


Medical Care-Related Decisions among Patients Diagnosed with Early Stage Malignant Brain Tumor: A Qualitative Study

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Abstract

Medical care-related decision-making among patients with malignant brain tumors has not been sufficiently discussed. This study aimed to develop a framework for understanding patients' experiences in the decision-making process. Semi-structured interviews with 14 patients were analyzed using a grounded theory approach, focusing on their 48 decision-making points. Additionally, interviews with two family members and seven healthcare providers, and participant observations were used to gain contextual insight into patients' experiences. Patients faced decisions while they *struggled in vulnerability* under shock, fear, and anxiety while hoping. Under this context, they showed four decision-making patterns: (1) *led by the situation*, (2) *controlled by others*, (3) *entrusted someone with the decision*, and (4) *myself as a decision-making agent*. Across these patterns, the patients were generally satisfied with their decisions even when they did not actively participate in the process. Healthcare providers need to understand patients' contexts and their attitudes toward yielding decision-making to others.

Keywords

Cancer, patient experience, treatment decision making, qualitative research, grounded theory, Japan

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Background

There has been a growing international debate regarding medical care-related decision-making among patients with cancer, and many studies have discussed the provision of support for patients during the decision-making process (Banning, 2008; Charles et al., 1999; Menard et al., 2012; Petersen et al., 2019; Zafar et al., 2009). Since the early 1990s, three typical decision-making approaches have often been described: paternalistic, informed, and shared. The paternalistic approach is characterized by physician control, the informed approach is characterized by patient autonomy, and the shared approach is characterized by simultaneous interaction between patients and healthcare providers (Charles et al., 2003).

Among these approaches, the shared approach has been recommended worldwide (Charles et al., 1999; Detering et al., 2010; Høglund et al., 2010; Hubbard et al., 2008), including in Japan (Ministry of Health, 2012). The shared approach includes three stages: information exchange, deliberation about alternative options, and reaching agreement on a final decision (Charles et al., 2003). Previous studies

revealed that most patients with cancer preferred the shared approach (Chewning et al., 2012; Tariman et al., 2010), and participation in decision-making has been shown to have positive outcomes such as increased patient satisfaction and decreased family anxiety (Basch, 2017; Detering et al., 2010; England & Evans, 1992). Thus, the discussion regarding the support of medical care-related decision-making has focused on how patients with cancer can make their own decisions.

Among all patients with cancer, those diagnosed with malignant brain tumors in particular need careful decision-making assistance because of their prognosis. The most frequent type of malignant brain tumor is glioma; grade III and IV glioma are defined as malignant, and the prognosis, especially for grade IV glioma, is poorer than that of many other cancer types; the 5-year survival rates for grade III and IV

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glioma are 28.7–54.0% (depending on the type of glioma) and 9.2%, respectively (Narita et al., 2015). Moreover, most patients experience recurrence despite intensive treatment including surgery, chemotherapy, and radiotherapy. There are no established standard treatments after tumor recurrence.

Patients diagnosed with malignant brain tumors need to be supported from an early stage by discussion about their decisions with physicians (Sizoo et al., 2012); however, they may not be sufficiently supported in their decisions because they are often considered as experiencing difficulties in making their own decisions. In particular, cognitive deficits in the early stage of diagnosis, a typical symptom of brain tumors, may cause difficulty with participation in medical care-related decisions (Hewins et al., 2019; Triebel et al., 2009). Some studies have shown high base rates of decisional incapacity in patients with high-grade intracranial tumors (Simon et al., 2014). Therefore, the shared approach among malignant brain tumor patients is more difficult than it is for other cancer patients.

To date, quantitative studies on decision-making among patients diagnosed with malignant brain tumors have shown that the percentage of physicians who knew the preferences of patients diagnosed with malignant brain tumors regarding end-of-life care was much lower than those reported in other cancer types (Abarshi et al., 2011; Sizoo et al., 2012). Another study has shown that physicians underestimated or failed to accurately establish patients' decisional capacity (Entwistle et al., 2004; Scott & Daniel, 2014). While these studies have confirmed the occurrence of decision-making challenges among patients with malignant brain tumors, they failed to clarify which decision-making process would be good for patients with malignant brain tumors.

While many previous studies about decision-making among cancer patients have focused on patients' perspectives (Shin et al., 2017; Smith et al., 2017; Zhang et al., 2017), qualitative studies on decision-making among patients diagnosed with malignant brain tumors have typically focused on the families' experiences of caring for the patients (Flechl et al., 2013; McConigley et al., 2010; Schubart et al., 2008), without exploration of the decision-making experiences of patients themselves. Only a few studies with patients as informants described their feelings about the disease and their care needs (Goebel & Mehdorn, 2019; Halkett et al., 2010; Lobb et al., 2011). A previous study noted patients' difficulties in participating in the decision-making process because of communication difficulties and physical or cognitive deficits (Halkett et al., 2010); however, the study did not reveal how the patients experienced medical care-related decision-making *per se*. Describing patients' perspectives in medical care-related decision-making from an early stage may be helpful for spurring further discussion about decision-making challenges, and developing a framework for the decision-making process using grounded theory may be helpful for providing appropriate support. The aim of this study was to develop a framework for understanding patients'

experience of the decision-making process, using grounded theory and multiple methods of data generation. The specific research questions were "How do patients with malignant brain tumors experience medical care-related decision-making?" and "How does the decision-making experience affect patients' satisfaction with decision-making process?"

