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Original Article

The process of life adjustment in patients at onset of glioma who are receiving continuous oral anticancer drug: A qualitative descriptive study

Koji Amano ^{a,*}, Kumi Suzuki ^b^a Faculty of Nursing, Doshisha Women's College of Liberal Arts, Kyoto, Japan^b Faculty of Nursing, Osaka Medical College, Osaka, Japan

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ABSTRACT

Objective: Patients with malignant gliomas have to adjust their daily lives because of the threat of impending death and declining abilities. Thus, clarifying the process of life adjustment in such patients would help them lead a normal life. To clarify the process of life adjustment in patients at the onset of glioma, who continuously receive oral anticancer drug.

Methods: The study institution consisted of two designated cancer centers. Semi-structured interviews were conducted with 10 patients, and the data were analyzed using the Modified Grounded Theory Approach of Kinoshita (M-GTA).

Results: As a core category representing the process of life adjustment in patients at the onset of glioma, “trials and errors for self-fulfillment even in a limited lifespan” was extracted. Patients began “seeking information about the unfamiliar life-threatening disease,” and “imaging their uncertain lives after the disease and the resulting disability” while “conducting repeated trials and errors to establish coping methods according to their abilities.” When facing difficulties in such trials and errors, they reported “losing self-confidence due to unexpected limitations.” However, they regulated their feelings by “resigning themselves to their unchangeable reality.” Contrarily, as “functional improvement enhanced their motivation to recover,” they attempted to promote functional recovery and organized their daily lives in “fulfilling their desires in their limited lifespan.”

Conclusion: The process of life adjustment in patients with malignant gliomas involved identifying a way of living despite limited lifespan. To ensure appropriate nursing care for patients at the onset of glioma, it is important to help them establish coping methods in accordance with their abilities.

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1. Introduction

Patients with glioma as a kind of brain tumor account for 26.6% of the entire population of patients with brain tumors in Japan [1]. The estimated annual incidence is approximately 4200 people [2]. Gliomas are more likely to result in death of the patients after disturbed consciousness due to growth of the tumor and cerebral edema. Even if death can be avoided, patients may be forced to change their lifestyle after the treatment due to residual symptoms such as convulsive seizures and higher brain dysfunction including

speech, cognitive, and vision impairments.

Brain tumor patients with suspected gliomas based on clinical evidence and imaging results receive surgical treatment for the purpose of definite diagnosis and resectioning of the tumor. As a result, patients with a definitive diagnosis of malignant glioma ranging from Grade III to Grade IV receive radiotherapy combined with chemotherapy (oral anticancer drugs; temozolomide) [3]. In addition, continuously, patients with malignant glioma receive temozolomide for two years after radiotherapy-temozolomide for prevention of recurrence [4]. Still, patient prognosis after the treatment is poor, and the median time to recurrence of Grade IV (Glioblastoma) can be as short as 6.2–7.5 months [5,6]. The 5-year survival rate of patients with malignant glioma is 23.4% for Grade III (anaplastic astrocytoma) and 7% for Grade IV (glioblastoma) [7]. Accordingly, once people develop malignant glioma, they are more

* Corresponding author. 97-1 Kodo Minami Hokotate, Kyotanabe-shi, Kyoto, 610-0395, Japan.

E-mail address: soccersoccersoccer0121@yahoo.co.jp (K. Amano).

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likely to experience recurrence in a short term and their condition may progress, commonly leading to death.

Patients who have been diagnosed with glioma would be told of the severity and seriousness of the disease and would thus suffer due to the threat of malignant brain tumors and being confronted with death [8]. Furthermore, patients experience forgetfulness and failure caused by higher brain dysfunction and do not realize that they have troubled the people around them [9]. After discharge, patients face themselves and find they are different people than in the past. Malignant glioma tends to occur in middle aged people who play a central role at home and in the workplace. Therefore, patients with malignant glioma often experience the feeling that their conventional life and self-presence have collapsed entirely [10]. In other words, patients with malignant glioma suffer from impaired function associated with various disorders and potential death, and are forced to adjust their current life because their conventional life has collapsed.

