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Priorities of Family Caregivers in Preserving Functional Abilities of Individuals with Alzheimer's Disease Living at Home: A Best-Worst Scaling Approach

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Purpose: The decline in cognitive abilities among individuals with Alzheimer's disease significantly impacts their Activities of Daily Living (ADLs), creating challenges and stress for their caregivers. This study aimed to investigate the priorities of family caregivers of community-dwelling individuals with Alzheimer's disease concerning the preservation of their loved ones' ADLs.
Methods: We employed a cross-sectional design with a best-worst scaling approach (BWS), and developed a BWS questionnaire utilizing the 10 daily living items from the Disability Assessment for Alzheimer's Disease scale. This questionnaire was administered to 132 caregivers of individuals with Alzheimer's disease. Data analysis was conducted using SPSS WIN 21.0 and the R statistical program.
Results: The results revealed that "using the toilet without accidents" emerged as the top-ranked ADL that family caregivers preferred to preserve for the longest duration among individuals with Alzheimer's disease living at home. In contrast, "Managing money appropriately" was identified as a daily living activity considered relatively less critical to preserve. The study further indicated a preference among caregivers for preserving physical ADLs over instrumental ADLs.
Conclusion: This research provides clinical evidence shedding light on the priorities of family caregivers in preserving the functional abilities of individuals with Alzheimer's disease within the community.

Keywords: Health priorities; Activities of daily living; Alzheimer disease; Caregivers

Introduction

Currently, over 55 million people worldwide are experiencing symptoms due to Alzheimer's disease, with nearly 10 million new cases occurring annually [1]. It ranks 7th globally as a major cause of disability and dependence in the elderly, with Alzheimer's disease being a significant [1]. Once Alzheimer's disease occurs, it is challenging to treat, and due to a prolonged deteriorative process, individuals often require assistance in their daily lives [2].

Alzheimer's disease has notable psychological, societal, and economic ramifications not only for patients, but also for caregivers, families, and society as a whole [1]. The decline in the intricate functional abilities associated with Alzheimer's disease renders independent living unattainable, thereby necessitating constant supervision and management around the clock. Caregivers place great importance on upholding the functional capabilities of their family members whom they attend to [3]. These individuals play a crucial role in safeguarding and monitoring the well-being of their care recipients, ensuring their cleanliness and comfort, providing them with nourishment and hydration, and engaging them in social and recreational activities [4]. The burdens faced by families caring for individuals with Alzheimer's disease, including anxiety, social isolation, financial challenges, and concerns about the future, are substantial and profound [5].

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Consequently, there exists a pressing need for programs and interventions that assist family caregivers in preserving the functional abilities of Alzheimer's patients and in surmounting the obstacles encountered in the caregiving process. Specifically, the decline in cognitive abilities associated with Alzheimer's disease, which affects the Activities of Daily Living (ADL) of patients, presents challenges and stress for caregivers [6]. The reduction in both ADL and Instrumental Activities of Daily Living (IADL) exacerbates the burden on caregivers [7,8]. Caregivers experience heightened burden and psychological stress, particularly when caring for individuals with Alzheimer's disease who have lower ADL, thereby leading to an overall decrease in their quality of life [9,10]. Consequently, there is a need for support and policies that alleviate the burden on family caregivers, provide respite, and assist with the ADL of individuals with Alzheimer's disease [11]. Understanding the priorities of family caregivers regarding the preservation of daily living skills in Alzheimer's disease patients is crucial because it helps in the tailored development of care plans that align with the most valued functions according to the patient and family caregivers' needs. Therefore, gaining an understanding of the activities that individuals with Alzheimer's disease desire to sustain and maintain without the assistance of caregivers can offer valuable insights for policy support and guidance.

The Best-Worst Scaling (BWS) method is widely used in the medical and health fields to measure individual preferences for various alternatives, allowing for the analysis of preferences from the perspective of users, such as patients or local [12-14]. A study utilizing BWS in the United States and Germany investigated the priorities for preserving the daily functional abilities of Alzheimer's disease patients from the perspective of caregivers. The results showed that in both countries, the ability to use the toilet without accidents was the most desired, while the ability to handle money was ranked as the least important [15]. The BWS method, requiring participants to choose the best and worst alternatives from given items, makes it easy for participants to respond, and the questionnaire typically includes around 15 items, minimizing the burden on participants.

When examining the existing research on Alzheimer's disease and its caregivers, it's clear that these studies largely concentrate on the mental, social, and economic challenges that caregivers of dementia patients face [16,17]. Nevertheless, a notable gap in this research area is the lack of focus on what family caregivers prioritize in maintaining the everyday functional capabilities of Alzheimer's disease patients. The objective of this research is to discern the priorities of family caregivers in maintaining the functional abilities of their loved ones with Alzheimer's disease residing at home, through the application of the Best-Worst Scaling (BWS) approach. The goal is to collect vital information to aid in creating support programs and policies for Alzheimer's disease, designed to reduce the burden on family caregivers. This will be achieved by gaining a deeper understanding of the aspects family caregivers deem most important in preserving the daily functional skills of Alzheimer's disease patients.