Methods

Study Design, Participants, and Setting

We used a qualitative design based on the grounded theory approach in order to develop a framework for obtaining detailed and deep descriptions of patients' experience in the decision-making process. The grounded theory approach enables the development of a comprehensive theory to explain phenomena (Corbin & Strauss, 2015). Participants were 14 patients diagnosed with malignant brain tumors in active treatment, either staying at hospital or visiting an outpatient clinic. We recruited these participants via three physicians who worked as certified neurosurgeons. The inclusion criteria were diagnosis with grade III or IV Glioma, aged over 20 years, ability to converse in Japanese, and the necessary decisional capacity for participation in this study. The recruiting physicians assessed decisional capacity through daily conversation. We included patients regardless of tumor recurrence and type of treatment, and excluded them if the physician considered the interview to be inappropriate or thought they were not ready for the interview due to cognitive compromise or mental illness.

First, the physicians approached the prospective participants and explained to them the purpose and content of the present study. We asked the physicians to recruit participants with various stages of disease. After the physicians received oral consent from participants, we explained the purpose and content of the study in more detail. When consent for participation was obtained, we received their contact information and scheduled an interview. We interviewed 15 participants and analyzed the data of 14 participants. Interview data from one participant was excluded because they were not able to communicate at the time of interview because of illness progression. Participants were recruited from the University of Tokyo Hospital in an urban area of Japan. Interviews took place at a time and location convenient for the participants (the hospital or a room at the university).

Data Collection

Before the interviews, we collected participants' basic information (e.g., diagnosis, time since diagnosis, and type of treatment) from the physicians, with the participants' permission. Data were collected through semi-structured interviews between April 2016 and January 2018. After obtaining some basic information (e.g., age, family structure, marital status), we asked participants to talk freely about their experience of

Table 1. Interview Guide.

For patients
About sociodemographic characteristics
How old are you?
Could you tell me your family structure?
About your experience from the time you knew your disease to the present
When did you know your disease?
How did you feel at that time?
How did you decide the hospital?
What treatment did you receive?
What treatment do you receive now?
How did you decide that?
How do you feel about your choice?
For family members
What is the relationship with the patient?
When did you know patient's disease?
How was the patient when he/she knew the disease?
How did you decide the hospital? What did the patient say about the hospital selection?
How did you decide the treatment? What did the patient say about the treatment?
What did the patient say about their choices?
For healthcare providers
What is the relationship with the patient?
Could you tell me the patient's treatment progress?
Could you tell me how the patient was hospitalized?
How did you discuss treatment decision with a patient or family member?
What did the patient or family member say about the treatment?

medical care-related decision-making, using an interview guide (Table 1).

The data collection and analysis occurred concurrently. We found no new categories after the 11th participant interview; therefore we stopped data collection with altogether 14 participants. The first author interviewed all participants, audio-recorded all interviews, and took fieldnotes. Participants were interviewed twice within 2 to 14 months, depending on their treatment status. Many participants had been recently diagnosed, and there was a possibility for making additional care-related decisions between the first and second interviews. Moreover, data generated from two interviews provided deep insight into patients' feelings about their past choices. There were 24 interviews in total; four participants did not participate in the follow-up interview because their disease had progressed or contact had been lost. Each interview lasted 30–60 min. Prior to data collection, in preparation for the interviews, we observed nurses, physicians, and patients at the hospital to grasp general patients' characteristics, and the nature of communication between patients and medical staff. Fieldnotes were taken during observation. At the time of our observations, most inpatients had been recently diagnosed and were receiving aggressive treatment, which were reflected in the

interviews. For example, we added the interview question "What did you discuss about medical care-related decisions with nurses?" as we observed some patients discussing their decisions with nurses. Fieldnotes contributed to subsequent analyses.

In addition, we interviewed one member each from two families, as well as two physicians and five nurses, using the interview guide (Table 1). We labeled patient participants as "participants," healthcare provider participants as "healthcare providers," and family member participants as "family members." The aim of the additional interviews was to develop a multilateral understanding of participants' conditions, and to contribute to the analysis. The inclusion criterion for healthcare providers was being in charge of participants' in-hospital care; the criteria for family members was being a key person in participants' lives (e.g., parents and children), being older than 20 years, and being able to converse in Japanese. We recruited two physicians directly, five nurses were recruited via the head nurse in the ward, and family members were recruited via the participants. We asked healthcare providers about how they interacted with the participants during decision-making processes.

