RESEARCH



The enjoyment of life in patients with Alzheimer's disease: correlations with caregivers' perceptions, caregiving attitudes, and empowerment levels



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Abstract

Aims This study aims to analyse the current state of life enjoyment among Alzheimer's disease patients; and explore the correlations between life enjoyment of patients with Alzheimer's disease and caregiver's knowledge of Alzheimer's disease, caregiving attitudes and caregiving empowerment.

Design This research adopted a cross-sectional study approach.

Methods A cross-sectional survey was conducted from May to August 2024. A convenience sampling method was employed to recruit 417 inpatients with Alzheimer's disease and their caregivers from tertiary-level hospitals, elderly healthcare facilities, and community welfare centres in Changsha, Hunan Province, China. The data collection tools included a general information questionnaire, the Pleasant Events Scale for Patients with Dementia (PES-AD), the Alzheimer's Disease Knowledge Scale (ADKS), the Scale of Attitude Toward with Dementia (ATD) and the Empowerment Scale for Family Caregivers with Dementia (EFCD). The SPSS27.0 software was utilized to analyse the current state and influencing factors of the life enjoyment of patients with Alzheimer's disease, and to investigate the correlations among caregivers' caregiving attitudes, caregiving empowerment, knowledge level about the disease and patients' life enjoyment.

Results Patients with Alzheimer's disease obtained scores of (17.33 ± 2.71) on the Pleasant Events Scale, (15.16 ± 2.99) on the Alzheimer's Disease Knowledge Scale, (24.70 ± 1.21) on the Scale of Attitude Toward with Dementia, and (26.88 ± 1.65) on the Empowerment Scale for Family Caregivers with Dementia. The results of the Pearson's correlation analysis indicated that there was a positive correlation between the Alzheimer's disease pleasant events of patients and the knowledge, attitude, and empowerment of caregivers regarding Alzheimer's disease (P < 0.05). The results of multiple linearregression analyses showed that patients' gender, age, self-care situations, severity of diseases, caregiver's cumulative duration of caregiving, the availability of shared caregivers, and whether caring for

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patients feels stress, whether or not educated about AD, knowledge of Alzheimer's disease, caregiving attitudes, and caregiving empowerment were the main influences on patients' sense of life enjoyment (P < 0.05).

Conclusion The life pleasure of Alzheimer's disease patients was at a medium level; caregivers' knowledge of Alzheimer's disease was at a medium level, while their caregiving attitude and caregiving empowerment were at a medium-high level. Future research can identify the most effective interventions based on caregivers' knowledge of Alzheimer's disease. This will facilitate the enhancement of disease-related health knowledge education and training, elevate caregivers' awareness of the disease, and thereby improve the life pleasure of Alzheimer's Disease (AD) patients.

Impact At present, the caregiving issues for Alzheimer's Disease Patients represents a global public health challenge, with caregiving capacity also significantly impacting patients' quality of life. Thus, in order to decelerate AD progression and improve patients' quality of life, a comprehensive analysis of caregivers' Alzheimer's Disease knowledge, caregiving attitudes, caregiving empowerment, and their correlation with patient outcomes is crucial for promoting the physical and mental health of AD patients in the future.

Introduction

With global socio-economic development and changes in lifestyle and dietary habits, Alzheimer's Disease (AD) has become a prevalent chronic condition among the elderly. According to Alzheimer's Disease International reports [1], approximately 50 million people worldwide suffer from dementia, with projections exceeding 152 million by 2050. China, undergoing rapid population aging [2], is predicted that by 2030, the population aged 60 and above in China will reach 409 million, of which the number of people suffering from dementia could exceed 20 million, accounting for about 1/4 of the global total number of dementia cases, ranking the world's 1st [3].

Alzheimer's Disease (AD), a primary degenerative neurological disorder, is characterized by cognitive dysfunction, memory decline, and reduced self-care capabilities [4]. It constitutes 60-80% of all dementia cases [5]. The disease's high morbidity and heavy burden pose significant challenges in prevention, diagnosis, and treatment, imposing severe economic costs on society, families, and individual [6]. (The World Alzheimer's Disease Report 2024》 [7], Alzheimer's disease treatment costs reached \$1.33 trillion in 2020, with China's annual costs at \$16.8 million. The continuous annual increase in the cost of AD treatment has further exacerbated the financial burden on society, families, and individuals [8]. The Healthy China Action 2019-2030 strategy emphasizes the goal of mitigating the rising prevalence of dementia among the elderly population from 2022 to 2030 [9]. Consequently, how to effectively intervene in Alzheimer's disease and delay its progression are critical challenges for achieving healthy development strategies [10].

Background

Pleasant events refer to providing dementia patients with activities that are appropriate for their ability level and interests [11]. These activities help alleviate negative emotions, reduce agitation, and enhance personal

adaptability, thereby promoting physical and mental well-being. Studies confirm that fulfilling AD patients' needs for meaningful activities significantly improves their quality of life, reduces behavioral and psychological symptoms, and fosters harmonious patient-caregiver relationships [12, 13]. However, research indicates that Alzheimer's Disease (AD) patients engage in activities at significantly lower levels compared to healthy elderly individuals in the community [14]. This disparity may stem from the disease's inherent characteristics, patients' reduced daily activity capacity, and caregivers' concerns about fall risks [15]. Previous studies show that dementia patients' participation in pleasant events varies: they engage more in sensory-stimulation activities, followed by family and emotionally stimulating activities [16]. These differences may be influenced by disease severity, self-care ability, caregivers' disease knowledge, and caregiving capacity. Moreover, Chen Hongyu and Zhang Qionget al. [17, 18] found that AD patients' involvement in pleasant events can independently predict caregiver self-efficacy, while caregivers' disease knowledge impacts early diagnosis and long-term rehabilitation.

