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Quality of life of primary brain tumor patients before and 3 months after discharge from a hospital in Bandung, Indonesia

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Abstract

Background: The quality of life of patients with primary brain tumor in Indonesia is poorly understood. Therefore, this study aimed to investigate the health-related quality of life of patients admitted to the Neurosurgery Department of Dr. Hasan Sadikin Hospital, Bandung, Indonesia, up to 3 months after discharge. Methods: Baseline data were collected from patients aged ≥18 years who were admitted to the hospital between October 9, 2015, and February 17, 2016. In-person interviews were then conducted 1–2 days pre-discharge (n = 65) and follow-up telephone interviews were made 1. 2, and 3 months post-discharge (n = 58, 55, and 54, respectively) to collect socio-demographic data, clinical characteristics, and EQ-5D-5L data. Results: Prior to discharge, one-third or less of the 65 patients interviewed reported “no problems” with mobility (32%), self-care (32%), usual activities (18%), and pain/discomfort (43%), whereas 74% reported “no problems” with anxiety/depression. By contrast, at 3 months post-discharge, an increased proportion of patients reported “no problems” with mobility (61%), self-care (67%), usual activities (56%), and pain/discomfort (76%), with little change in anxiety/depression (“no problems” 70%). Conclusions: While there was improvement, many patients were still reporting problems at 3 months post-discharge, highlighting the need for ongoing support and care to ensure the best possible outcomes.

Keywords: Indonesia, primary brain tumor, quality of life

Introduction

The incidence of brain tumors is increasing each year in some parts of the world.1,2 There are two types of brain tumors: primary tumors derived from the brain tissue, and metastases from other sites.3 Primary brain tumors are rare, accounting for 1.4% of all cancers and having an incidence of 17.6–22 per 100,000 population in America and Europe.4,5 In Indonesia, the incidence is 7 per 100,000 and the mortality rate from brain tumor is 4.25 per 100,000 population per year.5

Patients who are diagnosed with primary brain tumors and who need to undergo a course of treatment can experience various adverse effects on their health. A study reported that more than 74% of patients with primary brain tumor experience difficulties in several domains of life, including motor dysfunction, verbal communication barriers, physical weaknesses, and incontinence.6 Moreover, brain tumors can also affect patients economically and socially, with family members needing to cope with changes in the physical and cognitive capacities, personality, and mood of their relatives.6 Thus, a brain tumor can affect the quality of life of not only the patient but also their families and communities. In addition, numerous other studies have documented the impaired function of patients who have had primary brain tumors, as well as a high demand for supportive care that is often unmet.4

The management of primary brain tumors involves not only stabilizing tumor growth and prolonging the patient's life but also preserving the physical, cognitive, and emotional states of the patient.7 Management usually involves surgery but may also include chemotherapy, radiotherapy, and other adjuvant therapies,8 all of which have the potential to impact on the patient's quality of life.9 Therefore, the benefits of extended survival and/or progression delay have to be carefully balanced against the side effects of treatments and their potential negative impact on functioning and quality of life.10

Quality of life is an individual's perception of their physiological, social, and physical position in life according
to the prevailing cultural context and value system, and their own goals, expectations, and standards. Assessment of the health-related quality of life of patients with primary brain tumor is important as this can serve as an easy and cost-effective tool for recognizing early changes in the subjective clinical conditions of patients and their association with disease progression.

The provision of support services to patients after discharge from hospital may help alleviate the burden they and their family feel. However, little is currently known about the main problems and difficulties that patients with primary brain tumor in Indonesia face and thus what support services are appropriate. Therefore, the aim of this study was to investigate the quality of life of patients with primary brain tumor before, and 3 months after, discharge from a major tertiary referral hospital in Bandung, Indonesia.

