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ORIGINAL ARTICLE

Lived experiences of adult patients with moyamoya disease: A qualitative case study

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Abstract

Aim: To understand the daily lived experiences of adult moyamoya disease patients.

Methods: This qualitative study involved a purposive sample of 14 adult moyamoya disease patients diagnosed after 19 years or older at one university hospital in Seoul. Interviews conducted with patients included open-ended questions about the experience of living with moyamoya disease. The data were analyzed using Colaizzi's seven-step method, which derives the theme.

Results: Participants' experiences were divided into three themes and eight sub-themes. "Having an unexpected disease that suddenly struck my life" refers to confusion and depression due to the diagnosis of the unexpected illness; "being occasionally anxious about the illness" describes patients' uncertainty about the disease and worrying about passing the disease on to their child; and "living with the disease by going through the disease experience" refers to the process of accepting and adapting to the illness.

Conclusions: The findings provide a better understanding of the life changes and lived experiences of adult patients with moyamoya disease. Nurses should consider various aspects when providing care to adult moyamoya disease patients.

KEYWORDS

adaptation, adult, life change events, moyamoya disease, qualitative research

1 | BACKGROUND

Moyamoya disease is a rare, progressive, cerebrovascular occlusive disease characterized by occlusion or stenosis of internal arteries in angiography and compensatory arterial collateral network like a puff of smoke (Baba, Houkin, & Kuroda, 2008; Festa et al., 2010). It is highly prevalent in persons of Asian descent, especially the Japanese, Korean, and Chinese (Huang, Guo, Shi, Yang, & Rao, 2017; Scott & Smith, 2009). The prevalence of moyamoya disease was 10.3 per 100,000 people in the Hokkaido district, Japan, in 2006 (Baba et al., 2008). In Korea, the prevalence of moyamoya disease was 9.1 per 100,000 people in 2008 (Im et al., 2012). There is no recent report with exact statistics for the incidence of moyamoya disease in the western hemisphere, but a previous report explains that the incidence of moyamoya disease in the west is lower than that in Asians (Huang et al., 2017). In the recent years, as various ethnic groups have been living together in different countries, the disease has been observed worldwide, including the United States and Europe (Scott & Smith, 2009).

Based on the age of onset, moyamoya disease can be classified into two groups: pediatric moyamoya disease, onset before 18 years of age, and adult moyamoya disease, onset after 18 years of age (Festa et al., 2010).

Pediatric moyamoya disease was prevalent in the past; however, advancements in cerebral angiography, magnetic resonance imaging/magnetic resonance angiography, and brain check-ups have enabled the diagnosis of asymptomatic moyamoya disease in adults, and those diagnosed with asymptomatic moyamoya disease have gradually increased (Ahn et al., 2014; Baba et al., 2008). Based on the clinical characteristics of patients with moyamoya disease, it can be categorized as ischemic or hemorrhagic. Transient ischemic attacks can result in decreased consciousness, seizure, stroke, headache, and cognitive impairment (Fujimura, Bang, & Kim, 2016; Scott & Smith, 2009). Unlike pediatric moyamoya disease, adult moyamoya disease is hemorrhagic in nature rather than ischemic, which can be associated with poor outcomes such as cognitive dysfunction (Shang et al., 2018). Moreover, the survival rate for adult moyamoya disease was lower than that of pediatric moyamoya disease (Ahn et al., 2014). Further, the incidence of the disease peaks during 30–40 years (Fujimura et al., 2016), when patients are actively involved in social activities. Thus, attention should be paid to adult patients even without clinical symptoms, to ensure they can perform their daily activities.

Although studies on the genetic and environmental factors of moyamoya disease have been conducted, its etiology is still unknown (Scott & Smith, 2009). Treatment aims to prevent cerebral ischemia and reduce the risk of intracerebral hemorrhage. Operative methods include superficial temporary artery-to-middle cerebral artery bypass and indirect revascularization. With regard to pharmacotherapy, antithrombotic drugs such as aspirin, heparin, and argatroban are used for mild and asymptomatic moyamoya disease. Supportive treatment includes drugs for controlling blood pressure and seizures. However, data on treatment methods and their effectiveness are lacking (Ge et al., 2017; Shang et al., 2018). Therefore prevention through identification of the cause, early diagnosis, disease progression, or treatment is difficult.

