

# 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

2020, Vol. 19(5) 1712–1731

© The Author(s) 2018



Article reuse guidelines:

[sagepub.com/journals-permissions](https://sagepub.com/journals-permissions)

DOI: 10.1177/1471301218804981

[journals.sagepub.com/home/dem](https://journals.sagepub.com/home/dem)**Jill-Marit Moholt** 

Centre for Care Research North, Department of Health and Care Sciences, Faculty of Health Sciences, UiT The Arctic University of Norway, Norway

**Oddgeir Friborg**

Department of Psychology, Faculty of Health Sciences, UiT The Arctic University of Norway, Norway

**Bodil H Blix** 

Centre for Care Research North, Department of Health and Care Sciences, Faculty of Health Sciences, UiT The Arctic University of Norway, Norway

**Nils Henriksen**

Department of Health and Care Sciences, Faculty of Health Sciences, UiT The Arctic University of Norway, Norway

## 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

---

## Corresponding author:

Jill-Marit Moholt, Centre for Care Research North, Department of Health and Care Sciences, Faculty of Health Sciences, UiT The Arctic University of Norway, PB 6050 Langnes, N-9037 Tromsø, Norway.

Email: [jill-marit.moholt@uit.no](mailto:jill-marit.moholt@uit.no)

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 distinguish 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  $\geq 65$  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<sup>2</sup>) (Statistics Norway, 2018) compared to the density of the population in Norway overall (16.5 inhabitants/km<sup>2</sup>) and the density of the population in Europe (116.3 inhabitants/km<sup>2</sup>; 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  $\geq 65$  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

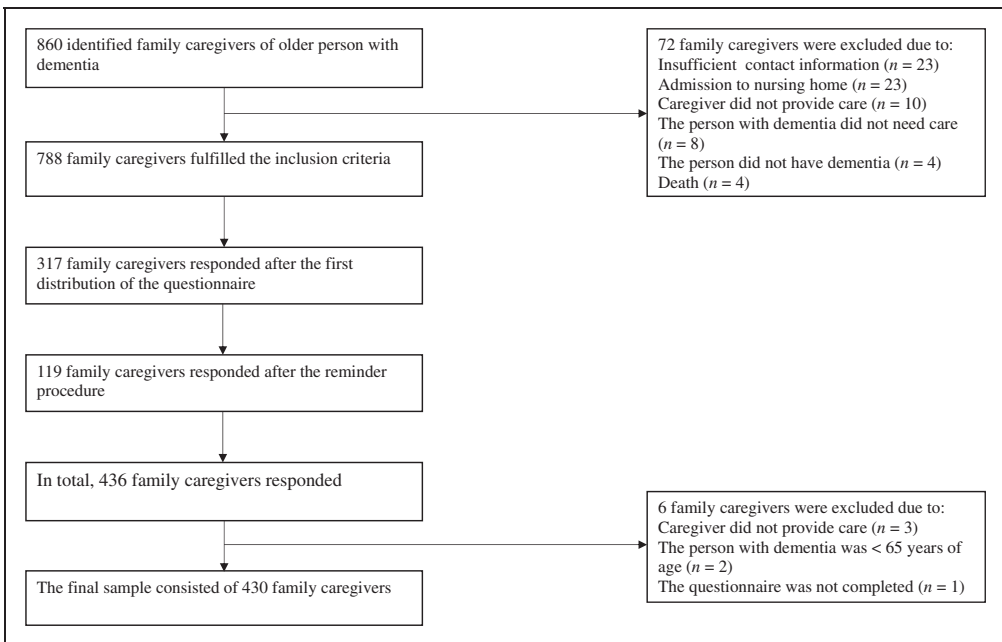


Figure 1. Flow chart over the inclusion procedure.

