

## RESEARCH ARTICLE

# Experiences of South Korean mothers of children with medical complexity under long-term hospitalization

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**Abstract**

**Aims:** To explore the experiences of South Korean mothers of their children with medical complexity under long-term hospitalization.

**Design:** A qualitative descriptive using thematic analysis.

**Methods:** Seven South Korean mothers of children with medical complexity underwent semi-structured interviews between February and April 2021. Data were analysed by six phases of thematic analysis. The consolidated criteria for reporting qualitative research guidelines were applied in the conduct of the research.

**Results:** Mothers of children with medical complexity experienced a journey beginning from within their vacillating minds towards the outside world. The mother's journey during the hospitalization of their children with medical complexity began from within their vacillating minds towards achieving resilience. The mothers received various support from the family, society and hospital staff during this period of vacillation. When the mothers achieved resilience, they in turn provided support to other mothers as an act of solidarity.

**KEYWORDS**

child nursing, feminism, long-term care

## 1 | INTRODUCTION

Children with medical, developmental or psychiatric conditions are collectively referred to as children with special healthcare needs (CSHCN). CSHCN with complex or critical illnesses are further classified as children with medical complexity (CMC) (Dewan & Cohen, 2013). CMC undergo a long period of recurrent hospitalization, which has increased to two decades with the increasing survival rates among CMC (Berry et al., 2011; Russell & Simon, 2014). In addition, this long hospitalization period significantly impacts the lives of CMC and those of their family members (Denis-Larocque et al., 2017; Thomson et al., 2016). The degree of the impact would

vary based on various contexts, such as the healthcare system, hospital environment and culture.

In the context of South Korean society, low nurse staffing and pervading cultural perceptions of motherhood largely determine the primary caregiver of CMC. The number of patients per nurse per shift in South Korea is 16.3, which is triple the ratio in the United States (5.3) and almost double that in England (8.6) (Cho et al., 2016). Therefore, in South Korea, one family member has to stay at the inpatient unit to take care of the patient during hospitalization (Yoo, 2015). The choice of caregiver among family members is driven by the South Korean patriarchal culture, which considers the children as the mother's responsibility and takes the mother's interests

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for granted (Kim & Jung, 2013; Kim & Oh, 2015). Thus, in South Korea, mothers are the default caregivers in the hospitalization of CMC (Cho et al., 2020).

Considering the statistically significant role of the mothers in the care and treatment of CMC, the period of hospitalization is also a personal journey for the mothers. However, while preliminary quantitative analyses have been conducted to examine the experiences of mothers of CMC, the South Korean mother's lived experiences of CMC have not yet been explored. Therefore, this study sought to explore the experiences of the mothers of CMC in a South Korean general hospital.

## 1.1 | Background

Even though some studies have tried to propose definitions of CMC, consensus on a standard definition of CMC has not been reached (Cohen et al., 2011; Russell & Simon, 2014). However, CMC are also characterized by repeat hospitalization and burden on family members (Berry et al., 2011; Cohen et al., 2011). Earlier studies have not focused on the experiences of family members or parents of CMC; thus, the experiences of family members and parents during the care of chronically ill children need to be assessed.

Parents or family members are often assigned as caregivers and face the burden of dealing with the various challenging consequences of the disease, such as complicated treatment procedures and the demand for constant care (Cohn et al., 2020). The burden stems from the tremendous involvement required of the family and healthcare systems during treatment and care (Cipolletta et al., 2015). Parents feel responsible for their children's health and experience the burden associated with the diagnosis, treatment and hospitalization. At the time of hospitalization, the mother of the child with a chronic disease spends the highest amount of time participating inpatient care at the inpatient unit (Coughlin & Sethares, 2017). Such close involvement can cause fatigue, endless worries, frustration and severe depression that may be accompanied by suicidal ideation (Coffey, 2006). Nabors et al. (2018) studied families with children with chronic illness and found that family members can be hospitalized due to the burden of care, emphasizing the importance of coping strategies for children and their families in response to stress. Arëstedt et al. (2015) reported that family members who cooperate in and share their experience of dealing with the child's disease and supporting the child form a strong bond among themselves, which can help build resilience against stressors.