Recent studies of adult moyamoya disease have focused on disease characteristics, pathogenesis, and treatment methods (Ding et al., 2018; Ge et al., 2017; Kwon et al., 2014; Shang et al., 2018). Only a handful of studies have investigated the quality of life and related factors in adult patients (Lee, 2018; Su, Hai, Zhang, Wu, & Yu, 2013), and patients' experiences after diagnosis are yet to be reported.

There is a growing body of nursing knowledge on patients with cerebrovascular diseases (Tulek, Poulsen, Gillis, & Jönsson, 2018; Van Dijk, Hafsteinsdóttir, Schuurmans, & de Man-van Ginkel, 2018); however, it is difficult to apply this knowledge to adult patients with moyamoya disease in the same way as that for patients with cerebrovascular diseases. This is because the pattern of adult moyamoya disease is often asymptomatic. In addition, given the differences in life cycle between pediatric and adult patients with moyamoya disease, there are limitations in understanding the experience of adult moyamoya patients (Ball, Steinberg, & Elbers, 2016; Lee, Rivkin, Kirton, DeVeber, & Elbers, 2017).

The purpose of the study was to explore lived experiences of patients with adult moyamoya disease by exploring their feelings after its diagnosis, daily life changes, and adaptation to the disease.

2 | METHODS

2.1 | Study design

The research design was a qualitative case study approach as proposed by Stake (1995), to understand the issue within the context of lived experiences of adult moyamoya disease patients following their diagnosis. Among the different types of qualitative research methodologies, qualitative case studies are widely used to gain an in-depth understanding of a case and examine how and why a phenomenon occurs by collecting and analyzing data on specific cases. A case study provides a better understanding of the interrelationships among present and past experiences, situational factors, and the phenomenon from the participant's viewpoint (Hyett, Kenny, & Dickson-Swift, 2014; Stake, 1995). According to qualitative case methodology, we tried to derive the meaning of lived experience of moyamoya disease patients through descriptive phenomenology.

2.2 | Participants

The inclusion criterion for participation was diagnosis of adult moyamoya disease (International Classification of Diseases - 10 code 167.5) at least 6 months earlier. In general, when a patient is diagnosed with moyamoya disease in adulthood, it is called adult moyamoya disease (Festa et al., 2010). Therefore, we included participants who were 19 years or older.

Patients receiving outpatient services at a university hospital in Seoul, South Korea, were selected and purposeful sampling was conducted to include factors such as the time period after diagnosis, patients' sociodemographic backgrounds, and disease adaptation in daily life. Exclusion criteria were the presence of psychiatric disorders or other neurological diseases.

Although sex differences in the causes of adult moyamoya disease have not been clearly identified, previous studies (Baba et al., 2008; Scott & Smith, 2009) have shown a higher prevalence rate in women than men. Therefore, we included more female participants (11 female patients and three male patients). Data were collected until themes reached saturation; that is, no new themes or concepts could be extracted from the interview data.

2.3 | Data collection

Data were collected through individual interviews from January to April, 2018. Each interview was conducted in a private room at the outpatient department of the hospital or a separate space at the participants' workplace. Every interview lasted for 30–60 mins and was conducted in Korean. After obtaining the participant's consent, the interviews were audio-recorded using the researcher's smartphone recorder. The interview questions were open-ended, which allowed participants to freely describe their disease adaptation processes and experiences in daily life after being diagnosed with moyamoya disease. The participants were asked about their experiences with adult moyamoya disease. Examples of specific questions include, "How did you feel after being diagnosed with moyamoya disease?", "How has your daily life changed after being diagnosed with moyamoya disease?", and "How have you adapted to the disease after being diagnosed?"

During the interview, the researcher carefully listened to and tried not to affect the participant's responses. The researcher observed participants' nonverbal responses and expressions, and recorded them after the interview. After each interview, the research team transcribed the interview verbatim by listening to the audio files several times.

2.4 | Ethical considerations

The study protocol was approved by the Institutional Review Board (IRB) of the Yonsei University Health System (IRB No. 4–2017-0956). Before starting the interview, participants were explained the purpose of the study, study methods, and information on the recording and confidentiality of interviews. They were also assured of their anonymity and that their data would be used for research purposes only; participants could withdraw from the study at any time. Written informed consent was obtained from all participants. The data were only accessible to the research team and kept in a secured computer.

