Global Health & Medicine. 2025; 7(1):72-73.

DOI: 10.35772/ghm.2024.01098

The process of post-traumatic growth for the main caregivers of patients with Alzheimer's disease

Yufeng Yu[1], Yuhui Wang[1], Ling Li[1], Wenlin Yi[1], Jing Li[1], Jianbin Hu[2,*]

[1] School of Nursing, Chengdu University of Traditional Chinese Medicine, Chengdu, Sichuan, China;
[2] Chengdu Aier Eye Hospital, Chengdu, Sichuan, China.

Abstract: Family members caring for individuals with Alzheimer's disease (AD) often experience significant psychological distress, which can lead to mental health issues such as severe depression, post-traumatic stress disorder, and anxiety. We conducted a study to explore the experiences of 18 primary caregivers of AD patients through semi-structured in-depth interviews. The study identified four key stages of post-traumatic growth (PTG): *i*) the pain period, *ii*) the struggle period, *iii*) the recovery period, and *iv*) the period of positive growth. Additionally, factors that contribute to PTG among caregivers include *i*) strong social support, *ii*) active coping strategies, *iii*) reflection on and understanding of their caregiving experience, and *iv*) future planning. Healthcare professionals should incorporate strategies to promote PTG in clinical practice to effectively support caregivers.

***Keywords*:** post-traumatic growth, Alzheimer's disease, primary caregiver

Alzheimer's disease (AD) is a debilitating condition that leads to a gradual decline in cognitive function and the ability to perform daily activities, ultimately imposing a significant burden on society and the economy (*1*). Family members who care for individuals with AD often experience substantial psychological strain, resulting in mental health issues such as severe depression, post-traumatic stress disorder, and anxiety (*2,3*). Post-traumatic growth (PTG) refers to the positive changes that can occur following a traumatic event (*4*). Previous studies have shown that caregivers of AD patients face significant mental, physical, and financial challenges (*2,3,5*). As AD progresses, patients lose their ability to care for themselves, which can deeply affect the physical and emotional well-being of their caregivers and ultimately influence the quality of care provided. Given the increasing number of AD patients and the associated disease burden, study of the PTG experienced by primary caregivers is crucial to enhancing the quality of care.

A study was conducted from a positive psychology perspective to explore the process of PTG and the experiences of primary caregivers of patients with AD in order to provide insights on how to effectively harness caregivers' PTG experiences to improve the quality of care provided to patients. Participants were 18 primary caregivers of AD patients at five medical facilities in Sichuan Province, China who were identified using purposive sampling from March 2020 to May 2021.

The inclusion criteria were as follows: *i*) the primary caregiver of an AD patient, responsible for the majority of caregiving tasks, which could include the patient's children, spouse, friends, or other relatives; *ii*) age ≥ 18 years; *iii*) daily caregiving time ≥ 4 hours, with at least 3 months of direct care experience; *iv*) living with the patient; *v*) alert and oriented, able to communicate, and able to understand this study; *vi*) informed consent and voluntary participation. Exclusion criteria included: *i*) caregivers of patients with other serious diseases and *ii*) paid caregivers, such as nannies.

Four major themes and their key characteristics

The process of PTG for primary caregivers of AD patients was explored through semi-structured in-depth interviews. Findings revealed the following four major themes and their key characteristics:

i) *Period of Pain*: Upon learning of the diagnosis, caregivers often experience an emotional period of pain, where their beliefs and worldviews are shaken. They struggle with feelings of helplessness and guilt, especially in managing the patient's condition and coping with the emotional toll. Common challenges include handling medications, dealing with patients' refusal to accept their condition, and the financial strain of long-term care. As one caregiver shared, "It's very stressful...

there is another family member with the same condition, and I have to take care of both of them". Guilt and self-blame were also prevalent, as caregivers questioned whether they could have prevented or better managed the illness.

ii) *Period of Struggle*: In this stage, caregivers begin to accept the reality of the disease. Despite the challenges, many increase their caregiving role and reflect on their experiences, finding strength in adversity. Caregivers often seek professional help or focus on non-drug interventions, such as diet and exercise, for the patient. Spiritual comfort also becomes a key source of motivation during difficult times.

