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The Spine Journal ■■ (2016) ■■–■■

THE SPINE JOURNAL

Clinical Study

What questionnaires to use when measuring quality of life in sacral tumor patients: the updated sacral tumor survey

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Received 13 June 2016; revised 23 August 2016; accepted 9 November 2016

Abstract

BACKGROUND CONTEXT: Patient-reported outcomes are becoming increasingly important when investigating results of patient and disease management. In sacral tumor, the symptoms of patients can vary substantially; therefore, no single questionnaire can adequately account for the full spectrum of symptoms and disability.

PURPOSE: The purpose of this study is to analyze redundancy within the current sacral tumor survey and make a recommendation for an updated version based on the results and patient and expert opinions.

STUDY DESIGN/SETTING: A survey study from a tertiary care orthopedic oncology referral center was used.

PATIENT SAMPLE: The patient sample included 70 patients with sacral tumors (78% chordoma).

OUTCOME MEASURES: The following 10 questionnaires included in the current sacral tumor survey were evaluated: the Patient-Reported Outcomes Measurement Information System (PROMIS) Global Item short form, PROMIS Pain Intensity short form, PROMIS Pain Interference short form, PROMIS Neuro-QOL v1.0 Lower Extremity Function short form, PROMIS v1.0 Anxiety short form, the PROMIS v1.0 Depression short form, the International Continence Society Male short form, the Modified Obstruction-Defecation Syndrome questionnaire, the PROMIS Sexual Function Profile v1.0, and the Stoma Quality of Life tool.

METHODS: We performed an exploratory factor analysis to calculate the possible underlying latent traits. Spearman rank correlation coefficients were used to measure to what extent the questionnaires converged. We hypothesized the existence of six domains based on current literature: mental health, physical health, pain, gastrointestinal symptoms, sexual function, and urinary incontinence. To assess content validity, we surveyed 32 patients, 9 orthopedic oncologists, 1 medical oncologist, 1 radiation oncologist, and 1 orthopedic oncology nurse practitioner with experience in treating sacral tumor patients on the relevance of the domains.

FDA device/drug status: Not applicable.

Author disclosures: ***ODRvWP:*** Nothing to disclose. ***SJJ:*** Nothing to disclose. ***JSW:*** Nothing to disclose. ***PCF:*** Nothing to disclose. ***GW:*** Nothing to disclose. ***PSR:*** Nothing to disclose. ***MJY:*** Nothing to disclose. ***FHS:*** Nothing to disclose. ***PJB:*** Nothing to disclose. ***JHH:*** Nothing to disclose. ***FJH:*** Nothing to disclose. ***JHS:*** Nothing to disclose.

Two of the authors (JHH and PJB) report that their institution receives partial funding from the National Cancer Institute of the National Institutes of Health (Grant #P30-CA008748).

The work for this study was done at the Massachusetts General Hospital.

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http://dx.doi.org/10.1016/j.spinee.2016.11.004

RESULTS: Reliability as measured by Cronbach alpha ranged from 0.65 to 0.96. Coverage measured by floor and ceiling effects ranged from 0% to 52% and from 0% to 30%, respectively. Explanatory factor analysis identified three traits to which the questionnaires that were expected to measure a similar construct correlated the most: mental health, physical function, and pain. Content validity index demonstrated low disagreement among patients (range: 0.10–0.18) and high agreement among physicians (range: 0.91–1.0) on the relevance of the proposed domains. Social health was identified by 50% of the commenting patients as an important yet missing domain.

CONCLUSIONS: The current sacral tumor survey is incomplete and time-consuming, and not all surveys are appropriate for the sacral tumor population. Our recommended survey contains less than half the questions and includes the newly recognized social health domain.

Keywords: Quality of life; Sacral; Sacral Tumor Study Group; Survey; Tumor; Validity

Introduction

Primary malignant bone tumors of the sacrum are often treated by partial sacrectomy with or without radiation [1,2]. The impact of these major surgeries on neurologic, physical, psychological, social, and emotional functioning is substantial, and can have a major impact on a patient's quality of life [3–7]. It is important to accurately measure these outcomes to (1) understand the impact of treatment on patients, (2) educate future patients, and (3) compare treatments. Although providers seem to agree about the importance of measuring these outcomes, there is little consensus about what tools to use to establish these outcomes in this patient population. Because symptoms can vary substantially, no single questionnaire can cover the full spectrum of symptoms and disability. In 2013, the Sacral Tumor Study Group—an international collaboration of orthopedic oncologists, medical oncologists, and radiation-oncologists from multiple institutions—compiled a list of questionnaires specifically for sacral tumor patients during an official meeting. The development of survey has not been published as a whole, but parts of the survey have been used in previous studies looking at the quality of life after sacral resection [5,8].

This study aims to analyze the coverage and reliability of the current survey developed by the Sacral Tumor Study Group. Second, we assessed the redundancy of questionnaires in an attempt to shorten the survey without losing valuable information. Based on these analyses, and supported by a survey among patients and expert clinicians about what aspects of disease they consider important, we provide recommendations for a new shorter yet more revealing survey to evaluate outcomes in patients with sacral tumors.

Materials and methods

Study design

Our institutional review board approved this cross-sectional survey study. All patients with a sacral tumor who visited our clinic were asked to complete the sacral tumor survey for quality improvement purposes. Patients younger than 18 years of age or non-native English speakers were excluded. Between February 2013 and August 2014, a total of 119 sacral tumor patients were seen at our Orthopaedic Oncology unit and were eligible to complete the sacral tumor survey. Eighty-eight (74%) patients completed the survey. We excluded 18 (20%) patients who completed less than half of the questionnaires that comprise the current sacral tumor survey. Patients were included irrespective of their tumor type and treatment to obtain input from a heterogeneous group of patients. Seventy patients remained for analysis; when multiple surveys per patients were completed, only the first one was included to avoid a learning curve on the survey completion and avoid violation of the statistical rule of independence. Patients completed the survey using a tablet computer and data were collected through REDCap (Vanderbilt University, Nashville, TN, USA). REDCap is an online data collection tool that allows for the creation of study-specific surveys to capture participant data securely online.

Outcome measures

Ten different questionnaires are included in the sacral tumor survey in the following order: (1) the Patient-Reported Outcomes Measurement Information System (PROMIS) Global Item short form; (2) PROMIS Pain Intensity short form (3a); (3) PROMIS Pain Interference short form (6b); (4) PROMIS Neuro-QOL v1.0 Lower Extremity Function short form; (5) PROMIS v1.0 Anxiety short form (6a); (6) the PROMIS v1.0 Depression short form (6a); (7) the International Continence Society (ICS) Male short form; (8) the Modified Obstruction-Defecation Syndrome (MODS) questionnaire; (9) the PROMIS Sexual Function Profile v1.0; and (10) the Stoma Quality of Life tool. The PROMIS questionnaires are designed to measure specific domains in the general population and were not specifically designed for sacral tumor patients.

For the PROMIS questionnaires, a T-score can be calculated. A higher score indicates more of the construct being measured. The T-score rescales the raw score into a standardized score with a mean of 50 and a standard deviation of 10, where a score of 50 represents the mean score of the general U.S. population. This allows comparison of patients' scores with the scores of the general U.S. population. Other countries may also develop such reference values.