framework of person-centred care for persons with dementia in institutional settings. A scoping review. Scand J Caring Sci 2019 May 20;[Epub ahead of print].

(15) Barbosa A, Lord K, Blighe A, Mountain G. Dementia Care Mapping in long-term care settings: a systematic review of the evidence. Int Psychogeriatr 2017 Oct;29(10):1609-1609-1618.

(16) Sharma T, Bamford M, Dodman D. Person-centred care: an overview of reviews. Contemp Nurse 2015 Oct-Dec;51(2-3):107-120.

(17) Levac D, Colquhoun H, O'Brien KK. Scoping studies: advancing the methodology. Implement Sci 2010 Sep 20;5:69.

(18) Waligora KJ, Bahouth MN, Han HR. The Self-Care Needs and Behaviors of Dementia Informal Caregivers: A Systematic Review. Gerontologist 2018 Jun 21.

(19) Nunnemann S, Kurz A, Leucht S, Diehl-Schmid J. Caregivers of patients with frontotemporal lobar degeneration: a review of burden, problems, needs, and interventions. Int Psychogeriatr 2012 Sep;24(9):1368-1386.

(20) Afram B, Verbeek H, Bleijlevens MH, Hamers JP. Needs of informal caregivers during transition from home towards institutional care in dementia: a systematic review of qualitative studies. Int Psychogeriatr 2015 Jun;27(6):891-902.

(21) McCabe M, You E, Tatangelo G. Hearing Their Voice: A Systematic Review of Dementia Family Caregivers' Needs. Gerontologist 2016 Oct;56(5):e70-88.

(22) Paré G, Trudel M, Jaana M, Kitsiou S. Synthesizing information systems knowledge: A typology of literature reviews. Information & Management 2015;52(2):183-199.

(23) Alzheimer Europe. Paris Declaration - 2006. 2015; Available at: https://www.alzheimer-europe.org/Policy/Paris-Declaration-2006. Accessed 03/31, 2020.

(24) Centers for Disease Control and Prevention, Alzheimer's Association. The Healthy Brain Initiative: a national public health road map to maintaining cognitive health. Chicago, IL: Alzheimer's Association 2007.

(25) Graneheim UH, Lindgren BM, Lundman B. Methodological challenges in qualitative content analysis: A discussion paper. Nurse Educ Today 2017 Sep;56:29-34.

(26) Elo S, Kyngas H. The qualitative content analysis process. J Adv Nurs 2008 Apr;62(1):107-115.

(27) Chan WC, Ng C, Mok C, Wong F, Pang SL, Chiu H. Lived experience of caregivers of persons with dementia in Hong Kong: a qualitative study. East Asian Arch Psychiatry 2010 12;20(4):163-168.

(28) Ducharme F, Kergoat M, Coulombe R, Lévesque L, Antoine P, Pasquier F. Unmet support needs of early-onset dementia family caregivers: a mixed-design study. BMC Nurs 2014 12/15;13(1):1-20.

(29) Barca M, Engedal K, Haugen P, Johannessen A, Thorsen K. Experiences of adult children of younger persons with dementia: A qualitative study. Int Psychogeriatr Conference: 16th International Congress of the International Psychogeriatric Association Seoul South Korea 2013 October;25(SUPPL. 1):S29-S30.

(30) Austrom M, Morhardt D. Frontotemporal dementia caregiver support groups: Benefits and challenges. Am J Neurodegenerative Dis 2014;3:371.

(31) Peeters JM, Van Beek APA, Meerveld JHC, Spreeuwenberg PMM, Francke AL. Informal caregivers of persons with dementia, their use of and needs for specific professional support: a survey of the National Dementia Programme. BMC Nurs 2010 01;9:9p-9p.

(32) Hennings J, Froggatt K, Payne S. Spouse's experiences and needs as supporters of people with dementia at the end of life in nursing homes in the united kingdom: An in-depth longitudinal pilot study. Palliative Med 2012;26(4):515.

(33) Killen A, Flynn D, De Brún A, O'Brien N, O'Brien J, Thomas AJ, et al. Support and information needs following a diagnosis of dementia with Lewy bodies. Int Psychogeriatr 2016 03;28(3):495-501.

(34) In Het VJ, Verkaik R, van Meijel B, Werkman W, Hertogh C, Francke A. Online focus groups to explore family caregivers' self-management of challenging behavior in their relatives with dementia. Int Psychogeriatr 2015;27:S54.

(35) McCann TV, Bamberg J, McCann F. Family carers' experience of caring for an older parent with severe and persistent mental illness. Int J Ment Health Nurs 2015 06;24(3):203-212.

(36) Millenaar JK, Bakker C, Koopmans RT, Verhey FR, Kurz A, de Vugt ME. The care needs and experiences with the use of services of people with young-onset dementia and their caregivers: a systematic review. Int J Geriatr Psychiatry 2016 Dec;31(12):1261-1276.

(37) Ducharme F, Lachance L, Kergoat MJ, Coulombe R, Antoine P, Pasquier F. A Comparative Descriptive Study of Characteristics of Early- and Late-Onset Dementia Family Caregivers. Am J Alzheimers Dis Other Demen 2016 Feb;31(1):48-56.

(38) Cox C. Factors Associated with the Health and Well-being of Dementia Caregivers. Curr Transl Geriatr Gerontol Rep 2013;2(1):31-36.

(39) Hemingway D, MacCourt P, Pierce J, Strudsholm T. Together but apart: Caring for a spouse with dementia resident in a care facility. Dementia (London) 2016 Jul;15(4):872-890.

(40) Førsund LH, Kiik R, Skovdahl K, Ytrehus S. Constructing togetherness throughout the phases of dementia: a qualitative study exploring how spouses maintain relationships with partners with dementia who live in institutional care. J Clin Nurs 2016 10;25(19):3010-3025.

(41) Cramer B, Nunnemann S, Kurz A, Leucht S, Diehl-Schmid J. Caregivers of patients with frontotemporal lobar degeneration: A review on burden, problems, needs and interventions. Dementia and Geriatric Cognitive Disorders Conference: 8th International Conference on Frontotemporal Dementias Manchester United Kingdom Conference Publication 2012 September 2012;34(Suppl. 1):115-116.

(42) DePalma JA. Update on evidence: Family caregivers in the home. Home Health Care Manag Pract 2007 04;19(3):206-208.

(43) Samia LW, Hepburn K, Nichols L. "Flying by the seat of our pants": what dementia family caregivers want in an advanced caregiver training program. Res Nurs Health 2012 Dec;35(6):598-609.

(44) Murphy K, Casey D, Cooney A, D'Eath M. Switching on the light: Carers' perceptions of what they need to know when caring for a relative with dementia. Alzheimer's Dementia 2014;10:P614-P615.

(45) Clesse A, Missotten P, Guillaume B, Adam S. Counseling program for caregivers of people with Alzheimer's disease: A case study. Int Psychogeriatr 2015;27:S113.

(46) Titzel MR. Moderating resources in the stress and coping process of Alzheimer's family caregivers. Gannon University: ProQuest Information & Learning; 2014.

(47) Wesson V, Chiu M, Feldman R, Nelles LJ, Sadavoy J. Dementia and caregiving. In: Chiu H, Shulman K, editors. Mental health and illness of the elderly. New York, NY: Springer Science + Business Media; 2017. p. 515-547.

(48) Boltz M, Chippendale T, Resnick B, Galvin JE. Anxiety in family caregivers of hospitalized persons with dementia: contributing factors and responses. Alzheimer Dis Assoc Disord 2015 Jul-Sep;29(3):236-241.

(49) Diehl-Schmid J, Cramer B. Problems, burden and needs of 90 German caregivers of patients with frontotemporal lobar degeneration. Dementia Geriatr Cogn Disord 2012;34:266-267.

(50) Chow TW, Pio FJ, Rockwood K. An international needs assessment of caregivers for frontotemporal dementia. Can J Neurol Sci 2011 Sep;38(5):753-757.

(51) Lord K, Livingston G, Robertson S, Cooper C. How people with dementia and their families decide about moving to a care home and support their needs: development of a decision aid, a qualitative study. BMC Geriatr 2016 Mar 21;16:68-016-0242-1.

(52) Billings J. The end-of-life family meeting in intensive care part I: Indications, outcomes, and family needs. J Palliative Med 2011;14(9):1042-1050.

(53) Sherman CW, Bauer JW. Financial conflicts facing late-life remarried Alzheimer's disease caregivers. Fam Relat 2008 10;57(4):492-503.

(54) Furlong KE, Wuest J. Self-care behaviors of spouses caring for significant others with Alzheimer's disease: the emergence of self-care worthiness as a salient condition. Qual Health Res 2008 Dec;18(12):1662-1672.

(55) Tretteteig S, Vatne S, Rokstad AM. The influence of day care centres designed for people with dementia on family caregivers - a qualitative study. BMC Geriatr 2017 Jan 5;17(1):5-016-0403-2.

(56) Wadham O, Simpson J, Rust J, Murray C. Couples' shared experiences of dementia: a meta-synthesis of the impact upon relationships and couplehood. Aging Ment Health 2016 05;20(5):463-473.

(57) Rosa E, Lussignoli G, Chito E, Kuffenschin G, Lamanna L, Di Cesare S, et al. Needs of caregivers' patients with dementia. Alzheimer's Dementia 2009;5(4):232.

(58) Steiner V, Pierce LL, Salvador D. Information Needs of Family Caregivers of People With Dementia. Rehabil Nurs 2016 May-Jun;41(3):162-169.

(59) McKechnie V, Barker C, Stott J. The effectiveness of an Internet support forum for carers of people with dementia: a pre-post cohort study. J Med Internet Res 2014 Feb 28;16(2):e68.

(60) Chandler BR. Ethnocultural variation in need for support among adult children caregivers. State University of New York at Stony Brook: ProQuest Information & Learning; 2010.

(61) Warrick N, Peckham A, Watkins J, Padjen M, Williams AP. Caring for caregivers of high-needs older persons. Healthc Q 2014;17(3):24-29.

(62) Robinson A, Lea E, Hemmings L, Vosper G, McCann D, Weeding F, et al. Seeking respite: issues around the use of day respite care for the carers of people with dementia. Ageing Soc 2012 02;32(2):196-218.

(63) Dam A, Boots L, De Vugt M, van Boxtel M, Verhey F. Development of an online social support intervention for people with dementia and their caregivers. Int Psychogeriatr 2015;27:S160-S161.

(64) Griffiths J, Bunrayong W. Problems and needs in helping older people with dementia with daily activities: Perspectives of Thai caregivers. Br J Occup Ther 2016 02;79(2):78-84.

(65) Huang HL, Shyu YI, Chen MC, Huang CC, Kuo HC, Chen ST, et al. Family caregivers' role implementation at different stages of dementia. Clin Interv Aging 2015 Jan 5;10:135-146.

(66) Evers C. Carer support and empowerment. Psychiatry (GBR) 2008;7(2):80-83.

(67) Freyne A, Dolan M, Cooney C. Carer-rated needs assessment of a cohort of people with dementia. Irish Journal of Psychological Medicine 2010;27(2):72-76.

(68) Lenihan E, Gowran R. The meaning of caring for a person with dementia: An occupational justice perspective. Ir J Med Sci 2013;182:S293.

(69) Anand P. Exploring the needs of middle-income family caregivers of persons with dementia: A descriptive study. Loma Linda University: ProQuest Information & Learning; 2016.

(70) Meyer J, Mc Cullough J, Berggren I. A phenomenological study of living with a partner affected with dementia. Br J Community Nurs 2016 Jan;21(1):24-30.

(71) MacLeod A, Tatangelo G, McCabe M, You E. There isn't an easy way of finding the help that's available. Barriers and facilitators of service use among dementia family caregivers: A qualitative study. Int Psychogeriatr 2017;29(5):765-776.

(72) Cations M, Withall A, White F, Trollor J, Loy C, Brodaty H, et al. Whyaren't people with young onset dementia and their carers using formal services? Alzheimer's Dementia 2016;12(7):P281.

(73) Gridley K, Brooks J, Glendinning C. Good practice in social care: the views of people with severe and complex needs and those who support them. Health Soc Care Community 2014 Nov;22(6):588-597.

(74) Muders P, Zahrt-Omar CA, Bussmann S, Haberstroh J, Weber M. Support for families of patients dying with dementia: a qualitative analysis of bereaved family members' experiences and suggestions. Palliat Support Care 2015 Jun;13(3):435-442.

(75) Jennings L, Wenger N, Tan Z, Evertson L, Serrano K., Reuben D. Dementia care comanagement improves one-year patient and caregiver health outcomes. Alzheimer's Dementia 2015;11(7):P720-P721.

(76) Moyle W, Bramble M, Bauer M, Smyth W, Beattie E. 'They rush you and push you too much ... and you can't really get any good response off them': A qualitative examination of family involvement in care of people with dementia in acute care. Australas J Ageing 2016 Jun;35(2):E30-4.

(77) de Jong JD, Boersma F. Dutch psychogeriatric day-care centers: a qualitative study of the needs and wishes of carers. Int Psychogeriatr 2009 Apr;21(2):268-277.

(78) Pagán-Ortiz ME, Cortés DE, Rudloff N, Weitzman P, Levkoff S. Use of an Online Community to Provide Support to Caregivers of People With Dementia. J Gerontol Soc Work 2014 Aug;57(6):694-709.

(79) Nunez-Naveira L, Alonso-Bua B, de Labra C, Gregersen R, Maibom K, Mojs E, et al. UnderstAID, an ICT Platform to Help Informal Caregivers of People with Dementia: A Pilot Randomized Controlled Study. Biomed Res Int 2016;2016:5726465.

(80) Shrestha S, Judge KS, Wilson NL, Moye JA, Snow AL, Kunik ME. Utilization of legal and financial services of partners in dementia care study. Am J Alzheimers Dis Other Demen 2011 Mar;26(2):115-120.

(81) Dimakopoulou E, Sakka P, Efthymiou A, Karpathiou N, Karydaki M. Evaluating the Needs of Dementia Patients' Caregivers in Greece: A Questionnaire Survey. Int J Caring Sci 2015 May;8(2):274-280.

(82) Vaingankar JA, Subramaniam M, Picco L, Eng GK, Shafie S, Sambasivam R, et al. Perceived unmet needs of informal caregivers of people with dementia in Singapore. Int Psychogeriatr 2013 Oct;25(10):1605-1619.

(83) Lee J, Nguyen H, Rousseau J, Gibbs L, Sorkin D, Zaragoza M, et al. The perceived experiences and unmet needs of Asian American dementia family caregivers. Annual Scientific Meeting of the American Geriatrics Society, AGS 2018. United States. Conference Abstract 2018;66(Supplement 2):S224.

(84) Seike A, Sumigaki C, Takeda A, Endo H, Sakurai T, Toba K. Developing an interdisciplinary program of educational support for early-stage dementia patients and their family members: an investigation based on learning needs and attitude changes. Geriatr Gerontol Int 2014 Apr;14 Suppl 2:28-34.

(85) Green T, Smith E, Hogan D, Pearson D, Roach P. Early-onset dementia: Needs of patients and carers in the early diagnostic stage. Alzheimer's Dementia 2012;8(4):P382.

(86) Diehl-Schmid J, Schmidt EM, Nunnemann S, Riedl L, Kurz A, Forstl H, et al. Caregiver burden and needs in frontotemporal dementia. J Geriatr Psychiatry Neurol 2013 Dec;26(4):221-229.

(87) Werner NE, Stanislawski B, Marx KA, Watkins DC, Kobayashi M, Kales H, et al. Getting what they need when they need it. Identifying barriers to information needs of family caregivers to manage dementia-related behavioral symptoms. Appl Clin Inform 2017 Feb 22;8(1):191-205.

(88) Borson S, Scanlan JM, Sadak T, Lessig M, Vitaliano P. Dementia Services Mini-Screen: a simple method to identify patients and caregivers in need of enhanced dementia care services. Am J Geriatr Psychiatry 2014 Aug;22(8):746-755.

(89) Rosa E, Lussignoli G, Sabbatini F, Chiappa A, Di Cesare S, Lamanna L, et al. Needs of caregivers of the patients with dementia. Arch Gerontol Geriatr 2010 Jul-Aug;51(1):54-58.

(90) Rayment G, Swainston K, Wilson G. Using photo-elicitation to explore the lived experience of informal caregivers of individuals living with dementia. Br J Health Psychol 2019 Feb;24(1):102-122.

(91) Queluz FN, Kervin E, Wozney L, Fancey P, McGrath PJ, Keefe J. Understanding the needs of caregivers of persons with dementia: a scoping review. Int Psychogeriatr 2019 Apr 10:1-18.

(92) de Vet HC, Terwee CB, Mokkink LB, Knol DL. Measurement in Medicine : A Practical Guide. Cambridge: Cambridge University Press; 2011.

(93) Brodaty H, Donkin M. Family caregivers of people with dementia. Dialogues Clin Neurosci 2009;11(2):217-228.

(94) Cheng ST. Dementia Caregiver Burden: a Research Update and Critical Analysis. Curr Psychiatry Rep 2017 Aug 10;19(9):64-017-0818-2.

(95) Wade DT, Halligan PW. The biopsychosocial model of illness: a model whose time has come. Clin Rehabil 2017 Aug;31(8):995-1004.

(96) Quinn C, Clare L, Woods RT. The impact of motivations and meanings on the wellbeing of caregivers of people with dementia: a systematic review. Int Psychogeriatr 2010 Feb;22(1):43-55.

(97) Quinn C, Nelis SM, Martyr A, Victor C, Morris RG, Clare L, et al. Influence of Positive and Negative Dimensions of Dementia Caregiving on Caregiver Well-Being and Satisfaction With Life: Findings From the IDEAL Study. Am J Geriatr Psychiatry 2019;27(8):838-848.

(98) Yu DSF, Cheng ST, Wang J. Unravelling positive aspects of caregiving in dementia: An integrative review of research literature. Int J Nurs Stud 2018 Mar;79:1-26.

(99) Millenaar JK, van Vliet D, Bakker C, Vernooij-Dassen M, Koopmans RT, Verhey FR, et al. The experiences and needs of children living with a parent with young onset dementia: results from the NeedYD study. Int Psychogeriatr 2014 12;26(12):2001-2010.

(100) Novais T, Dauphinot V, Krolak-Salmon P, Mouchoux C. How to explore the needs of informal caregivers of individuals with cognitive impairment in Alzheimer's disease or related diseases? A systematic review of quantitative and qualitative studies. BMC Geriatr 2017 Apr 17;17(1):86-(1-18).

(101) Dean SG, Siegert RJ, Taylor WJ. Interprofessional rehabilitation : a person-centred approach. Chichester, West Sussex, U.K.: Wiley-Blackwell; 2012.

(102) Lawrence V, Murray J, Samsi K, Banerjee S. Attitudes and support needs of Black Caribbean, south Asian and White British carers of people with dementia in the UK. Br J Psychiatry 2008 Sep;193(3):240-246.

(103) Bauer M, Fetherstonhaugh D, Blackberry I, Farmer J, Wilding C. Identifying support needs to improve rural dementia services for people with dementia and their carers: A consultation study in Victoria, Australia. Aust J Rural Health 2019 Feb;27(1):22-27.

(104) Burgstaller M, Mayer H, Schiess C, Saxer S. Experiences and needs of relatives of people with dementia in acute hospitals-A meta-synthesis of qualitative studies. J Clin Nurs 2018 Feb;27(3-4):502-515.

(105) Gibson A, Holmes SD, Fields NL, Richardson VE. Providing Care for Persons with Dementia in Rural Communities: Informal Caregivers' Perceptions of Supports and Services. J Gerontol Soc Work 2019 Aug;62(6):630-648.

(106) Lee K, Puga F, Pickering CEZ, Masoud SS, White CL. Transitioning into the caregiver role following a diagnosis of Alzheimer's disease or related dementia: A scoping review. Int J Nurs Stud 2019 08;96:119-131.

(107) Shanley C, Fetherstonhaugh D, McAuliffe L, Bauer M, Beattie E. Providing support to surrogate decision-makers for people living with dementia: Healthcare professional, organisational and community responsibilities. Health Soc Care Community 2017 Sep;25(5):1563-1570.

(108) Tatangelo G, McCabe M, Macleod A, You E. "I just don't focus on my needs." The unmet health needs of partner and offspring caregivers of people with dementia: A qualitative study. Int J Nurs Stud 2018 Jan;77:8-14.

(109) DiLauro M, Pereira A, Carr J, Chiu M, Wesson V. Spousal caregivers and persons with dementia: Increasing participation in shared leisure activities among hospital-based dementia support program participants. Dementia 2017 01;16(1):9-28.

(110) In Het Veld JG, Verkaik R, van Meijel B, Verkade PJ, Werkman W, Hertogh CMPM, et al. Self-Management Support and eHealth When Managing Changes in Behavior and Mood of a Relative With Dementia: An Asynchronous Online Focus Group Study of Family Caregivers' Needs. Res Gerontol Nurs 2018 May 1;11(3):151-159.

(111) Johannessen A, Helvik A-, Engedal K, Thorsen K. Experiences and needs of spouses of persons with young-onset frontotemporal lobe dementia during the progression of the disease. Scand J Caring Sci 2017;31(4):779-788.

(112) Slaboda J, Fail R, Bowman B, Wade A, Morgan L, Norman G. Focus group findings: Needs of family caregivers of dementia patients. Center to Advance Palliative Care National Seminar Practical Tools for Making Change, CAPC 2017. United States. Conference Abstract 2018;21(5):A47.

(113) Ryan KA, Coulas T, Talton K, Ramirez G, Weber M, Persad C, et al. Specific support services needed by caregivers of patients with mild cognitive impairment. Alzheimer's Dementia 2009;5(4):230.

(114) Ryan KA, Weldon A, Huby NM, Persad C, Bhaumik AK, Heidebrink JL, et al. Caregiver support service needs for patients with mild cognitive impairment and Alzheimer disease. Alzheimer Dis Assoc Disord 2010 Apr;24(2):171-176.

(115) Nichols LO, Martindale-Adams J, Greene WA, Burns R, Graney MJ, Lummus A. Dementia caregivers' most pressing concerns. Clin Gerontol 2009 01;32(1):1-14.

(116) Low LF, White F, Jeon YH, Gresham M, Brodaty H. Desired characteristics and outcomes of community care services for persons with dementia: what is important according to clients, service providers and policy? Australas J Ageing 2013 Jun;32(2):91-96.

(117) Jennings LA, Reuben DB, Evertson LC, Serrano KS, Ercoli L, Grill J, et al. Unmet Needs of Caregivers of Individuals Referred to a Dementia Care Program. J Am Geriatr Soc 2015 02;63(2):282-289.

(118) Vaingankar J, Subramaniam M, Picco L, Phua A, Goi K, Shafie S, et al. Needs of informal caregivers of people with dementia: A triangulation approach. Annals of the Academy of Medicine Singapore Conference: 3rd Singapore Health and Biomedical Congress, SHBC 2012 Singapore Singapore Conference Publication 2012 September 2012;41(9 Suppl. 1):S43.

(119) Gove D, Scerri A, Georges J, van Houten P, Huige N, Hayder-Beichel D, et al. Continence care for people with dementia living at home in Europe: a review of literature with a focus on problems and challenges. J Clin Nurs 2017 Feb;26(3-4):356-365.

(120) De Cola MC, Lo Buono V, Mento A, Foti M, Marino S, Bramanti P, et al. Unmet Needs for Family Caregivers of Elderly People With Dementia Living in Italy: What Do We Know So Far and What Should We Do Next? Inquiry 2017 Jan 1;54:46958017713708.

(121) Barker S, Lynch M, Hopkinson J. Decision making for people living with dementia by their carers at the end of life: a rapid scoping review. Int J Palliat Nurs 2017;23(9):446-456.

