Assessment of symptoms, functioning and needs of home-dwelling people with dementia

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Summary

Background

Dementia has considerable consequences for the person, their informal caregivers, their formal caregivers, and the wider society—and worldwide, the number of people with dementia is increasing. A timely diagnosis is important in order to start pharmacological and non-pharmacological treatment, to guide future medical treatment, and to provide individually tailored advice, support, and services. A diagnosis may help the person with dementia and their caregivers in understanding the symptoms and in planning for the future. Case-finding to identify people who should undergo a diagnostic evaluation of suspected cognitive impairment is important. The Cognitive Function Instrument (CFI) may be useful in such case-finding because it has a self-rated version and a proxy-rated version and it addresses cognitive functioning and activity limitations with questions that are easy to relate to.

The first signs of dementia may be a decline in memory or other cognitive functions, limitations in activities of daily living (ADL), or behavioural and psychological symptoms of dementia (BPSD). Although biomarkers have become increasingly important in diagnostics, dementia is still largely diagnosed based on evaluations of the clinical symptoms. Therefore, diagnostic evaluations include assessments of cognitive functioning, ADL limitations, and BPSD, in addition to medical and neurological evaluations, blood tests, and structural imaging. In Norway, diagnostic evaluations of people with symptoms of cognitive impairment are mainly the responsibility of primary health care and are performed by general practitioners, usually in collaboration with local dementia resource teams in the municipalities.

The impact of cognitive impairment, activity limitations, and BPSD on the life of a person with dementia is substantial and includes loss of independence, reduced quality of life, and higher mortality risk. Consequently, access to individually tailored treatment, advice, support, and services is important, and the provision of such depends on assessments of symptoms, functioning, and needs. Unmet needs are considered to contribute to BPSD. Knowledge of symptoms and needs in people with dementia is important on both an individual and a group level.

Aims

The main aim of this thesis was to explore different assessments of symptoms and functioning that are needed to diagnose dementia as well as assessments that are needed to plan treatment, advice, support, and services for home-dwelling people with dementia. We mainly explored how to evaluate the clinical symptoms of dementia and the corresponding needs. The thesis includes three studies, with the following aims:

I) To evaluate the validity of the Norwegian version of the CFI to discriminate between people with dementia, people with mild cognitive impairment (MCI), people with subjective cognitive impairment (SCI), and a reference group of healthy older adults.
II a) To describe patients assessed for cognitive decline in Norwegian primary health care by comparing them to patients assessed in specialist health care, and
II b) to examine factors associated with depression in people assessed for cognitive impairment.
III) To examine the association between BPSD and unmet needs for daytime activities and company.

Methods

In study I, we included 265 participants with dementia, MCI, SCI, and healthy controls, as well as proxies for 249 of the participants. We investigated the discriminatory power of i) the self-rated version and ii) the proxy-rated version of the CFI, using receiver operating characteristic analyses, and we calculated the area under the curve as well as the sensitivity and specificity for the cut-off points with the highest accuracy and a sensitivity of at least 70%. The correlation and the inter-rater reliability of the two versions was evaluated, and internal consistency was examined.

In study II, we recruited people who were undergoing a diagnostic evaluation of suspected cognitive impairment. We compared a primary health care cohort of 226 participants recruited by memory teams in 33 municipalities across Norway with a cohort of 1595 participants recruited from 14 specialist health care outpatient clinics. The primary health care cohort was compared to the specialist health care cohort both as a total, and as grouped into memory clinics and 'other' clinics (geriatric and old-age psychiatry outpatient clinics). Comparison was conducted using student's t-tests / Mann–Whitney U tests, and chi-square tests, and analyses adjusting for age were performed with binary and multinomial logistic regression analyses. Factors associated with depression were examined through binary logistic regression analyses, wherein we used the Cornell scale for depression in dementia as the dependent variable, dichotomised at a cut-off point of 5/6.

In study III, we included 451 dyads of people with dementia and their caregivers from eight European countries. The participants were assessed three times over the course of one year. Through a principal component analysis of the Neuropsychiatric Inventory Questionnaire (NPI-Q), BPSD were categorised into agitation, affective, and psychotic sub-syndromes. Linear mixed models were used to analyse the associations between each BPSD sub-syndrome and unmet needs for daytime activities and company.

Results

Paper I: The Norwegian versions of the CFI had the ability to distinguish people with dementia from people with MCI, people with SCI, and a reference group without cognitive impairment. The proxy-rated version was found to have better discriminatory power than the self-rated version.
Paper II: Patients assessed for cognitive impairment in Norwegian primary health care had more severe symptoms of cognitive impairment, functional limitations, and BPSD, and were older and more often lived alone, compared to patients assessed in specialist health care.
Depression in people assessed for cognitive impairment was associated with female gender, older age, more severe cognitive impairment, being assessed in primary health care, and a caregiver experiencing greater burden.
Paper III: Unmet needs for daytime activities and company were associated with higher scores on the NPI-Q affective and psychotic sub-syndromes.

Conclusions

Ensuring a timely diagnosis of people with dementia is important. The CFI may be a useful instrument for identifying people who should undergo a diagnostic evaluation of suspected cognitive impairment e.g., because it focuses on ADL limitations and has a self-report version. Service providers should be aware that patients assessed in Norwegian primary health care may have more severe symptoms of cognitive impairment, functional limitations, and BPSD compared to patients assessed in specialist health care. Assessing the needs of people with dementia and addressing unmet needs for daytime activities and company is important, as such unmet needs were found to be associated with affective and psychotic symptoms.

Sammendrag

Bakgrunn

Det er et økende antall personer med demens på verdensbasis. Demenssykdommen har store konsekvenser for personer med demens, deres pårørende, helse- og omsorgstjenestene og for samfunnet generelt. Rett diagnose til rett tid er viktig ved demens, slik at farmakologisk og ikke-farmakologisk behandling, individuelt tilrettelagte tjenester, veiledning og støtte kan tilbys. Det å være klar over en demensdiagnose er viktig fordi dette har betydning for eventuell fremtidig medisinsk behandling. En demensdiagnose kan hjelpe personer med demens og deres pårørende å forstå symptomene de opplever og bidra til at de får lagt planer og tatt viktige beslutninger.

Det er viktig å identifisere personer som trenger en diagnostisk utredning for kognitiv svikt. Kognitivt funksjonsinstrument (KFI) kan være nyttig for å identifisere disse, fordi det har en selvrapportert og en pårørenderapportert versjon og adresserer kognitiv funksjon og aktivitetsproblemer med spørsmål som er enkle å forholde seg til.

De første tegnene på demens kan være problemer med hukommelse eller andre kognitive funksjoner, begrensninger i utførelse av aktiviteter i dagliglivet (ADL) eller adferdsmessige og psykologiske symptomer ved demens (APSD). Selv om biomarkører er stadig viktigere i utredning av demens, blir demens fortsatt i stor grad diagnostisert basert på kliniske symptomer. Demensutredning inkluderer derfor kartlegging av kognitiv funksjon, ADL begrensninger og APSD, i tillegg til medisinske og nevrologiske undersøkelser, blodprøver og billeddiagnostikk. I Norge er demensutredning som hovedregel kommunehelsetjenestens ansvar og gjøres av fastlegene, ofte i samarbeid med kommunale hukommelsesteam.

Demenssykdommen og medfølgende kognitiv svikt, aktivitetsbegrensninger og APSD har store konsekvenser for livet til personen med demens, og inkluderer tap av selvstendighet, redusert livskvalitet og økt dødelighet. Tilgang til individuelt tilrettelagt behandling, tjenester, veiledning og støtte er derfor viktig, og denne oppfølgingen bør baseres på kartlegging av symptomer, fungering og behov. Udekkede behov er en medvirkende årsak til APSD, og kjennskap til symptomer og udekkede behov hos personer med demens er viktig både på individ- og gruppenivå.

Formål

Hovedmålet med denne avhandlingen var å studere kartlegging av symptomer og fungering, som er nødvendig for å diagnostisere demens og for å planlegge behandling, tjenester, veiledning og støtte til hjemmeboende personer med demens. Vi utforsket hovedsakelig hvordan kliniske symptomer på demens og de medfølgende behovene kan kartlegges. Avhandlingen inkluderer tre studier med følgende mål:

I) Å evaluere validiteten til den norske versjonen av KFI, brukt til å skille mellom personer med demens, mild kognitiv svikt (MCI), subjektiv kognitiv svikt (SCI) og en referansegruppe av friske eldre.
II a) Å beskrive personer som er utredet for kognitiv svikt i kommunehelsetjenesten i Norge ved å sammenligne dem med personer som er utredet i spesialisthelsetjenesten, og
II b) å undersøke faktorer som er assosiert med depresjon hos personer som er utredet for kognitiv svikt.
III) Å undersøke assosiasjonene mellom APSD og udekkede behov for daglige aktiviteter og sosial kontakt, hos personer med demens.

Metoder

I studie I inkluderte vi 265 personer med demens, MCI, SCI og friske kontroller, i tillegg til komparenter for 249 av deltakerne. Vi undersøkte hvor godt både i) den selvrapporterte og ii) den pårørerenderapporterte versjonen av KFI egnet seg til å skille mellom personer med demens, personer med MCI, personer med SCI og friske kontroller. Vi brukte ROC analyser og regnet ut arealet under kurven, samt sensitivitet og spesifisitet for de grenseverdiene med best presisjon og en sensitivitet på minst 70 %. Videre evaluerte vi intern konsistens for KFI og korrelasjon og samsvar mellom selvrapportert og pårørenderapportert versjon av KFI.

I studie II rekrutterte vi personer som var til utredning på grunn av mistanke om kognitiv svikt. Vi sammenlignet en gruppe av 226 deltakere fra kommunehelsetjenesten, som ble rekruttert av hukommelsesteam i 33 kommuner fra hele Norge, med 1595 deltakere som var rekruttert fra 14 poliklinikker i spesialisthelsetjenesten. Sammenligningen ble gjort med spesialisthelsetjeneste-gruppen som helhet, og spesialisthelsetjenestegruppen delt opp i hukommelsesklinikker og «andre» (geriatriske og alderspsykiatriske) poliklinikker. Sammenligningene ble gjort med student t-tester/ Mann–Whitney U tester og kji-kvadratanalyser. Analyser der vi justerte for alder ble gjort med bivariate og multinominale logistiske regresjonsanalyser.
Faktorer som er assosiert med depresjon ble undersøk med bivariate logistiske regresjonsanalyser, hvor vi brukte Cornell skala for depresjon ved demens som avhengig variabel, dikotomisert med grenseverdien 5/6.

I studie III inkluderte vi 451 dyader av personer med demens og pårørende, fra åtte europeiske land. Deltakerne ble kartlagt tre ganger i løpet av ett år. Etter en prinsipalkomponentanalyse av Nevropsykiatrisk intervjuguide (NPI-Q), ble APSD kategorisert under subsyndromene agitasjon, affektiv og psykotisk. Lineære «mixed» modeller ble brukt for å analysere assosiasjonene mellom hvert APSD subsyndrom og udekkede behov for daglige aktiviteter og sosial kontakt.

Resultater

Artikkel I: Den norske versjonen av KFI egnet seg til å skille mellom personer med demens, personer med MCI, personer med SCI og en frisk kontrollgruppe. Den pårørenderapporterte versjonen var bedre egnet til formålet enn den selvrapporterte.
Artikkel II: Personer som ble utredet for kognitiv svikt i norsk kommunehelsetjeneste, hadde mer alvorlige symptomer på kognitiv svikt og APSD, hadde større funksjonsbegrensninger og var i tillegg eldre og bodde oftere alene, sammenlignet med personer som ble utredet i spesialisthelsetjenesten. Depresjon hos de som ble utredet for kognitiv svikt var assosiert med kjønn (kvinne), høyere alder, mer alvorlig kognitiv svikt, utredning i kommunehelsetjenesten og med høyere pårørendebelastning.
Artikkel III: Udekkede behov for daglige aktiviteter og sosial kontakt var assosiert med høyere skåre på de affektive og psykotiske subsyndromene av NPI-Q.

Konklusjoner

Det er viktig at personer med demens får diagnose til rett tid, og KFI kan være et nyttig instrument for å identifisere personer der det bør gjennomføres en utredning ved mistanke om kognitiv svikt. Dette blant annet fordi KFI adresserer ADL begrensninger og har en selvrapporteringsversjon.
Tjenestetilbydere bør være klar over at personer med demens som har blitt utredet i kommunehelsetjenesten kan ha mer alvorlige symptomer på kognitiv svikt og APSD, samt større funksjonsbegrensninger, sammenlignet med personer som ble utredet i spesialisthelsetjenesten.
Det er viktig å kartlegge behovene til personer med demens og å adressere udekkede behov for daglige aktiviteter og sosial kontakt, fordi slike udekkede behov har vist seg å være assosiert med affektive og psykotiske symptomer.

List of papers

I Michelet M, Engedal K, Selbaek G, Lund A, Bjorklof GH, Horndalsveen PO, et al. The Validity of the Norwegian Version of the Cognitive Function Instrument. Dementia and Geriatric Cognitive Disorders. 2018;46(3-4):217-28. DOI: 10.1159/000493463.

II Michelet M, Lund A, Strand BH, Engedal K, Selbaek G, Bergh S. Characteristics of patients assessed for cognitive decline in primary healthcare, compared to patients assessed in specialist healthcare. Scandinavian Journal of Primary Health Care. 2020;38(2):107-16. DOI: 10.1080/02813432.2020.1753334.

III Michelet M, Selbaek G, Strand BH, Lund A, Engedal K, Bieber A, et al. Associations between unmet needs for daytime activities and company and scores on the Neuropsychiatric Inventory-Questionnaire in people with dementia: a longitudinal study. Aging & Mental Health. 2021:1-10. DOI: 10.1080/13607863.2021.1910792.

Abbreviations

ACE: The Addenbrooke's Cognitive Examination

Actifcare: The Access to Timely Formal Care (a research project)

AD: Alzheimer's Disease

ADL: Activities of Daily Living (includes Basic Activities of Daily Living (BADL) and Instrumental Activities of Daily Living (IADL))

AMPS: Assessment of Motor and Process Skills

APOE: Apolipoprotein E

ARD: Alcohol-Related Dementia

AUC: Area Under the Curve

BADL: Basic Activities of Daily Living

BPSD: Behavioural and Psychological Symptoms of Dementia

CANE: The Camberwell Assessment of Need for the Elderly

CANE-S: The Camberwell Assessment of Need for the Elderly – Short version

CERAD: The Consortium to Establish a Registry for Alzheimer's Disease

CDR: Clinical Dementia Rating

CDT: The Clock-Drawing Test

CFI: The Cognitive Function Instrument

CMAI: The Cohen-Mansfield Agitation Inventory

COVID-19: Coronavirus disease 2019

COWAT: Controlled Oral Word Association Test

CSDD: The Cornell Scale for Depression in Dementia

CT: Computerised Tomography

DAD: The Disability Assessment for Dementia

DAT-Scan: Dopamine Transporter Scan

DemiNor: Dementia teams in Norway (a project)

DSM-5: Diagnostic and Statistical Manual of Mental Disorders, fifth edition

ETUQ: The Everyday Technology Use Questionnaire

FDG PET: Fluorodeoxyglucose Positron Emission Tomography

FTD: Frontotemporal Dementia

GP: General Practitioner

IADL: Instrumental Activities of Daily Living

ICD-10: International Statistical Classification of Diseases and Related Health Problems, tenth revision

ICD-11: International Statistical Classification of Diseases and Related Health Problems, eleventh revision

ICF: The International Classification of Functioning, Disability and Health

ICHOM: The International Consortium for Health Outcomes Measurement

ICPC-2: The International Classification of Primary Care, second version

IPA: International Psychogeriatric Association

IQCODE: The Informant Questionnaire of Cognitive Decline in the Elderly

IQR: Interquartile Range

KT-NR3: Norsk revidert klokketest vs3 - the third Norwegian revised version of the Clock-Drawing Test (CDT)

LBD: Lewy Body Dementias (includes Dementia with Lewy Bodies (DLB) and Parkinson's Disease with Dementia (PDD))

LR+: Likelihood ratio for a positive outcome

LR–: Likelihood ratio for a negative outcome

MCI: Mild Cognitive Impairment

MMSE: The Mini-Mental State Examination

MMSE-NR3: Norsk revidert mini mental status evaluering vs3 – the third Norwegian revised version of the MMSE

MoCA: The Montreal Cognitive Assessment

MRI: Magnetic Resonance Imaging

NICE: National Institute for Health and Care Excellence

NorCog: The Norwegian register of persons assessed for cognitive symptoms

NPI: Neuropsychiatric Inventory

NPI-Q: The Neuropsychiatric Inventory Questionnaire

OR: Odds Ratio

PCA: Principal Component Analysis

PET: Positron Emission Tomography

PRPP: The Perceive, Recall, Plan and Perform; a system of task analysis

PSMS: The Physical Self-Maintenance Scale

ROC: Receiver Operation Characteristic

RSS: The Relatives' Stress Scale

RUDAS: The Rowland Universal Dementia Assessment Scale

SCI: Subjective Cognitive Impairment

SD: Standard Deviation

TIME: The Targeted Interdisciplinary Model for Evaluation and Treatment of Neuropsychiatric Symptoms

TMT: The Trail making test (includes part A (TMT-A) and part B (TMT-B))

TMT-NR3: Norsk revidert Trail Making Test vs3 - The third Norwegian revised version of the TMT A and B

UPSA: The University of California, San Diego (UCSD) Performance-Based Skills Assessment

VaD: Vascular Dementia

VIPS: Value, Individualised approach, Perspective of the person with dementia, and positive Social psychology

WHO: World Health Organization

1 Introduction

Approximately 90% of Norwegian municipalities have multidisciplinary dementia resource teams, which in this thesis will be referred to as memory teams [1]. These teams cooperate with general practitioners (GPs) in their work with diagnostic evaluations of patients with suspected dementia. The memory teams assess the patients' functioning, mainly in home visits. The teams also play a central role in assessing the needs of and ensuring the necessary treatment, advice, support, and services for people with dementia and their caregivers [2].

My work at Ageing and health involves the memory teams. I provide supervision and arrange courses and conferences for the teams, and I am in regular contact with them. My experience in this cooperation is that diagnostic evaluations of suspected dementia are often initiated too late in the progression of the disorder, partly because people do not recognise their symptoms as possible signs of dementia. Furthermore, the teams often find that the people they assess through diagnostic evaluations have considerable symptoms and needs, yet the teams are not always able to prioritise treatment, advice, support, and services after the evaluations. This is worrisome, as one of the main reasons for diagnosing people with dementia is to be able to offer the appropriate support and services. We cannot cure dementia, but we may promote activity and participation, ease symptoms, and help improve quality of life through individually tailored treatment, advice, support, and services [3, 4].

This thesis is based on three studies initiated by a need for research on: 1) instruments that may aid in identifying people who should undergo a diagnostic evaluation; 2) symptoms in people who have undergone diagnostic evaluation in primary health care compared to specialist health care; and 3) associations between behavioural and psychological symptoms of dementia (BPSD) and unmet needs for daytime activity and company. Even though the three papers address different issues, they are all related to each other in the same context: how to assess the functioning, symptoms, and consequences of cognitive impairment and dementia, to provide a timely dementia diagnosis, and to offer individually tailored treatment, advice, support, and services according to the person's needs. Incorporating the different issues addressed in the three studies, the thesis covers a rather broad field.

The Norwegian national guideline on dementia recommends a multidisciplinary approach to the various assessments involved in diagnostic evaluation and to the provision of individually tailored treatment, advice, support, and services for people with dementia [2]. I bring my occupational therapy background into this multidisciplinary setting—e.g., an emphasis on the relationships between activity, health, and well-being.

Biomarkers are becoming increasingly important in diagnosing cognitive impairment and dementia, and promising advances in medical treatment of the neuropathology of dementia will likely have a large impact on the lives of people with dementia in the future. However, biomarkers and medical treatment are not my field, nor did we address them in our studies. Therefore, biomarkers and medical treatment are only briefly discussed in this thesis. Furthermore, we focus on the person with cognitive impairment or dementia and thus only briefly address the informal caregiver's situation.

Dementia is often first recognised by a person exhibiting memory or functional impairment; however, it is not always evident to people whether the changes they experience are severe enough to justify a diagnostic evaluation. Therefore, a simple screening instrument that captures self-reported and proxy-reported cognitive impairment and indicates what a 'severe enough change' is would be useful in identifying people who should undergo a diagnostic evaluation.

Norway is one of the few countries where assessing and diagnosing people with suspected dementia is mainly a responsibility of primary health care [5]. (However, people under 65 years with symptoms of cognitive impairment, people with Sami or minority ethnic background or intellectual disabilities, and people presenting complicated or unclear symptoms should be referred to a specialist health care service [2].) Knowledge about common symptoms form a basis for planning and providing general treatment, advice, support, and services for people with dementia, but the characteristics of people assessed for cognitive impairment in Norwegian primary health care have not yet been described. Therefore, we wanted to describe a cohort of people assessed for dementia in primary health care compared to people assessed in specialist health care.

Depression is common in people referred for an assessment of suspected dementia [6], and it may lead to several negative outcomes [7]. Depression is a main differential diagnosis for dementia, as several symptoms of dementia and depression overlap, and depression may affect cognitive functioning. Knowledge about factors associated with depression may aid in assessing symptoms of depression in dementia, in assessing the needs of people with dementia, and in planning support for people with dementia who also have symptoms of depression.

Thorough assessments of individual needs are important for efficiently delivering individually tailored treatment, advice, support, and services. Unmet needs are widely considered to be one of the contributing factors of BPSD [8], and addressing unmet needs might be an appropriate first choice approach to preventing and treating BPSD. Studies investigating unmet needs in home-dwelling people with dementia have found that daytime activities and company are reported as two of the most common areas of unmet needs [9-11]. Therefore, we wanted to examine the association between BPSD and unmet needs for daytime activities and company in home-dwelling people with dementia.

In this thesis, we address three main symptoms groups of dementia: In chapter 2.2, we address cognitive impairment; in chapter 2.3, we address BPSD; and in chapter 2.4, we address functioning in activities of daily living (ADL). We elaborate on the assessments conducted in diagnostic evaluations in chapter 2.6 and on planning treatment, advice, support, and services by assessing needs in chapter 2.7. The Norwegian model for diagnostic evaluation and for providing individually tailored support for people with dementia is described in chapter 2.8.

Our focus in this thesis is on the assessments used to measure functioning and disability, both for diagnostic purposes and in planning treatment, advice, support, and services. As a theoretical framework and language to understand and describe the dynamic relationship between health conditions and functioning, we have applied the International Classification of Functioning, Disability and Health (ICF). The ICF provides a practical model for explaining how health conditions and their associated changes affect functioning and disability, defined as body functions, body structures, activities, and participation [12]. The ICF and the International Statistical Classification of Diseases and Related Health Problems tenth Revision (ICD-10) are complementary classifications from the World Health Organization (WHO); while the ICD-10 is primarily used to classify health conditions, the ICF classifies health and the associated dimensions of functioning [12].

The main aim of this thesis is to explore different assessments of symptoms and functioning needed to diagnose dementia as well as assessments needed to plan treatment, advice, support, and services for home-dwelling people with dementia. We mainly explore how to evaluate the clinical symptoms of dementia and the corresponding needs.

2 Background

2.1 Theoretical framework: The International Classification of Functioning, Disability and Health

The relationships between cognitive impairment/dementia, the symptoms ensuing from the syndrome, and the physical environment and social network around the person are complex. To understand this complexity, we tend to create systems for categorisation by using theoretical frameworks. In this thesis, we apply the International Classification of Functioning, Disability and Health (ICF) framework as an overall model to understand and describe the relationships between health condition, body functions and structures, activity, participation, and contextual factors [12].

The ICF is often used in multidisciplinary contexts because it includes terminology and definitions that contribute to a more common frame of reference across disciplines. The approach to dementia diagnostics and care in Norway is multidisciplinary, as are the project groups involved in our studies. The ICF has long served as a frame of reference for me to understand the relationships between diagnoses and their consequences in everyday life. We did not apply the ICF framework in the papers, but the framework has helped us in general in addressing the role of activity and participation in relation to diagnostic evaluation and to planning treatment, advice, support, and services. Nevertheless, we do not go into the depths of the framework nor apply the codes or qualifiers.

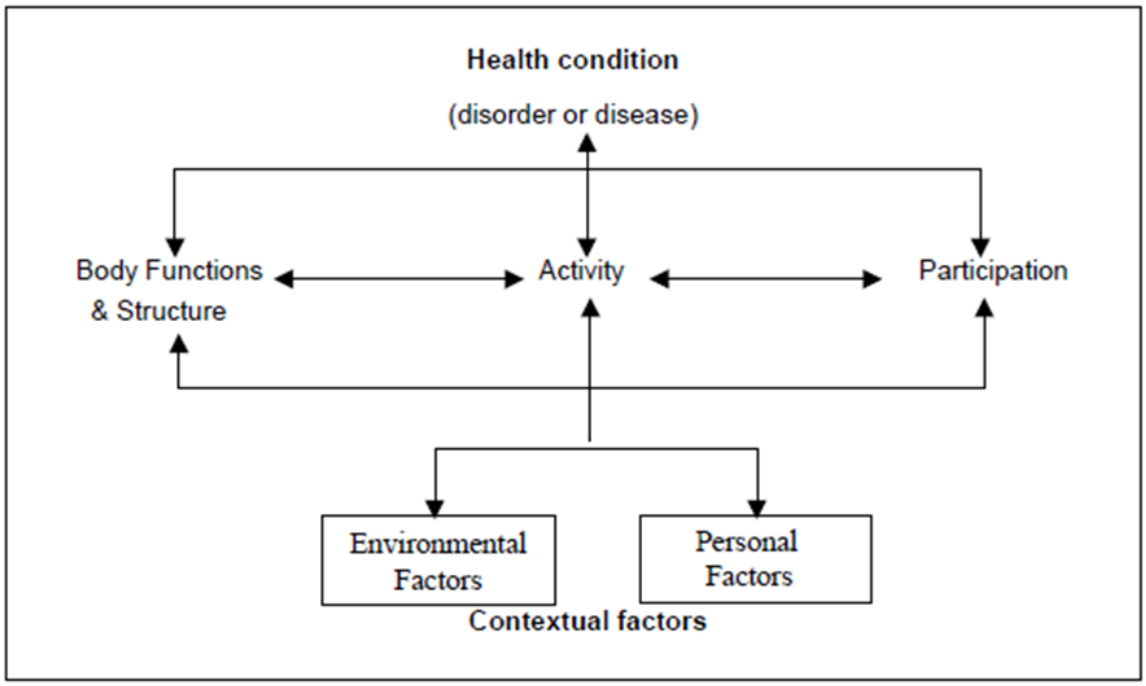
The ICF is an integrated biopsychosocial model of human functioning and disability. It is a multidisciplinary, multipurpose approach to health and health-related domains. In classifying functioning and disability associated with health conditions, the ICF complements the International Statistical Classification of Diseases and Related Health Problems Tenth Revision (ICD-10), which is used in this thesis and the included papers and which classifies diagnosis and causes of morbidity and mortality [12]. The ICF also complements the ICD-10's successor, the ICD-11.

The ICF organises information into two parts. Part 1 deals with functioning and disability, and part 2 covers contextual factors. Each part has two components [13]:

- Functioning and Disability
    - Body Functions and Body Structures
    - Activities and Participation
- Contextual Factors
    - Environmental Factors
    - Personal Factors

'Functioning' and 'disability' are understood as umbrella terms denoting the positive and negative aspects of functioning from biological, individual, and social perspectives [13]. *Functioning* is defined in the ICF as all body functions, activities, and participation. *Disability*, functioning's negative counterpart, is described as impairments, activity limitations, and participation restrictions [12]. Although separated in the model below, in the 2017 version of the ICF browser [14], the domains of the Activities and Participation component are given in a single list. This list covers the full range of life areas, from basic learning and self-care to more advanced areas such as social and civic life [14].

Figure 1. The ICF Model: Interaction between ICF components [13]



2.2 Cognition, cognitive impairment, and dementia

'*If our brains were so simple that we could understand them, we would be so simple that we could not.*' Anonymous, from Lezak et al. [15](p 15).

2.2.1 Cognition

No consensus exists in terms of how to define cognition, but it is often described as a process of thinking.

Under the ICF, cognitive functions are a type of body functions that are called 'mental functions' and described as 'the functions of the brain: both global mental functions, such as consciousness, energy, and drive, and specific mental functions, such as memory, language, and calculation mental functions'[14]. We consider cognitive functions and mental functions to represent the same concept and primarily use the term 'cognitive functions' in this thesis.

Cognition is not a unitary concept; rather, it involves several abilities, which are commonly referred to as different domains of cognition. The domains are often described as hierarchical, with basic sensory and perceptual processes at the bottom and executive functioning and cognitive control at the top, with the latter functions being more complex and involving the coordination of other less-complex functions [16]. In light of this complexity, a decline in any domain of cognition will have consequences for the person. In the following, we give a brief description of the domains that are most often affected in the common dementia disorders: orientation, attention, memory, language, visuospatial abilities, and executive functions.

Orientation

Orientation involves knowing and ascertaining one's relation to time, place, self, others, objects, and space [14]. Knowing year, time of the year, weekday, date, and time of day is an indication of orientation for time, while knowing country, city, address, or building indicates orientation for place

[17]. Since orientation for place can often be inferred by visual cues, orientation for time may be more sensitive to cognitive impairment [17]. Orientation for person or situation includes, e.g., knowing one's own identity, living arrangement, and family relations.

Attention

Attention is described in the ICF as 'mental functions of focusing on an external stimulus or internal experience for the required period of time' [14], and it is often divided into selective attention and sustained attention. Selective attention is the process of focusing on relevant information while ignoring information that is not relevant. Divided or dual task attention—e.g., attending to central and peripheral stimuli at the same time, and shifting attention—are also included in selective attention [16]; however, dual task attention can also be argued as being a separate subdomain of attention. Sustained attention, or attention over time, involves vigilance or ability to concentrate, (e.g., to detect one type of stimuli that is presented infrequently among other stimuli) [16]. Neglect is also related to attention, indicating reduced attention to stimuli from one side of the body.

Memory

Memory is often referred to as 'memory and learning' and concerns registering and storing information along with being able to retrieve information as needed [14]. This domain includes several subdomains. *Working memory* involves holding information in one's consciousness to make adaptive use of it [16]. Information contained in working memory is then processed and *encoded* for long-term *storage*. When information has been successfully encoded and stored, it can be recalled for a fairly long period of time afterwards [16]. Immediate recall is recall of information shortly after it is given and does not require its storage, while delayed recall depends on storage of the information. *Episodic memory* is related to personal experiences and is explicitly located in the past; it is accompanied by a feeling of remembering, not just knowing [18]. Other acquired knowledge is more factual, without personalised feelings attached to it regarding specific occurrences in the past [18]. *Procedural memory* is memory for motor actions or skills [16]: when learning a skill (e.g., how to use a coffee maker), the person consciously holds, encodes, and stores information, but as the skill becomes automated, it can be performed without conscious focus on the processes and retained for a long time, even with memory impairment. *Semantic memory* refers to the process of long-term storage of verbal information [16], usually facts and general information not related to specific situations in a person's life. *Prospective memory* is the ability to remember to do something in the future, either triggered by a stimulus (e.g., an alarm going off) or by specific times (e.g., taking one's medicines in the evenings [16]).

Language

Language involves reception, decryption, and the use of spoken, written, or other forms of language [14]. This domain includes *verbal fluency* (expressive or motor functions), *understanding language* (sensory or receptive functions), and *naming* (producing language). Reduced *verbal fluency* manifests as e.g., problems in producing words, using words and grammar correctly, or speaking in full sentences [19](pp 36-38). *Understanding* of language involves understanding what the words mean, what people are saying, and what is being read. A person can have problems responding to instructions, both oral and written [16]. It is important not to confuse hearing impairment and difficulty with oral comprehension. A person with problems in *naming* might try to explain the meaning of the word rather than using it, or use a similar word, and problems in naming most frequently apply to nouns and verbs [19](pp36-38).

Visuospatial functions

Visuospatial perception refers to distinguishing the relative position of objects in the environment or in relation to oneself [14], and visuospatial functions relate to spatial navigation, understanding maps, copying figures, and drawing [19](pp 39-40). Impairment in visuospatial functioning may lead to getting lost, having problems estimating distance, or struggling to perform construction-related house maintenance tasks. Visuospatial functions are often tested by assessments on copying interlocking pentagons or three-dimensional shapes (such as a cube) or entering the numbers and hands on a drawn clock face [17]. Several of these tasks have an organization component and thereby incorporate executive functioning demands as well [16].

Executive functions

Executive functions are complex; executive abilities include planning, problem solving, initiating an activity, inhibition of inappropriate/irrelevant information or response, and monitoring the effectiveness of one's behaviour [20]. In the conceptualisation of cognitive domains as hierarchical, executive functioning tasks often involve coordinating multiple, less complex functions, such as sensory, perceptual, and attentional functions [16]. Thus, executive functioning involves a set of high-level cognitive processes that manage multiple cognitive abilities to reason, solve problems, programme, plan, evaluate, and adjust goal-directed actions, tasks, or activities. An impairment in executive functions makes it difficult to learn new skills and to solve everyday problems. Independence in ADL and maintaining social relationships may become difficult, as impairments in executive functions tend to affect all aspects of behaviour and show up globally [15](p37).

2.2.2 Cognitive impairment

Cognitive impairment is often described as a hallmark of dementia; however, not all people with cognitive impairment have dementia. Cognitive impairment could be related to numerous psychiatric, neurological, or medical conditions, such as stroke or depression. The terms Subjective Cognitive Impairment (SCI) and Mild Cognitive Impairment (MCI) are used when the symptoms of cognitive impairment do not meet the criteria for dementia. SCI and MCI may represent symptomatic expressions of a preclinical dementia state [21] and thus subsequently progress into dementia, but they may also represent other diseases, such as depression, hypothyroidism, and side effects of medications.

Subjective cognitive impairment (SCI)

The most widely used definition for SCI is twofold: 1) self-experienced persistent impairment in cognitive capacity in comparison to a previously normal status and unrelated to an acute event; and 2) normal age-, gender-, and education-adjusted performance on standardised cognitive tests that are used to classify MCI or prodromal Alzheimer's Disease (AD) [22].

Several terms are used for SCI, such as subjective cognitive decline (SCD) and subjective memory complaints, but none of these terms are diagnoses. SCI is associated with an increased risk of an objective cognitive decline and impairment in the future and has been suggested to be a possible first symptomatic expression of preclinical dementia. Sperling and colleagues (2011) postulate a continuum of AD, with a model of clinical trajectory. In this model, SCI represents the preclinical phase, and MCI the first stage, of dementia [21]. In a multicentre study, Slot et al. (2019) found an overall dementia incidence rate in individuals with SCI of 17.7 per 1000 person-years, compared to 14.2 per 1000 person-years in controls without SCI [23].

Mild cognitive impairment (MCI)

According to the criteria by Winblad et al. (2004), a diagnosis of MCI is given to persons without dementia but with cognitive deficits that are measurable in some form or another, with preserved basic ADL and minimal to no impairment in complex instrumental functions [24]. The cognitive impairment may be in the memory domain but also in one or more other cognitive domains. Petersen and colleagues at the Mayo Clinic define the criteria for MCI as: 'a) complaint of defective memory, b) normal activities of daily living, c) normal general cognitive function, d) abnormal memory function for age, and e) absence of dementia' [25].

No consensus has been reached as to what 'minimal to no impairment in complex instrumental functions' entails, and clinical judgement may vary. However, according to the International Statistical Classification of Diseases and Related Health Problems 11th Revision (ICD-11) criteria for mild neurocognitive disorder (equivalent to MCI), the impairment in performance in one or more cognitive domains should not be 'sufficiently severe to significantly interfere with independence in the person's performance of activities of daily living'; in contrast, such interference with independence is present in dementia [26]. This distinction, with its emphasis on independence, may be a good way to differentiate between MCI and dementia: in MCI, the person may need to use greater effort and/or compensatory strategies for complex Instrumental Activities of Daily Living (IADL) but may not require any assistance [27, 28].

Winblad et al. emphasise that assessment of complex ADL in MCI is potentially of great interest, and that more knowledge is needed about which activities are impaired in MCI and whether there are tasks of complex activities that can help predict outcomes for persons with MCI [24].

According to Grimmer and Licata (2018), one should consider both cognitive and functional impairment as a continuum, spanning across the clinical stages of Alzheimer's Disease (AD). A clearer understanding of the onset and progression of functional impairment and a more precise assessment of subtle functional deficits in individuals in predementia stages of AD may improve patients' groupings as having MCI or dementia [27], and thus the clinical expression of functional impairment may be a diagnostic marker.

MCI could be a clinical stage on the continuum of cognitive impairment between 'normal ageing' and dementia. However, MCI may often have other causes, such as depression or stroke. When persons with MCI are followed over time, some progress to AD and other dementia types, but some remain stable or even recover [24]. In a clinical review, Langa and Levine (2014) found that the prevalence of MCI in adults aged ≥65 years was 10–20% and that risk increased with age and with male gender [30]. In a Norwegian population-based prevalence study, the prevalence of MCI among people ≥70 years was found to be 35.3% [29].

Risk estimates of patients with MCI developing dementia vary substantially, ranging from <5% to 20% annual conversion rates depending on the population studied [30]. Risk factors for MCI progression include older age, fewer years of education, stroke, diabetes, and amnestic MCI subtype. (Amnestic subtype is recognised by an impairment in memory and is further elaborated on in chapter 2.2.5.) As many as 40–70% of patients with MCI may not progress to dementia even after 10 years, and some MCI patients improve cognition after 1–2 years [30]. In a study of 200 participants with MCI, SCI, and healthy controls, examining the power of EEG to predict conversion from MCI and SCI to dementia, Engedal and colleagues found that 71% of MCI participants, 16% of SCI participants, and 1.5% of healthy controls converted to dementia during a mean of 62.5 months [31].

Since there is a risk of conversion from MCI to dementia, early detection is considered important, and people with MCI should be monitored through repeated cognitive assessments. It is

recommended that polypharmacy, cardiovascular risk factors, and signs of depression are considered as plausible causes for MCI in older patients, and aerobic exercise, mental activity, and social engagement may help decrease risk of further cognitive decline in patients with MCI [30].

2.2.3 The dementia syndrome

According to the World Health Organization (WHO), dementia is a syndrome characterised by deterioration in memory, thinking, behaviour, and the ability to perform everyday activities. Although dementia primarily affects older people, it is not a normal part of the ageing process [32]. As mentioned earlier, cognitive impairment is often described as a major feature of dementia. The cognitive domains described in chapter 2.2.1 are the domains most affected by dementia. However, it is important to note that in dementia, the cognitive impairment is often accompanied—and sometimes preceded—by various behavioural and psychological symptoms of dementia (BPSD). (BPSD are described in chapter 2.3.)

According to the WHO's diagnostic criteria for research ICD-10, a diagnosis of dementia requires a decline in memory and a decline in at least one other cognitive domain. This should be a decline from a previous level of cognitive functioning, and it must be severe enough to affect the individual's ability to carry out ADL [33], thereby constituting an impairment. Furthermore, there should be at least one symptom of decline in emotional control or motivation, or a change in social behaviour (referred to in this thesis as BPSD). The patient should have a preserved awareness of the environment (to exclude delirium), and the state of cognitive decline must have lasted for more than 6 months [33]. The diagnostic process and criteria are further elucidated in chapter 2.6.

Dementia can be caused by several different diseases, mainly brain disorders as well as injuries which affect the brain. Alzheimer's disease (AD) is the most prevalent of these, probably accounting for 60–70% of dementia cases [32]. The symptoms of dementia vary with the underlying cause: often, the first symptoms may be forgetfulness, poorer orientation for time, or getting lost in familiar places, but in other cases, the first symptoms could be BPSD or language difficulties. AD and the other diseases causing dementia are described in chapter 2.2.5.

2.2.4 Prevalence of dementia

It is estimated that around 50 million people worldwide are living with dementia. According to the WHO, the total number of people with dementia is expected to reach 82 million in 2030 and 152 million in 2050 [32]. Much of the increase in the number of people with dementia worldwide can be attributed to the rising numbers of people with dementia living in low- and middle-income countries [32]. A recent study estimated that 101,000 persons live with dementia in Norway in 2020, and that number is projected to increase to 237,000 in 2050 [29]. In Norway, the increase in the number of people with dementia is mainly caused by an increase in the number of older adults. The current overall prevalence was found to be 14.6% in people ≥70 years, with prevalence rates rising with age, from 5.6% in ages 70–74 years, 9.5% in ages 75–79 years, 17.9% in ages 80–84 years, 33.0% in ages 85–89 years, and 48.1% in people 90 years and older [29].

2.2.5 Dementia disorders

Various diseases and injuries to the brain can cause dementia. In a diagnostic evaluation, the underlying aetiological disease should be identified in order to take precautions concerning medical treatment, to consider new and review current pharmacological treatments, and to be able to prepare for challenges that may arise [34].

In the papers, we have not discriminated between the aetiological diseases; therefore, in this thesis, we usually do not differentiate between the dementia disorders when referring to 'dementia'. In the following, we describe only the most common dementia disorders; we do not go into detail about the different disorders, but only give a brief overview.

Alzheimer's disease

Alzheimer's disease (AD) is the most prevalent cause of dementia and represent 60–70% of the cases. AD typically presents with a subtle onset and a gradual progression. It is often first noticed as a decline or impairment in memory, learning, and language, which gradually becomes more severe [35, 36]. Although impaired memory is a core symptom of AD, memory impairment is not always the initial symptom. There are two main subtypes of AD, amnestic and non-amnestic. In the amnestic form, initial symptoms include reduced memory of recent events and impairment in orientation for time. The first symptoms of the non-amnestic form are usually changes in behaviour, depression, decline in language, orientation difficulties, and/or visual problems [37]. In the progression of the disease, executive dysfunction affects functioning—leading first to limitations in instrumental activities, and then to limitations in more basic activities. Eventually, virtually everybody with AD develops BPSD, and most develop motor symptoms. AD is associated with earlier death than healthy people of a similar age [36, 37].

The brain pathology of AD is neurodegeneration with aggregation of beta-amyloid plaques and neurofibrillary tangles, followed by a decrease in the neurotransmitter acetylcholine [36]. Recent research indicates that the pathophysiological processes of AD begin years, if not decades, before the clinical dementia diagnosis [21]. Drug treatment of AD includes cholinesterase inhibitors, which increase acetylcholine levels in the brain, which may reduce symptoms and stabilise cognitive performance and daily functioning for a limited time [34, 36]. Memantine treatment may be beneficial for patients with moderate to severe dementia [34, 36] by blocking the neurotransmitter glutamate and thereby preventing passage of too much calcium into the brain cells. Future biological treatment of AD includes medication to reduce amyloid plaques and tau tangles, with Aduhelm (aducanumab) becoming the first treatment to reduce amyloid plaque after it was approved by the United States Food and Drug Administration in 2021 [38].

