Identification of Questionnaire Improvements to Assess Familial Support in Malignant Brain Tumor Patient

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Abstract

BACKGROUND: To support decision-making for patients with malignant brain tumors, it is necessary to understand family needs during the hospitalization period. The assessment sheets and checklists generally used in the ward focus on the patient's condition with only a few items related to family information. Many checklists are not tailored to the patient's disease and therefore do not address changes in condition and neurological symptoms. Thus, based on previous research, this study aimed to extract items that clinical nurses consider necessary for the family members of patients with malignant brain tumors by filling out a self-administered assessment. **METHODS**: For the 92 self-made questions, the Delphi method was performed three times for the panelists; consensus was reached on the necessity of a family self-administered information gathering item. The patients' families answered questions using a 1 - 5 rating scale to assess support required, with 5 being necessary and 1 being unnecessary. In the analysis of the 3rd survey, the consensus rate was calculated as follows: out of 5 options for each question, scores of 5 and 4 were combined and judged to be necessary. The average value was calculated as 87.3% and this value was used as the criterion for agreement. **RESULTS**: In the final round, answers from 45 panelists were obtained, and consensus was obtained for 47 questions. The 47 questions were extracted using the Delphi method based on reasonable condition settings and yielded reliable results. **CONCLUSION**: The data collected in this study can contribute to support programs aimed at helping families of patients with malig-

nant brain tumors.

Keywords

1. Introduction

In Japan, in 2017, the number of people affected by brain and central nervous system tumors was 5778, and the prevalence rate was 4.6 persons per 100,000 population [1]. Malignant brain tumors exhibit various pathologies depending on the site of tumor development, including seizures [2]. Treatment of malignant brain tumors includes surgical removal within a safe margin, radiation therapy, and chemotherapy, resulting in a longer hospital stay for patients. While the average length of stay in general ward is usually short, the average stay in patients with brain tumors is longer [3]. Despite patients' discharge after long-term hospitalization, the prognosis of patients with malignant brain tumors remains poor, and recurrence rate is high [2]. Support for patients with brain tumors is crucial to facilitate return to their families and to allow them to live in a familiar place for as long as possible after completing inpatient treatment.

In patients with malignant brain tumors which impair consciousness, the choice of medical treatment is often left to the family. To obtain home health care, it is necessary for the caregiver to make a decision on the medical treatment, which reportedly leads to a shortening of the period required for discharge adjustment [4]. Patients with malignant brain tumors require early patient care and enhanced support systems. Impairment in the central nervous system creates a loss of independence, even in the early stages of the disease [2]. Family caregiver involvement in patients' malignant brain tumors is increased compared to other patients [5]. Family caregivers hesitate to make home care decisions due to anxiety and inexperience. Decisions on the next course of treatment take time and support during the hospitalization period. Therefore, it is necessary to assess each family member's concerns about home care during this time.

Customary assessment sheets and checklists focus on the patient's condition with only a few items relating to their family. Many are not tailored to the patient's disease, and therefore do not address changes in condition and/or neurological symptoms. This makes it difficult for families to gauge patient's prognosis. Additionally, many existing evaluation tools for the families of cancer patients are shared without specifying tumor site [6] [7] [8] and these tools are of limited use to families of malignant brain tumor patients [9]. This study aims to identify questions for a self-administered questionnaire that clinical nurses consider necessary to gauge family involvement and understanding in these unique patients.

2. Methods

2.1. Study Design

A questionnaire survey was conducted using the Delphi method [10] [11] [12], which is a consensus method in which an expert on the event to be investigated is selected as a target person (panelist) and seeks opinions for panelists on several occasions. This method reflects the unified view of experts by repeatedly asking the same expert for opinions while providing feedback on their results.

2.2. Participant Selection and Recruitment

The participants of this study were nurses who have been working in the neurosurgery/internal medicine ward for more than 3 years.

Using the medical function information system of each prefecture (administrative district) in Japan, the keywords "brain tumor resection" from "diseases/treatments that can be dealt with" were selected, identifying 1142 facilities. Of these, we requested a survey of 834 facilities with over 200 beds (the standard for regional medical support hospitals). The survey was conducted in 64 hospitals in which nursing directors provided consent to participate in the study in advance. We mailed eight copies of the survey form for nursing directors in the target facility and asked them to distribute the survey to three to eight nurses who have worked in the neurosurgery/internal medicine ward for more than 3 years. Participants were asked to complete an anonymous survey form by themselves and to return it to the team if they consented to the research. The return of the survey form was recognized as consent to participate in this study. The participants of the second and subsequent surveys were those who have been asked to enter their name, mailing address of materials, and whether or not they have consented to the study in the dedicated form on the Web and have shown their consent.

