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Exploring the Meaning of Family Caregiving for Disabled Elderly: A Qualitative Study

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Abstract

Background:Family caregivers play a critical role in supporting disabled elderly individuals, yet the meaning and significance of caregiving from the caregivers' perspective remain underexplored. This study aims to investigate the meaning of caregiving among family caregivers of disabled elderly individuals and its implications for healthcare support systems. Methods:A qualitative phenomenological approach was adopted. Purposive sampling was used to recruit 12 family caregivers of disabled elderly patients from a tertiary hospital in Huaibei, Anhui Province, China. Semi-structured in-depth interviews were conducted, and the data were analyzed using Colaizzi's 7-step method to identify key themes. Results:Five main themes emerged from the analysis, reflecting the meaning of caregiving: (1) acceptance of caregiving responsibilities, (2) proactive coping with caregiving challenges, (3) personal growth, (4) family growth, and (5) a positive outlook on life. These themes highlight the multifaceted impact of caregiving on caregivers' lives. Conclusion:The findings underscore the importance of recognizing the meaning of caregiving for family caregivers of disabled elderly individuals. Healthcare professionals should provide comprehensive support systems to help caregivers effectively address the challenges they face, thereby improving their well-being and caregiving outcomes.

Keywords

Disabled elderly, Family caregivers, Meaning of caregiving, Qualitative research.

1. Introduction

Disabled elderly refers to older adults who are unable to independently complete daily living activities and often require assistance from others [1]. According to relevant data, it is projected that by 2030, the number and proportion of disabled and semi-disabled elderly in China will rise to 69.53 million and 17.44%,respectively[2].The growing population of disabled elderly reflects an increasing demand for care. Surveys indicate [3] that 92.71%of disabled or semi-disabled elderly rely on their families for long-term care. Domestic and international studies suggest that burden, depression, and stress are the primary focuses of research on family caregiving burdens and negative impacts [4-6]. However, research aimed at addressing caregiving burdens has not achieved the expected results, failing to significantly reduce the caregiving burden or improve the physical and mental well-being of family caregivers of disabled elderly. With the development of positive psychology, the positive aspects of family caregiving have gradually garnered attention in nursing and sociological research [7]. Therefore, this study shifts its perspective to conduct a qualitative study on the meaning of caregiving for family caregivers of disabled elderly, aiming to more effectively guide caregivers to perceive the meaning of their caregiving through a positive mindset and mobilize their inner

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strength, thereby alleviating their caregiving burden and supporting their long-term caregiving behavior.

2. Objects and Methods

2.1. Research Objects

Using purposive sampling, family caregivers of disabled elderly who visited a tertiary hospital in Huaibei City, Anhui Province, from November 2023 to December 2023 were selected as interview participants. Inclusion criteria for disabled elderly: ① Age ≥ 60 years;② Determination of disability based on the Basic Activities of Daily Living (BADL)scale[8].Inclusion criteria for primary caregivers:①Age>18 years;②Serving as the primary caregiver; if multiple caregivers are present, the one with the longest caregiving duration is selected;③ Providing care for > 4 hours/day and for > 4 weeks;④Normal comprehension ability, with no mental illness or cognitive impairment;⑤ Informed consent. Exclusion criteria:① Paid caregivers;② Poor compliance or unwillingness to cooperate with the study. The sample size was determined by thematic saturation, i.e., until no new themes emerged [9]. Ultimately, 12 family caregivers of disabled elderly were selected. The general characteristics of the caregivers are shown in Table 1.

Table 1. Basic Information of Disabled Elderly and Their Primary Family Caregivers

Elderly Code	Gender	Age	Primary Caregiver Code	Age	Gender	Relationship to Elderly	Education Level	Residence
P1	Female	80	H1	31	Female	Granddaughter	Vocational School	Urban
P2	Female	83	H2	25	Male	Grandson	Bachelor's Degree	Urban
P3	Female	80	H3	56	Male	Son	Primary School	Rural
P4	Male	69	H4	45	Male	Son	Primary School	Rural
P5	Female	75	H5	48	Female	Daughter	Junior High School	Urban
P6	Female	76	H6	53	Female	Daughter	Primary School	Urban
P7	Female	90	H7	56	Female	Daughter-in-law	Primary School	Rural
P8	Male	76	H8	55	Male	Son	Junior High School	Rural
P9	Female	78	H9	55	Female	Daughter-in-law	Primary School	Rural
P10	Male	77	H10	50	Female	Daughter	Primary School	Urban
P11	Male	72	H11	42	Female	Daughter	Junior High School	Urban
P12	Male	66	H12	64	Female	Spouse	Primary School	Rural

