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Level of distress experienced by the patient with glioblastoma multiforme and the caregiver considering their medical education background: A qualitative study



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ABSTRACT

Introduction: Patients with glioblastoma multiforme (GBM) and their caregivers will face psychological distress. Identification of the distress level is crucial to control morbidity factors during treatment. This study aimed to describe the level of distress experienced by patients and their caregivers during the disease period by considering their medical education background. According to the author, this kind of study is limited.

Methods: The timeline was divided into the early stage of radiation treatment (T1) and the follow-up chemotherapy treatment (T2). All the subjects were screened for distress levels using the distress thermometer and National Comprehensive Cancer Network (NCCN) problem checklist followed by in-depth interviews. Significant distress was said to be positive if the DT score was > 4 . All of the subjects were divided into two groups, with and without a medical education background.

Results: From T1, subjects and caregivers with medical education (P-D) were higher than those without medical education (P-D > P-non D; C-D > C-non D). Another comparison shows that P-D was higher than C-D. In contrast, P-non D was lower than C-non D. Based on the time data collected, it showed DT: P-non D T2 > P-non D T1, but there was no difference between T2 and T1 in the caregiver's group: C-non D T1 = C-non D T2. From the NCCN problem checklist, it was known that they attributed their distress mostly to physical problems.

Conclusion: Knowledge of the disease is not only a helpful way to deal with GBM but also a contributing factor to the severity of distress. Providing 'wise' information for each patient and their caregiver is needed to achieve the therapeutic goal and optimally increase the patient's quality of life.

Keywords: caregiver; distress; DT scores; medical knowledge status; glioblastoma multiforme.

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INTRODUCTION

Glioblastoma multiforme (GBM) is a primary brain tumor with characteristics of easy recurrence with extensive infiltration of other tissues. The prognosis of patients with GBM is poor with a survival rate from 13 to 16 months. Due to the course of disease symptoms, treatment, and prognosis, the patient and their caregivers will face psychological distress. Identification of the distress level is crucial to control morbidity factors during treatment. This study aimed to describe the level of distress experienced by patients and their caregivers during the disease period by considering their medical education background. According to the author, this kind of study is limited.

METHODS

This study was performed using the convenience sampling method. Inclusion criteria for this study were patients with GBM, age ≥ 18 years old applied for the patient and their caregivers, and able to sign the informed consent letter applied for the patient and their caregiver. Exclusion criteria were patients who reached the palliative care phase and persons who were not able to understand the question because of their disabilities. Before the study data was collected, all informed consent had been obtained. This study accepted types of patient-caregiver relationships such as husband, wife, parent-children, or siblings. After the samples were collected, it divided into two

groups which were patients or caregivers with a medical education background and patients or caregivers without a medical education background. Participants were recruited between October 2005 and March 2012.

This study was a cross-sectional study and the data was taken from patients in Neurosurgery Clinic MRCCC Siloam Jakarta. The patient who had GBM along with their caregivers get a questionnaire-based survey and in-depth interviews. The questionnaire was made based on the thermometer (DT) and the National Comprehensive Cancer Network (NCCN) checklist to determine patients and their caregivers' levels of distress. In addition, histories of the disease

like diagnoses, anatomical pathology data, immunohistochemistry, stages of treatment, type of surgery, tumor location, and Karnofsky performance score (KPS) were collected to support this study. Time-setting data collection was divided into the early stages of radiation treatment (T1) and the follow-up chemotherapy treatment (T2). Four pairs of patient caregivers were assigned to T1, and two pairs of patient caregivers were assigned to T2. Most of the data was taken directly from the patient. We also separated the group of samples based on their educational background. The first group was a medically educated subject like a doctor and another was a non-medical educated subject.

DT score was a stress scale with a measuring method based on patient reports. The range of values was from 0 to 10. The interpretation of the sample distress level was in line with the numbers on the DT score. Another part of the questionnaire was a list of physical problems, family problems, emotional/mental problems, and spiritual problems. This section was accompanied by in-depth interviews conducted by doctors to support the study of descriptive data. Significant distress was said to be positive if the DT score was ³ 4.

RESULTS

Data from four pairs were collected at T1. They are in the early radiotherapy phase. Another specification of their clinical condition is explained below. Slight differences are still considered the same in this study.

Case 1 was a patient with a tumor on the left thalamus that had spread to the lateral intraventricular. The diagnosis was confirmed as GBM from a biopsy examination. O-6-methylguanine-DNA methyltransferase (MGMT) and epidermal growth factor receptor (EGFR) were negative. This patient had no complaints, so the KPS was 100. From the educational background, this patient was medically educated (P-D) and the caregiver was also medically educated (C-D).