(122) Moreno-Camara S, Palomino-Moral PA, Moral-Fernandez L, Frias-Osuna A, Parra-Anguita L, Del-Pino-Casado R. Perceived Needs of The Family Caregivers of People with Dementia in a Mediterranean Setting: A Qualitative Study. Int J Environ Res Public Health 2019 Mar 19;16(6):10.3390/ijerph16060993.

(123) Wawrziczny E, Pasquier F, Ducharme F, Kergoat MJ, Antoine P. Do spouse caregivers of young and older persons with dementia have different needs? A comparative study. Psychogeriatrics 2017 Sep;17(5):282-291.

(124) Oyebode J, LaFontaine J, Larkin M. Family experiences of living with behavioural variant Frontotemporal Dementia (bvFTD): Implications of a qualitative longitudinal research study for coping and interventions. J Neurochem 2016;138:259.

(125) Hovland-Scafe C. Preparedness for death: The experience of family caregivers of elders with dementia. The University of Wisconsin-Madison: ProQuest Information & Learning; 2014.

(126) Ebert P. Sons providing care at end-of-life: Common threads and nuances. Portland State University: ProQuest Information & Learning; 2008.

(127) Unmet Needs of Dementia Caregivers at Home. Alzheimer's and Dementia. Conference: Alzheimer's Association International Conference 2018. United States. 14 (7 Supplement) (pp P1630); Elsevier Inc.; 2018.

(128) Shyu YL, Yang C, Huang C, Kuo H, Chen S, Hsu W. Influences of mutuality, preparedness, and balance on caregivers of patients with dementia. J Nurs Res (Lippincott Williams & Wilkins) 2010 09;18(3):155-163.

(129) Pini S, Ingleson E, Megson M, Clare L, Wright P, Oyebode JR. A Needs-led Framework for Understanding the Impact of Caring for a Family Member With Dementia. Gerontologist 2018 Mar 19;58(2):e68-e77.

(130) Carduff E, Jarvis A, Highet G, Finucane A, Kendall M, Harrison N, et al. Piloting a new approach in primary care to identify, assess and support carers of people with terminal illnesses: a feasibility study. BMC Fam Pract 2016 Feb 11;17:18-016-0414-2.

(131) Wang XR, Liu SX, Robinson KM, Shawler C, Zhou L. The impact of dementia caregiving on self-care management of caregivers and facilitators: a qualitative study. Psychogeriatrics 2019 Jan;19(1):23-31.

(132) Cations M, Withall A, Horsfall R, Denham N, White F, Trollor J, et al. Why aren't people with young onset dementia and their supporters using formal services? Results from the INSPIRED study. PLoS One 2017 Jul 19;12(7):e0180935.

(133) Webb R, Harrison Dening K. In whose best interests? A case study of a family affected by dementia. Br J Community Nurs 2016 Jun;21(6):300-304.

(134) Hoffman A, Bateman D, Bartels S, Blandin K, Santulli R, Lee H, et al. Patient and caregiver needs and preferences for decision support interventions in alzheimer's disease. Am J Geriatr Psychiatry 2013;21(3):S98-S99.

(135) Nilsson E, Olaison A. What is yet to come? Couples living with dementia orienting themselves towards an uncertain future. QUAL SOC WORK 2019 05;18(3):475-492.

(136) Liddle J, Tan A, Liang P, Bennett S, Allen S, Lie DC, et al. "The biggest problem we've ever had to face": how families manage driving cessation with people with dementia. Int Psychogeriatr 2016 Jan;28(1):109-122.

(137) Iribarren S, Stonbraker S, Suero-Tejeda N, Granja M, Luchsinger JA, Mittelman M, et al. Information, communication, and online tool needs of Hispanic family caregivers of individuals with Alzheimer's disease and related dementias. Inform Health Soc Care 2019;44(2):115-134.

(138) Porock D, Bakk L, Sullivan SS, Love K, Pinkowitz J, Barsness S. National Priorities for Dementia Care: Perspectives of Individuals Living with Dementia and Their Care Partners. J Gerontol Nurs 2015 Aug;41(8):9-16.

(139) Bliss D, Rolnick C, Jackson J, Arntson C, Mullins J, Hepburn K. Health Literacy Needs Related to Incontinence and Skin Damage Among Family and Friend Caregivers of Individuals With Dementia. J Wocn 2013 Sep;40(5):515-523.

(140) Crowther JL, Lloyd-Williams M. Dementia: What care do patients and carers need in the last year of life and time surrounding death? Palliative Med 2012;26(4):442.

(141) Silva P, Kergoat MJ, Shatenstein B. Challenges in managing the diet of older adults with early-stage Alzheimer dementia: a caregiver perspective. J Nutr Health Aging 2013 Feb;17(2):142-147.

(142) O'Brien C, NiChorcorain A, Buckley C. An evaluation of met and unmet needs, carer burden andbarriers to accessing services amongstfamily carers of people with dementia: A qualitative study. Ir J Med Sci 2013;182:S295.

(143) De Bellis A, Bradley SL. Antipsychotic use for behaviours by persons with dementia in residential aged care: the relatives' perspectives. Aust J Adv Nurs 2017 Sep;35(1):23-32.

(144) Vaingankar J, Subramaniam M, Picco L, Abdin E, Chua B, Chong S. Informal caregivers' unmet needs for dementia care resources and services. Annals of the Academy of Medicine Singapore.Conference: Singapore Health and Biomedical Congress, SHBC 2013.Singapore.Conference Publication 2013 September 2013;42(9 Suppl. 1):S249.

(145) Olsson A, Engström M, Skovdahl K, Lampic C. My, your and our needs for safety and security: relatives' reflections on using information and communication technology in dementia care. Scand J Caring Sci 2012 03;26(1):104-112.

(146) Hirakawa Y, Kuzuya M, Enoki H, Uemura K. Information needs and sources of family caregivers of home elderly patients. Arch Gerontol Geriatr 2011 Mar-Apr;52(2):202-205.

(147) Papachristou I, Hickey G, Iliffe S. Dementia informal caregiver obtaining and engaging in food-related information and support services. Dementia 2017 01;16(1):108-118.

(148) Tyrrell M, Hilleras P, Skovdahl K, Fossum B, Religa D. Voices of Spouses Living with Partners with Neuropsychiatric Symptoms Related to Dementia. Dementia (London) 2019 Apr;18(3):903-919.

(149) Fowler C, Kim MT. Home visits by care providers - Influences on health outcomes for caregivers of homebound older adults with dementia. Geriatr Nurs 2015 Jan;36(1):25-29.

(150) Raivio M, Eloniemi-Sulkava U, Laakkonen M, Saarenheimo M, Pietilä M, Tilvis R, et al. How do officially organized services meet the needs of elderly caregivers and their spouses with Alzheimer's disease? Am J Alzheimers Dis Other Dementias 2007 Oct;22(5):360-368.

(151) Shivakumar P, Loganathan S, Philip M, Varghese M. Carer's needs assessment in dementia: Indian perspective. Alzheimer's and Dementia.Conference: Alzheimer's Association International Conference 2015.Washington, DC United States.Conference Publication 2015 July 2015;11(7 Suppl. 1):P720.

(152) Dawson R, Maruna J, Snyder P. Strategies to assist care partners become effective members of their DLB (dementia with lewy bodies) spouse's health care team. Am J Neurodegenerative Dis 2015;4:162.

(153) Bramble M, Moyle W, McAllister M. Seeking connection: family care experiences following long-term dementia care placement. J Clin Nurs 2009 11/15;18(22):3118-3125.

(154) Werner N, Gilmore-Bykovskyi A, Zenker R, Pardell C, Kind A. Enhancing teamwork across informal Alzheimer's disease care giving networks through novel health information technologies: A human factors engineering approach. Alzheimer's Dementia 2017;13(7):P504.

(155) Borson S, Scanlan J, DeMers S, Lessig M, Vitaliano P. Service needs through the eyes of dementia caregivers. Am J Geriatr Psychiatry 2009;17:A85.

(156) Lee M, Ryoo JH, Campbell C, Hollen PJ, Williams IC. Exploring the challenges of medical/nursing tasks in home care experienced by caregivers of older adults with dementia: An integrative review. J Clin Nurs 2019;28(23-24):4177-4189.

(157) Sarabia-Cobo CM, Perez V, de Lorena P, Nunez MJ, Dominguez E. Decisions at the end of life made by relatives of institutionalized patients with dementia. Appl Nurs Res 2016 Aug;31:e6-e10.

Appendix 1 Matrix with description of included articles (n=122)

Author, first	Title	Publication type	Year	Place of origin	Sample/ carer type	# of participants	Design/ data collection method	Setting	Diagnosis of the person cared for	Progression of dementia	Manifest/ latent interpretation of content	Summary of extracted data on carers' support needs
Afram, B. et al. (20)	Needs of informal caregivers during transition from home towards institutional care in dementia: a systematic review of qualitative studies	Article	2015	Netherlands	Informal carers	13 articles	Review	Institutional care	Dementia	Unknown	Manifest	Need for information and social support. Need to be involved in care. Need for family involvement. Need to develop communicational skills.
Anand, P. (69)	Exploring the needs of middle-income family caregivers of persons with dementia: A descriptive study	Dissertation	2016	USA	Informal carers/ professionals	37	Focus group and interview	Home care/institution	Dementia	Unknown	Manifest	Need to take care of own health, get sleep and emotional support. Need for information. Need to manage behavioural changes and to manage financial and legal issues. Need for information in society and access to community care services.
Austrom, M. et al. (30)	Frontotemporal dementia caregiver support groups: Benefits and challenges.	Conference abstract	2014	USA	Informal carers	Unknown	Cross-sectional study with questionnaire	Home care	FTD	Unknown	Manifest	FTD carers have a need for group support because of unique challenges due to marked changes in reasoning, judgment, and personal and emotional conduct in the person with dementia. Need for education.
Barca, M. et al. (29)	Experiences of adult children of younger persons with dementia: A qualitative study.	Conference abstract	2013	Norway	Informal carers (adult children)	14	Interview	Unknown	EOD	Unknown	Manifest	Need to be seen as an individual and need for group support.
Barker, S. et al. (121)	Decision making for people living with dementia by their carers at the end of life: a rapid scoping review	Article	2017	UK	Informal carers	40 articles	Review	Nursing home/hospital	Dementia	End of life	Latent	Need for emotional support and access to information about end of life care. Need for support to make decisions by communicating with professionals and being involved in care decisions
Bauer, M. et al. (103)	Identifying support needs to improve rural dementia services for people with dementia and their carers: A consultation study in Victoria, Australia	Article	2019	Australia	Informal carers	13	Focus group	Home care	Dementia	Unknown	Manifest	Need for social support groups. Need for support using telemedicine in rural areas.
Billings, J. A. (52)	The end-of-life family meeting in intensive care part I: Indications, outcomes, and family needs.	Article	2011	USA	Informal carers	12 articles	Review	Intensive care unit	Terminal illness (including dementia)	End of life	Manifest	Need to know the person with dementia is receiving high-quality care. Need for the family to be involved and informed in care to make decisions. Need to talk about death.
Bliss, D. et al. (139)	Health literacy needs related to incontinence and skin damage among family and friend caregivers of individuals with dementia	Article	2013	USA	Informal carers	48	Mixed methods study with focus group, interview and questionnaire	Home care	Dementia	Unknown	Manifest	Need for knowledge on incontinence and skin care.
Boltz, M. et al. (48)	Anxiety in family caregivers of hospitalized persons with dementia: contributing factors and responses	Article	2015	USA	Informal carers / person with dementia	100	Mixed methods study with interview and questionnaire	Home care	Dementia	Unknown	Latent	Need to be involved in care. Need for education and to learn problem-focused coping. Need for respite and emotional support.

Borson, S. et al. (155)	Service needs through the eyes of dementia caregivers.	Conference abstract	2009	USA	Informal carers	239	Questionnaire	Community care	Dementia	Unknown	Manifest	Caregivers' perception of needs was closely linked to their understanding of patients' needs. High stress is associated with high needs.
Borson, S. et al. (88)	Dementia Services Mini-Screen: a simple method to identify patients and caregivers in need of enhanced dementia care services	Article	2014	USA	Informal carers	215	Questionnaire	Home care	Dementia	Unknown	Latent	Changed behaviour of the person with dementia is an indicator of high needs. Need for psychosocial support.
Bramble, M. et al. (153)	Seeking connection: family care experiences following long-term dementia care placement	Article	2009	Australia	Informal carers	10	Interview	Nursing home	Dementia	Unknown	Latent	Need for information on dementia. Need to be involved in care.
Burgstaller, M. et al. (104)	Experiences and needs of relatives of people with dementia in acute hospitals-A meta-synthesis of qualitative studies	Article	2018	Switzerland	Informal carers	12 articles	Review	Hospital	Dementia	Unknown	Latent	Need for psychosocial support. Need for regular and proactive support from professionals. Need to be involved in care.
Carduff, E. et al. (130)	Piloting a new approach in primary care to identify, assess and support carers of people with terminal illnesses: a feasibility study	Article	2016	UK	Informal carers	83	Feasibility study with questionnaire and interview	Unknown	Dementia	Unknown	Latent	Need for timely information. Need for support to maintain self-care.
Cations, M. et al. (72)	Why aren't people with young onset dementia and their carers using formal services?	Conference abstract	2016	Australia	Informal carers/person with dementia	93	Questionnaire	Home care	EOD	Unknown	Latent	Need for flexible tailored services.
Cations, M. et al. (132)	Why aren't people with young onset dementia and their supporters using formal services? Results from the INSPIRED study	Article	2017	Australia	Informal carers/person with dementia	85	Questionnaire and focus group	Home care/nursing home	EOD	Unknown	Manifest	Need for group support to be appropriate to their age. Need for support to access services. Need for timely information
Chan, W. C. et al. (27)	Lived experience of caregivers of persons with dementia in Hong Kong: a qualitative study	Article	2010	Hong Kong	Informal carers	27	Focus group	Unknown	Dementia	Unknown	Latent	Need for information on dementia. Need for support to cope with changed behaviour. Need for emotional support. Female carers experience more stress than male carers.
Chandler, B. R. (60)	Ethnocultural variation in need for support among adult children caregivers	Dissertation	2010	USA	Informal carers (adult children)	35	Focus group	Home care	Dementia	Unknown	Manifest	Need for emotional support and support groups to share feelings and avoid isolation. Need for information about the disease and how to manage behavioural changes. Need for easy access to information of services available. Timing of the service provided is important.
Chow, T. W. et al. (50)	An international needs assessment of caregivers for frontotemporal dementia	Article	2011	Canada	Informal carers	79	Questionnaire	Unknown	FTD	Unknown	Manifest	Special needs for education about FTD with awareness of neuropsychiatric disturbances. Need for additional information via the Internet.
Clesse, A. et al. (45)	Counseling program for caregivers of people with Alzheimer's disease: A case study.	Conference abstract	2015	Belgium	Informal carers	1	Case study	Unknown	Dementia	Unknown	Latent	Need for information and to learn coping strategies focused on problem solving.

Cox, C. (38)	Factors Associated with the Health and Well-being of Dementia Caregivers.	Article	2013	USA	Informal carers	Unknown	Review	All	Dementia	Unknown	Latent	Need for social support and to learn coping strategies. Decision aid in relation to institutionalisation. Need for assistive technology regarding safety. Differences in carers' needs: spouses need help to preserve marital relationship, and ethnic groups may be more reluctant in seeking help.
Cramer, B. et al. (41)	Caregivers of patients with frontotemporal lobar degeneration: A review on burden, problems, needs and interventions.	Conference abstract	2012	Germany	Informal carers	19 articles	Review	Unknown	FTD	Unknown	Latent	Need for information and suitable care facilities. Carers experience social isolation and neglect personal needs.
Crowther, J. L. et al. (140)	Dementia: What care do patients and carers need in the last year of life and time surrounding death?	Conference abstract	2012	UK	Informal carers	40	Interview	All	Dementia	The last year	Latent	Informal carers wish to collaborate and to be included in all aspects of end of life care.
Dam, A. et al. (63)	Development of an online social support intervention for people with dementia and their caregivers.	Conference abstract	2015	Netherlands	Informal carers	27	Interview	Home care	Dementia	Unknown	Latent	Partners experience high threshold to ask for support, even though people in the social environment are willing to offer assistance.
Dawson, R. Et al. (152)	Strategies to assist care partners become effective members of their DLB (dementia with lewy bodies) spouse's health care team.	Conference abstract	2015	USA	Informal carers (spouses)	Unknown	Review	Unknown	LBD	All stages	Latent	Need to know how to communicate effectively with doctors before, during, and after their spouse's visits. Need to be prepared for emergency room visits and hospitalisations.
De Bellis, A. et al. (143)	Antipsychotic use for behaviours by persons with dementia in residential aged care: the relatives' perspectives	Article	2017	Australia	Informal carers	6	Interview	Home care/nursing home	Dementia	Unknown	Manifest	Need for information on medication and behavioural change. Need to be involved in care decisions
De Cola, M. C. et al. (120)	Unmet Needs for Family Caregivers of Elderly People With Dementia Living in Italy: What Do We Know So Far and What Should We Do Next?	Article	2017	Italy	Informal carers	59	Questionnaire	Unknown	Dementia	Unknown	Manifest	Need for information on disease management. Need for support to cope with stress of caring.
De Jong, J. D. et al. (77)	Dutch psychogeriatric day-care centers: a qualitative study of the needs and wishes of carers	Article	2009	Netherlands	Informal carers	9	Focus group	Home care/nursing home	Dementia	Unknown	Manifest	Need for information about dementia, the prognosis and care facilities available. Need to manage changed behaviour and to maintain safety. Need for transportation and flexible services. Need to be involved in care.
DePalma, J. A. (42)	Update on evidence: Family caregivers in the home	Article	2007	USA	Informal carers	7 articles	Review	Home care	General illness (including dementia)	Unknown	Latent	Need for professional care after hospitalisation. Need to take care of own health issues.
DiLauro, M. et al. (109)	Spousal caregivers and persons with dementia: Increasing participation in shared leisure activities among hospital-based dementia support program participants	Article	2017	Canada	Informal carers (spouses)	9	Interview	Home care	Dementia	Unknown	Latent	Need for activities together with the PWD. Need for support groups. Need for activities for the PWD. Need to share experiences.

Diehl-Schmid, J. et al. (49)	Problems, burden and needs of 90 German caregivers of patients with frontotemporal lobar degeneration.	Conference abstract	2012	Germany	Informal carers	90	Structured interview with questionnaire	Unknown	FTD	Unknown	Manifest	Need for information, psychosocial and financial support. Need for help with patients' care and FTLD awareness campaigns.
Diehl-Schmid, J. et al. (86)	Caregiver burden and needs in frontotemporal dementia	Article	2013	Germany	Informal carers	94	Cross-sectional study with questionnaire	Home care/nursing home	FTD	Unknown	Manifest	Need for information, psychosocial support through trained personnel, and financial support. Need for community care and practical care. Need to raise public awareness.
Dimakopoulou, E. et al. (81)	Evaluating the Needs of Dementia Patients' Caregivers in Greece: A Questionnaire Survey	Article	2015	Greece	Informal carers	248	Cross-sectional study with questionnaire	Home care	Dementia	Unknown	Manifest	Need for financial support, legal assistance and practical support. Need for psycho-education and how to manage changed behaviour.
Ducharme, F. et al. (28)	Unmet support needs of early-onset dementia family caregivers: a mixed-design study	Article	2014	Canada	Informal carers	32	Questionnaire	Unknown	EOD	Unknown	Manifest	Need for information on disease, offered services, treatment and financial assistance. Need for timely support. Need for help to reduce stress.
Ducharme, F. et al. (37)	A Comparative Descriptive Study of Characteristics of Early- and Late-Onset Dementia Family Caregivers	Article	2016	Canada	Informal carers	96	Structured interview with questionnaire	Home care/nursing home	Dementia and EOD	Moderate-severe	Latent	Different resources among carers of EOD and LOD. Need for psychoeducation. EOD carers need help to develop coping strategies.
Ebert, P. (126)	Sons providing care at end-of-life: Common threads and nuances	Dissertation	2008	USA	Informal carers (sons)	30	Interview	Unknown	Terminal illness (including dementia)	End of life	Latent	Need for professional care. Need to be prepared for death. Need to involve family.
Evers, C. (66)	Carer support and empowerment.	Article	2008	UK	Informal carers/ person with dementia	Unknown	Review	All	Dementia	All stages	Manifest	A structural change to the health and social care system is necessary to support carers' needs. Need for practical support and flexible respite services. Need for psychoeducation and support groups. Need to be involved in decisions about services.
Freyne, A. et al. (67)	Carer-rated needs assessment of a cohort of people with dementia	Article	2010	Ireland	Informal carers	40	Questionnaire	Homecare/ hospital	Dementia	Unknown	Manifest	Need for information and mental support. Existing services are not appropriate. Need for day care services.
Førsund, L. H. et al. (40)	Constructing togetherness throughout the phases of dementia: a qualitative study exploring how spouses maintain relationships with partners with dementia who live in institutional care	Article	2016	Norway	Informal carers (spouses)	15	Interview	Institutional care	Dementia	Moderate-severe	Latent	Need to feel togetherness.
Fowler, C. et al. (149)	Home visits by care providers -- Influences on health outcomes for caregivers of homebound older adults with dementia	Article	2015	USA	Informal carers	55	Questionnaire	Home care	Dementia	Unknown	Latent	Need for help in transportation. Need for help to maintain self-care.
Furlong, K. E. et al. (54)	Self-care behaviors of spouses caring for significant others with Alzheimer's disease: the emergence of self-care worthiness as a salient condition	Article	2008	Canada	Informal carers (spouses)	9	Interview	Home care	Dementia	Mild-moderate-severe	Manifest	Need for support to self-care. Need to accept the disease and to adjust to the new roles. Need to cope with the loss of mutuality in their marriage.

Gibson, A. et al. (105)	Providing Care for Persons with Dementia in Rural Communities: Informal Caregivers' Perceptions of Supports and Services	Article	2019	USA	Informal carers	11	Interview	Home care	Dementia	Unknown	Manifest	Need for accessible services and information especially living in rural areas. Need support to enable activities for the person with dementia and a network for themselves.
Gove, D. et al. (119)	Continence care for people with dementia living at home in Europe: a review of literature with a focus on problems and challenges	Article	2017	Luxembourg	Informal carers/ person with dementia	6 articles	Review	Home care	Dementia	Unknown	Latent	Need for help to manage continence issues. Need for helping aids to manage practical issues in daily life. Need financial support. Need for emotional support.
Green, T. et al. (85)	Early-onset dementia: Needs of patients and carers in the early diagnostic stage.	Conference abstract	2012	Canada	Informal carers/ person with dementia	7	Interview	Home care	EOD	Mild	Latent	Need for early guidance following the diagnosis. Need for knowledge of community services and dementia progression.
Gridley, K. et al. (73)	Good practice in social care: the views of people with severe and complex needs and those who support them	Article	2014	UK	Informal carers/ person with dementia	67	Interview	Unknown	Dementia, stroke and other people with complex needs	Unknown	Manifest	Need for continuity in support. Need for timely and flexible supportive services. Need to be involved in care. Need for information of disease.
Griffiths, J. et al. (64)	Problems and needs in helping older people with dementia with daily activities: Perspectives of Thai caregivers	Article	2016	Thailand	Informal carers/ professionals	30	Interview	Home care	Dementia	Unknown	Manifest	Need for practical support to care. Need for support from family. Need for financial support.
Hemingway, D. et al. (39)	Together but apart: Caring for a spouse with dementia resident in a care facility.	Article	2016	Canada	Informal carers (spouses)	28	Interview	Nursing home	Dementia	Advanced	Latent	Need for support to maintain own health and well-being.
Hennings, J. et al. (32)	Spouse's experiences and needs as supporters of people with dementia at the end of life in nursing homes in the united kingdom: An in-depth longitudinal pilot study.	Conference abstract	2012	UK	Informal carers (spouses)	10	Interview	Nursing home	Dementia	Advanced	Latent	Need to support own health. In need of help to deal with feelings of guilt. Need for support groups. Need to deal with uncertainty.
Hirakawa, Y. et al. (146)	Information needs and sources of family caregivers of home elderly patients	Article	2011	Japan	Informal carers	475	Questionnaire	Home care	Dementia versus no dementia	Mild-moderate-severe	Manifest	Need for information on: first aid, how to access services, specific knowledge on nutrition and cognitive changes due to the illness.
Hoffman, A. et al. (134)	Patient and caregiver needs and preferences for decision support interventions in Alzheimer's disease.	Conference abstract	2013	USA	Informal carers/ person with dementia /professionals	146	Questionnaire	Unknown	Alzheimer’s	Mild-moderate-severe	Latent	Need for help when making decisions about the future e.g. "when/whether to move your loved one into residential care".
Hovland-Scafe, C. (125)	Preparedness for death: The experience of family caregivers of elders with dementia	Dissertation	2014	USA	Informal carers	30	Interview	Unknown	Dementia	End of life	Latent	Need to feel prepared for the death of the person with dementia..

