Purpose: This study aimed to identify important factors to achieve successful nursing care for patients with epilepsy, from the experiences of women with epilepsy who were told of the disease in childhood and subsequently acquired a positive attitude toward the disease.

Methods: A semi-structured interview was conducted in 7 young women with childhood-onset epilepsy treated at specialized epilepsy outpatient clinics. Then a transcript was prepared from the interview data and analyzed qualitatively according to Burnard's method.

Results: One patient had generalized seizure and 6 patients had partial epilepsy (frontal lobe epilepsy in 2 and temporal lobe epilepsy in 4). The childhood experiences of the women with epilepsy were classified into six categories; (1) stage when disease was not clearly understood, (2) stage when being told of the diagnosis, (3) stage of self-isolation for having epilepsy, (4) stage of attempt to adjust to disease, (5) stage of rehabilitation of the mind, and (6) stage of appreciation to people and anticipation of the future. In the interview contents, “mother” was the most mentioned family member.

Discussion: For young women with childhood-onset epilepsy and their families, maintaining good medication compliance was an important personal experience for the child and their parents. Acceptance of independent spirit and behavior may foster a positive attitude and rehabilitation of the mind. Even patients with high seizure frequencies at onset and complicated by anxiety and depression talked passionately during the interviews about the process of acquiring a forward looking psychological state as their seizures became controlled.

Conclusion: The effects of epilepsy severity and seizure type on psychological outcome remain unknown. In providing nursing care for women with epilepsy and their families, it is necessary to understand the psychological state of the patients, provide specialist information oriented toward their future life stage, and coordinate with other health personnel to facilitate their AED treatment.
Introduction

Epilepsy is a common neurological disorder, affecting approximately 0.5-1% of the population [1]. Also, epilepsy is a chronic disease experienced by millions and a cause of substantial morbidity and mortality. It occurs in all ages regardless of sex, but many people experience seizures of epilepsy from childhood [1].

The development of antiepileptic drugs (AEDs) therapy over the past decades is expected to change the future and life cycle of people with epilepsy, with an increase in number of patients with a positive attitude toward life under treatment. However, the nursing care of patients with epilepsy in Japan remains undeveloped in many aspects, and the roles of nurses in epilepsy care is a major area to be established in epilepsy medical care.

For young women with epilepsy, the anxiety about the future is more serious than men. In these women, treatment for epilepsy has to be conducted with the goal to control seizures considering the various life events of women such as marriage, pregnancy, delivery, and child care, as well as work. Women with epilepsy require AEDs and nursing care that anticipate the future. Furthermore, the quality of life (QOL) of women with childhood-onset epilepsy may improve by appropriate early nursing care.

The QOL of people with epilepsy is known to be affected by the severity of depressive state and adverse effects of AEDs irrespective of seizure frequency [2-4]. People with epilepsy have a higher prevalence of psychiatric problems including depression compared to the general population [5, 6]. In one study, patients who became seizure free had more significant positive changes in QOLIE-31 and QOLIE-89 overall scores, and in SF-36 mental health summary score than those who did not [7]. In several studies, seizure-free patients reached the same levels as the norm in all SF-36 domains except social function [7-9]. In addition, deterioration of QOL has been reported to be caused by the gap between psychological expectation and real-life experience, and the perception of QOL has been shown to differ between medical personnel and patients and their families [4, 10, 11].

Reports concerning disease cognition and past explanations of the disease by doctors and family members may be related to the perception and acceptance of epilepsy, and may impact patients’ active participation in treatment and the degree of satisfaction [12, 13]. Important risk factors that worsen the psychosocial outcome of adolescents and young adults with epilepsy include insufficient support from the family, no seizure remission, high seizure frequency and low intellectual ability [14]. More support to young patients with epilepsy living in the community is needed.

There are few previous studies that focused on the psychological status of young women with epilepsy. A possible reason is that nurses do not have sufficient understanding of patients with epilepsy. In addition, most nurses feel difficulties in providing nursing care for patients with epilepsy. Therefore, the narrative of women with epilepsy who talked about their own experiences should be valuable data.

The purpose of this study was to analyze the psychological status of women with
childhood-onset epilepsy from the narrative of their life experience, and to examine how to provide better nursing care for epilepsy.

Subjects and Methods

Subjects

The main study was conducted between July 30, 2014 and July 30, 2015, at North-Tohoku Epilepsy Center. Selection criteria were patients with onset of epilepsy younger than 18 years of age (range: 3-17) who were currently receiving outpatient treatment with seizures controlled for 1 year or longer. We interviewed 10 patients. Among them, three patients whose treatment periods were less than 6 months at the center were excluded from analysis. Finally, seven women treated as outpatients at the North-Tohoku Epilepsy Center were analyzed.

Study method and data collection

Patients’ demographic and clinical data were collected from medical records. The data included epileptic seizure type and severity, seizure symptoms, EEG findings, antiepileptic drugs, duration of treatment from the beginning of treatment.

A semi-structured interview was conducted [15-17]. The interview contents included (1) the circumstances when being told the diagnosis, (2) the subsequent course of disease and seizure experience, and (3) outlook of the present and the future. The interview was scheduled on the day of the patient’s outpatient visit. After obtaining informed consent, interview was conducted in the outpatient department or a private room of the hospital. The interview was recorded using an IC recorder under consent. The duration of interview was approximately 30 to 40 minutes for each patient.

