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# Perceptions of Family Caregivers of Home-Dwelling Persons with Dementia regarding Access to Information and Involvement in Decisions

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## ABSTRACT

This cross-sectional study explored factors affecting information about available health services, content of services provided, and involvement in decisions regarding services as perceived by the family caregivers of home-dwelling persons with dementia in Northern Norway. Altogether, 788 family caregivers were invited to participate in a survey, with a response rate of 54.6% (n = 430). The respondents reported modest levels of perceived information and involvement. Few of the expected predictors were associated with the outcomes. Ordinal logistic regression analyses revealed that primary school as the highest level of education and perception of caregiving as moderately or very demanding predicted lower scores on family caregivers' perceived level of information about available services, information on service content, and involvement in decisions. In addition, medium household income predicted lower scores on information about service content. The results may point to mechanisms that create inequalities in the processing of information and involvement in care decisions regarding care arrangements among different caregiver groups. Health authorities should investigate potential social inequalities in complementary health care for home-dwelling persons with dementia.

## ARTICLE HISTORY

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## KEYWORDS

Dementia; family caregivers; home-based services; information; involvement; survey

## Introduction

Dementia is an umbrella term for diseases that are mostly progressive, that affect memory and other cognitive abilities and behaviors, and that interfere with a person's ability to maintain activities of daily living (World Health Organization, 2017). Reduced cognitive and functional abilities due to the progressive nature of dementia may result in an increased need for support from a caregiver (Taghizadeh & Österholm, 2014; Vilorio, Chung, Vigara, & Barahona-Alvarez, 2013). Family caregivers have multiple roles in dementia care. These caregivers take on substantial care responsibilities (Vossius et al., 2015) and are

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often involved in advocating and arranging for healthcare services (Bieber et al., 2018). In addition, family caregivers may have their own need for help and support. Throughout the course of dementia, family caregivers' situation may change considerably due to social isolation and loss of social network and the increased stress, strain, depression, and other health problems associated with caregiving (Brodaty & Donkin, 2009; Lethin, Hallberg, Karlsson, & Janlov, 2016). Support from healthcare services may reduce family caregivers' perception of strain and burden, which can further delay the time for the nursing home placement of persons with dementia (Feinberg & Levine, 2015; Gaugler, Kane, Kane, & Newcomer, 2005).

Norway is part of the Nordic welfare system, which is known for providing some of the world's most comprehensive and universal long-term services. Current Norwegian policy aims to enable persons with dementia to live at home for as long as possible and to postpone residential care (Norwegian Ministry of Health and Care Services, 2012, 2015a, 2015b); a recent study revealed that Norwegian family caregivers contribute substantially to daily care and provide the larger share of care for home-dwelling persons with dementia (Vossius et al., 2015). Studies also indicate that family caregivers' own needs for help and support are substantial (Black et al., 2013; Larsen, Blix, & Hamran, 2018).

Formal care organized according to a complementary care model in which healthcare services complement family care (Ward-Griffin et al., 2012) requires collaboration between professional and family caregivers and the communication of high-quality, two-way information regarding needs and available services. Access to information and involvement in decisions regarding living and care arrangements by both the person with dementia and family caregivers are vital to preserve the autonomy and quality of life of affected persons and family caregivers (Larsen, Normann, & Hamran, 2015). A review of research on the needs for information and knowledge among family caregivers of persons with dementia identified information and knowledge related to the disease and strategies regarding how to access healthcare services as important for the care of affected persons (McCabe, You, & Tatangelo, 2016).

The goal of the cross-cutting principles of the 2017–2025 World Health Organization (WHO) *Global action plan on the public health response to dementia* is to empower people with dementia and their family caregivers through involvement in planning and equitable access to a broad range of services (World Health Organization, 2017). Similar principles are reflected in Norwegian public health policies (Norwegian Ministry of Health and Care Services, 2012, 2015a, 2015b) and within primary and specialist healthcare services through legislation relating to patients' right to participate in healthcare decisions (Norwegian Ministry of Justice, 1999). National healthcare policy requires the provision of equitable healthcare services regardless of place of residence, as well as culturally appropriate services for the indigenous population of Norway, the Sami, within the regular national healthcare system.

