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Utilization of community healthcare services and family caregivers’ needs for support

A survey of family caregivers for older, home-dwelling persons with dementia in Northern Norway

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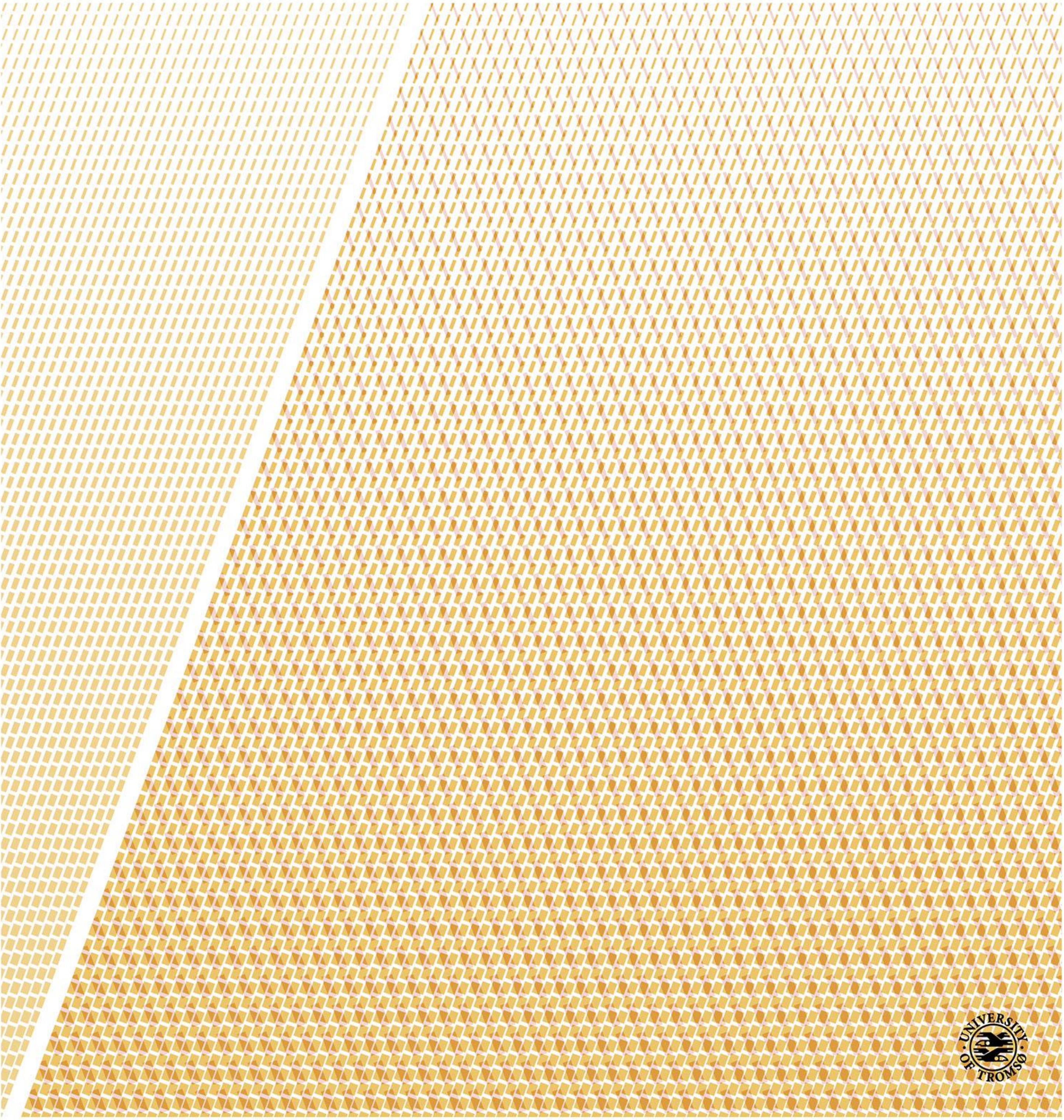

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Jill-Marit Moholt

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Abstract

Background: In line with the current aging policies, the majority of older persons with dementia live in their own home. Older persons with dementia may have substantial care needs, and informal care provided by family caregivers constitutes a major portion of the care provided. A range of community healthcare services is available for home-dwelling persons with dementia, but research has demonstrated that the services tend to be utilized to a limited extent. To secure adequate formal support and impede unintended variations in service use among persons with dementia and their family caregivers, knowledge regarding factors affecting the use and nonuse of services are required. In addition, there is a need for validated assessment tools that can be used to facilitate services that also comply with the family caregivers' needs.

Objectives: The main objectives of this study were 1) to examine the use and nonuse of community healthcare services in families in which an older (65+ years), home-dwelling person has dementia as reported by the family caregivers, and 2) to adapt and validate a Norwegian version of the Carers of Older People in Europe (COPE) Index, which is an assessment tool that can be used to detect family caregivers in need of help and support. A central aspect of the study was to illuminate the utilization of community healthcare services with regard to the estimated needs of the family caregivers.

Methods: The study has a cross-sectional design, and a survey was administered to family caregivers of older, home-dwelling persons with dementia in Northern Norway during the period of April-November 2016. In total, 788 family caregivers fulfilled the inclusion criteria. The final sample consisted of 430 family caregivers, corresponding to a response rate of 54.6%. We evaluated the construct validity of the COPE Index with exploratory and confirmatory factor analyses. In addition, the criterion validity and the reliability were examined (Paper I). Predictors of the use of community healthcare services were examined with bivariate correlation, multiple linear regression and Poisson regression analyses (Paper II). The nonuse of services was examined using both quantitative and qualitative analyses. First, we examined predictors of family caregivers' knowledge of unused services by bivariate correlation and multinomial regression analyses. Second, we examined reasons for the nonuse of services by thematic text analysis of written responses in an open-ended question (Paper III).

Results: The psychometric properties of the Norwegian version of the COPE Index were good. The construct validity evaluated with factor analyses confirmed a three-factor model as previously reported: 1) negative impact of caregiving, 2) positive values of caregiving, and 3) quality of support. Moreover, a second-order factor analysis confirmed that the three primary factors could be validly summarized in a total impact of caregiving score (Paper I). The results demonstrated that the majority of the person with dementia used homebased services, while respite care services were limited in use. Some variations in the use of services were unintended, e.g., that family caregivers with higher education reported use of more homebased services than those with low education level and that persons with dementia living in rural areas used fewer services than those living in urban areas. In addition, most of the factors reflecting family caregivers' needs for services (e.g., the COPE Index) were not associated with use of services (Paper II). The family caregivers' knowledge of unused community healthcare services was related to factors such as education level, information level and negative impact of caregiving. The reasons for nonuse of services could be ascribed to attributes of the persons with dementia (e.g., reluctance to use services), the family caregivers (e.g., no need for services) and/or the healthcare services (e.g., services not adapted to the families' needs). The results suggested that the needs for help and support among the family caregivers could be substantial even if services were unused (Paper III).

Conclusions: This study provides insight into the utilization of community healthcare services among older, home-dwelling persons with dementia and their family caregivers. Policy makers, healthcare managers and healthcare professionals should pay particular attention to service use among groups of persons with dementia and family caregivers such as male caregivers, spouses, daughters, Sami persons, those living in rural areas and those with lower education levels. Municipalities should evaluate the available information about healthcare services and promote the advantages of using such services. In addition, healthcare services should be adapted to persons with dementia and family caregivers at an individual level by performing systematic and regular assessments of their needs. I recommend that family caregivers are acknowledged as partners in care with needs in their own rights, and the COPE Index can be used as a first-stage assessment tool to detect family caregivers in need of help and support.

Norwegian abstract – sammendrag

Bakgrunn: I samsvar med helsepolitiske føringer bor de fleste personer med demenssykdom hjemme. Personer med demens kan ha betydelige omsorgsbehov, og uformell omsorg fra pårørende utgjør størstedelen av hjelpen som gis. En rekke kommunale helse- og omsorgstjenester er tilgjengelig for hjemmeboende personer med demens, men forskning viser at tjenestene blir forholdsvis lite brukt. Kunnskap om faktorer som påvirker bruk og ikke-bruk av kommunale helse- og omsorgstjenester er nødvendig for å sikre at personer med demens og pårørende får tilstrekkelig støtte og for å hindre utilsiktet variasjon i tjenestebruk. I tillegg er det behov for validerte kartleggingsinstrument som kan brukes for å tilrettelegge helse- og omsorgstjenester som også samsvarer med pårørendes behov.

Formål: Formålene med studien var 1) å undersøke pårørendes rapportering av bruk og ikke-bruk av kommunale helse- og omsorgstjenester i familier der en eldre (65+ år), hjemmeboende person har demenssykdom, samt 2) å tilpasse og validere en norsk versjon av Carers of Older People in Europe (COPE) Indeks som er et kartleggingsinstrument for å fange opp pårørende som har behov for hjelp og støtte. Et sentralt aspekt ved studien var å belyse bruk av kommunale helse- og omsorgstjenester i henhold til pårørendes estimerte behov.

Metode: Studien ble designet som en tverrsnittsundersøkelse, og et spørreskjema ble sendt til pårørende til eldre, hjemmeboende personer med demenssykdom i Nord Norge i perioden april til november 2016. Totalt oppfylte 788 pårørende inklusjonskriteriene. Det endelige utvalget besto av 430 pårørende, noe som utgjorde en svarandel på 54.6%. Vi undersøke begrepsvaliditeten til den norske versjonen av COPE Indeks med eksplorerende og konfirmerende faktoranalyse. I tillegg undersøkte vi instrumentets kriterievaliditet og reliabilitet (Artikkel I). Prediktorer for bruk av kommunale helse- og omsorgstjenester ble undersøkt med bivariate korrelasjonsanalyser, multiple regresjonsanalyser og Poisson regresjonsanalyser (Artikkel II). Ikke-bruk av tjenester ble undersøkt med både kvantitative og kvalitative analyser. Først undersøkte vi prediktorer for pårørendes kjennskap til ubrukte tjenester med bivariate korrelasjonsanalyser og multinomial regresjonsanalyse. Deretter undersøkte vi årsaker til at tjenester ikke ble brukt med tematisk tekstanalyse av et åpent spørsmål.

Resultater: De psykometriske egenskapene til den norske versjonen av COPE Indeks var gode. Begrepsvaliditet, evaluert med faktoranalyser, bekreftet en tre-faktor modell som også tidligere er rapportert: 1) negativ virkning av å gi omsorg, 2) positiv verdi av å gi omsorg og 3) kvalitet på støtte. Dessuten bekreftet en andreordens faktoranalyse at de tre primære faktorene kunne valid summeres i en total «virkning av å gi omsorg» skår (Artikkel I). Resultatene viste at flertallet av personene med demens brukte hjemmebaserte tjenester, mens avlastningstjenester ble begrenset brukt. Noen variasjoner i tjenestebruk var utilsiktet, for eksempel at pårørende med høyere utdanning rapporterte bruk av flere tjenester enn pårørende med lavt utdanningsnivå og at personer med demens som bodde i rurale områder brukte færre tjenester enn de som bodde i urbane områder. I tillegg var de fleste faktorene som gjenspeilet pårørendes behov for tjenester (blant annet COPE Indeks) ikke assosiert med tjenestebruk (Artikkel II). Pårørendes kjennskap til ubrukte kommunale helse- og omsorgstjenester var relatert til faktorer som utdanningsnivå, informasjonsnivå og negativ virking av å gi omsorg. Årsaker til at tjenester ikke ble brukt kunne tilskrives egenskaper hos personene med demens (for eksempel motvilje til å bruke tjenester), pårørende (for eksempel ikke behov for tjenestene) og/eller helse- og omsorgstjenestene (for eksempel at tjenestene ikke var tilpasset familiens behov). Resultatene viser at pårørendes behov for hjelp og støtte kunne være betydelig selv om tjenester ikke ble brukt.

Konklusjon: Studien gir innsikt i bruk av kommunale helse- og omsorgstjenester blant eldre hjemmeboende personer med demenssykdom og deres pårørende. Politikere, ledere og helsepersonell bør være oppmerksom på tjenestebruk blant særskilte grupper av personer med demens og pårørende, som menn, ektefeller, døtre, samer, de som bor i rurale områder og de med lavere utdanningsnivå. Kommunene bør evaluere tilgjengelig informasjonen om helse- og omsorgstjenestene og fremme fordelene med å bruke tjenester. I tillegg bør tjenestene bli tilpasset til personer med demens og pårørende på et individuelt nivå gjennom systematisk og regelmessig kartlegging av deres behov. Jeg anbefaler derfor at pårørende blir anerkjent som partnere i omsorgsarbeidet med egne behov, og COPE Indeks kan brukes for å kartlegge pårørende med behov for hjelp og støtte.

Sami abstract – čoahkkáigeassu

Duogáš: Dearvvašvuođapolitihkalaš láidestusaid vuođul eanaš olbmot, geain lea demeansadávda, orrot ruovttus. Olbmuin, geain lea demeansa, sáhttet leat mearkkašahtti fuolahusdárbbut, ja eahpeformála fuolaheapmi maid oapmahaččat dahket lea stuorámus oassi veahkis mii addo. Ollu suohkana/gieldda dearvvašvuođa- ja fuolahusbálvalusat leat olámuttus olbmuide geain lea demeansa ja geat orrot ruovttus, muhto dutkan čájeha ahte dát bálvalusat geavahuvvojit oalle unnán. Diehtu beliid birra mat váikkuhit dasa ahte suohkana/gieldda dearvvašvuođa- ja fuolahusbálvalusat geavahuvvojit dahje eai geavahuvvo, lea dehálaš go galgá sihkkaruššat ahte olbmot geain lea demeansa ja sin oapmahaččat ožžot doarvái doarjaga, ja go galgá eastadit sávakeahtes variašuvnna bálvalusaid geavaheamis. Dasa lassin lea dárbu validerет kártenreaiddu maid sáhttá geavahit go galgá fállat dearvvašvuođa- ja fuolahusbálvalusaid mat maiddái vástidit oapmahaččaid dárbbuide.

Ulbmil: Dán iskkadeami ulbmil lei iskat mo oapmahaččat raporterejit ahte sii geavahit dahje eai geavat suohkana dearvvašvuođa- ja fuolahusbálvalusaid bearrašiin gos lea vuoras olmmoš geas lea demeansadávda ja gii orru iežas ruovttus, ja heivehit ja validerет Carers of Older People in Europe (COPE) Indeks dárogielat veršuvnna, mii lea kártenreaidu mii galgá fuomášit oapmahaččaid geat dárbbašit veahki ja doarjaga. Guovddáš oassi iskkadeamis lei čuvgehit suohkana/gieldda dearvvašvuođa- ja fuolahusbálvalusaid geavaheami go buohtastahttá oapmahaččaid estimerejuvvon dárbbuiguin.

Metoda: Iskkadeapmi hábmejuvvui rastáčuohpahatguorahallamin, ja jearahallanskovvi sáddejuvvui áigodagas cuoŋománus gitta skábmamánnui 2016 sidjiide geat leat oapmahaččat vuoras olbmuide geain lea demeansadávda ja geat orrot iežaset ruovttus Davvi-Norggas. Oktiibuot 788 oapmahačča devde inklušuvdnagáibádusaid. Loahpalaš válljenmunis ledje 430 oapmahačča, mii dagai ahte vástidanoassi lei 54.6%. Mii iskkaimet COPE Indeks dárogielat veršuvnna doabavaliditehta eksplorerejeaddji ja konfirmerejeaddji fáktoranalysain. Dasa lassin iskkaimet reaiddu kriteriavaliditehta ja reliabilitehta (Artihkal I). Prediktorat suohkana/gieldda dearvvašvuođa- ja fuolahusbálvalusaid geavaheapmái iskojuvvojedje bivariáhta korrelašuvdnaanalysaiguin, multippel regrešuvdnaanalysaiguin ja Poisson regrešuvdnaanalysaiguin (Artihkal II). Dat ahte bálvalusat eai geavahuvvon iskojuvvui sihke kvantitatiiva ja kvalitatiiva analysaiguin. Álggos iskkaimet prediktoraid oapmahaččaid diđolašvuhtii ii-geavahuvvon bálvalusaide bivariáhta korrelašuvdnaanalysaiguin ja multinomiála regrešuvdnaanalysain. Dasto iskkaimet sivaid manne bálvalusat eai geavahuvvon ja dan dagaimet rabas gažaldagaid temáhtalaš teakstaanalysain.

Bohtosat: Cope Indeks dárogielat veršuvnna psykometralaš iešvuođat ledje buorit. Doabavaliditehta, mii evaluerejuvvui fáktoranalysain, nannii golbma-fáktor modealla mii maiddái ovdal lea raporterejuvvon: 1) negatiiva čuovvumuš fuolahusa addimis, 2) positiiva árvu fuolahusa addimis ja 3) doarjaga kvalitehta. Dasa lassin nannii nuppivuoru fáktoranalysa ahte dán golbma vuođđofáktora validalaččat sáhttá bidjat oktii totála «fuolahusa addima váikkuhus» boađusin (Artihkal I). Bohtosat čájehedje ahte eanetlohku olbmuin geain lea demeansa, geavahedje ruovttuvuođđuduvvon bálvalusaid, ja helpenbálvalusat geavahuvvojedje duššе muhtun muddui. Muhtun variašuvnnat bálvalusaid geavaheamis ledje sávakeahttá, ovdamearkka dihte ahte oapmahaččat geain lea alla oahppu raporterejedje ahte geavahedje eanet bálvalusaid go oapmahaččat geain lea vuollegis oahppodássi, ja ahte olbmot geain lea demeansa ja orro boaittobeale guovlluin geavahedje unnit bálvalusaid go sii geat orro urbána guovlluin. Dasa lassin eanaš fáktorat mat speadjalaste oapmahaččaid dárbbu bálvalusaide (earret eará COPE Indeks) eai lean assosierejuvvon bálvalusgeavahemiin (Artihkal II). Oapmahaččaid diehtu suohkana/gielddа dearvvašvuođa- ja fuolahusbálvalusain maid eai geavahan, lei relaterejuvvon fáktoriidda nugo oahppodássái, diehtodássái ja negatiiva váikkuhussii fuolahusa addimis. Sivaid, manne bálvalusat eai geavahuvvon, sáhtii čilget demeansaolbmo iešvuođaiguin (ovdamearkka dihte vuostehåhku geavahit bálvalusaid), oapmahaččaid iešvuođaiguin (ovdamearkka dihte ahte ii lean dárbu bálvalusaide) ja/dahje dearvvašvuođa- ja fuolahusbálvalusaid iešvuođaiguin (ovdamearkka dihte ahte bálvalusat eai lean heivehuvvon bearraša dárbbuide). Bohtosat čájehit ahte oapmahaččaid dárbbut veahkkái ja doarjagii sáhttet leat stuorrát vaikko bálvalusat eai geavahuvvo.

Konklušuvdna: Iskkadeapmi addá dieđuid dan birra mo vuoras olbmot, geain lea demeansadávda ja geat orrot iežaset ruovttus, ja sin oapmahaččat geavahit suohkana/gieldda dearvvašvuođa- ja fuolahusbálvalusaid. Politihkkárat, jođiheaddjit ja dearvvašvuođabargit berrejit atnit fuola das mo erenoamáš joavkkut olbmuin geain lea demeansa ja sin oapmahaččat geavahit bálvalusaid, nugo dievddut, náittosguoimmit, nieiddat, sápmelaččat, sii geat orrot boaittobeale guovlluin ja sii geain lea vuollegis oahppodássi. Suohkanat/gielddat berrejit evalueret daid dieđuid mat leat olámuttus dearvvašvuođa- ja fuolahusbálvalusaid birra ja loktet ovdan ovdamuniid mat leat bálvalusaid geavaheamis. Dasa lassin berrejit bálvalusat

heivehuvvot olbmuide geain lea demeansa ja sin oapmahaččaide individuála dásis systemáhtalaččat ja jeavddalaččat kártedettiin sin dárbbuid. Mun ávžžuhan dan dihte ahte oapmahaččat dohkkehuvvojit bealálažžan fuolahusbarggus iežaset dárbbuiguin, ja COPE Indeks sáhttá geavahuvvot kártet oapmahaččaid geain lea dárbu veahkkái ja doarjagii.

List of Papers

The thesis is based on the following papers, which will subsequently be referred to by Roman numerals:

I. Moholt, J-M., Friborg, O., Skaalvik, M.W. & Henriksen, N. Psychometric validation of the Carers of Older People in Europe Index among family caregivers of older persons with dementia. SAGE Open Medicine. 2018;6.

II. Moholt, J-M., Friborg, O., Blix, B.H. & Henriksen, N. Factors affecting the use of home-based services and out-of-home respite care services: A survey of family caregivers for older persons with dementia in Northern Norway. Dementia. 2018.

III. Moholt, J-M., Friborg, O., Henriksen, N., Hamran, T & Blix, B.H. Non-use of community healthcare services – an explorative cross-sectional study among family caregivers for older, home-dwelling persons with dementia. In review: Ageing & Society.

Abbreviations

GBP:	Great Britain Pound
ICD:	International Classification of Diseases
ILO:	International Labour Organization
ISPOR:	International Society for Pharmacoeconomics and Outcomes Research
LEON:	Lowest level of effective care
NOK:	Norwegian kroner
NSD:	Norwegian Centre for Research Data
OECD:	Organization for Economic Cooperation and Development
PDC:	Public dementia care
REDIC:	Resource use and disease course in dementia
REK:	The Regional Committee for Medical and Health Research Ethics
SAMINOR:	A population-based study of health and living conditions in areas with mixed Sami, Kven and Norwegian populations
SPSS:	Statistical Package for the Social Science
STN:	Sami Parliament subsidy scheme for cultural and economic development
US:	United States
US$:	United States-dollar
WHO:	World Health Organization

Measurements

CAT:	Common Assessment Tool
COPE Index:	Carers of Older People in Europe Index
M-SRS:	The Modified Social Restriction Scale
WHO-5:	The World Health Organization-5 Well-Being Index

Statistical terms

ANOVA:	Analysis of variance
CFA:	Confirmatory factor analysis
CFI:	Comparative fit index
EFA:	Exploratory factor analysis
EM:	Expectation maximization
MCAR:	Missing completely at random

OR:	Odds ratio
PCA:	Principal component analysis
RMSEA:	Root mean square error of approximation
SD:	Standard deviation
TLI:	Tucker-Lewis Index

1 Introduction

This study is a part of the research project ‘Public dementia care in terms of equal services – family, local and multiethnic perspectives’ (the PDC project). The overall project aims to provide knowledge about local and individual differences in the use and nonuse of community healthcare services among older persons with dementia and their family caregivers and to explore practice conditions to reveal and explain equalities and inequalities among communities, ethnic and social groups. The overall project consists of three studies investigating different aspects of community dementia care by applying different methodological approaches. This thesis is based on a cross-sectional study in which data were generated using a self-administrated questionnaire completed by family caregivers for older (65+ years), home-dwelling persons with dementia. The overall aims of this study were to examine the use and nonuse of community healthcare services and to adapt and validate a Norwegian version of an assessment tool to detect family caregivers in need of formal help and support.

From a global perspective, dementia is a key public health priority [1-3]. Every year, over 9.9 million individuals develop dementia worldwide, and approximately 47 million people lived with the condition in 2015. Due to the aging population, the number is predicted to almost double every 20 years, reaching 131.5 million in 2050 [4].

The exact number of persons living with dementia in Norway is unknown, and the Norwegian Institute of Public Health suggests that the prevailing number is between 80 000 and 100 000 persons [5]. Previous research has demonstrated that four-fifths of nursing home residents [6] and two fifths of older users (70+ years) of homebased services have dementia [7], accounting for 32000 and 43000 persons with dementia residing in nursing homes or receiving homebased services, respectively [8]. The estimates suggest that the majority of people with dementia are living in their own homes in the community rather than in institutions. In addition, an unknown number of persons with dementia use neither of these services [5].

In Norway, approximately 300 000 persons are close family members to a person with dementia [5]. Family caregivers take on huge care responsibilities [9] and are often involved in advocating and arranging for healthcare services [10]. Thus, it is reasonable to assume that they have important knowledge regarding utilization of the services. In addition, family caregivers may have their own needs for help and support. It is well known that caring for a person with dementia may expose the family caregiver to stress [11, 12], and chronic stress may increase the risk for physical diseases [12, 13]. Coordinated, integrated and adapted community healthcare services throughout the course of dementia are essential to improve the quality of life of those affected by the disease and their family caregivers [1]. Knowledge regarding factors that affect the use and nonuse of healthcare services may contribute to securing sufficient access to and use of such services through disclosure of potential unintended variations in service use and disclosure of barriers to service use. In Norway, research regarding community healthcare services is sparse, and further knowledge is needed to plan for, develop and improve services available to persons with dementia and their family caregivers [14].

Persons with dementia, family caregivers and healthcare professionals within community healthcare services are recognized as partners in a dementia care triad [15-17]. In this study, I focus on family caregivers and their assessment of the use and nonuse of community healthcare services available for home-dwelling persons with dementia and/or themselves. A central aspect of the study is to illuminate whether the utilization of services corresponds to the estimated needs of the family caregivers.

1.1 Definitions of family caregiving and family caregivers

In this study, I define family caregiving in accordance with Zarit and Edwards [18] as follows:

> Interactions in which one family member is helping another on a regular (daily, or nearly so) basis with tasks that are necessary for independent living. Included are ‘instrumental’ tasks, such as managing finances, transportation, shopping, cooking and housework, as well as ‘personal’ tasks such as bathing, dressing and toileting. In case of disabilities involving dementia, the ‘care recipient’ may require some ongoing supervision [18, p. 256].

Zarit and Edwards [18] distinguish caregiving from ordinary, ongoing exchanges of help and support that take place in most families, e.g., older spouses who provide mutual assistance to each other when they are sharing household tasks. A caregiving relationship occurs when a person becomes dependent on another family member or a closely related person to perform daily living activities, and this caregiving person provides and/or arranges for help and support [18, p. 256].

Family caregivers are distinguished as primary caregivers and secondary caregivers; the former group refers to the person who takes on the major care responsibilities, and the latter group refers to other family members who assist the primary caregiver [18]. Although secondary caregivers may take on huge care responsibilities, this study focuses on primary family caregivers.

According to the Patient’s Rights Act [19], the patient/user should appoint the next of kin. If he/she is not able to do this, the person who has the longest and most durable contact with the care recipient should act as the next of kin based on the following order of kinship relations: spouse or registered partner, cohabitant, adult children, parents, adult siblings, and other family members [19]. In this study, the family caregivers did not necessarily represent the closest next of kin to the persons with dementia in a legal sense. More distant relatives and significant others, such as friends and neighbors, were included in the study if they constituted the primary family caregiver and were registered as next of kin of the person with dementia in community healthcare service records.

The concept of informal care includes both unpaid care provided by the family, persons from the social network and other unpaid individuals providing regular care [1]. Thus, informal voluntary support provided by representatives from volunteer organizations may represent a source of informal support. This study solely focused on informal care provided by family caregivers.

2 Background

2.1 Dementia and dementia care needs

Dementia is a syndrome caused by damaged or destroyed nerve cells (neurons) in parts of the brain involved in cognitive functions [20, p. 326], which usually results in disease of a chronic and progressive nature [1]. The general criteria for dementia include impairment in more than one cognitive domain and functional impairment [21]. Characteristic symptoms are memory impairment and difficulties with problem-solving, language and other cognitive skills that affect a person's ability to perform daily living activities [20, 21]. A related condition is mild cognitive impairment, which involves cognitive deterioration from a previous level. In contrast to dementia, mild cognitive impairment does not significantly affect a person's ability to perform everyday activities, but the condition is a potential precursor for dementia [12].

Alzheimer's disease is the most common type of dementia, accounting for 60 percent to 80 percent of all dementia cases, followed by vascular dementia, dementia with Lewy bodies and frontotemporal dementia or disease caused by mixed pathology [12]. Dementia mainly affects older people, and the condition is one of the major causes of disability and dependence in old age [1, 2]. The prevalence of dementia doubles with every five-year increase in age after 65 years [1], and nearly half of all people in Europe over 95 years of age have a dementia-related disease [3]. Although the prevalence increases among older people, dementia is not considered a part of the normal aging [1].

Due to insufficient diagnostic routines, approximately half of all people with dementia in high-income countries are undiagnosed [3, 22, 23]. The Norwegian community healthcare services have an obligation to perform diagnostic procedures for persons with symptoms of dementia [8]. Despite this, research has demonstrated that approximately half of all nursing home residents and one-fifth of older, home-dwelling persons with dementia-specific symptoms receiving homebased services have a registered dementia diagnosis [6, 7]. These findings raise concerns, as the recognition of dementia is important for the evaluation of treatment [6] and planning for recent and future healthcare needs [3, 8, 14].

Persons with dementia have special care needs, often requiring more hours of care, more supervision and more personal care than care recipients without dementia [2]. The need for help and support is often long-lasting, as the mean course of the condition is approximately eight to twelve years [8]. Due to the deterioration of cognition and functional capacity, care needs usually increase over time [2]. Tasks that were previously a part of daily routines may become difficult to perform and may even become safety risks e.g., handling domestic electric appliances and wandering [3, 24]. Approximately 90 percent of all persons with dementia experience behavioral and psychological symptoms of dementia during the course of the disease. In addition, home-dwelling persons with dementia face a risk for becoming socially isolated because of their reduced involvement in social activities outside the home [3, 24].

The course of dementia varies among individuals [2], and the type of dementia and progression of the disease affects care needs [3]. The need for help and support from a caregiver often arises early and intensifies as the condition progresses [2, 25]. Typical care needs in an early stage are assistance with activities of daily living, e.g., household tasks, shopping, financial and social activities and emotional support. In the middle stage, the symptoms become worse, and care needs often include personal care, food preparation and help to manage behavioral disturbances. At this stage, living alone can be challenging. The last stage of dementia continues until death, and the persons are usually dependent on constant care, support and supervision [1, 2].

Older persons with dementia may have comorbidities, as physical and mental diseases and coexisting cognitive disorders occur more frequently as age increases [2, 3, 14]. It may be problematic to manage illness, treatment and medication even in an earlier stage of the disease; thus, comorbidities often result in increased care needs [2, 24].

2.2 International dementia care - strategies and challenges

International health policy strategies promote ‘aging in place’, which refers to “being able to continue living in one’s own home or neighborhood and to adapt to changing needs and conditions” [26, p. 1]. The majority of persons with dementia live in their own homes in the community [1]. Living at home is often in accordance with the persons’ own preferences [1, 3], can improve the quality of life and promote a greater sense of the persons’ independence and identity [3].

Long-term care refers to care that aims “to meet both the medical and nonmedical needs of persons with chronic illness or disability who are not able to care for themselves” [1, p. 53]. Increased prevalence of dementia increases demands for formal long-term care services provided by paid care workers and informal long-term care provided by unpaid family caregivers or friends [1, 2]. Relevant community long-term care services enabling persons with dementia to live at home as long as possible include homebased services, activity services, and respite care for family caregivers. Those with extensive care needs may require residential or institutional care [1, 2]. Institutional care is cost intensive [1], and providing care at home rather than in institutions reduces the cost of formal care [3].

Unpaid long-term care provided by family caregivers is described as the cornerstone of care [1, 2]. There will be an increased need for family caregivers in the future due to a projected increased number of people with dementia. Simultaneously, the number of available family caregivers may decline due to reduced fertility rates, changing family structures caused by greater geographic mobility and increased labor force participation among women [2, 3, 27]. Current healthcare models are reliant on informal care provided by family caregivers, but reduced availability of family caregivers may challenge the sustainability of the models [3].

Care provided by family caregivers might benefit persons with dementia, as they can remain living at home in familiar environments, and they receive care from someone they know and trust [3]. Despite the positive aspects of living at home, many persons with dementia face poor quality of life [28], and family caregivers may experience substantial strain [1-3]. Ideally, long-term services should form part of a continuum of care provided through the course of dementia [1], but adequate care coordination seems to be a remarkable failure of most health systems [2, 3, 22]. In addition, access to and availability of long-term services can be insufficient, even in high-income countries [3, 28]. A key message repeated in dementia policy strategies is that health care systems should do more to support those living with dementia and their family caregivers [1-3, 29].

In the published papers and remainder of this thesis, I use the terms community healthcare services or healthcare services when referring to long-term care services for home-dwelling persons with dementia. In Norway, community healthcare services also include other services such as general practitioners, rehabilitation services and long-term care in nursing homes. These services are not within the scope of this study.

2.3 Community healthcare services in Norway

The community healthcare services constitute a central part of the context of this study. In this section, I outline some health policy ideologies, strategies, and aspects regarding the organization and allocation of services that may influence individuals' access to and use of community healthcare services. In addition, the prevailing Norwegian dementia care strategy is briefly outlined.

2.3.1 Norwegian health policy ideologies and strategies

The Norwegian welfare system is well developed. Generous welfare services and benefits reduce citizens' dependence on the market to a minimum and ideally reduce the dependence on family care in long-term care [30, p. 15]. A core element in the welfare model is the principle of universalism, which means that public authorities guarantee same public benefits and services to all citizens [31]. This principle forms the basis for equity in healthcare, and the scale and intensity of a service or benefit should be proportional with the individuals' needs for help and support regardless of gender, economy, place of residence, ethnicity and religion [32]. This concept is described as proportional universalism and implies that people with equal needs should receive equal help and support [31, 33]. The principles and ambitions defined by the central government should be fulfilled by the municipalities, implying a decentralization of responsibilities to the local level [34, pp. 115-117]. Thus, the municipalities are obliged to provide essential healthcare services to residents who are in need of help and support or who are not able to care for themselves [35].

A prevailing strategy in the Norwegian healthcare policy is the principle of the lowest level of effective care (the LEON principle), which has influenced the Norwegian healthcare system since the 1970s. This principle implies that healthcare services should be provided at the lowest justifiable healthcare level within the healthcare system [36], and the strategy should ensure that everyone in need of help and support receive adequate healthcare at an equal level in a cost-effective manner [37]. The principle became particularly apparent in the Coordination reform implemented in the Norwegian healthcare system in 2012 [38]. As a consequence of the reform, the premises to the specialized healthcare services to provide specialized healthcare were strengthened, and the municipalities were obliged to undertake more responsibilities to provide healthcare to the residents [38]. This means that specialized healthcare services represent a higher level of effective care than the community healthcare services. The LEON principle is also prevailing within primary healthcare services at the municipal level, and homebased services represent lower levels of effective care than short-term and long-term care in nursing homes [36].

Previous and current health policy strategies have resulted in considerable development of community healthcare services. Over the last decades, national healthcare reforms have led to deinstitutionalization, and the municipalities have the main responsibility to provide healthcare to diverse user groups (e.g., mental health care and care to persons with intellectual impairments) [39]. The number of full-time equivalents almost doubled within homebased services during the period of 1994-2013, and the increase was mainly caused by services provided to younger patient and user groups (<67 years of age). Decreasing admission rates to nursing homes among older persons apparently follow from the healthcare strategies regarding aging in place and deinstitutionalization [39].

Decentralization of care and deinstitutionalization have led to shifts in care-responsibilities between care levels. It is asserted that several responsibilities are transferred to municipal homecare services, which strive to organize and provide sufficient services in a cost effective manner [40]. Healthcare professionals provide new and more complex care tasks [41, 42], and economic priorities have become more demanding [41]. In addition, the care recipients' and family caregivers' expectations of the services have increased [41, 42]. Due to the scarcity of healthcare resources, the threshold to receive community healthcare services has increased [42].

2.3.2 Organization of the community healthcare services and allocation of services

The Norwegian national government is responsible for the overall control, juridical acts and the financial framework of community healthcare services [43, 44]. The services are mainly funded by taxes and governmental block grants [44], but some services require out-of-pocket payment (e.g., domestic help). Altogether, the out-of-pocket payments account for a minor part of the total cost of the services [43]. The local governments of the municipalities have the main responsibility for providing and financing the services regulated by law [43, 44]. Among the typical long-term services, the municipalities have a statutory obligation to provide home nursing, practical assistance at home, support persons, care in nursing homes and respite care for family caregivers who perform comprehensive care [35, 44].

Norway has approximately 5.3 million inhabitants and a total of 422 municipalities dispersed over 18 counties [45]. The municipalities vary considerable with regard to size, settlements and number of inhabitants [46]. The large diversity in the demographic and geographical characteristics among municipalities may affect the organization of the community healthcare services, as the municipalities are entitled to adapt services to local conditions such as population structure and travel distance [47, 48]. In addition, the municipalities have authority to organize and provide nonstatutory services, e.g., meal delivery and remote control safety alarm [44]. Altogether, these factors can result in variations in service profiles across municipalities [43, 47, 48].

Municipalities organize services by using different organization models. The traditional model does not distinguish between providing care and administering services. Over the last few decades, several municipalities have implemented the purchaser-provider model, whereby the provision and administration of services are divided into separate units. In addition, some municipalities combine these models [49]. Within the purchaser-provider model, purchaser units assess individuals’ needs and allocate services. The providers should deliver care according to the decisions made by the purchaser unit [40].

Persons in need of help and support due to disability and/or disease can apply for community healthcare services in the municipality in which they are living or staying [50]. The allocation of services is based on an individual assessment provided by health professionals or case managers. The allocation follows the LEON principle, whereby the main objective is to allocate adequate services at the right time and to a sufficient extent to cover the needs of the applier. To ensure equal management of equal needs among applicants, the applications should be objectively assessed by using standardized assessment forms [50]. However, the allocation of services involves professional discretionary reasoning, and the assessment of an adequate level of effective care can vary among case managers [37]. Case management and assessment of needs require user involvement, which is a statutory right [19]. If the care recipient consents, family caregivers should be involved in care planning and healthcare delivery because they usually hold important knowledge about the care needs. Family caregivers for persons who are not able to consent should participate in decision-making processes together with the applier [19, 50].

2.3.3 Community dementia care

In Norway, the cost of public dementia care is calculated to be 28 billion NOK annually, and nursing home residents account for approximately 70 percent of total costs [9]. Reducing admission into nursing homes is an important political cost containment strategy, and a key dementia care priority is enabling persons with dementia to remain living at home as long as possible while receiving individually adapted healthcare services from their home [14]. A recent Norwegian study showed that persons with dementia lived approximately six years at home from the onset of symptoms to admission to a nursing home. At the time of admission, approximately 50 percent of the persons had moderate dementia and 20 percent had severe dementia [9]. In addition, a survey based on national community healthcare data showed that the majority of home-dwelling persons with a dementia diagnosis were registered with comprehensive care needs [51].

Norway was the first country in the world to launch a strategy aiming to improve healthcare services for persons with dementia in 2007 [52]. The strategy is a part of the Norwegian Ministry healthcare strategies, which is launched every five years [14, 52]. The prevailing dementia care strategy emphasizes that persons with dementia and their family caregivers should be at the center for the development of the healthcare services [14]. Relevant priority areas are strengthening the rights to self-determination and user involvement, preventive health initiatives, timely diagnosis and follow-up after diagnosis, activity and respite care, customized healthcare services through the course of dementia and research, knowledge and competence about dementia. In addition, the role of the family caregivers is acknowledged, and several initiatives regarding respite care, training and education are outlined [14]. In 2014, approximately three-fourths of the municipalities had established dementia/memory teams and/or dementia coordinators and/or school programs for family caregivers, which are important resources to provide information about and facilitate formal care. At the same time, the majority of municipalities had established day activity services [53]. Due to the substantial initiatives regarding adequate support and respite care for family caregivers, it is important to investigate utilization of the services and whether the use is in accordance with their estimated needs.

2.4 Family caregivers

2.4.1 Family caregivers' legal rights

Family caregivers have limited opportunity to receive healthcare services solely based on their own needs for help and support, but a recent legal provision declares that those with particularly burdensome care responsibilities can require respite care as well as training and counselling [54]. Thus, community healthcare services have an obvious obligation to assess the needs of family caregivers [48].

The family caregivers' legal rights are commonly related to the rights of the patient or the user of the healthcare services. They have the right to receive information about health and healthcare if the care recipient consents. A family caregiver is not entitled to decide whether the care recipient should use healthcare services or what type of service should be used [55]. If the care recipient is unable to consent, healthcare professionals decide whether healthcare is necessary. In such cases, the family caregivers should be informed about decisions made by the health professionals [19]. In the Patient's Rights Act [19], dementia is appointed as a potential cause that can affect the ability to consent and receive information. If the care recipient formally is deemed as not competent to consent, the family caregivers have rights to participate in user participation processes together with the person [19].

2.4.2 The impact of caregiving on the family caregivers

Currently, family caregiving consists of more complex caregiving tasks and more coordination between healthcare services than trends a few decades ago [56, 57]. In addition, medical advances, shorter hospitals stays and the management of chronic diseases in home settings have resulted in more long-lasting caregiving responsibilities for family caregivers [57]. Over the last few decades, the impact of caregiving on the family caregivers' health and well-being has been extensively investigated [57-59]. Compared with noncaregivers and other groups of family caregivers, those caring for a person with dementia are particularly exposed to mental ailments such as depression [12, 59-61], stress [11, 12] and increased risk of physical illness [11-13]. Family caregiving for a person with dementia is a long-term commitment, and it is reasonable that the combination of prolonged caregiving responsibilities and increased demands during the caregiver trajectory may increase the risk for health problems [12, 27].

Caregiver burden is a multidimensional concept used to describe “the physical, psychological or emotional, social and financial problems that can be experienced by family members” [62 p. 253]. Previous research has used various stress-coping models to identify factors associated with caregiver burden and to test interventions aiming to moderate the stressors’ impact on family caregivers [61, 63-65]. Despite an extensive body of research, predictors of caregiver burden are somewhat inconsistent across studies [66]. Researchers have further questioned why similar dementia care responsibilities seem to have different impacts on family caregivers, as some experience difficulties and several negative consequences of caregiving, while others cope well [66]. A recent meta-analysis demonstrated that approximately half of all family caregivers of persons with dementia perceives their caregiving role to be burdensome, while the other half perceived little or no caregiver strain [67]. Caregiver burden arises from the individual family caregivers’ perception of stressors and could, therefore, be influenced by factors such as disease severity and care needs of the person with dementia [63, 68]; characteristics of the family caregiver [58, 69, 70]; and social environment, culture and ethnicity [58, 71].

Over the last few decades, research has dedicated increased attention to the positive aspects and benefits of caregiving, which can further explain why some family caregivers cope better with caregiving responsibilities than others. Positive aspects of family caregiving for persons with dementia may arise from the caregiving provided, e.g., satisfaction, emotional rewards, personal growth and gaining a sense of competence and mastery and from the relationship between the family caregiver and the person with dementia, e.g., strengthened relationship, satisfaction in the notion of reciprocity and fulfilling a sense of duty. In addition, the quality of the prior relationship between the family caregiver and the person with dementia might affect satisfaction with the caregiver role [72]. Research has pointed to the multidimensionality of caregiving experiences, which implies that positive and negative aspects of caregiving are not opposite ends of the same continuum [72, 73]. Thus, a sense of burden and positive aspects of caregiving might exist simultaneously.

Studies indicate that family caregivers who are well supported and those who have found efficient problem solving strategies cope better with care situations [60]. Support from formal healthcare services may reduce family caregivers' perception of caregiver burden and caregiver strain, which further can delay the time for institutionalization of the person with dementia [56, 74]. Norwegian healthcare policies have recognized the burden associated with caregiving. The importance of formal support and respite care for family caregivers has been a recurrent theme in healthcare strategies and reports [14, 48, 52, 75, 76], and the significance of increased collaboration with family caregivers and assessment of their needs are outlined [48, 76, 77].

2.4.3 Family caregiver assessment

Family caregiver assessment implies the use of systematic methods to gather information about the caregiving situation and to identify the resources, strengths and needs of family caregivers [56, 57, 78]. The assessment should include elements such as caregiver tasks provided, social restrictions, social support, the family caregiver's health, levels of stress and well-being, challenges and benefits from caregiving, knowledge about the care-recipient's illness and available healthcare services and needs for help and support from healthcare services [57, 77-79]. Family caregiver assessment can be performed by healthcare professionals in the community, e.g., physicians, nurses and case managers [77, 78]. A national guideline regarding family caregiving recommends that family caregiver assessment should be performed during the allocation of services to the patient/user, and the assessment should be regularly repeated [77].

To facilitate family caregiver assessment, there is a need for suitable assessment tools [57, 80]. In this study, we translated and evaluated the psychometric properties of the Carers of Older People in Europe (COPE) Index (Paper I). The COPE Index is a first-stage assessment tool that can be used to detect family caregivers in need of formal support [73, 81]. The instrument was developed two decades ago as a response to challenges across European countries due to an aging population, where the ideology regarding aging in place and a complementary care model had resulted in increased involvement of family caregivers in caring for older people living at home [73, 79]. Furthermore, the COPE Index was developed on the basis of a theoretical model of family caregiving that emphasized the family caregivers' subjective perceptions of positive and negative aspects of caregiving and existing support structures rather than objective factors such as the functional level of the care recipient [73, 79]. Previous studies have demonstrated that the COPE index is multidimensional and covers three domains, namely, negative impact of caregiving, positive values in caregiving and quality of social support where the latter domain includes quality of support from family, social networks and healthcare services [81-83]. In addition to using COPE scores as predictors in the study, our intention was to make available a Norwegian first-stage assessment tool that can be used among healthcare professionals to evaluate the caregiver situation.

