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ORIGINAL RESEARCH

The Post-Traumatic Growth Experience in Family Caregivers of People with Dementia: A Descriptive Qualitative Study

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Purpose: To explore and illuminate the post-traumatic growth experience among family caregivers of people with dementia.

Patients and Methods: Descriptive qualitative research was conducted using purposive sampling. Between June and October 2024, 19 family caregivers of dementia patients were selected from an outpatient clinic for memory disorders and a mental health center in Shanghai. The NVivo 20.0 software was used to organize and code the interview data, and the data were analyzed and thematically condensed using the directed content analysis method.

Results: Four themes were identified, along with eleven sub-themes associated with them: cognitive-behavioral shift (transitioning family roles, recognizing disease characteristics, focusing on health management, and responding positively and effectively); personal strength enhancement (enhancing coping capacity, increased psychological resilience and increased responsibility); improved relationships with others (harmonizing in family relations and benefiting from social interactions); and changes in life perceptions (reshaping of values, and reconstructing the meaning of life).

Conclusion: Family caregivers of people with dementia experience multifaceted post-traumatic growth after a traumatic event of disease diagnosis and patient caregiving. It is necessary to focus on positive psychological resources for family caregivers to improve the burden of caregiving. Future research should take measures to promote family caregivers' positive perceptions, explore their own potential and strengths, and help them make full use of family and social support to enhance their post-traumatic growth.

Keywords: older adult, dementia, informal caregivers, post-traumatic growth

Introduction

Dementia is a progressive neurological syndrome characterized by acquired cognitive deficits that progressively diminish patients' capacity to perform activities of daily living (ADLs), fulfill occupational demands, and maintain social engagement.[1] According to the World Health Organization, the number of people worldwide with dementia is approximately 55 million, and it is projected to reach 139 million by 2050.[2] China has one of the largest and fastest-growing numbers of dementia patients globally, accounting for about 1/4 of the world's total. In 2020, among the elderly population over 60 in China, there were 15.07 million people with dementia, and it is expected to reach 48.98 million by 2050.[3] As the aging population continues to grow, dementia has become a prevalent condition among older adults and a leading cause of disability and death.[4]

As the disease progresses, the patient's ability to take care of themselves declines and is accompanied by psycho-behavioral symptoms, making them dependent on family members or healthcare professionals for support care.[5] Research has shown that more than 77.25% of dementia patients in China are cared for at home by family members.[6] Diagnosing disease and providing long-term care can be viewed as a traumatic stress event for caregivers. Understandably, problems such as mental stress, economic burden, intensified family conflicts, and social role conflicts may ensue.[7] Approximately 30% to 40% of family caregivers experience depression or anxiety,[8,9] and psychiatric

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morbidity ranges from 40% to 75%.[10] High levels of anxiety and distressing emotions, physical problems, and social isolation place a compounding burden on family caregivers, impacting their quality of life.[11,12]

However, research has shown that family caregivers' experiences of traumatic loss can lead to personal growth, marked by deeper existential reflection and the development of spiritual awareness.[13] According to the functional model of post-traumatic growth, individuals can experience growth after facing trauma, which may manifest as a greater appreciation for life, deeper interpersonal relationships, altered priorities, enhanced personal strength, and a richer existential and spiritual life experience.[14,15] Post-traumatic growth (PTG) is a positive psychological experience that occurs during an individual's struggle with an event of a traumatic nature.[15] It is one of the coping resources that significantly improves psychological problems such as depression and anxiety.[16] Additionally, these positive aspects of caregiving may alleviate the burden on family caregivers and improve outcomes for people with dementia, mitigating adverse consequences.[17]

It is essential to highlight the positive aspects of family caregivers of dementia in hopes of increasing attention to their positive caregiving experiences. A quantitative study by Li et al[18] revealed that family caregivers of dementia experience post-traumatic growth, with positive coping styles serving as a mediator between family functioning and this growth. Similarly, Jackson's study showed that post-traumatic growth among family caregivers with dementia was at a moderate level, providing insights into factors that may contribute to the process.[19] While post-traumatic growth is recognized as a distinct psychological change following trauma, the specific nature of such growth among family caregivers of people with dementia remains poorly understood. In particular, how caregivers make sense of and articulate these five growth domains in their own words remains unclear. To bridge this critical knowledge gap, it is essential to adopt a qualitative approach to explore how family caregivers for people with dementia experience and narrate post-traumatic growth. This study is grounded in the functional model of post-traumatic growth[15] and aims to investigate how the five domains of growth manifest in the lived experiences of caregivers. It also seeks to address this gap by examining the experiences of family caregivers in China's cultural context, where strong filial piety and collectivist traditions may uniquely shape caregiving perceptions and coping mechanisms. Moreover, it investigates underexplored dimensions of emotional growth that have not been studied in detail before. This exploration could inform therapeutic techniques and interventions for this group, ultimately serving dual objectives: mitigating caregivers' adverse physical and psychological consequences while concurrently optimizing care recipient outcomes through enhanced caregiver well-being.