2.5 | Data analysis

Each recorded interview was professionally transcribed. For publication purposes, the interview was translated from Korean to English by a professional translator, and reviewed by the research team. Colaizzi's seven-step process of descriptive phenomenology was applied to the collected data. (a) Each recorded interview was repeatedly listened to and the transcripts were read to gain a feeling for them. (b) Significant statements were extracted from each description related to the experience with adult moyamoya disease. (c) Meaning was derived from each significant statement related to the analysis of experience with adult moyamoya disease. (d) All the formulated meanings were categorized into clusters of themes. (e) All emergent themes were integrated into an exhaustive description. (f) The phenomena being analyzed were identified and described. (g) The findings were confirmed with participants (Holloway & Galvin, 2013).

2.6 | Rigor and trustworthiness

The rigor of the study was evaluated based on the following criteria proposed by Guba and Lincohn (1989): credibility, fittingness, auditability, and confirmability. To ensure the credibility of the data, sufficient response time was given, and a comfortable interview atmosphere was created for data saturation. After each researcher analyzed the recorded data, their opinions were integrated through discussions among the research team. Credibility was achieved by receiving confirmation from three participants (i.e., member checking) that the interpretations of their responses by the researchers were in keeping with what they intended to say. The results of the study were also reviewed by nurses experienced in providing care to adult moyamoya disease patients. Fittingness is a criterion for the applicability of the findings of the present study to other similar settings, and in this study, it was achieved by describing the participants and the context of each participant in detail. With respect to auditability, the research process while analyzing the data was described in detail, and meaning, theme formation, and quotations were presented. Confirmability is a criterion for the neutrality of the study, and it was ensured through the study's credibility, fittingness, and auditability.

3 | RESULTS

A total of 14 adult moyamoya disease patients participated in this study. The mean age of the participants was 43.3 years (range = 29–69 years). The number of years

since the diagnosis of moyamoya disease ranged from 0.8 to 17 years (mean number of years = 7.3). Seven participants were employed, and 12 were married. All participants were diagnosed with moyamoya disease when they visited the hospital because of facial, hand, and limb paralysis; loss of consciousness; and transient ischemic attacks. Two patients underwent direct or indirect vascular anastomosis, and 13 took medication. Based on the content analysis, three themes and eight sub-themes pertaining to the daily life experiences of adult patients following the diagnosis of moyamoya disease, were derived (Table 1).

3.1 | Theme 1: Having an unexpected disease that suddenly struck my life

Participants stated that they visited the hospital after suddenly experiencing unusual physical symptoms and were diagnosed with a disease with a strange name, called moyamoya disease. Two sub-themes were derived in this theme: "having my body feeling different than usual," and "having an unfamiliar disease with a strange name."

3.1.1 | Sub-theme1: Having my body feeling different than usual

Participants perceived their health condition to be usually not bad, but stated that they suddenly experienced speech problems, numbness in their hands, headache, and dizziness. In the early stage, they deemed these symptoms minor and temporary, but after repeatedly experiencing these symptoms, they visited a hospital. Some participants visited an emergency room due to transient ischemia, paralysis, and headache resulting from cerebral infarction or intracerebral hemorrhage, after which they were diagnosed with moyamoya disease.

I went to the amusement park, and suddenly I could not stand because one of my legs felt numb and weak. I thought that something was wrong. The next day, I could not speak because my tongue did not move. I couldn't pronounce my kids' names properly. So, I went to the hospital and got diagnosed. (Participant 2).

I went to the emergency room because of a headache while working. The doctor said that I had a higher intracranial pressure and prescribed medicine for reducing the intracranial pressure and headache. After I went home, the headache did not subside. So I went to another hospital, and heard that it was cerebral hemorrhage. So, I underwent a CT and was admitted to the ICU. At that time, I didn't know that it was a disease. Later, I was told that the moyamoya disease led to cerebral hemorrhage. (Participant 14).

TABLE 1 Themes and sub-themes of the lived experiences of adult moyamoya disease patients

Themes	Sub-themes
Having an unexpected disease that suddenly struck my life	• Having my body feeling different than usual • Having an unfamiliar disease with a strange name
Being occasionally anxious about the illness	• Being psychologically withdrawn in everyday life • Being anxious about my future health rather than my present health • Being worried about passing the disease on to my children
Living with the disease by going through the disease experience	• Gradually accepting and learning about the disease • Being indifferent to the disease by acknowledging it • Using this illness as an opportunity to become a new me

3.1.2 | Sub-theme 2: Having an unfamiliar disease with a strange name

As moyamoya disease is a rather rare disease, some participants felt "something hitting my head," "lost," and "hopeless" when they were diagnosed. Most of the participants stated that it was the first time they heard of the disease and that it was difficult to comprehend the severity of the disease due to lack of information. Through healthcare providers' explanations and information from the Internet, they found there is no medication to halt the progression of the disease or reverse the narrowing of the artery; they also learned about the possibility of serious complications, including death, due to cerebral hemorrhage and cerebral infarction. Thus, the participants were anxious about their treatment direction and health management and the future in general.