Vascular dementia

Vascular dementia (VaD) is the second most common dementia disorder, accounting for 10–20% of all cases. Brain pathology in the form of both ischaemic and haemorrhagic lesions, as well as small vessel disease, are seen in VaD [35]. Symptoms of cognitive impairment in VaD may start suddenly and follow a stepwise progression. VaD is virtually the only dementia which can start abruptly, but symptoms of VaD may also have a gradual onset, with multiple subcortical infarctions. Cognitive impairment in VaD varies depending on the extent and localisation of the vascular pathology, but decline in attention, information processing, and executive function is often seen, while other functions such as memory and language are much more variably affected [39]. Symptoms consistent with stroke, such as hemiparesis or visual field defects, are also seen [35]. Little evidence supports the idea of cholinesterase inhibitors having an effect on 'pure' VaD [39], but prevention of further vascular events is important.

Lewy body dementias

Lewy body dementias (LBDs) accounts for 10–15% of dementia cases: the term LBDs includes both Dementia with Lewy bodies (DLB) and Parkinson's disease with dementia (PDD). When a diagnosis of Parkinson's disease is established at least one year before the development of dementia, the disorder is termed PDD; if the diagnosis of dementia is established before the parkinsonism is diagnosed, the disorder is termed DLB. People with LBDs often have visual hallucinations, fluctuating cognition with pronounced variations in attention and alertness, and symptoms of parkinsonism [35, 40]. Another feature is rapid eye movement (REM) sleep behaviour disorder, where the usual muscular paralysis during REM sleep is not present and the patient moves around during REM sleep [35]. The onset of LBDs is subtle, and the progression is gradual. LBDs progress faster than other dementias, and the disease may appear more acute because of the fluctuations in symptoms. In LBDs, there are abnormal deposits of a protein called alpha-synuclein in the nerve cells in the brain. These deposits, called Lewy bodies, are accompanied by neuronal loss [40]. Establishing a diagnosis of an LBD is important because people with an LBD can be very sensitive to the neuroleptic drugs that are often used to treat their hallucinations and delusions [35]. Currently, no disease-modifying drugs for LBDs exist, and treatment is directed towards symptoms; however, extra caution is needed when initiating drug treatment for people with an LBD [40].

Frontotemporal dementias

The reported prevalence of frontotemporal dementia (FTD) varies greatly, especially among older people with dementia, where in a review, Hogan and colleagues found that FTD accounted for an average of 2.7% of all dementia cases [41]. FTD is more common in young onset dementia, and in their review, Hogan and colleagues found FTD to account for an average of 10.2% of dementias in people under the age of 65 years [41]. In a Norwegian study, the overall prevalence of FTD was found to be 2% [29].

Two main variants of FTD have been identified: the behaviour variant and the language variant. The language variant is often described as two different types: semantic dementia and progressive non-fluent aphasia [41]. The behavioural variant is characterized by changes in personality and behaviour, with e.g., disinhibition leading to socially inappropriate behaviour, apathy leading to reduced interest and inactivity, hyperorality and dietary changes, and loss of empathy or sympathy [35]. In this variant, social abilities and executive functions are often affected, and some patients have motor symptoms, but memory and learning are often not affected (at least not initially) [35]. People with the language variant have language dysfunction as the main symptom initially, with problems in language production, object naming, syntax, and/or word comprehension [42]. Symptoms of the different FTD variants can converge as the disorder progresses. People with FTD may be mistakenly perceived as having psychiatric conditions because of the prominence of behavioural features [42].

Hereditary factors with gene mutations are important risk factors, and brain pathology with disproportionate frontal and/or temporal lobe degeneration is found in FTD [35, 42]. Cholinesterase inhibitors and memantine are not recommended for FTD, and no disease-modifying drugs are currently available for FTD [4, 42]. However, due to the lower levels of serotonin in many people with FTD, antidepressants may have symptomatic effect in some patients.

Alcohol-related dementia

Alcohol-related dementia (ARD) accounts for between 3% and 24% of dementia cases, depending on the population, with a higher prevalence in young onset dementia [43]. People with ARD often have symptoms such as abstraction and visuospatial problems, impairment in short-term memory, and disturbed motor function [43, 44]. The main criteria for a diagnosis of ARD are symptoms of dementia in combination with a history of heavy alcohol consumption and with other causes of dementia

excluded [43]. Brain pathology showing a combination of a direct toxic effect related to alcohol use and a severe deficiency in thiamine is seen in ARD [43]. No diagnostic criteria for ARD are given in the ICD-10, but in the ICD-11, ARD is described as being characterised by a 'development of persistent cognitive impairments that meet the definitional requirements of Dementia that are judged to be a direct consequence of alcohol use and that persist beyond the usual duration of alcohol intoxication or acute withdrawal' [26].

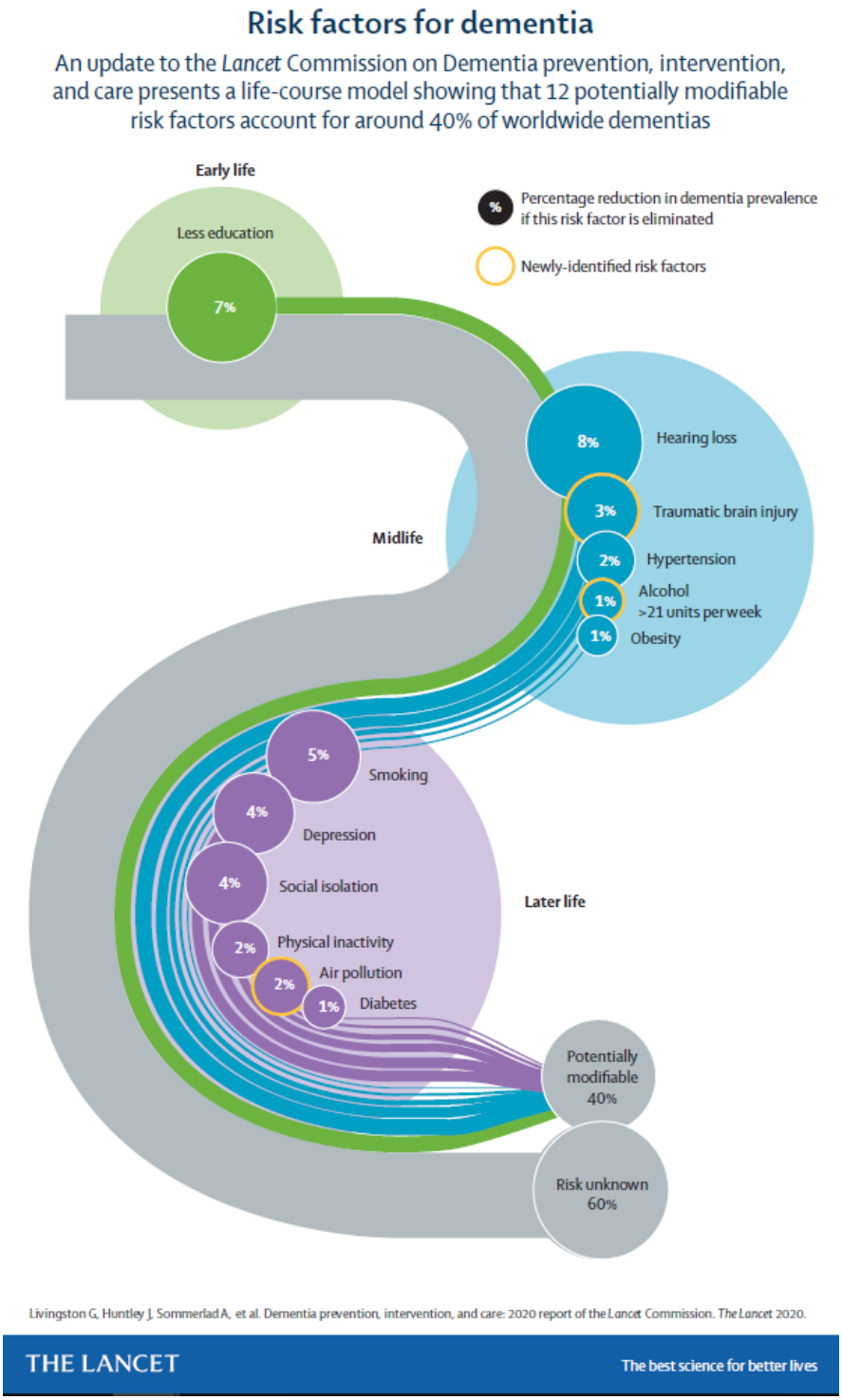
Mixed dementia

Often, dementia is caused by more than one underlying brain pathology, and mixed dementia might be the most common form of dementia, at least in the oldest people with dementia [45]. The most common combination is AD and VaD, followed by AD and DLB, and then all three (AD, VaD, and DLB in combination) [45]. Symptoms of mixed dementia vary by the combination of underlying diseases. Evidence of one underlying disease does not reduce the likelihood of another disease; therefore, identifying all contributing dementia conditions is important to targeting treatment. Treatment of a vascular component as well as use of cholinesterase inhibitors may have an effect in mixed dementia [45, 46]. The fact that mixed dementia is common highlights the importance of assessing individual symptoms and needs in order to provide appropriate treatment, advice, support, and services.

2.2.6. Risk factors for dementia

Several risk factors have been found for dementia, with age being the strongest one. Age is a non-modifiable risk factor, along with genetic factors such as apolipoprotein E (APOE) genotype. Several other genes have been associated with an increased risk of dementia, but with small individual effects. Other risk factors are potentially modifiable: improvements in health care, nutrition, education, and lifestyle changes may have caused the decrease in the age-specific incidence of dementia observed in many countries [47], and evidence supports a relatively strong association between a number of modifiable lifestyle factors and dementia risk. Livingston and colleagues have identified twelve such factors, accounting for a total of approximately 40% of dementia cases worldwide, which theoretically could be prevented or delayed [47].

Figure 2. Twelve potentially modifiable risk factors for dementia
This figure was published in a 2020 report of the Lancet Commission, *The Lancet* 2020, 396(10248), Livingston, G., Huntley, J., Sommerlad, A et al., *Dementia prevention, intervention, and care*, pp 413-446. Copyright Elsevier 2020. Reprinted with permission from Elsevier Health Content Management.



2.2.7 Consequences of dementia for caregivers, family, and society

Dementia has an impact on people's ability to remain independent in performing ADL, and it is one of the major causes of disability and dependency among older people worldwide [32]. In addition to the consequences for the individuals with the condition, which will be described in subsequent chapters, dementia also affects the relatives and other supporters of people with dementia, as well as society.

The family and friends of people with dementia must cope with seeing a family member or friend become ill and decline and see their relationship with the person change. Family caregivers usually respond to the person's gradually increasing needs and dependency, and cope with changes in their behaviour. The sum of needs, dependency, and BPSD may cause caregiver distress and burden, as informal caregivers often extend themselves far to help and care for their friend or family member with dementia. Informal caregivers of people with dementia more often develop major depression and anxiety disorders, and they have more physical health issues and a higher mortality rate compared to the general population [48]. Providing care to a family member with dementia can also have economic consequences, in cases where the informal caregiver must quit work or cut back on working hours. However, not all informal caregivers experience burden. Some caregivers emphasise that they feel a personal and social affirmation of role fulfilment; they accept the caregiving situation and find meaning in the caregiving experience [49]. Assessing and reassessing the caregiver's well-being and their need for support becomes increasingly important as the dementia progresses, as does balancing informal care with formal care services to meet the needs of people with dementia and their caregivers [50].

The Relatives' Stress Scale (RSS) is designed to measure caregivers' ratings of the degree of stress and burden they experience in caring for a person with dementia [51]. The scale consists of 15 questions asking about different aspects that may cause caregiver stress or burden, with each rated on a scale ranging from zero to four. The item scores are added together, resulting in a sum score ranging from zero to 60, with higher scores indicating a higher level of carer burden [51]. In this thesis, we do not focus on the situation of informal caregivers, only on their role in the assessment and support of people with dementia.

Dementia also affects the wider society. The treatment, advice, support, and services required by people with dementia are costly, and meeting the needs of the growing number of people with dementia is seen as a major challenge for society as a whole. The costs of dementia for society include direct costs such as services, medical expenses, and nursing homes, as well as indirect costs such as loss of income and need for disability payment for a person with dementia or an informal caregiver [52]. In 2015, the global societal cost of dementia was estimated to be US$818 billion, and the total cost as a proportion of gross domestic product (GDP) varied from 0.2% in low- and middle-income countries to 1.4% in high-income countries [32]. In 2013, the total cost of health- and care-services in Norway for one person with dementia throughout the whole course of the disorder was estimated to be 2.9 million NOK [53]. The provision of adequate services to people diagnosed with dementia places several demands on the health care services, such as ensuring staff knowledge about dementia and person-centred care, tailoring services (including hospitals and nursing homes) to be dementia specific, adjusting communication to the needs of the person with dementia, ensuring user involvement, and understanding the signs of dementia progression as well as symptoms of other diseases.

2.3 Behavioural and psychological symptoms of dementia (BPSD)

The term 'BPSD' was established at a consensus conference organised in 1996 by the International Psychogeriatric Association (IPA), and it was defined as 'Signs and symptoms of disturbed perception, thought content, mood, or behaviour that frequently occur in patients with dementia' [54, 55].

BPSD refers to a heterogeneous range of symptoms, and the debate over how to term these symptoms is ongoing. In addition to BPSD, terms like 'neuropsychiatric symptoms', 'non-cognitive symptoms of dementia', and 'behavioural disturbances' are also used. Some stakeholders seek to find a more psychosocial term that reflects the multiple causes of behaviour in dementia care [56]. We have chosen to use the term BPSD in this thesis because this term is frequently used in cited and similar literature.

BPSD are among the core symptoms of dementia, and the presence of BPSD is a diagnostic criterion of dementia in the ICD-10 [33]. One or more BPSD affect nearly all people with dementia during the course of the disorder [57-60]. BPSD are considered to be among the most complex, stressful, and costly aspects of care, and they lead to several negative health outcomes for the person with dementia—including excess morbidity, mortality, hospital stays, and early placement in a nursing home—as well as poor caregiver outcomes, such as distress and increased morbidity [57, 58, 60].

BPSD are usually assessed by observation of the person over time or by interviewing a proxy who has observed the person. Assessment of BPSD is addressed in chapter 2.6.6.

2.3.1 Types of symptoms

Different terms and classifications are used for BPSD. When assessing BPSD in Norway, evaluators often use the instrument Neuropsychiatric Inventory (NPI) [61]. Here, we give a brief description of the twelve symptoms which are addressed in the NPI.

Delusions are false beliefs, based on incorrect reasoning regarding external reality, which are strongly held by the patient despite evidence to the contrary [60]. Common delusions of people with dementia are that others are stealing from them, that they are in danger, or that their spouse is an impostor or has been unfaithful. Like hallucinations, delusions are entirely subjective, and if they are not described by the patient, they must be inferred from the patient's behaviour [61].

Hallucinations are perceptions without apparent stimulus which appear as real to the patient. Hallucinations can affect all senses, but visual hallucinations are the most common ones in dementia. Patients with visual hallucinations may see animals or objects that are not there or talk to people who are not present [62].

Agitation has been defined as 'inappropriate verbal, vocal, or motor activity that is not explained by needs or confusion per se' [63]. The agitated patient is seen as uncooperative or resistant to help from others, may hit others or self, throw things, or slam doors, or engage in using profanity or screaming [61, 62]. Agitation is often classified into three types: aggressive behaviour, physically non-aggressive behaviour, and verbally agitated behaviour [64]. IPA's Agitation Definition Work Group has defined that agitation is present when the person has cognitive impairment or dementia and exhibits behaviour consistent with emotional distress (manifesting as one of the three types described above) and causing excess disability which cannot be solely attributable to another disorder [65].

Depression: Depressive symptoms are common in dementia; they may be a first symptom of dementia, and they may be present at any stage of the disorder. Although the prevalence numbers vary, it is estimated that more than 20% of people with dementia have diagnosable depression at any

given time [4], and some studies indicate prevalence rates for significant depressive symptomatology to be as high as 50% [66]. Dementia may complicate the presentation of depressive symptoms—e.g., by masking them. Additionally, due to memory and communication problems, the person with dementia may not always be able to express feelings of sadness [60], which may lead to the symptoms being overlooked. Symptoms of depression in persons with dementia include loss of interest, irritability, anxiety, and withdrawal from social settings, but these are also common symptoms of dementia. Since symptoms of dementia and depression partially overlap, there has been a discussion regarding the validity of traditional diagnostic criteria for depression when evaluating depressive symptoms in patients with dementia. A set of diagnostic criteria for depression in people with AD have been proposed: The Provisional Diagnostic Criteria for Depression in Alzheimer's Disease [67]. According to these criteria, depression in people with AD requires the presence of three or more symptoms that have been present during the same 2-week period and that represent a change from previous functioning. Furthermore, the symptoms should cause clinically significant distress, should not only occur during delirium, should not be caused by the physiological effects of a substance, and should not be better accounted for by other conditions [67].

Different mechanisms are involved in depressive symptoms in dementia. It is hypothesised that in mild dementia, depressive symptoms may be caused by psychological factors, such as reactions to being diagnosed with a deadly disease or experiencing loss of meaningful activities, memory, or independence; while in severe dementia, depressive symptoms may also be related to the degenerative and vascular changes in the brain [4, 68]. Depression in earlier life is also a risk factor for dementia, with a 4% potential reduction in dementia prevalence if this risk factor is eliminated [4].

Anxiety: The most common anxiety symptoms in people with dementia are irritability and restlessness [69]. Other frequent symptoms of anxiety in people with dementia are worries about cognitive performance or physical health, sleep disturbances, motor tensions, or being frightened or tired [69].

Euphoria is described as a sustained and exaggerated feeling of cheerfulness or well-being that is out of proportion to the actual situation, and it is often associated with an increased emotional tone or emotional reactivity [60]. A patient with euphoria is described as, for instance, finding humour in and laughing at things that other people do not find funny [61].

Apathy is characterised by passivity and loss of or diminished motivation (but without the dysphoria of depression), as well as loss of spontaneous emotions, energy, initiative, and goal-directed behaviour [60, 62]. A patient with apathy appears less spontaneous and less active than usual [61].

Disinhibition involves socially inappropriate behaviour, saying crude things, being rude to strangers, or making sexual remarks that the person would not usually make [61].

Irritability refers to sudden flashes of anger [61] or an extensive feeling of unease with increased levels of hostile attitudes or actions, which can be worsened when the person is hungry or in pain [60].

Motor disturbance is described as purposeless activities, such as pacing and rummaging, compulsions, and repetitive behaviours [70]. In their definition of agitation, Cohen-Mansfield and Billing include aberrant motor activity as an expression of agitation through pacing, wandering, biting, and fighting [63].

Night-time behaviours refer to sleep disturbances, such as frequently waking up at night, increased sleep latency, waking up early in the mornings, or being sleepy and napping more frequently in the daytime [62].

Appetite: Changes in appetite due to dementia can be related both to eating more or less than before and to a change in preferred foods (e.g., an enhanced preference for sweets) [60].

Because BPSD are quite heterogeneous, they might be best considered and studied as groups of related symptoms [71, 72]. Thus, groups of correlated symptoms are often studied together (e.g., in examinations of interventions) [72], and then a principal component analysis is conducted on data from the cohort under study to identify the relevant clusters/groups of symptoms. Examples of commonly used symptom groups are affective symptoms, apathy, psychotic symptoms, hyperactivity, and euphoria [72, 73].

2.3.2 Prevalence of BPSD

Most people with dementia experience one or more BPSD during the course of the disorder [57, 58, 60], and the presence of BPSD is also one of the diagnostic criteria for dementia [33]. The most prevalent BPSD have been found to be apathy, depression, irritability, agitation, and anxiety, with the least prevalent being euphoria, hallucinations, and disinhibition [60, 74, 75].

Table 1. Prevalence rates (%) of neuropsychiatric symptoms, from studies of clinical outpatients with dementia assessed with the NPI [75]. Reprinted with permission from Norsk Epidemiologi 2012; 22 (2): 225-232.

	Garcia-Alberca 2011	Aalten, 2007	Toyota, 2007	Peters, 2006	Senanarong 2005	Piccinini, 2005	Fuh, 2005	Aalten, 2003	Benoit, 2003	Mega, 1996
	n=125	n=2354	n=261	n=576	n=73	n=50	n=320	n=199	n=499	n=50
Age	76.4 (6.1)	76.7 (7.8)	78.5 (5.1)	73.0 (8.5)	70.3 (8.1)	69.3 (7.5)	75.2 (7.2)	76.4 (8.0)	77.5 (7.1)	75.0 (6.6)
MMSE	14.5 (4.8)	17.8 (5.9)	19.0 (6.0)	20.7 (5.6)	18.4 (6.6)	16.8 (5.6)	17.1 (6.8)	18.1 (4.7)	19.7 (4.3)	16.2 (7.5)
Symptoms	AD[1]	AD[4]	AD[1]	Dementia[2]	AD[1]	AD[1]	AD[1]	Dementia[3]	AD[1]	AD[1]
Delusion	38	19	51	26	27	30	31	35	18	22
Hallucination	20	9	23	13	18	12	24	13	7	10
Agitation/aggression	55	31	45	36	36	32	39	29	39	60
Depression	60	37	39	49	30	68	47	57	40	38
Anxiety	54	37	39	36	43	54	37	39	45	48
Euphoria	4	5	7	9	7	24	8	7	7	8
Apathy	74	55	64	59	45	74	42	59	56	72
Disinhibition	30	10	17	27	30	24	21	13	12	36
Irritability	66	32	25	43	48	32	42	40	37	42
Ab. motor behaviour	47	28	44	36	43	46	31	35	22	38
Night-time behaviour	36	20		26	38		42	18		
Eating change	28	22		32	27		36	25		
At least one CS-NPS*	98			89				92	88	88
	NPI>0	NPI>3	NPI>0	NPI>0	NPI>0	NPI>0	NPI>0	NPI>0	NPI>3	NPI>0

[1] NINCDS-ADRDA Alzheimer's Criteria

[2] DSM-III-R

[3] DSM-IV

[4] Clinical dementia diagnosis

* CS-NPS = Clinically Significant Neuropsychiatric Symptom

BPSD are common in all stages of dementia, and symptoms tend to fluctuate episodically but may last for six months or more. Some BPSD are more common in some stages of dementia than others; for instance, delusions, hallucinations, and aggression are more common in moderate and severe stages of dementia, and agitation occurs at all stages of dementia but particularly in moderate to severe stages [58, 76]. A recent review using established staging criteria found that the prevalence of the affective symptoms of depression, anxiety, and apathy are high across all dementia stages, and no evidence was found for changes in their prevalence with the progression of dementia [77].

In a longitudinal study of 779 people with dementia living in the community, Brodaty and colleagues found that the levels of most symptoms (delusions, hallucinations, agitation, anxiety, apathy, disinhibition, irritability, aberrant motor behaviour, and appetite) increased over 3 years, while levels of depression, euphoria, and night-time behaviour did not increase significantly over the 3 years [78].

For some dementia disorders, specific BPSD are more common. In LBDs, visual hallucinations are prominent and appetite disturbance is rare. In FTD, disinhibition, agitation, anxiety, euphoria, and aberrant motor behaviour are pronounced, and overall levels of symptoms are severe. In VaD, depression is common; and AD is associated with less severe BPSD than other dementia disorders [55, 57, 58].

2.3.3 Possible causes of BPSD

Several factors are considered to contribute to BPSD, and unmet needs and other psychological and social factors are central contributors. BPSD are also associated with tau and amyloid neuropathology in AD, indicating that neurobiological mechanisms might underpin BPSD [47]. It is important to consider the possibility of delirium and to not confuse delirium with BPSD; however, differentiating BPSD from delirium can be difficult. In addition, drugs (through side effects and interactions) can lead to BPSD [58]. Thus, assessment of BPSD should consider the complexity of the symptoms and the potential underlying causes.

Kales and colleagues (2015) put forth a conceptual model of how interactions between different contributing factors can cause BPSD [58]. They describe the factors contributing to BPSD as:

1) *Factors related to the person with dementia*: neurobiology and neurodegeneration leading to increased vulnerability to stressors or triggers; acute medical conditions, such as pneumonia or constipation; pre-existing personality and psychiatric illnesses; or unmet needs resulting in pain, fear, boredom, etc.
2) *Factors related to caregivers:* burden or depression in caregivers; lack of knowledge about dementia; communication problems resulting in e.g., anger or screaming; or mismatch between what the caregiver is expecting and what is possible in the dementia stage.
3) *Environmental factors:* lack of or change in structure and routines; lack of access to activities; safety issues; barriers in the physical environment, such as light, noise or architectural factors; lack of stimuli or more stimuli than the person with dementia can manage.

In the Unmet Needs Model, Cohen-Mansfield et al. described ‘problem behaviours’ (defined in the same way as BPSD) as a result of unmet needs stemming from a decreased ability of people with dementia to communicate those needs and to provide for themselves [8]. Cohen-Mansfield and colleagues focused primarily on agitation and similar verbal, vocal, or motor activity. Furthermore, they focused on nursing home residents when describing their model. Nevertheless, the principle that BPSD is need-driven may also apply to other BPSD and to community-dwelling people with dementia, and this principle is included by Kales et al. (2015) as a factor related to the person with

dementia as well as an environmental factor [58]. Cohen-Mansfield et al. found that verbal/vocal behaviours were more often displayed by people who were rated as feeling pain, discomfort, or a sense of being alone, whereas physically nonaggressive behaviours were more common when the people with dementia were not engaged with any activity [8]. Unmet needs have been regarded as so central in understanding behaviour in dementia that 'unmet needs' has been suggested as an alternative term for BPSD [79]. Assessment of BPSD should keep the unmet needs model in mind and should focus on causes of BPSD, such as pain or discomfort, boredom, hunger, loneliness, worry, and a lack of meaningful activity that could cause the symptoms.

Person-centred care for people with dementia is the care philosophy of Tom Kitwood, a British social psychologist. Kitwood's work is considered a critique of the more medical-based deficit-focused approach which previously dominated support and care for people with dementia. Person-centred care focuses on personhood in dementia, with the term 'personhood' defined by Kitwood as 'a standing or status that is bestowed upon a human being by others, in the context of relationship and social being' [80](p8). In Kitwood's view, a person with dementia is a person in the fullest possible sense: 'he or she is still an agent, one who can make things happen in the world, a sentient, relational and historical being' [81]. Personhood is not dependent on abilities, and Kitwood described common symptoms as being related to 'a failure of understanding and care' [80](p 3), and this could be said to also apply to BPSD. The term 'positive person work' has been introduced to describe positive interactions, such as recognition, collaboration, and validation [80](pp 90-91). This may be in line with what Kales and colleagues described as caregiver-related contributing factors to BPSD [58]. (Person-centred care is also addressed in chapter 2.7 of this thesis.)

The ICF framework offers a biopsychosocial understanding of the mechanisms contributing to BPSD, as the model encompasses all the above-mentioned contributory factors. BPSD may be associated with factors in body function or structure, such as pain or brain atrophy; it may also be caused by unmet needs due to activity limitations, participation restrictions, or contextual factors, either in the person (e.g., personality) or in the environment (e.g., insufficient knowledge in staff or lack of proper facilitation).

2.3.4 Consequences of BPSD

BPSD may have consequences not only for the person with dementia but also the family and informal caregivers, as well as society and formal caregivers.

Consequences for the person with dementia: BPSD may add to the burden of having dementia. People with dementia with untreated BPSD have faster disease progression than those without such symptoms [58], and BPSD have been found to be associated with higher mortality risk [60]. BPSD can be distressing for the person with dementia, as several of the symptoms (such as hallucinations, delusions, or anxiety) can be frightening or confusing. BPSD can also result in reduced quality of life as well as poor patient health outcomes, including excess morbidity, hospital stays, and early placement in a nursing home [58, 60, 82]. In a study by Shin et al., quality of life in people with AD was negatively associated with depressive symptoms and (in proxy ratings only) with disinhibition symptoms [83]. Furthermore, in a two-year follow-up study of people with AD, an association was found between a decrease in quality of life (scored by proxy) and presence of mood and psychosis factors on the NPI [84]. Okura and colleagues (2010) found that people with cognitive impairment, no dementia (CIND) and people with dementia who also had three or more BPSD and one or more clinically significant BPSD more often had functional limitations. Those with clinically significant depression, anxiety, or aberrant motor behaviours had significantly higher odds of ADL limitations [85].

Consequences for informal caregivers: Managing BPSD is among the most challenging and distressing aspects of care provision, and BPSD are associated with caregiver burden and poor caregiver outcomes, including reduced quality of life, health issues, and reduced employment income [58, 60]. Caregivers living with people with dementia who have BPSD are more distressed or depressed (or both) than caregivers of people with dementia who do not have BPSD or with other chronic diseases [58]. Shin and colleagues found that the quality of life of caregivers of people with AD was negatively correlated with the person's agitation/aggression, irritability/lability, disinhibition, and anxiety, as well as total NPI score [83]. In a study by Craig et al., sleep disturbance, aggression/agitation, and depression/dysphoria caused caregivers of people with AD severe distress, while all other symptoms (except hallucinations and elation/euphoria) were described by the caregivers as moderately distressing [86]. A study by Tun and colleagues (2008) using a cluster approach to presence of BPSD and its contribution to burden in caregivers of people with AD found that BPSD subgroups could predict caregiver burden. Specifically, the caregivers of the 'highly symptomatic' subgroup experienced higher caregiver burden than those of the 'minimally symptomatic' (lowest mean score on the NPI) and the 'affective/apathetic' (moderate level of symptomatology and high scores in the affective groups) subgroups [87].

Consequences for formal caregivers and society: BPSD also increase the costs of care [60]. One-third of dementia care costs have been attributed to the management of these symptoms, owing to more use of health services, higher direct care costs, and more need for informal care provided by family caregivers [58]. BPSD have been found to be associated with resident-to-staff aggression in nursing homes, likely leading to stress among care staff and possible risk of retaliation or of avoiding interactions with residents perceived as aggressive [88]. There is a high prevalence of BPSD among people with dementia who are admitted to nursing homes [89], and BPSD—including psychosis and agitation—have been found to be associated with increased risk of institutionalisation [82]. Consequently, BPSD adds to the costs of dementia because nursing home placement is much more costly than care at home.

2.3.5 Treatment of BPSD

Psychosocial interventions are widely recommended as a first-choice approach in the treatment of BPSD. Psychosocial interventions should also be accessible by people with dementia during drug treatment [90].

Case conference models

The guideline from the National Institute for Health and Care Excellence (NICE) on managing non-cognitive symptoms (BPSD) state that before starting treatment of BPSD (non-pharmacological or pharmacological), a structured assessment should be conducted to explore possible reasons for the symptoms and to check for and address clinical or environmental causes (e.g., pain, delirium, or inappropriate care) [90]. In the NICE guideline, the term 'non-cognitive symptoms' is used for BPSD.

Case conference models can be used as a structured approach in assessing and managing BPSD. Such models consist of assessment, one or more case conferences (often in a multidisciplinary team), treatment/interventions, and evaluation of the effect on BPSD. This type of approach is called a DICE approach by Kales and colleagues [91], and is described as follows:

1) Describe the problem (get an accurate characterisation of the symptom(s) and the context).
2) Investigate the cause (examine possible underlying and modifiable causes, such as pain, sleep, or sensory changes, as well as factors related to caregiver and environment).

3) Create a plan (respond to causes identified in step 2: e.g., relieve pain, improve communication, adjust environmental demands and the approach to the person with dementia).
4) Evaluate the effectiveness (was the plan (step 3) followed, and if not, why not; if it was, did the symptoms and their consequences improve, how did the person react, should anything be adjusted, etc.) [91].

The VIPS practice model provides structured content for case conferences and ensures a focus on person-centred care [92]. VIPS is an acronym for the elements of person-centred care: Value, Individualised approach, Perspective of the person with dementia, and positive Social psychology. Each of these 4 elements has 6 indicators. The VIPS practice model outlines a weekly structured consensus team meeting, with set roles and functions to carry out the following: 1) Present a concrete daily care situation from what is thought to be the perspective of the person with dementia, based on knowledge of the person, communication, and observation; 2) Use the 24 indicators to analyse the situation; 3) Have a group discussion; and 4) Make decisions about interventions that are person-centred and may improve the quality of care/life for the person with dementia. These interventions are evaluated in a later case conference at a set date [92].

Another case conference model used in Norway is the Targeted Interdisciplinary Model for Evaluation and Treatment of Neuropsychiatric Symptoms (TIME) [93], a biopsychosocial model built within the framework of cognitive therapy. The components of TIME act together to provide mutual understanding of the situation and an approach to managing the BPSD using three overlapping phases: 1) registration and assessment, 2) guided reflection, including one or more case conferences, and 3) action and evaluation [93]. In a cluster randomised controlled trial, the TIME intervention was found to reduce agitation among nursing home patients with dementia [94].

Psychosocial interventions

The NICE guideline on managing non-cognitive symptoms recommends psychosocial and environmental interventions as the initial and ongoing management 'to reduce distress in people living with dementia'. [90]. The Norwegian national guideline on dementia also recommends using psychosocial interventions as a first choice before prescribing medication to people with dementia exhibiting BPSD, except in crisis situations [2]. Just as the ICF framework offers a biopsychosocial understanding of the factors contributing to BPSD, this understanding may be used to identify factors which can prevent or relieve BPSD.

Psychosocial interventions that promote activity and participation, adapt the physical environment, and enhance knowledge and competency in staff are all measures with very few negative side effects [58]. Individual and group interventions enabling people with dementia to engage in meaningful activities have been found to reduce behavioural symptoms, including depression, and to improve quality of life [95-97].

In a review, Keogh and colleagues (2019) identified three targets for psychosocial interventions for home-dwelling people with dementia: the person with dementia, the family caregiver, and the person−caregiver dyad [98]. In a review, Abraha et al. describe five categories of non-pharmacological interventions for BPSD treatment in older people with dementia: 1) sensory stimulation interventions; 2) cognitive-/emotion-oriented interventions; 3) behaviour management techniques; 4) multicomponent interventions; and 5) other therapies, such as exercise therapy and animal-assisted therapy [99].

Despite the consensus that non-pharmacological treatments like psychosocial interventions are the preferred treatment approach to BPSD in people with dementia, a lot of heterogeneity is found in studies investigating the efficacy and practicality of non-pharmacological interventions targeting BPSD—e.g., in the delivery of the interventions, the power of the studies, and which outcomes were studied.

Drug treatment

The Norwegian National Guideline on dementia suggests that antipsychotics may be used to treat psychotic symptoms and aggressive agitation in patients with AD, VaD, or mixed AD/VaD, if the patient suffers significantly or is in danger of self-harm. Furthermore, the guideline suggests that patients with LBD and FTD should generally not be offered antipsychotic medications, due to considerable risk for severe side effects [2]. The guideline strongly recommends against offering benzodiazepines or z-hypnotics as a sleeping aid to people with dementia. Antidepressants may be offered when needed to patients with severe depression, in addition to psychosocial interventions [2].

The NICE guideline on managing non-cognitive symptoms recommends that people with dementia continue to have access to psychosocial and environmental interventions while they are being prescribed antipsychotics and after they have stopped taking them. Furthermore, the guideline recommends offering personalised activities to people with dementia experiencing symptoms of agitation or aggression in order to promote engagement, pleasure, and interest [90].

2.4 Activity and participation in dementia

2.4.1 Dementia and the relationships between activities, participation, and functions

The ICF model illustrates the mutual relationships between impairments in mental functions, activity limitations, and participation restrictions [13]. In the ICF, actions and tasks performed by individuals are defined as activities, and involvement in life situations is defined as participation. The definitions of activities and participation differ, but the two are closely related, and every action may be considered as entailing participation, especially when it is performed in a social environment [13].

The ICF describes nine domains of activities and participation: 1) learning and applying knowledge; 2) general tasks and demands; 3) communication; 4) mobility; 5) self-care; 6) domestic life; 7) interpersonal interactions and relationships; 8) major life areas; and 9) community, social, and civic life [14]. In the 2017 version of the ICF browser, these domains of the activities and participation component are given in a single list that covers the full range of life areas, from basic learning, watching, and moving to more complex social interactions and participation in society [14].

In dementia research and clinical practice dealing with (diagnostic) evaluations, activities are often described as Activities of Daily Living (ADL), categorised into Basic Activities of Daily Living (BADL) and Instrumental Activities of Daily Living (IADL) [52, 100]. BADL include self-maintenance skills, such as eating, grooming, and dressing, while IADL include more complex activities, such as preparing meals, doing laundry, and handling finances [20, 52, 100, 101]. As ADL to some extent build on automated procedures, many of them may still be accomplished with the support of habits and routines in spite of cognitive impairment [102]. In the early stages of dementia, only the complex IADL are affected, but as the disorder progresses, more IADL become difficult, and gradually BADL are also affected, resulting in increasing need for assistance [52, 100, 103, 104].

Participation in leisure activities in old age has been suggested to have a protective role against developing cognitive impairment and dementia. Increased participation in leisure activities—such as

reading, playing board games, dancing, and playing musical instruments—was associated with a lower risk of dementia [105]. It has been suggested that these activities are cognitively stimulating and that participation in such activities may increase one's cognitive reserves, delaying the clinical or pathological onset of dementia or possibly slowing the pathological processes of the disorder during the preclinical phase of dementia [105]. Engaging in mentally stimulating activities in later life—such as craft activities, computer activities, playing games, and social activities—have also been found to be associated with a decreased risk of incident MCI [106].

Independence in complex IADL is used as a criterion for differentiating MCI from dementia. An affected ability to carry out ADL is a diagnostic criterion for dementia according to, among others, the ICD-10 [33]. In ICF terms, it could be said that limitations in activity are used as an indicator of severity of impairment on a body function level. In this description, an evaluation of ADL is implied, through observation or self-/proxy-given information about activity limitations. Therefore, a thorough assessment of activities should be a standard part of a diagnostic evaluation [27, 33, 107]. (Assessment of activity and participation is described in chapter 2.6.5.)

Dementia is often first suspected when one experiences problems in ADL, such as managing one's finances, misplacing things, or learning to use new appliances or everyday technology [100, 108]. A close relationship has been found between problems in IADL and cognitive impairment in early-stage dementia, and activity limitations may be used when screening for dementia, as they might be markers of dementia as many as 10 years before the clinical diagnosis [100, 108-110]. For example, a study by Dubbelman and colleagues included 1555 cognitively healthy as well as memory-clinic referred participants from six cohorts who had all been tested for amyloid biomarkers [111]. A total of 982 of the participants were amyloid-positive, and Dubbelman and colleagues found that complex IADL (such as managing paperwork) were especially sensitive to the earliest cognitive changes, with a decline in the early prodromal stage among amyloid-positive individuals which was distinct from the functional change observed in amyloid-negative, cognitively normal individuals [111]. In another study, Rosenberg and colleagues found that perceived difficulty in using everyday technology was higher in participants with MCI and was further heightened in participants with mild-stage dementia, compared to participants without cognitive impairment [112]. Furthermore, participants with MCI and dementia considered everyday technology to be less relevant to their life situation than did participants without cognitive impairment [112]. Barberger-Gateau and colleagues (1999) found that performance in the four IADL domains of handling finances, taking care of medications, managing the telephone, and using public transportation predicted cognitive deterioration and a diagnosis of dementia [113]. Each of the IADL domains had different specific associations with the neuropsychological tests, and a common cognitive component of both the IADL tasks and the neuropsychological tests is suggested to explain the predictive value of the IADL items [113].

Awareness of one's own forgetfulness has the potential to cause fear, embarrassment, anger, and/or low self-esteem [114], and it may be less socially desirable to admit memory loss than IADL problems [115]. Therefore, addressing IADL limitations when identifying who should undergo a diagnostic evaluation may be a good approach. Although cognitive impairment may be detected by advanced neuropsychological tests before it manifests as IADL limitations, only a few people can access such tests at an early stage, and the clinical presentation of IADL limitations may thus often be an early marker of dementia [108]. In our clinical experience, it is easier for people to detect and report problems with IADL than memory problems, as memory may be more complex and harder to pinpoint.

Information about activity limitations is also a way to understand the consequences of the functional impairments in the person's participation in everyday life. This may aid in planning support—not just

how much help the person needs, but also which types and parts of the activities the person is able to do independently, and how the supervision or help can best be given.

Increased ADL limitations have been found to be associated with dementia progression [116], and both functional and cognitive impairment may be viewed as a continuum across the clinical stages of dementia. [27]. Instruments such as the Clinical Dementia Rating (CDR) scale, a measure of dementia severity which addresses six domains of cognitive and functional performance, use the level of dependency in ADL as one of the indicators of presence and stage of dementia, underlining the close relationship between activity limitations and the determination of dementia and dementia severity [117]. In a study of noninstitutionalized patients with probable AD, Bianchetti and colleagues found that one year after discharge from a dementia unit, the number of lost ADL functions was the most important predictor of short-term mortality—independent of the degree of cognitive impairment, the duration of dementia, the age of the patient, and the number of chronic diseases [118].

Differences in activity limitations have been found across different subtypes of dementia. A study by Gure et al. (2010) comparing VaD, AD, and dementia due to other aetiologies found that patients with VaD and other dementias had a greater number of activity limitations overall compared to patients with AD; those with VaD had the highest mean number of IADL limitations [119]. A possible explanation could be that patients with VaD, having neurological sequelae after stroke, experienced limitations due to motor deficits in addition to cognitive impairment [119].

Cognitive tests often include components of observable tasks, such as drawing a clock or following instructions. By observing a person performing a task, a trained professional can interpret the underlying cognitive impairment of the performance problems they observe, in terms of which cognitive functions might be affected by dementia (or other conditions). Performance on these tasks and the use of corresponding test scores to assume cognitive impairment, as frequently done by e.g., physicians and psychologists, is another example of how, in ICF terms, activity limitations are used to indicate functional impairment.

Impaired cognition is not the only cause of ADL limitations: impaired motor function or other underlying conditions also play a role. When addressing ADL functioning, one must be careful to identify which limitations may be due to impaired motor function or other conditions, rather than assuming that all activity limitations are caused by impaired cognition. While impaired motor function can be caused by dementia, other conditions including orthopaedic issues, stroke, and other neurological disorders may also affect motor functioning. Contextual factors, both personal and environmental, also affect activity and participation [13].