Qualitative research focuses on a holistic and in-depth understanding of a social activity or phenomenon, which helps caregivers explore a phenomenon or experience in depth.[20] Consequently, this study employs a descriptive qualitative research method to examine the experiences of family caregivers of people with dementia as they navigate the challenges of the disease and caregiving. It also aims to explore their post-traumatic growth and provide a foundation for developing intervention strategies to enhance such growth.

Materials and Methods

Study Design

This research adopted a descriptive qualitative design, an effective method for studying phenomena that are not yet understood. This method was selected because it allows for a rich, straightforward description of participants' experiences and perspectives without requiring extensive theoretical interpretation.[21] It is especially suitable for understanding the various dimensions of post-traumatic growth experiences among family caregivers of people with dementia. Unlike phenomenological approaches, which seek to uncover the essence of lived experiences, or narrative inquiry, which focuses on how individuals construct meaning through storytelling over time, the descriptive qualitative approach aims to stay close to the data and present participants' accounts in their own terms. This methodological flexibility and clarity make it particularly suited to capturing the culturally and emotionally grounded realities of caregiving in the context of dementia.

Study Setting and Participants

The study settings were the memory disorders clinic of a tertiary hospital and the outpatient clinic of a mental health center in Shanghai. The maximum difference sampling strategy of purposive sampling was used, considering the duration

of the patient's illness, the participant's relationship with the patient, and the duration of care. The inclusion criteria for the patients were as follows: (1) aged ≥60 years; (2) met the diagnostic criteria for dementia as outlined in the 2018 China Dementia and Cognitive Disorders Diagnosis and Treatment Guidelines,[1] and who were definitively diagnosed with dementia by a physician. The exclusion criterion for the patients was as follows: (1) the presence of other serious diseases (eg, advanced cardiovascular disorders, active malignancies, or end-stage organ failure).

Inclusion criteria for family caregivers: (1) aged ≥18 years; (2) mentally competent with functional literacy and comprehension abilities; (3) legally or biologically related to the patient (eg, spouse, child, or other immediate family members); (4) designated as the primary caregiver, cohabiting with the patient, and providing ≥4 hours of daily care for a minimum duration of 3 months; (5) willing and able to provide informed consent for study participation. Exclusion criteria for family caregivers: (1) the presence of significant acute or chronic comorbidities (eg, acute cardiac failure, hepatic or renal insufficiency); (2) receiving compensation for caregiving; and (3) experiencing major traumatic life events (eg, recent bereavement) within the past six months of the household.

The sample size was determined by data saturation, defined as the point at which no new themes emerged from thematic analysis and further data collection failed to yield additional insights into participants' experiences.[22] In this study, no new information appeared when 17 cases were formally interviewed. Two interviews were added to confirm the saturation of information, and no new themes were extracted, so 19 cases of respondents were interviewed. Eleven interviews were conducted at the participants' homes, and eight were conducted in the vacant consultation rooms of the hospital outpatient clinic.

Data Collection

The interview outline was based on the post-traumatic growth function model[15] and combined with the literature review. An interview outline was drawn up after discussion with the research team. Two family caregivers of dementia patients were selected to conduct pre-interviews, and the interview outline was adjusted and modified according to the content of the pre-interviews. The research team carried out a group discussion to determine the final interview outline, with the following specific content: (1) Can you describe your initial emotional reactions and immediate actions when your family member was first diagnosed with dementia? (2) How would you characterize your psychological adaptation process and your family's evolving caregiving dynamics since the diagnosis? (3) In what ways has your self-perception or personal identity shifted throughout your caregiving journey? (4) What factors are most influential in shaping these personal transformations? (5) How has the caregiving role impacted your daily life routines, emotional well-being, and interpersonal relationships? (6) What specific systemic barriers (eg, healthcare access, financial constraints) and emotional dilemmas have you encountered in care provision? A descriptive qualitative research method was used to conduct face-to-face, semi-structured, in-depth interviews with dementia family caregivers. Data collection occurred from June to October 2024. The researcher has been following the Memory Disorders Clinic and the Mental Health Center Clinic for a long time and has established good contact with family caregivers. Before the interview, the participants were introduced to the purpose of the study, the content, and the interview method. The interview duration was 30–45 min, and the time and place of the interview were agreed upon after obtaining informed consent from the study participants. The interview location was an undisturbed room in the outpatient clinic or the caregiver's home to protect the interviewee's privacy. The researcher conducted interviews with a pre-determined outline, encouraging participants to share their thoughts and feelings. They were prompted to ask follow-up questions, clarify and repeat their answers, record their body language and facial expressions, and observe their emotional changes.