Methods

Study Population

The target population for this study consisted of family caregivers providing care for community-dwelling elderly individuals with Alzheimer's disease in South Korea. The inclusion criteria were as follows: 1) Family caregivers of community-dwelling elderly individuals diagnosed with Alzheimer's disease, 2) Family caregivers of Alzheimer's disease patients classified under long-term care insurance grades 3, 4, or 5 and cognitive support grade, 3) Individuals providing care for at least the past 6 months, 4) Those capable of responding to the survey, and 5) Those who understood the purpose of the study and agreed to participate. Family caregivers of Alzheimer's disease patients with comorbid vascular Alzheimer's disease were excluded.

Data Collection

The convenience sample was drawn from family caregivers utilizing Alzheimer's disease relief centers at public health centers in K city, J city, and W county. Prior to data collection, the researcher explained the study's objectives and participation methods to each center's manager and obtained approval for data collection. Research assistants conducted pre-education sessions in two parts for Alzheimer's disease patients' caregivers, covering the daily living abilities of Alzheimer's disease patients, research objectives, ethical considerations, and confidentiality. To enhance the validity of data collection, a manual outlining the survey procedures and methods was developed, and training sessions were conducted and distributed.

After receiving the two-part pre-education, trained research assistants explained the research objectives, participation methods, confidentiality, and survey response procedures to family caregivers of Alzheimer's disease patients. Written consent was obtained, and the survey was then conducted using self-administered questionnaires. Participants were informed that they could discontinue the survey at any time if they chose not to respond to specific questions. The participants filled out the question-

naire in a private space, and for the safety of Alzheimer's disease patients, a designated area was provided within the Alzheimer's disease relief center. The center was equipped with an automated external defibrillator and had medical personnel available to address any emergency situations that might arise in Alzheimer's disease patients.

The survey was conducted from July 27, 2020, to September 29, 2020, with a total of 150 participants. 7 participants (4.7%) declined, and 11 participants (7.3%) provided incomplete or insincere responses, leaving 132 (88%) completed surveys for analysis. After completing the survey, participants were offered token gifts as a gesture of appreciation.

Measurements

Daily Living Abilities

Daily living abilities were measured using scores obtained from the Disability Assessment for Alzheimer's disease (DAD), a scale developed for assessing the disability of Alzheimer's disease patients and other Alzheimer's disease patients [18]. The DAD consists of 40 items about hygiene, dressing, toileting, eating, meal preparation, making phone calls, going out, financial and letter management, medication, leisure, and housework. Caregivers were asked to evaluate whether patients could perform these activities in the past two weeks without assistance or instructions, using a scoring system of [0 = No, 1 = Yes, × = Not Applicable]. The total scor e was obtained by dividing the sum of scores (excluding "Not Applicable") by the total number of items, resulting in scores ranging from a minimum of 0 (completely disability) to a maximum of 100 (full function). Higher DAD scores indicate fewer disabilities, while lower scores suggest more significant impairments.

Questions of BWS Survey

For the BWS method, the study referred to a previous study conducted in the United States in 2014 [15] and utilized the Korean version of DAD to construct 10 daily living ability items (hygiene, dressing, toileting, eating, meal preparation, making phone calls, going out, financial and letter management, medication, leisure, and housework). The survey design aimed to determine the minimum number of response items for BWS analysis using the R statistical program. The study employed a main effects orthogonal design to ensure no correlation or interaction among factors. Table 1 presents the results of the main effects orthogonal design.

In Table 1, rows represent 12 choice sets (questions) composed of daily living ability items, and columns represent 10 daily living ability items. Supplementary Figure 1 illustrates an example of the BWS survey, where Question 1 is composed of four daily living ability items (item 1, 5, 8, 10), and participants indicate the item they most want to preserve and the one they least want to preserve relative to each other. The survey design resulted in sets with 4 daily living ability items (Sets 1, 5, 6, 7, 8), 5 items (Sets 2, 3, 9, 10, 11, 12), and 10 items (Set 4). Each daily living ability item appeared in 5 to 7 of the 12 choice sets.