Huang, H. L. et al. (65)	Family caregivers' role implementation at different stages of dementia	Article	2015	Taiwan	Informal carers / person with dementia	176	Cross-sectional study with questionnaire	Home care	Dementia	All stages	Latent	Need for help to manage changed behaviour. Need for community services and help with transportation and practical care.
In Het Veld, J. H. et al. (34)	Online focus groups to explore family caregivers' self-management of challenging behavior in their relatives with dementia.	Conference abstract	2015	Netherlands	Informal carers	36	Focus group	Unknown	Dementia	Unknown	Manifest	Need to be heard. Need to share experiences. Need for information and learning skills.
In Het Veld, J. H. et al. (110)	Self-Management Support and eHealth When Managing Changes in Behavior and Mood of a Relative With Dementia: An Asynchronous Online Focus Group Study of Family Caregivers' Needs	Article	2018	Netherlands	Informal carers	36	Online focus group	Home care	Dementia	Unknown	Manifest	Need for information on dementia and how to manage behavioural changes. Need to feel appreciated. Need for contact with others in the same situation.
Iribarren, S. et al. (137)	Information, communication, and online tool needs of Hispanic family caregivers of individuals with Alzheimer's disease and related dementias	Article	2019	USA	Informal carers	24	Participatory design/interview	Unknown	Alzheimer’s	Unknown	Latent	Need for support to communicate with professionals, the person with dementia and other relatives. Need for online tools to access information quickly. Need for support to manage changed behaviour.
Jennings, L. A. et al. (75)	Unmet needs of caregivers of individuals referred to a dementia care program	Article	2015	USA	Informal carers	307	Cross-sectional	Unknown	Dementia	Unknown	Latent	Need to know where to access practical and emotional support. Need for GPs to offer support.
Johannessen, A. et al. (111)	Experiences and needs of spouses of persons with young-onset frontotemporal lobe dementia during the progression of the disease	Article	2017	Norway	Informal carers (spouses)	16	Interview	Home care/nursing home	Young FTD	All stages	Latent	Need for flexible respite. Need for age-appropriate support groups.
Killen, A. et al. (33)	Support and information needs following a diagnosis of dementia with Lewy bodies	Article	2016	UK	Informal carers/ person with dementia	107	Questionnaire	Unknown	LBD	Unknown	Manifest	Need for information and emotional support. Timing of support is important.
Lawrence, V. et al (102)	Attitudes and support needs of Black Caribbean, south Asian and White British carers of people with dementia in the UK	Article	2008	UK	Informal carers	32	Interview	Unknown	Dementia	Unknown	Latent	Need to know how to get help. Need for help to take care of own health.
Lee, J. et al. (83)	The perceived experiences and unmet needs of Asian American dementia family caregivers	Conference abstract	2018	USA	Informal carers	35	Interview	Home care	Dementia	Unknown	Manifest	Need for respite in the home. Need for dementia care education programs that included caregiving skills, social and emotional support, including support groups, and stress management.
Lee, K. et al. (106)	Transitioning into the caregiver role following a diagnosis of Alzheimer's disease or related dementia: A scoping review	Article	2019	USA	Informal carers	29 articles	Review	Unknown	Dementia	Early stage	Latent	Need for emotional support and peer support. Need for information on dementia. Need for support to plan care.

Lee, M. et al. (156)	Exploring the challenges of medical/nursing tasks in home care experienced by caregivers of older adults with dementia: An integrative review.	Article	2019	USA	Informal carers	13 articles	Review	Home care	Dementia	Unknown	Latent	Need for information and skills-training in medical tasks.
Lenihan, E. et al. (68)	The meaning of caring for a person with dementia: An occupational justice perspective.	Conference abstract	2013	Ireland	Informal carers	Unknown	Interview	Unknown	FTD	Unknown	Manifest	Need for help to sustain interconnectedness between carer and care recipient. Need for respite in their home.
Liddle, J. et al. (136)	The biggest problem we've ever had to face: How families manage driving cessation with people with dementia.	Article	2016	Australia	Informal carers/ person with dementia/ professionals	32	Interview	Unknown	Dementia	Unknown	Latent	Need to take into consideration unique family dynamics and support to manage different levels of conflicts.
Lord, K. et al. (51)	How people with dementia and their families decide about moving to a care home and support their needs: development of a decision aid, a qualitative study	Article	2016	UK	Informal carers/ person with dementia	20	Interview	Home care/residential care	Dementia	Unknown	Manifest	Need to secure the safety of the person with dementia. Need for family support to make decisions. Need for knowledge on progression of the disease. Need for help to navigate the system. Need to prepare for the future.
Low, L. et al. (116)	Desired characteristics and outcomes of community care services for persons with dementia: what is important according to clients, service providers and policy?	Article	2013	UK	Informal carers/ person with dementia/ professionals	64	Interview	Home care	Dementia	Unknown	Latent	Need for respite and personal care of the person with dementia. Need for high-quality care. Need for emotional support.
Macleod, A. et al. (71)	There isn't an easy way of finding the help that's available. Barriers and facilitators of service use among dementia family caregivers: a qualitative study	Article	2017	Australia	Informal carers	24	Interview	Home care	Dementia	Mild- severe	Latent	Need for information on how to access services. Need for financial and legal guidance. Need for flexible respite care. Need for a supportive network.
McCabe, M. et al. (21)	Hearing Their Voice: A Systematic Review of Dementia Family Caregivers' Needs	Article	2016	Australia	Informal carers	12 articles	Review	Unknown	Dementia	Unknown	Manifest	Need for information and knowledge. Need for support in managing care recipients' activities of daily living and changed behaviour. Need for formal care support. Need to address physical and psychological health and to manage own life. Need for respite.
McCann, T. V. et al. (35)	Family carers' experience of caring for an older parent with severe and persistent mental illness	Article	2015	Australia	Informal carers	30	Interview	Home care	Dementia and organic, functional, psychiatric disorders	Unknown	Latent	Need to cope with disagreement in family. Need to feel appreciated. Need for social support. Need to maintain own well-being. Financial support need.

McKechnie, V. et al. (59)	The effectiveness of an Internet support forum for carers of people with dementia: a pre-post cohort study	Article	2014	UK	Informal carers	61	Mixed methods study with questionnaire and telephone interview	Unknown	Dementia	Unknown	Latent	Need to share experiences with others in the same situation. Need for online forums to get support and information. Need to cope with changed behaviour and to learn problem-solving.
Meyer, J. et al. (70)	A phenomenological study of living with a partner affected with dementia	Article	2016	Sweden	Informal carers (spouses)	7	Interview	Home care/residential care	Dementia	Unknown	Latent	Need for knowledge on dementia. Need for help to adapt to the new roles and relation. Need to manage changed behaviour. Need to adjust to loss of togetherness. Need of community support. Need for flexibility in services offered.
Millenaar, J. K. et al. (99)	The experiences and needs of children living with a parent with young onset dementia: results from the NeedYD study	Article	2014	Netherlands	Informal carers (children)	14	Interview	Unknown	EOD	Unknown	Latent	Need for support at their own pace. Need for information of diagnosis.
Millenaar, J. K. et al. (36)	The care needs and experiences with the use of services of people with young-onset dementia and their caregivers: a systematic review	Article	2016	Netherlands	Informal carers/ person with dementia	27 articles	Review	Unknown	EOD	Unknown	Latent	Need for information of available services. Specific need for practical information to deal with their parent with EOD. Need for help to make decisions and to prepare for the future.
Moreno-Camara, S. et al. (122)	Perceived Needs of The Family Caregivers of People with Dementia in a Mediterranean Setting: A Qualitative Study	Article	2019	Spain	Informal carers	82	Focus group	Home care	Dementia	Mild to severe	Manifest	Need for support to manage instrumental care and to manage behavioural changes in person with dementia. Need for time for themselves. Need for emotional support and to feel appreciated and to maintain own health
Moyle, W. et al. (76)	'They rush you and push you too much ... and you can't really get any good response off them': A qualitative examination of family involvement in care of people with dementia in acute care	Article	2016	Australia	Informal carers	30	Interview	Hospital care	Dementia	Unknown	Manifest	Need for information and to be involved in professional care. Need for emotional support.
Murphy, K. et al. (44)	Switching on the light: Carers' perceptions of what they need to know when caring for a relative with dementia.	Conference abstract	2014	Ireland	Informal carers/ professionals	43	Interview	Home care	Dementia	Unknown	Manifest	Need for carers to stay well. Need for help with legal and financial issues. Need for knowledge on dementia and how to manage challenging behaviour. Need for support to learn from others in the same situation.
Muders, P. et al. (74)	Support for families of patients dying with dementia: a qualitative analysis of bereaved family members' experiences and suggestions	Article	2015	Germany	Informal carers	310	Cross-sectional study with questionnaire containing open-ended questions	Unknown	Dementia	End-of-life	Manifest	Need for information and communication with professionals. Need for more care for the person with dementia. Need to be prepared for death.
Nichols, L. O. et al. (115)	Dementia caregivers' most pressing concerns	Article	2009	USA	Informal carers/ person with dementia	330	RCT	Unknown	Dementia	Mild-moderate-severe	Manifest	Need to manage incontinence and diet of person with dementia. Need to cope with behavioural changes. Need for emotional support. Need to manage family issues.

Nilsson, E. et al. (135)	What is yet to come? Couples living with dementia orienting themselves towards an uncertain future	Article	2019	Sweden	Informal carers (spouses)	15	Interview (dyade)	Home care	Dementia	Mild-moderate	Latent	Need for information on dementia and what to expect.
Novais, T. et al. (100)	How to explore the needs of informal caregivers of individuals with cognitive impairment in Alzheimer's disease or related diseases? A systematic review of quantitative and qualitative studies	Article	2017	France	Informal carers	70 articles	Review	Unknown	Dementia	Unknown	Latent	Need for information on dementia and knowledge about medication. Need for emotional support and coping skills training.
O'Brien, C. et al. (142)	An evaluation of met and unmet needs, carer burden and barriers to accessing services amongst family carers of people with dementia: A qualitative study.	Conference abstract	2013	Ireland	Informal carers	Unknown	Interview	Unknown	Dementia	Moderate-advanced	Manifest	Need for information and more service availability. Need for financial support and for transportation. Feelings of isolation and uncertainty about what is available to support them.
Olsson, A. et al. (145)	My, your and our needs for safety and security: relatives' reflections on using information and communication technology in dementia care	Article	2012	Sweden	Informal carers (spouses)	14	Interview	Home care/nursing home	Dementia	Unknown	Latent	Need for information technology to keep the person with dementia safe.
Oyebode, J. et al. (124)	Family experiences of living with behavioural variant Frontotemporal Dementia (bvFTD): Implications of a qualitative longitudinal research study for coping and interventions.	Conference abstract	2016	UK	Informal carers/ person with dementia	19	Interview	Unknown	FTD	Multiple times in the progression	Latent	Need to develop strategies for managing the impact on the relationship. Partners in particular experience grief and loss of the past relationship.
Pagán-Ortiz, M. E. et al. (78)	Use of an Online Community to Provide Support to Caregivers of People With Dementia	Article	2014	USA	Informal carers	95	Mixed methods study with interview and quasiexperimental two group design	Unknown	Dementia	Unknown	Latent	Need for information about the disease and how to maintain self-care.
Papachristou, I. et al. (147)	Dementia informal caregiver obtaining and engaging in food-related information and support services.	Article	2017	UK	Informal carers	20	Interview	Home care	Dementia	Mild-severe	Manifest	Need for information on food services.
Peeters, J. M. et al. (31)	Informal caregivers of persons with dementia, their use of and needs for specific professional support: a survey of the National Dementia Programme	Article	2010	Netherlands	Informal carers	984	Questionnaire	Home care/nursing home	Dementia	Unknown	Manifest	Need for additional professional support and legal advice. Need to cope with changed behaviour. Need for information on services available. Different needs of children and spouses: Children need more support to cope with behaviour and information about progression of the disease and coordination of professional support. Spouses need emotional support and support from family.

Pini, S. et al. (129)	A Needs-led Framework for Understanding the Impact of Caring for a Family Member With Dementia	Article	2018	UK	Informal carers	42	Interview	Home care	Dementia	Unknown	Latent	Need to preserve the relationship with the person with dementia. Need to share feelings and to take care of self. Need for practical support and time for themselves.
Porock, D. et al. (138)	National Priorities for Dementia Care: Perspectives of Individuals Living with Dementia and Their Care Partners	Article	2015	USA	Informal carers/ person with dementia	388	Questionnaire	Unknown	Dementia	Unknown	Latent	Need for financial support and education. Need to increase public awareness.
Queluz, F.N. et al. (91)	Understanding the needs of caregivers of persons with dementia: A scoping review.	Article	2019	Brazil	Informal carers	31 articles	Review	Unknown	Dementia	Unknown	Latent	Need for emotional support. Need for formal or informal help. Need for information about dementia and dementia care.
Raivio, M. et al. (150)	How do officially organized services meet the needs of elderly caregivers and their spouses with Alzheimer's disease?	Article	2007	Finland	Informal carers (spouses)	1214	Questionnaire	Home care	Alzheimer's	Unknown	Manifest	Need for timely offered services. Lack of offered services to person with dementia.
Rayment, G. et al. (90)	Using photo-elicitation to explore the lived experience of informal caregivers of individuals living with dementia	Article	2019	UK	Informal carers	6	Photo and interview	Home care/nursing home	Dementia	All stages	Latent	Need for information on dementia and care. Need for support groups. Need for time on their own and support to take care of self. Carers needs dependent on person with dementia.
Robinson, A. et al. (62)	Seeking respite: issues around the use of day respite care for the carers of people with dementia	Article	2012	Australia	Informal carers	27	Interview	Home care	Dementia	Unknown	Latent	Need of easy access to information of services available. Need to know the person with dementia is safe. Need to manage refusal from that. Need for respite.
Rosa, E. et al. (57)	Needs of caregivers' patients with dementia.	Conference abstract	2009	Italy	Informal carers	112	Questionnaire	Unknown	Dementia	Moderate-severe	Manifest	Need to learn communication skills and how to manage cognitive and behavioural disorders. Need for emotional stress management. Need for better knowledge of the disease and the exact diagnosis.
Rosa, E. et al. (89)	Needs of caregivers of the patients with dementia	Article	2010	Italy	Informal carers	112	Questionnaire	Home care/nursing home	Dementia	Moderate-severe	Manifest	Need for additional information about the illness and suitable pharmacological approaches. Carers experiencing high burden have more emotional needs.
Ryan, K. A. et al. (113)	Specific support services needed by caregivers of patients with mild cognitive impairment.	Conference abstract	2009	USA	Informal carers/ person with de-mentia/ matched healthy persons	160	Questionnaire	Unknown	Alzheimer's /Mild cognitive impairment	Unknown	Manifest	Need for transportation and financial counseling. Need for mental health support and help from family or support groups.
Ryan, K. A. et al. (114)	Caregiver support service needs for patients with mild cognitive impairment and Alzheimer disease	Article	2010	USA	Informal carers	124	Questionnaire	Unknown	Alzheimer's /Mild cognitive impairment	Unknown	Manifest	Need for mental support and formal care. Increased need for support when the person with dementia has high functional impairment.

Samia, L. W. et al. (43)	'Flying by the seat of our pants': What dementia family caregivers want in an advanced caregiver training program	Article	2012	USA	Informal carers	168 (of which 26 participated in focus group)	Mixed methods study with questionnaire and focus group	Unknown	Dementia	Unknown	Manifest	Need to feel prepared for the future and death of the person with dementia. Need to manage changed behaviour. Need for support from family. Need for information on how to access services. Need to take care of oneself.
Samus, Q. M. et al. (127)	Unmet Needs of Dementia Caregivers at Home	Conference abstract	2018	USA	Informal carers	647	Cross sectional	Home care	Dementia	Unknown	Manifest	Need for knowledge on dementia and skills training. Need for legal support and how to access services. Need for respite and support from other relatives and to take care of own mental health.
Sarabia-Cobo, C. et al. (157)	Decisions at the end of life made by relatives of institutionalized patients with dementia	Article	2016	Spain	Informal carers	84	Focus group	Nursing home	Dementia	Moderate-severe	Latent	Need to be prepared for death.
Seike, A. et al. (84)	Developing an interdisciplinary program of educational support for early-stage dementia patients and their family members: an investigation based on learning needs and attitude changes	Article	2014	Japan	Informal carers/ person with dementia	170	Questionnaire	Unknown	Dementia	Moderate	Manifest	Need of information about the disease and progression of the disease and management of changed behaviour.
Shanley, C. et al. (107)	Providing support to surrogate decision-makers for people living with dementia: Healthcare professional, organisational and community responsibilities	Article	2017	Australia	Informal carers	34	Telephone interview	Home care	Dementia	Unknown	Manifest	Need for awareness in community about dementia. Need for support to make decisions about the future early on. Need for support groups.
Sherman, C. W. et al. (53)	Financial conflicts facing late-life remarried Alzheimer's disease caregivers	Article	2008	USA	Informal carers (spouses)	9	Interview	Home care	Alzheimer's	Unknown	Latent	Need for help to handle financial issues and conflicts in the family regarding money decisions.
Shivakumar, P. et al. (151)	Carer's needs assessment in dementia: Indian perspective.	Conference abstract	2015	India	Informal carers/ person with dementia	45	Structured interview with questionnaire	Unknown	Dementia	Unknown	Manifest	Need for information. Need to manage psychological distress. Need for information on how to receive benefits. Need for activities for the person with dementia.
Shrestha, S. et al. (80)	Utilization of legal and financial services of partners in dementia care study	Article	2011	USA	Informal carers/ person with dementia	186	Questionnaire	Unknown	Dementia	Unknown	Manifest	Need for legal and financial services.
Shyu, Y. I. et al. (128)	Influences of mutuality, preparedness, and balance on caregivers of patients with dementia	Article	2010	Taiwan	Informal carers/ person with dementia	176	Questionnaire	Unknown	Dementia	Unknown	Latent	Need for support to feel mutuality. Need to feel prepared and to balance own needs against the needs of the person with dementia.
Silva, P. Et al. (141)	Challenges in managing the diet of older adults with early-stage Alzheimer dementia: a caregiver perspective	Article	2013	Canada	Informal carers/ person with dementia	33	Interview	Home care	Alzheimer's	Early stage	Latent	Need for guidance to manage diet. Need for information. Need for confidence in caring tasks.

Slaboda, J. et al. (112)	Focus group findings: Needs of family caregivers of dementia patients	Conference abstract	2018	USA	Informal carers	56	Focus group and online discussion	Unknown	Dementia/stroke/Parkinson's	Unknown	Latent	Need for knowledge on dementia, medication and how to manage behavioural changes. Need for support to connect with other carers.
Steiner, V. et al. (58)	Information Needs of Family Caregivers of People With Dementia	Article	2016	USA	Informal carers/ professionals	92	Questionnaire	Home care	Dementia	Unknown	Manifest	Need to manage changed behaviour. Need to cope with emotional stress. Need for information.
Tatangelo, G. et al. (108)	I just don't focus on my needs. The unmet health needs of partner and offspring caregivers of people with dementia: A qualitative study	Article	2018	Australia	Informal carers	24	Interview	Home care	Dementia	Mild-severe	Manifest	Need to maintain own health including mental health, exercise and diet. Need for emotional support and social relationships.
Titzel, M.R. (46)	Moderating resources in the stress and coping process of Alzheimer's family caregivers	Dissertation	2014	USA	Informal carers	34	Mixed methods study with interview and questionnaire	All	Alzheimer's	All stages	Latent	Need for education, social support, daycare services, coping strategies, practical help and family support.
Tretteteig, S. Et al. (55)	The influence of day care centres designed for people with dementia on family caregivers - a qualitative study	Article	2017	Norway	Informal carers	17	Interview	Home care	Dementia	Mild-moderate	Latent	Need for emotional support and how to manage the new role. Need for respite and flexible services. Need to take care of themselves. Need for information to manage nutrition.
Tyrrell, M. et al. (148)	Voices of Spouses Living with Partners with Neuropsychiatric Symptoms Related to Dementia	Article	2019	Sweden	Informal carers (spouses)	14	Interview	Home care	Dementia	Unknown	Latent	Need for individualised support. Need for support for themselves. Need for support to activate the person with dementia.
Vaingankar, J. A. et al. (118)	Needs of informal caregivers of people with dementia: A triangulation approach.	Conference abstract	2012	Singapore	Informal carers	63	Focus group and interview	Unknown	Dementia	Unknown	Manifest	Need for information on services, early recognition and treatment. Need for financial support and support from employers. Need for emotional and social support arising from poor assistance from family and society, resulting in stigma, anxiety, anger and frustration. Need for aesthetically and ethnically appropriate facilities.
Vaingankar, J. A. et al. (144)	Informal caregivers' unmet needs for dementia care resources and services.	Conference abstract	2013	Singapore	Informal carers	53	Questionnaire	Unknown	Dementia	Unknown	Manifest	The highest unmet need was for financially affordable professional services.
Vaingankar, J. A. et al. (82)	Perceived unmet needs of informal caregivers of people with dementia in Singapore	Article	2013	Singapore	Informal carers	63	Focus group and interview	Unknown	Dementia	Unknown	Manifest	Need for information, emotional and social support. Need for financial support to cover costs and accessible and appropriate facilities.
Wadham, O. et al. (56)	Couples' shared experiences of dementia: a meta-synthesis of the impact upon relationships and couplehood	Article	2016	UK	Informal carers (spouses)	10 articles	Review	Unknown	Dementia	Unknown	Latent	Need to feel togetherness. Need to manage stress.
Wang, X. R. et al. (131)	The impact of dementia caregiving on self-care management of caregivers and facilitators: a qualitative study	Article	2019	USA	Informal carers	45	Interview	Home care	Dementia	All stages	Manifest	Need for support to maintain own health and time for oneself. Need for formal support and support from informal network.

Warrick, N. et al. (61)	Caring for caregivers of high-needs older persons	Article	2014	Canada	Informal carers/ person with dementia	406	Questionnaire	Home care	Dementia	Unknown	Latent	Need for knowledge on where to access help. Need for support for budget management and coordination of services.
Wawrziczny, E. et al. (123)	Do spouse caregivers of young and older persons with dementia have different needs? A comparative study	Article	2017	Canada	Informal carers (spouses)	78	Interview	Home care	Dementia	Mild- severe	Manifest	Need to unwind, need to stimulate and pay attention to the person with dementia, need to break the isolation, and to be more prepared and confident.
Webb, R et al. (133)	In whose best interests? A case study of a family affected by dementia	Article	2016	UK	Informal carers (sons)	1	Case study	Home care	Alzheimer’s	Moderate	Latent	Need for support to make decisions along the journey of dementia.
Werner, N. E. et al. (87)	Getting what they need when they need it. Identifying barriers to information needs of family caregivers to manage dementia-related behavioral symptoms	Article	2017	USA	Informal carers	26	Focus group	Unknown	Dementia	Unknown	Manifest	Need for information through information technology. Need for support groups to avoid feeling alone.
Wesson, V. et al. (47)	Dementia and caregiving	Chapter in book	2017	Canada	Informal carers	Unknown	Unknown	All	Dementia	Unknown	Manifest	Carers' needs are related to the needs of the person with dementia. Need for clinical systematic assessment. Timing is important. Need for carers to attend to their own self-care. Need for psychoeducation, problem-solving and stress management.