Several studies on CMC and their family members have examined the effects of the child's illness on the family (George et al., 2011; Hatzmann et al., 2014; Nassery & Landgren, 2019), children and family members' adaptive processes and coping strategies (Compas et al., 2012; Nabors et al., 2019) and parents' experiences with children with chronic illnesses (Coffey, 2006; Rennick et al., 2019; Smith et al., 2015). However, these studies have been primarily conducted in Western countries, including the US, Canada,

Austria and the Netherlands. Conversely, Asian countries have cultural differences in their social atmosphere around hospitals and healthcare systems for chronic illnesses. Thus, parents' experiences and adaptability in these countries may also differ, especially among mothers. Specifically, studies on the experiences of Korean mothers are limited.

## 2 | THE STUDY

### 2.1 | Aims

This study aimed to explore the experiences of mothers of CMC under long-term hospitalization in South Korea.

### 2.2 | Design

This study employed a qualitative descriptive using thematic analysis (TA) (Braun & Clarke, 2006). Although social constructionism provided insights into the lived experiences of mothers of CMC in this study, we did not produce a full assessment of the specific theoretical methodology. TA is a fundamental and widely used type of qualitative data analysis because it provides insights into situations or phenomena that researchers are not aware of and is useful in organizing and describing accounts of detail-rich data sets (Pietkiewicz & Smith, 2014). One of the benefits of TA is its flexibility. According to Braun and Clarke (2006), TA is compatible with both essentialist and constructionist paradigms, and researchers need not subscribe to the implicit theoretical commitment of certain theories. TA was selected in the present study to uncover the lived experiences of mothers in-depth about the reality of caring for CMC and understand patterns of meaning created by and through these experiences.

### 2.3 | Sample/participants

We employed a purposive sampling strategy to recruit participants who are mothers of CMC (Denzin & Lincoln, 2008). The inclusion criteria were mothers who had a child with medical complexity and mothers who stay with and take care of their CMC. Seven mothers who stayed with their CMC were recruited from a children's hospital in South Korea. Since no specific criteria of hospitalization for CMC exist, recurrent hospitalization was thus used as the criterion (Berry et al., 2011; Cohen et al., 2011). The length of hospitalization was considered in the context of South Korean health care, in which the National Health Insurance Service stipulates the maximum length of hospital stay up to 3 months except in cases of critical illnesses (Jae & Lee, 2013). Over 3 months of hospitalization or more than two hospitalizations were thus used as criteria for inclusion as CMC in this study. Those who were judged to be difficult to conduct in-depth physical and mental interviews were excluded from the participants.

## 2.4 | Data collection

Data were collected from February to April 2021 through in-depth, semi-structured interviews conducted one on one using open-ended questions. The potential participants were chosen by JA, a registered nurse specializing in paediatric sedation currently working in a paediatric ward. Subsequently, the participants were recruited following established ethics protocols. The semi-structured interview questions were developed by JA and SK and included the following: (1) "Can you tell us about the situation when your child was first diagnosed?"; (2) "How did you feel at the time?"; and (3) "Can you tell us about your experiences with hospital life?" The interviews were conducted in a natural flow based on the participants' responses, and the researchers ensured not to interrupt the participants while speaking. The interviews were mostly conducted in paediatric ward conference rooms or single-occupancy rooms, as per the participants' preferences. The number of interviews conducted ranged between one and three, with an average of two interviews that lasted an average of 2.25 h. Interviews are one method by which one's study results reach data saturation (Fusch & Ness, 2015). After the first interview, additional interviews were conducted until a new story was revealed through the analysis process. In other words, data were collected until theoretical saturation was reached when no other new meanings or topics emerged. The interviews were recorded, and memos were obtained with the participants' consent. The memos included the contextual perceptions of JA before and after the interviews and all the researchers' interpretations of the interview data, which enriched the research data collected.

## 2.5 | Ethical considerations

The institutional review board of the Kyungpook National University Hospital approved this study and confirmed its conduct within the ethical principles of beneficence, non-maleficence, autonomy and justice (2021-01-013-001). Participants were informed about the

purpose and confidentiality of the data collected, their right to withdraw from the study at any time and the destruction of the collected data after the study results are published. After providing this information, written consent was obtained from all participants.

## 2.6 | Data analysis

Data analysis was performed following the six phases of TA to find patterns of meanings (Braun & Clarke, 2006; Ritchie et al., 2014). The process of data analysis is presented in Table 1.

