CHORDOMA SYMPTOMS AND LIFE CHALLENGES

Results of the first large-scale survey to characterize the experience of living with chordoma

WHO IS REPRESENTED?

50/50 EVEN SPLIT BETWEEN PATIENTS & FRIENDS/FAMILY
27% MOBILE SPINE
40% SKULL BASE
31% SACRAL
72% OF RESPONDENTS WERE AGE 45 OR OLDER

PATIENTS

FEMALE 44%
MALE 56%

CAREGIVERS

FEMALE 66%
MALE 34%

1 IN 5 PATIENTS REPORTED HAVING ADVANCED OR METASTATIC DISEASE

SYMPTOMS REPORTED

SYMPTOM BURDEN VARIES BASED ON LOCATION OF TUMOR, DISEASE STATUS, AND TYPE OF TREATMENT RECEIVED.

MOST COMMON SYMPTOMS REPORTED BY ALL PATIENTS WERE:

- CHRONIC PAIN: 38%
- DEPRESSION OR SEVERE ANXIETY: 35%
- CHRONIC FATIGUE: 34%
- DIFFICULTY WALKING OR BALANCE IMPAIRMENT: 31%

SKULL BASE PATIENTS

- DOUBLE VISION: 56%
- DEPRESSION OR SEVERE ANXIETY: 35%
- CHRONIC FATIGUE: 34%
- CHRONIC SINUS PROBLEMS: 34%

SACRAL PATIENTS

- DIFFICULTY SITTING: 62%
- DIFFICULTY WALKING: 54%

MOBILE SPINE PATIENTS

- CHRONIC PAIN: 57%
- DIFFICULTY WALKING: 40%

CHALLENGES

MEDICAL, EMOTIONAL, AND LOGISTICAL

CAREGIVERS REPORTED EXPERIENCING MANY CHALLENGES AT HIGHER RATES THAN PATIENTS

- REDUCED ABILITY TO WORK
- LONG-TERM DISABILITY
- DELAYED DIAGNOSIS
- CONFUSION OR ANSWERED QUESTIONS
- LONELINESS/ISOLATION
- GRIEF
- HELPING PATIENT CARE

A COMPLETE LIST OF CHALLENGES IS INCLUDED IN THE ARTICLE

WHY THIS MATTERS

1. HELPS PATIENTS KNOW WHAT TO EXPECT
2. HELPS INFORM DESIGN OF FUTURE CLINICAL TRIALS
3. HELPS CLINICIANS UNDERSTAND AND MANAGE PATIENTS’ SYMPTOMS

DATA SOURCE: CHORDOMA FOUNDATION COMMUNITY SURVEY (2016)