A preliminary survey was conducted with 30 family caregivers of Alzheimer's disease patients to ensure the meaningfulness of the survey items, participant understanding of the items, and the appropriateness of the survey format. Initially, all family caregiv-

Table 1. BWS choice sets by Orthogonal main Effects Design (OMED)

ADL BWS questions	Item1	Item2	Item3	Item4	Item5	Item6	Item7	Item8	Item9	Item10
1	×				×			×		×
2	×	×	×				×			×
3		×		×	×	×				×
4	×	×	×	×	×	×	×	×	×	×
5	×	×				×			×	
6			×		×	×				×
7		×	×	×				×		
8				×			×		×	×
9			×			×		×	×	×
10	×			×		×	×	×		
11	×		×	×	×				×	
12		×			×		×	×	×	

Item1: Hygiene, Item2: Dressing, Item3: Continence, Item4: Eating, Item5: Meal preparation, Item6: Telephoning, Item7: Going on an outing, Item8: Finance and correspondence, Item9: Medication, Item10: Leisure and housework

ers of community-dwelling Alzheimer's disease patients were considered as potential study participants. However, based on the preliminary survey, it was found that caregivers of severe Alzheimer's disease patients had difficulty responding to priority items related to the daily living abilities of patients who could not perform these tasks on their own. Therefore, the final study participants were limited to those caring for Alzheimer's disease patients classified under long-term care insurance grades 3 to 5 and cognitive support grade.

Analysis

The collected data were analyzed using SPSS WIN 21.0 and the R statistical program. Characteristics of Alzheimer's disease patients' family caregivers and Alzheimer's disease patients were analyzed using frequency and percentages. The daily living abilities according to the characteristics of Alzheimer's disease patients were analyzed using means and standard deviations. Comparative analyses were performed using independent t-tests, One-way ANOVA, and Scheffé post-hoc tests. To analyze the priorities of daily living abilities that caregivers most prefer to preserve, both counting approach and modeling approach were employed. Both approaches were conducted using the DoE.base package [19] and support. BWS package [20] in R statistical programming.

BWS analysis: Counting approach

The analysis of collected data can be conducted using a counting approach and a modeling approach. In this study, both methods were employed to assess the degree of consistency in research findings. However, it has been demonstrated in previous studies [21,22] that there is generally little difference in the prioritization of items determined by the counting approach and the modeling approach. The counting approach determines the priority of items based on the frequency with which instrumental activities of daily living (IADL) i, desired to be preserved the longest in a set of 12 choices by respondents (N), are selected as abilities one wishes to preserve the most and abilities one wishes to preserve the least. The scores derived from the following formula can be utilized to understand the prioritization and relative importance of instrumental activities of daily living items [23].

$$BW_i = B_i - W_i \quad (1)$$

$$std.\ BW_i = \frac{BW_i}{Nr} \quad (2)$$

$$sqroot.\ BW_i = \sqrt{\frac{B_i}{W_i}} \quad (3)$$

$$std.sqoot \cdot BW_i = \frac{sqroot \cdot BW_i}{max \cdot sqroot \cdot BW_i} \quad (4)$$

In Equation (1), B_i represents the frequency with which respondents (N) selected instrumental activities of daily living item i as the one they desire to preserve the longest, W_i represents the frequency with which respondents selected item i as the one they wish to preserve relatively less, and BW_i indicates the difference in frequency between B_i and W_i. In Equation (2), $std.BW_i$ is the standardized difference between B_i and W_i, calculated as the ratio of the frequency of each item entered in the BWS survey divided by Nr (For example, the hygiene item (carefully and thoroughly washing and drying one's body) (item1) is included in questions 1, 2, 4, 5, 10, and 11, totaling 6 occurrences in Table 2). This value is utilized to determine the priority among instrumental activities of daily living items. Equation (3) introduces $sqroot.BW_i$, the square root of the ratio of B_i and W_i, which is used to standardize the values. In Equation (4), $std.sqroot.BW_i$ represents the standardized value from Equation (3). It is obtained by dividing the $sqroot.BW_i$ of the most important instrumental activity of daily living item in a specific respondent's $sqroot.BW_i$, thereby discerning the relative importance among instrumental activities of daily living items.

Ethical Considerations

The study was conducted with ethical considerations in mind, having obtained approval from the Institutional Review Board (IRB No: 2020-06-016-001) at Jeonbuk National University. All information was strictly used for research purposes only.

Participants were informed that they could withdraw from the study at any time without facing any disadvantages, and explanations were provided regarding the benefits and risks associated with research participation. Personal information was coded to ensure only the researchers could identify individuals, maintaining confidentiality. Participants were notified that all collected data would be securely discarded by the researchers three years after the completion of the study. Additionally, research assistants received prior training related to the study and participated in the research after signing a confidentiality agreement.