2.5 Sharing of care responsibilities between healthcare services and family caregivers

Although Norway has a generous healthcare system, family caregivers' contributions to care for older adults have been maintained [84, p.127]. Nevertheless, national healthcare strategies prepare for increased informal involvement in care [48, 76]. Families, social networks, local communities and society should undertake more care responsibilities, which is justified by fellow citizenship and solidarity between generations. Thus, citizens should not perceive themselves as consumers of services but instead contribute to reducing the requirement for services to ensure economical sustainability within the public healthcare sector [76].

The relationship between formal and informal care is often described with reference to the substitution theory, which refers to an inverse relationship between family caregiving and healthcare service provision [85, 86]. Thus, when the formal healthcare system supplies more services, less care is provided by the family [85]. It is possible that the theory had particular relevance at the time before the modernization of community healthcare services and the subsequent deinstitutionalization of welfare services, as formal institutional care could potentially replace family caregiving [87]. However, the substitution theory has again gained relevance as research suggests that family caregiving substitutes formal care [88-93]. This shift in care responsibilities is denoted as an "inversed substitution" and might indicate that family caregivers are filling the emerging gaps in care for older persons in need of help and support [94, p. 272]. Other studies across European countries have demonstrated that the substitution effect of family caregiving is relatively small [92] and that the effect disappears when care recipients have severe disabilities [95]. The results of a Norwegian survey showed that care provided by healthcare services and by family caregivers (adult children) constitutes approximately equal portions of the care provided to older care recipients [96]. Likewise, national community healthcare statistics show that care recipients with extensive care needs receiving much family care additionally received comprehensive care from the formal services [97]. Altogether, these results indicate that formal care and family care complement rather than substitute each other.

Within the complementary theory, two common models are the family support theory and the specialization theory [85, 86]. The first theory implies that the family and the healthcare services form a partnership in caregiving where the formal healthcare services supplement family caregiving [85]. Reciprocal sharing of care burdens between formal and family caregivers may further result in increased willingness to accept family care among care recipients and family caregivers [86]. The specialization theory implies that formal and family care provide different care tasks, for example, that healthcare services provide instrumental care, while family caregivers provide social support [86]. In Norwegian health policy strategies and reports, we find elements of both theories. A governmental report describes that community healthcare services provide the heaviest care tasks, while family caregivers provide practical and emotional care, which indicates a specialization theory [75]. Other policy documents promote the sharing of care responsibilities, where the formal services should supplement family caregiving and provide relief to family caregivers to avoid caregiver strain and burden [14, 48]. Although the majority of the persons with dementia in this study received both formal healthcare and family care in accordance with a complementary care theory, the results demonstrated variations in the use of community healthcare services and we identified groups of family caregivers who possibly substitute formal care to a higher degree than other groups.

2.6 Provision and utilization of community healthcare services

Variations in healthcare service provision exist across municipalities, within the municipalities and across groups of care recipients. Variations might be intended, for example, to allow healthcare services to be adapted to local conditions or different service provisions to be provided to those with different support needs [48]. Variations contrary to the central regulations, legislations and principles of best professional practices are unintended. For example, unintended age variations might occur in the use of homebased services, as municipalities receive governmental grants for groups of younger care recipients (<67 years of age) with extensive care needs, while these grants are not available for the group of older people with similar needs. Moreover, difference in service provision across municipalities may result in unintended variations in the availability of services [48]. Unintended variations might result in inequity in healthcare. According to Dahlgren and Whitehead [98], equity in healthcare refers to conditions such as equal geographic, economic and cultural access to available healthcare services for all in equal need for care. This means that aspects such as location of services, payment for services and cultural acceptability can result in inequities in healthcare among social groups [98]. In this study, we investigated how individual factors of the person with dementia and the family caregivers were associated with the use of services. Based on previous research, I assume that variations in service use according to characteristics such as gender, ethnicity, socioeconomic status and place of residence may indicate unintended variations.

Variations in service use between males and females

The family caregiver role has evolved from the family relationship and from personal and cultural norms, values and beliefs [27, 68, 99, 100]. Despite great diversity among the family caregivers, particular groups may take on higher care responsibilities than others. Family caregiving is traditionally considered a woman's responsibility [56], and estimates indicate that women constitute two thirds of all family caregivers of persons with dementia [12, 27]. Research points to gender differences related to caregiving activities, as women provide care for a longer period of time [12, 27, 101], constituting more hours of care [12], and are more likely than men to provide personal care [27, 70].

Studies have demonstrated gender differences in service use among persons with dementia and their family caregivers [27, 101-103]. Women with dementia tend to use more homebased services than men [101, 103] and male family caregivers are more likely to receive formal help and support than female caregivers [27]. Notably, studies across different countries and care settings show that women are more exposed to caregiver burden [27, 70, 104], depression and lower levels of physical health [12, 70] than men who provide care. It is therefore suggested that female family caregivers benefit from formal help, support and respite care [27]. Because dementia caregiving seems to rely to a high degree on the efforts of women, it is important to investigate gender differences in the utilization of community healthcare services. Formal support might enable women to provide care while simultaneously feeling cared for themselves [27].

Variations in service use between socioeconomic groups

In Norway, inequalities in health exist among social groups of citizens, and overall, the health is poorer among persons with low education level and low income level [31, 105]. International literature regarding inequalities in health emphasizes that high-quality healthcare services contribute to reducing morbidity and disability, reliving suffering and improving the quality of life of those who are ill [98]. Healthcare systems are considered to be a social determinant of health, and the systems are influenced by and influence the effects of other social determinants [106]. Thus, it is important to examine differences in service utilization among socioeconomic groups.

Findings from Norwegian studies indicate that factors such as higher education level and/or higher income are related to the use of more medical specialist services [31, 32, 107], while persons in lower socioeconomic groups have more visits to general practitioners [32, 107]. Few Norwegian studies have examined the relationship between socioeconomic status and the use of community healthcare services, such as homebased services, activity services and respite care services. A Norwegian study among older homecare recipients found that those with high education level received more home nursing than those with low education level [108]. A study using survey data from Sweden and Denmark demonstrated that older persons with shorter education used family care to a higher degree than those with longer education, while those with higher education more often purchased market care [109]. International studies among family caregivers who provide care for older people [110] and among family caregivers for persons with dementia [111, 112] indicate that a higher educational level is associated with the use of more community healthcare services. Related to dementia caregiving, it is reasonable that the socioeconomic status of the family caregivers may be of particular importance regarding service utilization, as the family caregivers often advocate for the care recipient and arrange for formal help and support [20].

Variations in service use between Sami and non-Sami people

In Norway, the Sami people are a minority population of indigenous people. The Sami's rights are safeguarded in the International Labour Organization (ILO) Convention No. 169 concerning Indigenous and Tribal Peoples [113] and in Norwegian legislation [114], which apply to encounters with healthcare services [115]. According to the ILO Convention, healthcare services provided to indigenous people should be community-based when possible and should be planned and provided in cooperation with the people served [113]. Norwegian healthcare policies promote the provision of culturally adapted services to the Sami within the established health care system rather than developing services explicitly for the Sami people [115].

Few studies have compared the utilization of healthcare services between Sami people and the majority population in Norway. A study carried out in the 1980s found that Sami people consulted primary physicians less often than non-Sami. The study concluded that cultural and linguistic barriers impeded Sami persons from visiting the doctor [116]. In a recent literature review, Blix [115] found that the Sami used healthcare services to the same extent as non-Sami, but Sami people were less satisfied with the services than the majority population. Studies investigating the utilization of community long-term services among the Sami people are lacking, and very few studies have focused on family caregivers for persons with dementia and the interactions with community healthcare services within the Sami population [115].

Variations in service use between persons residing in rural and urban areas

Approximately two-fifths of the population of Norway live in urban areas, while two-thirds of the population of European Union countries live in urban areas [117]. Several rural communities in Norway are characterized by long distances between settlements and a limited range of public services [118]. The proportion of people >65 years of age and the use of healthcare services is higher in small municipalities (<2000 inhabitants) than in larger municipalities [119]. National surveys have shown an association between the community healthcare service coverage and number of inhabitants, namely, that small municipalities have higher home-nursing coverage while large municipalities (cities) have higher coverage of long-term care in nursing homes [120, 121]. There were no systematic differences among municipalities regarding the extent of services delivered [120]. However, smaller municipalities might face greater burden regarding providing healthcare due to their high proportions of older inhabitants compared with larger municipalities with lower proportions of older inhabitants [119].

A national survey showed that older people residing in rural municipalities were more satisfied with homebased services than those residing in urban areas. In addition, older people in rural areas reported greater contact with friends and neighbors than those in urban areas, and neighbors were a source of help and support [118]. A review of international research indicated that older adults who resided in urban areas had higher availability of formal healthcare services and simultaneously tended to use more formal support than those who lived in rural areas. In addition, rural care recipients were more likely to use informal support than those who lived in urban areas [122]. In an interview study of family caregivers of persons with dementia in rural settings in Canada, the participants identified a lack of availability of homebased services [123]. In a study regarding dementia care provisions in rural Scotland, many of the care recipients and their family caregivers referred to inappropriate delivery of services, and they therefore used family and social networks to fulfill their needs for help and support [124]. There are few Norwegian studies regarding differences in service use between persons residing in rural and urban areas, and such studies are virtually absent within the field of dementia care.

2.7 Nonuse of community healthcare services

Appropriate healthcare services are considered important for achieving the best outcomes for both the person with dementia and their family caregivers [27], but reasons for nonuse of services have been sparsely investigated, particularly in the Nordic countries. Although persons with dementia in Norway receive more community healthcare services than care recipients without dementia [9, 51], several of the services tend to be used to a limited extent [51]. A report regarding resource use and disease course in dementia demonstrated that approximately one-third of all home-dwelling persons with dementia did not use community healthcare services. One-half used home-nursing and one-fourth used domestic help in the period immediately before admission to a nursing home. At the same time, nine out of ten of all home-dwelling persons with dementia received informal help provided by family or friends, and family caregivers provided approximately ten times more care than home nurses [9].

International research has demonstrated similar tendencies of low utilization of community healthcare services among home-dwelling persons with dementia and their family caregivers [25, 93, 103, 125, 126]. Based on a review of research on family caregivers of people with dementia, Brodaty and colleagues [127] developed a typology of service nonuse that included the following categories: family caregivers managing the recipient’s care (e.g., services not needed or adequate family support being received), reluctance to use services (e.g., denial of need, feeling of invasion of privacy or care recipient refusing to use services), service characteristics (e.g., services inappropriate for needs, services not available, cost and concerns about quality of care) and lack of knowledge about existing services. Aspects such as caregiver burden and the functional status of the person with dementia were related to nonuse of services, e.g., those who were reluctant to using services were characterized by a high level of caregiver burden, and they cared for someone with a high level of impairment [127].

Shortage of available community healthcare services [128], lack of awareness of available services [129], insufficient information about services [127, 130-132] and problems regarding accessing services [132] seem to be important barriers for service use among family caregivers for persons with dementia. In a study about the diagnostic process, almost all family caregivers reported that they did not receive enough information about available community healthcare resources at the time of diagnosis. Furthermore, three-fifths of the participants had still not received sufficient information about community healthcare resources one year after the diagnosis [133]. In a study of family caregivers and healthcare providers, family caregivers reported that they were primarily informed about medications and to a lesser extent about healthcare resources. The healthcare providers, who were physicians and nursing staff, reported limited time and lack of awareness about community healthcare services [15]. Without information and support from healthcare professionals who have the initial contact with families after diagnosis, families themselves might be left with the responsibility to learn more about the disease and to access assistance and support from the community healthcare services [133]. Few studies have examined nonuse and barriers to use of formal healthcare services among persons with dementia. Results from a recent cross-national European study indicate that persons tried to avoid formal care as long as possible. Others did not accept the diagnosis and some lacked awareness of their care needs. Persons with dementia also reported lack of information about the disease and about available healthcare services [128].

2.8 Person-centered or relationship-centered dementia care?

Dementia care strategies stress the importance of person-centered care [3, 29] that refers to a "holistic and individual-centered best-care practice of people with dementia" [134, p. 362]. Person-centered care was launched in dementia care in the 1990s as a response to the prevailing reductionist biomedical approach where persons with dementia were seen as "passive victims" and "sufferers" of the disease with limited degree of awareness, control and insight [135 p. 38]. The concept of 'personhood' is a central element in person-centered care and Kitwood [136] defined it as "a standing or status that is bestowed upon one human being, by others, in the context of relationship and social being. It implies recognition, respect and trust" [136, p. 8]. Therefore, personhood is established through social relationships, and well-being is asserted to be a result of the quality of relationships with others [137]. Central components of person-centered care for persons with dementia include acknowledgement of the personhood in all aspects of care, personalization of the care and the surroundings, shared decision-making, interpreting behavior from the care recipients' viewpoint and prioritizing the relationship as much as the care tasks [134, p. 363]. The ideas are recommended for clinical care because it reflects respectful, humanitarian, and ethical values in practice [134].

Although person-centered care has considerably influenced dementia care research and healthcare practices, the ideas are also criticized for highlighting the person with dementia at the expense of the rest of the family [138, p. 48]. Nolan and colleagues [139, p. 203] asserted that person-centered care "does not fully capture the interdependencies and reciprocities that underpin caring relationships”, and they further argued for a relationship-centered approach, which better reflects relational aspects of dementia care [139]. This approach recognizes the multidimensional aspects of relationships through the course of the disease [135] and the dynamic interactions between those involved in care [135, 140]. A core idea is that care is provided within a care triad comprising the person with dementia, the family caregiver and the healthcare providers [16, 135, 139], also described as a triadic relationship [139], triadic care [135] or a healthcare triad [17].

Based on previous research and theories, Fortinsky [17] presented a conceptual model of triadic dementia care, which illustrated how people with dementia, family caregivers and physicians bring different factors into an encounter. For people with dementia and family caregivers, both demographic characteristics and health-related factors are suggested to influence the encounter. The quality of the encounter can further influence health-related outcomes, for example, improved health and well-being and increased use of formal support [17]. Other studies have focused on communication and interactions among parties in dementia care triads [16, 141]. A qualitative interview study including persons with dementia and their spousal caregivers and nurses showed that members of the caregiving triad strived to balance the views of the other members against their own needs. For example, family caregivers tried to balance the perspectives of the care recipients with their own perspectives and needs, and the nurses tried to balance the needs of the person with dementia and their family caregivers. In addition, coalitions between two of the parties could occur [141]. Adverse alliances and marginalization of one of the parties within the care triad is also described by Adams and Gardiner [16], for example, that family caregivers and healthcare professionals ignore the viewpoint of the person with dementia or do not involve him/her in decision-making processes [16]. Thus, it is important to recognize each member in the care triad to ensure that all parties are involved in decision making [135].

Others have rejected relationship-centered care as an independent care approach [142, 143] and McCormack and McCance [143] claimed that the ideas were components of person-centered care or as constructs that explain different dimensions of person-centeredness. Having a person-centered approach relies on knowing the care recipients in their social context and include others significant to the care recipient and the needs of both the formal and informal caregivers [142]. In their recent work, McCormack and McCane promote the concept ‘person-centeredness’ that they define as:

> an approach to practice established through the formation and fostering of healthful relationships between all care providers, service-users and others significant to them in their lives. It is underpinned by values of respect for persons, individual right to self-determination, mutual respect and understanding. It is enabled by cultures of empowerment that foster continuous approaches to practice development [143, p. 3].

The definition points to the complexity of person-centeredness [144] and includes all relationships in any healthcare situation or context [143]. The emphasis on the relationship among the service users, care providers and significant others resembles the triadic perspective within relationship-centered care.

Although I focus on the family caregivers in this study, I also emphasize the relational aspects of dementia care. Thus, essential ideas from relationship-centered care and person-centered care influenced this study. I assume that care takes place in care triads consisting of the person with dementia, the family caregiver and healthcare professionals within the community healthcare services. The triadic care perspective recognizes the central and integrated position of family caregivers in dementia care. Based on this, I assume that family caregivers should not solely represent important caregiving resources but should be recognized and included in care and care planning as persons with needs for help and support in their own rights.

3 Study aims and research questions

The main objectives of this study were 1) to examine the use and nonuse of community healthcare services in families in which an older, home-dwelling person has dementia as reported by the family caregivers, and 2) to adapt and validate a Norwegian version of the COPE Index, which is an assessment tool that can be used to detect family caregivers in need of help and support.

In this thesis, the second main objective constitutes the first substudy, as the COPE index was used as a predictor in the analyses in subsequent substudies.

Aims of substudy I (Paper I)

The overarching aim of this substudy was to examine the psychometric properties of the Norwegian version of the COPE Index among family caregivers of older persons with dementia living at home.

The specific aims of this study were as follows:

- To examine the construct validity of the COPE Index by conducting initial exploratory and confirmatory cross-validation factor analyses and to examine if a second-order factor model may replace the primary factor model.
- To examine the criterion validity by examining if the retained COPE Index subscales and the second-order factor model correlated as expected with the included criterion variables (e.g., the World Health Organization-5 Well-Being Index).
- To examine the reliability of the retained measurement model in terms of internal consistency (Cronbach’s alpha) and stability (test-retest correlations).

Aim and research questions of substudy II (Paper II)

The overarching aim of this substudy was to explore the use and predictors of use of homebased and out-of-home respite care services available for older home-dwelling persons with dementia, as reported by their family caregivers. The research questions were as follows:

- What types of community healthcare services do older, home-dwelling persons with dementia and their family caregivers use?

- Which individual characteristics of the persons with dementia and the family caregivers are related to the use of services?
- Which factors reflecting the family caregivers' needs for help and support are associated with the use of services?

Aim and research questions of substudy III (Paper III)

The aim of this study was to examine family caregivers' knowledge of unused services and their self-reported reasons for non-use of such services. The specific research questions were as follows:

- Which demographic and socio-demographic characteristics of the family caregivers are associated with their knowledge of unused community healthcare services?
- Which factors related to the caregiving circumstances are associated with their knowledge of unused services?
- What reasons do family caregivers report for nonuse of services?

4 Materials and methods

4.1 Study design

The design of the overall PDC project was sequential, starting with a survey to family caregivers and focus group interviews with representatives of senior citizen interest groups and healthcare professionals [145, 146]. Family caregivers among the survey responders were recruited to participate in individual interviews [147, 148]. The interview studies and subsequent studies based on questionnaire data constitute independent studies and are not included in this thesis.

This study has a descriptive, cross-sectional design, and data were generated with a self-administered survey to family caregivers of older, home-dwelling persons with dementia. The study consisted of two phases: In the first phase, we developed the questionnaire, which included translation of the items and scales into Norwegian and North Sami and pilot testing. In the second phase, data were gathered, analyzed and reported.

4.2 Development of the questionnaire

We performed an extensive search for questionnaires and scales at the initial stage of the project, but no existing studies presented a fully validated instrument covering all of the purposes of the current study. Thus, we developed a questionnaire mainly based on relevant existing validated scales and items found in national and international research studies and reports. The questionnaire covered the following topics: care provided by family caregivers, social support, use and nonuse of community healthcare services, involvement of family caregivers in dementia care, family caregivers' needs and perceptions of their life situation and the caregiver role, future care, attendance of a school program for family caregivers and characteristics of the person with dementia and the family caregivers. We used an interview questionnaire, the Common Assessment Tool (CAT), as a guide in this process, and several items and scales were developed from this survey. The CAT was developed, validated and used in the EUROFAMCARE project conducted among family caregivers of older people in six European countries [81, 149]. Permission to use copyrighted scales was obtained before translation and use.

During the development of the questionnaire, we collaborated with an expert group consisting of geriatric clinical professionals and researchers experienced in the development of research instruments. Moreover, a preliminary proposal of the questionnaire was presented to the PDC projects' reference group consisting of representatives from interest groups and volunteer organizations, healthcare professionals, the Sami parliaments' council for senior citizens, an experienced university lecturer and several researchers within relevant research areas. The parties contributed valuable feedback regarding the content and design of the survey.

4.2.1 Translation and pilot test

Several of the items retrieved from the CAT questionnaire were not available in Norwegian, among other the COPE Index. The Norwegian translations conformed with the principles of the International Society for Pharmacoeconomics and Outcomes Research (ISPOR) [150]. A professional translation company specialized in patient-reported outcomes performed the translations of the English language items. The research team conducted the stages of client review and pilot testing in close collaboration with the translation company (Figure 1).

Two experienced translators who were native speakers of Norwegian and fluent in English carried out independent forward translations based on a concept elaboration document that defined each item and the conceptual meaning behind the items. An in-country investigator produced a reconciled version of the translations. Two experienced translators independently back translated the reconciled forward translation. These translators were native speakers of English and fluent in Norwegian. The research team reviewed the reconciled forward translation and the back translations against the original items and identified some sentences, words and idioms that were incompatible with the normal speech patterns and colloquialisms in the Norwegian language. The translated items were presented to the expert group, who agreed with our considerations.

The entire questionnaire, including the translated items, was pilot tested on five adult family caregivers. These represented the target population and differed with respect to age, gender, kinship with the person with dementia, educational level and years spent caregiving. We conducted individual interviews with the participants after they responded to the questionnaire. We asked them to comment on response options and on any items that were difficult to understand and to suggest alternative wordings for the items that they found difficult. We also asked the participants to describe in their own words what each item meant to them; this process is also termed cognitive debriefing. Cognitive debriefing can be used to assess the level of comprehensibility and the cognitive equivalence of the translations [150]. The participants understood the items and could describe them in their own words, and the level of cognitive equivalence was good. The participants noted the same considerations as the research team and the expert group regarding the wording of some items. We discussed this feedback with the translators who took the considerations into account; thus, the cultural acceptability of the items was good in the final version of the questionnaire.

The questionnaire was further translated to the North Sami language following the same procedure. An expert in Sami language performed reconciliation of the two forward translations, the back-translation review and proofreading of the final questionnaire. We were not able to include any Sami-lingual family caregivers to participate in a pilot study. The back-translations (performed by two independent translators) had a high degree of equivalence with the original questionnaire. Furthermore, we endeavored to translate the questionnaire into the Lule Sami language, but we were unable to find any translators. Study assistants distributed information and questionnaires in both the Sami and Norwegian languages to participants in municipalities included in the administrative area for the Sami language. Only four of the participants used the Sami-language questionnaire despite the fact that 15 of the participants reported Sami as their first language. The low use of the Sami language questionnaire is consistent with experiences from previous research [151].

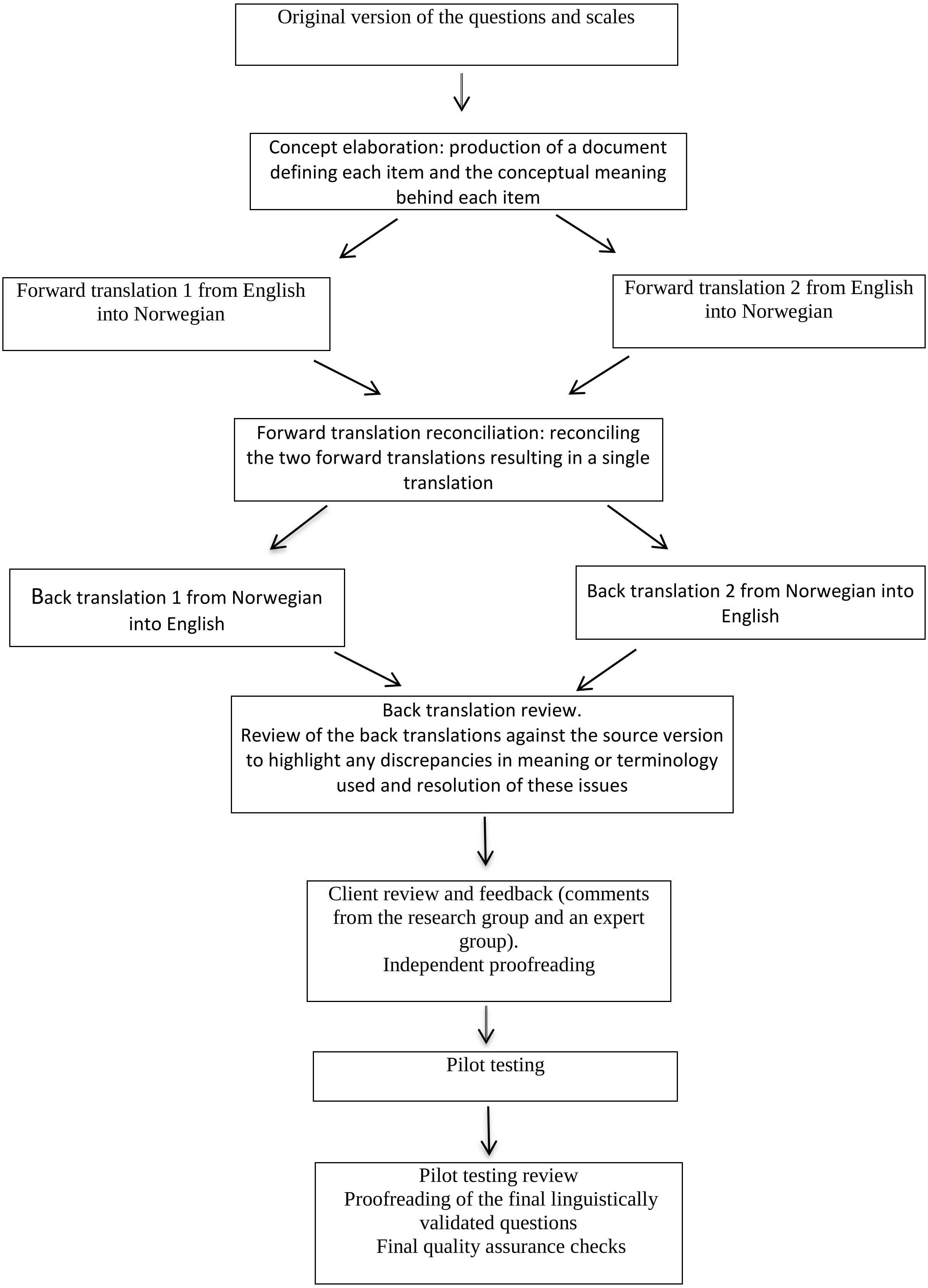

Figure 1. Flowchart of the translation procedure

4.3 Study setting and definitions

The geographical area of this study was Northern Norway, which consists of three counties. We included municipalities situated in the northern part of Nordland, Troms and Finnmark. The density of the population is Northern Norway is low, as the area covers approximately 35% of the Norwegian mainland but consists of only 9.1% of the total population [45]. There are large differences among municipalities situated in the study area with regard to geographical characteristics, number of inhabitants and age composition. Statistical trends show that typical rural municipalities are generally sparsely populated and have a higher number of older inhabitants than municipalities that include a city or a smaller town [45, 46]. In this study, we distinguished between rural and urban areas rather than types of municipalities because several municipalities include both densely populated areas and sparsely populated areas. Urban areas refer to densely populated areas such as town centers, towns or smaller towns, while rural areas refer to densely populated areas in rural municipalities (e.g., villages and municipality centers in rural municipalities) or areas in the countryside.

Northern Norway is situated within Sápmi, which is the traditional area for Sami settlements [152]. The exact size of the Sami population has not been ascertained in Norway, although estimates suggest a population size between 50 000 to 65 000 people [153]. Substantial cultural variations exist within the Sami population; for example, three Sami languages exist in Norway [115]. Previous estimates indicate that approximately 25 000 Sami speak one of these languages [154]. The history of assimilation policy and the interactions and intermarriages among several ethnic groups, i.e., Sami, Kvens (descendants of immigrants from Finland) and Norwegians, have resulted in a complex ethnic situation. Thus, there is not a straightforward way to define who are Sami and who are not Sami [145]. In this study, we defined Sami ethnicity as a self-perceived ethnicity of Sami or the perception by the family caregiver that the person with dementia was of Sami ethnicity. In addition, we considered Sami as a first language as a second marker of Sami ethnicity.

The community healthcare services included in this study are long-term care services that are considered relevant for home-dwelling persons with dementia and/or their family caregivers and include home-based services, activity services and respite care/short-term care in nursing homes. We endeavored to include statutory services and nonstatutory services available in the majority of the municipalities. The following is a short description of the services.

Home-nursing and *domestic help* refer to typical homebased services [155, p.13]. Within the public healthcare sector, home nursing is replaced and included in the broader term ‘healthcare services in home’ and domestic help is included in ‘practical assistance - activities of daily living’ [120]. In this study, we used the “old” terms ‘home-nursing’ and ‘domestic help’ as these are well established, and both the healthcare professionals and the family caregivers who participated in the development of the questionnaire were familiar with these concepts. The services are statutory and available in all municipalities. Domestic help requires out-of-pocket payment regulated by laws, while home nursing is free of charge [156].

Meal-delivery (‘meals on wheels’) refers to the delivery of ready-made meals to the care-recipient’s home. The service requires out-of-pocket payment and is not statutory [120].

Remote-control safety alarm refers to an electronic alarm the care recipient releases when acute assistance is needed. A municipal center receives the alarm, which should be followed by an individual assessment of the situation to determine whether the care recipient has a need for acute assistance [120]. The service is not statutory [44].

Day center refers to a day activity service for persons who need supervision and activities, aiming to maintain or improve the physical, mental and social function of care recipients. The content varies with regard to local conditions and the needs of the care recipients [120]. The establishment of day activity services is one of the main priority areas of the Norwegian dementia strategies, and the service will be statutory in 2020 [14, 52]. At the time of data collection, in-home day activities were rarely available for persons with dementia [53]; thus, we use the term ‘day center’ in this study.

Support persons is a statutory service that should help the care recipient with meaningful leisure time and social activities with others [120].

Respite care in a nursing home and short-term care in a nursing home refer to statutory, time-limited stays in a nursing home. Respite care aims to relieve family caregivers while short-term care aims to treat, rehabilitate or provide assistance to the care recipient [120, 156]. During the development of the questionnaire, both healthcare professionals and family caregivers noted that it was challenging to distinguish among these services; thus, these services were merged in this study. In Paper II, we used the term ‘respite care in a nursing home’. Respite care in nursing homes is free of charge, while short-term-care requires payment per 24 hours of care [156].

4.4 Recruitment of participants and data collection

4.4.1 Municipalities and research assistants

Because no registry of people with dementia diagnoses or their family caregivers was available, we collaborated with healthcare services in the municipalities to recruit participants. Initially, the research team established contact with chief officers in the local government administration and/or chief managers within the municipal healthcare services in 46 nonrandomly selected municipalities in Northern Norway. To reach Sami participants, all municipalities within (n = 21) and partially within (n = 10) the Sami Parliament subsidy scheme for cultural and economic development (STN area) were invited to participate in the study. In addition, a sample of 15 municipalities, stratified according to characteristics such as number of inhabitants, site and population composition, outside the STN area were invited to participate.

All managers received written information about the study along with an invitation to participate. In total, managers in 32 municipalities consented to participate. The main reason for not participating was lack of personal resources to assist with the recruitment of participants. The included municipalities varied with regard to geographical and demographical characteristics; 15 of the municipalities were inside, 6 were partially inside, and 11 were outside the STN area.

The managers in each of the 32 municipalities appointed research assistants to assist with data collection. All research assistants were registered nurses or licensed practical nurses and were experienced in dementia care within the homecare services or respite care services. Several were dementia coordinators and/or members of a memory team and/or had special education in geriatrics. Some of the research assistants were middle managers within the homebased services. All research assistants received written information about the study along with an inclusion scheme and written guidelines regarding the inclusion criteria and the recruitment procedures. Prior to recruitment of participants, the research team conducted telephone meetings or personal meetings or group meetings with all the research assistants that included a detailed examination of the inclusion criteria and the recruitment procedure.

4.4.2 Inclusion criteria

Inclusion criteria for family caregivers were those over 18 years of age who provided the major portion of unpaid help and support at least once a week to the person with dementia and who were an immediate family member, a more distant relative, a friend or a neighbor of the care recipient. If several family caregivers provided care, an invitation to participate was forwarded to the person who provided the most care. The included family caregivers should not have cognitive impairment themselves and should be competent in Norwegian language or in North Sami language to ensure that they understood the meaning of consent to participate. Help and support by the family caregivers were broadly defined as providing personal care, emotional and psychological support, regular visits and phone calls, help with financial matters, and organization of care [157].

Primarily, we intended to include family caregivers of persons with a dementia diagnosis. After the initial contact with the healthcare managers and the research assistants, we noticed that a large proportion of persons with cognitive impairment and symptoms consistent with dementia were undiagnosed. A low diagnosis rate is also documented in the literature and research regarding dementia [3, 6, 7, 22, 23]. Exclusion of the family caregivers of these persons would lead to a substantial loss of participants. Thus, we defined dementia as a dementia diagnosis or cognitive impairment with symptoms consistent with dementia. These symptoms include progressive memory loss and difficulties with cognitive skills [20]. If cognitive impairment was caused by other conditions (e.g., brain injury, brain tumor or delirium), the family caregivers were not included in the study. The persons with dementia should be ≥65 years of age and live at home. Home was defined as the persons’ own home or assisted living facility with access to formal care from the community healthcare services at the same level as those who lived in their own home [158]. Moreover, the persons with dementia were also required to be dependent on at least some help and support from the family caregivers to perform daily life activities.

4.4.3 Inclusion procedure

The research assistants used local healthcare service records to identify persons with dementia and their family caregivers. Each of the municipalities received a unit of serial numbers, and the research assistants assigned potential participants to a unique number. To ensure consistency, the research assistants used a standardized inclusion scheme. On behalf of the research team, the research assistants forwarded invitations to participate along with the questionnaire to family caregivers per post. Participants returned the completed questionnaire directly to the research team in a stamped and addressed envelope. Only the researchers involved in the survey study had access to the responses. We arranged telephone meetings with the research assistants about four weeks after the questionnaires were distributed to conduct a reminder procedure. Information regarding distributed and received questionnaires was shared by using the serial numbers; thus, no personal data were provided. Approximately four weeks later, we arranged new telephone meetings to identify the total number of participants in each of the municipalities. The research assistants distributed two lottery tickets worth 50 NOK (approximately 5 GBP/US$6) to the responders as a gift for participating in the study.

To examine the test-retest reliability of the COPE Index (reported in Paper I), a heterogeneous group of 40 participants was invited to complete the questionnaire a second time four weeks later. These participants had given their consent to participate in the retest in the first questionnaire.

4.4.4 Sample

Overall, the research assistants identified 860 family caregivers as potential participants. After a thorough examination of the inclusion criteria during the training of the research assistants and the inclusion procedure, 72 family caregivers were excluded from the study. Reasons for the exclusion of caregivers were insufficient contact information for the family caregivers (n = 23), admission of the care recipient to nursing home (n = 23), caregivers did not provide care (n = 10), the person with dementia did not need care (n = 8) or the care recipient died (n = 4). Some of the family caregivers contacted the research team because they did not want to participate in the study. Although we did not ask, several of the caregivers spontaneously conveyed their reasons for not participating. A few of the family caregivers considered that the person did not have cognitive impairment or dementia (n = 4). These family caregivers were excluded from the study because they did not fulfil the inclusion criteria. In total, 788 family caregivers fulfilled the inclusion criteria, and of these, 436 family caregivers returned the questionnaire. Thorough review of the questionnaires revealed six more responders who did not meet the inclusion criteria due to not providing care (n = 3), the person with dementia was <65 years of age (n = 2) and the questionnaire was not completed (n = 1). Hence, the final sample consisted of 430 family caregivers, yielding a response rate of 54.6%.

4.4.5 Data preparation

We developed a coding manual for all nominal and ordinal variables. Data from the completed questionnaires were scanned and transferred to the statistical program IBM Statistical Package for the Social Science (SPSS) for Windows. First, we checked the data for wild coding and errors by visually controlling all data in the data file against the completed questionnaires. If the data diverged, two researchers proofread the materials and corrected the mistakes in the data file. Next, we used frequency analysis to assess the data for outliers and for missing data. Outliers were scrutinized, as such data can distort study results and cause errors in statistical decision making [159, p. 433].

The string variables in the SPSS data file were controlled against the written text in the questionnaires. The research team corrected minor typos due to scanning. We anonymized text data in cases, e.g., when names of places or institutions were given. A Sami language expert at the UiT The arctic university of Norway translated text data written in Sami into Norwegian.

4.5 Measures

4.5.1 Demographic and socio-demographic variables

An overview of the variables used in the papers is presented in Table 1. Demographic characteristics of family caregivers included age, gender, marital status and ethnicity, while sociodemographic characteristics included education level, income level and employment status. Characteristics of the persons with dementia included age, gender, ethnicity, urban/rural place of residence, cohabitation status, living in an assisted living facility, and ability to manage themselves alone. The variables and procedures regarding merging of the response options and coding are described in Papers II and III. In the following, single items and scales are outlined.

4.5.2 Single items

Demands of caregiving were assessed with a single item drawn from a Norwegian survey that previously was used to evaluate school programs for family caregivers [160]. The item was adapted for this study and we asked the responders: "How demanding do you think it is to help the person?" (Item 17 in Appendices 6 and 7). The response options were recorded on a four-point scale ranging from very demanding (coded as 1) to not demanding (coded as 4). In Paper I, we used the item to assess the criterion validity of the COPE Index. We assumed that higher scores on the COPE subscales (e.g., low negative impact) were correlated with higher scores on the item (less demanding). Before the analysis in Paper II, we reversed the response options from not demanding (coded as 1) to very demanding (coded as 4). We used the item as a predictor, and we assumed that those who experienced caregiving as demanding used more healthcare services.

General health status was assessed by using the following item from the Tromsø study [161]: ”How would you rate your health overall?” (Item 38). The response options were recorded using a five-point scale ranging from very good (coded as 1) to very poor (coded as 5). In Paper I, we used the item to assess criterion validity, and we assumed that higher scores on the COPE subscales (e.g., less negative impact) were correlated with lower scores on the item (better health). In Paper II, the item was used as a predictor, and we assumed that those with poor health had higher needs for and greater use of healthcare services. The scores followed a curve linear distribution, which was transformed by squaring the scores before the regression analyses.

Use of community healthcare services was determined with the following item: "Which healthcare services does the person receive from the municipality?" (Item 21). The item was drawn from a previous Norwegian survey evaluating a caregiver school program [160], and the response options were home nursing, domestic help, support person, day center and short-term care/respite care in a nursing home. We added two relevant services, namely, meal delivery (named meals on wheels in Paper II) and remote-control safety alarm. Family caregivers should tick off all services that were used (coded as 1). Those not ticked off were rated as nonuse (coded as 0). Principal component analysis (PCA) of the seven variables extracted two components with eigenvalues >1, c.f., the Kaisers criterion, which accounted for 44.1% of the total variance. The first component was labeled homebased services and accounted for home nursing, domestic help, meal delivery and remote-control safety alarm. The second component was labeled respite care services and accounted for a support person, day center and short-term care/respite care in a nursing home. In Paper II, we used the average scores of the number of services in each component as dependent variables. In Paper III, the respective services types were used as predictors of knowledge of services, and we assumed that those who knew of unused services used fewer services than those who reported unawareness of unused services.

Knowledge of unused community healthcare services was assessed by the following categorical item: "Are there any community healthcare services that are still unused?" As an explanation, we added the following text: "We are thinking about services you have knowledge of and that can contribute to helping and supporting the person and/or relieving yourself" (Item 24). The response categories were "Yes", "No" and "I do not know". Moreover, we asked those who reported knowledge of unused services to describe their reasons for not using the services in their own words in an open-ended question. The research group created the question, as we did not obtain any appropriate items or scales regarding knowledge of unused services and reasons for nonuse. In Paper III, we used the categorical item as a dependent variable. We labeled the response options as follows: the "yes" category was labeled "knowledge of unused services" (coded as 0), the "no" category was labeled "unawareness of unused services" (coded as 1) and the "I do not know" category was labeled "uncertainty about unused services" (coded as 2).

Perceived information level was drawn from a generic scale assessing patients' experiences with specialized healthcare services [162]. We adapted the item for this study, and we asked the participants: "Have you received information regarding available healthcare services in your municipality?" (Item 27a). The response options were given on a five-point scale ranging from "not at all" (coded as 1) to "a very high degree" (coded as 5). A "not applicable" option was coded as missing (n = 18). The item was used as a predictor in the quantitative analysis in Paper III, and we assumed that those who reported high information levels knew of unused community healthcare services.

4.5.3 Scales

The Carers for Older People in Europe Index (The COPE Index) is described in the Background chapter of this thesis. The original index consists of 15 items (Item 41). The scale was translated into Norwegian using the procedure as previously described. The response options were recorded using a four-point scale: ‘never’, ‘sometimes’, ‘often’ and ‘always’, where higher scores on the subscales indicate less negative impact, greater positive values of caregiving and greater social support. A “not applicable” response option was added to five items regarding how caregiving influenced relationships with friends and family and how caregiving influenced support from friends/neighbors, family and healthcare services. Based on the results from Paper I, the total COPE index was used as a predictor of use of community healthcare services (Paper II) and knowledge of unused services (Paper III). The rationale for using the index in the analyses was that we assumed that a higher negative impact of caregiving could influence the needs for and use of services and the family caregivers’ knowledge of unused services. In the analyses, we used the average score of all item raw scores (range 1 - 4), where lower scores indicated a greater negative impact of caregiving.

The World Health Organization-5 Well-Being Index (WHO-5) is a generic scale that assesses the family caregivers’ subjective perception of well-being (Item 40). The five items indicate how well or unwell the respondents had felt over the last two weeks. The responses were recorded using a six-point scale ranging from all the time (coded as 5) to never (coded as 0), where higher scores indicate better well-being. The scale has been used to measure subjective quality of life [163], and a review demonstrated that the scale was sensitive as a screening tool for depression [164]. The applicability of the scale across study fields is considered to be very high [164], and the scale has previously demonstrated good validity in terms of construct and criterion validity [163, 164] and good reliability in terms of internal consistency [163]. In this study, Cronbach’s alpha was high (0.92). In the analyses, we used the average of the raw scores of all items. In Paper I, we used the scale in evaluation of the criterion validity of the COPE Index, and we assumed that higher scores on the COPE subscales (e.g., less negative impact of caregiving) were correlated with higher scores (better well-being) on the WHO-5. In Paper II, we used the WHO-5 as a predictor, and we assumed that a lower level of well-being was associated with greater use of healthcare services. The items had a relatively large proportion of missing data (ranging between 4 - 7.7%).

The Modified Social Restriction Scale (M-SRS) was drawn from the CAT survey used in the EUROFAMCARE study [81, 149] and consists of two items that assess caregiving role inflexibility by measuring the ease of obtaining help to provide care for the person with dementia if the family caregiver became ill or needed a break from caregiving (Item 19 and 20). The response options were “Yes, I could find someone quite easily (coded as 1), “Yes, I could find someone but with some difficulties” (coded as 2), and “No, there is no one” (coded as 3). Previous studies have demonstrated good reliability in terms of internal consistency measured by Cronbach’s alpha (0.74-0.89) [81, 165]. A study among family caregivers of older people reported acceptable concurrent validity of the scale [165]. In this study, the internal consistency was good ($\alpha = 0.84$). We used the scale in the evaluation of the criterion validity of the COPE Index in Paper I. We assumed that higher scores on the COPE subscales (e.g., higher quality of social support) were correlated with lower scores on the M-SRS (low social restriction).

Table 1. Variables used in Papers I, II and III

Variables (Item number in the questionnaire)	Paper I	Paper II		Paper III
	Family caregiver	Person with dementia	Family caregiver	Family caregiver
Demographics and sociodemographics				
Gender (Item 1 and 49)	X	X	X	X
Age (Item 2 and 50)	X	X	X	X
Kinship relationship (Item 5)	X		X	X
Marital status (Item 51)	X			
Ethnicity (Item 3, 4, 52 and 54)	X	X	X	X
Urban/rural place of residence (Item 10)		X		
Cohabitation with family caregiver (Item 6)		X		
Assisted living facility (Item 8)		X		
Education level (Item 55)			X	X
Employment (Item 56)			X	X
Income (Item 59)			X	X
Single items				
Ability to manage being alone (Item 9)		X		
Duration of caregiving (Item 12)			X	X
Demand of caregiving (Item 17)	X		X	
General health status (Item 38)	X		X	
Homebased services (Item 21)			X	X
Respite care services (Item 21)			X	X
Knowledge of unused service (Item 24)				X
Perceived information level (Item 27)				X
Scales				
The COPE Index (Item 41)	X		X	X
The WHO-5 (Item 40)	X		X	
The M-SRS (item 19 and 20)	X			

4.6 Data analyses

In Paper I, we used IBM SPSS Statistics for Windows version 23.0 for all analyses except for the CFA, which was conducted using Mplus 7.4 [166]. In Papers II and III, IBM SPSS Statistics for Windows version 24.0 was used for all analyses, except for the multiple imputation of the missing questionnaire data related to the COPE Index and the WHO-5, which was conducted using the expectation maximization (EM) function in PRELIS/LISREL 9.20 for Windows [167].

We used graphs to visually inspect the variables with regard to normality, and explorative statistics were used to assess skewness and kurtosis of the measures. Descriptive characteristics of the study population are presented as the mean and standard deviation (SD) for continuous variables or as the proportion of subjects within the categories.

In Paper III, we included those who responded to the dependent variable (knowledge of unused services) in the analyses; thus, the numbers of participants and the descriptive characteristics vary slightly between the first two papers and Paper III ($n = 430$ and $n = 419$, respectively).

The level of statistical significance was set to two-sided p values <0.05.