Note: Abbreviations used in the appendix: Frontotemporal Dementia (FTD), Lewy Body Dementia (LBD), Early Onset Dementia (EOD), United Kingdom (UK)

Paper II

’I know his needs better than my own’ – carers’ support needs when caring for a person with dementia

Scandinavian Journal of
Caring Sciences

doi: 10.1111/scs.12875

'I know his needs better than my own' – carers' support needs when caring for a person with dementia

Trine Holt Clemmensen MHSc (Senior Lecturer, Ph.D. student)[1,2], **Henrik Hein Lauridsen** PhD (Associate Professor)[2], **Karen Andersen-Ranberg** PhD (Clinical Professor)[3,4] and **Hanne Kaae Kristensen** PhD (Professor)[1,4]

[1]Health Sciences Research Centre, UCL University College, Odense, Denmark, [2]Institute of Sports Science and Clinical Biomechanics, University of Southern Denmark, Odense, Denmark, [3]Department of Public Health, University of Southern Denmark, Odense, Denmark and [4]Department of Clinical Research, University of Southern Denmark, Odense, Denmark

Scand J Caring Sci; 2020

"I know his needs better than my own" – carers' support needs when caring for a person with dementia

Background: Caring for a person with dementia predisposes informal carers (carers) to mental and physical disability. Carers tend to focus on the needs of the person with dementia and have difficulties expressing their own needs for support. No instrument has yet been developed to directly assess carers' support needs. The aim of this study is to clarify the main categories of carers' support needs to inform future development of an instrument to assess carers' support needs.
Methods: A qualitative approach combining focus group interviews with carers and professionals and individual interviews were used.
Results: Carers' support needs were categorised into four areas: (i) daily life when caring for a person with dementia, (ii) focus on themselves, (iii) maintain own well-being, and (iv) communicate and interact with surroundings.
Discussion: Carers have support needs in common regardless of the relation to the person with dementia. Carers tend to focus on the needs of the person with dementia, thus not knowing their own needs. The four main categories clarified in this study may inform the foundation of developing an instrument to facilitate dialogue between carers and professionals with the purpose of assessing carers' support needs.

Keywords: dementia, Alzheimer's, carer, caregiver, needs assessment, support needs, service needs and interview.

Submitted 16 August 2019, Accepted 21 April 2020

Introduction

An informal carer (carer) is any person who helps a partner, family member, or friend and in need of personal and/or practical assistance motivated by the personal relation rather than financial compensation (1). A consequence to the ageing populations in many countries (2) is an increasing number of persons with dementia. In Denmark, approximately 85.000 people have dementia, while approximately 400.000 carers are influenced by the consequences of caring (3,4). Dementia carers experience more physical, emotional and economic stressors, are more likely to experience mental and physical disability themselves and have higher risk of mortality compared to carers of patients with other types of chronic illness (5,6). Carers tend to neglect their own well-being and often report that supervising the person with dementia and managing the cognitive impairment and behavioural problems are challenging stressors (7). These stressors may amplify because the person with dementia is less likely to express gratitude for the help they receive (5). In addition, stress often intensifies over time, as carers often provide care for many years (2). Meaney et al. showed that carers of a person with dementia exhibit high levels of unmet needs and low levels of service use (8). Therefore, action is needed, and using a validated instrument to assess carers' support needs may constitute a standardised way of assessing carers' needs for support (9) to improve their well-being and reduce their risk of disability, thereby also facilitating the well-being of the person with dementia (10).

To our knowledge, no robust instrument has been published that directly assesses carers' support needs for use in a healthcare and social care setting (11). Most existing instruments focus on measuring the impact of

Correspondence to:
Trine Holt Clemmensen, Health Sciences Research Centre, UCL University College, Niels Bohrs Allé 1, 5230 Odense M, Denmark.
E-mail: thcl@ucl.dk

carer burden with no indication of what carers consider important to meet their own support needs (10,12). Also, existing needs assessment instruments are not developed as self-reported measures for use in health and social care with the primary purpose of uncovering carers' support needs (13,14). Consequently, there is a need for a feasible self-reported instrument to guide assessment of carers' support needs (11,15). Such an instrument may assist professionals in offering purposeful and relevant supportive interventions to carers (2,16).

A self-reported standardised instrument also offers assessment of support needs without professional prejudice (17). Carers and professionals have different perspectives of carers' support needs (11), with professionals focusing on needs in relation to the care of the person with dementia and thus not always acknowledging the carers other needs (18). Further, carers tend to focus on the person with dementia's needs for care and have difficulties expressing their own needs (19,20); thus, other ways to recognise carers support needs are needed. Some studies have already investigated carers' needs (20-22). However, these studies have a narrow focus on support needs in relation to disease severity of the person cared for. When identifying carers' individual support needs, a more appropriate approach may instead depend on the relationship to the person with dementia (23), and carers own experience of phases due to the challenges of adapting to changes throughout the progression of dementia (24). Allowing a broader focus, a framework to understand different expressions of support needs is defined by four types of needs: felt, normative, comparative and expressed needs (19). A 'felt' need is the carer's actual need for support. 'Normative' and 'comparative' needs are based on professional knowledge and the public opinion. 'Expressed' needs are what carers are able to articulate, and in practice, a lack of translation is seen between the different expressions of carers' needs for support (19). When assessing carers' support needs, it is therefore important to incorporate both carers' and professionals' perspectives to get a complete understanding of this abstract phenomenon (25). Furthermore, needs should be assessed regularly because needs in general change over time and carers' needs may change because of the progression of the condition (10,18).

Several studies describe the experience of caring for a person with dementia (20,26-28). In common, carers experience substantial changes in the relationship to the person with dementia (20,28) which calls for carers to manage new roles (27,29) and sets high expectations on how to adapt and adjust in daily life when caring for a person with dementia (24). Although few studies have directly investigated carers' support needs as the primary study objective, a systematic review of carers needs shows that carers in general need information on how to provide the best care and how to manage their own physical and emotional health (20). Though a variety of supporting interventions exists such as home care, respite care, group-based psychological education and communication skills training (30), carers experience that these do not entirely meet their support needs (11). This points to the lack of concurrence between carers support needs and supportive services, which may be explained by a complex interaction between carers' needs and the carers' whole life situation, including the needs of the person with dementia (20).

To embrace this complex interaction, the biopsychosocial model offers a dynamic and holistic theoretical approach to perceive carers' support needs (31). The model defines health as the 'state of total biological, social and emotional well-being' (32). It allows for professionals within social and health care to acknowledge the multidimensional support needs of carers (11) not related to a diagnoses but to the subjective experience of well-being (33). In this model, the carer's well-being is a result of an interaction between physical, emotional and social components including contextual factors such as the person with dementia's health and well-being (31), and needs for supportive services arise in this dynamic interaction. Adapting this theoretical approach thus allows for identification of both biomedical and psychosocial support needs due to changes in relation to the person with dementia, and contains both positive and negative aspects of caring (34).

The aim of this study is to clarify main categories of carers' support needs when caring for a person with dementia in order to inform a foundation for the development of a multidimensional instrument to assess carers' support needs that may facilitate the dialogue between carers and professionals in every day social and health care.

Methods

Design

This qualitative study used focus group interviews with first professionals and then carers to explore main characteristics and personal perspectives on carers' support needs (35,36). We then conducted individual interviews with carers, to pursue the meaning of the personal and sensitive experiences of support needs (37). A combination of qualitative data collection is suitable when developing a nuanced understanding of carers' support needs, because it allows for contribution of overlapping and complementary findings and therefore a wider exploration of the phenomenon (38,39). However, qualitative investigation alone is not enough to inform development of an assessment instrument, and this study were therefore part of a greater development process (40).

Participants

To comply with the inclusive definition of carers in this study, a strategy of purposive sampling was conducted in two municipalities in Denmark to achieve maximum variation among participants regarding gender, cohabitation, progression of dementia and relation to the person with dementia (see Table 1 for inclusion criteria) (41). Evaluation of progression of dementia was based on carers subjective assessment of the person cared for following the criteria from the Danish Health Authority (mild, moderate and severe) (42). Heterogeneity in participants were strived for to get as nuanced description of the abstract concept of carers' support needs considering that support needs may be hard to express and emerge in different ways (19). Key professionals in each municipality led recruitment to promote a heterogeneous group of participants. Due to their familiarity with carers in the municipality, the key professionals were in a unique position to approach carers who might not have otherwise volunteered because of lack of initiative to commit in research.

Data collection

Focus groups. Firstly, we held two focus group interviews with professionals to explore carers' support needs as observed by professionals. Secondly, we held three focus group interviews with carers to explore their various support needs in the past and present. Data collection was an iterative process, and carers were allowed to reflect upon the professional perspective on carers' support needs to validate their relevance. Using focus groups allowed dialogue between people in the same situation and facilitated the rethinking and discovery of unexpected perspectives of carers' support needs (35). Each focus group had four to eight participants to enable a group dynamic where everyone was able to express their views (43). The professionals in each focus group came from the same municipality but had different professional backgrounds and experience with dementia care. Participants in the carer groups were assembled based on cohabitation and relation to the person with dementia in each municipality (35).

Table 1 Inclusion criteria for participants in interviews

Interview type	*Number of participants*	*Inclusion criteria*
Focus group interviews, professionals	13	Working in dementia social care or health care
Focus group interviews, carers	18	≥18 years, provides help on a regular basis because of a personal relationship rather than financial compensation to a closely related person who has received a dementia diagnosis, able to communicate in Danish
Individual interview, carers	5	

Individual interviews. Five individual semi-structured interviews with carers were conducted. Striving for including different types of carers, participants were sampled to complement participants in the focus groups (43).

Interview guide. We developed an interview guide to enable consistency in interviews and to comply with the different contexts of interviews (35). The guide was organised in terms of participants presented their situations as well as described and discussed their support needs. To facilitate discussion, we introduced text cards that described areas of carers' support needs. Using such an activity should elicit participants less comfortable in the situation or those who needed extra time to express their thoughts (44). Examples of topics in the text card were'Financial issues – I need help to manage financial tasks' and 'Worrying – I need help to manage changes in daily life'. Participants were asked to discuss the cards expressing their most important support needs. Participants were also encouraged to add topics not represented in the cards. A systematic search of the literature including keywords such as 'dementia', 'caregiver' and 'support needs' guided the development of text cards. Topics for discussion were derived through an extensive work of inductive content analysis (38) of support needs identified in the literature (10,20,45) resulting in 16 sub-categories written on the cards.

Settings

Two-hour focus group interviews were hosted at a local meeting facility. Individual interviews lasted one hour and were hosted in the participants' homes. All interviews were conducted by the first author with the assistance of an experienced co-moderator in the focus group interviews (35). All interviews were audio-recorded and transcribed verbatim.

Data analyses

Data were analysed with an inductive qualitative content analysis approach (38,46) where data were grouped into categories to describe the manifest content (47). Coding was done in NVIVO 11 (http://www.qsrinternational.com/nvivo/nvivo-products/nvivo-11-for-windows). Content analysis of data involved three stages: open coding, creating categories and abstracting, as described in Fig. 1. The first stage started with a thorough reading of the material where after meaningful units in the text were coded. In the second stage, codes referring to the same content were grouped into sub-categories; thus, the different perspectives of carers and professionals were integrated by looking for understandings in common. Lastly, abstraction of sub- and generic categories was conducted in discussion between all authors and meaningful patterns were pursued across the material, resulting in four main categories that provide an overall description of carers' support needs including both perspectives. The seven generic and four main categories are presented in Fig. 2. Also, Table 2 shows examples of the abstraction process directly linking the meaningful units to sub-, generic, and main categories.

Ethics

Ethical considerations were given to the fact that participants may share sensitive information on the person cared for without this person having the means to defend themselves. To ensure unnecessary sharing of information, participants were encouraged to talk solely concerning their own views and the caring situation. The study followed the principles of the Helsinki Declaration (48) and was registered with the Danish Data Protection Agency (2015-57-0016-020a). According to Danish law, no ethics committee approval was required (49). All participants gave informed written consent to participate and were anonymised by giving all participants a unique number in the transcribed material. Secure storage of all personal data followed the General Data Protection Regulation (GDPR). Hence, documents and audio and text files were stored in a safe or on a secure server with a code and a log of access.

Results

Content analysis of carers views complemented by professionals views on carers' support needs resulted in four main categories: (i) carers' support needs in daily life when caring for a person with dementia, (ii) carers' support needs to focus on themselves, (iii) carers' support needs to maintain own well-being and (iv) carers' support needs to communicate and interact with surroundings (see Fig. 2).

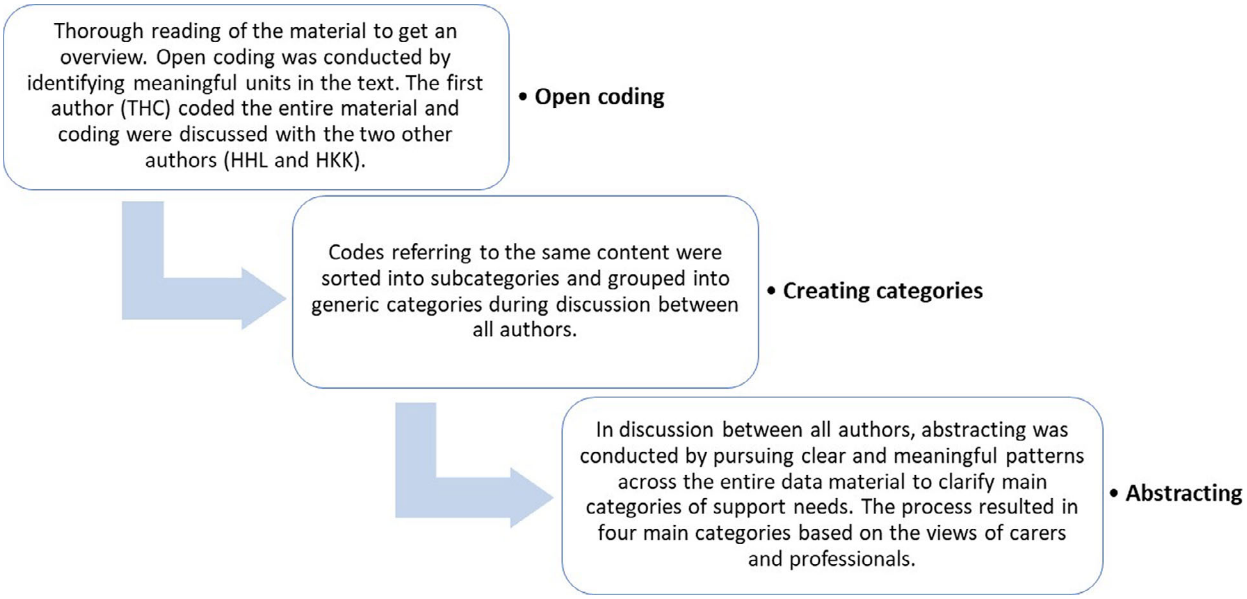
The demographics of participants illustrate the heterogeneity of both carers and professionals regarding age, progression of dementia, relationship (carer) and experience (professional) (see Table 3).

Carers' support needs in daily life when caring for a person with dementia

Carers' support needs in daily life involves adjusting offered formal care to the overall situation of both the carer and the person cared for. Additionally, carers need continuous access to knowledge in how to deal with symptoms of dementia.

Need for support to care for a person with dementia. Carers express worries and struggles when dealing with dementia in daily life but not for managing practical care issues, for example cleaning or helping the person with dementia get dressed. A carer describes how she finds the practical day-to-day tasks easy to manage:

> Anyway, regarding the practical issues of caring, I am quite good at dealing with what has to be done. (Friend P2)



Thorough reading of the material to get an overview. Open coding was conducted by identifying meaningful units in the text. The first author (THC) coded the entire material and coding were discussed with the two other authors (HHL and HKK).

Codes referring to the same content were sorted into subcategories and grouped into generic categories during discussion between all authors.

In discussion between all authors, abstracting was conducted by pursuing clear and meaningful patterns across the entire data material to clarify main categories of support needs. The process resulted in four main categories based on the views of carers and professionals.

Figure 1 Description of the three stages in the content analysis process

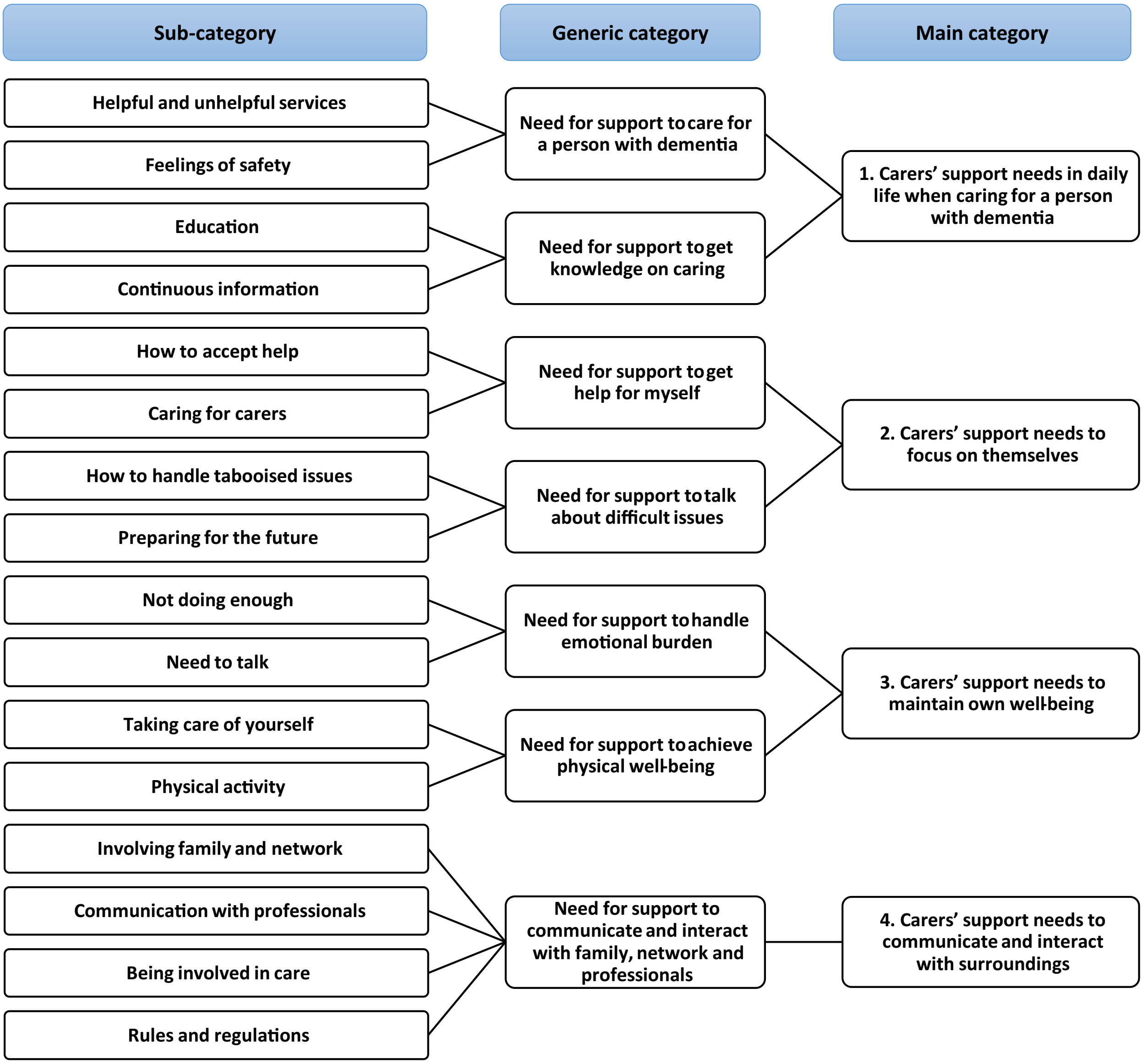


Figure 2 Coding tree presenting main, generic and sub-categories derived through the inductive content analysis process

In contrast, professionals describe how they focus on carers needs for practical support in day-to-day tasks:

> It is obvious that we support managing household chores in accordance to our service level…but for …gardening we can't provide any help. We only offer personal care'. (Professional P27)

Though well-intentioned offered supportive services may not be the kind of support, carers need the most. Regarding needed support, carers describe that caring consumes their thoughts around the clock. They need to know the person with dementia is safe and is offered appropriate activities. Carers call for someone to share the responsibility of ensuring the well-being of the person with dementia living at home, because it is not possible to be present all the time. A daughter describes how she comes to the person with dementia's rescue:

> Now she only lives one and a half kilometres from me, which is easy…but…before she lived seventeen kilometres away and…sometimes…well, things happened and then the next. And she was so sad. And then I had to go all this…way just to find out it was nothing special… (Daughter P4)

Carers express how consuming it is to be constantly on guard. To avoid having to put their own plans on standby, they need support to secure the well-being and safety of the person with dementia.

When providing formal support to comply with carers' needs, both professionals and carers agree upon the need for flexible solutions that correspond to both the support

Table 2 Examples of the inductive content analysis showing the process from codes to categorisation

Meaningful unit	*Code*	*Sub-category*	*Generic category*	*Main category*
'Anyway, regarding the practical issues of caring, I am quite good at dealing with what has to be done' (Friend P2)	Practical help	Helpful and unhelpful services	Need for support to care for a person with dementia	1. Carers' support needs in daily life when caring for a person with dementia
'You have to be careful not to take something away from them that they would have liked to do themselves'. (Professional P26)				
'Then I know she has been interacting with someone and has been stimulated….and really has had her need for company met'. (Daughter P4)	Activities for the person with dementia			
'Now she only lives one and a half kilometres from me, which is easy…but…before she lived seventeen kilometres away and ….sometimes…well, things happened and then the next. And she was so sad. And then I had to go all this…way just to find out it was nothing special…'. (Daughter P4)	Being vigilant	Feelings of safety		
'Many carers express that they focus on all of those nice experiences together and they often find it hard to organise themselves'. (Professional P30)	Initiating nice experiences	Not doing enough	Need for support to handle emotional burden	3. Carers' support needs to maintain own well-being
'I told him as it was, even though it was harsh. A friend's wife got the Alzheimer's disease two years after my wife. It was my damn luck. Now we have each other to talk to'. (Husband P20)	Contact with others in the same situation	Need to talk		

needs of the person with dementia and those of the carer. A professional says:

> You have to be careful not to take something away from them that they would have liked to do themselves. (Professional P26)

Supportive interventions may be more helpful when the carers' situation is taken into account.

Need for support to get knowledge on caring. A common need among carers is easy access to knowledge of how to deal with symptoms. Many carers describe uncertainty about what is the best thing to do when caring for a person with dementia. Carers express wanting to care for the person with dementia, but they need support in *how* to care. A daughter says how she needs support to feel confident in the carer role:

> I just feel…that I am going around in the dark and… am I doing it right?...Well, I did not know that there was a Dementia Clinic I could turn to. (Daughter P4)

The type of knowledge carers need is how to act in everyday life and to understand what common behaviour is, when living with dementia. A professional explains how she experiences carers calming down when they know what to expect:

> When they hear it is not uncommon that you may act like this or that, and that it is normal to be distrustful. A lot of things are common thing when you have a dementia disease….Then they calm down and say well, okay, then it's just the way it is. (Professional P32)

The need for knowledge continues throughout the progression of the condition. Although information on dementia is important at the time of diagnosis, the need for knowledge continues as the disease and the challenges in daily life progress. Carers experience that the information provided often would have been of use much earlier and not only at the time of diagnosis.

