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ORIGINAL ARTICLE

A Qualitative Study on the Caregiving Experiences of Parents of Young Adults with Mental Disorders

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Purpose: The incidence of mental disorders in young adults has been increasing since the COVID-19 pandemic. The specific characteristics of young adults with mental disorders can lead to significant caregiving challenges. Understanding these challenges can help healthcare professionals provide timely interventions and support. Thus, this study aimed to understand the caregiving experiences of parents of young adult children with mental disorders and to grasp their essential meaning. **Methods:** A qualitative phenomenological design was adopted. Semi-structured individual interviews were conducted with nine parents and the data were analyzed using the phenomenological method. Data collection was conducted by nine parents of young adult children with mental disorders from July to October 2023 at S General Hospital. **Results:** The analysis revealed the overarching theme of "A journey of finding hope in a dark tunnel," supported by three main themes: 1) life feels like walking on eggshells with the child; 2) being aware of the changing family lifestyle and seeking balance; and 3) lifelong tasks for parents and society. **Conclusion:** Parents experienced various difficulties intertwined with their own and their child's developmental tasks. However, both the parents and children grew, discovering positive elements such as happiness and hope.

Key Words: Qualitative research; Parents; Caregiver; Mental illness; Young adult

INTRODUCTION

In the Republic of Korea, the number of individuals in their 20s and 30s with mental health issues has increased since the COVID-19 pandemic [1,2]. The high incidence of mental disorders among young adults often leads healthcare professionals to encounter parents who face challenges in caring for their afflicted children. Young adults with mental disorders experience diverse challenges intertwined with their biological, psychological, and social developmental processes [3]. Mental disorders require long-term management of various pathological symptoms, and most young adults with mental disorders remain dependent, unable to achieve vocational and social independence, and have a higher need for parental caregiving [4]. Parents of young adults perceive a crisis when their child first exhibits psychiatric symptoms or is diagnosed with a mental disorder, leading them to feel mentally and physically vulnerable and sometimes, even devastated. A child with a mental disorder emotionally impacts both parents and family members. This necessitates that healthcare professionals develop interventions for parents during their children's recovery period and provide appropriate support. To achieve this, healthcare professionals must understand the caregiving experiences of parents of young adults with mental disorders.

1. Background

Based on the Confucian culture, it is customary for parents in the Republic of Korea to live with their unmarried young-adult children. Consequently, the burden of caring

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for young-adult children with mental disorders is greater than in other countries [5] Parents experience various mental health difficulties caused by caregiving, such as coping with their child's psychiatric symptoms, financial pressure, fear of relapse, shame, guilt, anger, and uncerainty about their prognosis [6]. Moreover, they carry the psychological burden of hiding the truth from outsiders to avoid social stigma, which often severs social relationships, and experience difficulties owing to a lack of support systems [7]. Furthermore, excessive parental anxiety can be projected onto the child, increasing their anxiety or leading to excessive dependence, social regression, and negatively impacting treatment effectiveness [8]. Parental caregiving is an essential and significant predictor of the overall course of treatment for young adults with mental health issues. If their parents fail to understand their problems and do not intervene appropriately, the family may enter a state of crisis or confusion.

Recent research shows that parents often have negative experiences during the early stages of a mental disorder diagnosis. However, coping abilities improve over time, leading to growth and positive caregiving experiences. Studies on caregiver satisfaction have become increasingly common [9]. Shiraishi and Reilly [9] emphasized the concept of caregiving satisfaction, which views caregiving, not as a burden but as an experience through which caregivers can feel gratitude, satisfaction, positive emotions, and other desirable aspects. Caregivers can obtain psychological and emotional rewards, thus enabling them to maintain their quality of life. These approaches not only reframe the caregiving process as positive but are also closely associated to resilience in recovery, enabling individuals to overcome difficulties and adapt to change [10-12].

Parents of young adults with mental disorders require support to recognize both the negative and positive aspects of caregiving, enabling them to fulfill the role of an appropriate support system. In other countries, research is ongoing on various experiential aspects of caregivers for young adults with schizophrenia [7,13,14]. Quantitative and qualitative studies conducted in the Republic of Korea have predominantly focused on the negative experiences associated with parenting children with chronic mental illnesses, emphasizing the burdens and challenges faced by caregivers. This research trend highlights the psychological, social, and economic pressures experienced by these parents, as well as the stigma and isolation often accompanying their caregiving roles [4,15,16]. These findings provide valuable insights into the adversities faced by caregivers, but they may also overlook the potential for resilience, coping strategies, or positive outcomes that some parents might experience in these situations. However, research on the caregiving experiences of parents with children who have mental illnesses and exhibit developmental characteristics of early adulthood is scarce, emphasizing the need for further studies.