Previous studies have reported that the use of complementary community care varies among groups of family caregivers. For example, it is reported that higher education levels among family caregivers are associated with the use of more healthcare services (Moholt, Friborg, Blix, & Henriksen, 2018; Toseland, McCallion, Gerber, & Banks, 2002). Possible explanations are 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. Moreover, previous studies have reported that caregiver characteristics such as gender, ethnicity, duration of caregiving, and demands associated with caregiving might influence family caregivers' needs and use of services (e.g., Erol, Brooker, & Peel, 2015; Lethin et al., 2016). A Norwegian study, for example, revealed that persons with dementia and family caregivers living in urban areas received more home-based services and respite care services than persons and family caregivers in rural areas and indicated that Sami ethnicity was associated with the use of fewer home-based services (Moholt et al., 2018). Few studies have investigated the association among family caregiver characteristics and access to information and involvement in decisions about services.

The right to make independent, informed decisions is arguably the most essential individual civil right in modern societies, and both international conventions and national legislation protect this right (European Court of Human Rights & Council of Europe, 2010; Norwegian Ministry of Justice, 1999). Hence, investigating factors associated with family caregivers' experiences regarding equitable access to information and involvement in decisions may illuminate areas of formal care with important civil rights aspects. The aim of this study was to explore demographic, socioeconomic, and cultural variations in the perceptions of family caregivers of home-dwelling persons aged 65 years or older living with dementia regarding access to information about community healthcare services and involvement in decisions regarding care.

This exploratory study poses the following specific research questions: (1) Do family caregivers' demographic, socioeconomic, and cultural statuses predict access to information about available services and content of services provided and their involvement in service decisions? (2) Do the duration and amount of caregiving and demands associated with caregiving predict access to information about available services and content of services provided and family caregivers' involvement in service decisions?

## **Materials and methods**

### ***Study setting***

The geographical area of this study was Northern Norway. We included a convenience sample of municipalities situated above the Arctic Circle in the northern part of Nordland and in Troms and Finnmark counties. The

population density of the area is low, as the area covers approximately 35% of the Norwegian mainland but hosts only 9.1% of the total population (Statistics Norway, 2019a). Municipalities differ substantially with regard to size, population density, and ethnic (indigenous Sami and Norwegians) and age composition. Typical rural municipalities are generally sparsely populated and have a higher percentage of older residents than urban municipalities (Statistics Norway, 2019b). In this study, we distinguished between rural and urban areas rather than among municipalities because several municipalities include both densely populated areas (town centers, towns, or smaller towns) and sparsely populated areas (villages and municipality centers in rural municipalities or areas in the countryside).

The survey included statutory services (home nursing, domestic help, support person, respite care) and non-statutory services (meal delivery, remote control safety alarm, day centers) available in most municipalities. The Norwegian national government is responsible for the overall control, juridical acts and the financial framework of community healthcare services, while the local municipal governments have the main responsibility for providing the services regulated by law (Ministry of Health and Care Services, 2019).

### **Sample**

Family caregivers of home-dwelling persons with dementia in a convenience sample of 32 municipalities in Northern Norway were invited to participate in this study. The municipalities were nonrandomly selected according to size, geographical dispersion, urban vs. rural areas, and full ( $n = 15$ ), partial ( $n = 6$ ), or no ( $n = 11$ ) affiliation with the STN area (communities under the Sami Parliament funding scheme for cultural and economic development). Due to insufficient public registration of persons with dementia and their next of kin, research assistants (registered nurses or licensed practical nurses who were involved in dementia care work) appointed by healthcare managers in each of the 32 community healthcare services used local healthcare service records to identify people who fulfilled the inclusion criteria. These criteria included providing unpaid help and support at least once a week to people  $\geq 65$  years with dementia living at home; being over 18 years of age; being either a spouse, son/daughter, friend, or more distant relative; and providing the majority of informal support and help. We defined dementia as a dementia diagnosis or cognitive impairment with symptoms consistent with dementia, i.e., difficulties with memory, language, problem solving, and other cognitive skills that affect a person's abilities to perform everyday activities (Alzheimer's Association, 2018). Support and help were broadly defined as personal care, emotional and psychological support, regular visits and phone calls, financial help, and organization of the care provided by formal caregivers (Lamura et al., 2008).