Results

General Characteristics of Study Participants

The general characteristics of the study participants are presented in Table 2. A total of 132 participants were included, having an average age of 58.70 years (±14.90) and comprised 53 males

Table 2. Characteristics of the participants (Family caregivers) (*N*=132)

Characteristics	Category	n	(%) or M ± SD
Age	≤ 59	67	(50.8)
	60~69	24	(18.2)
	70~79	29	(22.0)
	≥ 80	12	(9.0)
			58.70 ± 14.90
Sex	Men	53	(40.2)
	Women	79	(59.8)
Education	No education	10	(7.6)
	Primary	23	(17.4)
	Middle school	24	(18.2)
	High school	33	(25.0)
	≥ College	42	(31.8)
Marital status	Married	105	(79.5)
	Single	21	(15.9)
	Divorced, separated, bereaved	6	(4.6)
Occupation	Yes	88	(66.7)
	No	44	(33.3)
Religion	Protestant	39	(29.5)
	Buddhism	11	(8.3)
	Catholic	9	(6.8)
	None	68	(51.5)
	Others	5	(3.9)
Subjective health level	Bad	26	(19.7)
	Moderate	63	(47.7)
	Good	43	(32.6)
Relationship with patient	Spouse	40	(30.3)
	Son	36	(27.3)
	Daughter	28	(21.2)
	Daughter-in-law	14	(10.6)
	Son-in-law	1	(0.8)
	Others	13	(9.8)
Cohabitation with patient	Yes	72	(54.5)
	No	60	(45.5)
Period of caregiving (month)	< 12	23	(17.4)
	12 ~ < 36	54	(40.9)
	36 ~ < 60	24	(18.2)
	≥ 60 months	31	(23.5)
			41.05 ± 44.64
Average hours of care a day	< 8	81	(61.4)
	8 ~ < 16	14	(10.6)
	≥ 16	37	(28.0)
			9.02 ± 9.05

Table 3. Characteristics of patients with Alzheimer's Disease (*N*=132)

Characteristics	Category	n	(%) or M ± SD
Age	≤ 69	7	(5.3)
	70~79	50	(37.9)
	80~89	61	(46.2)
	≥ 90	14	(10.6)
			80.88 ± 6.80
Sex	Men	46	(34.8)
	Women	86	(65.2)
National Long-Term Care Insurance	Level 3	18	(13.6)
	Level 4	24	(18.2)
	Level 5	84	(63.6)
	Cognition-supporting level	6	(4.6)
Period of dementia diagnosed (month)	< 12	26	(19.7)
	12 ~ < 60	73	(55.3)
	≥ 60	33	(25.0)
			40.39 ± 39.60
Medication	Yes	129	(97.7)
	No	1	(0.8)
	Do not know	2	(1.5)
ADL(DAD-K)			52.17 ± 32.19

DAD-K; Korean version of Disability Assessment for Dementia

(40.2%) and 79 females (59.8%). The majority had an education level of college or higher (31.8%), and most were married (79.5%). Among the participants, 88 (66.7%) were employed, and 68 (51.5%) identified as having no religious affiliation. Subjective health status was reported as 'moderate' by 63 participants (47.7%) and 'good' by 43 participants (32.6%). Regarding the relationship with the care recipient, 76 participants (57.6%) cared for a spouse or son, and 42 participants (31.8%) cared for a daughter or daughter-in-law. Others, including siblings, nieces/nephews, and grandchildren, accounted for 13 participants (9.8%). Of the participants, 72 (54.5%) were living with patients. The average daily caregiving time for caregivers of Alzheimer's disease patients was 9.02 (± 9.05) hours, with a total caregiving duration averaging 41.05 (± 44.64) months.

Key Characteristics of Alzheimer's disease Patients

The general characteristics of Alzheimer's disease patients are presented in Table 3. The average age of the patients was 80.88 years (± 6.80), consisting of 46 males (34.8%) and 86 females (65.2%). The majority of participants were classified under a long-term care insurance level of 5 (84 participants, 63.6%), followed by level 4 (24 participants, 18.2%), level 3 (18 participants, 13.6%), and cognition-supporting level (6 participants, 4.6%). The average duration of Alzheimer's disease among the participants was 40.39 months (± 39.60), with 129 (97.7%) undergoing medication treatment. The average score on the Disability Assessment for Alzheimer's disease-Korean version

(DAD-K) was 52.17 (±32.19) out of 100.

Results of BWS Analysis

The results of the prioritization of daily living activities by study participants using the counting approach are presented in Table 4. In Table 4, B represents the frequency with which participants chose an activity as the one they most want to preserve, W represents the frequency with which they chose an activity as the one they least want to preserve, and BW represents the difference in frequencies as per Equation (1). *stdBW, sqrtBW,* and *std.sqrt.BW* represent the results of Equations (2), (3), and (4), respectively. The std.BW scores are used as an indicator of the prioritization of daily living activities. The top-ranked daily living activities were 'Using the toilet without accidents' as the 1st priority, 'Going out and reach a familiar destination without getting lost' as the 2nd priority, and 'Stay safely at home by himself/herself when needed' as the 3rd priority. Lower-ranked activities were 'Dress himself/herself completely,' 'Carry out an appropriate telephone conversation,' and 'Handel adequately his/her money (make change),' ranked 8th, 9th, and 10th, respectively. The std.sqrt.BW values indicate the relative importance of daily living activities, with the 1st priority activity having a value of 1, and other activities having values less than 1.

