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Research Paper

The relationship between proxy decision-making content and cues by families of patients with malignant brain tumor: A descriptive qualitative study



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ABSTRACT

Objectives: This study aimed to clarify the relationship between the content of proxy decision-making made by families of patients with malignant brain tumors regarding treatment policies and daily care and the cues leading to those decisions.

Methods: Semi-structured personal interviews were used to collect data. Seven family members of patients with malignant brain tumors were selected to participate in the study by purposive sampling method from June to August 2022 in the Patient Family Association of Japan. Responses were content analyzed to explore the relationship between the content of decisions regarding "treatment policies" and "daily care" and the cues influencing those decisions. Semi-structured interviews were analyzed by using thematic analysis.

Results: The contents of proxy decisions regarding "treatment policies" included implementation, interruption, and termination of initial treatments, free medical treatments, use of respirators, and endof-life sedation and included six cues: treatment policies suggested by the primary physician, information and knowledge about the disease and treatment obtained by the family from limited resources, perceived life threat from symptom worsening, words and reactions from the patient regarding treatment, patient's personality and way of life inferred from their treatment preferences, family's thoughts and values hoping for better treatment for the patient. Decisions for "daily care" included meal content and methods, excretion, mobility, maintaining cleanliness, rehabilitation, continuation or resignation from work, treatment settings (outpatient or inpatient), and ways to spend time outside and included seven cues: words and thoughts from the patient about their way of life, patient's reactions and life history inferred from their preferred way of living, things the patient can do to maintain daily life and roles, awareness of the increasing inability to do things in daily life, family's underlying thoughts and values about how to spend the remaining time, approval from family members regarding the care setting, advice from medical professionals on living at home.

Conclusions: For "treatment policies," guidelines from medical professionals were a key cue, while for "daily care," the small signs from the patients in their daily lives served as cues for proxy decisionmaking. This may be due to the lack of information available to families and the limited time available for discussion with the patient. Families of patients with malignant brain tumors repeatedly use multiple cues to make proxy decision-making under high uncertainty. Therefore, nurses supporting proxy decision-making should assess the family's situation and provide cues that facilitate informed and confident decisions.

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What is known?

• Patients with malignant brain tumors may experience a cognitive and physical decline from an early stage, requiring their families to assume the role of surrogate decision-makers.

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- Due to the rapid progression of malignant brain tumors and early cognitive decline, difficulty in fully implementing advanced care planning is considered, which has gained importance in recent years. Consequently, families make surrogate decisions based on various cues while facing significant burdens and challenges.
- However, insufficient information exists on the specific cues that guide families in making surrogate decisions.

What is new?

- Decisions regarding treatment policies and care arrangements involve distinct considerations—about "life" and "living," respectively—leading to differences in the cues used for each.
- Families of patients with malignant brain tumors repeatedly use multiple cues to make proxy decision-making under high uncertainty.
- It is essential to consider comprehensive and continuous nursing support for families facing proxy decision-making challenges and accurately understand their current situation.

1. Introduction

Medical advancements in the treatment of malignant brain tumors have extended median survival to 14 months; however, the disease remains known for its poor prognosis [1]. Patients with malignant brain tumors often experience rapid disease progression, with many developing progressive neurological impairments during the illness [2,3]. Among these impairments, cognitive decline has been reported to hinder decision-making regarding future treatment and care [4]. Due to these clinical characteristics, when patients experience cognitive decline, families assume the role of surrogate decision-makers.

In recent years, advancements in early cancer diagnosis and treatment have extended the period of living with cancer, while the promotion of advance care planning (ACP) has increased opportunities for discussions about treatment and care [5]. Various decision-making support tools for ACP in a patient with a malignant brain tumor have been evaluated for their effectiveness [6,7]. However, research on ACP for these patients still faces challenges in initiating and structuring discussions, with the study highlighting the limited effectiveness of ACP programs in this population [8].

The rapid tumor progression, tumor-related seizures, and cognitive decline in patients with malignant brain tumors hinder meaningful discussions. Additionally, significant individual differences, variability, and unpredictable prognoses further complicate the ACP process [9]. Despite increasing research on ACP aimed at respecting patients' wishes, families of patients with malignant brain tumors continue to struggle with proxy decision-making [5,10—12].

Compassionate decision-making support from nurses has been reported to positively influence the illness experience of families living with patients with malignant brain tumors [13]. Therefore, nurses working with these patients and their families must provide proxy decision-making support to respect the patient's preferred way of living while alleviating the family's burden and distress.