On behalf of the research team, the research assistants distributed information about the study and the questionnaire by mail from April–November 2016 to the 788 family caregivers they had previously identified. Participants returned the completed questionnaire directly to the research team in a stamped and addressed envelope; thus, only the researchers had access to the responses. One selective reminder procedure was carried out after 4 weeks. In total, 436 respondents returned the questionnaire. Data cleaning was performed, resulting in a final sample of 430 (response rate: 54.6%). Community collaborators registered the gender and kinship relations of all invited persons, which allowed for an anonymized overview of nonrespondents. Among the nonrespondents, 33.2% were men, 19.7% were spouses, 44.9% were daughters, 25.5% were sons, and 9.8% were others. Differences between respondents and nonrespondents were statistically significant, with response rates higher for spouses and lower for sons, respectively.

### **Variables**

The dependent variables in the present study included family caregivers' perceived level of information regarding available municipal healthcare and care services; information about the content of services provided to the person; and involvement in decisions regarding the delivery of healthcare services to the person. Perceived information level was measured as follows: 'Have you received information regarding available healthcare services in your municipality?' and 'Have you received information regarding the content of services provided to the person?' Involvement in decisions was measured by the following: 'Are you asked for advice on decisions regarding healthcare services for the person?' Response options for these three items were graded on a 5-point Likert scale ranging from (1) 'not at all' to (5) 'to a very large degree'; a 'not applicable' option was also included. Between 18 and 20 respondents used the 'not applicable' option on each item and were excluded from the analyses.

The independent variables included demographic characteristics and care context variables. The demographic characteristics of family caregivers included age, gender, ethnicity, kinship relation, cohabitation arrangements, education, and household income. In addition, we included place of residence of the person with dementia and coded it as rural area (smaller town/village or sparsely populated area = 1) or urban area (city, town, or town center = 2). Two markers of ethnicity were retrieved from the SAMINOR study (Brustad, Hansen, Broderstad, Hansen, & Melhus, 2014) and were defined as first language and self-perceived ethnicity. The variables were merged and coded into (1) non-Sami, (2) positive for either Sami marker, or (3) positive for both Sami markers. Kinship relations were coded as (1) spouse; (2) daughter; (3) son; and (4) others. Living with the person with dementia was coded as (1) yes or (2) no. Education and income levels were drawn

from the Tromsø study (Jacobsen, Eggen, Mathiesen, Wilsgaard, & Njolstad, 2012). Response options for highest level of education attained were (1) 'primary school up until 10 years'; (2) 'secondary school, minimum three years'; (3) 'college/university, less than four years'; and (4) 'college/university, four years or more', with the latter two categories merged in the analysis. Yearly household income was rated on eight intervals from 'less than NOK 150 000' to 'more than NOK 1 000 000', and these categories were merged and recoded into (1) 'less than or equal to NOK 350 000' (lower income); (2) 'NOK 351–550 000' (medium income); and (3) 'more than NOK 550 000' (higher income).

The care context variables included years spent caregiving, which was measured as the number of years of caregiving after the appearance of dementia symptoms, adapted from the Family Collaboration Scale (Lindhardt, Nyberg, & Hallberg, 2008). In addition, hours of caring per week were reported. The degree to which caregiving was perceived as demanding was derived from a survey used to evaluate a caregiving teaching program for family caregivers (Norwegian National Advisory Unit on Ageing and Health (Ageing and Health), 2011) and was further adapted for the present study. Response options were graded on a four-point scale from (1) 'not demanding' to (4) 'very demanding' and dichotomized in the analysis into (1) 'not/a little demanding' and (2) 'moderately/very demanding'.

### **Data analysis**

All statistical analyses were performed in IBM SPSS for Windows, version 24.0. For the comparisons between groups (gender, ethnic group, kinship relation, cohabitation, place of residence of the person with dementia, education and income levels, and degree to which care is demanding) regarding the statements on information and involvement, average scores are reported and were tested by nonparametric tests (Mann–Whitney U tests for dichotomous grouping variables and Kruskal–Wallis tests for grouping variables with more than two values). Associations among information and involvement and age, duration and amount of caregiving are reported as Spearman's correlation coefficients.