**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 <sup>a</sup> (M, SD)	Comparison <sup>c</sup>	Respite services <sup>b</sup> (M rank)	Comparison <sup>c</sup>
<b>Persons with dementia</b>					
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	
<b>Family caregivers</b>					
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 <sup>a</sup> (M, SD)	Comparison <sup>c</sup>	Respite services <sup>b</sup> (M rank)	Comparison <sup>c</sup>
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.

<sup>a</sup>Home-based services, <sup>b</sup>Respite care services, <sup>c</sup>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 ( $\chi^2$ ) 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, & Njølstad, 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 ( $\chi^2$ ) 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)	$\beta$	$p$ value
Persons with dementia <sup>a</sup>			
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 <sup>b</sup>			
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;  $\beta$ : standardized beta coefficient; 95% CI: confidence interval of the unstandardized beta coefficient.

<sup>a</sup>Intercept = -0.82.

<sup>b</sup>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)	<i>p</i> value
Persons with dementia <sup>a</sup>		
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 <sup>b</sup>		
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).

<sup>a</sup>Goodness of fit (Pearson  $\chi^2/df = 0.92$ , intercept = 0.42).

<sup>b</sup>Goodness of fit (Pearson  $\chi^2/df = 0.89$ , 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, health-care 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.

## Acknowledgement

We would like to thank the management and the healthcare providers for their assistance with data collection.

## 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.

## Funding

The author(s) disclosed receipt of the following financial support for the research, authorship, and/or publication of this article: the Research Council of Norway (Grant No. 238146). The funding body played no role in the study design, data collection, analysis, data interpretation or manuscript preparation.

## ORCID iDs

Jill-Marit Moholt  <http://orcid.org/0000-0002-8660-1522>

Bodil H Blix  <http://orcid.org/0000-0002-1049-4636>

## References

- Alzheimer's Association. (2017). 2017 Alzheimer's disease facts and figures. *Alzheimer's & Dementia*, 13(4), 325–373. DOI: 10.1016/j.jalz.2017.02.001.
- Balducci, C., Mnich, E., McKee, K. J., Lamura, G., Beckmann, A., Krevers, B., . . . Oberg, B. (2008). Negative impact and positive value in caregiving: Validation of the COPE index in a six-country sample of carers. *The Gerontologist*, 48(3), 276–286.



