Informal and formal care among persons with dementia immediately before nursing home admission.

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Abstract

Background: This study assesses the use of formal and informal care resources among home-dwelling persons with dementia during the last month before nursing home admission. It also describes providers of informal care and assesses clinical and sociodemographic factors associated with the use of care stratified by living situation.

Methods: In this cross-sectional study, data were collected from 47 nursing homes in four counties in Norway from January 2012 to August 2014. The subjects were persons with dementia who were newly admitted to a permanent nursing home. The main outcome measures were the use of formal care and informal care by the family caregiver and the extended social network.

Results: A total of 395 persons were included. The amount of informal care provided by the family caregiver was 141.9 hours (SD=227.4). Co-resident patients received five times more informal care than non-co-residents. Informal care from the extended social network was provided to 212 patients (53.7%) with a mean of 5.6 (SD=11.2) hours per month. Formal care was provided to 52.7% of the patients with a mean of 18.0 (SD=50.1) hours per month. Co-residency was significantly associated with more informal care, and the associations varied with respect to age, relation to the caregiver, and the caregiver’s working situation. Good/excellent general health was associated with less formal care.

Conclusion: Persons with dementia on the verge of admission to a nursing home are mostly supported by the family caregiver, and the use of informal care is particularly high among co-residents. Future research should explore the unrealized care potential in extended social networks, as well as the potential for increasing the number of recipients and utilization of formal care services directed at persons with dementia and their caregivers in order to delay nursing home admission.
Background

The number of people living with dementia worldwide was estimated as 35.6 million in 2010, and the numbers are expected to double over the next 20 years [1]. Strategies are needed to secure sufficient support of people living with dementia as well as their informal and professional caregivers without financially overstraining health and welfare systems. Health economic evaluations show that nursing home placement is the most cost driving factor in dementia care and that the interval from diagnosis to institutionalization is about 30–40 months [2–5]. A considerable amount of informal care is provided in the patient’s home, and the burden of care is one of the most important factors associated with nursing home admission (NHA) [6–11]. Factors associated with increased informal care are dementia severity, severe neuropsychiatric symptoms, and increased functional impairment [7, 8, 12–15]. Living alone is associated with more formal care, while living with a spouse or child caregiver is associated with more informal care [12, 13, 16].

The Norwegian Ministry of health published the first national Dementia Strategy in 2007 to better meet the needs of patients, proxies and the health care system in an increasing number of persons with dementia. This strategy was updated in 2015. One of the main goals of the Norwegian Dementia Strategy 2020 [17] is to enhance the support to the family caregivers and better the cooperation with the voluntary sector to empower persons with dementia to participate more actively in society and to live longer in their own homes. However, knowledge about the extent of informal care delivered during the period before NHA, and the providers of informal care, not only including primary caregivers but also the extended social network, is scarce. Better insight to the extent of care provided in patients’ homes, who provides the care, and what factors are related to the amount of care in the period before NHA may assist the development of new services aiming to prolong time to nursing home admission.
The aim of this study was to assess the resource use in formal and informal care among home-dwelling persons with dementia during the last month before NHA, as well as to describe the providers of informal care (both the closest caregivers and the extended social network), and to assess clinical and sociodemographic factors associated with the use of care.

Methods

Setting:
Cross-sectional design assessing baseline data in a sample drawn from the REDIC-NH project.

Study population
The study population was a sub-sample of participants in the Resource Use and Disease Course in dementia – Nursing Home (REDIC-NH) project. The REDIC-NH study is a longitudinal observational study that includes newly admitted patients from 47 small and large nursing homes in four Norwegian counties and follows them from admission to the NH over a course of 5 years or death [19]. Patients older than 65 years, or younger than 65 years but with established dementia, were included. In addition, the expected stay in the NH had to be more than four weeks. Patients with a life expectancy shorter than six weeks were not eligible. The study included a convenience sample of 695 persons, and recruitment took place between January 2012 and August 2014.

To increase homogeneity and describe the resource use in a dementia population exclusively, patients without dementia, or not permanently admitted to NH where excluded from the present study, as were participants without complete Resource Utilization in Dementia (RUD) questionnaire.

To be admitted to a long-term NH stay in Norway, the person must apply to the municipality. The application is evaluated based on a need assessment, and available
places are allocated based on urgency. If there are no available places, the applicant usually enters a waiting list, with a waiting period from a few days up to several weeks.

Data collection

Data were collected by healthcare workers at the nursing home, mainly registered nurses (74%), under the supervision of 10 research nurses after admission to NH. The research nurses completed five days of training prior to the start of the study, and the data collectors completed two days of training. Data were collected through cognitive and physical tests and structured interviews with the patients, their family caregivers, and the health workers.