We used ordinal logistic regression analyses to investigate factors associated with information on available services, information on service content, and involvement in decisions, with age as a covariate and gender, ethnic group, kinship relation, level of education, household income, and degree to which care is demanding as independent variables. Female gender, relation as spouse, higher education, household income  $\geq$  NOK 550 000, and caregiving perceived as not/a little demanding were used as reference categories. Goodness-of-fit statistics were good for models for all three dependent variables. Proportional odds assumptions were fulfilled for information on available services and involvement in decisions but were less satisfactory for

information on service content. Hence, we advise the cautious interpretation of results for this variable.

The significance level for all statistical tests was 5% ( $p < .05$ ). We also report associations that may indicate trends ( $p < .10$ ) and included them in the regression models.

### **Ethical considerations**

The study conformed to the Helsinki Declaration Principles (World Medical Association, 2013). The Regional Committee for Health Research Ethics determined that the study protocol did not require its approval (Ref. No. 2015/1107/REK North), and the Norwegian Social Science Data Services (NSD) gave approval for the recruitment and data handling procedures (Ref. No. 2015/43778). The participants received written information about the study and were informed that participation was voluntary, that they had the right to withdraw without having to state a reason, and that they consented to participate by returning the questionnaire. Respondents received two lottery tickets (~7 USD) as a reward for participation.

### **Results**

Table 1 presents sample characteristics and bivariate associations. Overall, the average scores on the dependent variables ‘Information on available services’, ‘Information on service content’, and ‘Involvement in decisions’ fluctuated near 3.00, which indicated that respondents perceived these conditions as fulfilled ‘to some degree.’ Scores on information on available services indicated a trend toward lower scores for males, persons with lower education, and persons who perceived caregiving as moderately or very demanding. Information on service content displayed a trend toward lower scores with increasing age and for caregivers living with the care recipient. Increasing levels of education and household income correlated positively with this variable, while respondents who perceived caregiving as moderately or very demanding reported lower scores. Involvement in decisions displayed decreasing scores with age, lower scores for spouses and others, and higher scores for increasing education levels and household income, while caregivers who perceived caregiving as moderately or very demanding reported lower scores. Duration and amount of caregiving, gender, ethnicity, and living with the person were not associated with any of the dependent variables.

Table 2 displays the results from the ordinal logistic regression analysis regarding predictors for level of information on service content. Primary school as highest education level (OR = 0.57, 95% CI 0.33–0.96) and perception of care as moderately or very demanding (OR = 0.65, 95% CI 0.43–0.99) predicted

**Table 1.** Associations between family caregiver characteristics and information about available services and the content of healthcare services, and participation in decisions (N = 430)<sup>a</sup>.

Characteristics	M (SD) or %	Information		
		Information on available services <sup>b,c</sup>	Information on service content <sup>b,c</sup>	Participation in decisions <sup>b,c</sup>
All cases M (SD) or %		3.05 (1.10)	3.16 (1.07)	2.97 (1.17)
Age (years)	61.80 (11.70)	-0.01	-.10 <sup>d</sup>	-.13**
Duration of caregiving (years)	4.15 (3.2)	-0.03	0.02	0.02
Amount of caregiving (hours/week)	17.3 (28.5)	-0.07	-0.04	-0.02
Gender				
Male	31.1%	2.90 <sup>d</sup>	3.13	2.93
Female	68.9%	3.12	3.18	2.99
Ethnicity				
Non-Sami	93.0%	3.04	3.16	2.96
Sami, one marker	3.5%	2.59	2.91	2.59
Sami, two markers	3.5%	3.84	3.63	3.5
Relation				
Spouse	28.8%	3.1	3.02	2.82*
Daughter	42.4%	3.03	3.17	3.06
Son	18.3%	2.95	3.32	3.16
Others	10.5%	3.16	3.08	2.6
Living with person				
Yes	31.5%	3.07	3.00 <sup>d</sup>	2.87
No	68.5%	3.04	3.23	3.01
Place of residence (person with dementia)				
Rural area	57.9%	3.05	3.13	3
Urban area	42.1%	3.06	3.22	2.93
Level of education				
Primary school	28.8%	2.89 <sup>d</sup>	2.76***	2.67**
Secondary school	34.4%	3.02	3.28	3.01
Higher education	36.8%	3.21	3.34	3.14
Household income				
≤350 000	19.2%	2.98	2.75**	2.67*
351 000–550 000	33.3%	2.95	3.28	3
>550 000	47.6%	3.17	3.34	3.14
Degree to which care is demanding				
Not/a little	37.1%	3.16 <sup>d</sup>	3.41***	3.23**
Moderate/very	62.9%	2.99	3.01	2.82