Previous studies determined the actual situation of quality of life (QOL) of patients with malignant glioma [11], the association between QOL and fatigue [12], and explorations of the patients' way of life [13]. However, there have not been any previous studies focusing on the patients' way of adjustment to life after discharge, despite the fact that patients with malignant gliomas have a shorter time to recurrence. By determining the adjustment process of the life of patients with malignant glioma, it may be possible to suggest specific supportive content for their life after discharge as well as timing of such support, which may allow the patients to adjust their own lives early on during the short time to recurrence.

Therefore, this study aims to examine the way that patients with malignant glioma adjust their life after discharge and use this to create a suggestion for nursing care that promotes the adjustment process for patients at the onset of malignant glioma who continue oral anticancer drug.

2. Methods

2.1. Study design

This is a qualitative descriptive study using the Modified Grounded Theory Approach of Kinoshita (M-GTA) [14–16]. In the M-GTA, data-based analysis is conducted to generate a substantive theory and is suitable to a region that is characterized by process-like phenomenon of the study participant within the limited range [14]. The phenomenon that is clarified in this study is a series of processes that patients adjust in their life after they have been diagnosed with glioma, and has process-like characteristics. In addition, considering that the data were limited to the patients at onset of glioma who were receiving continuous oral anticancer drug after discharge, an analytical procedure with M-GTA was thought to be suitable for our study.

2.2. Definitions

According to a report by Amano et al. [17], life consists “not only [of] personal daily life, but also [of] a multilayered compilation of the person's identity that has been continuously built for many years, with the core consisting of personal desires or goals as well as their relationship with society and their behavior with other people.” Using this as a foundation, in our study, life is defined as including role performance in society, relationships with others, and management of disease and treatment. For the purposes of this study, we define adjustment of life as patients' coping with various events in their life caused by disease and treatment.

2.3. Study institutions

The study institution consisted of two designated cancer centers where craniotomies for tumor resections have been performed in at least 10 patients with glioma per year.

2.4. Participants

The study participants were defined as “patients at onset of glioma who were diagnosed with malignant glioma after a craniotomy for tumor resection and underwent radiotherapy combined with oral anticancer drug.” The patients who met all of the following criteria were selected: a patient who (1) was discharged at least one month prior, (2) had received oral anticancer drug since discharge up to the present date, (3) was less than 75 years and older than 20, and (4) can communicate verbally. We asked the physicians in charge of medical care and those engaging with outpatients in the institutions studied to choose candidates who could be interviewed in the study. The candidates were informed of the purpose of this study verbally and in the written form, by the researchers who had no conflict of interest with the study candidates. Among these candidates, the patients who provided their consent were included in this study.

2.5. Data collection

The first author collected the data by conducting a semi-structured interview based on the interview guide and surveying the medical records. The first author is a teacher at the university, has experience as a male nurse in a neurosurgery ward, and had received training in qualitative research during his master's course. After we obtained each patient's consent, the contents of the interview were recorded with an IC recorder, and the verbatim record of the contents was prepared on print media and also used as data. His observations of the patient's facial expression, attitude, and others during the interview were recorded in a notebook to be used as reference material for analysis. An information sheet was provided to each of the participants to explain the purpose and contents of this study verbally and in written form, ask them for their cooperation, and obtain their consent. The interview was conducted in a private room to ensure privacy during each patient's waiting time for medical examination, using the interview guide prepared by the researchers. The interviews were conducted once per participant, and each interview took approximately 40 min. The contents of the interview guide included the questions: “During hospitalization, how did you think about the life after discharge?”; “How the patient thought and dealt with the changes in their life before and after onset of disease?”; “How do you imagine your future life, and what are you doing to lead your desirable life?” The demographic characteristics of the participants were defined as age, occupation, symptoms, and the detailed explanation of disease provided by a physician, and were collected from the participants' medical records after we obtained the permission of the physicians in charge of medical care and the nursing director of the relevant outpatient department in the study institutions.