Data Analysis

We analyzed data extracted from the patients' interviews; other data were used to inform our analysis. Constant comparison, an analytical approach of grounded theory, was used for data analysis (Corbin & Strauss, 2015). First, all interview transcripts were transcribed verbatim by the first author and a transcription company. Then we read the transcripts multiple times and coded line-by-line upon comparing and interpreting various meanings of data. During analysis, we used fieldnotes regarding the situations and body language during the interviews to capture participants' emotions. We sorted and grouped multiple codes to form categories while we also used fieldnotes. In analyzing the data, we recognized that one category, "I (participant) had a choice/did not have a choice," had a distinctive significance in their experience of decision-making. Then we compared the difference between "I had a choice" and "I did not have a choice," in further comparing each decision-making point.

Altogether 48 medical care-related decision points were found in the interviews regarding surgery, radiotherapy, chemotherapy, and hospital selection. We reiteratively read the transcript regarding medical care-related decision points, compared each point, and grouped them loosely at first, focusing on the differences among conditions and their properties, such as the person who decides, decision-making topics, and participants' understanding. Thereafter, we discussed the validity of our grouping several times, and thus developed several patterns. Once we developed the tentative patterns, we explored whether other decision points fit the patterns. If some decisions did not fit any developed patterns, we returned to the data and repeatedly redeveloped patterns.

After grouping decision patterns, we found four patterns that could be explained by two properties. We then explored the conditions that influenced each pattern. We confirmed data saturation by exploring each pattern in depth, identifying its properties under different conditions, and finding no new decision patterns. Finally, we counted the number of occurrences of each decision pattern.

In our analyses, we were particularly inspired by the book *Awareness of Dying* (Glaser & Strauss, 1965), in which the context for patient awareness is categorized into patterns based on their conditions, and we relied on their approach to develop a typology. We analyzed the transcript in the patients' native language, and then we began translating the quotations into English. The first author translated quotations, and the other authors confirmed them.

Charmaz's framework was used to ensure the quality (credibility, originality, resonance, and usefulness) of our qualitative research (Charmaz, 2014). Most importantly, in order to assure credibility, we used data from interview transcripts and self-reflective memos written by the first author. Further, frequent memos concerning reflections and feelings were made by the first author to minimize pre-conceived ideas, especially because the first author had the experience of working in neurological wards as a registered nurse. And the entire process of data collection and analyses was conducted along with continuous, occasional group discussions with multiple healthcare providers.

The group included registered nurses, physicians, and non-healthcare researchers with experience in qualitative research. There were seven members in the group. The roles of the seven members were as follows: two were supervisors who had experienced qualitative study several times; the others were researchers who took a course of qualitative study and gave the possibilities of several interpretations in order to read the data openly. In this project, these seven members had 20 discussion meetings, which occurred once a week for 1 hr; some members were missing in several meetings due to scheduling difficulties. In the group discussions, group members read part of the primary data or data summary, and multiple interpretations and ways of coding were examined and challenged in the pursuit of credibility, originality, resonance, and usefulness. If there was disagreement in the analysis after discussion among the group, the first author made the final decision.

The interview transcripts of family members and healthcare providers were transcribed verbatim and were used to inform the analysis. For example, these interviews described some episodes participants did not discuss in their interviews and we could consider the meaning of those episodes for the participants, enabling us to gain a deeper understanding.

We explained the study purpose and procedures to all participants, participants' families, and medical staff, as well as the protection of their privacy, and the voluntary nature of their participation. The interviewer confirmed consent of participants, participants' families, and healthcare providers prior to each interview, and the researchers confirmed participants' and healthcare providers' consent prior

to observation. This study was approved by the ethical board of The University of Tokyo (No. 11160).

Results

We interviewed 14 participants, 6 (43%) male, with an age range of 38 to 79 years. Time since diagnosis was from 1 to 80 months, and 9 (64%) were grade III (Table 2).

Forty-eight decision points were identified from the 24 interviews. The interview data revealed that the decision-making of patients diagnosed with malignant brain tumors took place in the context of *struggling in vulnerability*, being shocked by diagnosis along with a poor prognosis, fearing symptoms caused by the brain tumor, and being anxious about an uncertain future, while desperately hoping for recovery. In this context, we found four patterns in participants' experience of medical care-related decision-making. Every participant described following the same decision-making pattern at the second interview. The framework is shown in Figure 1. A detailed description of each category follows, and many participants experienced various decision patterns at different points.

Struggling in Vulnerability: Context of Decision-Making

Through analysis, we soon identified the characteristic state of mind of participants related to decision-making, namely *struggling in vulnerability*. The context relates to participants' struggle with being shocked about diagnosis along with a poor prognosis, fearing symptoms caused by the brain tumor, and being anxious about an uncertain future, while desperately hoping for recovery. In addition to the general side effects of radiotherapy and chemotherapy, such as hair loss, nausea, and taste disorders, patients diagnosed with brain tumors experienced a variety of symptoms including paralysis, memory deficits, aphasia, and seizures, all of which can be directly threatening to their lives, depending on the tumor site. These symptoms occurred gradually but were steadily deteriorating patients' physical and cognitive conditions. Most participants received several treatments, desperately hoping for their positive effect. Their hope was often mixed with the fear of tumor recurrence, and they felt deeply uncertain of their future; decision-making occurred in that mixed mindset of fear and desperate hope.