Alzheimer's Disease (AD) knowledge refers to the understanding and awareness of AD among patients, caregivers, and healthcare professionals [19]. The 2023 Diagnostic Guideline for Alzheimer's disease emphasizes the importance of providing caregivers with relevant education and support to proactively prevent and slow disease progression [20]. Caregiving attitude reflects behaviors such as empathy, consideration, and responsibility in daily interaction [21]. It has been found that a negative attitude, such as criticism, reduces caregivers' positivity, while encouragement and praise enhance their motivation andemotional well-being [22]. Caregiving empowerment involves behaviors and coping strategies, including fostering positive attitudes, actively engaging in caregiving, improving competencies, and building interpersonal relationships [23]. In the process of caregiving,

caregivers not only provide essential support and assistance but also empower patients to develop autonomy, so that they enable patients to more effectively navigate the difficulties and challenges. Research has demonstrated that targeted interventions aimed at enhancing caregiver empowerment significantly enhance AD patients' quality of life and alleviate the caregiving burden on caregivers [24]. Consequently, assessing caregivers' AD knowledge, refining their attitudes, and strengthening their empowerment are crucial for optimizing outcomes in AD patients.

The Knowledge-Attitude-Practice (KAP) theoretical model [22], a widely recognized framework for understanding how personal knowledge, beliefs, and attitudes influence health-related behavior change, serves as a cornerstone for promoting health behaviors. Initially proposed by British scholar Kirsty [25], the model posits that individuals with adeep understanding of disease-related knowledge are more likely to develop positive attitudes and beliefs, which in turn drive beneficial changes in health behaviors. Within this framework: Knowledge refers to the acquisition and comprehension of information, forming the foundation for behavior. Attitude encompasses beliefs and perspectives, acting as the driving force behind behavior. Practice represents the adoption of healthy behaviors, ultimately aiming to achieve sustained behavioral change. The KAP theoretical model is widely applied in disease prevention, diagnosis, nursing management, and education, demonstrating its feasibility and effectiveness [26]. Studies have further validated that knowledge significantly influences health behaviors, either directly or indirectly, while individuals' beliefs about disease prevention shape their attitudes toward health-promoting practices [27].

Based on the KAP theoretical model, the participation of AD patients in pleasant events is related to their cognitive and behavioral capacities, as well as caregivers' understanding of AD, their caregiving attitudes, and level of caregiving empowerment. Accordingly, this study aims to investigate the current status and influencing factors of pleasant events among AD patients, and based on the KAP theoretical model, to analyse how caregivers' AD knowledge, caregiving attitudes and their empowerment correlate with the frequency and quality of pleasant activities experienced by AD patients. The findings aim to improve patients' quality of life, alleviate caregiver burden, and enhance caregiving competencies, offering valuable insights for developing effective caregiving strategies in the future.

Method

Participants

The study employed a convenience sampling method to select 417 inpatients with Alzheimer's disease (AD) and

their respective caregivers from a tertiary-level hospital, a nursing medical institution, and a community welfare center in Changsha, Hunan Province, China, from May to August 2024, as the study subjects.

Patient inclusion criteria: ① Patients diagnosed with dementia according to the diagnostic criteria outlined in the 11th edition of the International Classification of Diseases (ICD-11) by the World Health Organization and were diagnosed as grade 3–6 on the General Debility Scale [28]; ② Patients with a physician-confirmed dementia diagnosis for ≥ 6 months; ③ Follow the principle of voluntary and informed consent. Patient exclusion criteria: ① Patients with serious disease and combination of other diseases, such as cancer, or cardiovascular disease, etc.

Caregiver inclusion criteria: ① Caregivers who were either family members (spouses, children, parents, siblings) or employed individuals providing care to the patients;② Caregiver's age \geq 18 years old, \leq 75 years old; who provided care for \geq 4 h/day, \geq 5d/week, and had been caring for the patient for \geq 1 month [29]; ③ Consciousness and language communication without any obstacles; ④ Follow the principle of voluntary, and sign the informed consent form. Caregiver exclusion criteria: ① Caregivers with severe chronic diseases, such as a history of psychiatric illness, or other cognitive dysfunction, etc.

The sample size for this study was determined based on M. Kendall's sample size estimation method [30], which recommends a sample size of 10–20 times the maximum number of items in the questionnaire, and 10% invalid samples were taken into account. The required sample size ranged from 334 to 660 cases, and the finalised sample size of 417 cases was selected for the study.

Data collection

General information questionnaire

Based on a comprehensive review of relevant literature and multiple rounds of discussions within the research team, a general information questionnaire was developed. This questionnaire encompassed the following key aspects: Patient information: gender, age, place of residence, marital status, educational level, self-care situations, severity of disease, duration of the disease, and payment method for medical expenses; Caregiver information: gender, age, place of residence, educational level, marital status, relationship to the patient, self-perceived health status, cumulative hours spent caregiving perday, cumulative duration of caregiving (in months/years), availability of shared caregivers, and whether caring for patients feels stress, whether or not educated about AD, etc.

The pleasant events schedule-AD, PES-AD

The Pleasant Events Schedule-AD Scale was originally developed by Teri and Logsdon [31] in 1991, and was subsequently translated and adapted into a Chinese version by Wang Zhiwen, a domestic scholar, in 2015 [32]. The scale is a caregiver-reported proxy measure designed to assess the frequency of participation in various activities bypatients with AD. The scale is used to evaluate the engagement of dementia patients in pleasurable activities at different stages of disease. The content of the Chinese version of the PES-AD comprises 18 items grouped into 4 dimensions: Familial activities (6 items), Sensory stimulation activities (6 items), Emotionally stimulating activities (3. items), and Autonomy activities (3 items). Each item was categorized into 3 levels according to the frequency of participation in each activity, and assigned a score of 0, 1, 2, respectively, 0 = "none," 1 = "<3 times/week," and $2 = " \ge 3$ times/week," and the total score ranged from 0 to 36, with higher scores indicating greater participation in pleasurable activities by the patient. The scale demonstrated strong reliability, with atotal Cronbach's α coefficient of 0.841.