2.4.2 The impact of limitations in activities and participation in dementia

Limitations in functional abilities is one of the troubling aspects of dementia [107], and the social and economic burden of dementia is closely related to the person's need for assistance and support in ADL [103]. Because the cognitive impairments cause activity limitations, ADL gradually become more difficult as the disorder progresses, resulting in an increasing loss of independence and need for assistance from either informal family caregivers or formal care services [27, 103]. Loss of independence in everyday functioning can cause reactions of sorrow and despair for the person with dementia, and it has been reported that the next of kin of people with dementia are more concerned about the person's limitations in ADL abilities than they are about their cognitive test scores [20]. Increasing ADL limitation is also a contributing factor to the need for nursing home admission.

Dementia also affects motor functioning, such as hand function [120], balance [121], gait speed, mobility, and muscle strength [122]. A relationship has been found between the severity of cognitive impairment and increased gait abnormalities [122, 123]. The cognitive domain most strongly associated with motor function is executive function, which is associated with hand function [120], balance [121], and gait [124]; in fact, motor symptoms may be early manifestations of dementia, and they are also associated with biomarkers for AD in persons with MCI [125]. People presenting with a combination of slow gait and self-reported cognitive symptoms have been found to have an increased risk of dementia [123]. Motor symptoms may be contributing factors to ADL limitations, dependency, and reduced physical activity.

Activity limitations not only lead to dependency: they also result in loss of meaningful activities in everyday life, which in turn may lead to decline in quality of life, reduced self-esteem, or increase in BPSD, including depression [52, 96, 126, 127]. Loss of ability to perform ADL is also associated with caregiver burden [20]. Therefore, focusing on activity is often recommended in interventions for people with dementia. For example, the NICE guideline on interventions to promote cognition, independence, and well-being recommends offering a range of activities to promote well-being that are tailored to the person's preferences [90].

Early in the disorder process, loss of ability to function in ADL may lead to feelings in the person with dementia of uselessness, of dependence, and of being a burden to one's family [20]. Activity limitations may also lead to social isolation and a feeling of hopelessness. The social stigma of having a dementia diagnosis may also negatively affect access to meaningful activities for people with dementia, including fewer opportunities to remain socially engaged [128]. Later in the progression of the disorder, ADL problems increase and may lead to issues regarding personal hygiene, toileting, and eating [20].

Identifying activity limitations in dementia early, and addressing these limitations through treatment, advice, support, and services, may be useful and improve quality of life for people with dementia [27, 129, 130]. Interventions which address activity limitations as perceived by the person with dementia, such as cognitive rehabilitation, have been found to improve everyday functioning in relation to the individual goals targeted in the therapy [131]. Participation in enjoyable and meaningful activities may result in positive feelings, and the absence of such activities may maintain or intensify depressive symptoms in older people [96]. Different interventions that target activities (such as leisure activities) may be useful in preventing or treating depression in people with cognitive impairment [126], and promoting activities tailored to the person's interests, abilities, and physical and social environment may help reduce BPSD [95, 127]. Performing enjoyable activities and experiencing social stimuli in companionship with others by attending a day care service for people with dementia have been found to have a positive effect on the everyday lives of the attendees [132]. Participation in activities should not be seen as something special happening at specified times; actively taking part in everyday tasks and activities that happen naturally during the day may be just as important [133].

2.5 Assessments in dementia

Which assessment(s) to use for people with dementia depends on the purpose of the assessment [15](pp 4-11). Being aware of the purpose of the assessment is important: for instance, if the purpose is to diagnose, assessments that provide information regarding the diagnostic criteria are prioritised, while if the purpose is to plan or evaluate treatment, advice, support, and services, other assessments should be used. Often, assessments are conducted with more than one purpose—e.g., diagnostic as well as treatment and care planning. The main purpose of the assessment tools presented in chapter 2.6 is diagnostic evaluation, but assessment tools with the purpose of planning

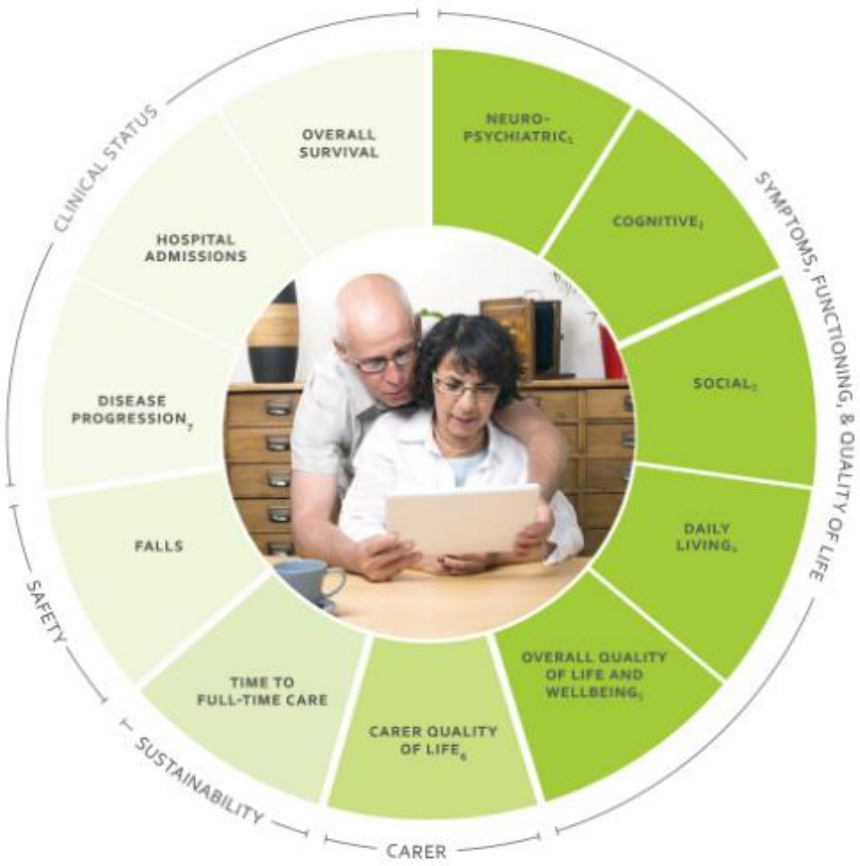
treatment, advice, support, and services are also addressed in the chapter (2.6). Different assessment purposes are further elaborated on in chapter 2.5.1.

A number of assessment tools are used to assess people with dementia or cognitive impairment. The International Consortium for Health Outcomes Measurement (ICHOM) has defined global standard sets of what they refer to as 'outcome measures that matter most to patients'. ICHOM standard sets have been developed for several conditions, including dementia. The working group for the dementia standard set is an international group of people with dementia, researchers, and clinicians [134], and they have identified a comprehensive standard set of assessments that are applicable to all types and stages of dementia [134]. The aim of using a standard set of assessment tools is to evaluate issues that aid in the understanding of how to improve the lives of people with dementia. These assessments may be used mainly for the first three purposes described by Lezak [15](pp 4-11): diagnosis, treatment and care planning, and evaluation.

The ICHOM standard set for dementia includes assessments, referred to by ICHOM as 'outcome measures', for the following domains [134]:

- Symptoms, functioning, and quality of life (BPSD, cognitive functions, social functioning such as community affairs and relationships, ADL, and overall quality of life and well-being)
- Caregiver outcomes (quality of life for caregiver)
- Sustainability (time to full-time care)
- Safety (falls)
- Clinical status (disease progression, hospital admissions, and overall survival)

Figure 3. ICHOM standard set for dementia [134]
Reprinted with permission from ICHOM International Consortium for Health Outcomes Measurement from https://connect.ichom.org/standard-sets/dementia/



The measurements we use should evaluate what matters to the patients and what they really care about [135]. Using a broad set of assessments like the ICHOM standard sets can provide a broad understanding of the total impact of living with dementia. Having established this foundation, in this thesis, we will not address all these aspects and measures, but rather primarily the assessments related to symptoms and functioning.

2.5.1 Why assess?

Before any assessment, awareness of the purpose of the assessment is crucial, answering the question 'what do we want to explore?' Lezak and colleagues describe six purposes for an assessment: 1) diagnosis; 2) patient care and planning; 3) treatment–i: treatment planning and remediation; 4) treatment–ii: treatment evaluation (i.e., evaluating the worth of a treatment with regard to cost and usefulness); 5) research; and 6) forensic neuropsychology [15](pp 4-11). Here, we address 3 purposes of assessment adapted from Lezak and colleagues: 1) diagnosis; 2) planning of treatment, advice, support, and services; and 3) evaluation of effects and adjustments of current treatment, advice, support, and services. As mentioned above, assessments may have more than one purpose—that is, e.g., assessments performed to establish a diagnosis often provide useful information in planning care, and assessments performed to plan care may reveal information of value for a diagnostic process. Assessments are often conducted with a research purpose, such as clinical trials. For papers I and III, assessments were conducted for research purposes, whereas in paper II, data from assessments conducted for diagnostic purposes were collected and used in analyses.

Purpose 1 - diagnosis

In the diagnostic process, other potential causes of cognitive decline or impairment are evaluated and, if present, possibly treated; the diagnostic criteria for dementia are explored, along with the degree of the cognitive decline. If the diagnostic criteria for dementia are met, the underlying dementia disorder—i.e., the aetiological diagnosis—is determined. The different assessments included in a diagnostic evaluation serve to provide enough information for a diagnosis of dementia to be established or rejected. The assessments may result in the unravelling of other potentially treatable causes of cognitive decline, such as delirium, sensory impairment, depression, normal pressure hydrocephalus, or medicines associated with increased anticholinergic burden [4, 90, 136].

A dementia diagnosis may lead to more support for handling multimorbidity as well as preventing delirium by guiding medical treatment and follow-up of the dementia disorder itself and of other medical conditions [47].

Getting a diagnosis early in the progression of dementia is important for several reasons. For one thing, an early diagnosis allows people with dementia to plan while they still have the capacity to make important decisions about their future care [137]. For another thing, an early diagnosis makes it possible for people with dementia and their informal caregivers to do things and have experiences they would otherwise have delayed [4]. Furthermore, a diagnosis is often a gate-opener for treatment, advice, support, and services [137]. However, not all dementia cases are identified: only 20–50% of those with dementia in high-income countries have a diagnosis recorded in the patient's primary care medical journal, and this number is lower in low-income countries [4, 137]. A dementia diagnosis will often be an answer to questions people, or their caregivers, have asked themselves, or an explanation for changes in behaviour and symptoms which they have experienced.

Purpose 2 - Planning of treatment, advice, support, and services

A dementia diagnosis alone does not predict service needs, length of hospitalisation, level of care, or functional outcomes [12]. To be able to plan the necessary individually tailored treatment, advice, support, and services for people with dementia, information is needed about the consequences of the diagnosis with regards to needs, functioning, and disability [12]. Dementia may affect the person's ability to drive a car, to handle weapons, and eventually to take care of other people or pets/animals. Furthermore, the ability to consent to and make decisions about different issues, such as financial matters, uptake of services, or participation in research, is also increasingly affected throughout the course of the disorder. Assessments which evaluate ability to consent for each type of decision should be conducted regularly as part of treatment, advice, support, and services.

Assessments conducted as part of the diagnostic evaluation may also serve another important cause: they establish a basis for planning individually tailored treatment, advice, support, and services [15](pp 4-11). An assessment of ADL functioning can confirm that the cognitive impairment is so severe that the diagnostic criterion for dementia is fulfilled; at the same time, this assessment is a description of the challenges the person with dementia has with functioning in everyday life, the resources and needs they have, and the type and degree of assistance they require.

Assessing BPSD is necessary to see whether the ICD-10 diagnostic criterion G3 is fulfilled [33]. However, these assessments also describe central challenges faced by the person with dementia and their caregivers every day. BPSD are described as the most challenging part of dementia [57, 58], and knowledge derived from the BPSD assessment is a crucial source for guiding how to best support the person and the caregivers.

The assessments of cognition, functioning, and BPSD conducted in diagnostic evaluations may often indicate needs; however, targeted needs assessments should also be conducted in order to plan treatment, advice, support, and services. Such needs assessments should include the perspective of the person with dementia. (Needs assessments are described in chapter 2.7.) Depending on how comprehensive the diagnostic evaluation was and the measures it contained, there is often a need for additional assessments that give more extensive information about the level of functioning and disability and about the goals of the person in question. This includes addressing activities included in a normal day in the areas of physical self-maintenance, household activities, and leisure activities. Asking about interests, family and social networks, preferences, and wishes helps tailor the support.

In short, findings from the diagnostic evaluation should be used in combination with additional needs assessments in planning how to support the person and the caregivers. Individually tailored treatment, advice, support, and services may improve prognosis by reducing or delaying the progression of cognitive impairment and BPSD. Evidence-based interventions and therapies may improve coping skills and reduce the risk of developing affective disorders [4]. If people are supported in various tasks (e.g., paying bills and taking prescribed medication), crises can be prevented or reduced, and nursing home entry can be delayed [4]. Dementia has a physical, psychological, social, and economic impact, not only on people with dementia but also on their caregivers, families, and the society at large [32]. Only with a full picture of the consequences of dementia in each individual case can a plan for individually tailored treatment, advice, support, and services for people with dementia and their caregivers be made.

In addition to providing a basis for planning individual support, knowledge of typical symptoms and needs are useful on a system level for health care providers who plan services. Provision of suitable services targeting, e.g., symptoms of depression or limitations in ADL may benefit many home-dwelling people with dementia.

Purpose 3 - Evaluation of effects and adjustments of current treatment, advice, support, and services

Regular reassessments are necessary to monitor the disease progression, to evaluate the effects of treatments and interventions, and to revise the person's functioning and needs status [15](pp 8-9). The results from the initial assessment may serve as 'baseline measures' in the monitoring of the effects of different treatments and progression of the disorder. Measuring ADL functioning may be a good approach to assessing responses to therapeutic interventions; however, such assessment requires effective instruments for measuring ADL in dementia [52].

As a result of reassessments, the treatment effects of, e.g., cholinesterase inhibitors can be evaluated, and this can inform further use of the medication. Another treatment intervention which includes regular (re)assessing is cognitive rehabilitation [131], where the different strategies or even goals may be adjusted, in cooperation with the person with dementia, according to new assessments. The effects of other interventions, such as cognitive stimulation therapy [97] or cognitive training [138, 139], should also be monitored and modified by reassessments.

Treatment, advice, support, and services should be regularly reconsidered with regard to type and extent of the services. Reassessments of functioning may reveal a need for more extensive services (e.g., for personal care) or that the services should be delivered in a different way, such as fewer people delivering the service or expanding the help from supervision to practical assistance. Assessments of BPSD or quality of life may reveal a need for more services, such as day activity services, support groups, or supervision of informal caregivers. How often reassessments should be conducted depends on the setting: in primary care, reassessments are recommended at a minimum of every 6–12 months, and more often if changes in behaviour, cognition, or function are observed [50].

2.6 Diagnostic evaluation of dementia symptoms

A comprehensive process should take place before a diagnosis of dementia is established. A multidisciplinary approach is beneficial in order to properly evaluate the different diagnostic criteria as well as the consequences of the symptoms. This is recommended in the Norwegian national guideline on dementia [2]. In the following sections, the different elements of a comprehensive diagnostic evaluation are described.

2.6.1 Diagnostic criteria

In Norway, the ICD-10 criteria for research [33] are used in specialist health care, and the International Classification of Primary Care, second version (ICPC-2) diagnostic criteria [140] are used in primary health care. However, in the recommended tool for use in a general practitioner's (GP's) diagnostic evaluation of cognitive impairment [141], the ICD-10 criteria for research are outlined and are therefore also often used when diagnosing dementia in primary health care. A version of the ICD-10 for clinical use is also available [142], but as the descriptions of dementia are more general than the research criteria, we will refer to the ICD-10 diagnostic criteria for research in this thesis.

Box 1. ICD-10 diagnostic criteria for research for dementia [33]:

G1: 1) A decline in memory
2) A decline in at least one other cognitive ability

The degree of cognitive decline must be so severe that it affects the individual's ability to carry out activities of daily living

G2: Preserved awareness of the environment

G3: A decline in emotional control or motivation, or a change in social behaviour, manifest as at least one of the following: 1) emotional lability, 2) irritability, 3) apathy, 4) coarsening of social behaviour

G4: The state of cognitive decline (G1) must have lasted for more than 6 months

The G1 criterion addresses impairment in at least two cognition domains, one of them being memory. The criterion states that the degree of cognitive decline must be 'sufficient to interfere with everyday activities', hence constituting an impairment. This criterion is to distinguish dementia from MCI: although some reduction in IADL ability is expected in MCI, such that the person requires greater effort and/or uses compensatory strategies in complex IADLs, the person is still independent [27, 28]. As mentioned in chapter 2.2.2 on cognitive impairment, there seems to be agreement that any need for assistance from others 'qualifies' a person for a diagnosis of dementia [27, 28]. Therefore, in the process of establishing a diagnosis of dementia, assessment of functioning and ability to perform ADL is an important part of evaluating whether the diagnostic criteria G1 is met.

The G2 criterion is included to exclude the presence of delirium, which is characterised by clouding of consciousness or reduced clarity of awareness of the environment, with reduced ability to focus, sustain, or shift attention [33].

The G3 criterion addresses symptoms we have chosen to term as BPSD. Hence, BPSD are a prerequisite for a dementia diagnosis in the ICD-10 diagnostic criteria. (BPSD, their possible causes, and their consequences are addressed in chapter 2.3.)

The G4 criterion states that the cognitive decline should have been present for at least six months for one to be confident of the diagnosis of dementia. If the period since the manifested onset is shorter, the diagnosis can only be tentative [33].

The WHO has released an update for diagnostic criteria, the ICD-11, in which dementia is characterised by a decline from a previous level of cognitive functioning [26]. Furthermore, the use of the term 'impairment' in the criteria indicate the degree of decline which is required for a diagnosis. The ICD-11 criteria do not specify that memory impairment should be present, but that cognitive impairment should be present in two or more domains [26]. This change is appropriate, since memory is not an initial symptom in all dementia diseases. 'Affected ability to carry out activities of daily living' has been updated to 'significant interference with independence in the person's performance of activities of daily living', which presents a clarifying specification. In the ICD-11, presence of BPSD is not a criterion for dementia on a general level, but it is specified in the coding of each specific etiological disease, which should always be performed [26]. Although the updated ICD-11 criteria have been released, they have not yet been implemented in Norway; therefore, we are using the ICD-10 criteria in this thesis.

In the Diagnostic and Statistical Manual of Mental Disorders (DSM-5), dementia is referred to as a 'major neurocognitive disorder' and MCI as a 'mild neurocognitive disorder' [143]. The DSM-5 criteria resemble the ICD-11 criteria in that the cognitive decline (from a previous level of performance) should be in one or more cognitive domains, without requiring that one of them is memory. Furthermore, like the ICD-11, the DSM-5 criteria for major neurocognitive disorder require the cognitive decline (referred to as a deficit) to be severe enough to interfere with independence in everyday activities; additionally, presence of BPSD is not a criterion for major neurocognitive disorder in general, but it is specified under the different aetiological diagnoses [143].

2.6.2 Who should undergo a diagnostic evaluation of dementia symptoms?

It may not always be easy to decide whether oneself or a relative has symptoms of dementia, nor whether perceived symptoms of cognitive impairment are within the normal range or an inevitable part of ageing. Additionally, people with memory problems may deny the problems or be reluctant to consult their GP about them. Moreover, one could imagine that GPs can be unsure of how to detect cognitive decline in older adults as part of routine patient management.

Although universal screening for dementia is generally not recommended [4, 144], a case-finding approach might be useful in primary care. With this approach, patients and families are asked about concerns regarding rapidly progressing cognitive problems, which might delineate a group who are more likely to have an underlying medical condition (such as dementia) that warrants further evaluation with cognitive, laboratory, and other testing [46].

The NICE guideline recommends that when cognitive impairment is suspected, an initial assessment should be conducted in non-specialist settings before referring the patient to a specialist dementia diagnostic service. The initial assessment includes taking the person's history from the person and, if possible, from someone who knows the person well, along with a physical examination, blood and urine tests, and a brief structured cognitive instrument [90]. The Norwegian guideline recommends that people with symptoms of cognitive impairment be assessed and diagnosed mainly by the primary health care service and the GPs, preferably in collaboration with a community-based multidisciplinary memory team [2]. This model is further described in chapter 2.8.

To help identify people who should undergo a diagnostic evaluation by their GP, a simple screening tool might be useful, and several such tools are available. The Cognitive Function Instrument (CFI) can be used to screen for cognitive and functional impairment in older persons. The instrument consists of 14 items/questions about memory function, orientation, social participation, and functioning in IADL. Each question is answered with 'no' (= 0 points), 'maybe' (= 0.5 points), or 'yes' (= 1 point), with the maximum score being 14 points and a higher score indicating greater cognitive impairment. The CFI has two similarly phrased versions, one self- and one proxy-rated version [145]. A study by Amariglio et al. suggests that the CFI can serve as a sensitive functional outcome measure in secondary prevention trials [146], and it may also be useful for deciding whether cognitive symptoms are profound enough that a diagnostic evaluation should be initiated. Several similar instruments indicating cognitive decline are in use, such as the Informant Questionnaire of Cognitive Decline in the Elderly (IQCODE) [147], which is further described in chapter 2.6.4. Questions about performance in four complex IADL items, as described in chapter 2.4.1, have been found to have predictive value for cognitive impairment [113].

2.6.3 Medical and neurological evaluation, blood tests, and structural imaging

The specific routines regarding the medical part of the diagnostic evaluation varies depending on the health care system, country, and type of patient, but generally some main components are common [4, 46]:

- Anamnesis from the patient and a next of kin, with detailed information about the symptoms and course of the disorder.
- Physical and neurological examination.
- Review of prescribed medication, – e.g., to evaluate side effects and make judgments regarding medicines associated with increased anticholinergic burden.
- Blood tests and sometimes tests of cerebrospinal fluid, to aid in diagnosing the underlying disease and to detect comorbid illness(es) and rare reversible causes of dementias.
- Structural imaging of the brain—computerised tomography (CT) or magnetic resonance imaging (MRI), and sometimes Fluorodeoxyglucose Positron Emission Tomography (FDG-PET), amyloid PET, and Dopamine Transporter Scan (DAT-Scan)—to elucidate the cause of the cognitive impairment/ the underlying disease and to exclude rare treatable causes.

These assessments are an important part of a diagnostic evaluation; however, we do not go into detail about them in this thesis.

2.6.4 Assessing cognitive function

Cognition is referred to as 'mental functions' in the ICF [13]; in chapter 2.2.1, we have described the cognitive domains which are most often affected in dementias. Cognitive functions can be assessed in several ways, and the use of different types of assessments in combination may give a particularly good overview.

Questionnaires about cognitive functions

Patient case history with regard to cognitive functioning and changes in cognitive functioning often provide valid information about the patient's cognition. According to Arvanitakis and colleagues (2019), the patient case history remains the most important diagnostic tool and should be obtained from both the patient and a close family member or friend [46]. The patient case history should capture the nature, severity, and course of changes/symptoms [46]. This history can also disentangle medical information, as described in the previous chapter. The patient case history can be taken by interviewing, and it is recommended to ask the patient and a proxy to answer a questionnaire.

A widely used proxy-based questionnaire is the Informant Questionnaire of Cognitive Decline in the Elderly (IQCODE) [147]. The IQCODE has high reliability and validity, and it measures change in cognition compared to ten years earlier. It provides an average score ranging from one to five [147]. Different versions of IQCODE vary by number of items. In Norway, the 16-item version is used, which has comparable validity to the full 26-item version [147]. As a cut-off, we use a mean score above 3.44 to indicate a significant decline in cognitive function [148].

Questionnaires about cognition often address functioning in or changes related to ADL. Given the relationship between activity and mental functioning, and the fact that dementia is often first detected through limitations in ADL [100, 108], enquiring about ADL is therefore common in questionnaires about cognitive functions. These questionnaires will be described in chapter 2.6.5.

Most of the questionnaires about cognitive function are proxy-based, probably because the answers should not be biased by the potentially poor insight of the person with dementia. However, self-

reports of this type of information are also valuable. As part of the Alzheimer's Disease Cooperative Study, Amariglio and colleagues (2015) investigated the utility of the Cognitive Function Instrument (CFI) (self- and proxy-rated versions) in tracking early changes in cognitive function [146]. A total of 468 older individuals without cognitive impairments at baseline were followed annually for four years. Scorings on both the self- and the proxy-rated CFI were associated with longitudinal cognitive impairment; however, the findings suggest that the self-reported version may be more accurate than the proxy-rated version at an early stage in the process of cognitive decline [146], while later in the process, the proxy-rated version seems to be more accurate than the self-rated version [146]. A plausible explanation for the lower accuracy of the self-reported version of the CFI in people with more severe cognitive impairment is poor insight. Nevertheless, self-reported information may be valuable in revealing the perspective of the person with dementia—and, when both the self- and the proxy-rated version are used, the discrepancies between this perspective and that of the proxy. As the IQCODE is less useful in differentiating MCI from SCI [149], the CFI may be a good alternative, since it has been found to be more valid in the early stage of cognitive decline.

Cognitive tests

Several cognitive or neuropsychological tests are available: here, we describe the ones that are most used in diagnostic evaluations when dementia is suspected.

The Mini-Mental State Examination (MMSE) was developed in 1975 as a quick way to assess cognition in hospital in-patients, and it is still in use. It is a screening test measuring several cognitive domains—orientation, attention, memory, language, and visuospatial functions—and cannot replace a comprehensive evaluation to issue a final diagnosis [150]. MMSE scores range from zero to 30, with a higher score indicating better cognitive performance. The original MMSE has been copyrighted, and updated versions in several languages have been developed by the publisher. Parallel to this, a Norwegian version which is significantly different from the copyrighted one has been developed, also with scores ranging from zero to 30. The Norwegian version of the MMSE has been revised twice; the second version (MMSE-NR2) was in clinical use when data for studies I and II were collected and is thus used in those studies. The Norwegian version currently in use is MMSE-NR3 [151].

Another screening test is the Clock-Drawing Test (CDT). The CDT is often used as a complement to the MMSE and measures visuospatial abilities and executive function. Placing the correct numbers on a pre-drawn clock circle and then drawing hands that indicate the given time is a quick way to assess cognitive function [152]. A higher score indicates better cognitive performance. Different versions exist, with different time and scores; the available Norwegian version uses 11:10 as the time the patient is instructed to indicate, and it has scores ranging from zero to five. The Norwegian version has been revised twice, and the second version ('Norsk revidert klokketest vs2'–KT-NR2) was in clinical use when data for studies I and II were collected and is thus used in those studies. The Norwegian version currently in use is KT-NR3 [153]. A dichotomised score is sometimes used for the CDT, with a cut-off of 3/4 [154].

The Trail Making Test (TMT) parts A and B was originally a part of the Army Individual Test Battery, but it was adapted by Reitan in 1955 and added to the Halstead battery [155](p655). The patient is asked to make a pencil line connecting 25 circled numbers randomly spread on a page (part A) and then 25 numbers and letters, also randomly spread, in alternating order (part B) [155](pp 655-658). Before each part of the test is started, a practice exercise is used. Each part is timed, and time used is given as the score. Both parts A and B measure attention, and part B provides a more specific measure of the more-complex divided attention [155](pp 655-658); in addition, part B requires executive function. The TMT parts A and B has been found to be sensitive to detecting cognitive

impairment in dementia [155](p670). A Norwegian version of the TMT parts A and B is available, and the version currently in use is the third revised version (TMT-NR3) [156].

The Montreal Cognitive Assessment (MoCA) is a cognitive screening tool developed to screen people with MCI. It is a 30-point test, with higher scores indicating better cognitive function [157]. The MoCA evaluates memory, orientation to time and place, abstraction, attention and working memory, and language. It includes the CDT to evaluate visuospatial abilities and an adapted version of the TMT part B to evaluate executive functions [157]. The validity study of the MoCA indicated high sensitivity and specificity for detecting MCI [157], and the MoCA is considered to be more useful than the MMSE in milder forms of cognitive impairment (including MCI with executive dysfunction) and in assessment of cognitive impairment in non-AD dementias [46].

The Addenbrooke's Cognitive Examination (ACE) was designed to detect mild dementia and to differentiate AD from FTD. It is a valid and reliable 100-point test battery that assesses six cognitive domains—orientation, attention, memory, verbal fluency, language, and visuospatial abilities [158]. Compared to the MMSE, it is more sensitive to early changes in that the tasks are more difficult, and it is probably most useful in patients with early and mild dementia. All items of the MMSE are included in the ACE, and an MMSE score can be derived from the ACE. Scores for each of the six domains can be calculated separately, and their sum gives the composite score for the ACE [158]. Patients with FTD usually perform better on orientation and episodic memory domains, which the MMSE focuses a lot on, whereas the ACE focuses more thoroughly on domains which patients with FTD tend to struggle with, such as verbal fluency and language [158].

The Consortium to Establish a Registry for Alzheimer's Disease (CERAD) has developed a brief, comprehensive, and reliable battery of neuropsychological tests for assessing the most prevalent cognitive symptoms of AD. The CERAD battery includes the following neuropsychological tests, of which some are also included in the Alzheimer's Disease Assessment Scale [159]: *The Verbal Fluency test* measures verbal production, semantic memory, and language; the patient is asked to name as many animals as possible in one minute, and the score is the total number of different animals named*. The Modified Boston Naming Test* measures language (naming) by asking patients to name 15 objects, presented as line drawings and grouped into three groups according to how frequently the word is used; the score is one point per object named. *The Mini-Mental State Examination (MMSE)* – is included in a slightly modified version. *The Constructional Praxis* measures visuospatial and constructional abilities by asking the patient to copy four line-drawings of figures in order of increasing complexity (a circle, a diamond, intersecting rectangles, and a cube). A constructional praxis recall measure, to be administered 2–2.5 minutes after the constructional praxis copy measure, was added to the CERAD battery several years after the initial battery was developed [160]. *The Word List Memory* measures immediate recall by presenting ten words to the patient, in three trials, with different orders of the words in each trial; after each trial, the patient is asked to recall as many words as possible. *The Word List Recall* is conducted five minutes after the Word List Memory is finished, and it measures delayed recall: the patient is asked to recall as many of the ten words on the word list as possible. *The Word List Recognition* measures recognition of the 10 words in the Word List Memory task when they are presented among 10 distractor words. [161, 162].

In addition to the verbal fluency test (animal naming) included in CERAD, a phonemic fluency test, such as the Controlled Oral Word Association Test (COWAT), is often used to measure verbal fluency. The patient is given one minute three times to say as many words as possible beginning with the letters F, A, and S, respectively [155](pp499-502).

A common issue with some of the frequently used cognitive tests is that they may be sensitive to ethnicity, education, literacy, and language. Therefore, in evaluations of cognitive function, it is important to consider the test results in light of factors such as age, gender, and education. Furthermore, in diagnostic evaluations of someone with low literacy or education, tests that are specifically developed for these groups should be used. One such commonly used test is the easily administered 6-item Rowland Universal Dementia Assessment Scale (RUDAS) [163]. The RUDAS has been found to have excellent reliability and diagnostic accuracy as well as to be unaffected by gender, years of education, or preferred language. RUDAS assesses multiple cognitive domains, including memory, praxis, language, judgment, drawing, and body orientation. [163]. Other types of information, such as those drawn from patient case history and observations, may be particularly useful when evaluating these groups.

Table 2. Overview of commonly used cognitive tests and the main cognitive domains assessed.

Cognitive domain	Tests
Orientation	MoCA, ACE, MMSE
Attention	MoCA, ACE, MMSE, TMT A and B
Memory	MoCA, ACE, MMSE, CERAD: Word List Memory, Word List Recall, Word List Recognition, and Constructional Praxis Recall
Language	MoCA, ACE, MMSE, COWAT CERAD: Verbal Fluency test and Modified Boston Naming Test
Visuospatial function	MoCA, ACE, MMSE, CDT, CERAD: Constructional Praxis and Constructional Praxis Recall
Executive functions	MoCA, CDT, TMT B, COWAT

Abbreviations: MoCA: Montreal Cognitive Assessment, ACE: Addenbrooke's Cognitive Examination, MMSE: Mini-Mental State Examination, TMT: Trail Making Test, CERAD: Consortium to Establish a Registry for Alzheimer's Disease, COWAT: Controlled Oral Word Association Test, CDT: Clock-Drawing Test

Observations aiming at evaluating cognitive functions

Observing a person performing an activity and how they choose, use, handle, attend, initiate, navigate, adjust, etc. can provide information about the person's cognitive function. As described in chapter 2.4.1, observations of activities and skilled interpretations of them may aid in indicating cognitive impairment. Some components of cognitive tests, such as drawing a cube or writing a sentence, can be considered observations of activities, as they are a type of evaluation of the 'output' of cognition. Evidence of a link between ADL and executive dysfunction in early dementia has been found, and according to a meta-analysis, there is a consistent moderate association between executive functions and ADL [164].

Need for assistance in ADL is a diagnostic criterion for dementia [33]. Often, ADL is assessed by questionnaires, which have some limitations. Usually, only success or failure in completing the activity independently (or the degree of assistance needed) is recorded, not the time, effort, efficiency, or compensatory strategies used. Observations have the potential to elucidate the process of performing the activity. Observations of performance of an activity to determine presence and magnitude of cognitive impairment are further described under 'Observations aiming at evaluating activity and participation' in chapter 2.6.5.

2.6.5 Assessing activity and participation

When an assessment is conducted solely for diagnostic purposes [15](pp 4-5), activity and participation are assessed to determine whether the cognitive decline is severe enough to affect the individual's ability to carry out ADL independently [27].

In practice, assessments performed as part of a diagnostic evaluation often may also serve as an assessment to inform the planning of individually tailored treatment, advice, support, and services, —Lezak's second purpose of an assessment [15](pp 5-8). Assessments of BADL and IADL abilities are key indicators of a person's ability to live alone, the type of treatment/interventions they need, as well as the level of treatment, advice, support, and services that they may require. In the following sections, we address both these purposes when describing the assessment of activity and participation. In ICF terms, assessing activity and participation sheds light on both the person's cognitive function and on their everyday life. Contextual factors, both personal and environmental, may affect activity and participation [13], and these factors should be kept in mind.

As described in chapter 2.4.2, the need for assistance and support in ADL contributes to the social and economic burden of dementia, and it represents one of the main challenges of dementia [103, 107]. To understand the consequences of the disorder on a person's life, it is necessary to address and assess activity and participation.

Questionnaires assessing activity and participation

Several questionnaires about activity and participation are available, usually to be answered by a proxy or staff. Some ADL measures are generic while others are disease specific. Dementia specific scales are more sensitive to the changes seen in dementia [20], but comparison with other diseases (e.g., in research) is more difficult with these scales. A large number of (I)ADL questionnaires are available and widely used with people with (suspected) dementia, but little attention has been paid to the scales' psychometric properties [165].

Two of the most commonly used tools to assess ADL are the generic Lawton and Brody instruments from 1969—the Physical Self-Maintenance Scale (PSMS) and the Instrumental Activities of Daily Living scale (IADL scale) [28]. In Norway, these two scales are recommended for diagnostic evaluation of cognitive impairment in both primary and specialist health care, even though they are not dementia specific.

The PSMS addresses six BADL activities: toileting, feeding, dressing, grooming, physical ambulation, and bathing [101]. A proxy is asked to rate performance in these six activities on a scale from one to five, where a score of one indicates independence in the activity and higher scores indicate greater need for help; for some items, a score of five indicates resistance to help from others [101]. The items can also be scored dichotomously—i.e., a score of zero points or one point, with one point indicating independence in the activity [101]. No cut-off has been established for either item- or sum-scores, but the description of each score provides an overview of the level of functioning and need for assistance.

The IADL scale measures eight instrumental activities: use of telephone, shopping, food preparation, housekeeping, laundry, transportation, taking medication, and handling finances [101]. These activities are rated on a scale from one to three, four, or five, depending on the item. A score of one indicates independence in the activity, higher scores indicate greater need for assistance. The items can also be scored dichotomously—i.e., a score of zero points or one point [101]. Lawton and Brody described that gender differences were to be expected in IADL abilities [101], and although gender roles have changed considerably since 1969, one should check which activities the person has traditionally been

able to do when considering ADL limitations. In addition to indicating the degree of dependence, the different alternatives offer a description of what type of assistance is required. Like the PSMS, no cut-off has been established for either item- or sum-scores.

The two scales by Lawton and Brody were developed in 1969. BADL is mostly performed in the same way today as in 1969, but a lot has changed since then with regard to the items in the IADL scale. In 1969, using a telephone meant picking up the phone when it rang or dialling a number; now, the phone is used for a lot more. Dialling with a smart phone usually requires finding the correct application and then finding the number in one's contacts or finding the dialling pad/screen. Other uses of the phone, such as text messages, e-mails, and various other applications, are not covered by this IADL scale. Another example of IADL activity that has changed is handling finances: whereas in 1969, handling finances was about writing checks and going to the bank, today the use of internet banking, bank machines, and payment terminals are required to handle finances. To address the IADL of today's world, questions about use of everyday technology—including smartphones, computers, social media, various remote controls, and ticket machines—have been included in the assessment tool used by health care personnel in diagnostic evaluations of cognitive impairment in Norwegian primary health care [166].

A measure of competence in using everyday technology has been established. The 'Everyday Technology Use Questionnaire'' (ETUQ) is based on a semi-structured standardised interview and consists of 86 items related to a variety of both newly developed technology, such as the internet and airport check-in machines, as well as well-known technology, such as coffeemakers and irons [167]. The items are divided into the following eight activity areas: household activities, activities in the home, personal care, power tools, accessibility, data and telecommunications, economy and shopping, and transportation [167]. Only items that are relevant to the person are scored; this selection is based on the information given by the participant or their proxy. The following three-category rating scale is used: 3 = Use without difficulty, 2 = Use with difficulty, and 1 = Does not use anymore [167]. A psychometric evaluation found the ETUQ to have acceptable levels of sensitivity, scale validity, and person response validity for use among older adults with and without cognitive impairment [167]. Findings from the ETUQ may also be helpful in planning interventions targeting specific technologies that the person feels are relevant but find difficult to use.

For several of the dementia specific ADL questionnaires, the psychometric properties have not been properly evaluated [165]. In a review aiming to identify ADL questionnaires that are useful in identifying early dementia, Sikkes and colleagues (2009) evaluated the psychometric properties of twelve (I)ADL questionnaires. They found that a large percentage of the measures' properties remained unknown or unclear, and it was impossible to give a judgment on several important quality criteria, such as responsiveness, reproducibility, construct validity, and interpretability [165]. For instance, minimal important change was not defined for any of the questionnaires in the review. Overall, the Disability Assessment for Dementia (DAD) and the Bristol Activities of Daily Living (Bristol-ADL) received the best ratings for their psychometric properties, but in view of all psychometric criteria, these questionnaires were only of moderate quality [165].

The DAD scale was developed as a measure of functional ability in dementia [104]. It is a 40-item questionnaire which assesses both BADL (17 items) and IADL (23 items), including leisure activities, and it has no gender bias [104]. To understand the cognitive dimensions of ADL disabilities, the ADL items are subdivided according to the main executive function that is required to perform the activity (initiative, planning and organisation, and effective performance) [104]. DAD is based on interviews with a proxy/caregiver, and the sum score is converted to a percentage score indicating global function in

ADL, with higher scores representing less disability in ADL [168]. In the review by Sikkes and colleagues, the DAD was found to be of moderate quality in terms of content validity and reliability [165].

The Bristol-ADL scale was designed specifically to be used with people with dementia [169]. It is caregiver rated and consists of 20 daily living abilities which also include cognitive symptoms, such as communication and orientation for time and space. Both BADL and IADL, including games/hobbies, are addressed [169]. The scale has been found to have face validity, construct validity, and concurrent validity, as well as good test-retest reliability [169]. Sikkes and colleagues also gave the Bristol-ADL a positive rating on content validity in their review [165].

Currently, IADL questionnaires are mostly informant-based, not self-rated. A self-rated IADL assessment may be a valuable contribution to the diagnostic evaluation in the early stages of cognitive impairment. Studies have found that subjective reporting of an impairment in cognitive functioning is associated with mild MCI and incident dementia [170-172]. The Cognitive Function Instrument (CFI) includes questions about difficulties in performing ADL as an indicator of cognitive impairment. When investigating the utility of the CFI, Amariglio and colleagues found that the self-reported version may be more accurate than the proxy-rated version at an early stage in the process of cognitive decline [146]. Self-reports of ADL functioning are also valuable in later stages of cognitive decline: even if the self-reported information does not agree with the proxy-reported information, it is useful to have information about the person's perspective and experience in order to understand the impact of the disorder as well as to better plan treatment, advice, support, and services for people with dementia and their caregivers.

Use of ADL scales may be experienced as less invasive by older persons than e.g., cognitive testing, and it is a good approach for clinical use in diagnosing cognitive disorders. ADL assessments may also provide possibilities for clinical treatment, rehabilitation, advising, and coaching [28]. Furthermore, the functional nature of ADL assessments provides a more concrete and understandable way to communicate with people with dementia and families about the practical consequences of the disorder and how different cognitive functions are integrated into common behaviours [104].

When addressing ADL and assessing functioning with ADL scales, one should keep in mind that there may be gender differences in the ability to perform different activities, as a result of roles and habits [20]. It is also important to keep in mind any non-cognitive reasons for activity limitations, such as impaired vision or orthopaedic injuries, and not automatically attribute all limitations to cognitive impairment.

Better tools to assess ADL are needed. Several ADL scales that are in widespread use have shortcomings, e.g., they have poorly described psychometric properties, the minimal important change is often not defined, the scoring systems are not sensitive enough to detect subtle deficits, and they do not identify causes of limitations in ADL [28, 107, 165]. Furthermore, the commonly used proxy-based ADL measures have been criticised for not being able to detect subtle deficits in complex instrumental activities at earlier stages of dementia [173, 174]. Translations of scales into other languages should be performed properly, with forward- and back-translations and subsequent evaluation of the psychometric properties of the new version [175].

Observations aiming at assessing activity and participation

In some way, it can be argued that most ADL assessments are based on observations: a proxy will base their reporting of performance in activities on their own observations when they answer an ADL questionnaire. However, ADL scales usually only assess whether the person is able to do an activity, and if not, how much help is required. In addition to these scales, an observation conducted by a

trained health care professional can provide information about the quality of the performance along with the effort and time used. To avoid the limitations of informant-based measures, other methods for functional assessment have been developed, such as the UCSD Performance-Based Skills Assessment (UPSA) developed at the University of California, San Diego [176], and its short version [174]. The UPSA addresses IADL tasks by asking the participant to utilise props (e.g., creating a shopping list based on a recipe while excluding the items already present in a mock pantry) to demonstrate how to perform the activities. Several studies have found that the UPSA is able to discriminate between people with AD, people with MCI, and healthy controls [173].