Carers' support needs to focus on themselves

In general, carers describe needs for support that focuses on their own situation. Carers feel that they suppress talking about difficult issues, thereby preventing themselves from finding solutions.

Need for support to get help for myself. Carers seem to experience difficulties acknowledging a need for help for themselves as opposed to getting help for the person with dementia. A professional carer explains:

> Often, I actually experience that informal carers find it hard to express their own needs because they are so deeply into caring. Then we have to go in and help them…figure it out. (Professional P26)

Caring is new to most carers, and even though it is to be expected that carers take responsibility for their own

Table 3 Demographic characteristics of participants in the interviews (focus group and individual)

Carers (n = 23)			*Professionals (n = 13)*		
Gender (female)		15	Gender (female)		13
Mean age (range)		64.7 (34–83)	Mean age (range)		47.8 (31–62)
Relationship	Wife	6	Education	Nurse	4
	Husband	6		Therapist	2
	Daughter	5		Social care or healthcare assistant	5
	Son	2		Social care or health service helper	2
	Daughter-in-law	1	Mean experience in years (range)		14.4 (3–30)
	Sister	2			
	Friend	1			
Cohabiting	Yes	13			
	No	10			
Employment	Retired	15			
	Employed	4			
	Unemployed	3			
	Sick leave	1			
Diagnosis of cared-for person	Alzheimer’s	16			
	Vascular	1			
	Other	5			
	Don’t know	1			
Stage of disease	Mild	3			
	Moderate	9			
	Severe	9			
	Deceased	2			
Care service for the person with dementia	No use of care	2			
	Home care	11			
	Nursing home	8			

well-being, they are overwhelmed by the complexity of caring. Carers do not ask for help if they are unaware of their own needs or they do not have the strength to act on them. A daughter expresses:

> Just the thought of me getting help for myself…I haven’t thought of it…though it would have been fantastic. (Daughter P5)

Carers may not recognise their own needs because they do not know that this is a possibility. They suppress their own needs because they are constantly aware of the person with dementia’s needs. A carer says:

> I think I know his needs better than my own. (Ex-wife P18)

Carers’ lack of ability to acknowledge own needs constitutes a need for support to help differentiate the carer’s needs from the person with dementia’s needs, and carers need to be acknowledged by professionals. Often carers describe that they feel as if they are not seen or heard by anyone, and the person with dementia gets all attention. A carer describes:

> I feel very alone…Sometimes I would have liked to talk about how I am doing? (Wife P13)

Carers portray a reality with little focus on carers’ needs. A change of attitude is called for among carers and professionals if carers’ support needs are to be identified.

Need for support to talk about difficult issues. Carers explain that some issues are difficult to talk about, and they need help to confront sensitive issues such as intimacy, violence and death. Notably, talking about death is tabooed. When asked, carers describe a heartfelt need for someone to help them confront this issue and to prepare for the future. A carer explains:

> I missed some knowledge, right? I can see my mother getting worse and worse. And how am I to tackle this? (Son P6)

When no one confronts tabooed issues, carers are left alone dealing with the dire consequences of the disease – emotionally and practically. Also, these issues are difficult for professionals to uncover. A professional says:

> He [the person with dementia] had started having hallucinations…my colleague was there and she sensed…something…but she couldn’t quite tell. So

> she left. Suddenly she heard a sound…she went back and saw that he had pushed her, causing her arm to fracture. (Professional P35)

As this example express, carers need emotional and practical support to handle difficult issues when caring because of the carers' unlimited compassion and patience towards the person with dementia.

Carers' support needs to maintain own well-being

Carers say their emotional well-being depends on a strong relationship with the person with dementia or someone else. They also call for opportunities to maintain physical well-being by being physically active.

Need for support to handle emotional burden. Most carers feel guilty for not doing enough. Carers describe a need for forgiveness from the person with dementia, their surroundings and themselves. A carer describes:

> I feel a bit…stuck. I may say I have a thing today, so I'm not coming over and that's fine…but this feeling of bad conscience; it…goes on in the back of my head. (Daughter P4)

Carers express that they feel inadequate, which makes it difficult to achieve success in the caring role. The relationship with the person may suffer from this, and carers need help to preserve positive interactions with the person with dementia. A professional explains:

> Many carers express that they focus on all of those nice experiences together and they often find it hard to organise themselves. (Professional P30)

When carers impose themselves with thoughts of not doing enough, caring may become an emotional burden. Carers describe that they need help to feel connected to the person with dementia and to preserve the relationship without feeling inadequate. A carer describes how keeping up singing together with the person with dementia is a positive experience to him:

> We have that joy of singing in a choir…and I am so fortunate that three friends have offered to be there when my wife can't go anymore…if you leave a choir you lose a great community. Music really helps me. (Husband P17)

However, this carer prepares for a time when they will not be able to sing together, which he cannot do in good conscience unless someone helps him to this.

Furthermore, carers describe feeling alone because the illness prevents sharing their feelings with the person with dementia. A carer describes how he by chance has found comfort:

> I told him as it was, even though it was harsh. A friend's wife got the Alzheimer's disease two years after my wife. It was my damn luck. Now we have each other to talk to. (Husband P20)

Carers have a need for support to find someone to share their feelings with because they feel too vulnerable to pursue emotional support on their own.

Need for support to achieve physical well-being. Carers describe that they find it hard taking care of their own physical well-being. Carers suppress signals of stress and strain. A wife says:

> I just passed out driving in my car…I thought I was fine. But I wasn't. (Wife P13)

This carer points to the issue that carers may not be able to identify whether their body is exhausted, thus leaving carers with a need for help to recognise their own physical limitations. Carers describe how they receive well-intentioned concern from the surroundings but with no backup of action. A carer says:

> I hate it when someone tells me to take care of myself. I could just hit them…You don't know how to do that? (Ex-wife P18)

When carers explain what makes it hard taking care of themselves, they emphasise that they do not have the extra energy after having cared for the person with dementia. A carer says:

> Something's gotta give. It has taken a toll…in the end it has taken so much, that your own needs is the only thing you have to give away. (Son P3)

Carers do not feel as if they have a choice of prioritising own well-being over the person with dementia. Consequently, carers have a need for someone to help look after themselves. Carers feel responsible for the person with dementia and neglect their own physical well-being. Several carers describe that no one takes their health seriously, not even themselves, because everything revolves around the person with dementia. A way of prioritising carers' health is for example by enabling physical activity to offload and reconnect with themselves. A carer explains:

> Now I go for long runs. And I found out that trees don't talk back. So I let my anger go just by yelling and screaming. Getting rid of my frustrations. (Son P3)

Carers find that physical activity is a way to take care of oneself and to focus on something other than caring. Carers experience that respite care is often too rigid to comply with the varying needs of carers to maintain their own physical well-being.

Carers' support needs to communicate and interact with surroundings

Communication and interaction with one's surroundings are very challenging, and carers need help to mobilise close network, as well as representatives of the system.

Need for support to communicate and interact with family, network and professionals. Carers describe a need to involve family, friends or other closely related persons in care. They feel obligated to make decisions on behalf of the person with dementia though feeling insecure. A daughter describes how she feels forced to make decisions:

> When a decision had to be made…on behalf of my father, they came to me and not my brother. (Daughter P1)

Carers indicate a need for support to involve the person with dementia or this person's closest network in decision-making, which represents a risk of starting a conflict due to different expectations about responsibility and degree of involvement. A professional describes how she witnesses disagreements:

> Well, a lot of them experience that they do not get the necessary support from the family. (Professional P31)

Carers have a need for support to involve the close network in daily care. When carers feel supported in caring, they find daily living easier.

Further, carers describe that communication with professionals is important, and carers need to get day-to-day information about the well-being of the person cared for. A carer says:

> And that's what I think is missing, that they contact you and tell how it is going; that there has been someone to check up on her…But I 'always have to ask. (Sister P9)

Caring is less problematic when professionals share knowledge and plans for formal care. This provides carers with reassurance that the person with dementia is well and the best course of action is taken – otherwise carers have to take action. Carers express that they need to be acknowledged and involved when professionals decide on treatment or care for the person with dementia.

Another area of need for support is how carers communicate and get information and support from different public institutions, for example citizen service centres, hospitals and banks. Attaining relevant knowledge is vital to manage the uncertain future of the person with dementia and themselves. A daughter describes having many questions about the future:

> Regarding financial situation, well what is the future gonna look like for her? What about the house she lives in? What is going to happen when she can no longer live there? (Daughter P5)

Carers point to a support need of where to find answers to their questions. Carers deal with problems not only related to the person with dementia's health but also their citizen rights, insurance and financial issues. Both carers and professionals express that carers have a strong need for support and guidance to manage these problems – problems that go beyond legislative areas and institutions.

Discussion

When developing a new instrument, multiple steps of investigations are needed, including qualitative investigation of the target population and experts' perspectives on the phenomenon in focus (40). Based on the mutual perspectives among a heterogeneous group of professionals and carers to persons with dementia, this qualitative study has identified four main categories of carers' support needs that may inform future development of an assessment instrument: (i) carers' support needs in daily life when caring for a person with dementia, (ii) carers' support needs to focus on themselves, (iii) carers' support needs to maintain own well-being and (iv) carers' support needs to communicate and interact with surroundings. Our findings also reveal that carers have support needs in common regardless of the relation to the person with dementia and that support needs emerge in the context of caring, which is influenced by carers experience of caring and different expectations to the caring role. Studies have shown that success in the caring role may depend on carers finding meaning in this (50,51) assisted by positive experiences and high-quality relationship with the person cared for (23,51,52). Also, for some carers the caring role comes more natural. For example, close kinship and co-residence indicate higher motivation (53) and greater chance succeeding in the caring role (54). However, inconsistency regarding the influence of factors such as gender and spousal or child relationship on caregiver burden confuse this picture (41,55,56), which may support our finding that carers have support needs in common regardless of relation, suggesting the importance of individual assessment.

Our most distinctive finding is that carers tend to focus on the needs of the person with dementia, thus not knowing their own needs. Caring for a person with dementia has been described as more burdensome than caring for other chronic illness (5), which may be enhanced by not recognising their own need for support. One explanation could be that articulation of needs is difficult. A mixed-method study found that carers may express a support need, but they are not able to articulate their actual felt needs (19). Carers neglecting their own needs may also be explained by the paradox that even though carers are in need of support, they may only be able to recognise their own needs for support in retrospect (57). Being able to recognise your own needs can be argued as being part of a transition process (58). Carers may not have the ability to acknowledge how demanding the situation is to themselves, and they may not be able to recognise their own support needs until they have come to terms with how the dementia disease affect themselves even in the early stages of caring (24,57). In addition, it is paramount that professionals identify carers' support needs in a timely manner, as minor problems may accumulate and spin out of control without carers realising it (57).

Another significant finding of carers' support needs is related to the degree of effort needed to sustain the well-being of the person with dementia. Carers, irrespective of relation, cohabitation status and gender, experience that constantly being attentive of the well-being of the person cared for takes up most of their time. Especially when the person cared for is living in his or her own home, carers describe an extraordinary feeling of responsibility towards the person with dementia, and they are willing to jeopardise their own well-being for the benefit of this person. Closely aligned to this, a review has shown that time spent caring and carers' feeling of preparedness for caring have an important influence on carers' support needs (41). If carers spend most of their time caring but do not feel prepared, they find it hard to manage the responsibilities of caring (59).

Findings in our study indicate that multiple dimensions of the caring situation influence carers' need for support including carers own beliefs and experience of caring and also different expectations to the caring role. The biopsychosocial model introduced earlier embrace this complex interaction when identifying needs for support to achieve physical, psychological or social well-being without defining illness or disability as solely defined by a diagnose (33). Reflecting upon the multidimensionality of the four categories of support needs identified, we introduce the International Classification of Functioning, Disability and Health (ICF) founded in the biopsychosocial model (60). The ICF is conceptualised into three main components of functioning (body functions/structure, activity and participation) and two contextual factors (environmental and personal). The ICF provides a dynamic framework to understand what is important to carers' daily functioning. Within this framework, it is possible to categorise physical, psychological and social aspects of carers' support needs to maintain daily functioning (18,61). The transferability of the support needs identified in our study may be illuminated when considering that carers' support needs are represented across all areas of this framework (18,62). In Fig. 3, we have linked the four main categories to the ICF by the generic categories in the content analysis (61). The linking shows that all categories are relatable to the ICF framework and that each generic category can be explained by a component or factor within the ICF framework. For example, the generic category '…get help for myself' is included in the Activity and Participation component 'Self-care' in the ICF, and it allows support needs in relation to this to be addressed on equal footing with more traditionally acknowledged needs defined by the aetiology of a disability (63). In many ways, the ICF provides a holistic framework to classify carers' support needs, though further research is needed to confirm if the model is applicable.

Also, integrated in the ICF framework is that needs change over time influenced by the environment (25,63). Although findings in our study are based on carers and professionals views on carers' support needs throughout the disease trajectory, no close link was found to the progression of the dementia disease in itself. Several studies suggest that carers have their own experience of the progression of the disease (24,64,65), and their support needs may more likely relate to this. Carers are continuously faced with new challenges in the caring situation, and they repeatedly go through a process of having to acknowledge and adjust to a new situation because of the progression of the disease (24,64). Professionals need to know that carers' support needs change dependent on where they are at in such a process and needs assessment considering this should precede any supportive services offered.

Findings in our study are in line with other studies investigating carers' needs in end-of-life care (20,66,67), which suggest that carers in general are in need for support to provide the best care. However, specific to dementia carers are their need for support to balance own needs in relation to the person with dementia (20). Considering whether our findings are specific to

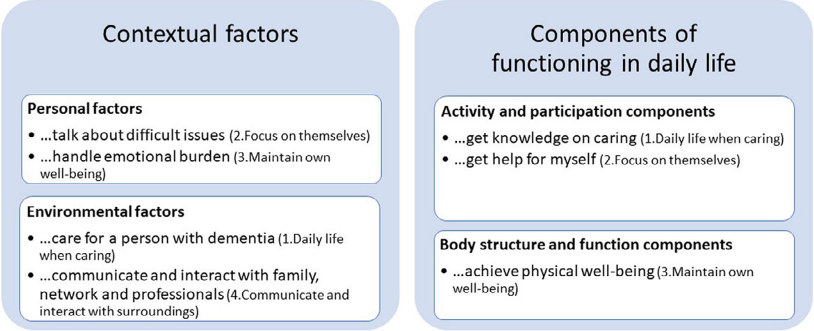


Figure 3 Linking main and generic categories to the ICF framework

dementia, other studies investigating dementia carers' support needs show a resemblance to the four categories presented. Pini et al. have developed a framework to describe carers' needs (66) that highlight the relational aspects of carers' needs. Their categories 'take care of myself' and 'share/express my thoughts and feelings' (66) are very similar to the generic categories 'get help for myself' and 'talk about difficult issues' in our study. In both Pini et al.'s (66) and our study, carers' support needs develop in relation to high commitment to the person with dementia and not being understood by surroundings, which puts carers in a vulnerable position. Further, Wancata et al. identify 18 problem areas for carers to a person with dementia, and they resemble to the support needs identified in our study (13). Particularly, their problem areas regarding the lack of information about dementia, treatment and services are in line with our findings of carers' need of knowledge. Using the ICF framework to ensure a holistic approach that also addresses the influence of the environment, the main categories in our study stand out from other studies by including all of the support needs identified in the empiric results and existing literature and framing them in a familiar way for health and social care (31). Hence, the main categories identified in our study may not be new per se, but the heterogeneous sampling of carers has made it possible to include multiple and nuanced perspectives of carers' support needs. The categories are likely to embrace carer's whole life situation regardless of relation to the person cared for, context and progression of dementia, which is important when developing an instrument to guide the multidimensional assessment of carers' support needs. On that account, next step involves a systematic process of item generation based on knowledge from our study in combination with a review of the literature followed by systematic pilot and field-testing of the new instrument in the target population (40).

Limitations

Though one third of carers in our study were men, most participants were female or spouses. A pattern of high representation of females or spouses is also seen in other studies (66). Even though the key professionals recruiting participants were aware of the importance of a heterogeneous sampling of carers, it may have been difficult to recruit other types of carers. However, a national survey in Denmark shows that women in general are more likely to take on the caring role, which leads to a naturally larger group of female carers (68). Female carers have been seen to experience higher burden and report more health problems than male carers (69). This may be due to female carers' use of an emotion-focused coping strategy that may not be the most effective (41). Findings in our study may therefore represent more emotion-focused needs.

A limitation to recruitment of participants is that the majority of carers reported caring for a person with moderate to severe dementia, which may have forced carers to take more responsibility in their relationship with the person with dementia (70). Research have shown that relationship quality is important to carers' motivation and positive experience of caring (23,51), and important differences in carers' support needs in relation to severity of the disease and the person with dementia's disabilities may have been disregarded. Another limitation to our recruitment strategy is a lack of focus to include carers with a minority ethnic background. This group have previously been described to have support needs different from the majority due to a poor understanding of what supportive services provide (71), and when developing an assessment instrument their perspective on support needs may not be fully considered.

A possible bias in the study is the text cards used in the interviews to prompt participants' discussion of support needs. To consider this bias, participants were also given blank text cards to encourage discussing support needs not described (35). Most participants made use of this option, which suggests that the four main categories in our study represent participants own thinking of carers' support needs. As an example, the need for support to talk about death and violence were topics brought up by carers themselves. Hence, we consider it unlikely that the use of text cards has biased our findings.

Analysing qualitative data is sensitive to subjective interpretation (47). To enhance the credibility of our interpretation of the data, coding, creating categories and abstractions followed the rigorous process of analysis described by Elo and Kyngäs (47) involving continuously dialogue between all authors. Within content analysis, two different approaches of interpretation exist: latent and manifest (47). We have chosen to use manifest interpretation, where categories can be identified as a thread throughout the codes. However, interpretation with a manifest approach has a descriptive purpose and entail that all content is reflected in exhaustive and mutually exclusive categories. This feature is important when conducting the next step in developing an assessment instrument, because dimensionality of an instrument depends on items belonging to only one dimension of the construct of interest (40). Also, supporting trustworthiness of our findings is that no new categories emerged in the individual interviews following focus group interviews and that the same codes emerged over and over again across the entire data material, suggesting saturation in the clarification of categories of carers' support needs (72).

Implications

Carers contribute significantly to the well-being of the person with dementia, and carers may need support when caring. However, carers to a person with dementia may not acknowledge or articulate their support needs, stressing that assessment of carers' support needs should be a focus in future dementia care. Carers describe receiving inadequate support, and new ways to address carers' support needs have to be developed. A new approach may be developing an instrument that facilitates dialogue between carers and professionals to help carers acknowledge and articulate their support needs in a timely manner. When developing a new assessment instrument, several steps of investigations are needed to generate items and ensure robust psychometric properties. The four main categories identified in our study may inform a foundation for item generation when developing such an instrument to improve carer support in dementia social and health care.

Acknowledgements

This work was supported by the Health Sciences Research Centre at UCL University College Denmark; the Danish Alzheimer Association; and the Association of Danish Physiotherapists.The authors would like to thank all participants, our contact persons and the management in the municipalities of Odense and Svendborg, Denmark.

Conflict of interest

The authors declare no conflict of interest.

References

1 Medical directorate and Nursing directorate. NHS England's commitment to carers. NHS England. May 2014.

2 World Health Organization and Alzheimer's Disease International. Dementia: a public health priority. 2012;ISBN: 978 92 4 156445 8.

3 Farina N, Page TE, Daley S, Brown A, Bowling A, Basset T, Livingston G, Knapp M, Murray J, Banerjee S. Factors associated with the quality of life of family carers of people with dementia: A systematic review. *Alzheimers Dement* 2017; 13(5): 572-81.

4 Jorgensen K, Waldemar G.The prevalence of dementia in Denmark. Ugeskr Laeger 2014 Nov 24;176(48).

5 Schulz R, Sherwood PR. Physical and mental health effects of family caregiving. *Am J Nurs* 2008; 108(9 Suppl): 23–27.

6 Roehr S, Pabst A, Luck T, Riedel-Heller SG. Is dementia incidence declining in high-income countries? A systematic review and meta-analysis. *Clin Epidemiol* 2018; 18: 1233–47.

7 Schulz R, Martire LM. Family caregiving of persons with dementia: prevalence, health effects, and support strategies. *Am J Geriatric Psychiat* 2004; 12: 240–49.

8 Meaney AM, Croke M, Kirby M. Needs assessment in dementia. *Int J Geriatr Psychiatry* 2005; 20: 322–29.

9 Brodaty H, Thomson C, Thompson C, Fine M. Why caregivers of people with dementia and memory loss don't use services. *Int J Geriatr Psychiatry* 2005; 20: 537–46.

10 Novais T, Dauphinot V, Krolak-Salmon P, Mouchoux C. How to explore the needs of informal caregivers of individuals with cognitive impairment in Alzheimer's disease or related diseases? A systematic review of quantitative and qualitative studies. *BMC Geriatr* 2017; 17: 86.

11 Mansfield E, Boyes AW, Bryant J, Sanson-Fisher R. Quantifying the unmet needs of caregivers of people with dementia: a critical review of the quality of measures. *Int J Geriatr Psychiatry* 2017; 32: 274–87.

12 Van Durme T, Macq J, Jeanmart C, Gobert M. Tools for measuring the impact of informal caregiving of the elderly: a literature review. *Int J Nurs Stud* 2012; 49: 490–504.

13 Wancata J, Krautgartner M, Berner J, Alexandrowicz R, Unger A, Kaiser G, Marquart B,Weiss M. The Carers' Needs Assessment for Dementia (CNA-D): development, validity and reliability. *Int Psychogeriatr* 2005; 17 (3): 393-406.

14 Reynolds T, Thornicroft G, Abas M, Woods B, Hoe J, Leese M, Orrell M.Camberwell Assessment of Need for the Elderly (CANE). Development, validity and reliability. *Br J Psychiatry* 2000; 176: 444-452.

15 Mosquera I, Vergara I, Larranaga I, Machon M, Del Rio M, Calderon C. Measuring the impact of informal elderly caregiving: a systematic review of tools. *Qual Life Res* 2016; 25: 1059–92.

16 Higgs J. *Clinical Reasoning in the Health Professions*, 3rd edn. 2008, Elsevier, Churchill Livingstone, Edinburgh; New York.

17 Bangerter LR, Griffin JM, Zarit SH, Havyer R. Measuring the needs of family caregivers of people with dementia: an assessment of current methodological strategies and key recommendations. *J Appl Gerontol* 2019; 38: 1304–18.

18 Dean SG, Siegert RJ, Taylor WJ. *Interprofessional Rehabilitation: A Person-Centred Approach*. 2012, Wiley-Blackwell, Chichester, West Sussex, UK.

19 Stirling C, Andrews S, Croft T, Vickers J, Turner P, Robinson A. Measuring dementia carers' unmet need for services-an exploratory mixed method study. *BMC Health Serv Res* 2010; 13: 122.

20 McCabe M, You E, Tatangelo G. Hearing their voice: a systematic review of dementia family caregivers' needs. *Gerontologist* 2016; 56: e70–88.

21 Bunn F, Goodman C, Sworn K, Rait G, Brayne C, Robinson L, McNeilly E, Iliffe S. Psychosocial factors that shape patient and carer experiences of dementia diagnosis and treatment: a systematic review of qualitative studies. *PLoS Med* 2012; 9(10): e1001331

22 Jacobson J, Gomersall JS, Campbell J, Hughes M. Carers' experiences

when the person for whom they have been caring enters a residential aged care facility permanently: a systematic review. *JBI Database systematic Rev Implement Rep* 2015; 13: 241–317.

23 Quinn C, Clare L, Woods RT. Balancing needs: the role of motivations, meanings and relationship dynamics in the experience of informal caregivers of people with dementia. *Dementia (London)* 2015; 14: 220–37.

