Rediscovering one's identity: A qualitative meta-synthesis study on the resilience experiences of family caregivers of patients with dementia

Sung Ok Chang (✉ sungok@korea.ac.kr)

Korea University

Eun Young Kim

Korea University

Research Article

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Abstract

Aims: To integrate the results of qualitative research on the resilience experiences of family caregivers for patients with dementia.

Design: A qualitative meta-synthesis study was conducted.

Methods: Five electronic bibliographic databases (PubMed, EMBASE, CINAHL, PsycINFO and Web of Science) were used in a comprehensive literature search. We used meta-ethnography methods and systematically reviewed.

Results: Through the process, three themes emerged: 'Seeing life as a caregiver as one's duty', 'Setting boundaries in life', 'Moving forward toward a developing life.' These themes illustrated how family caregivers of patients with dementia overcome the adversities they encounter.

Conclusion: This study shows the positive power of family caregivers of patients with dementia possess for overcoming their difficult situation. The results of this study suggest an important direction that can lead to positive ways to solve the problems of caring for dementia patients while reducing the suffering of caregivers and improving their quality of life.

Introduction

More than 55 million people worldwide have dementia, with nearly 10 million new cases occurring each year [1]. With the elderly population steadily increasing, the importance of dementia, considered to be the most important risk factor for aging populations [2], can only be expected to become more prominent in the future. Dementia is a disease caused by various disorders or injuries that affect the brain, such as Alzheimer's disease or stroke, resulting in cognitive impairment, which affects mental abilities very important for maintaining daily life, including memory, understanding, learning, language, and judgment [3]. Cognitive impairment generally accompanies or precedes changes in mood, emotion, control, and behavior [4]. Because their condition is a neurological disease accompanied by cognitive impairment, most dementia patients have no choice but to live as highly dependent beings [5].

It is estimated that 83% of dementia patients are cared for at home by unpaid caregivers such as family members. For example, in the United States, 11 million caregivers provide unpaid care to dementia patients [6]. Due to living with a significant burden of care, family caregivers suffer from physical problems such as cardiovascular disease and musculoskeletal symptoms [7,8] and mental problems such as stress, depression, and anxiety due to care [7,9,10]. This burden is negatively correlated with caregivers' quality of life [11], and ultimately, the quality of care provided to dementia patients [12]. In addition, it worsens patient's physical problems and causes serious social problems, such as abuse of dementia patients [13]. Therefore, we need to pay attention to the burdens of family caregivers of dementia patients, and research on protection strategies that can buffer the negative effects of those burdens is needed.

Resilience, an important concept for describing protection strategies in the study of caregivers, refers to the ability of a caregiver to adapt to the physical and psychological requirements of his or her role [14]. In some previous studies, family caregivers for patients with dementia were found to have high satisfaction with their caring roles and to have positive experiences despite the difficult situation, characteristics which were found to be related to resilience [14,15]. Resilience is a process of effectively negotiating, adapting or managing important causes of stress or trauma [16] and has been continuously studied for caregivers of patients with dementia. Their resilience has been shown to increase both their physical and mental well-being [17] while reducing their anxiety and depression and facilitating coping [18]. Recently, studies on the resilience of family caregivers caring for dementia patients have been increasing, but studies that can lead to a deeper understanding of that resilience by integrating previous studies' results have not yet been sufficiently undertaken. Moreover, there are some practical limits to understanding the resilience experiences of family caregivers of patients with dementia reported in previous studies due to the differences in study results. Therefore, this study integrates the results of various qualitative studies on the resilience of family caregivers of patients with dementia to formulate a new interpretation and reveal comprehensive aspects of the phenomenon. This can suggest future research directions and provide basic information for interventional research that can help reduce the difficulties of caregivers and improve the quality of care they provide to dementia patients. Ultimately, it will help improve the health and quality of life of dementia patients.

Qualitative meta-synthesis is a method of synthesizing and analyzing individual qualitative research, one that is used to derive more accumulated knowledge, expand on that knowledge and produce new interpretations from the results of research areas and phenomena suggested by existing studies [19,20]. In addition, it can enable more specific suggestions for future studies [19,20].