M: mean; SD: standard deviation

<sup>a</sup>N may vary slightly due to varying missing rates

<sup>b</sup>Spearman's rho for correlation with age

<sup>c</sup>Mann-Whitney U test for two and Kruskal-Wallis test for more than two subgroup comparisons

<sup>d</sup> $p < 0.10$ ; \* $p < 0.05$ ; \*\* $p < 0.01$ ; \*\*\* $p < 0.001$

lower scores on information on available services. The variables in the model explained 5% of the variation in the dependent variable.

Primary school as the highest level of education (OR = 0.40, 95% CI 0.23–0.71), household income from 350 to 500 000 NOK (OR = 0.56, 95% CI 0.35–0.90), and perception of caregiving as moderately or very demanding (OR = 0.65, 95% CI 0.43–0.99) predicted lower scores for the item 'Information on service content'. The variables in the model explained 13% of the variation in the dependent variable.

**Table 2.** Ordinal logistic regression<sup>1</sup> of perceived level of information on available services, information on service content, and participation in decisions (1 = not at all, 5 = to a very large degree) among family caregivers.

Variable	Information on available services (N = 321) OR 95% CI	Information on service content (N = 345) OR 95% CI	Participation in decisions (N = 312) OR 95% CI
Gender			
Male	0.53(0.27, 1.03)	0.51 (0.25, 1.05)	0.66(0.33, 1.31)
Female	Ref.	Ref.	Ref.
Relation			
Others	0.79(0.35, 1.79)	0.51(0.21, 1.22)	0.37(0.16, 0.83)
Son	0.79(0.25, 1.93)	1.27(0.49, 3.27)	1.02(0.41, 2.53)
Daughter	0.52(0.25, 1.07)	0.57(0.26, 1.23)	0.64(0.31, 1.33)
Spouse	Ref.	Ref.	Ref.
Level of education			
Primary school	0.57(0.33, 0.96)	0.40(0.23, 0.71)	0.60(0.35, 1.03)
Secondary school	0.72(0.46, 1.11)	1.02(0.65, 1.61)	0.85(0.55, 1.33)
Higher education	Ref.	Ref.	Ref.
Household income <sup>2</sup>			
≤350 000	0.83(0.46, 1.50)	0.89(0.47, 1.67)	1.03(0.57, 1.88)
351 000–550 000	0.73(0.47, 1.15)	0.56(0.35, 0.90)	0.72(0.45, 1.13)
>550 000	Ref.	Ref.	Ref.
Degree to which care is demanding			
Moderate/very	0.65(0.43, 0.99)	0.46(0.29, 0.71)	0.50(0.32, 0.76)
A little/not at all	Ref.	Ref.	Ref.
Nagelkerke R <sup>2</sup>	0.05	0.13	0.09

<sup>1</sup>Age (years) as covariate; <sup>2</sup>NOK

OR: odds ratio; 95% CI: 95% confidence interval for odds ratio; Ref.: Reference category

Relation status as ‘other’ (OR = 0.37, 95% CI 0.16–0.83) and perception of caregiving as moderately or very demanding (OR = 0.50, 95% CI 0.32–0.76) significantly predicted lower scores on involvement in decisions. The variables in the model predicted 9% of the variation in the dependent variable.