2.6. Data analysis method

In data analysis, the verbatim records of the interviews were used as data and the procedures of the M-GTA were used. In the analytical procedures of M-GTA, an analysis theme is established before data analysis. Kinoshita explained that “an analysis theme was to indicate the direction that would be clarified by the person by an analysis” [15]. We would collect data based on the study theme and establish and adjust the analysis theme while

confirming all the collected data. Our study's analytic themes was defined as “the series of processes and incidents encountered by patients from the time of diagnosis with glioma to the current treatment period, as well as how the patients accepted, acted upon, and adjusted their lives according to these incidents.” In addition, Kinoshita explained that “data collection would end when we reached saturation (i.e., there was no further concept, category, [or] relationship between categories to be added in the analysis process)” [16]. In our study, we judged that the data had achieved saturation when data collection from ten participants was completed, and therefore, we ended data collection.

The data were analyzed according to the following procedures (1) to (8). (1) Chose and carefully read the data of the participants who provided discussion about our study's analytic themes. (2) Extracted the relevant descriptions from participant discussions related to our study's analytic themes. (3) Interpreted the extracted description to understand what it implied for participants and generated a concept. Prepared one worksheet per concept including the definition of the generated concept and the specific examples. (4) In consideration of the cases with generated similar or opposite concepts, generated the next concept while continuously comparing them. (5) The data collected from the viewpoint of generated concepts were confirmed. The data which were judged as specific examples of the generated concept were added to the field of “specific example” on the analysis worksheet. (6) Confirmed the relationship between the generated concepts and generated categories. (7) Examined the mutual relation among the categories and prepared a relationship diagram and storyline. (8) Generated one core category to summarize the multiple original categories.

2.7. Trustworthiness

We applied strategies for ensuring trustworthiness [18] throughout the study. To enhance credibility, we adapted research methods that have been well established in Japan. We promoted an early familiarity with the culture of the participating organizations, and enhanced informant honesty guaranteeing voluntary participation. We confirmed the accuracy of the data by having the members check whether the captured articulations matched what the informants intended. In addition, the actual situations that have been investigated and the contexts that surround them were described in detail. The first author conducted all the analyses and discussed the interpretation and completeness of the data with the second author who was a specialist in cancer care. Furthermore, the cancer care specialists were repeatedly committed to peer review using the generation method of concept and categories, along with assessments of the adequacy of and relationships between the categories. Transferability was enhanced by describing the number of organizations taking part in the study and their locations, as well as the number of participants involved in the data collection process, the data collection method used, the duration of the interviews, and the data collection period. To enhance dependability, we described the research design and implementation and how the data were collected.

2.8. Ethical considerations

This study was performed after obtaining the approval of the ethical committee of Osaka Medical College (Nursing 28–1933) and the ethical committee of the study institution. The participants were informed of the purpose and method of this study, the guarantee of voluntary participation in this study, the right to withdraw from the study, the protection of their personal data, and the consideration to mental and physical burden both verbally and in written form. Participants then provided their consent to

participate in this study in written form. In consideration of the participant's mental and physical burden during the interview, we established a system to provide follow-up in the clinical department when the participant had mental or physical hardship.

3. Findings

3.1. Summary of the participants

There was no participant who refused to cooperate with this study, resulting in a total of 10 participants (4 men and 6 women), who were introduced by the physicians in charge of medical care and those engaged in outpatient care in the institutions studied (Table 1). The mean age was 46.3 years (the youngest participant was 30 years old; the oldest participant was 63 years old). Five of the participants had an occupation and seven of the participants were married. The mean period between diagnosis and interview was one year 11 months. Nine of the participants had disorders and symptoms. The participants experienced disorders including paralysis and memory decline, as well as symptoms including sleepiness, convulsions, and fatigue after taking oral anticancer drugs. Interview was conducted one time per participant and the mean interview time was 37.1 min.

3.2. Explanation and specific examples of the categories

A total of 19 concepts were generated and classified into seven categories (Table 2).

3.2.1. Seeking information about the unfamiliar life-threatening disease

This category indicates that patients, who initially cannot understand the disease itself immediately after glioma is diagnosed by the physician, gradually notice the seriousness of the disease that threatens their life by investigating the disease via the internet and books and finding the symptoms and disorders of persons with same disease.