## 2.7 | Rigour

Rigour was ensured in this study by applying the criteria for credibility, transferability, auditability and confirmability proposed by Lincoln and Guba (1985). Participants were asked to verify the data obtained during the data collection step. Furthermore, the credibility of the analytical and interpretation processes was ensured by the three researchers, who analysed the data to extract abstract meanings and themes and discussed the differences in the findings. In order to establish the possibility of transferability, participants were selected as a purposeful sampling strategy, and data collection and analysis were conducted until the state of saturation where new contents were no longer released, and the research result was described as abundantly as possible. Auditability refers to the degree of understanding among readers about the research process and study results. Therefore, detailed descriptions about the participant recruitment and data collection procedures were provided, and participant statements were inserted along with the results to explain the association between the raw data and the derived themes. Lastly, confirmability refers to maintaining neutrality and excluding biases during the study. In this study, the researchers used epochs to prevent the prejudices and biases of the researchers from affecting the interview

TABLE 1 Phases of thematic analysis (Braun & Clarke, 2006, p.87)

Phases	Process
1. Becoming familiar with the data	JA repeatedly listened to the interview recordings and was entered into a computer from the audio recordings
2. Generating the initial codes.	JA, SK and HC checked the transcriptions and meaningful characteristics from the data were identified and codified
3. Identifying the themes	Codes were combined into potential broad themes, which were developed using the relevant collected data
4. Reviewing the themes	The meaningful characteristics from the data focusing on the experiences of mother of CMC were coded and discussed among the researchers (Braun & Clarke, 2006; Ritchie et al., 2014). Subsequently, HC identified categories, themes and linkages in-between them. And theme maps were generated for data analysis
5. Defining and naming themes	Each theme and category were discussed in order for analytic decisions in the regular meeting with all researchers. Therefore, three themes were confirmed by the researchers
6. Producing the report	Selection of vivid, compelling extracted examples, the final analysis of these selected extracts, and produced a report of the analysis

TABLE 2 Characteristics of participants and their CMC

Participants		Participants' CMC									
Age	Educational attainment	Occupation	Religion	Marriage	Gender	Age	Diagnosis	Duration after the diagnosis	Number of hospitalization	Siblings	Duration between admission to hospital and the date of recruitment
1	47	Undergraduate	None	Married	Male	19-year-old	Hereditary cerebellar ataxia	17 years	Over 20 times	Older sister (passed away)	6 months 20 days
2	55	High school	None	Married	Male	18-year-old	Status epilepticus, cerebral palsy	18 years	Over 20 times	Younger sister and brother	27 months
3	41	Undergraduate	Christianity	Married	Male	4 years 7 months old	Congenital short bowel syndrome	4 years 7 months	Twice	Two older sisters (one of them has passed away)	47 months
4	34	Undergraduate	Christianity	Married	Male	3 years 9 months old	Infantile spasm, Chronic kidney disease	3 years	Eight times	None	13 months
5	53	Undergraduate	None	Bereaved	Female	18-year-old	Congenital myopathy	13 years	Over 20 times	Older brother	29 months
6	46	High school	Christianity	Married	Male	Nine-year-old	Medulloblastoma	3 years	Six times	Five older sisters, one older brother and two younger brothers	5 months 10 days
7	42	Undergraduate	None	Married	Female	12-year-old	Congenital short bowel syndrome	12 years	Over 20 times	Older sister	3 months 12 days

and analytical processes. Rigour is described as demonstrating integrity within a study (Aroni et al., 1999). The step-by-step process of analysis that is outlined in this study is a method of demonstrating transparency of how the researcher formulated the overarching themes from the initial participant data (Fereday & Muir-Cochrane, 2006).

### 3 | FINDINGS

A total of eight participants were selected, but one mother's child was admitted to the intensive care unit, so seven participants were recruited. The age of the participants ranged from 34 to 55 years. Five participants attained an undergraduate degree, whereas the remaining two graduated high school. Three participants were Christian, whereas the remaining four did not practice a religion. The age of the CMC ranged from four to 18 years. The participants' CMC all underwent repeated hospitalization, and the length of hospitalization varied from three to 47 months. Further information on the characteristics of the participants and their CMC is presented in Table 2.

Three themes and 15 sub-themes were identified (Table 3). The relationships between themes and sub-themes are presented in Figure 1. The first theme identified was "motherhood: the full extent of responsibility" included five sub-themes of "my child," "unhelpful spouse," "peer support," "staff support" and "family support." The theme describes how participants perceive themselves in the context of their relationships with the outside world, CMC, spouse, other mothers, hospital staff and family members. Being a mother of CMC was carried as an identity and a duty of the participants to their relationships with the outside world. The identity and duty as a mother were defined by their CMC's need of their devotion. When the participant perceived their spouses as unhelpful, they experienced support during the hospitalization period from other mothers of CMC, hospital staff (nurses, physicians and social workers) and other family members. Participants were not only vulnerable mothers of CMC who needed support from their outside world but also became supporters of other mothers of CMC when they achieved resilience.