Data Analysis

The researcher repeatedly listened to the audio recordings for 48 hours after the interviews, combined with the interview process recordings to form a transcript, and forwarded the interview data to the interviewees for confirmation. The NVivo 20.0 software was utilized for data management. The data analysis employed the direct content analysis method.[23] The initial coding framework was constructed by integrating the textual materials from the interviews based on the functional model of post-traumatic growth[15] and the research questions. Next, the audio recordings were listened to repeatedly, and the interview texts were analyzed and coded sentence by sentence, paragraph by paragraph. Afterward, the coded

materials were organized into categories and summarized, and the main themes and core ideas were refined through induction, comparison, and deduction. Finally, the coding and analyses were checked to determine whether theoretical saturation had been achieved; if no new necessary codes and themes emerged, it was concluded that theoretical saturation had been reached. All interview transcripts underwent rigorous quality checks, including detailed reviews, to ensure completeness before analysis. Two researchers (Y.W. and N.S). independently implemented a dual coding process to enhance methodological rigor. When inconsistencies arose in organizing and analyzing the data, the research team refined and confirmed the final theme after discussions and analysis.

Quality Control

The study's rigor and trustworthiness depend on four aspects: credibility, transferability, dependability, and confirmability, as noted by Lincoln and Guba.[24]

To ensure credibility, the researchers and peers thoroughly discussed the key statements and interpretations derived from the original data. Furthermore, the researcher possessed prior experience in clinical nursing practice and demonstrated strong communication skills with family caregivers. The members of this research team have completed several studies in the field of dementia and possess extensive knowledge of managing dementia, allowing them to quickly recognize and comprehend the psychological changes experienced by family caregivers. To reduce potential communication bias from the researcher's professional background and prior relationships with participants, the interviews were conducted using a neutral and non-directive method. The researcher deliberately avoided sharing personal opinions or guiding responses during the interviews. Furthermore, the research team participated in continuous reflexive discussions during the study to closely analyze how their viewpoints could influence data interpretation.

To promote transferability, a maximum difference sampling strategy was employed that considered participants' gender, literacy levels, relationships with the patient, and the duration of their caregiving to thoroughly investigate the post-traumatic growth experience of family caregivers for individuals with dementia.

To enhance dependability, the research team adopted systematic data stewardship protocols, including digitally archived backups of interview guides, verbatim interview transcripts timestamped 48 hours after recording, and annotated audit trails that document iterative coding processes and logs of analytical decision-making.

To further enhance confirmability, the researcher transcribed the audio recordings of the interviews, promptly returned the interview texts to the interviewees, and made adjustments or additions based on their feedback. Additionally, two researchers independently analyzed and coded the data, resolving inconsistencies through team discussions. Specifically, the researchers maintained a reflexive journal to record personal reflections, emotional responses, and assumptions throughout the research process. This addition highlights our efforts to increase self-awareness and minimize potential bias, further enhancing the objectivity and trustworthiness of our findings.

Ethics Approval

This study received approval from the Ethics Committee of Shanghai Fifth People's Hospital, Fudan University (Ethical Approval Form (2024), Ethics Review No. 002). The research was conducted in full compliance with the Declaration of Helsinki. All participants signed a paper-based informed consent form. Informed consent was obtained from participants, specifically by publishing their anonymized responses or direct quotes.

Results

The total duration of the interview recordings was 1,030 minutes. Individual interviews ranged from 25 to 80 minutes, with a mean duration of 54 minutes. As shown in Table 1, the age range of family caregivers is from 27 to 81 years (median: 63 years old). The duration of caregiving lasted from 1 to 6 years and primarily involved the patient's spouse or children. The analysis revealed four major themes that captured family caregivers' experiences of post-traumatic growth during caregiving: cognitive-behavioral shift, personal strength enhancement, improved relationships with others, and changes in life perceptions (Table 2). Representative participant quotations were used to verify and validate the study findings.