“At first, I could not understand the disease. And I was optimistic about it. (text omitted) Recently, I was able to look it up on the internet, etc. and I found that the disease is very serious.”[ID: I]

“I'll be devastated if I lose movement in all four limbs and I cannot move by myself in the future. (text omitted) I'll be unconscious; a brain tumor will be terrible.”[ID: C]

3.2.2. Imagining their uncertain lives after the disease and the resulting disability

This category indicates that patients estimate the future instability of their life and are ready for possible dysfunction and physical symptoms once they know the clinical condition of malignant glioma.

“Because I underwent surgery on my brain, I have no idea whether I can work in the same way as in the past after discharge. (text omitted) I was worried until I actually returned to life after discharge because it was only after discharge that I could judge whether I could live like I had prior to admission.”[ID: B]

“The physician told me that I may gain weight or lose my hair. I've begun to experience such symptoms. Although I had an image from scenes I've seen in movies, I haven't yet experienced weight gain, severe nausea, or sudden hair loss.”[ID: J]

Table 1
Participant's characteristics.

ID	Age (Years)	Sex	Employment status	Material status [Number of children]	The period from discharge to participating in this interview	Disorders and Symptoms
A	60	M	Retired	Married [2]	9 months	Facial paralysis, Right-sided weakness
B	40	M	Working	Married [0]	5 months	Mild motor and sensory aphasia, Sleepiness, Feebleness after taking oral anticancer drug
C	40	F	Retired	Married [0]	1 year 2 months	Headache, Left-sided hard of hearing, Declining memory, Visual impairment, Muscle weakness, Constipation, Sleepiness, Hair removal
D	30	M	Working	Married [1]	8 years	N/A
E	60	F	Not working	Married [2]	7 months	Declining memory
F	50	F	Not working	Single	4 years	Feebleness after taking oral anticancer drug, Nausea
G	30	F	Not working	Married [2]	11 months	Hair removal, Feebleness after taking oral anticancer drug
H	30	F	Working	Single	1 year 4 months	Headache, Mood changes, Feebleness after taking oral anticancer drug
I	50	M	Working	Married [3]	2 years 1 month	Occasional convulsions on the left side
J	30	F	Working	Single	5 months	Occasional convulsions, Headache, Feebleness after taking oral anticancer drug, Anorexia

Table 2
Categories and concepts that constitute the process of life adjustment in patients at the onset of glioma, who continuously receive oral anticancer drug.

Category	Concept
Seeking information about the unfamiliar life-threatening disease	Realizing that this is the end of life Increasing fear of losing oneself
Imagining their uncertain lives after the disease and the resulting disability	Exploring the identity of an unfamiliar disease Imagining that life will become unstable as it progresses
Conducting repeated trials and errors to establish coping methods according to their abilities	Preparing for dysfunction and physical symptoms that may occur in the future Identifying what he/she could and could not do Individually taking measures to cope with what one cannot do Consulting a doctor regarding painful symptoms that cannot be managed
Losing self-confidence due to unexpected limitations	Seeking help from people around me for things one cannot do Inability to move the body more than expected due to paralysis or tiredness Experiencing conflict regarding the anticancer drug that one cannot terminate despite wanting to do so
Resigning themselves to their unchangeable reality	Losing confidence because of inability to do what one usually does unconsciously Trying to not think about the disease or disability Reluctantly resigning to the situation that one is placed in
Functional improvement enhanced their motivation to recover	Thinking that one cannot help but accept that the end is drawing near Continuing with rehabilitation
Fulfilling their desires in their limited lifespan	Enhancing motivation as one is able to do what he/she could not do Taking care of oneself without strain Living as one desires for the rest of the life

3.2.3. Conducting repeated trials and errors to establish coping methods according to their abilities

This category indicates that patients determine their own abilities in the face of dysfunction and painful symptoms that impair their life after discharge, seek help from people around them, and figure out possible actions according to their abilities.