This study aimed to explore the meaning and significance of caregiving experiences among parents of young adults with mental disorders. The primary research question was: "What are the caregiving experiences of parents of young adults with mental disorders?"

METHODS

1. Design

The caregiving experiences of parents of young adults are inherently subjective and are best understood through the lens of the parents' lived experiences. Consequently, this study employed Giorgi's phenomenological research method [17], which involves identifying meaning units, transforming them into psychological insights, and synthesizing these insights to capture the essence of participants' experiences. This approach provides a structured and rigorous framework for exploring lived experiences.

2. Participants

Participants were recruited from a daycare center and outpatient center at the psychiatric unit of a university hospital in the Republic of Korea. Parents were included in the sample if they had the lived experience of caregiving for young-adult children aged 19 to 34 years with a mental disorder, and could participate in an interview to describe their experiences verbally (in the Korean Framework Act on Youth, the young-adult period is defined as the ages between 19 to 34 years). Parents who understood the research purpose and voluntarily agreed to participate were included, and those who were themselves diagnosed or receiving treatment for severe mental disorders were excluded. Participant characteristics are presented in Table 1.

3. Data Collection and Analyses

Recruitment notices were posted on the outpatient and daycare center bulletin boards of the Department of Psychiatry from July to October 2023. Convenience and snowball sampling were used to recruit participants. Data were collected through face-to-face interviews. Written informed consent was obtained from the parents before data

Table 1. General Characteristics of the Participants

Case	Participants (caregivers)			Young adult children with mental disorders			
	Sex	Age (year)	Education	Sex	Age (year)	Diagnosis	Duration of disorders (year)
A	F	53	College	F	21	Schizoaffective disorder	8
B	F	47	College	F	19	Bipolar disorder	10
C	F	60	College	M	32	Schizophrenia	13
D	F	55	High school	F	23	Major depressive disorder	3
E	F	58	College	M	34	Schizophrenia	20
F	F	58	High school	F	34	Schizophrenia	17
G	F	58	College	F	21	Schizophrenia	5
H	F	52	College	M	19	Schizophrenia	2
I	M	56	College	F	23	Schizoaffective disorder	6
Average		55.2			25.1		9.3

M=male; F=female.

collection.

Interviews were conducted by a nurse with a doctor's degree, who had more than 10 years of psychiatric nursing experience and specialized training in mental health. Peer debriefing was used to reduce researcher bias and improve the credibility of our study. The researchers confirmed the participants' eligibility and explained the purpose and significance of the study, its benefits and risks, and methods of participation. The participants were given a 3-day period to decide, ensuring ample time for careful consideration. The voluntary nature of participation and no adverse consequences of nonparticipation were explained. Throughout the study, confidentiality was ensured.

Semi-structured individual interviews were conducted in person. Nine parents who could provide diverse experiences and rich information were interviewed to collect data until saturation was established. After the 9th interview, no new insights were gained, and existing themes were further solidified. Data analysis involved repeated readings of transcripts by researchers and reviewers to identify meanings and categorize common themes, followed by obtaining participants' confirmation until the best thematic structure was achieved.

4. Ethical Considerations

This study complied with the most recent Helsinki Declaration (revised in 2013) and ICH-GCP guidelines, was approved by the relevant institutional review board (IRB No-3207-016-1445), and is presented according to the consolidated criteria for reporting qualitative studies (COREQ) checklist. Additionally, specific measures were taken to ensure participant anonymity, such as the use of pseudonyms and secure data storage procedures, demonstrating a thorough commitment to protecting privacy.

RESULTS

The analyses showed that the overall caregiving experience of the parents can be articulated as a "journey of finding hope in a dark tunnel." While the experience of caring for a young adult with a mental disorder entails numerous challenges, both parents and their young-adult children grew through the caregiving process, which was perceived as a journey towards hope and happiness, albeit an imperfect one. Additionally, three main themes emerged: "life feels like walking on eggshells with the child," "being aware of the changing family lifestyle and seeking balance," and "lifelong tasks for parents and society," with 10 subthemes.

1. Life Feels Like Walking on Eggshells with the Child

1) Bombshell-like verdicts, life stalled as if in hell

The onset of a child's mental disorder was an unimaginable experience for the parents; it was shocking and confusing, as if the sky had fallen. Everything came to a halt, “like falling into hell,” and parents experienced incredibly difficult emotions of “choking up and collapsing” to the point where their memory failed. Initially, they wondered why such a cruel fate had befallen them and searched for reasons. They felt angry and resentful towards their inexplicable fate, lamenting the heavens and experiencing rage. Moreover, they socially withdrew owing to negative thoughts about their children’s mental disorder. They blamed themselves for not being able to protect their children.

