

The Experiences of Mother's of Children with Epilepsy

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Abstract

This is qualitative research using grounded theory to examine the experiences that mothers of children with epilepsy can have. Data were collected through in-depth interviews, observation, and memo-taking with a total of 13 participants in this study—10 mothers taking care of children with epilepsy and 3 principal informants—and the data were analyzed using the method developed by Strauss and Corbin (1998). As a result of data analysis, 163 concepts, 26 subcategories and 8 categories were formed through open coding. Such categories were analyzed by the paradigm of the grounded theory, and as a result the experiences of the mothers of epileptic children were based on a causal condition of 'confrontation' and the central phenomenon of 'Wandering around the forest under a yoke'. The contextual conditions, which exerted influence on phenomena, were 'stigma cognition', 'personality traits' and 'health of children.' The action/interaction strategy selected by participants was 'Quietly pulling through: Bracing myself, Getting to know my enemy and myself', 'Taking care while hiding, Putting out one step at a time, Establishing a foothold. The intervening condition affecting action/interaction was 'the support system', and its result was 'watching.'

Keywords: Epilepsy, Mother, Experience, Qualitative study, Grounded theory

1. Introduction

Across all ages and countries, taking care of her sick child is a mother's painful duty and the fate of a woman. Especially if the child is suffering from a chronic illness or disability, the pain and suffering of the mother would be hard to imagine. Epilepsy is one of the diseases that can cause such pain and suffering. About 1% of the world's population suffers from epilepsy, most of which are reported to develop before the age of 20, and 50% of them before the age of 5. This shows that epilepsy is a typical childhood chronic neurological disorder [1].

Children with epilepsy have a higher incidence of internal and external behavioral disorders than children with other chronic diseases [2], and these problems are related to the various psychological and social problems of the families of parents as well as direct factors related to disease such as the child's age, sex, seizure control, and side effects from medication [3]. Parents of epileptic children experience stress, anxiety, concern, depression, anger, guilt, frustration, and chronic sadness associated with their child's illness [4], and this has negative effects on the parents' attitude toward and response to epilepsy, the relationship between parents and children, and the interaction type. The more positive the parent's attitude toward epilepsy, the more positive the coping type and the more likely it was to affect the parenting behavior [5], which shows that the attitude

Manuscript received: July 17, 2018 / revised: July 24, 2018 / Accepted: August 6, 2018

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and behavior of the parent is an important variable for the health care of children with epilepsy.

The mothers and fathers of epileptic children show different attitudes and behaviors; while the fathers are less concerned about the child's health problems over time after the child's first seizure, mothers showed various demands with constant concern even after a certain period of time [7]. As mothers are primarily responsible for taking care of their children, when their children have health problems, they have difficulties in basic health care, taking care of other family members, housework, ect [6]. In addition to the difficulty of parenting, mothers suffer from the uncertainty about diagnosis and progress [8], recognition of social stigma [4], concern about the future, loss of self-confidence as a parent, stress, depression and anxiety, and experience more stress and depression as the duration of illness lasts longer [9]. In particular, due to the nature of epilepsy, predictive seizures can disrupt discipline and eventually lead to failure in parenting, as mothers display poor parenting, such as excessive control and overprotection [5, 10]. Considering the position and role of mothers in a family, the psychological and social difficulties of mothers of epileptic children are important nursing problems that must be addressed not only for themselves but also for the health of the children with epilepsy and the whole family. Nevertheless, the medical field focuses solely on medical aspects such as seizure control, while the psychological and social difficulties of mothers are not only overlooked but also lack research. Studies on epilepsy have steadily increased since the 1970s, resulting in a four-fold increase in the quantity of research over the past 30 years, while research on the families has made no progress at all [11]. In particular, only a few studies were performed on mothers of epileptic children in Korea; most of them are quantitative research [4,6,9,12-14] which have limitations in understanding the experiences of mothers of epileptic children from a fundamental and comprehensive perspective. The qualitative studies on parents of epileptic children are mostly overseas studies [8], and considering that Korea has more negative perceptions and emotions toward epilepsy than western countries [15], it is difficult to understand the experiences of Korean mothers through previous studies from other countries. In addition, although the need for research on epileptic children and their families is significant, it is difficult to conduct quantitative research on a large number of children and their families as it is not easy to approach the parents as well as the epileptic children due to the tendency to avoid exposure to the public because of the nature of the disorder. Nursing interventions for children with epilepsy and their families must be based on the understanding and theories of their experiences and adaptation processes, and in order to do so, research is needed to derive their inner consciousness and experience. Therefore, this study attempts to develop clues for nursing interventions for epileptic children and their mothers and families by understanding the experiences of the mothers of epileptic children in depth from a psychosocial perspective and by identifying their adaptation process and presenting a substantive theory about the process. The purpose of this study is to develop a substantive theory on their adaptation process based on understanding the experiences of mothers of epileptic children. The main research question is 'What kind of experience do you have raising an epileptic child?'

