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Research paper

Psychological well-being of spousal caregivers of persons with Alzheimer's disease and associated factors



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ABSTRACT

Objective: To explore feelings and psychological well-being of spousal caregivers of persons with Alzheimer's disease related to caregiving and experiences with the service system and associated factors. **Methods:** A cross-sectional survey of Alzheimer patients' spouses included items on caregiving and the Psychological Well-being Scale (PWB). An open-ended question: "What kind of problems have you faced with the services?" was included. Those responding to the question ($n = 728$) were analyzed combining both quantitative and qualitative responses.

Results: According to PWB, 10.8% had poor well-being. They had poorer subjective health, their care recipient had poorer functioning and they more often felt that their closest ones did not understand caregiving situation than those with better PWB. No difference existed between these groups in proportions satisfied with the services. In the responses of the open-ended question, the caregivers described both positive and negative feelings related to everyday caregiving as well as problems related to using services. Positive feelings were associated with being satisfied with services and caregivers' good subjective health. Negative feelings included bitterness, feeling of being isolated and distress. Bitterness was associated with being dissatisfied with services, the relationship with the spouse or closest ones and poor PWB. Feeling isolated was associated with the view that the closest ones do not understand their situation.

Conclusions: Caregivers' feelings are intertwined with their personal characteristics and life situation with their spousal relationship and closest ones. Traditional home service may not be equipped to deal with the complexity of these feelings. A more psychological approach is needed.

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1. Introduction

Burden, distress, depression and anxiety have been identified as major problems in dementia caregiving [1–6]. Although caregiver burden and strain have been investigated in a number of earlier studies, less attention has been paid to other feelings of caregivers of persons with Alzheimer's disease (AD). Experiences of isolation, guilt, uncertainty, loneliness, anger and depression have also been suggested to describe caregivers' feelings [2].

Females and those with a sparse support network report negative feelings, whereas those with good support and a satisfactory relationship with person with dementia report positive feelings [7–11]. Caregiver's age, gender, education, personal coping style, competence and sense of coherence and care recipient's severity of disease, psychiatric symptoms and functional limitations impact the caregiver's burden [3,6].

Several effective support services have been developed for dementia families [12,13]. However, available services do not always meet caregivers' needs sufficiently [14–18]. To our knowledge, previous studies have not explored how the service system contributes to caregivers' psychological well-being and feelings.

Although many studies have examined the burden of caregivers, few studies have described how caregivers perceive their feelings related to caregiving or their life situation. Furthermore,

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little is known about how caregivers' negative and positive feelings are associated with their psychological well-being or their personal views of the caregiving situation. Here, we:

- investigate the psychological well-being of spousal caregivers of persons with AD and associated factors;
- explore the feelings caregivers describe related to the caregiving context. We combine quantitative and qualitative data on feelings associated with the caregiving situation and psychological well-being.

2. Patients and methods

A random sample of persons using AD drugs and living with a spouse was gathered from the register of the Social Insurance Institution of Finland. Sample recruitment has been described in detail in our previous study [17]. Briefly, the sample included patients receiving drug reimbursement for AD drugs. Reimbursement requires detailed cognitive and laboratory tests as well as brain imaging to receive a proper diagnosis of AD according to the NINCDS-ARDR [19]. A postal questionnaire was sent to 1943 spouses residing with persons with AD in five urban and non-urban regions in Finland to get a representative sample. The response rate was 77% [17]. Further, 728 responded to the open-ended question on caregiving and services. These subjects were included in this study.

The questionnaire included demographic variables. Caregiver's subjective health was questioned with: "How do you consider your own subjective health at the moment?" with response options (1) good, (2) fairly good, (3) poor and (4) fairly poor (categorized as good [1 and 2]/poor [3 and 4]).

This survey used six questions to explore psychological well-being [20–22]. These questions have been used in our studies since 1989, and they show good test-retest reliability and prognostic validity [20–22]. They inquire about (1) life satisfaction (yes/no), (2) feeling needed (yes/no), (3) having plans for the future (yes/no), (4) having zest for life (yes/no), (5) feeling depressed (seldom or never/sometimes/often or always), (6) suffering from loneliness (seldom or never/sometimes/often or always). Psychological well-being score is created from these questions, where each question is represented by 0 ("no" in questions 1–4, "often or always" in question 5 or 6), 0.5 ("sometimes" in question 5 or 6) or 1 ("yes" in questions 1–4, "seldom or never" in question 5 or 6) point. The score was created by dividing the sum of these items by the number of questions answered by the participant. Thus, a score of 1 represent the best well-being and 0 the poorest. The score has shown good concurrent and content validity with quality of life instruments [20]. We categorized those with PWB < 0.40 as having poor psychological well-being.