Through observations, the evaluator can examine the process of task performance, detect changes in everyday functioning, and address causation in observable behaviours [28]. Observations of the performance of daily activities within the home context may shed light on the influence that cognitive impairments have on the person's daily life and their participation in society [177]. Motor performance, such as stabilising, gripping, and pacing, can also be evaluated in observations.

Process skills are described as 'the observable actions of performance the person enacts to logically sequence the actions of the ADL task performance over time, select and use appropriate tools and materials, and adapt his or her performance when problems are encountered' [178]. Thus, in an observation, how the person e.g., initiates, handles, organises, notices, and responds while performing an activity is evaluated. Occupational therapists have several structured reliable and valid instruments for performance-based assessment through observation, such as the Assessment of Motor and Process Skills (AMPS) [178] and the Perceive, Recall, Plan and Perform (PRPP) [177, 179](pp 150-160). An AMPS observation is mainly conducted with standardised household tasks or IADL, and it measures quality of performance in the process as well as motor skills. In the PRPP, the activity to be performed is chosen by the person based on individual preferences and needs, and errors and effectiveness of cognitive information processing in its performance are evaluated [177, 179](pp 150-160).

Performance-based structured observation instruments such as the AMPS and the PRPP have limitations: they are time-consuming and use of them requires training of the assessors. Furthermore, the AMPS and the PRPP are only available for occupational therapists and thus cannot be used by all health care personnel [28]. However, observations and interpreting observed activity performance in terms of functional impairment can also be achieved through unstructured observations by experienced health care staff of different professions. A guide on how to do this, and what to look for in these observations, has been provided in the Norwegian assessment tool for health care personnel in primary health care [166]. Such observations are included as part of the memory team's assessment, which is usually conducted in the person's home. Training and experience add to the value of these observations and their reporting.

Although performance-based functional assessments represent an alternative form of assessing cognition, they are appealing because of their immediate clinical relevance as a direct measure of functioning and not as a distal measure, such as 'desktop cognitive tests' [173]. Evaluating activity limitations through observations may also make more sense to the person who is being assessed. The impact on daily life of the result of a cognitive test may not be entirely clear to the person, while identifying activity limitations then and there during the performance of the activity might be a meaningful way to address how dementia affects their everyday life.

2.6.6 Assessing BPSD

BPSD are usually assessed by observation of the person over time (e.g., in institutional settings) or by interviewing a proxy who has observed the person over time (for people living at home). Some symptoms, such as delusions and hallucinations, may be difficult to observe, and knowledge about these symptoms depends on the patient describing them, or on interpreting other signs or behaviour as a result of these subjective symptoms [61]. Interviewing the patient about their own symptoms is necessary in order to get information about how troublesome the patient perceives the symptoms to be. This can inform treatment (e.g., the distress of hallucinations as experienced by the patient can guide which type of treatments are given). Gitlin and colleagues (2012) emphasise that while the patient should be interviewed about BPSD in order to consider their perspective, the patient may not be able to fully or accurately report or remember BPSD or comprehend risks associated with BPSD; thus, proxy information from a caregiver is important [76]. In a study investigating the impact of delusions and hallucinations on the person experiencing them, based on caregivers' reports, Cohen-Mansfield and colleagues found that around 40% of persons experiencing delusions did not experience discomfort resulting from the delusion, and some even experienced positive feelings as a result [180]. The reactions to hallucinations were found to be less potent than the reactions to delusions [180].

Several questionnaires are available to record BPSD. Some, such as the NPI, have a broad approach, targeting a wide range of BPSD; other scales, such as the Cornell Scale for Depression in Dementia (CSDD) or the Cohen-Mansfield Agitation Inventory (CMAI), focus on specific symptoms.

The NPI is a valid and reliable instrument based on a structured interview with a caregiver who knows the person with dementia well. It addresses the 12 most common BPSD: delusions, hallucinations, agitation, depression, anxiety, euphoria, apathy, disinhibition, irritability, motor disturbance, night-time behaviours, and appetite. [61]. The two latter items were included in the NPI after the original scale had been completed, in order to provide a more complete evaluation of BPSD common in dementia [59, 70]. For each symptom, a screening question is initially asked to identify the presence of the symptom. If the symptom is present, the symptom is then rated for severity (1 = mild, 2 = moderate, 3 = severe) and frequency (1 = occasionally, 2 = often, 3 = frequently, 4 = very frequently). [61]. An item score can be calculated by multiplying the frequency and severity scores, giving an item-score that ranges from zero to twelve. Caregiver distress is scored for each neuropsychiatric symptom present on a scale from 0 (no distress) to 5 (very severe or extreme distress), and a total behaviour-related distress score consists of the sum of the individual scores [59, 70].

The Neuropsychiatric Inventory Questionnaire (NPI-Q) is a brief version of the NPI which addresses the same twelve symptoms as the NPI. In the NPI-Q, when a symptom is present, only the severity of the symptom is rated (on the same scale as the NPI; 1 = mild, 2 = moderate, 3 = severe) [181]. The NPI-Q is given as a self-administered questionnaire rather than an interview. The sum score represents the sum of individual symptom scores and ranges from 0 to 36 [181]. Caregiver distress is rated on the same scale as in the NPI, ranging from 0 (no distress) to 5 (very severe or extreme distress), and adding up to a total NPI-Q distress score ranging from 0–60 [181]. In the validation study by Kaufer and colleagues, the NPI-Q showed acceptable psychometric properties, with adequate test-retest reliability and construct validity. When compared to the NPI, the prevalence of analogous symptoms reported on the NPI and NPI-Q differed on average by 5%, and the NPI-Q symptom severity score was highly correlated with the composite frequency x severity score from the NPI [181]. In papers II and III of this thesis, the NPI-Q was used, but without the caregiver distress ratings.

BPSD are quite heterogeneous, and they are often considered and studied as groups of correlated symptoms [71, 72]. Examples of commonly used symptom groups are affective symptoms, psychotic symptoms, hyperactivity, and euphoria [72]. When the NPI-Q is used in research, a sum score of the 12 symptoms in analyses (as described by Kaufer 2000) might be misleading: the BPSD profile of a person with a sum score of 12 as a result of symptoms of depression, anxiety, apathy, and appetite will be quite different from the BPSD profile of a person with a sum score of 12 as a result of symptoms of disinhibition, irritability, agitation, and motor disturbance. Additionally, using each NPI-Q symptom as a variable might result in too many variables in the analyses. Moreover, when NPI-Q symptoms are combined into groups/syndromes, each syndrome will have a larger range (0–9/12/15) than each individual symptom (which in the NPI-Q ranges from 0–3).

The Cornell Scale for Depression in Dementia (CSDD) is a 19-item instrument used in an interview with the patient and a caregiver and addresses symptoms of depression [182]. The CSDD is performed in two steps: first, a caregiver is interviewed on the severity of each item, which is rated as absent, mild or intermittent, or severe; then, the patient is interviewed using Cornell Scale items as a basis for inquiry and observation [182]. The rating is based on observations of the patient's behaviour during the week prior to the interview. A sum score is produced by adding all item scores. Different countries use different cut-offs for the threshold of significant symptoms of depression; in Norway, a cut-off of 5/6 has been found to have the best sensitivity and specificity in a study of home-dwelling people who had undergone a diagnostic evaluation in memory clinics [183].

The purpose of the Cohen-Mansfield Agitation Inventory (CMAI) is to assess the frequency of agitated behaviours in older adults [64, 184]. The CMAI was specifically constructed to measures 29 agitated or aggressive behaviours. For each behaviour, the average frequency of occurrence over the previous 2 weeks is indicated on a seven-point scale (1–7) ranging from 'never' to 'several times an hour' [64, 184]. Agitation scores may be calculated by weighing behaviours according to their disruptive impact or grouping them into three factors of agitation: aggressive behaviour, physically nonaggressive behaviour, and verbally agitated behaviour [184].

The scoring of instruments measuring BPSD may be influenced by the culture of the informant and depends on the informant's memory of behavioural events. Direct or video-captured observations documenting behavioural occurrences may aid in more objective ratings; however, such methods are most feasible in long-term care settings [185]. When choosing which instrument to use, one should consider several aspects, such as the purpose of the assessment (e.g., broad screening or more specific symptoms), the setting (including who will assess and if observation or proxy interview will be conducted), and the time available for the assessment [185]. It may be wise to begin with an instrument with a broad approach, such as a screening, before choosing a measure that targets specific symptoms that are identified in the broad measure [76].

2.7 Needs and assessing the needs of people with dementia

People with dementia may have complex needs, as they have symptoms in many domains combining physical, social, and psychological needs [186]. These needs are related to cognition, neuropsychiatric symptoms, ADL, and comorbid physical illnesses [4]. Unmet needs are widely considered to be one of the contributory factors of BPSD [8, 56, 58, 187] and to be associated with a lower health-related quality of life [10, 188-191].

"Needs" is a broad term; in this thesis, we restrict needs to a definition related to potentially available treatment, advice, support, and services [186]. This definition enables separating needs into

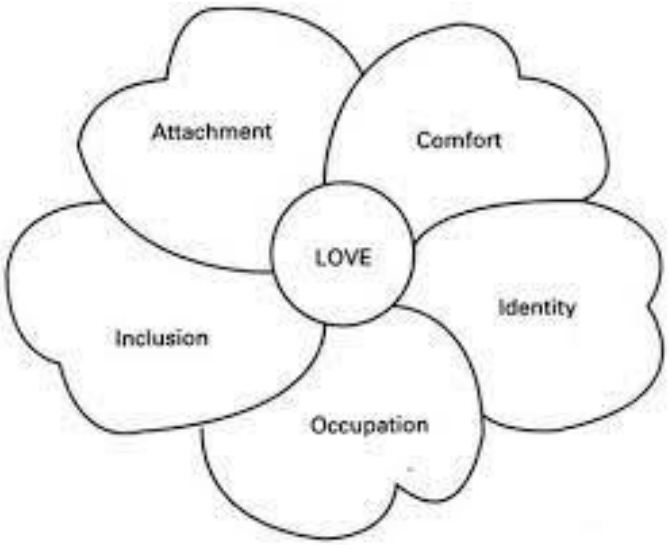
those that are presently met and those that are unmet and therefore may require action, such as assessment, intervention, or care [186]. Unmet needs are not only related to functioning, because if the proper intervention is in place, an existing need may be met. Of two people with the same activity limitations (e.g., related to getting to social events), one can have an unmet need due to lack of services, and the other can have a met need because transportation is provided. Furthermore, the same two people can have different needs, depending on their habits and preferences in everyday life.

Person-centred care and the basic psychological needs

In person-centred care, personhood is described as a standing or status that is bestowed upon a human being by others [81]. Impairments and limitations due to dementia do not change one's personhood; the person is still 'an agent (….) a sentient, relational and historical being' [81], with the same basic psychological needs.

Kitwood described a 'cluster of needs' in dementia and that the need for love is all-encompassing. The five needs for comfort, attachment, inclusion, occupation, and identity overlap and come together in the one central need for love [80](pp 80-85). In paper III, we focused on the need for daytime activities and company, as these needs are often reported as unmet by people with dementia and by proxy information from their caregivers. In person-centred care, daytime activities can be said to be related to the basic psychological need for occupation. Company may be mainly related to the basic psychological need for inclusion, although attachment and comfort may also be argued as being related to company. Since needs overlap, meeting one need will also to some extent have an impact on meeting other needs. For example, when the need for occupation is met in a social setting, needs for inclusion and identity may also be met.

Figure 4. The main psychological needs according to Kitwood [80](p 82)



Kitwood described occupation as being involved in the process of life in a personally significant way, drawing on one's abilities and powers. One can have an occupation in the company of others or alone; it can be an obvious action, or reflection or relaxation [80](p 83). People with dementia need occupations just like other people do, and lack of occupation may lead to boredom or apathy and, eventually, to loss of ability and/or self-esteem [80](p 83).

Bonding with others is described as promoting safety, and such attachment illustrates that humans are a social species. This social nature of humans is also seen in the need for inclusion [80](p 83), which

is described as being met when a person is 'recognised as having a distinct place in the shared life of a group' [80](p 83).

In person-centred care, the perspective of the person with dementia is incorporated into the care planning. The basic needs for occupation and inclusion should be met by considering the person's remaining skills and using those skills to facilitate ADL as well as social activities and settings [80](p 84).

The NICE guideline on assessment, management, and support for people living with dementia and their carers have applied the principles of person-centred care. These principles underpin good practice in dementia care, and they are reflected in the recommendations [90]. The Norwegian national guideline on dementia is also based on person-centred care, and providers of health and social care should establish routines for person-centred care in treatment of people with dementia [2].

The importance of assessing occupational needs

Although Kitwood does not refer to occupational science, the emphasis of occupation as a main psychological need is very much in line with the core focus of occupational science and the known association between occupation, health, and well-being [192, 193].

Occupational science is a multidisciplinary science that addresses human activities performed in a context. Occupation is defined by the World Federation of Occupational Therapists as 'the things that people do in their everyday lives' [194]. Humans are considered to be 'occupational beings', with an integral need to engage in occupation [195]. The occupations people choose influence their lifestyles and personalities as well as their health, well-being, and participation in society [192].

The need for daytime activities is frequently reported as an unmet need by people with dementia [9, 10, 191]. The understanding of humans as 'occupational beings', combined with the fact that people with dementia often experience a loss of meaningful activities as a result of impaired functioning, may explain why this need often goes unmet. Occupational science underlines the negative impact of functional impairment resulting from dementia. Losing one's abilities not only deprives a person of their independence; the loss of occupations also affects the person's fundamental psychological needs [196].

The English language distinguishes between activity and occupation, with activity included in occupation. Occupation is described as activity that is both meaningful and purposeful to the person who engages in it [178] and as intentional or goal-directed meaningful activities that characterize daily human life [195]. However, in the Scandinavian languages, both 'occupation' and 'activity' are translated to the same word—*aktivitet* [197]. In line with Kaae Kristensen and colleagues, even though this thesis is written in English, we use the terms 'occupation' and 'activity' interchangeably.

Another need which is frequently reported as going unmet in people with dementia is company [9, 10, 191]. Activity and company are often associated; most (if not all) social interaction happens during activity. In the measure Camberwell Assessment of Need for the Elderly (CANE), both activity and company are considered social needs. In occupational science, occupation is described as frequently providing the context for interaction with others, and the experience of belonging through engagement in co-occupations with others is important [192, 193].

A study interviewing people with mild and moderate dementia found that being active and doing as much as they possibly could was the single most important driving force in their lives [198]. The participants found a range of activities meaningful, including leisure pastimes, household chores, work-related endeavours, and social involvements. Being involved in these activities promoted a sense of connection and belonging as well as a sense of autonomy and personal identity [198]. The

meaningfulness of the activity is drawn from several aspects of the activity, including remaining independent, taking pleasure in the activity, the social interactive part of the activity, etc [198].

Through engaging in activities with others, people can maintain and strengthen their relationship with society and experience a sense of belonging and connectedness to family, friends, and community, all of which contributes to well-being [193, 197]. A narrative review stresses that providing activities for people with dementia is not just about promoting pleasure but also contributing to meeting fundamental psychological needs [196]. This underscores the importance of daytime activities and company, and it may explain why these needs are often reported as going unmet in people with dementia.

2.7.1 Assessing needs

Findings from assessments conducted as part of a diagnostic evaluation may reveal needs, although a needs assessment is not required to be in a diagnostic evaluation. A comprehensive assessment of needs is important in order to be able to plan individually tailored treatment, advice, support, and services for people with dementia [186]. Needs change during the course of the dementia progression, and therefore, reviewing the needs regularly is necessary [186].

Assessments in care planning are conducted with the purpose of supporting the individual and their family to live the best possible life with dementia [50]. In an assessment conducted with the purpose of planning treatment, advice, support, and services [15](pp 5-8), the needs and preferences as perceived by the person should be assessed, in addition to obtaining a caregiver's view on met and unmet needs [186]. Services for people with dementia are often initiated according to informal caregivers' needs or by professional caregivers' assessments. In a study in which people with dementia were interviewed about their needs, they described needs related to staying connected, being active, and participating and living in the moment [199]. Stephan et al. (2018) found that people with dementia wished to be involved in decision-making related to their care and to remain independent for as long as possible [200]. The person's perceptions of unmet and met needs may differ from those of informal caregivers or health care professionals; people with dementia have been found to generally report fewer unmet needs than staff or their informal caregivers report them to have [9, 191]. What is important for the person, what they find challenging, and which needs they have should be explored in the process of tailoring the treatment, advice, support, and services to the person.

Assessments starting with the person's situation, occupational strengths, and concerns rather than exploring body functions is described by Fisher and colleagues as a 'true top-down approach' [201](pp 40-42). This approach first explores the person's own view of which occupations they want to prioritise in order to be more satisfied with their occupations and participation in society, and then the quality of the occupational performance is analysed [201](pp 40-42). This approach requires active collaboration with the person in goal setting, assessment, planning of treatment/interventions, and in reassessments and adjustments of treatment or interventions.

A top-down approach may be useful in the initial process of planning treatment, advice, support, and services for people with dementia. When assessments are conducted for a diagnostic purpose, a different approach (bottom-up) is used which generally emphasises evaluating body functions. As previously described, an assessment often has more than one purpose. Regardless, keeping the focus on the person's strengths, roles, goals, and priorities when assessing needs to plan support is useful irrespective of approach. Needs should be assessed through a person-centred approach to aid in empowering people with dementia to engage in decisions regarding provision of treatment, advice,

support, and services. During assessment, this approach may be practiced by prioritizing information about individual preferences, needs, values, routines, sources of joy, and personal meaning [50].

The Camberwell Assessment of Need for the Elderly (CANE)

The CANE was derived from the original Camberwell Assessment of Need (CAN), and it is a comprehensive measure assessing needs in older individuals [186]. The CANE has good psychometric properties [202], is suitable for use in assessing needs in people with dementia, and is administered via a semi-structured interview. It is built on a definition of need as a 'problem or difficulty requiring intervention or assessment', which makes it useful in care planning by identifying needs as met or unmet [186].

The CANE instrument consists of 24 areas addressing the person's needs plus 2 areas addressing the caregiver's needs (see box 2). Information is collected by separate interviews with the person, the caregiver, and the staff. The measure consists of four sections [186]. In the first and main section, the aim is to assess whether there is a need in the specific area, and if there is, whether it is met or unmet. In the second section, degree of assistance from informal sources (such as relatives) is recorded; in the third section, the degree of assistance received and needed from local services is recorded. The fourth and final section asks whether the person feels that the patient/user is receiving the right type of help with the need/problem and if the patient/user is satisfied with the assistance they are receiving [186]. The main goal of using the CANE is to identify and assess needs, but total CANE scores can be calculated by adding total number of met needs, total number of unmet needs, and total number of met AND unmet needs (all out of 24) [186].

Box 2. The 24 plus 2 areas of the CANE instrument [186]:

1. accommodation
2. looking after the home
3. food
4. self-care
5. caring for someone else
6. daytime activities
7. memory
8. eyesight/hearing/communication
9. mobility/falls
10. continence
11. physical health
12. drugs
13. psychotic symptoms
14. psychological distress
15. information
16. deliberate self-harm
17. inadvertent self-harm
18. abuse/neglect
19. behaviour
20. alcohol
21. company
22. intimate relationships
23. money/budgeting
24. benefits

A. caregiver's need for information
B. caregiver's psychological distress

In paper III, we investigated associations between BPSD and two of the areas assessed by the CANE: daytime activities and company. Both people with dementia and caregivers commonly report unmet needs in these areas, and in the following section, we focus on assessing these two needs.

2.7.2 The need for daytime activities

As a syndrome affecting cognition, dementia affects the ability to organise and perform activities. People with dementia often need help to be able do things they enjoy (for example, listen to music, or go to gardens and parks) [47].

In the CANE instrument, the item 'daytime activities' is introduced by asking '*How do you spend your day? Do you have enough to do?*'. The item includes 'adequate social, work, leisure, or learning activities'. Although not specified in the CANE, we assume that this area also includes activities performed in the evenings. Limitations in occupying oneself represent a need, which can be met by having appropriate activities organised or arranged by informal or formal caregivers; formal help is exemplified in the CANE as adult education, day centre, or day hospital [186].

Lack of access to activities is described as one of the environmental factors that may contribute to BPSD [58]; thus, meeting the daytime activity needs of people with dementia is important and may prevent or reduce BPSD. Unmet needs for daytime activities are frequently found in studies exploring needs among people with dementia [9, 10, 191]. Interestingly, unmet needs in this area were frequently reported even if the person was receiving professional support around daytime activities [9], indicating that the frequency or type of activity services provided in these cases may not be sufficient.

The Norwegian Quality Reform for Older Persons, titled *A full life–all your life* states (section 5.1. Enjoyable moments): 'Seniors should be offered at least one hour of activity daily, based on their own interests, wishes, and needs. Activities will provide enjoyable experiences and moments in daily life, and will stimulate the senses, trigger memories, and facilitate movement and participation in the social community' [203]. The reform further recommends a systematic approach to creating enjoyable moments and meaningful activity in the daily lives of older people. Norwegian local authorities are obliged by law to offer day activity services to home-dwelling people with dementia [2].

As described by Kitwood and in occupational science, occupation is a main psychological need, and humans are occupational beings. Thus, it is not surprising that a commonly reported unmet need by people with dementia is daytime activities.

2.7.3 The need for company

Social engagement is necessary for well-being throughout life. Social activity has been suggested as improving quality of life in people with dementia, and for many successful group interventions, positive social engagement might be an important mechanism [4]. However, unmet needs for company are frequently found in studies exploring needs among people with dementia [9, 10, 191].

In the CANE instrument, the item 'company' is introduced by asking *'Are you happy with your social life? Do you wish you had more social contact with others?'.* People with the ability to organise enough social contact are considered as not having a need, whereas people with very few social contacts and/or who frequently feel lonely and isolated are considered to have an unmet need. Needs can be met through informal help from friends who help with social engagement or who visit to provide company. Formal help for company is exemplified as social worker involvement, social

skills training, visits from befriender or voluntary worker, day centre, lunch club, or other organised social activity [186].

Lack of social contact may lead to negative outcomes in people with dementia, such as loneliness, depression, and other BPSD. These negative effects of the loss of social contact have been sadly illustrated during the lockdown periods of the Coronavirus disease 2019 (COVID-19) pandemic, but the mechanisms may well exist in lack of social contact for other reasons. Social isolation measures enforced during the COVID-19 pandemic have been found to be associated with manifestation and/or worsening of BPSD—even in older adults without cognitive impairment [204]. In a review investigating the consequences of enforced prolonged social isolation due to COVID-19, Manca and colleagues (2020) found that different BPSD emerged and/or intensified in older adults with and without dementia. The symptoms most commonly found in people with dementia were agitation, apathy, depression, and irritability, and a direct correlation was found between length of lockdown periods (leading to social isolation) and severity of symptoms [205].

Activity and socialisation are target areas of the Norwegian Quality Reform for Older Persons called *A full life–all your life*. To meet the challenges of loneliness in older people and their failure to meet social needs, solutions aiming to increase activity, create good experiences, and improve socialisation have been recommended in the reform [203]. The Norwegian national guideline on dementia states that the activity services which the municipalities are obliged to offer should include activities that are socially, cognitively, and physically stimulating. One of the aims of activity services is to prevent or reduce isolation and loneliness [2].

2.7.4 How to meet needs in home-dwelling people with dementia

The results of the assessments conducted as part of the diagnostic evaluation, in combination with the needs assessment, should be considered when planning treatment, advice, support, and services for people with dementia. In the planning process, one should consider the person as a whole and consider a broad range of needs, including medical, emotional, psychological, and social needs. Each person has individual needs which will change during the course of dementia; therefore, individually tailored treatment, advice, support, and services is required [4].
In addition to understanding individual requirements, assessing the needs of people with dementia is useful at a macro level in the planning of health care provision [202, 206].

Timely access to formal services and care

The existence and availability of services may not be sufficient to ensure timely access to formal care for people with dementia. Several barriers to access have been identified, such as lack of information regarding available services, acceptance of need for and attitudes towards receiving services, financial barriers, and not knowing how to initiate appropriate services [200]. In a scoping review, Røsvik and colleagues identified five types of potential interventions to enhance access to and utilisation of services. Case management interventions had the most solid effect, while less robust evidence was found for referral-enhancing interventions, awareness- and information-focused interventions, monetary support interventions, and inpatient-focused interventions [207].

Following a Delphi consensus process, best practice recommendations addressing how to overcome barriers to access and use of community care services have been made, as part of the Access to Timely Formal Care (Actifcare) project. The first and most important recommendation is that people with dementia and their carer/family should have a named contact person; this contact person should be proactive and trained in dementia and person-centred care and should serve as a

coordinator and e.g., provide information and continuous support [208]. Other recommendations address e.g., the provision of tailored information, the training of staff, monetary support, transportation, staff continuity, and services being person-centred and dementia specific [208].

Planning how to meet needs in home-dwelling people with dementia

People with dementia may need several types of treatment, advice, support, and services in order to address the symptoms and needs identified in the diagnostic evaluations and the needs assessments. The scope of this thesis only allows for mentioning a few of these. The person with dementia should be involved in the process of planning the support, and they may need help in having their voice heard [50]. A named key contact person who acts as a coordinator/case manager is an important aspect to ensure access to appropriate treatment, advice, support, and services for people with dementia [4, 50, 207].

Home alterations and the use of assistive technology may promote safety and independence, provided that the technology is individually tailored to the person and the use is supported [209, 210]. Cognitive rehabilitation has been found to improve everyday functioning and enhance independence in people with early-stage dementia [131]. When help is needed for activities, several measures may increase participation in the activities, such as task simplification, cueing, and activity-specific strategies [50]. Continuity of staff delivering home-based services helps build trust and ensure security for the person with dementia [200].

Psychosocial interventions may reduce BPSD (including depression), improve quality of life and communication, fulfil social needs, and increase independence in ADL for community-dwelling people with dementia [97, 98]. Promoting social participation and meaningful activities as part of everyday life has been found to be beneficial to people with dementia [91, 95, 96].

Individually tailored and age-appropriate day care may serve to reduce depression and other BPSD in people with dementia and increase social engagement through participation in activities with peers, thereby reducing isolation and loneliness [132, 211]. Physical activity is beneficial to overall health and can help maintain physical functioning, such as strength and balance. Furthermore, physical activity may improve independent functioning, decrease depression, and sustain general psychological well-being and selfhood in dementia [212, 213].

2.8 The Norwegian model for diagnostic evaluation and support of home-dwelling people with dementia

In Norway, diagnostic evaluations of people with symptoms of cognitive impairment are (with some exceptions) mainly a primary health care responsibility and performed by GPs, usually in collaboration with a community-based multidisciplinary dementia resource team [5]. The Norwegian national guideline on dementia strongly recommends that the municipalities organise multidisciplinary teams skilled in dementia care [2]. The dementia resource teams have different names in different municipalities; in this thesis, we refer to them as *memory teams*.

The memory teams assist the GPs in their diagnostic evaluations of persons suspected of having dementia or cognitive decline, and they ensure that people with dementia and their family carers receive treatment, advice, support, and services as needed throughout the course of the disorder. Furthermore, they should ensure that people with dementia have one key contact person in the municipality who acts as a coordinator and case manager during the whole time they live at home [2]. Usually, a registered nurse and often an occupational therapist are members of the teams [214].

Preferably, the teams should include a physician who can supervise the memory team as well as the GPs. Other team members may be assistant nurses, social educators, or physiotherapists. Municipalities that do not have memory teams should have other ways to support the GPs in assessing suspected cognitive impairment as well as in ensuring treatment, advice, support, and services to home-dwelling people with dementia [2].

Some municipalities have had memory teams for 15–20 years. The number of memory teams rose during the period of the first Norwegian dementia plan, called 'Dementia plan 2015: Making the most of the good days', where one of the aims was ensuring diagnosis [215]. In 2015, 75% of the Norwegian municipalities had a memory team and/or a dementia coordinator, and in 2018 the proportion was 90% [1].

Even though diagnostic evaluations of people with symptoms of cognitive impairment are mainly a primary health care responsibility in Norway, complicated diagnostic evaluations should be conducted in the specialist health care system (this is further elaborated on in chapter 2.8.2). An evaluation tool for use in primary health care and a guide for extended evaluations in specialist health care are in place. We refer to the tool chiefly used in primary health care is the 'basic' tool (*basal* in Norwegian) and the evaluations primarily conducted in specialist health care as 'extended' (*utvidet* in Norwegian). When appropriate, the basic tool can be used in specialist health care, and primary health care can use (parts of) the extended evaluation if needed. Both of these evaluations are comprehensive: they include medical and neurological evaluation, blood tests, structural imaging, cognitive assessments, assessment of BPSD, and assessment of ADL functioning. The evaluations conducted in specialist health care have more extensive neuropsychological tests, along with additional structural imaging and testing of biomarkers. The evaluations conducted in primary health care allow for observations of activities in the person's own home and thereby offer a unique opportunity to better understand their mental function. Observation of the patient's home itself also enables useful discoveries regarding how the person manages at home and possible needs for services.

2.8.1 Diagnostic evaluation by GPs, in cooperation with municipality memory team

The Norwegian national guideline on dementia recommends that basic evaluations of suspected cognitive impairment should be conducted with a multidisciplinary approach [2].

Box 3. The contents of a basic diagnostic evaluation according to the Norwegian national guideline on dementia [2]:

- medical examination
- blood tests
- assessment of delirium
- assessment of cognitive side effects of drugs
- CT/MRI
- interview with a proxy
- assessment of cognition
- assessment of BPSD

The Norwegian national guideline on dementia further recommends that the diagnostic evaluation should be performed over at least two GP consultations and in cooperation with the municipality's memory team. A routine for the evaluation is outlined in the guideline and is elaborated on in the

two basic evaluation tools (one for GPs and one for other health care personnel) and their manuals [2, 141, 166, 216, 217]. After the first consultation, depending on the patient's consent, the GP refers the patient to the memory team. Usually, two members of the memory team conduct a home visit and meet with the patient and a proxy/caregiver, where they interview the patient and the proxy/caregiver separately. Guides for these interviews are provided in the basic evaluation tool. In each case, the GP and the memory team agree who should conduct the different assessments, but usually most of the assessments below are conducted by the memory team. In addition to the interviews, the following assessments are recommended in the tool:

With the person with suspected dementia or cognitive decline

- The Norwegian revised version of the MMSE (MMSE-NR3)
- The Norwegian revised version of the Clock Drawing Test (KT-NR3)
- Observations
    - While performing an activity
    - General observations of functioning in the home
    - Checklist of safety in the home

With the proxy/caregiver

- The Informant Questionnaire of Cognitive Decline in the Elderly (IQCODE)
- The Activities of Daily Living scale (IADL scale)
- The Physical Self-Maintenance Scale (PSMS)
- Questions regarding use of everyday technology
- The Cornell Scale for Depression in Dementia (CSDD)
- The Neuropsychiatric Inventory Questionnaire (NPI-Q)
- Relatives' Stress Scale (RSS)

After the home visit, the memory team sends the GP a report with the results of the assessments and their evaluations. The patient then has one or more new GP consultations for further evaluations, which a proxy/caregiver should preferably also attend. Based on the result of the history-taking, medical and neurological evaluations, blood tests, structural imaging, and the report form the memory team, the GP concludes on a diagnosis. The diagnosis should also include an aetiological dementia diagnosis [141].

The GP conveys the diagnosis and the results of the assessments to the patient. For support and help understanding and remembering these results, it is recommended that a caregiver attends this consultation, given the patient's consent [2]. The memory team may also attend this or other GP consultations to aid in planning treatment, advice, support, and services [2].

The Norwegian national guideline on dementia advises that there should be routines in place for cooperation between the GPs and the municipality's memory team regarding the evaluations [2]. In 2018, 74% of municipalities reported that they had established such routines [1].

2.8.2 Diagnostic evaluation in specialist health care

According to the Norwegian national guideline on dementia and the Dementia Plan 2025, some people with suspected cognitive impairment should have their diagnostic evaluations performed in specialist health care. These include people under the age of 65 years, people with intellectual disabilities, and people with Sami or minority ethnic background, where barriers related to language, education, and/or culture make diagnostic evaluations more complicated [2, 218]. People who are normally evaluated by their GP may also be referred to a specialist health care evaluation, e.g., in cases with complicated or unusual symptoms or where the GP is unable to conclude on a diagnosis.

In Norway, memory clinics as well as geriatric-, old-age psychiatry-, and neurological outpatient clinics assess people with suspected dementia.

A diagnostic evaluation in specialist health care includes the assessments in the basic evaluation tool, followed by one or two steps of an extended evaluation. The first step of the extended evaluation is an MRI, along with further cognitive tests such as Trail Making Test A and B (TMT-NR3) and tests from the CERAD battery (described in chapter 2.6.4). If a diagnosis is still not established, a second step of the extended evaluation is suggested, consisting of neuropsychological tests, testing of cerebrospinal fluid, and functional brain imaging such as FDG-PET, amyloid PET, and/or DAT-scan [2, 219]. In complicated cases, more extensive neuropsychological tests as well as more biomarkers and functional brain imaging enable better understanding of comorbidities, better aetiological differentiation, and evaluation of mild or rare symptoms, especially in young and middle-aged people.

Assessments tailored to the patient may also be used when appropriate. For example, with people with an ethnic minority background who do not speak Norwegian well and/or have limited education, instruments such as the RUDAS may be used. An extended evaluation is especially useful for assessing younger people, people with unusual symptoms or an unusual debut of symptoms, people with comorbidities or unclear premorbid functioning, or people for whom a basic evaluation by a GP is complicated for other reasons [219].

The Norwegian national guideline on dementia recommends that the GPs follow up with people diagnosed with dementia—including patients diagnosed in specialist health care—and that they ensure that treatment, advice, support, and services are provided as needed. The GP should cooperate with informal caregivers and personnel from the municipality health care services, such as the memory team [2]. It is important that people diagnosed with dementia have contact with the municipality health care services, who can assess their needs for treatment, advice, support, and services. The person may not need personal help at an early stage of the disease, but other support services—such as education about dementia and emotional support—are often needed. Thus, establishing a key contact person for people with dementia and their caregivers, remaining with them from diagnosis throughout the course of the disorder, is recommended in the guideline [2].

2.8.3 Treatment, advice, support, and services for people with dementia living at home

In addition to assisting the GPs in diagnostic evaluations of people with suspected cognitive impairment, the memory teams should ensure that people with dementia and their caregivers are offered the necessary treatment, advice, support, and services. One key contact person should be appointed [2]. The time (person-month effort) the memory teams have allocated for their work varies across different municipalities, from no time or hardly any time at all in smaller municipalities to 500% of a full-time position in larger municipalities [214]; thus, the support provided by the teams varies. The Norwegian national guideline on dementia suggests that the following support is provided [2]:

Box 4. Suggested support from the memory teams for home-dwelling people with dementia [2]:

- Assist the GP in evaluating progression of the dementia disorder
- Offer tailored information about dementia to people with dementia and caregivers
- Provide guidance to people with dementia on everyday coping
- Offer regular home visits in addition to contact as needed
- Offer information about legal and economic rights and issues
- Evaluate need for assistive technology and provide advice on fire prevention measures, assistive technology, and possible alterations of the home
- Offer information about relevant offers and services from both public and volunteer providers
- Motivate people with dementia and (when relevant) their caregivers to use available services
- Facilitate formalised cooperation between the memory team, the GP, and the municipality health and social services

If the memory team has not been involved in the diagnostic evaluation, the GP should obtain permission from the patient to refer them to the memory team for further treatment, advice, support, and services, and for the appointment of a key contact person [218]. People who need prolonged and coordinated health and social services have the right to a coordinator and, if they wish, to have an individual plan made [2]. An individual plan is a formal plan used as a tool in the provision of treatment, advice, support, and services, and which is continually evaluated. People with mild dementia are not designated as having a need for prolonged and coordinated services, but given that they will reach such a designation at a later stage, it is advisable to appoint a coordinator and create an individual plan at the stage of mild dementia [2].

A systematic approach to treatment, advice, support, and services is recommended [218]; however, in 2018, only 55% of Norwegian municipalities reported that they had routines in place for such systematic support for home-dwelling people with dementia [1]. Routines for cooperation between GPs and memory teams regarding treatment, advice, support, and services for home-dwelling people with dementia are also important; in 2018, 60% of municipalities reported having such routines [1].

2.9 Summary of rationale

Treatment, advice, support, and services should be provided to home-dwelling people with dementia, and actual resources for meeting the needs of this group should be in place. To be able to provide the treatment, advice, support, and services needed, the following steps are necessary:

1. People with symptoms of cognitive impairment and who should undergo a diagnostic evaluation need to be identified
2. A diagnostic evaluation should be carried out, evaluating a broad set of signs, symptoms, and consequences
3. The needs of the person with dementia should be assessed in order to identify unmet needs, which should be targeted when planning treatment, advice, support, and services

There is a need for

- a simple validated instrument in Norwegian to identify people who should undergo a diagnostic evaluation
- more knowledge about people assessed for suspected dementia or cognitive decline in primary health care compared to those assessed in specialist health care in Norway
- more knowledge about the associations between unmet needs and BPSD

3 The present thesis

3.1 Aims

Main aim:
The main aim of this thesis was to explore different assessments of symptoms and functioning that are needed to diagnose dementia, as well as assessments to plan treatment, advice, support, and services for home-dwelling people with dementia. We mainly explored how to evaluate the clinical symptoms of dementia and the corresponding needs.

Aim paper I
To evaluate the validity of the Norwegian version of the Cognitive Function Instrument (CFI), used to discriminate between people with dementia, people with MCI, people with SCI, and a reference group of healthy older adults.

Aim paper II
a) To describe patients assessed for cognitive decline in Norwegian primary health care compared to patients assessed in specialist health care.

b) To examine factors associated with depression in people assessed for cognitive decline.

Aim paper III
To examine prospectively, over twelve months, the association between unmet needs for daytime activities and company and the severity of different BPSD sub-syndromes.

3.2 Methods

Table 3. Overview of the three papers.

	Paper I	**Paper II**	**Paper III**
Name of paper	The Validity of the Norwegian Version of the Cognitive Function Instrument	Characteristics of patients assessed for cognitive decline in primary health care, compared to patients assessed in specialist health care	Associations between unmet needs for daytime activities and company and scores on the Neuropsychiatric Inventory-Questionnaire in people with dementia: A longitudinal study
Aim	To evaluate the validity of the Norwegian version of the Cognitive Function Instrument (CFI), used to discriminate between people with dementia, people with MCI, people with SCI, and a reference group of healthy older adults	a) To describe patients assessed for cognitive decline in Norwegian primary health care, compared to patients assessed in specialist health care b) To examine factors associated with depression in people assessed for cognitive decline	To examine prospectively, over twelve months, the association between unmet needs for daytime activities and company and the severity of different BPSD sub-syndromes.
Study design	Validity study	Observational study	Longitudinal cohort study

Table 3 continues

	Paper I	Paper II	Paper III
Setting and participants	265 participants with dementia, MCI, and SCI, and healthy controls, along with proxies for 249 of the participants	1821 participants from 14 outpatient clinics and 33 GPs and memory teams across Norway	451 dyads of participants and caregivers from eight European countries, assessed three times over one year
Ethics	Approvals from the Regional Committee for Medical and Health Research Ethics in Southeast Norway, the Norwegian centre for research Data, and the data protection agency at Oslo University Hospital.	One cohort with permission from the Norwegian Data Protection Authority; the other approved by the Regional Committee for Medical and Health Research Ethics in Southeast Norway	Ethical considerations differ across the eight Actifcare countries. Each country/ research team applied for, and was granted, ethical approval according to local regulations.
Data collection	2015–2016	2011–2012 and 2013–2014	November 2014–August 2016
Measures	MMSE-NR2, KT-NR2, IQCODE, IADL scale, RSS, diagnosis, and demographic data	MMSE-NR2, KT-NR2, IQCODE, IADL scale, PSMS, CSDD, RSS, diagnosis, and demographic data	CANE-S, NPI-Q, CDR, Charlson Comorbidity Index, IADL, diagnosis, and demographic data
Analysis	SPSS version 24.0. Mean (SD), percent, Spearman correlation coefficient, Wilcoxon signed-rank test, Kappa, Cronbach's alpha, receiver operation characteristic analyses, likelihood ratio, linear regression.	SPSS version 25.0. Principal component analysis, mean (SD) or median (IQR), percent, t-tests/Mann–Whitney U tests and chi-square tests, binary and multinomial logistic analyses.	SPSS version 25.0 and STATA version 16.0. Principal component analysis, mean (SD) or median (IQR), percent, chi-square, linear mixed models.

Abbreviations: MMSE-NR2 = the second revised Norwegian version of the Mini-Mental State Examination, KT-NR2 = the second revised Norwegian version of the Clock Drawing Test, IQCODE = the Informant Questionnaire of Cognitive Decline in the Elderly, IADL = the Instrumental Activities of Daily Living scale, PSMS = the Physical Self-Maintenance Scale, CSDD = the Cornell Scale for Depression in Dementia, NPI-Q = the Neuropsychiatric Inventory Questionnaire, CDR = the Clinical Dementia Rating scale, CANE-S = the short version of the Camberwell Assessment of Need for the Elderly, RSS = the Relatives' Stress Scale, SD= Standard Deviation, IQR = Interquartile Range.

3.2.1 Study design

Paper I

A validity study of the Norwegian version of the Cognitive Function Instrument (CFI) [145, 146], used to discriminate between people with dementia, people with MCI, people with SCI, and people without a subjective or assessed cognitive impairment. We applied the criteria for validity studies described by Qizilbash et al. [220](pp18-19). According to these criteria, a validity study should include the following [220] (pp18-19):

1. An independent comparison with an acceptable reference standard should be applied.
2. A broad and appropriate spectrum of patients should be included.
3. The sample should be recruited consecutively or at random.
4. Both the reference standard and the test being validated should be applied to all participants.

Prior to this study, the CFI had been translated into Norwegian by three different persons who were fluent in English and Norwegian and who had clinical experience in dementia. Drawing on the three translations, two other experienced clinicians prepared the first version of the Norwegian CFI, which was back translated by an independent native English clinician who was also fluent in Norwegian [221]. After final adjustments, the new translated version of the CFI was used in this validation study.

Paper II

An observational study of patients assessed for cognitive impairment in primary health care compared to patients assessed in specialist health care.

Paper III

A longitudinal cohort study investigating the association between BPSD and unmet needs for daytime activities and company in home-dwelling people with dementia, who were assessed three times over one year. This study was a part of the larger Access to Timely Formal Care (Actifcare) project, which aimed to develop best-practice recommendations to ensure timely access to formal care for community-dwelling people with dementia and their informal carers.