2. Research Method

2.1 Research Design

This is a qualitative study that applies the grounded theory approach to develop a substantive theory about the adaption process of mothers of epileptic children based on exploring the experiences of mothers of epileptic children.

2.2 Selecting Research Participants

The selection of participants in this study was based on the theoretical sampling method [16] of the grounded theory study presented by Strauss and Corbin (1998). The pediatrics department of 2 medical

institutions introduced 10 mothers raising children who are diagnosed with and receiving treatment for epilepsy, and 2 mothers were contacted through an Internet cafe operated by mothers of epileptic children. After providing oral and written explanations of the purpose of this study, 5 people who agreed to participate in this study were selected as primary participants. After interviewing the primary participants, secondary participants were selected and data collection was performed while proceeding with analysis. As a result, a total of 15 people participated in this study including various important information providers such as doctors and nurses who are in charge of the children's treatment, and the mothers of the mothers of epileptic children.

2.3 Data Collection

The data collection period was from December 2007 to March 2016, and the data was collected through in-depth interviews with a total of 15 participants including 12 mothers of epileptic children and 3 important information providers. In addition, a posting from the Internet cafe by one of the participants, notes recorded at the time of the interviews, and field memos recording observations during the interviews were used as data. Before the in-depth interviews, one or two prior contacts were made to have the participants feel comfortable, and the interviews were performed at places preferred by the participants. The participants were interviewed 1~3 times, and each interview took about 1 hour and 30 minutes to 2 hours. The interviews started with the question 'What kind of experience do you have raising an epileptic child?' And, for unclear situations or situations that required more details, without interrupting the statements of the participants, the interviews were continued with the following questions, depending on the contents of the interviews. 'Could you explain the situation in more detail?', 'How did you feel at the time?', 'Why did you feel that way?', 'How did you solve the situation?', 'What helped you at the time?'

The interviews were recorded using a digital recorder, and the researcher and a research assistant immediately took notes and the researcher made corrections while listening to the recordings. The interviews with 2 participants who refused to record the interviews were conducted by summarizing the main points of the conversation and then immediately documenting the contents of those memos along with details remaining in the researcher's memory after the interviews. In addition, the observation of participants during the interviews and the feelings and thoughts of the researcher were carefully organized; these notes were also used as research data.

2.4 Data Analysis

Data analysis and collection was performed at the same time, and open coding, axial coding, and selective coding were employed according to the analysis method of Strauss and Corbin (1998). Through reviewing the data, concepts were identified from the data; concepts and categories were discovered and named through continuous comparative analysis; and each category was classified into attributes and dimensions. The paradigm model including causality, situation, phenomenon, interventional conditions, action/interaction strategies and the results was identified based on the dimensions of the categories and attributes of the relationship between the derived categories. In addition, the core category and the adaption process were revealed in the process of abstracting the categories, and based on them, the adaptation process of mothers of epileptic children was derived by presenting the relationship between each process and category.

3. Results

3.1 The Paradigm Model of Mothers of Epileptic Children

The core category of the experiences of mothers of epileptic children is to 'quietly pull through,' which represents a contradictory life in which mothers are forced to hide their epileptic children while quietly

suffering great anxiety and struggling with the illness.

■ Causal condition: Impact of the encounter

The mother's experience, such as the panic from a sudden seizure without warning, came to encounter an unimaginable reality following the diagnosis of 'epilepsy.'

At that time, I was so scared and... I did not cry, but my heart was beating so hard that my arms and legs were trembling and my heart was trembling so much that I could not speak...then I thought 'What if my child dies?'...I could not say such thing out loud, but I got the thought deep in my mind...and I thought what if my child, the child I love so much, really dies...I was really struck blind by the thought. I'll probably never forget that moment. The moment still seems to have been imprinted in my mind. (Participant J)

■ Central phenomenon: Wandering around the forest under a yoke

Despite their children's diagnosis of epilepsy, most mothers did not believe it or did not want to believe it, and had experience visiting a variety of hospitals and doctors. They become confused again when they stop the medication thinking that the doctor's diagnosis was wrong or when the side effects of the medication occur. They asked around and tried all sorts of measures such as alternative medicine, folk remedies, and even gut (or exorcism). However, they live with their hearts in their mouths because of concerns about seizures without warnings, and their hearts are filled with sorrow, guilt, resentment, and anger toward people around them whenever they see their children. When the fact that you can't complain about your child's illness becomes too much to bear, they even feel the urge to put down their burden as a mother.