Alzheimer's disease knowledge scale, ADKS

The Alzheimer's Disease Knowledge Scale is designed to assess the level of knowledge about Alzheimer's Disease (AD) among patients, caregivers, and healthcare professionals. The original version of the scale was compiled by Brian [33] in 2007, and it was sinicized and revised into a Chinese version by a Chinese scholar He Runlian in2013 [34]. The scale comprises 30 items organized into 7 dimensions: AD impact on life (3items), Symptoms (4 items), Treatment management (4 items), Caregiving (5 items), Assessment and diagnosis (4 items), Disease courses (4 items), and Risk factors for AD (6 items). Each item on the ADKS is presented as a statement, and respondents are required to indicate whether the statement is "true" (value 1) or "false" (value 0). Notably, 18 items are positively scored (where "true" is the correct response), and the remaining 12 items are reversescored (where "false" is the correct response). The total score ranges from 0 to 30, with higher scores indicating a higher level of knowledge about Alzheimer's disease. The scale demonstrated strong reliability, with a total Cronbach's α coefficient of 0.816.

The scale of attitude toward with dementia

The scale of Attitude Toward with Dementia was initially developed by McParland in 2012 [35], to assess public attitudes towards the care, participation and social interaction of people with dementia, and it was later translated and revised into a Chinese version by Wu Jianwei in 2020 [36]. The scale consists of 9 items with 2 dimensions: Interaction (5 items) and Caregiving (4 items). Items are measured on a 5-point Likert scale (ranging from 1="strongly agree" to 5="strongly disagree"), and a total score ranges from 9 to 45, with higher scores indicating more positive attitudes toward dementia. The scale demonstrated strong reliability, with a total Cronbach's α coefficient of 0.772.

Empowerment scale for family caregivers with dementia, EFCD

The Empowerment Scale for Family Caregivers with Dementia was developed by scholar Sakanshi in 2020 [37] to comprehensively assess the differences in caregiving empowerment levels of dementia caregivers. In 2023, it was subsequently adapted into a Chinese version by Xiao Hongmei [23]. The scale consists of 16 items organized into 4 dimensions: Nursing practice (8 items), Understanding the nature of caregiving (3 items), Taking care of each other (3 items), and Peer support (2 items). The scale was recorded on a 4-point Likert, ranging from 0 to 3 on a scale from '0 = disagree' to '3 = strongly agree'. Its total score ranges from 0 to 48, with higher scores indicating greater caregiving empowerment. The scale demonstrated strong reliability, with a total Cronbach's α coefficient of 0.904.

Procedures

The questionnaires were uniformly distributed by the researchers, who provided detailed explanations of the study's purpose, significance and requirements of the study, and requirements to ensure participants fully understood the content, and the questionnaires were completed and collected promptly. For participants who were unable to fill in the questionnaires independently due to low literacy levels or other reasons, the investigator verbally relayed the questions to the research subjects and recorded the responses on their behalf. In this study, a total of 428 questionnaires were distributed and all 428 were recovered, resulting in a 100% recovery rate. Among them, after excluding invalid responses, 417 valid questionnaires remained, yielding an effective response rate of 97.42%.

Data analysis

Statistical analyses were performed using IBM SPSS 27.0. Descriptive statistics for the general data questionnaire were represented as frequency and percentage (%). Measurement data, including scores for life enjoyment of patients with Alzheimer's disease, caregivers' knowledge of Alzheimer's disease, caregivers' attitudes, and caregiving empowerment, were normally distributed and expressed as mean±standard deviation. Differences in the participation of patients in pleasant events across groups were compared using one-way independent samples t-tests and ANOVA. Pearson's correlation analysis was conducted to examine the relationships among life enjoyment of patients with Alzheimer's disease, caregiver's knowledge of Alzheimer's disease, caregiver's attitudes and empowerment for caregiving. Multivariate linear regression was conducted to analyze the multifactorial influences on life enjoyment of patients with Alzheimer's disease. A significance level of "P < 0.05" was used to determine statistical significance.

Ethical approval

This study received ethical approval from the Ethics Committee of Hunan Provincial Institute of Traditional Chinese Medicine Hospital (Approval number: 202491). And has obtained the consent from the administrators of the hospital and the participating institution. In this study, the caregivers provided an informed consent agreement before filling out and submitting the questionnaire. Participants were explicitly informed on the front page of the questionnaire that all collected information would be kept confidential and retained solely for research purposes.

Results

General demographic characteristics of patients with Alzheimer's disease

A total of 417 patients with Alzheimer's disease were included in this study. The general characteristics of the patients were as follows: 264 (63.3%) were male, and 153 (36.7%) were female; the mean age of the patients was (81.07 ± 7.18) years; regarding disease severity of AD patients: 86 (20.6%) patients had a Global Deterioration Scale (GDS) score of grade 3, 102 (24.5%) had a GDS score of grade 4, 132 (31.7%) had a GDS score of grade 5, and 97 (23.3%) patients had a GDS score of grade 6; duration of the disease: 101 (24.2%) patients had been diagnosed for <1 year, 275(65.9%) for 1–3 years, and 45(9.8%) for >3 years.

General demographic characteristics of caregivers with Alzheimer's disease

A total of 417 caregivers with Alzheimer's disease were included in this study. The general characteristics of the caregivers were as follows: 59 (13.9%) were males and 359 (86.1%) were females; caregivers' ages ranged from 18 to 75 years, with a meanage of (49.94 \pm 7.46) years; in terms of their relationships to the patient: 49 (11.8%) were spouses, 134 (32.1%) were children, 10 (1.2%) were other relatives, and 229 (54.9%) were employed caregivers; regarding the cumulative duration of caregiving: 175 (42%) caregivers had provided care for \leq 12 months, while 242 (58%) had provided care for > 1 years.