Paper I

In this study, we examined the psychometric properties of the Norwegian version of the COPE Index. In the initial analysis, one item measuring the financial implications of caregiving appeared to be uncorrelated to any of the factors. Thus, we excluded the item from further analysis. We examined construct validity by a cross-validation approach. The sample was randomly split ($n_1 = 215$ and $n_2 = 215$). The first half of the sample was used to identify the measurement model using an exploratory factor analysis (EFA). We used principal axis factoring method, and because correlations between factors were expected, the solution was promax rotated. A scree plot of the eigenvalues was examined. Factors with eigenvalues >1 were extracted, and factor loadings <0.4 were suppressed. The second half of the sample was used to cross-validate the model using a confirmatory factor analysis. The CFA-estimated factor scores and loadings were extracted using the robust maximum likelihood methods because several items had negatively or positively skewed distributions. The model fit was examined using the comparative fit index (CFI), the Tucker-Lewis Index (TLI), the root mean square error of approximation (RMSEA) and the chi-square test. A CFI/TLI close to 0.95 and a RMSEA close to 0.06 indicate a good model fit [168]. Spearman's rank order correlation was used to assess the criterion validity by examining the correlations between the COPE Index factors and the criterion variables and to examine test-retest reliability. In addition, we used Cronbach's alpha to assess the internal consistency of the extracted factors.

Missing data points due to selection of the "not applicable" option as a response for five of the items (7.2% -23.5%) were not found to be missing completely at random, as assessed by Little's Missing Completely at Random (MCAR) test. We did not consider imputation of the data feasible in this study because the imputation model could differ from the analysis model; thus, the missing values were excluded pairwise.

Paper II

In this study, we examined the use of homebased services and out-of-home respite care services (dependent variables) and factors associated with the use of the respective services. We intended to use the COPE Index and the WHO-5 as predictors of service use, but we realized that the missing data related to the scales would result in large proportions of deleted cases in the regression analyses. We decided to impute missing data by using the expectation maximization (EM) method, which involves an iterative procedure with a maximum-likelihood-based algorithm to produce the best parameter estimates [159, p. 432].

Crude relationships between the dependent and independent variables were explored using Pearson's correlation, Student's t-test or analysis of variance (ANOVA) for continuous scores and Spearman's rank order correlation, the Mann-Whitney U-test or the Kruskal-Walllis test for ranked scores. The scores on the dependent variable representing homebased services followed a normal distribution; hence, the associations with the independent variables were assessed by using linear multiple regression analysis with a backward stepwise procedure. The scores of the dependent variable reflecting respite care services followed a Poisson distribution; hence, Poisson regression analyses were performed. In the respective regression analyses, we explored two different models. The first included independent variables regarding characteristics of the person with dementia, and the second included characteristics of the family caregivers and factors that could affect the family caregivers' need for healthcare services (e.g., the COPE Index). The goodness-of-fit of the linear regression models and the Poisson models were assessed by the adjusted R^2 and by the Pearson chi square statistic, respectively.

Paper III

In this substudy, the crude relationships among those who reported knowledge of unused community healthcare services, those who reported unawareness of unused services and those who reported uncertainty about unused services were examined by using the ANOVA/Kruskal-Wallis test for continuous variables and Pearson's chi-square/Fisher's exact test for nominal data. A Bonferroni-corrected significance level of $p < 0.01$ was applied due to the number of tests performed. In this paper, we reported the results of the ANOVA analyses, although some of the independent variables were not normally distributed. For these variables, we additionally conducted Kruskal-Wallis tests to control the group differences and the level of significance. The results did not differ, and we decided to retain the ANOVA results due to the post hoc tests (Bonferroni correction). The relationship between knowledge of unused services and the independent variables was examined using a multinomial logistic regression analysis with a backward stepwise regression procedure. The goodness-of-fit of the model was assessed by the Nagelkerke pseudo R^2 and the Pearson chi square statistic.

We analyzed an open-ended question regarding family caregivers' self-reported reasons for not using community healthcare services. This was a follow-up question to the initial question regarding knowledge of services (Item 24). Overall, 174 participants responded to this question, which was slightly more than those who reported knowledge of unused services. All text data were included in the subsequent analysis because a few of the participants who reported uncertainty about unused services stated their reasons, e.g., insufficient information about available services or that they did not need additional services. The length of the written responses varied from short notes to lengthy sentences that consisted of approximately 200 words.

We analyzed the text material according to the principles of thematic text analyses, as described by Braun and Clarke [169]. The method involves searching across the data set to find repeated patterns of meaning. The analysis could be inductive or theory driven, and the method is described as flexible because different theoretical frameworks can be used [169]. Although we endeavored to approach the data open-mindedly, the analysis was theory driven because we were informed by the care triad described in relationship-centered care and person-centered care approaches [135, 139, 143]. Hence, we assumed that reasons for nonuse of services could be related to the person with dementia, the family caregiver and the community healthcare services. In accordance with the phases of the thematic analysis described by Braun and Clarke [169], we initially read the data several times. Next, the entire data set was coded, and then, the codes were collated into potential themes. The themes were further reviewed, revised and finally named. The analysis process was recursive, which means that we moved back and forth between the different phases. The appropriateness of the codes and themes was continuously evaluated against the aim of the study and the research question [169]. An example of coding and collations of themes is presented in Table 2.

One of my supervisors (BHB) and I independently carried out the initial analysis and subsequently met to discuss the initial themes and conduct the sorting of codes in broader themes. Such investigator triangulation reduces the risks for biased interpretation and decisions [159, p. 566]. Overall, there was high consistency between the researchers regarding the coding and composition of themes. Discrepancies were solved through inspection of the data, reanalysis and consensus discussions.

Table 2. Examples of codes, subthemes and themes of the thematic text analysis

Text from the open-ended question	Code	Subtheme	Theme
“In the autumn, we found a place for her at the day center. Until then, I was alone with the care responsibilities, and I did not know of available services (…). At that point in time, I was exhausted. Friends contacted the community healthcare services (…).The day centre is now a great help for us. I feel that the information from general practitioners about the disease and available healthcare services is insufficient. This disease may still not be talked about, or kept within the family (…)”	Family caregiver had substantial needs for services Family caregiver received insufficient information about available services	The services did not meet the needs	Reason related to aspects of healthcare services
“We live 25 km from the town center. My request regarding an activity service for the person with dementia was refused because we lived far away from the town”	Family caregiver has applied for services but the application was declined due to long travel distance	Family caregiver had applied for but did not receive services	
“I think it is the best for him that several strangers are not involved in his care. A support person would be fine, but the municipality has problems finding someone”	Family caregiver does not want to involve strangers (healthcare professionals) in care Low availability of needed service	Family caregiver is reluctant to use services The services did not meet the needs	Reasons related to the family caregivers and the healthcare services
“I want to manage on my own. Meal delivery was previously used, but since we received all dinners for the week at the same time, there was a practical problem with storage of the food. Therefore, we stopped using the service”	Family caregiver wants to take on the care responsibilities The service is not suitable for the family’s needs	Family caregiver did not yet need services The services did not meet the needs	

4.7 Ethical considerations and approvals

The study was performed in accordance with the Helsinki declaration for research ethics [170]. The Regional Committee for Medical and Health Research Ethics for Northern Norway evaluated the study and concluded that their approval was not required (Ref. No. 2015/1107/REK North) (Appendix 1). The study, including the data collection procedure, obtaining informed consent and the data handling procedure, was approved by the Norwegian Centre for Research Data (NSD) (Ref. No.2015/43778/3/KS) (Appendix 2). In accordance with comments from both authorities, we restricted data collection regarding persons with dementia to a few demographic characteristics, the degree of dependency of help and support and formal/informal care provided. Hence, we did not have the opportunity to collect data regarding the health and functional status of the care recipients without their consent.

All municipalities involved in the recruitment of participants gave written informed consent to participate in the study (Appendix 3). In the written guidelines regarding the inclusion procedure and during the individual training of the research assistants, the research team emphasized how to safely store the study material and how to secure anonymity and confidentiality of the participants. All inclusion records were securely stored, and unauthorized persons did not have access to the data. The inclusion records were stored for approximately six months in case any of the participants wanted to withdraw from the study after submission of the questionnaire.

Along with the questionnaire, all invited family caregivers received written information about the study and that participation was voluntary (Appendices 4 and 5). Confidentiality and anonymity were guaranteed. In the information letter, the family caregivers were informed that they consented to participate by completing and returning the questionnaire to the research team. All invited family caregivers had the opportunity to contact a person in the research team if they needed more information about the study, had questions or needed help filling out the questionnaire. Some contacted us to convey that they did not want to participate or to ensure that they were in the target group for the study. A few invitees asked for more information about the study. None of the responders withdrew from the study after responding.

In the information letter and the questionnaire, we asked the participants if they wanted to participate in individual interviews. Family caregivers who wanted to participate provided their contact information on an attached sheet in the questionnaire. Overall, 189 participants consented to be interviewed. Their contact information was not scanned into the data file, and the contact information sheets were securely stored with the questionnaires. Only a few members of the research team had access to the data. In total, 30 interviews were performed, and the interview data were used in the qualitative substudies of the overall research project. The results from these studies are reported in papers independently from this study [147, 148]. After the interviews, the contact information sheets were shredded.

5 Results

This chapter provides a summary of the main findings of Papers I-III.

5.1 Paper I

The main objective of this substudy was to examine the psychometric properties of the Norwegian version of the COPE Index among family caregivers (n = 430) of older persons with dementia living at home. The exploratory factor analysis revealed three factors with eigenvalues >1, explaining 58% of the variance. These were labeled negative impact, quality of support and positive values. The factor model was comparable to previously published models based on EFA [81-83]. In the confirmatory factor analysis, the three-factor model had a good model fit in terms of both misspecification (RMSEA) and relative fit (CFI and TLI). Moreover, we found that a more parsimonious model specifying a second-order factor, which accounted for the correlation among the three primary factors, fit the data equally as well as the correlated three factor model. This finding supports the use of the total COPE Index score as a general indicator of family caregivers' appraisal of the caregiving role.

We assessed the criterion validity of the COPE Index by examining whether the bivariate correlations between the extracted factors and the criterion variables were in the expected directions. Overall, the criterion validity was good. The negative impact factor was strongly correlated with the variables that measured demands of caregiving and well-being (WHO-5), while the correlations with the other criteria were moderate. The factors of quality of support and positive values had significant correlations with the criteria in the expected directions, although the level of associations ranged from weak to moderate. The second-order factor was strongly correlated with the WHO-5, while the levels of correlations with the other criteria were moderate. This finding might indicate that the general COPE factor is related to aspects of well-being or burden/negative impact associated with caregiving. However, the exact meaning of the factor was difficult to define due to the limited number of selected criterion variables.

Finally, we conducted reliability analyses in terms of test-retest reliability and internal consistency of the extracted factors. To examine test-retest reliability, a heterogeneous sample of 32 family caregivers completed the questionnaire a second time after four weeks. The negative impact and the positive value factors had high test-retest correlations (r = 0.91 and r = 0.92, respectively), while the quality of the support factor had a lower but still acceptable correlation (r = 0.76). The negative impact and the quality of support factors had good internal consistency using Cronbach's alpha (α = 0.86 and α = 0.76, respectively), while the result for the positive values factor (α = 0.64) was lower than the recommended value of 0.7 [171, p. 83]. This result is compatible with findings from previous studies [81-83]. The internal consistency of the total COPE Index was good (α = 0.87; the value is reported in Paper II).

Overall, the psychometric properties of the COPE Index tested among family caregivers of older persons with dementia were good. We concluded that the instrument can be used by healthcare professionals to assess the situation of family caregivers across the three primary factors reflecting negative impact, positive values and quality of support or, alternatively, validly summarizes the factors in global impact of caregiving score.

5.2 Paper II

The main objective of this substudy was to explore the use and predictors of use of homebased services and out-of-home respite care services available to older home-dwelling persons with dementia, as reported by the family caregivers (*n* = 430). We found that persons with dementia used an average of 1.97 (SD = 1.28) homebased services, and the majority used home nursing (80.2%) followed by domestic help (47%). Approximately one-third of all persons with dementia used meal delivery and a remote-control safety alarm. Based on previous research, we assumed that the characteristics of both the person with dementia and the family caregivers could predict service use. In addition, we assumed that factors reflecting the caregiving circumstances and the family caregivers' needs could influence the use of services. Multiple regression analyses were used to assess the predictors of use of homebased services. The use of more homebased services among persons with dementia was predicted by higher age (p <0.001); living in an urban area (p = 0.003); and living in an assisted living facility (p = 0.01). Cohabiting with the family caregiver (p <0.001) and the ability to manage alone >24 hours (p = 0.001) were negatively associated with the use of homebased services. Comparable analyses of the family caregiver revealed that the use of more home-based services was predicted by higher age (p = 0.001); being a daughter (p <0.001), son (p <0.001) or other kin (p <0.001) (spouse was the reference group); higher education (p = 0.004); and full-time employment (p = 0.008). Those confirming two Sami ethnicity markers (self-perceived ethnicity and first language) used fewer homebased services (p = 0.012). None of the predictors reflecting the family caregivers' needs for services predicted the use of homebased services.

Respite care services were used to a lesser extent than homebased services. Persons with dementia used an average of 0.56 (SD = 0.72) respite care services. The majority of persons with dementia did not use any of the services (56%), while approximately one-third used one of the services. Day centers were used most often (26%) followed by respite care in a nursing home (16.5%) and a support person (13.5%). Poisson regression analyses were conducted to assess predictors of the use of respite care services. For persons with dementia, the odds of using more of these services were higher among males than females (OR = 1.43, p = 0.004) and higher among those living in urban areas than those living in rural areas (OR = 1.36, p = 0.014). For family caregivers, the odds of using respite care services were lower among males than females (OR = 0.70, p = 0.032) and lower among daughters than spouses (OR = 0.68, p = 0.01). The following two predictors reflecting the family caregivers' needs for services increased the odds of using more respite care services: perception of caregiving as more demanding (OR = 1.29, p = 0.001) and longer duration of caregiving (OR = 1.05, p = 0.003).

The study indicated variation in the use of homebased and respite care services among home-dwelling persons with dementia and their family caregivers. We concluded that in order to ensure equity in service use, healthcare services should be tailored to all families in need of support and to particular groups of persons with dementia and family caregivers, such as those who live in rural areas, the Sami, spouses and family caregivers with lower education levels.

5.3 Paper III

The main objective of this substudy was to examine family caregivers' knowledge of unused services and their self-reported reasons for non-use of such services. The results showed that 40.2% of family caregivers reported knowledge of unused services, 11.6% reported unawareness of unused services, and 45.6% reported uncertainty about unused services. In total, 419 family caregivers responded to the dependent variable and were included in the subsequent analysis (missing data points = 2.6%). We assumed that the demographic and sociodemographic characteristics of the family caregivers and factors related to the caregiving circumstances could predict knowledge of unused services. Multinomial regression analysis demonstrated that the use of more homebased services and higher scores on the COPE Index (less negative impact of caregiving) increased the odds of reporting unawareness of unused services (OR = 1.94, $p < 0.001$ and OR = 2.95, $p = 0.015$, respectively). Family caregivers with elementary school or high school education levels had higher odds of reporting uncertainty regarding unused services (OR = 4.51, $p < 0.001$ and OR = 2.57, $p = 0.01$, respectively) than family caregivers with higher education levels. Using more homebased services increased the odds of reporting uncertainty regarding unused services (OR = 1.42, $p = 0.002$). Daughters and family caregivers who scored higher for perceived information level had lower odds of reporting uncertainty regarding unused services (OR = 0.28, $p = 0.006$ and OR = 0.65, $p = 0.001$, respectively) than other kin groups and caregivers who had lower scores on perceived information level.

Family caregivers' reasons for the non-use of community healthcare services were explored by using qualitative text analysis of written responses to an open-ended question. The first theme comprised reasons related to the person with dementia. Several of the family caregivers reported that the person with dementia was reluctant to use services. The reasons for their reluctance were diverse, but the persons could lack insight into their own situation or deny a need for help. Family caregivers indicated that reluctance regarding service use could be an unresolved problem, as family caregivers recognized a high need for help and support. Others reported that the person with dementia had a good functional level and did not yet need additional services. The second theme comprised reasons related to the family caregivers. Several family caregivers reported that they did not yet need services despite the fact that some family caregivers reported high efforts related to caregiving. Family caregivers were also reluctant to use healthcare services. The third theme comprised reasons related to aspects of healthcare services. The aspects included services applied for but not received, services previously used that did not meet the needs of the person with dementia or of the family caregivers, or services considered of poor quality. Several of the family caregivers' responses were related to aspects that touched on multiple themes; hence, the fourth theme comprised reasons related to the person with dementia and/or the family caregiver and/or the healthcare services. For example, the family caregivers' reluctance to use services was often closely related to the reluctance of the person with dementia, as the family caregivers could not force the person with dementia to use the services. Although services were unused, several family caregivers indicated substantial needs for the services.

The study showed that family caregivers’ knowledge of unused services varied among demographic and social subgroups of family caregivers, and the reasons for nonuse of services were multifaceted and complex. We suggest that healthcare professionals should provide individually adapted information about available services and information about the benefits of service use for both the person with dementia and the family caregivers. To ensure utilization of community healthcare services, the services should be adapted in accordance with both the care-recipients’ and the family caregivers’ needs. Hence, we recommended a relationship-centered approach to dementia care.

6 Discussion

In this section, I will provide a general discussion of the main results followed by a discussion of methodological considerations related to the study. The chapter ends with possible implications of the findings for future research, community healthcare services and health policy.

6.1 Discussion of the main results

6.1.1 Utilization of homebased and respite care services

Overall, the results demonstrated that the use of homebased services was high, and the persons with dementia used an average of two out of four services. Approximately four-fifths used home nursing, about one-half used domestic help and one-third used remote control safety alarm and meal delivery (Paper II). The use of services found in this study was considerably higher than that reported in a Norwegian study regarding resource use and disease course in dementia (the REDIC study), wherein approximately half of all home-dwelling persons with dementia used home nursing, one-fourth used domestic help, and one-fifth used meal delivery shortly before admission to nursing homes [9]. The average use of home nursing in the present study was also higher than reported in other Nordic studies that investigated service use among home-dwelling persons with dementia [102, 103]. Other studies have reported results comparable to those in this study. A report from the Norwegian Directorate of Health showed that the majority of persons diagnosed with dementia received both home nursing and domestic help, but the use of other relevant homebased services is limited. Persons with dementia used more services than persons without dementia, but they also had more comprehensive care needs than other care recipients [51]. A previous study from the US found that family caregivers of persons with dementia used a range of services to assist them in care. Although the majority of caregivers reported high levels of service use, they still indicated high needs for additional services [172]. This corresponds with findings from our study as several family caregivers indicated substantial needs for the unused services (Paper III).

In this study, the high number of users of homebased services could be explained by the recruitment procedure, as the majority of the study assistants were employed as homebased service providers and used local records to identify potential participants. On the other hand, home nursing and domestic care are statutory services that should be available for all persons in need of healthcare [44], and the extensive use of the services might indicate high accessibility and high coverage rates of these services. A Norwegian survey showed that home nursing, domestic care and remote control safety alarms served as typical “introduction” services to older care recipients who had recently started using services, which means that these services represent the lowest level of effective care [36]. The allocation of services in accordance with the LEON principle could explain the differences in the use of homebased services and respite care services in this study because homebased services might represent a lower level of effective care than respite care services.

The use of respite care services was low, and persons with dementia used an average of only 0.56 services. The results demonstrated that more than half of all persons with dementia did not use any of the three included services. The use of day centers was somewhat higher than reported in the REDIC study [9] (26% and 20%, respectively) (Paper II). As the majority of municipalities had established day centers at the time for data collection [53], I expected that even more persons with dementia would have been using the service in this study. The low use of day centers can be explained by the restricted capacity of the services. In 2014, the estimated number of available places corresponded to approximately one-sixth of all home-dwelling persons with dementia, and there were almost two users per available day center place [53].

In this study, some family caregivers reported that day centers were not used due to the lack of appropriate activities, the long distances between the person’s home and the locations of day centers, and insufficient transportation services (Paper III). It is possible that day centers represent a new type of service among more established services and that this service was under development in the municipalities at the time of data collection. Day centers and other day activity services intend to provide persons with dementia the opportunity to engage in meaningful and beneficial activities and experiences, to serve as respite care for family caregivers during the daytime, and ultimately, to delay admission to a nursing home [52]. Thus, municipalities should endeavor to provide services that correspond to the needs of the families and to increase their availability for those who live in rural areas, for example, by providing flexible transportation services.

A support person is a statutory service that should provide social activities and meaningful leisure time for the care recipients [120, 173]. In addition, the service can provide the family caregivers respite from care obligations [173]. In this study, we found that this service was used the least (13.5%) (Paper II). Although approximately 65% of the municipalities offered the service to person with dementia in 2014, the coverage could be lower due to difficulties finding appropriate support persons [53]. This complies with findings from this study, as some family caregivers reported low availability of support persons (Paper III). A national survey based on register data showed that approximately one-fifth of those who utilized support persons were older care recipients (>67 years of age) [97]. In a study of five municipalities, case managers allocating services considered that being younger in age was compatible with an active lifestyle and being older of age was compatible with a more passive lifestyle. Thus, older care recipients had a lower probability of receiving services such as personal assistance or support persons [39], which may indicate an unintended variation in the use of support persons among younger and older care recipient in favor of younger people. A support person might be useful for persons with dementia because they are able to interact with the same person over time, thus, increasing the feeling of confidence both for the care recipients and the family caregivers.

In this study, one-sixth of the persons with dementia used short-term care or respite care in nursing homes (Paper II). Recent estimates demonstrate that almost all Norwegian municipalities offer residential respite care for family caregivers [23], and due to the extensive health policy focus on respite care for family caregivers, I had expected that even more would have used these services. A study regarding municipal respite care services showed that respite care in nursing homes often was provided on a regular basis, e.g., four weeks at home and two weeks in the nursing home. The number of available places could be restricted, particularly in the largest municipalities. This could result in challenges regarding regular respite care for persons with dementia [173]. However, low use of residential respite care can be related to the person with dementia and/or the family caregivers. In this study, several family caregivers reported that the care recipient was reluctant to use the service (Paper III). The findings from an Irish study among persons with dementia suggested that although the persons with dementia preferred home-based respite care, they perceived day services as more acceptable than residential respite care [174]. In a Norwegian study, spouses of persons with dementia experienced short-term care as “a place of storage” and they preferred to provide care at home. However, they were prepared to accept the service if they knew that the care recipients were satisfied when they returned back home [175, p. 4].

A support person is allocated based on the needs of the care recipient, while day center and short-term care in a nursing home are allocated based on the needs of the person with dementia or as respite care to family caregivers [173]. We found that one of the main reasons for the nonuse of services was that one or more services were applied for but not received (Paper III). Several of the respondents described lengthy processing time or waiting lists, while others reported that their applications had been rejected. These aspects were particularly related to services in terms of support persons, respite care in nursing homes and long-term care in nursing homes. Overall, family caregivers reported an extensive need for the services they had applied for, either to fulfill the needs of the person with dementia or as respite care for themselves. Studies have suggested that restricted formal resources might result in prioritization among care recipients with similar care needs, for example, by giving lower priority or allocating less services to care recipients with access to help and support from the family [176, 177]. Such practices are incongruent with the principle of universalism. In a Norwegian study, interviews with case managers showed difficulties regarding separating real needs for services from family caregivers' concerns. For example, spouses could apply for respite care in nursing homes because they were worried about insufficient help and support at home. Moreover, adult children's applications for respite care could reflect worries rather than actual needs for the service. In such cases, the case managers could offer more homebased services instead of respite care [173]. In this study, some of the family caregivers reported that the healthcare professional lacked insight into the situation of the family (Paper III). Thus, the needs of the person with dementia and their family caregivers should be thoroughly assessed before services are allocated to adapt services in accordance with the families' needs.

Variation in the use of healthcare services might be a consequence of the degree of information and knowledge of services among those in need of help and support. Unawareness of services and lack of information about available services are previously related to the nonuse of services among family caregivers of persons with dementia [127, 130, 131, 178]. In this study, those who reported unawareness of unused services and uncertainty about unused services used more homebased services than those who reported knowledge of unused services, while the use of respite care services was comparable between the groups (Paper III). This finding might indicate that family caregivers who used fewer homebased services were aware of them, while those who reported unawareness or uncertainty regarding unused services received more services. An important finding was that those who reported uncertainty of unused services had a significantly lower information level than those who reported knowledge of unused services. In addition, several of those who knew of unused services reported lack of information about the services as a reason for why services were unused (Paper III).

Information about available healthcare services may be crucial to help persons with dementia and family caregivers find adequate services corresponding with their needs. In a Swedish interview study, family caregivers reported an increased need for formal care as the dementia disease progressed, while formal healthcare services did not respond adequately to their needs. Several of the family caregivers struggled to find information regarding how to get in contact with the services [179]. A recent systematic review regarding family caregivers of older care recipients demonstrated that family caregivers needed more information exchange with the homebased services and help navigating community healthcare services [144]. Altogether, the findings from the present study and previous research suggest that information about available services and assistance finding relevant services should be improved at the municipal level.

6.1.2 Intended and unintended variations in the utilization of services

Variations in access to and the use of healthcare services can be classified as intended and unintended variations [48]. In this study, some factors related to service use might represent intended variations, e.g., that higher age among persons with dementia and family caregivers predicted the use of more homebased services (Paper II). It is reasonable that higher age is related to higher care needs, as comorbidities more frequently occur as age increases [2, 3], and older family caregivers might have more needs for help and support due to their declining health [110]. Moreover, persons with dementia managing alone more than 24 hours used significantly fewer services than those who managed less than 2 hours alone. This might reflect intended variation in service use, as I assume that those who managed for a long time alone were less dependent on help and support. The duration of caregiving was not associated with the use of homebased services but predicted the use of respite care services, which can be interpreted as intended variations in service use through the course of dementia. Homebased services might be introduced at an earlier phase of the disease (in line with the LEON principle), while respite care is introduced when the needs increase. Although this variation may seem logical, support and interventions for family caregivers should take place along the course of caregiving, from the initial diagnosis to the end-of-life care [1]. In addition, persons with dementia are disposed to social isolation [3, 12], and it is reasonable that meaningful social activity services might improve their quality of life. We found that several of the persons with dementia were reluctant to use services, among other respite care services (Paper III). It is possible that the introduction of the services at an early stage of the disease could increase the acceptability of services. In a cross-national European study, healthcare professionals reported that early contact facilitated service use because this provided time to get to know the persons with dementia and their families and to establish a bond of trust [128].

According to the ideal of universalism, the public guarantees the same public benefits and services to all citizens, regardless of geographical and socioeconomic status [31]. In the Background chapter, I outlined four factors that have been previously related to unintended variations in service use and that were of particular interest in this study, namely, variations related to gender, socioeconomic groups, ethnicity and place of residence. In the following sections, variations related to these factors are discussed.

Gender

In line with previous research of family caregivers, the majority of the respondents were women [e.g., 27, 81, 129, 180]. Male persons with dementia tended to use more respite care services than females, and male family caregivers tended to use less respite care services than female family caregivers (Paper II). Similar findings were reported in a Finnish study among spouses, in which females providing care used more support services and respite care in nursing homes than males [102]. In a recent Swedish large sample study, female persons with dementia received more homebased services than males, while male persons with dementia received more short-term care and respite care than females [103]. It is possible that female family caregivers have higher needs for respite care services, as studies have found that they generally report higher levels of caregiver burden, stress and depression than males [12, 27, 181]. In addition, studies have reported that wives who provide care are less likely to receive support from family and friends than husbands who provide care [27, 181]. However, male caregivers for persons with dementia are underrepresented in research pertaining to family caregiving [181, 182]. In a Canadian qualitative study among male family caregivers, perceived restrictions on access to available healthcare services included a lack of formal healthcare resources, lack of healthcare professionals to meet their needs and rationing of resources [182]. This indicates that also male caregivers experience inadequate formal support. Thus, I cannot disregard an unintended variation in the use of respite care services in disfavor of male family caregivers in this study.

Furthermore, the results suggested that being a daughter, a son or a family caregiver of other kinship relations to the person with dementia was related to greater use of homebased services, and daughters used significantly fewer respite care services than spouses (Paper II). Although it is reasonable that spouses cohabiting with the care recipient had high needs for respite care, it is difficult to explain why family caregivers with other kinship relations did not use fewer respite services than spouses, while daughters did. A survey experiment among care managers in 219 municipalities in Norway [183] showed that a fictive older woman in need of healthcare services with an adult daughter received approximately one-third less formal care per week than a woman with an adult son as a family caregiver. The study suggested that care managers took the family situation into account when allocating services, and the results indicated patterns of gender discrimination in the allocation process. This is in contrast to the prevailing principle of universalism within the healthcare system [183]. Studies have found that daughters of persons with dementia can struggle with the competing duties of caregiving, their own family and managing their career, and balancing several responsibilities might increase the risk for strain and burden [27, 184]. However, sons might take on substantial care responsibilities and a study demonstrated that adult children caring for persons with dementia experienced greater caregiver burden and more feelings of guilt than spouses [185]. Hence, it is important that both adult daughters and sons are provided opportunities for respite care in accordance with their care responsibilities and needs.

Socioeconomic status

In this study, high education level and full-time employment were associated with the use of more homebased services (Paper II), and family caregivers with a lower education levels (elementary school and high school) had significantly higher odds of reporting uncertainty regarding unused services than family caregivers with a high education level (Paper III). Higher use of healthcare services among full-time employed caregivers is not necessarily unintended. Formal support may enable family caregivers to continue working [48]; thus, it is reasonable that full-time employed caregivers use more services to compensate for their limited time available to provide care themselves [186]. On the other hand, the findings might indicate that unemployed or retired family caregivers substitute formal care to a higher degree than employed caregivers.

Lower use of healthcare services in disfavor of persons with lower education levels might indicate an unintended variation, as it is assumed that equal access to services among socioeconomic groups can reduce inequalities in health [105] . In a previous Norwegian interview study among healthcare professionals in community healthcare services, patients and family caregivers who were perceived as resourceful and demanding received more healthcare resources at the expense of other patients with legitimate care needs [177]. The study did not relate the results to the socioeconomic status of the patients or the family caregivers, but other studies have suggested that family caregivers with higher education levels are more aware of their rights to access services and more competent in obtaining information about their rights [108, 110]. A national governmental strategy [105] claimed that patients' statutory rights to necessary healthcare, information and participation in decision-making processes might result in social inequalities in healthcare. To utilize these rights, knowledge regarding the application procedures, user participation and availability of healthcare services is required. It is thus reasonable that individuals with the capacity to obtain such knowledge are more capable of maintaining their rights to healthcare than other groups. In addition, out-of-pocket payment and organization of healthcare services can affect access to healthcare, and thus; contribute to strengthen or weaken the principle of universalism at a local level [105]. A division between those who make decisions of services and those who provide the services in accordance with the purchaser-provider model should increase user choice and may reinforce service guarantees and contribute to justice and universalism [187]. However, complex organization structures can result in challenges for the care recipients and their family caregiver, as it is not obvious where and from whom they should request help [128, 188, p. 18].

Ethnicity

Sami ethnicity according to two Sami markers (Sami as a first language and self-perceived Sami ethnicity) among family caregivers was negatively associated with the use of homebased services (Paper II), but the remaining results indicated that Sami ethnicity did not predict the use of community healthcare services (Paper II) and family caregivers' knowledge of unused services (Paper III). Moreover, none of the respondents reported reasons for nonuse of services related to ethnical aspects. Despite several insignificant results, the tendencies in the initial analysis showed that family caregivers confirming one Sami marker on average reported a somewhat greater use of services than the other groups (Paper II). The low proportion of Sami participants and the low statistical power may explain the few significant associations. Overall, the results suggested that there might be unintended variation in use of homebased services in disfavor of Sami family caregivers. However, this result should be interpreted with caution, as this variation did not necessarily apply to all those who perceived themselves as Sami.

Very few studies have investigated the use of healthcare services among Sami and non-Sami people. A previous study using data regarding public expenditures of somatic hospitals and specialist services found that the overall expenditures in Sami municipalities were higher than the national average use. In addition, the expenditures were equivalent compared to corresponding non-Sami municipalities in the geographical area included in the study [189]. However, the study used aggregated data at a municipal level, not at an individual level, and it is therefore difficult to compare the results with this study. International research has demonstrated that persons with dementia from minority ethnic groups are presented to diagnostic services later than majority populations [190, 191]. Once they received a diagnosis, the overall use of community social healthcare services did not vary between the groups, but minority populations were less likely to use 24-hour services [190]. A recent review study indicated that indigenous populations experienced low formal dementia care and support compared with nonindigenous populations [192]. Factors such as lower socioeconomic status, rural location and communication differences are previously identified as barriers to utilization of healthcare services among indigenous people [193].

The low use of health care services among Sami people is a prevailing assumption in Norwegian health policy strategies [194]. For example, the Coordination reform [38] stated that the Sami population has a long tradition of self-help through use of the family and social networks and that Sami are reluctant to seek healthcare services even when the need for help seems obvious. Sami families may experience their encounters with healthcare services as alienating due to differences in communication styles and a general lack of knowledge of Sami culture among the health care providers [38, pp. 117-119]. Others have indicated that individual and collective experiences with assimilation and stigmatization might affect the interaction with the healthcare services [115]. A substudy in the PDC project reported that healthcare professionals assumed that Sami families take care of their own family members with dementia and were reluctant to seek and accept help from healthcare services. Such assumptions may lead to omissions and neglect and increased barriers in offering help to Sami people in need of help and support [145]. Altogether, the findings from this study and previous research indicate that the use of healthcare services within the Sami population and between Sami and non-Sami is a complex issue that might be affected by contextual, cultural, and individual factors and norms.

Place of residence

Persons with dementia living in rural areas used fewer homebased services and respite care services than those living in urban areas (Paper II). In addition, some reported that the services were not used due to long travel distances between the location of the services and the care recipients’ home (Paper III). The results might indicate an unintended variation in service use in disfavor of those living in rural areas, which further challenges the prevailing welfare ideal of universalism [31]. Previous international research has also explained low service use among persons with dementia living in rural areas with limited availability or inappropriate delivery of healthcare services [123, 124]. A population-based Swedish study in rural areas suggested that informal dementia care provided by family caregivers substituted for formal care in these areas as the amount of informal care provided was almost six times higher per day than the amount of formal care provided [195].

A qualitative study in the PDC project interviewed healthcare professionals and senior representatives in addition to a sample of eleven family caregivers who responded to the questionnaire [148]. The results corroborated the results of the present study and indicated a mismatch between the care needs of home-dwelling persons with dementia and the extent of homebased services that could be provided in traditional homes, particularly when the care recipient lived in remote communities. To provide an adequate level of formal care to those with comprehensive care needs, the persons had to move to an assisted living facility in the municipal center [148]. In the present study, comprehensive care needs can explain why persons who lived in assisted living facilities used more homebased services than those who lived in ordinary housing (Paper II). According to the LEON principle, assisted living facilities may represent a higher level of effective care in the healthcare service portfolio [36]. Higher use of homebased services among those living in the facilities than among those living at home might not necessarily indicate an unintended variation if the residents have higher needs for the services. However, the ideal of aging in place might be challenged when persons with dementia living in remote or rural areas have to move to a central area to receive an adequate level of care, as the remote community represents the care recipient's home-place rather than the community center [148].

Other factors related to the utilization of healthcare services

In this study, persons with dementia who cohabited with the family caregivers used fewer homebased services than those who did not cohabit with the family caregiver. Moreover, spouses used fewer homebased services than adult child caregivers and caregivers of other kinship relations to the person (Paper II). In the open-ended question, the findings were somewhat nuanced (Paper III). Some responders reported that they performed household tasks as a natural part of daily life, e.g., cleaning and cooking, and that they did not need services. It is thus reasonable that cohabiting care-recipients and family caregivers found services such as domestic help and meal delivery redundant and that persons with dementia who lived alone were more dependent on formal support to maintain daily living activities.

The boundary between ordinary, ongoing household tasks and caregiver tasks may be blurred. A review regarding women and dementia reported that wives caring for their husbands with dementia rarely identified themselves as family caregivers, and the role of being a caregiver was seen as an extension of their commitment to caring for their family [27]. Increased work at home might be accepted as an extension of regular duties implied by the spousal role [178]. In this study, several family caregivers who reported that they did not yet need the services described that they were about to reach a limit for how much care they could provide, and some referred to reduced caregiving capacity due to their own health problems (Paper III). Family caregiving is a dynamic process that evolves over time and in relation to the progression of dementia. In addition, similar caregiving activities can be perceived differently and are dependent on a range of factors that serve to define the caregiving circumstances [196, p.136]. Thus, it might be difficult to determine which families are in need of formal support and when formal support should be introduced without a thorough assessment of the needs of the persons with dementia and their family caregivers.

Research has indicated that the presence of family caregivers might result in less formal support [176, 177], which can be understood as unfair care practices. The findings from the present study indicated that certain groups of family caregivers such as spouses and cohabitants might substitute for homebased services to a higher degree than other groups. For some family caregivers, caregiving is in line with their own wishes. Nevertheless, the healthcare professionals need to be proactive and follow-up with those who provide substantial caregiving tasks that otherwise should or could have been provided by the healthcare services. Those who considered that they did not need services should receive information about the availability of the services, potential costs of the services, the quality of the services, and the individual advantages of using homebased services. Such information could enable family caregivers to decide whether the services are necessary or not [197].

A prominent reason for not using services was that the persons with dementia were reluctant to receive formal help and support (Paper III). Several of the family caregivers described this as a dilemma, as the need for services was substantial and they could not force the persons to use the services. The finding may indicate that the persons with dementia were involved in decisions making processes regarding their own healthcare. In addition, the family caregivers often found it difficult to overrule their wishes, despite increased caregiving efforts. International and national dementia care strategies highlight the importance of person-centered care and involvement of persons with dementia in care and care planning [1, 2, 14, 29]. For example, the Norwegian dementia care strategy emphasizes that persons with dementia are capable, with some assistance, to express how formal healthcare services should be adapted and to plan for future healthcare. Involvement in decisions and control over one's own life may contribute to maintaining the individuals' self-esteem and dignity [14]. A recent study including persons with dementia in eight European countries reported that although persons with dementia experienced benefits of formal care (e.g., creating security or protecting the family from caregiving obligations), formal care was perceived as a threat to their independence [128]. Although maintaining of independence is considerable important for many people with dementia [27], this study and other studies suggest that individual decisions regarding service use might result in consequences for the family caregiver in terms of more caregiving when the persons' need for care is high. An interview study including 12 family caregivers recruited from the present survey showed that although the persons with dementia had substantial care needs, they all refused admission to nursing homes. None had been assessed for their ability to consent, and the family caregivers questioned the abilities of the persons with dementia to make such solitary decisions, which ultimately strongly affected the life situation of the family caregivers [147]. An interview study among family caregivers of older care recipients indicated that the care-recipients refused to give up their independence and they did not want to have strangers do things that the family could do [198]. In this study, several family caregivers reported similar reasons for the nonuse of services (Paper III).

Previous studies have demonstrated that persons with dementia reported fewer unmet care needs than their family caregivers [131, 199], and different understandings of the needs may result in conflicts in decision-making regarding the acceptance of care [131]. Although family caregivers have statutory rights as caregivers, they cannot decide whether the person with dementia should use healthcare services or determine the appropriate type of healthcare, not even when the person is formally deemed unable to consent [55]. I suggest that a triadic healthcare approach including the person with dementia, the family caregivers and the healthcare services is of particular importance in the decision-making processes. Recognition of the positions of all members in the care triad provides an opportunity to ensure equal participation in decision making [135]. Family caregivers should be involved in decisions that affect their caregiver role, and ultimately, might have a negative impact on their life situation. Thus, it is crucial to balance the integrity and dignity of the person with dementia and the needs of the family caregivers.

A somewhat surprising finding was the lack of associations between predictors reflecting family caregivers' needs and the use of homebased services (Paper II). Among several included variables, only duration of caregiving and a single item that assessed caregiving demands were related to the use of more respite care services. Either factors such as family caregivers' well-being, self-perceived health and impact of caregiving are unrelated to the use of services, or we failed to include relevant variables for measuring the family caregivers' estimated needs. As previously described, several of the family caregivers reported substantial needs for the unused services in the open-ended question (Paper III). In addition, the two interview studies in the PDC project involving family caregivers recruited from the present survey demonstrated that the care needs among the persons with dementia were substantial [147, 148] and that family caregivers strived to balance caregiving duties with their needs to care for themselves [147]. Altogether, the results indicate that several family caregivers had unmet care needs, which ultimately could result in negative consequences for their health and well-being.

6.1.3 Assessment of family caregivers' needs

Formal identification, adequate assessment, and responses to the needs of family caregivers are highlighted in health strategies [48, 77] and in research [15, 57, 73, 79]. The COPE Index is a brief, first-stage assessment tool that can enable healthcare professionals to screen family caregivers to identify those requiring comprehensive assessment, to develop targeted interventions to reduce the negative impact of caregiving, and to enhance the quality of support and the positive aspects of caregiving experiences [81]. Although the psychometric properties were evaluated as good (Paper I), some refinements are required. To improve the applicability of the instrument in healthcare practice, future studies should examine the creation of a usable cut-off criterion for the three dimensions and the global impact of the caregiving score. I also recommend omitting the "not applicable" response option, as is it difficult to determine an appropriate score when the option is selected. A weakness is that the appropriateness of the instrument in clinical practice has been rarely reported. A small-sample study among general practitioners in New Zealand indicated that the COPE Index improved the practitioners' understanding of the family caregivers' needs [200]. Moreover, it is suggested that the instrument may not be sufficiently sensitive to evaluate changes in the caregiver situation over time [201]. A counterargument is that the COPE Index is designed as a first-stage assessment tool, and dialogs and more detailed assessments are required to customize interventions according to individual needs [81].

Each family caregiver is affected by caregiving in a unique manner, and how family members provide care and adjust to the shifting demands of caregiving will differ [100, 196]. Although the assessment of family caregivers’ needs is recommended, the procedure is not a statutory right. The dementia diagnosis procedure includes an interview with the primary family caregiver, the family caregiver’s evaluation of the cognitive changes and functional status of the care recipient, and an evaluation of the degree of caregiver burden. The patient and the family caregivers should be followed-up by healthcare professionals in the municipality in which they live, and an annual screening of caregiver burden is recommended [80]. It is asserted that focusing solely on the functional status of the care recipient and caregiver burden may restrict the innovation and development of support services for family caregivers, as opportunities to enhance the satisfaction and rewards gained from caregiving could be ignored [73, 79]. An assessment should therefore be holistic and include multidimensional aspects such as the family caregivers’ perception of the situation, the positive and negative impacts of caregiving and the need for help and support [79]. However, comprehensive assessments are time-consuming [73] and might be hampered by restricted formal resources. Hence, brief tools evaluating several aspects of caregiving might be appropriate to identify those who require an in-depth assessment [81]. Although some refinements are warranted, I recommend that the COPE Index be adapted and tested among healthcare professionals working in the area of dementia care in community healthcare services.

6.2 Discussion of methodological considerations

6.2.1 Study design

Cross-sectional survey research is well suited for descriptive studies that aim to observe certain phenomena at a single point in time and to explore important factors associated with the phenomena. Such a design allows for acquisition of a large amount of data about the topic under study by including a large number of participants, and the acquired information can be used to make inferences about the broader population [159, pp. 168-170, 202]. In addition, findings from cross-sectional surveys can be used to generate hypotheses that can be tested in experimental or analytic studies [203, p. 216]. However, cross-sectional survey research also has some disadvantages. The design is not suitable for identifying causality and, and the results should be considered tentative [159, p. 208]. The data may lack details and depth regarding the phenomena being investigated, and the researchers may often struggle to achieve an appropriate response rate [202]. Cross-sectional survey data can also be biased in different ways; thus, biases should be assessed, reported and taken into consideration when interpreting the results [159, p. 162].

6.2.2 Representativeness

Representativeness of the included municipalities

We intended to include family caregivers in 46 municipalities, but 14 municipal managers declined to participate in the study. We compared the characteristics of the participating municipalities with the nonparticipating municipalities, and minor differences were detected. Regarding the affiliation of municipalities with the STN area, 71% of the invited municipalities inside, 60% of the municipalities partly inside and 73% of the municipalities outside the area participated. Overall, the 32 included municipalities were diverse, and I assume that these municipalities were representative of all the municipality types within the geographical area of this study.

Representativeness of the sample

In this study, the response rate was 54.6%, while an acceptable response rate for reducing the risk for nonresponse bias is considered to be at least 65%. However, postal questionnaires that are sent without previous contact between researchers and respondents usually have a much lower response rate (approximately 20 %) [202]. Kelley and colleagues [202] emphasized that a low response rate can lead to misleading results that are merely representative of those who participate. Thus, potential differences between the responders and the nonresponders should be outlined and discussed. In this study, the research assistants recorded the gender of the family caregivers and their kinship relationship to the person with dementia in the inclusion records. Deidentified summarized data were shared with the research team to compare responders and nonresponders. There was a higher portion of spouses among the responders than among the nonresponders (28.8% and 19.7%, respectively) and a higher portion of sons among the nonresponders than the responders (25.5% and 18.3%, respectively). In a study of factors affecting willingness to participate in health research surveys, older people and women reported higher willingness to participate than men and younger people [204]. In addition, studies indicate that younger people and men prefer online surveys over postal surveys [151, 204]. These issues could explain the higher portion of sons among the nonresponders in this study. Other studies have found that nonresponders are more likely to be older, from ethnic minorities [205] and to provide care for more impaired care recipients compared with the responders [206]. In a population-based study on health and living conditions in areas with mixed Sami and Norwegian settlements (SAMINOR 1 and 2), the participation rates increased with higher levels of education and income [151]. In this study, the information regarding nonresponders was restricted to two characteristics, and therefore, we cannot rule out the possibility that other nonresponse biases exist.