24 Clemmensen TH, Busted LM, Søborg J, Bruun P. The family's experience and perception of phases and roles in the progression of dementia: An explorative, interview-based study. *Dementia* 2016; 2016: 6.

25 Hjortbak BR. Rehabiliteringsforum Danmark editors. Challenges to rehabilitation in Denmark. Aarhus: Rehabiliteringsforum Danmark; 2011.

26 Hellstrom I, Hakanson C, Eriksson H, Sandberg J. Development of older men's caregiving roles for wives with dementia. *Scand J Caring Sci* 2017; 31: 957–64.

27 Egilstrod B, Ravn MB, Petersen KS. Living with a partner with dementia: a systematic review and thematic synthesis of spouses' lived experiences of changes in their everyday lives. *Aging Ment Health* 2019; 23: 541–50.

28 Hennings J, Froggatt K. The experiences of family caregivers of people with advanced dementia living in nursing homes, with a specific focus on spouses: A narrative literature review. *Dementia* 2019; 18: 303–22.

29 Busted LM, Nielsen DS, Birkelund R. The experience of being in the family of a person with early-stage dementia-a qualitative interview study. *Eur J Pers Cent Healthc* 2019; 7: 145–54.

30 Piersol CV, Canton K, Connor SE, Giller I, Lipman S, Sager S. Effectiveness of interventions for caregivers of people with Alzheimer's disease and related major neurocognitive disorders: a systematic review. *Am J Occup Ther* 2017; 71: 1–10.

31 Wade DT, Halligan PW. The biopsychosocial model of illness: a model whose time has come. *Clin Rehabil* 2017; 31: 995–1004.

32 Wade D. Rehabilitation–a new approach. Overview and Part One: the problems. *Clin Rehabil* 2015; 29: 1041–50.

33 Engel GL. The need for a new medical model: a challenge for biomedicine. *Science* 1977; 196: 129–36.

34 Parkinson M, Carr SM, Rushmer R, Abley C. Investigating what works to support family carers of people with dementia: a rapid realist review. *J Public Health* 2017; 39: e290–e301.

35 Hennink MM. *International Focus Group Research: A Handbook for the Health and Social Sciences*. 2007, Cambridge University Press, Cambridge.

36 Seale C. Quality in qualitative research. *Qual Inq* 1999; 5: 465–478.

37 Kvale S, Brinkmann S. *Interviews: Learning the Craft of Qualitative Research Interviewing*, 3rd edn. 2014. Sage Publications, Thousand Oaks, CA.

38 Elo S, Kyngas H. The qualitative content analysis process. *J Adv Nurs* 2008; 62: 107–15.

39 Lambert SD, Loiselle CG. Combining individual interviews and focus groups to enhance data richness. *J Adv Nurs* 2008; 62(2): 228–37.

40 de Vet HC, Terwee CB, Mokkink LB, Knol DL. *Measurement in Medicine: A Practical Guide*. 2011, Cambridge University Press, Cambridge.

41 Etters L, Goodall D, Harrison BE. Caregiver burden among dementia patient caregivers: a review of the literature. *J Am Acad Nurse Pract* 2008; 20: 423–28.

42 Sundhedsstyrelsen. Center for Evaluering og Medicinsk Teknologivurdering. CEMTV. Udredning og behandling af demens - en medicinsk teknologivurdering. København: Sundhedsstyrelsen; 2008.

43 Stalmeijer RE, Mcnaughton N, Van Mook WN. Using focus groups in medical education research: AMEE Guide No. 91. *Med Teach* 2014; 36: 923–39.

44 Colucci E. "Focus groups can be fun": The use of activity-oriented questions in focus group discussions. *Qual Health Res* 2007; 17: 1422–33.

45 Queluz FN, Kervin E, Wozney L, Fancey P, McGrath PJ, Keefe J. Understanding the needs of caregivers of persons with dementia: a scoping review. *Int Psychogeriatr* 2019; 10: 1–18.

46 Krippendorff K. *Content Analysis: An Introduction to its Methodology*, 3rd edn. 2013, SAGE, London; Los Angeles.

47 Graneheim UH, Lundman B. Qualitative content analysis in nursing research: concepts, procedures and measures to achieve trustworthiness. *Nurse Educ Today* 2004; 24: 105–12.

48 World Medical Association. World medical association declaration of Helsinki: Ethical principles for medical research involving human subjects. *JAMA* 2013; 310: 2191–94.

49 Ministry of Health and the Elderly. Komitéloven. Bekendtgørelse af lov om videnskabsetisk behandling af sundhedsvidenskabelige forskningsprojekter. LBK nr. 1083 15/9/2017. Lovtidende A 2017 22-09-2017;LBK nr 1083 af 15/09/2017 (European legislation identifier /eli/lta/2017/1083).

50 McGovern J. Couple meaning-making and dementia: challenges to the deficit model. *J Gerontol Soc Work* 2011; 54: 678–90.

51 Quinn C, Clare L, McGuinness T, Woods RT. The impact of relationships, motivations, and meanings on dementia caregiving outcomes. *Int Psychogeriatr* 2012; 24: 1816–26.

52 Hellström I, Nolan M. Lundh U. Sustaining 'couplehood': Spouses' strategies for living positively with dementia. *Dementia* 2007; 6: 383–409.

53 Quinn C, Clare L, Woods RT. The impact of motivations and meanings on the wellbeing of caregivers of people with dementia: a systematic review. *Int Psychogeriatr* 2010; 22: 43–55.

54 Cherry MG, Salmon P, Dickson J, Powell D, Sikdar S, Ablett J. Factors influencing the resilience of carers of individuals with dementia. *Rev Clin Gerontol* 2013; 23: 251–66.

55 Tatangelo G, McCabe M, Macleod A, Konis A. I just can't please them all and stay sane: Adult child caregivers' experiences of family dynamics in care-giving for a parent with dementia in Australia. *Health Soc Care Community* 2018; 26: e370–e377.

56 Teahan Á, Lafferty A, McAuliffe E, Phelan A, O'Sullivan L, O'Shea D

et al Resilience in family caregiving for people with dementia: A systematic review. *Int J Geriatr Psychiatry* 2018; 33: 1582–95.

57 Boots LM, Wolfs CA, Verhey FR, Kempen GI, de Vugt ME. Qualitative study on needs and wishes of early-stage dementia caregivers: the paradox between needing and accepting help. *Int Psychogeriatr* 2015; 27: 927–36.

58 Kralik D, Visentin K, Van Loon A. Transition: a literature review. *J Adv Nurs* 2006; 55: 320–29.

59 Veld Huis In Het, JG, Verkaik R, Mistiaen P, van Meijel B, Francke AL. . The effectiveness of interventions in supporting self-management of informal caregivers of people with dementia; a systematic meta review. *BMC Geriatr* 2015; 11: 147.

60 World Health Organization. ICF - International classification of functioning, disability and health. Geneva: World Health Organization; 2001.

61 Cieza A, Fayed N, Bickenbach J, Prodinger B. Refinements of the ICF Linking Rules to strengthen their potential for establishing comparability of health information. *Disabil Rehabil* 2016; 41: 1–10.

62 Ohman A. Qualitative methodology for rehabilitation research. *J Rehabil Med* 2005; 37: 273–80.

63 World Health Organization. How to use the ICF: A practical manual for using the International Classification of Functioning, Disability and Health (ICF). 2013;October.

64 Willoughby J, Keating N. Being in control: the process of caring for a relative with Alzheimer's Disease. *Qual Health Res* 1991; 1: 27–50.

65 Wilson HS. Family caregivers: the experience of Alzheimer's disease. *Appl Nurs Res* 1989; 2: 40–45.

66 Pini S, Ingleson E, Megson M, Clare L, Wright P, Oyebode JR. A Needs-led framework for understanding the impact of caring for a family member with dementia. *Gerontologist* 2018; 58: e68–e77.

67 Ewing G, Grande G. National Association for Hospice at Home. Development of a Carer Support Needs Assessment Tool (CSNAT) for end-of-life care practice at home: a qualitative study. *Palliat Med* 2013; 27: 244–56.

68 The Danish Alzheimer Association. Living with dementia. Report of a survey among informal caregivers to a person with dementia in Denmark. 2018;February.

69 Pillemer S, Davis J, Tremont G. Gender effects on components of burden and depression among dementia caregivers. *Aging Ment Health* 2018; 22: 1162–67.

70 Ericsson I, Kjellström S, Hellström I. Creating relationships with persons with moderate to severe dementia. *Dementia* 2013; 12: 63–79.

71 Johl N, Patterson T, Pearson L. What do we know about the attitudes, experiences and needs of Black and minority ethnic carers of people with dementia in the United Kingdom? A systematic review of empirical research findings. *Dementia (London)* 2016; 15: 721–42.

72 Saunders B, Sim J, Kingstone T, Baker S, Waterfield J, Bartlam B et al Saturation in qualitative research: exploring its conceptualization and operationalization. *Qual Quant* 2018; 52: 1893–1907.

Paper III

Development and Field-testing of the Dementia Carer Assessment of Support Needs Tool (DeCANT)

Original article

Development and Field-testing of the Dementia Carer Assessment of Support Needs Tool (DeCANT)

Trine Holt Clemmensen, M.H.Sc. [1, 2], Hanne Kaae Kristensen, Ph.D., Prof. [1, 3], Karen Andersen-Ranberg, Ph.D., Clin.Prof. [3, 4], Henrik Hein Lauridsen, Ph.D., Assoc.Prof. [2]

1 Health Sciences Research Centre, UCL University College, Denmark, Niels Bohrs Allé 1, DK-5230 Odense M. 2 Dept. of Sports Science and Clinical Biomechanics, University of Southern Denmark, Campusvej 55, DK-5230 Odense M. 3 Dept. of Clinical Research, University of Southern Denmark, Winsløwparken 19, 3rd floor, DK-5000 Odense C. 4 Dept. of Public Health, University of Southern Denmark, J.B. Winsløws Vej 9B, 2nd floor, .DK-5000 Odense C.

Corresponding author: Trine Holt Clemmensen, Niels Bohrs Allé 1, DK-5230 Odense M. Email address: thcl@ucl.dk orcid.org/0000-0002-6080-8883

Abstract

Objectives: Caring for a person with dementia is associated with poor mental, physical and social health, which makes it important to consider how carers are best supported in their caring role to preserve both their and the person with dementia's well-being. At present, a robust instrument to assess carers' support needs does not exist. This study aimed to develop a self-reported questionnaire to assess the support needs of carers of people with dementia. The objectives were to: 1) generate items, 2) pilot test, and 3) field-test the questionnaire.

Design: Development and field-testing of a new questionnaire.

Settings: Primary and secondary health and social care of informal carers and people with dementia in nine municipalities and one Dementia Clinic in a hospital in Denmark.

Participants: 8 experts, 12 carers and 7 digital users participated in pilot testing. 301 carers participated in field-testing.

Measurements: Items for inclusion were generated based on interviews and literature review. An iterative process of data collection was applied to establish face and content validity of the Dementia Carer Assessment of Support Needs Tool (DeCANT) using Content Validity Index among experts and cognitive interviews with carers. Field-testing of DeCANT among carers included using the 12-item Short Form Health Survey, the Barthel-20 Index and the Neuropsychiatric Inventory.

Results: Initially, an item pool of 63 items was generated, and pilot testing reduced this to 42 items. Subsequent field-testing resulted in a 25-item version of DeCANT, and Confirmatory Factor Analysis of three hypothesized models demonstrated a marginally better fit to a four-factor model with fit indices of: $\chi2=775.170$ ($p<0.001$), RMSEA=0.073, CFI=0.946, TLI=0.938 and WRMSV=1.265.

Conclusions: DeCANT is a 25-item carer-reported questionnaire that can be used to help identify their support needs when caring for a person with dementia to enable supportive interventions and improve carers' health and well-being.

Keywords

Dementia, Alzheimer's, carer, informal caregiver, support needs, instrument, questionnaire, assessment.

Introduction

Dementia is an illness that affects multidimensional aspects of daily living (Prince et al., 2015), not just for the individual with dementia, but also for the family and friends providing care (Giebel et al., 2019). Caring for a person with dementia is associated with poor mental, physical and social health of the carer (Schulz and Sherwood, 2008; Brodaty and Donkin, 2009). It is therefore important to consider how carers are best supported in their caring role to preserve their health and well-being, and subsequently the health and well-being of the person with dementia (Jackson and Browne, 2017). From a societal perspective, supporting carers may postpone the need for formal care, including institutionalisation, thereby significantly reducing costs (Jakobsen et al., 2011).

Carers report having unmet needs for support (Handels et al., 2018), and at the same time they are hesitant to use the formal supportive services available (Kerpershoek et al., 2019; Neville et al., 2015). The reported paradox of carers only being able to recognize their own needs retrospectively (Boots et al., 2015; McCabe et al., 2016) may explain why carers experience a lack of supportive interventions. In the context of health and social care, a systematic and holistic approach does not currently exist to assess carers' needs for support. Developing such an approach is important for effective targeting of supportive services. A holistic approach when organizing interventions is a rehabilitation process that suggests needs assessment and goal-setting precede any intervention, and that every single intervention be evaluated in accordance with this (Wade, Derick, 2016). Therefore, a logical first step would be to develop an instrument to assess carers' needs for support taking the physical, mental and social threats to health and well-being into consideration before initiating targeted supportive interventions.

Recent systematic reviews (Novais et al., 2017; Mansfield et al., 2017) of existing instruments assessing dementia carers' needs show only one instrument to be psychometrically robust – the Carers' Needs Assessment for Dementia (CNA-D) (Wancata et al., 2005). However, the CNA-D has been developed for research purposes only, and is not feasible for use in clinical settings, because it relies on a one-hour long professional interview. Another review also concludes that existing measures fail to take into account a conceptual framework developed for use in the context of carers focusing on both their carer role and the impact that their caring has on their well-being (Bangerter et al., 2019). The authors recommend that response options allow the carers to express the extent of their needs.

Carers' needs for support change throughout the disease trajectory of the person with dementia (Novais et al., 2017), and regular assessments are necessary to comply with the ever-changing challenges of daily living with dementia. It is therefore of paramount importance that any new instrument be feasible, easy to use and support the communication between the professional and the carer in order to give the right support at the right time. In addition, developing an instrument to assess the support needs of carers requires a comprehensive approach recognizing the multidimensional aspects of caring (McCabe et al., 2016; Tatangelo et al., 2018).

The aim of this study was to develop a self-reported questionnaire for carers to assess their support needs in caring for a person with dementia, which may be used collaboratively between carers and health and social care professionals throughout the disease trajectory and across settings. The objectives were to: 1) generate items, 2) pilot test a version of the questionnaire, and 3) field-test the questionnaire before further validation.

Methods

We developed a self-reported questionnaire following the procedures outlined by de Vet et al. (de Vet et al., 2011). The process included a review of existing literature and interviews with carers and professionals in primary and secondary care to represent the support needs of various types of carers (spouse, child, friend etc.) caring for a person with dementia at different stages of the disease.

Conceptual model

A person-centred approach, as reflected in the Biopsychosocial Model, was used as a conceptual model to define carers' support needs, as physical, psychological and social (Engel, 1977; Wade, D. T. and Halligan, 2017). Support needs arise in response to carers' functioning and ability to maintain health and well-being in daily life (Wade, D., 2015). Based on this, the new instrument was assumed to be multidimensional, comprising reflective items (de Vet et al., 2011).

Item generation

An item pool was generated based on the results of a scoping review of carers' support needs (unpublished data) and by qualitative interview findings (Clemmensen et al., 2020). To ensure comprehensiveness of support needs, items were generated for each sub-category identified in the review and the interviews. Words were carefully selected to reproduce carers' own language, and items were generated using an iterative process by the authors. Hence, item generation, reorganization and reduction were an ongoing process at this stage.

A four-point response scale of: *No (not relevant/need met); Yes, a little more*; *Yes, quite a bit more; Yes, very much more* was developed with inspiration from The Carer Support Needs Assessment Tool (CSNAT) for end-of-life care practice at home (Ewing et al., 2013). This was chosen to enable respondents to assess the relevance and importance of their support needs, not just the existence of a need.

Pilot testing

An iterative process of pilot testing in different care settings was applied to strengthen generalizability to relevant care settings and allow distribution by paper or electronically.

Pilot Test 1

The first draft of the Dementia Carer Assessment of Support Needs Tool (DeCANT) was evaluated with the content validity index (CVI) among a panel of experts to ensure comprehensiveness and comprehensibility (Artino et al., 2014; Polit and Beck, 2006). Experts were selected based on the following criteria (Artino et al., 2014): representative of dementia carers in general, or professionals in the area of dementia from different professions, and from different care settings (primary and secondary care).

Using a content validity index for items (I-CVI), the members of the expert panel were asked to independently evaluate representativeness, relevance and clarity of the items on a scale ranging from 1=*'Not relevant'* to 4=*'Highly relevant'* (Polit et al., 2007). The experts were also given the opportunity of free text commenting on, for example, sensitive wording, order of the items, and suggestions for improvement.

To calculate I-CVIs, the ordinal scale was dichotomized into relevant (ratings 3-4) and not relevant (ratings 1-2) and the proportion of experts in agreement with respect to relevance was calculated, and kappa statistics were used to measure agreement (Polit et al., 2007). I-CVIs with kappa above 0.75 were considered excellent agreement (Fleiss et al., 2003; Cicchetti and Sparrow, 1981), and items with low I-CVI and a kappa below 0.75 were evaluated for adjustment or removal based on experts' agreement and free text comments.

Pilot Test 2

Cognitive interviewing was used to pilot test prospective participant's responses to DeCANT (Artino et al., 2014). We used purposive sampling (Bernard, 2017) of participants in collaboration with health professionals in primary and secondary care settings based on the following criteria: 1) provide help to a person with dementia on a regular basis because of a personal relationship rather than financial compensation, 2) able to communicate in Danish, and 3) >18 years old.

A combination of verbal probing and think-aloud techniques were used in the interviews (Artino et al., 2014; de Vet et al., 2011). While filling out the instrument, participants were asked to think aloud which was followed by questions concerning comprehensibility, relevance, completeness, acceptability and feasibility.

The qualitative data were analyzed using deductive content analysis (Elo and Kyngas, 2008; Graneheim et al., 2017). Predefined categories comprising the probing questions guided coding of data from interviews to get an understanding of how participants interpret items.

Pilot Test 3

Due to both electronic and paper distribution in the following field-test, a supplementary pilot test was conducted to test the feasibility of an electronic version of the instrument. REDCap electronic data capture hosted at the Odense Patient data Explorative Network (OPEN), Odense University Hospital, Denmark was used for electronic data collection and management (Harris et al., 2019). Participants were purposively sampled (Bernard, 2017) to meet different criteria of age range (young to old), educational background (short to long) and use of electronic devices (PC, tablet or mobile phone). An e-mail with a link to the electronic version of DeCANT was sent and participants were asked to comment on comprehensibility and feasibility. Participants with comments highlighting problems were asked to participate in a short telephone interview. Qualitative analysis of comments was conducted as described in Pilot Test 2.

Field-test

A field-test was carried out to reduce the number of items and examine the structural validity of DeCANT.

Participants

Sample size was determined based on seven cases per item and a minimum of 100 participants (de Vet et al., 2011). A heterogeneous sample of carers was recruited by purposive sampling (Bernard, 2017) to achieve a study population representative of carers in different care settings and levels of progression of dementia in the person cared for. Inclusion criteria were the same as in Pilot Test 2. Participants were recruited from 1) nine municipalities in Denmark, 2) one dementia clinic in a hospital (Odense University Hospital), and 3) social media. Participants were contacted by telephone or e-mail to confirm their preference for distribution (e-mail or mail) of the survey.

Scoring issues

A profile of carers' support needs was created by summing responses for each subscale with *No* representing the value 0, *Yes, a little more* representing the value 1, *Yes, quite a bit more* representing the value 2 and *Yes, very much more* representing the value 3.

Instruments

In addition to DeCANT, the following instruments were used to describe participants and the person cared for:

The 12-item Short Form Health Survey (SF-12) was used to gather information on carers' general health and well-being. The SF-12 measures eight domains of physical functioning, physical role, bodily pain, general health, vitality, social functioning, emotional role, and mental health (Christensen et al., 2013). A summary of physical (PCS) and mental health (MCS) components was calculated as a T-score ranging from 0-100 with 100 reflecting better health.

The Barthel-20 Index (Barthel-20) was used to screen the level of functioning in Activities of Daily Living (ADL) in the person with dementia. It consisted of a total of 10 items and the carers filled out the questionnaire to the best of their ability to rate the level of independence of the person they cared for (Maribo et al., 2006; Collin et al., 1988). Barthel-20 was scored 0-20, with 20 representing independence in daily activities.

The Neuropsychiatric Inventory (NPI-Q) was used to measure cognitive and functional decline in the person with dementia. The NPI-Q assesses severity of symptoms and also carers' distress based on 10 items asking about neuropsychiatric symptoms such as apathy, depression and agitation (Kaufer et al., 2000; Kørner et al., 2008). Severity was scored 0-36, with 36 representing high severity. Distress was scored 0-60, with 60 representing high distress.

Follow up by telephone and e-mail was done after 4 to 6 weeks if participants did not respond.

Statistical analysis

Descriptive characteristics of carers were collected regarding carers' age, residence, education, employment and time spent caring. Also, information concerning the person with dementia was collected, e.g. specific diagnosis, the extent to which the person with dementia was affected by the disease in general and their utilisation of formal care. Frequencies, frequency distributions, mean, median, standard deviation and interquartile range were calculated for categorical and numerical variables.

Item score distribution

Frequencies of the responses were inspected at item level to consider whether all responses were informative and to evaluate the redundancy of items where a large proportion of participants chose the same response resulting in less discriminative power (de Vet et al., 2011).

Partial inter-item correlation

The relationship between items was examined using partial correlation to promote retention of unambiguous items in DeCANT (Marais and Andrich, 2008). Partial correlation between items should approach zero. Therefore, item pairs with partial correlation above 0.3 (van der Velde et al., 2009; Lundgren Nilsson and Tennant, 2011) were closely scrutinized, and items were dropped if content overlap was considered large and therefore redundant (Streiner et al., 2015).

Confirmatory Factor Analysis

Two four-factor models and one post hoc analysis model were hypothesized to reflect the multidimensionality of carers' support needs.

Model 1

Initial grouping of items was guided by a conceptual framework of four main categories (factors) derived from an inductive analysis of carers' and professionals' views on carers' support needs (Clemmensen et al., 2020). Carers' support needs were categorized into: 1) communicating and interacting with surroundings (i33, i37, i38, i41, i42), 2) daily life when caring for a person with dementia (i1, i3, i4, i6, i9), 3) maintaining own well-being (i22, i23, i24, i26, i27, i28, i30, i31, i32) and 4) focusing on themselves (i12, i13, i16, i18, i19, i21).

Model 2

The International Classification of Functioning (ICF) (World Health Organization, 2001) is based on the Biopsychosocial Model (Engel, 1977) and has been suggested as a framework to identify carers' support needs (World Health Organization, 2001). The ICF reflects a dynamic relationship between components of carers' functioning and contextual factors when caring. Linking rules described by Cieza et al. (Cieza et al., 2016) were used to categorize items into a first level ICF category: 1) environmental factors (i1, i21, i22, i26, i33, i37, i38, i41, i42), 2) activity and participation components (i3, i4, i6, i23, i28, i30, i31, i32), 3) personal factors (i9, i12, i13, i27), and 4) body structure/function components (i16, i18, i19, i24).

Post hoc analysis of Model 2

We believe the theoretical framework of ICF defining Model 2 to be a stronger model to describe the dimensionality of carers' support needs, because it explains the interaction of factors under the construct to be measured. In Classical Test Theory, local independence is implicitly assumed (Henning, 1989). Consequently, an inaccurate model may be hypothesized if local dependency exists, and hence we checked whether this assumption was fulfilled. If it was not, we allowed the corresponding items to correlate to take this local dependence into account, resulting in a third model.

