

# Distress persists in long-term brain tumor survivors with glioblastoma multiforme

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## Abstract

**Introduction** Glioblastoma multiforme (GBM) is the most common and aggressive type of primary brain tumor. The prognosis for GBM patients is extremely poor with an estimated median survival of 12 months. Despite this statistic, a number of GBM patients are living longer than in the past as new detection and treatment approaches are used. However, little is known about the psychological correlates of this disease. To address this issue we investigated distress and its sources in long-term survivors (LTS) of this disease.

**Materials and methods** Participants were asked to complete the National Comprehensive Cancer Network's (NCCN) Distress Thermometer, a single-item rapid screening tool for distress. Participants were also asked to designate sources of distress from a 34-item list developed by the NCCN. Distress scores and sources of distress for long-term GBM survivors (>18 months) were compared to patients diagnosed within the last 18 months (<18 months). **Results** Eighty-three brain tumor patients participated in this study. Fifty-nine percent of LTS met the  $\geq 4$  cut-off score for distress ( $M=4.61$ ,  $SD 3.12$ ) as compared to 49% of patients diagnosed less than 18 months ( $M=3.93$ ,  $SD=2.21$ ;  $\chi^2=0.406$ , NS), LTS reported fewer items of concern while more LTS reported being distressed.

**Conclusions** This study indicates that LTS of GBM report experiencing distress at similar levels to other brain tumor patients. Level of distress for LTS is directly related to the total number of concerns in both emotional and physical domains.

**Implications for cancer survivors** Regardless of LTS status, distress continues to be a part of the disease trajectory for many GBM patients. As such, attention to distress in these survivors of a major life threatening disease is warranted in follow up surveillance visits.

**Keywords** Distress · Long-term survivors · Brain tumors

## Introduction

Despite the historically poor prognosis for patients diagnosed with primary brain tumors, population-based Surveillance Epidemiology and End Results data indicates that the survival for adult patients with brain tumors has improved over the last three decades [1]. The most common and aggressive type of brain tumor is glioblastoma multiforme (GBM) accounting for approximately 40% of all primary brain tumor cases [2]. The median survival for patients with GBMs is about 12 months [3]. The one, three, and 5 year survival rates for GBM patients is 46, 7, and 4% respectively [4]. Some sources suggest that the increase in survival rates has been in part due to scientific advances leading to early diagnosis and improvements in treatment [5–8]. It is important to recognize that survivors of GBM face new challenges as their survival permits them to attempt to return to their previous life, e.g., family, work, etc. [9].

Despite increased survival rates, a GBM diagnosis remains serious and has a high probability of mortality. Previous research on the psychological health of adult brain tumor patients has focused on the acute problems associated with a brain tumor diagnosis and its subsequent treatment. Studies identified that brain tumor patients are at increased risk of experiencing depression, perceived stress, general levels of distress, sadness, anxiety, anger and

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