3.2.2 Setting and participants

Table 4. Overview of participants.

	Paper I (n*=265)	**Paper II (n*=1821)**	**Paper III (n*=451)**
Name of paper	The Validity of the Norwegian Version of the Cognitive Function Instrument	Characteristics of patients assessed for cognitive decline in primary health care, compared to patients assessed in specialist health care	Associations between unmet needs for daytime activities and company and scores on the Neuropsychiatric Inventory-Questionnaire in people with dementia: A longitudinal study
Age in years	Mean (SD): 74.7 (10.6)	Mean (SD): 73.0 (10.6)	Mean (SD): 77.8 (7.9)
Female gender	57.8%	55.1%	54.5%
Living alone	N/A	40.8%	19.5%
MMSE-NR2	Mean (SD): 24.8 (5.1)	Median (Q1, Q3): 25.0 (21, 28)	N/A
CDR, sum of boxes	N/A	N/A	Mean (SD): 7.1 (2.4)
IQCODE	Mean (SD): 3.6 (0.6)	Mean (SD): 3.83 (0.57)	N/A
Lawton and Brody IADL scale	Mean (SD): 12.3 (6.2)	Median (Q1, Q3): 6 (4, 7)	Mean (SD): 3.5 (2.0)
Diagnosis	Dementia: 41.1% MCI: 15.5% SCI: 9.8% Healthy reference group: 33.6%	Dementia: 46.6% MCI: 31.8 % SCI/ not dementia: 21.6%	AD: 48.3 % VaD: 11.8% Mixed: 12.4% LBD: 1.3% Other/unspecified: 26.2 %
NPI-Q **Agitation** **Affective** **Psychotic**	N/A	Median (Q1, Q3): 1 (0, 2) 3 (1, 5) 0 (0, 0)	Mean (SD): 2.9 (2.8) 3.4 (2.6) 1.5 (1.8)

*N refers to number of participants in total. For the n for different variables, please consult the tables in the respective paper(s). Abbreviations: MMSE = the second revised Norwegian version of the Mini-Mental State Examination, CDR = the Clinical Dementia Rating scale, IQCODE = the Informant Questionnaire of Cognitive Decline in the Elderly, NPI-Q = the Neuropsychiatric Inventory Questionnaire, SD = standard deviation, Q1 = first quartile, Q3 = third quartile, MCI = Mild Cognitive Impairment, SCI = Subjective Cognitive Impairment, AD = Alzheimer's Dementia, VaD = Vascular Dementia, LBD = Lewy body dementia, Mixed = AD in combination with VaD and/or LBD.

Paper I

A total of 265 participants with dementia, with MCI, with SCI, or without subjective or assessed cognitive impairment were included in the study. For 249 of the participants, we also included a family member as an informant.

- A total of 95 patients (+ 95 proxies) were recruited from two memory clinics to which they had been referred for an extended diagnostic evaluation.
- A total of 81 patients (+ 81 proxies) were recruited from primary health care, where the GP had conducted a basic diagnostic evaluation in cooperation with the municipality memory team.

These participants were included by memory teams who had volunteered to contribute to the study.

- A total of 89 older people without cognitive impairment were included as a reference group; for 73 of these, we also included a proxy. This reference group was a convenience sample which had been recruited as part of another study [222] through senior centres, through various voluntary organisations, by advertisements in local newspapers, and by including home-dwelling older people who were receiving in-home health care services.

The memory clinic patients were diagnosed with dementia according to the ICD-10 criteria for research [33], with MCI according to the Winblad criteria [24], and with SCI when they did not fulfil either the dementia or the MCI criteria. The patients in primary health care were diagnosed by their GP using the ICPC-2 classification system [140]—P70 for dementia and P20 for MCI. The reference group had undergone cognitive testing annually for 2 years with the MMSE-NR2 and the KT-NR2. The participants who were evaluated as still being without cognitive impairment were included in the present study.

Paper II

A total of 1821 participants:

- 1595 from 14 specialist health care outpatient clinics
- 226 from 33 memory teams cooperating with GPs across Norway

All participants were included in the process of diagnostic evaluation for cognitive impairment. In addition to consenting to participate, the only inclusion criterion was being referred to specialist health care for a diagnostic evaluation or to a memory team for assessment as part of a primary health care diagnostic evaluation.

The primary health care participants (PrimCare) were recruited by the memory teams, through the project "Dementia teams in Norway" (DemiNor), which was financed through the Dementia Plan 2015. (Dementia team is another name for memory team.) The DemiNor project investigated and reported data on, among other things, the composition and organisation of the memory teams, the tasks they were assigned, their use of time, and the patients the teams had assessed upon referral from the GPs. The PrimCare participants were diagnosed by their GPs using the ICPC-2 criteria [140]. For this study, they were also assigned research diagnoses by two experienced psychiatrists in consensus. These research diagnoses were established based on the information available—for dementia, according to the ICD-10 criteria for research [33], and for MCI, according to the Winblad criteria [24]. SCI was determined in cases with subjective cognitive complaints who did not fulfil either the dementia or the MCI criteria, and no dementia/other diseases was assigned in cases when no objective or subjective impairment was present.

The specialist health care participants (SpecCare) were recruited from the Norwegian register of persons assessed for cognitive symptoms (NorCog), a consent-based quality and research register. The SpecCare participants came from outpatient clinics: memory clinics, geriatric clinics, and old-age psychiatry clinics. Memory clinics primarily represent a type of highly specialised multidisciplinary clinic, as they tend to have patients with suspected neurodegenerative diseases. Geriatric and old-age psychiatry clinics also assess patients with other diseases, and they differ from the memory clinics in terms of the demographic characteristics of the patients [223](pp 80-82). To compare participants from different types of outpatient clinics with participants from primary health care, the outpatient clinics were dichotomised into memory clinics and 'other' clinics (geriatric and old-age psychiatry outpatient clinics). The SpecCare participants were diagnosed with dementia according to the ICD-10 criteria for research [33], with MCI according to the Winblad criteria [24], and with SCI when they did not fulfil either the dementia or the MCI criteria.

Paper III

The Access to Timely Formal Care (Actifcare) study was an EU Joint Programme–Neurodegenerative Disease Research (JPND) project exploring access to and uptake of formal community care services in the following eight European countries: Germany, Ireland, Italy, the Netherlands, Norway, Portugal, Sweden, and the United Kingdom [224]. The Actifcare project included 451 dyads of people with dementia and their informal caregivers.

For the present study, only the data describing people with dementia were included. Inclusion criteria were having a diagnosis of mild to moderate dementia—indicated by a Clinical Dementia Rating scale (CDR) score of 1 or 2 or a score on the MMSE of 24 or lower—and living at home. Furthermore, the participants should not have been receiving personal care related to dementia upon inclusion, but a health care professional should assume that they would require such care within one year. The participants were recruited from different settings through different sources, including memory clinics, GPs, community resource teams, and advertisements in local and national newspapers.

All the researchers who collected the data had clinical experience. To coordinate inclusion and data collection and to ensure a common understanding of how to administer the measures, joint training sessions were carried out for the research teams from all eight countries.

3.2.3 Ethics

Paper I

The Regional Committee for Medical and Health Research Ethics in Southeast Norway reviewed this study and considered it to be a quality assurance project; thus, the study fell outside the scope of The Act of Medical Research in Norway (cf. §§ 2 and 4 of The Act). The project was presented to the Norwegian Centre for Research Data and the data protection agency at Oslo University Hospital; both authorities approved the study. Data from the patients collected by the memory teams were registered anonymously and were part of an assessment of cognitive impairment. The informed consent from the participants from the memory clinics and the reference group were considered to cover the use of data for the purpose of this study. The data from the memory clinics and the reference group were received without ID numbers or other identifiable information.

Paper II

The SpecCare participants were covered by the NorCog permission from the Norwegian Data Protection Authority to collect data until 2029. The PrimCare participants were covered by the approval of the DemiNor project by the Regional Committee for Medical and Health Research Ethics in Southeast Norway, reference number 2012/1997. All participants and their participating relatives in both the PrimCare and the SpecCare cohorts signed informed consent forms. Data from the two cohorts were first completely anonymised and then merged into one data file for analyses. This was confirmed by the Norwegian Centre for Research Data to be in accordance with the regulations.

Paper III

Procedures regarding ethical approval differed across the eight Actifcare countries. Each country/ research team applied for, and was granted, ethical approval according to their own local regulations. After an introduction of the consent forms and the option to discuss the content or ask questions if needed, written informed consent forms were signed by both the person with dementia and the informal caregiver. If the person with dementia had reduced ability to consent, the written informed consent form was signed by an informal caregiver or legal representative. For the

Norwegian part of the study, approval from the Regional Committee for Medical and Health Research Ethics in Southeast Norway was obtained, reference number 2014/862.

3.2.4 Data collection

Paper I

In this validation study, the participants and their proxies filled in the CFI independent of each other. The physicians were blinded to the CFI scorings when diagnosing dementia and cognitive impairment. Data was collected in 2015 and 2016.

Paper II

PrimCare data was collected from the beginning of 2013 to the end of 2014. GPs sometimes refer their patients to specialist health care for a diagnostic evaluation after their own evaluation, so to ensure that no patients would appear in both cohorts, SpecCare data from 2011 and 2012—before the collection of PrimCare data—was used.

Paper III

Data was collected three times over one year (baseline, six months, and twelve months). The first baseline assessment was conducted in November 2014, and the last twelve-month assessment was conducted in August 2016.

3.2.5 Measures

The measures used in the studies which are not described in this chapter have been described in chapters 2.2, 2.6, and 2.7 in this thesis.

Paper I

The CFI was developed by the Alzheimer's Disease Cooperation Study for use in an AD prevention trial. The CFI consists of 14 items on memory, orientation, social participation, and functioning in IADL, and it can be used to screen for functional and cognitive impairment in older people. There are two versions, with similarly phrased questions: one version of self-report and one of proxy-report. Each item is scored as yes = 1, maybe = 0.5, or no = 0 point, and scores are added to give a sum score with the maximum score being 14 points and a higher score indicating greater cognitive impairment [145, 146].

The following measures—all included in the basic dementia diagnostic evaluation tool—were used in this study: MMSE-NR2 [150], KT-NR2 [152], IQCODE [147], Lawton and Brody IADL scale [101], RSS [51], and diagnosis (dementia, MCI, SCI, or without subjective or assessed cognitive impairment). In addition, the following demographic data was collected: age and gender of both participant and proxy, and relation between participant and proxy. Medical examination and blood testing were not conducted in the reference group, and thus these data were not included.

Paper II

All the measures in the basic dementia diagnostic evaluation tool which are also included in an extended dementia diagnostic evaluation were of interest to use in terms of obtaining a broad description of the characteristics of patients assessed for cognitive impairment in primary health care. Consequently, the following assessments were included: MMSE-NR2 [150], KT-NR2 [152], IQCODE [147], Lawton and Brody IADL scale [101], PSMS [101], CSDD [182], NPI-Q [181], RSS [51], and diagnosis (SCI/no dementia,

MCI, and dementia). In addition, the following demographic data was collected: age of participant and proxy, participant gender, education, and living situation (alone/with someone).

Paper III

The Actifcare project included a broad set of measures assessing health, BPSD, cognition, quality of life, needs, health economics, and more. For the present study, the following measures were used: BPSD was measured with NPI-Q [181]; needs for 'daytime activities' and 'company' were measured by the short version of the Camberwell Assessment of Need for the Elderly (CANE-S) [186, 202]. The CANE-S only assesses whether a need is present in the specific area, and if so, if it is met or unmet. We used the scores for needs as assessed by the researchers, which are based on the reports from the person with dementia and the informal caregiver, together with all other information that was available to the researcher. The categories 'no need' and 'met need' were collapsed into one category and compared to 'unmet need'. The CDR scale [117]was used to measure level of dementia. In the CDR, six domains of cognitive and functional performance are characterised on a scale of 0–3, where 0 indicates normal function and 3 indicates severe decline. The researchers completed the CDR after each interview based on all available data, and the sum of boxes scores (where the six item scores are added up (0–18 points)), were used for this study [225]. Aetiological dementia diagnosis was recorded when available. The Charlson Comorbidity Index [226] was used to indicate comorbidity, with higher scores indicating more comorbidities. We applied updated weights for each of the items, in line with Quan [227]. IADL was measured with the Lawton and Brody IADL scale [101]. The following demographic data were also recorded: gender, age, living situation (living alone or with someone), region of residence (North: Sweden and Norway; Middle: the Netherlands, Germany, the UK, and Ireland; and South: Portugal and Italy), and education of person with dementia.

3.2.6 Analysis

Paper I

Almost half of the participants and their proxies did not answer question 7 of the CFI, addressing trouble with driving; therefore, this item was not included in the sum score. If data was missing on one or two items other than item 7, data were imputed with the value 0. Descriptive statistics of participants' characteristics were calculated with mean (standard deviation (SD)) and percent.

Median scores and non-parametric statistics were used because the distribution of the CFI sum scores within each diagnostic group was not normal. Kappa was used to examine inter-rater reliability, understood here as the consistency of the self- and proxy-rated versions of the CFI, analysing the agreement of scores on each item on the CFI. Spearman correlation coefficient was used to examine the relationship between the sum scores of the self-rated and those of the proxy-rated CFIs, analysing the agreement between the two assessors. Wilcoxon signed-rank test was used to compare the two samples: the difference between total scores on the self-rated and those on the proxy-rated CFI. Cronbach's alpha was used to examine internal consistency as a measure of scale reliability—i.e., how closely related the items of the CFI are as a group, and whether they measure the same underlying concept. Cronbach's alpha was calculated for the self- and proxy-rated versions of the CFI, and we analysed the impact on Cronbach's alpha by removing one item at a time from the scale.

Receiver operation characteristic (ROC) analyses were conducted to test the discriminatory power of the self-rated CFI and the proxy-rated CFI—i.e., the 'diagnostic ability' to separate persons with dementia from (a) the reference group, (b) persons with MCI, (c) persons with SCI, (d) persons with

MCI or SCI, and (e) all persons without a dementia diagnosis. Area under the curve (AUC) with 95% confidence interval was calculated as a measure of how well the CFI versions can distinguish between the diagnostic groups described - a summary of the ROC curve. Sensitivity (true positive rate - the proportion of positives that are correctly identified) and specificity (true negative rate - the proportion of negatives that are correctly identified) were calculated for the cut-off points that produced the highest accuracy and had a sensitivity of at least 70%. Likelihood ratios for a positive (LR+) and a negative (LR-) outcome were reported: LR+ is the probability of having the disorder if the test is positive [sensitivity/(1 – specificity)], while LR- is the probability of not having the disorder if the test is negative [(1 – sensitivity)/specificity].

Linear regression analyses were conducted to examine which factors were associated with the CFI self- and proxy-rated scores. We used the 'enter' method, with self- and proxy-rated CFI as the dependent variable and age, gender, MMSE-NR2, KT-NR2, IADL, and RSS scores as independent variables.

Paper II

Missing data: Data were missing on all proxy-based measures in 4% of the primary health care participants and in 10% of the specialist health care participants. The proportion of missing data within scales was examined and found to be relatively low, and we wanted to impute values using prediction based only on values within each single scale. For the participants with only partially missing data within scales, we therefore used a simple approach to imputing data: single imputation with the expectation maximation algorithm in SPSS. To quality check this imputation, all main analyses were also conducted in a parallel file into which we had imputed participant means in scales with a maximum 20% of missing items. The quality check results were comparable to the ones presented in the paper, with similar trends for *p*-values and odds ratios.

Initially, a principal component analysis (PCA) was performed on all the 12 items of the NPI-Q to group the symptoms and reduce number of variables. The PCA was performed with varimax rotation and an eigenvalue greater than 1, indicating that the given principal component explains a large enough variance in the data. The PCA resulted in the following three sub-syndromes, which were then used in the analyses:

- Agitation (agitation, euphoria, disinhibition, and irritability)
- Affective (depression, anxiety, apathy, appetite, night-time behaviours, and motor disturbance)
- Psychotic (delusions and hallucinations)

For the specialist health care cohort, analyses were carried out both as one group and dichotomised into memory clinics and 'other' clinics, as described in chapter 3.2.2. Descriptive statistics were calculated with mean (SD) or median (Interquartile Range (IQR)), and percent.
To compare the two cohorts' characteristics, we used t-tests or Mann–Whitney U tests for continuous variables and chi-square tests for categorical variables. Age is a criterion for whether a person should undergo diagnostic evaluation in primary health care or in specialist health care; therefore, we wanted to adjust our analysis for age, and we used binary and multinomial logistic analyses (the latter when the specialist health care cohort was dichotomised), with cohort/place of assessment as the dependent variable. One model was used for each of the other independent variables together with age. Models with the following other independent variables were used: gender, relative's age, education, living with someone, diagnosis, MMSE-NR2, KT-NR2, IQCODE, PSMS, IADL, CSDD, NPI-Q sub-syndromes, and RSS.

To examine factors associated with depression, we used a binary logistic regression. CSDD was used as a measure of depression and the dependent variable. The distribution of the CSDD data were highly skewed, which is why we used a logistic rather than a linear regression model. We dichotomised the CSDD scores using a cut-off of 5/6, which was found to be a valid cut-off in a study of home-dwelling people who had undergone a diagnostic evaluation in Norwegian memory clinics [183]. We selected the independent variables and predefined the order in which to enter them into the model based on a combination of theoretical, clinical, and statistical factors. The independent variables were entered in the following order: demographics (gender, age, education, and living with someone), cognition (MMSE-NR2 and IQCODE), PSMS, RSS, diagnosis, and place of assessment (primary health care vs. specialist health care). When all independent variables had been entered, the variable with the highest *p*-value was removed, and this process continued until no variables had *p*-values above 0.05, which happened in the following order: education, diagnosis, PSMS, living with someone.

Paper III

Initially, we conducted a principal component analysis (PCA) on all 12 items of the NPI-Q, so as to group the symptoms and reduce number of variables. The PCA was performed with varimax rotation and an eigenvalue greater than 1, indicating that the given principal component explains a large enough variance in the data. The items were placed in the factor onto which they loaded most heavily, and the PCA resulted in the following three sub-syndromes for use in the analyses:

- Agitation (agitation, euphoria, disinhibition, irritability, and motor disturbance)
- Affective (depression, anxiety, apathy, and appetite)
- Psychotic (delusions, hallucinations, and night-time behaviours)

Descriptive statistics were calculated with mean (SD) or median (IQR), and proportions were calculated in percentages. We categorised the sum score in each NPI-Q sub-syndrome into three groups in order to describe the proportion of the participants who had clinically significant symptoms: no/not significant symptoms, mild/moderate symptoms, and severe symptoms. No common agreement has been reached on such cut-offs for the NPI-Q, but similar cut-offs have been applied to the NPI [71, 228], and we used cut-offs in line with these. We used chi-square analyses with the following two categories 'no/not significant symptoms' vs. 'mild, moderate, and severe symptoms' when investigating difference in proportions of clinically relevant BPSD between participants with no/met need and unmet need.

Linear mixed models are regression models, which account for dependency in the data (such as the dependency between repeated measurements within individuals). Thus, they are useful in longitudinal studies, such as ours, which contained three repeated measures of the same participants. We used linear mixed models with random intercepts and slopes, with the three NPI-Q sub-syndromes as the dependent variables (one by one) and unmet needs vs. met needs/no needs for daytime activities or company as the independent variables.

A likelihood ratio test showed that both the random intercept and slope significantly improved the fit of the models, which is why both terms were included, thereby allowing each individual to have both a different starting point at baseline and a different development over time. We used the simpler continuous linear variable (assuming that the association is linear with time rather than going up and down) because a likelihood ratio test showed that it had equally good fit as the more complex three level dummy variable.

The CDR, the Charlson Comorbidity Index, the IADL scale, and a time variable (coded as 0 for baseline, 1 for six months, and 2 for 12 months) were entered as time-dependent covariates in the

analyses. The rest of the variables—gender, age at baseline, aetiological diagnosis, region, and education—were entered into the model as fixed time-invariant variables. Six unadjusted linear mixed models were first used, and then we used six adjusted models wherein CDR, region, Charlson Comorbidity Index, IADL, age, gender, diagnosis, region, education, and living together/alone were added to the model. To test whether differences changed over time, an interaction term (needs by time) was added.

3.3 Results from the papers

3.3.1 Paper I

The Validity of the Norwegian Version of the Cognitive Function Instrument
The paper describes a validity study done to evaluate the Norwegian version of the CFI. Other studies have investigated the ability of the CFI to detect the earliest signs of cognitive decline. Our main aim was to evaluate whether the CFI can be used later in the progression of cognitive decline to indicate if a diagnostic evaluation should be initiated by the GP. Therefore, we investigated the ability of the CFI to separate people with dementia from people with MCI, people with SCI, and a reference group without cognitive impairment.

Results
The Norwegian CFI was found to be a useful, valid, and robust instrument, which had the power to discriminate between people with dementia and people with MCI, people with SCI, and people without cognitive impairment.

Cronbach's alpha analyses showed an internal consistency of 0.86 for the self-rated version and 0.94 for the proxy-rated version and indicated that all the items of the CFI scales measure the same underlying concept. The self-rated and the proxy-rated versions had a weak correlation: Kappa was very low for most of the items, and none of the items reached 0.5, regardless of diagnostic group. The CFI scores were significantly higher (indicating greater cognitive impairment) in the proxy-rated version compared to the self-rated version in the dementia group, whereas the opposite was the case for the SCI group. Lower MMSE-NR2 sum score (indicating more cognitive impairment) and higher IADL sum score (indicating activity limitations) were associated with higher scores on both the self-rated and proxy-rated CFI in the adjusted analysis. Higher scores on the RSS (indicating caregiver burden) were associated with higher proxy-rated CFI scores. Explained variance of self-rated CFI was 0.18, and that of proxy-rated CFI was 0.62.

In our participants, the proxy-rated version had better power than the self-rated version in discriminating between people with dementia and people with MCI, people with SCI, and people without cognitive impairment. The AUC for the proxy-rated version varied from 0.79 to 0.99 depending on the comparison groups, while the AUC for the self-rated version varied from 0.56 to 0.85. The results of the ROC analyses indicated different cut-off points depending on the version of the instrument and the comparison groups. Based on these results, we suggest the following cut-off values to identify individuals in need of a cognitive assessment: for the self-rated version, 5 or higher; for the proxy-rated version, 7 or higher.

3.3.2 Paper II

Characteristics of patients assessed for cognitive decline in primary health care, compared to patients assessed in specialist health care

In order to contribute knowledge that is needed for the provision of individually tailored treatment, advice, support, and services to home-dwelling people with dementia, as well as future recommendations on how assessing and diagnosing people with suspected cognitive impairment should be organised, we aimed to describe patients assessed for cognitive impairment in primary health care. We did this by comparing these patients to patients assessed in specialist health care, the latter as one group and by type of outpatient clinic: 1) memory clinics, and 2) geriatric- and old-age psychiatry outpatient clinics. Because depression is common in people with dementia and may lead to several negative outcomes, we also aimed to examine factors associated with depression in people assessed for cognitive impairment.

Results

Patients assessed in primary health care were older (mean age: 81.3 vs. 73.0 years); had fewer years of education; had poorer cognition (MMSE median 22 vs. 25); had more ADL limitations, both in BADL and IADL; had more BPSD, including depressive symptoms (CSDD median 7 vs. 5); more often lived alone (60% vs. 41%); and were more often diagnosed with dementia (86% vs. 47%) compared to patients diagnosed in specialist health care. Patients from both types of outpatient clinics were significantly different from the primary health care patients, although the patients from primary health care were more similar to the geriatric- and old-age psychiatry outpatient cohort than to the memory clinic cohort. These differences cannot be accounted for only by age, as the overall results did not change when we adjusted the regression models for age. However, the difference between the primary health care cohort and the total specialist health care cohort on NPI-Q affective and agitation sub-syndrome scores became significant when adjusting for age, with more severe symptoms seen in the primary health care cohort.

Depression was associated with female gender, older age, more severe impairment in cognitive functioning (IQCODE, Odds Ratio (OR) 1.65), higher caregiver burden (RSS, OR 1.10), and being assessed in primary health care (OR 1.53). In the regression model, confounding effects were observed between caregiver burden as assessed by RSS and the variables gender, living situation, IQCODE, and PSMS.

3.3.3 Paper III

Associations between unmet needs for daytime activities and company and scores on the Neuropsychiatric Inventory-Questionnaire in people with dementia: A longitudinal study

Since unmet needs are widely considered to be one of the contributory factors of BPSD, meeting unmet needs might be an appropriate first-choice approach to prevent and treat BPSD. We wanted to examine specific unmet needs and their association with BPSD in home-dwelling people with dementia. This paper aimed to examine prospectively, over twelve months, the association between unmet needs for daytime activities and company and the severity of different BPSD sub-syndromes.

Results

A total of 28.9% of the participants had unmet needs for daytime activities, and 27.3% had unmet needs for company.

Daytime activities: Participants with unmet needs for daytime activities had higher scores on NPI-Q affective items at baseline, six, and twelve months, with mean scores 0.74 (p<0.001), 0.76 (p<0.001),

and 0.78 (p=0.001) points higher, respectively. Unmet needs for daytime activities were also associated with more severe symptoms on the psychotic factor of the NPI-Q at baseline (mean 0.39 points, p=0.007) and at six months follow-up (mean 0.31 points, p=0.006).
The differences in the scores on NPI-Q affective and psychotic items between the groups with no/met and unmet needs did not change over time. Scores on the agitation factor of the NPI-Q were not associated with unmet needs for daytime activities.

Company: Participants with unmet needs for company had higher scores on NPI-Q affective items at baseline, six, and twelve months, with mean scores 0.44 (p=0.033), 0.67 (p<0.001), and 0.91 (p<0.001) points higher, respectively. Unmet needs for company were associated with more severe symptoms on the psychotic factor of the NPI-Q at baseline (mean 0.40 points, p=0.005) and at six months follow-up (mean 0.35 points, p=0.002).
The differences in the scores on NPI-Q affective and psychotic items between the groups with no/met and unmet needs did not change significantly over time. Scores on the agitation factor of the NPI-Q were not associated with unmet needs for company.

4 Discussion

In the following sections, we discuss the findings of our studies in chapter 4.1 and the methodological considerations in chapter 4.2 before we suggest issues which could be of interest to further research in chapter 4.3.

4.1 Discussion of results

The main aim of this thesis was to explore different assessments of symptoms and functioning which are needed to diagnose dementia as well as assessments to plan treatment, advice, support, and services for home-dwelling people with dementia. We mainly explored how to evaluate the clinical symptoms of the dementia syndrome and the corresponding needs.

We found that the Norwegian version of the CFI had the ability to separate people with dementia from people with MCI, people with SCI, and a reference group without cognitive impairment. Therefore, the CFI may be useful in identifying people who should undergo a diagnostic evaluation (paper I). Furthermore, we found that patients assessed in Norwegian primary health care had more severe symptoms of cognitive impairment, functional limitations, and BPSD, in addition to being older and more often living alone, compared to people assessed in specialist health care. We also found that depression in people assessed for cognitive impairment was associated with female gender, older age, more severe cognitive impairments, higher caregiver burden, and being assessed in primary health care (paper II). Finally, we found that unmet needs for daytime activities and for company were associated with higher scores on the NPI-Q affective and psychotic sub-syndromes (paper III).

In this discussion, we discuss why a timely diagnosis is important, the value of self- and proxy-given information, and how one can identify who should undergo a diagnostic evaluation. Furthermore, we discuss the characteristics and symptoms of patients diagnosed in primary and in specialist health care, the difference between these two groups, and some implications of these findings. We also discuss unmet needs, especially in the areas of daytime activities and company, along with related matters. Finally, we discuss the advantages and disadvantages of the Norwegian model for diagnostic evaluation and treatment, advice, support, and services in relation to the findings of the three papers of this thesis. In this discussion, we focus on the clinical relevance of our findings. Rather than including all the issues discussed in the papers, we primarily focus on topics related to more than one of the studies. We also include some relevant studies which were published in the years after our papers.

4.1.1. Detecting people who need diagnostic evaluation

Why is diagnosing dementia important?

For home-dwelling people with dementia, treatment, advice, support, and services are important to improving their daily life and giving good care when needed. A natural first step in the process of accessing appropriate services is defining the cause of the changes the person is experiencing, their symptoms, and their activity limitations.

Undiagnosed dementia is common in Norway and in other countries, and it represents a barrier to receiving appropriate support and services. In high-income countries, only 20–50% of those with dementia have a dementia diagnosis recorded in their primary care medical journal, and this number

is even lower in low-income countries [4, 137]. In a Norwegian study of 1000 older people who received domiciliary care, the researchers assessed all collected data about the participants and found that 415 of them (41.5%) had dementia according to the ICD-10 criteria. Of these participants, only 19.5% had a dementia diagnosis that was known to the people themselves, their caregiver, or health workers in the domiciliary care service [229]. Even in nursing homes, many people with dementia are undiagnosed: in a study by Røen and colleagues assessing 696 patients upon admission to a nursing home, 84% of the participants had dementia, but only 56% of those with dementia had been diagnosed [89].

An evaluation and a determination of whether experienced symptoms are caused by a dementia disorder is important for several reasons:

- Other potentially treatable or reversible conditions—such as delirium, sensory impairment, depression, normal pressure hydrocephalus, or medicines associated with increased anticholinergic burden—can be identified or ruled out [4, 90, 136].
- Future medical treatment and follow-up can be guided, adverse effects of medication can be avoided, and additional support to handle multimorbidity can be provided.
- A diagnosis may help the person with dementia and their caregivers understand the symptoms they are experiencing, and they may learn about dementia, achieve a sense of empowerment, and start future care planning.
- Medical treatment with cholinesterase inhibitors may be introduced and potentially have symptomatic effects on cognitive function.
- A diagnosis is often a gate-opener to treatment, advice, support, and services.

It is often stated that a dementia diagnosis should be made as early as possible, preferably at the time the diagnostic criteria are met [137]. This is based on the assumptions that drug treatments, psychological and psychosocial interventions, and support for caregivers may be more effective if initiated early, resulting in increased quality of life for people with dementia and their caregivers—and possibly also saved costs, by potentially delaying institutionalisation. With an early diagnosis, people with dementia and their families may be better able to plan and make important decisions for the future [34, 137].

Sometimes the patient and the relatives are not prepared to be diagnosed with dementia early, and a modification of early diagnosis is 'timely diagnosis', which is defined by the INTERDEM group (a pan-European network of experts) as the time when the patient or caregiver and the primary care physician recognise that a dementia syndrome may be developing [137].

Although early dementia diagnosis has been emphasised and supported by many stakeholders, including user representatives in Alzheimer's associations [137], the time at which the diagnosis feels 'timely' for a person may vary. Some people may prefer to not know about such a serious diagnosis and may feel that their quality of life would be better if they did not know. However, in a study of 50 patients with mild dementia and their caregivers, 92% of the patients answered that they wished to be informed of their diagnosis, and 98% of the caregivers said that they would wish to be told if they were to develop dementia [230]. It should be noted that in the same study (2003), 26% of the caregivers did not want the dementia diagnosis to be disclosed to the patient. Although the general approach tends towards early diagnosis, evidence is lacking with regard to the positive and negative impacts of receiving a dementia diagnosis and whether it should be diagnosed at an earlier or later stage [231].

Case-finding

Generally, screening whole populations for cognitive impairment is not considered to be cost-effective, but a proactive approach to identify people who may begin to exhibit symptoms of

dementia (i.e., case-finding) could promote case detection [137]. Several tools are available for use in case-finding when cognitive impairment is suspected. Such case-finding tools should be easy to administer, with questions regarding everyday life which are easy to relate to. In paper I, we reported a validation study of the Norwegian version of the CFI. We found that this instrument has the power to discriminate between people with dementia and people with MCI, people with SCI, and people without cognitive impairment. We suggested that this instrument could be used to identify people who should undergo a diagnostic evaluation of cognitive impairment, when they or a next of kin notice symptoms which make them concerned.

We found that the CFI questions are phrased in a simple and non-threatening way, and they address common symptoms of cognitive impairment and dementia. The choice of answers is also easy to understand (limited to 'yes', 'no', 'maybe'). Several of the questions address changes related to activity performance, such as new limitations in managing money, work performance, using household appliances, and social participation. Emerging of such IADL limitations have been found to be early signs of cognitive impairment [100, 108, 112], and as the ICF model describes, there is a mutual relationship between impairments in cognitive functions and activity limitations [12]. The phrasing of questions related to well-known IADL might be one of the CFI's strengths, as it might be easier to pinpoint ADL limitations than to, for example, judge how much one's memory has declined. Clinicians who have used the CFI have given us the feedback that it gives a good starting point for talking to people about changes in cognition and functioning and about how the people with dementia themselves perceive these changes/symptoms.

By using a case-detection instrument related to everyday life (such as the CFI), people may understand which changes or limitations should cause concern. If a person is worried about their own or a relative's cognitive changes, the case-finding tool may be instructive in terms of what signs to look for, and the CFI is a practical tool to address their suspicions. It can also be introduced to patients and caregivers by GPs who suspect cognitive impairment in their patients, and it can be used by health care personnel in primary care services who suspect cognitive impairment in their service users. The instrument could be made available to older people at senior centres, pharmacies, or GP offices, and it could also be made commonly available and promoted to the public via relevant websites, newspapers, or information campaigns. The Norwegian version of the CFI is freely available for non-commercial use via Ageing & Health's website [232, 233], and it has been promoted by Ageing & Health to the public at *Arendalsuka*, a large gathering for civic engagement through debate and meetings with political leaders, business leaders, entrepreneurs, governmental organisations, media, and NGO's.

Who to select for diagnostic evaluation?

By filling in the CFI, people can document their symptoms and worries for their GP. In cases where the CFI sum score indicates objective cognitive impairment, the GP can consider whether a diagnostic evaluation should be initiated or if the symptoms could be explained by other factors and the diagnostic evaluation should wait.

In the original longitudinal United States validation study, the objective was to track early changes in cognitive function in older individuals who did not have clinical cognitive impairment at baseline [146]. In our validation study, we explored whether the CFI could be useful in a later stage of the progression of cognitive impairment to discriminate between people with dementia and people without dementia. In Norwegian primary health care, the focus is usually on discrimination at this stage; diagnosing dementia rather than MCI or SCI. Diagnosing SCI and MCI requires an extended evaluation and is primarily performed in specialist health care. With the proportion of undiagnosed

dementia remaining high, separating dementia from MCI/ SCI/cognitively healthy is still the main ambition in primary health care. However, people with scores on the CFI below the cut-offs and where they or their relatives are concerned about cognitive functioning, should receive guidance and be closely followed by the GP and the memory team. For instance, a plan should be made for a new evaluation from the GP and memory team at a later time, or the GP should consider referring the patient to a specialist health care outpatient clinic for an extended evaluation of their symptoms.

Self- vs. proxy-report

Another strength of the CFI is that it has a self-report version. To the best of our knowledge, no other validated Norwegian instruments that focus on early signs of dementia by addressing cognitive impairment and activity limitations allow for self-report. Proxy information is considered important in assessments of suspected cognitive impairment because relatives often notice changes in cognition and can describe them in comparison to previous functioning, whereas the patients may not always give correct information about their own symptoms [234]. However, self-report of symptoms is also valuable in these assessments. While it is true that in dementia of moderate or severe degree, insight may be a challenge in self-reporting of cognitive impairment—and therefore proxy information may be more reliable—it has been found that in earlier stages, self-report of impairments in cognitive functioning is reliable [170-172]. Other studies using the CFI suggest that the self-report version may be more accurate early in the progression and that accuracy of the proxy-report version improves with progression to cognitive impairment [146, 235].

A meta-analysis by Mitchell and colleagues, including both community and memory clinic-based samples of older adults, found that self-reported cognitive complaints were measured in a number of different ways, from one or a few questions to various scales [236]. The results of the meta-analysis indicated that people with subjective cognitive complaints, but no objective deficits, were twice as likely to develop dementia compared to people who did not report such cognitive complaints [236]. In a systematic review, Mendonça et al. found evidence that people with subjective cognitive complaints had an increased risk of progressing to objective cognitive impairment. However, since only a few people with subjective cognitive complaints actually progress to cognitive impairment, care should be taken to not overestimate the value of subjective cognitive complaints [237]. Mendonça et al. further found a higher risk of progression to cognitive impairment in people with complaints who were worried about their cognitive complaints, in people who reported impact of the cognitive complaints on ADL, and when the cognitive complaints were confirmed by a proxy [237]. In a cross-sectional study by Engedal and colleagues investigating 309 home-dwelling people aged 70 years and older who had participated in the Trøndelag Health Study (HUNT), an association was found between self-reported complaints about significant memory problems over the last five years and lower scores on the MMSE-NR3 and MoCA [238].

The role of the proxy, and whether the proxy lives with the person, may influence the accuracy of the proxy's information. In a recent study following 450 cognitively normal participants aged 75 years or older, conducting annual visits for 4 years, participants were in general found to be better at predicting future cognitive performance than their proxies [239]. This was especially true for participants who had non-spousal proxies. For participants with more cognitive symptoms, spousal proxies outperformed participants in recognising current cognitive performance [239].

In study I, people who were diagnosed with SCI scored themselves as having significantly more cognitive symptoms than their proxies did (median sum score 4.5 vs. 1.9). This group may have sought diagnostic evaluation because they were concerned. Since we do not have follow-up data on the people diagnosed with SCI, we cannot tell if their cognition did in fact decline, but Amariglio et al.

and Li et al. conducted longitudinal studies and found that higher scores on self-reported, proxy-reported, and a combination of the two versions were associated with clinical progression of cognitive decline [146, 235]. A recent study using the Italian version of the CFI in a one-year follow-up study of a cohort of healthy older adults found that the CFI scores correlated with other neuropsychological tests [240]. Both the self- and the proxy- reported CFIs at one-year follow-up correlated with the baseline CFIs, and the authors suggest that the Italian version of the CFI is suitable for tracking cognitive changes [240].

In our study, no significant difference was found between self-report and proxy-report in the MCI group, which may indicate that both self- and proxy-reports are valid for MCI. Furthermore, in our dementia group, the self-reported sum scores were significantly lower than the proxy-reported sum scores, and the proxy scores were found to have higher discriminatory power. Still, the people who were diagnosed with dementia scored themselves as having more cognitive impairment than people with SCI/MCI/no cognitive impairment scored themselves, indicating that the self-report does have some value. In our study, the CFI was filled in during the process of the diagnostic evaluation. One may assume that concern about cognitive changes had been growing prior to the diagnostic evaluations. One can then speculate that if, in these cases, the CFI had been used to guide who should undergo a diagnostic evaluation, the instrument may have been filled in months earlier, and there might have been a stronger association between the self- and proxy-reported versions, as well as a more reliable self-report. Our cut-off (5 or higher on the self-rated version and 7 or higher on the proxy-rated version), which discriminates between people with dementia and people without dementia, may then be somewhat high for use in case-finding, and slightly lower scores may indicate a reason to start a diagnostic evaluation of cognitive impairment. The cut-offs should not be the only factor to consider; rather, a flexible approach should be taken, bearing in mind the setting and the degree of concern, to ensure that people with dementia do not remain undiagnosed.

Self-report of cognitive symptoms may be less accurate than proxy-report, especially when dementia is moderate or severe in degree, due to reduced insight; however, proxy-report may also be inaccurate [241]. In our study, when we explored factors associated with CFI sum scores, caregiver burden as measured by RSS was significantly associated with caregivers' scoring of the CFI, and it contributed to the explained variance of the proxy-reported CFI. In paper II, in the analyses of factors associated with depression in people assessed for cognitive impairment, we found a similar result in the confounding effects of RSS on gender, living situation, IQCODE, and PSMS. Caregivers scored themselves as having a higher burden when the patient was male, living with the caregiver, had less education, more cognitive impairment/dementia, and more limitations in BADL. One explanation may be that greater cognitive impairment (in paper I) and more symptoms of depression (paper II) in the patient result in higher levels of caregiver burden; however, it may also be that caregivers who experience more burden report greater cognitive impairment and more symptoms of depression in the patient. A clinical implication of this is that comprehensiveness of diagnostic evaluations of people with suspected cognitive impairment is important. A diagnosis should be informed by medical and neurological evaluation, blood tests, structural imaging, cognitive tests, and evaluations of BPSD, in addition to proxy- and self-reported cognitive functioning and activity limitations. If a caregiver experiences high burden and also reports many symptoms in the patient, it is important to conduct thorough and comprehensive assessments, both to 'quality-check' the caregiver's information and to ensure individually tailored respite for the caregiver.

With the increasing emphasis on timely diagnosis of dementia, self-reported symptoms may be an increasingly valid source of information. Including questions about new limitations in complex IADL may contribute to the relevance and user-friendliness of instruments for use in case-finding. Using

non-threatening questions like those of the CFI may be perceived as less stigmatising and stressful, than case-detection conducted e.g., with cognitive testing. Our experience further suggests that instruments addressing self-report of functioning (e.g., the CFI) may also be useful in later stages of the disorder in terms of exploring the perspective of the person with dementia, the degree of association with the proxy-report, and as a starting point for talking with the person with dementia about the consequences of dementia.

4.1.2 What is important to know about people who have undergone diagnostic evaluations?

A description of symptoms and characteristics of people who have undergone a diagnostic evaluation is an important starting point for planning the provision of treatment, advice, support, and services. Thus, symptoms such as depression, agitation, and other BPSD, along with cognitive impairment, functional limitations, and demographic information such as living situation should be assessed. This is true on a group level –which treatment interventions, advice, support, and health- and care-services that should be available to the population depend on the needs of the population. This is also true on an individual level –which specific symptoms and limitations a person has, and the corresponding needs, should be considered. If the Norwegian model's division of where diagnostic evaluations are performed results in groups of patients with differences in characteristics, symptoms, and functioning, the patients may consequently have different needs for treatment, advice, support, and services, depending on the place of diagnostic evaluation.

In the Norwegian model, people under the age of 65 years, as well as people with complicated diagnostic evaluations, should be evaluated in the specialist health care system [2]. The former group, being younger, may have better physical functioning and health conditions than older patients. Furthermore, if they are diagnosed at an earlier stage of dementia, their symptoms, functioning, and corresponding needs could be quite different from those of people who have been diagnosed at a later stage of the disorder. When we investigated characteristics and symptoms in paper II, we found several differences between the groups: people diagnosed in primary health care were older, more often lived alone, had poorer cognition, had more ADL limitations, and showed more BPSD than people diagnosed in specialist health care. They were also more often diagnosed with dementia compared to people diagnosed in specialist health care, which is not surprising given that cognitive decline, activity limitations, and BPSD are the main indicators of dementia. The differences in characteristics and symptoms were not only related to age, as adjusting for age did not change the overall results.