Case 2 was a patient who had a tumor on the right parietal. The diagnosis was confirmed as GBM from a biopsy examination. MGMT and EGFR were positive. This patient had minor complaints

without any interference with daily life, so the KPS was 90. From the educational background, this patient was medically educated (P-D), but the caregiver was not medically educated (C-non D).

Case 3 was a patient who had a tumor on the right frontal. The diagnosis was confirmed as GBM from a biopsy examination. MGMT and EGFR were positive. This patient had no complaints, so the KPS was 100. From the educational background, this patient was not medically educated (P-D), but the caregiver was medically educated (C- non D).

Case 4 was a patient who had a tumor on the right parietal. The diagnosis was confirmed as GBM from a biopsy examination. MGMT was negative and EGFR was positive. This patient had no complaints, so the KPS was 100. This patient and caregiver were not medically educated (P-non D, C-non D).

Data from two pairs were collected at T2. They were in the follow-up chemotherapy treatment phase. Another specification of their clinical condition is explained below. Slight differences were still considered the same in this study. We included these two cases to support an analytical view of this study. Case 5 and 6 had the same clinical condition and educational background. Both of the cases are pairs of patients and caregivers without medical education background (P-nonD, C-non D).

We obtained data from T1 and found that patients with medical education (P-D) had higher DT scores than patients without medical education. This result is similar to the caregiver's group, where those who have a medical education background have a higher DT score than those who do not have (C-D is > C-Non D). An additional analysis was performed to compare patients and caregivers. The result is that P-D had a higher DT score than C-D. In contrast, P-non D had a lower DT score than C-non D.

After cases 5 and 6 were assigned to T2, comparisons were made between P non-D T1 and P non-D T2. The distress experienced by patients without medical education at T2 was more severe than in patients from T1 (DT: P-non D T2 > P-non D T1). There was no difference between T2 and T1 in the caregiver's group (C-non

D T1 = C- non D T2). Another part of the questionnaire was a list of physical problems, family problems, emotional/mental problems, and spiritual problems. In-depth interviews accompanied this section, and the results showed that the patients who had a medical education background felt that their knowledge was a contributing factor to distress and a positive supporter when dealing with illness and the course of therapy.

From the NCCN problem checklist, it was known that they attributed their distress mostly to physical problems. This occurred in all groups, both patients and caregivers with or without a medical education background. Other problems detected were very diverse, ranging from financial stressors, therapeutic decisions, interpersonal relationships, and emotional problems such as fear, anxiety, depression, and spiritual belief.

DISCUSSION

Glioblastoma multiform is a primary brain tumor with characteristics of very easy to recur with extensive infiltration of other tissues. Treatments such as resection and adjuvant chemotherapy do not cure but only increase survival to 13 – 16 months. Although GBM is the most common primary brain tumor and the number of cases is 45.2%, it has a poor prognosis.¹⁻³ GBM requires an anticancer that penetrates the blood-brain barrier and can accumulate at therapeutic levels in tissues to provide effective anticancer treatment in patients. Another difficulty of GBM therapy is the poor response of tumors to conventional DNA-damaging chemotherapy. This is associated with tumor characteristics that are molecular heterogeneity and highly mutable. The currently available and FDA-approved chemotherapy regimen options are temozolomide for newly diagnosed GBM and bevacizumab for recurrent GBM.^{2,4} After the patient underwent surgery, therapy followed by radiotherapy combined with temozolomide increases the survival rate, although it does not have a curative effect.^{5,6}

The effects of disease caused by brain tumors, both physical and cognitive, the patient's independence in carrying out activities of daily living (ADLs), and

mood changes make the patient have to experience transitions in economic, social, and interpersonal relationships with family members. These changes affect the quality of life of the patients, families, and communities.⁷ The patient is susceptible to psychological problems; about 74% of patients show this problem.⁸ Patients with brain tumors must face the diagnosis of malignancy, future unavoidable treatments, and prognosis. Early diagnosis and treatment of psychological distress are steps to treat comorbid factors to provide the best medical care for patients.⁹

Distress can affect how patients cope with the diagnosis, treatment, and prognosis of malignant disease. Malignant disease or cancer makes the patient undergo a troublesome period of psychological, social, spiritual, and physical nature during his life. The range of complaints felt by patients when experiencing distress is vast, from common normal feelings of vulnerability, sadness, and fears to symptoms of mood disorders that provide impairment in mental health.¹⁰ For example, depression has an incidence in 58% of patients and 34% report anxiety symptoms.¹¹ The NCCN Distress Management Panel launched the Distress Thermometer, which is used to estimate the level of patient distress during screening. These tools consist of a range score of 0 – 10, with higher scores indicating higher levels of distress.¹⁰ More specific interpretations can describe the severity of distress: 3–4 refers to significant distress, 5 is moderate distress, and 10 is very severe distress.¹⁰ Another part of the NCCN Distress Management Panel is a screening tool that includes a 39-item problem list, which is on the same page as the DT. These tools are expected to be able to measure and identify sources of patient distress.¹⁰ Patients' changes and disabilities during their illness make them need support from familial caregivers.¹²⁻¹⁴ Feelings of anxiety, depression, insomnia, agitation, fatigue, and decreased concentration experienced by familial caregivers during the patient's treatment process led to distress, where 85% of them have higher scores than patients.^{15,16} The high rate of distress will have an effect that is in line with daily life activity problems during their chemotherapy phase.¹⁷