One participant hoped for the effect of treatment and tried to cheer herself up; however, at the same time, she feared the disease because of her symptoms and uncertain future:

Compared to other people, I am in a lucky circumstance because my family supports me. However, if I were to say I was not apprehensive about my future, I would be lying. I actually worry about my disease, because . . . you know, I related with my friends with cancer who looked in pain at the end-of-life stage. I wonder if I would drop off like them . . . But, of course, I try to do my best and hope the treatment is effective. Well . . . but, to

Table 2. Participant Characteristics.

Characteristics	Statistics
Patients (N= 14)	
Sex	
Male	6
Female	8
Age range*	
30–39	1
40–49	4
50–59	5
60–69	2
70–79	2
Family structure	
Live	
With spouse	3
With spouse and children	4
With children	1
With parents (and brothers/sisters)	4
Alone	2
Grade [†]	
III	9
IV	5
Tumor site [‡]	
R/Front	4
R/Temporal	3
L/Front	2
L/Temporal	3
L/Parietal	2
Cognitive status: JCS [§]	
0	9
I-I	5
Disease duration at the first interview	
0–6 months	4
6–12 months	6
Over 1 year	4
Family member (N=2)	
Relationship with patient	
Parent	1
Spouse	1
Sex	
Male	1
Female	1
Age	
40–49	1
60–69	1
Healthcare provider participants (N=7)	
Physician	2
Nurse	5
Physicians' age	
30–39	1
40–49	1
Physicians' sex	
Male	2

(continued)

Table 2. (continued)

Characteristics	Statistics
Years of physician experience	
10–19	1
20–29	1
Nurses' age	
20–29	2
30–39	3
Nurses' sex	
Female	5
Years of nurse experience	
0–5	1
6–10	4

*The age at the first interview.

[†]Grade III: Anaplastic astrocytomas, Anaplastic oligodendrogliomas or Anaplastic oligoastrocytomas, Grade IV: Glioblastoma.[‡]R: right, L: left/front: front lobe, temporal: temporal lobe, parietal: parietal lobe.[§]Japan Coma Scale: 0: Lucidity, I-I: No disorientation but no lucidity, ※ Participants' JCS at the second interview was same as the first interview.

be honest, I worry I will not get well completely. I lost appetite these days . . . (ID13)

Another participant described her *struggling in vulnerability* context when she learned about her tumor recurrence and underwent chemotherapy with worrisome side-effects. When she did not feel supported by her family and physician, her anxiety became too much for her to continue treatment:

When I knew about the tumor recurrence, I thought, no way! What a hell! Certainly, I was aware of the possible recurrence of the tumor, but [when it actually occurred,] it was unacceptable for me. It was all over, I thought. Even for me, I got too depressed to pretend to be cheerful [. . .] After the chemotherapy and radiotherapy, I was very tired and lay down at home. My family asked me, "Why are you lying down?" Why couldn't they understand my condition? Of course, I suffered from fatigue because of the treatment! I was so shocked to hear what they said. I experienced that kind of thing, and I went to see a psychiatrist eventually [. . .] In addition, I couldn't get along with the physician either. I was very anxious about my disease and asked many questions, but he didn't give me any answers. No one supports me. Ha. . . I thought, I can't continue the treatment like this, that's impossible! That was my limit! (ID6)

In this context of *struggling in vulnerability*, participants had to face various major medical care-related decisions.

Decision Patterns

In analyzing the data, we came to recognize that there were different types of decision-making among various decision