2.3. Survey Procedure

At the time of the first survey, an explanatory document of the study was enclosed, and those who agreed to participate in the study were asked to answer the survey form. The answer results were summarized in feedback materials, along with free response questions. Feedback was incorporated and revised second survey forms were mailed to the participants who consented. Materials summarized the distribution and average of the answers, along with the free response from family members. The free response revealed the most important considerations, as perceived by the family regarding support needs. We asked the participants to respond to the survey form after referring to the feedback materials. Finally, we repeated the survey again and the results were analyzed.

2.4. Survey Items

Questionnaires were a useful tool for assessing the needs of the families of patients with malignant brain tumors. We created the questions needed to assess

specific needs from families of malignant brain tumor patients. We wrote 92 questions by reviewing all the subcategories from seven previous studies that qualitatively analyzed the thoughts and difficulties for families [13]-[19]. The questions were divided as follows: 15 questions regarding long-term care, 13 questions on thoughts for the future, 12 questions addressing communication with patients, 12 questions clarifying environments for long-term care, 11 questions assessing family acceptance and grief, 11 questions on thoughts regarding treatment, 11 questions evaluating the quality of life (QOL) of caregivers, and finally 7 questions considering patient wishes. Participants were asked to provide answers on a 1 - 5 rating scale, with 5 being necessary and 1 being unnecessary. In the first and second surveys, free description fields were provided to describe the questions that should be added and opinions on the questions.

Panelist Attributes

We asked that for nurses answering the questions to disclose their years of experience on the final survey.

2.5. Statistical Analysis

The selection rate and average value of the answers to each question were calculated for each survey. Questions were corrected, added, or deleted, with reference to the contents of the free response. The mean value was analyzed using the Mann-Whitney test for the first and second surveys, and the second and third surveys, respectively, in order to confirm the change in the mean value at each survey.

In the analysis of the third survey, out of five possible answers for each question, responses of five and four were combined and judged to be necessary, and the consensus rate was calculated accordingly. The average value of the consensus rate for all the questions used in the third survey was calculated, and 87.3% was set as the criterion for consensus. IBM SPSS Statistics for Windows, version 27.0 (IBM Corp., Armonk, N.Y., USA) was used for analysis in this study.

2.6. Ethical Considerations

This study was conducted with the approval of the Research Ethics Committee of the institution (approval number 2019-037). The researcher explained to the participants in writing about the anonymization of participants, the importance of protection of personal information, the data management methods, and the freedom to withdraw from the study.

3. Results

3.1. Participants' Years of Nursing Service

The 45 nurses who participated in the third survey had been working on an average of 14.7 ± 7.6 years and in the neurosurgery/internal medicine ward, an average of 7.3 ± 3.1 years (Table 1).

Table 1. Participants' years of nursing service in the third survey ($N = 45$).

	Mean	SD
Years of experience as a nurse	14.7	7.6
Years of experience in neurosurgery/internal medicine ward	7.3	3.1

3.2. First Survey

Out of all the nurses in each hospital distributing three to eight copies of the survey form (in 64 hospitals that consented to the study), 134 copies were collected. The average value of answers ranged from 3.3 to 4.6/5. The consensus rate ranged from 47.4% to 91.8%, with an average of 75.3%. There were 54 free responses regarding the questions (Table 2). Five additional questions were added after confirming that there was no duplication with other questions after the first survey. Based on the free responses, the wording of 29 questions was revised. This left four questions with duplicate contents for deletion. The total number of questions was changed to 93.

3.3. Second Survey

The second survey form was mailed to 94 nurses who agreed to the surveys, and of those, 49 copies were collected (recovery rate: 52.1%). The range of average values of answers was 3.6 - 4.8, showing significant improvement from the first survey (Mann-Whitney test, p < 0.001). The consensus rate ranged from 54.1% to 98.0%, with an average of 86.4%. There were 36 free responses regarding the questions. Based on those opinions, the terminology of 14 questions was revised, and four duplicate questions after revision were deleted. This resulted in the total number of questions as 81 in the second survey.