Table 5 presents the estimated utilities (coefficients) between each daily living activity using the model approach with the conditional logit model. 'Stay safely at home by himself/herself when needed' serves as the reference daily living activity with a fixed coefficient of 0, acting as a baseline to indicate the differences in utilities for other daily living activities. 'Using the toilet without accidents' was ranked 1st, 'Going out and reach a familiar destination without getting lost' and 'Stay safely at home by himself/herself when needed' were ranked 2nd. 'Take his/her medications as prescribed (according to the right dosage)', 'Eat his/her meals at a normal space and with appropriate manners', 'Undertake to wash himself/herself or to take a bath or a shower' and 'Prepare or cook a light meal or a snack safely' were ranked 4th, 5th, 6th, and 7th, respectively. Lower-ranked activities were 'Dress himself/herself completely,' 'Carry out an appropriate telephone conversation,' and 'Handel adequately his/her money (make change) ranked 8th, 9th, and 10th, respectively. The coefficients in Supplementary Table 1 for daily living activities are utilized in calculating the share of preference, representing the relative importance of daily living activities. The sum of these coefficients is 1. Supplementary Figure 2 depicts the share of preference (%).

Discussion

This study aimed to identify the prioritization of daily living activities preferred by family caregivers for Alzheimer's disease patients using the BWS analysis method. The analysis results unveiled that, based on the Korean version of the Disability Assess-

Table 4. The priorities of preferred preserving activities of daily living by family caregivers of patients with Alzheimer's disease dwelling in the community: by Counting Approach (*N*=132)

ADL item	B	W	BW	std.BW	sqrt.BW	std.sqrt.BW	Priority
Use the toilet without "accidents"	425	29	396	0.50	3.83	1.00	1
Go out and reach a familiar destination without getting lost	262	103	159	0.20	1.60	0.42	2
Stay safely at home by himself/herself when needed	231	80	151	0.19	1.70	0.44	3
Take his/her medications as prescribed (according to the right dosage)	173	109	64	0.08	1.26	0.33	4
Eat his/her meals at a normal pace and with appropriate manners	149	105	44	0.06	1.19	0.31	5
Undertake to wash himself/herself or to take a bath or a shower.	130	100	30	0.04	1.14	0.30	6
Prepare or cook a light meal or a snack safely	93	201	-108	-0.14	0.68	0.18	7
Dress himself/herself completely	54	202	-148	-0.19	0.52	0.14	8
Carry out an appropriate telephone conversation	51	253	-202	-0.26	0.45	0.12	9
Handle adequately his/her money (make change)	16	402	-386	-0.49	0.20	0.05	10

N=Number of respondents, B=the frequency at which the Activities of Daily Living(ADL) item was responded to be the most preferred preserving; W=the frequency at which the ADL item was responded to be the least preferred preserving; BW=the difference in frequency between B and W (B-W), the ADL item with the largest BW value represents which the participants perceived as the most preferred preserving, and the ADL item with the lowest value indicates which they perceived as the least preferred preserving; std.BW=standardized BW, BW/N*the number of times the ADL item were entered into the BWS question(r), the value obtained by dividing BW by the number of respondents (N) and the number of times the ADL item were entered into the BWS question (r). (BW=Nr, ex., Use the toilet without "accidents" 396/132X6=0.50); Sqrt.BW=the square root of the ratio of B and W ($\sqrt{(B/W)}$); Std.sqrt.BW=standardized value of Sqrt.BW obtained by std.BW of the symptom divided by std.BW of the 1st rank showing the relative importance (eg., Go out and reach a familiar destination without getting lost=1.595/3.828=0.417).

Table 5. The priorities of preferred preserving activities of daily living by family caregivers of patients with Alzheimer's disease dwelling in the community: by Modeling Approach (*N*=132)

ADL item	Coefficient	Standard error	*p*-value	Share of preference (%)	Priority
Use the toilet without "accidents"	0.84	0.09	< .001	30.0	1
Go out and reach a familiar destination without getting lost	0.08	0.08	.354	14.0	2
Stay safely at home by himself/herself when needed (reference)	0.00	-	-	13.0	2
Take his/her medications as prescribed (according to the right dosage)	-0.28	0.08	< .001	9.8	4
Eat his/her meals at a normal pace and with appropriate manners	-0.30	0.08	< .001	9.6	5
Undertake to wash himself/herself or to take a bath or a shower.	-0.47	0.08	< .001	8.1	6
Prepare or cook a light meal or a snack safely	-0.92	0.09	< .001	5.2	7
Dress himself/herself completely	-1.07	0.09	< .001	4.5	8
Carry out an appropriate telephone conversation	-1.24	0.09	< .001	3.8	9
Handle adequately his/her money (make change)	-1.87	0.09	< .001	2.0	10

