



High psychosocial burden in relatives of malignant brain tumor patients

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ARTICLE INFO

Keywords:

Neurooncology
Psychooncology
Anxiety
Depression
Stress
Caregiver

ABSTRACT

Objective: Not only tumor patients suffer enormously from their disease, also the caregivers are massively affected by the disease of their relatives. In this study, we investigate the psychological burden in caregivers of outpatient malignant brain tumor patients.

Patients and Methods: Fifty caregivers of patients with primary malignant brain tumors were included in our study. Study participants filled in a form with demographic details, a self-established questionnaire concerning general well-being and three established psychological questionnaires to assess anxiety, depression, stress and social support: The “Hospital Anxiety and Depression Scale” (HADS), the “Perceived Stress Scale” (PSS-10) and the “Social Support Questionnaire” (F-SozU).

Results: Caregivers of patients with primary malignant brain tumors showed in the HADS clinically relevant anxiety in 49% and depression in 20% of the cases. The stress level of the caregivers was increased (mean: 18 points) compared to the general population mean: 13 points), although they felt well supported by their social environment (mean: 4.25 points; general population 3.99 points). There was a significant positive correlation between anxiety and depression ($p < 0.001$). Female caregivers suffered significantly more from anxiety ($p = 0.017$) and stress ($p = 0.012$) than their male counterparts. No correlation was found between tumor grade, age of relatives and patients or the state of living together with the patient and anxiety or depression.

Conclusions: Although the caregivers felt well supported by their social environment, stress, anxiety and depression are common phenomena in caregivers of patients with malignant brain tumors. Especially female ones have an increased risk for developing these comorbidities.

1. Introduction

It is not only the patients with cancer that suffer from anxiety, depression and stress, but also their family members and close friends who suffer enormously. Relatives are often overburdened with the situation of taking care of the patient, they feel alone and socially isolated [1]. Studies showed an increased risk for caregivers for not only stress, anxiety and depression, but also an increased morbidity and mortality [2]. It was indicated that in the first three months after diagnosis, partners of brain tumor patients might be even more affected than the patients themselves with almost half of them suffering from a psychiatric disorder, mainly adjustment disorder [3].

Especially patients with a malignant brain tumor (WHO grade III or IV) have a short life expectancy with only a few months or years to live.

In contrast to other primary cancer types, brain tumors do not only affect motoric and sensory functions, but also cognitive function and personality. This might result in a higher burden for caregivers of malignant brain tumors compared to those of other cancer types [4]. Boele et al. [5] found that relatives of high-grade glioma patients showed lower mental scores and lower social functioning than caregivers of a comparable non-CNS-cancer group.

With progression of the disease patients become more and more cognitively restricted and relatives have to take care of decisions they might not be prepared to take. Time for own activities becomes less to non-existing; many caregivers have to give up their job or reduce their employment [6].

The aim of our study was to analyze psychological well-being, anxiety, depression and stress in relatives of outpatients with malignant

Abbreviations: CNS, central nervous system; HADS, Hospital Anxiety and Depression Scale; PSS, Perceives Stress Scale; WHO, World Health Organization; F-SozU, Fragebogen zur sozialen Unterstützung (“Social Support Questionnaire”)

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<https://doi.org/10.1016/j.clineuro.2018.04.023>

Received 15 January 2018; Received in revised form 10 April 2018; Accepted 22 April 2018

Available online 24 April 2018

0303-8467/ © 2018 Published by Elsevier B.V.

Table 1
Study population.

	n
<i>Gender</i>	
Female	30 (60%)
Male	20 (40%)
<i>Age [years]</i>	
Mean/Median	49/51
Range	21–72
<i>Tumor grade of the patient</i>	
III	30 (60%)
IV	19 (38%)
Not known	1 (2%)
<i>Relationship to the patient</i>	
Spouse/unmarried partner	32 (64%)
Child	10 (20%)
Parent	4 (8%)
Other	4 (8%)

n: number of participants.

brain tumors and correlate these factors with each other, social support, patient's details and demographic factors of the relatives.