"I've tried various ways, but it is hopeless by myself when I cannot remember the name of a person immediately. (text omitted) I leave what I cannot do by myself to my husband. And I praise myself if I can do it by telling myself 'you can do it.'"[ID: C]

"Because I was so sleepy, I consulted my doctor to ask him to change the dosage (I took all doses at night to reduce the dose in the morning). (text omitted) At night, I take the rest of the medicine intended for the morning to control daytime sleepiness as much as possible. However, it doesn't help and I'm still sleepy."[ID: B]

3.2.4. Losing self-confidence due to unexpected limitations

This category indicates that patients experience troublesomeness from the anticancer drug that they cannot terminate despite wanting to do so. Patients also lose their confidence because of their new inability to complete tasks that they used to perform unconsciously while trying various methods for coping with the dysfunction and symptoms that now affect their life.

"Often, I experience that I have no idea why such a thing occurs just after discharge. I lose things even though I'm living normally otherwise. There are many times that I have no idea, which makes me feel depressed."[ID: C]

"I thought that I could do everything by myself and left the hospital. So, I'm stressed because I cannot enjoy my life as there are still many things that I cannot do by myself."[ID: E]

3.2.5. Resigning themselves to their unchangeable reality

This category indicates that patients were concerned about disease, death, and disorder after they were diagnosed with glioma, faced the reality that they could not solve these issues by themselves, and then accepted the situation.

"One of the reasons that I think so is that I watched my parents die early and therefore I have no sense of fear for dying. (text omitted) Even if death approaches, there is nothing that can be done immediately. All I can do is accept it. That's what I think."[ID: B]

"Worrying is a waste of time. Suffering from this disease is unfortunate for me, but I cannot do anything about it. (text omitted) Maybe it is better to focus on positive things and just do the best that I can."[ID: G]

3.2.6. Functional improvement enhanced their motivation to recover

This category indicates that patients can be aware that their ADL and remaining function improves by repeating rehabilitation for dysfunction that affects their life, which enhances their motivation for further recovery of the function.

"I try rehabilitation hard at home when I have time. I do exercise to move the fingers hard. (text omitted) My left-hand swelling has improved by rehabilitation and treatment little by little, so I do my best." [ID: A]

"Although my walking was unstable, I am able to walk smoothly now (through rehabilitation). The distance I can walk has increased little by little, which made me extremely happy just after being discharged. I'm thankful to even be able to trivial things (such as use a kitchen knife)." [ID: C]

3.2.7. Fulfilling their desires in their limited lifespan

This category indicates that patients take care of themselves and live freely and reasonably for the rest of their life after looking back on their past lifestyle through the disease and the trials and errors to find what is convenient in their life.

"I try to rest well to prevent stress. (text omitted) Though I finish work late, I think it may be better not to overdo it." [ID: D]

"Previously, I tended to tolerate things more, but now, I try not to tolerate it." [ID: J]

3.3. Storyline (Fig. 1)

Storyline is explained using one core category and seven categories.

The life adjustment of the patients at onset of glioma who received continuous oral anticancer drug was a process with a core category of "trials and errors for self-fulfillment even in a limited lifespan," which indicated that they utilized trials and errors to find a life-style that allowed them to continue being themselves in their shortened life.

Patients began "seeking information about the unfamiliar life-threatening disease," and "imaging their uncertain lives after the disease and the resulting disability" while "conducting repeated trials and errors to establish coping methods according to their abilities." When facing difficulties in such trials and errors, they reported "losing self-confidence due to unexpected limitations." However, they regulated their feelings by "resigning themselves to their unchangeable reality." Contrarily, as "functional improvement enhanced their motivation to recover," they attempted to promote functional recovery and organized their daily lives in "fulfilling their desires in their limited lifespan."