Analytical methods

Information obtained from the interview was analyzed by referring to the process of qualitative content analysis developed by Burnard [15-17]. Based on the recording contents of the IC recorder, a transcript was prepared. The contents of the transcript were read carefully. To extract common topics from the transcript, researchers immersed themselves in the data, read the descriptive data repeatedly, took notes, and generated categories freely. Finally, similar categories in the category list were deleted. Taking care not to distort the semantic content of the transcript, each statement was extracted as one unit of data. Each data unit was numbered such that the data could be traced back to the original record any time during the analysis.

For each unit of data, the descriptive content representing the theme of the whole sentence was extracted, categorized, and sub-categorized using expressions that reflect the descriptive contents.

The categories were named and coded while continuously comparing the codes and categories to ensure similarity in semantic contents between the two. Similar titles were deleted, and multiple researchers adjusted the category, subcategory and title lists. The main categories were extracted step-by-step and analyzed qualitatively a posteriori. During the process of data analysis, one medical doctor and three nursing researchers with at least three years of experience in an epilepsy center examined the data and analytical results thoroughly to ensure reliability and validity.
**Ethical consideration**

Permission to study the outpatients was obtained from the director of the North-Tohoku Epilepsy Center and the attending doctors. This study was approved by the ethics committees of the research institute of the North-Tohoku Epilepsy Center and Hachinohe Gakuin University (No13-11).

**Results**

*Patient background and outline of experience*

The age of the seven female patients was 26.14 ± 5.67 (mean ± standard deviation) years. The age of epilepsy onset was 10.14 ± 4.45 years. The duration of treatment from onset was 16 ± 8.02 years. The duration of seizure control was 2.21 ± 1.55 years.

Patients were engaged in part-time jobs or were self-employed, and were independent in daily living. At the time of study, the patients visited the hospital once every 1 to 2 months, escorted by the family. Table 1 shows the clinical background and treatment outline of these patients. For seizure type, Cases 1, 3, 4, 5, 6 and 7 manifested partial seizure and secondary generalized seizure, while Case 2 manifested generalized seizure (tonic-clonic seizure) with no aura. Among those with partial seizures, Cases 1 and 3 had frontal lobe epilepsy, and Cases 4, 5, 6 and 7 had right temporal lobe epilepsy. The seizure experience extracted from the interview are also summarized in Table 1.

In all patients, interview was conducted at the time when seizures had been controlled by AED for over one year. The interviews were conducted in an attempt to identify the roles of nursing from the time the young patients were told of the disease to the time they became adolescents and adults, a period that is particularly important for females. After the interview, a transcript was prepared, and the data were categorized. The process was conducted according to Burnard’s method. Analysis of patient’s experiences of disease and treatment was performed from the viewpoint of nursing. Table 2 shows the stages identified.

From the contents of childhood experience, a total of 69 codes were extracted, which were classified into 8 sub-categories and finally consolidated into 6 categories: stage when disease was not clearly understood, stage when being told the diagnosis, self-isolation for having epilepsy, stage of attempt to adjust to disease, stage of rehabilitation of the mind, and appreciation to people and looking forward to the future (Table 2).

Among the narratives of experiences, the most common character mentioned was “mother”, followed by the patients themselves, people around them, classmates or friends, colleagues at work, teachers at school, attending doctors, persons with the same disease, and the general public.

Due to the small number of cases, the relationship between the psychological stage of the 7 cases and disease severity or seizure type could not be analyzed.

*Experiences of being told as having epilepsy*

Regarding the experience of being told as
having epilepsy, 29 codes were extracted, which were classified into three categories: **stage when disease was not clearly understood**, **stage when being told the diagnosis**, and **self-isolation for having epilepsy**. Hereinafter, categories in sentences are indicated in bold font, sub categories in [ ], and major codes in < >.

**Stage when disease was not clearly understood.** The following experiences from around the time of primary school age were extracted. One subject spoke about while not particularly conscious about her illness, she was <told strongly by mother not to tell anyone> (Case 1). Another described feeling abnormal changes beyond understanding, and was <desperately trying to hide the seizures> (Case 6). Regarding epilepsy, some said that since they did not understand the disease themselves, they were [hiding the disease without telling anyone] (Cases 2, 6 and 7). They felt [themselves different from other children], expressed as feeling <different from other children>, <something abnormal in my body>, and <something strange> (Cases 1, 4 and 7). The diagnosis of epilepsy was <explained (by mother and other people) but did not understand>, <did not understand>, and <made no sense> (Cases 3, 5, 6 and 7). When they heard explanations of the disease, although they thought <"so that’s what it is">, they <had little memory> in some aspects (Cases 1, 2 and 6).

**Stage when being told the diagnosis.** The following experiences from around the time of primary school age were extracted. In school life, the [disease had become known and could no longer be hidden]. They talked about seizure episodes being seen by classmates and friends. The disease that they had been trying to hide all the time became <known by people around me>, <difficult to tell a lie>, <the truth came out>, and <could hide no longer> (Cases 1, 3 and 5). The situations at the time when they [finally understood the diagnosis] were extracted as follows: <finally knowing the diagnosis>, the <perception of epilepsy was different>, they <did not think that the disease was so serious>, <the disease can be so mild>, and it was <not the serious type known by the general public> (Cases 1, 4, 5 and 6). One subject described the situation as: although <I visited hospital, I did not know about the disease or medications> (Case 7). In other subjects, the disease was explained as hypotension and anemia, and the diagnosis was being told by parents around the time of junior high school to senior high school graduation (Cases 1 and 7).