However, previous studies have not reported how families of patients with malignant brain tumors make surrogate decisions or what cues they rely on. Existing ACP and proxy decision-making support tools do not incorporate these aspects [8,14]. Decision-making for cancer patients other than brain tumors also requires proxy decision-making, especially in the terminal stage, where the patient's condition or treatment often renders them incapable of

making decisions [15,16]. In the case of cancer patients, proxy decision-making is often necessary in the terminal stage, primarily concerning matters such as the place of treatment and end-of-life sedation [17,18]. Brain tumor patients may experience cognitive decline from the early stages of diagnosis, making it likely that the timing and content of proxy decision-making will differ from those of other cancer patients. Clarifying these elements would facilitate family discussions, ensuring that the patient's wishes are effectively reflected in ACP programs.

Promoting meaningful proxy decision-making is crucial so families can accept and understand their circumstances and challenges [14]. A thorough analysis of the cues families use in decision-making and the connections between these cues and decisions can provide new insights into developing supportive approaches that positively impact families living with patients with malignant brain tumors. Therefore, this study aimed to clarify the relationship between the content of proxy decision-making and the cues leading to those decisions using a narrative approach based on the real experiences of families of patients with malignant brain tumors. The findings will provide insights for nursing support tailored to the content of proxy decision-making.

2. Methods

2.1. Study design and participants

This study utilized a qualitative descriptive design employing semi-structured interviews to explore the relationship between the content of proxy decisions and the cues leading to those decisions. This methodology facilitated the generation of comprehensive descriptive summaries of participants' experiences [19,20], enabling researchers to delve into their perceptions, feelings, thoughts, and associated emotions.

Since malignant brain tumors are rare cancers, and it was difficult to secure participants, we approached the Patient Family Association, which had many potential participants. As only one Patient Family Association exists in Japan, we requested and received their cooperation. Recruiting participants from these Patient Family Association settings was intended to enhance the representativeness of the participant sample. Although there was great heterogeneity in age, kinship, and care duration, which may affect the fullness of the results to a certain extent, recruiting participants was difficult due to the rarity of malignant brain tumors. Therefore, the following inclusion criteria were applied to recruit participants who had experienced proxy decisions: 1) had made proxy decisions regarding treatment policies and daily care for patients with malignant brain tumors, 2) could effectively communicate in Japanese, 3) did not have any mental or physical disabilities that would interfere with participation in the study, and 4) would be the primary caregiver of the patient, who knew the patient's condition the most. Proxy decision-making by families of patients with malignant brain tumors often begins early after diagnosis, requiring families to make life-critical decisions from the time initial treatment is needed. Additionally, as patients frequently require caregiving, families simultaneously make decisions about care arrangements that significantly impact the patient's quality of life. Decisions regarding treatment policies and care arrangements involve distinct considerations—about "life" and "living," respectively—leading to differences in the cues used for each. This is because decisions about care are more likely to reflect individual preferences and emotions than decisions about treatment policies [21,22]. Therefore, this study distinguished between treatment policies and care arrangements when gathering information.

2.2. Recruitment and enrolment

The researcher (R. Tokunaga) explained this study's purpose and process to the Family Patient Association president and obtained consent for research cooperation. The president asked members of the Family Patient Association to send an email containing the study's purpose, process, and information on how to participate and cooperate. If an eligible member viewed the email and wished to participate in the study, the researcher (R. Tokunaga) received an email from the applicant. At the onset of each interview, the researcher (R. Tokunaga) explained the study's purpose and procedures orally and in writing and then obtained written consent from the participants. Interviews were conducted after participants had completed the written informed consent form.

2.3. Ethical considerations

As mentioned above, participants were briefed on the purpose and procedures of data collection before commencement. They were assured that participation was voluntary and that declining participation would not result in work-related repercussions. Furthermore, participants were informed that their data would be anonymized using pseudonyms and solely utilized for this study. This study was approved by the Sophia University Ethics Committee (Approval No. 2022-004).