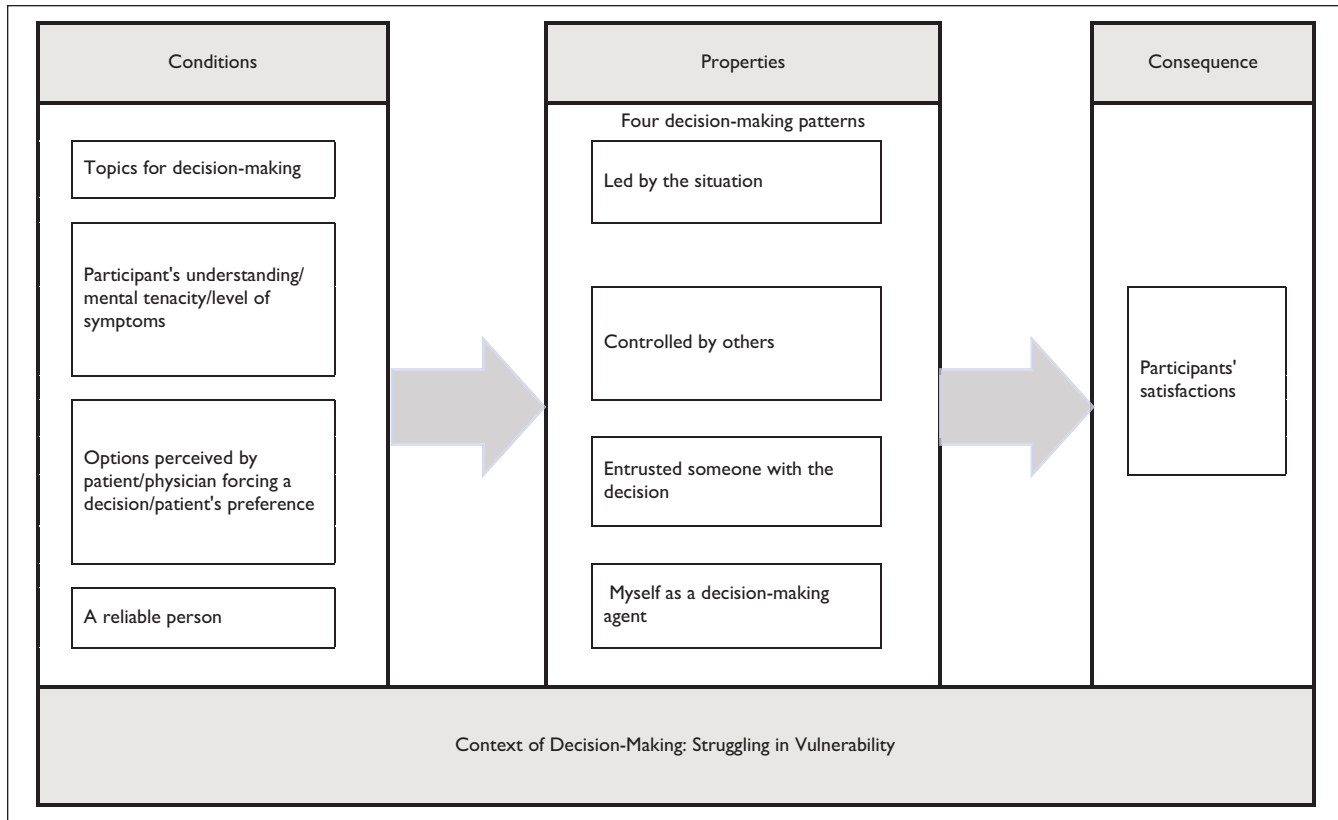


Figure 1. Framework of study.

points discussed in the interviews. We developed four patterns of medical care-related decisions. In descending order of frequency, they were *led by the situations* (18 decision points), *controlled by others* (12), *entrusted someone with the decision* (9), and *myself as a decision agent* (9) (Table 3). These patterns were largely based on two properties of decisions, regardless of the participants or topic of decision-making: (1) what/who made the decision and (2) whether the participant had decided what/who would make the decision. A detailed description of each pattern is described below.

Led by the situation. On some decision points, the participants discussed that the decision was determined *by the situations* rather than person(s). They used such terms as “*I had to. . .*” or “*I had no choice but to. . .*” This pattern often occurred in the decision of undergoing surgery. Many participants in this pattern seemed to accept the necessity of treatment without question and deemed that there were no other choices. They often were required to decide promptly, and they typically did not have much time to think. Moreover, they did not seem aware of their own preferences about both the content of decision and to what extent they wanted to participate in the decision.

In this pattern, the participants said that they felt the physician led them to choose one specific choice (e.g., undergoing surgery) and that severe symptoms led them to accept the

necessity of the treatment without question. Where there were no obvious symptoms, participants seemed to understand the need of therapeutic regimens after detailed explanations by their physicians. Whether participants had a person on whom they could rely or not was unknown because they did not refer to such a person in talking about these decision points. For example, one participant experienced a seizure and underwent surgery. Although he was shocked when he learned about his condition, he had a firm belief that he was in critical condition because of the combination of symptoms, test results (Magnetic Resonance Imaging; MRI), and physician’s explanations:

Last year, my left hand and lip suddenly twitched convulsively. I felt strange and my colleague called an ambulance. It was horrible, I was hospitalized suddenly. I knew I was in a critical condition because my brain was swollen in the MRI images [. . .] The doctor told me I had no time to lose, and I knew I was sick enough to require surgery. And then, I had the surgery. (ID4)

Most participants in this pattern seemed to believe that they did not have other choices, and they were convinced of the necessity. They were satisfied with the decision-making process. For this pattern to occur, and for the participants to be satisfied with the decision, the participants’ conviction that there were no other choices seemed necessary.

Table 3. Characteristics of each decision-making pattern.