**Self-isolation for having epilepsy.** One subject described being in an <isolated> situation, and epilepsy and seizures were experiences that <can only be understood by someone affected> (Case 3). One described <no good memories> during childhood (Case 7). Others spoke of entering a stage of [isolation, my life as an odd person], <not telling friends about the disease>, <can’t talk about the disease even to good friends>, <can’t be bothered with poor explanation>, and <feeling fed up> (Cases 2, 5 and 7). One subject described an inclination to disclose the disease in her heart: <wishing to tell all now, rather than being exposed later> (Case 7).
Experiences of acquiring a positive attitude to life under treatment

Forty codes were extracted for experiences of acquiring a positive attitude to life under treatment; including stage of attempt to adjust to disease, stage of rehabilitation of the mind, and appreciation to people and looking forward to the future.

Stage of attempt to adjust to disease. For experiences during junior high school period, a subject talked about [incorrect knowledge on medication and disease] such as <may be all right to adjust medications by myself> (Case 4). A subject who had a history of pediatric asthma thought that antiepileptic drugs were like drugs for controlling asthma attacks. She mentioned that she <did not think seriously> about epilepsy and drugs, and actually adjusted the medications by herself without causing serious seizures (Case 4). Likewise, several subjects <did not think seriously> about the disease (Cases 1, 2, 4 and 5). Those who had seizures repeatedly described their experience as <only I myself know what it’s like> (Cases 3 and 7). One subject said that she herself and others did not have enough understanding of epilepsy. <Unlike nowadays, epilepsy was not a familiar word in the society> (Case 6). For job hunting activities, one subject talked about the experience of <disclosing the medications (AEDs) that she was taking> rather than being found out late at the workplace (Case 5). She talked about repeatedly undertaking job-finding tests, revealing his disease and drugs in some, and hiding them in others (Case 5). For one subject, since epilepsy was diagnosed in childhood, <at that time having a driving license seemed so far away>. However, at the time of job-hunting, when others were getting driving license, she felt that in reality <not having a driving license causes troubles> (Case 4).

Rehabilitation of the mind. Using expressions such as <gradually> and <recently>, some subjects talked about encounters with specialists in hospitals or attending doctors: [the drugs worked, I became relieved], and [with increasing social contact (with people at work), I grew up naturally into an adult] (Cases 2, 3 and 7). After becoming high school student, some subjects <gradually came to accept> the disease, and <gradually the drugs worked> and they began to feel relieved physically and mentally (Cases 3 and 7). Some subjects spoke about <increasing social contact> outside school, and <friends who can talk about anything> made them [grow up naturally into an adult]; even when feeling bad, they were <able to change mood>, and felt <different from the past> (Cases 2 and 3). Some spoke of: a change in attitude to [face challenge of the disease], feeling themselves <different from the past>, <seriously thinking about curing by themselves>, <firm commitment to get cured>, and <will definitely get cured> (Cases 1, 3 and 4). When they began to work, one subject managed medications <using self-designed methods>, <so as not to forget taking drugs> (Case 4). Regarding living with epilepsy, another subject recounted that [epilepsy and drugs have become a part of my life] because it is important to <take medications> in everyday life, but <epilepsy can be managed by taking medications> and <the disease can be over-
come> (Case 7). Others described <encouragement (from mother) that God is always there>, and encounter with someone who helped them find an employment (<if you are motivated from your heart>) (Cases 5 and 7). In addition, young persons who found occupation or part-time job with help from various people remarked that <things in life gained through work are important> and work became their <rehabilitation of communication>. Since [work is rehabilitation of the mind], they <desire to continue working> (Cases 3 and 7).

Appreciation to people and looking forward to the future. A subject described her mother and family as people <to whom she can express herself without restraint> and a place where she can return to and feel relieved (Case 4). Others expressed [appreciation to people around them]: <thankful to doctors of this hospital>, <encouraged (by people around them) that God is always there> while she failed in various attempts of job-hunting, and <thankful (to persons at work) for giving me the opportunity>” (Cases 3 and 5). About the future, one subject expressed [gratitude to parents, family and people around her], her <wishes to cherish her parents> and <to get a driving license as soon as possible>, that she <will talk about the disease to her future companion>, <wishes to give birth to a child> <for the sake of her parents>, and <wish to continue working> (Case 7). Also, she gave the following messages to children with the same disease: <epilepsy can be managed by taking medications>, <the disease can be overcome>, <enjoy life, live life to the full>, <do your best with a positive attitude>, <be alive!> (Cases 4 and 7).

Discussion
The subjects of this study were adolescent women with childhood-onset epilepsy referred to the epilepsy center. Using semi-structured interview with an interview guide according to Burnard’s method, we attempted to explore in depth the psychological status of adolescent women with epilepsy [15-17]. This interview and qualitative analysis of the contents were conducted to analyze the psychological state of the young woman with epilepsy from the standpoint of the nurses. We analyzed the contents narrated by these subjects about their experiences from childhood to the present on their lives as well as anxiety and hope of the future. In Japan, there is no report analyzing the interview contents of adolescent women with epilepsy. However, it is very important for medical personnel to understand the psychological conditions during the life stages of love, marriage, pregnancy, the childbirth of young women with epilepsy.