## Discussion

Overall, the results of this exploratory study on family caregivers of home-dwelling persons with dementia revealed modest levels of information regarding available services and the content of services provided and involvement in decisions regarding services. Several studies have demonstrated the importance of providing relevant information to family caregivers of persons with dementia. A Norwegian small-scale qualitative study reported that family caregivers experienced a lack of mutual communication and clarification about the roles and responsibilities regarding services for persons with dementia living alone and had limited knowledge of service personnel and service organizations (Aaasgaard, Disch, Fagerström, & Landmark, 2014). An Australian focus group study of family caregivers found that access to appropriate dementia information at the right time was critically important

for family caregivers (Robinson et al., 2009). In that study, some participants reported encountering hurtful and dismissive attitudes toward their initial requests for information and diagnosis. A review of the needs of family caregivers of persons with dementia revealed a wide range of information needs, spanning from feeding and weight challenges through the quest for a diagnosis and information about the disease to knowledge about available services (McCabe et al., 2016).

Failure to meet information needs can occur for reasons of omission (oversight, disruption due to competing activities, and poor professional communication) or commission (denying informational needs and withholding information) (Tones, Tilford, & Robinson, 1990). Satisfactory communication requires helping family caregivers recognize and communicate their information needs; helping health-care professionals recognize that needs exist and that they should fully elicit them; developing positive attitudes toward sharing information and an institutional climate and resources that facilitate sharing; increasing understanding of the ways that information sharing is constrained; and identifying effective and efficient means of information sharing (Tones et al., 1990). Recent Norwegian governmental reforms have transferred the political responsibilities for several healthcare services from the specialist (state and regional) to the primary (municipal) healthcare level. In this process, the formal caregiver role in Norway has been characterized as experiencing a 'task and responsibility overflow' due to insufficient resources for service provision in municipalities (Vike, 2004). Healthcare professionals may be conceived of as street-level bureaucrats (Lipsky, 1980) who negotiate service provision with the population 'face to face'. In a situation with insufficient resources to solve caregiving needs, professionals may address this dilemma by withholding information. According to Vike (2004), Norwegian policy changes have altered the professional gatekeeper role from a patient advocate to a more legitimizing and depoliticized role with a focus on reducing expenditures. Moreover, Vabø argued that demographic and organizational changes, accompanied by the displacement of service perspectives in the direction of fiscal accountability, have made services less sensitive to particular individual needs (Vabø, 2012). Our data are not suited for investigating these topics further. Hence, they should be the subject of future in-depth, qualitative studies.

In this study, sociodemographic differences were observed for reported levels of information about available services, information about the content of services, and involvement in decisions, as lower levels of education and, to some degree, income were associated with lower scores for information and involvement in decisions. Lower information scores among respondents with primary school as highest education level corroborates findings from the Maximizing Independence at Home Study from Baltimore, U.S., of unmet needs among 246 informal caregivers of persons with dementia. In their study, family caregivers with significantly higher unmet needs had lower

education levels. In addition, family caregivers' most unmet needs related to resource referrals, followed by caregiver education (Black et al., 2013). In the present study, medium household income predicted lower scores on information on service content. Apart from this finding, income level did not appear to impact perceptions of information and involvement.

Perception of caregiving as moderately or very demanding predicted lower scores on the variables reflecting information and involvement in decisions. This relationship might indicate that caregivers who experience substantial burdens are insufficiently involved in information and decision-making processes. Lower scores on these variables may also express a more general level of exhaustion. Hence, we cannot rule out the possibility of reverse causation, as persons with heavy caregiver burdens may have less energy to demand healthcare services or to interact with service providers. Robinson, Clare, and Evans (2005) suggested that burdened caregivers may not have the capacity to make decisions or seek help. Our data do not allow for further investigations into this topic, and future studies should address this issue more thoroughly.

Family caregivers classified as others scored lower on involvement in decisions, which probably follows from their more distant position compared to spouses and adult children. Age, duration of caregiving, and hours of caregiving per week were not associated with any of the dependent variables. This finding was somewhat contrary to our expectations that a prolonged caregiver career would contribute to increased levels of cooperation and, accordingly, to higher scores on the information and involvement variables. Nor did gender correlate significantly with the outcome variables, although a trend occurred toward lower scores for males on the information variables in the initial analysis. This distinction probably mirrors gender roles in caregiving, where women are known to take the larger share of tasks (Erol et al., 2015). No differences appeared between Sami and non-Sami participants in the present study. This trend might be due to the limited number of Sami respondents. Despite focused recruitment efforts, only 7% of the study participants were Sami. Hence, we advise careful interpretation of these results, and future studies should include more Sami family caregivers and thus generate sufficient statistical power to allow for reliable comparison.

