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Understanding the burden and influencing factors in family caregivers' medication assistance for patients with dementia: a survey study

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Abstract

Background This study aimed to elucidate the sense of burden and the factors that affect medication assistance among family caregivers who provide long-term care to elderly patients with dementia.

Methods Survey method: A sample size of 96 was predetermined, and a web-based survey was conducted to caregivers who met the qualifying criteria. The survey encompassed following components: (1) assessment of burden, (2) determination of difficulty during medication assistance, (3) evaluation of comprehension of medication purposes, (4) evaluation of caregiver's ability to recall administration method, (5) measurement of satisfaction with current medication, (6) examination of harmony between medication and lifestyle habits, (7) cohabitation status with the patient, (8) quantification of oral medications, (9) determination of medication doses (doses) per day, and (10) estimation of time spent on medication assistance. The respondents were categorized into "high burden" and "low burden" groups, and the distribution of responses for items (2) to (7) was compared between these groups using a chi-square test. Mean responses for items (8) to (10) were compared between the groups using a Student's *t*-test. Furthermore, multivariate analysis was performed using burden as the target variable, and significant differences identified between the groups using chi-square and Student's *t*-tests as explanatory variables. The significance level was established at 5%.

Results The study comprised 100 respondents, 90% of whom offered medication assistance. Among the caregivers, 38.9% reported experiencing burden, 56.7% faced challenges with medication assistance, and 36.6% faced medication refusal. Additionally, 15.5% of participants experienced disharmony between their medication and lifestyle. The multivariate analysis results highlighted associations between burden and factors such as the presence/absence of difficulty in medication assistance, number of doses per day, medication refusal, and level of harmony between medication and lifestyle.

Conclusion The burden was influenced by various factors indicating "difficulty." The study highlighted the importance of simplifying medication usage by reducing the number of doses, addressing medication refusal through third-party intervention, and customizing assistance to individual needs based on the psychological conditions of patients and caregivers. These approaches aim to alleviate disharmony between medication and lifestyle.

Keywords Dementia, Care burden, Medication assistance

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Background

At present, approximately 55 million people worldwide suffer from dementia, with approximately 10 million new cases reported annually [1]. About 5.84 million people will have dementia and 6.13 million people will have MCI in 2040. About 15%, or 1 in 6.7 persons, of the elderly aged 65 and over will suffer from dementia, a significant increase from the 4.43 million people in 2022. Even more elderly people are expected to develop MCI [2]. In 2019, Japan's long-term care insurance system identified 6.558 million people eligible for long-term care or support, with dementia representing the highest percentage (18.1%) among the factors necessitating care [3]. Japan's "New Orange Plan" established in 2017, designated "support for caregivers" as one of the seven pillars for fostering dementia-friendly communities. The role of community pharmacists was highlighted in providing "support for caregivers aiming to lessen the care burden of caregivers" [4].

Many individuals diagnosed with dementia experience multiple comorbidities and rely on drug therapy to manage both their symptoms and disease progression [5, 6]. However, as the quantity of medications they consume increases, so does the probability of inappropriate prescriptions [7]. Polypharmacy, the problematic use of multiple medications, affects approximately 40–90% of dementia patients, a rate higher than that observed in the general elderly population [8–10]. Moreover, medication adherence tends to decline earlier than the decline in instrumental activities of daily living (IADL) among dementia patients [11]. For example, research indicates that medication adherence among patients experiencing cognitive decline ranges from approximately 10.7%–38.0% [12]. Factors such as the frequency of doses per day and the total number of medications taken have been linked to declines in medication adherence [13–15].

Caregivers' burden associated with medication administration to patients with dementia remains frequent, and caregivers express an obligation to take responsibility for the medication administration [16, 17]. In addition, caregivers face challenges particularly due to factors such as polypharmacy, cognitive decline, poor medication adherence, and the potential for inappropriate medication use [17, 18]. Consequently, this increases the burden of care on caregivers [19]. Moreover, the increasing reliance of patients with dementia on caregivers for daily activities further exacerbates this burden [20, 21]. For example, the prolonged duration required for medication administration and the additional fluids needed for swallowing can extend the caregiving process, adding to the overall care burden [22].