4. Discussion

The participants in this study could not immediately realize the seriousness of their situation at the time that the physician provided the disease name and were therefore optimistic for their future. However, the participants realized they could be facing the end of their life by seeking information about the unfamiliar life-threatening disease. These results are similar to the report [10] that patients experienced the fear of brain tumors by facing the possibility of dysfunction due to life-threatening cancer in the brain, although they did not regard their disease as serious at the onset because they believed that they would recover completely by resection of the tumor. In other words, it was speculated that the threat of death increased in the participants' process of investigating the disease after disclosure of the disease name because they were unfamiliar with the difference between malignant glioma and

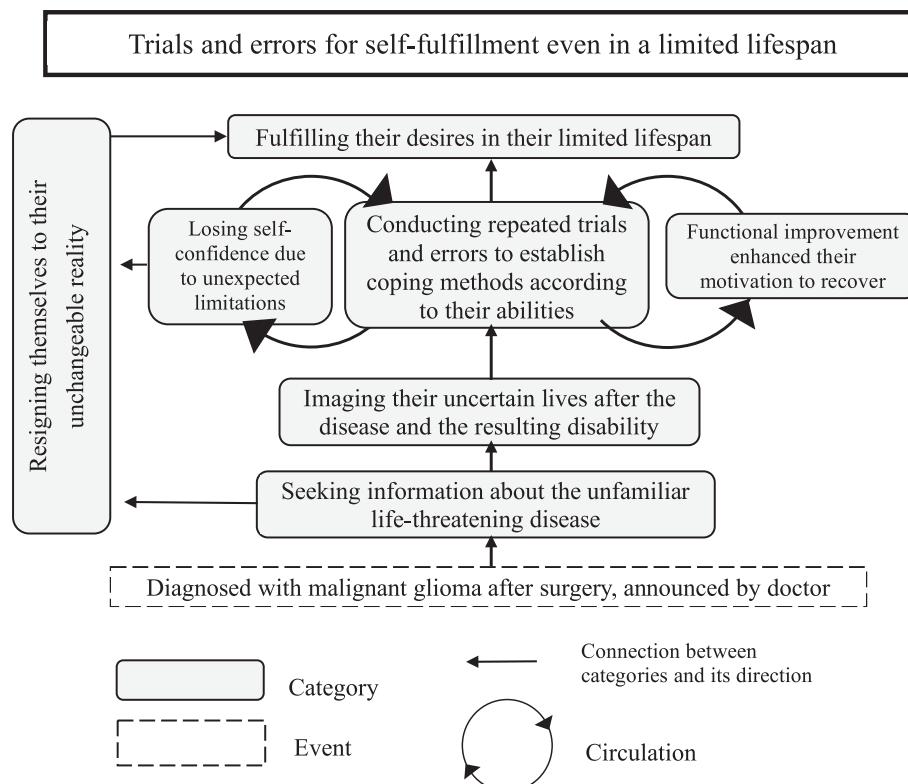


Fig. 1. The process of life adjustment in patients at the onset of glioma, who continuously receive oral anticancer drug.

common cancer. In addition, in patients with malignant glioma, the brain, as the site that regulates thoughts and perception, has been damaged, resulting in a loss of the ability to manage information that had once come naturally [19]. Therefore, they felt fear that they would become somebody other than themselves and that they did not know what would happen in the future. In patients with malignant glioma, even after surgical treatment and radiotherapy combined with oral anticancer drugs, the mean survival time is thought to be only one or a few years, and many of them will experience recurrence [20], which seemed to constantly bring about fear of the increase of their tumor. These results seemed to be a characteristic experience in patients with malignant glioma. Consequently, it was thought to be important to confirm that patients understood unfamiliar glioma and to help them by providing information according to each patient's needs.

The participants imagined their uncertain lives after the disease and the resulting disability based on the information obtained by exploring the identity of the disease. The reason that the participants predicted difficulties in continuing living their current life was due to dysfunction and painful symptoms caused by a damaged brain. According to a report by Sterckx et al. [21], patients with malignant glioma experience anxiety and uncertainty in life. Therefore, it was thought that they became ready for the uncertain life by imagining their future since the course of disease was uncertain. Therefore, it was necessary to help participants obtain a perspective on their life after discharge by confirming their desire regarding their life following discharge, assessing individual clinical condition and dysfunction, and providing continuous care.