> When I heard that my daughter had a mental illness, I was shocked. At that time, it felt like the sky was falling. It really felt suffocating, dark, and like my heart was collapsing... It was horrifying. (Participant C)

2) A parent is expected to be a jack-of-all-trades while caring for a child as delicate as an orchid

Taking care of a young-adult child with a mental disorder was described as extremely difficult, akin to “raising delicate orchids”. Parents thought of their children as “sore thumbs” and assumed the role of friends, counsellors, and lawyers to support their children who faced difficulties with social relationships and encountered various challenges in society.

> Caring for our daughter feels like raising orchids. You have to understand the characteristics of orchids well for them to survive. It's not like they thrive just by watering them a lot; in fact, they could rot instead... (Participant A)
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> My child is like my sore thumb... She has no friends. She can't solve any problems on her own... That's why I have to be her friend, her pharmacist, her lawyer, her doctor-I have to do everything. ... Moms just have to be everything... (Participant F)

3) Driving in a dark cave without an end in sight

Although the parents felt that caring for their young-adult children was their destiny, they expressed frustration over its endlessness. They experienced feelings of exhaustion and weariness because of the prolonged caregiving and responsibility. They described themselves as being unable to escape from a tunnel and constantly running without an end.

> I have to care for and be responsible for her until I die... It's like I'm trapped in a cave. When you drive, if it's a short tunnel, you come out quickly. But this is like “continuously running through a tunnel” ...I just can't seem to get out of that tunnel.(Participant E)

Furthermore, the parents experienced conflicts within the family and high emotional stress while providing long-term care without clear directions for symptom management. Some mentioned feeling exhausted and overwhelmed and even thought of giving up or committing suicide. However, these conflicting emotions caused psychological turmoil in the parents, and the thought of giving up led to feelings of guilt.

> At first, I was desperate and didn't even know what to do... In extreme situations, I think it would be better if I were dead... Sometimes I think I'd rather she was dead. ... I feel guilty about it. (Participant F)

4) Acceptance and belief in finding happiness despite the mental disorder

Many of the parents hid their child’s condition and even gave up social benefits because of social prejudices. Participant C chose to conceal their child's mental health diagnosis. However, despite their children’s efforts, they repeatedly faced situations wherein they had to give up and felt defeated by the symptoms, leading to emotional scars for both the parents and the children. As their children repeatedly faced problems and interrupted life tasks, parents realized that accepting the mental disorder is better than hiding.

> In fact, my son didn't disclose his mental disorder at work... As a result, it became so difficult that he had no choice but to give up in the middle. As I watched from the sidelines, I felt a lot of frustration... (omitted) ... but after disclosed my sun’s problem, he received help from the center. he’s been able to maintain his job until now. (Participant C)

Participants B, C, and F, accepted and embraced the diagnoses of their children, understood them, and found hope in the process of recovery. They acknowledged and appreciated the small joys in everyday life, and lived in a state of gratitude. Through their positive experience of caring for their children, parents gradually nurtured the belief that “I can still find happiness despite my child having a mental disorder.”

> As my daughter gets better, I feel grateful for everything. ...I'm so grateful for my daughter having a job; I want to say that I can still find happiness despite my

> child having a mental disorder. (Participant F)

2. Being Aware of the Changing Family Lifestyle and Seeking Balance

1) Parents' own life disappeared

Parents were completely focused on monitoring changes in their children's symptoms and devoting almost all of their time to caregiving. Consequently, they could not pursue travel and leisure activities in their daily lives. Additionally, most of the parents were in their 50s and 60s, commonly referred to as middle age. They experienced uncertainty about planning for the elderly and emotional struggles.

> As you know, my entire 24 hours revolve around [child's name]. I don't have a life of my own. (Participant B)
>
> My own life has completely disappeared for the past 20 years... (tearfully) When I think about it, my life seems so pitiful. At this age, ... what I truly want, traveling and various things, right? Not being able to do ···. it makes me so sad. (Participant E)

2) Guilt over depriving other children of being the center of the family

Caring for an adult child with a mental disorder means neglecting other children who are often less prioritized. They become increasingly sensitive, clash frequently, and do not always receive adequate attention from their parents. The prolonged focus on caregiving for a child with a mental disorder leads to gradual disconnection from other children. The parents also recognized that their children without mental disorders were deprived of parental care during adolescence, which led to feelings of loneliness and depression. Consequently, the parents experienced guilt and remorse for not being able to properly care for their children.