The representativeness of the sample may be further weakened by the use of a convenience sampling method and because we included participants who were in contact with community healthcare services. These factors imply that family caregivers of persons with dementia who were unknown to the healthcare services did not receive invitations to participate and that nonusers of services might be underrepresented in this study. However, I assume that the results may be generalized to persons with dementia and their family caregivers known to the community healthcare services.

Persons with dementia and family caregivers

During the training of the research assistants, we stressed that those who did not have a dementia diagnosis should have symptoms consistent with dementia and that the cognitive impairments should affect the ability of the person to perform daily living activities. In general, the research assistants did not find these criteria to be problematic, as the assistants were all experienced in dementia care. Moreover, we instructed them to not include family caregivers if they were in doubt as to whether or not the person had dementia. Despite this, we cannot disregard that family caregivers of persons who actually did not have dementia may have responded. We did not have permission to register the diagnoses, health status or functional level of the care recipient; thus, we could not control whether the persons with dementia fulfilled the inclusion criteria. A few family caregivers contacted the research team to declare that the person did not have noteworthy cognitive impairment or that the person managed daily living activities without help and support. Therefore, family caregivers may have thoroughly evaluated whether the person whom they cared for met the scope of the study, which may strengthen the representativeness of our sample.

Insufficient dementia diagnostic routines have been widely reported worldwide [3, 23, 29]. In a Norwegian study of randomly selected samples of older users of homebased services, 41.5% of the participants fulfilled the ICD-10 criteria for dementia. Of these, only 19.5% had a dementia diagnosis known to themselves or their family caregivers or that was registered in the records of homebased services [7]. It is possible that general practitioners avoid undertaking diagnostic procedures or that they omit communicating the diagnosis to the patients, family caregivers or homebased services [7]. Until diagnosis routines are improved within community healthcare services, the exclusion of undiagnosed persons with dementia and their family caregivers could result in substantial data loss that may further result in selection bias.

The family caregivers included in this study should provide care at least once a week. The initial analyses revealed that almost half of the participants provided care every day, and two-fifths of the participants provided care several times per week (Item 14). In the total sample, family caregivers had provided an average of 6.5 caregiving activities over the last 12 months (Item 13) (results not reported in the papers). Overall, these estimates suggest that the family caregivers were representative of this study.

Despite the recruitment efforts, a low proportion of the family caregivers (7%) and the persons with dementia (10%) were of Sami ethnicity. In Norway, the use of Sami ethnicity as a variable in quantitative studies is challenging, given insufficient existing Sami-demographical data and indistinct Sami-ethnic boundaries. Sami ethnicity has been defined in various ways, and both measurements and the way Sami ethnicity is perceived have changed over time [207]. Thus, it is difficult to compare the proportion of Sami in our study with other studies. In a population-based study on health and living conditions in areas with mixed Sami and Norwegian settlements (the SAMINOR 2 questionnaire study), 34.1% of participants had some type of Sami affiliation, and 20% reported self-perceived Sami ethnicity [151]. These previous data may indicate that Sami were underrepresented in this study. Three municipalities included in the administration area of the Sami language law declined to participate; thus, we were unable to invite participants from these areas with dense Sami populations. It is also possible that the Sami are less likely to use community healthcare services [38] and, consequently, were unknown to the research assistants in the municipalities.

6.2.3 Validity of the measurements

The quality of the data derived from translated measures relies on the translation procedure [150]. The accuracy of our procedure, including cultural adaptation of the items and the scales, can be considered a methodological strength of this study. Unfortunately, we were not able to include Sami family caregivers in a pilot test of the North Sami language questionnaire. A pilot test is important for testing comprehensibility and identifying whether participants interpret the items and response options as intended by the developers [150, 171, p. 184]. Omitting this step might result in bias related to respondents' misunderstanding of items [150]. To reduce this potential risk and to ensure cultural adequacy, any discrepancies and considerations regarding wording were thoroughly discussed with a Sami language expert.

Validity of the COPE Index

A strength of this study is the cross-validation approach, which allowed for comparing the construct validity by EFA and CFA in two randomized samples (Paper I). CFA plays a crucial role in validation studies and involves "testing a measurement model which specifies the hypothesized relationships among underlying latent variables (constructs) and the manifested variables (items)" [159, p. 346]. The three-factor structure revealed in the EFA was verified in the CFA, and the fact that the model was comparable with previous validation studies [81-83] strengthens the generalizability of the COPE Index. Previous studies have found that reliability in terms of internal consistency (Cronbach's alpha) is satisfactory for the negative impact dimension (0.79-0.87) but questionable for the positive value (0.54-0.66) and quality of the support (0.56-0.78) dimensions [81-83]. In this study, the negative impact and the quality of support factors had good internal consistency (0.86 and 0.76, respectively), whereas the positive values factor was less consistent (0.64). It is possible that the internal consistency was weakened due to the low numbers of items in the positive value factor (3 items), as Cronbach's alpha is influenced by the numbers of items included in the analysis [208].

A limitation of the analyses was the large proportion of missing data due to the “not applicable” response option on five of the items in the COPE Index. Missing values that are not missing completely at random can bias the statistical analysis [159, pp. 430-431]. To evaluate the randomness of the missing values, we compared age, gender, ethnicity, marital status and kinship relationship between those who selected and those who did not select the “not applicable” option. Overall, the differences were small, which may indicate that the missing data points were missing at random [159], despite the fact that MCAR test indicated that the missing data were not missing completely at random.

Single items

A limitation of this study could be the use of single items and brief scales in the analyses. Although single items are easy to implement [163], they can be an inadequate measure of broad concepts [203, p. 300]. Single items are sensitive to effects from preceding questions. Multi-item scales often dilute these effects, as the items form references for one another, and the score is based on the set of items [163]. In this study, we found that single items were appropriate for use as outcome variables (Paper III) and predictors. However, some of these variables have never been or have been rarely used in previous research (e.g., knowledge of unused services and demands of caregiving), and thus, the results should be interpreted with caution.

Nonuse of community healthcare services

We created a categorical question regarding knowledge of unused healthcare services for this study (Paper III). We cannot disregard that the question was too brief to capture family caregivers’ knowledge of unused services or that the response option did not appropriately distinguish among the groups. Despite the limitations of the question, the results of the statistical analysis showed relevant group differences, e.g., that those who were unaware unused services used more homebased services than those who knew of unused services.

We used an open-ended question to assess the reasons for nonuse of community healthcare services (Paper III). Open-ended questions following closed questions are useful for clarification of reasons and explanations, and they are suitable where replies are unknown or too complex to precode. Open-ended questions might be more suitable in interview surveys than in self-administered questionnaires because the quality of the data is dependent on the respondents' willingness and capacity to write their replies [203, p. 295]. In this study, the generated data were surprisingly rich and allowed thorough thematic text analysis of the text material. Initially, we were receptive to using thematic text analysis to create categories for use in statistical analyses. However, during the analysis, we abandoned this plan, as we realized that the main themes were unsuitable for use as categories because they were too broad and included diverse reasons for the nonuse of services. In addition, we realized that important information regarding the nonuse of services could be lost if we quantified the data in such manner. For example, several of the quotes reflected both reasons for the nonuse of services and the family caregivers' perceived need for the unused services. These nuances would be difficult to capture in statistical analysis. Similar experience with the use of open-ended questions following items or scales is also reported elsewhere [209, 210].

Altogether, the text data provided detailed information regarding reasons for the nonuse of services. The results were also comparable with results from international studies, for example, some of the subthemes reflected categories included in Brodaty's typology for nonuse of services, as presented in the Background chapter of this thesis (e.g., reluctance to use services and services were not needed) [127]. In addition, the results from the qualitative analysis nuanced the results regarding the use of and the factors affecting the use of community healthcare services (Paper II) and knowledge of unused services (III). I consider that the use of different analyses contributed to a deeper understanding of service utilization and family caregivers' needs for help and support.

6.2.4 Generalizability

This is the first large-sample study performed among family caregivers of persons with dementia in Northern Norway, and we intended to include all available family caregivers who fulfilled the inclusion criteria in a given time period. The large, heterogeneous sample might strengthen the generalizability of the results. The characteristics of the participants in terms of age, gender, marital status and employment status were comparable with previous family caregiver research [e.g., 112, 125, 180, 197, 211]. We mainly included validated scales and items used in previous research in the analyses; the selection of criteria (Paper I) and predictors of use of community healthcare services (Paper II) and predictors of knowledge of unused services (Paper III) were mainly based on findings from relevant studies. Altogether, we were able to compare our results with those of other studies, which increases the generalizability of the results.

In this study, we included family caregivers of persons with dementia in different stages of the disease. The progressive nature of dementia affects the care needs of care recipient [1, 2] and family caregivers [179]. The cross-sectional design did not allow for the investigation of the progression of service use during the course of dementia, and it is likely that those in an early stage of dementia used formal support to a lesser extent than those in subsequent stages. In addition, behavioral disturbances and disease severity are among the characteristics of persons with dementia that appear to influence family caregivers' well-being [212] and caregiver burden [58] and the utilization of formal care [213, 214]. We did not have permission to collect data regarding disease and disease severity and could, therefore, not adjust the prediction estimates accordingly in the regression analyses; the results should be interpreted with this limitation in mind. Another limitation is that we have not evaluated the amount of services used in terms of times per day/week due to a large proportion of missing data and coding errors of the intended item (Item 22). It is possible that access to valid data for this item could provide a more detailed description of service use and variations in service use.

A considerable amount of research on family caregivers has focused on the burden inflicted by caring for a family member with a disability [67, 215, 216]. The lack of a validated instrument to measure caregiver burden may be considered a weakness of this study for several reasons. In Paper I, a caregiver burden instrument could have been appropriate for evaluating the criterion validity of the general COPE factor to define the exact meaning of the underlying construct. The variables reflecting family caregivers' needs and caregiving circumstances in Papers II and III might not fully capture the burden associated with caregiving. However, the selection of a caregiver burden-specific instrument is not a straightforward issue. A multitude of instruments exists, several of which are based on other constructs such as 'impact', quality of life', 'risk', 'stress' and 'strain'. There is also a lack of standardization among measurements due to the multidimensionality of the construct [216], and these issues might impede the comparison of results across studies. During the development of the questionnaire, we carried out a purposive selection of variables to cover relevant topics for the current study and for other substudies within the main project. In the pilot test, some family caregivers commented that the entire questionnaire was comprehensive and quite time consuming to complete (the respondents took an average of 25 minutes to complete the questionnaire). Overall, multidimensional caregiver burden instruments are comprehensive [216], and including additional scales would further lengthen the questionnaire.

The use of stepwise methods in the regression analyses is subject to risks of overfitting (including too many variables) or underfitting (leaving out important predictors) the model. Use of the stepwise method is justifiable when the analysis is explorative and not based on established models [217, pp. 322-324], which was the case for the regression analyses in this study. Moreover, we used a backward method, which reduces the risk of missing predictors that actually predict the dependent variable. Missing relevant predictors might result in type II error, which means that no relationship is observed between the dependent and independent variables when a relationship actually exists [217, p. 324].

6.2.5 Ethical considerations

Several of the research assistants had a professional caring relationship with the person with dementia and his/her family caregivers. In the information letter sent to the family caregivers, we declared that healthcare professionals within the community healthcare services had appointed them as potential participants, although the research assistants' identities were unknown to the family caregivers. The information about the study and the questionnaire was forwarded on behalf of the research team, and the completed questionnaires were returned directly to the researchers at the university. Yet, I cannot rule out the possibility that the relationship between research assistants and family caregivers may have had an impact on the family caregivers' willingness to participate in the study.

The data also involve a second person, namely the person with dementia. Although data regarding persons with dementia are considerably limited, the family caregivers' evaluation might provide an incomplete evaluation of the dependence level and formal or informal care received. In addition, most of the healthcare services included in this study were allocated to the person with dementia rather than the family caregivers. It is possible that several of the persons with dementia were capable of evaluating their own care needs, use and reasons for nonuse of services. In this study, I intended to focus on the family caregivers' role in dementia care and their evaluation of formal support and the relationship between service use and family caregivers’ needs. I assumed that family caregivers were involved in arranging for formal help and support and that they evaluated the actual use of healthcare services to the best of their knowledge.

6.3 Implications for research, healthcare services and health policy

Implications for research

This study is based on the assumption that caregiving for older, home-dwelling persons with dementia takes place in a healthcare triad comprising the care recipient, the family caregivers and healthcare professionals within the community healthcare services. In this study, I have solely focused on family caregivers and their evaluation of service use and nonuse. Future studies should endeavor to include all parties of the healthcare triad to obtain a more complete picture of the caregiving situation. For example, there is a need for more research regarding the nonuse of healthcare services among older persons with dementia, and a qualitative interview study including persons with dementia, family caregivers and healthcare professionals could address this issue in more nuanced and detailed manner. Together with the results of the present study, a qualitative study could form the basis for the development of a required research instrument addressing the nonuse of community healthcare services among persons with dementia and their family caregivers.

As outlined in the Background chapter of this thesis, healthcare policies and strategies regarding deinstitutionalization and decentralization of healthcare have resulted in considerable development of community healthcare services. Studies carried out after the Coordination reform [38] suggest more demanding economic priorities in the municipal healthcare sector [41] and an increased threshold to receive community healthcare services [42]. The results of this study indicate that several family caregivers did not receive the healthcare services that they or the person with dementia needed. Future studies should investigate how underlying structures and mechanisms such as the organization of community healthcare services, economical budgets and priorities within the municipal healthcare system potentially affect the availability and use of services among persons in need of help and support.

A future large-sample, population-based study should address the use of community long-term care services and family caregivers’ contributions to caregiving in a multiethnic population of Sami and non-Sami people, as experiences from this study indicate that it is somewhat difficult to include Sami participants and to obtain an adequate sample size. Data from a population-based study might contribute to valuable knowledge regarding variations in service use and variations in informal care provided among Sami and non-Sami and within the Sami population. Health policy documents and strategies are informed by findings from previous studies carried out in small samples and in small areas within Sápmi [194], and data from large sample studies are better equipped to generalize the findings. A population-based study within Sápmi could also compare the amount of formal care and family care provided to persons with dementia living urban and rural areas. In addition, it could be interesting to explore differences related to cultural norms and attitudes towards caregiving between Sami and non-Sami and between those living in urban and rural areas to obtain further knowledge regarding the factors that could promote or impede the use of community healthcare services.

An important finding of this study was that the education level of the family caregivers was associated with the use of homebased services and family caregivers’ knowledge of services. Although studies have investigated the use of healthcare services among socioeconomic groups [32, 107], very few Norwegian studies have addressed this issue regarding the use of community long-term care services [108]. A limitation of this study was that we did not have data about the socioeconomic status of the persons with dementia. In future studies, it would be interesting to explore the association between socioeconomic status and the use of community long-term care services in a large sample of older care recipients with different diagnoses, including their family caregivers.

This and other studies have demonstrated that both persons with dementia and family caregivers have unmet needs for care [131, 132, 180, 199]; studies of older care-recipients in general and family caregivers have reported similar results [144]. Future studies should investigate the interaction between families and healthcare services, how their needs are assessed and how their needs are met by services. Furthermore, interventions aiming to improve the interaction and collaboration among all parties in the healthcare triad should be applied.

Implications for community healthcare services and health policy

Altogether, the findings of this study indicate intended and unintended variations in the use of healthcare services within various demographic and sociodemographic subgroups of persons with dementia and family caregivers. Adequate use of community healthcare services among persons with dementia and their family caregivers is important, as healthcare services may contribute to improving the quality of life, relieving suffering and reducing disability of those who are in need of help and support [98]. I suggest that community healthcare services should endeavor to tailor services to the care recipient’s evolving care needs over the course of dementia. Hence, regular assessments of the needs of both the person with dementia and the family caregivers are required, particularly among cohabitants, spouses, and others who provide a substantial amount of care. Moreover, politicians, healthcare managers and healthcare professionals at the municipal level should dedicate attention to particular groups of persons with dementia and their family caregivers to reduce potential inequalities in access to and use of services. For example, it is relevant to address whether more highly educated patients and family caregivers make more demands for services and use more services than other groups and whether those living in rural and remote areas have equal access to and use of healthcare services as those living in municipal centers/towns. Moreover, municipalities that include a Sami population should address how healthcare services are adapted to and correspond with the needs of Sami families.

This study suggests that knowledge of unused healthcare services differs among groups of family caregivers, and several caregivers reported that they had insufficient information about unused services. All of the municipalities in this study have websites that contain information regarding available healthcare services, how to apply for services and contact information. This seems insufficient to reach all those in need of support, and we suggest that information about services and the benefits of service use for both the person with dementia and the family caregivers should be individually adapted and conveyed in personal meetings. The majority of municipalities have dementia coordinators and/or memory teams that should provide information about dementia and available support services [53]. Family caregivers need to be aware of these services, and both primary physicians and healthcare professionals within the homebased and respite care services should assist with sharing of information and referring family caregivers to the relevant healthcare resources.

In this study, respite care for family caregivers was used to a limited extent. To meet the needs of the increasing numbers of persons with dementia and their family caregivers, these services should be further developed, and the availability of the services should be improved. In addition, the development of flexible and beneficial services for persons with dementia and their family caregivers is required, e.g., in-home respite care, activity services adapted to the recipient's functional level and flexible residential respite care.

Health policy strategies refer to family caregivers as resources in caregiving [48, 76]. The latest Norwegian reform within the community healthcare services even describes family caregivers as "a renewable resource" if taken care of [48, p. 47]. I suggest that family caregivers should be acknowledged and valued as partners in care with needs for help and support in their own rights rather than as resources. Thus, future healthcare strategies should focus on the integration of family caregivers in dementia care and the interplay between family caregiving and formal care provided by community healthcare services. To adapt community healthcare services corresponding to family caregivers' needs for help and support through the caregiving trajectory, strategies regarding the assessment of family caregivers' needs should be a priority.

7 Conclusions

The ideology regarding aging in place presupposes adequate availability of community healthcare services for older persons with dementia in need of support. Furthermore, this ideology rests on the family caregivers' capacity and willingness to provide care and the healthcare services' ability to support the family caregivers [147]. To my knowledge, this is the first large-sample study performed among family caregivers of older, home-dwelling persons with dementia in Northern Norway, and this study contributes to knowledge regarding utilization of community healthcare services. Overall, the majority of the families used one or more homebased services. Similar to other studies, services that can serve as respite care for family caregivers were utilized to a limited extent. The amount of service use may indicate unintended variations in access to and use of services within demographic and socioeconomic subgroups, contrary to the welfare state policy aim. In addition, family caregivers' knowledge of unused services varied between subgroups of family caregivers, and the family caregivers' reasons for nonuse of services were related to multiple attributes of those involved in dementia care, namely, the person with dementia, the family caregivers and the community healthcare services.

Family caregivers contributed substantially to caring for home-dwelling people with dementia. Although most factors estimating family caregivers' needs for services displayed weak associations with the use of community healthcare services, several family caregivers reported a considerable need for unused services. I suggest that family caregivers should be offered formal help and support based on their own needs, and family caregiver assessment should be a priority area within community dementia care. The assessment of family caregivers requires validated and adapted assessment tools. As part of this study, we made available a Norwegian version of the COPE Index, which is a first-stage assessment tool that can be adapted and used among healthcare professionals to detect family caregivers in need of support from community healthcare services.

Knowledge about utilization of services and family caregivers' needs is essential for the formation of genuine partnerships between healthcare services and family caregivers and, thereby, optimal integration of professional and family care for persons with dementia. Adequate integration of care might enable the care recipient to live at home as long as possible and reduce the potential negative long-term impacts of care on family caregivers. To balance the needs of both the persons with dementia and the family caregivers, I recommend that community healthcare services develop formal caregiving based on a relationship-centered care or a person-centered care approach that also applies to family caregivers.

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PAPER I

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Psychometric validation of the Carers of Older People in Europe Index among family caregivers of older persons with dementia

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Abstract

Objectives: The Carers of Older People in Europe Index is a first-stage assessment tool to detect family caregivers in need of support. This instrument assesses caregivers' subjective perceptions of their caregiving circumstances. The present study examines the psychometric properties of the Norwegian version of the Carers of Older People in Europe Index among family caregivers for older persons with dementia living at home.

Methods: Cross-sectional survey data were collected from 430 dementia caregivers. The sample was randomly split as follows: the first half of the sample was used to identify the measurement model using an exploratory factor analysis, and the second half of the sample was used to cross-validate the model using a confirmatory factor analysis. The criterion validity and reliability (internal consistency and test–retest reliability) of the Carers of Older People in Europe Index were also examined.

Results: Using an exploratory factor analysis, we extracted three factors that were consistent with previous findings: negative impact of caregiving, positive values of caregiving and quality of support. This model fit the data well using a confirmatory factor analysis. Moreover, a second-order model could replace the three-factor correlated model without sacrificing the model fit, supporting the use of a global impact of caregiving score. The three factors and the global factor correlated with the criteria measures in the expected directions. The internal consistency was assessed using Cronbach's alpha and was good for the negative impact ($\alpha = 0.86$) and the quality of support ($\alpha = 0.76$) factors. The positive values factor was less consistent ($\alpha = 0.64$). The test–retest reliability was examined using Spearman's rank order correlation and was good for all three factors.

Conclusion: The psychometric properties of the Norwegian version of the Carers of Older People in Europe Index are good. The instrument assesses dementia caregivers' situations across three primary factors or alternatively validly summarizes the factors in a global impact of caregiving score.

Keywords

Dementia, dementia caregivers, factor analysis, questionnaire, validation

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Background

The prevalence of dementia is increasing worldwide,[1–3] and the disease is among the leading causes of disability, dependence[3,4] and death[5] in old age. Hence, dementia is a key public health issue.[3] The recognition of the impact and challenges of this illness on healthcare systems, communities and affected families is growing worldwide,[2,3,5] including in Norway.[6] International and national policies addressing dementia care challenges acknowledge the informal care provided by dementia caregivers as an important healthcare resource.[3–6] The efforts of dementia caregivers are important for meeting health

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needs[3,5] and improving the quality of life[7] of the recipients of care. Informal care constitutes a large proportion of the total care provided and contributes to reducing the societal cost associated with dementia care.[2,5,8,9] Thus, studies investigating factors that support or reinforce dementia caregivers in their caregiving roles are important.

Considerable research has focused on the burden or negative consequences that can be inflicted by caring for a family member with dementia.[10,11] Dementia caring may heighten the risks of stress[12] and depression[13] or may undermine the well-being of caregivers compared to non-caregivers.[12] In addition, the chronic caregiver burden may lead to physiological stress-related changes with diverse functional consequences, such as impaired cognitive functioning, risks of developing cardiovascular diseases or reduced sleep quality.[14] Thus, a dementia caregiver can be described as an "invisible second patient" with potentially unrecognized support and guidance needs.[3,7]

The extensive focus on negative health outcomes may have restricted innovation and development of support services for dementia caregivers[10,15] because caregivers can derive a great deal of satisfaction from their role[16] and experience a strengthened relationship with the care recipient.[15] These positive experiences can enhance motivation and meaning and have an impact on the dementia caregiver's well-being.[17] Moreover, providing care during the early phases of dementia encompasses expectations and needs other than those required as the dementia progresses.[3,18] The advanced stages of dementia require more effort and time[9,19] and involve more complex tasks[3,20] and increased collaboration with formal caregivers.[18,20] Hence, dementia caregivers should receive support that adjusts to their needs and the shifting demands over time to ensure their well-being.[18] Norms related to generation, gender and culture are contextual factors that may further moderate the dementia caregiver's situation[7,10] and, ultimately, the relationship between the caregiver and the care recipient.

Due to the multidimensional factors underpinning the dementia caregiver's situation, formal healthcare professionals may benefit considerably from using systematic methods to obtain information. Such methods may also be favorable for dementia caregivers, as the information can be used to adapt targeted interventions based on individual needs. The Carers of Older People in Europe Index (COPE Index) is an instrument developed as a screening tool to detect family caregivers in need of support.[21,22] The COPE Index is based on a theoretical model reflecting both the positive and negative aspects of caregiving, including the family caregivers' subjective perceptions of the caregiver role, the quality of the relationship with the care recipient and support from the family, social network or health and care services.[21–23] The COPE Index has been used in several studies, including studies assessing family caregivers of older care recipients living at home,[24–28] caregivers of disabled people in different age groups,[29] caregivers of persons with bipolar disorders,[30] and dementia caregivers.[20,31,32] Several studies have applied the subscales as outcome measures to evaluate caregiver support interventions[27,30] or assess changes in the caregivers' situations over time.[20,25] The appropriateness of the instrument for longitudinal studies and intervention research has been discussed to some extent, although the instrument may not be sufficiently sensitive to evaluate changes.[20] Nevertheless, the instrument was designed to be a first-stage assessment tool, and more detailed assessments and dialogs with caregivers are warranted to adapt interventions to individual needs.[23]

The psychometric properties of the original 2003 COPE Index[21] were sub-optimal; hence, a revised version was adopted in 2006 in a six-country European survey of family caregivers of older people (EUROFAMCARE study).[23] An exploratory factor analysis revealed that the following three components underpinned the 15 items: negative impact of caregiving, positive values of caregiving and quality of support.[23] Subsequent factor analysis studies have used similar exploratory methods to identify a similar three-factor structure.[25,29] However, while exploratory factor analyses (EFA) are entirely empirically driven and most suitable for exploring the number and structure of the underlying dimensions of items, a confirmatory factor analysis (CFA) is more suitable for examining the replicability of a factor structure or how well an a priori defined model matches the collected data.[33] Thus, a good-fitting CFA model has better properties for generalizability than an EFA model.

Criterion validity tests among family caregivers of older people[21,23] and caregivers of older persons with dementia[31] have shown that overall the subscales correlate satisfactorily with the chosen criteria. The test score reliability in terms of internal consistency (Cronbach's alpha) has previously been examined in populations of family caregivers of older people[23], caregivers of older homecare clients (not including clients with cancer, dementia or psychiatric disorders)[25] and caregivers of disabled people.[29] In these studies, the internal consistency was satisfactory for the negative impact subscale (0.79–0.87) but questionable for the positive values (0.54–0.66) and quality of support (0.56–0.78) subscales. To date, the test–retest reliability has not been examined, although this measure is recommended for reliability analyses.[33,34]

Objectives

The aim of the present study is to examine the psychometric properties of the translated Norwegian version of the COPE Index among family caregivers of older people with dementia living at home. The construct validity was examined using a cross-validation approach by first conducting an EFA in an exploration sample, followed by a CFA in a second cross-validation sample. We assessed the criterion validity by examining whether the bivariate correlations of the criterion variables were in the expected directions. This study is the first to examine the test–retest reliability of the COPE Index.

Methods

This study is a part of a research project titled "Public dementia care in terms of equal services—family, local and multiethnic perspectives." The overarching project aims to provide new knowledge concerning access, use, quality and content of municipal healthcare services available to dementia caregivers in Northern Norway and investigate dementia caregivers' experiences and perceptions of their caregiver roles. The project consists of two separate sub-studies that focus on different aspects of dementia care. The first sub-study involves qualitative interviews with senior volunteers and healthcare professionals.[35,36] The second sub-study is a quantitative cross-sectional study involving a self-administered questionnaire measuring different aspects of the situation of dementia caregivers. The current study is the first paper from the quantitative part of the project.

Sample and setting

Dementia caregivers in 32 municipalities in Northern Norway were invited to participate in the study. The municipalities were selected based on size, geographical dispersion, urban/rural areas, and location inside ($n=5$), partially inside ($n=17$), or outside ($n=10$) the area under the Sami Parliament subsidy scheme for cultural and economic development (STN area). Sami people are indigenous people and the majority live in Norway.[37]

Because no registry of persons with dementia diagnoses and their relatives was available, we collaborated with research assistants in each of the 32 municipalities. Initially, the municipal healthcare managers approved the study and appointed research assistants who were registered nurses or licensed practical nurses. All research assistants worked with dementia care within community homecare services or respite care services, and several assistants had special education in geriatric and dementia care. The research team carried out individual training sessions with the research assistants prior to the recruitment of the participants. The training included a detailed examination of the inclusion criteria, how to safely storage the study materials, and how to secure the anonymity and confidentiality of the participants.

The research assistants identified dementia caregivers of persons who received home-based services and/or respite care services and met the inclusion criteria. The inclusion criteria were as follows: provided unpaid help and support at least once a week to people aged ⩾65 years with dementia living at home; were over 18 years of age; were a spouse, son/daughter, friend or a more distant relative; and provided most informal support and help. Support and help were broadly defined as personal care, emotional and psychological support, regular visits and phone calls, financial help and organization of care provided by formal caregivers.[24]

The initial contact with the research assistants disclosed that several care recipients did not have a dementia diagnosis due to insufficient diagnostic procedures. In these cases, the condition was described as cognitive impairment or memory loss. Hence, dementia was defined as a dementia diagnosis or cognitive impairment with symptoms consistent with dementia. These symptoms included progressive memory loss and difficulties with cognitive skills (e.g. language and problem-solving) that affected the care recipients' ability to perform everyday activities.[5] If cognitive impairment was caused by other conditions (e.g. brain injury, brain tumor or delirium), the caregiver was not included in the study. If the research assistants were unsure whether the cognitive impairment was caused by conditions other than dementia, they were instructed to not include the caregiver in the study.

The research assistants identified 788 dementia caregivers who met the inclusion criteria. To obtain the general characteristics and carry out a selective reminder procedure, the research assistants recorded information pertaining to gender, the dementia caregivers' relationship with the care recipient, and the contact information of the potential participants. Individual information was not shared with the research team. The research assistant distributed the questionnaire by mail between April and November 2016, followed by a reminder after 4 weeks. In total, 436 responders agreed to participate in the study. After the data cleaning, 430 dementia caregivers were included in the final sample, yielding a response rate of 54.6%. Among the responders, 31.1% were men and 68.9% were women. The relationships between the responders and the care recipients included spouses (28.8%), daughters (42.4%), sons (18.3%) and other (10.5%). The responders ranged in age between 29 and 95 years (mean age = 61.8 years, standard deviation (SD) = 11.7 years, median age = 60 years), and approximately 81% of the responders were married, 11% of the responders were single, 7% of the responders were divorced and 1% of the responders were widows or widowers. In total, 7% of the dementia caregivers were Sami. De-identified summarized data from the inclusion records regarding the gender and kinship relationships of all invited dementia caregivers were used to compare the responders and non-responders. The non-responders differed from the responders as follows: 33.2% were men, 19.7% were spouses, 44.9% were daughters, 25.5% were sons, and 9.8% were other. To examine the test–retest reliability, a heterogeneous group of 40 participants was invited to complete the questionnaire a second time 4 weeks later.

Instruments

The demographic data included age, gender, ethnicity, marital status, and kinship relationship. The COPE Index consists of 15 items (see Table 1) that assess the family caregiver's

Table 1. Exploratory and confirmatory factor analyses of the COPE Index in the exploration ($n_1 = 215$) and cross-validation ($n_2 = 215$) samples, respectively.

Item	Latent factors					
	1 (NI)		2 (QS)		3 (PV)	
	EFA	CFA	EFA	CFA	EFA	CFA
7. Feeling trapped in the caregiver role ($n = 210$)	0.80	0.71				
14. Caregiving has a negative impact on emotional well-being ($n = 208$)	0.73	0.71				
3. Caregiving causes difficulties with friend relationships ($n = 192$)	0.72	0.70				
4. Caregiving has a negative impact on physical health ($n = 207$)	0.68	0.69				
2. Caregiving is too demanding ($n = 219$)	0.66	0.76				
5. Caregiving causes difficulties with family relationships ($n = 190$)	0.60	0.64				
15. Overall support in caregiver role ($n = 203$)			0.89	0.87		
12. Feeling supported by health and social services ($n = 182$)			0.61	0.68		
13. Feeling appreciated as a caregiver ($n = 205$)			0.55	0.61		
10. Feeling supported by family ($n = 200$)			0.53	0.61		
8. Feeling supported by friends and neighbors ($n = 162$)			0.50	0.53		
9. Feeling that caregiving is worthwhile ($n = 207$)					0.76	0.70
11. Relationship with the person cared for ($n = 210$)					0.51	0.52
1. Coping well as a caregiver ($n = 208$)					0.48	0.60
6. Caregiving causes financial implications[a]	0.16		0.23		–0.13	
Eigenvalues (unrotated)	5.20		1.86		1.07	
Cronbach's alpha	0.86		0.76		0.64	

COPE: Carers of Older People in Europe; EFA: factor loadings based on an exploratory factor analysis; CFA: factor loadings based on a confirmatory factor analysis specifying a correlated three-factor model; NI: negative impact; QS: quality of support; PV: positive values.

[a] The item measuring the financial implications of caregiving was excluded from the EFA and CFA due to low factor loadings. The reported factor loadings were obtained from the initial analysis.

situation across the following three dimensions: negative impact of caregiving (NI, seven items), positive values of caregiving (PV, four items) and quality of social support (QS, four items).[23] The responses were recorded using a 4-point Likert-type scale response format (1 = never, 2 = sometimes, 3 = often and 4 = always). A "not applicable" response option was added to five items regarding how caregiving influenced relationships with friends (item 3), relationships with family (item 5), support from friends/neighbors (item 8), support from family (item 10) and support from health and social services (item 12).[21] These items had a large proportion of missing data (ranging between 7.2% and 23.5%) due to the "not applicable" option. Student's *t*-tests and chi-square tests were used to compare age, gender, ethnicity, marital status and relationship and revealed small differences between those who selected and those who did not select this option.

The World Health Organization-5 Well-being Index (WHO-5), general health status, the Social Restriction Scale and a single item assessing demand associated with caregiving were used to evaluate the criterion validity. Three of the criteria (WHO-5, general health status and the Social Restriction Scale) were used in a previous comprehensive validation study of the COPE Index.[23] The rationale for using several of the same criteria was to allow for a comparison of the results.

The WHO-5 is a five-item generic scale that assesses the subjective perception of well-being over the previous 2 weeks. The scores range from 0 to 25, and higher scores indicate better well-being.[38] The WHO-5 has demonstrated good validity[39] and reliability.[23] In the present study, the scale demonstrated high internal consistency (Cronbach's alpha = 0.92).

The general health status was assessed using the following single item drawn from the Tromsø Study:[40] "How would you rate your health overall?." The responses were recorded using a 5-point scale ranging from 1 (very good) to 5 (very poor).

We assessed caregiver role inflexibility with two items drawn from the Common Assessment Tool (CAT) used in the EUROFAMCARE survey study[23] that were originally adapted from the Social Restriction Scale.[41] The responses were recorded using a 3-point scale, and higher scores indicate more social restriction.[23] In the present study, the internal consistency of the two items was satisfactory (Cronbach's alpha = 0.84).

The single item assessing the demands associated with providing care was drawn from a Norwegian project that evaluated school programs for dementia caregivers.[42] The responses were recorded using a 4-point scale ranging from 1 (very demanding) to 4 (not demanding). This item has not been previously used as a criterion, and in this study, we assumed that dementia caregivers who consider caregiving demanding also experienced a high negative impact due to caregiving.

The Norwegian translations of the COPE Index and the Social Restriction Scale conformed with the principles of the International Society for Pharmacoeconomics and Outcomes Research (ISPOR).[43] The forward translations were performed by using two translators, followed by back translation by two independent translators. Any discrepancies were resolved through a consensus discussion. The entire questionnaire, including the COPE Index, was pilot tested on five adult dementia caregivers. These dementia caregivers should represent the target population and differed in gender, age, educational level and kinship relationship to the care recipient. The pilot test included an interview regarding how the respondents interpreted the meaning of the items. The feedback of the respondents resulted in minor revisions and refinements that did not significantly alter the items.

Statistical analyses

We used IBM SPSS Statistics for Windows version 23.0 for all analyses, except for the CFA, which was conducted using Mplus 7.4.[44]

Construct validity. The construct validity investigation followed a cross-validation approach. The sample was randomly split ($n_1=215$ and $n_2=215$) using the first and second half to conduct the EFA and the CFA, respectively. The two samples did not differ in demographics, such as age, gender, ethnicity, educational level and kinship relationship to the care recipient. The preferred EFA model from sample 1 was retested using CFA methodology on sample 2 ($n=215$). The EFA used the principal axis factoring method. Because the correlations between the factors were expected, the solution was promax rotated ($k=5$). Factors exceeding initial eigenvalues >1 (cf. Kaiser's criterion) were extracted, and factor loadings <0.4 were suppressed. In addition, a scree-plot of the eigenvalues was examined. The missing data were mainly due to the response option "not applicable" on five of the items. The Little's Missing Completely at Random (MCAR) Test was statistically significant for these items, indicating that the data not were missing completely at random. Moreover, imputation was not considered entirely feasible as the imputation model would differ from the analysis model (i.e. regression vs factor model). Thus, the missing variables were excluded pairwise as this option included all available data in the factor analysis, basing the correlations on all available pairs. In the initial analysis, one item measuring the financial implications of caregiving (originally in the negative impact dimension) appeared to be uncorrelated to any of the factors and was, therefore, excluded from further analysis (Table 1).

The CFA-estimated factor scores and loadings were extracted using the robust maximum likelihood method as several items had negatively (Z ranging from -3.99 to -11.01) or positively (Z ranging from 2.02 to 2.95) skewed distributions. Kurtosis was also higher for several of these items (Z ranging from -3.99 to 2.7). This robust method adjusts the standard errors appropriately. The measurement model fit was evaluated using the comparative fit index (CFI), Tucker–Lewis Index (Tucker–Lewis Index (TLI)), root mean square residual (root mean square error approximation (RMSEA)), and chi-square test. The RMSEA, CFI and TFI values range from 0 to 1, where a CFI/TLI close to 0.95 and RMSEA close to 0.06 indicate a good model fit.[45] The preferred EFA model should fit better than a null model (fixing all item-factor correlations to zero) or a one-factor model. In addition, we examined whether replacing the correlated three-factor EFA model with a general second-order factor could fit the data equally well. If supported, a single sum score may be used if brevity is needed.

Criterion validity. The bivariate associations of the criterion measures were examined using Spearman's rank order correlations and associated p-values.

Reliability. Cronbach's alpha was used to assess the internal consistency of each of the COPE Index subscale scores. The test–retest reliability was assessed using Spearman's rank order correlation. The statistical power analysis indicated that at least 35 participants should be included considering a Spearman test–retest correlation of 0.8 representative of an acceptably high stability and a coefficient below 0.5 unacceptably low (power$=$0.80).

Ethics approval and consent to participate

The Regional Committee for Medical and Health Research Ethics for Northern Norway evaluated the study and concluded that their approval was unnecessary, as no data regarding the health and functional status of the dementia patients were gathered (Ref. No. 2015/1107/REK North). This study, including the research assistants' use of local records to identify potential participants, data collection procedure, obtaining of informed consent, data handling procedure ensuring the anonymity and confidentiality of the participants, and use of de-identified numbers, was approved by the Norwegian Center for Research Data (NSD) (Ref. No. 2015/43778/3/KS). Written consent was not obtained from the participants before the distribution of the questionnaire. Along with the questionnaire, all invited persons received written information about the purpose of the study and that participation was voluntary. Confidentiality and anonymity were guaranteed. In the information letter, the invited persons were informed that their informed consents were given by completing and returning the questionnaire anonymously to the research team. The participants received a gift of two lottery tickets worth approximately US$6.

Results

Construct validity

The EFA revealed three factors with eigenvalues >1 that explained 58.0% of the variance. The numbers of extracted

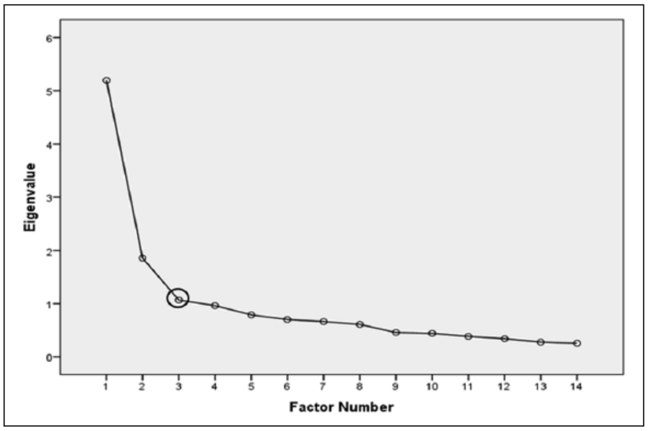

Figure 1. Scree-plot of the eigenvalues of the COPE Index. The point of inflection is marked.

factors were supported by examining the point of inflection in the scree-plot (Figure 1). Factor one accounted for six items ($R^2=37.1\%$) and was labeled “negative impact” (Table 1). The second factor accounted for five items ($R^2=13.3\%$) and was labeled “quality of support.” The third factor accounted for three items ($R^2=7.6\%$) and was labeled “positive values.”

In the CFA, the three-factor EFA model was compared with several other factor models. Expectedly, the null model fit poorly (Table 2). The one-factor model was clearly better than the null model, but also fit poorly. The correlated three-factor EFA model had a good model fit in terms of both model misspecification (RMSEA) and relative fit (CFI and TLI). A more parsimonious model specifying a second-order factor fit the data equal well as the correlated three-factor model. An even more parsimonious model constraining all second-order factor loadings as equal did not yield a significantly worse fit, supporting the use of a global score.

Criterion validity

The zero-order correlations between the three COPE factors, the second-order factor and the criterion variables are presented in Table 3. The NI factor was strongly correlated in the expected directions with variables measuring the demands of the caregiving role and the caregivers’ subjective perceptions of well-being (WHO-5). Moreover, the associations between the NI factor, the general health status item and the two items measuring social restriction were moderate. The QS and PV factors demonstrated statistically significant correlations in the expected directions using the criterion measures, although the absolute level of the associations ranged from weak to moderate. The second-order factor was generally moderately to strongly correlated with the criterion variables. In addition, the inter-correlations between the NI, QS and PV factors were moderate.

Table 2. Comparisons of the measurement model fit of the COPE Index.

Model	χ^2	df	RMSEA	95% CI	CFI	TLI
Null model	883.3	91	0.202	0.190–0.214	0.000	0.000
One factor	314.1	77	0.120	0.106–0.134	0.701	0.646
Three factors	113.1	74	0.050	0.030–0.067	0.951	0.939
2nd order	113.1	74	0.050	0.030–0.067	0.951	0.939
2nd-order EQ	113.8	76	0.048	0.028–0.066	0.952	0.943

COPE: Carers of Older People in Europe; χ^2: chi-square; df: degree of freedom; RMSEA: root mean square error of approximation; 95% CI: RMSEA confidence interval; CFI: comparative fit index; TLI: Tucker–Lewis index; 2nd order: a second-order factor accounting for all three factors; 2nd-order EQ: same as second order but with equal second-order loadings.

Reliability

The internal consistency, which was evaluated using Cronbach’s alpha (α), was 0.86 for the factors reflecting a negative impact, 0.76 for the five items reflecting the quality of support and 0.64 for the positive values subscale (Table 1). To examine the test–retest reliability, a heterogeneous group of 32 dementia caregivers completed a second questionnaire. The mean values of the test–retest scores and Spearman’s rho are presented in Table 4. The mean scores of all three factors were slightly lower after the second measurement. The NI and PV factors had high test–retest correlations ($r=0.91$ and 0.92, respectively), whereas the QS factor had a relatively lower correlation ($r=0.76$).

Discussion

Construct validity

This study is the first to evaluate the construct validity of the COPE Index using CFA methodology, which is recommended to ensure the replicability of a factor structure or model.[33] The large sample size allowed for the creation of two subsamples; the first subsample was used to identify the most suitable measurement model using EFA, and the second subsample was used to cross-validate the model using CFA. Our EFA model revealed the following three factors: negative impact, quality of support and positive values. The good fit of the three-factor measurement model supported the assumption of a multidimensional theoretical construct. This model was verified in a subsequent CFA and was comparable to previously published models,[23,25,29] strengthening the generalizability of the COPE Index. As shown in previous psychometric studies, the dimensional structure included both negative and positive appraisals of the caregiving role; hence, these factors are independent contributors to the overall caregiving index.[21,23]

We also extended the CFA by including a second-order factor that accounted for the correlations between the three primary factors. A second-order factor analysis represents a

Table 3. Bivariate correlations between the COPE Index factors and the criterion validity measures ($N = 430$).

	Negative impact	Quality of support	Positive values	COPE global
COPE: negative impact				
COPE: quality of support	0.39**			
COPE: positive values	0.42**	0.43**		
General health status item	–0.42**	–0.26**	–0.23**	–0.37**
WHO-5	0.63**	0.39**	0.37**	0.62**
Demands of caregiving item	0.61**	0.19*	0.31**	0.49**
Social restriction scale 2 items	–0.32**	–0.27**	–0.20**	–0.33**

COPE: Carers of Older People in Europe; COPE global: a second-order factor accounting for all three factors; WHO-5: World Health Organization-5 Well-Being Index.
*$p < 0.01$ (two-tailed).
**$p < 0.001$ (two-tailed).

Table 4. Test–retest reliability of the COPE Index ($n = 32$).

Factors	Test		Retest		Spearman's rho*
	N	Mean (SD)	N	Mean (SD)	
Factor 1: negative impact	29	18.86 (3.78)	28	18.25 (3.65)	0.91
Factor 2: quality of support	23	14.22 (3.10)	28	13.29 (3.74)	0.76
Factor 3: positive values	32	9.38 (1.62)	32	9.25 (1.57)	0.92

COPE: Carers of Older People in Europe; Spearman's rho: Spearman's rank order correlation; SD: standard deviation.
*$p < 0.001$ (two-tailed).

second (and new) factor analysis based on the latent factor scores (rather than the item scores per se), thus examining whether the factor scores may be further reduced to a fewer set of "super factors." If the reduction in fit is minor compared to the model from the primary factor analysis, the second-order model is favored as it is more parsimonious. Since the fit of this model was comparable to the more "complex" three-factor model, a total COPE Index score can be safely used as a general indicator of family caregivers' appraisal of the caregiving role.