2.4. Data collection

From June to August 2022, semi-structured interviews were conducted in private rooms or online to protect privacy. Each interview session was conducted once, with an average time of 61 min. The researcher (R. Tokunaga) and a nursing professor (F. Ishikawa) designed the semi-structured interview guide, and the researcher (R. Tokunaga), trained in qualitative research, conducted all the interviews. A semi-structured interview guide was used to obtain rich, informative, and multi-perspective interview data. Participants were asked about the basic attributes of the patients and participants. Interviews focused on the content of proxy decision-making regarding "treatment policies" and "daily care," as well as the cues for judgment. Four interview questions were asked: 1) Can you tell us about your experience making proxy decisions regarding treatment policies and convalescence? 2) What were some of the things that helped you make decisions on the patient behalf? 3) What did that cue mean to you and the patient? 4) What did you consider important as a cue? 5) What support did you receive from your healthcare provider in making decisions on patients' behalf? In this study, "cues" are defined, with reference to the Shinmeikai Japanese Dictionary [23], as "the basis upon which families rely when making decisions about treatment policies and living arrangements for care." With the participants' permission, the interviews were recorded on an IC recorder and transcribed verbatim. The researcher (R. Tokunaga) bracketed her prior experiences to reduce personal bias, then acted as an interviewer by asking questions and encouraging the participants to express their opinions and share their experiences. Participant recruitment continued until data saturation was achieved, signifying no emergence of new information. A gift voucher of JPY1,000 was provided to each participant upon completion of the interview. A nursing professor (F. Ishikawa) reviewed the interview notes and provided interpretation and supervision of subsequent interviews.

2.5. Data analysis

IC recorded data was transcribed verbatim, and thematic analysis, following the method proposed by Graneheim & Lundman

[24], was employed to identify common cues for proxy decisions. Initially, the researcher repeatedly reviewed the verbatim transcripts to develop an overarching understanding of the interview data. Subsequently, transcripts were deconstructed into smaller meaningful units, and codes were assigned to represent the cues for proxy decisions among family members of patients with malignant brain tumors. These coded data were then compared with other data, with similar codes grouped into categories. Categories were further organized into themes based on their conceptual similarities. Afterward, we carefully reviewed the extracted cues to determine what decisions (contents) were being discussed.

2.6. Trustworthiness

To ensure the transparency and reproducibility of the study, this study was carried out with reference to the COnsolidated criteria for REporting Qualitative (COREQ) research checklist [25]. Several approaches were undertaken to establish the study's trustworthiness to ensure its credibility, confirmability, and dependability [26]. To establish credibility or the truthfulness of the study findings, the researcher conducted interviews with compassion and without exerting any form of coercion, thereby encouraging honest responses from participants. The researcher (R. Tokunaga) had no previous experience caring for the participants, although they had experience working in a neurosurgery unit at a cancer hospital, which is important to note. Additionally, member checking was conducted by returning the interview transcripts to the participants and asking them to verify that they accurately represented their perspectives [27,28]. To ensure the confirmability of the findings, which involves maintaining the neutrality of a researcher's perspective [26], the first author maintained a neutral stance toward the participants' narratives when analyzing the data. Furthermore, the second author (F. Ishikawa), proficient in qualitative research, scrutinized the analysis process and outcomes. Finally, to assure the findings' dependability or consistency [26], repeated data readings rigorously evaluated the appropriateness of the extracted codes, categories, and themes. Two nurse researchers confirmed the results to ensure the credibility and confirmability of the relationship between the content of proxy decision-making and cues.

3. Results

Participants were seven family members who belonged to the Patient Family Association and had made proxy decision-making for the patient with a malignant brain tumor. Participant and patient characteristics are presented in Table 1. No one refused to participate or dropped out.

3.1. Relationship between proxy decision-making content and cues of treatment policies

Data analysis from the seven participants revealed that the content of proxy decisions regarding treatment policies included the implementation, interruption, and termination of initial treatments, free medical treatments, use of respirators, and end-of-life sedation (Appendix A). The content and cues leading to these decisions are outlined below.

3.1.1. Treatment policies suggested by the primary physician

These cues included treatment plans presented by the primary physician that were convincing to the family or those explained as having no alternative options. The contents of decision-making included the implementation, interruption, and termination of initial treatments and access to free medical treatments. For

Table 1 Participants' characteristics.

ID	Research participants			Patients			
	Age	Gender	Relationship to patient	Age	Gender	Social role	Length of illness
Α	Early 40s	Female	Wife	Early 40s	Male	Office worker	3 years
В	Late 30s	Female	Wife	Late 30s	Male	Office worker	2 years and 11 months
C	Early 50s	Male	Father	Late teens	Female	Student	7 years and 2 months
D	Early 50s	Female	Wife	Early 50s	Male	Office worker	1 year
E	Late 50s	Female	Wife	Early 60s	Male	Unemployed	4 years and 6 months
F	Early 40s	Female	Daughter	Early 60s	Female	Homemaker	1 year
G	Early 60s	Male	Father	Early 20s	Male	Student	6 years and 6 months

example, "We listened together in the consultation room and decided on this policy, and then just followed the flow. Following this course, we decided to proceed with additional chemotherapy." (A), or "We could not see the effects of the treatment ourselves. However, we find it difficult to decide to stop. After the doctor explained it to us, we understood it might be ineffective. Therefore, we agreed to stop."(D).

