

Erratum to: Symptom burden and life challenges reported by adult chordoma patients and their caregivers

Paula H. Song¹ · Hadi Beyhaghi¹ · Josh Sommer² · Antonia V. Bennett¹

Published online: 19 May 2017
© Springer International Publishing Switzerland 2017

Erratum to: Qual Life Res DOI 10.1007/s11136-017-1544-2

In the original publication of the article, there are minor inconsistencies between the results reported in Tables 3 and 4 and how it is described in the manuscript. The results reported and published in Tables 3 and 4 are correct. We would like an opportunity to revise the published manuscript to be consistent with the results in the tables. This would result in changes of data in the subhead appearing in Abstract, and the sub sections “Patient-reported symptoms” and “Challenges experienced by Chordoma patients and caregivers” appearing in the Result section. The correct version was provided in this erratum.

Results Among the survey participants, 358 identified themselves as chordoma patients and 208 as caregivers. The majority of the patients were over 45 years (72%), male (56%), educated beyond high school degree (87%), and from North America (77%). Skull base was the most

prevalent tumor location (40%). Chronic pain (38%) was the most commonly reported symptom followed by depression or severe anxiety (35%), and chronic fatigue (34%). Among patients, the most commonly-reported challenges included delayed diagnosis (37%), long-term disability (33%), and change in career or reduced ability to work (33%). For caregivers, grief (55%), delayed diagnosis (47%), and difficulty helping the patient cope with his or her disease (45%) were most common.

Patient-reported symptoms

The most common symptoms that chordoma patients reported include chronic pain (38%), depression or severe anxiety (35%), chronic fatigue (34%), difficulty walking (31%), and balance impairment (29%). The majority of patients in our sample reported experiencing at least one symptom (93%) while more than 36% experience 5 or more symptoms as a result of suffering from chordoma. Thirty patients (8%) did not respond to the question about symptoms.

The majority of self-reported symptoms were significantly associated with the location of tumor (Table 3, last column). Among patients with skull base tumors (40%), the three most common symptoms were double vision (56%), depression or severe anxiety (35%), and chronic sinus problems (34%). Among patients with sacro-coccygeal tumors (31%), difficulty sitting (62%), difficulty walking (54%), and chronic pain (51%) were the most common, and among patients with mobile spine tumors (11%), the most common symptoms were chronic pain (57%), difficulty walking (40%), and chronic fatigue (39%). The majority of common symptoms were significantly different in their prevalence across different types of treatment received and current disease status (Tables 4, 5).

The online version of the original article can be found under doi:10.1007/s11136-017-1544-2.

✉ Paula H. Song
psong@unc.edu

¹ Department of Health Policy and Management, The University of North Carolina at Chapel Hill, 1105A, McGavran-Greenberg Hall, CB #7411, Chapel Hill, NC 27599-7411, USA

² Chordoma Foundation, Durham, NC, USA

Challenges experienced by chordoma patients and caregivers

Table 6 reports the prevalence of challenges that patients and caregivers experienced as a result of chordoma in the following domains: emotional health and coping; employment and finances, access to care and information; and quality of care. Eight patients (2%) and four caregivers (2%) did not respond to the question about challenges faced as a result of suffering from chordoma. The most common challenges reported by patients were delayed diagnosis (37%), long-term disability (33%), change in career or reduced ability to work (33%), feelings of loneliness or isolation (29%), confusion or unanswered

questions about chordoma (28%), difficulty finding experienced physicians or treatment centers (27%), difficulty coping with illness (26%), misdiagnosis (24%), and short-term disability (24%). Among caregivers, the most frequently reported challenges included grief (55%), delayed diagnosis (47%), difficulty helping the patient cope with his/her illness (45%), confusion or unanswered questions about chordoma (45%), feelings of loneliness or isolation (43%), difficulty finding experienced physicians or treatment centers (43%), difficulty helping children or other family members cope (33%), and change in career or reduced ability to work (31%).