When I heard "moyamoya" for the first time, I was like, "what?" At first, I did not know about moyamoya disease. But after searching about it, I realized that it is a serious disease, and my heart sank and I felt hopeless. (Participant 4).

When I was diagnosed with moyamoya disease, I felt like something hit my head. Doctors explained that the blood vessels to the brain has dried out. However, I did not know what that meant and thought that I might die right away. I felt like being sentenced to death. (Participant 9).

3.2 | Theme 2: Being occasionally anxious about the illness

Participants reported they were often worried about the recurrence and aggravation of symptoms and the possibility of early death, despite living a mostly normal life. In addition, according to the information provided by the healthcare providers and various online sources, they learned and became concerned that other family members may also have moyamoya disease and particularly, the disease might be inherited by their children. In this theme, the following three sub-themes were derived: "being psychologically withdrawn in everyday life," "being anxious about my future health rather than my present health," and "worrying about passing on the disease to my children."

3.2.1 | Sub-theme 1: Being psychologically withdrawn from everyday life

Most participants felt psychologically withdrawn and engaged in limited daily activities, such as intense exercise or domestic labor, because they were anxious that the symptoms may reappear. Participants felt psychologically withdrawn because they could not do the things they were able to do without any restrictions prior to being diagnosed with the disease.

I used to exercise very often. But now I exercise less. After being diagnosed, I have become less confident. I think the oxygen used for my brain might be used for other purposes if I exercise... so I don't exercise intensely any more. I only do (light) exercises, like walking. (Participant 1).

3.2.2 | Sub-theme 2: Being anxious about my future health rather than my present health

Most of the participants stated they were anxious about their future health rather than focusing on the current symptoms, as they did not have any physical symptoms at present. They mentioned they worried about the possibility of cerebral infarction, cerebral hemorrhage, or dementia if their health worsens, although they were fine at the time of the interviews. Some participants worried about dying and its effect on their families. Some experienced panic disorder and depression, as they were anxious about the recurrence and aggravation of symptoms, and the side effects of the medication.

My life will be shortened anyway, and later, there will be brain damage due to decreased blood flow to the brain. I am worried whether I can continue my job and whether I will develop conditions like dementia earlier. (Participant 2).

As there are no symptoms, I sometimes forget about this disease, However, I still have anxiety that the symptoms may reappear and worsen. (Participant 8).

3.2.3 | Sub-theme 3: Being worried about passing the disease on to my children

Among the participants, female participants expressed anxiety about the inheritance of the disease. In particular, mothers of young children expressed anxiety and concern because they worried that their children may suffer from this rare disease. Some participants even made their children undergo a genetic test. One participant stated that all of her family members underwent medical examinations given the possibility of having the same disease. She thought that her parents felt guilty that they passed on the moyamoya-related gene to her. In addition, one participant said that her brother was worried that he may develop the disease.

I am afraid that my children may have moyamoya disease because of me... So my first child underwent a test, because I was scared. I was so relieved when the doctor said that he would not get moyamoya disease. (Participant 5).

What makes unmarried people worry the most is whether they can get married and have children and what makes people with children worry the most is whether their children may have the same disease. I think this disease runs in the family. (Participant 9).

3.3 | Theme 3: Living with the disease by going through the disease experience

Participants described the uncertainty of the disease owing to its unknown cause and lack of treatment; however, they expressed that they were trying to understand the disease. They imparted a positive meaning to living with the disease, and adopted a new lifestyle. Although moyamoya disease is incurable, some participants stated they could live longer with better disease management and the disease not being different from other chronic diseases. Most participants said that they had extreme anxiety at the beginning of the diagnosis. However, as they did not have physical symptoms over time, nor did they visit outpatient clinics often, they became indifferent to the disease. In this theme, the following sub-themes were derived: "gradually accepting and learning about the disease," "being indifferent to the disease by acknowledging it," and "using this illness as an opportunity to become a new me."