The second and third themes illustrate the internal world of the participants. "Vacillating minds" represents the fluctuations in the participants' thoughts in the struggle to achieve resilience. Even though participants articulated their achievement of resilience, the achievement was not stepwise but, instead, was vacillating. Therefore, the seven sub-themes of "marginalized mother," "abandon and sacrifice self," "heartbreak," "hopelessness," "accepting reality," "compromised hopes" and "gratefulness" were demonstrated at different points during the hospitalization period by participants. When the participants achieved resilience, they extended their identity and duty beyond merely being a mother of CMC. The "religious comforting" and "self-fulfilment" sub-themes were articulated by participants who have achieved resilience beyond simply being a mother of CMC.

TABLE 3 Themes and categories

Themes	Sub-themes
Motherhood: full extent of responsibility	My child
	Unhelpful spouse
	Peer support
	Staff support
	Family support
Vacillating minds	Marginalized mother
	Abandon and sacrifice self
	Heartbreak
	Hopelessness
	Accepting reality
	Compromised hopes
Achieving resilience	Gratefulness
	Religious comforting
	Helping others
	Self-fulfilment

### 3.1 | Motherhood: Full extent of responsibility

The theme “motherhood: full extent of responsibility” was assigned to the outside world and illustrated the identity and duty of the participants. The five sub-themes of “my child,” “unhelpful spouse,” “peer support,” “staff support” and “family support” represented the participants' relationships in the outside world with their CMC, spouse, other mothers, hospital staff and family members.

I can sacrifice everything (...) My life was completely changed from for my own to for my child.

(Participant 2)

Being a parent is my duty. I gave birth to my child, so I have the full responsibility.

(Participant 1)

#### 3.1.1 | My child

The sub-theme “my child” supported the identity of motherhood. The identity of the participants was defined as a mother of CMC, rather than an individual living her own life. They found the meaning of their life and the strength to live in the presence of their child who is suffering.

My child is my greatest source of strength.

(Participant 7)

Since my child perseveres, I must persevere as well.

(Participant 4)

I can bear anything for my child (...) I must have courage for my child to live.

(Participant 1)

#### 3.1.2 | Unhelpful spouse

The study participants identified their experiences of their spouses as unhelpful. The participant's spouse, the father of the sick child, did not participate in the care for the sick child both at home and at the hospital. Since participants were unable to share the burden with their spouses, participants' responsibility and duty to take care of their sick children had to be the full extent, which links the sub-theme of “unhelpful spouse” to the theme of “motherhood: the full extent of responsibility.”

The father of my child used to not help at all, although he has changed and now helps take care of our child. But, back then, I took care of our child 24 hours a day, 7 days a week.

(Participant 7)

I do not have time to breathe at home; I have to check on my husband, do household chores and care the child. I even find myself napping at the toilet.

(Participant 1)

The father of my child visits the hospital once a week on Sundays. He and I have lunch together for an hour, then he leaves. It's awkward, but it is our routine.

(Participant 2)

#### 3.1.3 | Peer support

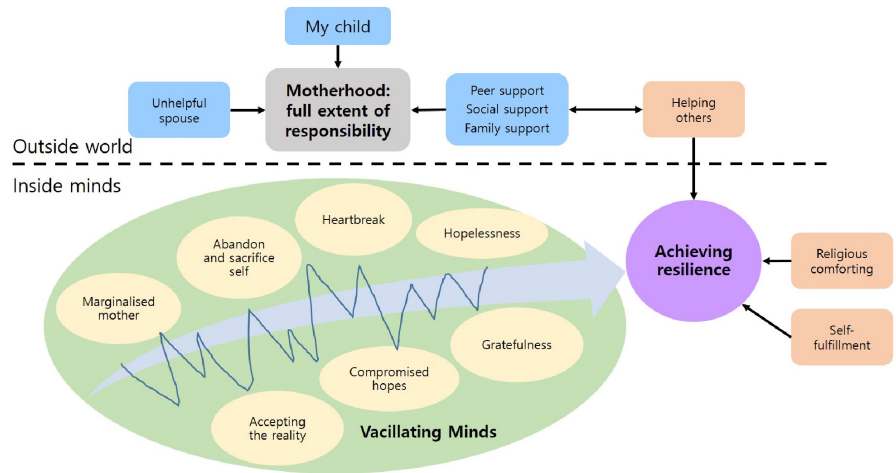
Even though participants did not receive their spouse's support, they experienced supports from other mothers who also had CMC. Participants who are mothers of CMC formed a strong and special bond by comforting, understanding and supporting one another. The bonds with the mothers of CMC experienced by participants were made by sharing similar experiences during the hospitalization of their CMC. According to the participants, the experiences enabled mothers of CMC to understand, sympathize and support one another.