- Black, B. S., Johnston, D., Rabins, P. V., Morrison, A., Lyketsos, C., & Samus, Q. M. (2013). Unmet needs of community-residing persons with dementia and their informal caregivers: Findings from the maximizing independence at home study. *Journal of the American Geriatrics Society, 61*(12), 2087–2095.
- Blix, B. H., & Hamran, T. (2017). They take care of their own: Healthcare professionals' constructions of Sami persons with dementia and their families' reluctance to seek and accept help through attributions to multiple contexts. *International Journal of Circumpolar Health, 76*(1), 1328962. DOI: 10.1080/22423982.2017.1328962.
- Brandao, D., Ribeiro, O., & Martin, I. (2016). Underuse and unawareness of residential respite care services in dementia caregiving: Constraining the need for relief. *Health & Social Work, 41*(4), 254–262. DOI: 10.1093/hsw/hlw041.
- Brodady, H., & Donkin, M. (2009). Family caregivers of people with dementia. *Dialogues in Clinical Neuroscience, 11*(2), 217–228.
- Brodady, H., Thomson, C., Thompson, C., & Fine, M. (2005). Why caregivers of people with dementia and memory loss don't use services. *International Journal of Geriatric Psychiatry, 20*(6), 537–546. DOI: 10.1002/gps.1322.
- Brustad, M., Hansen, K. L., Broderstad, A. R., Hansen, S., & Melhus, M. (2014). A population-based study on health and living conditions in areas with mixed Sami and Norwegian settlements – The SAMINOR 2 questionnaire study. *International Journal of Circumpolar Health, 73*(1), 1–8. <https://doi.org/10.3402/ijch.v73.23147>.
- Dohl, O., Garasen, H., Kalseth, J., & Magnussen, J. (2016). Factors associated with the amount of public home care received by elderly and intellectually disabled individuals in a large Norwegian municipality. *Health & Social Care in the Community, 24*(3), 297–308. DOI: 10.1111/hsc.12209.
- Ehrlich, K., Bostrom, A. M., Mazaheri, M., Heikkila, K., & Emami, A. (2015). Family caregivers' assessments of caring for a relative with dementia: A comparison of urban and rural areas. *International Journal of Older People Nursing, 10*(1), 27–37. DOI: 10.1111/opn.12044.
- Forbes, D. A., Morgan, D., & Janzen, B. L. (2006). Rural and urban Canadians with dementia: Use of health care services. *Canadian Journal on Aging, 25*(3), 321–330. DOI: 10.1353/cja.2007.0003.
- Friedemann, M. L., & Buckwalter, K. C. (2014). Family caregiver role and burden related to gender and family relationships. *Journal of Family Nursing, 20*(3), 313–336. DOI: 10.1177/1074840714532715.
- Friedemann, M. L., Newman, F. L., Buckwalter, K. C., & Montgomery, R. J. V. (2014). Resource need and use of multiethnic caregivers of elders in their homes. *Journal of Advanced Nursing, 70*(3), 662–673.
- Fylkesnes, K., & Førde, O. H. (1991). The Tromsø study: Predictors of self-evaluated health – Has society adopted the expanded health concept?. *Social Science & Medicine, 32*(2), 141–146.
- Glass, D. C., Kelsall, H. L., Slegers, C., Forbes, A. B., Loff, B., Zion, D., & Fritschi, L. (2015). A telephone survey of factors affecting willingness to participate in health research surveys. *BMC Public Health, 15*, 1017. DOI: 10.1186/s12889-015-2350-9.
- Goins, R. T., Spencer, S. M., & Byrd, J. C. (2009). Research on rural caregiving. *Journal of Applied Gerontology, 28*(2), 139–170. DOI: 10.1177/0733464808326294.
- Graessel, E., Luttenberger, K., Bleich, S., Adabbo, R., & Donath, C. (2011). Home nursing and home help for dementia patients: Predictors for utilization and expected quality from a family caregiver's point of view. *Archives of Gerontology and Geriatrics, 52*(2), 233–238. DOI: 10.1016/j.archger.2010.04.001.
- Greenwood, N., Habibi, R., Smith, R., & Manthorpe, J. (2015). Barriers to access and minority ethnic carers' satisfaction with social care services in the community: A systematic review of qualitative and quantitative literature. *Health & Social Care in the Community, 23*(1), 64–78. DOI: 10.1111/hsc.12116.
- Herron, R. V., & Rosenberg, M. W. (2017). Dementia in rural settings: Examining the experiences of former partners in care. *Ageing & Society, 1*, 18. DOI: 10.1017/s0144686x17000952.