Spousal relationship was explored with: "How do you experience your relationship with your spouse?" with response options: (1) very satisfactory, (2) satisfactory, (3) moderately satisfactory, (4) unsatisfactory, (5) very unsatisfactory (categorized as being satisfied [1–3] and being dissatisfied [4 and 5]).

Support from closest ones was inquired about with "Do you feel your closest ones understand your life situation?" with response options: (1) they understand well, (2) moderately, (3) they do not understand (categorized as "closest ones do not understand" (3) and others "closest ones understand" [1 and 2]).

We inquired about use and needs of various services; these findings have been reported in our previous articles [11,17,23]. In Finland, these services include the following social and health care services: home aid, home nursing, house cleaning, meals-on-wheels, physiotherapy, assistive devices, daycare, respite care, financial support, physicians' services. Satisfaction with these services was elicited with options: (1) very satisfied, (2) satisfied,

(3) moderately satisfied, (4) unsatisfied, (5) very unsatisfied (categorized as not being satisfied [4 and 5] and being satisfied [1–3]).

Physical functioning of the spouse with AD was examined with: "What is your spouse's functioning in daily activities?" with options: (1) very good, (2) good, (3) moderate, (4) poor, (5) very poor (categorized as good [1–3] and poor [4–5] functioning).

Care recipient's behavioral symptoms in caregiving situations were charted with several questions, e.g. "Do you have situations where your spouse will not co-operate or refuses to accept help?" In addition, hallucinations and agitation were charted (all with response options yes/no).

At the end of the questionnaire, we posed an open-ended question: "What kind of problems have you faced with the services?" with space to write a freehand response.

Helsinki University Hospital Ethics Committee approved the research protocol.

3. Data analysis

Males and females were compared with Chi² test for categorical variables and Mann-Whitney *U* test for non-normally distributed continuous variables. We used thematic content analysis to analyze responses to the open-ended question. These responses concerning the difficulties experienced with services by the caregivers of spouses with AD were systemically examined several times to identify different themes. Data were organized into codes and further into broader categories encompassing the initial codes. Each item was compared with the rest of the data to establish analytical categories (constant comparison) [24]. The data were reviewed and coded independently by two authors (MMR, KHP) to ensure reliability. In some cases, the authors had discussions to reach a consensus. Attention was also paid to deviating phenomena [24].

Main categories (positive feelings, bitterness, feeling of isolation, distress) representing both positive and negative feelings from the qualitative analysis were cross-tabulated with quantitative survey responses. Chi² test, Fischer exact test and Mann-Whitney *U* test were used to explore differences between person with poor psychological well-being (PWB < 0.40) and those with moderate to good psychological well-being (PWB ≥ 0.40). Logistic regression analysis was used to test which characteristics of the caregiving situation predicted poor psychological well-being.

4. Results

Of the 728 spousal caregivers, 65.6% were females. Of respondents, 10.8% had poor psychological well-being (PWB < 0.40). Caregivers with poor PWB were older (78.7 vs. 77.7 years, $P = 0.049$), more often had low education (70.1% vs. 50.5%, $P = 0.016$), poor subjective health (68.8% vs. 37.1%, $P < 0.001$), more often felt that their closest ones do not understand their caregiving situation (20.8% vs. 3.8%, $P < 0.001$) and more often were dissatisfied with the relationship with their spouse with AD (33.8% vs. 12.7%, $P < 0.001$) than caregivers with moderate/good PWB. Care recipients of caregivers with poor PWB more often had poor functioning (81.8% vs. 62.0%, $P < 0.001$), more often resisted help from the caregiver (59.7% vs. 46.0%, $P = 0.025$) and more often had hallucinations (59.5% vs. 46.9%, $P = 0.025$) than those recipients with a caregiver with moderate/good PWB. No differences between the groups were found in age, care recipients' agitation or satisfaction with services (Table 1).

4.1. Qualitative analysis

In responses to the open-ended question, caregivers expressed a range of feelings from thankfulness and love to being isolated,

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