To date, systematic reviews of the resilience of family caregivers for patients with dementia have been attempted in various ways [14,21,22], but a qualitative meta-synthesis done by analyzing the experiences of those caregivers from various perspectives has not been undertaken. Due to the nature of the concept of resilience, which reveals inner strength [23,24], it is judged that it will be very meaningful to conduct a qualitative analysis that studies the resilience experiences of caregivers of patients with dementia.

Aim

The purpose of this study is to comprehensively understand in-depth the existing qualitative studies on the resilience experiences of family caregivers of patients with dementia by conducting a systematic review and qualitative synthesis.

Design

This study utilizes a qualitative meta-synthesis design that integrates and synthesizes qualitative research results exploring the experiences of family caregiver resilience in patients with dementia. From the existing qualitative meta-synthesis research methods, the seven phases of Nolte and Hare's meta-

ethnography [25] were applied. This study was conducted in compliance with the guidelines of Enhancing transparency in reporting the synthesis of qualitative research statement (ENTREQ)[26].

The study's research question was:

- "What experiences do family caregivers of patients with dementia have in coping with the difficult situations they face?"
- "What is the strength that enables family caregivers of patients with dementia to overcome adversity?"

The study was registered in the international prospective register of systematic reviews (PROSPERO: CRD42021278764).

Literature Search

A literature search was conducted in November 2021. Five electronic bibliographic databases (PubMed, EMBASE, CINAHL, PsycINFO and Web of Science) were used to conduct a literature search. The search terms were selected from the MeSH term list ("caregivers", "family caregivers", "spouse caregivers", "qualitative research", "resilience, psychological" and "dementia") and were used in the search in different combinations with the Boolean operators "AND" and "OR". Publication years were not limited for the comprehensive literature searches.

The inclusion criteria applied to the research search were as follows: (a) studies aimed at examining the resilience experiences of family caregivers of patients with dementia, (b) studies published in peer-reviewed journals, (c) studies published in English and (d) studies that included participants older than 18 years. The exclusion criteria were as follows: (a) studies not suitable for the purpose of this study, (b) studies not published in English, (c) studies in which qualitative methods were not used, (d) studies with children or adolescents and (e) systematic reviews, meta-syntheses, and secondary analyses.

We identified 665 studies and excluded 328 duplicates. After examining the study titles and abstracts to ensure that they met the inclusion criteria, we excluded 120 studies. After scrutinizing the full texts of the remaining 217 studies to assess their eligibility according to the inclusion criteria, we eliminated 206 studies. Eleven studies were chosen for the final review (see supplementary Table S1 for search strategies).

Methods

Quality Appraisal

To evaluate the quality of the 11 included studies, the Critical Appraisal Skills Programme (CASP) qualitative checklist, consisting of 10 questions, was used to evaluate each study's reliability, truthfulness and rigor [27]. Each of the two researchers evaluated each study using the CASP checklist, and any disagreements between the evaluations were resolved through discussion. As a result of the evaluation, three studies met 70% of the CASP criteria, three met 80% of the CASP criteria and four met 90% of the CASP criteria; no studies were excluded. The CASP results are presented in supplementary table S2

Data extraction

The two researchers read each study intensively and repeatedly to understand and familiarize themselves with the studies' details. The two researchers independently extracted data that were considered meaningful and relevant to the resilience experiences of family caregivers of patients with dementia, including author details, participant characteristics, research methods and citations, and organized them using a customized format in Microsoft Excel. The data were extracted into first-order constructs and second-order constructs. First-order constructs refer to the participants' interpretations in original studies, second-order constructs refer to the original researchers' interpretations and third-order constructs refer to the researchers' new interpretations concerning the first- and second-order constructs [19,20].

Data synthesis

Employing the meta-ethnography method, the researchers continuously contrasted and compared the first- and second-order constructs. To clarify the concept, key concepts were extracted from the first- and second-order constructs, and the third-order constructs, which are regarded as the main themes, were derived through a process of abstraction by the researchers [28]. During the process of analysis and synthesis, the researchers discussed and resolved differences in interpretation that arose due to differences in academic and clinical backgrounds.

Ethical Approval

This study is a literature review study, and ethical approval and informed consent were not required.