In Japan, more than half of caregivers have reported difficulties in administering medication to dementia patients

[23, 24]. However, no studies have quantitatively investigated the burden of medication assistance and its related factors in dementia patients. This study aimed to analyze the burden and factors influencing medication assistance by family caregivers for dementia patients, discuss the challenges, propose corresponding measures, and develop the following hypotheses:

1. The burden of medication assistance correlates with prescription characteristics such as the number of medications, frequency of doses, alignment between dosage and daily life, etc.
2. Difficulties enhance the perceived burden of medication assistance.
3. The burden of medication assistance is associated with the caregiver's perception and comprehension of the medication.

Methods

Survey

A preliminary screening was conducted on the Kanden CS Forum website, a web-based contract research organization, to select potential caregivers who met the eligibility criteria for providing care to dementia patients and administering prescribed medications. The following items were used to select the subjects for the screening survey.

- Are they caring for a dementia patient at home?
- Does the patient receive prescriptions for medications?

From among the candidates meeting the criteria, only those who consented to participate in the survey were selected. Participants who experienced difficulty in completing the web-based survey were excluded. The homepage of the contract research organization can be accessed at <https://www.kcsf.co.jp/company/outline.html>.

The minimum required sample size was estimated to be 96, considering a confidence level of 95%, a margin of error of 10%, and a response probability of 50%. The population size of caregivers of dementia patients is assumed to be 4.40 million. Ultimately, 100 participants were recruited. The survey was conducted from November 12 to November 17, 2021.

The main survey elements included attributes related to both dementia patients and caregivers. For patients, these included gender, age, type of dementia, and the presence or absence of behavioral and psychological symptoms of dementia (BPSD). Caregiver attributes included gender, age, relationship with the patient, level of care burden, average weekly caregiving time, co-habitation status with dementia patient, frequency of medication assistance (rated on a 3-point scale: always/sometimes/not at all),

burden of medication assistance (rated on a 4-point scale: very burdensome/somewhat burdensome/somewhat not burdensome/not burdensome), difficulty in medication assistance (rated on a 3-point scale: always/ sometimes/ never), specific difficulties encountered in cases of difficulty (multiple-choice question), method used by caregivers to confirm medication intake, maximum time required for medication assistance (in minutes), patient’s refusal of medication (rated on a 3-point scale: do not dislike/ sometimes dislike/ always dislike), number of types of oral medication, number of doses per day, caregiver’s ability to recall the method of administration (rated on a 5-point scale: remember all/ mostly remember/ remember about half/ mostly don’t remember/ do not remember), understanding of the purpose of medication (rated on a 5-point scale: know all/ mostly know/ know about half/ mostly do not know/ do not know at all), level of satisfaction with current medication (rated on a 5-point scale: satisfied/ mostly satisfied/ not sure/ somewhat dissatisfied/ dissatisfied), and harmony between medication and lifestyle habits (rated on a 4-point scale: yes/ generally yes/ somewhat no/ no). The level of care burden was assessed using 22 items from the Japanese version of the Zarit Caregiver Burden Interview (J-ZBI) [25]. The J-ZBI is a caregiver burden scale developed by Arai et al. [25] and consists of 22 items regarding physical burden, psychological burden, and economic difficulties. Each item is assessed on a 5-point scale with scores ranging from 0 (indicating no burden at all) to 4 (indicating constant burden).

Analysis

Caregivers who provided medication assistance were identified, and those expressing feelings of either “very

burdensome” or “somewhat burdensome” were categorized into the “high burden group,” while those reporting “somewhat not burdensome” or “not burdensome” were categorized as the “low burden group.” A Student’s t-test was used to compare these two groups regarding the number of types of oral medication, number of doses per day, average weekly caregiving time, and time required for medication assistance. Additionally, a chi-squared test was performed for each of the six items (as shown in Table 1) to examine differences in responses and cohabitation status between the groups. Moreover, a stepwise linear regression analysis was performed to identify factors influencing the burden of caregivers’ medication assistance. The target variable was the burden of caregivers’ medication assistance (Converted to binary data with the high burden group as 1 and the low burden group as 0 as shown in Table 1), while the explanatory variables comprised those exhibiting significant differences between the two groups in previous tests. Statistical analyses were performed using IBM SPSS (for Windows, version Ver. 28) with a significance level set at 5%.

Ethical considerations

This study was approved by the Research Ethics Committee of the Osaka Medical and Pharmaceutical University (No. 0087).