- Hong, S.-I., Hasche, L., & Lee, M. J. (2011). Service use barriers differentiating care-givers' service use patterns. *Ageing & Society, 31*(8), 1307–1329.
- Hughes, T. B., Black, B. S., Albert, M., Gitlin, L. N., Johnson, D. M., Lyketsos, C. G., & Samus, Q. M. (2014). Correlates of objective and subjective measures of caregiver burden among dementia caregivers: Influence of unmet patient and caregiver dementia-related care needs. *International Psychogeriatrics, 26*(11), 1875–1883. DOI: 10.1017/S1041610214001240.
- Innes, A., Blackstock, K., Mason, A., Smith, A., & Cox, S. (2005). Dementia care provision in rural Scotland: Service users' and carers' experiences. *Health & Social Care in the Community, 13*(4), 354–365. DOI: 10.1111/j.1365-2524.2005.00569.x.
- Jacobsen, B. K., Eggen, A. E., Mathiesen, E. B., Wilsgaard, T., & Njolstad, I. (2012). Cohort profile: The Tromsø Study. *International Journal of Epidemiology, 41*(4), 961–967. DOI: 10.1093/ije/dyr049.
- Jöreskog, K. G., & Sörbom, D. (2015). *LISREL 9.20 for Windows [Computer software]*. Skokie, IL: Scientific Software International, Inc.
- Kadushin, G. (2004). Home health care utilization: A review of the research for social work. *Health and Social Work, 29*(3), 219–244. DOI: 10.1093/hsw/29.3.219.
- Karlsson, S., Bleijlevens, M., Roe, B., Saks, K., Martin, M. S., Stephan, A., . . . Hallberg, I. R. (2015). Dementia care in European countries, from the perspective of people with dementia and their caregivers. *Journal of Advanced Nursing, 71*(6), 1405–1416.
- Kasper, J. D., Freedman, V. A., Spillman, B. C., & Wolff, J. L. (2015). The disproportionate impact of dementia on family and unpaid caregiving to older adults. *Health Affairs (Project Hope), 34*(10), 1642–1649. DOI: 10.1377/hlthaff.2015.0536.
- Kelley, K., Clark, B., Brown, V., & Sitzia, J. (2003). Good practice in the conduct and reporting of survey research. *International Journal for Quality in Health Care, 15*(3), 261–266.
- Kerpershoek, L., de Vugt, M., Wolfs, C., Woods, B., Jelley, H., Orrell, M., . . . Actifcare Consortium. (2017). Needs and quality of life of people with middle-stage dementia and their family carers from the European Actifcare study. When informal care alone may not suffice. *Ageing & Mental Health, 1*–6. DOI: 10.1080/13607863.2017.1390732.
- Kleinbaum, D. G., Kupper, L. L., Nizam, A., & Muller, K. E. (2008). *Applied regression analysis and other multivariable methods* (4th ed.). Belmont, CA: Brooks/Cole.
- Lamura, G., Mnich, E., Nolan, M., Wojszel, B., Krevers, B., Mestheneos, L., . . . EUROFAMCARE Group. (2008). Family carers' experiences using support services in Europe: Empirical evidence from the EUROFAMCARE study. *The Gerontologist, 48*(6), 752–771.
- Laparidou, D., Middlemass, J., Karran, T., & Siriwardena, A. N. (2018). Caregivers' interactions with health care services – Mediator of stress or added strain? Experiences and perceptions of informal caregivers of people with dementia – A qualitative study. *Dementia, 1*-17. DOI: 10.1177/1471301217751226.
- Lethin, C., Hallberg, I. R., Karlsson, S., & Janlöv, A. C. (2016). Family caregivers experiences of formal care when caring for persons with dementia through the process of the disease. *Scandinavian Journal of Caring Sciences, 30*, 526–534.
- Lindhardt, T., Nyberg, P., & Hallberg, I. R. (2008). Relatives' view on collaboration with nurses in acute wards: Development and testing of a new measure. *International Journal of Nursing Studies, 45*(9), 1329–1343. DOI: 10.1016/j.ijnurstu.2007.10.006.
- Lüdecke, D., Mnich, E., & Kofahl, C. (2012). The impact of sociodemographic factors on the utilisation of support services for family caregivers of elderly dependents – Results from the German sample of the EUROFAMCARE study. *GMS Psycho-Social-Medicine, 9*, 1–11.
- McKee, K. J., Philp, I., Lamura, G., Prouskas, C., Oberg, B., Krevers, B., . . . Cope Partnership. (2003). The COPE index – A first stage assessment of negative impact, positive value and quality of support of caregiving in informal carers of older people. *Ageing & Mental Health, 7*(1), 39–52. DOI: 10.1080/1360786021000006956.