Characteristics of experiences of young women with childhood-onset epilepsy
The subjects of this study were seven female patients who were receiving treatment from epilepsy specialists. Onset was during infancy (aged 3 year) in 1 patient (Case 2) and during school ages in the other 6 patients (aged 8-17 years). The onset age was defined as the age of epilepsy diagnosis by a doctor, and was also the time when the patient was told about the disease. Due to the requirement of follow-up observation for a diagnosis of childhood epilepsy and
the difficulties in arriving at a definitive diagnosis, there may be deviation between the age of diagnosis and the actual onset age.

Two patients had frontal epilepsy. The actual seizure frequencies of these patients were 5-6 times a year in Case 1 and 5-6 times a year in Case 3. However, during the interview, both patients used the expressions “many times” and “frequently”. Patients perceived a higher seizure frequency than it actually was. In one patient who lost consciousness in the public, she was shocked when being told about it afterwards.

One case (Case 2) had generalized seizures with infantile onset. Seizure frequency was once a year, and the patient narrated that “seizures were not too frequent”. She expressed anxiety over convulsive seizures without prior warning sign and relapses, and could not talk to others about her disease, following her mother’s advice.

Cases 4 to 7 had right temporal lobe seizures. Their seizure frequencies varied, and seizures occurred during sleep. One patient was able to predict seizure occurring from warning signs since childhood. Another did not think her disease was that serious.

There was only 1 case of generalized seizure, and therefore it was not possible to compare epilepsy types, seizure symptoms, or seizure frequencies by statistical analysis. From the interview contents, perception of disease severity at the childhood stage tended to vary among patients. In addition, whether other people in school or workplace found out about the disease, and later disclosure of their disease may impact the psychological process.

In the interview contents, mother was mentioned the most among family members. The fact that the subjects are women may also account for the strong bond with their mothers from puberty to adolescence. The strong bond between mother and child as described above may create a situation that interferes with the child’s verbal expression of seizure symptoms as perceived by herself and her explanations to others. Therefore, in pediatric patients, training to talk about symptoms and seizure experiences in their own words is important. If a child can recognize the changes of her body from childhood and express them in her own words, this will facilitate information sharing in later school life and active educational intervention of ways to cope with seizures.

In their experiences during school age and adolescence, teachers at school and school nurses were rarely mentioned. Moriguchi and Nagai [18] conducted a study in collaboration with schools, and found that parents found it difficult to report and explain epilepsy to schools. Epilepsy differs from other diseases with respect to information sharing. Without information provided by the parents, fewer people around the children with epilepsy would understand the disease. A role of nurses may be to act as intermediate for the children who are still too immature to express themselves properly or their families, and facilitate smooth information sharing of symptoms and psychological state.

Experiences of being told as having epilepsy

The average age of epilepsy onset was
around 8 years. As shown in Table 1, Cases 1 and 6 had onset during lower grades of primary school. These children perceived epileptic seizures as something unusual but were not able to understand the diagnosis. However, more than 20 years had passed since they were told of the disease and it is possible that explanations about childhood epilepsy was too complicated in the past.

The subjects experienced being told about epilepsy when they did not know much about the disease, and talked about the changes in relation with the people around them. They were in lower grades of primary school, and still could not understand the meaning of words such as seizures and epilepsy.

When they had seizure in front of friends and classmates, the relationship with friends changed compared to before seizure occurred. In addition, even for children with a diagnosis of childhood epilepsy, the impact of stigma is great. Experience related to social prejudice caused by seizures occurring in public and problem with family acceptance influence the future QOL of people with epilepsy [19, 20].

Furthermore, despite achieving good seizure control, QOL is low in some patients, which may be related to "experiences" in the growth process. Therefore, it is necessary to examine the process of rehabilitation also from the psychosocial aspect [19, 20].

Apart from Case 2, all the other 6 patients were complicated with anxiety disorder or depression. Especially, Cases 4 and 7 with right temporal epilepsy had onset during school age and was treated by pediatricians. At onset, seizure frequency was as high as daily. When they were referred to our center, they were complicated with depression. However, during this interview, both patients expressed their own experiences from onset and were able to narrate calmly. They were probably in the acceptance phase of their disease.

Depression and anxiety disorder in childhood are difficult to diagnose and treat, and may affect QOL beyond adulthood [5]. In this context, Kaneko et al. [21, 22] stated the importance of selecting drugs that do not adversely affect “cognitive function”, which hinders patients from fulfilling social roles.

Adolescence is an important stage to consider the future, and acquisition of identity is a developmental challenge. Their remarks indicate that while adolescents with epilepsy desire to seek help from people around them, they do not want others to know their disease, and thus are in a state of turmoil and conflict.

Experiences of acquiring a positive attitude toward life under treatment

Adjustment of medications by self-judgment is one of the meaningful actions toward self-management in the growth and development stage of an adolescence. In the present study, subjects described their experience of "incorrect knowledge such as may be all right to adjust medications by myself", sometimes resulting in failure such as severe seizures. It is important to realize that such actions originate from independence of adolescents and create opportunities to educate correct knowledge on medical care while respecting their feelings and intensions.

At the stage of thinking about career, the subjects talked about "those drugs (AEDs) in job hunting, and that job hunting failed
because of their disease. However, despite the hesitation and resistance of disclosing that they were taking AEDs, the subjects did not give up job hunting activities and repeatedly took employment examinations.

In addition, some recounted that while acquiring a driving license was not so important during childhood when epilepsy was diagnosed, after adolescence, driving license was often a condition for employment and not having one limited the scope of activities in social life. They spoke of the inconvenience of not able to go out alone or move freely, the troubles to other people and at the workplace, and their desire to obtain a driver's license if permitted in the future.