Observations *N*=35,640, events=1,584; Likelihood Ratio Test: $X^2(df)$=1,364(9), *p*-value=<.001.
p-value indicates for whether the share of preference of each symptom is significantly different compared to the reference.

ment for Alzheimer's disease (DAD-K), "Use the toilet without accidents" emerged as the highest-priority daily living activity that family caregivers aimed to sustain the longest in individuals with Alzheimer's disease. On the contrary, "Handle adequately his/her money" was identified as a daily living activity deemed relatively less crucial to preserve. It is noteworthy that " Use the toilet without accidents " aligns with physical activities of daily living (PADL), while " Handle adequately his/her money " pertains to instrumental activities of daily living (IADL). This implies a distinct preference among family caregivers for prioritizing the preservation of PADL over IADL in Alzheimer's disease patients. The fact that " Use the toilet without accidents " emerged as the top priority is consistent with the results of a previous study conducted with Alzheimer's disease caregivers in the United States and Germany [15]. In this study, the average age of respondents was 58.7 years, with 59.8% being females. It is inferred that the respondents, who are typically older individuals and female spouses or children of Alzheimer's disease patients, may experience physical strain when assisting Alzheimer's disease patients with toileting. Additionally, concerns about economic burdens may arise due to issues such as urinary or fecal incontinence, leading to the use of diapers. Understanding these concerns becomes more apparent when considering the results of a longitudinal study tracking Alzheimer's disease patients for three years, which indicated the highest functional losses in bowel control (25.4%), bathing (25.4%), dressing (22.9%), and bladder control (22.9%) [24].

Urination and defecation are basic physiological activities for all humans, requiring toilet use more than 7 to 8 times a day. This poses a considerable caregiving burden on Alzheimer's disease caregivers. A study tracking 1,001 seniors aged 70 or older (average age 83.4, 68% female) over 12, 18, and 36 months revealed that Alzheimer's disease patients experienced difficulties with toileting at all points compared to non-Alzheimer's disease seniors [25]. Alzheimer's disease patients commonly face issues of urinary and fecal incontinence [26], related to medication side effects, physical impairments, and psychosocial factors [27]. As Alzheimer's disease progresses, patients may struggle to remember the location and proper use of the toilet and may not perceive the need to empty their bladder. Impaired judgment may also lead to challenges in deciding when to use the toilet or how to handle soiled clothing from urine or feces [28]. Furthermore, Alzheimer's disease patients often have comorbid conditions like anxiety or depression that can exacerbate bladder and bowel control problems[29]. To address these issues, medical professionals or nurses with incontinence training can help identify the causes. Therapeutic approaches such as behavioral therapy, toilet training, and bladder training programs should be considered early in the disease, and the judicious use of antimuscarinic agents can aid in bladder training programs [26].

To assist with preventing problems related to toileting, caregivers can keep a record of the times Alzheimer's disease patients typically use the toilet and take appropriate measures. For instance, providing comfortable elastic waist pants during urination and defecation, ensuring a clear path to the toilet without obstacles, and preventing falls by placing the toilet close to the Alzheimer's disease patient's sleeping area can be helpful. Additionally, having items such as diapers or portable urinals readily available can reduce mistakes related to urination and defecation [30]. Alzheimer's disease safety centers, available in each local

government, support Alzheimer's disease patients by providing items such as diapers and waterproof sheets for one patient [31]. Although the National Health Insurance Corporation partially subsidizes costs, such support is limited to short-term assistance, and there is a lack of support to enhance or preserve patients' activities of daily living. While Alzheimer's disease safety centers offer personalized services through case management by visiting Alzheimer's disease patients' homes, assessments of living conditions, and environmental evaluations related to urination and defecation are often not conducted in detail. Nurses from Alzheimer's disease safety centers and public health office visiting care program coordinators can visit Alzheimer's disease patients, assess toilet environments, usage frequency, times of use, and educate family caregivers to minimize discomfort during toilet use. Moreover, they can coordinate with local community resources to install safety handrails in toilets. It would be beneficial to consider policy support for care assistance tools, such as robotic bidets, in the long-term care supplies coverage. Incorporating such advanced technologies not only enhances the autonomy and dignity of individuals with disabilities but also supports caregivers by reducing the physical and emotional burden associated with personal care tasks.