We used CFA to assess the fit of the hypothesized models. Since the items were categorical, all models were fitted using Weighted Least Square Mean and Variance (WLSMV) estimation (Muthén and Muthén, 1998-2017). The goodness of fit of the model to the data was evaluated using five criteria: the chi-squared test (χ^2) including degrees of freedom (df) and p-values, the weighted root mean residual (WRMR), the root mean square error of approximation (RMSEA), the Tucker-Lewis Index (TLI) and the Comparative Fit Index (CFI) (Schreiber et al., 2006). We followed Schreiber et al.'s guidelines to indicate a close model fit for categorical data: χ^2 with non-significant p-values, WRMR < 0.90, RMSEA < 0.06, TLI > 0.95, CFI> 0.95 (Schreiber et al., 2006).

Local dependency within Model 2 was checked by calculating partial correlations (Greene, 2018), and values >0.3 indicated possible local dependency between items (van der Velde et al., 2009). Furthermore, we looked at modification indices and standardized residuals to see whether they suggested any improvements to the estimated model (Schreiber et al., 2006; Boateng et al., 2018).

Data were analyzed with Stata 15 IC (StataCorp, College Station, TX, USA), RUMM2030 (RuMM Laboratory P/L, Duncraig WA, Australia) and Mplus version 7.0 (Muthén and Muthén, 1998-2017).

Ethical considerations

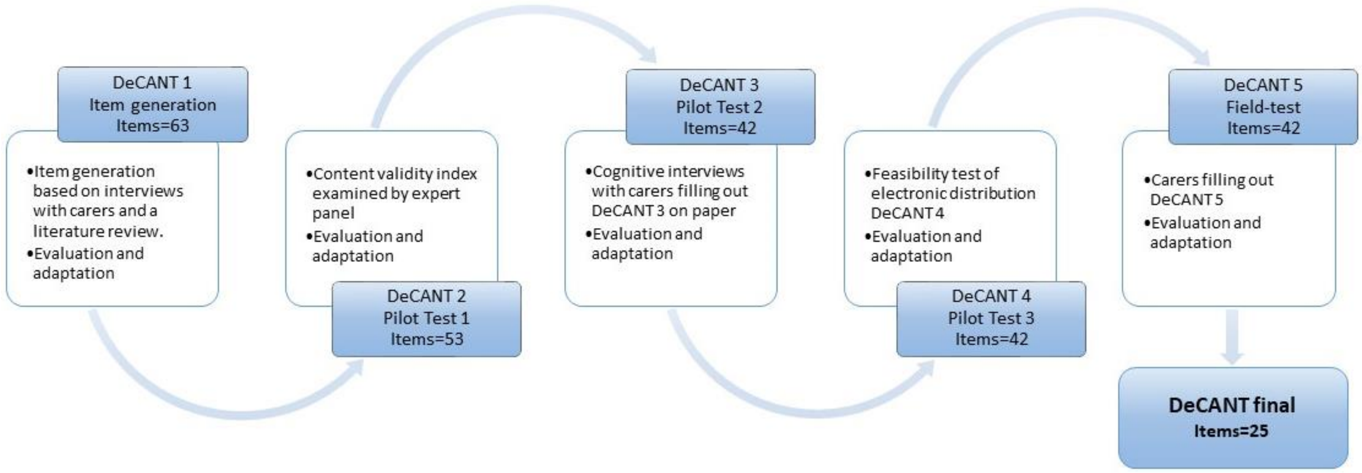
All participants gave their informed written consent, and the study was registered with the Danish Data Protection Agency (2015-57-0016-020a). According to Danish law, ethics committee approval was not required (Ministry of Health and the Elderly, 2017).

Results

Item generation

We initially generated 63 items reflecting carers' support needs (DeCANT 1). All items started with: 'Consider your present situation caring for the person with dementia. Do you have a need for support…' followed by the specific support need, for example '…to maintain your social network?' (item 4). Next, redundant items with similar wording and content were removed leaving a pool of 53 items. Figure 1 illustrates the development process of the DeCANT.

Figure 1 Flowchart of the development process of DeCANT from item generation to final version



Pilot testing

In Pilot Test 1, eight experts (1 carer, 1 NGO consultant, 2 nurses, 1 MD, 1 psychologist, 1 physiotherapist and 1 occupational therapist) rated the DeCANT using the CVI. I-CVIs ranged from 0.50-1.00 with Kappa values from fair to excellent (see supplementary material Appendix 1). Items with I-CVI < 0.78 (17 items) were more closely scrutinised by considering expert comments. This resulted in replacing some words and removing 11 items. For example, the item 'Do you have a need for support to get better opportunities to carry out daily activities?' was removed as experts found it less relevant and difficult to understand in addition to a low I-CVI (0.63).

In Pilot Test 2, 12 carers of a person with dementia participated in cognitive interviews. Participants comprised a heterogeneous group of carers from different care settings (the person with dementia was: 1) living at home n=4, 2) living in a nursing home n=6, 3) deceased n=2) and with varying relationships to the person cared for (2 brothers, 5 wives, 3 daughters, 1 ex-wife, 1 husband).

The participants spent 10 to 25 minutes answering DeCANT. Some found the item on sexuality inappropriate and the word ‘intimacy’ was used instead. Furthermore, the item ‘Do you have a need for support to be involved as an important collaborator in this collaborative caring work?’ (item 37) was found to be offending, because the carer assumed that he/she was an important collaborator. The item was changed to ‘Do you have a need for support to be involved in this collaborative caring work?

In Pilot Test 3, the electronic version was tested on 10 different electronic devices by seven participants. Follow up telephone interviews were conducted with three participants to elucidate difficulties. In general, participants found items and response options understandable, and they were able to fill out DeCANT without having questions or comments.

In summary, the pilot tests resulted in a 42-item version of DeCANT, which was used in the field-test (see supplementary material Appendix 2).

Field-test

In total, 434 carers were invited to participate. Three-hundred-and-one participants filled in the field-test version of the DeCANT on paper (19.93%) or electronically (80.07%). It was a heterogeneous sample comprised of carers with different relationships to the person cared for and by having different sociodemographic backgrounds (Table 1). The largest group of carers consisted of women and spouses of a person with Alzheimer’s, though other types of carers were also represented.

Table 1 Demographic characteristics of participants in the field-testing phase (n total=301)

Variable		
Sex (female), n (%)	236	(78.41)
Age (years), mean (min-max)	61,7	(23-95)
Relation to person with dementia, N (%)		
Spouse/partner	161	(53.67)
Child	123	(41.00)
Sibling	2	(0.67)
Other	14	(4.67)
Education, n (%)		
Elementary education	21	(7.22)
Secondary education	112	(38.49)
Higher education	139	(47.77)
Other	19	(6.53)
Employment, n (%)		
Paid employment	121	(40.88)
Unemployed/retired	161	(54.39)
Other (e.g. sick leave)	14	(4.73)
Residential status, n (%)		
Co-resident with person with dementia	128	(42.52)
Resides away from person with dementia	168	(55.81)
Living in the same municipality, n (%)		
Same municipality	212	(70.90)
Different municipalities	87	(29.10)
SF-12 carer, mean (SD)		
Physical health component	49.49	(11.29)
Mental health component	44.43	(12.59)
Diagnosis of person with dementia, n (%)		
Alzheimer's	198	(67.35)
Frontotemporal dementia	17	(5.78)
Lewy Body dementia	14	(4.76)
Vascular dementia	13	(4.42)
Mixed dementia diagnosis	14	(4.76)
Other	23	(7.82)
Don't know	15	(5.10)
Barthel-20 person with dementia, median (IQR*)	18	(6)
NPI-Q, median (IQR)		
Severity	6	(7)
Distress	7	(10)
Impact of dementia rated by carer, n (%)		
None	3	(1.01)
Low	34	(11.45)
Moderate	153	(51.52)
Severe	100	(33.67)
Don't know	7	(2.36)

* IQR, interquartile range

Item score distribution

In general, participants used all response categories and a maximum of 1% of the scores were missing per item. The most frequently used response category for almost all items was *No (not relevant/met need)*. Also, distribution of item scores showed that three items (i24, i29, i39) had a very high proportion of participants choosing the same response option yielding a right skewed distribution (Table 2).

Table 2 Frequencies table of item score distribution during DeCANT field-testing

Item # DeCANT version 5	N	Missing	No (not relevant/ need met)*	Yes, a little more*	Yes, quite a bit more*	Yes, very much more*
i1	298	3	150 (50.3)	89 (29.9)	36 (12.1)	23 (7.7)
i2	298	3	116 (38.9)	107 (35.9)	45 (15.1)	30 (10.1)
i3	298	3	190 (63.8)	62 (20.8)	26 (8.7)	20 (6.7)
i4	299	2	178 (59.5)	60 (20.1)	39 (13.0)	22 (7.4)
i5	299	2	193 (64.5)	51 (17.1)	33 (11.0)	22 (7.4)
i6	299	2	118 (39.5)	95 (31.8)	54 (18.1)	32 (10.7)
i7	298	3	129 (43.3)	99 (33.2)	44 (14.8)	26 (8.7)
i8	298	3	100 (33.6)	126 (42.3)	49 (16.4)	23 (7.7)
i9	299	2	102 (34.1)	105 (35.1)	54 (18.1)	40 (13.4)
i10	299	2	94 (31.4)	116 (38.8)	61 (20.4)	28 (9.4)
i11	299	2	117 (39.1)	118 (39.5)	41 (13.7)	23 (7.7)
i12	298	3	155 (52.0)	75 (25.2)	39 (13.1)	29 (9.7)
i13	298	3	143 (48.0)	84 (28.2)	48 (16.1)	23 (7.7)
i14	298	3	115 (38.6)	94 (31.5)	59 (19.8)	30 (10.1)
i15	298	3	139 (46.6)	92 (30.9)	46 (15.4)	21 (7.0)
i16	299	2	98 (32.8)	91 (30.4)	68 (22.7)	42 (14.0)
i17	299	2	110 (36.8)	113 (37.8)	50 (16.7)	26 (8.7)
i18	298	3	145 (48.7)	79 (26.5)	41 (13.8)	33 (11.1)
i19	299	2	125 (41.8)	79 (26.4)	52 (17.4)	43 (14.4)
i20	299	2	84 (28.1)	127 (42.5)	60 (20.1)	28 (9.4)
i21	299	2	95 (31.8)	97 (32.4)	67 (22.4)	40 (13.4)
i22	299	2	181 (60.5)	83 (27.8)	23 (7.7)	12 (4.0)
i23	299	2	175 (58.5)	72 (24.1)	34 (11.4)	18 (6.0)
i24	299	2	201 (67.2)	50 (16.7)	33 (11.0)	15 (5.0)
i25	299	2	161 (53.8)	84 (28.1)	39 (13.0)	15 (5.0)
i26	299	2	165 (55.2)	92 (30.8)	32 (10.7)	10 (3.3)
i27	299	2	148 (49.5)	101 (33.8)	38 (12.7)	12 (4.0)
i28	299	2	169 (56.5)	87 (29.1)	34 (11.4)	9 (3.0)
i29	299	2	199 (66.6)	71 (23.7)	24 (8.0)	5 (1.7)
i30	299	2	158 (52.8)	95 (31.8)	36 (12.0)	10 (3.3)
i31	299	2	131 (43.8)	102 (34.1)	51 (17.1)	15 (5.0)
i32	298	3	179 (60.1)	83 (27.9)	25 (8.4)	11 (3.7)
i33	300	1	161 (53.7)	80 (26.7)	38 (12.7)	21 (7.0)
i34	300	1	160 (53.3)	89 (29.7)	28 (9.3)	23 (7.7)
i35	299	2	121 (40.5)	109 (36.5)	41 (13.7)	28 (9.4)
i36	300	1	115 (38.3)	103 (34.3)	51 (17.0)	31 (10.3)
i37	299	2	137 (45.8)	96 (32.1)	38 (12.7)	28 (9.4)
i38	300	1	175 (58.3)	81 (27.0)	30 (10.0)	14 (4.7)
i39	299	2	200 (66.9)	58 (19.4)	23 (7.7)	18 (6.0)
i40	300	1	172 (57.3)	77 (25.7)	33 (11.0)	18 (6.0)
i41	300	1	91 (30.3)	95 (31.7)	75 (25.0)	39 (13.0)
i42	300	1	192 (64.0)	56 (18.7)	27 (9.0)	25 (8.3)

* N (%)

Partial inter-item correlation

We found 41 instances with high partial correlation between item pairs (>0.3). Each item pair was closely scrutinized for content overlap, item score distributions and the findings from the cognitive interviews, and this information was used to decide whether both items or only one item should be retained. Altogether, seventeen items were removed (i2, i5, i7, i8, i10, i11, i14, i15, i17, i29, i25, i29, i34, i35, i36, i39 and i40) resulting in a final 25-item version of the DeCANT (see supplementary material Appendix 3).

Confirmatory Factor Analysis

The factor structure of the 25-items version of the DeCANT was investigated by CFA.

Model 1: The 25 items were distributed, conforming to the four main categories guiding the structure of DeCANT: 1) communicating and interacting with surroundings (five items), 2) daily life when caring for a person with dementia (five items), 3) focusing on themselves (nine items) and 4) maintaining own well-being (six items) (see Appendix 2). All items had reasonable factor loadings ranging between 0.50 and 0.88. Fit indices for the model are represented in Table 3 and show a moderate fit.

Model 2: The 25 items were each linked to a first level ICF category (Cieza et al., 2016): 1) environmental factors (nine items), 2) activity and participation components (eight items), 3) personal factors (four items), and 4) body structure/function components (four items) (see Appendix 3). Significant factor loadings of items to the corresponding factor ranged between 0.47 and 0.92 (p<0.001). Further, analysis showed estimates of goodness of fit resembling the estimates of Model 1 (see Table 3).

Table 3 CFA fit indices for the analyzed models (n=298)

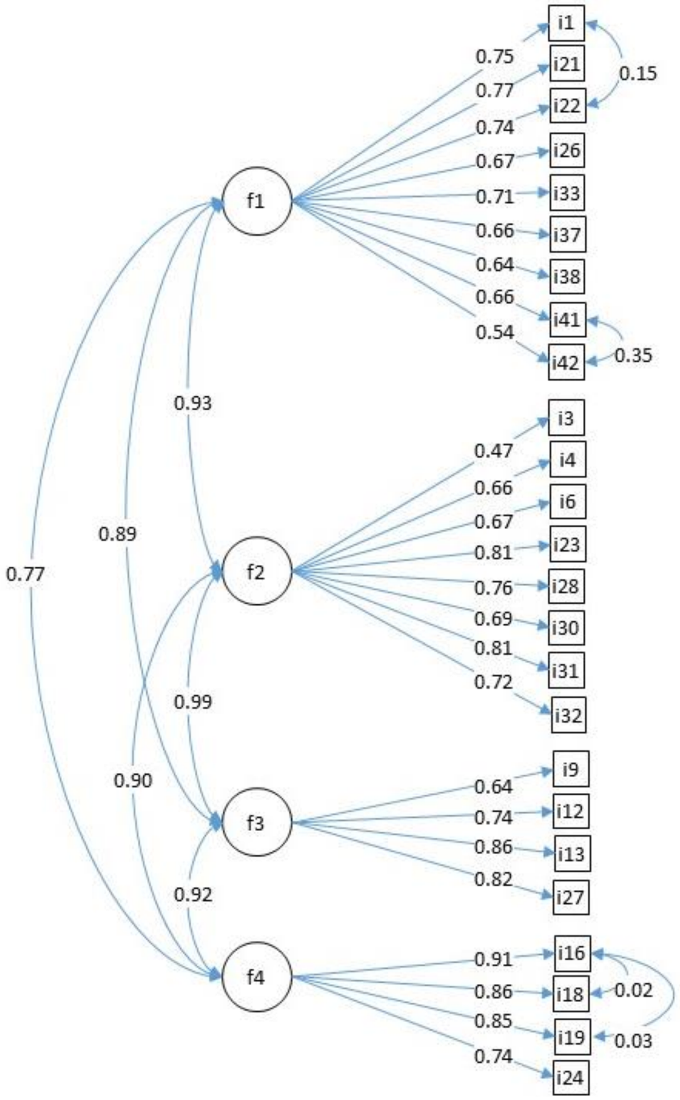
	Chi-squared (χ^2)	**Degrees of Freedom**	**P-Value**	**RMSEA (90% C.I.)**	**Probability RMSEA <= .05**	**CFI**	**TLI**	**WRMR**
Model 1: Four factor model based on inductive categories	833.447	269	<0.001	0.083 (0.077-0.090)	0.000	0.934	0.927	1.342
Model 2: Four factor model based on ICF framework	851.985	270	<0.001	0.084 (0.078-0.091)	0.000	0.932	0.925	1.393
Post hoc analysis of Model 2	775.170	266	<0.001	0.073 (0.068- 0.079)	0.000	0.946	0.938	1.265

Post hoc analysis of Model 2: We found possible local dependency between four item pairs (i1 and i22, i16 and 18, i16 and i19, i41 and i42), and we allowed these items to correlate in this post hoc model as an addition to Model 2. CFA resulted in some improvement in all fit indices compared with Models 1 and 2 with estimates of

χ^2=775.170 (p<0.001), RMSEA=0.073, CFI=0.946, TLI=0.938 and WRMSV=1.265 (Table 3). Factor loadings of the improved model ranged between 0.47 and 0.91 (Figure 2).

Inspection of modification indices and standardized residuals showed no indicators for improvement of the analyzed models.

Figure 2 Diagram showing factor loadings of the post hoc analysis of Model 2



Note The circles represent the four factors in the Post hoc analysis of Model 2 (f1=factor 1, f2=factor 2, f3=factor 3, f4=factor 4), and the squares represent items, i.e. i1=item 1. The arrows between factors describe factor correlations. The arrows from factors to items describe item factor loadings. Arrows between items show their correlated error.

Discussion

We have addressed the need for a self-reported instrument to assess carers' support needs when caring for a person with dementia throughout the disease trajectory and across settings in health and social care. Careful investigation of the literature and carers' and professionals' views on carers' support needs resulted in a 25-item version of the DeCANT that measured four dimensions of carer support needs when caring for a person with dementia: 1) communicating and interacting with surroundings, 2) daily life when caring for a person with dementia, 3) focusing on themselves and 4) maintaining own well-being.

The Biopsychosocial Model (Engel, 1977; Wade, D. T. and Halligan, 2017), used as an overall conceptual model to understand the complexity of carers' support needs, has its origin in the health sciences, which may seem inappropriate as caring in itself is not characterised as a health problem. However, caring has been shown to threaten carers' health, well-being and functioning in daily life (Schulz and Sherwood, 2008; Brodaty and Donkin, 2009), and the Biopsychosocial Model allows for a person-centred and multidimensional way of identifying carers' support needs when caring for a closely related person with dementia. Issues related to carers' social or psychological functioning are thus considered equal to potential physical disabilities (Engel, 1977; Wade, D. T. and Halligan, 2017).

The construct of carers' support needs measured by DeCANT has required substantial work focused on maximising the extent to which generated items reflect the support needs of the target population (de Vet et al., 2011). When assessing support needs, it is essential that carers' subjective views on what is helpful is emphasised as opposed to only those arising from professional judgment (Hjortbak and Rehabiliteringsforum Danmark, 2011). However, including both views when generating items is important, because carers may not be able to acknowledge (Boots et al., 2015) and/or articulate (Stirling et al., 2010) all of their own needs. Furthermore, our response categories were specifically designed to reflect a person-centred approach (Sharma et al., 2015) respecting both subjective and professional views when assessing carers' support needs, because carers have to decide whether a support need is relevant to them or not, and if considered to be so, to assess the extent of needed support.

Content validity of items was investigated using several methods. In Pilot Test 1, a panel of experts assessed the comprehensiveness and comprehensibility of the first draft of DeCANT. However, the criteria used for selection of the expert panel members may have resulted in too much focus on professional judgment, and we therefore decided that items with I-CVI<0.78 were not automatically removed. Instead, removal of items at this stage was decided among the author team using information from both I-CVI and investigations preceding item generation to boost the carer's perspective. During the cognitive interviews in Pilot Test 2, carers pointed out that the sensitive content in DeCANT obligated professionals to follow up on identified needs. This is important when implementing DeCANT in future health and social care, because DeCANT in itself may start a dialogue between carers and professionals. Creating a trusting relationship with professionals is the most important facilitator of carers' use of supportive services (Stephan et al., 2018). Using DeCANT may therefore be a feasible way of facilitating a positive and balanced dialogue between carers and professionals.

Investigating the item score distributions revealed a floor effect in all items for the response category '*No (not relevant/met need)'*. This was to be expected, as the response option contains three different answers of 'no': 'no need for support', 'support need is not relevant' and 'support need is met'. Designing the response category in this way may have caused problems discriminating carers' responses. However, the focus of DeCANT was to provide information that identified support needs: not why a carer did not have a need for support.

CFA of Model 1 and Model 2 demonstrated almost the same fit indices of a moderate fitting model. Post hoc analysis of Model 2 including possible local dependency showed a marginally improved fit and we believe this model to be the best fit when describing the factor structure of DeCANT, because it is based on a strong theoretical framework (Schreiber et al., 2006) taking into account the dynamic interaction of carers' support needs in the context of caring (Clemmensen et al., 2020). Although fit indices from post hoc analysis of Model 2 imply an acceptable fit of observed data, further testing of the factor structure should be performed in more and larger samples (Boateng et al., 2018; Hu and Bentler, 1999).

In the post hoc analysis of Model 2, all items demonstrated high factor loadings above 0.60. Only one item (i3: 'Do you have a need for support to manage everyday chores?') showed a lower loading of 0.47, which we considered acceptable. This item differed from other items by containing information on support needs of the person with dementia, not the carer, indicating that the item may describe a latent trait different from that intended. Nevertheless, we believe that item i3 is an example of the inter-relatedness of carers' support needs in the context of caring as described by the theoretical framework. Thus, indirectly asking about the need for support in daily living from the person with dementia clarified if the carers' individual resources to manage care were balanced.

Using DeCANT

Consensus on a comprehensive framework to identify dementia carers' support needs is lacking (Bangerter et al., 2019). In future health and social care, DeCANT, with its holistic and person-centred approach based on the ICF framework and Biopsychosocial Model, may be used to identify carers' support needs in general. We designed DeCANT to enable an individually tailored and quick way of profiling support needs most important to carers in the specific context of caring. Carers' needs are complex, because they are affected by the support needs of the person cared for, the individual resources and priorities of the carers, as well as the context in which the caring occurs (Bangerter et al., 2019; McCabe et al., 2016). By summing each subscale, professionals can track individual support needs and follow them over time, thereby evaluating individual progress and the effects of implementing new carer support initiatives.

Strength and limitations

We strived for a heterogeneous sampling of carers in the field-testing of DeCANT to be applicable to the various settings intended for use. Although a strategy of recruiting a heterogeneous sample of carers was used in this study, participants were primarily female or spouses, which may reduce the representativeness of the sample. However, this seems to be a general pattern in dementia research when recruiting carers (The Danish Alzheimer Association, 2018). In contrast, our sample included a large proportion of non-spousal carers and carers reporting great variety of dementia severity in the person cared for, which suggests that our sample may be more representative of various types of carers and caring contexts.

A limitation of our study is the small sample size (n=301). Larger samples with a larger participant/ item ratio of at least 10 participants per item is preferable in CFA (Boateng et al., 2018) as more stable factor loadings and lower measurement errors are obtained. Thus, replication of DeCANT's factor structure is necessary to ensure generalisability of the suggested structure in similar populations (Boateng et al., 2018).

Development of DeCANT followed a rigorous stepwise procedure for questionnaire development (de Vet et al., 2011). However, before using DeCANT in practice, further research is needed to examine its psychometric properties (de Vet et al., 2011). Hence, we recommend investigation of its construct validity by comparing DeCANT with existing measures of carers' health and well-being and test-retesting of reliability as next steps.