3.3.1 | Sub-theme 1: Gradually accepting and learning about the disease

All participants expressed the disease as an "incurable disease" given its identified cause and lack of treatment. Some participants considered it "a death penalty" but they started to gradually accept and learn about the disease through explanations from healthcare providers, advice from other patients with moyamoya disease, self-help groups, and their own experiences.

Without symptoms, patients with moyamoya disease are the same as normal people. As there are no symptoms, I don't manage my health, just as usual. Unless my doctor says I need surgery, which means that my brain condition is very poor, I continue my daily life as I normally do. But I know that when the blood flow is insufficient, the symptoms will reappear. (Participant 8).

I sometimes talk over the phone with another patient who I befriended at the hospital. I told her that she should think positively. At first, she had a tough time, but now I can see that her personality has changed a lot in a positive way. (Participant 11).

3.3.2 | Sub-theme 2. Being indifferent to the disease by acknowledging it

Most of the participants experienced extreme anxiety, depression, and despair at the beginning of the diagnosis, but because they did not have any physical symptoms over time, they gradually tended to forget about their disease in their everyday life. Some participants said that they tried to intentionally forget about the disease because they believed that worrying about the disease would be harmful to their health. Most participants said they recognized the presence of their disease only when they had to visit the hospital for an outpatient appointment. Some working participants stated they also controlled their situation to reduce work stress by transferring to a different department within the company and changing their job. Further, in terms of interpersonal relationships, they stated they minimized conflict and consciously controlled their emotions.

As some time has passed since I was diagnosed, I forget about it most of the time. My doctor said that it is best not to get stressed. So I'm trying to live by forgetting that I have moyamoya disease. (Participant 5).

I get stressed often and tend to swallow my anger. Now I'm trying not to be stressed as much as possible and, because of the disease I am trying even more. I would not make any stressful situation (for myself). (Participant 1).

3.3.3 | Sub-theme 3: Using this illness as an opportunity to become a new me

Participants regarded the disease as a ticking time bomb. However, all participants were able to come out of their shock and despair, and started managing their health by exercising, drinking moderately, quitting smoking, and trying to think positively. They stated that although the disease may be incurable, it is possible to manage the disease through appropriate healthcare measures and a positive mindset.

I have to live with my disease for the rest of my life, so I try to be optimistic. (...) I used to drink a lot. If I didn't have this disease, I would have become a drunkard without caring about my health, so I may have been knocked down by other diseases. I made up my mind— if I manage my health well, I will not die. I will just accept it and think of it as a good opportunity. (Participant 1).

Before being diagnosed with moyamoya disease, I fought with my husband a lot. When I had a lot of stress, I couldn't control myself. However, since I became sick I thought, "let's live freely." This thought made me relax —I should not get stressed, so I have become more tolerant. My life has become much better. (Participant 14).

4 | DISCUSSION

This study explored the experiences of adult moyamoya disease patients when they were diagnosed with the disease and how they adapted to it in their daily lives. In the theme, "having an unexpected disease that suddenly struck my life," participants who had not experienced any health abnormality prior to the diagnosis visited the hospital after experiencing unusual physical symptoms. This theme shows the experiential process of the patients after being diagnosed with a disease they had never heard of. Participants stated having had physical symptoms before diagnosis, such as slurred speech, headache, dizziness, hyperventilation, vomiting, and inability to move their limbs. They deemed these symptoms temporary and sudden. Our findings are similar to those of previous studies, where the initial clinical manifestations were ischemic symptoms and intracranial hemorrhage. The symptoms were also similar to those of cerebral infarction (Horne, Lincoln, Preston, & Logan, 2014).

Most of the participants had not heard of the disease before they were diagnosed and were unaware of the severity of the disease. However, through an online search, they recognized the seriousness of the disease and experienced anxiety and fear. Generally, in the case of a rare, incurable disease with a strange name, which is not known to the general public, it has been reported that

patients experience confusion and fear (Von der Lippe, Diesen, & Feragen, 2017). In particular, some participants experienced panic disorder and insomnia due to severe anxiety and fear while accepting the disease, which led to limitations in their lives. In addition, this unexpected disease appears similar to post-traumatic stress disorder, and the mental responses to it include anxiety, fear, feelings of helplessness, loss of control, and trauma in severe cases (Cordova, Riba, & Spiegel, 2017; Tedstone & Tarrier, 2003).