> My daughter (without mental illness) has been deeply hurt too. ... she ends up getting less attention from us. She told me she can't talk anything because she doesn't want to burden us. I am sorry to my daughter. (Participant E)

3) Strengthening family cohesion while maintaining balance

Following the onset of their children's disorders, the parents experienced various forms of conflicts and emotional difficulties within the family. However, over time, they realized that conflicts and discord did not help anyone. Participants A and F realized that Families grow by supporting each other.

> We were constantly fighting, the house was always noisy, and our family members were getting exhausted... But then, at some point, we came back together, giving each other some breathing room, and we made a lot of effort to live together. Now, all the family members are working together to care for each other with love. (Participant A)

3. Lifelong Tasks for Parents and Society

1) Surrounded by distorted media and narrow societal perspectives

Most participants felt fearful and anxious about the stigma and belief that treatment for early psychiatric diagnoses would not work. They were conscious of the "shame," "ridicule," and "whispers" from those around them. Consequently, they hesitated about treatment, fearing criticism. Many parents also had to confront the stigma surrounding mental disorders.

> I was extremely scared and frightened. Because of comments like "crazy" or "mentally ill," I kept thinking that it would be difficult to recover from the mental disorder. (Participant C)

Participant H's husband was resistant to his son's treatment for various reasons such as "psychiatric medication leads to addiction," "you have to take it lifelong," "treatment does not make you better," and "I know someone who committed suicide even after treatment." Participant H secretly sought treatment for her son without discussing it with her husband.

> My husband always said, "My son is perfectly fine, but his mother keeps giving him medication." He believes that medication only leads to addiction... My husband keeps opposing it... So, even now, I am secretly providing treatment... (Participant H)

Parents are anxious about their young adult child's future when they see news about criminals by people with mental disorders or encounter individuals with mental disorders on the streets. They expressed to change societal views and prejudices surrounding mental disorders.

> If my son stops medication... Whenever incidents happen and news of violence is seen on TV··· it hurts so

> much. ... (I worry that our child might end up like that) It's truly terrifying. It hurts even more. (Participant E)

2) Hope and concerns about independence

The parents hoped that their young-adult child would be accepted and integrate into society without discrimination, and live independently. They hoped that their child could participate in society by engaging in employment, attending school, and visiting centers. However, they were ambivalent about their young-adult child's employment. While recognizing the importance of securing employment for financial independence and social adaptation, they also feared that employment stress would worsen mental health symptoms.

> Employment is necessary, but I worry that while working and interacting with people, there might be instances of being taken advantage of, or perhaps if my daughter experiences stress, it might worsen. (Participant A)

3) Desire for a social support system that provides empathy and shares information

The parents were unable to share their difficulties because of social prejudices and expressed a lack of access to appropriate information or support. They emphasized the need for spaces where they could share their caregiving experiences and receive mutual support and encouragement. Three of the parents were engaged in sharing empathy and information through an online support group called “Beautiful Companions,” where they obtained help and information. Given the opportunity, parents expressed that they would participate in gatherings or organizations for patients with mental health issues, as they wanted to hear about various experiences.

> It’s difficult for me to talk about our child's disorder anywhere... So I try to deal with it alone... It's overwhelming... But things improved after I found “Beautiful Companions”. Talking with other moms there makes me feel relieved, and it helps release stress. I get advice on how to handle different situations and share my experiences, which has been very helpful for my mental well-being.(Participant G)

Parents expressed that the challenges of caregiving could not be solved by individuals, it was a societal issue requiring collective effort. They hoped to eradicate social prejudice and create an environment wherein young adults with mental disorders could freely pursue their aspirations. They also expected the government to establish support systems to help them become independent and provide social care when necessary.

> We wish for a more systematic welfare system for families with young adults with mental disorders. It would be nice if there were systems in place to provide comprehensive care, and hope there’s a system where we can donate all our assets to support such causes when we pass away, and even request ongoing care for them until the end.(Participant I)

DISCUSSION

This study showed that parents of young adults with mental disorders exhibit various emotional reactions throughout the caregiving process. Many studies have reported that families caring for individuals with mental disorders experience emotional difficulties from the onset of the disorder, throughout treatment and recovery [7,13, 18].