Results

Eleven studies that included 221 caregiver participants were included in the analysis (Table 1). One study was conducted in Australia, six in the United Kingdom and four in the United States. Of the participants, 117 (53%) were spouses, 85 were children (38%), 6 were grandchildren (3%), 6 were significant others (3%), 4 were siblings (2%) and 3 were friends (1%). As a result of the synthesis of 11 qualitative literature analyses, 3 themes, 6 sub-themes was derived.

Table 1

Summary of the included studies

Article No.	Author, year/Country	Sample size (M:F)	Caregiver age range(years)	Type of caregiver (n)	Employment	Caring period range (years)	Research aim	Research design	Data collection method
A1	O'Dwyer et al., 2013 / Australia	9 (4:5)	25-82	Daughter (3), Spouse(4), Son-in-law (1), Grandson (1)	Part-time : 3 Unemployed : 5 Job seeker :1	0.5-11	To conduct an initial exploration of carers' experiences of suicidality and identify factors associated with risk and resilience, which could be used to guide further research	A descriptive qualitative study	In-depth interview
A2	Donnellan et al., 2015/UK	20 (7:13)	62-89	Spouse (20)	Not presented	2-10	To assess whether spousal dementia carers can achieve resilience and to highlight which assets and resources they draw on to facilitate or hinder resilience, using an ecological framework	A qualitative study	In-depth interview
A3	Donnellan et al., 2017 / UK	23(7:16)	62-89	Spouse (23)	Not presented	2-10	to explore social support as a key component of resilience to identify the availability, function and perceived functional aspects of support provided to older spousal dementia carers	A qualitative study	In-depth interview
A4	Roberts et al., 2018/USA	33(4:29)	39-83 Median : 61	Daughter, son, daughter-in-law, son-in-law : 18 Wife : 12 Husband : 2 Sibling :1	Not presented	Not presented	To address this major public health challenge through the lens of caregiver resilience and caregiver respite programming	A mixed-method study	Face-to-face interview
A5	Jones et al., 2019/UK	13(Not presented)	40-81	Wife : 6 Son :1 Housemate :1 Daughter :2 Husband :2 Daughter in law :1	Part-time : 2 Retired : 8 Full time :2 Not working : 1	Not presented	(a) explore discrepancies and congruency between definitions of resilience in the academic literature and carers own conceptualisations; (b) assess differences and similarities in conceptualisations of resilience between carers with high, medium and low resilience scores; (c) compare carers' perceived level of resilience with the level of resilience when measured on a standardized tool.	A cross-sectional qualitative study	Semi-structured interview
A6	Donnellan et al., 2018/UK	13(4:9)	65-85	Spouse : 13	Not presented	3-13	To examine trajectories of resilience and which assets and resources are	A qualitative longitudinal study	In-depth interview

							associated with resilience and care status transitions in spousal dementia carers		
A7	Han et al., 2019/USA	39(9:30)	Mean:62	Adult child :82.1% Spouse/partner:7.7% Niece:5.1% Friend : 5.1%	Full or part time job : 18 Not employed : 21	6 months or less - 3 years or more	To identify challenges, possible solutions that are resources for resilience, and expected consequences from the perspective of family caregivers of hospice patients with dementia	A theory-driven, deductive content analysis study of secondary data obtained from a clinical trial	Indiv inter
A8	Conway et al., 2020/UK	12(Not presented)	Not presented	Spouse/partner : 12	Not presented	3month - 6	To explore what resilience means in the context of couplehood in dementia, how dyads experience a shared sense of resilience, how they develop and maintain resilience and how this impacts upon their relationship	A qualitative study	In-de inter
A9	Jensen et al., 2020/USA	19(4:15)	20s-80s	Child :7 Grandchild : 5 Spouse/significant other : 1 Sibling : 2 Other family member :3 Friend : 1	Not presented	Not presented	to identify characteristics of resilience using surveys in 50 bereaved caregivers for persons with dementia who lost their care recipient in the past 6 month	A qualitative descriptive study	Indiv inter
A10	Donnellan et al., 2021/UK	13(2:11)	47-81	Adult daughters : 6 Spouse : 7	Not presented	1-9	To identify the factors that facilitate or hinder resilience in spousal and adult daughter carers, and whether these factors can be mapped on to ecological resilience framework	A qualitative study	Semi struc inter
A11	Liu et al., 2021/USA	27(22%:78%)	50-89	Spouse: 46% Adult Children : 50% Sibling:4%	Full-time or part-time employed : 33.3% Retired or unemployed : 66.7%	Mean : 2.48	To investigate the resilience of a growing but largely underserved and understudied population—Chinese American dementia caregivers	A qualitative study	Semi struc inter

F:female; M:male; CASP: Critical Appraisal Skills Programme checklist

Table 2.