iii) *Period of Recovery*: During the recovery phase, caregivers reflect on their lives and develop a deeper sense of purpose in their caregiving role. They begin to focus on the present moment. As one caregiver explained, "When he passes away one day, our lives will lose a huge part of their meaning". Social support is crucial, with caregivers who received help from family or friends feeling more confident and motivated. As one caregiver shared, "My brothers provide financial assistance and visit him during major holidays". Caregivers also prioritize their physical health, recognizing that their well-being is vital to providing quality care. As one caregiver said, "I can't be the first to go down – who will she rely on in the future?"

iv) *Period of Positive Growth*: In this stage, caregivers demonstrate resilience with a more active and positive attitude, reflecting on their growth as they manage caregiving responsibilities. They develop a deeper understanding of humanity and life. Caregivers are also willing to offer support and share their experiences with others facing similar challenges. Focused on providing the best care for patients, they actively seek opportunities to enhance their caregiving skills through training and education.

Factors facilitating PTG

i) *Social Support*: Higher levels of social support reduce negative emotions and increase the likelihood of adopting positive coping strategies, leading to a better quality of life and a greater appreciation of caregiving (*6,7*).

ii) *Active Coping*: Active coping enhances immunity and helps caregivers shift their perspectives, improve their cognitive function, and alleviate their caregiving stress (*8,9*).

iii) Reflection on Caregiving: Reflecting on caregiving experiences allows caregivers to gain new perspectives, reduce feelings of helplessness and foster personal growth.

iv) *Planning for the Future*: Caregivers who set goals, such as improving caregiving skills or seeking professional support, demonstrate greater adaptability in managing caregiving challenges.

Despite immense challenges, caregivers can experience positive psychological changes that enhance their resilience and caregiving abilities. Healthcare professionals should integrate strategies to foster PTG in clinical practice, ensuring caregivers receive the support necessary to improve their well-being and the quality of care they provide to AD patients.

Funding: None.

Conflict of Interest: The authors have no conflicts of interest to disclose.

References

1. Li R, Qi J, Yang Y, Wu Y, Yin P, Zhou M, Qian Z, LeBaige MH, McMillin SE, Guo H, Lin H. Disease burden and attributable risk factors of Alzheimer's disease and dementia in China from 1990 to 2019. J Prev Alzheimers Dis. 2022; 9:306-314.
2. Frederiksen KS, Lanctôt KL, Weidner W, Hahn-Pedersen JH, Mattke S. A literature review on the burden of Alzheimer's disease on care partners. J Alzheimers Dis. 2023; 96:947-966.
3. Kim B, Noh GO, Kim K. Behavioural and psychological symptoms of dementia in patients with Alzheimer's disease and family caregiver burden: A path analysis. BMC Geriatr. 2021; 21:160.
4. Dell'Osso L, Carpita B, Nardi B, Bonelli C, Calvaruso M, Cremone IM. Biological correlates of post-traumatic growth (PTG): A literature review. Brain Sci. 2023; 13:305.
5. Vu M, Mangal R, Stead T, Lopez-Ortiz C, Ganti L. Impact of Alzheimer's disease on caregivers in the United States. Health Psychol Res. 2022; 10:37454.
6. Ning J, Tang X, Shi H, Yao D, Zhao Z, Li J. Social support and posttraumatic growth: A meta-analysis. J Affect Disord. 2023; 320:117-132.
7. Nemcikova M, Katreniakova Z, Nagyova I. Social support, positive caregiving experience, and caregiver burden in informal caregivers of older adults with dementia. Front Public Health. 2023; 11:1104250.
8. Stowell J R, Kiecolt-Glaser JK, Glaser R. Perceived stress and cellular immunity: When coping counts. J Behav Med. 2001; 24:323-339.
9. Geiger JR, Wilks SE, Lovelace LL, Chen Z, Spivey CA. Burden among male Alzheimer's caregivers: Effects of distinct coping strategies. Am J Alzheimers Dis Other Demen. 2015; 30:238-246.

Received November 12, Revised January 20, 2025; Accepted January 29, 2025.

**Address correspondence to*:
Jianbin Hu, Chengdu Aier Eye Hospital, No.115, 1st Western Section, First Ring Road, Wu Hou District, Chengdu, Sichuan 610000, China.
E-mail: hujianbin@aierchina.com