Unifactorial analysis of pleasant events in patients with Alzheimer's disease

Comparison of scores on pleasant events among AD patients based on various factors, including different genders, ages, education levels, whether they had other chronic diseases, self-care situations, severity of diseases, duration of the disease, and payment method for medical expenses were all revealed statistically significant (P < 0.05). Additionally, caregiver-related factors such as cumulative duration of caregiving, availability of shared caregivers, and whether caring for patients feels stress, whether or not educated about AD, also showed statistically significant differences (P < 0.05) in their impact on the scores of pleasant events for AD patients (Tables 1 and 2).

Life pleasure of AD patients and caregivers' knowledge of Alzheimer's disease, caregiving attitudes, and caregiving empowerment scores

The total score on the Pleasant Events Schedule-AD (PES-AD) for patients was (17.33 ± 2.71) , indicating an intermediate level. The scores for the individual dimensions, in descending order, were as follows: sensory stimulation activity (0.69 ± 0.43) , familial activity dimension (0.86 ± 0.07) , affective stimulation activity (1.07 ± 0.17) , autonomy activity (1.67 ± 0.04) . For caregivers, the overall score on the Alzheimer's Disease Knowledge Scale (ADKS) was (15.16 ± 2.99) , reflecting an intermediate level. The caregiving attitude score was (24.70 ± 1.65) , and the caregiving empowerment score was (26.88 ± 1.65) , both indicating an upper-middle level, respectively (Table3).

Analysis of the correlation between life enjoyment of AD patients and the knowledge, caregiving attitudes and caregiving empowerment of caregivers on Alzheimer's disease

Pearson's correlation analysis showed that the patient's pleasant events score was positively correlated with the caregiver's attitude score (r = 0.504, P < 0.001), positively correlated with the caregiving empowerment score (r = 0.174, P < 0.001), and positively correlated with the Alzheimer's disease knowledge score (r = 0.112, P < 0.05); Caregiving empowerment was positively correlated with the caregiving attitude score was positively correlated (r = 0.122, P < 0.05), and with Alzheimer's disease knowledge score (r = 0.361, P < 0.001) (Table 4).

Multiple linear regression analysis of variables impacting life pleasure in Alzheimer's disease patients

Multiple linear regression analyses were performed with the score of pleasant events of Alzheimer's disease patients as the dependent variable, and variables that were statistically significant in univariate and correlation analyses as

Variable	Category	Pleasant events scores	N	%	t/F	Р
Gender	Male	16.95±2.66	264	63.30%	-3.892	0.001
	Female	18.01±2.68	153	36.70%		
Age (years)	<60 years	18.06±2.81	18	4.20%	5.022	< 0.001
	60–74 years	17.81±2.71	142	34.10%		
	75–89 years	17.05 ± 2.57	199	47.80%		
	≥90 years	16.43±2.59	58	13.90%		
Education level	Junior high school and below	17.12±2.63	361	86.60%	4.071	0.001
	High School/College	18.15±2.00	31	7.40%		
	Bachelor's degree and above	18.67±3.96	25	6.00%		
Whether they had other chronic disease	1–2 types	20.06±2.01	19	4.50%	17.915	<0.001
	3–5 types	19.31±2.37	45	10.80%		
	>5 types	16.95±2.60	353	84.70%		
Self-care situations	Fully self-care	20.65 ± 2.08	52	12.50%	92.306	< 0.001
	Partially self-care	18.26±2.53	196	47.00%		
	Completely incapable of self-care	15.25±0.82	169	40.50%		
Severity of diseases	Grade 3	20.38±1.83	86	20.60%	78.443	< 0.001
	Grade 4	18.76±2.61	102	24.50%		
	Grade 5	15.58±1.22	132	31.70%		
	Grade 6	15.53±1.29	97	23.30%		
Duration of the disease	<1 years	19.90±2.26	101	24.20%	84.283	<0.001
	1–3 years	16.59±2.37	275	65.90%		
	>3 years	16.02±1.71	41	9.80%		
Payment method for medical expenses	Urban employee medical insurance	17.86±2.82	112	26.90%	9.352	<0.001
	Urban resident medical insurance	17.48±2.79	222	53.20%		
	Others	16.25±1.97	83	19.90%		

Table 1	Univariate analysis	s of general	demographic	characteristics of AD	patients and their	pleasant events scores	(n=417) 🗴	$K \pm S$
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Table 2 Univariate analysis of general demographic characteristics of caregivers and scores on pleasant events of people with AD (n=417) $\mathbf{X} \pm \mathbf{S}$

Variable	Category	Pleasant events scores	N	%	t/F	Р
Cumulative duration of caregiving	1–5 months	18.51±2.79	5	1.00%	32.903	< 0.001
	6-12months	16.54±2.31	170	41.00%		
	>1 years	16.39±2.32	242	58.00%		
Availability of shared caregivers	0	16.86 ± 2.60	116	27.80%	5.087	0.002
	1	17.17±2.66	184	44.10%		
	2	17.97 ± 2.66	107	25.70%		
	≥3	19.20 ± 3.67	10	2.40%		
Whether caring for patients feels stress	No	19.50 ± 3.26	20	4.80%	5.604	< 0.001
	Occasionally	17.75 ± 2.74	95	22.80%		
	Sometimes	17.12±2.65	231	55.40%		
	Often	16.78±2.33	71	17.00%		
Whether or not educated about AD	Yes	17.76±2.73	212	50.80%	3.262	0.001
	No	16.90 ± 2.63	205	49.20%		

N: sample size; %: ratio; t: T-test; F: ANOVA; P: P-value

independent variables. The results showed that patientrelated factors, including gender, age, self-care situation and severity of disease, significantly influenced the life pleasure of AD patients (P < 0.05). Caregiver's cumulative duration of caregiving, availability of shared caregivers, Whether or not educated about AD, caregiving empowerment, caregiving attitude and the level of knowledge about Alzheimer's disease, were also significant determinants of AD patients' life pleasure (P < 0.05), which accounted for 65.1% of the total variance. Meanwhile, the severity of diseases, self-care situations, cumulative duration of caregiving, availability of shared caregivers, and EFCD variables had the greatest impact on the life pleasure of AD patients (P < 0.001) (Tables 5 and 6).