In addition, in this study, the patients with malignant glioma conducted repeated trials and errors to establish coping methods according to their abilities so that they could identify what they could and could not do, which is the main method for the patients to adapt to the “new” lives. It seemed that the patients conducted repeated trials and errors to establish coping methods according to their abilities after they could no longer live their usual life because the brain, which controlled the whole body, was damaged by disease and treatment and various disorders occurred. In addition, after discharge, there remain many things that the participants cannot do that they had previously done by themselves since the malignant glioma is progressive and its rate of tumor enlargement is fast [22]. Therefore, participants seemed to have to review past methods and repeat trials and errors to tailor their abilities to new dysfunction and painful symptoms. Identifying what they could and could not do according to their new abilities by repeating trials and errors is thought to be key to seeking help from people around the participants. Generally, Japanese people tend to keep a reserved attitude around others and commonly live life while taking others' feelings into account [23]. Therefore, it is hard for them to ask for support from other people. In our study, participants identified what they could not do and sought help from the people around them, their self-esteem increased. Consequently, nurses must support patients so that they can identify what they can and cannot do. It is also important to adjust the relationship between the participant and the surrounding people so that he/she can be supported when he/she needs.

The distress of patients with glioma includes life-threatening situations due to malignant brain tumor, decrease of self-subsistence, and damaged self-presence associated with their existence [8]. The participants in our study likewise had life-threatening experiences, felt fear that they would not remain themselves, and experienced inconvenience due to dysfunction. Some participants were discharged before they sufficiently imagined their future life and thus experienced a gap between the imagined life after discharge and the reality, which led to lost self-confidence due to unexpected limitations. As compared to patients

with other cancers, patients with glioma in particular required time to think of the association between their discomfort and disease [9] and seemed to have a hard time imagining their future life. Therefore, they could not identify their limitations, embrace things by themselves, or understand that they could not do what they usually did, which seemed to lead loss of self-confidence. It was thought that the participants tried to stabilize their feelings by resigning themselves to their unchangeable reality.

After this resignation, the participants seemed to be able to fulfill their desires in their limited lifespan by utilizing the established method of trial and error to discover their possible actions according to their abilities. Kitazoe [24] reported that patients with cancer can realize value they did not previously notice by looking back on the meaning of their life and their own individuality. Consequently, it was considered important that nurses establish an opportunity for patients to look back on their past life and support them by helping them to realize what they could still do and what they could deal with by obtaining help.

5. Limitations of the study

This study concluded that theoretical saturation was reached at the point at which the data collection for the ten participants was completed. However, there is the possibility that a new concept could be generated by the further accumulation of data collection. Additionally, since this study did not restrict the presence, type, or degree of functional disorder or pain symptoms, the subjects varied greatly from those who barely had any functional disorder to those who showed comorbidity of various disorders such as quadriplegia, speech impediment, and memory disorder. This research indicated that depending on the presence and/or type of functional disorders and pain symptoms, the content of treatment methods and trials and errors differed. For this reason, it is necessary to examine specific nursing assistance that matches the type and degree of the subjects' functional disorders and pain symptoms, thus linking the findings to nursing practices that promote the life adjustment process of glioma patients.

6. Conclusion

In the life adjustment process of patients at the onset of malignant glioma who received continuous oral anticancer drug, the core category was “trials and errors for self-fulfillment even in a limited lifespan.” Patients with malignant glioma explored the real nature of the disease that threatened their existence, imagined their uncertain life, and partook in trials and errors for their way of life in accordance with their ability. After losing self-confidence due to unexpected limitations, they resigned themselves to their unchangeable reality. On the other hand, when their intention of recovery increased with improvements in their abilities, they followed the process and led their desirable life.

Important nursing care was indicated as follows: support patients to minimize the gap between the imagined life after discharge and the real life and help patients establish coping methods according to their abilities by identifying what they can or cannot do.

Conflicts of interest

There is no conflict of interest to declare.

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Appendix A. Supplementary data

Supplementary data to this article can be found online at <https://doi.org/10.1016/j.ijnss.2018.12.009>.

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