They understand me. Even though family members try to understand, their points of view are different because the other mothers and I share the same reality (...) Communication with other mothers comforts me to live another day.

(Participant 6)

The other mothers understand even with the slightest of clues. They understand the situation the most. (...)

**FIGURE 1** Mapping of themes and categories.



If I am away for a moment to make a telephone call or use the toilet, they take care of my child, such as help them expel sputum. I am truly grateful for that. We do not need to talk but we just know.

(Participant 1)

An interesting experience in the bonding among mothers of CMC was that they support one another by looking after the CMC of other mothers. The experience was because of the low staffing level of the inpatient units and contributed to the bonding.

### 3.1.4 | Staff support

Participants illustrated their experiences of care and support from the medical staff during the hospitalization of their CMC. The kind gestures of medical staff supported participants and shared their responsibilities of caring for their children.

I had to be awake for 24 hours a day when my child's health was deteriorating. (...) At that time, my child's doctor recommended I sleep for a couple of hours and stayed with my child like a family member. I could not thank her more. She was even better than the members of my household.

(Participant 2)

There was support by the hospital staff recognized by participants which considered medical cost. As explained in the introduction, hospitalization of CMC required the devotions of participants which can load financial burdens on the households. Therefore, the social workers' support in providing information on available resources was particularly recognized by participants.

A social worker visited and explained the resources available to me. There were many ways to get financial help.

(Participant 6)

It was fortunate to pass the evaluation because the funding support shouldered a significant portion of the expenses. The medical fees are very expensive, despite the national insurance support. Thus, the financial support we received was enormously helpful.

(Participant 4)

### 3.1.5 | Family support

Even though the participants experienced unhelpful spouses, they experienced support from extended family members. When the primary family members became vulnerable in the course of the child's illness, extended family members, especially women such as mother, mother-in-law, and sisters-in-law, helped the mother in supporting the primary family.

I felt very sorry for but also grateful to my sister-in-law. She took care of my older child even after having just given birth to her own baby. She took care of my older child, even during the day of her delivery.

(Participant 7)

My mother-in-law took care of my two children and helped do the household chores.

(Participant 2)

When I had to take my sick child to physiotherapy, my mother looked after the other child and stayed with me.

(Participant 1)

The theme of "motherhood: the full extent of responsibility" showed identity and responsibility of participants. The theme of "motherhood: the full extent of responsibility" showed the identity and responsibility of participants. As the mothers of CMC, participants were given support from the peer mothers, female family members and hospital staff, while their spouses were experienced as unhelpful. Caring for and nurturing a sick child is a weighted

responsibility that rests on a mother's shoulders, but the presence of her child has given her the strength to carry the burden.

### 3.2 | Vacillating minds

The second theme, "vacillating minds," refers to the fluctuations in the participants' inside minds while caring for their CMC during hospitalization. "Vacillating minds" consists of the seven sub-themes of "marginalized mother," "abandon and sacrifice self," "heartbreak," "hopelessness," "accepting reality," "compromised hopes" and "gratefulness." The sub-themes of "marginalized mother," "abandon and sacrifice self," "heartbreak," "hopelessness" represented the negative responses of the participants, whereas the sub-themes of "accepting reality," "compromised hopes" and "gratefulness" showed the participant's efforts on coping with the situation of CMC.

The "vacillating minds" was a journey of participants. Each sub-themes were not linear steps that participants went through until the achievement of resilience. However, participants illustrated that they experienced each sub-theme randomly, backward and forward.

#### 3.2.1 | Marginalized mother

"Marginalized mother" was one of the immediate responses of the mothers about their child's illness. This sub-theme showed the participants' vulnerability in the social relationship. After learning of their child's illness, the mothers tended to feel isolated from her relationships because her world had been changed. Since the mothers lost common ground with people whom they used to be with and had difficulty communicating and empathizing, they rather chose to be alone.