3.1.2. Information and knowledge about the disease and treatment obtained by the family from limited resources

These cues involve making decisions based on the information the family manages to obtain. The contents of proxy decision-making included implementing and terminating initial treatment and free medical treatments. For example, "I had no relatives with brain tumors to consult. Therefore, I researched online extensively and concluded that this was the only treatment. The result of my research became a cue to decide on the initial treatment choice." (F), or "I read an article from an overseas paper that said if I continued radiation therapy even without taking Temozolomide, this much effect could be expected; therefore, I decided to stop taking Temozolomide."(E).

3.1.3. Perceived life threat from symptom worsening

These cues include the patient's progression of symptoms, which involved feeling the tumor's enlargement and the risk to life. The contents of proxy decision-making included the implementation of initial treatments. For example, "When seizures started, I begged the doctor to do something. After observing the patient's condition, I thought that there was no choice but to proceed with treatment, and finally, I was able to make the decision for surgery." (E), or "Because we were together every day, I could see how the patient gradually became unable to move, with their limbs completely paralyzed. I realized this would be too late if I did not decide on the initial treatment quickly." (F).

3.1.4. Words and reactions from the patient regarding treatment

These cues include the words and reactions that can be received from the patient. The contents of proxy decision-making included the implementation, interruption, and termination of initial treatments, use of respirators, and end-of-life sedation. For example, "When the patient was diagnosed with a brain tumor, they said this. I want to live longer; therefore, please remove as much of the tumor as possible.' This was our foundation for continuing the treatment." (C), or "The patient had communicated that they did not want life-sustaining measures. They strongly felt that they did not want to burden their family; therefore, when deciding whether to use a ventilator, I referred to this." (B).

3.1.5. Patient's personality and way of life inferred from their treatment preferences

These cues include the family's assumptions about the patient's wishes. The contents of proxy decision-making included the termination of initial treatments, the use of respirators, and end-of-life sedation. For example, "He never wanted to be a burden and said

he would rather die than live like this. Therefore, we carefully considered what we believed to be their true wishes and made decisions such as stopping treatment." (B), or "I believe that his identity was defined by being lively and humorous; accordingly, when considering whether he would want to live with a ventilator, I thought that he probably would not want that." (G).

3.1.6. Family's thoughts and values hoping for better treatment for the patient

These cues include the family's values. The contents of proxy decision-making included free medical treatments, respirators, and end-of-life sedation. For example, "I just could not see him suffer anymore and asked for sedation" (G), or "I felt sorry for my mother, who was working hard with the treatment; however, since I wanted her to live as long as possible, I thought that I wanted her to use the ventilator."(F).

3.2. Relationship between proxy decision-making content and cues of daily care

The analysis of data from the seven participants revealed that the content of proxy decision-making regarding daily care included meal content and methods, excretion, mobility, maintaining cleanliness, rehabilitation, continuation or resignation from work, treatment settings (outpatient or inpatient), and ways to spend time outside (Appendix B). The following sections outline the content and cues leading to these decisions.

3.2.1. Words and thoughts from the patient about their way of life

These cues include the patient's statements regarding their life. The contents of proxy decisions included meal content and methods, excretion, mobility, maintaining cleanliness, and ways to spend time outside. For example, "My husband loved his coffee. Therefore, we made sure he had it every day. In this way, I respected the patient's feelings, even in small matters, allowing them to maintain their sense of self." (A).

3.2.2. Patient's reactions and life history inferred from their preferred way of living

These cues include the family's assumptions about the patient's feelings. The contents of proxy decision-making included meal content and methods for maintaining cleanliness. For example, "He always preferred bathing in the morning, and we continued that. I wanted to maintain the habits from when the patient was working, choosing that lifestyle rhythm." (B), or "He loved to eat, so he adjusted his diet to allow him to eat as many of the things he liked as possible, rather than just to get nutrition." (C).