Conclusion

We developed a 25-item self-reported instrument (DeCANT) to identify carers' support needs when caring for a person with dementia. Confirmatory Factor Analysis demonstrated a moderate fit to a four-factor model assessing carers' support needs in daily life, maintaining own well-being, focusing on themselves, and communicating and interacting with surroundings. We suggest that DeCANT be used a) to help identify carers' support needs when caring for a person with dementia to enable supportive interventions in a timely manner; b) to increase the awareness of carers' support needs to improve carers' health and well-being and, by extension, the person being cared for; and c) as an outcome measure, to evaluate supportive interventions in everyday health and social care.

Conflict of interest

None.

Description of authors' roles

THC designed the study, carried it out, analyzed the data and wrote the manuscript. HHL contributed to the design, supervised the data collection and data analysis and assisted with writing the manuscript. HKK and KAR contributed to the design, supervised the data collection and critical revision of the article. All authors contributed to the generation, evaluation and discussion of the items.

Acknowledgements

This work was supported by UCL University College Denmark, The Danish Alzheimer Association and The Association of Danish Physiotherapists. Also, a special thanks to Jens Søndergaard Jensen, University Hospital of Aarhus, Denmark, for supervising the statistical analysis.

Supplementary files

Appendix 1: Content validity assessments in Pilot Test 1 of DeCANT version 2

Appendix 2: Presentation of items in the DeCANT field-testing version 5 (42 items)

Appendix 3: Presentation of items in the DeCANT final version (25 items).

References

Artino, A.R.,Jr, La Rochelle, J.S., Dezee, K.J. and Gehlbach, H. (2014). Developing questionnaires for educational research: AMEE Guide No. 87. Medical teacher, vol. 36, no. 6, pp. 463-474. doi:10.3109/0142159X.2014.889814.

Bangerter, L.R., Griffin, J.M., Zarit, S.H. and Havyer, R. (2019). Measuring the Needs of Family Caregivers of People With Dementia: An Assessment of Current Methodological Strategies and Key Recommendations. Journal of Applied Gerontology, vol. 38, no. 9, pp. 1304-1318. doi:10.1177/0733464817705959.

Bernard, H.R. (2017). Research methods in anthropology: Qualitative and quantitative approaches, 6th edn. Lanham: Rowman & Littlefield.

Boateng, G.O., Neilands, T.B., Frongillo, E.A., Melgar-Quinonez, H.R. and Young, S.L. (2018). Best Practices for Developing and Validating Scales for Health, Social, and Behavioral Research: A Primer. Frontiers in public health, vol. 6, pp. 149. doi:10.3389/fpubh.2018.00149.

Boots, L.M., Wolfs, C.A., Verhey, F.R., Kempen, G.I. and de Vugt, M.E. (2015). Qualitative study on needs and wishes of early-stage dementia caregivers: the paradox between needing and accepting help. International psychogeriatrics, vol. 27, no. 6, pp. 927-936. doi:10.1017/S1041610214002804.

Brodaty, H. and Donkin, M. (2009). Family caregivers of people with dementia. Dialogues in clinical neuroscience, vol. 11, no. 2, pp. 217-228.

Christensen, L.N., Ehlers, L., Larsen, F.B. and Jensen, M.B. (2013). Validation of the 12 Item Short form Health Survey in a Sample from Region Central Jutland. Social Indicators Research, vol. 114, no. 2, pp. 513-521. doi:10.1007/s11205-012-0159-9.

Cicchetti, D.V. and Sparrow, S.A. (1981). Developing criteria for establishing interrater reliability of specific items: applications to assessment of adaptive behavior. American Journal of Mental Deficiency, vol. 86, no. 2, pp. 127-137.

Cieza, A., Fayed, N., Bickenbach, J. and Prodinger, B. (2016). Refinements of the ICF Linking Rules to strengthen their potential for establishing comparability of health information. Disability and rehabilitation, vol. 41, no. 5, pp. 1-10. doi:10.3109/09638288.2016.1145258.

Clemmensen, T.H., Lauridsen, H.H., Andersen-Ranberg, K. and Kristensen, H.K. (2020). 'I know his needs better than my own'–carers’ support needs when caring for a person with dementia. Scandinavian Journal of Caring Sciences, .

Collin, C., Wade, D., Davies, S. and Horne, V. (1988). The Barthel ADL Index: a reliability study. International disability studies, vol. 10, no. 2, pp. 61-63. doi:10.3109/09638288809164103.

de Vet, H.C., Terwee, C.B., Mokkink, L.B. and Knol, D.L. (2011). Measurement in Medicine : A Practical Guide, . Cambridge: Cambridge University Press.

Elo, S. and Kyngas, H. (2008). The qualitative content analysis process. Journal of advanced nursing, vol. 62, no. 1, pp. 107-115. doi:10.1111/j.1365-2648.2007.04569.x.

Engel, G.L. (1977). The need for a new medical model: a challenge for biomedicine. Science (New York, N.Y.), vol. 196, no. 4286, pp. 129-136. doi:10.1126/science.847460.

Ewing, G., Grande, G. and National Association for Hospice at Home (2013). Development of a Carer Support Needs Assessment Tool (CSNAT) for end-of-life care practice at home: a qualitative study. Palliative medicine, vol. 27, no. 3, pp. 244-256. doi:10.1177/0269216312440607.

Fleiss, J.L., Levin, B. and Paik, M.C. (2003). Statistical methods for rates and proportions, 3rd edn. New Jersey: John Wiley & Sons.

Giebel, C.M., Davies, S., Clarkson, P., Sutcliffe, C., Challis, D. and HoSt-D (Home Support in Dementia) Programme Management Group (2019). Costs of formal and informal care at home for people with dementia:‘Expert panel’opinions from staff and informal carers. Dementia, vol. 18, no. 1, pp. 210-227. doi:10.1177/1471301216665705.

Graneheim, U.H., Lindgren, B.M. and Lundman, B. (2017). Methodological challenges in qualitative content analysis: A discussion paper. Nurse education today, vol. 56, pp. 29-34. doi:S0260-6917(17)30142-9 [pii].

Greene, W.H. (2018). Econometric analysis, 8th edn. New York, NY: Pearson.

Handels, R.L., et al (2018). Quality of life, care resource use, and costs of dementia in 8 European countries in a cross-sectional cohort of the actifcare study. Journal of Alzheimer's Disease, , no. Preprint, pp. 1-14. doi:10.3233/JAD-180275.

Harris, P.A., et al (2019). The REDCap consortium: Building an international community of software platform partners. Journal of Biomedical Informatics, vol. 95, pp. 103208-(1-10). doi:10.1016/j.jbi.2019.103208.

Henning, G. (1989). Meanings and implications of the principle of local independence. Language testing, vol. 6, no. 1, pp. 95-108. doi:10.1177/026553228900600108.

Hjortbak, B.R. and Rehabiliteringsforum Danmark (eds) (2011). Challenges to rehabilitation in Denmark. Aarhus: Rehabiliteringsforum Danmark.

Hu, L. and Bentler, P.M. (1999). Cutoff criteria for fit indexes in covariance structure analysis: Conventional criteria versus new alternatives. Structural Equation Modeling: A Multidisciplinary Journal, vol. 6, no. 1, pp. 1-55. doi:10.1080/10705519909540118.

Jackson, G.A. and Browne, D. (2017). Supporting carers of people with dementia: what is effective? BJPsych Advances, vol. 23, no. 3, pp. 179-186. doi:10.1192/apt.bp.113.011288.

Jakobsen, M., Poulsen, P.B., Reiche, T., Nissen, N.P. and Gundgaard, J. (2011). Costs of informal care for people suffering from dementia: evidence from a danish survey. Dementia and geriatric cognitive disorders extra, vol. 1, no. 1, pp. 418-428. doi:10.1159/000333812.

Kaufer, D.I., et al (2000). Validation of the NPI-Q, a brief clinical form of the Neuropsychiatric Inventory. The Journal of neuropsychiatry and clinical neurosciences, vol. 12, no. 2, pp. 233-239. doi:10.1176/jnp.12.2.233.

Kerpershoek, L., et al (2019). Optimizing access to and use of formal dementia care: Qualitative findings from the European Actifcare study. Health & social care in the community, vol. 27, no. 5, pp. e814-e823. doi:10.1111/hsc.12804.

Kørner, A., Lauritzen, L., Lolk, A., Abelskov, K., Christensen, P. and Nilsson, F.M. (2008). The Neuropsychiatric Inventory—NPI. Validation of the Danish version. Nordic journal of psychiatry, vol. 62, no. 6, pp. 481-485. doi:10.1080/08039480801985146.

Lundgren Nilsson, A. and Tennant, A. (2011). Past and present issues in Rasch analysis: the functional independence measure (FIM) revisited. Journal of Rehabilitation Medicine, vol. 43, no. 10, pp. 884-891. doi:10.2340/16501977-0871.

Mansfield, E., Boyes, A.W., Bryant, J. and Sanson-Fisher, R. (2017). Quantifying the unmet needs of caregivers of people with dementia: a critical review of the quality of measures. International journal of geriatric psychiatry, vol. 32, no. 3, pp. 274-287. doi:10.1002/gps.4642.

Marais, I. and Andrich, D. (2008). Formalizing dimension and response violations of local independence in the unidimensional Rasch model. Journal of applied measurement, vol. 9, no. 3, pp. 200-215.

Maribo, T., Lauritsen, J., Wæhrens, E.E., Poulsen, I. and Hesselbo, B. (2006). Barthel indeks til vurdering af funktionsevne: Dansk konsensus om brug. Ugeskrift for læger, vol. 168, no. 34, pp. 2790-2792.

McCabe, M., You, E. and Tatangelo, G. (2016). Hearing Their Voice: A Systematic Review of Dementia Family Caregivers' Needs. The Gerontologist, vol. 56, no. 5, pp. e70-88. doi:10.1093/geront/gnw078.

Ministry of Health and the Elderly (ed) (2017). Komitéloven. Bekendtgørelse af lov om videnskabsetisk behandling af sundhedsvidenskabelige forskningsprojekter. LBK nr. 1083 15/9/2017.

Muthén, L.K. and Muthén, B.O. (1998-2017). Mplus User's Guide. Eighth edn. Los Angeles, CA: Muthén & Muthén.

Neville, C., Beattie, E., Fielding, E. and MacAndrew, M. (2015). Literature review: Use of respite by carers of people with dementia. Health & Social Care in the Community, vol. 23, no. 1, pp. 51-63. doi:10.1111/hsc.12095.

Novais, T., Dauphinot, V., Krolak-Salmon, P. and Mouchoux, C. (2017). How to explore the needs of informal caregivers of individuals with cognitive impairment in Alzheimer's disease or related diseases? A systematic review of quantitative and qualitative studies. BMC geriatrics, vol. 17, no. 1, pp. 86-(1-18). doi:10.1186/s12877-017-0481-9.

Polit, D.F. and Beck, C.T. (2006). The content validity index: are you sure you know what's being reported? Critique and recommendations. Research in nursing & health, vol. 29, no. 5, pp. 489-497. doi:10.1002/nur.20147.

Polit, D.F., Beck, C.T. and Owen, S.V. (2007). Is the CVI an acceptable indicator of content validity? Appraisal and recommendations. Research in nursing & health, vol. 30, no. 4, pp. 459-467. doi:10.1002/nur.20199.

Prince, M., Guerchet, M.M., Ali, G.C., Wu, Y. and Prina, M. (2015). World Alzheimer Report 2015 - The Global Impact of Dementia: An analysis of prevalence, incidence, cost and trends, Alzheimer's Disease International.

Schreiber, J.B., Nora, A., Stage, F.K., Barlow, E.A. and King, J. (2006). Reporting Structural Equation Modeling and Confirmatory Factor Analysis Results: A Review. Journal of Educational Research, vol. 99, no. 6, pp. 323-338. doi:10.3200/JOER.99.6.323-338.

Schulz, R. and Sherwood, P.R. (2008). Physical and mental health effects of family caregiving. The American Journal of Nursing, vol. 108, no. 9 Suppl, pp. 23-27. doi:10.1097/01.NAJ.0000336406.45248.4c.

Sharma, T., Bamford, M. and Dodman, D. (2015). Person-centred care: an overview of reviews. Contemporary nurse, vol. 51, no. 2-3, pp. 107-120. doi:10.1080/10376178.2016.1150192.

Stephan, A., et al (2018). Barriers and facilitators to the access to and use of formal dementia care: findings of a focus group study with people with dementia, informal carers and health and social care professionals in eight European countries. BMC geriatrics, vol. 18, no. 1, pp. 131-(1-16). doi:10.1186/s12877-018-0816-1.

Stirling, C., Andrews, S., Croft, T., Vickers, J., Turner, P. and Robinson, A. (2010). Measuring dementia carers' unmet need for services-an exploratory mixed method study. BMC health services research, vol. 10, pp. 122-(1-10). doi:10.1186/1472-6963-10-122.

Streiner, D.L., Norman, G.R. and Cairney, J. (2015). Health measurement scales: a practical guide to their development and use, Fifth edn. USA: Oxford University Press.

Tatangelo, G., McCabe, M., Macleod, A. and You, E. (2018). "I just don't focus on my needs." The unmet health needs of partner and offspring caregivers of people with dementia: A qualitative study. International journal of nursing studies, vol. 77, pp. 8-14. doi:S0020-7489(17)30218-3 [pii].

The Danish Alzheimer Association (2018). Living with dementia. Report of a survey among informal caregivers to a person with dementia in Denmark. Copenhagen: The Danish Alzheimer Association.

van der Velde, G., Beaton, D., Hogg-Johnston, S., Hurwitz, E. and Tennant, A. (2009). Rasch analysis provides new insights into the measurement properties of the neck disability index. Arthritis Care & Research: Official Journal of the American College of Rheumatology, vol. 61, no. 4, pp. 544-551. doi:10.1002/art.24399.

Wade, D. (2016). Rehabilitation–a new approach.Part three: the implications of the theories. Clinical Rehabilitation, vol. 30, no. 1, pp. 3-10. doi:10.1177/0269215515601176.

Wade, D. (2015). Rehabilitation - a new approach. Part two: the underlying theories. Clinical rehabilitation, vol. 29, no. 12, pp. 1145-1154. doi:10.1177/0269215515601175.

Wade, D.T. and Halligan, P.W. (2017). The biopsychosocial model of illness: a model whose time has come. Clinical rehabilitation, vol. 31, no. 8, pp. 995-1004. doi:10.1177/0269215517709890.

Wancata, J., et al (2005). The Carers' Needs Assessment for Dementia (CNA-D): development, validity and reliability. International psychogeriatrics, vol. 17, no. 3, pp. 393-406. doi:10.1017/S1041610205001699.

World Health Organization (2001). ICF - International classification of functioning, disability and health. Geneva: World Health Organization.

Appendix 1: Content validity assessments in Pilot Test 1 of DeCANT version 2.

Item# DeCANT version 2	**Content validity assessments**								**Experts in agreement[a]**	**I-CVI**	**Kappa[b]**	**Evaluation**
	Expert 1	**Expert 2**	**Expert 3**	**Expert 4**	**Expert 5**	**Expert 6**	**Expert 7**	**Expert 8**				
i1	4	4	4	4	4	3	4	4	8	1.00	1.0	Excellent
i2	2	2	3	4	4	4	3	4	6	0.75	0.72	Good
i3	2	3	4	2	4	3	4	3	6	0.75	0.72	Good
i4	4	4	3	4	3	3	3	4	8	1.00	1.0	Excellent
i5	4	3	2	4	4	4	2	4	6	0.75	0.72	Good
i6	4	4	2	3	3	3	2	2	5	0.63	0.53	Fair
i7	4	4	4	3	4	4	4	4	8	1.00	1.0	Excellent
i8	4	4	4	4	4	4	4	3	8	1.00	1.0	Excellent
i9	4	4	4	3	4	4	4	2	7	0.88	0.88	Excellent
i10	4	4	4	4	4	4	4	2	7	0.88	0.88	Excellent
i11	4	4	4	4	4	4	4	3	8	1.00	1.0	Excellent
i12	4	4	4	2	4	4	4	4	7	0.88	0.88	Excellent
i13	4	4	4	4	4	4	4	4	8	1.00	1.0	Excellent
i14	4	3	2	2	4	3	2	3	5	0.63	0.53	Fair
i15	1	4	4	2	4	3	4	4	6	0.75	0.72	Good
i16	4	4	3	3	4	4	3	4	8	1.00	1.0	Excellent
i17	4	4	2	3	4	3	2	4	6	0.75	0.72	Good
i18	4	4	3	3	4	4	3	4	8	1.00	1.0	Excellent
i19	4	2	4	4	4	4	4	2	6	0.75	0.72	Good
i20	4	3	3	3	3	4	3	4	8	1.00	1.0	Excellent
i21	4	3	4	4	4	4	4	4	8	1.00	1.0	Excellent
i22	4	4	4	3	4	4	4	3	8	1.00	1.0	Excellent
i23	1	4	4	3	4	4	4	4	7	0.88	0.88	Excellent
i24	4	2	2	2	3	3	2	3	4	0.50	0.31	Poor
i25	1	4	3	3	4	4	3	2	6	0.75	0.72	Good
i26	1	3	3	3	3	4	3	2	6	0.75	0.72	Good
i27	4	3	2	3	3	3	2	4	6	0.75	0.72	Good
i28	3	4	4	3	4	3	4	2	7	0.88	0.88	Excellent
i29	3	4	4	4	4	4	4	3	8	1.00	1.0	Excellent
i30	1	4	3	4	4	4	3	4	7	0.88	0.88	Excellent
i31	1	4	2	4	4	4	2	2	4	0.50	0.31	Poor
i32	4	4	2	4	4	4	2	4	6	0.75	0.72	Good
i33	3	4	3	4	4	4	3	4	8	1.00	1.0	Excellent
i34	4	4	3	4	4	4	3	4	8	1.00	1.0	Excellent
i35	4	4	4	4	4	4	4	4	8	1.00	1.0	Excellent
i36	4	4	4	3	4	4	4	4	8	1.00	1.0	Excellent
i37	4	3	4	3	4	4	4	4	8	1.00	1.0	Excellent
i38	4	4	4	4	3	4	4	4	8	1.00	1.0	Excellent
i39	4	3	3	2	4	4	3	4	7	0.88	0.88	Excellent
i40	4	4	4	4	4	4	4	4	8	1.00	1.0	Excellent
i41	1	4	4	3	4	4	4	4	8	0.88	0.88	Excellent
i42	4	4	4	4	4	4	4	4	8	1.00	1.0	Excellent
i43	4	4	4	4	4	4	4	4	8	1.00	1.0	Excellent
i44	4	4	3	3	4	4	3	3	8	1.00	1.0	Excellent
i45	1	3	2	3	3	3	2	2	4	0.50	0.31	Poor
i46	4	4	3	3	3	4	3	4	8	1.00	1.0	Excellent
i47	1	4	3	2	3	1	3	4	5	0.63	0.53	Fair
i48	4	4	4	4	4	4	4	4	8	1.00	1.0	Excellent
i49	4	4	4	3	3	4	4	4	8	1.00	1.0	Excellent
i50	4	4	4	3	4	4	4	4	8	1.00	1.0	Excellent
i51	4	4	4	4	4	4	4	4	8	1.00	1.0	Excellent
i52	4	4	4	3	4	4	4	2	7	0.75	0.72	Good
i53	4	4	3	4	4	4	3	3	8	1.00	1.0	Excellent
Proportion relevant[a]	0,79	0,94	0,83	0,87	1,00	0,98	0,83	0,81				

[a] Based on dichotomised scores of relevance (1-2= irrelevant, 3-4=relevant). [b] Kappa of I-CVIs are calculated according to Polit et al. (Polit et al., 2007).

Appendix 2: Presentation of items in the DeCANT field-testing version 5 (42 items).

Item# DeCANT version 5	**42 item version of DeCANT used in the field-testing**
Consider your present situation caring for the person with dementia. Do you have a need for support...	
Daily life when caring for a person with dementia	
i1	...to make sure that services targeted the person with dementia conform to your daily life?
i2	...for activities to the person with dementia
i3	...to manage everyday chores (e.g. dressing, cleaning, transportation)?
i4	...to maintain your social network?
i5	...to transportation of the person with dementia (e.g. to the GP, hairdresser etc.)?
i6	...to manage changed behaviour in the person with dementia (e.g. aggressive, restless or passive behaviour)?
i7	...to improve your communication skills in relation to the person with dementia?
i8	...to manage the person with dementia's loss of memory?
i9	...to manage person with dementia's lack of disease awareness?
i10	...to solve problems in everyday life with the person with dementia?
i11	...to get information on assistive aids (e.g. assistive technologies)?
Focusing on themselves	
i12	...to feel appreciated in what you are doing for the person with dementia?
i13	...to ask for help for yourself?
i14	...to get information on help and counselling for yourself?
i15	...to accept supportive services for yourself?
i16	...to cope with your own emotions (e.g. loss or grief)?
i17	...to cope with everyday worries?
i18	...to manage stress?
i19	...to deal with bad conscience or guilt?
i20	...to get information on challenges that may occur in the progression of dementia?
i21	...to prepare for deterioration of the situation (e.g. moving into nursing home)?
Maintaining own well-being	
i22	...to get respite from everyday caring?
i23	...to prioritise your own health?
i24	...to sleep better?
i25	...to get more time for yourself?
i26	...to get in contact with others in the same situation as you?
i27	...to feel confident in the caring role?
i28	...to make decisions regarding the person with dementia?
i29	...to maintain a good relationship with the person with dementia?
i30	...to create nice experiences together with the person with dementia?
i31	...to share the responsibility of caring with someone else?
i32	...to talk to someone about intimacy?
Communicating and interacting with surroundings	
i33	...to get information about who to contact for support?
i34	...to get information on what services professionals (e.g. nurse) may offer?
i35	...of professionals offering support to you?
i36	...to get information on the collaborative caring work in relation to the person with dementia?
i37	...to be involved in this collaborative caring work?
i38	...to involve family/network in tasks or decision making in relation to the person with dementia?
i39	...to deal with disagreements within the family/network in relation to the person with dementia?
i40	...to communicate with family/network and surroundings about how dementia affects the person with dementia?
i41	...to navigate rules and legislation?
i42	...to manage financial issues on behalf of the person with dementia?

Appendix 3: Presentation of items in the DeCANT final version (25 items). Items in each factor are linked to the ICF framework following Cieza et al.'s linking rules (Cieza et al., 2016).

Item#	**DeCANT Final**
Consider your present situation caring for the person with dementia. Do you have a need for support...	
Environmental factors	
i1	…to make sure that services targeted the person with dementia conform to your daily life?
i21	…to prepare for deterioration of the situation (e.g. moving into nursing home)?
i22	…to get respite from everyday caring?
i26	…to get in contact with others in the same situation as you?
i33	…to get information about who to contact for support?
i37	…to be involved in this collaborative caring work?
i38	…to involve family/network in tasks or decision making in relation to the person with dementia?
i41	…to navigate rules and legislation?
i42	…to manage financial issues on behalf of the person with dementia?
Activity and participation component	
i3	...to manage everyday chores (e.g. dressing, cleaning, transportation)?
i4	...to maintain your social network?
i6	...to manage changed behaviour in the person with dementia (e.g. aggressive, restless or passive behaviour)?
i23	…to prioritise your own health?
i28	…to make decisions regarding the person with dementia?
i30	…to create nice experiences together with the person with dementia?
i31	...to share the responsibility of caring with someone else?
i32	…to talk to someone about intimacy?
Personal factors	
i9	…to manage person with dementia's lack of disease awareness?
i12	…to feel appreciated in what you are doing for the person with dementia?
i13	…to ask for help for yourself?
i27	…to feel confident in the caring role?
Body structure/function component	
i16	…to cope with your own emotions (e.g. loss or grief)?
i18	...to manage stress?
i19	...to deal with bad conscience or guilt?
i24	…to sleep better?