We noted a few disparate psychometric findings. In the EFA, the item concerning the financial implications of caregiving did not correlate with any of the three factors and was therefore excluded from further analysis. This item had an extreme negative skew, which normally weakens the association with other items.[46] In this study, this item may not have been associated with the other items because more than 80% of the participants did not experience financial difficulties due to caregiving (results not shown). The Scandinavian welfare system, which ensures equal health, care and socio-economic services for all, may be an important contributing factor.[47] Furthermore, only seven dementia caregivers (1.6%) reported working less due to increased caregiving demands, and none of the caregivers had to quit working or work part-time to manage their caregiving responsibilities.

The item "Do you feel that anyone appreciates you as a caregiver?" (item 13) did not correlate with the positive values factor as expected and instead correlated with the quality of support factor. Similar results emerged in the Swedish and Italian datasets in the EUROFAMCARE study[23] and two Finnish validation studies.[25,29] These loading patterns may be due to cross-cultural differences, which cannot be disregarded.[29] We chose to retain this item due to its theoretical relevance because it can be associated with support. Sherbourne and Stewart[48] described five dimensions of social support, including emotional support, informational support and affectionate support. Support from family, friends or formal caregivers may cause feelings of being appreciated as a caregiver and vice versa.

Criterion validity

The criterion validity of the COPE Index was good. As expected, the NI factor correlated particularly well with the WHO-5 well-being scale.[38] The WHO-5 is widely used to measure quality of life[49] and may even be used to screen for depression.[39] The negative impact of caregiving has been suggested to have a stronger relationship with mental health and quality of life than with the other dimensions,[23] and the results of the current study support this assumption. Furthermore, the relatively strong association between the second-order factor, which measures the common underlying construct, and the WHO-5 is interesting. A previous study found that higher psychological well-being is related to reduced caregiver burden and a higher quality of life among caregivers of persons with dementia living at home.[50] Thus, the underlying construct of the COPE Index may be related to the dementia caregivers' perception of caregiver burden. As none of the criteria used were burden-specific instruments, this assumption should be addressed in detail in future studies.

Expectedly, the general health status item was moderately correlated with the NI factor and the second-order factor. In this study, the magnitude of these correlations was greater than previously reported.[23] The single item concerning demands associated with caregiving[42] has not been previously used as a criterion variable. We assumed that dementia caregivers who perceived caregiving as demanding would also report a higher negative impact of caregiving. The magnitude of the correlations between the item, the NI factor and the second-order factor was as expected and indicated the appropriateness of the item as a criterion in the current analysis. The Modified Social Restriction Scale measured the ease of obtaining substitute help if the caregiver became ill or needed a break from caregiving.[23] The magnitude of the associations between the QS and NI factors was relatively weaker than that expected and previously reported[23] but considered acceptable.

Reliability

The overall reliability of the COPE Index is considered good. The stability correlations (test–retest) were high for the NI and PV factors, whereas the correlation of the QS factor was somewhat lower. The sample size (32 participants) was slightly lower than that calculated prior to the analysis as the statistical power analysis indicated that at least 35 subjects should be included considering a Spearman test–retest correlation of 0.8. However, since two of the three stability estimates were above 0.90, we considered the current sample size sufficient.

The NI and QS factors had good internal consistency, and the Cronbach's alpha values were greater than the recommended value of 0.7.[51] The lower value of the PV factor is consistent with outcomes reported in previous studies.[23,25,29] Cronbach's alpha depends on the number of items included in the analysis,[52] and the PV factor consists of only three items. An easy future solution could be to reformulate the existing questions[29] or add items.[23,29] A counter-argument is that one of the strengths of the index is its brevity;[21,23] therefore, adding items or dimensions may affect its properties as a first-stage assessment tool.[23] However, the developers emphasized the importance of providing a measurement reflecting both the positive and negative aspects of caregiving,[21,22] and a refinement of the PV scale should be accomplished to improve the reliability of the instrument.

Strengths and limitations of the study

The response rate of 54.6% may be considered high for a mail survey.[53] The analysis of gender and kinship relationships with the care recipient showed no great differences between the responders and non-responders. There was a larger proportion of sons among the non-responders and more spouses among the responders. This finding is consistent with outcomes reported in previous studies in which men and younger people exhibited a lower willingness to participate in health research surveys.[54] Moreover, the questionnaire is based on items and scales that have been evaluated as appropriate and used to assess caregivers' situations in previous studies. Thus, our results are comparable to results from other studies.

The current analysis was somewhat limited by the large proportion of missing data for several items mainly due to the inclusion of a fifth response option ("not applicable") on three items measuring support and two items measuring the extent to which caregiving causes relationship difficulties with families and friends. The rationale is that social circumstances may vary, and the response option provides the opportunity to score the item as not relevant to the individual. This response option may cause a substantial loss of data that may bias the statistical analysis,[55] and we recommend omitting this response option in the future. However, due to the sufficient number of participants with complete data, we consider the bias related to non-responsiveness and missing data minor. Furthermore, the factor structure was consistent with existing EFA analyses,[23,25,29] confirming the validity of the current analysis.

The evaluation of criterion validity is based on brief instruments and single items; thus, questions may emerge regarding their properties as criteria measurements. In addition, we used several of the same criteria used by Balducci et al.[23] in their comprehensive validation study of the revised COPE Index. The assessment of criterion validity is recommended as a part of the cross-cultural validation process when an instrument is translated and/or used in a new population,[33] and these results are considered a supplement to previous research. Moreover, the association between the second-order factor and the criterion variables generates valuable information about the validity of this factor that measures a common underlying construct. The exact meaning of the second-order factor is difficult to define due to the limited number of selected criterion variables. Future studies should address this issue in detail.

Conclusion

The cross-validation approach used in this study enabled us to perform EFA and CFA in two separate samples, and the factor solution of the COPE Index was replicated in both samples. The three-factor solution had a good model fit, supporting theoretical assumptions that dementia caregivers' perception of caregiving is a multidimensional construct. Moreover, the good model fit of the second-order factors indicates that a common underlying construct exists, supporting the use of a general score to assess the overall impact of caregiving.

Overall, the psychometric properties of the Norwegian version of the COPE Index tested among dementia caregivers are good. The instrument includes important aspects of the dementia caregivers' situation and can be used by healthcare professionals (e.g. medical practitioners and nurses) as a first-stage assessment tool to identify dementia caregivers in need of help and support. This instrument may be used to assess the caregivers' situation at the general level and across each of the three factors and, thus, may serve as a tool to adapt healthcare services and interventions to the individual needs of caregivers. Future research may examine the creation of a usable cut-off criterion for the three dimensions or global score to screen for caregivers who need additional attention from healthcare professionals.

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Declaration of conflicting interests

The author(s) declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

Ethical approval

The Regional Committee for Medical and Health Research Ethics for Northern Norway evaluated the study and concluded that their approval was unnecessary, as no data regarding the health and functional status of the dementia patients were gathered (Ref. No. 2015/1107/REK North). This study, including the research assistants' use of local records to identify potential participants, data collection procedure, obtaining of informed consent, data handling procedure ensuring the anonymity and confidentiality of the participants, and use of de-identified numbers, was approved by the Norwegian Center for Research Data (NSD) (Ref. No. 2015/43778/3/KS).

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Informed consent

Because no registry of persons with dementia diagnoses and their relatives was available, research assistants (registered nurses or licensed practical nurses) in each of the 32 community healthcare services identified family caregivers who fulfilled the inclusion criteria and distributed the invitations to participate along with the questionnaire. Written consent from the participants was not obtained before distribution of the questionnaire. Along with the questionnaire, all invited persons received written information about the purpose of the study and that participation was voluntary. Confidentiality and anonymity were guaranteed. In the information letter, the invited persons were informed that their informed consent was given by completing and returning the questionnaire anonymously to the research team. This procedure was approved by the Norwegian Center for Research Data (NSD).

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PAPER II

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Factors affecting the use of home-based services and out-of-home respite care services: A survey of family caregivers for older persons with dementia in Northern Norway

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Abstract

Background: Family caregivers contribute substantially to the care for older home-dwelling people with dementia, although community healthcare services tend to be underutilized. In this

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study, we aimed to explore the use and predictors of use of home-based and out-of-home respite care services available to older home-dwelling persons with dementia, as reported by the family caregivers.

Method: A cross-sectional survey was administered to family caregivers ($n = 430$) in Northern Norway during April to November 2016. The use of healthcare services was categorized into two types according to principal component analysis: home-based services and out-of-home respite care services ($R^2 = 44.1\%$). Predictors of service use were examined with bivariate correlation, multiple linear regression, and Poisson regression analyses.

Results: The use of home-based services among persons with dementia was significantly higher for persons with advanced age, persons living in urban areas, persons living in an assisted living facility, persons living alone, and persons able to manage being alone for a short period of time. Among the family caregiver variables, higher age, status as a daughter, son, or other family member, higher educational level, and full-time employment also predicted greater use of home-based services. Same ethnicity was associated with use of fewer home-based services. The use of out-of-home respite care services was significantly higher among male persons with dementia and among those living in urban areas. In addition, fewer out-of-home respite care services were used by male caregivers or daughters of the care recipient, while the use was higher when the caregivers experienced more caregiving demands or had provided care for longer periods of time.

Conclusions: These results indicate areas that policymakers and healthcare providers should consider to identify families who underutilize healthcare services and to achieve a more equal and efficient allocation of services in accordance with families' needs.

Keywords

dementia, family caregivers, home-based services, respite care, healthcare professionals, use of services, survey

Introduction

The growing number of older people developing dementia is causing greater demands on community healthcare services. In line with international ageing policies, the majority of older persons with dementia receive long-term care in their own home (Alzheimer's Association, 2017; World Health Organization, 2012). Home-dwelling people with dementia receive more formal healthcare services than those without cognitive impairment (Alzheimer's Association, 2017). However, informal care provided by family caregivers constitutes a major portion of the care provided to older persons with dementia (Kasper, Freedman, Spillman, & Wolff, 2015; Vossius et al., 2015).

As part of the Nordic welfare system, the Norwegian healthcare services aim to provide health and social care to all who are deemed in need of support, regardless of age, gender, financial situation, social status and family situation (Vabo, 2012). A range of community healthcare services is available for home-dwelling persons with dementia, including home-based services and out-of-home respite care services (further referred to as respite care services). Family caregivers may require respite care services if they become particularly strained, and they should be included in service planning and decisions if the person with dementia is unable to legally consent (Norwegian Ministry of Health and Care Services, 1999). Applications for services are assessed by care managers in the local healthcare system, and services are allocated according to the estimated needs of individuals (Norwegian Directorate of Health, 2016).

Despite a well-developed healthcare system, the use of home-based services and respite care services is limited. In a Norwegian study regarding resource use and disease course in dementia, Vossius et al. (2015) reported that persons with dementia received an average of 16 h of home nursing per month shortly before admission to nursing homes, while the total amount of care provided by family members was almost 10 times higher. In addition, one-fifth of people with dementia utilize day centres. International studies have reported similar tendencies of low use of community healthcare services (Brandao, Ribeiro, & Martin, 2016; Nelson et al., 2002; Odzakovic, Hydén, Festin, & Kullberg, 2018). Simultaneously, the unmet care needs among persons with dementia and their family caregivers are substantial (Black et al., 2013; Forbes, Morgan, & Janzen, 2006; Kerpershoek et al., 2017; van der Roest et al., 2009).

In this study, we aimed to explore the factors associated with the use of home-based and respite care services available to home-dwelling persons with dementia aged $\geq$65 years, as reported by family caregivers. We assumed that the use of healthcare services was dependent on dyadic factors of both the care recipient and the family caregiver. Compared with other family caregivers, the caregivers of persons with dementia are more likely to advocate for the care recipient and to be involved in the coordination of formal healthcare services (Alzheimer's Association, 2017).

Based on a review of previous research, characteristics of the care recipients that could be related to increased use of healthcare services included higher age (Graessel, Luttenberger, Bleich, Adabbo, & Donath, 2011; Kadushin, 2004), higher level of disability (Dohl, Garasen, Kalseth, & Magnussen, 2016; Sævareid, Thygesen, Lindstrom, & Nygaard, 2012), living alone (Dohl et al., 2016; Toseland, McCallion, Gerber, & Banks, 2002) and living in an urban area (Goins, Spencer, & Byrd, 2009). In addition, female care recipients tend to use more home-based services than male care recipients (Kadushin, 2004). Regarding ethnicity, minority ethnic groups often fail to access services (Greenwood, Habibi, Smith, & Manthorpe, 2015) and indigenous people are less likely to use formal healthcare services (Marrone, 2007). This feature is relevant for our study because the indigenous Sami people represent a minority ethnic group in Norway.

The family caregivers' characteristics reported to influence the use of services are age (Graessel et al., 2011; Martindale-Adams, Nichols, Zuber, Burns, & Graney, 2016), relationship to the care recipient (Robinson, Buckwalter, Reed, & Forbes, 2005) and educational level (Lüdecke, Mnich, & Kofahl, 2012; Martindale-Adams et al., 2016; Toseland et al., 2002). The association between gender of the caregiver and service use is more ambiguous. In a meta-analysis, Pinquart and Sorensen (2006) found no gender differences among family caregivers and use of formal support, although later studies reported that male caregivers utilized more support services (Lüdecke et al., 2012) and home-based services (Raivio et al., 2007) than female caregivers. The relation between income and service use is also unclear. Hong, Hasche, and Lee (2011) found an association between higher income and increased service use, whereas Brandao et al. (2016) found no relation between these variables.

Family caregivers providing care to those in the middle and later stages of dementia require more support from healthcare services (Lethin, Hallberg, Karlsson, & Janlöv, 2016). Previous studies have found that family caregivers who reported lower life satisfaction (Brodaty, Thomson, Thompson, & Fine, 2005) and those who perceived higher levels of stress (Friedemann, Newman, Buckwalter, & Montgomery, 2014) and caregiver burden (Brodaty et al., 2005; Hughes et al., 2014; van der Roest et al., 2009) had a greater need for formal support. We therefore assumed that factors reflecting increased needs or demands for services were also related to the amount of healthcare services used.

Few large-sample studies have examined the use of community healthcare services by older persons with dementia and from the perspective of family caregivers within the context of the Nordic welfare system. Most previous studies did not examine both home-based and respite care services or did not distinguished between them. Our rationale for distinguishing between the two types of service is that predictors may have different associations with the type of service used.

The objectives of this study were (1) to describe the use of home-based services and respite care services among home-dwelling persons with dementia aged ≥65 years, (2) to explore the individual characteristics of persons with dementia and family caregivers related to the respective use of these services, and (3) to explore the associations between factors reflecting the family caregivers' needs for support and the use of healthcare services.

Method

Participants and data collection

Family caregivers of older home-dwelling persons with dementia in 32 municipalities in Northern Norway were invited to participate in the survey. The municipalities varied with regard to size, geographical dispersion, communities included and not included in the Sami Parliament funding scheme for cultural and economic development and residential area (urban vs. rural). In the geographical area of this study, the density of the population is low (4.3 inhabitants/km^2) (Statistics Norway, 2018) compared to the density of the population in Norway overall (16.5 inhabitants/km^2) and the density of the population in Europe (116.3 inhabitants/km^2; Norwegian Ministry of Local Government and Modernization, 2014). In this study, urban areas are defined as smaller towns or middle-sized cities with 3500–80,000 inhabitants. Rural areas are defined as smaller towns/villages with <3500 inhabitants or sparsely populated areas (Norwegian Ministry of Local Government and Modernization, 2014).

The inclusion criteria were providing the major portion of unpaid care at least once a week to a home-dwelling person with dementia ≥65 years of age; an immediate family member, distant relative, friend or neighbour; and age of at least 18 years. Dementia was defined as a diagnosis of dementia or cognitive impairment consistent with dementia. Care was broadly defined as personal care, emotional and psychological support, regular visiting and phoning, support in handling personal finances and organizing care provided by formal caregivers (Lamura et al., 2008). Home was defined as the care recipient's own home or assisted living facility. In Norway, there are different types of assisted living facilities, namely those with access to formal healthcare services 24 h, with partial access to formal healthcare services (e.g. at daytime) or with access to formal healthcare services (e.g. home nursing) at the same level as those who live in their own homes (Otnes, 2015). In this study, we included family caregivers of persons with dementia who lived in assisted living facilities with access to formal healthcare at the same level as those who lived in their own home.

We collaborated with research assistants in each of the 32 municipalities to identify the family caregivers, distribute the questionnaire and carry out a reminder procedure. The managers of the community healthcare services appointed registered nurses or licensed practical nurses as research assistants, who used the local records to identify potential participants ($n = 860$). During the inclusion procedure, 72 family caregivers were excluded from the study, and finally, 788 family caregivers fulfilled the inclusion criteria (Figure 1). The questionnaire was distributed by mail to the family caregivers between April and November 2016. A selective reminder procedure was sent four weeks later. Altogether, 436 family caregivers returned the questionnaire. Further review of the data revealed six respondents who did not meet the inclusion criteria, yielding a final sample of 430 participants (response rate of 54.6%). The research assistants recorded the gender and kinship relation of all family caregivers who fulfilled the inclusion criteria in order to compare responders and non-responders. The characteristics of the responders are presented in Table 1. The non-responders differed somewhat from the responders, because 33.2% were men, 19.7% were spouses, 44.9% were daughters, 25.5% were sons, and 9.8% were others.

Measures

Dependent variables

The items used to register the use of healthcare services were derived from a previous Norwegian study evaluating a caregiver school programme (Norwegian National Advisory Unit on Ageing and Health (Ageing and Health), 2011). The response options

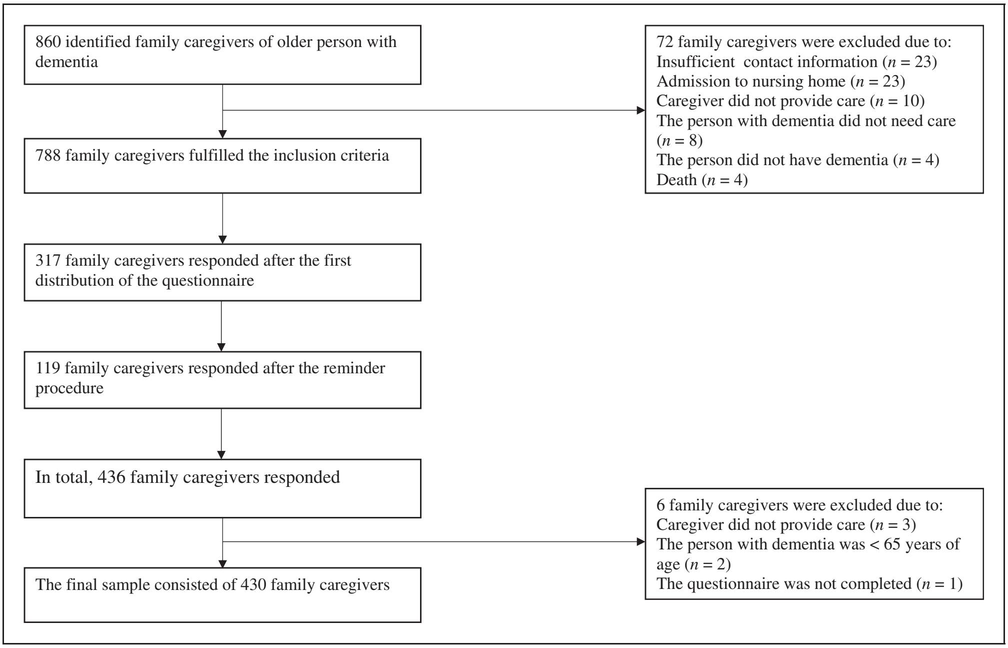

Figure 1. Flow chart over the inclusion procedure.

Table 1. Characteristics of persons with dementia and family caregivers and relationships with home-based and respite care services used ($N = 430$).

Characteristics	M (SD) or %	Home services[a] (M, SD)	Comparison[c]	Respite services[b] (M rank)	Comparison[c]
Persons with dementia					
Age	82.59 (6.86)		$r = 0.36^{**}$		$r = -0.02$
Gender					
Female	63.5%	2.17 (1.24)	$t_{428} = 4.52^{***}$	203.34	$z = -3.02^{**}$
Male	36.5%	1.61 (1.27)		236.65	
Ethnicity					
Non-Sami	89.8%	1.98 (1.28)	$F_{2,427} = 0.36$	215.89	$\chi^2 = 0.67$
Sami, one marker	5.3%	1.87 (1.22)		224.59	
Sami, two markers	4.9%	1.76 (1.48)		198.33	
Place of residence					
Rural area	57.9%	1.76 (1.26)	$t_{428} = -3.98^{***}$	203.77	$z = -2.59^{*}$
Urban area	42.1%	2.25 (1.26)		231.64	
Cohabiting with the family caregiver					
No	68.8%	2.38 (1.19)	$t_{428} = 11.99^{***}$	206.00	$z = -2.66^{**}$
Yes	31.2%	1.06 (0.99)		236.49	
Assisted living facilities					
No	82.6%	1.86 (1.26)	$t_{412} = -4.93^{***}$	205.78	$z = -0.72$
Yes	17.4%	2.65 (1.18)		215.65	
Ability to manage being alone					
< 2 h	27.8%	1.64 (1.36)	$F_{3,420} = 10.67^{***}$	238.04	$\chi^2 = 11.26^{*}$
2–12 h	55.4%	2.25 (1.21)		206.50	
13–24 h	7.1%	2.00 (1.20)		204.73	
>24 h	9.7%	1.32 (1.08)		179.09	
Family caregivers					
Age, mean (SD)	61.80 (11.70)		$r = -0.28^{***}$		$r = 0.07$
Gender					
Female	68.9%	1.93 (1.30)	$t_{426} = -0.76$	221.1	$z = -1.85$
Male	31.1%	2.03 (1.25)		199.86	
Ethnicity					
Non-Sami	93.0%	1.96 (1.28)	$F_{2,427} = 3.43^{*}$	216.13	$\chi^2 = 1.41$
Sami, one Sami marker	3.5%	2.67 (0.90)		229.27	
Sami, two Sami markers	3.5%	1.47 (1.51)		184.83	
Relation to the person with dementia					
Spouse	28.8%	1.02 (0.97)	$F_{3,423} = 39.73^{***}$	235.21	$\chi^2 = 8.24^{*}$
Daughter	42.4%	2.30 (1.16)		201.80	
Son	18.3%	2.44 (1.15)		202.39	
Other	10.5%	2.31 (1.41)		225.21	
Education level					
Elementary school	28.8%	1.53 (1.21)	$F_{2,421} = 13.44^{***}$	222.35	$\chi^2 = 2.61$
High school	34.4%	1.94 (1.27)		201.45	
Higher education	36.8%	2.31 (1.26)		215.14	
Employment					
Not employed or retired	48.6%	1.53 (1.25)	$F_{2,425} = 27.47^{***}$	221.19	$\chi^2 = 2.01$

(continued)

Table 1. Continued

Characteristics	*M* (*SD*) or %	Home services[a] (*M*, *SD*)	Comparison[c]	Respite services[b] (*M* rank)	Comparison[c]
Part-time	11.4%	2.14 (1.15)		217.95	
Full-time	40.0%	2.44 (1.17)		205.37	
Income					
≤350,000 NOK	19.2%	1.59 (1.18)	$t_{410} = -2.98$**	199.63	$z = -0.65$
>350,000 NOK	80.8%	2.07 (1.30)		208.13	
Demand of caregiving (range: 1–4)	2.77 (0.90)		$r = -0.22$**		$r = 0.20$**
COPE index total (range: 1–4)	2.90 (0.48)		$r = 0.16$**		$r = -0.09$
Self-rated health (range 1–5)	2.30 (0.97)		$r = -0.14$**		$r = 0.13$**
WHO-5 well-being scale (range 0–5)	3.03 (1.12)		$r = 0.17$**		$r = -0.08$
Duration of caregiving (years)	4.15 (3.22)		$r = 0.14$**		$r = 0.17$**

M: mean; *SD*: standard deviation.
[a]Home-based services, [b]Respite care services, [c]Use of services compared with the characteristic variable (e.g. age) using Pearson correlation (*r*), Student's t-test (*t*), or analysis of variance (*F*) for continuous scores or Spearman's rank order correlation (*r*), the Mann–Whitney U-test (*z*), or the Kruskal–Wallis test (χ^2) for ranked scores.
*$p < 0.05$, **$p < 0.01$ and ***$p < 0.001$.

were home nursing, domestic help, support person, day centre or respite care in a nursing home. For this study, we added two services: meals on wheels and a remote-control safety alarm. All items were rated as non-use (0) and use (1). Principal component analysis (PCA) of the seven variables extracted two components with Eigenvalues above 1 (1.9 and 1.2 respectively). The first component accounted for four items (home nursing, domestic help, meals on wheels and remote-control safety alarm) and was labelled home-based services. The second component accounted for three items (support person, day centre and respite care in a nursing home) and was labelled respite care services. The components explained 27.6% and 16.5% of the variance, respectively. We used the average score of the number of services in each component as dependent variables.

Independent variables

Independent variables for the persons with dementia were age, gender (coded as 0 = female, 1 = male), ethnicity, place of residence, cohabiting with a family caregiver (coded as 0 = no, 1 = yes), living in an assisted facility (coded as 0 = no, 1 = yes), and ability to manage being alone at home. Ethnicity was assessed with two items derived from the SAMINOR study (Brustad, Hansen, Broderstad, Hansen, & Melhus, 2014), namely self-perceived ethnicity and first language. The variables were merged and coded into three categories: non-Sami (0), positive for either Sami marker (1) and positive for both Sami markers (2). Place of residence was measured at five levels and merged into two categories: rural area (smaller town/village or sparsely populated area = 0) and urban area (city, town or town centre = 1). One item assessing the ability to manage being alone at home was retrieved from the Family Collaboration Scale (Lindhardt, Nyberg, & Hallberg, 2008). The response options were merged and coded into four groups based on the number of hours the care recipient is able to manage being alone: 0–2 h (0), 2–12 h (1), 13–24 h (2) and more than 24 h (3).

Independent variables for the family caregivers included age, gender, ethnicity, marital status, relationship to the person with dementia, educational level, and income level. Gender and ethnicity were coded as previously described. Relationship to the person with dementia was coded as spouse (0), daughter (1), son (2) and other (3). Educational level, employment status and income level were all drawn from the Tromsø study (Jacobsen, Eggen, Mathiesen, Wilsgaard, & Njolstad, 2012). Educational level was coded as elementary school (0), high school (1) and higher education (2). Employment status was measured at eight levels and further merged into three categories: not employed (0), employed part-time (1) and employed full-time (2). Income level was measured at eight levels and further dichotomized into a lower income group (household income $\leq$350,000 NOK = 0) and a higher income group (household income >351,000 NOK = 1), based on the European Union's definition of low income as less than 60% of the median income in the population (Statistics Norway, 2016).

Family caregivers' need variables

In this study, factors reflecting family caregivers' needs are conditions that may influence the need for support from healthcare services, such as demands related to caregiving, negative impact of caregiving, health status, well-being and duration of caregiving.

A single item assessing the demands related to caregiving derived from a survey used to evaluate a caregiver teaching programme (Norwegian National Advisory Unit on Ageing and Health (Ageing and Health), 2011) was used and further adapted for the present study. The response options were recorded using a four-point scale ranging from not demanding (1) to very demanding (4).

The negative impact of caregiving was assessed with The Carers for Older People in Europe (COPE) Index (Balducci et al., 2008; McKee et al., 2003). The original COPE index consisted of 15 items assessing the family caregivers' perception of caregiving across three domains: negative impacts of caregiving, positive values of caregiving and quality of social support (Balducci et al., 2008). A previous cross-validation study using the same sample as the current study confirmed the psychometric properties of the measurement. This study also demonstrated that using a general factor to summarize the three primary factors fits the data as well as the three-factor model (Moholt, Friborg, Skaalvik & Henriksen, 2018) . Thus, the general factor was used in the present study by calculating the average score of all COPE item raw scores (range 1–4), with lower scores indicating more negative impacts of caregiving. The internal consistency of the scale was good (Cronbach's alpha = 0.87). In the COPE index, the response option 'not applicable' was added for five items regarding caregivers' social circumstances. Due to the inclusion of this option, these items had a large proportion of missing data (ranging between 7.2% and 23.5%). The expectation maximization (EM) method was used to impute missing data. The correlation between the imputed variables and the original variables was almost perfect ($r = 0.993$).

Self-reported general health status was assessed using a single item drawn from the Tromsø study (Fylkesnes & Førde, 1991). The response options were recorded using a five-point scale ranging from very good (1) to very poor (5). The item scores followed a curve linear distribution, which was transformed by squaring the scores and further included in the multiple regression analysis.

The World Health Organization-5 Well-Being Index (WHO-5) assesses the family caregivers' subjective perception of well-being (World Health Organization, 1998). The WHO-5 has previously demonstrated good validity (Topp, Ostergaard, Sondergaard, & Bech, 2015) and reliability (Balducci et al., 2008). In the present study, the index demonstrated high internal consistency (Cronbach's alpha = 0.92). In the analyses, we used the average score of all item raw scores (range of 0–5), where higher scores represent better well-being. Missing data (ranging between 4% and 7.7%) were imputed by the EM method.

The duration of family caregiving was assessed using an item retrieved and adapted from the Family Collaboration Scale (Lindhardt et al., 2008). This item assessed how many years the family caregivers had cared for the person with dementia after appearance of dementia symptoms.

Data analyses

Missing questionnaire data related to the COPE index and the WHO-5 were replaced by multiple imputation using the EM function in PRELIS/LISREL 9.20 for Windows (Jöreskog & Sörbom, 2015).

IBM SPSS for Windows, version 24.0, was used for descriptive, bivariate and regression analyses. The descriptive data are presented as the means and standard deviations or as proportions of subjects within the categories (Table 1). Crude relationships between services used and the included variables were examined using Pearson correlation (*r*), Student's t-test (*t*) or analysis of variance (*F*) for continuous scores and Spearman's correlation (*r*), the Mann–Whitney U-test (*z*), or the Kruskal–Wallis test (χ^2) for ranked scores. Based on the bivariate analyses, independent variables with $p < 0.10$ were included in the regression analyses.

The distributional properties of the two outcome variables (home-based and respite care services) required fitting of two different regression models, an ordinary least square model and a Poisson model, respectively. In the former case, the analysis was performed using a backward stepwise regression procedure for removing non-significant variables. The scores of the dependent variable representing respite care services followed a Poisson distribution; hence a Poisson regression model linearizing the relationship through a log change rate function was used (Kleinbaum, Kupper, Nizam, & Muller, 2008). The exponentiation of the beta coefficient (exp *B*), or the odds, indicates how many times higher (or lower) a service will be used given a unit score change in a covariate. The goodness-of-fit values of the Poisson models were assessed by Pearson's chi-square statistics, where the estimates should be close to 1.

For all analyses, *p* values <0.05 were considered statistically significant.

Ethics

The study complied with the Helsinki declaration for research ethics (World Medical Association, 2018). The Regional Committees for Medical and Health Research Ethics for Northern Norway reviewed the study protocol and concluded that approval by the committee was unnecessary (Ref. No. 2015/1107/REK North). The study, including the data collection procedure with participant informed consent and the data handling procedure, was approved by the Norwegian Centre for Research Data (NSD) (Ref. No. 2015/43778). Written informed consent was not obtained from the participants before distribution of the questionnaire. Along with the questionnaire, all invited persons received written information about the purpose of the study, how the family caregivers were identified, and that participation was voluntary. In the information letter, the invited persons were informed that completing and returning the questionnaire constituted their informed consent. Participants received a gift of two lottery tickets, worth approximately 5 GBP, for participating.

Several of the research assistants had a professional caring relationship to the persons with dementia and their family caregivers. We assume that this relationship did not influence the family caregivers' decisions regarding participation, as the questionnaire was forwarded on behalf of the research group at the university and the research assistants' identities were unknown to the family caregivers. The completed questionnaires were returned directly to the research group at the university, and only the research group had access to the data.

Results

Use of home-based services

The persons with dementia utilized an average of 1.97 ($SD = 1.28$) home-based services, ranging from 0 to 4 services. In total, 14.7% of persons with dementia did not use any home-based services, 24.8% used one service, 24.7% used two services, 20.9% used three services and 14.9% used all four services. The majority of the persons with dementia used home nursing (80.2%), followed by domestic help (47%), a remote-control safety alarm (34.9%) and meals on wheels (34.4%).

The bivariate associations between the average number of home-based services used and characteristics of the persons with dementia and the family caregivers are presented in Table 1. For persons with dementia, the use of services was related to age (more use by those older in age), gender (more use by females), place of residence (more use by those in urban areas than rural areas), cohabitation (more use by those who did not cohabit with the family caregiver), living in assisted living facilities (more use by those who lived in an assisted living facility) and ability to manage being alone (more use by those who required partial daily support). For family caregivers, the use of home-based services was related to age (more use by those younger in age), ethnicity (less use by those confirming two Sami markers), relationship to the person with dementia (less use by spouses), educational level (less use by those with an elementary school education), employment status (less use by those not employed) and income level (less use by those with lower income). Weak to moderate significant correlations were observed between the need variables of the family caregivers and the use of home-based services. The results indicated that the use of home-based services was higher when the family caregivers considered caregiving less demanding, experienced a lower negative impact of caregiving, were in better general health, exhibited better well-being and had provided care for a longer period of time.

Table 2. Predictors of use of home-based services based on multiple regression analyses ($N = 430$).

	Beta (95% CI)	β	*p* value
Persons with dementia[a]			
Adj $R^2 = 0.34$			
Age	0.04 (0.02, 0.05)	0.19	<0.001
Urban area (1) vs. rural area (0)	0.32 (0.11, 0.53)	0.12	0.003
Cohabiting with the family caregiver (1) vs. living alone (0)	−1.12 (−1.34, −0.87)	−0.40	<0.001
Assisted living facility (1) vs. not assisted living facility (0)	0.36 (0.09, 0.64)	0.11	0.010
Ability to manage being alone (<2 h alone, 0)			
2–12 h alone (1)	0.23 (0.00, 0.45)	0.09	0.05
>24 h alone (1)	−0.68 (−1.07, −0.29)	−0.16	0.001
Family caregivers[b]			
Adj $R^2 = 0.27$			
Age	0.03 (0.01, 0.04)	0.22	0.001
Sami ethnicity, two Sami markers (1) vs. non-Sami (0)	−0.80 (−1.42, −0.17)	−0.11	0.012
Relation to the person with dementia (Spouse 0)			
Daughter (1)	1.58 (1.18, 1.98)	0.60	<0.001
Son (1)	1.67 (1.24, 2.11)	0.51	<0.001
Other relationship (1)	1.45 (0.99, 1.91)	0.35	<0.001
Higher education (1) vs. elementary school (0)	0.35 (0.11, 0.58)	0.13	0.004
Full-time (1) vs. not employed (0)	0.37 (0.10, 0.64)	0.14	0.008

Beta: unstandardized beta coefficient; β: standardized beta coefficient; 95% CI: confidence interval of the unstandardized beta coefficient.

[a] Intercept = −0.82.

[b] Intercept = −0.98.

Multiple regression analyses

The beta coefficients of the multiple linear regression analysis with home-based services as the outcome are shown in Table 2. The use of home-based services by persons with dementia was significantly predicted by higher age, living in an urban area, living in an assisted living facility or living alone. The ability to manage being alone for part of the day was borderline significantly related to the use of more home-based services, and the ability to manage being alone for more than 24 h was negatively associated with service use. Comparable analyses of the family caregivers showed significantly higher use of services among those who were older, those who were a daughter, son or other kin, those with a higher education and those full-time employed. Sami ethnicity according to two Sami markers was negatively associated with service use. None of the caregiver need variables corresponded to an additional contribution in the second step, and thus, the caregiver background characteristics were the sole contributors.

Use of out-of-home respite care services

The average number of respite care services used was 0.56 ($SD = 0.72$), ranging from 0 to 3 services. The majority of the persons with dementia (56%) did not use services, 33% used one service, 9.8% used two services, and 1.2% used all eligible respite care services. Day centres were used most often (26.0%), followed by respite care in nursing homes (16.5%) and a support person (13.5%).

The bivariate correlations between the average numbers of respite care services used and characteristics of the persons with dementia and the family caregivers are presented in Table 1. For persons with dementia, the use of respite care services was related to gender (more use by males), place of residence (more use by those in urban areas), cohabitation (more use by those who cohabited with the family caregiver) and ability to manage being alone (more use by those who could only manage being alone for less than 2 h). For family caregivers, the use of respite care services was significantly related to the relationship with the person with dementia (less use by daughters and sons). All need variables for family caregivers were significantly or borderline significantly related to the use of respite care services. The direction of the correlations indicated that the use of services increased when the family caregivers considered caregiving more demanding, experienced a greater negative impact of caregiving, had poorer health, exhibited a lower well-being, and had provided care for a longer period of time.

Poisson regression analyses

The coefficients from the Poisson regression analysis with respite care services as the outcome for persons with dementia and family caregivers are presented in Table 3. For persons with dementia, the odds of using respite care services were significantly higher among males compared to females, and among those living in an urban area compared to those living in a rural area. For family caregivers, the odds of using respite care services were significantly lower among males compared to females and among those who were daughters of the care recipient compared to spouses. Among the variables measuring caregivers' needs for services, the perception of caregiving as more demanding and longer duration of caregiving significantly increased the odds of using more respite care services.

Table 3. Predictors of use of respite care services based on Poisson regression analyses ($N = 430$).

	Exp *B* (95% CI)	*p* value
Persons with dementia[a]		
Male (1) vs. female (0)	1.43 (1.12, 1.82)	0.004
Urban area (1) vs. rural area (0)	1.36 (1.06, 1.73)	0.014
Family caregivers[b]		
Male (1) vs. female (0)	0.70 (0.51, 0.97)	0.032
Relationship to the person with dementia		
Daughter (1) vs. spouse (0)	0.68 (0.50, 0.91)	0.010
Need variables		
Demand of caregiving	1.29 (1.11, 1.50)	0.001
Duration of caregiving	1.05 (1.02, 1.08)	0.003

Exp (*B*): odds ratio; 95% CI: Wald confidence interval for Exp (*B*).

[a] Goodness of fit (Pearson χ^2/df = 0.92, intercept = 0.42).

[b] Goodness of fit (Pearson χ^2/df = 0.89, intercept = 0.28).

Discussion

The results from this study showed that the majority of the persons with dementia used home-based services, and to a lesser extent respite care services. The results indicate a somewhat higher use of day centres than previously reported (Norwegian Ministry of Health and Care Services, 2015; Vossius et al., 2015). Because day centres have been established in almost all Norwegian municipalities (Norwegian Ministry of Health and Care Services, 2015), we had expected that more individuals would be using this service.

Factors associated with the use of services

Age is typically related to utilization of home-based services (Kadushin, 2004). In this study, the age of the person with dementia and the age of the family caregiver were positively associated with the number of home-based services used, but not with the use of respite care services. Moreover, gender was a significant predictor related to use of respite care services, but did not predict the use of home-based services. Notably, male care recipients used more respite care services than female care recipients, whereas male family caregivers reported the use of fewer services than female family caregivers. Female caregivers might have increased need for these services, as they are more likely to cohabit with the care recipient (Odzakovic et al., 2018) and to report higher levels of burden and depression, and lower levels of subjective well-being and physical health (Pinquart & Sorensen, 2006).

The use of home-based and respite care service was more frequent among those who lived in urban areas compared to those who lived in rural areas. Northern Norway is characterized by large geographical areas with dispersed populations that may complicate an effective provision of services. Previous studies have demonstrated that the needs of rural families are not met by the community healthcare services due to restricted hours and limited availability (Herron & Rosenberg, 2017; Morgan, Semchuk, Stewart, & D'Arcy, 2002) or inappropriate deliveries of the services (Innes, Blackstock, Mason, Smith, & Cox, 2005). Rural caregivers may receive more support from other family members (Ehrlich, Bostrom, Mazaheri, Heikkila, & Emami, 2015). However, a higher degree of family involvement may be a consequence of inappropriate delivery of healthcare services (Innes et al., 2005), rather than a result of cultural norms and attitudes towards caregiving among people living in rural areas. We have no data to evaluate this possibility, and this issue should be further investigated.

To our knowledge, no quantitative studies have examined the association between Sami ethnicity and the use of home-based and respite care services. In this study, the family caregiver fulfilling both Sami criteria used home-based services less often than non-Sami. This result may be viewed in connection with an interview study showing that community healthcare professionals' believe that Sami caregivers take care of their own family members with dementia and are reluctant to seek and accept help from formal services. Such assumptions may lead to omissions and neglect as well as increased barriers to offering help (Blix & Hamran, 2017). Previous studies among minority ethnic groups or indigenous people have reported that factors contributing to low service use include rural locations (Marrone, 2007), communication/language barriers (Brodaty & Donkin, 2009), concerns about the cultural appropriateness of the services (Greenwood et al., 2015) and beliefs that dementia is a part of the normal ageing process (Mukadam, Cooper, & Livingston, 2011). The low use of health care services among the Sami may, thus, be related to lack of knowledge, and cultural adaptations that the Sami experiences as an alienating practice. The involvement of Sami care recipients and their family caregivers should therefore be prioritized.

The persons with dementia who lived alone used more home-based services than those who cohabited with the family caregiver. Moreover, spouse caregivers used fewer services compared with adult child caregivers and caregivers of other kinship relations to the care recipient. Since almost all the caregivers who cohabited with the person with dementia were spouses, we find it reasonable to interpret the results from the two analyses together. The low use of home-based services might indicate that those who cohabited with the care recipient performed caregiver tasks that otherwise would have been performed by the healthcare services. This interpretation is in line with previous studies, which have suggested that cohabitants substitute rather than complement professional care (Dohl et al., 2016; Nelson et al., 2002; Toseland et al., 2002). These findings might also indicate that spouses are reluctant to seek help or engage the community healthcare services (Friedemann & Buckwalter, 2014). Notwithstanding, being a spouse is previously reported to be related to higher levels of caregiver stress and burden, which might be explained by the fact that they provide more care to the care recipient than caregivers of other kinship relations (Pinquart & Sörensen, 2011). Thus, spouses and others who cohabit with the persons with dementia might be in special need of support and potentially should be the targets of healthcare interventions aiming to reduce the caregiving demands.

Persons with dementia who lived in assisted living facilities used a higher number of home-based services than individuals in other living arrangements. This finding is consistent with a recent Norwegian study on use of homecare among older adults and persons with intellectual disabilities (Dohl et al., 2016). Residents in assisted living facilities may be more frail and have more extensive needs for care, and the services may be more accessible in assisted living facilities than in traditional homes (Dohl et al., 2016) as the facilities are often located in the municipality centres nearby the location of the healthcare services. Due to limited research on the topic, the results are difficult to explain, and future studies should address this question more thoroughly.

Full-time employment and higher educational level among family caregivers were associated with increased use of home-based services. It is reasonable that full-time employed caregivers use formal care to compensate for their more limited time available to provide care themselves (Kadushin, 2004). In addition, individuals with higher educational levels may be more aware of their rights to access services (Sævareid et al., 2012) and more capable of obtaining information about the eligible services (Toseland et al., 2002). To ensure equity in access to and use of healthcare services, healthcare professionals and politicians should improve the availability of information about the services at the community level and inform persons with dementia and family caregivers about their statutory rights for help and support.

In this study, the use of respite care services was associated with a longer duration of caregiving and higher demands related to caregiving. According to Montgomery and Kosloski (2009), caregiving for a person with dementia is a dynamic process, which means that the care responsibilities as well as the family caregivers' experiences change as the disease progresses. Thus, respite care services might be required in the later stages of dementia when the demands of the care recipient most likely increase.

Associations among variables reflecting family caregivers needs for services and the amount of healthcare services used have been demonstrated in previous studies (Hong et al., 2011; Martindale-Adams et al., 2016). In this study, we found no associations between the need variables and the use of home-based services. Robinson et al. (2005) reported similar results and suggested that burdened caregivers may not have the capacity to make decisions or seek help. Others have suggested that family caregivers may delay the use of home-based services until the care recipient's impairments become severe and the caregiver's burden becomes high (Kadushin, 2004). Stress and caregiver burden are previously found to be related to higher needs for healthcare services (Friedemann et al., 2014). Adequate formal support may provide help and relief to family caregivers, reduce the negative consequences of caregiving and postpone institutionalization of the person with dementia (Laparidou, Middlemass, Karran, & Siriwardena, 2018). Karlsson et al. (2015) suggested that it is crucial to balance the needs of both the persons with dementia and the family caregivers. Thus, a dyadic approach complying with the integrity of the person with dementia and the family caregivers' needs for support is necessary in dementia care.

Strengths and limitations

This is the first large-sample study performed among family caregivers of persons with dementia in Northern Norway. As the participating municipalities represent a diverse portfolio of communities, the results should generalize well beyond these areas. Moreover, few studies have distinguished between home-based and respite care services, that is important as the factors related with the use of home-based services differ from those related with respite care services.