I could not talk about my situation to acquaintances. It was not because of my wounded pride (...) They were living in a different world.

(Participant 4)

I blocked everyone who knew me. I did not answer any phone calls from them.

(Participant 1)

#### 3.2.2 | Abandon and sacrifice self

Since the mother of the CMC had to stay at the inpatient unit during the hospitalization because of the low nurse-patient ratio in South Korea, the mother's priorities in life were consequently changed. Participants gave up their own comfort and job to prioritize caring for their children.

I've never skipped my child's physiotherapy because of my personal difficulties; only when my child is too ill to attend the session.

(Participant 2)

No matter how hard it is for me, caring for my child is the priority. I take contraceptives for menstrual pain because I cannot ask for help or take a break because of it.

(Participant 1)

It was not optional, but I had to. So, I decided to resign from my work.

(Participant 4)

Even though the Participant 4 articulated that quitting her job was not optional, it was their choice to sacrifice their job in order to look after CMC.

#### 3.2.3 | Heartbreak

The sub-theme "heartbreak" refers to the participants' experience of emotional breakdown. Participants were emotionally vulnerable, so they easily felt heartbroken by ignorant and insensitive words.

I followed all the medical recommendations. If they advised to discharge, I complied. If they prescribed medications, I also complied. How could they say "what have you done?" (...) I did give everything my best.

(Participant 7)

There is always someone asking insensitively. (...) Their interest in our situation might be because they have not seen it before. But it breaks the hearts of the parents of sick children.

(Participant 2)

While the ignorant and insensitive words were clearly critical to the participants, their vulnerability was also a reason why mothers of CMC felt heartbreaking in ordinary circumstances.

One day, my friend called me via FaceTime (...) she wanted to cheer me up with her daughter (...) After the phone call, I felt something unbearable in my heart.

(Participant 4)

#### 3.2.4 | Hopelessness

"Hopelessness" was the most severe negative emotion of participants. Considering the severe, chronic and incurable illnesses of CMC, participants sometimes felt hopeless about the current circumstances. Participants' feelings of hopeless sometimes linked to the thoughts of dying and death of their CMC.



It is a very long journey. But there's no exit but death.  
(Participant 7)

This is endless, which makes me weary. It was hard at the beginning. But now, this is not only hard but also being helpless and hopeless.  
(Participant 3)

On the other hand, participants illustrated their efforts to deal with their reality of being a mother of CMC, which were shown as “accepting reality,” “compromised hopes” and “gratefulness.” However, the efforts were not the achievement of resilience because participants often returned to the negative responses. Therefore, the sub-themes, “accepting reality,” “compromised hopes” and “gratefulness,” were placed under the theme of “vacillating minds.”

### 3.2.5 | Accepting the reality

In order to deal with the reality of being a mother of CMC, participants had to face and accept the reality. Subsequently, accepting the current circumstances helped participants to have peace in their minds.

It is hard, but I must endure these difficulties. My life has changed financially and emotionally once my child became sick.  
(Participant 6)

As time goes by, I have learned to give up my desires. I did not mean to, but I had to. Then, I found peace of mind. Sometimes, I would feel genuinely at peace.  
(Participant 4)

The acceptance of reality was the basis for participants to emotionally cope with life changes and to attain inner peace.

### 3.2.6 | Compromised hopes

After accepting the reality, participants compromised their wishes and hopes to more realistic desires for their CMC. From the full recovery of the CMC, participants' wishes were changed to small goals in daily routines. Participants hoped to have dinner with their CMC at home and wished a smile of their CMC. Also, they wanted the illnesses of their CMC to stay in the status without deterioration.

What I hope the most is (...) having dinner all together at home.  
(Participant 3)

I only wish my child to recognise me and smile at me. Only once will be more than enough.  
(Participant 1)

I know the illness is chronic and progressive, so it will get worse. But I mostly hope that the process gets delayed and that things stay as they currently are.  
(Participant 5)

Furthermore, the participants' hopes concern the death of their child. If the death of CMC is inevitable, participants wished a comfortable death without suffering from their CMC.