**Stage of rehabilitation of the mind**

Case 3 with right frontal -temporal lobe epilepsy and Case 7 with right temporal lobe epilepsy talked much about their experience of gradually entering the stage of psychological stability. Both patients had partial seizure with secondary generalization, and over 10 years had passed since onset in adolescence. Accompanying the transition to adulthood, their seizures were controlled. These patients were at the stage in which they felt psychological recovery.

When the subjects became adolescents, the phase of rapid physical growth had passed. They used the expression of “growing up naturally into an adult”. After epileptic seizures were controlled, they felt relieved physically and mentally.

These developments probably led to the attitude of [facing challenge of the disease]. The subjects used expressions of feeling physically and mentally <different from the past> and realizing their own mental development. For a young person with epilepsy, having a job leads to discipline in daily life and has a positive effect on the management of epilepsy.

Transition from adolescence to young adult is an important period for social rehabilitation, and experiences related to work promote rehabilitation of the mind to face the challenge of the disease with a positive attitude. Confidence of their capability of self-management based on accurate guidance on drug taking and the attitude to face and accept the disease without being impatient resulted in [epilepsy and drugs becoming a part of life].

**Appreciation to people and looking forward to the future**

At this stage (Table 2), Cases 4 and 7 who had right temporal lobe epilepsy complicated by depression were talked most eloquently about their future. The fact that they were able to achieve a positive psychological state was the result of appropriate AED therapy and psychological therapy provided by warm and enthusiastic doctors and other health professionals.

A subject expressed that mother and family who cared for her since childhood were the ones who understood her most, and <to whom she can express herself without restraint>. In this study, a subject spoke what she wanted to do things for her mother and all those who cared for her, because she was [thankful to parents, family and people around her]. She wished to cherish her parents, wished to give birth to a child for the sake of her parents, and wished to continue working. As a woman who has
reached childbearing age, she talked about marriage and childbirth, not for herself, but to reassure her parents and others who have been worried about her.

**Implications for nursing**

Advances in AED for the treatment of epilepsy are expected to increase the number of people whose seizures are controlled and who require social support in the future. In addition, social prejudice against epilepsy is gradually being rectified, and patients’ perception of their own illness also has undergone significant changes.

However, in medical care for childhood epilepsy, information provided by medical personnel including support staff remains inadequate. Provision of accurate information to important supporters during childhood is important, and interventions of medical personnel and nurses with specialized knowledge are urgently needed. In this study, the subjects mentioned various social supports while talking about their experiences of the relationship with mother and family. In addition, some young persons achieved smooth control of seizures, found jobs, and contributed greatly to the society. These subjects received early treatment, and early intervention through transitional medical care during adolescence or young adulthood.

The important points were understanding of the disease and medication management. During the important stage of growth and development up to higher grades of primary school, to receive proper AED therapy and achieve control of epileptic seizure are extremely important. In the future, it is necessary to identify the roles of transitional medical care and nursing from a novel point of view; for example, clinical care at epilepsy outpatient department and care for patients receiving long-term outpatient care and their families.

For adolescents, events related to medication management probably arise from their desire of self-management and not wanting to trouble the parents. These events may represent a challenge in the growth process, and interventions should take into account the timing of adolescents’ independence from mother and guardians. For nurses involved in epilepsy care, their roles are to promote transition based on mental development from adolescence to young adulthood and the stage of rehabilitation, to implement transition, and to coordinate with other health personnel to facilitate transition. Other roles of nurses are to provide specialized information for understanding and accepting the disease, as well as for their positive future. Furthermore, as a provider of specialist knowledge and information for patients and their families who are going to receive long-term medical care from specialized clinics or hospitals, the new roles of nurses as a coordinator of daily living (different from those of psychiatric social worker) should be examined.

**Limitations of the present study and future issues**

The limitation of this study was that we studied only seven female patients who are undergoing medical treatment at an epilepsy center. Young women with epilepsy may have different views from male patients regarding outlook for the future beyond adolescence and early adulthood. In this
study, because of the small number of subjects, the effects of disease severity and seizure types on the transition of psychological state could not be analyzed. Future studies should include a larger number of cases and subjects with different upbringing environment, and analyze the effects of gender difference, age difference, and differences in epilepsy severity and seizure type on psychological process. Studies should also examine the support needed to meet the expectations of psychological aspects and social roles accompanying growth and development, and interventions to facilitate transition from childhood to young adulthood.

Conclusion

The purpose of this study was to clarify the psychological status from the narratives of life experiences of women with childhood-onset epilepsy, and to examine how to provide better nursing care of patients with epilepsy.

1. In the interview contents, mother was mentioned most frequently among family members. The contents of childhood experience were classified into 6 categories: (1) stage when disease was not clearly understood, (2) stage when being told the diagnosis, (3) stage of self-isolation for having epilepsy, (4) stage of attempt to adjust to disease, (5) stage of rehabilitation of the mind, and (6) stage of appreciation to people and looking forward to the future.

2. For women with epilepsy and their families, maintaining good drug compliance was an important personal experience for the child and their parents.

3. The effects of epilepsy type and seizure frequency on the psychological process could not be studied in the present study. However, during the interviews, even patients who had high seizure frequencies and complicated by anxiety disorder or depression talked eloquently about their positive psychological state.

4. In providing nursing care for women with epilepsy and their families, it is necessary to understand the psychological state of the patients, provide specialist information oriented toward their future life stage, and coordinate with other health personnel to facilitate their AED treatment.