This study also has limitations. First, the response rate was 54.6%, which is actually quite high nowadays for postal surveys of this kind (Kelley, Clark, Brown, & Sitzia, 2003). Nevertheless, it may be a potential source of bias. The research assistants involved in this study recorded the gender and kinship relationships of all invited persons. The non-responders differed somewhat from the responders, as there was a larger proportion of sons among the non-responders and a larger proportion of spouses among the responders. This non-response bias is in line with other studies, for example Glass et al. (2015).

A record of all older persons with dementia in the included municipalities does not currently exist. Consequently, all respondents were persons previously known to the health care professionals, potentially excluding persons with dementia who were unknown to the services. This may have resulted in inappropriate descriptions of service use and non-use among the overall population. Moreover, the use of healthcare services is assessed by the family caregivers and may therefore not be consistent with the actual use of services. However, family caregivers are often involved in contacting healthcare services and seeking help (Alzheimer's Association, 2017). Hence, we assumed that the participants estimated their actual use to the best of their knowledge.

Despite focused recruitment efforts, only 7% of the family caregivers and 10% of the persons with dementia were Sami. It is possible that the Sami are less likely to use the services and, consequently, are unknown to the healthcare professionals who identified the potential participants. The low representation of Sami may explain the few significant associations between ethnicity and service use, and further research is needed to explore issues regarding the use of community healthcare services.

Although several significant associations of service use were identified, a substantial proportion of the variance in use of home-based services remained unexplained. Other relevant factors explaining service use may therefore have been omitted, such as the functional disability of the care recipients (Dohl et al., 2016). We did not have permission to collect such data, and could therefore not adjust our prediction estimates accordingly. Moreover, the evaluation of the family caregivers' needs was based on single items and brief instruments, which may not fully capture the caregiving circumstances and the burden associated with caregiving. Future research should include more burden-specific instruments, and if possible and ethically acceptable, include measures indicating the progress in dementia disease.

Conclusions

This study provides information about the use of home-based and respite care services by persons with dementia and their family caregivers. Our results suggest that the amount of service use may indicate unequal access to and use of services within various demographic and social subgroups, contrary to Nordic welfare state policy aims. To ensure equity, healthcare services should be tailored to all families in need of support and to particular groups of persons with dementia and family caregivers (e.g. those who live in rural areas, the Sami, spouses and caregivers with lower educational levels). Moreover, the missing associations between service use and family caregivers' needs in terms of the negative impact of caregiving and self-perceived health and well-being give rise to concerns. These issues and the implications for family caregivers and persons with dementia require further investigation.

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PAPER III

Moholt, J-M., Friborg, O., Henriksen, N., Hamran, T & Blix, B.H. Non-use of community healthcare services – an explorative cross-sectional study among family caregivers for older, home-dwelling persons with dementia. In review: Ageing & Society.

Non-use of community healthcare services —an explorative cross-sectional study among family caregivers for older, home-dwelling persons with dementia

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Abstract

Community healthcare services for older, home-dwelling persons with dementia tend to be underutilized. Family caregivers provide substantial care and they often arrange for and coordinate healthcare services on behalf of persons with dementia. The aim of this study was to examine family caregivers' knowledge of unused services and their self-reported reasons for non-use of such services. We gathered cross-sectional survey data from 430 family caregivers of older persons with dementia in Northern Norway. Multinomial logistic regression analysis was used to identify predictors of family caregivers' knowledge of unused services. An open-ended question regarding reasons for non-use of services was analysed by thematic text analysis. Characteristics of family caregivers (e.g., education level) and factors related to the caregiving circumstances (e.g., negative impact of caregiving) predicted family caregivers' knowledge of unused services. Reasons for non-use of services were multifaceted and complex, and were related to attributes of the person with dementia and/or the family caregiver (e.g., reluctance to use services) and/or the healthcare services (e.g., low quality). Although services were unused, several family caregivers indicated substantial needs of the services. Strategies aimed at addressing the non-use of services should emphasize individuals' and families' needs and the adaptation of information about available services and their benefits for both care recipients and family caregivers. A relationship-centred care approach is thus recommended in dementia care.

Keywords: dementia, healthcare services, family caregivers, survey, service use, service non-use

Background

In 2015, dementia affected 47 million people worldwide, and the condition is a major cause of disability and dependency among older people (World Health Organization 2017). Dementia care strategies propose that people with dementia should be enabled to live in the community and to receive care aligned with their wishes and preferences (Ministry of Health and Care Services 2015; OECD 2015; World Health Organization 2017). Living at home as long as possible may benefit people with dementia because it may promote a greater sense of independence and identity, and ultimately, lead to a better quality of life than living in institutions. In addition, providing informal care at home can reduce public care costs (OECD 2015).

People with dementia may have special care needs, often requiring more supervision, personal care and more hours of care than care recipients without dementia (Prince, Prina and Guerchet 2013). Family caregivers take on substantial care responsibilities (Prince, Prina and Guerchet 2013; Vossius et al. 2015; World Health Organization 2012) and they are faced with increasing demands over time due to the progressive nature of the disease (Prince, Prina and Guerchet 2013; World Health Organization 2012). Ultimately, the strains that family caregivers experience may cause psychological stress (Gilhooly et al. 2016) and increase the risk of physical ailments (Fonareva and Oken 2014). A recent meta-analysis demonstrate that almost one-third of all family caregivers of persons with dementia experience depression and approximately one-half perceive their caregiving role to be burdensome (Collins and Kishita 2019). Factors such as higher level of caregiver burden (Hughes et al. 2014) and longer duration of caregiving (Lethin et al. 2016) have previously been related to greater needs for healthcare services.

As part of the Nordic welfare system, Norway provides one of the world’s most universal and comprehensive long-term care services (Christensen and Waerness 2018).

Although home-dwelling persons with dementia receive more services than care recipients without dementia (Kjelvik et al. 2015; Vossius et al. 2015), several of the services are used to a limited extend (Kjelvik et al. 2015). A recent Norwegian study revealed that at the time immediately prior to admission to a nursing home, half of all persons with dementia had moderate dementia and one-fifth had severe dementia (Vossius et al. 2015), which indicate substantial care needs (Prince, Prina and Guerchet 2013; World Health Organization 2012). At the same time, approximately half of all persons with dementia received home nursing, one-fifth used meal delivery and one-fifth used day centres. Moreover, nine out of ten received informal care from family caregivers or social networks, and the amount of informal care constituted the major part of the total care provided (Vossius et al. 2015).

Low utilization of community healthcare services seems to be an international trend (e.g., Brandão, Ribeiro and Martín 2016; Lethin et al. 2016; Odzakovic et al. 2018; Weber, Pirraglia and Kunik 2011). At the same time, several studies have disclosed substantial unmet care needs among persons with dementia and/or their family caregivers (Black et al. 2013; Kerpershoek et al. 2017; van der Roest et al. 2009). Characteristics of the person with dementia, of family caregivers and of the healthcare service system might influence the low utilization of services. For example, the person with dementia might wish to remain independent for as long as possible (Stephan et al. 2018) and they might be reluctant to use formal help and support (Brodaty et al. 2005; Macleod et al. 2017; Stirling et al. 2010). Family caregivers and/or the persons with dementia might have low needs for the services (Brodaty et al. 2005) or may be unaware of or lack information about available services (Brodaty et al. 2005; Macleod et al. 2017; Stephan et al. 2018; Stirling et al. 2010). Other reasons for the low uptake of services might be related to financial barriers and cultural and language barriers (World Health Organization 2012) and previous studies indicate that ethnic minorities and indigenous people report significant barriers to access services (Greenwood et al. 2015; Marrone 2007). Moreover, the services may not meet families' needs (Sutcliffe et al. 2015) or they may be of poor quality or inflexible (Macleod et al. 2017).

Few large-sample studies have investigated the non-use of community healthcare services, particularly in the Nordic countries. To evaluate and improve the utilization and quality of community healthcare services for those in need of help and support, policy makers, healthcare managers and healthcare professionals need to understand why these services are utilized to a limited extent. The present study provides such knowledge from the perspective of family caregivers. This perspective is of particular importance because family caregivers of persons with dementia are likely to have knowledge of and information about the person with dementia (World Health Organization 2017) and are likely to advocate for the care recipient and arrange for healthcare services (Alzheimer's Association 2017). In addition, family caregivers might have substantial needs for help and support; hence, they should have access to formal support and respite care tailored to their own needs (World Health Organization 2017).

The aim of this study was to examine family caregivers' knowledge of unused services and their self-reported reasons for non-use of such services. The specific research questions addressed in this study were: 1) Which demographic and socio-demographic characteristics of the family caregivers are associated with their knowledge of unused community healthcare services? 2) Which factors related to the caregiving circumstances are associated with their knowledge of unused services? 3) What reasons do family caregivers report for non-use of services?

Methods

Study design

The study has a cross-sectional design, and data were generated with a self-administered survey to family caregivers. We used different analyses to answer the central research questions. First, we used quantitative analyses to explore family caregivers' knowledge of unused community healthcare services. We compared caregivers who knew of unused services with those who were unaware of unused services and those who reported uncertainty regarding unused services. A previous study using the same sample as the current study indicated that demographic characteristics (e.g. age, gender, ethnicity, relationship to the person with dementia) and socio-demographic characteristics (e.g., education level and employment status) of family caregivers were associated with the amount of healthcare services used (reference is blinded for review). Thus, we assumed that these characteristics of family caregivers and factors related to the caregiving circumstances could predict family caregivers' knowledge of unused services. Ethnicity is relevant for this study because indigenous Sami people represent a minority ethnic group in Norway. Secondly, family caregivers' reasons for the non-use of community healthcare services were explored by using qualitative text analysis of written responses to an open-ended question. This question was a follow-up question to those who reported knowledge of unused services. The findings are integrated in the discussion.

Community healthcare services

We use the terms community healthcare services, healthcare services or services when referring to relevant long-term care services for home-dwelling persons with dementia, i.e., home nursing, domestic help, remote control safety alarm, meal delivery, day centre, support person and respite care in nursing homes. Norwegian municipalities have a statutory obligation to provide home nursing, domestic help and a support person to those in need of support. In addition, family caregivers who perform comprehensive care may require respite care (Ministry of Health and Care Services 2011). Other relevant services for home-dwelling persons with dementia available in most municipalities are remote-control safety alarms, meal delivery and day centres (Ministry of Health and Care Services 2019). Day centres and support persons may provide activity services for persons with dementia and/or respite care for family caregivers (Jessen 2014). Home nursing, support persons and respite care in nursing homes are free of charge (Ministery of Health and Care Services 2011) while the other services require out-of-pocket payment.

Participants and sampling

The target population was adult family caregivers of home-dwelling persons with dementia who were ≥ 65 years of age. We define family caregiving in accordance with Zarit and Edwards (2008: 256) as follows: “interactions in which one family member is helping another on a regular (daily or nearly so) basis with tasks that are necessary for independent living”. Although several family caregivers may be involved in caregiving activities, we focused on family caregivers who take the major part of the care responsibilities. In this study, we use the term family caregivers although the participants were not necessarily family members or represented the closest next of kin in a legal sense. More distant relatives, friends or neighbours were included if they provided the major part of care and were registered as next of kin of the person with dementia in community healthcare service records.

As several of the persons with dementia were undiagnosed, dementia was defined as a dementia diagnosis or cognitive impairment with symptoms consistent with dementia, i.e., progressive memory loss and difficulties with cognitive skills that affected the ability to perform daily life activities (Alzheimer's Association 2017). If cognitive impairment was caused by other conditions, e.g., traumatic brain injury, brain tumour or delirium, the family caregivers were not included in the study.

In total, 32 municipalities in Northern Norway participated in the study. The municipalities varied with regard to size, geographical dispersion, residential areas (urban vs. rural areas) and ethnic composition (indigenous Sami and Norwegians). Local healthcare managers approved the study and appointed research assistants who were nurses or licenced practical nurses. All the research assistants were experienced in dementia care within the home-care services or respite care services. The research assistants used local healthcare service records to identify potential participants, thus, the participants were family caregivers of persons with dementia who were users or previous users of the services. Prior to the recruitment of participants, all research assistants received individual training regarding the inclusion criteria and inclusion procedure, how to safely store inclusion records and how to secure anonymity and confidentiality. Personalized data from the research assistants' inclusion records were not shared with the research team.

We used a convenience sampling method and all eligible family caregivers who fulfilled the inclusion criteria were included in the study (n = 788). On behalf of the research team, the research assistants distributed information about the study and a 63-item, self-administered survey by mail to family caregivers during April-November 2016. The survey covered different aspects of informal care provided by the family caregivers and formal care provided by healthcare services. Participants returned the completed questionnaire in a stamped and addressed envelope directly to the research team; thus, only the researchers had access to the responses. One selective reminder procedure was carried out after four weeks. The final sample consisted of 430 family caregivers, yielding a response rate of 54.6 per cent.

Dependent variable

As no appropriate validated item regarding knowledge of unused healthcare services was available, we created the following question: “Are there any community healthcare services that are still unused? We are thinking about services you have knowledge of and that can contribute to helping and supporting the person with dementia and/or relieving yourself”. The response options were “Yes”, (0), “No” (1) and “I do not know” (2). In the following, the “yes” category is labelled knowledge of unused services, the “no” category is labelled unawareness of unused services and the “I do not know” category is labelled uncertainty about unused services. To support face and content validity, the item was presented along with the entire questionnaire to an expert group of experienced researchers and geriatric clinical professionals and pilot tested with five family caregivers of varying genders, ages and kinship relations to the care recipients. The pilot included an interview regarding how the respondents interpreted the meaning of the items. The face and content validity of the item in question was evaluated as good among all parties.

Independent variables

Demographic variables for the family caregivers included age, gender (woman = 0, man = 1), relationship to the person with dementia (spouse = 0, daughter = 1, son = 2 and other = 3) and ethnicity. Ethnicity was assessed with two items, namely, self-identification as a Sami and Sami as first language (Brustad et al. 2014). The variables were merged and coded into three categories: non-Sami = 0, confirming one Sami marker = 1 and confirming both Sami markers = 2. Socio-demographic variables assessing education level, employment status and income level were all drawn from the Tromsø study (Jacobsen et al. 2012). Education level was measured at four levels and further merged into three categories (elementary school = 0, high school = 1 and higher education = 2). Employment status was measured at eight levels and merged into three categories (not employed = 0, part-time employed = 1 and full-time employed = 2). Income level was measured at eight levels and further dichotomized into two categories: a lower income group (household income < 350 000 Norwegian kroner (NOK) = 0) and a higher income group (household income > 351 000 NOK = 1). The classification was based on the European Union's definition of low income as less than 60 per cent of the median income in the population (Statistics Norway 2016).

In this study, factors related to the caregiving circumstances that might underpin the family caregivers' knowledge of unused services were duration of caregiving, perceived information level, amount of services used and negative impact of caregiving. Duration of caregiving after the appearance of dementia symptoms was assessed by using an item retrieved and adapted from the Family Collaboration Scale (Lindhardt, Nyberg and Hallberg 2008). An item assessing perceived information level was retrieved from a generic scale assessing patient experiences with specialized healthcare services (Sjetne, Bjertnæs and Iversen 2009) and adapted for this study. We asked the participants: "Have you received information regarding available healthcare services in your municipality?" The responses were given on a 5-point Likert scale ranging from (1) "not at all" to (5) "to a very large degree". In the current analyses, a "not relevant" option was coded as missing (n = 18).

An item assessing the amount of healthcare services used was derived from a previous Norwegian study evaluating a caregiver school programme (Norwegian National Advisory Unit on Ageing and Health 2011) and further adapted for this study. The services were categorized into two types according to principal component analysis and labelled home-based services (home nursing, domestic help, meals on wheels and remote-control safety alarm) and respite care services (day centre, respite care in a nursing home and support person) (Blinded for review). In this study, we used the average score for the number of services in each component as independent variables.

The impact of caregiving on family caregivers was assessed with the Carers for Older People in Europe (COPE) Index, which is a screening tool developed to detect family caregivers in need of support (Balducci et al. 2008; McKee et al. 2003). In the analyses, we used the average score of all item raw scores (range 1-4), where lower scores represent more negative impacts of caregiving. The response option “not applicable” (coded as missing) was included for five items and thus introduced a large proportion of missing data (ranging between 7.2 per cent and 23.5 per cent). The expectation maximization (EM) method was used to impute missing data. The correlation between the imputed variables and the original variables was almost perfect ($r = 0.993$).

Statistical analyses

The statistical analyses were conducted in IBM Statistical Package for the Social Sciences (SPSS) for Windows version 24.0. Missing data related to the COPE Index were replaced by the EM function in PRELIS/LISREL 9.20 for Windows (Jöreskog and Sörbom 2015). Descriptive data are presented as proportions, means and standard deviations for those who knew of unused services, those who were unaware of unused services and those who reported uncertainty about unused services. Significant differences between the groups were examined by using F or chi-square/Fisher exact tests for continuous and nominal data, respectively. The alpha value was reduced to < 0.01 due to the number of tests (Bonferroni method). A multinomial logistic regression analysis was used to assess the association between the outcome and the independent variables. The analysis was performed using a backward stepwise regression procedure for removing non-significant variables. An alpha value of < 0.05 was used as an indication of statistical significance.

Qualitative analyses

In an open question, participants who knew of unused community healthcare services were invited to describe their reasons for not using the services in their own words. Overall, 174 participants responded to this question. The length of the written responses ranged from short notes to lengthy sentences (~ 200 words). The text material was analysed according to the principles of thematic analyses, as described by Braun and Clarke (2006). The analysis process was recursive, as the initial phase consisted of repeated reading of the data, followed by a text coding phase and a code sorting phase to create broader themes. Two of the authors (XXX and XXX) independently carried out the initial phases of the analyses and subsequently met to discuss the initial themes and conduct the sorting of codes in broader themes. The themes were further revised and finally named in collaboration. The involvement of two researchers in this process provided opportunities for investigator triangulation to moderate the risk for biased interpretations (Polit and Beck 2017: 566). While we endeavoured to approach the data set open-mindedly, the analysis was informed by relationship-centred care theories and was hence theory driven (cf., Braun and Clarke 2006). Based on such theories, we assumed that non-use of healthcare services could be related to the features of those involved in caregiving, i.e., the person with dementia, the family caregiver and/or the healthcare services (Adams and Gardiner 2005; Nolan et al. 2002).

Ethics

The study complied with the Helsinki declaration for research ethics (World Medical Association 2018). The Norwegian Centre for Research Data (NSD) approved the study with regard to the procedures related to the use of local records to identify participants, data collection, and data privacy (e.g., de-identification and anonymity) and obtaining informed consent. Along with the questionnaire, all invited family caregivers received written information about the purposes of the study, which also stated that participation was voluntary and included a description of how confidentiality and anonymity were ensured. Participants consented by completing and returning the questionnaire to the research team. An honorarium of two lottery tickets worth 50 NOK (approximately 5 Great Britain Pound, GBP), was given.

Results

Knowledge of unused community healthcare services – quantitative analyses

The descriptive characteristics of the family caregivers and knowledge of unused community healthcare services are presented in Table 1. In total, 40.2 per cent of the participants knew of unused community healthcare services, 11.6 per cent were unaware of unused services, and 45.6 per cent reported uncertainty regarding unused services. The portion of missing data was low (2.6 per cent); hence, 419 participants were included in the analyses.

<Please insert Table 1 about here>

Group differences are presented in Table 1. Differences in the knowledge of unused community healthcare services were related to the following characteristics of the family caregivers: gender (more females reported knowledge of unused services than males), relationship to the person with dementia (more daughters reported knowledge of unused services than spouses, sons and those with other kinship relations), education level (more caregivers with higher education reported knowledge of unused services than those with lower education), employment status (more of those who were not employed or retired reported uncertainty about unused services than those who were employed full-time) and income level (more caregivers with higher incomes reported knowledge of unused services than those with lower incomes). In addition, the following factors were significantly correlated with family caregivers' knowledge of services: information level (those who were uncertain about unused services reported lower levels of information about available healthcare services than those who knew of and those who were unaware of unused services), negative impact of caregiving (those who were unaware of unused services had lower negative impacts of caregiving than those who knew of unused services and those who were uncertain), and use of home-based services (those who were unaware of unused services used more home-based services than those who knew of unused services and those who were uncertain).

Multinomial regression analysis

The variables that were significantly associated with the dependent variable (according to Table 1) were included as predictors in a multinomial regression analysis. Participants who knew of unused services represented the reference group. The odds ratios, confidence intervals and *p* values are presented in Table 2.

The use of more home-based services and higher scores on the COPE Index (less negative impact of caregiving) significantly increased the odds for reporting unawareness of unused services. Family caregivers with lower education levels (elementary school or high school) and caregivers using more home-based services had significantly higher odds of reporting uncertainty about unused services than caregivers with higher education levels and caregivers using fewer home-based services. Conversely, daughters and caregivers who scored higher for perceived information level had significantly lower odds of reporting uncertainty regarding unused services than other kin groups and caregivers who had lower scores for perceived information level.

<Please insert Table 2 about here>

Reasons for non-use of community healthcare services – qualitative analysis

The initial text codes were examined, sorted, revised and finally merged into four overarching themes: 1) reasons related to the persons with dementia, 2) reasons related to family caregivers, 3) reasons related to the healthcare services system, and 4) reasons related to several of the themes.

Reasons related to the person with dementia

This theme includes the following sub-themes: the person with dementia was reluctant to use services and the person did not yet need services. The majority of the responses were related to the persons' reluctance to use community healthcare services. The reasons for reluctance were diverse, including that the persons with dementia needed help and support but refused to use services. Several of the family caregivers indicated that the person with dementia lacked insight into his/her own situation:

> *"Community healthcare services are not used. He lacks insight in his own situation and he does not understand the necessity of these services".*

Moreover, some reported that the persons with dementia experienced help and support as humiliating or stigmatizing. In addition, help and support could be a reminder of lost capacity:

> *"She experiences the day centre as stigmatizing and simultaneously as a reminder about loss of capacity. These are the same reasons for not using respite care in the nursing home."*

Several respondents described that persons with dementia preferred to receive help from their families. Other respondents described that the care recipient did not want to interact with strangers or felt unsafe in unfamiliar environments, e.g., at the day centre.

> *“She has a place at the day centre twice a week. She does not want to use this service. She is afraid and unsafe because she does not know where she is.”*

To meet the needs for help and support, some of the family caregivers reported that they performed care tasks that could and perhaps should have been performed by health care professionals. Several of the family caregivers considered that the person with dementia had high needs for the services they refused to use:

> *«He needs more help in terms of home nursing, personal care, cleaning, shopping, meal delivery and respite care in a nursing home, but he is reluctant to receive help. He thinks he manages everything. The home nurses offer him more support, but he refuses. Thus, I have to help him”.*

Reluctance to use services might be an unresolved problem, as several family caregivers expressed a high need for the unused services, e.g., respite care in a nursing home, day centres or a support person:

> *“I have been healthy until recently. The night wandering is burdensome. In periods, I sleep poorly. He smokes at nighttime and sometimes he loses the cigarette on the floor or on the tablecloth. I am very afraid of fire. I need respite care, but he refuses!”*

The second sub-theme reflects that the person with dementia did not yet need services. Some family caregivers described that the disease was in an early phase and that the need for services was therefore not yet present. Others described that the person with dementia wanted to manage with limited or no help from healthcare services:

> *“She does not want more help. Still, she is managing at home in familiar environments. She wants to perform tasks such as cleaning and cooking.”*

Reasons related to the family caregiver

The theme includes the following sub-themes: the family caregiver did not yet need services and the caregiver was reluctant to use services. Within this theme, the majority of responses indicated that the family caregivers did not yet need help and support. Several of the family caregivers reported knowing of unused healthcare services that could be relevant in the future, e.g., personal care, respite care and long-term care in an assisted living facility or in a nursing home. Some family caregivers reported that they considered their own help and support, such as household work and cooking, to be a natural part of daily life. However, several reported that they were about to reach the limit for how much care they could provide:

> *"I have performed tasks that I feel are natural within a marriage. In my situation, I am now struggling with physical diseases, which limits how much I can help my husband. We have an adult child who contributes a lot with practical assistance. Conclusion: the society is saving a lot, economically speaking".*

The second sub-theme reflects that the family caregivers were reluctant to use healthcare services. The family caregivers' reluctance was closely associated with the reluctance of the person with dementia, as the family caregivers could not force the person to use services. Some were worried about conflicts with the care recipient:

> *"He does not understand that he is ill. Initiating healthcare services will make problems for me, e.g., suspicion/aggression. Thus, I have not applied for services".*

*Reasons related to aspects of healthcare service***s**

This theme includes the following sub-themes: the family had applied for but not received services, the services did not meet the needs of the person with dementia or of family caregivers, and the quality of the services was poor. The main reason for non-use was that one or more services were applied for but not received. Several respondents referred to lengthy processing and long waiting lists, particularly related to services such as support persons, respite care in a nursing home and long-term care in a nursing home. Several of the family caregivers reported an extensive need for services:

> *(...) I have applied for the day centre and for respite care when I am away. I think it is madness that she is on her own (...). I have still not received a response to the applications. I am also ill (...).*

Others reported that their applications had been rejected. The long distance between the location of the services and the care recipients' home was sometimes a reason for rejection. Several family caregivers described reasons for the rejections such as services not being available. This issue was particularly related to a support person, which is a statutory service. Others described that the person with dementia was considered too healthy to receive the service. However, the family caregivers could disagree strongly with the assessment:

> (…) *she did not receive short-term care in the nursing home, they said she is too healthy. Those who administer the services do not know anything about that. They are never here to see how frail she is* (...).

The sub-themes reflecting that the community healthcare services did not meet the needs of the persons with dementia and/or of family caregivers and that the quality of the services was poorer than expected are closely related. Some described that the service was not meaningful:

> *"I have been offered respite care once a week. We have tried, but he is too "healthy", he was just sitting there with persons with severe dementia. Nothing to do, no activities".*

Several caregivers explicitly reported that the services were of low quality, which was often related to a low quality of readymade meals (meal delivery) or cleaning (domestic help). In addition, lack of transportation services could result in non-use of day centres.

Reasons related to the person with dementia and/or the family caregiver and/or the healthcare services

Several of the family caregivers' responses related to aspects that carried across the themes. As described above, the family caregivers' reluctance regarding the use of healthcare services was closely related to the reluctance of the person with dementia. Moreover, some of the caregivers described that the person with dementia refused to use a particular service and that other services were perceived as unnecessary.

> *"I have chosen to stay at home and take care of my husband. (...) He refuses to meet the support person. I am familiar with the care tasks; thus, home nursing is not relevant".*

Several respondents described that the reluctance of the person with dementia was closely related to the quality of the services or insufficient adaptation of the services:

> "*(...) She used meal delivery, but she did not find the dinners tasty (...). Currently, she has a place at the day centre twice a week, but she does not want to go there because they are simply sitting in a chair*".

Some of the family caregivers reported that they managed with limited assistance or without help from the formal healthcare services, but their responses simultaneously indicated that they did not have knowledge of additional support. Others reported that help from healthcare services was initiated too late and that the information about available healthcare services was insufficient:

> *"In the autumn, we found a place for her at the day centre. Until then, I was alone with the care responsibilities, and I did not know of available services (...). At that point in time, I was exhausted. Friends contacted the community healthcare services. The day centre is now a great help for us. I feel that the information from the general*

practitioners about the disease and available healthcare services is insufficient. This disease may still not be talked about or kept within the family".

Discussion

The current study employed both quantitative and qualitative data regarding the non-use of community healthcare services. The quantitative data suggest that characteristics of family caregivers and factors related to the caregiving circumstances were associated with family caregivers' knowledge of unused services. The qualitative data showed that reasons for non-use of services were multifaceted and complex, and were related to attributes of the person with dementia and/or the family caregiver and/or the healthcare services. Although services were unused, several family caregivers indicated substantial needs of the services.

The majority of the participants reported uncertainty regarding unused healthcare services, whereas approximately two-fifths reported knowledge of unused services. Only one of ten were unaware of unused services. As expected, the use of formal support varied between the groups. Those who were unaware of unused services reported use of more home-based services than the other groups, and simultaneously, they reported less negative impact of caregiving.

The results indicated that the information level regarding available community healthcare services varied. Those who reported uncertainty about unused services had a significantly lower information level compared to those who knew of unused services. Moreover, the qualitative data indicated that several participants who reported to know of unused services also described a lack of information about additional services. These results concur with those of other studies. A study among persons with dementia and family caregivers in eight European countries reported substantial unmet information needs. The study indicated that insufficient information about available services most likely leads to nonuse of services (Kerpershoek et al. 2017). A qualitative interview study suggested that insufficient information is a key barrier to service use, as family caregivers do not know where to find or how to gain access to relevant information (Macleod et al. 2017).

In this study, the groups also differed with regard to education level, as the odds for reporting uncertainty regarding unused services were more than four times higher for those with an elementary school level of education and about two and a half times higher for high school-educated respondents compared to those with higher education. Higher education level has previously been associated with the use of more community healthcare services (Lüdecke, Mnich and Kofahl 2012; Martindale-Adams et al. 2016), also in Norwegian studies (Moholt et al. 2018; Sævareid et al. 2012). Individuals with higher education levels might be more aware of their rights to access services (Sævareid et al. 2012) or more prone to obtain information about eligible services than individuals with lower education levels. Altogether, the results suggest that the availability of information about healthcare services should be improved and adapted to individuals at the municipal level to ensure equal access to and use of healthcare services. Raising awareness of appropriate healthcare services is important to achieve the best outcomes for both the family caregivers and the person with dementia for whom they are caring (Erol, Brooker and Peel 2015: 38).

The qualitative data showed that one of the most commonly reported reasons for not using healthcare services was that the family caregivers did not yet need such services. It is reasonable that persons with dementia in the early stage of the disease can manage well with limited formal and informal assistance or that some family caregivers can manage their care responsibilities well through the course of the disease. In addition, services might be assessed as unnecessary, e.g., some of the family caregivers reported that they performed household tasks as a natural part of daily life. Stirling et al. (2010) reported that normative expectations of the spousal role could be the reason that practical help at home was the least used service in their study. The increase in work at home was accepted as an extension of the regular duties implied by the spousal role. A Swedish interview study of women caring for a partner with dementia showed that caregivers tended to downplay their need for formal support. Although they acknowledged that they needed support, they were not yet ready to accept it (Eriksson, Sandberg and Hellström 2012). In our study, several family caregivers who did not need services also described that they were about to reach their limit for how much care they could provide, and some referred to their own health problems and reduced capacity to provide help and support. A previous study of non-use of healthcare services reported that family caregivers might deny a need for healthcare services despite a low level of satisfaction with their caregiver role and a high level of overload (Brodaty et al. 2005). To be proactive and offer service options adjusted to a family's needs, healthcare professionals should not only inform about available services but also point out the individual advantages of using formal support (Graessel et al. 2011).

In this study, a commonly reported reason for not using community healthcare services was that the care recipients were reluctant to use such services. Moreover, several of the family caregivers recognized crucial needs for the unused services. In a cross-national European study, people with dementia (mostly younger persons with dementia) expressed that they wanted to remain independent as long as possible and formal care was considered as a threat to the individual independence (Stephan et al. 2018). Although maintaining identity and independence is a strong personal driver for many persons with dementia (Erol, Brooker and Peel 2015: 6), this might increase the demands on family caregivers when the need for help and support is extensive. In a Norwegian qualitative interview study among family caregivers of older home-dwelling persons with dementia, all family caregivers described that the person they cared for refused admission to nursing homes despite extensive care needs. Simultaneously, the family caregivers strived to balance the assumed duty to provide care with their own needs (Larsen, Blix and Hamran 2018). Despite increased attention to family caregivers in Norwegian governmental white papers (Ministery of Health and Care Services 2018; Ministry of Health and Care Services 2015), family caregivers have limited statutory rights regarding their own needs for services. In addition, services are allocated according to the estimated needs of the care recipient (The Norwegian Directorate of Health 2016) rather than the caregivers' needs. Although previous studies have reported similar findings to those from the current study (Brodaty et al. 2005; Macleod et al. 2017; Phillipson, Magee and Jones 2013), few strategies have been suggested to facilitate service use when care recipients with substantial care needs are reluctant to use services. Future research should address this issue in more detail, e.g., with use of methods such as in-depth interviews with both care recipients and family caregivers.

In this study, a third prominent reason for not using services was related to diverse aspects of the healthcare services. Long waiting lists, lengthy processing and the rejection of applications indicated that the allocation of services is not a straightforward procedure. Nonetheless, several of the family caregivers reported an extensive need for the services. A previous Norwegian study reported that although allocation of healthcare services should be performed in accordance with the principle of proportional justice (justice between competing claims for priority), limited resources might result in prioritizing care recipients with urgent needs and fewer coping resources, such as limited access to help and support from family (Vabø 2011). Other studies have reported that care recipients who live alone use more home-care services than those who cohabit with family caregivers (Døhl et al. 2016; Moholt et al. 2018). Altogether, these findings might indicate that informal care from family caregivers substitute for formal care from healthcare services. Future studies should investigate how healthcare professionals deal with the needs of both care recipients and family caregivers when allocating services.

Others respondents described that the care recipients were reluctant to use the services due to the low service quality or the inability of the services to fulfil care needs. With respect to day centres, some respondents reported a lack of appropriate activities. Similar findings are reported in a recent Norwegian qualitative study among family caregivers of persons with dementia. The results indicated that day centres lacked meaningful activities, and the activities were not tailored to care recipients’ physical functional levels (Granbo et al. 2019). However, a qualitative study carried out in Norway and Scotland reported that the use of day care resulted in benefits and positive experiences for persons with dementia, e.g., increased well-being and increased social engagement. Although the persons with dementia were initially reluctant to use the day centre, several reported growing acceptance through everyday experience with the service. Then, once the family caregivers believed that the care recipients were well cared for, they were able to take a break from the caring role (Rokstad et al. 2017). This finding might indicate that services providing positive experiences for the person with dementia, and ultimately for family caregivers, are required to ensure the use of such services.

Although the family caregivers reported diverse reasons for not using services, we noticed that those who reported knowledge of unused services also reported a more negative impact of caregiving than those who were unaware of unused services. This finding might indicate that family caregivers who reported knowledge of unused services did not receive adequate support in their caregiving role. Due to the complexity of the responses, we did not have the opportunity to investigate the negative impact of caregiving in sub-groups of those who reported knowledge of unused services. Future studies should address the relationship between non-use of services and the negative impact of caregiving/caregiver burden more thoroughly.

The fact that responses regarding reasons for non-use of services disclosed substantially unmet care needs might indicate that more attention should be paid to the efforts of family caregivers. Ward-Griffin (2012) argues that the complementary care approach to home-based services contributes to inadequate support for family caregivers. Within this approach, formal care from healthcare services supplements informal care when the needs of the care recipient exceed the resources of the formal caregiver. Formal support to family caregivers, e.g., respite care, is often “too little” and “too late” to have the intended effects (Ward-Griffin 2012: 176). Schulz and Czaja (2018) suggest that healthcare providers should see family caregivers as partners who may need information, care and support rather than just as a resource in the treatment of the care recipient. Family caregiving is often presumed, as caregivers are not asked about their ability to provide care (Schulz and Czaja 2018). A key finding arising from our study was the complexity regarding why healthcare services are not used. The reasons were related to aspects of the care recipient and/or the family caregivers and/or the healthcare services. Thus, a holistic care approach that include family caregivers, such as relationship-centred care, is recommended (Schulz and Czaja 2018; Ward-Griffin 2012). This approach is based on dynamic interactions between those involved in caring: the person with dementia, family caregivers and healthcare professionals (Adams and Gardiner 2005; Nolan et al. 2002).

Study limitations

In this study, the majority of the participants were family caregivers of persons who were users or previous users of healthcare services. Thus, we had limited opportunities to examine knowledge of unused services and reasons for non-use of services among those who did not utilize services at all. This constraint, combined with the fact that we used a convenience sampling method, may limit the generalizability of the results.

We created a single item about knowledge of unused healthcare services with categorical response options for this study. It is possible that the three categories did not fully capture family caregivers’ knowledge of unused services or did not distinguish appropriately among the groups. The interpretation of the “I don’t know” category as an expression of “uncertainty”, i.e., insufficient knowledge about unused services, may raise some concerns. Pilot testing of the survey questionnaire among family caregivers revealed that respondents interpreted the statement correspondingly. Furthermore, the fact that participants who reported higher level of perceived information had lower odds of choosing the “I don’t know’ category may seem to support this interpretation. However, future studies may benefit from developing and including validated instruments to capture knowledge of unused services and reasons for the non-use of services.

We used a single open-ended question to evaluated reasons for non-use of healthcare services. Open-ended questions following closed questions are useful for clarification of reasons and explanations, and the method can provide informative data. The method requires more deliberation and is more demanding for respondents than closed questions and the quality of the data is dependent on the participants’ willingness and ability to write their replies (Bowling 2014: 295). In this study, the generated text-data were surprisingly rich. The main themes identified in the qualitative text analysis were not suitable to create categories that could be analysed by quantitative methods. Thus, we could not examine whether the characteristics of family caregivers were associated with the diverse reasons for the non-use of services. However, the results emerging from the analyses may guide future research, e.g., in-depth interview studies, or form the basis for developing research instruments to assess the non-use of community healthcare services.

Although several significant associations of family caregivers’ knowledge of unused community healthcare services were identified, a substantial proportion of the variance in the analysis remained unexplained. Other relevant factors explaining knowledge of unused services may therefore have been omitted, such as the progression of the dementia disease and the degree of disability of the person with dementia. It is reasonable that the need for formal help and support increases as the disease progresses (Prince, Prina and Guerchet 2013, World Health Organization 2012), which might affect family caregivers' knowledge of services. We did not have permission to collect such data and therefore could not adjust our prediction estimates accordingly. If ethically acceptable, future research about the non-use of healthcare services should include measures regarding the progression of the dementia disease and the cognitive and functional capacity of the person with dementia.

Conclusions

This study provides information about family caregivers' knowledge of unused community healthcare services and reasons for the non-use of services. The results may have implications for both the community healthcare services and future research. To ensure equal access to and use of healthcare services, our results suggest that healthcare professionals should provide individually tailored information about available services and information about the benefits of service use for both the care recipient and the family caregiver. Non-use of services might result in more caregiving demands on the family caregivers. Thus, strategies to facilitate service use are needed and future research on non-use of services should include both persons with dementia and family caregivers to address this issue in a more nuanced manner. To ensure utilization of healthcare services, the services must be developed and adapted in accordance with both the care recipients' and family caregivers' needs. Thus, we recommend a relationship-centred approach to dementia care.

Ethical standards

The Regional Committee for Medical and Health Research Ethics for Northern Norway evaluated the study and concluded that their approval was not required (blinded for review).

The Norwegian Centre for Research Data (NSD) approved the study with regard to the procedures related to the use of local records to identify participants, data collection, and data privacy (e.g., de-identification and anonymity) and obtaining informed consent (blinded for review).

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Author contributions

XXX participated in the study design, development of the questionnaire, data collection, statistical analysis, qualitative analysis and data interpretation, and writing of the manuscript. XXX participated in the study design and the development of the questionnaire and was responsible for the statistical analysis and interpretation of results in addition to writing and revising the manuscript. XXX was responsible for the study design, development of the questionnaire and data collection in addition to the interpretation of results and the writing and revising of the manuscript. XXX participated in the study design, development of the questionnaire, data collection and writing and revising the manuscript. XXX participated in the study design and was responsible for the qualitative analysis and interpretation of the results in addition to writing and revising the manuscript. All authors read and approved the final manuscript.

Conflict of interests

The authors declare that they have no competing interests.

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Table 1. Characteristics of family caregivers and knowledge of unused community healthcare services

Characteristics	Total *M* (SD) or %	Knowledge of unused services *M* (SD) or (%)	Unawareness of unused services *M* (SD) or %	Uncertainty about unused services *M* (SD) or %	Comparison
Age	61.5 (11.5)	61.1 (11.1)	58.7 (11.2)	62.5 (11.9)	$F_{2,415} = 2.35$
Gender					
Male	31.4 %	31.3 %**	13.0 %	55.7 %	$\chi^2 = 8.0$*
Female	68.6 %	45.8 %**	11.5 %	42.7 %	
Ethnicity					
Non-Sami	92.8 %	41.6 %	11.9 %	46.5 %	$\chi^2 = 3.8$
Sami, one marker	3.6 %	26.7 %	6.6 %	66.7 %	
Sami, two markers	3.6 %	46.7 %	20.0 %	33.3 %	
Relation to the person with dementia					
Spouse	27.4 %	42.1 %	5.3 %	52.6 %	$\chi^2 = 20.4$**
Daughter	43.5 %	49.2 %***	13.8 %	37.0 %***	
Son	18.5 %	28.6 %	16.9 %	54.5 %	
Other	10.6 %	31.8 %	9.1 %	59.1 %	
Education level					
Elementary school	27.8 %	27.0 %***	9.6 %	63.4 %***	$\chi^2 = 30.3$***
High school	34.5 %	37.8 %	11.9 %	50.3 %	
Higher education	37.7 %	55.1 %***	14.1 %	30.8 %***	
Employment					
Not employed or retired	47.6 %	39.2 %	6.5 %**	54.3 %**	$\chi^2 = 15.7$**
Part-time	11.7 %	36.7 %	18.4 %	44.9 %	
Full-time	40.7 %	45.3 %	16.5 %	38.2 %**	

Income					
≤ 350 000 NOK	18.8 %	27.7 %**	10.5 %	61.8 %**	χ^2 = 9.0*
> 350 000 NOK	81.2 %	44.8 %**	11.9 %	43.3 %**	
Duration of caregiving (years)	4.1 (3.1)	3.9 (2.5)	4.0 (2.6)	4.3 (3.6)	$F_{2,407}$ = 0.93
Perceived information level (range 1-5)	3.1 (1.1)	3.2 (1.0)[a]	3.5 (1.2)[a]	2.8 (1.1)[a]	$F_{2,391}$ = 11.4***
COPE Index total (range 1-4)	2.9 (0.5)	2.9 (0.5)[b]	3.2 (0.5)[b]	2.9 (0.5)[b]	$F_{2,416}$ = 8.47***
Use of home-based services (range 0-4)	2.0 (1.3)	1.8 (1.2)[c]	2.6 (1.2)[c]	2.0 (1.3)[c]	$F_{2,416}$ = 9.5 ***
Use of respite care services (range 0-3)	0.6 (.07)	0.5 (0.7)	0.6 (0.7)	0.6 (0.7)	$F_{2,416}$ = 2.12

Notes: n = 419. M: mean; SD: standard deviation, χ2: chi square; F: analysis of variance.

* $p < 0.05$; ** $p < 0.01$; *** $p < 0.001$

[a] Adjusted p-values (Bonferroni method) are significant at the 0.001 level between the “knowledge of unused services” group and “uncertainty about unused services” group and between the “unawareness of unused services” group and “uncertainty about unused services” group.

[b] Adjusted p-values (Bonferroni method) are significant at the 0.001 level between the “knowledge of unused services” group and “unawareness of unused services” group and at the 0.01 level between the “unawareness of unused services” group and “uncertainty about unused services” group.

[c] Adjusted p-values (Bonferroni method) are significant at the 0.001 level between the “knowledge of unused services” group and “unawareness of unused services” group and at the 0.01 level between the “unawareness of unused services group and “uncertainty about unused services” group.

Table 2. Predictors of family caregivers' knowledge of unused community healthcare

	Exp B (95 % CI)	P value
Unawareness of (1) vs. knowledge of (0) unused services[a]		
Relationship to the person with dementia		
Spouse (1) vs. other kin (0)	0.77 (0.12, 4.87)	0.78
Daughter (1) vs. other kin (0)	1.09 (0.25, 4.76)	0.91
Son (1) vs. other kin (0)	1.72 (0.35, 8.39)	0.51
Education level		
Elementary school (1) vs. higher education (0)	2.57 (0.91, 7.28)	0.08
High school (1) vs. higher education (0)	1.86 (0.78, 4.42)	0.16
Perceived information level	0.94 (0.65, 1.36)	0.76
COPE Index total	2.95 (1.23, 7.09)	0.015
Use of home-based services	1.94 (1.35, 2.79)	< 0 .001
Uncertainly about (1) vs. knowledge of (0) unused services[b]		
Relationship to the person with dementia		
Spouse (1) vs. other kin (0)	0.56 (0.21, 1.49)	0.25
Daughter (1) vs. other kin (0)	0.28 (0.12, 0.69)	0.006
Son (1) vs. other kin (0)	0.68 (0.25, 1.82)	0.44
Education level		
Elementary school (1) vs. higher education (0)	4.51 (2.33, 8.75)	< 0 .001
High school (1) vs. higher education (0)	2.57 (1.44, 4.57)	0.001
Perceived information level	0.65 (0.51, 0.83)	0.001
COPE Index total	1.24 (0.71, 2.16)	0.46
Use of home-based services	1.42 (1.14, 1.78)	0.002

Notes: n = 419. Exp (B) = odds ratio, 95 % CI = confidence interval for Exp (B). Nagelkerke pseudo R^2 = 0 .25, goodness of fit (Pearson χ^2/d.f). = 1.06

[a] Intercept = - 6.37

[b] Intercept = 0.17

Appendices 1-7

1. Decision Regional Committee for Medical and Health Research Ethics for Northern Norway
2. Approval Norwegian Centre for Research Data (NSD)
3. Information letter to healthcare managers
4. Information letter to family caregivers
5. Information letter to Sami family caregivers
6. Questionnaire Norwegian language
7. Questionnaire North Sami language

APPENDIX 1

Decision Regional Committee for Medical and Health Research Ethics

REK
REGIONALE KOMITEER FOR MEDISINSK OG HELSEFAGLIG FORSKNINGSETIKK

Region:	**Saksbehandler:**	**Telefon:**	**Vår dato:**	**Vår referanse:**
REK nord	Veronica Sørensen	77620758	02.06.2015	2015/1107/REK nord
			Deres dato:	**Deres referanse:**
			29.05.2015	

Vår referanse må oppgis ved alle henvendelser

Nils Henriksen
Det helsevitenskapelige fakultet/Institutt for helse- og omsorgsfag

2015/1107 Spørreundersøkelse til pårørende som yter hjelp eller omsorg til hjemmeboende personer over 65 med demenssykdom

Vi viser til innsendt fremleggingsvurderingsskjema datert 29.05.2015.