Convulsive seizures occur without warning, so I always stare at my child even at home. If it is too quiet when I'm doing housework, I call out my child's name, and when answered I feel relieved, but go looking after the child whenever the child is out of sight, so I practically live with my eyes and ears open. I'm a housewife, so whenever my child goes to school, I'm worried that I might receive a phone call from school. Every once in a while...there's people who collapse on the street due to seizures. So I wonder if someday I'll get a phone call...so I keep staring at my phone. (Participant B)

■ Contextual condition: Stigma, Health problems, Personality traits

Contextual condition refers to a set of special conditions that create situations or problems that people must respond to through action/interaction, and there is a difference in the degree of wandering depending on the 'stigma' about epilepsy, 'personality traits' of the mother, and 'health problems' of the family. Due to the social stigma of epilepsy, even the mother herself has difficulties in taking care of the child due to the negative experiences and perceptions toward epilepsy. In addition, if the mother's personality is introspective and negative, or if the children also suffers from other large and small diseases accompanied, the wandering was found to be even worse.

- Stigma

You can't get married, can't get a job, can't join the army, and you can't even get a driver's license...a man who can't drive or join the army...what would you say if you can't even join the army? You can't say it's because of epilepsy. There's nothing you can do. Do you think you can get a job with epilepsy? They won't hire you if they find it. It causes a huge problem for living, even surviving. If you can't get a job, you can't get married, you can't do anything. What about marriage? People think that epilepsy is inherited. To be honest, even if my son suffers from epilepsy, if you ask me if I can live with an epileptic daughter-in-law? I would

simply say I can't. (Participant E)

- Health problems

My daughter is bright and active so she will do anything...but I didn't even expect this much from my daughter knowing how difficult it is to raise a disabled child. I truly respect her, even if she's my daughter. (Participant L)

- Personality traits

My child lived in the hospital due to all sorts of diseases. Getting sick from tuberculosis, my child was hospitalized because of a low platelet level, and for whatever reason...my husband told me that we could even build a building with the money we poured in the hospital. (Participant D)

■ Intervention conditions

- Support system

While some participants received much information and support from friendly and caring doctors, some were hurt from unfriendly and authoritative doctors and felt frustrated whenever they were mistreated at the hospital or when they failed to receive proper consultation due to the tight consultation hours. But most importantly, it was the support from close family members that counted the most, especially the encouragement and cooperation of the husband.

My husband always tells me that I'm incredible. Taking care of the sick child, raising the little one, and doing housework...he's astonished about how I take care of the child without getting a good night's sleep. He always says he can't do anything without a good night's sleep. But the only reason I can't sleep is that I feel uneasy because my child is sick, and he is astonished at that. My husband acknowledges me. and that's a great deal of support. (Participant B)

■ Action/Interaction: Quietly pulling through

The central phenomenon of wandering around the forest under a yoke appeared to be an adaptation process that uses strategies such as bracing yourself, getting to know your enemy and yourself, taking care while hiding, putting out one step at a time, and establishing a foothold.

- Bracing myself

The process of bracing myself is necessary to find your way away from struggling without admitting the reality, the pain from anxiety, concern, and worry and the wandering you want to put down because it's too much to bear.

When stress builds up...I just cry. I feel somewhat relieved after I cry out loud, but then it starts all over again. I really cried a lot. (interruption) Then I...well...I don't know if I'm greedy or not, but I worry that something will go wrong if I start to get greedy. Then I realized that nothing was going to change even if I pushed or urged. Just as people have different personalities, my child's capacity is like this...I worry that the seizures will happen again if I want much regardless of the child's capacity. That kind of thought crossed my mind. (Participant L)

- Getting to know my enemy and myself

The mothers began to learn about epilepsy, the disorder that was bothering their child. They began to understand the disorder one step at a time by consulting with experts, talking to mothers with the same worries, searching books and the Internet. In addition, they said that they were able to properly understand epilepsy by carefully observing and recording their progress while comparing them based on their own experience.