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References


[4] Iwasa H, Iwaki H, Kikuchi T, Kudo S,


[21] Kaneko S. Epilepsy class. Tokyo:
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<th>Seiko Yamanouchi, et al.</th>
<th>Psychological status of young women with epilepsy</th>
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</table>
### Table 1. Summary of clinical background and treatment.

<table>
<thead>
<tr>
<th>Case No.</th>
<th>Age (yrs)</th>
<th>Classification of epilepsy</th>
<th>Seizure type</th>
<th>Symptoms</th>
<th>EEG findings</th>
<th>AED</th>
<th>Duration of seizure control (year)</th>
<th>Treatment duration (years)</th>
<th>Narrated seizure experience</th>
<th>Origin of referral</th>
<th>Seizure frequency</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>28</td>
<td>Partial seizure</td>
<td>secondarily</td>
<td>Clonic convulsions of right hand and leg</td>
<td>Spike-wave complex in left frontal areas</td>
<td>ZNS CBZ CLB LEV</td>
<td>1.5</td>
<td>20</td>
<td>Didn't know what happened in the beginning. Was shocked to hear afterwards that sometimes I passed out and foamed in the mouth. Realized I was different from other children, and the way I fell and amnesia were different. During junior high school, fell multiple times. Also experienced big seizure, biting my own lips.</td>
<td>Pediatrician</td>
<td>5~6/year</td>
</tr>
<tr>
<td>2</td>
<td>25</td>
<td>Generalized seizure</td>
<td>(tonic-clonic seizure)</td>
<td>Suddenly falling down forward and showing clonic seizures in right chest. No myoclonic seizure</td>
<td>No abnormal EEG</td>
<td>VPA</td>
<td>5</td>
<td>22</td>
<td>Found out about seizure when fell down while in junior high school. Seizures are not so frequent. Fell again and now taking medication.</td>
<td>Brain surgeon at onset followed by pediatrician</td>
<td>1/year</td>
</tr>
<tr>
<td>3</td>
<td>No</td>
<td>Partial seizure</td>
<td>(frontal lobe epilepsy)</td>
<td>Concentration difficulty, feeling of losing consciousness. Also showing photosensitivity</td>
<td>Spike-wave complex in right frontal and temporal regions</td>
<td>LTG TPM</td>
<td>4.5</td>
<td>14</td>
<td>Seizures happened many times. I began to accept the situation. Seizure happened at school, so other people knew about it. Fell in front of other people. Pay attention to warning signs of seizure and take care. Could not talk or even say a word about it.</td>
<td>Neurologist</td>
<td>5~6/month</td>
</tr>
<tr>
<td>4</td>
<td>19</td>
<td>Partial seizure</td>
<td>(temporal lobe epilepsy)</td>
<td>Twitching of eyelids followed by loss of consciousness.</td>
<td>Spike-wave complex in right temporal region.</td>
<td>CBZ CLB</td>
<td>≥5</td>
<td>7</td>
<td>Felt something strange with my body at around 6th grade in primary school. Was always dweil, and felt it was not usual. Around second grade of junior high school, had a big seizure, so big that it shocked everyone.</td>
<td>Pediatrician</td>
<td>1~2/day</td>
</tr>
<tr>
<td>5</td>
<td>25</td>
<td>Partial seizure</td>
<td>(temporal lobe epilepsy)</td>
<td>Nausea followed by aural automatism. No convulsion</td>
<td>Spike-wave complex in right temporal and occipital areas</td>
<td>CBZ</td>
<td>2.5</td>
<td>8</td>
<td>Was at home, and suddenly didn't know what day of the week it was. Felt sick and sometimes felt blank in the head. People around me often asked whether I was all right because I looked blank or tired. Always forget things. Have no convulsion. Didn't think I was that serious.</td>
<td>Neuropsychiatrist</td>
<td>3~5/month</td>
</tr>
<tr>
<td>6</td>
<td>37</td>
<td>Partial seizure</td>
<td>secondarily</td>
<td>Feeling sick and unpleasantness in the chest</td>
<td>Spike-wave complex in right temporal lobe</td>
<td>ZNS CBZ LTG</td>
<td>2</td>
<td>29</td>
<td>First seizure was at around age 8, was sick in front of parents. At first, seizures occurred frequently, at night or day. They finished after about a minute if I didn't notice. night. Since I could sense seizure coming, I could crouch.</td>
<td>Pediatrician at onset followed by neuro-psychiatrist</td>
<td>1/month</td>
</tr>
<tr>
<td>7</td>
<td>22</td>
<td>Partial seizure</td>
<td>secondarily</td>
<td>Weakness of left hand, involuntary movements of right eyelid, tonic seizure of left hand.</td>
<td>Spikes in left temporal region</td>
<td>ZNS CLB LEV Relapse in July 2015</td>
<td>12</td>
<td>4~5 week</td>
<td>Eyes and hands were twitching, felt strange. Was never been told about seizure by people around me. When working, felt some kind of numbness and sensed something wrong. It was a feeling that I felt before, then, the same hand, the same eye, it was a relapse, unbelievable!</td>
<td>Pediatrician</td>
<td>4~5 week</td>
</tr>
<tr>
<td>8</td>
<td>Depression</td>
<td>Anxiety disorders</td>
<td></td>
<td></td>
<td></td>
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<td>9</td>
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<tr>
<td>10</td>
<td>Depression</td>
<td></td>
<td></td>
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</tbody>
</table>

AED: antiepileptic drugs, ZNS: zonisamide, CBZ: carbamazepine, CLB: clobazam, LEV: levetiracetam, VPA: valproate, LTG: lamotrigine, TPM: topiramate, LTG: lamotrigine,
### Table 2. Categories, subcategories and major codes extracted from interview data.