Results

1. Frequency of medication assistance (N= 100)

It emerged that caregivers accounted for approximately 90% of medication assistance, delineated as

Table 1 Response option segments

Item	Response option	Segment
Burden of medication assistance	somewhat not burdensome/ not burdensome very burdensome/ somewhat burdensome/	low burden high burden
Difficulty in medication assistance	never sometimes/ always	not difficult difficult
Medication refusal	do not dislike sometimes dislike/ always dislike	no medication refusal medication refusal
Caregiver’s ability to recall the method of administration	remember all mostly remember/ remember about half/ mostly don’t remember/ do not remember	remember do not remember
Understanding of the purpose of medication	know all mostly know/ know about half/ mostly do not know/ do not know at all	high understanding low understanding
Level of satisfaction with current medication	satisfied/ mostly satisfied not sure/ somewhat dissatisfied/ dissatisfied	high satisfaction low satisfaction
Harmony between medication and lifestyle habits	yes/ generally yes somewhat no/ no	high harmony low harmony

“always” (56.0%), “sometimes” (34.0%), and “not at all” (10.0%). A subsequent analysis was conducted based on responses from 90 caregivers engaged in providing medication assistance.

2. Attributes of patients with dementia

Women comprised of 64.4% of the participants, with a mean (SD) age of 84.0 (8.0) years. The types of dementia, listed in descending order of frequency, were Alzheimer’s type (51.1%), mild cognitive impairment (MCI) (21.1%), vascular (11.1%), Lewy body type (6.7%), frontotemporal (2.2%), unknown (7.8%), with 14.4% exhibited BPSD. Regarding eligibility certification for long-term care or support, categories 1 and 2 for support needs were 4.4% and 7.8%, respectively. Long-term care needs categories 1 to 5 were 25.6%, 23.3%, 18.9%, 8.9%, and 7.8% respectively, with 2.2% being uncertified and 1.1% categorized as unknown.

3. Attributes of caregivers

Participant’s ethnicity is Japan. Women constituted 58.9% of caregivers, with a mean (SD) age of 55.9 (12.1) years. The relationships with the patient, listed in descending order of prevalence, included children (including in-laws) (83.3%), spouses (8.9%), grandchildren (5.6%), and siblings (2.2%).

4. Level of care burden, time spent in care, and cohabitation

The mean J-ZBI score (SD) was 35.8 (18.5), with 76.7% of caregivers reporting a “mild” or more severe care burden (Table 2). The mean (SD) weekly caregiving time was 21.0 (25.7) hours, and 67.8% of caregivers reported cohabitation with the patient.

5. Burden of medication assistance

The distribution of responses was as follows: “very burdensome”: 5 (5.6%), “somewhat burdensome”: 30 (33.3%),

“somewhat not burdensome”: 27 (30.0%), and “not burdensome”: 28 (31.1%). Despite variations in burden levels, 68.9% perceived medication assistance as burdensome to some degree.

6. Difficulty with medication assistance

The distribution of responses was as follows: “always” (5.6%), “sometimes” (51.1%), and “never” (43.3%). The top three difficulties reported by percentage were “forgetting to take medication” (49.0%), “medication refusal” (33.3%), and “inability or difficulty in swallowing” (31.4%) (Table 3). Regarding medication refusal, the breakdown was: “always dislike” (4.4%), “sometimes dislike” (32.2%), and “do not dislike at all” (63.3%), with approximately 36.6% of caregivers reporting instances of medication refusal.

7. Caregivers’ methods of confirming medication use, number of types of oral medications, number of doses per day, and maximum time required for medication assistance

Regarding the method of confirming medication taking, the corresponding responses were as follows: “stay by the patient’s side until the medication ingestion is completed” (59.0%), “verify that the medicine sheet/package is empty” (31.0%), “confirm by asking the patient” (7.0%), and “utilizing other methods” (3%). The mean (SD) for the number of types of oral medication was 4.5 (2.9), and for the daily dosage frequency was 2.1 (1.0). Regarding responses about the maximum

Table 2 Caregiving burden segments

Segment	J-ZBI score	number of subjects	%
Low	less than 21	21	23.3
Mild	21~40	32	35.6
Moderate	41~60	28	31.1
High	61 and above	9	10.1

Table 3 Difficulty in medication assistance (n=51, multiple answers allowed)