2.2. Methods

2.2.1. Development of the Interview Guide

The interview guide was developed based on the research objectives, literature review, team discussions, and consultations with relevant experts. It was further revised after conducting pre-interviews with two family caregivers of disabled elderly. The final guide included the following questions: 1)What are your feelings and experiences during the process of caring for a disabled elderly person?2)How do you perceive your caregiving behavior for the disabled elderly?3)What motivates you to continue caring for the patient?4)What have you gained from

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caring for the disabled elderly?5)Has your perspective on caregiving changed after realizing its meaning?

2.2.2. Data Collection Methods

Interviews were conducted in a private room to ensure the privacy and comfort of the participants. Before the interview, the researcher explained the purpose and significance of the study, obtained informed consent, and recorded the interview with the participant's permission. The interviews followed the guide and used open-ended questions, continuing until the caregiver fully expressed their feelings. Each interview lasted approximately 40 to 60 minutes.

2.2.3. Data Analysis Methods

Within 24 hours of the interview, the recordings were transcribed into text. The transcripts were then returned to the caregivers for verification. The data were analyzed using Colaizzi's 7-step analysis method [10]

3. Results

3.1. Theme 1: Accepting the Caregiving Role

3.1.1. Responsibility

Family caregivers of disabled elderly often accept the caregiving role out of genuine concern for the care recipient. Those with less intimate relationships may take on the role out of a sense of duty.H1: "First, I believe that as children, it is our duty to care for our elderly parents. Second, seeing them struggle with daily tasks or walk unsteadily makes me want to help and care for them."H2: "Although I am not his son, I am his grandson. Since my parents are not around, I must take on the responsibility of caring for him."H4: "This is my father, and it is my obligation to care for him."H7: "I believe that as children, we should respect and care for our parents. It is our responsibility."

3.1.2. Social Ethics

Caregivers are influenced by traditional Chinese values such as filial piety and the concept of raising children for old-age support.H6: "As long as I have food to eat, they will have food to eat. Filial piety comes first."H8: "He cared for me when I was young, so it is natural for me to care for him now. This is a traditional virtue."H10: "Raising children is not easy. Filial piety is a traditional virtue of the Chinese people. We must set an example for our children to follow."

3.1.3. Being the Best Candidate for Caregiving

Caregivers often take on the role due to their personal advantages in providing care.H1: "I feel more at ease caring for her myself. I have experience caring for my mother-in-law and am familiar with hospital procedures and basic rehabilitation knowledge."H2: "I have more free time as a part-time teacher, so I can dedicate most of my time to caring for her."H3: "I have poor eyesight and cannot work outside, so I stay home to care for her."H9: "Among my siblings, I am the most available to care for her, allowing others to focus on earning a living."

3.2. Theme 2: Actively Coping with Caregiving Challenges

Caregivers strive to adapt to the caregiving environment and manage stress by utilizing various coping strategies and resources.H2: "I prioritize her needs over my work and personal time."H5: "No matter what, caring for her is my top priority."H6: "I learned to ride a tricycle to take her out more often, which makes her happier."H12: "I ask doctors and nurses for advice on massage and turning techniques to improve her care."

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3.3. Theme 3: Personal Growth

3.3.1. Increased Caregiving Knowledge and Skills

Caregivers reported gaining knowledge about caregiving and related diseases, improving their problem-solving abilities.H7: "I learned rehabilitation techniques from the hospital and applied them at home, such as gently lifting her legs and massaging her body."H11: "Over time, I learned to manage my stress and sleep better despite the challenges."

3.3.2. 3.3.2 Enhanced Personal Qualities

The long and arduous caregiving process helped caregivers develop patience and emotional resilience.H6: "I have become more patient and less prone to anger as I adapt to her personality."H7: "Despite the challenges, I remain committed to caring for her without complaints."

3.4. Theme 4: Family Growth

Long-term caregiving strengthened family relationships and set a positive example for younger generations.H1: "As I care for her more, she has become more dependent on me, and our relationship has improved."H2: "My parents and relatives praise my efforts, which motivates me to continue caring for her."H5: "Her mood improves whenever I visit, which brings joy to the family."H8: "By caring for the elderly, we set an example for our children to follow."H10: "Caring for my parents has deepened our bond and reinforced the importance of filial piety."