3.2.3. Things the patient can do to maintain daily life and roles

These cues include the consideration for maintaining the patient's independence. The contents of proxy decision-making included mobility and rehabilitation. For example, "He could still

walk short distances, and we encouraged him to walk a bit every day. I made sure to provide more opportunities for walking." (C), or "She had forgotten how to cook. However, my mother never stopped standing in the kitchen. I tried to give her some role by cooking together in the kitchen."(F).

3.2.4. Awareness of the increasing inability to do things in daily life

These cues include prioritizing safety by the patient's functional decline. The contents of proxy decision-making included meal content and methods, excretion, mobility, and ways to spend time outside. For example, "We noticed he could not chew well anymore, we, therefore, switched to softer foods. The content of the meals was decided based on observing the swallowing condition." (D), or "Since he had started getting lost on the road, I made sure he would not go outside alone and tried to find ways to spend time together so we could go outside together." (B).

3.2.5. Family's underlying thoughts and values about how to spend the remaining time

These cues include the family's thoughts and values. The contents of proxy decision-making included continuation or resignation from work, treatment settings (outpatient or inpatient), and ways to spend time outside. For example, "We decided to resign from work to spend more time together. I knew there was little time left to spend together. Therefore, I tried to create as many memories as possible." (E), or "Since he had always been someone who worked, I made sure to make choices that would help him maintain some connection with society." (A).

3.2.6. Approval from family members regarding the care setting

These cues involve the consent of the family living together. The contents of proxy decision-making included continuation or resignation from work and treatment settings (outpatient or inpatient). For example, "The family agreed to bring him home for his final days. With this shared consent, we decided he would spend his remaining time at home." (F), or. "With my family supporting me in making the decision, I was able to decide for him retiring from his job." (A)

3.2.7. Advice from medical professionals on living at home

These cues involve practical advice from healthcare professionals. The contents of proxy decision-making included ways to spend time outside and in treatment settings (outpatient or inpatient). For example, "The nurse suggested daily outings to improve his mood. As a result, I made an effort to go outside as much as possible to get some fresh air and exercise, to refresh my mood." (G), or "I learned that it is possible to go on trips in a wheelchair, and that allowed me to create memories as a family." (A).

4. Discussion

4.1. Relationship between the content and cues of proxy decision-making by family members of patients with a malignant brain tumor

Family members relied on cues—such as the patient's thoughts, feelings, and reactions—when making important decisions. No specific relationship between the content of the choices and the use of cues was observed; families used multiple cues repeatedly when making surrogate decisions. This suggests the uncertainty inherent in proxy decision-making for patients with malignant brain tumors. Previous studies have shown that families often make decisions without being certain of the patient's true feelings [29], often experiencing distress or difficulty understanding the patient's wishes while wishing to know their true thoughts [30]. Medical

decision-making, such as treatment plans and care choices, significantly affects both the patient's and the family's future life [31]. Therefore, families in this study used various cues, including the patient's statements, reactions, and family relationships, when making decisions. Generally, medical decision-making involves uncertainty [19], and to reduce uncertainty, diverse information and effective organization are necessary [32]. In the case of patients with a malignant brain tumor, uncertainty is higher due to early cognitive decline, making it more difficult for families to make decisions.

However, a relationship between proxy decision-making content and cues was observed in some instances. For example, many cues were used in decisions related to the treatment plan, such as initial treatment, discontinuation, or alternative therapies. In contrast, decisions regarding the use of a ventilator and end-of-life sedation cues were primarily based on the patient's reactions or estimated wishes and the family's values, with less influence from healthcare professionals. These decisions typically occur during a phase where palliative care plays a more significant role in the treatment, leading to families prioritizing their perspective on what would be best for the patient rather than relying on healthcare professionals.

The family faced many subtle, everyday issues in decisions regarding the patient's daily care. Previous research has shown that proxy decision-making generally focuses on major decisions, such as selecting a care location or deciding when to end treatment [33,34]. This study, however, revealed that families are faced with numerous small decisions on a daily basis. Furthermore, families used more cues when deciding on care-related matters than treatment-related decisions. In these situations, families did not feel a strong sense of needing to make a decision but were exploring ways to improve the patient's quality of life, which led them to use a wider range of cues. This may contribute to the challenges and difficulties families face in proxy decision-making. Although this study did not directly explore the distress or difficulties involved, the use of multiple cues in decision-making, despite uncertainty, suggests that families may experience struggles related to decision-making, difficulty knowing how to decide, and a desire to understand the patient's true thoughts.