Prosjektleder: Nils Henriksen

Bakgrunn og formål (original):
De fleste personer med demensrelatert sykdommer bor hjemme. Pårørende kan være sterkt berørt av sykdommen. Støtte og avlastning kan forebygge helseproblemer og utbrenthet og styrke rollen som uformell omsorgsyter. En rekke kommunale helsetjenester rettet både mot pårørende og personer med demens, er etablert. Kunnskapen om pårørendes situasjon, deres bruk og effekt av tjenester er utilstrekkelig, særlig i områder med samisk befolkning. En surveyundersøkelse til pårørende i et utvalg nordnorske kommuner i og utenfor området for Sametingets tilskuddsordninger til næringslivet gjennomføres for å fremskaffe kunnskap om lokale og individuelle forskjeller i bruk av tjenester for å avdekke og forklare likheter og ulikheter mellom kommuner, etniske og sosiale grupper. Undersøkelsen kartlegger omfang av uformell omsorg, mestring, livskvalitet, bruk og evaluering av kommunale tjenester samt barrierer for bruk av tjenester.

Framleggingsplikt
De prosjektene som skal framlegges for REK er prosjekt som dreier seg om "medisinsk og helsefaglig forskning på mennesker, humant biologisk materiale eller helseopplysninger", jf. helseforskningsloven (h) § 2. "Medisinsk og helsefaglig forskning" er i h § 4 a) definert som "virksomhet som utføres med vitenskapelig metodikk for å skaffe til veie ny kunnskap om helse og sykdom". Det er altså formålet med studien som avgjør om et prosjekt skal anses som framleggelsespliktig for REK eller ikke.

I dette prosjektet samles det inn opplysninger om selvvurdert helse og opplevd livskvalitet hos den pårørende som yter hjelp. Videre kartlegges ikke helseopplysninger tilknyttet personen med demens direkte, men derimot etterspørres grad av selvstendighet (Hvor lenge kan personen med demenssykdom være uten hjelp og tilsyn?) samt hvilke hjelpeoppgaver den pårørende vanligvis har utført i løpet av de siste 12 måneder (personlig pleie, fysisk hjelp, etc..). Det foretas ingen detaljert scoring av funksjonsnivået hos personen med demenssykdom.

Formålet er å få kunnskap om pårørendes situasjon, deres bruk og effekt av tjenester . En surveyundersøkelse til pårørende i et utvalg nordnorske kommuner i og utenfor området for Sametingets tilskuddsordninger til næringslivet gjennomføres for å fremskaffe kunnskap om lokale og individuelle forskjeller i bruk av tjenester for å avdekke og forklare likheter og ulikheter mellom kommuner, etniske og sosiale grupper. Undersøkelsen kartlegger omfang av uformell omsorg, mestring, livskvalitet, bruk og evaluering av kommunale tjenester samt barrierer for bruk av tjenester.

Slik prosjektet er fremlagt kommer det ikke inn under helseforskningslovens rammer, prosjektet skal således ikke vurderes etter helseforskningsloven.

REK legger til grunn at den pårørende får informasjon om prosjektet og at det blir opp til den pårørende selv å kontakt prosjektleder for deltagelse, slik at taushetsplikten ivaretas.

Godkjenning fra andre instanser
Det påhviler prosjektleder å undersøke hvilke eventuelle godkjenninger som er nødvendige fra eksempelvis personvernombudet ved den aktuelle institusjon eller Norsk samfunnsvitenskapelig datatjeneste (NSD).

Komiteen har vurdert forespørsel om fremleggelsesplikt med hjemmel i helseforskningsloven § 10, jfr. forskningsetikkloven § 4.

Vedtak
Etter søknaden fremstår prosjektet ikke som et medisinsk og helsefaglig forskningsprosjekt som faller innenfor helseforskningsloven. Prosjektet er ikke fremleggingspliktig, jf. hfl §§ *2 og 9, samt forskningsetikkloven § 4.*

Klage
Komiteens vedtak kan påklages til Den nasjonale forskningsetiske komité for medisin og helsefag, jfr. helseforskningsloven § 10, 3 ledd og forvaltningsloven § 28. En eventuell klage sendes til REK nord. Klagefristen er tre uker fra mottak av dette brevet, jfr. forvaltningsloven § 29.

Vi ber om at alle henvendelser sendes inn via vår saksportal: http://helseforskning.etikkom.no eller på e-post til: post@helseforskning.etikkom.no.

Vennligst oppgi vårt referansenummer i korrespondansen.

Med vennlig hilsen

May Britt Rossvoll
sekretariatsleder

Veronica Sørensen
Seniorrådgiver

Kopi til:

APPENDIX 2

Approval Norwegian Centre for Research Data (NSD)

Norsk samfunnsvitenskapelig datatjeneste AS
NORWEGIAN SOCIAL SCIENCE DATA SERVICES

NSD

Harald Hårfagres gate 2
N-5007 Bergen
Norway
Tel. +47-55 58 21 17
Fax: +47-55 58 96 50
nsd@nsd.uib.no
www.nsd.uib.no
Org.nr. 985 321 884

Nils Henriksen
Institutt for helse- og omsorgsfag
UiT Norges arktiske universitet
9037 TROMSØ

Vår dato: 07.09.2015 Vår ref:43778 / 3 / KS Deres dato: Deres ref:

TILBAKEMELDING PÅ MELDING OM BEHANDLING AV PERSONOPPLYSNINGER

Vi viser til melding om behandling av personopplysninger, mottatt 16.06.2015. All nødvendig informasjon om prosjektet forelå i sin helhet 04.09.2015. Meldingen gjelder prosjektet:

43778	*Spørreundersøkelse til pårørende som yter hjelp eller omsorg til personer over 65 år med hukommelsessvikt eller demenssykdom*
Behandlingsansvarlig	*UiT Norges arktiske universitet, ved institusjonens øverste leder*
Daglig ansvarlig	*Nils Henriksen*

Personvernombudet har vurdert prosjektet, og finner at behandlingen av personopplysninger vil være regulert av § 7-27 i personopplysningsforskriften. Personvernombudet tilrår at prosjektet gjennomføres.

Personvernombudets tilråding forutsetter at prosjektet gjennomføres i tråd med opplysningene gitt i meldeskjemaet, korrespondanse med ombudet, ombudets kommentarer samt personopplysningsloven og helseregisterloven med forskrifter. Behandlingen av personopplysninger kan settes i gang.

Det gjøres oppmerksom på at det skal gis ny melding dersom behandlingen endres i forhold til de opplysninger som ligger til grunn for personvernombudets vurdering. Endringsmeldinger gis via et eget skjema, http://www.nsd.uib.no/personvern/meldeplikt/skjema.html. Det skal også gis melding etter tre år dersom prosjektet fortsatt pågår. Meldinger skal skje skriftlig til ombudet.

Personvernombudet har lagt ut opplysninger om prosjektet i en offentlig database, http://pvo.nsd.no/prosjekt.

Personvernombudet vil ved prosjektets avslutning, 28.02.2021, rette en henvendelse angående status for behandlingen av personopplysninger.

Vennlig hilsen

Bjørn Henrichsen

Katrine Utaaker Segadal

Kontaktperson: Katrine Utaaker Segadal tlf: 55 58 35 42
Vedlegg: Prosjektvurdering

Personvernombudet for forskning

Prosjektvurdering - Kommentar

Prosjektnr: 43778

Formålet med prosjektet er å gjennomføre en surveyundersøkelse til pårørende som yter hjelp eller omsorg til personer over 65 år med hukommelsessvikt eller demenssykdom i et utvalg nordnorske kommuner for å fremskaffe kunnskap om lokale og individuelle forskjeller i bruk av tjenester, samt å avdekke og forklare likheter og ulikheter mellom kommuner, etniske og sosiale grupper. Undersøkelsen kartlegger omfang av uformell omsorg, mestring, livskvalitet, bruk og evaluering av kommunale tjenester samt barrierer for bruk av tjenester. Oversatte skalaer fra engelsk vil bli testet for validitet og reliabilitet.

Utvalget informeres skriftlig om prosjektet og samtykker til deltakelse. Revidert informasjonsskriv mottatt 04.09.2015 er godt utformet.

Det behandles sensitive personopplysninger om etnisk bakgrunn og helseforhold.

Det behandles enkelte opplysninger om tredjeperson. Det skal kun registreres opplysninger som er nødvendig for formålet med prosjektet. Opplysningene skal være av mindre omfang og ikke sensitive, og skal anonymiseres i publikasjon. Så fremt personvernulempen for tredjeperson reduseres på denne måten, kan prosjektleder unntas fra informasjonsplikten overfor tredjeperson, fordi det anses uforholdsmessig vanskelig å informere.

Personvernombudet legger til grunn at forsker etterfølger UiT Norges arktiske universitet sine interne rutiner for datasikkerhet.

Spørreskjema vil bli framstilt i optisk lesbar form og hjelp til registreringen vil bli kjøpt av Fag- og forskningssenteret ved Universitetssykehuset Nord-Norge. Universitetssykehuset Nord-Norge er databehandler for prosjektet. UiT Norges arktiske universitet skal inngå skriftlig avtale med Universitetssykehuset Nord-Norge om hvordan personopplysninger skal behandles, jf. personopplysningsloven § 15. For råd om hva databehandleravtalen bør inneholde, se Datatilsynets veileder: http://www.datatilsynet.no/Sikkerhet-internkontroll/Databehandleravtale/.

Forventet prosjektslutt er 28.02.2021. Ifølge prosjektmeldingen skal innsamlede opplysninger da anonymiseres.
Anonymisering innebærer å bearbeide datamaterialet slik at ingen enkeltpersoner kan gjenkjennes. Det gjøres ved å:
- slette direkte personopplysninger (som navn/koblingsnøkkel)
- slette/omskrive indirekte personopplysninger (identifiserende sammenstilling av bakgrunnsopplysninger som f.eks. bosted/arbeidssted, alder og kjønn)

Vi gjør oppmerksom på at også databehandler Universitetssykehuset Nord-Norge må slette personopplysninger tilknyttet prosjektet i sine systemer.

APPENDIX 3

Information letter to healthcare managers

Institutt for helse- og omsorgsfag
Deres ref.:
Vår ref.:
Dato:

Forespørsel om tillatelse til å gjennomføre forskningsprosjektet «Offentlig demensomsorg – likheter og ulikheter i bruk av kommunale helse- og omsorgstjenester i områder med samisk og norsk befolkning»

Ansvarlig prosjektleder: Professor Torunn Hamran

Prosjektmedarbeidere: Professor Nils Henriksen, førsteamanuensis Mari Wolff Skaalvik og stipendiat Jill-Marit Moholt.

Forskningsansvarlig: Senter for omsorgsforskning, nord, Institutt for helse- og omsorgsfag, Det helsevitenskapelige fakultet, UiT Norges arktiske universitet

Prosjektets varighet: 1.2.2015 – 28.2.2019

Prosjektet er finansiert av Norges Forskningsråd.

Dette er en forespørsel om tillatelse til å gjennomføre en spørreskjemaundersøkelse i forbindelse med ovennevnte prosjekt. Invitasjon til å delta er rettet til pårørende til hjemmeboende personer over 65 år med demensrelatert sykdom i din kommune.

Bakgrunn og hensikt med studien

Bakgrunn for studien er at mange personer med hukommelsessvikt og demenssykdom bor hjemme og er avhengig av hjelp og støtte for å klare seg i dagliglivet, og pårørende er ofte sentrale hjelpere. Det er etablert en rekke kommunale helse- og omsorgstjenester rettet mot personer med hukommelsessvikt/demens og deres pårørende, men vi vet for lite om hvem som benytter seg av disse tilbudene, om pårørendes tilfredshet med dem, om de får oppfylt sine behov for hjelp og støtte og hva pårørende eventuelt ønsker mer hjelp til. Dette ønsker vi å få kunnskap om gjennom en spørreskjemaundersøkelse. Vi vil også undersøke omfanget av hjelp som pårørende gir, hvordan de mestrer hjelperrollen og hvordan de opplever sin livssituasjon. Spørreskjemaet er satt sammen av relevante spørsmål og skalaer, og det er testet slik at det er i tråd med studiens hensikt.

Spørreskjemaundersøkelsen skal utføres blant pårørende til personer med demensrelatert sykdom i ca. 40 kommuner i Nord- Norge for å sammenligne pårørendes erfaringer på tvers av kommuner og mellom befolkningsgrupper som bor i landsdelen.
Alle opplysninger vil bli behandlet konfidensielt, og alle data om enkeltkommuner og persondata vil bli anonymisert ved publisering av funn. Studien er framlagt for og godkjent av Regionale komiteer for

medisinsk og helsefaglig forskningsetikk (REK) og av Norsk samfunnsvitenskapelige datatjeneste, Personvernombudet for forskning (NSD).

Gjennomføringen av studien

Spørreskjemaet deles ut i tidsperioden 1.4-1.6 2016, etter nærmere avtale med dere. På forhånd vil en av prosjektmedarbeiderne avtale et møte for å informere om studien og planlegg det videre samarbeidet med dere. Møtet kan skje ved hjelp av telekommunikasjon/Skype, hvis det er ønskelig.

Det finnes per i dag ingen registre med oversikt over personer med hukommelsessvikt/ demenssykdom. Vi trenger derfor hjelp til å identifisere og dele ut spørreskjema til pårørende i den aktuelle brukergruppen i din kommune. Demenskoordinator, demensnettverket, fagansvarlig sykepleier eller en leder for hjemmetjenesten, kan være aktuelle samarbeidspartnere. Ansvarlige for studien på UiT, Norges arktiske universitet og studiemedhjelper(e) i kommunene må samarbeide og holde tett kontakt i perioden for spørreskjemaundersøkelsen. Studiemedhjelperne vil bli bedt om å opprette kontaktliste til pårørende, distribuere spørreskjema i posten, samt foreta en påminnelse til de som ikke har svart innen oppgitt svarfrist og være behjelpelig med å formidle en belønning til de pårørende som returnerer utfylt spørreskjema. Vi har ikke anledning til å lønne studiemedhjelpere, men vil gi en fagbok om demenssykdom til hver kommune som kan brukes av ansatte i tjenesten. Studiemedhjelpere er med i trekningen av tre Ipad.

Resultatene fra undersøkelsen vil bli tilbakeført til kommunene gjennom Senter for omsorgsforskning, nord. De vil også offentliggjøres i en doktorgradsavhandling med vitenskapelige artikler, samt i lokalaviser og fagtidsskrifter.

Studien er et viktig bidrag til kunnskapsbasen om pårørendes situasjon og hvor mye hjelp og støtte familiene får og ønsker fra offentlige pleie- og omsorgstjenester. Vi planlegger en konferanse for våre samarbeidspartnere med presentasjon av resultatet fra prosjektet, og arbeider for å finansiere deltakelse for en person fra helse- og omsorgstjenesten i kommunene som deltar i undersøkelsen.

Vi håper at dere vil bidra i gjennomføringen av forskningsprosjektet. Vi ber om at du som leder signerer og eventuelt stempler vedlagte svarbrev og sender det til oss i den vedlagte ferdig frankerte konvolutten innen en uke. Du kan også skanne signert svarbrev og sende det til oss som epost.

Dersom du har spørsmål eller ønsker ytterligere informasjon, ta kontakt med stipendiat Jill- Marit Moholt, telefon 776 60701. Epost: jill-marit.moholt@uit.no

Med vennlig hilsen

Nils Henriksen
Professor

Mari Wolff Skaalvik
Førsteamanuensis

Jill-Marit Moholt
Stipendiat

Prosjektet «Offentlig demensomsorg – likheter og ulikheter i bruk av kommunale helse- og omsorgstjenester i fleretniske områder»

Jeg har lest vedlagt informasjon og godkjenner at forskningsstudien «Pårørendeundersøkelsen, en spørreskjemaundersøkelse til personer som yter hjelp til hjemmeboende over 65 år med hukommelsessvikt/ demenssykdom», utføres i ____________________________ kommune.

Med vennlig hilsen

______________________________ ____________________________

(Navn) (Tittel)

______________________________ _____________________________

(Dato) (Sted)

APPENDIX 4

Information letter to family caregivers

UiT
NORGES
ARKTISKE
UNIVERSITET

Institutt for helse- og omsorgsfag
Deres ref.:
Vår ref.:
Dato:

Forespørsel om deltakelse i forskningsprosjektet «Pårørendeundersøkelsen- en spørreskjemaundersøkelse til personer som gir hjelp til hjemmeboende over 65 år med hukommelsessvikt/demenssykdom»

Bakgrunn og hensikt med studien

De fleste personer med hukommelsessvikt og demenssykdom bor hjemme og er avhengig av hjelp og støtte for å klare seg i dagliglivet, og pårørende er ofte sentrale hjelpere. Det er etablert en rekke kommunale helse- og omsorgstjenester for personer med hukommelsessvikt/demenssykdom og deres pårørende, men vi vet for lite om hvem som benytter seg av disse tjenestene, om pårørende er tilfreds med dem, om de får oppfylt sine behov for hjelp og støtte og hva pårørende eventuelt ønsker mer hjelp til. Vi mangler også kunnskap om hjelp som pårørende gir, hvordan de mestrer hjelperrollen og hvordan de opplever sin livssituasjon. Dette ønsker vi å få kunnskap om gjennom en spørreskjemaundersøkelse.

Ledelsen for pleie- og omsorgstjenesten har godkjent at studien gjennomføres i din kommune, og en studiemedhjelper med oversikt over hjemmeboende personer med hukommelsessvikt/demenssykdom og deres pårørende har vurdert at du er aktuell som deltaker.

Studien inngår i et større forskningsprosjekt finansiert av Norges forskningsråd, og det er knyttet til Senter for omsorgsforskning-nord ved Universitetet i Tromsø, Norges arktiske universitet. Leder for prosjektet er professor Torunn Hamran. Ansvarlige for spørreskjemaundersøkelsen er professor Nils Henriksen, førsteamanuensis Mari Wolff Skaalvik og stipendiat Jill- Marit Moholt. Resultatet av studien vil publiseres i en doktorgradsavhandling, vitenskapelige artikler, lokale aviser og fagtidsskrifter. Resultatene vil gi et viktig bidrag i undervisning om pårørendes situasjon.

Hva innebærer studien for deg?

Deltakelse i studien innebærer at du som pårørende fyller ut det vedlagte spørreskjemaet. Det tar ca. 25 minutter. Hvis du vil delta i undersøkelsen, returnerer du det ferdig utfylte skjemaet i vedlagte, ferdig frankerte svarkonvolutt innen to uker. Den har returadresse direkte til studieansvarlig ved Universitet i Tromsø. Når vi mottar ferdig utfylt spørreskjema vil vi sende deg 2 Flax-lodd som takk for hjelpen. Dersom du trenger hjelp til å fylle ut spørreskjemaet, ber vi om at du får et annet familiemedlem eller en nærstående til å hjelpe deg. Du kan også ringe stipendiat Jill-Marit Moholt på telefon77660701/90513510 og be om hjelp, så ringer hun deg tilbake og hjelper til med utfyllingen.

Det kan være ønskelig å intervjue noen av deltakerne i spørreskjemaundersøkelsen. Hvis du kan tenke deg å delta i en oppfølgingsstudie, skriver du navn, adresse og telefonnummer nederst på spørreskjemaet. Om du svarer ja til dette vil en forsker i prosjektgruppa kontakte deg. Du er likevel ikke forpliktet til å delta dersom du ombestemmer deg. Opplysningene du oppgir vil kun være tilgjengelige for forskere i prosjektgruppen.
For å få testet spørreskjemaet best mulig ønsker vi at noen fyller det ut en gang til ca. tre uker etter første utfylling. Hvis du svarer «ja» til dette vil det være til stor hjelp.

Hva skjer med informasjonen om deg?

Informasjonen som registreres om deg skal kun brukes i tråd med studiens hensikt. Det vil ikke bli innhentet andre opplysninger om deg eller din pårørende enn de som fremkommer i spørreskjemaet. Alle opplysninger vil bli behandlet konfidensielt, og det vil ikke være mulig å identifisere deg eller din pårørende i forskningsartiklene eller andre publikasjoner.
En kode knytter spørreskjemaet til en navneliste som oppbevares innelåst hos en sykepleier med lederansvar i din kommune. Det er kun denne personen som har adgang til listen som brukes for å ha oversikt over hvem som har mottatt og besvart spørreskjemaet. Navnelisten blir makulert ved utgangen av 2016.

De ferdig utfylte spørreskjemaene vil bli oppbevart i henhold til Universitetet i Tromsø sine regler om oppbevaring av forskningsdata. Det vil si at de er forsvarlig innelåst og at bare personer tilknyttet forskningsgruppen har tilgang til materialet.
Prosjektet skal etter planen avsluttes i 2021. Alle data anonymiseres.

Frivillig deltakelse

Det er frivillig å delta i studien. Du kan når som helst, og uten å oppgi noen grunn trekke ditt samtykke til å delta. Dette vil ikke få konsekvenser for deg eller din pårørendes kontakt med og hjelp fra de kommunale pleie- og omsorgstjenestene. Hvis du trekker deg fra studien kan du kreve å få slettet innsamlede opplysninger inntil dataanalysene er utført.

Dersom du ønsker å delta i studien gjør du dette ved å returnere spørreskjema som tidligere beskrevet innen to uker.
Dersom du sender inn spørreskjema, men senere ønsker å trekke deg, ta kontakt med leder for hjemmetjenesten i din kommune.

Hvis du ønsker utfyllende opplysninger, har spørsmål eller ønsker hjelp til å fylle ut spørreskjemaet er du velkommen til å kontakte stipendiat Jill- Marit Moholt på telefon 77660701/90513510 fra klokken 0900-1500 mandag til fredag.

Med vennlig hilsen

Nils Henriksen
Professor
Institutt for helse- og omsorgsfag
UiT Norges arktiske universitet

Mari Wolff Skaalvik
Førsteamanuensis
Institutt for helse- og omsorgsfag
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Jill- Marit Moholt
Stipendiat
Senter for omsorgsforskning, nord /Institutt for helse- og omsorgsfag
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APPENDIX 5

Information letter to Sami family caregivers

UiT
NORGGA
ÁRKTALAŠ
UNIVERSITEHTA

Dearvvašvuođa- ja fuolahusfágaid instituhtta
Du čuj.:
Min čuj.:
Beaivi:

Jearaldat searvat dutkanprošektii: “Oapmahašiskkadeapmi – jearahallanskovveiskkadeapmi sidjiide geat veahkehit olbmuid geat leat boarrásit go 65 jagi, geat orrot ruovttus ja geain lea muittohisvuohta/demeansadávda”

Dutkosa duogáš ja ulbmil

Eanas olbmot geain lea muittohisvuohta ja demeansadávda, orrot ruovttus ja dárbbašit veahki ja doarjaga vai birgejit árgabeaivválaččat, ja oapmahaččat leat dávjá guovddáš veahkit. Leat ásahuvvon olu suohkana/gieldda dearvvašvuođa- ja fuolahusbálvalusat sin váste geain lea demeansa ja sin oapmahaččaide, muhto mii eat dieđe doarvái sin birra geat atnet dáid bálvalusaid, leatgo oapmahaččat duhtavaččat, gokčojuvvojitgo sin dárbbut veahki ja doarjaga dáfus, ja masa oapmahaččat háliidit eanet veahki. Mis váilu maid diehtu oapmahaččaid veahki birra, movt sii hálddašit veahkkerolla ja movt sii vásihit iežaset eallindilálašvuođa. Dáid áššiid birra háliidit háhkat dieđuid jearahallanskovveiskkadeami bokte.

Dikšo- ja fuolahusbálvalusa jođiheaddjit leat dohkkehan ahte dutkkus čađahuvvo du gielddas/suohkanis, ja okta dutkanmielbargi geas lea oppalaš govva daid olbmuid badjel geain lea demeansadávda ja orrot ruovttus ja sin oapmahaččaid badjel, lea árvvoštallan ahte don heivet oassálastin.

Dutkkus gullá stuorát dutkanprošektii man Norgga dutkanráđđi ruhtada ja mii lea čadnon Romssa universitehta – Norgga árktalaš universitehta Fuolahusdutkama guovddážii – davvi. Prošeavtta jođiheaddji lea professor Torunn Hamran. Professoris Nils Henriksenis, vuosttašamanueanssas Mari Wolff Skaalvikas ja stipendiáhtas Jill-Marit Moholtas lea ovddasvástádus jearahallanskovveiskkadeapmái. Dutkosa bohtosat almmuhuvvojit nákkosgirjjis, dieđalaš artihkkaliin, báikkálaš aviissain ja dieđalaš áigečállagiin. Bohtosat addet dehálaš dieđuid maid sáhttá atnit ávkin go oahpaha oapmahaččaid dilálašvuođa birra.

Maid dutkkus mearkkaša dutnje?

Oassálastin dutkosii mearkkaša ahte don guhte leat oapmahaš deavddát jearahallanskovi mii lea mielddusin. Ádjána sullii 25 minuhta. Jus háliidat searvat iskkadeapmái, de máhcahat guovtti vahkku siste gárvves devdojuvvon skovi vástáduskonvoluhtain mii lea mielddusin, porto lea jo máksojuvvon. Dan máhcahančujuhus lea njuolga iskkadeami ovddasvástideaddjái Romssa universitehtas. Go mii oažžut gárvves devdojuvvon jearahallanskovi, de mii sáddet dutnje 2 Flax-vuorbbi giitun veahki ovddas.
Jus dárbbašat veahki jearahallanskovi deavdimii, de bivdit du jearrat bearašlahtu dahje lagasolbmo alccet veahkkin. Sáhtát maid riŋget stipendiáhttii Jill-Marit Moholtii telefovdnanummarii 77660701/90513510 jearrat veahki, ja son riŋge dutnje ruovttoluotta veahkkin deavdit skovi.

Sáhttá leat sávahahtti jearahallat muhtin jearahallanskovveiskkadeami oassálastiid. Jus sáhtášit searvat čuovvolaniskkadeapmái, de čále nama, čujuhusa ja telefovdnanummara vuolemussii jearahallanskovis. Jus vástidat ahte searvvat dása, de váldá muhtin dutki prošeaktajoavkkus duinna oktavuođa. Don it leat goitge geatnegahtton searvat jus rievdadat oaivila. Du vástádusaid besset dušše prošeaktajoavkku dutkit oaidnit. Vai beassat iskat jearahallanskovi buoremus lági mielde, de sávvat ahte muhtin oasseváldit devdet seamma skovi nuppes sullii golbma vahkku maŋŋel. Jus vástidat “searvvan”, de dat livččii stuora ávkin midjiide.

Mii dáhpáhuvvá dieđuiguin du birra?

Dieđut mat registrerejuvvojit du birra adnojuvvojit dušše dutkosa ulbmila mielde. Eará dieđut go mat jearahallanskovis bohtet ovdan du ja oapmahaččat birra, eai vižžojuvvo. Buot dieđut meannuduvvojit anonymalaččat ja luohttevaččat, iige leat vejolaš identifiseret du dahje oapmahaččat dutkanartihkkaliin dahje eará almmuhemiin.
Jearahallanskovvi čadno koda bokte nammalistui man vurkkoda muhtun buohccidivššár geas lea jođihanovddasvástádus du gielddas/suohkanis. Lea dušše dát persovdna gii beassá listtu oaidnit vai sus lea oppalaš govva das geat leat ožžon ja vástidan jearahallanskovi. Nammalistu makulerejuvvo 2016 loahpas.

Gárvves devdojuvvon jearahallanskovit vurkkoduvvojit Romssa universitehta dutkanmateriála vurkkodeami njuolggadusaid mielde. Dat mearkkaša ahte lássejuvvojit dohkálaččat ja dušše persovnnat geat gullet dutkanjovkui besset oaidnit materiála.
Plána mielde loahpahuvvo prošeakta jagi 2021. Buot dieđut anonymiserejuvvojit.

Eaktodáhtolaš oassálastin

Iskkadeami oassálastin lea eaktodáhtolaš. Sáhtát geassádit iskkadeamis vaikko goas, ákkastallama haga. Dat ii váikkut du iige du oapmahačča gulahallamii gieldda/suohkana dikšo- ja fuolahusbálvalusain iige dan veahkkái maid oažžubeahtti gieldda/suohkana dikšo- ja fuolahusbálvalusas. Jus geassádat iskkadeamis, de sáhtát gáibidit, ovdal go leat geargan analysereme dieđuid, ahte čohkkejuvvon dieđut du birra sihkkojuvvojit.

Jus háliidat searvat iskkadeapmái, de máhcahat jearahallanskovi nu movt ovdalaččas lea čilgejuvvon guovtti vahkku siste.
Jus máhcahat jearahallanskovi, muhto maŋŋel háliidat geassádit, de válddát oktavuođa iežat gieldda/suohkana ruovttubálvalusa jođiheddjiin.

Jus háliidat eambbo dieđuid dahje jus dus leat gažaldagat dahje háliidat veahki jearahallanskovi deavdimii, de leat buresboahtin váldit oktavuođa stipendiáhtain Jill-Marit Moholtain telefovnna bokte 77660701/90513510 diibmu 0900 rájes 1500 rádjai mánnodagas bearjadahkii.

Dearvvuođaiguin

Nils Henriksen
professor
Dearvvašvuođa- ja fuolahusfágaid instituhtta
UiT Norgga árktalaš universitehta

Mari Wolff Skaalvik
vuosttašamanueansa
Dearvvašvuođa- ja fuolahusfágaid instituhtta
UiT Norgga árktalaš universitehta

Jill-Marit Moholt
stipendiáhtta
Fuolahusdutkama guovddáš, davvi /
Dearvvašvuođa- ja fuolahusfágaid instituhtta
UiT Norgga árktalaš universitehta

APPENDIX 6

Questionnaire Norwegian language

Pårørendeundersøkelsen

Løpenr: ☐☐☐☐

Vi ber deg som har ansvar for å hjelpe og støtte en eldre, hjemmeboende person med hukommelsessvikt/demenssykdom om å fylle ut dette spørreskjemaet. Vanligvis er det familie eller slekt som hjelper mest, men også naboer eller venner kan svare.

Hvis dere er flere pårørende som deler på ansvaret, ber vi om at en av dere svarer. Hvis du synes det vanskelig å svare, kan du be et annet familiemedlem eller en nærstående hjelpe deg.

Informasjon om utfylling av skjemaet:

Skjemaet skal leses maskinelt, så du må bruke blå eller svart penn. Vennligst bruk blokkbokstaver og skriv så tydelig som mulig.
Det er også viktig at du krysser av presis inni rutene.

Slik: ☒ Ikke slik: ☐X

Skriv tallet 1 som en rett strek. Slik: 1 Skriv tallet syv slik: 7

Hvis du har skrevet feil tall, korriger ved å sette en strek over tallet som er feil og skriv det riktige tallet ved siden av. Eksemplet nedenfor viser at riktig tall er 3.

3
~~2~~

Generelle spørsmål om personen du hjelper og støtter

I spørsmålene blir personen med hukommelsessvikt/demenssykdom omtalt som personen og han/hun.

Kryss av ved ett svaralternativ dersom det ikke er oppgitt noe annet.

1) Er personen du hjelper/støtter: ☐ Mann ☐ Kvinne

2) Hvor gammel er personen? ☐☐ år

(Sett ett siffer i hver rute. For eksempel 7 og 5 for 75 år)

3) Hvilket hjemmespråk har personen?
(Sett ett eller flere kryss)

☐ Norsk
☐ Samisk
☐ Kvensk
☐ Annet, beskriv ☐

4) Hva er personens etniske bakgrunn?
(Sett ett eller flere kryss)

☐ Norsk
☐ Samisk
☐ Kvensk
☐ Annet, beskriv ☐

5) Hva er din relasjon til personen?

☐ Ektefelle/samboer/partner
☐ Datter
☐ Sønn
☐ Barnebarn
☐ Søsken
☐ Svigerbarn
☐ Niese/nevø
☐ Annet (for eksempel svigersøsken, grandniese/ grandnevø, venn/venninne, nabo etc.), beskriv

6) Hvor bor du og han/hun?

☐ I samme husholdning
☐ I forskjellige husholdninger, men i samme bygning
☐ I gåavstand
☐ Innen 10 minutter med bil eller buss
☐ Innen 30 minutter med bil eller buss
☐ Innen 1 time med bil eller buss
☐ Over 1 time med bil eller buss

7) Om dere ikke bor i samme husholdning, bor personen:

☐ Alene
☐ Med ektefelle/samboer/partner
☐ Med andre, spesifiser

8) Bor personen i kommunal omsorgsbolig?

☐ Ja ☐ Nei

9) Hvor lenge synes du det er forsvarlig at personen er uten hjelp, støtte eller tilsyn?

☐ Ikke i det hele tatt
☐ Mindre enn to timer
☐ 2- 5 timer
☐ 6- 12 timer
☐ Mer enn 12 timer
☐ Ett døgn eller mer

10) Hvordan vil du beskrive området personen bor i?

☐ Sentrum i by
☐ I by, men ikke i sentrum
☐ Småby
☐ Tettsted i landkommune
☐ Spredtbygd strøk/bygd

11) Oppgi avstand til legekontoret som personen vanligvis bruker:

Angi avstand i kilometer. Omtrent ☐☐ km

(Skriv ett siffer i hver rute, for eksempel 0 og 5 for 5 kilometer eller 2 og 5 for 25 kilometer)

Videre følger spørsmål om hjelp og støtte som du gir til personen

Hjelp og støtte betyr det du gjør for at hverdagslivet skal fungere best mulig for personen med hukommelsessvikt/demenssykdom. Dette innebærer alt fra telefonkontakt, besøk og turgåing til praktisk og personlig hjelp.

Kryss av ved ett svaralternativ dersom det ikke er oppgitt noe annet.

12) Hvor lenge har du hjulpet personen etter at han/hun fikk hukommelsessvikt/demenssykdom?

Omtrent ☐☐ år

Rund av til antall hele år som du har hjulpet personen.

(Skriv ett siffer i hver rute. For eksempel 0 og 2 for 2 år eller 1 og 0 for 10 år)

13) Hva har du vanligvis gjort for personen de siste 12 månedene?

Sett kryss ved alt som passer.

☐ Personlig hjelp og pleie?
(For eksempel påkledning, bading, vasking, barbering, klipping av negler, mating, bruk av toalettet)

☐ Fysisk hjelp?
(For eksempel hjelp til å gå, gå opp og ned trapper, legge seg og stå opp fra sengen)

☐ Hjelp med å håndtere omsorgstjenester og sosiale ytelser? (For eksempel å gjøre avtaler og ringe, fylle ut skjemaer)

☐ Hjelp med papirarbeid eller til å håndtere økonomi.
(For eksempel å skrive brev, sende kort, fylle ut skjemaer, håndtere regninger, kontakt med banken)

☐ Annen praktisk hjelp? (For eksempel lage mat, handle, klesvask, husarbeid, hagearbeid, oppussing, reparasjoner i huset, skyss til lege eller sykehus)

☐ Holde han/henne med selskap?
(For eksempel besøke, sitte sammen med, lese for, snakke med, spille kort eller spill)

☐ Ta han/henne med ut?
(For eksempel gå tur eller ta en kjøretur, ta med for å besøke venner eller slektninger)

☐ Gi medisiner?
(For eksempel passe på at han/hun tar tabletter, gi injeksjoner, bytte bandasjer)

☐ Holde øye med han/henne for å se om han/hun har det bra?

☐ Gi følelsesmessig støtte?

☐ Annen hjelp? Skriv hva slags hjelp dette er:

☐

14) Hvor ofte hjelper du personen?

☐ Aldri

☐ 1 gang i uken eller mindre

☐ 2-3 ganger i uken

☐ 4-6 ganger i uken

☐ Hver dag

15) Hvor mange timer i uken hjelper og støtter du personen?

Omtrent ☐☐ timer per uke

(Skriv ett siffer i hver rute. For eksempel 0 og 5 for 5 timer eller 1 og 5 for 15 timer)

16) Hvilke faktorer påvirket din beslutning om å hjelpe og støtte han/henne?

(Kryss av "ja" eller "nei" for hver uttalelse)

	Ja	Nei
Pliktfølelse	☐	☐
Det var ikke noe alternativ	☐	☐
Kostnadene for profesjonell omsorg ville blitt for høye (For eksempel egenandeler, betaling for hjemmehjelp, korttidsplass på sykehjem og boutgifter i omsorgsbolig)	☐	☐
Følelsesmessige bånd (kjærlighet, hengivenhet)	☐	☐
Jeg får en god følelse av å hjelpe/støtte han/henne	☐	☐
Han/hun ønsker ikke at noen andre skal hjelpe/støtte han/henne	☐	☐
På grunn av min religiøse tro	☐	☐
Det var tilfeldig at jeg endte opp i denne situasjonen uten at jeg tok et valg	☐	☐
Det var økonomiske fordeler for meg og/eller han/henne	☐	☐
En personlig forpliktelse overfor han/henne som et familiemedlem	☐	☐

Annet, vennligst spesifiser:

☐

17) Hvor krevende synes du det er å hjelpe personen?

☐ Svært krevende

☐ Middels krevende

☐ Litt krevende

☐ Ikke krevende

De neste spørsmålene handler om hjelp, støtte og avlastning som du som pårørende mottar fra familien og omgangskretsen

Kryss av ved ett svaralternativ dersom det ikke er oppgitt noe annet.

18) Hvor ofte bruker du din omgangskrets til hjelp og støtte i forbindelse med personens sykdom?

For eksempel å se til eller gå en tur med din pårørende. *(Sett ett kryss i hver linje)*

	Daglig	Ukentlig	Flere ganger i måneden	En gang i måneden	Sjeldnere	Aldri
a) Din familie	☐	☐	☐	☐	☐	☐
b) Naboer	☐	☐	☐	☐	☐	☐
c) Venner eller bekjente	☐	☐	☐	☐	☐	☐

19) Er det noen som vil stille opp og hjelpe han/henne hvis du blir syk?

☐ Ja, det vil bli ganske enkelt å finne noen

☐ Ja, jeg kan finne noen, men det vil ikke bli så lett

☐ Nei, det finnes ingen andre

20) Er det noen som vil ta seg av han/henne for deg hvis du trenger avlastning fra omsorgsrollen?

☐ Ja, det vil bli ganske enkelt å finne noen

☐ Ja, jeg kan finne noen, men det vil ikke bli så lett

☐ Nei, det finnes ingen andre

Videre spør vi om hjelp personen og du mottar fra kommunale pleie- og omsorgstjenester og din vurdering av tjenestene.

Kryss av ved ett svaralternativ dersom det ikke er oppgitt noe annet.

21) Hvilke pleie- og omsorgstjenester får personen fra kommunen?

Sett kryss ved alt som passer.

☐ Hjemmehjelp

☐ Hjemmesykepleie

☐ Middagsombringing

☐ Trygghetsalarm

☐ Dagsenter

☐ Støttekontakt

☐ Korttidsplass eller avlastningsplass på sykehjem

☐ Annet, skriv hva slags tjenester dette er:

☐

22) Hvor mye hjelp og støtte får personen fra kommunen?

(Skriv antall ganger per dag, uke eller måned etter hver tjeneste som personen bruker)

Hjemmesykepleie	☐	ganger per dag
Hvis ikke daglig:	☐	ganger per uke
Hjemmehjelp	☐	ganger per uke
Hvis ikke ukentlig:	☐	ganger per måned
Middagsombringing	☐	ganger per uke
Dagsenter	☐	ganger per uke
Støttekontakt	☐	timer per uke
Korttidsplass eller avlastningsplass på sykehjem	☐	uker per måned
Hvis ikke månedlig:	☐☐	ganger per år

23) Hva slags type hjelp og støtte har personen fått fra kommunen de siste 12 måneder?

Sett kryss ved alt som passer.

☐ Personlig stell

☐ Sårstell

☐ Medisiner

☐ Matlaging

☐ Hjelp/støtte til måltider og oppfølging under måltider

☐ Vask av hjem og/eller klær

☐ Bistand til fritidsaktiviteter og sosialt samvær

☐ Annet, spesifiser:

☐

24) Er det noen kommunale pleie- og omsorgstjenester som ennå ikke er brukt?

Vi tenker da på tjenester du vet om og som kan bidra til å hjelpe og støtte personen og/eller som kan avlaste deg.

☐ Ja ☐ Nei ☐ Vet ikke

<u>Hvis ja</u>, hva er de viktigste grunnene til at du ikke har brukt disse tjenestene? Vennligst skriv i feltet nedenfor.

25) Får du ditt behov for avlastning oppfylt på nåværende tidspunkt?

☐ Ja

☐ Delvis

☐ Nei

☐ Nei, jeg ønsker ikke avlastning

26) Får <u>du</u> den hjelpen du trenger for å få din hverdag til å fungere?

☐ Ja

☐ Delvis

☐ Nei

☐ Nei, jeg ønsker ikke avlastning

27) Har du fått informasjon om:

- Tilgjengelige pleie- og omsorgstjenester i din kommune?

☐ Ikke i det hele tatt

☐ I liten grad

☐ I noen grad

☐ I stor grad

☐ I svært stor grad

☐ Ikke aktuelt

- Innholdet i pleie- og omsorgstjenestene som han/hun får?

☐ Ikke i det hele tatt

☐ I liten grad

☐ I noen grad

☐ I stor grad

☐ I svært stor grad

☐ Ikke aktuelt

28) Blir du tatt med på råd i spørsmål som gjelder pleie- og omsorgstjenestene til han/henne?

☐ Ikke i det hele tatt

☐ I liten grad

☐ I noen grad

☐ I stor grad

☐ I svært stor grad

☐ Ikke aktuelt

29) Er hjelpen og støtten han/hun og du får fra pleie- og omsorgs-tjenestene alt i alt tilfredsstillende?

☐ Ikke i det hele tatt

☐ I liten grad

☐ I noen grad

☐ I stor grad

☐ I svært stor grad

☐ Ikke aktuelt

30) Når du ser tilbake, mener du det burde vært søkt hjelp fra kommunen på et tidligere tidspunkt enn da det ble gjort?

☐ Ja ☐ Nei ☐ Vet ikke

31) Ble hjelp fra kommunen iverksatt raskt nok da det ble søkt?

☐ Ja ☐ Nei ☐ Vet ikke

De neste spørsmålene handler om bruk av andre typer tjenester

Dette kan være tjenester som dere bruker for å dekke personens behov for tilrettelegging i hjemmet, rehabilitering, hjelp , tilsyn og aktiviteter i hverdagen eller for å dekke ditt eget behov for avlastning.

Kryss av ved ett svaralternativ dersom det ikke er oppgitt noe annet.

32) Har personen de siste 12 månedene mottatt

a) Ergoterapitjenester? ☐ Ja ☐ Nei ☐ Vet ikke

b) Fysioterapitjenester? ☐ Ja ☐ Nei ☐ Vet ikke

33) Kjøpes det private pleie- og omsorgstjenester?

☐ Ja

☐ Nei

☐ Nei, slike tjenester er ikke tilgjengelig i min kommune

Hvis ja, hvor mange timer i måneden?

I gjennomsnitt ☐☐ timer per måned

(Skriv ett siffer i hver rute, for eksempel 0 og 4 for 4 timer og 1 og 0 for 10 timer)

34) Benyttes det tjenester fra frivillige organisasjoner?

(Tjenester kan være kafetilbud, besøksvenner og turtilbud arrangert i regi av for eksempel Røde Kors, demensforeninger, pensjonistforeninger eller lignende).

☐ Ja

☐ Nei

☐ Nei, slike tjenester er ikke tilgjengelig i min kommune

Hvis ja, hvor mange timer i måneden?

I gjennomsnitt ☐☐ timer per måned

(Skriv ett siffer i hver rute, for eksempel 0 og 4 for 4 timer og 1 og 0 for 10 timer)

Videre ber vi deg om å vurdere dine behov som pårørende

35) Vi vil gjerne vite hva du har behov for av støtte for å kunne ivareta omsorgen for personen du hjelper og støtter, og hva du selv har behov for av støtte.

Etter hvert utsagn er det fire svaralternativer, vennligst kryss av i ruten som best representerer dine behov akkurat nå.

Har du behov for mer støtte i forhold til …

	Nei	Litt mer	En del mer	Mye mer
… å forstå din pårørendes sykdom?	☐	☐	☐	☐
… å ha tid for deg selv i løpet av dagen?	☐	☐	☐	☐
… å håndtere din pårørendes symptomer, inkludert å gi medisiner?	☐	☐	☐	☐
… dine egne økonomiske, juridiske eller arbeidsrelaterte utfordringer?	☐	☐	☐	☐
… å hjelpe din pårørende med personlig hygiene (for eksempel påkledning, dusj og toalettbesøk)?	☐	☐	☐	☐
… å mestre dine egne følelser og bekymringer?	☐	☐	☐	☐
… å vite hvem du kan kontakte dersom du er bekymret for din pårørende (også om natten)?	☐	☐	☐	☐
… å ta vare på egen helse (fysiske problemer)?	☐	☐	☐	☐
… å få tak i nødvendig utstyr for å kunne hjelpe din pårørende?	☐	☐	☐	☐
… din tro/ditt livssyn eller andre åndelige/ eksistensielle spørsmål?	☐	☐	☐	☐
… å snakke med din pårørende om hans/hennes sykdom?	☐	☐	☐	☐
… praktisk hjelp i hjemmet?	☐	☐	☐	☐
… å vite hva du kan forvente i tiden fremover når du har omsorgen for din pårørende?	☐	☐	☐	☐
… å få avlastning fra omsorgsansvaret om natten?	☐	☐	☐	☐

... noe annet (skriv det gjerne her)?