The goal of therapy is to improve the patient's quality of life by controlling non-tumor morbidity factors such as distress. Therefore, the distress identification for the patient and the caregiver is important.

DT score ³ 4 is used as a cut-off point to determine if the participants experience significant distress or not. Patients with GBM are known to have significant distress with a prevalence rate of 38.2%. Out of the total sample, 41.1% had a DT score ³ 4, and 29.7% had a DT ³ 6.¹⁸ From time setting 1 (T1), the average DT value for both patients and caregivers with medical educational backgrounds was 10. This score was interpreted as severe distress.¹⁰ In contrast, with patients and caregivers who did not have a medical educational background, the DT score was only five, although this also indicated distress. Considering the medical education background as the value of knowledge of the disease, this is contrary to other experimental studies, which show the effects of knowledge provide significantly less anxiety; these data were taken in the radiation therapy phase.¹⁹ Other studies have also shown that patient knowledge of the disease and treatment phase has a positive effect by reducing the incidence of depression and increasing adherence and understanding during therapy.²⁰

The use of cut-off points can be different. Other studies are using DT ³ 6 to indicate significant distress in the intracranial tumor setting.²¹ In this study, a DT score ³ 4 was interpreted as significant distress, ³ 5 was moderate distress, and 10 was severe distress. This cut-off point determined the route of referral for distress cases to provide the best treatment for patients with GBM. Clinical interviews to screen anxiety and depression by the oncology team may be reserved for mild distress (DT4). If necessary, the oncology team should refer them to a psychologist, social worker, or spiritual counselor based on the causes of distress identified in the NCCN Problem List. This prevention is reserved for those with a DT score ³ 4.¹⁰

This study also tries to describe the distress experienced by the caregivers of patients with GBM. Like in the patient group, we divided the caregivers into two groups: with and without medical educational background. From the time

setting one (T1), all of the participants felt significant distress. Nevertheless, the medical education background variable shows the effect of the mean DT score, C-D had 5 points greater than C-non D. Studies assessing the distress felt by caregivers have been conducted with the results that up to 85% of participants have a DT score ³ 4. This study was conducted in the setting of caregivers from patients with brain tumors; the mean DT scores were recorded to be higher than patients.^{15,16} To better understand the distress felt by the patient and their caregivers, two pairs of participant data were added later. Data collection for these two pairs was carried out in the post-chemo phase (T2). Because both cases were patients and caregivers who do not have a medical education background, the comparison was only based on the time of collection. The patient's DT score (P-non D) was increasing 5 points from T1 to T2. Meanwhile, caregivers showed the same mean score between T1 and T2. Increasing the mean DT score from T1 to T2 may be related to the coping mechanism of the participants. This is based on the results of a study showing that the patient's distress is higher after passing one-week post-diagnosis and continues to rise until the fourth week.²²

Participants who attended the interview indicated that stress screening is a form of comprehensive treatment that has positive benefits for the patient's physical and mental health. Knowledge of disease and treatment is an important factor in considering how to inform patients and caregivers. People with medical education backgrounds need data-based explanations. In addition, this knowledge not only helps patients deal with GBM but also increases the respondent's stress.

CONCLUSION

Patients with GBM have more than just a problem with their diagnosis. The physical and mental changes experienced by patients cause distress for patients and their caregivers. Knowledge of disease and treatment possessed by patients or caregivers helps them deal with GBM and the entire course of treatment. However, this is also a contributing factor to the severity of distress based on the DT score.

Providing 'wise' information for each patient and their caregiver is needed to achieve the therapeutic goal and optimally increase the patient's quality of life.

CONFLICT OF INTEREST

There is no conflict of interest related to the materials or methods used in this study.

AUTHOR CONTRIBUTION

All authors contributed to the conception and design or analysis and interpretation of the data and drafting or revising the articles. All authors approved the final version and agreed to be responsible for all aspects of their work.

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ETHICAL APPROVAL

This research has obtained Ethical Clearance from the research ethics board of MRCCC Siloam Semanggi Hospital Jakarta.

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