<table>
<thead>
<tr>
<th>Category</th>
<th>Subcategory</th>
<th>Major codes</th>
<th>Case No.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Stage when disease was not clearly understood</td>
<td>[Hiding the disease without telling anyone]</td>
<td>&lt;Told strongly by mother not to tell anyone&gt;, &lt;Desperately trying to hide seizure&gt;</td>
<td>1</td>
</tr>
<tr>
<td></td>
<td>[Myself different from other children]</td>
<td>&lt;Felt something abnormal in my body&gt;, &lt;Felt something strange&gt;, &lt;Different from other children&gt;, &lt;Did not understand&gt;</td>
<td>4, 7, 1</td>
</tr>
<tr>
<td></td>
<td>[Disease not well understood]</td>
<td>&lt;Made no sense&gt;, &lt;Was explained by someone, but did not understand&gt;, &lt;Thinking &quot;now I know&quot;&gt;, &lt;Had little memory&gt;</td>
<td>2, 6, 7, 3, 6, 5, 7</td>
</tr>
<tr>
<td>Stage when being told the diagnosis</td>
<td>[Disease could no longer be hidden]</td>
<td>&lt;Known by people around me&gt;, &lt;difficult to tell a lie&gt;, &lt;The truth came out&gt;, &lt;could no longer hide&gt;, &lt;Finally knowing the diagnosis&gt;</td>
<td>3, 5, 1, 5</td>
</tr>
<tr>
<td></td>
<td>[Finally understood the diagnosis]</td>
<td>&lt;The perception of epilepsy was different&gt;, &lt;Did not think that the disease was so serious&gt;, &lt;The disease can be so mild&gt;, &lt;Not the serious type known by the general public&gt;</td>
<td>4, 5, 1, 4, 5, 6</td>
</tr>
<tr>
<td>Self-isolation for having epilepsy</td>
<td>[Isolated, my life as an odd person]</td>
<td>Partial seizure (temporal lobe epilepsy)</td>
<td>3</td>
</tr>
<tr>
<td></td>
<td>[Can’t be bothered with explanation]</td>
<td>&lt;No good memories&gt;, &lt;My life changed&gt;, &lt;Not telling friends about the disease&gt;, &lt;Can't talk about the disease even to good friends&gt;, &lt;Can't be bothered with poor explanation&gt;, &lt;Just kept quiet&gt;, &lt;Feeling fed up&gt;, &lt;Wishing to tell all now, rather than being exposed later&gt;</td>
<td>7, 2, 7, 5</td>
</tr>
<tr>
<td>Stage of attempt to adjust to the disease</td>
<td>[Incorrect knowledge on medications and disease]</td>
<td>&lt;Incorrect knowledge such as, may be all right to adjust medications by myself&gt;, &lt;Did’n’t think that the disease was serious&gt;, &lt;Unlike nowadays, epilepsy was not a familiar word in the society&gt;, &lt;Disclosing the medications (AED) that she was taking&gt;, &lt;Not having a driving license causes troubles&gt;, &lt;At that time having a driving license seemed so far away&gt;, &lt;So that I don't cause troubles to others&gt;</td>
<td>4, 1, 2, 5</td>
</tr>
<tr>
<td></td>
<td>[Causing trouble to others]</td>
<td>&lt;Grading social contact&gt;, &lt;friends who can talk about anything&gt;, &lt;Growing up naturally into an adult&gt;, &lt;able to change mood&gt;, &lt;Different from the past&gt;, &lt;if you are motivated from your heart&gt;, &lt;Talk about my disease to someone whom I can talk to&gt;, &lt;Seriously thinking about curing by myself&gt;, &lt;will definitely get cured&gt;, &lt;Firm commitment to get cured&gt;, &lt;So as not to forget taking drugs&gt;, &lt;using self-designed methods&gt;, &lt;Taking medications&gt;, &lt;Things in life gained through work are important&gt;, &lt;wish to continue working&gt;, &lt;Rehabilitation of communication&gt;</td>
<td>3, 2, 3, 4, 4, 7</td>
</tr>
<tr>
<td>Stage of rehabilitation of the mind</td>
<td>[The drugs worked, I became relieved]</td>
<td>&lt;Gradually came to accept&gt;, &lt;gradually the drugs worked&gt;, &lt;Increasing social contact&gt;, &lt;friends who can talk about anything&gt;, &lt;Growing up naturally into an adult&gt;, &lt;able to change mood&gt;, &lt;Different from the past&gt;, &lt;if you are motivated from your heart&gt;, &lt;Talk about my disease to someone whom I can talk to&gt;, &lt;Seriously thinking about curing by myself&gt;, &lt;will definitely get cured&gt;, &lt;Firm commitment to get cured&gt;, &lt;So as not to forget taking drugs&gt;, &lt;using self-designed methods&gt;, &lt;Taking medications&gt;, &lt;Things in life gained through work are important&gt;, &lt;wish to continue working&gt;, &lt;Rehabilitation of communication&gt;</td>
<td>3, 7</td>
</tr>
<tr>
<td></td>
<td>[Grow up naturally into an adult]</td>
