

Symptom Profiles in Adult Patients with ependymoma: Report from the Ependymoma Outcomes (EO) Project

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Need for the Study

- Improving patient care, health care practices and standardized care within brain and spine ependymoma patients
- Results helpful for future trials in survival and outcome in patient population

Abstract

Aims: The Ependymoma Outcomes Project (EO Project) is an online survey designed to collect information on the clinical course and current health status of patients with ependymoma. Gathering accurate patient information through this online survey can assist in assessing treatment and health practices for a rare disease.

Methods: Adult patients diagnosed with an ependymoma were invited to complete the Ependymoma Outcomes Questionnaire (EOQ) regarding patient demographics, clinical course, symptom severity using the M.D Anderson Symptom Inventory- Brain and Spine instruments (MDASI-BT & MDASI-SP)). Descriptive statistics are used to report associated demographic and symptom characteristics.

Results: Ninety-seven patients (41male, 56 female) participated. Median age was 48 years (range 22 -77) and median time for diagnosis was 55 months (range 2-458). The most common symptoms at initial presentation in patients with brain ependymoma (n=44) included headaches (52%), visual problems (46%) and nausea/vomiting (41%). Over half the patients (55%) reported having symptoms less than six months prior to diagnosis. For patients with spine ependymoma (n = 47), numbness/tingling (62%) was the most frequent symptom at initial presentation followed by weakness (43%) and back pain (26%). Fifty-seven percent of spine patients reported symptoms of at least one year prior to diagnosis. In all ependymoma patients, moderate-severe symptoms (defined as greater than 4 on a 0-10 scale) included fatigue in 44% and numbness/tingling (22%). Patients with brain ependymoma described significant cognitive issues (58%) and weakness (18%). Nearly half the spine tumor patients have significant weakness (49%) and sexual dysfunction (20%).

Conclusions: These results demonstrate that an online outcomes survey is feasible even in rare tumors. Furthermore, the results indicate that there are differences in symptom presentation and length of symptoms at initial diagnosis between patients with brain and spine ependymoma patients. However, certain symptoms such as fatigue and sensory abnormalities are common to both groups.

Clinical & Social Information

- Depression was just as likely to be reported in both brain and spine ependymoma patients prior to their first surgery
- A majority (85%) of participants reported living with someone who could help take care of them.

Presenting Symptoms

| Brain Ependymoma | | Spine Ependymoma | |
|------------------|-----|-------------------|-----|
| Headaches | 52% | Numbness/Tingling | 62% |
| Visual Problems | 46% | Weakness | 43% |
| Nausea/Vomiting | 41% | Back Pain | 26% |

- Brain ependymoma patients (27%) had symptoms of less than one month prior to diagnosis
- Spine ependymoma patients (36%) had symptoms from 1 to 4 years prior to their diagnosis
- Both groups reported an average number of 3 symptoms
- Patients with tumor located in the brain and spine reported an average of 2 symptoms

Demographic Characteristics

| Patient Characteristics | n | % |
|-------------------------|----|----|
| Gender | | |
| Male | 41 | 42 |
| Female | 56 | 58 |
| Marital | | |
| Never married | 12 | 12 |
| Married | 72 | 74 |
| Divorced | 6 | 6 |
| Widowed | 1 | 1 |
| Education | | |
| Some high school | 2 | 2 |
| High school graduate | 5 | 5 |
| Some college | 19 | 20 |
| College graduate | 33 | 34 |
| Postgraduate | 34 | 35 |
| Employment | | |
| No | 47 | 49 |
| Full-time | 37 | 38 |
| Part-time | 9 | 9 |
| Household Income | | |
| Less than \$20,000 | 4 | 4 |
| \$20,000-\$39,999 | 6 | 6 |
| \$40,000-\$59,999 | 12 | 12 |
| \$60,000-\$79,999 | 10 | 10 |
| \$80,000-\$99,999 | 7 | 7 |
| \$100,000 or more | 40 | 41 |
| Prefer not to say | 14 | 14 |

Clinical Characteristics

| Clinical Characteristics | n | % |
|--|----|----|
| Surgery Type | | |
| Biopsy(needle, stereotactic) | 3 | 3 |
| Craniotomy with part of tumor removed | 18 | 19 |
| Craniotomy with all of tumor removed | 31 | 32 |
| Spine surgery for biopsy | 1 | 1 |
| Spine surgery with part of tumor removed | 9 | 9 |
| Spine surgery with all of tumor removed | 30 | 31 |
| No surgery yet | 2 | 2 |
| Diagnosis | | |
| Ependymoma | 60 | 62 |
| Anaplastic ependymoma | 9 | 9 |
| Myxopapillary ependymoma | 12 | 12 |
| Subependymoma | 4 | 4 |
| Tanycytic ependymoma | 2 | 2 |
| Giant cell ependymoma | 1 | 1 |
| Did not know the name | 9 | 9 |
| Tumor group | | |
| Did not know the grade | 41 | 42 |
| II | 37 | 38 |
| III | 9 | 9 |
| Other | 9 | 9 |
| Location | | |
| Brain | 44 | 45 |
| Spine | 47 | 49 |
| Brain & Spine | 6 | 6 |

Brain & Spine Specific Symptoms

| BRAIN | Moderate-Severe (Rating ≥ 4) | | Severe (Rating ≥ 7) | |
|---------------------------------|------------------------------|----|---------------------|----|
| | n | % | n | % |
| Weakness | 9 | 18 | 5 | 10 |
| Difficulty understanding | 9 | 18 | 5 | 10 |
| Difficulty speaking | 9 | 18 | 4 | 8 |
| Difficulty concentrating | 11 | 22 | 4 | 8 |
| Vision | 11 | 22 | 6 | 12 |

Nearly ¼ of patients with brain lesions have significant cognitive issues and weakness.

| SPINE | Moderate-Severe (Rating ≥ 4) | | Severe (Rating ≥ 7) | |
|---|------------------------------|----|---------------------|----|
| | n | % | n | % |
| Radiating pain | 16 | 30 | 11 | 21 |
| Weakness | 26 | 49 | 13 | 25 |
| Loss of control of bowel/bladder | 6 | 11 | 5 | 9 |
| Change in bowel pattern | 15 | 28 | 6 | 11 |
| Sexual function | 24 | 45 | 20 | 38 |

Nearly 1/2 of patients with spine tumors have significant weakness and sexual dysfunction.

Discussion

1. The EO project demonstrates the utility of online surveys for uncovering longitudinal clinical and symptom data from a patient population with a rare disease.
2. The preliminary data demonstrates that although the majority of patients are currently not undergoing active treatment, the majority are experiencing significant symptoms resulting from their tumor or its treatment.
3. These results suggest that symptom management and other issues of survivorship are areas of need in the adult ependymoma patient population.

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