Measures

Demographic data included the patients’ age and gender and were collected by reviewing the patients’ journals kept at the NHs. A diagnosis of dementia according to the ICD-criteria [18] was independently established by two of the authors (SB and GS) based on all available information about the patients. Both SB and GS are specialists in psychiatry and experienced in elderly psychiatry and research. If no consensus was reached, a third psychiatrist was consulted.

The clinical measures dementia severity and severity of physical health were obtained using the following instruments: The General Medical Health Rating (GMHR) [19], a four-category, reliable, and valid global bedside assessment tool for rating the severity of physical health. The score is based on an overall assessment by health care workers. The Clinical Dementia Rating Scale (CDR) assesses the severity of dementia as no dementia, possible dementia, and mild, moderate, or severe dementia. CDR comprises six items (memory, orientation, judgement and problem solving, community affairs, home and hobbies, and personal care). A score is calculated according to an algorithm where the memory item is given more weight. For statistical purposes, we calculated the CDR sum of
boxes (CDR-SB), which offers an extended range of values and is calculated by adding the item scores (range 0-18). Higher scores indicate more severe dementia [20].

The extent of formal care and the extent and providers of informal care were recorded by the RUD questionnaire and included the following information about the family caregiver [21]: Age, gender, relation to the patient, co-residential status, work status, hours worked last month, and lost work hours due to care tasks in the last month. Information about the extended social network included: Relation to patient and hours of provided informal care last month. The extent of informal care provided by the family caregiver last month was recorded in regard to the following three aspects: 1) the time used to help the patients with personal activities of daily living (PADL), 2) the time used on instrumental ADL (IADL), 3) and the time used on supervision, like helping the patient with orientation or preventing behavior that is distressing to the patient. We calculated the total informal care time by summarizing the amounts of time for these three types of care. If this sum exceeded 24 hours per day, a total informal care time of 24 hours per day was set. The time provided by professional home care service was used to calculate formal care due to insufficient or lacking data on services like home help, meal delivery, day care centres, or respite care.

Statistical analysis

Data are described by the means and standard deviations (SD) or frequencies and percentages. Differences between groups were assessed by Independent Samples t-test for continuous variables and the χ²-test for categorical variables. Associations between predefined covariates (gender, age, caregiver gender, caregiver relation to patient, caregiver in work, co-residency with family caregiver, GMHR, and CDR) and the three outcome variables were assessed by estimating bivariate and multiple linear mixed models. Random effects for nursing homes were included in the models to adjust the
estimates for possible within-nursing-home correlations. Stratification by living with or without a caregiver was performed by including interactions between the dichotomous variable (co-residency with or without caregiver) and all covariates. Interactions with p<0.1 were kept in the model. Missing values in variables co-resident, carer relation, and carer in work were imputed by logical rules whenever possible. The analyses were performed using IBM SPSS Statistics for Windows version 25.0 (Armonk, NY: IBM Corp.) and SAS v 9.4. Results with p-values less than 0.05 were considered statistically significant.

**Ethical considerations**

The patients’ capacity to consent was assessed by the nursing home staff, including a physician. Written informed consent was obtained from patients with the capacity to consent or from the family caregivers on behalf of the patients in cases of reduced capacity to consent. The study was approved by the Regional Committee for Medical and Health Research Ethics (2011/1738).

**Results**

**Study population**

The REDIC-NH cohort consists of 696 patients, among which 445 had dementia and were permanently admitted to a nursing home. However, 50 patients had to be excluded due to missing or incomplete RUD questionnaires. Thus, the study included 395 patients with a mean age of 84.4 (SD = 7.5) years, and 265 (67.1%) patients were female. According to the CDR, 277 (73.9%) had moderate or severe dementia. There were no differences between patients who completed the RUD questionnaire and those who did not. The extent of formal and informal care is presented in Table 1.
| Variable                                                                 | Formal care recipients, n (%) | Mean hours recipients last month (SD) | Mean hours total sample last month (SD) |
|-------------------------------------------------------------------------|-------------------------------|--------------------------------------|----------------------------------------|
| Formal care recipients, n (%)                                          | 208 (52.7)                   | 34.2 (64.9)                          | 18.0 (50.1)                            |

| Informal care by the primary carer, mean hours last month (SD)          |                               |                                      |                                        |
| PADL                                                                    | 74.8 (170.5)                 | 65.9 (142.1)                        | 55.9 (158.9)                          |
| IADL                                                                    |                               |                                      | 141.9 (227.4)                         |
| Supervision                                                             |                               |                                      |                                        |
| Total informal care by the primary carer                                |                               |                                      |                                        |
| Informal care by wider social network, mean hours last month (SD)       |                               |                                      |                                        |
| Family                                                                  | 3.8 (10.2)                   | 0.4 (3.0)                            | 0.1 (0.8)                             |
| Relatives                                                               |                               |                                      |                                        |
| Friends                                                                 | 0.2 (1.0)                    | 0.9 (4.0)                            |                                        |
| Neighbours                                                              |                               |                                      |                                        |
| Others                                                                  | 5.6 (11.2)                   |                                      |                                        |
| Total informal care by the extended social network                      |                               |                                      |                                        |

NHA = Nursing Home Admission, SD = Standard Deviation.

The extent of informal care

The mean care time provided by the family caregiver was 141.9 (SD = 227.4) hours per month, while the total contribution of the patients’ extended social network, including family members, was 5.6 (SD = 11.2) hours per month.

The extent of formal care

Formal care was provided to 208 (52.7%) of the patients with a mean of 34.2 (SD = 64.9) hours per month among those receiving formal care. For the whole sample, the mean amount of formal care per month was 18.0 (SD = 50.1) hours.

Informal care – characteristics of the family caregiver

Characteristics of the family caregivers and the extended social networks are presented in Table 2. Of the 395 patients, 379 (95.9%) had a family caregiver, of whom 228 (60.2%) were females, 255 (67.3%) were the patients’ children, while 81 (21.4%) were spouses.

The mean age was 57.4 (SD = 8.9) years for family caregivers who were the patients’ children and 77.7 (SD = 7.6) years for family caregivers who were the patients’ spouses.

Co-resident caregivers accounted for 105 (26.6%) of the sample. A total of 194 (54.2%) caregivers were doing paid work, and they worked 34.9 (SD = 10.3) hours per week. Of the
caregivers in paid work, 60 (30.8%) reported a mean loss of 11.2 (SD = 9.6) working hours per week due to care tasks.

Table 2
Description of the family caregivers (n = 379) and the patient's extended social network.

| Family caregiver’s relation to patient, n (%) | 81 (21.4) |
|--------------------------------------------|-----------|
| - spouse                                   | 255 (67.3) |
| - child                                    | 43 (11.3)  |
| - others                                   |           |
| Age, mean (SD)                             | 77.7 (7.6) |
| - spouse-carers                            | 57.4 (8.9) |
| - child-carers                             |           |
| Gender, n (%) female                       | 228 (60.2) |
| Co-resident, n (%) yes                     | 105 (26.6) |
| In paid work, n (%) yes                    | 194 (54.2) |
| Hours worked per week if in paid work, mean (SD) | 34.9 (10.3) |
| Carers that lost working hours due to care tasks, n (%) | 60 (30.8) |
| Mean hours lost per week, if reporting lost hours (SD) | 11.2 (9.6) |
| Care benefit as part of paid work, n (%) yes | 8 (4.0)  |
| Mean hours care benefit per week, if receiving care benefit, mean (SD) | 7.6 (5.6)  |
| Number of additional care providers, n (%) | 183 (46.3) |
| - 0                                        | 172 (43.5) |
| - 1                                        | 28 (7.1)  |
| - 2                                        | 12 (3.7)  |
| Additional care providers’ relation to patients, n (%) | 154 (72.6) |
| - family                                   | 29 (13.7)  |
| - relatives                                | 15 (7.1)  |
| - friends                                  | 22 (10.4)  |
| - neighbours                               | 44 (20.8)  |

SD = Standard Deviation

Informal care - characteristics of the extended social network

In our study sample, 212 (53.7%) patients received support from at least one member of their social network, whereas 183 (46.3%) had no additional carers beside the family caregiver. Of the 212 patients that received help from their extended social network, 154 (72.6%) received help from family members, while 29 (13.7%) received help from more distant relatives, 15 (7.1%) received help from friends, 22 (10.4%) received help from neighbours, and 44 (20.8%) received help from others (Table 2).

The impact of sociodemographic and clinical factors on the use of care

Male patients received more informal care than female patients (187.1 versus 120.3 hours per month, p = 0.016). There was no statistical difference between genders regarding
formal care. Co-resident patients received more informal care (343.1 versus 67.4 hours per month, p < 0.001) and less formal care than patients living alone (9.1 versus 21.2 hours per month, p = 0.001), while informal care by the extended social network showed no statistical difference between co-residents and non-co-residents (Fig. 1). The ratios of informal to formal care were 37.7:1 for co-resident patients and 3.2:1 for patients living alone. Family caregivers who did paid work provided less informal care than those who were not working (74.2 versus 228.7 hours per month, p < 0.001). There were no statistical differences in formal care between patients with working and non-working family caregivers.

According to the bivariate linear mixed models presented in Table 3, more hours of informal care by the family caregiver was significantly associated with lower age, having a family caregiver not doing paid work, male gender, having a spouse as a family caregiver as opposed to a child, more severe dementia, and co-resident caregivers. Having a family caregiver doing paid work was associated with more informal care from the social network. Having a spouse as the family caregiver as opposed to a child, good/excellent GMHR, and co-residency were associated with less formal care.
In the multiple model, female gender of caregiver was significantly associated with more hours of informal care by the family caregiver. Several interactions with co-residency were present in the model. Co-resident patients had significantly more hours of informal care than non-co-resident patients with differences varying between strata. There were no
differences between male and female patients. Differences in provided informal care between spouses and children caregivers were significantly larger among non-co-resident patients than co-resident patients. Differences in received informal care from working and non-working caregivers were significantly higher among co-resident patients than non-co-resident patients. Higher age was associated with fewer hours of informal care, and there was a significantly stronger reduction among co-resident patients than non-co-resident patients. Less formal care was only associated with good/excellent GMHR.

Discussion

This study assessed the use of formal and informal care among home-dwelling persons with dementia during the last month before permanent admission to a nursing home. For the two-thirds of the patients living alone, their closest caregiver was mainly one of their children, while for the patients living in co-residency, the caregiver was most frequently the spouse. Half of the sample received formal care in the form of home care services. The extent of informal care was substantially larger than the extent of formal care. However, the majority of the informal care was delivered by the family caregiver, while the extended social network only contributed 3.8%. Half of the primary caregivers even reported to have no additional help at all, including the majority of spouses living with the patient. Only a small portion of 10% received care from two or more persons in their extended social network; however, the low hourly contribution suggests that the help was somewhat sporadic.

As care contributions from the extended social network have not been investigated or discussed in previous studies, we can only suggest possible reasons for the low contribution. Norway has high employment rates among both genders, possibly reducing the opportunity to support relatives [22]. Another explanation could be the increasing urbanization causing longer geographical distance between relatives [23]. The massive
expansion of the public care services during the last fifty years might also lead to a perception that the provision of care to elderly relatives is a state- rather than a family-
responsibility [24].

We found that a mean of 142 hours per month of informal care was provided by the family caregiver. In contrast, a previous study conducted in eight European countries with a similar cohort regarding age and stage of dementia reported 360 hours per month, while studies observing cohorts with younger patients in earlier stages of dementia have reported the use of informal care in a range of 82 to 160 hours per month [12, 16, 25, 26]. The difference in informal care between previous studies and the current one may be due to the substantially lower share of co-resident family caregivers in our study. Alternatively, residential long-term care in Norway might be more accessible than in other European countries [25]. Cultural differences regarding the experienced obligation to care for elder family members might as well impact the amount of formal care.

The large difference in informal care between co-residents and non-co-residents might also be an indication of “supply creates its own demand” [27] as co-resident caregivers (the spouse in most cases) might be more involved than needed when assisting the patients with daily tasks and supervision. Thus, due to the close and non-professional relationship between spouses, it could be difficult to distinguish the formerly shared household activities from care activities related to impairments, resulting in an overestimation of care time. On the other hand, more severe dementia was associated with more informal care, suggesting that the amount of informal care is adjusted to the severity of dementia. A higher extent of informal care provided by primary caregivers has been linked to increased caregiver burden [25], thus, better support by the formal care services and as well the extended social network might contribute to delaying the time to NHA.
In the current study, the extent of informal care was to a high degree related to co-residency as opposed to non-co-residency suggesting that these two subgroups should be approached differently in the planning and provision of formal care.

Only about half of the sample received formal care, although two-thirds of the patients suffered from moderate to severe dementia. Our finding of 4.5 hours of formal care per week is considerably lower than the findings in a comparable study that reported 7.5 hours [16]. In recent years, dementia strategies have asked for more differentiated care services and a more individualized approach toward persons with dementia and their family caregivers. Consequently, we would expect a higher amount of formal care time and dementia-specific clinical measures to be associated with the extent of formal care, but we found that only somatic health was related to it. A possible explanation could be that Norwegian home care services mainly cover help with tasks related to ADL dependencies and, to a lesser degree, with tasks related to IADL dependencies and supervision of the patients [28].