3.4. Third Survey

The survey form was mailed to the same 94 people as in the second survey, and 45 copies were collected (recovery rate: 47.9%). The range of average values was 3.8 - 4.8, showing no significant difference from the 2nd questionnaire. The results of 81 questions used in the third survey were analyzed upon receipt. The agreement rate in the 3rd survey was 64.4% - 97.8%, and an average of ≥87.3% was considered an agreement, which was 47 items (Table 3). The number of questions that were agreed upon by category was as follows: six questions for family acceptance and grief regarding illness and symptoms, five questions for thoughts on treatment, six questions for thoughts on patient intentions, seven questions for environment for long-term care, five questions for communication with patients, six questions for QOL of caregivers, eight questions for thoughts on long-term care, and four questions for thoughts regarding the future.

4. Discussion

Few tools have been developed that are specific to the families of malignant brain

tumor patients [9]. The aim of our study was to gather information that clinical nurses consider necessary for assessing the family involvement in malignant brain tumor patients. As a result of this study, 47 questions reached a consensus and were determined to be of value to the nurses.

Table 2. Results of responses to the survey form.

	First survey (N = 134)	Second survey (N = 49)	Third survey (N = 45)
The range of average values of answers	3.3 - 4.6	3.6 - 4.8	3.8 - 4.8
Median	4.2	4.5	4.5
Consensus rate (%)	47.1 - 91.8	54.1 - 98.0	64.4 - 97.8
mean	75.3	86.4	87.3

** = p < 0.001, Mann-Whitney test.

Table 3. Questions agreed upon in the 3rd survey (N = 45).

Category	Items	Consensus rate (%)
Thoughts on long-term care	Do you want to know more about the course of treatment and the patient's condition?	97.8
	Do you want to know information regarding long-term care?	95.6
	Are you worried about what to do if you have a seizure?	95.6
	Do you want to use the available social resources? * Examples of social resources: systems, facilities, funds, etc.	95.6
	Do you want to get rid of the patient's pain?	93.3
	Do you feel it difficult to lead a long-term care life after discharge?	93.3
	Are you worried if you can support your patient's feelings?	93.3
	Do you ever feel anxious about your patient being in trouble when you are not with them?	88.9
Thoughts on the future	Do you have any concerns about your future life?	95.6
	Are you worried if you can no longer care for yourself in the future?	93.3
	Is there anything you care about your family other than the patient?	91.1
	Are you worried about your patient's ability to lead a daily life after discharge?	91.1
Communication with patients	Do you ever use non-verbal communication methods such as speaking or gesturing by changing words and expressions to communicate with patients?	95.6
	Do you feel confused when patients have difficulty expressing their intentions in words?	95.6
	Can you take a long time to understand the patient's words?	93.3
	Do you feel happy when you have a conversation with your patient?	91.1
	Do you feel confused about the changes in the patient's personality?	91.1
Environment for long-term care	Do you ever want someone to talk to you about possible changes and how to deal with them?	97.8
	Is there a financial burden?	93.3
	Is there anyone close to you that you can trust?	91.1
	Do you feel anxious when you hear information about a patient's illness?	88.9

Continued

Family acceptance and grief over illness and symptoms	Is it likely that you will be able to receive support from those around you when you are not feeling well?	88.9
	Do you ever want to interact with a family member who supports a patient with the same illness?	88.9
	Is there anyone you can talk to?	88.9
	Are you worried about the patient's recurrence of illness or worsening of symptoms?	97.8
	Are you worried about the appearance of dementia symptoms and their exacerbations? * Dementia symptoms are a decrease in the ability to understand and judge stories. Dementia-like symptoms such as forgetfulness and depression	93.3
	Are you worried about the appearance and exacerbation of paralysis?	93.3
	Do you accept that the patient has become ill?	88.9
	Is there anything you would like to do with your patient?	88.9
	Do you ever get confused when you see a patient sad?	88.9
Thoughts on treatment	Do you feel the effect of treatment by watching the patient's (symptomatic) course?	93.3
	Can you ask hospital staff such as doctors and nurses?	93.3
	Are there times when a patient is worried about being able to tolerate the side effects of treatment?	91.1
	Would you like to hear from doctors at other institutions about your patient's treatment?	91.1
	Do you want to do what you can to treat your patients?	88.9
Quality of life (QOL) of caregivers	Can your feelings be affected by the ups and downs of the patient's mood?	93.3
	Does long-term care interfere with your work?	93.3
	Are you careful about your health?	91.1
	Do you have a meal?	91.1
	Do you think that nursing care will prevent you from doing what you want to do?	88.9
	Are you able to take a break?	88.9
Thoughts on patient intentions	Do you ever want to know the patient's true intentions?	97.8
	Do you want to respect the patient's intentions?	95.6
	Can you talk to the patient about his or her illness?	93.3
	Do you feel that the patient's perception of illness is different between the patient and yourself?	91.1
	Can you talk to the patient about your future life?	91.1
	Is it painful to be entrusted with important treatment decisions on behalf of the patient?	88.9