I wish my child to live a little longer. But, on the other hand, I wish her a peaceful death without suffering because I know how much pain she has suffered.  
(Participant 2)

Nowadays, I have nurtured the hope to meet my child again in heaven. The hope keeps me alive.  
(Participant 4)

### 3.2.7 | Gratefulness

The sub-theme, “gratefulness,” was an attitude that some participants tried to have. Participants tried to be grateful for present circumstances such as another day living of their CMC and unchanged hospitalization.

It would be brilliant if my child completely recovers and walks again. But I think I should be grateful for every day that my child lives.  
(Participant 4)

There are a few things to be grateful for. I have not heard about the discharge or transfer while others have heard at least once.  
(Participant 3)

With regard to Participant 3's statement, the South Korean national insurance system does not allow a patient to stay in the general hospital after the acute stage of illness. Therefore, participants had to either find a rehabilitation centre or consider discharge to home once the acute stage of illness has been passed.

The theme, “vacillating minds” includes both positive and negative minds of participants on the process of “achieving resilience” in the inside minds of the participants.

## 3.3 | Achieving resilience

After going through a meandering process without a logical sequence, mothers achieved resilience at some point. The resilience was found in their interactions and relationships with other people. The mothers found positivity and comfort in humour beyond the “vacillating minds.”



Life is short enough to love only. We do not know who will pass on first. I often reflect on myself, which helps strengthen my bond with family.

(Participant 6)

It is sad but funny. The other mothers and I have learned to joke about "who is more miserable." We share the sad experiences and wipe away one another's tears.

(Participant 3)

Some people would say, "how pitiful you are to be stuck in a hospital." I would answer, "you are just as pitiful staying at home due to COVID-19."

(Participant 4)

"Achieving resilience" consists of three sub-themes: "religious comforting," "helping others" and "self-fulfilment."

### 3.3.1 | Religious comforting

More than half of the participants were Christian. Participants, particularly Christians, relied on their religious belief to find meaning in their suffering.

I live with the power of prayer. I cannot imagine not having someone to pray for me. It would be the same with other religions. (...) It's everything.

(Participant 4)

God gave me a challenge I can go through. If I go on, I will find him; religion is a source of strength to me.

(Participant 6)

### 3.3.2 | Self-fulfilment

Although participants despaired and isolated themselves at the beginning of their child's illness, they eventually realized the importance of caring for themselves at some point. They tried to find healthy methods to nourish themselves, such as working out, taking a course and studying. Those activities helped them to remind themselves of not only being the mother of CMC.

After staying in a hospital for a while, I felt weak and unhealthy. So, I started walking every morning for an hour.

(Participant 2)

I obtained a certificate in teaching origami and got a job with it. Now, I teach origami. The only thing left is my child's recovery.

(Participant 7)

Staying at the inpatient unit is hard. But I am grateful to have some time for myself in between caring for my child. Although the time is short, it is solely mine to spend on studying.

(Participant 2)

### 3.3.3 | Helping others

While "religious comforting" and "self-fulfilment" were founded in the participants' minds, "helping others" was founded in their relationships with other mothers. The participants expressed their resilience by helping other mothers they met at the inpatient unit. It was linked to "peer support" received from the other mothers.

If a mum needs to leave even for a second, the child is left alone. How can I not help? I sometimes help to suction the saliva when the mother is away.

(Participant 5)

Given my child's circumstances, I cannot afford to help others. But I would be willing to help if I could.

(Participant 4)

The "achieving resilience" is the only theme emerged in both outside world and inside minds of participants. "Gratefulness" and "religious comforting" were illustrated as the minds of participants, whereas "helping others" was found in the participant's interactions with other mothers.

## 4 | DISCUSSION

The findings of this qualitative study provided insights into the experiences of mothers of CMC in the Korean cultural context. Our study shows that a mother of a CMC lives in a hospital and plays multiple roles, including as a caregiver, patient advocate and coordinator in the treatment and care of their child beside the mother's natural role as a fosterer. The distinct contribution of the findings is the mother's coping mechanisms in the difficult practice of taking on the primary role of caring for an ill child. This aligns with the understandings of feminism by Butler (1990) who asserted gender as a performance. The women in this study had an identity as mothers of CMC and performed as expected to mothers. Even though the identity of being a mother of CMC was assigned by default, the mothers actively devoted themselves to the care of their children and acquired the resilience to establish their personhood. Moreover, these mothers of CMC are in solidarity with other mothers. They deeply empathized with the suffering of other mothers and took the initiative in supporting themselves. This altruism of mothers demonstrates women living under unavoidable circumstances as subjective beings.