Table 3 Life pleasure of AD patients and caregivers' knowledge

 of Alzheimer's disease, caregiving attitudes, and caregiving

empowerr	nent sco	ores $\mathbf{\bar{X}} \pm \mathbf{S}$		
Item	Entries	Average score	Dimension score	Total score
PES-AD				17.34±2.71
PES-AD1	6	0.86 ± 0.07	5.18±0.68	
PES-AD2	6	0.69 ± 0.43	4.19±2.59	
PES-AD3	3	1.07 ± 0.17	3.21±0.53	
PES-AD4	3	1.67 ± 0.04	5.02 ± 0.14	
ATD				24.70 ± 1.21
ATD1	5	2.78 ± 0.11	13.93 ± 0.59	
ATD2	4	2.69 ± 0.24	10.77±0.98	
EFCD				26.88 ± 1.65
EFCD1	8	1.71 ± 0.14	13.72 ± 1.18	
EFCD2	2	1.50 ± 0.35	3.00 ± 0.71	
EFCD3	3	2.00 ± 0.33	6.00 ± 0.09	
EFCD4	3	1.38 ± 0.16	4.15 ± 0.48	
ADKS				15.16 ± 2.99
ADKS1	4	0.64 ± 0.18	2.57 ± 0.74	
ADKS2	4	0.53 ± 0.19	2.13±0.79	
ADKS3	4	0.49 ± 0.19	1.98±0.79	
ADKS4	6	0.38 ± 0.27	2.32 ± 0.82	
ADKS5	4	0.65 ± 0.32	2.63±1.09	
ADKS6	5	0.40 ± 0.19	2.00 ± 0.96	
ADKS7	3	0.35 ± 0.28	1.07±0.85	

Abbreviations: PES-AD, The Pleasant Events Schedule-AD; PES-AD1, Familial activity; PES-AD2, Sensory stimulation activity; PES-AD3, Affective stimulation activity; PES-AD4, Autonomy activity; ATD, Attitude Toward with Dementia; ATD1, Interaction; ATD2, Caregiving; EFCD, Empowerment Scale for Family Caregivers with Dementia; EFCD1, Nursing practice; EFCD2, Peer support; EFCD3, Taking care of each other; EFCD4, Understanding the nature of caregiving; ADKS, Alzheimer's Disease Knowledge Scale; ADKS1, Caregiving; ADKS2, Symptoms; ADKS3, Disease course; ADKS4, Risk factors; ADKS5, Treatment/management; ADKS6, Assessment/Diagnosis; ADKS7, AD impact on life

Discussion

Analysis of the current status of life enjoyment of Alzheimer's disease patients

The complexity of Alzheimer's disease, its slow progression, and the high rate of intellectual disability have resulted in different degrees of impact on patients' ability to perform daily life in the later stages of the disease. According to the results of this study, the level of participation in pleasant events among AD patients was at a moderate level, which is consistent with the findings of Zhang Qiong et al. [38]. The reasons for this observation

Table 5 Dumb variable assignments

Independent variable	Assignments
Patient	
Gender	Male = 1, Female = 2
Age	<60 years = 1, 60–74 years = 2,
	75–89 years = 3, ≥ 90 years = 4
Self-care situations	Fully self-care = 1, Partially self-
	care = 2, Completely incapable = 3
Sverity of diseases	Grade $3 = 1$, Grade $4 = 2$, Grade
	5 = 3, Grade $6 = 4$
Caregiver	
Cumulative duration of	1–5 months = 1, 6–12 months = 2,
caregiving	> 1 years = 3
Availability of shared caregivers	$N_0 = 1, 1 = 2, 2 = 3, \ge 3 = 4$
Whether or not educated about	Yes = 1, $No = 2$
AD	
ATD	Original value input
EFCD	Original value input
ADKS	Original value input

Table 6	Multiple linear	regression	analysis of A	AD patients' life
pleasure				

preasare					
Variable	b	Sb	β	t	Р
(Constant)	23.993	2.836		8.461	< 0.001
Patient					
Gender	-0.443	0.188	-0.079	-2.357	0.019
Age	-0.496	0.163	-0.140	-3.047	0.002
Self-care situations	-1.299	0.208	-0.322	-6.247	< 0.001
Sverity of diseases	-1.174	0.139	-0.459	-8.461	< 0.001
Caregiver					
Cumulative dura-	-1.039	0.165	-0.296	-6.312	< 0.001
tion of caregiving					
Availability of	0.581	0.165	0.170	3.515	< 0.001
shared caregivers					
Whether or not	-0.857	0.265	-0.158	-3.260	0.001
educated about AD					
CTD	0.192	0.078	0.117	2.457	0.014
EFCD	1.020	0.144	0.326	7.165	< 0.001
ADKS	0.096	0.044	0.105	2.160	0.031

Abbreviations: ATD, Attitude Toward with Dementia; EFCD, Empowerment Scale for Family Caregivers with Dementia; ADKS, Alzheimer's Disease Knowledge Scale; $R = 0.807^a$, $R^2 = 0.651$, F = 39.055, $P < 0.001^b$

are as follows: (1) Among the research subjects selected for this study, the majority of AD patients (79.5%) had a Global Deterioration Scale (GDS) score of 4–6, indicating moderate to severe stages of the disease. and the

Table 4 Analysis of the correlation between life enjoyment of AD patients and the knowledge, caregiving attitudes and caregiving empowerment of caregivers on Alzheimer's disease (r)