At first, it seemed like there would be a huge problem because of the seizures. But after this kind of experience builds up...you learn to wait. And after a couple of times, you learn to cope with it and keep your composure. You start to take notes with constant interest and compare them with a few months ago. I always keep a note of what happens to my child. I collect the notes and compare them, and start to understand. I also ask around and search the Internet. If you want to win, you need to know about the disease. (Participant J)

- Taking care while hiding

As a mother, it's natural to take care of your child, but the participants appealed that it was difficult to freely look after their child because, if they would do so, people who don't know their inside story would start to ask questions.

This is all that I can do, fixing nice meals for my child. My child says school meals are always like dog food...so even though it's a little bit of trouble, I prepare lunch boxes. My child is a junior in high school, so I pack 2 lunch boxes. Every morning I prepare gimbap, because it's my child's favorite. I personally deliver them myself. We promise to meet at the schoolyard when it's time to take the medicine. In doing so, my child can take the medicine on time avoiding the eyes of the classmates. Then when my child comes home after self-studying at school it's right time to take the medicine. Without showing it to others. (Participant E)

- Putting out one step at a time

The mothers began to open up to the people around them, thinking that it was not a good thing just to hide the illness. They had no choice but to let people know because they realized that they could not take care of their children forever.

I visit the homeroom teacher whenever we change schools or a new school year starts. I explain why my child takes medicine, how to react to seizures, and ask the teacher to reach out to me whenever there's an emergency. Deep inside, I don't want to tell the truth...nobody would do. But I have to...to prepare for emergencies. As a result, the homeroom teacher called me a couple of times, so I went to school to pick up my child(Participant M).

- Establishing a foothold

The mothers wanted to make the most robust foothold in their situation. They started to work on realistic solutions by changing the environment, educating their child about epilepsy, guiding their children how to take care of their health, and giving them special education.

I could not trust the world. In the city, it's really difficult for my child, even adults. That's why we decided to

change schools. It's a small neighborhood, and the kids are so innocent growing up in the countryside. That's why we moved to this school, we have no property to leave behind so being healthy is the best. My husband agreed to everything...he said let's go. So, we moved here. We can't take care of our child forever. And, now we're training him to take care of himself little by little. Starting with cleaning his room and taking his medicine by himself. That's all that we can do, preparing him so that he can live on his own Participant L).

■ Results: Watching

As the scope of strategies and strategic targets that the mothers used has gradually expanded and they became aware of the relationship of mutual growth, they were able to observe their child growing independent. However, according to the degree of observing, the mothers were swayed by themselves, their children, and the circumstances surrounding them.

Other people can't imagine how hard it would be to raise such a child...but we enjoy ourselves in our own way. Even if it's not enough, we laugh and think of the best. We're really happy in our own way. Others will never know. At first, I was like them. I even could not imagine raising a handicapped child like that, but as time goes by, life goes on. (Participant L)

4. Discussion

This is a qualitative study that applies the grounded theory approach to understand the experiences of mothers of epileptic children and to develop a substantive theory about their experiences. We conducted in-depth interviews with a total of 15 participants including 12 mothers of epileptic children and 3 important information providers. This study intends to discuss the paradigm model and the adaptation process obtained by analyzing data including interview details and field notes and memos.

Children's chronic diseases are a great pain to their parents, which is a common phenomenon found in many studies [4,14,17,18]. A sick child is one of the main factors of a middle-aged woman's Hwa-Byung (mental or emotional disorder as a result of repressed anger or stress) [17], which indicates the mental scars and physical fatigue, the pain of stigma from epilepsy, anxiety about seizures, and the fear of loss [8]. Unlike overseas studies, this study shows a sense of burden, which is considered to be an influence of the Korean parenting attitude [19], which features a longer parenting period, is relatively self-sacrificing and shows stronger affection and control over children compared to other countries, due to the difficulty of entrance exams and employment. Therefore, in the nursing intervention for the mother and family of epileptic children, understanding the social and cultural background of Korea should come first.

Stigma was also considered to be an important factor that influences the mother's adaptation in previous studies [20]. Negative perspectives toward epilepsy have always existed in the East and the West, but those negative perceptions are stronger in the East including Korea [21]. This may be because the fact that epilepsy has a genetic predisposition as well as the characteristics of the disease that shows changes in consciousness stand out due to the culture that emphasizes blood ties and the spiritual world compared to western societies. The question to consider in terms of the hereditary nature of the disease is the 'guilt as a woman.' Most married women are not only responsible for taking care of their children in the event of any health problems, but also feel guilty and self-defeated in the midst of 'maternal love' as they consider that cause of the disorder to be their fault. In addition, they feel guilty again, thinking that separating themselves from their children's life and going on the path of self-discovery as a result of adaptation can conflict with the appearance of motherhood. This ambivalence has a negative impact on the mother's health as well as the child's health; thus institutional measures are required to solve this at the macroscopic level, and the mothers need to free themselves from being guilty as a woman and distorted maternal love so as to face the issues with more confidence. However, the mothers of epileptic children braced themselves and tried to learn everything about epilepsy, repeating 'if you know your enemy and yourself, you can win every battle.' They also began to bring their children out into the world one step at a time, thinking that they could not hide and take care of their children forever. In the end, they realized that the children needed to learn to be independent and experienced the action/interaction