The theme, "living with the disease by going through the disease experience," indicates adult moyamoya patients' adaptation to the disease over time, whereby patients independently found the cause of the disease and developed a way to manage their health on their own. Patients with rare, incurable diseases often become experts in their diseases, actively collect information, and are sensitive to current health information (Von der Lippe et al., 2017), similar to the characteristics of adult moyamoya disease patients. By offering information on health behaviors and the range of activities, healthcare providers should help the patients continue their daily lives.

Participants experience depression and anxiety regarding the fact that moyamoya disease is incurable. However, as they have been learning about and living with the disease, they perceive their life positively and manage their health. They did not experience serious symptoms after the acute phase had passed and acquired information about the disease. Therefore, they were able to change their attitudes toward the disease and life as the disease progressed. Most participants considered the disease as part of their lives and tried to have a positive mindset and lead a healthy life by quitting smoking and drinking moderately. These findings are similar to those of a previous study, in which patients with stroke recognized the importance of their health and strived for a healthy life after experiencing the disease (Mavaddat et al., 2018).

Most participants in this study were asymptomatic. This experience is different in patients with other rare diseases or cancer. In case of other rare diseases, there are direct clinical symptoms (Von der Lippe et al., 2017), and in general, patients with cancer have clinical symptoms and receive chemotherapy. However, the patients in the present study visited the outpatient clinic about once every 6 months or a year; thus, they tended to forget about the disease and became neglectful of their health care. Therefore, healthcare providers should continuously monitor patients' healthcare behavior and provide interventions to ensure that patients care about their health despite the absence of tangible symptoms.

Regarding care for incurable diseases, quality of life should be considered because patients live with the disease for the rest of their life, and it is necessary to provide nursing care based on the life cycle (Vegni, Fiori, Riva, Giovannini, & Moja, 2010). Among the participants in this study, women of childbearing age expressed great concern pertaining to marriage, birth, and passing on the disease to their children. Male participants in their 30s worried about exercise and health deterioration due to stress at work.

4.1 | Limitations of the study

Participants in this study comprised those who received outpatient services after their acute phase. Therefore, this study is limited in understanding the disease experience of adult patients in the acute phase. We recruited participants recommended by healthcare providers, and selected those who were willing to share their experiences with us. These characteristics of participants might influence their attitudes toward the disease differently from those of patients who were unwilling to participate in the study. Additionally, participants were recruited from a single university hospital in a metropolitan city, and experience of the participants may differ from those of people who could not be treated in the same way. However, this is the first qualitative study of adult moyamoya disease patients. Thus, it is significant in that it provides an understanding of lived experience in everyday life after diagnosis.

4.2 | Implications of the study

The findings of this study showed that adult moyamoya disease patients experienced physical and psychological changes in everyday life. The need for interventions for adult moyamoya disease patients, considering their physical and psychological aspects. For physical health, education on lifestyle changes, prevention of symptom recurrence, and coping with symptoms should be provided to improve patients' health management. With respect to the psychological aspect, there is a need for nursing interventions that take into consideration patients' shock, fear, and anxiety and help patients to positively accept the disease. Even if the patients are asymptomatic, a management program is necessary to help patients manage their health better. In addition, personalized education and counseling according to gender, age, and life cycle should be provided to improve quality of life.

5 | CONCLUSION

The purpose of this qualitative case study was to understand the daily lived experiences of patients with adult moyamoya disease. Interviews with 14 participants revealed the following themes: "An unexpected disease that suddenly struck my life," "Being occasionally anxious about the illness," and "Living with the disease by going through the disease experience." These themes show that patients experienced anxiety due to their unfamiliarity with the name of the disease, lack of information on the disease, abnormal physical symptoms, and stress. However, they were also growing accustomed to living with the disease and tried to live a healthy life with a positive mindset. Our findings provide a better understanding of the disease adaptation of adult moyamoya disease patients, and thus contribute to the development and application of interventions that consider the patient's life experiences. In addition, based on the results of this study, follow-up studies of anxiety intervention, health promotion programs, and personalized counseling by life cycle are needed for adult patients from the early stage of diagnosis.

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DISCLOSURE

The authors declare no conflict of interest.

AUTHOR CONTRIBUTIONS

M.C., G.W.R., and Y.S.Y. contributed to the study design, data collection, and analysis; M.C. and G.W.R. drafted the manuscript; M.C. critically reviewed the manuscript and supervised the whole study; K.W.S. critically reviewed the manuscript for important intellectual content. All the authors read and approved the final manuscript.

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