	0					
Variable	PES-AD1	PES-AD2	PES-AD3	PES-AD4	PES-AD	EFCD
ATD	0.179**	0.519**	0.161**	0.105*	0.504**	0.122*
EFCD	0.063	0.179**	0.127**	0.121*	0.174**	1
ADKS	0.096*	0.105*	0.051	0.025	0.112*	0.361**

Abbreviations: PES-AD, The Pleasant Events Schedule-AD; EFCD, Empowerment Scale for Family Caregivers with Dementia; ADKS, Alzheimer's Disease Knowledge Scale; ATD, Attitude Toward with Dementia; PES-AD1, Familial activity; PES-AD2, Sensory stimulation activity; PES-AD3, Affective stimulation activity; PES-AD4, Autonomy activity; *P<0.05, **P<0.001

more serious the disease, the lower the participation level of patients in pleasurable activities; (2) The caregivers of employed people account for a larger proportion (54.9%). For patients with GDS scores of 5-6, participation in pleasant events often requires to be completed under the help of the caregiver. However, the time and energy constraints of employed caregivers may limit patients' ability to facilitate such activities, thereby reducing patients' engagement; (3) Most AD patients in this study were cared for by family members or employed caregivers, and as the disease progresses, AD patients' cognitive function, memory function and daily life ability will be affected, and then they will be more dependent on the caregiver for survival. This heightened dependency places a heavier burden on the caregiver, further affecting the patient's participation in social and pleasurable activities; (4) Caregivers' knowledge of AD-related information scored moderately overall, with scores ranging from 2.63 ± 1.09 to 1.07 ± 0.85 across different dimensions, and their related disease knowledge level is relatively weak, and the patients' life pleasure is relatively low, which is consistent with the findings of Liu Xiaofeng [39]. Therefore, caregivers should pay close attention to AD patients with low self-care abilities and to provide them continuous and effective rehabilitation training, in order to help delay disease progression of AD patients and improve their quality of life level.

Analysis of factors influencing life pleasure of Alzheimer's disease patients

The results of the multiple linear regression analysis in this study showed that patients' age, self-care situations, severity of diseases, cumulative duration of caregiving, availability of shared caregivers, whether or not educated about AD, caregiving empowerment, caregiving attitudes, and knowledge of Alzheimer's disease were the influencing factors on the sense of life enjoyment of AD patients (P < 0.05).

Severity of diseases

The results of this study showed that patients with GDS scores of 5–6, representing moderate to severe Alzheimer's disease (AD), had the lowest scores for participation in pleasant events, which on the one hand maybe related to the gradual decline of patients' cognitive function and self-care ability, and the further loss of their mobility, which aligns with the findings of Ankuda C K [40]; on the other hand, caregivers reduce the scheduling of various types of activities for moderately and severely ill patients in order to avoid the risk of exercising, which may inadvertently limit their opportunities for social engagement. Therefore, caregivers should evaluate the patient's ability toperform daily living tasks and based on this assessment, identify and facilitate activities that the patient

can safely and effectively engage in [41]. Additionally, for patients with moderate to severe AD, caregivers can assist patients to perform sensory stimulation or emotionally stimulating activities, such as listening to music, staying outside, experiencing nature's sounds, and reminiscing or talking about the past, in order to help enhance patients' sense of life pleasure and overall well-being.

The cumulative duration of caregiving

The results of this study showed that caregivers who had cared for patients for an accumulated period of 1-5 months reported the highest patient pleasant events scores, the cumulative duration of caregiving for patients >1 years is more, but had the lowest patient pleasant events scores. This finding is consistent with previous research by UtneI et al. [42], which suggests that as the patient's condition worsens and the cumulative caregiving duration increases, caregivers expend more time and energy, often without effectively alleviating their negative emotions, resulting in a growing burden of care. And they often prioritize maintaining the patient's cleanliness, health, and safety as their main care tasks, so the caregiver doesn't have enough energy and time to co-ordinate patients with more severe conditions to participate in pleasant events, thus reducing patients' opportunities to engage in enjoyable events and diminishing their sense of life pleasure. Therefore, individualised psychological interventions should be provided to address the influencing factors of caregivers' coping styles, while correctly guiding caregivers to adopt positive caregiving attitudes, improving their emotional well-being, and alleviating their caregiving burden. By doing so, caregivers may be better equipped to support patients in participating in pleasant activities, ultimately enhancing patients' sense of pleasure in life.

Availability of shared caregivers

The availability of shared caregivers is also a significant factor that affects caregiver burden as the disease continues to progress. The results of this study showed that patients without co-caregivers had lower pleasant event scores compared to those with co-caregivers. This can be attributed to the complex and progressive nature of Alzheimer's disease, which leads to a decline in patients' self-care abilities, often rendering them entirely dependent on caregivers. When caregivers face dementia patients, due to the lack of knowledge about the disease, caregiving ability, and support from co-caregivers, resulting in the quality of life for patients tends to deteriorate, and the risk of hospital readmission increases, which is similar to the conclusions of the previous study conducted by Pan Xiaona et al. [43]. Furthermore, when caregivers encounter difficulties in providing care, due to the absence of external assistance and social support

exacerbates their negative emotions, increasing their psychological burden and ultimately diminishing their ability to provide effective care. Therefore, family members and caregivers should strengthen communication, mutual understanding and emotional support, so that help both caregivers and patients can experience a sense of family belonging and security; at the same time, according to the relationship between family members and patients, caregiving can be rotated appropriately to alleviate caregivers' pressure.