	(1) Led by the situation	(2) Controlled by others	(3) Entrusted someone with the decision	(4) Myself as a decision-making agent
The number of decision points	18	12	9	9
Properties of categorization				
(1) What/who would decide	Situation	Other persons	Other persons	Myself
(2) Whether the participant decided what/who would decide	No	No	Yes	Yes
Conditions observed frequently				
Topics of decision	Undergoing surgery	Multiple	Multiple	Choosing hospital
Patient's understanding	Very well (for necessity)	Little	Little	Well (for contents)
Patient's perception of options	No options	No options	Uncertainty	Some options
Patient's preference	Not aware	Occasionally	almost always (for decision approach)	almost always (for contents)
Patient's mental tenacity	Not enough	Not enough	Not enough	Enough
Level of symptoms	Severe	Multiple	Multiple	Multiple
Physician forcing a decision	Often	Often	Seldom	Seldom
Reliable person	Not considered	Not considered	Family or physician	Family
Consequence				
Patient satisfaction	To some extent	Low - to some extent	High	High

Controlled by others. The participants also mentioned some decision points where a choice was made by someone other than themselves and they had to obey this choice. This pattern occurred for multiple decision topics. These decisions were characterized by the patient's lessened understanding about the decision topic and its necessity, even after a physician's explanations such as treatment effects and therapeutic regimen. They often did not remember the possible options explained by the physician. In this decision pattern, the level of symptoms varied, and it did not seem to affect the decision. The participants who talked mentioned this decision pattern emphasized that they felt they were strongly urged to choose one specific choice, even though the physicians' explanation was difficult to understand due to their cognitive deficit and low mental tenacity. Whether participants had a person on whom they could rely or not was unknown because they did not refer to such a person.

The participants who mentioned this decision pattern seemed on many occasions to perceive the decision process as modestly satisfactory, while in some cases participants expressed dissatisfaction with the process. This pattern seemed to occur when the participants were aware of their own preference but the decision went in a different direction. Some had their preferences from the beginning, while others were not aware of their preference at first and eventually became aware of or came to have a preference afterwards. For example, one participant talked about his experience of deciding to start chemotherapy. He did not have a good understanding of the physician's explanation at first, and yet the treatment was started. He did not have much trouble with this decision at first; however, after experiencing a side

effect, he came to realize that his condition was not improving despite the physician's assurance at first, and he became resentful about continuing chemotherapy:

[First interview]

I wonder about what the doctor said. He said I had something small, something like a tumor. I did not remember, but he probably said it [chemotherapy] would be effective or was likely to be effective for me. So, I okayed it. (ID3)

[Second interview, two months later]

I have no idea why I fainted, but I don't want to receive this chemotherapy anymore, I've had enough of it. Why on earth am I having this [fainting] happen again and again!? [At the time of deciding upon chemotherapy] I wasn't given any choices, no choices, whatsoever! It was like "Here it is [your medicine]." Give me a break! (ID3)

The feeling of being controlled by others without having a clear understanding about treatment or possible options became an issue after a negative event occurred.

Entrusted someone with the decision. At some decision points, it was revealed that the participants preferred not to participate in decision-making but rather chose a person whom they could trust as the decision-maker and entrusted him or her with the decision. Because they were already *struggling in vulnerability* with the diagnosis and various symptoms, they were already overwhelmed and it was not possible for them to decide by themselves. What they did actively was only to *choose whom to delegate with decision-making authority*. The level of symptoms varied, and it did not seem to have

affected the decision; this pattern occurred in multiple decision topics. One participant delegated the authority of decision-making related to chemotherapy and radiotherapy to her children, expressing that she was pleased with the fact that her children and physician discussed her treatment earnestly for her. To her, it did not matter that she did not understand the therapeutic regimen well:

The doctor explained something about treatment to my children. I did not understand it; but I told them it was OK because they thought the treatment would be effective for me. I did not understand doctor's explanation, but my children asked the doctor many questions about the treatment. I was happy to see the situation that my child asked the doctor something about my treatment. I was also happy the doctor carefully answered each question from my child. I was grateful to them. (ID10)

In this pattern, the participants often seemed neither to have a good understanding regarding decision topic or the physician explanation nor to be certain about whether they had options. However, this did not bother them, and they were mostly satisfied with the decision process because they just trusted the decision made by the delegated individual or individuals. Participants often delegated decision-making authority to family and their physicians. This decision pattern was possible only where participants had a sense of trust and support from reliable persons to whom they could delegate the decision-making authority.

Myself as a decision-making agent. In our analysis, only in the pattern of *myself as a decision-making agent* did the participants decide that they themselves would make a decision and then do so. This pattern often occurred when they chose a hospital. Most decided, with the support from reliable persons such as family members, after gaining an understanding of the details including hospital characteristics or the therapeutic regimen used there. The participants perceived that there were some options in the decision; some sought the options by themselves and others were provided with options by their physician or other familiar persons. Most were aware of their own preferences regarding their treatment or hospital and chose according to their preference; therefore, they did not feel they were controlled by others. The level of symptoms varied and did not affect the decision.

One participant explained that she decided to receive treatment from the second hospital they visited rather than the first, because she wanted to go to the larger hospital recommended by her friend. She hesitated to voice her preference to the physician, and her child delivered her preference to the physician:

After the hospitalization, the doctor at the first hospital explained the need for surgery to me and my child. Though I knew he was a very good doctor, I worried that there were few doctors at the hospital. I wanted to go to a larger hospital and knew my friend had recommended B hospital before. So, I wanted to go there,

and told my child my preference. Then, he said [to the doctor of the first hospital], "My mother is strongly motivated to go to B hospital." I asked my child to convey my preference to my doctor, because I hesitated to say such a thing to my doctor directly [. . .] After that, I went to B hospital and felt relieved. (ID10)

In this category, it seemed most participants were satisfied with the decision process. For this pattern to occur, participants need to have enough mental tenacity to make their own decision while being aware of their preference about the content of the decision.