Table 1 General Information of Dementia Patients and Family Caregivers (N=19)

ID	Caregivers							Patients			
	Age	Gender	Education Level	Working Condition	Relationship with Patients	Monthly per capita Income of Household (RMB)	Duration of Care (year)	Age	Gender	Duration of Disease(year)	Type of Dementia
N1	74	Male	University	Retired	Spouse	>10000	5	73	Female	5	AD
N2	81	Female	Senior high school	Retired	Spouse	>10000	4	89	Male	4	AD
N3	77	Female	Junior college	Retired	Spouse	5001~10,000	1	86	Male	1	AD
N4	52	Female	University	Employed	Daughter	3001~5000	1.5	82	Female	1.5	AD
N5	27	Female	Junior college	Employed	Daughter	5001~10,000	2	72	Male	2	VD
N6	78	Male	University	Retired	Spouse	5001~10,000	2	74	Female	2	AD
N7	76	Male	Senior high school	Retired	Spouse	>10000	2	75	Female	2	AD
N8	68	Female	Postgraduate	Retired	Daughter	5001~10,000	3	95	Female	3	AD
N9	43	Female	Junior college	Unemployed	Daughter	>10000	1	77	Male	1	AD
N10	50	Female	Junior college	Employed	Daughter	5001~10,000	2	75	Female	2	VD
N11	73	Male	Junior high school	Retired	Spouse	>10000	2	71	Female	2	VD
N12	63	Male	Junior college	Retired	Son	5001~10,000	4	92	Female	8	AD
N13	63	Male	Junior high school	Retired	Spouse	3001~5000	5	63	Female	5	AD
N14	50	Female	University	Unemployed	Daughter	1001~3000	6	78	Female	6	AD
N15	53	Male	Senior high school	Employed	Son	5001~10,000	4	87	Male	4	AD
N16	78	Female	University	Retired	Spouse	5001~10,000	4	76	Male	4	AD
N17	87	Male	University	Retired	Spouse	5001~10,000	6	83	Female	6	AD
N18	40	Female	University	Employed	Daughter	5001~10,000	1	72	Female	1	AD
N19	63	Female	University	Retired	Daughter	5001~10,000	4	96	Female	4	AD

Notes: AD stands for Alzheimer's disease, and VD stands for vascular dementia.

Theme 1: Cognitive-Behavioral Shift

Transitioning Family Roles

The diagnosis of the patient brings shock to the family caregivers, which is manifested as shock, frustration, and inability to accept. However, with changes in the family's functional structure and the need for caregiving, they have to take the objective reality of their loved one's illness, detach themselves from their original roles, and adjust to the change in family roles.

> After all, Dad is still part of the kind of backbone of the family, and suddenly, I feel like the sky has collapsed. If I'm still at home as a little princess, no one can protect me anymore; I must stand up and take care of it all. (N5)

> Shocked, I can't figure out how she got this. My life has completely changed; it was all about her taking care of me, but now it's all the way around; I have to give it back to her. I have to put up with it. The mindset is right; she is my wife, and two people accompany it. (N11)

> It's frustrating to know. that my mother was the head of the family before she had the disease, and she was in charge of everything. But now, if the family needs help, I would volunteer to take on more. (N19)

Recognizing Disease Characteristics

Family caregivers experiencing helplessness and breakdown in response to illness, coping with traumatic stress, and experiencing multiple caregiving dilemmas were able to revisit the traumatic event of the disease itself and break free from negative emotions and feelings of shame about the illness.

> There used to be a time when I heard people pointing fingers, and this one is very sensitive (frowns) as if it's passed on to feel uncomfortable Frankly, I've stopped dwelling on others' opinions. These ailments are part of life's course - what truly matters is providing her with proper care.(N17)

> People have 3,000 illnesses, and this is also an illness; at first, I felt that this was humiliating to talk about, but now that I understand it, I know to take care of her in a more positive way and line with her situation. (N18)

In addition, family caregivers were able to fight the disease proactively, including learning about it, reflecting on and analyzing its causes, and facing caregiving dilemmas more positively.

> I read much information on my own and listened to experts' explanations, and I know that this disease is irreversible. There is no specific medicine for it either, so I pay attention to it and my diet and her nutrition. (N7)

> After I went to learn about this disease, I realized that memory loss and Alzheimer's disease are two completely different concepts. I also always read things on this subject and ask my doctor friends how to care for such a patient and what to do when the disease strikes. (N15)

> He's more introverted, he's an introvert, he talks very little, so he's prone to this dementia. (N2)

> Is a secondary disaster of an epidemic that turns a person with a clear head into an increasingly stupid state due to lack of social contact. (N8)

> Because she's had four brain infarcts, I think that's what caused it, clogged blood vessels. (N19)

Focusing on Health Management

Family caregivers recognize the significance of physical and mental health. They can focus on their own and their family members' health and take the initiative to adopt health-promoting behaviors.