Whether or not educated about AD

The results of this study indicated that patients cared for by caregivers who had not received education on Alzheimer's disease (AD) knowledge had lower pleasant event scores compared to those cared for by caregivers who had received such education. This disparity can be attributed to the lack of health education and training among caregivers, which limits their access to essential knowledge and caregiving skills, resulting in a relatively weak level of disease knowledge and caregiving capabilities, which is consistent with the conclusions of the previous study conducted by Xie Xiyan et al. [44]. Additionally, a significant proportion of caregivers in this study were aged 50 years orolder. Advanced age may further hinder their ability to acquire and retain disease-related knowledge, thereby restricting their caregiving effectiveness. The findings underscore the importance of whether caregivers have received AD-related education as a critical factor influencing patients' life pleasure. Therefore, in the future, it is essential to strengthen health education initiatives focused on Alzheimer's disease and related conditions, by improving caregivers' understanding of these diseases and enhancing their caregiving skills, so as to improve the quality of life for patients.

Analysis of the current status of Alzheimer's disease knowledge, caregiving attitudes and caregiving empowerment among caregivers of AD patients

① The overall score of the caregiver's caregiving attitude was (24.70 ± 1.21) , with the interaction dimension scoring 13.93 ± 0.59 , and the caregiving dimension scoring 10.77 ± 0.98 , which is in the mid-to-upper level in general of caregiving attitude, with both interaction and caregiving dimensions being the primary factors affecting the caregiver's attitude. Due to the main characteristics of the disease, patients are often unable to express their own wishes, and making caregivers become the main communication conduit, while the extensive caregiving experience of the caregivers, which can deepen the understanding of AD and contribute to the generation of positive attitudes, which is in line with the results of the previous research by Kang Fengjuan et al. [45]. And, the caregivers in this study predominantly

comprised females, and research shows that women tend to score significantly higher than men in attitudes toward Alzheimer's disease [46], as women have more potential empathy and are better able to take on the caregiver role than men, a result consistent with the findings of previous research by Zhou Guangli et al. [47]. Consequently, more care and support should be given to female caregivers in the future, as this will facilitate the cultivation of positive caregiving attitudes.

^② The total score of caregiving empowerment was (26.88 ± 1.65) , with the peer support dimension scoring 3.00 ± 0.71 and the understanding the nature of caregiving dimension scoring 4.15±0.48. These dimension scores were relatively low, which may be attributed to two main factors. On the one hand, it may be related to the lack of caregiving knowledge, skills and coping strategies of the caregiver; on the other hand, the limited methods and channels for accessing social support may have contributed to the lower scores in these dimensions. Despite this, the overall caregiving empowerment scores were at a moderately high level. This could be linked to the caregivers' ability to acquire relevant knowledge through various channels while caring for elderly individuals and interacting with dementia patients in their daily lives, and were more willing to take the initiative to learn the knowledge about Alzheimer's disease, thus promoting their caregiving empowerment. Therefore, health education on knowledge, skills and strategies related to Alzheimer's disease should be carried out in the future, and the available social support and corresponding channels should be expanded to help caregivers enhance their caregiving ability.

③ The total knowledge score of Alzheimer's disease among caregivers was 15.16 ± 2.99 , with both the overall score and the scores of individual dimensions falling within the medium range. The reason for this is that caregivers in elderly healthcare facilities and community welfare centres often possess rich practical experience and a deeper understanding of the knowledge, attitudes and abilities of the disease, and they tend to have a relatively stronger grasp of knowledge dimensions such as disease care precautions, risk factors, and care management, which aligns with the results of the study conducted by LIN P C et al. [48]. At the same time, the age structure of the caregivers in elderly healthcare facilities is predominantly concentrated in the 40 to 50-year-old range [49], which is similar to the demographic observed in this study, and as caregivers age, their learning ability and capacity to absorb new knowledge tend to decline. Therefore, it is crucial to enhance caregivers' knowledge training in AD areas such as the disease's impact on daily life, assessment, and diagnosis in the future, in order to improve caregivers' knowledge of the disease in all aspects.

Analysis of the correlation between life enjoyment of AD patients and caregivers' knowledge of Alzheimer's disease, caregiving attitudes and caregiving empowerment

The study results revealed that patients' pleasant events scores were positively correlated with caregiver caregiving attitudes and Alzheimer's disease knowledge scores, and caregiving empowerment was positively correlated with Alzheimer's disease knowledge scores, suggesting that caregivers with a higher level of knowledge about Alzheimer's disease tend to exhibit better caregiving empowerment, which in turn enhances patients' participation in pleasant events. These findings align with the results of the study conducted by Teichmann B et al. [50], indicating that caregivers who possess more knowledge and skills about AD are better equipped to adapt to their caregiving role confidently, while improving their own caregiving empowerment, and effectively impacts patients' physical and mental health, as well as their overall quality of life. Furthermore, the study demonstrated that the total score of patients' pleasant events, as well as the scores of each dimension, were positively correlated with the scores of carergivers' attitudes, and the scores of caregiving empowerment were positively correlated with caregiving attitude scores. It indicates that caregivers' attitudes and their level of caregiving empowerment indirectly influence dementia patients' participation in pleasant events. Specifically, the more positive the caregivers' attitudes, the higher their level of caregiving empowerment, and the better the patients' participation in pleasant events. These findings are consistent with the study by Mausbach et al. [51], which found that caregivers who adopt more positive coping styles tend to facilitate higher levels of participation in pleasant events of dementia patients, meanwhile influencing their own participation in pleasant events indirectly affects AD patients' engagement in social activities. Secondly, as employed caregivers who understand that the health status of AD patients will deteriorate as the illness progresses, they will pay closer attention to the physical changes in patients during the caregiving process. Additionally, due to the professional demands of their work, they receive regular education on disease knowledge and nursing training, which gradually enhances their caregiving abilities. In line with Ma Jinlong et al. and other studies [52], the caregivers with experience and training in Alzheimer's diseaserelated care are better equipped to understand the longterm challenges faced by patients. As a result, they are more likely to adopt positive coping strategies, ultimately improving the patients' quality of life.