The first theme, the full extent of responsibility of mother, demonstrated the unequal distribution of responsibility between

parents in the care of CMC. While the mothers in this study embraced the extended responsibility of motherhood, their spouses were not as devoted as mothers. This finding confirms those in a meta-synthesis by Coffey (2006) and an integrative literature review by Coughlin and Sethares (2017). Mothers of CMC gave up their careers to care for their children, which often resulted in social isolation (Coffey, 2006). Coughlin and Sethares (2017) justified the mother's role as primary caregiver with the coping strategy of sorrow between mother and the spouse since the sorrow was permanent to mothers, whereas the spouses tried to end the sorrow.

The second theme is "vacillating minds," which represents the internal process undergone by mothers of CMC towards resilience. Mothers of CMC experienced feelings of hopelessness, heartbreak, self-sacrifice and isolation with the prolonged stay at the hospital. However, they eventually experienced thoughts and feelings of acceptance, letting go of compromised hopes while expressing gratitude simultaneously. They eventually found their way towards achieving resilience. In psychology, the dual process theory describes how human thoughts can arise in two opposite ways and identifies a dynamic, regulatory coping process of oscillation (Lizardo et al., 2016). We have incorporated and adapted ideas from the dual process theory to explain the fluctuating thoughts and emotions of mothers of CMC in everyday life.

The mothers of CMC feel hopeless because they realize that their child could not be cured, with the only foreseeable end of the situation being the death of their child. However, they did not succumb to despair, but instead found renewed hope in such simple aspirations as "having dinner all together at home, 'the child smiling at them' and even 'peaceful death.'" Frankl (1966) recognized human beings as free beings and believed that we had the freedom to choose our attitude towards situations we are facing, although not necessarily freedom from the situation. In situations where we cannot change our destiny, the important thing is to have the right attitude towards it (Nabors et al., 2018).

After the unpredictable forward and backward coping process of vacillating, mothers of CMC achieved resilience. Finding comfort in religion and self-fulfilment contributed to achieving resilience, as eventually shown in their ability to embrace humour. The most distinct findings of this research were solidarity among the mother, which helped them achieve resilience. These acts of solidarity among mothers of CMC have also been reported previously (Boss et al., 2020; Cipolletta et al., 2015; Nassery & Landgren, 2019). Boss et al. (2020) investigated peer support among family members of CMC via social media, while Cipolletta et al. (2015) identified a distinct connection among family members of CMC. However, while Boss et al. and Cipolletta et al. explored the experiences of family members of CMC both during hospitalization and after discharge, Nassery and Landgren (2019) explored the experiences of parents of CMC at an inpatient unit and found that these parents deeply understood one another due to being in the same boat.

This look at motherhood with CMC was presented from the mothers' perspective, which is anthropologically and socio-culturally

constructed and must be understood within a cultural context (Barlow & Chapin, 2010). The findings of this study unveiled insights into the journey of a mother of a CMC, from vacillation towards resilience, in the South Korean context, which nevertheless feature the universal fundamentals of motherhood.

#### 4.1 | Limitations

Participants of this study were common in mothers of long-term hospitalized CMC, but it varied in their children's diagnosis and age. Also, the study was conducted in one setting only thus may limit transferability of study findings.

### 5 | CONCLUSION

This study provides insight into the intrinsic and extrinsic journeys of mothers of hospitalized CMC. Mothers of CMC helped themselves by empathizing and showing solidarity with other mothers. While they vacillated between positive and negative emotions and thoughts, the mothers consciously chose to hope and achieved resilience. This study provides useful insights for clinical nurses to recognize and support mothers of hospitalized CMC as individuals struggling through a desperate situation and in need of as much support as can be provided.

#### ACKNOWLEDGEMENTS

The authors appreciate Dr. Yeo Hyang Kim at the Kyungpook National University for supporting the Institutional Review Board process in the Kyungpook National University Hospital.

#### FUNDING INFORMATION

This research received no specific grant from any funding agency in the public, commercial or not-for-profit sectors.

#### CONFLICT OF INTEREST

The authors have no conflicts of interest to declare.

#### DATA AVAILABILITY STATEMENT

The data that support the findings of this study are available on request from the corresponding author.

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**How to cite this article:** An, J. Y., Kwon, S.-H., & Choi, H. R. (2023). Experiences of South Korean mothers of children with medical complexity under long-term hospitalization. *Nursing Open*, 10, 1840–1851. <https://doi.org/10.1002/nop2.1446>