- Marrone, S. (2007). Understanding barriers to health care: A review of disparities in health care services among indigenous populations. *International Journal of Circumpolar Health*, 66(3), 188–198.
- Martindale-Adams, J., Nichols, L. O., Zuber, J., Burns, R., & Graney, M. J. (2016). Dementia caregivers' use of services for themselves. *The Gerontologist*, 56(6), 1053–1061. DOI: 10.1093/geront/gnv121.
- Montgomery, R., & Kosloski, K. (2009). Caregiving as a process of changing identity: Implications for caregiver support. *Generations*, 33(1), 47–52.
- Morgan, D. G., Semchuk, K. M., Stewart, N. J., & D'Arcy, C. (2002). Rural families caring for a relative with dementia: Barriers to use of formal services. *Social Science & Medicine*, 55(7), 1129–1142. DOI: 10.1016/s0277-9536(01)00255-6.
- Mukadam, N., Cooper, C., & Livingston, G. (2011). A systematic review of ethnicity and pathways to care in dementia. *International Journal of Geriatric Psychiatry*, 26(1), 12–20. DOI: 10.1002/gps.2484.
- Nelson, T., Livingston, G., Knapp, M., Manela, M., Kitchen, G., & Katona, C. (2002). Slicing the health service cake: The Islington study. *Age & Ageing*, 31(6), 445–450. DOI: 10.1093/ageing/31.6.445.
- Norwegian Directorate of Health. (2016). *Veileder for saksbehandling – Tjenester etter helse-og omsorgstjenesteloven §§ 3-2 første ledd nr.6, 3-6 og 3-8 [Guidelines for case management]*. Oslo: The Norwegian Directorate of Health.
- Norwegian Ministry of Health and Care Services. (1999). Lov om pasient-og brukerrettigheter (pasient- og brukerrettighetsloven). [Act relating to patients rights (Patients Rights Act)]. Retrieved from <https://lovdata.no/dokument/NL/lov/1999-07-02-63>
- Norwegian Ministry of Health and Care Services. (2015). *Demensplan 2020. Et mer demensvennlig samfunn [Dementia plan 2020. A more dementia-friendly society]*. Oslo: Norwegian Ministry of Health and Care Services.
- Norwegian Ministry of Local Government and Modernization. (2014). *Regionale utviklingstrekk 2014 [Regional trends of development 2014]*. Oslo: Norwegian Ministry of Local Government and Modernization.
- Norwegian National Advisory Unit on Ageing and Health (Ageing and Health). (2011). *Evalueringsskjema for påvørende etter siste samling [Appraisal form for school program]*. Tønsberg: Norwegian National Advisory Unit on Ageing and Health (Ageing and Health).
- Odzakovic, E., Hydén, L.-C., Festin, K., & Kullberg, A. (2018). People diagnosed with dementia in Sweden: What type of home care services and housing are they granted? A cross-sectional study. *Scandinavian Journal of Public Health*. 1-11. . DOI 10.1177 1403494818755600.
- Otnes, B. (2015). Utviklingen i pleie- og omsorgstjenesten 1994–2013 [The development of nursing and care services 1994–2013]. *Tidsskrift for Omsorgsforskning*, 1(1), 48–61.
- Pinquart, M., & Sorensen, S. (2006). Gender differences in caregiver stressors, social resources, and health: An updated meta-analysis. *The Journals of Gerontology: Series B*, 61(1), P33–P45. DOI: 10.1093/geronb/61.1.P33.
- Pinquart, M., & Sörensen, S. (2011). Spouses, adult children, and children-in-law as caregivers of older adults: A meta-analytic comparison. *Psychology and Aging*, 26(1), 1.
- Raivio, M., Eloniemi-Sulkava, U., Laakkonen, M.-L., Saarenheimo, M., Pietilä, M., Tilvis, R., & Pitkälä, K. (2007). How do officially organized services meet the needs of elderly caregivers and their spouses with Alzheimer's disease? *American Journal of Alzheimer's Disease & Other Dementias*, 22(5), 360–368.
- Robinson, K., Buckwalter, K., Reed, D., & Forbes, D. (2005). Predictors of use of services among dementia caregivers Western. *Journal of Nursing Research*, 27(2), 126–140.
- Sævareid, H. I., Thygesen, E., Lindstrom, T. C., & Nygaard, H. A. (2012). Association between self-reported care needs and the allocation of care in Norwegian home nursing care recipients. *International Journal of Older People Nursing*, 7(1), 20–28.
- Statistics Norway. (2016). *Økonomi og levekår for ulike lavinnteksgrupper 2016 [Economy and living conditions for low-income groups 2016]*. Oslo-Kongsvinger: Statistisk sentralbyrå.