> Like I will force my mom to go for medical checkups every year now, and she used to be maybe lazy and go once every two or three years, but now I say you have to go. (N5)

> We share any information about dementia on the internet inside the family group for everyone to know. Remind each other how to eat and take care of life, including how to care for these older adults when you see small videos of them at home. Even if someone in the family has a sign, I will remind him to go for a checkup. (N12)

> Because this disease is supposed to have some genetic factors in it, so I will go to the literature to see which ones, for example, to judge for myself if I have an early condition. Or do something to prevent it actively. For example, I pay more attention to protecting my heart function if I have high blood pressure. I usually actively engage with society by going for daily walks, enjoying the sun, and reaching out to others. (N14)

Responding Positively and Effectively

Family caregivers have worked out and learned ways to relieve stress and adapt to themselves during their caring responsibilities. Through different forms of catharsis, such as listening to music, diverting attention, and practicing self-compassion, they can help themselves eliminate their painful emotions.

> It takes a little bit of getting used to; she is a patient. When I'm upset, I go for walks, brisk walks, talking to myself while I walk, and self-digesting as I go. (N12)

> I just think to myself from time to time, my mind is like the sea, traveling in the starry sky, so slowly, I always read these old poems. (N16)

> I have more hobbies and interests. I like sports channels, and it's very depressing to watch. My mom likes to sing, so I play karaoke for her, so it's de-stressing for her, and it's de-stressing for me (ha ha ha laughs) so that I don't trap myself in anxiety. (N19)

In addition, family caregivers achieved more effective illness coping with internal and external resources by proactively seeking help from family and society.

> I often turn to my aunt for help with things I don't know how to do. Her mother-in-law also has dementia, and she'll teach me how to deal with it; for example, my dad is always doing one thing over and over again or is very moody; she helped me a lot. (N9)

> We are still more aligned and consistent in our family, and when we ask for help with a problem, they solve it right away. (N18)

Table 2 Themes and Sub-Themes Identified in the Analysis

Themes	Sub-Themes
Cognitive-behavioral shift	Transitioning family roles
	Recognizing Disease Characteristics
	Focusing on health management
	Responding positively and effectively
Personal strength enhancement	Enhancing coping capacity
	Increased psychological resilience
	Increased responsibility
Improved relationships with others	Harmonizing in family relations
	Benefiting from social interactions
Changes in life perceptions	Reshaping of values
	Reconstructing the meaning of life

There is something, I contact the family doctor on WeChat all day and night, and if there is anything, I look for him, and he gives me an answer right away, and helps me a lot. (N2)

The government, ah, our government is still perfect. You see, applying for this long-term care insurance, ah, five times a week, door to door, to help me clean, bathe her, door to door, is also convenient. I'm not convenient for myself, because she sometimes does not listen to me. (N11)

Theme 2: Personal Strength Enhancement

Enhancing Coping Capacity

The traumatic events of illness and trauma that brought challenges to family caregivers also tapped into their potential and facilitated the enhancement of their capacity to better cope with the difficulties and unforeseen events of the caregiving process.

I kept dealing with doctors and relatives during this process, and I am much better in this aspect of my social skills, and this experience is an experience for me so that in the future if my mom develops this problem, I at least know how to go about it. (N5)

Having a patient at home and being half a doctor myself and a full care worker, I am learning and growing. Knowing how to pay attention to her mental state, taking care of her, I have to be responsible for her in all aspects. (N6)

Now I know how to take care of someone who is sick, to pay attention to their emotional state, especially like patients with dementia who can be emotionally unstable, and I know how to cope with that. (N9)

It's important to get a grip on her psychology because she won't tell you 'How am I doing now,' you can't go against her when she's having a seizure; just wait until she's distracted; that's what I've learned. (N11)

Increased Psychological Resilience

As a result of the caregiving process, family caregivers reported more patience, changes in temperament and personality, and greater inner resilience in the face of personal difficulties.

My change is that I have become more patient with my old mom. (N10)

I can solve a lot of things by myself now and keep going. (N4)

Taking care of my mom is building my patience, and it's making me tougher, in the words of my friend, 'If you want to do it, there's nothing you can't do'. (N8)

Increased Responsibility

Long-term, complex caregiving tasks affected family caregivers' physical and mental health and personal development. They also allowed them to recognize family responsibilities and kinship ties and take the initiative to assume responsibility as family members.