Synthesized themes of resilience of family caregivers of patients with dementia

Key concepts from first-and second order constructs	Sub-themes	Synthesized themes
Past good memories ^{A1, A3, A5, A8, A9} Affection with family ^{A2, A3, A4, A8, A10} Understanding about life of patients ^{A2, A7, A8, A10} Sharing experiences ^{A2, A3, A8, A10} Building trust relationships with patients ^{A2, A4, A7, A8, A10}	1. Building a sense of bonding based on life with the patient	1. Seeing life as a caregiver as one's duty
Accepting the current situation ^{A1, A2, A4, A5, A7, A8, A10} Awareness of the finiteness of the situation ^{A1, A2, A5, A8, A9} Expressing/controlling their own emotions ^{A1, A2, A3, A4, A5, A7} Perceiving the value of their life ^{A2, A3, A4, A5, A7, A8} Taking the situation positively ^{A1, A2, A5, A6, A8, A9, A10}	1. Acknowledging their life as a caregiver	
Building a sense of unity from the same caregiver community ^{A1, A2, A3, A5, A6, A7, A8, A11} Getting help from their family ^{A1, A2, A3, A6, A7, A8, A9, A10} Interacting with the community (social support) ^{A1, A2, A3, A5, A6, A7, A8, A10, A11} Communicating with friends and neighbors ^{A1, A2, A3, A5, A6, A7, A8, A9, A10} Receiving help from experts ^{A2, A7, A8}	1. Finding stable life through help from supportive relationships	1. Setting boundaries in life
Having personal time ^{A1, A2, A4, A5, A6, A7, A9, A11} Striving for self-development ^{A1, A2, A7, A11} Trying to maintain one's identity ^{A1, A2, A5, A6, A7, A9, A11} Separating themselves from patient care ^{A1, A2, A4, A5, A6, A7, A9, A10, A11} Focusing on the present ^{A2, A4, A5, A10, A11} Recognizing the importance of rest ^{A1, A2, A4, A5, A6, A10, A11}	1. Rediscovering independent life	
Staying work life ^{A1, A4, A6, A8, A10} Doing one's role ^{A4, A5, A10, A11} Taking one's responsibility ^{A4, A5, A10, A11} Managing their routine activities ^{A1, A2, A5, A10, A11} Financial reward ^{A2, A5, A6, A7, A8}	1. Maintaining sociality	1. Moving forward towards a developing life
Learning professional knowledge ^{A1, A2, A5, A7} Building confidence ^{A1, A2, A4, A5, A7} Be active in life (as a caregiver) ^{A1, A2, A4, A5, A7} Developing skills and insights ^{A1, A2, A4, A5, A7}	1. Developing professionalism in the role of a caregiver	

Ⅹ. Seeing life as a caregiver as one's duty

Family caregivers of dementia patients developed bonds with patients based on their lives with the patients and acknowledged and accepted their roles as caregivers. They considered life as a caregiver a duty and tried to fulfill that duty. This sense of duty became the driving force behind their work as caregivers, and this became the basis for their overcoming difficult situations.

1. Building a sense of bonding based on life with the patient

Good past memories (A1,3,5,8,9) made with patients with dementia and the affections shared with family members (A2,3,4,7,10) acted as positive forces when family caregivers had to cope with difficult situations. In their efforts to understand patients and their lives (A2,7,8,10), family caregivers found meaning in sharing their experiences (A2,3,8,10) and forming trusting relationships with their patients (A2,4,7,8,10), eventually building a sense of bonding. The formation of a sense of bonding provided justification for their roles as caregivers and became the basis for overcoming difficult situations.