- Statistics Norway. (2018). *Samisk statistikk 2018 Sámi statistihkka 2018 [Sami statistics 2018]*. Oslo-Kongsvinger: Statistisk sentralbyrå.
- Topp, C. W., Ostergaard, S. D., Sondergaard, S., & Bech, P. (2015). The WHO-5 Well-Being Index: A systematic review of the literature. *Psychotherapy and Psychosomatics*, 84(3), 167–176. DOI: 10.1159/000376585.
- Toseland, R. W., McCallion, P., Gerber, T., & Banks, S. (2002). Predictors of health and human services use by persons with dementia and their family caregivers. *Social Science & Medicine*, 55(7), 1255–1266. DOI: 10.1016/s0277-9536(01)00240-4.
- Vabo, M. (2012). Norwegian home care in transition – Heading for accountability, off-loading responsibilities. *Health & Social Care in the Community*, 20(3), 283–291. DOI: 10.1111/j.1365-2524.2012.01058.x.
- van der Roest, H. G., Meiland, F. J., Comijs, H. C., Derksen, E., Jansen, A. P., van Hout, H. P., . . . Droes, R. M. (2009). What do community-dwelling people with dementia need? A survey of those who are known to care and welfare services. *International Psychogeriatrics*, 21(5), 949–965. DOI: 10.1017/S1041610209990147.
- Vossius, C., Selbæk, G., Ydstebø, A. E., Benth, J. S., Godager, G., Lurås, H., & Bergh, S. (2015). *Ressursbruk og sykdomsforløp ved demens (REDIC) [Resource Use and Disease Course in Dementia (REDIC)]*. Ottestad: Alderspsykiatrisk forskningssenter Sykehuset Innlandet HF.
- World Health Organization. (1998). *WHO info package: Mastering depression in primary care, version 2.2*. Copenhagen: WHO, Regional Office for Europe.
- World Health Organization. (2012). *Dementia: A public health priority*. Geneva: World Health Organization.
- World Medical Association. (2018). WMA Declaration of Helsinki: Ethical principles for medical research involving human subjects. Retrieved from <https://www.wma.net/policies-post/wma-declaration-of-helsinki-ethical-principles-for-medical-research-involving-human-subjects/>

**Jill-Marit Moholt** is PhD student at Centre for care research north, Department of Health and Care Sciences, Faculty of Health Sciences, UiT The Arctic University of Norway. Her research interest includes gerontology, dementia care, family caregiving and health care inequities.

**Oddgeir Friborg** is professor at the Department of Psychology, Faculty of Health Sciences, UiT The Arctic University of Norway. His research interests include health psychology, resilience, clinical psychology, sleep and diurnal rhythm, psychometrics and multivariate statistical modelling.

**Bodil H Blix** is associate professor at Department of Health and Care Sciences, Faculty of Health Sciences, UiT The Arctic University of Norway. Her research interests concern gerontology, indigenous older adults, health care inequities, dementia care, narrative care, and narrative inquiries.

**Nils Henriksen** is professor of Ageing and Health at Department of Health and Care Sciences, Faculty of Health Sciences, UiT The Arctic University of Norway. His research interests include health promotion, clinical learning environments for students, respite care, nursing home placement, social inequality in health, and experiences of family caregivers of persons with dementia.