This study evaluated the need for more detailed questionnaires to be filled out by patients' family members to aid in communication with the nursing staff. The Delphi method aggregates the opinions of experts without being strongly influenced by them [10] [11] [12].

Nurses make decisions based on their own experiences and those items could be answered more objectively by summarizing the decisions based on the individual experiences of each nurse [20].

The reliability of the Delphi method's reliability is dependent on appropriate conditions having been set [11]. The participants in this study had an average of ≥7 years of work experience in the neurosurgery/internal medicine ward. Ac-

cording to the Benner Nursing Theory [21], nurses who have worked in similar situations for ≥5 years are positioned at the master level. An expert acts based on a deep understanding of the situation. Borel *et al.* also support this theory. A minimum of 30 participants is required for statistical power [12]; our study enrolled 45 participants, thus ensuring data reliability. The percentage of agreement is often used as the criterion for agreement [12]. Romero also reported that the criterion for consensus was considered rational if more than 70% of experts agree [12]. The consensus rate in this study was 87.3%; therefore, the settings of the Delphi method in this study are valid, and the results obtained using these parameters, reliable.

The novel 47 questions in this study overlapped with some items when compared to the generalized evaluation tool for the families of patients with cancer [6] [7] [8] [9], though this study had a greater focus on patient support goals. Because there was the category of "thoughts on patient intentions" in this study, patients with malignant brain tumors may have difficulty communicating. Confirming the family's thoughts on the patient's intention can greatly contribute to patient decision-making. We believe that the reason for this characteristic in this study is the difference in national culture. "Nursing to snuggle up" in Japan includes detecting the pessimistic feelings of the patient and supporting the decision-making [22]. Communication in Japan is based on educated guessing about others' behavior, and there is a need to focus on empathizing with the thoughts and needs of specific patient populations [22] [23]. From the above, there is a clear need for specific questionnaire items according to differences in national culture to ensure context for the information gathered.

Some items in this study had fewer questions related to neurological symptoms caused by malignant brain tumors than did the items previously developed [9]. It is worth considering items regarding anxiety-related to symptoms in the development of a family-specific tool for brain tumor patients.

Family caregivers of cancer patients have unmet needs and seek help with them [24] [25] [26]. Unsatisfied family needs lead to the poor emotional health of the family [25] [26]. In the case of malignant brain tumors with different patient symptoms and courses, the needs of the family also change with the course; thus, a continuous evaluation is required [26]. The questions selected in this study include questions to sympathize with the thoughts and needs of the family; utilizing the questions in this study may help clarify the needs and their changes of individual family caregivers. In the future, after designing the questions in this study as a tool, it will be necessary to verify the effectiveness of clinical screening.

In addition, we can expect that snuggling up to family will make it easier to build a relationship of trust. Studies show that a lack of communication between nurses and families causes issues [27] [28], especially in their interpretation of explanations inconsistent with the intention of the medical staff. Supporting relationship building between nurses and the patients' families can contribute to improving the quality of family support.

One limitation of this study is differences in the questions according to national culture. The questions extracted in this study are valid only in Japan. Timing of questionnaire administration during the patient's hospital stay was not determined; the score of each question might have been influenced by the hospitalization period in which they were answered. Future studies that clarify the timing of utilization, as well as national/cultural translation, are needed for broader application.

5. Conclusions

From the results of this study, we were able to clarify the 47 questions for assessing familial support for brain tumor patients. We believe that using these questions for information gathering and assessment tools will contribute to the understanding of the psychological state of the family, aiding nurses in developing strong relationships for the benefit of the patient.

Focusing information gathering items in clinical settings, it can be expected that nurses will be able to eliminate differences in perception based on years of experience and provide consistent care to the patient and family. The ease of self-administration also helps reduce the workload of nurses.

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Conflicts of Interest

The authors declare no conflicts of interest regarding the publication of this paper.

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