Item	Response distribution	
	n	% ^a
Forget taking medication	25	49.0
Refuse medication	17	33.3
Inability/difficulty in swallowing	16	31.4
Need longer time to swallow	14	27.5
Cannot confirm medication taking	12	23.5
Spill water when taking medication	7	13.7
High number of medications and number of doses	5	9.8
Mistake in method and dose of taking medication	4	7.8
Does not take medication owing to no perception of disease	3	5.9
Resists the form of the medication	1	2.0
High number of medication timings	1	2.0
Other	1	2.0

^a Percentage among 51 respondents

time required for one instance of medication assistance, “within 5 minutes” represented 62.2%, and “more than 30 minutes” accounted for 12.2%, with a mean (SD) of 11.1 (18.7) minutes.

8. Memory of the method of taking medication and understanding its purpose

The distribution of responses regarding recollection of the medication administration method were as follows: “remember all” (47.8%), “mostly remember” (32.2%), “remember about half” (15.6%), “mostly don’t remember” (1.1%), and “do not remember” (3.3%). This indicates that approximately 20% of caregivers had difficulty in recalling the method of medication administration. For understanding the purpose of medication, the response distribution was as follows: “know all” (40.0%), “mostly know” (43.3%), “know about half” (10.0%), “mostly do not know” (6.7%), and “do not know at all” (0.0%). This shows that about 16.7% of caregivers lacked understanding of the medication’s purpose.

9. Level of satisfaction with current medications

The responses to the question “How would you feel if the current medication continued lifelong for the patient you are caring for?” were distributed as follows: “satisfied” (14.4%), “mostly satisfied” (21.1%), “not sure” (48.9%), “somewhat dissatisfied” (11.1%), and “dissatisfied” (4.4%), with approximately 15.5% of caregivers expressing dissatisfaction.

10. Harmonization between medication and lifestyle

The responses to the question, “Do you think that the use of medication has become part of the patient’s lifestyle, like eating or brushing teeth?” were as follows: “yes” (52.2%), “generally yes” (32.2%), “somewhat no” (13.3%), and “no” (2.2%), with about 15.5% of caregivers indicating disharmony.

11. Factors associated with caregivers’ burden of medication assistance

The results of Student’s t-tests indicated notable differences between the two groups concerning the “number of doses per day” and the “time required for medication assistance” (Table 4). Moreover, the results of chi-square tests indicated significant differences between the two groups regarding “difficulty in medication assistance,” “patient’s refusal of medication,” “harmony between medication and lifestyle,” and “cohabitation status with the patient needing care” (Table 5).

12. Factors influencing caregivers’ burden of medication assistance

Table 4 Student-t test results

	Low burden group (n = 55)	High burden group (n = 35)	P
Number of types of oral medication	4.4	4.8	0.527
Number of doses per day	2.0	2.5	0.022
Average time spent per week in care	19.6	23.1	0.528
Time required for medication assistance	6.1	18.9	0.001
J-ZBI score	33.7	39.2	0.175

The results from the linear regression analysis suggest that the burden of caregivers’ medication assistance was influenced by four factors: “difficulty in medication assistance,” “number of doses per day,” “medication refusal,” and “level of harmony between medication and lifestyle” (Table 6).

Discussion

The data showed that 38.9% of caregivers experienced burden when providing medication assistance. This burden was primarily influenced by difficulties in providing such assistance. The findings suggest that factors such as the “number of doses per day,” “medication refusal,” “harmony between medication and lifestyle,” “forgetting to take medication,” and “difficulty in swallowing” directly affect medication adherence. Approximately 20% of the factors that complicate drug therapy, such as the number of doses and medications, have been reported as being addressed through simple modifications in the dosing regimen [26]. Moreover, studies indicate that the threshold for the number of medications associated with an increased risk of adverse events is six [27]. Therefore, recommendations include optimizing the number of medications, simplifying dosages, designing dosage forms, and crafting simple prescriptions to facilitate easier management of medications for patients and their families [28]. Specifically, reducing the number of medications and doses can be achieved by using medical compounds or consolidating dosages into once-a-day administration.

In cases where a patient refuses oral medication, intervention from a third party or exploring alternative methods, such as patches, may be considered. The use of barrier-free medication, tailored to a patient’s ability to swallow, can also be helpful. For instances where medication is forgotten, self-managed adherence aids such as medication calendars and medication support robots can be beneficial. However, caregivers should exercise caution, as alterations in prescription and the introduction of assistive tools may inadvertently heighten stress and burden [29].