To address the difficulties faced by family caregivers related to urination and defecation in Alzheimer's disease care, active listening and emotional support are essential. Policy-wise, efforts should be made to eliminate the barriers in the toilet threshold of Alzheimer's disease patients' homes, replace the bathroom floor with slip-resistant tiles, and implement the "Alzheimer's disease Patient Toilet Renovation Project." Although South Korea has been implementing housing renovation projects since 2006 to improve living conditions for severely disabled individuals in rural areas, all home-based Alzheimer's disease patients should benefit from this initiative.

In this study, the second function among the daily living abilities of home-dwelling Alzheimer's disease patients that family caregivers wished to preserve for an extended period was "Go out and reach a familiar destination without getting lost" and "Stay safely at home by himself/herself when needed." The safety concerns of Alzheimer's disease patients persisted even after considering cognitive and functional impairments, as evidenced by continuous caregiver burden in the 6-month and 12-month follow-up surveys [32].

In South Korea, the number of reported missing cases of Alzheimer's disease patients has been steadily increasing from 2018 to 2022. As of January 25, 2023, a total of 63,986 cases were reported to the police, with 63,959 of them fortunately finding the missing Alzheimer's disease patients. However, 27 cases remained 'unfound' [33]. To prevent the disappearance of Alzheimer's disease patients, the government has implemented various measures, including issuing recognition tags for wandering seniors, renting tracking devices, fingerprint pre-registration, and the use of Alzheimer's disease check applications [34].

Despite these efforts, the distribution rate of tracking devices has remained very low over the past five years, with figures ranging from 0.40% (as of August 2020) to 0.61% (2017) in comparison to the total number of Alzheimer's disease patients [35]. The low adoption rate is attributed to the complex documentation process required for device rental, including long-term care certification, care usage plans, and welfare aid confirmation. Additionally, caregivers must bear the cost of the device (valued at 250,000 won) if it is lost. Therefore, there is a need for simplified rental procedures, financial support, and promotional activities [36]. Community nurses visiting home-dwelling Alzheimer's disease patients should emphasize campaigns and promotions to prevent missing cases. They should educate Alzheimer's disease patients and family caregivers on utilizing government-provided services for preventing Alzheimer's disease patient disappearance, such as Alzheimer's disease check apps, tracking services, and fingerprint pre-registration. The challenges and complexities surrounding tracking device adoption should be addressed through simplified procedures, financial support, and effective public awareness campaigns [36].

As Alzheimer's disease patients experience a decline in cognitive function, family caregivers often develop anxiety about leaving them alone at home [37]. The reduced ability of Alzheimer's disease patients to respond effectively in emergency situations adds to this anxiety. While monitoring Alzheimer's disease patients is crucial for their well-being and safety, family caregivers may feel increased stress and a lack of personal time, leading to constraints on social activities. The survey results of this study highlight that among the ten daily living abilities, the ability "Stay safely at home by himself/herself when needed" emerged as the second most important function. Community nurses play a crucial role in assisting family caregivers who spend extended periods caring for Alzheimer's disease patients, ensuring that they do not experience physical and mental exhaustion. The long-term care insurance for the elderly provides various home care services, including home care visits, bathing assistance, nursing visits, day and night care, and short-term care services [38]. Community nurses should collaborate with family caregivers to determine the most necessary services for Alzheimer's disease patients and provide information to facilitate their access

to relevant benefits.

Moreover, the installation of monitoring systems becomes essential to allow family caregivers brief breaks, such as going to the supermarket or taking a shower, while still keeping a watchful eye on the actions of Alzheimer's disease patients. These monitoring systems, based on the Internet of Things (IoT), can connect to the smartphones of family caregivers, enabling them to check on the safety of Alzheimer's disease patients at any time and from anywhere. While considerations about protecting the human rights of Alzheimer's disease patients are important, the effectiveness of addressing both the safety of Alzheimer's disease patients and the caregiving burden of family caregivers is deemed significant. Therefore, policy discussions and support are crucial to developing solutions that balance these considerations.

In 2017, with the implementation of the National Alzheimer's disease Responsibility System in South Korea, Alzheimer's disease Safety Centers were established in 256 public health centers nationwide. This initiative strengthened customized case management for Alzheimer's disease patients and provided integrated Alzheimer's disease care services. Starting in 2018, long-term care benefits were regraded for Alzheimer's disease specialization, introducing a new cognitive support grade. Additionally, facilities specializing in Alzheimer's disease care were expanded.

The national policies regarding Alzheimer's disease have undergone a shift towards a service system centered around Alzheimer's disease patients and their families. However, there is a continuous need for policy enhancements. Therefore, the evaluation of Alzheimer's disease patients' activities of daily living (ADL) by family caregivers, as indicated by the DAD score and the priority of preserving ADL, can not only influence the direction of disease and treatment but can also assist in shaping policies related to patient care based on the preferences of family caregivers.