Participants' Experienced Various Patterns

In accordance with the circumstances and contents of the decisions, many participants experienced various decision patterns in their treatment process, as an exemplar below shows (ID10).

One participant fell at a train station and was taken to the hospital; she was subsequently diagnosed as having a brain tumor. She panicked and was in disbelief. Her husband preferred a larger hospital and decided that she receive treatment at another hospital. She entrusted the decision to her husband and delegated the decision-making authority to him (*entrusted someone with the decision*); not understanding the situation well and having someone to rely on, she gained a sense of support. After that, her surgeon explained that she needed to undergo surgery; she recognized she was in critical condition and that she should undergo surgery without question (*led by the situation*), understanding the necessity, that there were no options, and that she had symptoms. After the surgery, the physician explained that her brain tumor was malignant and she needed chemotherapy. At that time, she was suggested to participate in a clinical trial by her doctor. She did so because she had a preference of receiving the latest treatment, and she understood the therapeutic regimen well (*myself as a decision-making agent*): having some understanding, some options, and confirming her own preferences. Eventually, she looked for more effective treatments, being influenced by her family's search for various treatments.

As described above, participants in our study experienced various medical care-related decision patterns through the course of treatment. The decisions were affected by various conditions such as the level of understanding or whether they recognized other options. These decision patterns seemed to have a direct impact on participants' satisfaction, depending on the situation.

Discussion

This study elucidated the experience of medical care-related decisions among people diagnosed with malignant brain tumors amidst active treatment. The experiences of

decision-making were categorized into four patterns. They experienced multiple patterns in their medical care process on various decision topics. To the best of our knowledge, this is the first study to report the types of medical care-related decision experiences and their related conditions among Japanese people diagnosed with a brain tumor from their own perspective.

This study revealed that participants did not make medical care-related decisions by themselves in three out of four patterns, even though our participants represented a select group of patients who do have decisional capacity, and yet they were generally satisfied with their decisions. Despite the prevalent principle and value on independent, logical, and autonomous decision-making in healthcare (Beauchamp and Childress, 2001), not making decision by themselves seemed more prominent among people with brain tumors in Japan. In our analysis, this result is largely due to their extraordinary *struggling in vulnerability* context, which is a significant source of difference from findings on patients with other cancer types (Tariman et al., 2010; Watanabe et al., 2008). In fact, the condition of poor mental tenacity led to the patterns in which participants did NOT make medical care-related decisions. Many participants discussed how desperately they were struggling with life-threatening symptoms and anxiety about their future, consistent with findings from a prior study revealing that people diagnosed with malignant brain tumors felt uncertain about their prognosis, their quality of life, and the loss of self because of their symptoms (Halkett et al., 2010). Their symptoms of malignant brain tumors such as paralysis, memory deficits, and seizures were more subjectively recognizable than those with other cancers. The poor prognosis also seemed the foundation for this vulnerable mindset. In order to understand their experience of decision-making, it seemed essential for healthcare providers to know that they were too vulnerable to be an active decision-making agent.

The participants revealed that in such a struggling in vulnerability, not making decisions by themselves can be satisfying. In *led by the situation* and *entrusting someone with the decision* patterns, they mostly showed satisfaction. One reason for this satisfaction may be characteristic of Japanese individuals; it has been noted that Japanese people are more collectivistic, and Japanese society is ordered via a social pattern consisting of closely linked individuals who see themselves as parts of one or more collectives, than in Western countries (Kitayama et al., 2009). In addition, Japanese people exhibit more of an external locus of control than Western people. (Parsons & Schneider 1974; Spector et al., 2002). *Locus of control* is a psychological concept capturing individuals' beliefs about the extent to which they control the events that affect them. Those with an external locus of control generally attribute life's outcomes to external factors, whereas those with an internal locus of control believe that much of what happens in life stems from their own actions (Gatz & Karel 1993). Three decision patterns

except the *myself as a decision maker* pattern seemed pertinent to external locus of control. In addition, Japanese people tend to make decisions interdependently and prefer reliance on others rather than independence (Akechi et al., 2012; Alden et al., 2015). A book on the concept of *amae* described it as a unique sense of dependence among Japanese (Doi, 2001). This cultural context of not deciding themselves may have caused the *led by the situation* and *entrusted someone with the decision* to be satisfactory, at least in Japan, for many participants.

