Self Catheterization and Patient Comments Are Essential for Comprehensive Outcome Evaluation in a Sacral Tumor Survey

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INTRODUCTION: Patient reported outcome measures are used in clinical practice and research to improve care and evaluate treatments, with most conditions requiring multiple instruments to capture both health status and lived experience. In 2013, the Sacral Tumor Study Group, an international collaboration of medical professionals including orthopaedic oncologists, neurosurgeons, physical medicine and rehabilitation, psychiatrists, colo-rectal surgeons, urologists, medical oncologists and plastic surgeons developed a survey to evaluate outcomes in sacral tumor patients, a small population within oncology and spine care that experiences substantial burden from their condition and its treatments. Maximal tumor removal is the recommended treatment, but the extent of nerve root sacrifice, particularly in high sacral resections at S3 and above, strongly predicts functional impairment and quality of life impact [1]. Accurate measurement of these outcomes is critical to (1) understanding the effects of treatment, (2) informing future patients, and (3) comparing treatment approaches. Since its development, the tool has been revised multiple times to add new health domains, track function over time, and reach broader patient groups. In this evaluation, we examined the value of adding context on colostomy and catheterization, improving usability for potential clinical adoption, and incorporating open-ended comments to capture qualitative insights [2].
METHODS: This cross-sectional survey study was IRB-approved and first introduced at the Chordoma Foundation's 2024 Annual Meeting before being distributed to attendees, shared via the foundation's newsletter and website, and disseminated by physicians. From November 2024 to May 2025, 108 responses were collected, with 64 (59.2%) completed in full, using tablet-based surveys captured securely in REDCap. The survey battery included ten validated quantitative questionnaires covering health domains relevant to sacral tumor care, interspersed with eight qualitative questionnaires for open comments, beginning with a custom intake form to address the study's remote nature and concluding with a two-item survey assessing perceptions of survey length (Table 1). All analyses were conducted in Python (v3.12) using pandas, scipy, and pingouin. Internal consistency was evaluated with Cronbach's alpha [3]. Item-level response rates and floor/ceiling effects were calculated. Associations between domains were examined with Spearman's correlations, interpreted per [4]. Open-ended responses were analyzed using an NLP pipeline with translation, vectorization, topic modeling, and manual validation.
RESULTS SECTION: Of 108 participants who initiated the survey, 64 completed all questionnaires. The demographic form was completed by 94 respondents (46 male, 47 female, 1 undisclosed), with 91.5% reporting chordoma. Participants were grouped as All Respondents, No Colostomy or Catheter (No CC), Colostomy Only, and Catheter Only. The survey demonstrated strong statistical validity across all evaluated metrics, including internal consistency, floor and ceiling effects, and Spearman correlations, and across all stratified groups. Among respondents who completed the full questionnaire battery, the average completion time was 10.1 minutes, with 68.8% rating the length as "just right," 25% as "a little too long," and 75% reporting that survey length would not impact their willingness to complete it again, indicating strong acceptability and re-engagement potential. The analysis of open-ended comments provided valuable qualitative insight into the lived experiences of patients who completed the survey with 38.3 percent of respondents leaving at least one comment and 13.8 percent leaving comments in at least half of the available fields. Comments were also successfully analyzed in the context of the specific questionnaires they followed, providing more granular insights into the issues facing sacral tumor patients.
DISCUSSION: This study has several limitations. The sample size was relatively small, with only 70 complete records, limiting statistical power and generalizability, though still reasonable given the rarity of sacral tumors. Each participant completed the questionnaire only once, preventing evaluation of functional change or pre-operative baselines. The survey was distributed globally but only in English, introducing potential language-based response bias among non-native speakers. Additionally, this iteration used version 1 of several PROMIS instruments, including now-retired Global Health and sexual function measures, which may reduce the relevance of some findings under current standards. Despite these limitations, the most recent version of the sacral survey demonstrated strong statistical validity across multiple measures, affirming its reliability. Its streamlined design made it well-suited for integration into routine care, while the inclusion of optional comment sections added undeniable value by offering rich qualitative insights that contextualized both individual outcomes and broader trends. Ultimately, it achieved the objective of developing a viable and useful outcome measure that can be accessed virtually and made available to a wide range of sacral tumor patients.
SIGNIFICANCE/CLINICAL RELEVANCE: A survey instrument that efficiently evaluates functional outcomes in sacral tumor patients helps overcome prior barriers by enabling large-scale data collection, supporting longitudinal follow-up, improving accessibility across diverse populations, and incorporating qualitative comments that deepen insight into how this group is understood. Broader use of such a tool could also promote consistency in outcomes tracking while capturing a more complete picture of patient experiences.

Assessment	Number of items per scale
Physical Health	
PROMIS SF v1.1 – Global Health	4 items
Mental Health	
PROMIS SF v1.1 – Global Health	4 items
Pain	
PROMIS Scale v1.0 – Pain Intensity 3a	3 items
Gastrointestinal Symptoms	
PROMIS Gastrointestinal Symptoms Scale	
Constipation	9 items
Bowel Incontinence	4 items
Sexual Function	
PROMIS Sexual Function Profile v10 Male	
Male Satisfaction	2 items
Male Interest	2 items
Male Orgasm	1 item
Erectile Function	3 items
PROMIS Sexual Function Profile v10 Female	
Female Satisfaction	2 items
Female Interest	2 items
Female Orgasm	1 item
Lubrication	2 items
Discomfort	3 items
Urinary Incontinence	
Urinary Distress Inventory	7 items
Social Health	
PROMIS Ability to Participate in Social Roles and Activities†	4-12 items
†Computer adaptive test (CAT)	

Table 1: Survey Components.

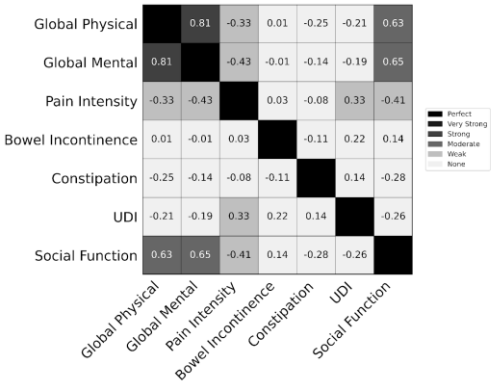

Figure 1: Convergent and discriminant validity for all the respondents.

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