The scores for Alzheimer's disease knowledge, caregiving attitude, and caregiving empowerment, as well as the scores for each dimension, were positively correlated. According to the theoretical model of Knowledge-Attitude-Practice [25], knowledge serves as the foundation for behavioral change, beliefs act as the driving force for such change, and the three elements interact in a continuous and dynamic process. In this context, "knowledge" refers to the caregiver's understanding of Alzheimer's disease, "attitude" pertains to the caregiver's beliefs and attitudes toward caring for individuals with Alzheimer's disease, and "practice" refers to the caregiver's actual caregiving behaviors. The higher the caregiver's knowledge of the disease, the more positive the caregiving attitude, and consequently, the stronger their caregiving abilities. Consistent with the results of a previous study [53], which demonstrated that caregivers with higher levels of dementia knowledge tend to have more positive attitudes toward patients with dementia. Conversely, if a caregiver's attitude toward dementia patients is negative, their willingness to actively acquire knowledge and learn caregiving skills will diminish, further weakening their caregiving abilities and ultimately compromising the quality of patient care. Furthermore, non-pharmacological interventions and continuity of care are key measures for the prevention and treatment of dementia [54], the level of Alzheimer's disease knowledge and the cognitive attitudes of caregivers play a crucial role in determining the quality of patient care, too. Therefore, it is suggested that caregivers should have solid knowledge of Alzheimer's disease and be able to deeply understand the necessity of acquiring knowledge about the disease at the belief level, and the importance of health education and training in improving caregivers' quality of care, and the prerequisite for enhancing the standard of caregiver services in elderly healthcare facilities, so as to make changes in health behaviours, thereby improving caregivers' selfcare empowerment. To achieve this, caregivers should be strengthened to Alzheimer's disease knowledge base in practice and provide them with more social support pathways in the future. This will further deepen their cognitive attitudes toward the disease, enabling knowledge, attitude, and practice to reinforce one another and create a virtuous cycle, thus promoting the enhancement of caregivers' empowerment, reducing their caregiving burdens, and ultimately enabling patients with dementia to receive the elderly care services they need and contributing to promoting the development of healthy ageing.

Limitations

This study has several limitations. Firstly, the questionnaire survey was conducted exclusively among inpatients with Alzheimer's disease and their caregivers from tertiary-level hospitals, elderly healthcare facilities, and community welfare centres in Changsha, Hunan Province, China. The absence of random sampling from other regions outside the province may introduce selection bias in the research site. Secondly, while caregivers primarily completed the questionnaire, for some caregivers with limited literacy or other reasons were assisted by researchers through face-to-face interviews, but this approach may introduce memory bias from the investigators, potentially affecting data accuracy. Therefore, future research could address these limitations by incorporating qualitative interviews or longitudinal studies to more comprehensively explore the factors influencing patients' sense of life satisfaction and dynamic changes, as well as to conduct multi-centre, large-sample, high-quality intervention studies, which will provide references to improve the quality of life of patients and enhance caregivers' capabilities.

Conclusion

This study revealed that the level of pleasure in life among patients with Alzheimer's disease is significantly associated with the caregiver's level of AD knowledge, caregiving attitude and caregiving empowerment. The results showed that the caregiver's attitude was the most influential factor affecting the patients' sense of life pleasure, followed by caregiving empowerment and the caregiver's level of AD knowledge. Therefore, in the future, we should prioritize enhancing caregivers' understanding of AD through targeted health education, skills training, and social support services. Additionally, it is essential to strengthen the social support methods and pathways. For example, healthcare institutions can develop network platforms, such as WeChat public accounts or ADspecific mobile applications, to enhance the publicity of the knowledge of dementia-related, increase caregivers' cognition of the disease, and positively influence their attitudes toward caregiving, make up for the lack of professional guidance for home caregivers, provide personalised support to enhance their caregiving abilities, and ultimately improve the positive of AD patients to engage in pleasant activities.

Statement

- The Pleasant Events Schedule-AD Scale (PES-AD) was originally compiled by Teri and Logsdon in 1991, and was later translated and adapted into a Chinese version by Wang Zhiwen, a domestic scholar, in 2015.
- 2. The Alzheimer's Disease Knowledge Scale (ADKS), the original version of the scale was compiled by Brian in 2007, and it was subsequently sinicized and revised into a Chinese version by He Runlian, a Chinese scholar, in 2013.
- 3. The Scale of Attitude Toward with Dementia was initially developed by McParland in 2012, and was later translated and adapted into a chinese version by Wu Jianwei in 2020.

4. The Empowerment Scale for Family Caregivers with Dementia (FECD) was developed by Sakanshi in 2020. In 2023, it was adapted and revised into a Chinese version by Xiao Hongmei.

Abbreviations

AD	Alzheimer's disease
PES-AD	The enjoyment of life of patients
ADKS	Alzheimer's disease knowledge
ATD	Attitude Toward with Dementia

EFCD Empowerment for Family Caregivers with Dementia

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Author contributions

Jianhong Lv: Writing-original draft, Writing-review and editing, Resources, Project administration, Methodology, Investigation, Funding acquisition, Formal analysis, Data curation. Wenting Xu: Writing-review, Supervision, Resources, Investigation, Conceptualisation. Hongyan Mao: Writing-review, Resources, Investigation, Data curation, Conceptualisation. Fen Zhao: Writingreview and editing, Supervision, Resources, Investigation. Wenxia Zhang: Writing-review, Supervision, Resources, Investigation, Conceptualisation. Jing Huang: Writing-review, editing, Supervision, Resources, Project administration, Funding, Acquisition, Formal analysis, Conceptualisation.

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Data availability

No data sets were generated or analysed during the current study.

Declarations

Ethics approval and consent to participate

Ethics approval and consent to participate This study was approved by the Ethics Committee of the Affiliated Hospital of Hunan Academy of Traditional Chinese Medicine. All methods were carried out in accordance with relevant guidelines and regulations. Signed informed consent was obtained from all individual participants included in the study.

Consent for publication

Not applicable.

Patient or public contribution

No patient or public contribution.

Competing interests

The authors declare no competing interests.

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