It is yet to be known how patients from other countries experience their decision-making in a similar situation. However, our result at least casts the possibility that the central value and principle of independent, logical, and autonomous decision-making may not hold in some extraordinary situations such as the experience of brain tumor and still people can be satisfied with the decision-making. Without such understanding, if physicians urge their patients to make all decisions, which is one of the conditions, it may not be supportive and lead to patient dissatisfaction. In addition, a previous study showed that physicians underrecognized decisional capacity among malignant brain tumor patients, and physicians tended to assess the patients had enough decisional capacity even if they did not (Simon et al., 2014). In this study, though the physicians regarded the participants to have decisional capacity both prior to and for the duration of the study, there is a possibility that we included participants without decisional capacity, which might have precipitated the results where most participants did not decide by themselves. Physicians need to assess patients' decisional capacity appropriately, using assessment tools, and reflect on the ways they could support patients' decision-making while also considering their realities. For example, close communication with the patient's significant others (e.g., family, partners) may be required and assisting the patients to identify their proxy to whom they can comfortably entrust the decision seem essential.

Our study found that patients' patterns of decision-making vary over time, depending on the conditions that affect each decision-making pattern. Previous studies described patients' decision-making at a single point (Diaz et al., 2009; Watanabe et al., 2008), and there has been little evidence that patients' decision-making pattern varies over the course of medical care. This study newly revealed that participants experienced various patterns of decision-making at different points, and the various patterns could follow based on each situation. Some studies showed that patients' characteristics such as age and nationality affected patients' decision-making (Akechi et al., 2012; Arora & McHorney 2000; Ryan & Sysko 2007). Our study suggested that it is not age, sex, tumor site, or grade differences that affect decision-making patterns, but rather other conditions, such as decision contents, understanding of the disease, and treatment effect. One person could take various attitudes toward decision-making depending on the situation at each decision point. Therefore,

it seems vital to assess the conditions in which the decision is embedded, which may vary at each decision point. However, previous studies showed that as tumor site or grade affect cognitive impairment (Meyers & Hess 2003; Sizoo et al., 2012), it could affect both the situation such as participant understandings and also decision patterns. In this study, there was not much difference among the participants' cognitive level, which could have led to this result; future studies need to carefully explore the effects of tumor site and grade on results.

One of the difficulties in assisting decision-making of patients with brain tumor is that on some occasions, especially soon after diagnosis, the patient may not even know their own preference regarding decision-making, even though by the time they would develop their preference the patient may lose mental capacity for making decisions. On many decision points we have learned in the interview, especially in decisions that belonged to the *led by the situation*, the participants themselves did not seem to be aware of their own preference—the contents of decision and even the level of participation—and, in their view, there were not multiple options in their given situation. We interviewed participants in the initial/early stages of the medical care process. Most participants were within 1 year of diagnosis, so they may not have developed their own preferences yet. Although previous research suggested that in decision-making support, it is vital for healthcare providers to assess patients' preferred level of participation in decision making (Hubbard et al., 2008; Tariman et al., 2010; Watanabe et al., 2008), it could be difficult to do so when they are not even aware of their preferences, both for decision content and level of participation.

In those occasions, it may be necessary for healthcare providers to engage in a circle of dialog with patients and determine together the best decision for the patient. There should be more discussion on how to assist those in early stage of brain tumor diagnosis regarding their medical care-related decisions, based on a richer understanding about what they are experiencing. Although we do not know how each decision pattern will affect a patient's overall illness process and quality of life, it is critical to assess decision-making patterns using the conditions elucidated in this study at each decision-making point.

Limitations

There are several limitations to this study. First, because we recruited participants from only one university hospital in an urban area in Japan, there could be sampling bias. Our findings may be affected by the characteristics of the hospital and the relationship between the physician and patients. There is a possibility that different decision patterns are observed at different hospitals. However, we recruited the participants via multiple physicians, which may have been helpful to gain variability in our participants. Another limitation is that

many participants were in the initial stage of treatment when we interviewed them; therefore, their preference for decision making and consequence of each decision pattern may change as the disease progresses. Although we asked the physicians to recruit participants in different disease stages, continued interviews including patients in an advanced clinical stage and at end-of-life should be examined in future research. In addition, we did not collect socioeconomic or functional data (such as can be assessed using the Karnofsky Performance Status Scale) from the participants, which may affect decision-making patterns.

Despite these limitations, this study is valuable because it is based upon the interviews of a hard-to-reach population, patients with a brain tumor who are undergoing active treatment, and the results show a new finding that suggests the possible merit of patient themselves NOT deciding by themselves. We need more exploration into their experience of having a brain tumor and the development of effective ways to support their decision making. In further research, we need to explore quantitatively the association between each decision pattern and leading factor or outcomes (e.g., satisfaction, quality of life, quality of death).

Conclusion

The findings of this study indicate that patients diagnosed with malignant brain tumors amidst active treatment faced many decisions in the context of *struggling in vulnerability* due to life-threatening symptoms and a poor prognosis. Patients experienced four decision patterns concerning medical care-related decisions. There was only one pattern where they decided actively: *myself as a decision-making agent*. In the other patterns, participants did not decide actively: *led by the situation*, *entrusted someone with the decision*, and *controlled by others*. Some participants were not even aware of their own preference regarding the decision contents and level of participation. It is necessary that healthcare providers understand patients' *struggling in vulnerability*, identify reasons why they may seek to yield the decision-making process to others, assess patients' awareness of decisional choices at multiple stages of decision-making, and explore how best to assist these patients.

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