We've been together nearly 50 years. Would I feel like this if I'd only been together 7, 8, 10?.....We're comfortable. We've been together for so long, so it couldn't be more comfortable. (A8).

My dad became acutely ill with aspirate pneumonia, so that we had 5 days as a family to come together. We kept a vigil so that he was never left alone, and most of the time there was more than one of us there 24/7. We had time together individually with him and as a family. Many memories and stories were shared in the middle of the night—I cherish that time (A9).

2. Acknowledging their life as a caregiver

The participants accepted their current situations, (A1,2,4,5,7,8,10) rather than complaining about the situation, recognizing that it was a finite one with an eventual end (A1,2,5,8,9). They tried to express their feelings without hiding them (A1,2,3,4,5,7), acknowledging the importance and value of their work (A2,3,4,5,7,8) and of themselves. They perceived their situation positively and wanted to view their lives in a positive way (A1,2,5,6,8,9,10).

I'm positive. I laugh and I sing and she laughs and I act gently in the house. I've even talked to one of my neighbours about my singing, and she said [Mr Go.] it's a good thing we've got a detached house. I sing at the top of my voice (A2).

'Doing what you can, if there's something you can't do, don't do it or do it differently. Look for the positives and don't beat yourself up (A5).

3. Setting boundaries in life

Caregivers, who live a life in which the boundaries between their own lives and the lives of patients are ambiguous, set the boundaries of their lives. Rather than shouldering the difficult burdens of their lives alone, they actively sought supportive relationships. They wanted to focus on their own lives and lead independent lives.

3. Finding a stable life through help from supportive relationships

They realized that it would be more helpful to rely on different forms of support than to tackle their difficult situations alone. They found help by joining a local community or self-help group of people in the same situation, gaining solace from them, and forming a sense of unity (A1,2,3,4,6,7,8,11). They also received help from their families, who directly assisted with the act of caring while providing them psychological stability (A1,2,3,6,7,8,9,10). In addition, they sought social support from important acquaintances around them and received help (A1,2,3,5,6,7,8,10,11). While forming new social relationships, they maintained good social relations with friends and neighbors, from whom they received help (A1,2,3,5,6,7,8,9,10). They also got help from experts who can provide professional advice when they needed it (A2,7,8). They did not hesitate to seek help and actively sought out the help available to them, and supportive relationships provided them with stability.

I [got] involved somehow with advocacy [for other carers]... I quickly became empowered...and then I was actually advocating for other people, so that was one way that I coped (A1).

Coming here(self-help group) has helped me because the people that come here are in the same position as I am. Some of them have been in it longer than me, so I can use their experience and I can relate to what they're saying (A2).

'The caregiver group is a godsend because sometimes you've just got to dump and you can do it there. It makes me feel better because I know I'm not alone. Every other one of those wives is going through what I'm going through. It's the neatest, tireddest looking group of women I've ever seen. We have days when we laugh and cry; it's like this little amount of light. Without the groups, I wouldn't have made it' (A4).

4. Rediscovering an independent life

By building their own lives and domains separate from their roles as caregivers, they were able to develop the strength to overcome the crisis of dealing with dementia. They tried to relieve their stress by spending personal time away from caring (A1,2,4,5,6,7,8,9,11). They focused on self-development (A1,2,7,11) and made efforts to maintain their individual identities (A1,2,5,6,7,9,11). To do this, caregivers focused on time (A2,4,5,10,11) and tried to make them feel separated from their time caring for the patient (A1,2,4,5,6,7,9,10,11), realizing the importance of rest and trying to secure the time necessary for sufficient rest (A1,2,4,5,6,10,11). Creating temporal space for themselves in these ways was recognized as an effective method to cope with their difficult situations.

I love getting up in the morning at 5 am, going for my hour's walk, and that's my time ... that's my "clear my head" time. If I didn't have that right now, I think things would be different, but it's just giving me that little bit more strength to think straight (A1).

I'm getting a respite on weekends. I really do know the meaning of recharging my batteries now. I feel more, you know, on Monday morning right, let's get on with the day (A2).

If I feel stressed, I sing loudly when taking a shower. ... I like singing old songs that were popular when I was young (A11).