Løpenr: ☐☐☐☐

Vi vil gjerne spørre deg om hvordan du ser på å skulle hjelpe og støtte personen i fremtiden.

36) Er du villig til å fortsette å hjelpe/støtte han/henne i året som kommer?

☐ Ja, og om nødvendig vil jeg vurdere å øke omfanget av hjelp og støtte som jeg gir.

☐ Ja, jeg vil vurdere å øke omfanget av hjelp og støtte som jeg gir i en begrenset periode.

☐ Ja, jeg er klar for å fortsette å gi hjelp og støtte hvis situasjonen forblir den samme.

☐ Ja, jeg er klar for å fortsette å gi hjelp og støtte til han/henne, men bare hvis jeg får mer støtte (fra offentlig og/eller private tjenester, familie, venner osv.)

☐ Nei, jeg er ikke klar for å fortsette å hjelpe og støtte han/henne uansett hvilken ekstra støtte som jeg mottar.

37) Vil du være villig til å la han/henne flytte på sykehjem?

☐ Nei, ikke under noen omstendigheter.

☐ Ja, men bare hvis tilstanden hans/hennes blir verre.

☐ Ja, selv om tilstanden hans/hennes er slik den er nå.

Videre følger spørsmål om din livssituasjon som pårørende

Kryss av ved ett svaralternativ dersom det ikke er oppgitt noe annet.

38) Hvordan vurderer du din egen helse sånn i alminnelighet?

☐ Meget god

☐ God

☐ Verken god eller dårlig

☐ Dårlig

☐ Meget dårlig

39) Hvordan synes du din helse er sammenlignet med andre på din alder?

☐ Mye bedre

☐ Litt bedre

☐ Omtrent lik

☐ Litt dårligere

☐ Mye dårligere

40) Ved å svare på spørsmålene nedenfor kan du gi oss et bilde av hvor bra eller dårlig du føler deg for tiden. Vennligst kryss av for det svaret som passer best for hver uttalelse om hvordan du for det meste har følt deg gjennom de siste to ukene.

I de siste to ukene har jeg.....

	Hele tiden	Det meste av tiden	Mer enn halve tiden	Mindre enn halve tiden	Av og til	Aldri
… følt meg glad og i godt humør	☐	☐	☐	☐	☐	☐
… følt meg rolig og avslappet	☐	☐	☐	☐	☐	☐
… følt meg aktiv og sterk	☐	☐	☐	☐	☐	☐
… følt meg opplagt og uthvilt når jeg våkner	☐	☐	☐	☐	☐	☐
… følt at mitt daglige liv har vært fylt av ting som interesserer meg	☐	☐	☐	☐	☐	☐

41) Vi vil gjerne vite hvordan du oppfatter din situasjon som hjelper og støtteperson.

(Vennligst kryss av for det alternativet som best beskriver deg)

	Alltid	Ofte	Noen ganger	Aldri	Ikke relevant
Føler du at du mestrer omsorgsrollen godt?	☐	☐	☐	☐	
Syns du at omsorgsrollen er for krevende?	☐	☐	☐	☐	
Forårsaker omsorgsrollen vanskeligheter i forholdet ditt til dine venner?	☐	☐	☐	☐	☐
Har omsorgsrollen en negativ innvirkning på din fysiske helse?	☐	☐	☐	☐	
Forårsaker omsorgsrollen vanskeligheter i forholdet ditt til din familie?	☐	☐	☐	☐	☐

	Alltid	Ofte	Noen ganger	Aldri	Ikke relevant
Forårsaker omsorgsrollen økonomiske vanskeligheter for deg?	☐	☐	☐	☐	
Føler du deg fanget i omsorgsrollen?	☐	☐	☐	☐	
Føler du at du får god støtte av venner og/eller naboer?	☐	☐	☐	☐	☐
Synes du at omsorgsrollen er givende?	☐	☐	☐	☐	
Føler du at du får god støtte fra din familie?	☐	☐	☐	☐	☐
Har du et godt forhold til personen du har omsorg for?	☐	☐	☐	☐	
Føler du at du får god støtte fra helsevesenet og sosialtjenesten? (for eksempel offentlig, privat, frivillig organisasjon)	☐	☐	☐	☐	☐
Føler du at noen verdsetter deg som omsorgsperson?	☐	☐	☐	☐	
Har omsorgsrollen en negativ innvirkning på ditt følelsesmessige velvære?	☐	☐	☐	☐	
Føler du totalt sett at du får god støtte i omsorgsrollen?	☐	☐	☐	☐	

Videre har vi noen spørsmål om pårørendeskole

Kryss av ved ett svaralternativ dersom det ikke er oppgitt noe annet.

42) Har du deltatt på pårørendeskole? ☐ Ja ☐ Nei

Hvis ja, når var dette?

☐ Mindre enn 12 måneder siden

☐ Mer enn 12 måneder siden

Hvis nei, hva er grunnen til at du ikke har deltatt?
(Du kan krysse av på flere svaralternativer)

☐ Jeg har ikke hørt om tilbudet

☐ Jeg har valgt å ikke delta da jeg mener jeg ikke trenger tilbudet

☐ Det er for stor avstand fra mitt hjemsted til kursstedet

☐ Jeg har ingen som kan se etter personen

☐ Kurset avholdes på et tidspunkt som ikke passer for meg

☐ Kurset er ikke tilgjengelig i min kommune

☐ Annet, skriv det gjerne her

Spørsmål 43 til og med 48 besvares bare hvis du har deltatt på pårørendeskolen.
Hvis ikke, gå videre til spørsmål 49

43) Synes du alle temaene som ble tatt opp på pårørendeskolen var relevante for deg?

☐ Ja ☐ Nei

Hvis nei, kan du nevne hvilke temaer som ikke var relevante? *(Vennligst skriv i feltet nedenfor)*

44) Var det temaer du savnet?

☐ Ja ☐ Nei

Hvis ja, kan du nevne hvilke temaer du savnet? *(Vennligst skriv i feltet nedenfor)*

45) Var gruppesamtaler en del av pårørendeskoletilbudet da du deltok?

☐ Ja ☐ Nei

Hvis ja, når du vurderer alle gruppesamtalene i løpet av pårørendeskolen under ett, mener du at:

(Sett ett kryss per linje)	Helt enig	Delvis enig	Uenig
Gruppesamtalene var nyttige	☐	☐	☐
Jeg lærte av å høre på andres erfaringer	☐	☐	☐
Jeg fikk komme til orde i gruppesamlingen	☐	☐	☐
Det var passe antall deltakere i gruppesamlingen	☐	☐	☐
Det var en god balanse mellom gruppesamtaler og foredrag	☐	☐	☐

46) Har din deltakelse på pårørendeskolen ført til at du takler dine omsorgsoppgaver:

☐ Dårligere

☐ Uforandret

☐ Av og til bedre

☐ Bedre

47) Har du hatt problemer med å komme på pårørendeskolen fordi personen med hukommelsessvikt/demenssykdom ikke kunne være alene?

☐ Ja ☐ Nei

48) Har pårørendeskolen bidratt til nye kontakter?

☐ Ja ☐ Nei

Hvis ja, på hvilken måte har pårørendeskolen bidratt til nye kontakter?

(Her kan du krysse av på flere alternativer)

☐ Mer kontakt med andre pårørende.

☐ Mer kontakt med hjelpeapparatet.

☐ Mer kontakt med interesseorganisasjoner som demensforening og lignende.

☐ Andre, skriv det gjerne her.

☐

Generelle spørsmål om deg.

Disse spørsmålene vil hjelpe oss til å få en bedre oversikt over de som har svart på spørreskjemaet.

Kryss av ved ett svaralternativ dersom det ikke er oppgitt noe annet.

49) Er du: ☐ Mann ☐ Kvinne

50) Hva er din alder? ☐☐

(Skriv ett siffer i hver rute. For eksempel 5 og 5 for 55 år).

51) Hva er din sivilstand?

☐ Gift/samboende/registrert partner

☐ Ugift/enslig

☐ Enke/ enkemann

☐ Separert/skilt

52) Hvilket hjemmespråk har du?

(Sett ett eller flere kryss)

☐ Norsk

☐ Samisk

☐ Kvensk

☐ Annet, beskriv ☐

53) Hva regner du deg selv som?

(Sett ett eller flere kryss)

☐ Norsk

☐ Samisk

☐ Kvensk

☐ Annet, beskriv ☐

54) Har du hjemmeboende barn?

☐ Ja ☐ Nei

Hvis ja, hvor mange er under 18 år? ☐

Skriv antallet i ruten.

55) Hva er din høyeste fullførte utdanning?

(Sett ett kryss)

☐ Grunnskole/framhaldsskole/folkehøyskole inntil 10 år

☐ Yrkesfaglig utdanning/realskole/videregående/gymnas minimum 3 år

☐ Høyskole/universitet mindre enn 4 år

☐ Høyskole/universitet 4 år eller mer

56) Hva er din hovedaktivitet? *(Sett ett kryss)*

☐ Yrkesaktiv heltid

☐ Yrkesaktiv deltid

☐ Hjemmeværende

☐ Alderspensjonist

☐ Uføretrygdet/mottar arbeidsavklaringspenger

☐ Delvis uføretrygdet

☐ Mottar sosialstønad

☐ Arbeidsledig

☐ Skoleelev/ student

☐ Annet, spesifiser

☐

Hvis du jobber deltid, har du redusert stilling på grunn av omsorgsansvaret for personen?

☐ Ja ☐ Nei

57) Har du helsefaglig utdanning?
(Besvares også av de som ikke er yrkesaktive)

☐ Ja ☐ Nei

58) Har du mulighet til å påvirke eldreomsorgen i din kommune gjennom frivillige foreninger, politiske partier eller lignende?
(Frivillige foreninger som jobber for eldreomsorgen er for eksempel pensjonistforeninger og demensforeninger).

☐ Ja

☐ Ja, men er ikke interessert

☐ Nei

☐ Vet ikke

59) Hva var din husstands samlede bruttoinntekt siste år?
(Ta med alle inntekter fra arbeid, trygder, sosialhjelp og lignende).

☐ Under 150 000 kr

☐ 150 000-250 000 kr

☐ 251 000-350 000 kr

☐ 351 000-450 000 kr

☐ 451 000-550 000 kr

☐ 551 000-750 000 kr

☐ 751 000-1 000 000 kr

☐ Over 1 000 000 kr

60) Hvordan opplever du din husstands økonomiske situasjon?

☐ Bra ☐ Moderat ☐ Dårlig

61) Er det flere som du gir denne type hjelp og støtte til minst en gang i uka?

☐ Ja ☐ Nei

Hvis ja, skriv antall personer i ruten: ☐

Avsluttende spørsmål

62) Har noen hjulpet deg med å fylle ut dette spørreskjemaet?

☐ Ja ☐ Nei

63) For å få testet spørreskjemaet grundig, vil vi gjerne at noen fyller ut samme skjema en gang til om 3 uker. Kunne du tenke deg å gjøre dette?

(Kryss av i ruten som passer for deg).

☐ Ja, jeg kan gjerne fylle ut skjemaet en gang til

☐ Nei, jeg ønsker ikke fylle ut skjemaet en gang til

Til slutt:

Vi ønsker å invitere noen personer til å delta i en oppfølgingsundersøkelse til denne studien i form av et personlig intervju.

Kunne du tenke deg å delta i en slik undersøkelse?

(Selv om du svarer «ja», så medfører ikke dette noen framtidig forpliktelse til å delta i en slik undersøkelse).

☐ Ja, og jeg har skrevet navn, adresse og telefonnummer på neste side

☐ Nei (ikke fyll ut navn, adresse og telefonnummer på neste side)

Vennligst se etter at du har svart på alle spørsmålene i spørreskjemaet.

Takk for at du hjalp oss med å fylle ut spørreskjemaet.

Vennligst returner skjemaet til oss i den vedlagte svarkonvolutten innen 14 dager. Du trenger ikke å sette frimerke på konvolutten – porto er betalt.

Pårørendeundersøkelsen

Løpenr:

Navn:

Adresse:

Telefonnummer:

APPENDIX 7

Questionnaire North Sami language

Oapmahašiskkadeapmi

Løpenr: ☐☐☐☐

Mii bivdit du geas lea ovddasvástádus veahkehit ja doarjut vuoras olbmo gii orru ruovttus ja geas lea muittohisvuohta/demeansadávda, deavdit dán jearahallanskovi. Dábálaččat leat bearašlahtut dahje fuolkkit geat veahkehit eanemusat, muhto ránnját ja ustibat sáhttet maid vástidit.

Jus lehpet máŋga oapmahačča geat juogadehpet ovddasvástádusa, de bivdit ovtta dis vástidit. Jus du mielas lea váttis vástidit, de sáhtát jearrat veahki eará bearašlahtus dahje muhtin lagasolbmos.

Dieđut dan birra movt skovi galgá deavdit:

Skovvi galgá lohkkojuvvot optihkalaččat. Geavat alit dahje čáhppes kuvlapeanna. Čále stuora bustávaiguin ja nu dárkilit go vejolaš.
Lea maiddái dehálaš ahte russet njuolga ruvtto sisa.

Ná: ☒ Ii ná: ☐ X

Čále logu 1 njulges sáhcun. Ná: 1 Čále logu čieža ná: 7

Jus čálát boasttulogu, de divustat go sárggastat logu badjel ja čálát rievttes logu dasa gurrii.
Ovdamearka mii lea vuolábealde čájeha ahte rievttes lohku lea 3.

3
~~2~~

Oppalaš gažaldagat olbmo birra gean don veahkehat ja doarjjut

Gažaldagain namuhuvvo dat persovdna geas lea muittohisvuohta/demeansadávda sániiguin persovdna ja son.

Russe ovtta vástádusa jus eará ii leat namuhuvvon.

1) Leago persovdna gean veahkehat/doarjjut:

☐ Dievdu ☐ Nisu

2) Man boaris lea persovdna? ☐☐ jagi

(Bija ovtta logu juohke ruvttui.
Ovdamearkka dihte 7 ja 5 lea 75 jagi)

3) Mii lea persovnna ruovttugiella?

(Russe oktii dahje máŋgii)

☐ Dárogiella

☐ Sámegiella

☐ Kvenagiella

☐ Eará, čilge ☐

4) Mii lea persovnna čearddalaš duogáš?

(Russe oktii dahje máŋgii)

☐ Norgalaš

☐ Sápmelaš

☐ Kvena

☐ Eará, čilge ☐

5) Makkár oktavuohta lea dus persovdnii?

☐ Náittosguoibmi/ovttasássi/guoibmi
☐ Nieida
☐ Bárdni
☐ Áhkkut/áddjut
☐ Oabbá/viellja
☐ Mannji/vivva
☐ Neahpi/goaskit/muoŧŧal/siessal/čeahcet/eahkit
☐ Eará (ovdamearkka dihte mannji/gálojeatni/sivjjot/máhka/spile, neabi/goaskiba/muoŧŧala/siessala/čeahceba/eahkiba nieida/bárdni, ustit, ránnjá jna.), čilge

☐

6) Gos doai orrubeahtti?

☐ Seamma báikedoalus
☐ Goabbat báikedoaluin, muhto seamma visttis
☐ Vácci olámuttos
☐ 10 minuhta duohken biillain dahje bussiin
☐ 30 minuhta duohken biillain dahje bussiin
☐ 1 diimmu duohken biillain dahje bussiin
☐ Badjel 1 diimmu duohken biillain dahje bussiin

7) Jus eahppi oro seamma báikedoalus, orrugo persovdna:

☐ Okto
☐ Ovttas náittosguimmiin/ovttasássiin/guimmiin
☐ Ovttas earáiguin, čilge

☐

8) Orrugo persovdna gielda/suohkana fuolahusásodagas?

☐ Juo ☐ Ii

9) Man guhká orru du mielas dorvvolaš ahte persovdna lea veahki, doarjaga dahje geahču haga?

☐ Ii obage
☐ Unnit go guokte diimmu
☐ 2- 5 diimmu
☐ 6- 12 diimmu
☐ Guhkit go 12 diimmu
☐ Jándora dahje guhkit

10) Movt govvidat guovllu gos persovdna orru?

☐ Gávpotguovddáš
☐ Gávpot, muhto ii guovddážis
☐ Smávvagávpot
☐ Čoahkkebáiki giligielddas/-suohkanis
☐ Boaittobealde/gilli

11) Čále man guhkki lea dan doavtterkantuvrii maid dát persovdna dábálaččat geavaha:

Čále galle kilomehtera. Sullii ☐☐ km

(Čále ovtta logu juohke ruvttui, ovdamearkka dihte 0 ja 5 lea 5 kilomehtera dahje 2 ja 5 lea 25 kilomehtera)

Čuovvovaččat leat gažaldagat dan birra movt don veahkehat ja doarjjut persovnna

Veahkki ja doarjja mearkkaša dan maid don dagat dan persovnna ovddas geas lea muittohisvuohta/demeansadávda vai su árgabeaivi doaimmašii buoremus lági mielde. Dat sisttisdoallá visot nugo telefovdnaoktavuođa, go finat su guossis, go mannabeahtti váccašit ja buot geavatlaš ja persovnnalaš veahki.

Russe ovtta vástádusa jus eará ii leat namuhuvvon.

12) Man guhká leat don veahkehan persovnna maŋŋel go son muittohuvai/oaččui demeansadávdda?

Sullii ☐☐ jagi

Jorbe olles jagiide man guhká leat veahkehan persovnna.

Čále ovtta logu juohke ruvttui. Ovdamearkka dihte 0 ja 2 lea 2 jagi dahje 1 ja 0 lea 10 jagi)

Oapmahašiskkadeapmi

Løpenr: ☐☐☐☐

13) Movt leat dábálaččat veahkehan persovnna maŋemus 12 mánu? *Russe buot mii heive.*

☐ Persovnnalaš veahkki ja dikšu?
(Ovdamearkka dihte gárvodit, lávggodit, basadit, ráhket, gaccaid čuohppat, borahit, fitnat hivssegis)

☐ Fysalaš veahkki?
(Ovdamearkka dihte veahkehit vázzit, tráhpáid vázzit, velledit ja čuožžilit seaŋggas)

☐ Veahkkin hálddašit fuolahusbálvalusaid ja sosiála doarjagiid? (Ovdamearkka dihte dahkat šiehtadusaid, riŋget, skoviid deavdit)

☐ Veahkkin hoidet báberbargguid dahje hálddašit ekonomiija? (Ovdamearkka dihte reivviid čállit, koarttaid sáddet, skoviid deavdit, rehkegiid hálddašit, doallat oktavuođa báŋkkuin)

☐ Eará geavatlaš veahkki? (Ovdamearkka dihte biepmu ráhkadit, gávppašit, biktasiid bassat, viessobarggut, gilvvagárddi dikšut, viesu ođasmahttit, divodit viesu ja divodeamit viesus, sáhtostit doaktára lusa dahje buohccivissui)

☐ Leat suinna fárrolaga?
(Ovdamearkka dihte guossis fitnat, gáfestallat/čohkkát suinna ovttas, lohkat sutnje, humadit suinna, koarttaiguin dahje spealuiguin speallat)

☐ Váldit su mielde olggos?
(Ovdamearkka dihte váccašit olgun dahje vuojašit, fitnat suinna ustibiid dahje fulkkiid guossis)

☐ Addit dálkasiid?
(Ovdamearkka dihte váruhit ahte son váldá dálkasiid, injekšuvnnaid addit, hávvečanastagaid molsut)

☐ Geahččat bearrái ahte sus lea buorre dilli?

☐ Doarjut dovdduid dáfus?

☐ Eará veahkki? Čále makkár veahkki:

☐

14) Man dávjá veahkehat persovnna?

☐ In goassege

☐ 1 geardde vahkkus dahje unnit

☐ 2-3 geardde vahkkus

☐ 4-6 geardde vahkkus

☐ Beaivválaččat

15) Galle diimmu vahkkus veahkehat ja doarjjut persovnna? Sullii ☐☐ diimmu vahkkosaččat

(Čále ovtta logu juohke ruvttui. Ovdamearkka dihte 0 ja 5 lea 5 diimmu dahje 1 ja 5 lea 15 diimmu)

16) Mii váikkuhii du mearrádussii ahte áiggut veahkehit ja doarjut su?
(Russe "juo" dahje "ii" juohke cealkámuššii)

	Juo	Ii
Geatnegasvuođadovdu	☐	☐
Ii lean eará molssaeaktu	☐	☐
Profešunealla fuolahus livččii menddo divrras (Ovdamearkka dihte iežasosiid máksit, máksit ruovttuveahki ovddas, oanehisáiggesaji ovddas buhcciidruovttus ja orrungoluid ovddas fuolahusásodagas)	☐	☐
Dovdduid dihte (ráhkisvuohta, váimmolaš beroštupmi)	☐	☐
Oaččun buori dovddu go veahkehan/doarjjun su	☐	☐
Son ii hálit ahte oktage eará galgá su veahkehit/doarjut	☐	☐
Iežan religiovnnalaš oskku dihte	☐	☐
Gevven dán dillái soaittáhagas almmá válljekeahttá	☐	☐
Ledje ekonomalaš ovdamunit munnje ja/dahje sutnje	☐	☐
Persovnnalaš geatnegasvuohta go lean su bearašlahttu	☐	☐

Eará, čilge:

☐

17) Man gáibideaddji lea du mielas veahkehit persovnna?

☐ Hui gáibideaddji

☐ Oalle gáibideaddji

☐ Veaháš gáibideaddji

☐ Ii leat gáibideaddji

36602

Čuovvovaš gažaldagat leat veahki, doarjaga ja helpema birra maid don oapmahažžan oaččut bearrašis ja birrasis

Russe duššе ovtta vástádusa jus eará ii namuhuvvo.

18) Man dávjá geavahat iežat birrasa veahkkin ja doarjjan persovnna dávdda oktavuođas?
Ovdamearkka dihte bearráigeahččat dahje vázzit tuvrra du oapmahaččain

(Russe oktii juohke linnjás)

	Beaivválaččat	Vahkkosaččat	Máŋgii mánus	Oktii mánus	Hárvvibut	In goassege
a) Du bearaš	☐	☐	☐	☐	☐	☐
b) Ránnját	☐	☐	☐	☐	☐	☐
c) Ustibat dahje oahppásat	☐	☐	☐	☐	☐	☐

19) Leago oktage gii veahkehivččii persovnna jus don buohccát?

☐ Juo, gávnnašin álkit muhtima

☐ Juo, gávnnašin muhtima, muhto in nu álkit

☐ Ii, eai gávdno earát

20) Gávdnogo oktage gii du ovddas sáhttá veahkehit persovnna jus don dárbbašat bottu fuolahusrollas?

☐ Juo, gávnnašin álkit muhtima

☐ Juo, gávnnašin muhtima, muhto in nu álkit

☐ Ii, eai gávdno earát

Čuovvovaččat jearrat mii veahki birra maid doai persovnnain oažžubeahtti gieldda/suohkana dikšo- ja fuolahusbálvalusain, ja movt don árvvoštalat bálvalusaid

Russe ovtta vástádusa jus eará ii leat namuhuvvon

21) Makkár dikšo- ja fuolahusbálvalusaid oažžu persovdna gielddas/suohkanis?
Russe buot mii heive.

☐ Ruovttuveahkki

☐ Ruovttubuohccidikšu

☐ Mállásiid buktin

☐ Dorvoalárbma

☐ Beaiveguovddáš

☐ Doarjjaolmmoš

☐ Oanehisáiggesadji dahje helpensadji buhcciidruovttus

☐ Eará, čále makkár bálvalusaid:

☐

22) Man ollu veahki ja doarjaga oažžu persovdna gielddas/suohkanis?
(Čále galle geardde beaivválaččat, vahkkosaččat dahje mánnosaččat juohke bálvalussii maid persovdna geavaha)

Ruovttubuohccidikšu	☐	geardde beaivválaččat
Jus ii beaivválaččat:	☐	geardde vahkkosaččat
Ruovttuveahkki	☐	geardde vahkkosaččat
Jus ii vahkkosaččat:	☐	geardde mánnosaččat
Mállásiid buktin	☐	geardde vahkkosaččat
Beaiveguovddáš	☐	geardde vahkkosaččat
Doarjjaolmmoš	☐	diimmu vahkkus
Oanehisáiggesadji dahje helpensadji buhcciidruovttus	☐	vahkku mánnosaččat
Jus ii mánnosaččat:	☐☐	geardde jahkásaččat

23) Makkár veahki ja doarjaga lea persovdna ožžon gielddas/suohkanis maŋemus 12 mánu?
Russe buot mii heive.

☐ Persovnnalaš dikšu

☐ Háviid dikšun

☐ Dálkasat

☐ Biebmoráhkadeapmi

☐ Veahkki/doarjja borramii ja čuovvoleapmi borrama oktavuođas

☐ Viesu ja/dahje biktasiid bassan

☐ Veahkki astoáiggedoaimmaide ja servvoštallamiidda

☐ Eará, čilge:

☐

24) Leatgo makkárge gieldda/suohkana dikšo- ja fuolahusbálvalusat mat eai leat vel geavahuvvon?
Dan oktavuođas oaivvildit bálvalusaid maid birra diehtát ja mat sáhtašivčče leat ávkin persovdnii ja/dahje mat geahpidivččе du barggu.

☐ Juo ☐ Ii ☐ In dieđe

Jus leat, mii lea deháleamos ággan dasa ahte it leat geavahan daid bálvalusaid? Čilge dás.

25) Oaččutgo gokčojuvvot iežat helpendárbbu dál?

☐ Juo

☐ Muhtin muddui

☐ In

☐ In hálit helpema

26) Oaččutgo don dan veahki maid dárbbašat vai du árgabeaivi doaibmá?

☐ Juo

☐ Muhtin muddui

☐ In

☐ In hálit veahki

27) Leatgo ožžon diehtuid:

- **Dikšo- ja fuolahusbálvalusaid birra mat leat du gielddas/suohkanis?**

☐ In obage

☐ Veaháš

☐ Muhtin muddui

☐ Oalle ollu

☐ Hui ollu

☐ Ii leat áigeguovdil

- **Dikšo- ja fuolahusbálvalusaid sisdoalu birra maid son oažžu?**

☐ In obage

☐ Veaháš

☐ Muhtin muddui

☐ Oalle ollu

☐ Hui ollu

☐ Ii leat áigeguovdil

28) Beasatgo leat mielde mearrideame áššiid mat gusket su dikšo- ja fuolahusbálvalusaide?

☐ In obage

☐ Veaháš

☐ Muhtin muddui

☐ Oalle ollu

☐ Hui ollu

☐ Ii leat áigeguovdil

29) Leatgo oppalaččat duhtavaš dainna vehkiin ja doarjagiin maid doai oažžubeahtti dikšo- ja fuolahusbálvalusain?

☐ In obage

☐ Veaháš

☐ Muhtin muddui

☐ Oalle ollu

☐ Hui ollu

☐ Ii leat áigeguovdil

30) Go geahčat maŋos, oaivvildatgo ahte gielddas/suohkanis lei veahkki galgat ohccojuvvot árabut go maid dahkkui?

☐ Juo ☐ Ii ☐ In dieđe

31) Álggahuvvuigo gieldda/suohkana veahkkedoaibma doarvái jođánit go ohccojuvvui?

☐ Juo ☐ Ii ☐ In dieđe

Čuovvovaš gažaldagat leat eará bálvalusaid geavaheami birra

Sáhttet leat bálvalusat maid dii geavahehpet gokčan dihte persovnna dárbbuid heivehallat ruovttu, gokčan dihte persovnna dárbbuid veajuiduhttimii, veahkkái, gehččui ja árgabeaivválaš doaimmaide dahje gokčan dihte du iežat dárbbu helpemii.
Russe ovtta vástádusa jus eará ii namuhuvvo.

32) Leago persovdna daid maŋemus 12 mánu ožžon

a) Ergoterapiijabálvalusaid? ☐ Juo ☐ Ii ☐ In dieđe
b) Fysioterapiijabálvalusaid? ☐ Juo ☐ Ii ☐ In dieđe

33) Ostojuvvojitgo priváhta dikšo- ja fuolahusbálvalusat?

☐ Juo
☐ Eai
☐ Eai, dakkár bálvalusat eai gávdno mu gielddas/suohkanis

Jus juo, galle diimmu mánnosaččat?

Gaskamearalaččat ☐☐ diimmu mánnosaččat
(Čále ovtta logu juohke ruvttui, ovdamearkka dihte 0 ja 4 lea 4 diimmu ja 1 ja 0 lea 10 diimmu)

34) Geavahuvvojitgo eaktodáhtolaš organisašuvnnaid bálvalusat?
(Bálvalusat sáhttet leat kafeafálaldagat, gallestallanustibat ja mátkefálaldagat maid ovdamearkka dihte Rukses Ruossa, demeansasearvvit, penšunistasearvvit ja sullasaččat lágidit).

☐ Juo
☐ Ii
☐ Ii, mu gielddas/suohkanis eai gávdno dakkár fálaldagat

Jus juo, galle diimmu mánnosaččat?

Gaskamearalaččat ☐☐ diimmu mánnosaččat
(Čále ovtta logu juohke ruvttui, ovdamearkka dihte 0 ja 4 lea 4 diimmu ja 1 ja 0 lea 10 diimmu)

Čuovvovaččat mii bivdit du árvvoštallat iežat dárbbuid oapmahažžan

35) Mii áinnas háliidit diehtit makkár doarjjaga don dárbbašat vai nagodat áimmahuššat dan persovnna gean veahkehat ja doarjjut, ja makkár doarjjaga don ieš dárbbašat.
Juohke cealkámušas leat njeallje vástidanvejolašvuođa, russe dan ruvttu mii buoremusat ovddasta dárbbuid mat dus leat dál.

Dárbbašatgo eanet doarjjaga ...	In	Veaháš eanet	Oalle ollu eanet	Ollu eanet
... ipmirdit du oapmahačča dávdda?	☐	☐	☐	☐
... vai dus lea áigi alccet maid beaivvi mielde?	☐	☐	☐	☐
... hálddašit du oapmahačča dávdamearkkaid, ja maiddái dálkasiid addit?	☐	☐	☐	☐
... du iežat ekonomalaš, juridihkalaš dahje bargui gullevaš hástalusaid ektui?	☐	☐	☐	☐
... veahkehit du oapmahačča persovnnalaš ráinnasvuođain (ovdamearkka dihte gárvodemiin, basademiin ja hivssetfitnamiin)?	☐	☐	☐	☐
... dan ektui ahte hálddašit iežat dovdduid ja fuolastuvvamiid?	☐	☐	☐	☐
... vai dieđát geainna sáhtát váldit oktavuođa jus leat fuolastuvvan du oapmahačča dihte (maiddái ihkku)?	☐	☐	☐	☐
... vára váldit iežat dearvvašvuođas (fysalaš váttisvuođat)?	☐	☐	☐	☐
... vai oaččut dárbbašlaš rusttegiid vai sáhtát du oapmahačča veahkehit?	☐	☐	☐	☐
... iežat oskku/eallinoainnu dahje eará vuoiŋŋalaš/eksisteanssalaš jearaldagaid ektui?	☐	☐	☐	☐
... hupmat du oapmahaččain su dávdda birra?	☐	☐	☐	☐
... geavatlaš veahki dáfus ruovttus?	☐	☐	☐	☐
... dan ektui ahte diehtit maid sáhtát boahtteáiggis vuordit go leat don gii fuolahat du oapmahačča?	☐	☐	☐	☐
... ásahit helpendoaimmaid ijaide?	☐	☐	☐	☐

... eará (čále áinnas dákko)?

Mii háliidit jearrat maid don jurddašat dan birra ahte veahkehit ja doarjut persovnna boahtteáiggis.

36) Áiggutgo joatkit veahkehit/doarjut su čuovvovaš jagi?

☐ Juo, ja sáhtán árvvoštallat eanet vel veahkehit ja doarjut jus lea dárbu

☐ Juo, ja áiggun árvvoštallat lasihit iežan veahki ja doarjaga muhtin ráddjejuvvon áigodahkii.

☐ Juo, mun lean gearggus joatkit veahkehit ja doarjut persovnna jus dilálašvuohta bissu seammaláganin

☐ Juo, lean gearggus joatkit veahkehit ja doarjut su, muhto dušše jus oaččun eambbo doarjaga (almmolaš ja/dahje priváhta bálvalusain, bearrašis, ustibiin jna.)

☐ In, mun in leat gearggus joatkit veahkehit ja doarjut su vaikko makkár liigedoarjaga oččošin

37) Divttášitgo su fárret buhcciidruktui?

☐ In, vaikko movt livččii

☐ Juo, muhto dušše fal jus su dilálašvuohta vearránivččii

☐ Juo, vaikko su dilálašvuohta bisošii nu movt dál lea

Čuovvovaččat bohtet gažaldagat du eallindilálašvuođa birra go leat oapmahaš

Russe dušše ovtta vástádusa jus eará ii namuhuvvo.

38) Movt árvvoštalat iežat dearvvašvuođa oppalaččat?

☐ Hui buorre

☐ Buorre

☐ Ii buorre iige heittot

☐ Heittot

☐ Hui heittot

39) Makkár orru du dearvvašvuohta earáid ektui geat leat du agis?

☐ Ollu buoret

☐ Veaháš buoret

☐ Sullii seamma

☐ Veaháš heajut

☐ Ollu heajut

40) Go vástidat dáidda gažaldagaide mat leat vuollelis, de oažžut gova das movt leat dovdan iežat daid maŋemus áiggiid. Russe vástádusaid dan mielde mii heive buoremusat dasa <u>movt don leat dovdan iežat dan maŋemus guokte vahkku</u>.

Guokte maŋemus vahkku lean .....

	Čađat	Eanas áiggi	Eambbo go beali dan áiggis	Unnit go beali dan áiggis	Muhtomin	In obage
… dovdan iežan ilolažžan ja buori movttas	☐	☐	☐	☐	☐	☐
… dovdan iežan ráfálažžan ja lotkadin	☐	☐	☐	☐	☐	☐
… dovdan iežan doaimmalažžan ja gievran	☐	☐	☐	☐	☐	☐
… dovdan iežan vuoŋisin ja doarvái vuoiŋŋastan go lihkan	☐	☐	☐	☐	☐	☐
… dovdan ahte mu beaivválaš eallin lea devdojuvvon dakkár áššiiguin main mun beroštan	☐	☐	☐	☐	☐	☐

41) Mii háliidivččiimet diehtit movt don vásihat iežat dilálašvuođa go leat veahkki ja doarjja.
(Russe dan molssaeavttu mii buoremusat čilge du)

	Álo	Dávjá	Muhtomin	Ii/in goassege	Ii leat relevánta
Dovddatgo ahte nákcet fuolahusrolla bures?	☐	☐	☐	☐	
Leago du mielas fuolahusrolla menddo gáibideaddji?	☐	☐	☐	☐	
Čuohcágo fuolahusrolla negatiivvalaččat du oktavuođaide iežat ustibiiguin?	☐	☐	☐	☐	☐
Čuohcágo fuolahusrolla negatiivvalaččat du fysalaš dearvvašvuhtii?	☐	☐	☐	☐	
Čuohcágo fuolahusrolla negatiivvalaččat du oktavuhtii iežat bearrašiin?	☐	☐	☐	☐	☐

	Álo	Dávjá	Muhtomin	Ii/in goassege	Ii leat relevánta
Dagahago fuolahusrolla ekonomalaš váttisvuođaid dutnje?	☐	☐	☐	☐	
Dovddatgo darvánan fuolahusrollii?	☐	☐	☐	☐	
Dovddatgo ahte ustibat ja/dahje ránnját dorjot du bures?	☐	☐	☐	☐	☐
Dovddatgo ahte fuolahusrolla lea addevaš?	☐	☐	☐	☐	
Dovddatgo ahte du bearaš doarju du bures?	☐	☐	☐	☐	☐
Leago dus buorre oktavuohta persovnnain gean don fuolahat?	☐	☐	☐	☐	
Dovddatgo ahte dearvvašvuođabálvalus ja sosiálabálvalus dorjot du bures? (ovdamearkka dihte almmolaš, priváhta, eaktodáhtolaš)	☐	☐	☐	☐	☐
Dovddatgo ahte muhtin atná du árvvus fuolaheaddjin?	☐	☐	☐	☐	
Čuohcágo fuolahusrolla negatiivvalaččat du dovdduide?	☐	☐	☐	☐	
Dovddatgo ahte oppalaččat oaččut buori doarjaga fuolahusrolla dáfus?	☐	☐	☐	☐	

Čuovvovaččat leat mis muhtin gažaldagat oapmahašskuvlla birra

Russe ovtta vástádusa jus eará ii namuhuvvo.

42) Leatgo searvan oapmahašskuvlii? ☐ Lean ☐ In

Jus leat, goas?

☐ Oanehet go 12 mánu áigi

☐ Guhkit go 12 mánu áigi

Jus it leat, manne it leat searvan?
(Sáhtát russet máŋga vástádusa)

☐ In leat gullan fálaldaga birra

☐ Lean válljen ahte in searvva go oaivvildan ahte in dárbbaš

☐ Lea menddo guhkki mu ruovttubáikkis kursabáikái

☐ Mus ii leat oktage gii sáhttá bearráigeahččat persovnna

☐ Kursa dollojuvvo dakkár áiggis mii munnje ii heive

☐ Kursa ii gávdno mu gielddas/suohkanis

☐ Eará, čále áinnas dása

Gažaldagaid 43 rájes 48 rádjai vástidat dušše jus leat searvan oapmahašskuvlii.
Jus it leat, joatkke 49. gažaldagain

43) Ledjego visot fáttát mat oapmahašskuvllas gieđahallojuvvojedje relevánttat dutnje?

☐ Juo ☐ Eai

Jus eai, sáhtátgo namuhit fáttaid mat eai lean relevánttat? *(Leage buorre ja čále dása)*

44) Váillahitgo muhtin fáttáid?

☐ Juo ☐ In

Jus juo, sáhtátgo namuhit makkár fáttáid váillahit?
(Leage buorre ja čále dása)

45) Ledjego oapmahašskuvllas joavkoságastallamat dalle go servet?

☐ Juo ☐ Eai

Jus juo, go oppalaččat árvvoštalat buot joavkoságastallamiid mat ledje oapmahašskuvllas, oaivvildatgo ahte:
(Russe oktii juohke linnjái)

	Áibbas ovtta-oaivilis	Muhtin muddui ovtta-oaivilis	In leat ovtta-oaivilis
Joavkoságastallamat ledje ávkkálaččat	☐	☐	☐
Ohppen go gullen earáid vásáhusaid	☐	☐	☐
Ožžon sáni saji joavkkus	☐	☐	☐
Ledje muttát ollu oasseváldit joavkkuin	☐	☐	☐
Lei buorre dássedeaddu joavkoságastallamiid ja logaldallamiid gaskkas	☐	☐	☐

46) Leago du oassálastin oapmahašskuvlii dahkan ahte nagodat iežat fuolahanbargguid:

☐ Heajubut

☐ Ii leat rievdan

☐ Muhtomin buorebut

☐ Buorebut

47) Leatgo dus leamaš váttisvuođat beassat oapmahašskuvlii go persovdna geas lea muittohisvuohta/demeansadávda ii sáhttán leat okto?

☐ Juo ☐ Ii

48) Leatgo ožžon ođđa oktavuođaid oapmahašskuvlla bokte?

☐ Juo ☐ In

Jus leat, mainna lágiin lea oapmahašskuvla addán ođđa oktavuođaid?
(Dás sáhtát russet máŋga vástádusa)

☐ Eambbo oktavuohta eará oapmahaččaiguin

☐ Eambbo oktavuohta veahkkebálvalusain

☐ Eambbo oktavuohta beroštusorganisašuvnnaiguin nugo demeansaservviin ja sullasaš servviiguin

☐ Eará, čále áinnas dása

☐

Oppalaš gažaldagat du birra

Dát gažaldagat leat midjiide ávkkálaččat vai buorebut beassat diehtit sin birra geat leat jearahallanskovi vástidan.

Russe ovtta vástádusa jus eará ii namuhuvvo

49) Leatgo: ☐ Dievdu ☐ Nisu

50) Mii du ahki lea? ☐☐

(Čále ovtta logu juohke ruvttui. Ovdamearkka dihte 5 ja 5 jus leat 55 jagi).

51) Mii lea du siviiladilli?

☐ Náitalan/ovttasássi/registrerejuvvon guoibmi

☐ Ii náitalan/okto

☐ Leaska

☐ Sierranan/earránan

52) Mii lea du ruovttugiella?
(Russe oktii dahje moddii)

☐ Dárogiella

☐ Sámegiella

☐ Kvenagiella

☐ Eará, čilge ☐

53) Maid logat iežat leat?
(Russe oktii dahje moddii)

☐ Norgalaš

☐ Sápmelaš

☐ Kvena

☐ Eará, čilge ☐

54) Leatgo dus mánát geat orrot ruovttus?

☐ Juo ☐ Eai leat

Jus leat, gallis sis leat vuollel 18 jagi? ☐
Čále logu ruvttui.

55) Mii lea du alimus čađahuvvon oahppu?
(Russe oktii)

☐ Vuođđoskuvla/framhaldskuvla/álbmotallaskuvla gitta 10 jagi

☐ Fidnofágalaš oahppu/reálaskuvla/joatkkaskuvla/gymnása unnimusat 3 jagi

☐ Allaskuvla/universitehta unnit go 4 jagi

☐ Allaskuvla/universitehta 4 jagi dahje guhkit

56) Mii lea du váldodoaibma? *(Russe oktii)*

☐ Ollesággi barggus

☐ Oasseáiggi barggus

☐ Lean ruovttus

☐ Penšunista

☐ Bargonávccaheapme/oaččun bargočielggadanruđaid

☐ Belohahkii bargonávccaheapme

☐ Oaččun sosiáladoarjaga

☐ Bargguheapme

☐ Oahppi/studeanta

☐ Eará, čilge

☐

Jus barggat oasseáiggis, leatgo geahpidan du virggi persovnna fuolahusovddasvástádusa dihte?

☐ Juo ☐ Ii

57) Leago dus dearvvašvuođafágalaš oahppu?
(Dan gažaldahkii vástidit maiddái sii geat eai leat barggus)

☐ Juo ☐ Ii

58 Leago dus vejolašvuohta váikkuhit iežat gieldda/suohkana boarrásiidfuolahusa nugo eaktodáhtolaš servviid, politihkalaš bellodagaid ja sullasaččaid bokte?
(Eaktodáhtolaš searvvit mat barget boarrásiidfuolahusa ovddas leat ovdamearkka dihte penšunistasearvvit ja demeansasearvvit).

☐ Juo ☐ Juo, muhto in beroš ☐ Ii ☐ In dieđe

59) Mii lei du báikedoalu oppalaš bruttosisaboahtu maŋemus jagi?
(Váldde mielde buot sisaboađuid mat bohtet barggus, oajus, sosiálaveahkis ja sullasaččas).

☐ Vuollel 150 000 kr

☐ 150 000-250 000 kr

☐ 251 000-350 000 kr

☐ 351 000-450 000 kr

☐ 451 000-550 000 kr

☐ 551 000-750 000 kr

☐ 751 000-1 000 000 kr

☐ Badjel 1 000 000 kr

60) Movt du mielas lea du báikedoalu ekonomalaš dilálašvuohta?

☐ Buorre ☐ Muttát ☐ Heittot

61) Leatgo eambbosat gean veahkehat ja doarjjut dán láhkai unnimusat oktii vahkkus?

☐ Juo ☐ In

Jus juo, čále ruvttui galle persovnna: ☐

Loahpalaš gažaldagat

62) Leago oktage veahkehan du deavdit dán jearahallanskovi?

☐ Juo ☐ Ii

63) Vai beassat iskat jearahallanskovi dárkilit, de háliidit ahte muhtimat vástidit seamma skovi nuppes 3 vahkku geahčen. Sáhtášitgo don dan dahkat?
(Russe ruvtto mii dutnje heive).

☐ Juo, sáhtán áinnas deavdit skovi nuppes fas

☐ In, mun in hálit deavdit skovi šat nuppes

Loahpas:

Mii soaitit muhtimiid bovdet searvat persovnnalaš jearahallamii mii lea oassin dán dutkama čuovvolaniskkadeamis.

Searvvašitgo dákkár iskkadeapmái?

(Vaikko vástidatge "juo", dat ii mielddisbuvtte geatnegasvuođa boahtteáiggis searvat dakkár iskkadeapmái).

☐ Juo, ja mun lean čállán nama, poastačujuhusa ja telefovdnanummara dása vuolábeallai

☐ In (ale čále nama, poastačujuhusa ja telefovdnanummara dása vuolábeallai)

Leage nu buorre ahte dárkkistat ahte leat vástidan buot gažaldagaide jearahallanskovis.

Giitu go veahkehit min ja devdet jearahallanskovi.

Máhcat midjiide skovi 14 beaivvi siste konvoluhtain mii lea mielddusin. It dárbbaš bidjat poastamearkka konvoluhttii – porto lea máksojuvvon.

Oapmahašiskkadeapmi

Løpenr:

Namma:

Poastačujuhus:

Telefovdnanummar: