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Original Study

Caring for a Person With Dementia on the Margins of Long-Term Care: A Perspective on Burden From 8 European Countries

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A B S T R A C T

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Objectives: To explore associations between carer burden and characteristics of (1) the informal carer, (2) the person with dementia, and (3) the care support network in 8 European countries.

Design: Cross-sectional study.

Setting: People with dementia judged at risk of admission to long-term care (LTC) facilities in 8 European countries (Estonia, Finland, France, Germany, Netherlands, Spain, Sweden, United Kingdom).

Participants: A total of 1223 people with dementia supported by community services at home or receiving day care or respite care and their informal carers.

Measurements: Variables regarding the informal carer included familial relationship and living situation. Variables relating to the person with dementia included cognitive functioning (S-MMSE), neuropsychiatric symptoms (NPI-Q), depressive symptoms (Cornell depression scale), comorbidity (Charlson Comorbidity Index), and physical functioning (Katz Activity of Daily Living [ADL] Index). The care support network was measured using hours of caregiving (ADLs, instrumental ADLs [IADLs], supervision), additional informal care support, and service receipt (home care, day care). Experience of carer burden was recorded using the Zarit Burden Interview. Logistic regression analysis was used to determine factors associated with high carer burden.

Results: Carer burden was highest in Estonia (mean 39.7/88) and lowest in the Netherlands (mean 26.5/88). High burden was significantly associated with characteristics of the informal carer (family relationship, specifically wives or daughters), of the person with dementia (physical dependency in ADLs; neuropsychiatric symptoms, in particular nighttime behaviors and irritability), the care support network (hours of caregiving supervision; receipt of other informal care support) and country of residence.

Conclusion: A range of factors are associated with burden in informal carers of people with dementia judged to be on the margins of LTC. Support for informal carers needs to take account of gender differences. The dual challenges of distressed behaviors and difficulties in ADLs by the person with dementia may be addressed by specific nonpharmacological interventions focusing on both elements. The potential protective effect of additional informal support to carers highlights the importance of peer support or better targeted home support services. The implementation of appropriate and tailored interventions to reduce burden by supporting informal carers may enable people with dementia to remain at home for longer.

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The RightTimePlaceCare Consortium partners and their affiliations are listed in [Appendix 1](#).

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The care of people with dementia falls mainly on the shoulders of informal carers, who also bear the largest cost.^{1–3} As a consequence of the associated caring responsibilities, many carers can suffer psychological distress,^{4,5} have poorer quality of life,⁶ or experience burden.^{7,8} Although the term “burden” has negative connotations, it is acknowledged that the caring role can equally include positive aspects,^{9–11} perhaps derived from satisfaction with the potential for improving their relative’s quality of life.¹² Burden has thus been described as “the global impact of caring, including both positive and negative impacts.”¹³

There is an abundance of literature, including systematic reviews,^{14–16} that have identified challenging or distressed behaviors as a significant factor in relation to increased carer burden. A review by Ornstein and Gaugler¹⁵ showed that some behavioral symptoms, such as aggression and sleep disturbance had a greater negative impact on carers. Previous research has identified gender as an influential factor in carer burden, with female carers^{17,18} and wives^{19,20} experiencing comparatively higher levels. Studies also have shown that higher levels of carer burden are associated with increased hours of informal caregiving.^{14,21} Nevertheless, outcomes from research into carer burden have been less clear-cut regarding factors such as the influence of additional informal social support to family carers,^{16,22} and dependency in activities of daily living (ADLs) of people with dementia.^{18,23} Furthermore, differences in outcomes between countries have been identified in previous cross-national studies.²⁴

The value of research into the attributes of burden and its effects on people with dementia and carers is the potential to devise and implement more effective types of assistance or training to support informal carers in their role. A systematic review and meta-analysis has found that nonpharmacological and psychoeducational interventions have at best had only moderate impact on carer burden and distress.^{25,26} The aim of this article was to explore associations between carer burden and characteristics of (1) the informal carer, (2) the person with dementia, and (3) the care support network in 8 European countries. Significantly, the study comprised a specific group of people with dementia, who were deemed to be at the margins of entry to long-term care (LTC) facilities. Existing literature has rarely focused on the experience of carer burden at a point when decisions relating to the future care of people with dementia may be considered. Thus, identifying factors that can be addressed to reduce carer burden could be beneficial for people with dementia in view of the difficulties associated with transfer to LTC.²⁷

Methods

Design

This cross-sectional study was part of a large-scale project (RightTimePlaceCare [RTPC]) carried out in 8 European countries (Estonia, Finland, France, Germany, Netherlands, Spain, Sweden, and the United Kingdom). The project sought to improve health and social care services for European citizens with dementia. The objectives of this study were to examine factors associated with transition to LTC of people with dementia around the time of admission; and investigate the health and well-being of people with dementia and their informal carers receiving either care in the home or in an LTC facility. A particular focus was the quality of care and quality of life of the person with dementia, and carer burden and quality of life of informal carers of people with dementia living in both care settings. Further details relating to the design and protocol of the study have been published elsewhere.²⁸

Sample

Participants were recruited to the study from 2 care settings. The first group were people with dementia who were living at home and

receiving community care services, but judged by a formal care provider (eg, nurse, general practitioner, social worker) responsible for their care to be at risk of admission to LTC in the next 6 months. Reasons for being judged at risk could vary between countries. The second group had recently made the transition to an LTC facility between 1 and 3 months previously. The present article focused solely on the first group, being supported by community services at home, and used data collected across all 8 countries. Participant inclusion criteria included: being aged 65 or older; a diagnosis of dementia; a score of 24 or less on the Standardized Mini Mental State Examination (S-MMSE) measure of cognition; being in receipt of community care services; and being supported by an informal carer who lived with or visited the person with dementia at least twice a month. Informal carers could include spouses/partners, other family members, relatives, friends, neighbors or other unpaid individuals within their social network, usually with an already existing social relationship with the cared-for person.²⁹

Procedures

Ethical approval was obtained by each country independently in accordance with their national regulations and standards. People with dementia and their carers were recruited from a variety of organizations providing home care or other community services, with a minimum of 10 facilities per country to ensure within-country variation. Written informed consent was gained from all participants before participation in the project. Face-to-face interviews were conducted with both the person with dementia and their informal carer who also acted as the best informed proxy of their relative. These were undertaken by trained interviewers guided by a written manual and who were qualified to at least Bachelor’s degree level. Data were collected between November 2010 and April 2012.

Measures

Information recorded in the questionnaire included background characteristics of both the carer and person with dementia such as age, gender, and marital status. Informal carers completed measures of carer burden, and hours spent caregiving. Details relating to the person with dementia included type of dementia illness, cognitive functioning, mental and physical health status, and abilities in ADLs. Care input included details of any service receipt and availability of informal support. The impact of carer burden was measured using the Zarit Burden Interview (ZBI).³⁰ Carers responded to 22 statements relating to the care of their relative with dementia. It used Likert scale scoring which ranged from “Never” to “Nearly Always.” A higher score range 0 to 88 denoted a higher level of carer burden. The S-MMSE^{31,32} measured the level of cognitive impairment. Higher scores (range 0 to 30) indicated better cognitive functioning. The Charlson Comorbidity Index,³³ developed primarily to determine mortality risk, was used to record presence of chronic comorbid disease. Higher scores (range 0 to 37) indicated greater comorbidity and risk of mortality. Dependence in ADLs was measured using the Katz ADL index.³⁴ This scale rates an individual’s ability to undertake 6 activities (dressing, bathing, eating, using the toilet, transferring, and continence). A higher score (range 0 to 6) denoted less physical dependency. The shortened neuropsychiatric inventory questionnaire (NPI-Q)^{35,36} measured the presence and severity of 12 neuropsychiatric symptoms. A higher score on this measure (range 0 to 36) corresponded to a higher level of psychopathology. Presence of depressive symptoms was assessed using the Cornell Scale for Depression in Dementia (CSDD).³⁷ A higher score (range 0 to 38) indicated greater depressive symptomatology. The Resource Utilization in Dementia instrument³⁸ recorded the frequency of use of community services, availability of additional informal support, and length of time devoted to informal caregiving.

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