> Just stay with him, and the two of us just take care of each other and go through this life, I guess. (N2)

> So I am accepting such a fact with high hopes. A kind of responsibility to her, a mother-daughter emotion, a blood bond, a very pure sense of responsibility. (N8)

> People out there say, 'you're quite strenuous in taking care of her,' and yes, strenuous is very real, very hard. On the flip side, she's your (wife), right? Your significant other, what do you say you take care of it just fine; take care of her to the best of your ability. (N11)

In addition, family caregivers were more concerned about social support for similar patients and family caregivers. Based on their own experiences, they called on society to give more support and understanding to such families and to enhance support for family caregivers.

> If I meet a similar patient in my family, I will also take the initiative to communicate with each other and try to help as much as I can. (N2)

> It's the kind of psychological help that the community gives to the caregiver. For example, there is a psychological organization that enables caregivers to go and pour their hearts out. (N8)

> I'm concerned if there is that kind of special medicine or treatment that can come out. Because it's not only painful for the patient himself, but more for the family, and I hope that more family caregivers can be benefited. (N14)

Theme 3: Improved Relationships with Others

Harmonizing in Family Relations

The family must cooperate with the progressive development of the patient's illness and the specificity of the cognitive and psycho-behavioral symptoms. In response to the traumatic events of the disease, family members were more closely connected. They had a more harmonious relationship, and family caregivers felt the warmth of their family and cherished the relationship.

> My sister came back from Canada to stay with me for two months, and she said, 'You're too skinny, and I don't feel relieved to take care of you by myself'. I don't have any children, but my nieces and nephews all care for me. My niece cooks me food every week and takes us out for some meals or to have fun and give me a break. We're getting closer, and I'm fortunate. (N3)

> My mother is currently in such a good condition because all of us kids do our best to take care of the elderly. My siblings and I see each other weekly; they visit and get together, and we all agree to take good care of our old mom. My loved ones also support my decision and can understand me, so I think it's good right now.(N12)

Benefiting From Social Interactions

Family caregivers benefited from interpersonal interactions as they received help and support from healthcare professionals and outside organizations in coping with caregiving events.

> Colleagues from the unit often came to see her and talked to each other. From time to time, Dr. Wu organizes these family members to participate in memory disorder exchange activities, where they share their caregiving experiences and take lessons from each other for comfort and consolation. (N1)

> This family doctor of ours, he helped me a lot, taught me how to monitor his blood pressure, ah, what do I have to do when he has a seizure. (N2)

The family doctor talked to me; he said, 'You have to think positively; he (old partner) is still lucky if he runs ahead of you, so you must hang in there,' he often enlightened me, and I was very comforted.(N3)

A group of our friends who play better often ask us to go out and go on trips. Ah, they will help us get it all together and take her with us when we go out. They help me along to relieve me, and I dare to go out and play. Otherwise, I wouldn't go out at all. (N11)

Theme 4: Changes in Life Perceptions

Reshaping of Values

Experiencing struggles with negative experiences of illness care, family caregivers' mindset and pursuits changed, re-examining life and measuring gains and losses, clarifying life priorities, and living with a more positive and open attitude.

I need to be physically well myself now, and to be physically well to take care of her is to be open about it. We are living one day at a time, cherishing every day now; what's the use of complaining about heaven and earth? (N6)

I took the initiative to quit my job to accompany my mom to send her off on her last journey, and I got complete satisfaction. I don't know her end time, but I take care of her and live my life; that's what I should be doing now, living the life in front of me. (N8)

I've lost my job, but I've preserved myself and my mom, right? So you must give and take, make trade-offs, and can't have everything. In the future, I hope to make her life a little more comfortable and less painful through my efforts. I'm also trying to get my body and mind to live a few more years, do what I want, and then take my time with my life in Homington. (N14)

Reconstructing the Meaning of Life

Family caregivers experiencing traumatic events of illness and coping with multiple caregiving issues can actively think about the meaning of life, including the preservation of the dignity of life, looking at death with equanimity, and considering the significance of the continuation of life.

With my partner, it's just that I want to see the continuation of her life to have a quality of life, to be able to grow old with dignity. (N7)

I used to be very still calculating about things, but now it's just about feeling very healthy and at peace with life, and a day lived is a day won. (N18)

I can now think flat and loosely about how my mom will be in 100 years, and it's all acceptable I think people need to think through and contribute as much as they can; I'm going to donate my remains. (N12)

Discussion

This study demonstrated that family caregivers of people with dementia experience post-traumatic growth to varying degrees, which includes cognitive-behavioral shifts, personal strength enhancement, improved relationships with others, and changes in life perceptions. This finding aligns with earlier research, which reports moderate scores of post-traumatic growth among family caregivers of people with dementia.[18]