process of quietly pulling through to prepare a stepping-stone for their children. The intervention conditions that influence these actions and interactions are the support system, and in particular, the support of the husband was considered to be the most powerful interventional condition. The mothers with active support from their husbands could find themselves adapting successfully with a problem-oriented and aggressive 'pulling through' approach. Although the fathers are less likely to be directly involved in the care than the mothers, they also suffered from the uncertainty about the disease, depression, and coping difficulties [22]. More research is required on the fathers of the children because the attitudes of the fathers have an absolute effect on the adaptation and care of the mother as well as the children. Most mothers hide their children's diseases out of fear of social prejudice, which results in a weak support system, a lack of information on the resources they should use and avoiding the use of given support systems and resources [10]. In addition, Also, consideration and comfort for the patient was found to be insufficient in an authoritative and hospital-oriented care system; this situation aggravated the mothers' difficulties. It is a very unfortunate result that proper support of nurses was not observed during this process. Considering the results of previous studies [23] that suggested the support of professional nurses with accurate knowledge who had relatively more time than doctors with only limited time was more effective, the active interest of nurses with expertise in this field is required for nursing children with epilepsy and their families.

The fact that the role of the school nurse who is responsible for the health of the children and adolescents hardly appears in this study is a matter that needs to be reconsidered. A previous study [24] reported that the teachers' knowledge and self-efficacy about seizure management were improved through educational programs related to epilepsy for teachers. If the teachers cannot properly cope with seizures that suddenly occur at schools, it may result in psychosocial problems as well as physical problems for the children; the mothers are concerned about this matter. The school nurse should play the role of providing information and knowledge about children's health care to general teachers who are the health managers of the children and also have much direct contact with the children. However, the role of the school nurse was rarely observed in this study, and in some cases, they were not aware of the role at all. Therefore, an active role is required from school nurses, such as understanding the special needs of general teachers, epileptic children and their families and providing related education.

The mothers experience support from the people around them, but they also experience bitterness, conflict and loneliness due to the negative perception of epilepsy and lack of understanding by the general public. The negative thoughts about epilepsy is a result of ignorance of the disease. In Korea, there is still a lack of understanding of epilepsy and also a negative attitude toward epilepsy patients such as the belief that epilepsy is a mental illness or that epilepsy patients should be isolated from society [26]. The understanding and efforts of the whole society are required to solve this problem, and public awareness about epilepsy should be promoted through mass media including TV that recently aired many health-related programs.

5. Conclusion

This study is a grounded theory study conducted to develop a substantive theory on their adaptation processes based on understanding the experience of mothers of epileptic children.

The core category of the experiences of mothers of epileptic children is 'quietly pulling through' which starts with the process of wandering through the forest of thorny bushes under a yoke due to the shock of encountering epilepsy. The stigma of epilepsy, personality traits, and other health problems of the children affected the wanderings. The mothers used strategies such as bracing themselves, learning about epilepsy, quietly taking care of their children, bring their children out into the world one step at a time, and preparing a stepping-stone for independence to go through the process of the wandering phase full of shock and chaos, the problem recognition and exploration phase, the implementation phase, and the phase of reconfiguring relationships. During this process, the support system of the family and society was found to be an important intervention condition and eventually led to observation.

The lives of mothers of epileptic children are like walking through a thick bush which is full of epileptic seizures, social stigma, and prejudice, under the yoke of motherhood. However, the name "mother" is a breath of hope that overcomes many difficulties in the children's lives, and from the mother's appearance, the children

are expected to gain another courage, overcome epilepsy, and meet the world.

In conclusion, the following suggestions are made based on the study findings.

1. To understand the comprehensive experience of the family, further research is required to observe interactions with other family members including the epileptic children's father, and based on the result, an intervention program for a family of an epileptic child should be developed.
2. As shown in the results of this study, the understanding and consideration of the teacher provide a significant support system. Thus, this study suggests that education for epilepsy should be provided to general and special education teachers, centering on school nurses.

Acknowledgement

This Study was supported by Y'sU (Yongsan University) Research Fund 2016.

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