<td>&lt;Gradually came to accept&gt;, &lt;gradually the drugs worked&gt;, &lt;Increasing social contact&gt;, &lt;friends who can talk about anything&gt;, &lt;Growing up naturally into an adult&gt;, &lt;able to change mood&gt;, &lt;Different from the past&gt;, &lt;if you are motivated from your heart&gt;, &lt;Talk about my disease to someone whom I can talk to&gt;, &lt;Seriously thinking about curing by myself&gt;, &lt;will definitely get cured&gt;, &lt;Firm commitment to get cured&gt;, &lt;So as not to forget taking drugs&gt;, &lt;using self-designed methods&gt;, &lt;Taking medications&gt;, &lt;Things in life gained through work are important&gt;, &lt;wish to continue working&gt;, &lt;Rehabilitation of communication&gt;</td>
<td>3, 7</td>
</tr>
<tr>
<td></td>
<td>[Facing challenge of the disease]</td>
<td>&lt;Gradually came to accept&gt;, &lt;gradually the drugs worked&gt;, &lt;Increasing social contact&gt;, &lt;friends who can talk about anything&gt;, &lt;Growing up naturally into an adult&gt;, &lt;able to change mood&gt;, &lt;Different from the past&gt;, &lt;if you are motivated from your heart&gt;, &lt;Talk about my disease to someone whom I can talk to&gt;, &lt;Seriously thinking about curing by myself&gt;, &lt;will definitely get cured&gt;, &lt;Firm commitment to get cured&gt;, &lt;So as not to forget taking drugs&gt;, &lt;using self-designed methods&gt;, &lt;Taking medications&gt;, &lt;Things in life gained through work are important&gt;, &lt;wish to continue working&gt;, &lt;Rehabilitation of communication&gt;</td>
<td>7</td>
</tr>
<tr>
<td></td>
<td>[Epilepsy and drugs become a part of life]</td>
<td>&lt;Grading social contact&gt;, &lt;friends who can talk about anything&gt;, &lt;Growing up naturally into an adult&gt;, &lt;able to change mood&gt;, &lt;Different from the past&gt;, &lt;if you are motivated from your heart&gt;, &lt;Talk about my disease to someone whom I can talk to&gt;, &lt;Seriously thinking about curing by myself&gt;, &lt;will definitely get cured&gt;, &lt;Firm commitment to get cured&gt;, &lt;So as not to forget taking drugs&gt;, &lt;using self-designed methods&gt;, &lt;Taking medications&gt;, &lt;Things in life gained through work are important&gt;, &lt;wish to continue working&gt;, &lt;Rehabilitation of communication&gt;</td>
<td>4, 4, 7</td>
</tr>
<tr>
<td></td>
<td>[Work is rehabilitation of the mind]</td>
<td>&lt;Gradually came to accept&gt;, &lt;gradually the drugs worked&gt;, &lt;Increasing social contact&gt;, &lt;friends who can talk about anything&gt;, &lt;Growing up naturally into an adult&gt;, &lt;able to change mood&gt;, &lt;Different from the past&gt;, &lt;if you are motivated from your heart&gt;, &lt;Talk about my disease to someone whom I can talk to&gt;, &lt;Seriously thinking about curing by myself&gt;, &lt;will definitely get cured&gt;, &lt;Firm commitment to get cured&gt;, &lt;So as not to forget taking drugs&gt;, &lt;using self-designed methods&gt;, &lt;Taking medications&gt;, &lt;Things in life gained through work are important&gt;, &lt;wish to continue working&gt;, &lt;Rehabilitation of communication&gt;</td>
<td>3, 7</td>
</tr>
<tr>
<td></td>
<td>[Thank people around me]</td>
<td>&lt;Thankful to doctors of this hospital&gt;, &lt;Thankful to someone for giving me the opportunity&gt;, &lt;Encouraged by someone that God is always there&gt;, &lt;For the sake of parents&gt;, &lt;wish to cherish my parents&gt;, &lt;Being told that I am their precious one&gt;, &lt;To whom I can express myself without restraint&gt;, &lt;Will talk about the disease to her future companion&gt;, &lt;Wish to get a driving license as soon as possible&gt;, &lt;Wish to give birth to a child&gt;, &lt;Epilepsy can be managed by taking medications&gt;, &lt;The disease can be overcome&gt;, &lt;Enjoy life, live life to the full&gt;, &lt;Do your best with a positive attitude&gt;, &lt;Be alive!&gt;</td>
<td>3, 5, 7</td>
</tr>
<tr>
<td>Appreciation to people and looking forward to the future</td>
<td>[Can overcome epilepsy]</td>
<td>&lt;Thankful to doctors of this hospital&gt;, &lt;Thankful to someone for giving me the opportunity&gt;, &lt;Encouraged by someone that God is always there&gt;, &lt;For the sake of parents&gt;, &lt;wish to cherish my parents&gt;, &lt;Being told that I am their precious one&gt;, &lt;To whom I can express myself without restraint&gt;, &lt;Will talk about the disease to her future companion&gt;, &lt;Wish to get a driving license as soon as possible&gt;, &lt;Wish to give birth to a child&gt;, &lt;Epilepsy can be managed by taking medications&gt;, &lt;The disease can be overcome&gt;, &lt;Enjoy life, live life to the full&gt;, &lt;Do your best with a positive attitude&gt;, &lt;Be alive!&gt;</td>
<td>7, 7, 4, 7</td>
</tr>
</tbody>
</table>