3.5. Theme 5: Positive Outlook on Life

Caregivers applied the lessons learned from caregiving to other aspects of their lives.H5: "Everyone grows old. We should approach life with a selfless attitude."H6: "Helping others is helping oneself."

H7: "I am grateful for the opportunity to care for her, even if it is challenging."H12: "My goal is to care for my husband well, ensuring his and our family's well-being."

4. Discussion

4.1. The Formation of Caregiving Meaning is a Multi-Stage Process

The interviews revealed that the formation of caregiving meaning is a dynamic, multi-stage process. The initial stage involves accepting the caregiving role, driven by caregivers' values of reciprocity. Studies indicate that domestic family caregivers are more inclined to derive caregiving meaning from family responsibilities and filial piety [11], which motivates them to take on caregiving duties. After accepting the role, family caregivers gradually identify with their new responsibilities and begin adjusting their life rhythms and priorities. As caregiving continues, both parties reflect on the caregiving experience, and family caregivers may develop a sense of achievement, responsibility, or emotional fulfillment. Chen Fengyi's research [12] also shows that caregivers' self-efficacy positively predicts their psychological coping mechanisms. Bandura [13] points out that individuals' behaviors and experiences are transmitted to others through observation and learning, and the transmission of caregiving meaning follows this pattern. This study found that caregiving meaning is not limited to immediate interactions but can also be perpetuated through memories, stories, or shared experiences. Caregivers' behaviors may influence others, and the experiences of care recipients may inspire more people to recognize the value of caregiving.

4.2. Family Caregivers Resiliently Accept Reality and Actively Cope with Challenges

Among family caregivers of disabled elderly, positive and effective coping strategies are seen as crucial resources for deriving caregiving meaning. Research shows [14] that positive coping

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mechanisms are essential for patients dealing with trauma. In this study, family caregivers resiliently accepted their circumstances, adapted to new lifestyles, and developed an optimistic mindset, enabling them to better cope with the challenges of caring for disabled elderly. By reframing caregiving as an opportunity to accompany and spend time with loved ones, caregivers were better able to manage the stress of caregiving. In clinical practice, healthcare professionals should strengthen the assessment and intervention of caregivers' coping strategies, guiding them to adopt positive approaches through methods such as WeChat group sharing and seminars. Additionally, interventions like meaning therapy and mindfulness-based self-compassion can significantly improve caregivers' mental health [15].

4.3. Personal and Family Growth are Key Components of Caregiving Meaning

Family caregivers demonstrate a process of growth when facing caregiving challenges. This growth is primarily reflected in the following aspects: enhanced self-efficacy, increased sense of social support, and closer family relationships. By proactively learning and mastering caregiving skills through self-management and self-improvement, caregivers strengthen their self-efficacy, thereby improving their ability to cope and fostering greater self-confidence. To enhance family caregivers' sense of caregiving meaning, it is essential to acknowledge their efforts and contributions, affirm their caregiving behaviors, and establish a comprehensive and dynamic social support system. Encouraging group activities where caregivers with similar experiences can share their feelings and medical knowledge can further improve their caregiving capabilities [16].

4.4. Generalization of Gains is a Significant Feature of Caregiving Meaning

Family caregivers accept the caregiving role, actively address caregiving challenges, and apply the benefits to their personal perspectives and worldviews. In the process of caring for disabled elderly, caregivers integrate their caregiving experiences into new social environments or identities, leading to long-term changes. In this study, family caregivers found deeper meaning in life by setting new goals and values. Xie Minjuan et al. [17] found that a strong sense of meaning in life can effectively help individuals cope with stress and negative life events. Healthcare professionals should pay attention to caregivers' sense of caregiving meaning, implement narrative therapy, and combine it with psychological care to help family caregivers reconstruct their life meaning [18].

5. Conclusion

This study conducted semi-structured in-depth interviews with 12 family caregivers. The findings reveal that caregivers derive meaning from their caregiving experiences after traumatic events, which helps them better cope with the negative impacts of such events. Therefore, it is recommended that healthcare professionals actively intervene to assist family caregivers in recognizing the meaning of caregiving. This study has certain limitations, as the research on the interviewees was static. Future studies are encouraged to explore the trajectory of caregiving meaning among family caregivers of disabled elderly and develop targeted intervention strategies for different stages of caregiving.

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