In other words, these results can significantly contribute to understanding the caregiving burden related to the ADL of Alzheimer's disease patients that family caregivers bear. The findings can serve as foundational data for medical service providers, as well as national and local entities involved in Alzheimer's disease-related policies and services. Given that family caregivers consistently play the role of surrogate decision-makers for Alzheimer's disease patients and maintain regular contact and communication with medical service providers and entities executing Alzheimer's disease-related policies and services, the suppliers of Alzheimer's disease-related services can gain a better understanding of the caregiving burden on family caregivers. This understanding can help them realize tailored services to meet the demands of caregivers in terms of support and provision of delegated services.

In this study, a Best-Worst Scaling (BWS) survey was conducted using the 10 items of the Disability Assessment for Alzheimer's disease (DAD) as a basis for creating survey questions. Consequently, there is a possibility that daily living abilities not covered by the DAD might not be identified. To address this limitation, future research could involve in-depth interviews with family caregivers of community-dwelling Alzheimer's disease patients. Through qualitative research, the study could identify the daily living abilities that pose the most significant burden in caregiving. The insights gained from these interviews could then be considered when developing BWS survey questions.

This study aimed to use the Best-Worst Scaling method, not previously employed in health and nursing research in South Korea, to explore the priority of preserving activities of daily living for community-dwelling Alzheimer's disease patients as preferred by family caregivers. While research on the caregiving burden of Alzheimer's disease patients' families is common, this study holds significance as it is the first in South Korea to apply BWS to survey the preferences of family caregivers regarding the preservation of activities of daily living for Alzheimer's disease patients.

Conclusion

This study represents the first domestic research into the preferences of family caregivers regarding the preservation of activities of daily living for Alzheimer's disease patients. The results of this study revealed that family caregivers' preferred preservation priorities for the activities of daily living (ADL) of community-dwelling Alzheimer's disease patients were ranked as follows: 'Use the toilet without "accidents,' 'Go out and reach a familiar destination without getting lost,' and 'Stay safely at home by himself/herself when needed.' When implementing intervention programs and creating supportive environments for Alzheimer's disease patients and their family caregivers, the prioritized ADL identified in this study can be considered. In the implementation of community-based home nursing services, it is not only crucial to assess the ADL of Alzheimer's disease patients but also to incorporate the caregiving priorities of family caregivers. This information can be valuable when coordinating local caregiving resources and setting goals for home nursing services, reflecting the opinions of family caregivers.

The study's findings can be utilized as foundational data during the formation stages of Alzheimer's disease-related initiatives, preliminary investigations, or policy enhancements. Based on these research results, the following recommendations are

proposed. Firstly, the application of Best-Worst Scaling (BWS) in health-related studies is suggested, emphasizing its quantitative and scientific application in identifying the prioritized needs of service recipients and policy priorities in health settings with limited resources and personnel. Secondly, the development and implementation of Alzheimer's disease patient intervention strategies based on the prioritized preferences of family caregivers are recommended. Lastly, considering the survey results on the preferences for ADL preservation, it is suggested to utilize this information when planning Alzheimer's disease management initiatives, incorporating it into the prioritization of specific projects and resource allocation for each project.

The significance of nursing research, especially in the context of person-centered care interventions based on the prioritization of daily living abilities, can be delineated across educational, research, and practical dimensions. Firstly, it contributes to the formation of an empirical knowledge base that explains person-centered nursing interventions. This enriches the educational content for training healthcare professionals, providing them with evidence-based practices that are focused on individual patient needs. Secondly, the research underscores the necessity for varied forms of customized services tailored to the preferred daily living skills of individuals, along with studies on the effectiveness of these services. This not only advances scientific inquiry but also enhances the quality of care provided to patients. Lastly, from a practical standpoint, the findings offer evidence that supports the provision of acceptable and sustainable services within community-based visiting nurse programs. This aspect of nursing research plays a crucial role in the ongoing development and implementation of services that are both effective and feasible in real-world settings. This comprehensive approach highlights the broad and impactful nature of nursing research in improving patient care and healthcare systems.

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Supplementary materials

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Conflict of interest

Youngran Yang has been an editorial board member of the Journal of Korean Community Health Nursing. She was not involved in the review process of this manuscript. No conflict of interest has been declared by all authors.

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Authors' contributions

Eunhye Cho contributed to conceptualization, data curation, formal analysis, methodology, visualization, writing – original draft and investigation. Youngran Yang contributed to conceptualization, project administration, visualization, writing - review & editing, resources, software, supervision, and validation. Hyun Kyung Kim contributed to writing - review & editing, and supervision. Hye Young Kim contributed to writing - review & editing, and supervision.

Data availability

Please contact the corresponding author for data availability.

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