The findings of study II may indicate that people with milder and more unspecific symptoms seem to be evaluated in specialist health care, and it is natural that these diagnostic conclusions are more seldom dementia. More severe symptoms (of cognitive impairment, activity limitations, and BPSD) seem to be evaluated in primary health care. The greater severity of the symptoms may make them easier to recognise as symptoms of dementia: as a result, these patients may not require the skills of a specialist health care physician for a diagnostic evaluation. On the other hand, the severity of the symptoms may indicate that these patients need health care at the specialist level. We elaborate more on this in chapter 4.1.4.

For providers of treatment, advice, support, and services to home-dwelling people with dementia, knowledge of the symptoms and functioning in both these groups may be helpful in the planning of support and services in the municipalities. Our findings of more ADL limitations and more BPSD (including depression) in the primary health care cohort is worth noting. An emphasis on BPSD in assessment of and support-planning for this group, along with interventions to improve everyday

functioning, may be beneficial. Targeting these symptoms and limitations through primary care interventions may potentially relieve BPSD, promote independence in ADL, and improve quality of life for home-dwelling people with dementia, as well as reduce caregivers' burden and improve quality of life for informal caregivers.

The differences we found between people diagnosed in primary health care and those diagnosed in specialist health care were present at the time of the diagnostic evaluation and are likely to be related to the fact that those in the primary health care cohort were diagnosed at a later stage of dementia. Despite fewer or less severe symptoms in the specialist health care cohort, service providers in primary care should be aware of the symptoms and activity limitations present in this group. We found that people diagnosed in specialist geriatric and old-age psychiatry clinics had the same median score on the IADL scale as those diagnosed in primary health care, although the interquartile range indicated higher scores and better functioning in people diagnosed in specialist geriatric and old-age psychiatry clinics. Patients diagnosed in specialist health care had lower scores on the NPI-Q as a group, but nevertheless, individual BPSD should not be overseen in this group. We did not find differences in caregiver burden between the people diagnosed in primary health care and those diagnosed in specialist geriatric and old-age psychiatry clinics, which indicates that service providers should be aware of perceived burden in caregivers regardless of place of diagnostic evaluation.

4.1.3 Needs in people with dementia

In paper II, we found more severe symptoms and poorer functioning in the primary health care cohort, which may consequently indicate more/greater needs for treatment, advice, support, and services in this group than in the specialist health care group. However, needs are not only related to symptoms and functioning but also to personal factors and existing support, as needs may be met by, e.g., informal caregivers. One person can have several ADL limitations but no unmet needs, whereas another person with fewer ADL limitations can have several unmet needs. Therefore, in needs assessment, a broader approach is advisable, wherein not only functioning and symptoms are considered but also the factors described in the ICF model as contextual factors: personal factors, such as age, education, preferences; and environmental factors, such as social network or stigma. In paper II, we found that the contextual factors of older age and living alone were more prevalent in the primary health care group and that depression was associated with older age and female gender. In the CANE instrument (used to measure needs in paper III), needs in each area are described as no need, met need, or unmet need, and informal help is also recorded [186]. Informal help is a contextual environmental factor, and access to such help may contribute to one's present needs being met rather than unmet; the latter being the main concern in the provision of treatment, advice, support, and services.

Needs should be assessed through both self- and proxy-reported information. As we argue in paper I, self-report from people with dementia might be influenced by the person's (lack of) insight, but it is nevertheless important. One may consider the reporting of needs to be less influenced by insight than the reporting of, e.g., symptoms or changes in cognitive function. At the same time, needs reporting also depends on personal contextual factors, such as personality and expectations.

Assessing and targeting unmet needs

The needs of people with dementia should be assessed as part of the planning of treatment, advice, support, and services and then regularly throughout the course of the disorder, in order to identify unmet needs, to adjust the services and support provided accordingly, and to evaluate whether the

support and services being received contribute sufficiently to meeting unmet needs. These regular needs assessments should rely on the person with dementia and what matters to them, together with reports from both informal and formal caregivers. Informal caregivers of people with dementia often have their own needs related to their caregiving role; therefore, assessing informal caregivers' needs is also important, and two areas of the CANE are directed towards informal caregivers [186].

Using a combination of self- and proxy-reports when assessing needs in people with dementia might be a good approach, as described earlier in relation to the CFI. In the Actifcare study, where the data for paper III was collected, the CANE was used in separate interviews with the person with dementia and with the caregiver. After these interviews, the researchers completed a third version of the CANE, drawing on the two first interviews and adding all other information obtained by the researchers during the extensive assessment for the case report forms. This could include information received from the person with dementia or from the proxy during interviews regarding e.g., use of services, quality of life, or ADL.

The focus on needs in planning treatment, advice, support, and services is a way to ensure a person-centred approach in the individual tailoring of support and services. No service that suits all people with dementia exists; rather, individual solutions must be created. In paper II, we found that people who were diagnosed in primary health care had more symptoms (of cognitive impairment, activity limitations, and BPSD), and in chapter 4.1.2 we argue that targeting primary care interventions towards these symptoms and limitations is important. This builds on an assumption that symptoms may have corresponding unmet needs.

Unmet needs are widely considered to be contributing factors to BPSD [8, 79], and in paper III we investigated whether unmet needs in two specific areas were associated with BPSD. The areas we chose were daytime activities and company, and we found significant associations between unmet needs in both these areas and higher scores on the NPI-Q affective and psychotic sub-syndromes. These areas of unmet needs were not randomly selected: studies investigating unmet needs in home-dwelling people with dementia have found that daytime activities and contact are two of the most frequently reported areas of unmet needs [9, 10, 191].

In a recent review (2021) addressing the complexity of needs of dependent older people (60 years or older), with and without dementia, the number of unmet needs were found to be higher in institutionalised people than in home-dwelling people [242]. For home-dwelling people, participants with mild to moderate dementia had a higher mean of unmet needs than participants without cognitive impairment, and unmet needs were most frequently found in the areas of company, daytime activities, and psychological distress [242]. A lack of agreement was found between reports from the participant and reports from their proxy, in that informal caregivers reported higher levels of total needs. The factor most frequently found to be associated with a high number of unmet needs was depressive symptoms in the participant [242].

In paper III, we reflect on the possible mechanisms of the associations between unmet needs for daytime activities and company, and psychotic and affective symptoms. Psychotic symptoms may lead to loss of motivation and withdrawal from social interactions and activities, or unmet needs may contribute to psychotic symptoms in people with dementia. The affective sub-syndrome includes apathy, depression, and anxiety; people with these symptoms may take less initiative in engaging in social contact and activities, and thus these symptoms may lead to unmet needs for daytime activities and company. Alternatively, unmet needs for daytime activity and company may lead to the affective symptoms. The mechanism could also work in both directions, as a downward spiral.

Participation in enjoyable and meaningful activities may create positive feelings, and the absence of such activities may maintain or intensify depressive feelings [96]. The primary health care patients in paper II had more severe symptoms of cognitive impairment, functional limitations, and BPSD compared to the specialist health care patients. One of the variables we found to be associated with depression was greater cognitive decline in comparison to 10 years earlier, as measured by IQCODE. As with the CFI, several IQCODE items describe decline in cognition by addressing decline in IADL functioning; hence, the cognitive decline described in the measure may be related to ADL limitations. ADL limitations might be a contributing factor to the depressive/affective symptoms in the primary health care group in study II, as the participants may be less able to meet their own needs for pleasant daytime activities and social life as a result of their impairments. Furthermore, poorer functioning may lead to feelings of dependency, loss of autonomy, and perhaps decreased feelings of self-worth.

In his care philosophy, Tom Kitwood (1997) described basic psychological needs for occupation, inclusion, attachment, identity, and comfort, which may elucidate the negative consequences of unmet needs for daytime activities and company for people with dementia [80](p 83). Fulfilling people's needs for daytime activities and company may potentially serve to meet several of these basic psychological needs. In occupational science, humans are described as 'occupational beings' who interact with the environment through occupations [192, 193]. Losing activities through ADL limitations not only interferes with a person's independence, but the loss of these occupations affects the person's fundamental psychological needs [196].

The needs for daytime activities and company are both considered to be social needs. Given that unmet needs in these areas affect psychological well-being, the association with BPSD is not surprising. During the COVID-19 pandemic, people have been subject to social isolation due to lockdown periods, and many of us have felt deprived of something essential in our lives with this restriction of access to our preferred activities and to our friends and family. Studies on social isolation measures enforced during the pandemic have found that these measures have resulted in manifestations and/or worsening of BPSD in older adults, both with and without dementia [204, 205].

People with dementia often have co-occurring cognitive impairment and activity limitations, and they often also have depressive symptoms. This often-overlapping triad of late-life depression, cognitive impairment, and disability is complex, as depression may promote disability, disability may foster depression, and cognitive impairment complicates this relationship by influencing both depression and disability [243]. This triad contributes to negative health outcomes, such as increased morbidity and mortality, decreased quality of life, and greater impairment in social and interpersonal functioning [243]. These mechanisms may be involved in the association we found in paper III between affective symptoms and unmet needs for daytime activities and company. Targeting the triad of late-life depression, cognitive impairment, and disability when treating depression in people with cognitive impairment may provide synergetic effects, by helping people adapt and cope with life [243]. Interventions such as individual goal-oriented cognitive rehabilitation, which targets individual goals in therapy [131], may be useful. A moderate level of evidence has been found that group cognitive stimulation therapy (CST) can improve quality of life in people with dementia [97]. Several other interventions for people with dementia are directed towards daytime activities and company, and these areas are important components of many psychosocial interventions.

In paper II, we found that people diagnosed in primary health care had more BPSD, which—in light of our findings in paper III—may indicate that they have more unmet needs. One implication is that evaluating needs in people diagnosed in primary health care is important. The fewer symptoms and activity limitations we found in people diagnosed in specialist health care may indicate that they have

fewer needs; however, unmet needs are not only related to the severity of symptoms, and it might be that this group simply has different needs than those diagnosed in primary health care. If the specialist health care cohort was in fact diagnosed earlier in the progression of their dementia, their needs at the time of evaluation may be more in the areas of advice, education, and emotional support than in personal assistance. Therefore, needs assessments are important in all stages of dementia, including for people recently diagnosed in specialist health care.

Although formal community dementia services strive to meet unmet needs in people with dementia by providing treatment, advice, support, and services, people might still report unmet needs. It has been found that people who receive professional support for daytime activities still report unmet needs in this area [9]. In the Actifcare study, the Norwegian participants reported overall higher levels of unmet needs compared to e.g., those in Italy and Portugal [188] (Table 1), even though Norway has a system of several formal care services in place for people with dementia. It is uncertain whether any health care system can meet all the needs of their citizens with dementia. Several factors could be involved in the reporting of unmet needs, such as expectations about which type of support and services should be available, or type and amount of support provided by informal caregivers. The provision of treatment, advice, support, and services should be informed by a broad assessment of needs and of whether they are met or unmet.

4.1.4 The Norwegian model

The Norwegian model for diagnostic evaluation and support of home-dwelling people with dementia (described in chapter 2.8) was an initiative to deal with the medical and social challenges associated with dementia disorders [5]. Multidisciplinary memory teams in municipalities assist GPs in the diagnostic evaluation of people with suspected dementia and ensure that treatment, advice, support, and services are offered; these may be helpful in ensuring timely diagnosis and individually tailored support for the growing number of people with dementia in Norway. This model has its merits and its drawbacks, and we will discuss our findings in relation to the model. We will address both the advantages and disadvantages, although our positive attitude towards the model is evident: with first-hand experience of the positive sides of the model through our cooperation with Norwegian municipalities, we are more likely to praise the model than to criticise it.

People with suspected dementia should be evaluated by a clinician with appropriate specialist expertise [231]. The main argument against assigning this responsibility to the primary health care and the GPs is that the expertise to diagnose dementia may be less developed in this part of the health care system than in specialist health care. Because general medicine is a broad field, GPs are not specialists in neurodegenerative disorders, and each GP may only handle a few patients with suspected dementia per year. Furthermore, GPs usually have less access to colleagues with whom to discuss complicated patients. Consequently, GPs' lack of specific education and expertise in dementia may lead to missed, delayed, or less-accurate diagnosis [244].

The Norwegian health authorities seek to strengthen GPs' expertise in diagnosing dementia and have launched an information campaign directed at GPs and other health care personnel about the importance of diagnosing dementia. In addition, the Norwegian Medical Association offers courses in dementia evaluation as part of their educational programs for specialising in several disciplines.

In paper II, 52 (23%) of the patients from primary health care had not received a diagnosis from their GP at the time of the data collection. While 23% is a high number and could indicate inconclusiveness regarding diagnosis in too many cases, we cannot simply assume that these patients were not

diagnosed. Like physicians in specialist health care, GPs may have found it too early to conclude and may have wanted to re-evaluate later. Furthermore, some of these cases may have been more complicated than first assumed, at which point the GP would seek supervision from specialist health care or refer the patient to an evaluation at the specialist health care level. This is often done in Norway and is in accordance with the recommendations. Since we lacked clinical diagnoses from these 52 participants from primary health care, in the analyses for paper II we used research diagnoses for all primary care participants as determined by two experienced psychiatrists in consensus based on all available information (which excluded diagnosis by GP). For the participants who did receive diagnoses from their GPs, agreement with the research diagnoses was found in 144 (82%) of the cases.

A clear disadvantage of primary care diagnostic evaluation is that the ICPC-2 diagnostic criteria used at this level does not identify aetiological diagnosis and therefore does not differentiate between dementia disorders. Knowledge of the underlying disease is important to taking precautions around medical treatment, considering new and reviewing current pharmacological treatment, and preparing for challenges that may arise [34]. To encourage the identification of the underlying aetiological disease, descriptions of the most common dementia diseases are provided in the basic diagnostic evaluation tool, and GPs are encouraged to identify aetiological disease [141].

Another disadvantage of primary care diagnostic evaluations is that they seldom include such examinations as spinal puncture (to identify markers for AD), FDG-PET scan, or more advanced biological markers. Such examinations are helpful in evaluating early signs of cognitive impairment and in identifying aetiological disease in complicated cases, and not having access to them in primary health care strengthens the argument that complicated cases should be referred to specialist health care.

It has been argued that particularly in mild dementia, where the diagnosis is more complex, diagnostic evaluations requires specialist expertise [231]. The Norwegian model does not assign all dementia assessments to primary health care: people under the age of 65 years and people with complex evaluations (e.g., mild dementia), as well as evaluations of people with Sami background, minority ethnic background, and intellectual disabilities, should be referred for diagnostic evaluation in specialist health care [2]. This leaves the less complicated cases to GPs. In paper II, we found that the patients evaluated in primary health care had more symptoms of cognitive impairment, more activity limitations, and more BPSD. This may indicate that they represent clearer cases of dementia and are easy for GPs to diagnose; however, it may also indicate that they have complex and complicated conditions and/or symptoms which are difficult to separate and interpret and which require evaluation or interventions at the specialist health care level. We did not have access to data regarding comorbidity, which may have potentially addressed this question. It is important to emphasise that the Norwegian model should not be used as an excuse to exclude older adults from admittance to specialist health care services when they require them.

The memory teams are multidisciplinary dementia resource teams in the municipalities who assist the GPs with the assessments as part of the diagnostic evaluation. The rationale for such a team is that it is a resource for the GP, both in terms of having knowledge about and experience in dementia assessment and support and in that they conduct assessments of people with symptoms of dementia upon the GP's referral. The teams also ensure that people with dementia and their family carers receive treatment, advice, support, and services as needed throughout the course of the disorder. Establishing memory teams is a strong recommendation in the Norwegian national guideline on dementia [2], and in 2018, 90% of Norwegian municipalities had a memory team and/or a dementia coordinator [1].

The recommendation states that the team personnel should have competence in the area of dementia. Health care personnel who work in the memory teams are typically experienced nurses, occupational therapists, social educators, and nursing assistants who have additional education in dementia and dementia care. With dementia as their main area of work, the teams are often highly skilled and well-experienced in assessing dementia and providing support for people with dementia, and thus they constitute a valuable resource for GPs. Furthermore, most of the teams are multidisciplinary, which enables them to take a broad approach in their work of assessments and support. With access to this type of assistance, diagnostic evaluations may be more easily and reliably performed by the GP than if the GP were the only one involved in the evaluation. Although 90% of Norwegian municipalities have reported having a memory team and/or a dementia coordinator [1], the time the team members have set aside for the work varies, from no time or hardly any time at all in smaller municipalities to several full-time positions in larger municipalities [214]. Furthermore, organising a memory team in the municipality is a strong recommendation [2] but is not mandatory. Municipalities may, and sometimes do, cut down on their memory team's resources when money is tight, making this a somewhat vulnerable service.

Case-finding and diagnostic evaluations

Everyone who is resident in a Norwegian municipality is entitled to a regular GP, and GPs play a crucial role in Norwegian health care. Even when diagnostic evaluations are performed in specialist health care, the GP still has to recognise dementia symptoms and make a referral to specialist health care for a diagnostic evaluation. When the GP has experience with evaluating dementia symptoms, as in the Norwegian model, they can more easily pick up symptoms of concern, and more people with cognitive impairment may be detected. GPs who suspect cognitive impairment based on previous knowledge of their patients could use the CFI to help decide whether they should initiate a diagnostic evaluation. A GP skilled in dementia and assessing dementia symptoms may also be in a good position to competently guide patients or proxies who have filled in a CFI, address the results of the CFI (or other screening or concern), and decide whether to start a diagnostic evaluation or give advice to wait and see. If the GP decides that a diagnostic evaluation should be initiated, and the recommendation in the Norwegian national guideline on dementia is that this evaluation should be performed in primary health care, the GP's previous knowledge of the patient and their medical history, the trust that has often been built over years, and their knowledge about different circumstances concerning the patient are all advantages in diagnostic evaluation.

The memory teams usually conduct their assessments as part of the diagnostic evaluations of home-dwelling people during home visits. This offers several opportunities to observe the patient and their functioning at home. At an in-home assessment, safety concerns may be identified, along with environmental barriers to functioning and additional assessment data that may not be shared in more formal clinical settings, such as living conditions, concerns related to caring for pets, and taking of medications [50]. Observations may provide important information about cognitive functioning and activity limitations that supplements cognitive tests and ADL questionnaires. Although some specialist health care outpatient clinics in Norway include observations of the patients performing activities in their diagnostic evaluations, the surroundings will be unfamiliar to the patient, and one's own home usually offers a better variety of activities that are relevant to the person.

It is often less stressful for the patient to have assessments (such as cognitive tests) conducted in a familiar environment, like their own home. One may argue that sometimes a certain amount of stress is desired, to evaluate how the patient performs under pressure, but usually the goal is that the patient performs at their best during a cognitive test. Travel distance to specialist health care is also considerable in many areas in Norway, and this may add stress and burden to the situation of

being evaluated. Evaluations conducted in a GP's office in combination with home visits may also be less demanding for the patient, since everything does not happen in one long session. Several home-visits can be conducted for one patient, and the assessment can be part of a process wherein trust is built and health care personnel gain a position to make valid and user-friendly assessments.

In paper II, we assume that the more severe symptoms in the primary health care cohort indicate that they have been diagnosed at a later stage in the progression of dementia, compared to the cohort diagnosed in specialist health care. This could be a sign of a weakness of the Norwegian model: that people diagnosed in primary health care are diagnosed too late. If we compare our primary health care participants to patients described in a study comparing AD patients diagnosed in memory clinics across Europe [245], our primary health care cohort had higher MMSE scores than the participants in the study by Hausner and colleagues. In their study, mean MMSE score varied between 19.8 and 21.6 depending on region, whereas our primary care cohort had a median MMSE score of 22 (our specialist health care cohort had a median MMSE score of 25). Nevertheless, an MMSE median score of 22 constitutes a considerable cognitive impairment, and our ambition should be to diagnose people with dementia at an earlier stage, including in primary health care.

The differences between the primary and specialist health care participants in study II may be considered as a sign of a large degree of adherence to the Norwegian national guideline on dementia regarding where diagnostic evaluations should be performed. The milder cases and the largest proportion of those who are diagnosed with SCI and MCI seem to have been evaluated in specialist health care, and those with more severe and 'obvious' symptoms of dementia seem to have been evaluated in primary health care. However, this difference is on a group level. Differences in the demographic characteristics of patients have been found between Norwegian memory clinics and geriatric- and old-age psychiatry clinics, as the latter also assess patients with other diseases [223]. Therefore, in study II, we compared the primary care cohort separately to the memory clinic patients and to the patients diagnosed in geriatric or old-age psychiatry outpatient clinics.

Adherence to the guideline regarding place of assessment may have improved over the past years. This could be related to improved competency in GPs and/or that several specialist health care outpatient clinics no longer accept referrals for patients they believe may be just as effectively evaluated in primary health care.

The guideline may not be the only determinant of where diagnostic evaluations are performed, and various underlying factors may influence who is referred to specialist health care for a diagnostic evaluation of suspected dementia. These could include contextual factors related to personality or ways of coping, or to the patients' own or caregivers' wish for such a referral, or to geographic location/availability of specialist health care, or to the individual GP's confidence in assessing symptoms of cognitive impairment. In paper II, the primary care cohort had fewer years of education (even after adjusting for age) and a larger proportion of them lived alone (even after adjusting for age), which may indicate that education and living with a caregiver somehow promotes referral to specialist health care.

Treatment, advice, support, and services

When the same memory team that assists in the diagnostic evaluation is responsible for providing treatment, advice, support, and services, no transition of care is involved: information about symptoms and needs do not have to be passed on to other health care personnel in a different part of the health care system. Alliances and trust can start to be built in the assessment process; unmet needs may be discovered as part of the diagnostic evaluation; and symptom progression may be monitored alongside needs assessment and reassessment. The GP may also be in a better position to

guide the patient after the diagnosis when the GP has taken part in the assessment process and was the one to conclude on the diagnosis.

On the other hand, when the same part of the health care system assesses symptoms and unmet needs and is responsible for the services to meet the needs, caution should be taken that provision of services is in fact based on the patients' needs and not on available services. It is possible that if a service is unavailable, such as respite or support groups, the health care personnel assessing needs may not include assessment for needs related to these services and may focus only on the needs for which they have services.

When the Norwegian memory teams assess needs, they already have first-hand knowledge about symptoms of cognitive impairment and activity limitations, which they can bear in mind during their needs assessment. Common unmet needs, such as daytime activities and company, may be identified early - during, or soon after the diagnostic process. Given the association we found in paper III between these common unmet needs and affective and psychotic symptoms, meeting these needs with timely provision of relevant services (such as day activity services) may help reduce BPSD.

The patients diagnosed in Norwegian primary care had more severe symptoms, as described in paper II. This may have made it easier to diagnose them, and their support and service needs may well be provided for by home care services. However, the severity of the symptoms may also indicate a need for geriatric follow-up which could require specialist health care interventions or supervision of the primary health care by specialist health care. This could be the case for some of the primary health care participants of study II with severe BPSD. Furthermore, comorbidity in older adults with cognitive impairment is common, and it may require special attention. When the main responsibility for diagnosing people above the age of 65 years with symptoms of cognitive impairment is assigned to primary health care, there is a risk that people who need evaluations and interventions from specialist health care are excluded from getting them. Caution should be taken to ensure that all patients with symptoms of cognitive impairment, regardless of age, have access to evaluations and interventions/treatment in specialist health care, and the possibility for supervision from specialist health care should be utilised when required.

In paper II, we found more severe symptoms of cognitive impairment, functional limitations, and BPSD in patients diagnosed in the primary health care. The memory teams who are involved in the assessment process in the diagnostic evaluation know about the patients' characteristics and symptoms. In addition, they know what the ICF model calls contextual factors: such as the patient's physical home environment, their social network and how they may contribute, and their habits, routines, and preferences.

Many examples can be found of interventions and services that target BPSD, and the choice from among them depends on factors related to the person, the caregiver, and the environment. Kales and colleagues (2015) describe the following five domains of generalised strategies to target BPSD as 'low-hanging fruit' in support and services [58], with the latter two strategies potentially also promoting independence in ADL:

- Providing education for the caregiver
- Enhancing effective communication between the caregiver and the person with dementia
- Creating meaningful activities for the person with dementia
- Simplifying tasks and establishing structured routines in everyday life
- Ensuring safety and simplifying and adapting the environment

The NICE guideline on dementia and the Norwegian national guideline on dementia recommend that people diagnosed with dementia should be provided with a case manager—a named key contact person who acts as a care coordinator and e.g., provides information and develops a care and support plan [2, 90]. The Norwegian health authorities have recognised the need to focus on supporting, advising, and treating people diagnosed with dementia; such support is addressed in several of the strategies of the Norwegian Dementia Plans 2020 [246] and 2025 [218] as well as in the quality reform *A full life – all your life* [203].

Individual goal-oriented cognitive rehabilitation has been found to be effective in enabling people with early- to moderate-stage dementia to improve their everyday functioning related to their own goals [131]. Group CST has been found to improve cognition in people with mild to moderate dementia, especially in the cognitive domain of language [4, 97, 247], and it may also improve quality of life in people with dementia [97].

Interventions promoting activities and company may be offered as low-threshold services; and even if tailoring and facilitating activities to people with dementia requires a degree of competence, these interventions are not excessively complicated. In Norway, several approaches have been taken in recent years targeting activity and company. Examples are interventions introduced by:

- Policymakers, such as the obligation of Norwegian local authorities to offer day activity services to home-dwelling people with dementia, and strategies described in the Norwegian Quality Reform for Older Persons, titled *A full life – all your life* [203].
- User organisations, such as the 'activity-friend' project and the initiative for a dementia-friendly society from the Norwegian Health Association, and the visiting service of the Norwegian Red Cross.

People diagnosed in specialist health care are described in paper II with fewer or milder symptoms of cognitive impairment, activity limitations, and BPSD. Those with a dementia diagnosis may benefit from timely diagnosis (as described in chapter 4.1.1), with an early start for drug treatments, psychological interventions, and psychosocial interventions. This may prepare them for the changes to come and help them live well with dementia for several years. Although this group may not need personal assistance at the time of the diagnostic evaluation, this does not mean they do not need home-based services. Several specialist health care services provide support and advice, such as education about dementia, and they often introduce and monitor medical treatment when relevant. Still, in the Norwegian system, the bulk of treatment, advice, support, and services for people with dementia is provided by the primary health care. Therefore, patients diagnosed in specialist health care need a smooth transition to primary care services. If they have been diagnosed early, they may not feel that they need to be in touch with primary health care and may consequently decline a referral to a memory team in primary health care. However, as the dementia progresses, they will most likely experience unmet needs; at that point, they may not know how to access primary care treatment, advice, support, and services. A case manager (key contact person) is beneficial in all stages of dementia [137]. As the dementia progresses in people diagnosed in specialist health care, one may assume that they will develop more symptoms and activity limitations, increasingly resembling (symptom- and functioning-wise) the group diagnosed in primary health care, which we described in paper II.

A total of 14 municipalities participated in a project initiated during the Dementia Plan 2020, which focused on a systematic approach to providing post-diagnostic support to people diagnosed with dementia who did not yet need personal help. The participating municipalities suggested strategies to ensure a systematic approach, including good transitions from specialist to primary health care. One suggestion was that the specialist health care should routinely focus on motivating their patients

with dementia to accept contact with a key contact person. Another suggestion was that the key contact person should visit the patient shortly after the diagnosis in order to establish contact and begin to assess needs, followed by a structured approach with more visits during the next year. Yet another suggestion was that if the patient declines contact with a key contact person, the GP should act as the main point of contact until a key contact person is established [248].

People undergoing diagnostic evaluation of suspected dementia may already have care or service needs. Sometimes establishing a diagnosis takes time; however, interventions to target unmet needs do not need a diagnosis. When the memory teams participate in the diagnostic evaluation, they may detect unmet needs during their assessments and can initiate relevant treatment, advice, support, or services as soon as symptoms and/or needs are identified.

4.2 Methodological considerations

4.2.1 Study design

For the CFI validity study of paper I, we used the criteria for validity studies set out by Qizilbash et al. [220](pp18-19). Regarding criteria 1—applying an independent comparison with an acceptable reference standard—we found diagnosis to be a better reference standard for this study than e.g., a cognitive test, like MMSE, or a questionnaire similar to the CFI, like the IQCODE. We wanted to examine the discriminatory power of the CFI—mainly, to discriminate between people with dementia and people without dementia; since a diagnosis is determined based on set criteria and takes all information into consideration, we found it to be the best standard of reference. The physicians concluding on the diagnoses were blinded to the results of the CFIs.

Study II was an observational study; this methodology was chosen because we wanted to investigate the characteristics of people at the time point when they had undergone a diagnostic evaluation. For the primary health care cohort, we did not receive diagnoses for 23% of the participants. As it may take a while to conclude on a diagnosis, we approached the memory teams throughout the project about diagnoses that were missing, to ask if the GPs had concluded on a diagnosis; however, we were only able to do this while the project was ongoing, and so we may have missed diagnoses that were concluded after the project, especially for participants included towards the end of the project.

In study III, we used a longitudinal design, which enabled us to indicate that the associations we found did not change over time in the year we followed the participants. Data for paper III were collected as part of the Actifcare study, the aim of which was best-practice development in providing timely access to formal care for home-dwelling people with dementia and their informal caregivers. We found the collected longitudinal data on (unmet) needs and BPSD to be useful for our aim in paper III. Including data on the uptake of services directed at unmet needs for daytime activities and company would have strengthened our study, as we could have examined how this may influence BPSD and the reporting of unmet needs. Such data was collected for the Actifcare study, but during the one-year follow-up, only a small proportion of the participants received such services (e.g., day-care) that could potentially address activity and company: rather, it was more common for participants to receive help addressing other needs, such as those relating to personal care. Consequently, we did not have sufficient data to explore this issue. Had we designed study III as an independent study, the best approach may have been a randomised controlled trial (RCT). Such a design could have offered interventions directed at affective and psychotic symptoms to examine whether they had an effect on reported unmet needs, or it could have examined interventions directed at meeting unmet needs for daytime activity and company to see whether these had an effect on affective and psychotic symptoms. However, we found the Actifcare data to be a unique

source for paper III, because it contained data of interest for 451 participants in eight European countries.

4.2.2 Settings and participants

To obtain a broad range of participants, we included people from several different settings for all three studies, which resulted in data being collected by several different clinicians and researchers. This may represent a weakness, because different data collectors may do things differently. However, the clinicians and researchers collecting data for all the studies were experienced and had received training in data collection procedures and in using the measures. The patients in study I and all participants in study II were interviewed by experienced clinicians, which may have helped us obtain a large degree of complete data. For study III, data was primarily collected by researchers, and specific training was provided as part of the Actifcare project. The same researchers interviewed the participants at baseline and at both follow-ups. Study III was a European study, and although training for the researchers was provided, cultural differences may have arisen (e.g., in how BPSD are perceived by the participants, and in what types and extent of needs are reported as unmet). For instance, participants may report fewer needs to differing degrees, to maintain a sense of coping or control or because they think that loss of activities are a normal part of ageing. However, such differences are generally inevitable in international studies.

One of the inclusion criteria in the Actifcare study was an MMSE sum score of 24 or below. The Norwegian version of the MMSE (MMSE-NR3), which was in clinical use in Norway when it was included in the Actifcare study, is different from the international MMSE used by the other countries at that time. For example, backwords spelling of the word WORLD gave points as an alternative to counting backward from 100 by sevens in the international version but is not included in the MMSE-NR3. This may result in the Norwegian version being slightly more difficult, although this has not been studied. In agreement with the Actifcare project management, we altered the inclusion criteria for the Norwegian participants to be 22 points or lower on the MMSE-NR3.

Generalisability in terms of the selection of and the representativeness of the participants should be addressed for all three papers, as most of the samples can be called convenience samples. This limits our ability to claim that our findings are representative for the general population of people with cognitive impairment and dementia.

In study I, the patients were recruited from two memory clinics (one in a rural area and one in an urban area), which included a convenience sample of 95 patients and proxies, and from several memory teams, which recruited 81 participants and proxies. The memory teams were recruited at a large annual conference for Norwegian memory teams: a total of 14 memory teams volunteered to supply data by anonymously sending us filled in CFIs along with other variables for the analyses. They used the CFI for patients who had been referred to them by GPs for assistance in diagnostic evaluations. As this was conducted anonymously, we do not know which or even how many memory teams sent us data, and we assume that the memory teams used the CFI with a convenience sample of the patients they assessed. The reference group of 89 participants was also a convenience sample, who were recruited by advertisements in the local newspaper, senior centres, and various voluntary organisations as well as by recruiting home-dwelling older people who received in-home nursing health care services and did not have cognitive impairment.

Study II had two cohorts. The specialist health care cohort consisted of patients enrolled in the NorCog register and included all participants included by all the participating centres in 2011 and

2012. There may have been bias related to which centres were included in the NorCog registry at this time, and we do not have information on the proportion of patients included at each centre nor the rationale behind who they chose to include. The primary health care cohort was recruited by memory teams from a convenience sample of 33 (out of 428) Norwegian municipalities. We invited memory teams we knew were experienced and included those who accepted the invitations. Teams from rural and urban areas were included, as well as teams representing small, middle-sized, and large municipalities in all four Norwegian health regions. The teams were asked to include all the patients who were referred to them by a GP for assistance in diagnostic evaluation; for patients they did not include, they were asked to record the reason why the patient was not included. Very few patients or caregivers who were asked to participate refused, and several teams included all their patients from the project period; the main reason for not including a patient was not because of refusal but was defined as 'other'. These 'other' reasons were often related to the capacity of the memory teams (in addition to the instruments included in the basic evaluation tool, a few other instruments had to be used for included participants), issues regarding alliances and cooperation with the patient, or if the referral from the GP was not about a diagnostic evaluation. Although this was only a small proportion of the non-participants, it might be that these 'other' reasons were associated with the more complex cases, hence constituting a selection bias.

Participants for paper III were included through the Actifcare study. One of the inclusion criteria was that the participant should not have been receiving formal personal care related to dementia at the baseline but a health care professional should have estimated that they would require such care within one year. This estimation of need for assistance was based on available sources, such as psychologists, GPs, memory clinic staff members, and other health care or social care professionals, and it differed across the eight countries. In Norway, all participants were recruited with the help of the memory teams. These teams knew the people with dementia in their municipality quite well, having taken part in the diagnostic evaluation and having provided treatment, advice, support, and services for them for some time. As a result, the prediction of need for personal assistance in the near future was perhaps more accurate when participants were recruited through memory teams compared to recruitment through, e.g., advertisements in local and national newspapers.

4.2.3 Measures and analyses

The sources of information in our measures were mainly clinicians/researchers and proxies. Ideally, we should use self-reports when assessing people, but in practice, when assessing suspected cognitive impairment and dementia, we often end up using proxy- and clinician-based information given the doubt around the insight of the person being assessed. For the CANE assessment, we used the researchers' ratings in study III, which built on both self- and proxy-information in addition to all other information that was available to the researchers. In this sense, self-report is included but only considered as one part of a larger estimation. In paper I, we argue that self-reported information is to some extent reliable and should be used, and it is a weakness that we have not used more self-reported information in the subsequent papers. As described in chapter 4.1.1, proxy information also has its weaknesses, which should also be considered when interpreting the results.

Data for study II were largely variables which had already been collected as part of diagnostic evaluations. For the specialist health care cohort, no extra variables were added for the purpose of study, and for the primary health care cohort, a few extra variables were added. This is a practical approach which makes it easier to collect data, and it can be a good ethical choice as it avoids placing extra burden on the participants. However, our choice of measures in the studies should be based on our aim, not simply built on the variables we already have access to. In study II, we included the

Charlson Comorbidity Index for the primary health care participants, but in the NorCog battery used for the specialist health care participants, a different measure for reporting comorbidity—made especially for NorCog—was used. The latter is not comparable to Charlson Comorbidity Index, and thus we could not compare the comorbidity of the two cohorts, something which would have strengthened study II considerably.

As reported, in study II, data was missing on all proxy-based measures from 4% of the primary health care participants and from 10% of the specialist health care participants. The absence of all proxy-based measures may simply mean that these data were not entered to the data file; however, it may also mean that these participants had been diagnosed without the physician having access to proxy information, which is not recommended. If so, this lack of data may represent a bias. People who undergo a diagnostic evaluation without involving a relative or a friend as a proxy may be different from those who do involve a proxy. For example, they could have milder symptoms and therefore be considered as not needing proxy information; they could have refused the collection of proxy data about them; or they could lack contact with relatives and friends to such a degree that no one can act as a proxy. In the analyses comparing the participants of the two cohorts, we only adjusted for age, and all participants were included for the variables we did have data for, regardless of whether or not we had the proxy-reported variables (NPI-Q, CSDD, IQCODE, IADL, PSMS, and RSS). However, in the analyses to examine factors associated with depression, the dependent variable was the CSDD, which is proxy-reported, and participants that did not have proxy data could not be included in this analysis. This is a limitation, because this model then only represents the participants who involved a proxy in the diagnostic evaluation.

In papers II and III, we conducted principal component analyses (PCAs) of the NPI-Q to identify clusters of symptoms, which we then grouped into sub-syndromes. These PCAs should be, and were, conducted separately in the data files of each of the studies, and both PCAs resulted in the following three sub-syndromes: affective symptoms, agitation symptoms, and psychotic symptoms. As a result of using sub-syndromes, some of the individual variability in the symptoms may not be explained by the factors [72], and significant findings on single items might be 'lost' in the factor; for instance, significant hallucinations may not increase the sub-syndrome score for psychotic symptoms if there are no other psychotic symptoms. Furthermore, the statistically derived symptom groups may not always be clinically meaningful; however, we found our sub-syndromes to be clinically useful, and there were several advantages of using sub-syndromes in the analyses, such as fewer variables in the analyses and a wider scale for the NPI-Q sub-syndromes than the 0–3 points for a single item.

4.2.4 Diagnoses

For all the participants in study II and the patients from specialist health care in study I, ICD-10 criteria for research were used to diagnose dementia and the Winblad criteria were used to diagnose MCI. In studies I and II, the primary care participants did not have aetiological diagnoses, and thus we did not include these data from the specialist health care patients either. Aetiological diagnosis may potentially have added value to studies I and II, especially to study II. In study III, all participants had a dementia diagnosis, and 80% of the participants also had an aetiological diagnosis; thus, this variable was used as a covariate in the mixed models.

For studies I and II, the participants from primary health care were diagnosed by their GP using the ICPC-2 diagnostic criteria. The ICPC-2 criteria for dementia are less specific than the ICD-10, but given the relatively low MMSE scores of this cohort, the participants would most likely have been diagnosed with dementia according to the ICD-10 criteria as well. In order to have comparable

diagnoses for the analyses, two different approaches were used in the two studies. In study I, specialist health care participants were diagnosed with no dementia/SCI/MCI/dementia, while the primary health care participants were diagnosed with no dementia/P20 memory disturbance/P70 dementia. For the primary care participants, P70 was used to diagnose dementia and P20 was used to diagnose MCI. In study II, all primary care participants were assigned ICD-10 research diagnoses by two experienced psychiatrists operating in consensus. This approach was chosen rather than study I's approach using P70 and P20 diagnoses for dementia and MCI because 23% of the primary health care participants in study II were missing a diagnosis. This assignment of research diagnoses is a limitation because researchers can only base these diagnoses on the available data, and the valuable clinical impression of the GP/other clinician is 'lost' with this approach. The patients from specialist health care in study II all had ICD-10 diagnoses. When reviewing the data, we found discrepancies between the collected data and the clinical diagnosis for seven of the 1595 specialist health care participants, and these seven participants were removed from the dataset. No other quality check was conducted with the specialist health care diagnoses, which may also be a limitation, as several different physicians performed these diagnostic evaluations, and we cannot be sure that all diagnoses were determined with similar or comparable reasoning.

4.2.5 Theoretical framework

We used the ICF as a language and theoretical framework in this thesis to understand and describe the dynamic relationship between health conditions and functioning. The ICF was useful in the thesis in that it provided a multidisciplinary model and terminology to use in order to understand how health conditions and their associated changes in body structure and function affect functioning. A multidisciplinary approach to diagnostic evaluation and to the provision of treatment, advice, support, and services is recommended in the Norwegian national guideline on dementia [2], and health care professionals can relate to the ICF model and its terminology regardless of professional background.

The ICF (or question sets based on the ICF) has not been used in any of our studies, although this could have been useful. The use of the ICF for population-based, census, or survey data is recommended as a reference text or framework, rather than as a direct source of questions [13]. Relating the findings to the ICF framework e.g., in the interpretation and discussion of the findings, might well have been a good approach in our studies—especially in studies II and III, which address levels of functioning and the need for services.

In line with occupational science, the ICF calls attention to the connection between health and occupation [249], as we discussed in chapter 2.4.1. However, the ICF framework has also been criticised from an occupational perspective. Hemmingsson and Johnsson summarise the criticism as related to two main issues:

1) In the ICF, participation is operationalised as a person's observed performance, without attention to the person's own subjective experience of participating. From an occupational perspective, it is argued that a person's experience of meaning in an occupation is a key factor in the context of health, and that e.g., simply 'being in the atmosphere of doing' may be experienced as having equal quality as actually doing [249].
2) The issue of autonomy and self-determination is not included in the ICF's description of participation. What people observably do in life may not be what they wish to do. From an occupational perspective, self-determination and autonomy are emphasised as important factors in how people experience participation in occupation. In real life, what people actually do may also be a result of pressure or lack of choices [249].

4.3 Suggestions for further research

In study I, we found that the group with SCI scored themselves with significantly more cognitive symptoms than their proxies did and that the group with MCI scored themselves with more cognitive symptoms than the reference group scored themselves. An interesting path of potential research would be a longitudinal study following CFI scores in these groups, to examine whether the participants with SCI and MCI who scored themselves with significant cognitive symptoms were more likely to experience a progression of cognitive impairment. Other longitudinal studies of people without cognitive impairment at baseline have found that higher scores on self-reports, proxy-reports, and a combination of the two versions were associated with clinical progression of cognitive decline [146, 235, 240]. A similar study with the Norwegian CFI may provide useful information about the predictive value of this instrument and whether it is useful in assessments in clinical settings in Norway.

The data used in study II are quite old: specialist health care data were from 2011 and 2012, and primary care data were from 2013 and 2014. An examination and comparison of updated data from specialist health care and primary health care would be interesting. Potentially, the competence in primary health care (including GPs) may have improved as a result of information campaigns and access to courses. In a new study, the rates and quality of diagnoses in primary health care could be targeted, along with comorbidities. Furthermore, future research could examine the rates and types of patients who are referred from GPs to specialist health care with or without the GP first conducting a basic diagnostic evaluation, and in which cases GPs seek supervision from specialist health care.