Methods

Study setting and design. Our prospective study was undertaken with patients aged 18 years and over who had been admitted to the Neurosurgery Department of Dr. Hasan Sadikin Hospital, Bandung, from October 9, 2015 to February 17, 2016, and diagnosed with a primary brain tumor. Baseline data collected at the time of admission were obtained from each patient's clinical notes. Once the patient was stabilized, a research nurse approached them to explain the study and seek their consent to participate. The interview schedule for consenting participants comprised an in-person interview at 1–2 days pre-discharge and a follow-up telephone interview at 1, 2, and 3 months post-discharge. All interviews were conducted in the Indonesian language by an experienced neurosurgery research nurse. Ethical approval was obtained from the ethics committees of the University of Otago, Dunedin, New Zealand (Reference No. H15/078), and the Faculty of Medicine, Universitas Padjadjaran, Bandung (No. 682/UN6.C1.3.2/KEPK/PN/2015).

Data collection. Patients were asked about their socio-demographic and clinical characteristics, as well as their health pathway prior to admission, such as their presenting symptoms and the time they waited before seeing a health professional. At each follow-up interview, the EQ-5D-5L was administered to assess each patient's health-related quality of life.13 The EQ-5D-5L has five dimensions: mobility, self-care, usual activities, pain/discomfort, and anxiety/depression. Patients self-report the level of difficulty they have in each of these dimensions according to a five-level scale: no, slight, moderate, severe, or extreme problems. We also used the EuroQol Visual Analogue Scale (EQ-VAS) which asks patients to indicate on a scale from 0 (worse) to 100 (best) how they describe their health state today.

Statistical analysis. All data were recorded onto a patient case report form, coded, and entered into a secure electronic database. The data were then cross-checked by two doctors. Quantitative data are reported as proportions for categorical data and as means, standard deviations, and ranges for continuous data. Data analysis was undertaken using Stata version 12.1.

Results

A total of 83 patients were admitted to the Neurosurgery Department during the recruitment period and diagnosed with a brain tumor. Eighteen of these patients died while in hospital and a further seven died following discharge. All of the surviving patients at the time of discharge (n = 65) consented to participate in this study, and 93% of those who were still alive after 3 months participated in the follow-up interview (Figure 1).

Of the 65 patients who completed the pre-discharge interview, the mean age was 44 years (range 18–76) and 69% were female. The majority were living in their own or their parents' home (95%), and were either in paid employment (34%) or working in the home or retired (57%). All participants were married. (Table 1).

The patients were diagnosed with meningioma (68%), glioma (14%), craniopharingioma (6%), and other tumors, such as rhabdomyosarcoma, adenocarcinoma, fibrous dysplasia, astrocytoma, pinealblastoma, and osteoma (12%). The majority of patients (60%) presented to another hospital before being referred to Hasan Sadikin Hospital, 17% were admitted directly to the Neurosurgery Department, and 23% were readmitted from a previous stay (Table 2). The majority of patients (97%) were discharged to their own home, with a family member being named as the main caregiver in nearly all cases. Half of the patients (49%) lived more than 2 hours travel time from Hasan Sadikin Hospital, but 69% were within 30 minutes of their nearest community health center (Table 3).

The majority (89%) of patients received surgical treatment, with only seven being treated conservatively (Table 2). At the time of discharge, 68% of patients reported problems with mobility, 68% with self-care, 82% with usual activities, 57% with pain/discomfort, and 26% with anxiety/depression (Table 4). Of those who reported problems with mobility, self-care, and usual activities, one-third or more reported that they were having extreme problems.