5. Moving forward toward a developing life

Caregivers tried not to become trapped in the work of caregiving. They sought to continue a life away from caregiving, maintaining their sociality while preserving their social positions. In addition, they tried to develop their skills as caregivers. Maintaining sociality and developing oneself were considered as one of the ways to hold on to their individual identities.

5. Maintaining sociality

Among the caregivers, there were those who had their own jobs other than the caregivers. They sought to maintain a social life and relationships (A1,4,6,8,10), while faithfully carrying out their assigned duties as caregivers (A4,5,10,11). They tried to manage their daily lives well (A1,2,5,10,11) and did their best in their responsibilities as caregivers (A4,5,10,11). They sometimes received financial rewards from social support services, communities of faith and other family members which were viewed as positive for handling their difficult situations (A2,5,6,7,8).

My brother-in-law moved her (mother-in-law) in with him to start with, but he worked during the day and I was concerned about her well-being during the day. I was afraid she was just eating Twinkies and things, not being able to prepare meals. I work from home, and I thought I could take care of her and work from home, so we brought her to our house (A4).

When I am at work.....we'll have a laugh about it (working). I think going to work helps me a lot (A10).

6. Developing professionalism in the role of caregiver

They strived to acquire professional knowledge (A1,2,5,7), gained confidence in their work (A1,2,4,5,7), and tried to live an active life as caregivers (A1,2,4,5,7). They also did their best to develop skills and insights related to care (A1,2,4,5,7).

I went on the internet, looked up what medication he should be on... and I was like a dog with a bone. We just became proactive. Within a couple of weeks I went to the Alzheimer's [support center] and I just sort of took on board everything. But it's 9 years later, and you're still learning all the time (A2).

I insist on exercising at home every day. Before he [care receiver] wakes up, I have some time to do that. If my health is poor, how can I take care of him? (A11).

6. The conceptual model of the resilience of family caregivers of patients with dementia

The resilience experience of caregivers of patients with dementia can be expressed as Figure 2. Caregivers recognize a sense of duty as a caregiver through their bond with the patient and acknowledgement of the caregiver's life, and this sense of duty is the basis for their lives as caregivers. They also set boundaries between their own lives and their role as caregivers by seeking help from supportive relationships and pursuing an independent life. Caregivers plan and live a developing life based on this clarity in their lives. This series of processes can be expressed comprehensively as rediscovering one's identity..

Discussion

Paying attention to the difficulties and how to overcome the difficulties of family caregivers taking care of patients with dementia in an aging society is as important as paying attention to dementia patients. The results of our study can help understand the resilience of family caregivers of dementia patients by facilitating an understanding of how they overcame difficult situations. The two most noteworthy aspects about the resilience experiences of family caregivers of patients with dementia that were revealed through this study are that they want to separate their lives from that of their role as caregivers and that they greatly value living their own individual lives.

The importance they placed on their own lives was similar to that found in a study on caregivers of patients with chronic diseases [29], but this study differs from previous studies in that one of the characteristics of resilience it found is a seeking to further develop one's own life. Among the attributes of resilience, this seeking contains the meaning of growth [30,31].

According to this study, family caregivers of patients with dementia were found to have many concerns and attachments in regard to their experiences related to resilience. They particularly valued familial affection and relationships and place importance on their relationships with patients. These results can be supported by those of previous studies that showed that the relationship with the patient and intimacy with the family had a positive effect on caregivers' abilities to overcome difficulties [21]. Based on these research results, we will be able to plan a family resilience promotion program with patients with dementia or their families to find the meaning of life, to help them form attachment to their lives and to improve relationships between families.

An additional characteristic that appeared in this study was that caregivers tried to acknowledge and accept their situation, recognizing that there was an end to the situation for which care must be provided. They worked to overcome the crisis by thinking about the value of life while remembering how important their role as caregiver was. Similar to the results of this study, a study on the resilience of chronic disease patients revealed that they sought to find meaning in their

lives and to accept their situation positively to cope with their condition(s) [32]. Therefore, if we develop a program to improve the resilience of caregivers for patients with dementia by reflecting their needs to find and realize the value of life, positive results can be expected.