This study revealed that family caregivers generally experienced a cognitive behavioral shift from "role conflict" to "internalization of responsibility". Contrary to PTG theory,[15] the theme "switching family roles" in this study revealed that family responsibility is also the crucial driver of cognitive adjustment. The objective of this study was the family caregivers of people with dementia, mainly consisting of the patient's spouse or children. Chinese Confucianism emphasizes filial piety and ethics, reinforcing the caregiver's responsibility to care for people with dementia. Acknowledging this role helps caregivers adjust cognitively and maintain family stability.[25] This study found that family caregivers proactively adopt various coping strategies. For example, diverting attention, practicing self-compassion, and seeking family and social resources for emotional support, in line with the findings of Wang et al.[26] These contribute to improving problem-solving skills in the challenges of caregiving events.[27] Cognitive shifts encourage individuals to adopt positive coping mechanisms, acting as a self-protective defense that motivates caregivers to actively seek various

strategies for dealing with traumatic stress and promoting post-traumatic growth.[28] Therefore, healthcare professionals should focus on positive psychology perspectives to guide caregivers in correctly recognizing and understanding the traumatic events of illness. They should also adopt cognitive control therapy and expressive writing to enhance positive cognition and self-role identity, promoting individual well-being and growth.[29] Furthermore, unlike other caregivers who concentrate solely on patients' health management,[30] family caregivers in this study engaged in bi-directional health management, meaning they focused on both their and the patient's health. This approach not only pragmatically adapts to the demands of irreversible and long-term dementia care but also embodies deeply rooted Confucian values. In Confucian culture, primarily through filial piety and familial interdependence, the well-being of all family members is regarded as a moral obligation.[25] Consequently, caregivers are motivated by the need to maintain their caregiving abilities and cultural responsibility to sustain family harmony and collective health. For example, a caregiver's poor physical and mental health can negatively affect the patient's quality of life,[31,32] resulting in a worse prognosis and potentially increased mortality.[33,34] Therefore, bi-directional health management is a culturally informed approach and a vital coping mechanism in progressive disease.

This study also showed that traumatic events related to the illness highlighted the intrinsic potential of family caregivers by improving their coping skills, bolstering psychological resilience, and fostering greater responsibility, which is consistent with the findings of Ke et al.[35] However, the uniqueness of dementia caregiving highlights the importance of strengthening personal strength pathways. On one hand, the psycho-behavioral symptoms of the disease, communication barriers, and comorbidities with multiple chronic illnesses pose ongoing challenges for caregivers,[5] urging them to develop multidimensional coping strategies. A caregiver's remark exemplifies this: "You can't fight against the patient when she is having an attack, and you have to learn to pay attention to the patient's psychological state." On the other hand, acquiring caregiving skills and problem-solving further contribute to developing a sense of control, which drives coping skills through a positive feedback loop.[36] Research has demonstrated that growth does not stem from removing existing caregiving stress and illness-related distress, but rather that individuals become more empowered and resilient in their struggle against adversity.[15] Psychological resilience buffers the adverse effects of negative events, and individuals with high levels of psychological resilience can mobilize resources to adjust their psychological state, adapt positively to traumatic events, and achieve growth.[37] Healthcare professionals are prompted to improve caregivers' sense of control and psychological resilience by conducting Focused Solution Model psychological interventions,[38] Positive Thought Therapy,[39] and tapping into positive psychological resources to facilitate caregivers' growth experiences. The last sub-theme is increased responsibility in the family and society. Caring for people with dementia helps caregivers understand the challenges they face. As a result, they tend to respond to other caregivers' needs and emotional conditions with improved accuracy and accountability, taking on the role of family caregivers and pushing for enhanced social support and aid.[40]

It was observed that family caregivers perceived harmonious family relationships and derived benefits from social interactions, consistent with prior findings in studies.[18,37] The material support and emotional assistance provided by family and society enable caregivers to understand the dynamics of coping with care, enhance their confidence in managing traumatic events, and effectively reduce their negative emotions, thereby facilitating the formation of post-traumatic growth.[17,41] In contrast, this study found that caregivers with unmet family support exhibited higher levels of anxiety, loneliness, and helplessness, and longed for more emotional support and assistance with material resources from their families. The reason for this difference in results may be related to the fact that some of the respondents were older adults, had limited social networks, and had inadequate access to information and social resources.[42] It may also be related to society being overburdened with family caregiving due to shrinking family size and insufficient intergenerational support.[43] Healthcare professionals should proactively assess the family situation of caregivers, identify their ability to cope with traumatic events, and help family caregivers to effectively use family social resources to cope with caregiving difficulties, such as cognitively impaired friendly communities, community support groups, or long-term care insurance to alleviate the burden of caregiving.[44] Additionally, this study revealed that peer support is a vital source of growth for caregivers. Interpersonal interactions among peers, such as communication, sharing, and encouraging listening, can alleviate caregivers' feelings of loneliness caused by social isolation, and help them find their inner self belonging.[45] A parallel theme emerged among family caregivers in Singapore, suggesting that they may find a sense of purpose in this experience sharing.[13] It is recommended that healthcare professionals carry out

multiple forms of peer support, such as information support and feedback from microblogging groups and the internet, to reduce caregivers' negative psychological feelings.