Month 1 follow-up. A smaller proportion of the 58 patients who were interviewed 1 month after discharge reported problems on the EQ-5D-5L compared with pre discharge. However, 50% continued to report problems with mobility, 49% with self-care, 72% with usual
Table 1. Characteristics of the 65 brain tumor patients who completed the pre-discharge interview

| Characteristic                              | n (%)  |
|--------------------------------------------|--------|
| **Sex**                                    |        |
| Male                                       | 20 (31)|
| Female                                     | 45 (69)|
| **Age mean ± SD (range)**                  | 44 ± 12 (18–76) |
| **Age group**                              |        |
| 18–29                                      | 10 (15)|
| 30–39                                      | 7 (11) |
| 40–49                                      | 29 (45)|
| 50–59                                      | 13 (20)|
| 60+                                        | 6 (9)  |
| **Education**                              |        |
| Primary school or less                     | 24 (37)|
| Junior high school completed               | 16 (25)|
| High school graduate                       | 21 (32)|
| College graduate or tertiary education      | 4 (6)  |
| **Occupation**                             |        |
| Employed                                   | 22 (34)|
| Not employed (including students)          | 6 (9)  |
| Housewife/husband or pensioner             | 37 (57)|
| **Married:**                               | 65 (100)|
| **Normal place of residence**              |        |
| Own home                                   | 56 (86)|
| Parents’ home                              | 6 (9)  |
| Other family or other residence            | 3 (5)  |
| **Number of people normally living in household** |    |
| 1–4                                        | 40 (62)|
| ≥5                                         | 25 (38)|

**Figure 1.** Flowchart of brain tumor patient participation
Table 2. Clinical characteristics of the 65 brain tumor patients who completed the pre-discharge interview

| Characteristic                                      | n (%) |
|-----------------------------------------------------|-------|
| **Type of tumor**                                   |       |
| Glioma                                              | 9 (14)|
| Meningioma                                          | 44 (68)|
| Craniopharingioma                                   | 4 (6) |
| Other                                               | 8 (12) |
| **Treatment**                                       |       |
| Surgical                                            | 58 (89)|
| Conservative                                        | 7 (11) |
| **Admission**                                       |       |
| Direct to Dr. Hasan Sadikin Hospital                 | 11 (17)|
| Referral from another hospital                       | 39 (60)|
| Readmitted from previous stay in Dr. Hasan Sadikin Hospital | 15 (23)|
| **First health professional seen after the onset of symptoms** | | |
| Emergency department staff                           | 18 (28)|
| Private doctor                                       | 8 (12) |
| Public health service (community clinic)             | 4 (6)  |
| Other (e.g. other specialist)                        | 35 (54)|
| **Time from the onset of symptoms to first seeing a health professional** | | |
| < 1 hour                                             | 4 (6)  |
| 1–24 hours                                           | 4 (6)  |
| 1–5 days                                             | 15 (23)|
| 6–30 days                                            | 11 (17)|
| 1–12 months                                          | 14 (22)|
| > 12 months                                          | 8 (12) |
| Not available                                        | 9 (14) |

Table 3. Discharge characteristics of the 65 brain tumor patients who completed the pre-discharge interview

| Characteristic                                      | n (%) |
|-----------------------------------------------------|-------|
| **Place of discharge**                              |       |
| Same as before admission                            | 63 (97)|
| Different                                           | 2 (3)  |
| **Caregiver after hospital discharge***             |       |
| Spouse                                              | 49 (75)|
| Child                                               | 35 (54)|
| Parent                                              | 10 (15)|
| Other family                                         | 5 (8)  |
| Friend                                              | 1 (2)  |
| **Travel time from place of residence to the Neurosurgery Department at Dr. Hasan Sadikin Hospital** | | |
| < 1 hour                                             | 4 (6)  |
| 1–2 hours                                            | 25 (39)|
| 3–4 hours                                            | 23 (35)|
| ≥ 5 hours                                            | 9 (14) |
| Not available                                        | 4 (6)  |
| **Travel time from place of residence to nearest hospital/primary health center** | | |
| <30 minutes                                          | 45 (69)|
| 30–59 minutes                                        | 12 (18)|
| ≥60 minutes                                          | 8 (13) |

*more than one caregiver may be indicated
activities, 45% with pain/discomfort, and 35% with anxiety/depression (Table 4). Of those who reported problems with mobility, self-care, and usual activities, between 21% and 29% reported that these were “extreme.”