In paper III, we suggest that the association between unmet needs for daytime activity and company and affective and psychotic BPSD could 'go both ways': unmet needs could arise due to BPSD, or BPSD could develop as a result of unmet needs. In the Actifcare project, the uptake of services was measured, but during the one-year follow-up, only a small proportion of the participants received services (such as day care) that would potentially address activity and company needs. To properly address how treatment, advice, support, and services affect unmet needs and BPSD, an intervention study could be carried out. This could e.g., be a randomised controlled study with three arms—one arm introducing individually tailored services targeting unmet needs, one arm introducing individually tailored services targeting BPSD, and one control group.

5 Conclusions

A systematic approach to case-finding, with validated tools, in people with suspected cognitive impairment is recommended. Easily accessible questionnaires addressing changes in cognition and functioning in ADL, like the CFI, seem to be a good approach to identifying people who should undergo a diagnostic evaluation. People who have undergone a diagnostic evaluation of suspected dementia in Norwegian primary health care have more severe symptoms of cognitive impairment, functional limitations, and BPSD, in addition to being older and more often living alone, compared to people who have undergone a diagnostic evaluation in specialist health care. These symptoms and characteristics are likely to result in unmet needs, which in general have been found to be associated with BPSD. Therefore, needs in people with dementia should be assessed. We specifically found that unmet needs for daytime activities and company were associated with more severe affective and psychotic BPSD.

5.1 Clinical implications

Evaluations performed to diagnose suspected dementia or cognitive impairment, and those performed to plan treatment, advice, support, and services, should be comprehensive and should include assessments of medical and neurological factors, cognitive function, physical function, ADL functioning, and BPSD. In other words, all the dimensions of health as described by the ICF should be addressed: body functions and structures, activity, participation, and contextual factors. Assessments of symptoms, functioning, and needs should rely on several sources, where medical examinations, biomarkers, cognitive tests, observations, self-reported information, and proxy-reported information are all important, as they complement each other. A multidisciplinary approach is advisable in diagnostic evaluations as well as in needs assessments.

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Papers I – III

Paper II

II

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RESEARCH ARTICLE

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Characteristics of patients assessed for cognitive decline in primary healthcare, compared to patients assessed in specialist healthcare

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ABSTRACT

Objective: The aim of this study was to describe patients assessed for cognitive decline in primary healthcare, compared to patients assessed in specialist healthcare and to examine factors associated with depression.

Design: This was an observational study.

Setting: Fourteen outpatient clinics and 33 general practitioners and municipality memory teams across Norway.

Subjects: A total of 226 patients assessed in primary healthcare and 1595 patients assessed in specialist healthcare outpatient clinics.

Main outcome measures: Cornell scale for depression in dementia (CSDD), Mini-Mental Status Examination (MMSE), Clock drawing test, Informant Questionnaire on Cognitive Decline in the Elderly (IQCODE), Instrumental Activities of Daily Living, Personal Self-Maintenance Scale, Relatives' stress scale (RSS), and Neuropsychiatric Inventory Questionnaire (NPI-Q)

Results: Patients assessed in primary healthcare were older (mean age 81.3 vs 73.0 years), less educated, had poorer cognition (MMSE median 22 vs 25), more limitations in activities of daily living (ADL), more behavioural and psychological symptoms of dementia (BPSD), more depressive symptoms (CSDD median 7 vs 5), more often lived alone (60% vs 41%) and were more often diagnosed with dementia (86% vs 47%) compared to patients diagnosed in specialist healthcare. Depression was associated with female gender, older age, more severe decline in cognitive functioning (IQCODE, OR 1.65), higher caregiver burden (RSS, OR 1.10) and with being assessed in primary healthcare (OR 1.53).

Conclusion: Post-diagnostic support tailored to patients diagnosed with dementia in primary healthcare should consider their poor cognitive function and limitations in ADL and that these people often live alone, have BPSD and depression.

KEY POINTS

People diagnosed in Norwegian primary healthcare had more needs than people diagnosed in specialist healthcare.

- They were older, less educated, had poorer cognitive functioning and activity limitations, more often lived alone, and had more BPSD and depression.
- Depression was associated with being female, older, having cognitive decline, being assessed in primary care and the caregiver experiencing burden
- Post diagnostic support for people with dementia should be tailored to the individual's symptoms and needs.

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Introduction

Globally, the number of people with dementia was estimated to be 35.6 million in 2010, a number expected to double every 20 years [1]. Thorough assessment and diagnosis are keys to providing effective medical treatment and individually tailored support for people with dementia. However, many with dementia are not assessed or given a timely diagnosis,

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and the rate of undetected dementia varies between 31% and 96% with a pooled rate of 62% [2]. Common unmet needs of people with dementia involve daytime activities, social companionship, and psychological needs [3]; thus, facilitating participation in meaningful activities may improve well-being in this population [4].

Depression is common in people with dementia [5] and may lead to negative outcomes including reduced quality of life, disability in activities of daily living (ADL), and a more rapid development of cognitive decline [6]. Therefore, assessing people with cognitive decline for symptoms of depression and targeting support when symptoms are present are important.

In Norway, assessing and diagnosing people over 65 years old with symptoms of cognitive decline is mainly a primary healthcare responsibility [7,8] and performed by general practitioners (GPs), usually in collaboration with a community-based multidisciplinary memory team, found in approximately 90% of municipalities. The teams also play a central role in post-diagnostic support for home-dwelling people with dementia. Those under 65 years with symptoms of cognitive decline, as well as older patients presenting complicated or unclear symptoms or severe behavioural and psychological symptoms of dementia (BPSD) should be referred to a specialist healthcare service [9]. The Norwegian national guideline on dementia recommends using a standardised basic diagnostic protocol in primary healthcare and a standardised comprehensive diagnostic protocol in specialist healthcare [9].

A Swedish study comparing patients diagnosed in specialist and primary healthcare found that primary healthcare patients were older, had more severe cognitive decline, and were more likely to receive in-home care or day care [10]. A UK study evaluating a primary healthcare dementia diagnostic service found that patients and caregivers generally experienced high-quality diagnostic service in primary care [11].

There is an ongoing discussion in Norway about whether GPs are fulfilling their role in diagnosing dementia. More knowledge about people assessed in primary healthcare may contribute to this debate and provide a better basis for recommending how assessing and diagnosing people with cognitive decline should be organised in the future. Such knowledge is also important for providing individually tailored post-diagnostic support to home-dwelling people with dementia.

Thus, the main aim of this study was to describe patients assessed for cognitive decline in primary healthcare compared to those assessed in specialist healthcare. As depression is common in dementia and may complicate the presentation of the symptoms, we also wanted to explore depressive symptomatology in patients and examine factors, including place of assessment, associated with depression.

Material and methods

Participants

Primary healthcare cohort (PrimCare)

In all, 226 home-dwelling patients with cognitive decline were recruited in 2013 and 2014. Data were collected by experienced memory teams from a convenience sample of 33 of a total of 428 Norwegian municipalities. The only inclusion criteria were a referral to a memory team by their GP and consenting to participate. There were no exclusion criteria.

Specialist healthcare cohort (SpecCare)

In all, 1,595 home-dwelling patients with cognitive decline were recruited from 14 outpatient clinics across Norway. All had been included in the Norwegian register of persons assessed for cognitive symptoms (NorCog), a consent-based quality and research register. There were no exclusion criteria. To ensure that no patients would appear in both cohorts, NorCog data from 2011 and 2012 were used. The NorCog register recruits patients from memory clinics, geriatric clinics and old-age psychiatry clinics. Memory clinics primarily assess patients with suspected neurodegenerative diseases and represent a type of highly specialised multidisciplinary clinic. The two latter types of clinics also assess patients with other diseases and differ from the memory clinics regarding demographic characteristics [12]. To compare participants from different types of outpatient clinics with participants from primary healthcare, the outpatient clinics were dichotomised into memory clinics and 'other' clinics (geriatric and old-age psychiatry outpatient clinics).

Assessment measures and diagnostic procedures

Measures

At the assessment the patients were accompanied by a next of kin, and the following measures, included in the diagnostic protocol both in primary and specialist healthcare, were used in the study:

Tests: the Norwegian revised version of the Mini Mental State Examination (MMSE-NR2) with scores ranging from zero to 30 and a higher score indicating better cognitive performance [13], the clock-drawing

test (CDT) with scores zero to five and a higher score indicating better cognitive performance, dichotomised with a cut-off of 3/4 [14].

Proxy-based measures: The Informant Questionnaire of Cognitive Decline in the Elderly (IQCODE), measuring change in cognition compared to ten years earlier and providing an average score ranging from one to five where a score above 3.44 indicates a significant decline in cognitive function [15], the Instrumental Activities of Daily Living (IADL) scale ranging from one to eight with a lower score indicating a higher level of dependence [16], the Physical Self-Maintenance Scale (PSMS) ranging from one to six with a lower score indicating a higher level of dependence [16], the Cornell Scale for Depression in Dementia (CSDD) ranging from zero to 38 and a higher score indicating more depressive symptoms [17], and the Neuropsychiatric Inventory-Questionnaire (NPI-Q) addressing the severity of 12 neuropsychiatric symptoms, each on a scale from one to three with three indicating more severe symptoms [18]. In addition, carers completed the Relatives' Stress Scale (RSS) ranging from zero to 60, with higher scores indicating a higher level of carer burden [19].

Diagnoses

PrimCare patients were given an ICPC-2 diagnosis by their GP [20]. Additionally, for the purpose of this study, they were given research diagnoses by two experienced psychiatrists in consensus based on all available information: 1) no dementia/other diseases, 2) subjective cognitive impairment (SCI), 3) mild cognitive impairment (MCI) and 4) dementia. Dementia was diagnosed using ICD-10 criteria for research [21] and MCI was diagnosed using the Winblad criteria [22]. SCI was used when the person had a subjective experience of cognitive decline but normal cognitive test results (MMSE and CDT).

In specialist healthcare in Norway, ICD-10 criteria for diagnoses are used. In the SpecCare cohort, the criteria for research diagnosis of dementia, MCI, and SCI were the same as in the PrimCare cohort. As information collected in PrimCare was insufficient to establish aetiological diagnoses, none were retrieved from SpecCare either.

Seven patients were excluded from the SpecCare cohort because the researchers found discrepancies between the collected data and the clinical diagnosis.

Missing data

A total of 4% of participants in the PrimCare cohort and 10% in the SpecCare cohort had missing data on all proxy-based measures.

Missing data imputation within scales was done for participants with a maximum of 50% of items missing on an individual scale using the expectation–maximisation imputation method. Parallel to this, a copy of the dataset was prepared, imputing subject mean on scales with a maximum 20% of missing items. To quality check the imputation done with the expectation–maximisation method, the main analyses were also performed in the file imputed with subject mean, and the results of these secondary analyses were comparable to those presented in this manuscript, with similar trends for *p*-values and odds ratios (secondary analyses not presented).

Statistics

Initially, to group symptoms and reduce the number of variables, a principal component analysis was performed on the items of the NPI-Q scale, in line with Trzepacz *et al* [23]. We used Varimax rotation and an eigenvalue greater than 1, resulting in the following three components used in the analyses: (i) psychosis symptoms (delusions and hallucinations); (ii) affective symptoms (depression/dysphoria, anxiety, appetite/eating, nighttime behaviours, apathy/indifference, and motor disturbance); and iii) agitation symptoms (agitation/aggression, disinhibition, irritability/lability and elation/euphoria).

To compare the PrimCare cohort with the SpecCare cohort (the latter as one group and dichotomised into memory clinics and 'other' clinics), we used descriptive analyses with *t*-tests or Mann–Whitney *U* tests for continuous variables and the chi-square test for categorical variables. Since age, according to the national guideline, is the main criterion for place of assessment, we analysed whether any differences between the cohorts remained when adjusting for age, using binary and multinomial logistic analyses.

Binary logistic regression was performed to examine factors associated with depression, and we used the CSDD as a measure of depression. CSDD scores were dichotomised using a 5/6 cut-off, found to be valid in a previous Norwegian study of home-dwelling people with cognitive decline assessed in memory clinics [5]. This method was preferred over linear regression due to a highly skewed distribution on CSDD. Selection of independent variables was done considering a combination of clinical, theoretical, and statistical factors. Only participants with data on all the selected variables were included in the regression analysis, 174 from the PrimCare cohort and 975 from the SpecCare cohort. Variables were entered in the model in steps predefined by the authors.

Data were analysed using IBM SPSS Statistics version 25.0.

Ethics

NorCog has permission from the Norwegian Data Protection Authority to collect data until 2029. The PrimCare project was approved by the ethics committee for medical research in South-East Norway with reference number 2012/1997. All participants and participating relatives in both cohorts signed informed consent. Data from the two cohorts were completely anonymised before being merged into one datafile for analyses, which was confirmed by the Norwegian Centre for Research Data to be in accordance with the regulations.

Results

Diagnoses

In all, 52 patients did not receive a diagnosis from their GPs. Of the 174 patients who did, agreement between the GPs' diagnoses and the research diagnoses made by the two experts for the purpose of the study was found in 144 (82%) cases.

Characteristics of patients in PrimCare compared to SpecCare

Compared to the total SpecCare cohort, the PrimCare cohort were older and less educated; had poorer cognition as indicated by scores on the MMSE-NR, CDT, and IQCODE; had more limitations in ADL as indicated by the PSMS and IADL; experienced more neuropsychiatric symptoms as indicated by the NPI-Q, and more symptoms of depression as indicated by the CSDD. A larger proportion of the patients lived alone and were diagnosed with dementia (Table 1).

Characteristics of the PrimCare cohort compared to the SpecCare memory clinics cohort

There was a larger proportion of women in the PrimCare cohort than in the memory clinic cohort; PrimCare relatives were older and reported higher caregiver burden; and PrimCare patients had significantly more symptoms on all three NPI-Q domains (psychosis, affective symptoms, and agitation).

Characteristics of the PrimCare cohort compared to SpecCare 'other' cohort

PrimCare patients had more psychotic and affective symptoms (NPI-Q), but not more agitation as compared to SpecCare patients.

Even though the differences between the PrimCare cohort and both cohorts within SpecCare were significant, the mean/median scores indicate that the PrimCare cohort was more similar to the 'other' SpecCare cohort than to the memory clinic cohort (Table 1).

Characteristics adjusted for age

Overall, results were somewhat attenuated when adjusting for age, but no significant changes were observed for most characteristics (see Tables 2 and 3). However, the difference between the PrimCare cohort and the total SpecCare cohort regarding scores on the NPI-Q affective and agitation subsyndromes became significant when adjusting for age, with more severe symptoms in the PrimCare cohort. Further, the OR for 'living with someone' versus 'living alone' did not remain significant between the PrimCare cohort and the SpecCare memory clinic cohort, even though the OR was in the same direction (Crude model: OR = 2.40, 95% CI 1.75, 3.28; age-adjusted model: OR = 1.35, 95% CI 0.95, 1.91). Gender differed between the PrimCare cohort and the memory clinic cohort in unadjusted analyses but not when adjusting for age.

Factors associated with depression

Female gender, older age, being assessed in primary care, cognitive decline compared to 10 years earlier (IQCODE), and higher caregiver burden were associated with depression in patients (Table 4). Further, poorer cognition as assessed by the MMSE was associated with depression in unadjusted analyses (OR 0.98, CI 0.95, 0.99), but as seen in Table 4, the direction of the OR changed in the adjusted model to 1.04 (CI 1.00, 1.08), and the association was no longer significant. However, confounding effects of IQCODE and RSS on MMSE were observed. Further, the contribution on the model of the variables gender, living situation, IQCODE, and PSMS changed, in that their OR changed by 20% or more without changing direction, when caregiver burden (RSS) was entered in the model according to the predefined step. However, confounding effects were observed between RSS and the mentioned variables; caregivers scored themselves as having a higher burden when the patient was male, living with the caregiver, less educated, had more cognitive decline and dementia, and had more limitations in ADL.

Table 1. Comparison between patients assessed in primary healthcare and patients assessed in specialist healthcare; the latter as one group and as two sub-groups.

		Specialist healthcare					
Variable	Primary healthcare $n = 226$	All $n = 1595$	p Value[1]	Geriatric and old-age psychiatry clinics $n = 967$	p Value[2]	Memory clinics $n = 628$	p Value[3]
Gender – % women	59.7	55.1	0.216	58.3	0.755	50.2	0.017
Age patient – mean (SD)	81.3 (6.7)	73.0 (10.6)	<0.001	76.2 (9.1)	<0.001	67.9 (10.8)	<0.001
Age relative – mean (SD)	63.1 (13.5)	61.3 (14.1)	0.087	62.1 (14.2)	0.330	60.5 (13.9)	0.018
	$n = 210$	$n = 1121$		$n = 621$		$n = 500$	
Education, years – median (Q1, Q3)	8.5 (7, 11)	11.0 (8, 14)	<0.001	10 (8, 13)	<0.001	12 (9, 15)	<0.001
	$n = 222$	$n = 1465$		$n = 858$		$n = 607$	
% living with someone	40.2	59.2	<0.001	57.5	<0.001	61.7	<0.001
	$n = 224$	$n = 1519$		$n = 916$		$n = 603$	
Diagnosis – %							
SCI/ not dementia	3.5	21.6		13.7		33.8	
MCI	10.6	31.8	<0.001	33.7	<0.001	28.8	<0.001
Dementia	85.8	46.6		52.6		37.4	
MMSE, sumscore – median (Q1, Q3)	22.0 (19, 25)	25.0 (21, 28)	<0.001	24 (20, 27)	<0.001	26 (23, 28)	<0.001
	$n = 223$	$n = 1565$		$n = 951$		$n = 614$	
Clock drawing test – % score 4 or 5	33.0	55.1	<0.001	47.2	<0.001	67.2	<0.001
	$n = 218$	$n = 1538$		$n = 931$		$n = 607$	
IQCODE score – mean (SD)	4.15 (0.49)	3.83 (0.57)	<0.001	3.91 (0.59)	<0.001	3.68 (0.53)	<0.001
	$n = 213$	$n = 1395$		$n = 863$		$n = 532$	
PSMS – median (Q1, Q3)	4 (3, 5)	5 (4, 6)	<0.001	5 (4, 6)	<0.001	6 (5, 6)	<0.001
	$n = 214$	$n = 1344$		$n = 826$		$n = 518$	
IADL – median (Q1, Q3)	5 (3, 6)	6 (4, 7)	<0.001	5 (4, 7)	<0.001	7 (5, 8)	<0.001
	$n = 186$	$n = 1175$		$n = 709$		$n = 466$	
CSDD – median (Q1, Q3)	7 (3, 12)	5 (2, 10)	0.001	5 (2, 11)	0.001	5 (3, 9)	0.001
	$n = 191$	$n = 1281$		$n = 772$		$n = 509$	
NPI-Q – median (Q1, Q3)							
Psychosis symptoms	0 (0, 1)	0 (0, 0)	<0.001	0 (0, 1)	<0.001	0 (0, 0)	<0.001
Affective symptoms	4 (1, 5)	3 (1, 5)	0.023	3 (1, 5)	0.039	2 (1, 6)	0.021
Agitation symptoms	1 (0, 3)	1 (0, 2)	0.047	1 (0, 2)	0.067	0 (0, 2)	0.048
	$n = 156$*	$n = 1337$*		$n = 827$*		$n = 510$*	
RSS – median (Q1, Q3)	11 (6, 22.75)	10 (4, 21)	0.069	11 (4, 23)	0.415	9 (3, 18.75)	0.002
	$n = 204$	$n = 1294$		$n = 798$		$n = 496$	

SD: standard deviation; Q: quartile; SCI: subjective cognitive impairment; MCI: mild cognitive impairment; MMSE: mini mental status examination; IQCODE: informant questionnaire on cognitive decline in the elderly – mean score of 16 items; PSMS: Physical Self Maintenance Scale; IADL: Instrumental Activities of Daily Living; CSDD: Cornell Scale for Depression in Dementia; NPI-Q: Neuropsychiatric Inventory-Questionnaire; RSS: Relatives' Stress scale. [1]p-value from t-tests; Mann–Whitney U tests or chi-square tests; for difference PrimCare vs SpecCare all. [2]p-value from t-tests; Mann–Whitney U tests or chi-square tests; for difference PrimCare vs SpecCare 'other'. [3]p-value from t-tests; Mann–Whitney U tests or chi-square tests; for difference PrimCare vs SpecCare memory clinic.

*N is different for the three subsyndromes of NPI-Q; this is the lowest n.

Discussion

We found that patients diagnosed in primary healthcare were older, less educated, had poorer cognition and more limitations in ADL, had more BPSD, more depressive symptoms, more often lived alone, and were diagnosed with dementia more often compared to patients diagnosed in specialist healthcare. As young age is the main criterion for assessment in

Table 2. Odds ratios of being assessed for cognitive decline in specialist healthcare (SpecCare – all) versus primary healthcare (PrimCare) by background factors, diagnoses and scores on cognitive and functional tests.

Primary healthcare : 0 Specialist healthcare = 1	Unadjusted			Adjusted for age		
	OR	95% CI	*p* Value	OR	95% CI	*p* Value
Gender (female = Ref) *n* = 226/1595	1.21	0.91, 1.61	0.191	0.98	0.73, 1.32	0.882
Age patient *n* = 226/1595	0.90	0.88, 0.91	<0.001			
Age relative *n* = 210/1121	0.99	0.98, 1.00	0.088	1.00	0.99, 1.01	0.671
Education *n* = 222/1465	1.19	1.13, 1.25	<0.001	1.13	1.07, 1.18	<0.001
% living with someone *n* = 224/1519	2.16	1.62, 2.87	<0.001	1.45	1.07, 1.97	0.016
Diagnosis *n* = 226/1595						
SCI/ not dementia	Ref			Ref		
MCI	0.49	0.22, 1.11	0.086	0.75	0.33, 1.72	0.503
Dementia	0.09	0.04, 0.18	<0.001	0.17	0.08, 0.36	<0.001
MMSE *n* = 223/1565	1.10	1.07, 1.14	<0.001	1.07	1.04, 1.10	<0.001
Clock drawing test *n* = 218/1538	2.49	1.84, 3.35	<0.001	1.60	1.17, 2.19	0.004
IQCODE *n* = 213/1395	0.36	0.27, 0.47	<0.001	0.52	0.39, 0.68	<0.001
PSMS *n* = 214/1344	1.40	1.29, 1.53	<0.001	1.25	1.14, 1.38	<0.001
IADL *n* = 186/1175	1.41	1.31, 1.53	<0.001	1.29	1.18, 1.41	<0.001
CSDD *n* = 191/1281	0.96	0.93, 0.98	<0.001	0.95	0.93, 0.98	<0.001
NPI-Q – psychosis	0.82	0.73, 0.92	0.001	0.87	0.78, 0.99	0.028
– affective	0.96	0.92, 1.01	0.084	0.95	0.91, 0.99	0.042
– agitation *n* = 156/1337*	0.94	0.87, 1.01	0.097	0.92	0.85, 0.99	0.040
RSS *n* = 204/1294	0.99	0.98, 1.00	0.143	0.99	0.98, 1.01	0.315

Estimated in logistic regression, crude and adjusted by age.
OR: odds ratio; CI: confidence interval; SCI: subjective cognitive impairment; MCI: mild cognitive impairment; MMSE: mini mental status examination; IQCODE: informant questionnaire on cognitive decline in the elderly – mean score of 16 items; PSMS: Physical Self Maintenance Scale; IADL: Instrumental Activities of Daily Living; CSDD: Cornell Scale for Depression in Dementia; NPI-Q: Neuropsychiatric Inventory-Questionnaire; RSS: Relatives' Stress scale. **N* is different for the three subsyndromes of NPI-Q; this is the lowest n.

specialist healthcare, the younger age for the SpecCare cohort was expected. However, the lower educational level and larger percentage of single households in the PrimCare cohort were not due to the older age in this group.

The reason why patients in the PrimCare cohort were more often diagnosed with dementia may be because they were older and less educated. More often living alone adds to the likelihood of being diagnosed at a later stage in the course of the dementia syndrome [24]. The high proportion of SCI and MCI diagnoses in SpecCare, especially in the memory clinics, may indicate that these are patients with complicated symptoms or who seek assessment in a very early stage of cognitive decline and that it is not (yet) possible to conclude if it is dementia. It may also indicate that the referral criteria for assessment in specialist healthcare should not allow for patients with modest symptoms. The MMSE median score was 22 in the PrimCare cohort compared to 25 in the SpecCare cohort. In comparison, a study from 2010 comparing AD patients in memory clinics across Europe found that the mean MMSE score varied between 19.8 and 21.6 depending on region [25].

People living alone seem to have less access to specialist healthcare, as living alone is more frequent in the PrimCare cohort compared to the SpecCare cohort. This is in line with previous studies [26] and could be because co-resident relatives act as facilitators to access such services.

The recommendation in the Norwegian national guideline regarding assessment and diagnosis of people with symptoms of cognitive decline is that people older than age 65 and without complicated or unclear symptoms should be assessed and diagnosed by primary care. The difference in age found in this study, and the fact that the researchers giving the PrimCare patients research diagnoses for use in the study found that a large majority of the PrimCare patients had dementia, may indicate that the recommendations were followed. However, without data on comorbidity we cannot tell if the complicated cases were indeed

Table 3. Odds ratios for being assessed for cognitive decline either in specialist healthcare (SpecCare), geriatric and old-age psychiatry clinics ('other') or SpecCare memory clinics versus in primary care (PrimCare) as reference category.

N = PrimCare/ SpecCare- 'other'/ SpecCare-memory clinic	SpecCare – 'Other' (*n* = 967) vs PrimCare (*n* = 226) – unadjusted			SpecCare – 'Other' vs PrimCare adjusted for age			SpecCare – memory clinics (*n* = 628) vs PrimCare (*n* = 226) – unadjusted			SpecCare – memory clinics vs PrimCare adjusted for age		
	OR	95% CI	*p* Value	OR	95% CI	*p* Value	OR	95% CI	*p* Value	OR	95% CI	*p* Value
Gender (female = Ref)	1.06	0.79, 1.42	0.698	0.92	0.68, 1.25	0.606	1.47	1.08, 2.01	0.014	1.17	0.83, 1.64	0.370
Age	0.92	0.90, 0.94	<0.001				0.85	0.83, 0,87	<0.001			
Age relative *n* = 210/ 621/ 500	0.99	0.98, 1.01	0.324	1.00	0.99, 1.01	0.970	0.99	0.98, 0.99	0.021	1.01	1.00, 1.02	0.140
Education *n* = 222/ 858/ 607	1.14	1.08, 1.20	<0.001	1.11	1.05, 1.17	<0.001	1.26	1.20, 1.33	<0.001	1.17	1.11, 1.24	<0.001
Living with someone *n* = 224/ 916/ 603	2.02	1.50, 2.72	<0.001	1.52	1.11, 2.07	0.009	2.40	1.75, 3.28	<0.001	1.35	0.95, 1.91	0.093
Diagnosis												
SCI/ not dementia	Ref			Ref			Ref			Ref		
MCI	0.82	0.36, 1.88	0.64	0.98	0.42, 2.25	0.96	0.29	0.13, 0.65	0.003	0.48	0.21, 1.13	0.093
Dementia	0.16	0.08, 0.33	<0.001	0.22	0.10, 0.46	<0.001	0.05	0.02, 0.10	<0.001	0.12	0.05, 0.25	<0.001
MMSE *n* = 223/ 951/ 614	1.06	1.03, 1.10	<0.001	1.05	1.02, 1.09	0.002	1.20	1.16, 1.25	<0.001	1.13	1.09, 1.18	<0.001
Clock drawing test *n* = 218/ 931/ 607	0.55	0.41, 0.75	<0.001	0.70	0.51, 0.97	0.031	0.24	0.17, 0.33	<0.001	0.46	0.32, 0.66	<0.001
IQCODE *n* = 213/ 863/ 532	0.46	0.35, 0.61	<0.001	0.57	0.43, 0.76	<0.001	0.22	0.16, 0.30	<0.001	0.38	0.27, 0.52	<0.001
PSMS *n* = 214/ 826/ 518	1.26	1.15, 1.37	<0.001	1.19	1.08, 1.31	<0.001	1.88	1.67, 2.11	<0.001	1.49	1.32, 1.68	<0.001
IADL *n* = 186/ 709/ 466	1.29	1.19, 1.40	<0.001	1.23	1.13, 1.35	<0.001	1.72	1.56, 1.89	<0.001	1.46	1.32, 1.62	<0.001
CSDD *n* = 191/ 772/ 509	0.96	0.93, 0.98	0.002	0.96	0.93, 0.98	0.001	0.94	0.92, 0.98	<0.001	0.94	0.91, 0.97	<0.001
NPI-Q – psychosis	0.84	0.74, 0.94	0.004	0.87	0.77, 0.99	0.031	0.78	0.69, 0.89	<0.001	0.87	0.75, 1.01	0.065
– affective	0.96	0.92, 1.01	0.125	0.96	0.91, 1.00	0.067	0.96	0.91, 1.00	0.073	0.94	0.89, 0.99	0.029
– agitation *n* = 156/ 827/ 510*	0.94	0.87, 1.02	0.114	0.93	0.85, 1.00	0.059	0.94	0.86, 1.02	0.125	0.91	0.83, 0.99	0.039
RSS *n* = 204/ 798/ 496	1.00	0.98, 1.01	0.598	1.00	0.98, 1.01	0.636	0.98	0.97, 0.99	0.007	0.98	0.97, 0.99	0.035

Estimated in multinomial logistic regression, crude and adjusted by age.

OR: odds ratio; CI: confidence interval; SCI: subjective cognitive impairment; MCI: mild cognitive impairment; MMSE: mini mental status examination; IQCODE: informant questionnaire on cognitive decline in the elderly – mean score of 16 items; PSMS: Physical Self Maintenance Scale; IADL: Instrumental Activities of Daily Living; CSDD: Cornell Scale for Depression in Dementia; NPI-Q: Neuropsychiatric Inventory-Questionnaire; RSS: Relatives' Stress scale.

**N* is different for the three subsyndromes of NPI-Q; this is the lowest n.

Table 4. Odds ratios for having depressive symptoms (Cornell scale for depression in dementia), estimated in logistic regression, $N = 1149$.

	Unadjusted			Fully adjusted for all included variables in table		
	OR	95% CI	*p* Value	OR	95% CI	*p* Value
Gender (female = Ref)	0.87	0.69, 1.10	0.255	0.68	0.51, 0.91	0.009
Age	1.00	0.99, 1.01	0.617	0.97	0.96, 0.99	0.001
Education	0.98	0.95, 1.01	0.187	1.00	0.96, 1.04	0.888
Living with someone	0.84	0.66, 1.06	0.147	0.79	0.59, 1.07	0.134
Diagnosis						
MCI vs SCI/ not dementia	1.12	0.78, 1.61	0.531	1.17	0.76, 1.80	0.471
Dementia vs SCI/not dementia	1.56	1.12, 2.16	0.008	0.90	0.57, 1.42	0.654
MMSE	0.98	0.95, 0.99	0.045	1.03	0.996, 1.07	0.084
IQCODE	3.21	2.55, 4.04	<0.001	1.65	1.16, 2.33	0.005
PSMS	0.69	0.63, 0.75	<0.001	0.92	0.82, 1.03	0.153
RSS	1.11	1.09, 1.12	<0.001	1.10	1.08, 1.12	<0.001
Place of assessment (specialist healthcare = Ref)	1.41	1.01, 1.95	0.041	1.53	1.02, 2.30	0.039

OR: odds ratio; CI: confidence interval; SCI: subjective cognitive impairment; MCI: mild cognitive impairment; MMSE: mini mental status examination; IQCODE: informant questionnaire on cognitive decline in the elderly – mean score of 16 items; PSMS: Physical Self Maintenance Scale; RSS: Relatives' Stress scale.

assessed by specialist healthcare. A majority of the PrimCare patients received a diagnosis from their GP; explanations for no diagnosis could be no dementia and that the GP had not yet concluded the work-up when data were retrieved.

It may however also be that the GP lacks the knowledge or confidence to conclude on a dementia diagnosis. Giving a dementia diagnosis, including an aetiological diagnosis, is vital in order to provide the right treatment and post-diagnostic support. The finding that as many as 52 of 226 of the PrimCare patients were not given a diagnosis raises concerns regarding the knowledge of Norwegian GPs to correctly and sufficiently diagnose dementia. Even though the ICPC-2 diagnostic system does not require an aetiological diagnosis, GPs are encouraged to give such diagnoses. In cases where GPs are unable to conclude on a diagnosis, e.g. in patients with complicated symptoms and/or high comorbidity, the National dementia guideline recommends a referral to specialist healthcare, regardless of age. This is frequently done and is the reason why we did not use SpecCare data that was newer than the PrimCare data. We do not have information on how many of the 52 undiagnosed PrimCare patients were referred to specialist healthcare for a conclusion on diagnosis.

Our findings of more severe symptoms in patients in the PrimCare cohort, may be an argument that some of these PrimCare patients should have been referred to specialised healthcare, as several symptoms could be better assessed there. It is important to stress that according to the guideline, anyone presenting complicating factors such as comorbidity or neuropsychiatric symptoms should be referred to specialist healthcare – regardless of age. Comorbidity increases with age, and age may therefore be an argument for assessment in specialist healthcare rather than against. There are clearly advantages of assessing patients with cognitive decline in specialist healthcare; the (usually) higher level of dementia-specific knowledge, including ability to assess comorbidity as well as better diagnosing being some of them. There are however also advantages of assessing patients in primary healthcare. As assessments in primary healthcare are usually done in the patients' home, the patients may be less stressed, and health care personnel can observe e.g. functional ability in the patients' own environment. Also, assessments can be done over time, and issues found in the assessment can be addressed immediately without a transition. It is an advantage that assessment, diagnosis and post-diagnostic support is done by the same few people. The GP usually knows the patient well and is therefore well suited to guide the patient after the diagnosis is given, health care personnel will after the assessment have first-hand information and will have already started forming an alliance. It may also be argued that the more severe symptoms in the PrimCare cohort represent more severe dementia rather than the patients being complicated to diagnose.

The patients from the geriatric and old-age psychiatry outpatient clinics were more comparable to the PrimCare patients than patients in the memory clinics were. This indicates that SpecCare is a heterogeneous cohort. It is often clear that a patient under 65 years with cognitive decline should be referred to a memory clinic, but it is less clear whether patients over 65 years with cognitive decline should be assessed by their GP or referred to specialist healthcare and to which type of outpatient clinic. It may be that patients in the latter group were diagnosed in specialist healthcare even though the GP could have done it. Factors such as geographic location/availability of specialist healthcare and the individual GP's confidence in assessing symptoms of cognitive decline may also play a role in where people are diagnosed.

Our findings underline the importance of post-diagnostic support. People diagnosed with dementia in primary healthcare need services tailored to their needs and reduced functioning. We suggest that service providers pay special attention to the relatively high presence of depression (CSDD median 7, IQR 3, 12), the limitations in ADL (PSMS median 4, IQR 3, 5), and the finding that these patients often live alone without daily supervision by a relative. People with dementia living alone are more isolated, and previous studies have found that they have more unmet needs than those living with others, which makes them a vulnerable and high-risk group [27].

In addition to depression being more prevalent in the primary healthcare cohort, our findings indicate that depression was associated with female gender, older age, and greater decline in cognitive functioning. Caregiver burden was also strongly associated with patients' depression which is in line with earlier studies [28]. This association might be because the patient's depression leads to higher caregiver burden. However, as the caregiver completes the depression scale in our study, it may also be that caregivers who experience high burden report more symptoms of depression in the patient.

The triad of late-life depression, cognitive impairment, and disability is complex. Depression promotes disability; disability fosters depression; and cognitive impairment complicates this relationship by influencing both disability and depression [29]. This complexity should be considered when tailoring post-diagnostic support for people diagnosed with dementia in primary healthcare. Poorer cognition and reduced performance in ADL among the PrimCare cohort may have led to less engagement in pleasant activities. According to behavioural models, depressive symptoms may be intensified or maintained by the absence of positive feelings resulting from participation in enjoyable and meaningful activities [30]. Individual and group interventions targeting activities, such as behavioural activation and Cognitive Stimulation Therapy (CST) have been found to reduce depressive symptoms and improve scores on ADL of community-dwelling older people [30,31]. A review by Nyman *et al.* (2016) highlights that providing activities for people with dementia goes beyond mere pleasure to meeting fundamental psychosocial needs [4]. The Norwegian national guideline on dementia strongly recommends psychosocial interventions based on the interests, preferences, and functional level of the person with dementia [9].

Strengths and limitations

The study's strengths are the large number of patients included and the use of standardised measures by experienced health personnel.

Its limitations are as follows: (1) the data are from 2011–2014, which may result in poorer generalisability today; (2) lack of comparable measures of comorbidity which makes it hard to say if the complicated cases have been handled by specialist healthcare; (3) the large number of municipalities and outpatient clinics represented, with a risk of data collectors using the instruments differently; (4) research diagnoses were used for all PrimCare participants relying only on data available and not considering other information of importance for the diagnoses; (5) 4% of the participants in the PrimCare cohort and 10% in the SpecCare cohort had missing data on all the proxy-based measures; (6) aetiological diagnoses were not used in this study; (7) causality has not been studied.

Conclusion

People assessed for cognitive decline in primary healthcare were older, less educated, had poorer cognitive functioning and more limitations in ADL, had more BPSD and more depressive symptoms, were more likely to live alone, and were more often diagnosed with dementia than people assessed in specialist healthcare.

The relatively high presence of depression and ADL limitations of people assessed in primary healthcare, as well as the finding that they more often lived alone, present important facts to consider when planning and providing post-diagnostic support for this group.

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Disclosure statement

No potential conflict of interest was reported by the authors.

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Paper III

III

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Associations between unmet needs for daytime activities and company and scores on the Neuropsychiatric Inventory-Questionnaire in people with dementia: a longitudinal study

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ABSTRACT

Objectives: To examine prospectively the association between unmet needs for daytime activities and company and behavioural and psychological symptoms of dementia.

Methods: We included 451 people with mild or moderate dementia, from eight European countries, who were assessed three times over 12 months. Unmet needs were measured with the Camberwell Assessment of Need for the Elderly. Three sub-syndromes of the Neuropsychiatric Inventory-Questionnaire were regressed, one-by-one, against unmet needs for daytime activities and company, adjusting for demographic and clinical-functional covariates.

Results: Unmet needs for daytime activities were associated with more affective symptoms at baseline, six and twelve months, mean 0.74 ($p < 0.001$), 0.76 ($p < 0.001$) and 0.78 ($p = 0.001$) points higher score respectively, and with more psychotic symptoms at baseline (mean 0.39 points, $p = 0.007$) and at six months follow-up (mean 0.31 points, $p = 0.006$). Unmet needs for company were associated with more affective symptoms at baseline, six and twelve months, mean 0.44 ($p = 0.033$), 0.67 ($p < 0.001$) and 0.91 ($p < 0.001$) points higher score respectively, and with more psychotic symptoms at baseline (mean 0.40 points, $p = 0.005$) and at six months (mean 0.35 points, $p = 0.002$) follow-up.

Conclusion: Interventions to reduce unmet needs for daytime activities and company could reduce affective and psychotic symptoms in people with dementia.

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Introduction

For people with dementia, thorough assessments of individual needs are important for efficiently delivering high-quality health and social services that are individually tailored (Curnow, Rush, Maciver, Gorska, & Forsyth, 2021; van der Roest et al., 2009). These assessments should include the perspective of the person with dementia, as his or her perceptions of unmet and met needs may differ from those of informal caregivers or health care professionals. Studies have shown that people with dementia generally report fewer unmet needs than researchers and their informal caregivers report them to have (Kerpershoek et al., 2018; van der Roest et al., 2009).

Studies investigating unmet needs in home-dwelling people with dementia by use of the widely used Camberwell Assessment of Need for the Elderly (CANE), found that daytime activities and company were two of the most commonly reported areas of unmet need (Mazurek et al., 2019; Miranda-Castillo et al., 2010; van der Roest et al., 2009). The item daytime activities include social, work, leisure and learning activities, and the item company is described as social contact. Other unmet needs frequently reported by people with dementia, as well as their caregivers, include needs related to memory problems, information and psychological distress (Curnow et al., 2021; Miranda-Castillo et al., 2010; van der Roest et al., 2009). In a large European cohort study including people with dementia from eight countries, daytime activities and company were again two of the items that both people with dementia and caregivers most frequently reported as unmet needs (Kerpershoek et al., 2018).

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Identifying and seeking to meet unmet needs of people with dementia is important because unmet needs have been found to be associated with a lower health-related quality of life (Handels et al., 2018; Hoe, Hancock, Livingston, & Orrell, 2006; Janssen et al., 2018; Kerpershoek et al., 2018; Miranda-Castillo et al., 2010). Miranda-Castillo et al. (2010) suggest that unmet needs mediate the relationship between behavioural and psychological symptoms of dementia (BPSD) and quality of life. BPSD is a term referring to a heterogeneous range of phenomena, considered to be highly prevalent and occur in the majority of people with dementia over the course of the disease (Kales, Gitlin, & Lyketsos, 2015). The term BPSD has lately been raised as controversial, and there is an ongoing discussion to find a more psychosocial term that reflects the multiple causes of behaviour in dementia care (Cunningham, Macfarlane, & Brodaty, 2019; Wolverson et al., 2019). Although we acknowledge the importance of this debate, we do not aim to take a stand in it. We have chosen to use the term BPSD in this manuscript, as this is the term most widely used in our references. BPSD have been cited as major risk factors for higher caregiver burden, greater functional impairment, more rapid cognitive decline, poorer quality of life and nursing home admission (Kales et al., 2015; Wergeland, Selbaek, Bergh, Soederhamn, & Kirkevold, 2015). The grouping of BPSD into sub-syndromes has been suggested as a more effective strategy for examining interventions than to report on each of the symptoms individually (van der Linde, Dening, Matthews, & Brayne, 2014). Symptom groups commonly used are affective symptoms, psychosis, hyperactivity and euphoria (van der Linde et al., 2014).

Unmet needs are widely considered to be one of the contributory factors of BPSD (Black et al., 2019; Cohen-Mansfield, Dakheel-Ali, Marx, Thein, & Regier, 2015; Cunningham et al., 2019; Kales et al., 2015). Many stakeholders in fact claim that BPSD are better considered as responses to unmet needs and suggest that the term 'unmet needs' might be used instead of BPSD (Wolverson et al., 2019). The links between unmet needs and BPSD may indicate that unmet needs should always be assessed, preferably with a standardised measure such as the CANE, in order to understand BPSD. These links may further indicate that meeting unmet needs should be a first choice to prevent and treat BPSD. From a research perspective, few studies have included a measurement of specific unmet needs when examining possible associations with BPSD in home-dwelling people with dementia. Thus, the aim of the current study was to examine prospectively over 12 months the association between unmet needs for daytime activities and company and the severity of different BPSD sub-syndromes.