4.2. Suggestions for future nursing

In proxy decision-making by the families of patients with malignant brain tumors, multiple cues were repeatedly used for a single decision. As mentioned earlier, this was due to the uncertainty of proxy decision-making, where important decisions were made in situations where the patient's wishes were unclear, or the future was uncertain due to the sudden onset of a brain tumor. When making uncertain decisions, guidelines suggest that decisions should be made cautiously from various perspectives, such as medical validity and appropriateness [35]. The use of diverse cues in this highly uncertain context suggests that, despite their uncertainty, families carefully considered various factors before deciding on proxy decision-making.

In decision-making support, appropriate information provision and explanation by healthcare professionals and ensuring access to information are necessary [36]. Providing cues that can be used depending on the decision content is considered part of appropriate information provision and can significantly advance the decision-making process. Additionally, providing cues may promote effective engagement between the patient and their family, leading to the exploration of the patient's true feelings and enabling the family to make a choice they can fully agree with. Furthermore, providing families with the necessary materials and time to consider each decision deeply will likely impact proxy

decision-making with fewer regrets and burdens. Therefore, nurses must first thoroughly assess the family's situation when making surrogate decisions. Information overload can increase personal uncertainty, potentially leading to depression, anxiety, and decreased judgment ability, which can influence decision-making [32]. Conversely, lacking information increases personal uncertainty and can affect decision-making [32]. Nurses need to carefully determine the timing to elicit the patient's wishes through care, understand those wishes, and provide the family with relevant information at the right time. Providing information in an appropriate amount and content is crucial.

Especially when making decisions about "daily living matters," which involve the intricate details of daily life, nurses should provide the family with the patient's responses gathered through daily living assistance during hospitalization. This will help facilitate informed proxy decision-making. While discussions about proxy decision-making regarding treatment plans have been ongoing, recent a study has focused on the effects of supportive care and the unmet needs of patients with rare cancers [37]. This suggests the increasing emphasis on the idea that patients with cancer should live with cancer in a way that preserves their individuality. Since proxy decision-making about "daily living matters" respects the patient's uniqueness, focusing on both the decision-making process and the life of the patient and the family's life after the decision is made is important.

However, this study is not without its limitations. Since the incidence of malignant brain tumors is low and there are few research reports, we believe that the data collected in this study is significant. Nonetheless, the findings obtained in this study are based solely on the information provided by the interview survey. Additionally, variations were observed in relationships, age of study participants and patients, and individual characteristics, which may have influenced the findings. Furthermore, although a relationship between the cues and the content was suggested, the nature of the analysis method prevented us from demonstrating this correlation. As such, a limit to the generalizability of the data exists. In the future, based on the findings of this study, we will examine the differences in cues depending on the basic attributes of the research participants and investigate effective nursing support while clarifying the relationship between the content of proxy decision-making and the cues.

5. Conclusions

This study's findings revealed the following points: for decisions related to "treatment policy," the family members considered aspects such as the implementation, discontinuation, and termination of initial treatments, private medical care, respirators, and terminal sedation. Six types of cues were used in making these decisions. Regarding decisions related to "daily care," the family members considered aspects such as the content and method of meals, methods of excretion, mobility, and hygiene maintenance, implementation of rehabilitation, continuation or retirement from work, outpatient or inpatient treatment, and ways of spending time outside. Seven types of cues were used in these decisions. Notably, no specific relationship was found between the content of the proxy decisions and the particular cues used. However, the evidence indicated that multiple cues were used for a single decision, suggesting that families are likely to make proxy decisions amidst high levels of uncertainty. Nurses involved in the proxy decisionmaking process for family members of patients with malignant brain tumors need to assess the family's situation carefully and provide cues that can aid in their decision-making. When supporting proxy decision-making, it is crucial to focus not only on the decisions themselves but also on the process of making these

decisions and the subsequent lives of the patients and their families.

CRediT authorship contribution statement

Runa Tokunaga: Conceptualization, Methodology, Formal analysis, Investigation, Data curation, Writing - original draft, Writing - review & editing, Funding acquisition. **Fumiyo Ishikawa:** Methodology, Supervision.

Data availability statement

The raw/processed data required to reproduce the above findings cannot be shared because survey respondents were assured raw data would remain confidential and would not be shared.

Declaration of competing interest

The authors have declared no conflict of interest.

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Appendices. Supplementary data

Supplementary data to this article can be found online at https://doi.org/10.1016/j.ijnss.2025.02.001.

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