

Introduction

Malignant brain tumors account for approximately 1% of all cancers. Based on Central Brain Registry of the United States (CBTRUS) statistics, the incidence rate of all primary, benign and malignant brain tumors is 14.0 cases per 100,000 person-years and 7.7 cases per 100,000 person-years for malignant brain tumors (1). Several studies have measured the QOL of patients with malignant brain tumors, which is an important component of treatment since malignant brain tumors greatly impact physical and cognitive functioning (2-6). Using semi-structured interviews and two focus groups with patients with all types of brain tumors and their family members, Fox and Lantz (1998) identified common themes that emerged from survivors and family members regarding QOL (2). Themes included difficulty in coping with changes in physical and cognitive functioning, loss of self, the impact on the patient and the family, making the best decision regarding treatment when faced with numerous options, and how the meaning of quality of life changed between individuals. In spite of these findings, rehabilitation is rarely recommended and discussions of quality of life are initiated only after all treatment options have been exhausted. Little is known about the patient and caregiver perceptions on the impact of cognitive-linguistic decline on quality of life.

Method

Twenty individuals with malignant gliomas were recruited as part of a larger study on QOL. Participants met the following eligibility criteria: age 18 or older, no tumor recurrence or progression after initial diagnosis, life expectancy ≥ 3 months, Karnofsky Performance Status (KPS) score ≥ 70 .

Participants with brain tumors completed two quality of life measures: the Functional Assessment of Cancer Therapy Scale-Brain (FACT-BR [7]) and the Quality of life Scale/Cancer Patient Cancer Survivor (QOL-CS). The FACT-Br is composed of 50 questions exploring physical, emotional, social/family, and functional well-being using a 5-point Likert scale. QOLCS is a forty one-item ordinal scale that measures the QOL of a cancer patient. Items representing the four domains of QOL include physical well-being, psychological well-being, social well-being, and spiritual well-being.

Two research team members facilitated a focus group attended by five individuals with brain tumors. A Focus Group Interview Guide was developed to guide the discussion and insure that the four QOL domains (physical, psychological, social, and spiritual) were addressed during the discussion. Open-ended questions were used to elicit information and encourage dialogue between group members. The focus group lasted approximately 90 minutes and was tape-recorded for later transcription and analysis. Statements regarding cognitive-linguistic functioning were coded for the impact (increasing or reducing) on QOL.

Results

FACT-Br: Average responses to items in the Additional Concerns subscale revealed many negative outcomes associated with the psychological, cognitive, and physical effects of brain tumors. Of particular concern were increased frustration, impaired concentration, impaired memory, impaired communication, difficulty expressing thoughts, and reduced independence (mean scores ranged from 2.44-2.74). Positive influences were associated with a lack of certain symptoms (e.g. good outcomes

associated with hearing, coordination, sensation, seizures, ability to read) and continued independence with self-care (mean scores ranged from 3.32-3.89).

QOLCS: The QOLCS contained only one question related to cognitive linguistic functioning. The average response to “Concentration and Memory” was on the better outcome end of the continuum.

Patient focus group: The psychological domain was more evenly divided between comments that indicate a positive quality of life and those that indicate a more negative one and revealed critical themes evident in the discourse of the brain tumor survivors. Education and information was a recurrent theme. Patients expressed anger and frustration over lack of information from medical personnel, particularly about coping with cognitive and physical symptoms associated with brain tumor. Patients reported educating themselves to better cope with the effects of the brain tumor. The cognitive changes associated with brain tumor had a negative impact on quality of life. Patients reported frustration with impaired memory, concentration, executive function, and language; particularly difficulty in coping with these changes.

I went to the doctors and I was telling him that I feel like I'm not. I have the words in my head but I can't get them out. And I'm thinking, am I trying to talk too fast? And he goes, well do you know what you want to say? And I said yeah, I know, it's in my head. I know what I want to say. But when I try to say it, it doesn't come out right. He just didn't say anything. He said, I'll see you in another year.

Patients expressed anxiety, frustration, stress, fear, grief, worry, and an overall sense that life activities were “harder.” Additional analysis will be conducted to measure the percentage of statements related to cognitive-linguistic disorders and the impact on quality of life.

Discussion

Cognitive-linguistic deficits are clearly a concern for individuals dealing with brain tumors and the consequences of treatment. Some QOL measures may underestimate the impact on these symptoms on QOL. Speech-language pathologists can provide linguistic and functional treatments that can improve quality of life.

References

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Table 1. Average response of patient group on FACT-Br Additional Concerns subsection

<u>Additional Concerns-Brain Tumor</u>			
Frustration	1.95	2	1.58
Bother by reduced concentration	2	2	1.53
Independence	2.11	2	1.29
Memory	2.44	3	1.04
Difficulty expressing thoughts	2.47	3	1.54
Able to find words	2.63	3	1.21
Able to concentrate	2.74	3	1.15
Afraid of seizures	2.74	3	1.56
Trouble seeing	2.74	3	1.28
Able to drive	2.74	4	1.76
Headaches	2.79	3	1.4
Bothered by change in personality	2.84	3	1.3
Responsibility	3	3	0.88
Able to put thoughts together	3	3	0.91
Able to write	3	3	1.16
Weakness in extremities	3	3	1.33
Able to read	3.16	3	0.96
Trouble hearing	3.21	4	1.32
Trouble with coordination	3.32	4	1.2
Able to put thoughts into action	3.47	4	0.7
Impaired sensation	3.63	4	1.01
Seizures	3.74	4	0.65
Need help for self-care	3.89	4	0.46
Additional Concerns Total	2.90	3.17	1.18

Scale: 0= not at all to 4= very much

Table 2: Average response of patient group on Psychological Well-Being Subsection of the Quality of Life Cancer Survivor (QOLCS)

<u>Psychological Well Being</u>			
Initial diagnosis distress	2.63	2	3.32
Cancer treatment distress	3.84	3	3.55
Fear of recurrent cancer	4.1	3.5	3.34
Control	4.95	4.5	3.56
Anxiety	5	5	3.40
Fear of second cancer	5	4.5	3.70

Appearance	5.05	5	3.30
Self-Concept	5.4	6	3.28
Usefulness	5.5	5	3.12
Fear of cancer spreading	5.5	5.5	3.79
Depression	5.6	6.5	3.12
Coping	5.75	6	3.26
Concentration/Memory	6	8	3.29
Happiness	6.15	5.5	2.94
Satisfaction	6.15	6.5	3.18
Fear of future tests	6.15	7	3.96
Time since treatment distress	6.44	7	2.94
Quality of life single item	6.75	6	2.53
Total Psychological subscale	5.34	5.56	2.13

Scale: 0= worst outcome or negative outcome to 10= best outcome or positive influence.