Despite having several needs related to the caregiving of a person with dementia [29], we found that co-resident patients received less formal care and more informal care than patients living alone which is consistent with previous studies [12, 16, 26, 30]. This finding indicates a substitutive rather than complimentary relationship between formal and informal care use and are in line with a recently published study in six Western-European countries [31]. The findings may also suggest that contributions from the extended social network and the primary carers are substitutive as more support was provided from the extended social network in cases with non-co-residency and when the primary carer was holding a job.

The low use of formal care substituted by a high use of informal care might be due to a lack of capacity or skill in the primary care services to offer specialized and individualized
dementia care, especially care and support directed towards co-resident caregivers. A cross-European study found that the formal services available to persons with dementia were non-specific and not tailored to the patient group or the specific individual's needs [32]. Other identified barriers to the use of formal care are that the family caregivers do not consider the need for the care, them or the patient having negative attitudes and beliefs towards formal care, low awareness of services available, poor accessibility of formal care services, or high costs. In addition, a public health strategy might be to exhaust family resources before formal home care services are made available [33–36].

Increasing the number of recipients of formal care or increasing the hours of care delivered to the respective recipients might have the potential to delay NHA and thus save public resources in the long run [5, 37].

Limitations and strengths

The strengths of this study include a large sample of nearly 400 home-dwelling persons with dementia who were assessed for informal and formal care used during the last month before NHA. Standardized interviews were carried out by adequately trained and supervised healthcare workers, thus securing high-quality data. Private entities rarely provide health care service in the municipalities in Norway. Thus, the municipalities are almost exclusively responsible for the provision of care services and provide a homogenous environment for health service research with similar criteria for NHA. A major limitation is that our sample might not be representative of the general population of persons with dementia in this stage in Norway as only patients that completed the BL examination were included, and the mean time from admission to BL was 10.5 weeks [38]. Thus, we could have excluded patients who were eligible for the study but who died shortly after admission to a nursing home, or eligible persons that did not have a family caregiver. Furthermore, the physical and cognitive tests were first
performed at the baseline BL examination and could be sensitive to changes during this time period or due to the event of admission. However, the GMHR and CDR have shown to be stable over time [39–41]. Moreover, caregiver-reported data from the RUD questionnaire may have yielded inaccuracies in the extent of formal and informal care. We equated formal care with home care services without taking into account other forms of services, such as meal delivery, day care centres, or respite care due to insufficient or lacking data. This might have resulted in an underestimation of the extent of formal care. However, we consider home care services as the most relevant type of formal care in Norway, and as well when comparing different health care systems.

Conclusion

We found that persons with dementia on the verge of admission to a nursing home are mostly supported by informal care provided by one primary carer, while the amount of care provided by the patients’ extended social network and the provision of formal care was low. Future research should explore the unrealized care potential in the extended social networks and the possibilities in more diverse formal care services directed to persons with dementia and their caregivers.

List Of Abbreviations

NHA
nursing home admission

REDIC-NH
Resource Use and Disease Course in Dementia-Nursing Home

RUD
resource utilization in dementia

P-ADL
personal activity of daily living

IADL
instrumental activity of daily living
Declarations

**Ethics approval and consent to participate**

The patients’ capacity to consent was assessed by the nursing home staff, including a physician. Written informed consent was obtained from patients with the capacity to consent or from the legal guardians on behalf of the patients in cases of reduced capacity to consent. The study with reference number 2011/1738 was approved by the Regional Committee for Medical and Health Research Ethics South-east Norway, University of Oslo.

**Consent for publication**

Not applicable.

**Availability of data and material**

The datasets generated and/or analysed during the current study are available for researchers in cooperation with the data owner, the Research Centre for Age-related Functional decline and Disease – Innlandet Hospital Trust. Information is available on the following page link: https://sykehuset-innlandet.no/avdelinger/alderspsykiatrisk-forskningscenter

**Competing interests**

The authors declare that they have no competing interests.
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**Authors’ contribution**

CV, GS, SB, JSB, and AEY developed the concept, study design and research questions. AEY and CV processed the data, performed descriptive analysis and prepared the manuscript. JSB, SB, and GS critically reviewed and added comments to the manuscript at all phases. JSB provided expert advice on the statistical analysis and performed the bivariate and multiple linear mixed models. All authors took part in revising the paper and approved the final version.

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**Figures**

![Figure 1](image)

*Figure 1*

Time used to care for patients during the last month before nursing home admission.

**Supplementary Files**

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