2. Patients and methods

2.1. Study population

In total, 50 relatives of patients with primary malignant brain tumors WHO grade III and IV were included in our cross-sectional survey; 30 (60%) were female and 20 (40%) male (Table 1). The median age was 51 years (range 21–72 years). Patients suffered from glioblastoma multiforme (WHO grade IV) in 19 cases (38%) and from a brain tumor WHO grade III (anaplastic astrocytoma/oligoastrocytoma/oligodendroglioma (n = 28) or anaplastic meningioma (n = 2)) in 30 cases (60%); one person did not provide information about the diagnosis of the patient (2%).

2.2. Study procedure

A five-page study document was created containing questions about age, gender and diagnosis of the associated patient, demographic questions about the caregiver, 16 self-designed questions about the general well-being of the participant and three established questionnaires as estimates for anxiety/depression, social integration and stress level (listed below). All questions were in German. No data was collected regarding the medical history and condition of the patient.

The study took place at the Department of Neurosurgery at the University Hospital Mainz, Germany, where the malignant brain tumor patients were followed up after radiotherapy and / or received chemotherapy. Relatives who accompanied the patient to the doctors' consultation were consecutively asked to complete the questionnaire anonymously if not already done previously. Typically, the patient was accompanied by one relative, but in only a few cases, this varied up to three caregivers. All of them were asked for study participation.

The study was approved by the local ethics committee (number 837.266.17). Informed consent was obtained.

2.3. Questionnaire

2.3.1. Self-established questionnaire

After initial discussions with selected relatives of brain tumor patients about their actual life, their needs and problems, highly relevant topics were identified and summarized in a 16 questions containing form. The first four questions deal with the general psychological well-being of the participant, the following six questions address changes in

daily activities and the last six questions address coping with the patient's disease. Participants could answer in five degrees varying from "not at all" to "very much".

2.3.2. Hospital Anxiety and Depression Scale (HADS) [7]

The Hospital Anxiety and Depression Scale is a well-established questionnaire to assess the extent of anxiety and depression during the last week. The questionnaire is divided into two parts with seven questions each for anxiety and depression, respectively. There are four different possibilities to answer an item with a score of zero to three. Summing up all answers for anxiety and depression respectively the participant can reach between zero and 21 points for each category. Results of seven points or lower are considered to be normal, between eight and ten are suspicious and eleven or more are assumed to detect clinically relevant anxiety or depression.

2.3.3. "Social support questionnaire", Fragebogen zur sozialen Unterstützung (F-SozU) [8]

The "Social Support Questionnaire" is a German questionnaire to assess support from the social environment. We used the short version F-SozU K22. It contains 22 items in different categories ("emotional support", "social integration", "practical support", "presence of a trusty person", "satisfaction with social support"). Every question can be answered in five different degrees from „not applicable“ to „fully correct“. The higher the result, the better the person feels socially supported.

2.3.4. Perceived Stress Scale (PSS-10) [9]

The Perceived Stress Scale is an instrument to measure the degree of stress. It consists of 14 questions that can be answered in four different categories from „never“ (zero points) to „very often“ (four points). Questions are held very general in nature and refer to the last month. The higher the overall score of the participant, the higher the individual stress level (range: zero to 40 points). Because the PSS-10 is not a diagnostic instrument, there are no specific cut-off values. It is only possible to compare evaluated groups of people. A mean threshold of stress of 13 points (female: 13.7 points, male: 12.1 points) could be considered to be "normal" as this is the mean value for the general population [10]. A recent publication confirmed these results for a representative German community sample [11].

2.4. Statistical methods

Statistical analysis was performed using the software program SPSS version 23 (IBM SPSS Statistics Software). Mean, median and range were calculated and Box-Whisker-Plots created to show differences between subpopulations. Mann-Whitney-U test and Kruskal-Wallis test were performed to analyze independent samples. Correlation coefficient was analyzed by Mann-Kendall test. A p-value of ≤ 0.05 was assumed to be statistically significant.

3. Results

The acceptance of participating in this study in general was 94%. Three relatives refused to participate, thus 50 caregivers were remaining.

3.1. Anxiety and depression (HADS)

Table 2 shows the level of anxiety and depression in our study population. Twenty-four relatives (49%) suffered from clinically relevant anxiety. Eleven caregivers (22%) showed values suspicious for anxiety, whereas only 14 (29%) showed no anxiety at all. Mean HADS-A value for anxiety was 10.6 points. Depression was less common with ten participants (20%) showing clinically relevant depression and another ten (20%) showing borderline depression. Normal results were seen in 29 caregivers (59%). The mean HADS-D value for depression was 7.2

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