### **Limitations**

The response rate of the study was 54.6%. According to Polit and Beck (2017), the risk of nonresponse bias in postal surveys with response rates greater than 65% may be small. However, they stated that a lower response rate is the norm. Although the response rate in our study may be considered fairly high in terms of survey research, we lacked information about a substantial portion of the population of family caregivers. Nonresponse is a potential source of bias because respondents and nonrespondents may differ with regard to essential aspects of the study. We have

no data to evaluate the exact nature and direction of potential biases, although the results for spouses are probably more reliable than those for sons with regard to the generalizability of our findings. Research assistants recorded the gender and kinship relations to the person with dementia in the inclusion records. We compared responders and nonresponders and found that there was a higher proportion of spouses among the responders than among the nonresponders (28.8% and 19.7%, respectively) and a higher proportion of sons among the nonresponders than the responders (25.5% and 18.3%, respectively). The information about nonresponders was restricted to two characteristics; therefore, we cannot rule out the possibility of other nonresponse biases. A convenience sample may be considered a limitation to descriptive inference, although results may nonetheless be transferable to similar settings.

Average scores fluctuated near 3.00, with statistically significant variations between subgroups on education, income, and the degree to which care is demanding. The clinical significance of the between-group differences between approximately 0.4 and 0.5 on both variable warrants interpretation. A review of evidence from 44 randomized controlled trials studying the effect of information and support on the quality of life of people caring for someone with dementia found positive effects on psychological morbidity (Thompson et al., 2007). The authors advocated that the clinical significance of such findings should be interpreted tentatively due to the difficulties involved in interpreting standardized mean differences as a measure of effect. Moreover, they concluded that there was little evidence that providing support and information is uniformly effective. Our findings might support this conclusion, as the observed differences among educational levels and, to a somewhat lesser extent, income levels indicate a social gradient in the distribution of these items. We have no data with which to evaluate whether these differences stem from the content of the information or from how the information is processed and by whom. Further investigations should explore these aspects in more detail.

The variables in the regression model explained a modest proportion of the variance in the dependent variables, and other factors appeared to be more significant predictors of perceived information and involvement. This fact should lead to a cautious interpretation of results, and more comprehensive and sophisticated models should be developed to enable more complex and thorough investigations than those allowed by our exploratory study.

## **Conclusion**

The findings of this study indicated that, overall, family caregivers perceived that they received information and were involved in decisions to a modest degree. Few of the expected predictors were associated with the outcomes. However, the findings revealed a gradient in disfavor of persons with primary school as the highest educational level and lower scores on the dependent variables among

persons who reported caregiving to be very demanding. Even within the context of the Nordic welfare state, user involvement appears to be limited, and our findings may point to mechanisms that create social inequity in the processing of information and involvement in decisions regarding care arrangements for persons with dementia.

Clinicians, administrators, and policy makers should raise awareness of these issues and promote discussion regarding the prevention of inequity through critical scrutiny of information and user-involvement aspects of the complementary care model. Future research should inquire about microinteractions regarding language, power relations, and communication, as well as organizational arrangements and policies. Special attention should be directed toward the situation of family caregivers who experience caregiving as burdensome to secure relevant information and include them in care decisions. Information and involvement are essential for establishing authentic partnerships among the person with dementia, the family caregivers, and the healthcare services. Such partnerships benefit the person with dementia, as the family caregivers often have extensive knowledge about the person's needs and preferences. Moreover, authentic partnerships may reduce potential caregiver burden.

Due to the projected increase in the number of persons with dementia and the resulting negative change in the caregiver-patient ratio in modern societies, research including all societal levels, from daily cooperation to policy development, should underpin these efforts. Although absolute poverty is not an essential issue in the Nordic welfare state context, our results indicate a need for investigations into the root causes of inequalities to cope with these specific challenges from dementia in a growing population of senior persons.

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## **Disclosure statement**

The authors have no conflicts of interest to declare.

## **Data availability statement**

There is no data set associated with the paper.

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