This study also found that the traumatic and stressful experience of caregiving for a disease triggered a more profound sense of life for family caregivers, which was expressed as a reshaping of values and a reconstruction of meaning in life. Family caregivers prioritized key aspects, including self-preservation, active resignation, and health management. This mirrors the dialectical thinking inherent in caregivers' negotiations as they handle the ongoing stress caused by circadian rhythm disruptions and psychiatric symptoms in dementia patients, aligning with the insights from Ni et al.[30] Through continuous reflection and scrutiny of trauma, individuals understand the preciousness of life and develop a sense of its value, thus maintaining a positive mindset and coping strategies and achieving further personal growth.[46] Research has shown that family caregivers who actively reflect on the value of life can balance resisting caregiving events with regulating their personal lives, thereby realizing the meaning of life and achieving self-transcendence.[47] This suggests that healthcare professionals can provide meaning-of-life therapy to help family caregivers approach illnesses with a positive mindset and recognize the value of life, ultimately achieving positive coping and personal growth.

Strengths and Limitations

A key strength of this study was its focus on a positive psychology perspective, which explored the positive psychological experiences of family caregivers for individuals with dementia. Another strength is the use of a descriptive qualitative research design to explore family caregivers' experiences of post-traumatic growth, using the Functional Model of Post-Traumatic Growth as a theoretical guide. Yet, this study also had some limitations. First, all participants were spouses or children of people with dementia and reported similar income levels. This likely reflects the homogeneous demographic and socioeconomic characteristics of the two urban districts in Shanghai where recruitment occurred. Such uniformity may limit the diversity of caregiving perspectives and reduce the transferability of findings to broader caregiver populations. Second, although the inclusion criterion required at least three months of caregiving, the final sample (1–6 years) reflected the natural distribution of willing participants. The caregiving durations under one year or over six years may limit insights into early-stage adjustment and long-term adaptation. Future research could broaden recruitment to rural and less economically developed regions, where caregiving structures and resources may differ. Collaborations with other research teams or healthcare institutions across China may also help access a broader range of caregiver roles and durations. Moreover, all participants in this study had provided care for at least one year, and the interviews relied on their recollections of prior experiences, potentially introducing bias. Future research could utilize longitudinal qualitative designs, incorporating methods such as diary studies, short-term follow-up interviews, or methodological triangulation, to offer a more nuanced understanding of the trajectory of post-traumatic growth among family caregivers at various stages of dementia progression. Finally, the study included only caregivers of individuals with Alzheimer's disease (AD) and vascular dementia (VD), the two most common subtypes in China, accounting for over 70% of dementia cases. Rarer forms such as Lewy body dementia (DLB), which represent 5–10% of cases, were not included.[1] Recruitment from two tertiary hospitals specializing in AD and VD limited access to caregivers of less prevalent and diagnostically complex dementias. As a result, the generalizability of findings to caregivers of other dementia subtypes remains uncertain. Future studies should explore whether these caregivers experience similar or distinct psychological adaptation and growth patterns.

Conclusion

This study explored the post-traumatic growth experiences of family caregivers for older adults with dementia, identifying four key areas: cognitive behavioral shift, personal strength enhancement, improved relationships with others, and changes in life perceptions. These findings reflect general psychological processes, such as resilience and meaning-making, and culturally specific influences, especially filial piety and family obligation within the Chinese context. By highlighting the dynamic interplay between personal transformation and sociocultural context, this study provides a more nuanced understanding of the caregiving experience. Importantly, while the study emphasizes growth, it does not overlook the emotional burdens, unresolved grief, and psychological strain that many caregivers continue to confront. Growth and suffering often coexist throughout the caregiving journey. Therefore, the findings carry practical implications

for both clinicians and policymakers: interventions should be culturally sensitive, acknowledging both the emotional challenges and growth potential of caregivers. Tailored programs that address caregiving's challenges and growth potential may enhance caregiver well-being and long-term sustainability.

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Disclosure

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