Caregivers were not reluctant to receive help, actively seeking out organizations and methods from which they could receive help. In a previous study, it was determined that the longer the time of caregiving, the greater the burden became for family caregivers of dementia patients [33]. Providing direct and indirect support will make it possible to reduce the burden of care on the families of dementia patients. Medical experts need to identify the needs of these family caregivers in order to help them and to develop specific measures so that they can receive appropriate support. For this, policy discussions will be necessary.

In this study, caregivers tried to overcome difficult situations by reserving time to focus on their own lives separate from their lives as caregivers. This can be interpreted similarly to previous studies which reported that absenting oneself from the difficult situation and developing a good coping strategy had positive effects on reducing stress and depression [21,34]. Therefore, medical professionals need to develop realistic alternatives that allow family caregivers of patients with dementia to be separated from their caregiver life and have more time to focus on their own lives.

Family caregivers wanted to move forward toward an evolving life, even if they were in a difficult situation. They wanted to maintain their jobs, fulfill their roles and responsibilities as caregivers, and sustain their daily routines. In addition, financial compensation from social support services, communities of faith and other family members was a helpful factor for them. In previous studies, family caregivers underwent negative psychological experiences, such as worsening mental health and increasing life stress levels, due to job instability including unemployment and turnover [35]. Therefore, the results of this study implies methods of reducing their burden of care, which is interpreted as having an important meaning in the resilience of family caregivers of dementia patients. Moreover, this supports the previous research that growth and development are the main attributes of resilience [30,31]. Based on these characteristics of resilience of family caregivers for patients with dementia, it is necessary to develop and provide various platforms so that they can develop their expertise. Their will for growth can change the paradigm for future family caregivers for patients with dementia, and they can grow as a professional group with a new specialty. Such a positive movement could provide an important solution to the social difficulties related to caring for patients with dementia.

Through this study, we were able to confirm the resilience experience of caregivers of patients with dementia and to understand them in depth. This study can provide basic data for developing a resilience promotion program for caregivers of dementia patients and can suggest directions for ways to reduce caregivers' difficulties and improve their quality of life. In addition, it can provide basic data for the development of educational programs for medical professionals who provide counseling and education for the caregivers of dementia patients.

Limitations

In this study, it was found that family caregivers consisted of various family members, with the percentage of spouses the highest at 53%. However, since different family member caregivers are included in our sample, it was difficult to distinguish the characteristics of spouse caregivers' resilience experiences. Therefore, it is necessary to conduct separate studies in more detail on the resilience of spouse caregivers and the resilience of children caregivers in the future to identify the characteristics of each. In addition, this study did not specify whether each family caregiver lived with their patients with dementia. In order to consider the quality of life of family caregivers and their lives separately from that of caregivers, it will be necessary in the future to study the resilience of family caregivers according to whether they live together with their patients.

Conclusion

As resilience is a positive force for overcoming crisis, understanding the resilience of caregivers for dementia patients is a very important cornerstone for designing a positive future for them and their patients. The experiences of resilience of family caregivers for patients with dementia present evidence for and directions on what medical professionals should do to ease their burdens and to assist them in their efforts. In order to prepare an alternative to caring for dementia patients, which is a socially important issue, it is necessary to raise the awareness that the resilience of a family caregiver is a very important concept. Measures to improve resilience should be discussed in policy and realized in detail, and for this, the efforts of medical experts and leaders will be required.

Declarations

Conflicts of interest

No conflicts of interest have been declared by the authors.

Competing interests

No conflicts of interest have been declared by the authors.

Ethics approval and consent to participate

Not applicable

Consent for publication

Not applicable

Availability of data and material

All data generated or analyzed during this study is included in this published article

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Author contributions

Conceived and designed the study : EYK, SOC

Performed the data collection : EYK, SOC

Analyzed the data: EYK, SOC

Contributed materials : EYK, SOC

Wrote the first draft of the manuscript : EYK, SOC

Agree with manuscript results and conclusion : EYK, SOC

Prepared figures 1,2 & Table 1,2 : EYK

All authors reviewed the manuscript

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Figures

Figure 1. Flow Chart of Systematic Review of Literature Selection Process

Figure 1

Please See image above for figure legend.

Figure 2. The Conceptual Model of the Resilience of Family Caregivers of Patients with Dementia

Figure 2

Please See image above for figure legend.

Supplementary Files

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