They expressed emotions such as anger, frustration, and guilt, and experienced psychological instability. Additionally, they felt despair and depression with the endless caregiving process. These emotional responses are similar to those mentioned in previous research indicating that parents experience significant shock and confusion regarding their child’s diagnosis [18], and may feel a sense of loss and despair, at times developing depression and suicidal impulses [13].

Furthermore, the age of parents of young adults is typically between 50 and 60 years, a period characterized by marking the onset of physical, mental, and biological aging. It is emotionally turbulent, as individuals face various changes, including health issues and changes in occupational status, friendships, and family relationships [19]. In this study, the parents mentioned experiencing emotional responses such as frustration and depression from being unable to integrate their lives and prepare for the next stage because of their dependent children. According to Erikson’s developmental stages, the 50s and 60s mark the transition from late adulthood to old age, and failing to integrate one’s life may cause despair and frustration [20].

If parents fail to properly address or neglect emotional responses, they could potentially lead to engage in impulsive suicidal behaviors or develop chronic depression as they transition into old age [19-21]. Therefore, emotional interventions tailored to the life stage of parents are crucial to ensure effective caregiving for young adults with mental disorders.

Shiraishi and Reilly [9] conducted a systematic review of 23 studies and found that families caring for individuals with mental disorders encounter diverse challenges and burdens. Nonetheless, the caregiving experience yielded nine beneficial aspects: empathy, family cohesion, confidence, personal growth, knowledge and skill acquisition, positivity, inspiration, and gratitude. In this study, despite the inherent difficulties and caregiving challenges, parents of young adults with mental disorders also expressed hope and positivity. They recognized the necessity of accepting the mental disorder, finding gratitude and hope amidst caregiving obstacles, and strengthening family cohesion by overcoming conflicts. These findings indicate that although caregiving for a child with a mental disorder requires significant time and energy, it can be rewarding, contributing to personal growth and caregiver satisfaction, and ultimately enriching one's life [22-24].

Employment enhances self-esteem in, economic independence, and social coping skills in individuals with mental disorders, aiding in their recovery [25]. However, in this study, the parents expressed ambivalent feelings about their young adult children having a job. According to Marwaha and Johnson [26], unemployment rates among individuals with severe mental disorders is 80%, and they experience disadvantages and difficulties in employment due to their mental health issues.

Finally, the parents emphasized that caregiving for children with mental disorders is not just a family issue but a societal challenge that needs to be addressed simultaneously. According to Di Lorenzo et al. [27], empathizing with caregivers reduces their burden, and is particularly critical in long-term care. Of the participants, those who engaged in activities by joining support groups such as "Beautiful Companions" reported receiving significant emotional support and assistance. Collaborating with others in similar situations, sharing experiences, and receiving empathy and understanding can provide emotional stability. Support networks and advocacy groups can also play societal roles.

The parents believed that it was necessary to reduce the burden of care through social, policy, and institutional support. Previous research has also suggested the need to introduce various mental health facilities to share caregiving responsibilities with society [28]. Active discussions are required to support the provision of rehabilitation services and establishing social care support systems is crucial. For instance, increasing access to mental health services, particularly in underserved areas, is essential. This can be achieved through expanding mental health facilities, implementing tele-mental health services, and promoting mental health literacy. Additionally, policies that prioritize mental health, such as reducing stigma and increasing funding for mental health research, can significantly impact societal attitudes and resource allocation.

The participants were limited to caregivers of patients receiving treatment at a single higher-end hospital, which limits the generalizability of the findings. Therefore, further research targeting participants from different hospitals and community settings is required to investigate parental care for young adults in diverse environments and economic backgrounds.

CONCLUSION

This study qualitatively analyzed the characteristics and significance of caregiving experiences of parents of young adults with mental disorders. The parents reported experiencing social and emotional challenges during caregiving; however, they also experienced growth and satisfaction. Based on these research findings, various nursing intervention programs aimed at enhancing caregiver satisfaction and the resilience of parents caring for young adults with mental disorders should be developed and implemented. Additionally, systematic social care supported by social and policy consensus should be advocated to care for individuals with mental disorders.

CONFLICTS OF INTEREST

The authors declared no conflicts of interest.

AUTHOR CONTRIBUTIONS

Conceptualization or/and Methodology: Lee, S, Seo, S, Choi, H, & Choi, DJ
Data curation or/and Analysis: , Lee, S, Seo, S, & Choi, DJ
Funding acquisition: Lee, S, Seo, S, & Choi, DJ
Investigation: Lee, S, Seo, S, & Choi, DJ
Project administration or/and Supervision: Choi, DJ
Resources or/and Software: Lee S, Seo, S, & Choi, DJ
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