Month 2 follow-up. A smaller proportion of the 55 patients who were interviewed 2 months after discharge reported problems in each of the dimensions compared with the previous month. However, 43% still reported problems with mobility, 40% with self-care, and 60% with usual activities (Table 4). Furthermore, 18%–25% of those reporting problems and difficulties in each of these dimensions indicated that they were “extreme.” In addition, 36% of patients reported problems with pain/discomfort and 31% with anxiety/depression.

Month 3 follow-up. Of the 54 patients who were interviewed 3 months after discharge, 39% continued to report problems with mobility, 33% with self-care, 44% with usual activities, 24% with pain/discomfort, and 29% with anxiety/depression (Table 4).

EQ-VAS. Prior to discharge the mean EQ-VAS was 81.4. This increased to a mean of 91.7 three months after discharge from the hospital.

Discussion

Our small prospective study of quality of life in patients with a primary brain tumor showed that 1, 2, and 3 months after discharge from the hospital patients mostly improved, particularly in the EQ-5D-5L dimensions of mobility, self-care and usual activities. For those who continued to experience problems in these dimensions, they were reported as being “extreme” problems. Pain and discomfort was reported by fewer patients after 3 months and this was mostly reported as being only “slight”. Unusually, very few people reported problems with anxiety or depression and those who did, reported only “slight” problems.

The majority of patients in our study were female which is in accordance with the literature where it is shown that the incidence of brain tumors is more common in

| Dimension          | Pre-discharge n = 65 | Month 1 n = 58 | Month 2 n = 55 | Month 3 n = 54 |
|--------------------|----------------------|----------------|----------------|----------------|
| EQ-5D Mobility     |                      |                |                |                |
| No problems        | 21 (32)              | 29 (50)        | 31 (57)        | 33 (61)        |
| Slight problems    | 15 (23)              | 6 (10)         | 9 (16)         | 9 (17)         |
| Moderate problems  | 8 (13)               | 10 (17)        | 4 (7)          | 2 (4)          |
| Severe problems    | 2 (3)                | 1 (2)          | 1 (2)          | 1 (2)          |
| Extreme/unable     | 19 (29)              | 12 (21)        | 10 (18)        | 9 (16)         |
| EQ-5D Self-care    |                      |                |                |                |
| No problems        | 21 (32)              | 30 (51)        | 33 (60)        | 36 (67)        |
| Slight problems    | 15 (23)              | 5 (9)          | 8 (15)         | 6 (11)         |
| Moderate problems  | 7 (11)               | 11 (19)        | 3 (5)          | 2 (4)          |
| Severe problems    | 2 (3)                | 0 (0)          | 1 (2)          | 1 (2)          |
| Extreme/unable     | 20 (31)              | 12 (21)        | 10 (18)        | 9 (16)         |
| EQ-5D Usual activities |                  |                |                |                |
| No problems        | 12 (18)              | 16 (28)        | 22 (40)        | 30 (56)        |
| Slight problems    | 12 (18)              | 11 (19)        | 10 (18)        | 7 (13)         |
| Moderate problems  | 12 (18)              | 12 (21)        | 7 (13)         | 4 (7)          |
| Severe problems    | 1 (2)                | 2 (3)          | 2 (4)          | 2 (4)          |
| Extreme/unable     | 28 (44)              | 17 (29)        | 14 (25)        | 11 (20)        |
| EQ-5D Pain/discomfort |                |                |                |                |
| No problems        | 28 (43)              | 32 (55)        | 35 (64)        | 41 (76)        |
| Slight problems    | 30 (46)              | 18 (31)        | 16 (29)        | 10 (19)        |
| Moderate problems  | 7 (11)               | 7 (12)         | 4 (7)          | 3 (5)          |
| Severe problems    | 0 (0)                | 1 (2)          | 0 (0)          | 0 (0)          |
| Extreme/unable     | 0 (0)                | 0 (0)          | 0 (0)          | 0 (0)          |
| EQ-5D Anxiety/depression |             |                |                |                |
| No problems        | 48 (74)              | 38 (65)        | 38 (69)        | 38 (71)        |
| Slight problems    | 16 (24)              | 14 (24)        | 13 (24)        | 11 (20)        |
| Moderate problems  | 1 (2)                | 5 (9)          | 4 (7)          | 5 (9)          |
| Severe problems    | 0 (0)                | 1 (2)          | 0 (0)          | 0 (0)          |
| Extreme/unable     | 0 (0)                | 0 (0)          | 0 (0)          | 0 (0)          |
women. The mean age of patients was 44 years which is lower compared to that found in many developed countries. Age is a strong prognostic factor affecting brain tumor survival. A study showed that younger age onset primary brain tumor survivors should receive years of systematic follow-up due to potential late morbidity and risk for impaired quality of life because of both somatic and psychosocial causes. However, an analysis shows that for older patients aged over 65, there was no apparent clinically significant improvement in survival rates for all brain tumor types compared with younger patients with anaplastic gliomas and medulloblastomas. In our study, the improvement in mobility, self-care and usual activities may be impacted by the greater number of younger patients who may be able to recover more quickly compared to older patients. It may also simply be the natural result of reduction in symptoms following surgery to remove the tumor which generally makes the patient feel and function better. The high death rate in our study (18 people while in hospital and 7 post-discharge) is in keeping with the literature on brain tumor mortality. It is also possible that those who survived, and were therefore included in our study, may have had a less severe type of tumor and were able to recover more quickly following surgery.