Table 5 Chi-square test results

	Low burden group (n = 55)		High burden group (n = 35)		P
	n	%	n	%	
Difficulty in medication assistance (yes)	20	36.4	31	88.6	< 0.01
Medication refusal (yes)	10	18.2	23	65.7	< 0.01
Caregiver ability to recall method of administration (yes)	28	50.9	15	42.9	0.520
Understanding of purpose of medication (high)	25	45.5	11	31.4	0.270
Satisfaction with medication (high)	21	38.2	11	31.4	0.652
Harmony between medication and lifestyle (high)	50	90.9	26	74.3	0.042
Cohabitation with care recipient (yes)	42	76.4	19	54.3	0.038

Table 6 Linear regression analysis results (only showing items exhibiting significant differences)

	Non-standardized coefficients		Standardized coefficients beta	t value	Significance probability	95% confidence interval for B	
	B	Standard error				Lower limit	Upper limit
(constants)	-0.525	0.253		-2.074	0.041	-1.029	-0.022
Difficulty in medication assistance	0.834	0.126	0.533	6.623	< 0.01	0.584	1.084
Number of doses per day	0.264	0.065	0.285	4.087	< 0.01	0.136	0.393
Level of harmony with lifestyle	0.194	0.082	0.167	2.368	0.020	0.031	0.357
Medication refusal	0.296	0.128	0.185	2.314	0.023	0.042	0.551

ANOVA $p < 0.001$: Adjusted $R^2 = 0.578$

The results suggest a direct correlation between caregiver burden and the disharmony between medication and patient’s lifestyle. For caregivers, maintaining a simple medication management process is essential, especially since dementia patients can experience disruption in their daily routines when new elements are added [30]. Caregivers often face challenges when they adopt the role of medication assistant for the first time, and difficulties may arise due to the care recipient’s lack of cooperation or inconsistent access to medications [31]. Additionally, caregivers prioritize the health of care recipients over their own well-being, resulting in inadequate support from medical professionals and heightened feelings of isolation [32–34]. It has been reported that counseling or interventions by pharmacists improves caregivers’ understanding of dementia and reduces caregiving burdens [35, 36]. Therefore, it is crucial that pharmacists actively engage in measures to address each challenge by gaining a deeper understanding of the living conditions, emotions, and perspectives of both patients and caregivers.

This study has several limitations. Firstly, this is a relatively small sample and may be relatively homogeneous, limiting generalizability. Secondly, there might be

a sampling bias, where caregivers experiencing more burden were more inclined to participate in the survey. Thirdly, recall bias and social desirability bias may have influenced participants’ responses to the survey. To generalize the findings, it is essential to continue conducting quantitative and qualitative surveys involving different subjects in the future.

Conclusion

The study revealed that 38.9% of caregivers experienced the burden of medication assistance. Additionally, 56.7% of caregivers encountered challenges in medication assistance, 36.6% dealt with medication refusal, and 15.5% perceived a disharmony between medication and lifestyle. The multivariate analysis indicated that factors such as the “number of doses per day,” “medication refusal,” and “disharmony between medication and patient lifestyle,” contributed to caregivers’ burden with medication assistance. This study suggests the need to simplify medication usage by reducing the number of doses, involving a third party in medication administration, addressing medication refusal, and providing personalized assistance based on patients’ and caregivers’ daily living and psychological conditions to alleviate medication-lifestyle disharmony.

Abbreviations

IADL	Instrumental activities of daily living
BPSD	Behavioral and psychological symptoms of dementia
J-ZBI	Japanese version of the Zarit Caregiver Burden Interview

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Authors' contributions

MI and KZ analyzed the data and wrote the main manuscript text. MS assisted with data management and analysis. HM assisted prior research review and questionnaire design. MO oversaw all aspects of the research preparation, implementation, data analysis, and paper writing. All authors read and reviewed the final manuscript.

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Data availability

The datasets generated and/or analyzed during the current study are not publicly available due to the university's regulations, but are available from the corresponding author on reasonable request.

Declarations

Ethics approval and consent to participate

This study was approved by the Research Ethics Committee of the Osaka Medical and Pharmaceutical University (No. 0087). Informed consent was obtained from all the study participants.

Consent for publication

Not applicable.

Competing interests

The authors declare no competing interests.

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