Methods

The Access to Timely Formal Care (Actifcare) study was an EU Joint Programme – Neurodegenerative Disease Research (JPND) project where access to and uptake of formal community care services were explored in the following eight European countries: Germany, Ireland, Italy, the Netherlands, Norway, Portugal, Sweden and the United Kingdom. This study included data from the Actifcare prospective cohort study, a longitudinal study following people with dementia and their informal caregivers. Details about the Actifcare project and its cohort study can be found in the protocol paper (Kerpershoek et al., 2016).

Before the initiation of the cohort study, a joint training session for the data collectors from all eight countries was carried out in order to coordinate data collection and ensure consistency and a mutual understanding of how to complete the measures.

Participants

In the Actifcare study, 451 dyads of people with dementia and their informal caregivers were included at baseline. For the present study, only data describing the people with dementia, not the informal caregivers, were included. Inclusion criteria were being home-dwelling and having a diagnosis of mild to moderate dementia indicated by a Clinical Dementia Rating scale (CDR) score of 1 or 2 or a score on the Mini Mental State Examination (MMSE) of 24 or lower. To be included, the participants should not have been receiving formal personal care related to dementia at baseline but should be believed by a health care professional to require such care within one year. A subjective risk estimate was used to estimate need for additional assistance, based on available sources such as psychologists, general practitioners, memory clinic staff members and other health care or social care professionals. These sources differed between countries and participants depending on where the participants were recruited from. Data were collected at baseline, six and twelve months.

Measures

Outcome measure: BPSD (collected at baseline, six and twelve months)

BPSD were measured using the brief version of the Neuropsychiatric Inventory-Questionnaire (NPI-Q) addressing the severity of the following twelve symptoms: delusions, hallucinations, agitation/aggression, depression/dysphoria, anxiety, elation/euphoria, apathy/indifference, disinhibition, irritability/lability, motor disturbance, night-time behaviours and appetite/eating, each on a scale from 0 to 3 with 3 indicating more severe symptoms (Kaufer et al., 2000). The NPI-Q was completed by the informal caregiver.

Main exposure variables: needs for daytime activities and company (collected at baseline, six and twelve months)

Needs were measured using the Camberwell Assessment of Need for the Elderly (CANE) scale (Reynolds et al., 2000). The CANE is an interview-based questionnaire designed to map the needs of older people ('needs present'; if answered with 'yes', then 'met' or 'unmet') and amount of help ('received' and 'needed') in relation to 24 items that address psychological, physical and environmental domains (Orrell & Hancock, 2004). The two items 'daytime activities' and 'company' were selected for this study for which only data on whether needs were present and, if so, met or unmet, were used. In the Actifcare study, needs of the person with dementia were reported by themself, the caregiver, and the researcher; based on an overall perspective from extensive interviews with the person with dementia and the caregiver. In this study, we wanted to include the perspective of the person with dementia along with all other information. We therefore used scores for needs assessed by the researcher which are based on the reports from the person with dementia and the informal caregiver, together with all other information available to the researcher. The categories 'no need' and 'met need' were collapsed into one category and compared to 'unmet need'. The needs variables were treated as time-dependent covariates in the analyses.

Covariates (collected at baseline, six and twelve months)

Level of dementia was measured with the Clinical Dementia Rating scale (CDR) (Hughes, Berg, Danziger, Coben, & Martin, 1982). Six domains of cognitive and functional performance are characterised using a scale of 0–3, where 0 indicates normal function and 3 indicates severe decline. The CDR was completed by the researchers after each interview based on all available data, and the sum of boxes scores, where the six item scores are added up (0–18 points) were used for this study (O'Bryant et al., 2008). Comorbidity was measured using the Charlson Comorbidity Index (Charlson, Pompei, Ales, & MacKenzie, 1987), where higher scores indicate more comorbidities. Quan et al. have suggested updated weights of the contribution of chronic comorbidities of this index as a result of advances in medical treatment (Quan et al., 2011), and these updated weights were applied for each of the Charlson Comorbidity Index item scores before a sum score was produced for use in the analyses. Instrumental activities of daily living (IADL) were measured with Lawton and Brody's IADL scale, ranging from 0 to 8 with a lower score indicating a higher level of dependence (Lawton & Brody, 1969). Living situation was divided into two categories: (1) living alone and (2) living with someone.

Covariates (collected at baseline only)

The participants were from different European regions and, grouped in line with Handels et al. (Handels et al., 2018): North (Sweden and Norway), Middle (the Netherlands, Germany, UK and Ireland) and South (Portugal and Italy). Furthermore, all participants had a diagnosis of dementia meeting the DSM-IV criteria (American Psychiatric Association, 2000) following an assessment by a clinical professional. When an aetiological dementia diagnosis was available, this was recorded using the following categories: Alzheimer's disease (AD), Vascular dementia (VaD), mixed AD and VaD, Lewy body dementia (LBD) or 'other' dementia. Education of person with dementia was used in the analyses as a continuous variable of years of full-time education.

Table 1. Principal component analysis of the Neuropsychiatric Inventory-Questionnaire (NPI-Q), Varimax rotation with Kaiser normalisation.

	Component		
Item	1	2	3
Disinhibition	0.73		
Agitation/aggression	0.73		
Irritability/lability	0.69		
Elation/euphoria	0.46		
Motor disturbance	0.31		
Depression/dysphoria		0.77	
Apathy/indifference		0.69	
Anxiety		0.49	0.38
Appetite/eating	0.33	0.40	
Hallucinations			0.78
Night time behaviours			0.72
Delusions	0.40		0.53

Table 2. Characteristics of the participants at baseline.

Age – Mean (SD), $n = 451$	77.77 (7.85)
Sex, female, $n = 451$	246 (54.5%)
Living alone, $n = 451$	88 (19.5%)
Education, years of full time education – Mean (SD), $n = 449$	9.82 (4.48)
Region, $n = 451$	
North (Sweden and Norway)	110 (24.4%)
Middle (UK, Ireland, the Netherlands and Germany)	222 (49.2%)
South (Portugal and Italy)	119 (26.4%)
Diagnosis, $n = 451$	
AD	218 (48.3%)
VaD	53 (11.8%)
Mixed	56 (12.4%)
LBD	6 (1.3%)
Other	27 (6.0%)
Unspecified dementia	91 (20.2%)
CANE daytime activities – with unmet needs, $n = 450$	130 (28.9%)
CANE company – with unmet needs, $n = 450$	123 (27.3%)
NPIQ agitation – Mean (SD), maximum 15 points, $n = 439$	2.93 (2.77)
NPIQ affective – Mean (SD), maximum 12 points, $n = 436$	3.37 (2.60)
NPIQ psychosis – Mean (SD), maximum 9 points, $n = 444$	1.46 (1.84)
Charlson Comorbidity Index, updated weights – Median (IQR), $n = 441$	2 (2, 3)
Clinical Dementia Rating, Sum of boxes – Mean (SD), $n = 448$	7.06 (2.43)
Instrumental Activities of Daily Living – Mean (SD), $n = 445$	3.45 (1.99)

Statistics

The 12 BPSD symptoms assessed with the NPI-Q are quite different and using a sum score in analyses is not a preferred solution as two different participants with the same sum score may have significantly different clinical presentation. To identify clusters and group the symptoms measured by the NPI-Q, a principal component analysis (PCA) was performed initially for the NPI-Q. We kept all items regardless of initial correlation and used varimax rotation and an eigenvalue greater than 1.0. The PCA resulted in three factors (see Table 1) that were used in the analyses: agitation (agitation, euphoria, disinhibition, irritability and motor disturbance), affective (depression, anxiety, apathy and appetite) and psychotic (delusions, hallucinations and night-time behaviours). The three items anxiety, appetite and delusions each loaded on two factors. These items were placed in the factor on which they loaded most heavily, which was also the factor in which they are commonly found to fit (van der Linde et al., 2014).

To describe the proportion of the participants with clinically relevant levels of BPSD at baseline, we have chosen to categorise the sum score in each NPI-Q sub-syndrome into 3 groups: no/not significant, mild/moderate and severe symptoms. There is no common agreement on cut-offs for clinically relevant symptoms using the NPI-Q, and we have used a cut-off between no/not significant and mild/moderate which is in line with similar cut-offs used for the NPI (Aalten et al., 2007; Lyketsos et al., 2002). The difference in proportion of clinically relevant symptoms between participants with no/met need and unmet need is investigated with Chi-square analyses using the following two categories: mild, moderate and severe symptoms vs no/not significant symptoms.

Linear mixed models with random intercepts and slopes were used, with the three NPI-Q sub-syndromes as the dependent variables (one-by-one) and unmet needs vs met needs/no needs for daytime activities or company as independent variables. The CDR, Charlson Comorbidity Index, IADL and a time variable (coded as 0 for baseline, 1 for six months and 2 for 12 months) were all treated as time-dependent covariates in the analyses. Because a linear time variable had equally good fit as the more complex three level dummy variable in a likelihood ratio test, the simpler continuous linear variable was preferred. The other variables were all treated as fixed time-invariant variables (dementia diagnosis, region, baseline age measured on the continuous scale). First six unadjusted linear mixed models were used, then six adjusted models where age, sex, CDR, region, Charlson Comorbidity Index, IADL, diagnosis and living together/alone were added to the model. An interaction term

Table 3. Proportions of participants with clinically significant symptoms at baseline, per subsyndrome, classified as no/not significant symptoms – mild/moderate symptoms – severe symptoms, grouped by no/met need and unmet need for daytime activities and company.

		Daytime activities			Company		
		No need/met need N (%) n = 304–308	Unmet need N (%) n = 125–129	Pearson Chi-square[a]	No need/met need N (%) n = 306–310	Unmet need N (%) n = 120–123	Pearson Chi-square[a]
Agitation Maximum score: 15	Score 0–4 no/not significant	235 (77.3%)	91 (71.1%)	$p = 0.212$	237 (77.5%)	87 (71.3%)	$p = 0.225$
	Score 5–10 Mild/ moderate	67 (22.0%)	32 (25.0%)		66 (21.6%)	31 (25.4%)	
	Score 11–15 Severe	2 (0.7%)	5 (3.9%)		3 (1.0%)	4 (3.3%)	
Affective Maximum score: 12	Score 0–3 no/not significant	189 (62.2%)	49 (39.2%)	$p < 0.001$	186 (60.8%)	50 (41.7%)	$p = 0.001$
	Score 4–8 Mild/ moderate	110 (36.2%)	67 (53.6%)		116 (37.9%)	60 (50.0%)	
	Score 9–12 Severe	5 (1.6%)	9 (7.2%)		4 (1.3%)	10 (8.3%)	
Psychosis Maximum score: 9	Score 0–2 no/not significant	250 (81.2%)	82 (63.6%)	$p < 0.001$	249 (80.3%)	81 (65.9%)	$p = 0.002$
	Score 3–6 Mild/ moderate	54 (17.5%)	42 (32.6%)		58 (18.7%)	36 (29.3%)	
	Score 7–9 Severe	4 (1.3%)	5 (3.9%)		3 (1.0%)	6 (4.9%)	

[a]For the Chi-square analyses the scores for mild/moderate and severe clinically significant symptoms have been collapsed and compared to the scores for no clinically significant symptoms.

Table 4. Mean difference in NPI-Q sub-syndromes between groups: no need/met need vs unmet need, concerning daytime activities and company.

			Mixed model – unadjusted		Mixed model – adjusted	
Variable	n	Visit	Difference – mean (95% CI)	p-value	Difference – mean (95% CI)	p-value
Daytime activities						
NPI-Q – agitation	432	Baseline	0.23 (–0.20, 0.66)	0.286	0.19 (–0.22, 0.59)	0.366
	376	6 months	–0.14 (–0.57, 0.29)	0.536	0.09 (–0.22, 0.40)	0.569
	332	12 months	0.39 (–0.15, 0.92)	0.154	–0.01 (–0.49, 0.47)	0.972
NPI-Q – affective	429	Baseline	0.76 (0.33, 1.18)	0.001	0.74 (0.34, 1.14)	<0.001
	372	6 months	0.80 (0.36, 1.24)	<0.001	0.76 (0.46, 1.06)	<0.001
	330	12 months	1.08 (0.58, 1.58)	<0.001	0.78 (0.32, 1.24)	0.001
NPI-Q – psychotic	437	Baseline	0.44 (0.14, 0.74)	0.004	0.39 (0.10, 0.67)	0.007
	380	6 months	0.26 (–0.05, 0.56)	0.100	0.31 (0.09, 0.52)	0.006
	342	12 months	0.37 (–0.00, 0.75)	0.052	0.22 (–0.12, 0.57)	0.205
Company						
NPI-Q – agitation	428	Baseline	0.11 (–0.33, 0.54)	0.636	0.21 (–0.19, 0.62)	0.304
	372	6 months	0.06 (–0.38, 0.50)	0.779	0.19 (–0.14, 0.51)	0.256
	327	12 months	0.46 (–0.12, 1.04)	0.119	0.16 (–0.35, 0.68)	0.538
NPI-Q – affective	426	Baseline	0.33 (–0.10, 0.77)	0.128	0.44 (0.04, 0.84)	0.033
	368	6 months	0.66 (0.21, 1.11)	0.004	0.67 (0.35, 0.99)	<0.001
	325	12 months	0.99 (0.43, 1.54)	<0.001	0.91 (0.41, 1.41)	<0.001
NPI-Q – psychotic	433	Baseline	0.26 (–0.04, 0.57)	0.090	0.40 (0.12, 0.69)	0.005
	376	6 months	0.27 (–0.05, 0.58)	0.094	0.35 (0.12, 0.58)	0.002
	336	12 months	0.40 (–0.00, 0.81)	0.052	0.30 (–0.07, 0.67)	0.114

(needs by time) was added to test whether differences changed over time. The inclusion of both the random intercept and slope improved the fit of the models significantly as revealed by a likelihood ratio test, and thus both terms were included.

Statistical analyses were performed using IBM SPSS Statistics version 25 and Stata version 16.0.

Ethical considerations

Ethical approval was obtained separately in each of the participating countries. Written informed consent was obtained from participants or, for people with dementia with reduced ability to consent, from an informal caregiver/legal representative.

Results

Data from between 425 and 437 (depending on which CANE item and which NPI-Q sub-syndrome was being analysed) participants were sufficiently complete to be used for baseline analyses. The mean age of the participants at baseline was 78 years (SD 7.85), and 55% were female. The mean CDR sum of boxes score was 7.1 (SD 2.43), indicating mild dementia. A total of 28.9% had unmet needs for daytime activities, and 27.3% had unmet needs for company. For other characteristics of the participants, see Table 2.

Table 3 shows proportions of participants with clinically significant BPSD at baseline. A larger proportion of the participants with unmet needs both for daytime activity and company had mild to moderate symptoms of affective and psychotic symptoms, compared to participants with no need or met need. Few participants had severe symptoms.

Daytime activities

Participants with unmet needs for daytime activities had higher scores on the NPI-Q affective items with a mean of 0.74 (95% Confidence Interval [CI] 0.34, 1.14, $p < 0.001$), 0.76 (95% CI 0.46, 1.06, $p < 0.001$) and 0.78 (95% CI 0.32, 1.24,

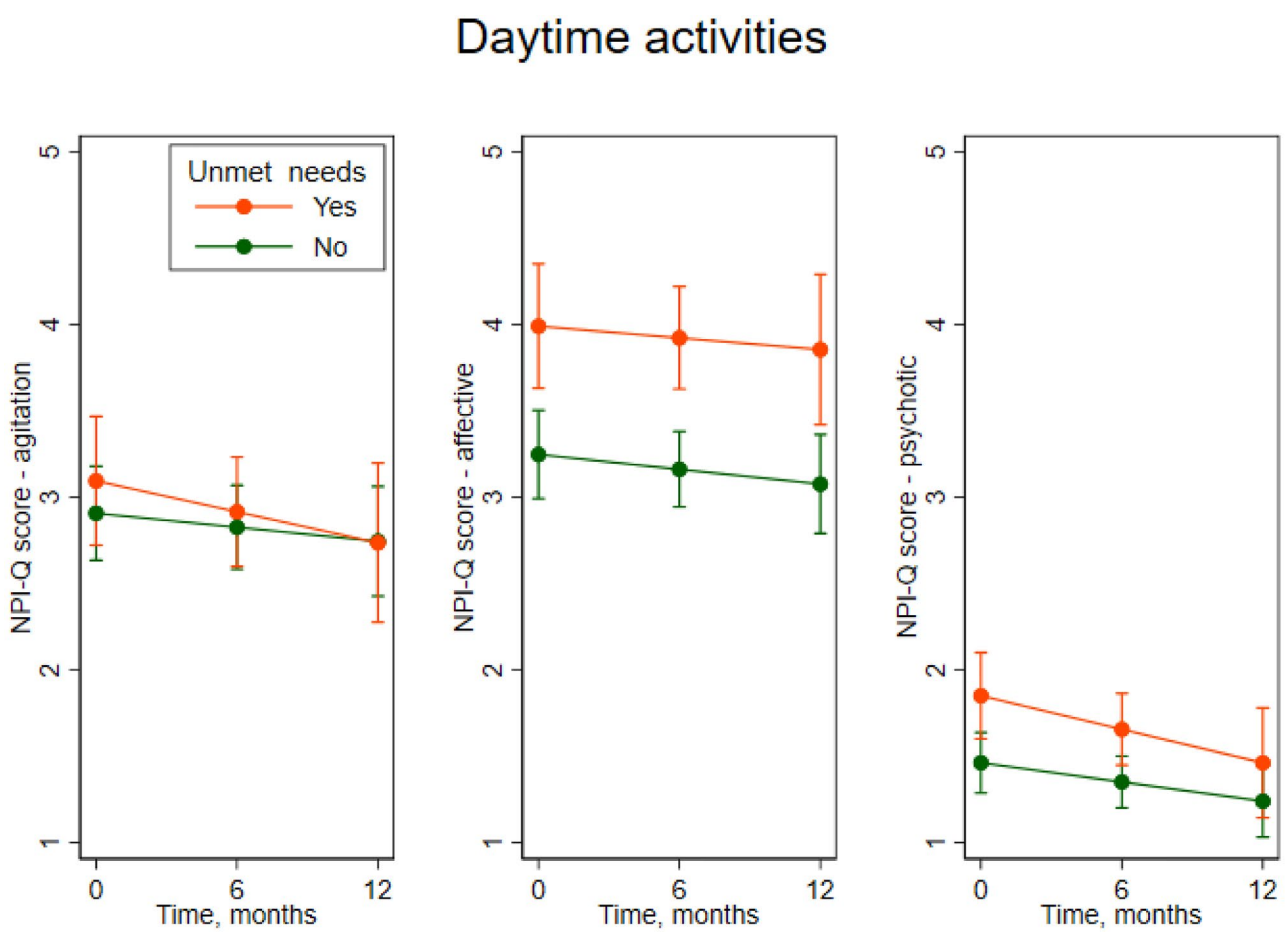
$p = 0.001$) points higher at baseline, six months and twelve months, respectively (Table 4, mixed model, adjusted). The SDs for NPI-Q affective scores for the reference groups (no/met need) were 2.46, 2.35 and 2.47 at baseline, six months, and twelve months, respectively. Thus, the effect sizes for the differences in scores on affective symptoms corresponded to 0.30, 0.32 and 0.32 SDs at baseline, six months and twelve months respectively. Unmet needs for daytime activities were also associated with more severe symptoms on the psychotic factor of the NPI-Q at baseline (mean of 0.39 points higher, 95% CI 0.10, 0.67, $p = 0.007$) and at the six-month follow-up (mean of 0.31 points higher, 95% CI 0.09, 0.52, $p = 0.006$). These effect sizes for psychotic symptoms corresponded to 0.23 SD at baseline and 0.19 SD at six months. The differences in the NPI-Q affective and psychotic items between the groups with no/met and unmet needs did not change over time (interaction terms unmet needs*time were not significant; $p = 0.935$ for affective items, $p = 0.500$ for psychotic items) see Figure 1. Scores on the agitation factor of the NPI-Q were not associated with unmet needs for daytime activities.

Company

Participants with unmet needs for company had higher scores on the NPI-Q affective items with a mean of 0.44 (95% CI 0.04, 0.84, $p = 0.033$), 0.67 (95% CI 0.35, 0.99, $p < 0.001$), and 0.91 (95% CI 0.41, 1.41, $p < 0.001$) points higher at baseline, six months and twelve months, respectively (Table 4, mixed model, adjusted). These effect sizes for the differences in scores on affective symptoms corresponded to 0.18, 0.29 and 0.36 SDs at baseline, six months and twelve months, respectively. Unmet needs for company were associated with more severe symptoms on the psychotic factor of the NPI-Q at baseline (mean of 0.40 points higher, 95% CI 0.12, 0.69, $p = 0.005$) and at the six-month follow-up (mean of 0.35 points higher, 95% CI 0.12, 0.58, $p = 0.002$). These effect sizes for difference in scores on psychotic symptoms corresponded to 0.24 SD at baseline and 0.21 SD at six months. The differences in the NPI-Q affective and psychotic items between the groups with no/met and unmet needs did not change significantly over time (interaction terms unmet needs*time were not significant; $p = 0.170$ for affective items, $p = 0.694$ for psychotic items), even though there was a tendency towards a larger difference in scores over time for affective symptoms (see Figure 2). Scores on the agitation factor of the NPI-Q were not associated with unmet needs for company.

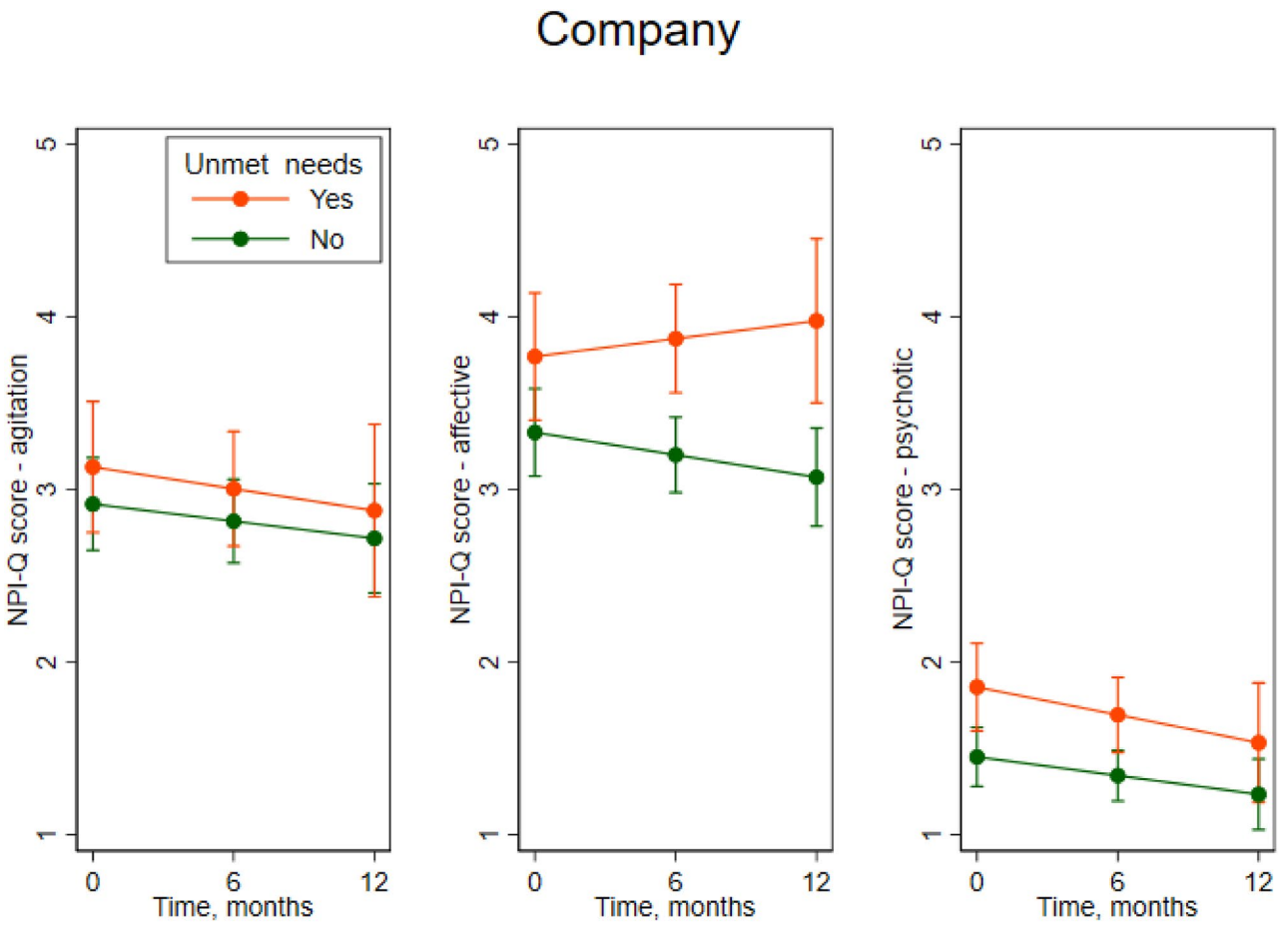
Discussion

In this longitudinal study, we found that unmet needs for daytime activities and for company were associated with more affective and psychotic symptoms over twelve months. We also found a lack of association between agitation symptoms and unmet needs for daytime activities and company.



NPI-Q agitation sub-syndrome = agitation, euphoria, disinhibition, irritability and motor disturbance – max score = 15
NPI-Q affective sub-syndrome = depression, anxiety, apathy and appetite – max score = 12
NPI-Q psychotic sub-syndrome = delusions, hallucinations and night-time behaviours – max score = 9

Figure 1. Mean Neuropsychiatric Inventory-Questionnaire (NPI-Q) scores over time for those with no need/met needs for daytime activities versus those with unmet needs. Vertical lines are 95% confidence intervals. Estimated in mixed regression where needs was modelled as a time dependent covariate, adjusted by age, sex, living alone/with someone, region, diagnosis, education, Charlson Comorbidity Index, Clinical Dementia Rating and Instrumental Activities of Daily Living.



NPI-Q agitation sub-syndrome = agitation, euphoria, disinhibition, irritability and motor disturbance – max score = 15
NPI-Q affective sub-syndrome = depression, anxiety, apathy and appetite – max score = 12
NPI-Q psychotic sub-syndrome = delusions, hallucinations and night-time behaviours – max score = 9

Figure 2. Mean Neuropsychiatric Inventory-Questionnaire (NPI-Q) scores over time for those with no need/met needs for company versus those with unmet needs. Vertical lines are 95% confidence intervals. Estimated in mixed regression where needs was modelled as a time dependent covariate, adjusted by age, sex, living alone/with someone, region, diagnosis, education, Charlson Comorbidity Index, Clinical Dementia Rating and Instrumental Activities of Daily Living.

The differences we have found are significant, but the effect sizes are small. This is, however, on a group level. As seen in Table 3, a larger proportion of the participants with unmet needs had clinically significant BPSD at baseline compared to those with no needs or met needs. On an individual level, the presence of clinically significant symptoms may make a large impact on the life of a person with dementia, as well as on their caregivers, and even a small reduction of symptoms may improve their everyday lives.

The association between unmet needs for daytime activities and company and affective and psychotic symptoms

According to previous studies, unmet needs are, in general, associated with BPSD (Miranda-Castillo et al., 2010). In the Unmet Needs Model, Cohen-Mansfield et al. described BPSD ('problem behaviours') as a result of unmet needs stemming from a decreased ability of people with dementia to communicate those needs and to provide for themselves (Cohen-Mansfield et al., 2015). They focussed mainly on agitation in nursing home residents when describing the model, which is a setting that likely includes people with more severe dementia than the participants in our study. Yet the principle that behaviour is need-driven may also apply to community-dwelling people in a mild or moderate phase of dementia and to other symptoms such as affective and psychotic symptoms.

Apathy, depression, and anxiety (all included in our affective factor) are the most prevalent BPSD, and anxiety and depression are common in an early stage of dementia (Kales et al., 2015). The participants in our study were in a mild or moderate stage of dementia where affective symptoms are common. They could be starting to experience a decrease in their ability to meet their own needs for daytime activities and social life due to ADL impairments. Impairment in ADL has been found to be associated with a higher number of unmet needs (Eichler et al., 2016). Experiencing loss of function may contribute to affective symptoms because one may lose one's sense of autonomy or feel less valued. Company and daytime activities are both considered to be social needs, and unmet social needs have been found to be associated with higher levels of depression along with unmet psychological needs (Alltag et al., 2018).

Depressive symptoms are described as being intensified or maintained by the absence of positive feelings resulting from participation in enjoyable and meaningful activities (Orgeta, Brede, & Livingston, 2017). Furthermore, having depressive symptoms, anxiety or apathy may lead to not taking the initiative to be active and to meet people even if it would be beneficial, thereby resulting in unmet needs for daytime activities and company.

To our knowledge, no previous studies have found an association between psychotic symptoms and unmet needs for daytime activities and company. Psychotic symptoms in dementia may share similarities with symptoms of schizophrenia, where reduced social activity and interest, loss of motivation and reduced productive activity are often present (Cipriani, Danti, Nuti, Di Fiorino, & Cammisuli, 2020). It might be that people with dementia who experience psychotic symptoms are withdrawing from activities and from social interaction since their symptoms make it difficult for them to function in some kinds of activities and social settings. Delusions may make it difficult to trust others and to communicate in a relevant way. Further, psychotic symptoms may make it harder for caregivers to fulfil needs in people with dementia. It may also be that unmet needs for daytime activities and company contribute to psychotic symptoms in people with dementia, for example due to lack of interaction with other people. On the other hand, too much stimuli may add to psychotic symptoms.

The lack of association between agitation and unmet needs for daytime activities and company

In this study, no associations were found between the agitation symptom cluster and unmet needs for daytime activities or company. Agitation itself is a heterogeneous term and is often used to describe diverse symptoms such as pacing, hoarding, making disruptive sounds, asking repetitive questions and becoming upset easily (Kales et al., 2015). In our PCA, the items included in the agitation factor were agitation, euphoria, disinhibition, irritability, and motor disturbance. Even if these items loaded on the same factor, they may have less in common than the items in the affective or psychotic factor. Van der Linde et al. found that studies using PCA on the NPI-Q generally suggest the following symptom groups: (1) affective symptoms, (2) psychosis, (3) hyperactivity and (4) euphoria (van der Linde et al., 2014). Our agitation factor includes both 3 and 4, indicating that this factor may be our most heterogeneous.

The need for daytime activities and company

In research on needs among people with dementia, unmet needs for daytime activities and company are frequently found (Kerpershoek et al., 2018; Miranda-Castillo et al., 2010; van der Roest et al., 2009). Even if professional support was frequently provided for company and daytime activities, unmet needs were still reported in these areas (van der Roest et al., 2009). Involvement in meaningful activities has been found to be important for people with dementia because it gives them feelings of enjoyment and pleasure, connection and belonging as well as autonomy and identity (Phinney, Chaudhury, & O'Connor, 2007). Daytime activities and company are connected to the essential psychological needs for occupation, inclusion and attachment in person-centred care (Kitwood, 1997), and their importance may be explained by the association between occupation, health and well-being (Christiansen & Townsend, 2011).

Studies have shown that social isolation and reduced access to their usual activities may increase the risk of mental health problems in older adults (Armitage & Nellums, 2020), and it is likely that people with dementia are at particular risk. Assessing at an early stage of the disease, as well as reassessing regularly, whether needs for daytime activities and company are met and providing these if needed may prevent or reduce BPSD and enhance quality of life in people with dementia.

Implications for post-diagnostic support to reduce unmet needs

Although we have found associations between unmet needs for daytime activities and company and affective and psychotic symptoms, the direction here may be discussed. It may be that unmet needs for daytime activities and company contribute to affective and psychotic symptoms; it is also possible that these symptoms contribute to unmet needs; or it could go both ways as a downward spiral. However, this implies that if post-diagnostic support can reduce either unmet needs or affective and psychotic symptoms, this could affect the other part of the equation.

Assessing the needs of people with dementia is useful both for helping to identify interventions and services that should be tailored to each individual and planning the provision of health care on a macro level (Curnow et al., 2021; Reynolds et al., 2000). An assessment of unmet needs should be carried out as early as possible in the process of dementia and updated regularly. Sometimes it takes a while to establish a diagnosis, but interventions to target unmet needs do not have to await the diagnosis. With the assessment of symptoms and functioning and post-diagnostic support assigned to the same municipal dementia-resource team, as provided by the Norwegian model, post-diagnostic support can even include pre-diagnostic support. Moreover, it can be individually tailored and be initiated as soon as symptoms and/or needs become known (Michelet et al., 2020).

Enabling people with dementia to engage in meaningful activities as part of their everyday lives should be part of post-diagnostic support (Gitlin et al., 2009; Kales et al., 2015; Lobbia et al., 2019; Orgeta et al., 2017). Person-centred care includes the promotion of social participation and meaningful activities, and these are important components of several psychosocial interventions for people with dementia. Evidence of efficacy has been found for a variety of such interventions delivered to home-dwelling people with mild to moderate dementia; however, the use of such interventions remains low (Keogh, Mountain, Joddrell, & Lord, 2019). Informal caregivers play a crucial role in several of the interventions. In this study, we address caregivers only as partners in the provision of interventions, even though several of the interventions may also have an effect on caregivers' health and well-being.

Adult day services such as day care for people with dementia may serve to meet the needs for daytime activities and company, given that the service is age appropriate and individually tailored (Strandenaes, Lund, & Rokstad, 2018, 2019). In a review, attending adult day care was found to increase social engagement for people with dementia through participation in activities with peers with whom they feel safe and comfortable. Further, participants who attended adult day care exhibited significantly less depression and fewer behavioural issues compared to participants who did not attend (Du Preez, Millsteed, Marquis, & Richmond, 2018).

Group interventions targeting activities, such as behavioural activation and Cognitive Stimulation Therapy (CST), have been found to offer several positive effects including reducing anxiety and depressive symptoms, improving quality of life and communication, reducing problematic behavioural symptoms,

and increasing scores on ADL for community-dwelling people with dementia (Lobbia et al., 2019; Orgeta et al., 2017). Caregivers being taught to use activities individually tailored to the capabilities and interests of people with dementia in the Tailored Activity Program (TAP) report reduced behavioural symptoms (Gitlin et al., 2009).

Strengths and limitations

The strength of this study is that the data were from a large cohort study with participants from eight countries across Europe and may, therefore, be representative of a larger group of people with dementia. However, this heterogeneity could also be a limitation as the recruitment of participants differed, including the sources used in estimating that need for additional assistance would likely be required within one year. The sample studied was a convenience sample. There might also have been heterogeneity among the researchers collecting data as the perceptions of different symptoms and use of the measures may differ across researchers in different countries. However, joint training was conducted, and there were meetings and regular contact within the project group to coordinate the data collection for consistency and improved inter-rater reliability.

Furthermore, in the analyses, the twelve NPI-Q items were reduced to three factors following a PCA. This may have resulted in the loss of some of the details in the data. Having three NPI-Q factors is, however, comparable to other studies that have used the NPI-Q (Truzzi et al., 2013). The NPI-scores are not based on direct observations or on the view of the person with dementia, but on proxy information, from an informal caregiver. This may be a limitation because proxy information could be influenced by caregiver distress or relationship quality.

From the needs assessment (CANE) data, the researchers' assessments were used rather than those of the people with dementia. The researchers did consider the scores from the people with dementia and the informal caregiver as well as other available information, but there is always a risk that the perspective of the people with dementia was not given enough weight in these scorings.

Conclusion

In this study, we found that unmet needs for daytime activities and for company were associated with more affective and psychotic symptoms but not with more symptoms of agitation. This is in line with previous findings and may serve to elaborate the importance of structured and repeated assessment of needs and a proactive approach towards fulfilling unmet needs for daytime activities and company for people with dementia. Psychosocial interventions in post-diagnostic support creating meaningful occupations and addressing social needs may reduce unmet needs for daytime activities and company and, thereby, reduce affective and psychotic symptoms.

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Appendices

In the appendices I have attached the Norwegian versions of the CFI; the self-rated and the proxy-rated versions

Aldring og helse
Nasjonal kompetansetjeneste

Revidert 2019
INTERN-NR: F-00028

Kognitivt funksjonsinstrument (KFI) – selvrapportert

Vennligst sett kryss i rutene som du mener best beskriver situasjonen, uten å konsultere andre. Besvar alle spørsmålene sammenliknet med for ett år siden (evt for litt mer enn ett år siden)

Navn: _____ Alder: _____ ☐ Mann ☐ Kvinne

Dato for utfylling: _____

		Ja	Nei	Kanskje
1.	**Synes du hukommelsen din er blitt vesentlig dårligere sammenliknet med for ett år siden?**	☐	☐	☐
2.	**Forteller andre deg at du ofte gjentar de samme spørsmålene?**	☐	☐	☐
3.	**Hender det oftere at du legger fra deg ting på feil sted (hvor de ikke pleier å ligge)?**	☐	☐	☐
4.	**Er du mer avhengig av skriftlige påminnelser (f.eks. handlelister, kalendere)?**	☐	☐	☐
5.	**Trenger du mer hjelp fra andre for å huske avtaler, familietilstelninger eller ferier?**	☐	☐	☐
6.	**Er det blitt vanskeligere å huske navn, finne riktige ord eller fullføre setninger?**	☐	☐	☐
7.	**Er det blitt vanskeligere å kjøre bil (f.eks. kjører saktere, vansker med å kjøre når det er mørkt, kjører deg lettere bort, involvert i ulykker, eller nestenulykker)?**	☐	☐	☐
8.	**Sammenliknet med for ett år siden, er det blitt vanskeligere å håndtere din personlige økonomi (f.eks. betale regninger, regne ut vekslepenger, fylle ut selvangivelse)?**	☐	☐	☐
9.	**Deltar du mindre i sosiale aktiviteter enn tidligere?**	☐	☐	☐
10.	**Er din arbeidskapasitet blitt vesentlig redusert i forhold til for ett år siden (både betalt og ubetalt arbeid)?**	☐	☐	☐
11.	**Er det blitt vanskeligere å følge med på nyheter, handlingen i bøker, filmer eller TV-program, sammenliknet med for ett år siden?**	☐	☐	☐
12.	**Er det noen aktiviteter (f.eks. hobbyer som kortspill eller håndarbeid) som er blitt vesentlig vanskeligere sammenlignet med for ett år siden?**	☐	☐	☐
13.	**Har du fått redusert evne til å orientere deg i omgivelsene eller går du deg lettere bort, f.eks. når du kommer til et nytt sted?**	☐	☐	☐
14.	**14.Er det blitt vanskeligere å bruke husholdningsapparater (som vaskemaskin, DVD-spiller eller datamaskin)?**	☐	☐	☐
	Sum skår (min 0 maks 13)			

Summering: Ja=1 poeng, kanskje=0,5 poeng, nei=0 poeng. Spørsmål 7 om bilkjøring regnes **ikke** med i sumskår

Oversettelse ved Knut Engedal, Anne Brækhus, Karin Persson, Anne Brita Knapskog, Susan Juel og Geir Selbæk

1. *Brukes med tillatelse fra NIA Alzheimer's Disease Cooperative Study (NIA Grant U19 AG10483). Denne tillatelsen omfatter ikke videreformidling eller videre utnyttelse av andre parter uten avtale med rettighetshaver.*
2. *Walsh, S.; Raman, R.; Jones, K.; Aisen, P.; og ADCS; "ADCS Prevention Instrument Project: The Mail-In Cognitive Function Screening Instrument (MCFSI)." Alzheimer's Disease and Associated Disorders, 2006. Vol 20(3) S170-S178.*

www.bk.no 11.2019 MM/TAA

Aldring og helse
Nasjonal kompetansetjeneste

Revidert 2019
INTERN-NR: F-00029

Kognitivt funksjonsinstrument (KFI) – pårørenderapportert

Vennligst fyll ut skjemaet uten å konsultere pasienten. Om du ønsker kan du konsultere andre familiemedlemmer, venner eller kolleger. Besvar alle spørsmålene sammenliknet med for ett år siden (evt for litt mer enn ett år siden).

Pårørendes navn: _____ Relasjon til pasienten: _____

Pårørendes alder: _____ ☐ Mann ☐ Kvinne Dato for utfylling: _____

		Ja	Nei	Kanskje
1.	**Synes du han/hun har fått vesentlig dårligere hukommelse sammenliknet med for ett år siden?**	☐	☐	☐
2.	**Har han/hun en tendens til å gjenta spørsmål?**	☐	☐	☐
3.	**Hender det oftere at han/hun legger ting på feil sted (hvor de ikke pleier å ligge)?**	☐	☐	☐
4.	**Synes du han/hun er mer avhengig av skriftlige påminnelser (f.eks. handlelister, kalendere)?**	☐	☐	☐
5.	**Trenger han/hun mer hjelp fra andre for å huske avtaler, familietilstelninger eller ferier?**	☐	☐	☐
6.	**Er det blitt vanskeligere for ham/henne å huske navn, finne riktige ord eller fullføre setninger?**	☐	☐	☐
7.	**Er det blitt vanskeligere for ham/henne å kjøre bil (f.eks. kjører saktere, vansker med å kjøre når det er mørkt, kjører seg lettere bort, involvert i ulykker, eller nestenulykker)?**	☐	☐	☐
8.	**Sammenliknet med for ett år siden, er det blitt vanskeligere for ham/henne å håndtere sin personlige økonomi (f.eks. betale regninger, regne ut vekslepenger, fylle ut selvangivelse)?**	☐	☐	☐
9.	**Er han/hun mindre interessert i å delta i sosiale aktiviteter enn tidligere?**	☐	☐	☐
10.	**Tror du, basert på egne observasjoner eller kommentarer fra hans/hennes kolleger, at arbeidskapasiteten er vesentlig redusert sammenliknet med for ett år siden (både betalt og ubetalt arbeid)?**	☐	☐	☐
11.	**Er det blitt vanskeligere for ham/henne å følge med på nyheter, handlingen i bøker, filmer eller TV-program, sammenliknet med for ett år siden?**	☐	☐	☐
12.	**Er det noen aktiviteter (f.eks. hobbyer som kortspill eller håndarbeid) som er vesentlig vanskeligere for ham/henne sammenliknet med for ett år siden?**	☐	☐	☐
13.	**Har han/hun fått redusert orienteringsevne eller går seg lettere bort, f.eks. når han/hun kommer til et nytt sted?**	☐	☐	☐
14.	**Er det blitt vanskeligere for ham/henne å bruke husholdningsapparater (som vaskemaskin, DVD-spiller eller datamaskin)?**	☐	☐	☐
	Sum skår (min 0 maks 13)			

Summering: Ja=1 poeng, kanskje=0,5 poeng, nei=0 poeng. Spørsmål 7 om bilkjøring regnes **ikke** med i sumskår

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