Of the patients who reported pain or discomfort pre-discharge this was mostly slight pain. This improved and after 3 months only a very small number were still reporting slight pain. In general, the pain felt by brain tumor patients is headache. There are several mechanisms that can cause headaches in brain tumor patients, which consist of suppressing tumor masses against arteries and veins around the meninges, inflammatory processes, and cerebral edema due to damage to the blood-brain-barrier. The mechanism that can cause headache can be overcome by reducing the mass effects of brain tumors, one of which is surgery, as done in the majority of patients in our study.

It was surprising that so few patients reported problems with anxiety or depression at each interview time particularly given that the experience of receiving a diagnosis of brain tumor, hospitalisation and undergoing major surgery are all major stresses on an individual. In the pre-discharge interview, there may be an element of relief that the surgery is over and they are able to be discharged. In the subsequent interviews, the low level of anxiety or depression may be because the symptoms felt by the patients are diminishing, they have increasing mobility, self-care and usual activities and are therefore generally feeling better. A study explained that there is a relationship between physical symptoms and emotional conditions in brain tumor patients, where the more physical disorders experienced by patients, the more it will make patients experience anxiety or depression.

Our study showed that the patient's EQ-VAS increased from pre-discharge to a value of almost 92 three months after discharge. No other studies in Indonesia, have reported on the quality of life of patients with brain tumor using the EQ-VAS but a study in Indonesian women with breast cancer reported a mean EQ-VAS of 69.1. This study, however, was undertaken before a definitive diagnosis of breast cancer so it likely to be different to a VAS recorded after treatment and discharge from hospital. Regardless, an EQ-VAS is a subjective judgment by the patient regarding their health or illness perception. Illness perception, which is a central concept in the self-regulatory common sense model of health and illness, may contribute to outcomes such as depressed and anxious mood states. A meta-analysis study explained that illness perception has an important role in causing symptoms of distress and emotional condition in a variety of physical health conditions of cancer patients. Understanding why patients in our study had such a high EQ-VAS value would require further research. Our study was limited by its small sample size. Study participants were from one tertiary public referral hospital in Bandung and may not be representative of the of all patients with a brain tumor in Indonesia.

Conclusions

Although more than half of the participants in this study stated that they were better 3 months after discharge from the hospital, many were still reporting problems. Therefore, there is a clear need for ongoing support and care of patients with a primary brain tumor to ensure they have the best possible outcomes.

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Conflict of Interest Statement

The authors declare no conflict of interest

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