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# Introducing the New Patient Expectations in Spine Oncology Questionnaire

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**BACKGROUND AND OBJECTIVES:** It has been hypothesized that a discrepancy between pretreatment expectations and perceived outcomes is a significant source of patient dissatisfaction. Currently, there is lack in understanding and tools to assess patient expectations regarding the outcomes of treatment for spinal metastases. The objective of this study was therefore to develop a patient expectations questionnaire regarding the outcomes after surgery and/or radiotherapy for spinal metastases.

**METHODS:** A multiphase international qualitative study was conducted. Phase 1 of the study included semistructured interviews with patients and relatives to understand their expectations of the outcomes of treatment. In addition, physicians were interviewed about their communication practices with patients regarding treatment and expected outcomes. In phase 2, items were developed based on the results of the interviews in phase 1. In phase 3, patients were interviewed to validate the content and language of the questionnaire. Selection of the final items was based on feedback from patients regarding content, language, and relevance.

**RESULTS:** In phase 1, 24 patients and 22 physicians were included. A total of 34 items were developed for the preliminary questionnaire. After phase 3, a total of 22 items were retained for the final version of the questionnaire. The questionnaire is divided into 3 sections: (1) patient expectations regarding treatment outcomes, (2) prognosis, and (3) consultation with the physician. The items cover expectations related to pain, analgesia requirements, daily and physical function, overall quality of life, life expectancy, and information provided by the physician.

**CONCLUSION:** The new Patient Expectations in Spine Oncology questionnaire was developed to evaluate patient expectations regarding the outcomes after treatment for spinal metastases. The Patient Expectations in Spine Oncology questionnaire will allow physicians to systematically assess patient expectations of planned treatment and thus help guide patients toward realistic expectations of treatment outcome.

**KEY WORDS:** Spinal metastases, Patient expectations, Health-related quality of life, Patient physician communication, Qualitative research

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**ABBREVIATIONS:** PEP SO, Patient Expectations in Spine Oncology.

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The life expectancy of patients with cancer has significantly improved over the past couple of decades due to substantial advances in systemic treatments and improved diagnostics.<sup>1</sup> Consequently, with these patients living longer, the number of patients with symptomatic spinal metastatic disease is increasing. Surgery and radiation therapy have been shown to be effective palliative treatments to manage symptoms and maintain or improve health-related quality of life (HRQOL) in patients with spinal metastases.<sup>2-5</sup> Despite their proven effectiveness, these treatment modalities are not without the risk of adverse events and poor outcomes. Unfortunately, up to 23% of patients report dissatisfaction with the results of their treatment for spinal metastases.<sup>6</sup> A discrepancy between pretreatment patient expectations of outcomes and the perceived actual outcomes of treatment may explain patient dissatisfaction.<sup>7</sup>

For patients to make an informed treatment decision, it is vital that they understand the goals of treatment and have realistic expectations about the likely benefits, risks, recovery time, and overall prognosis of their condition. Previous studies demonstrated that patients with advanced stages of cancer overestimated their life expectancy and had inaccurate beliefs regarding the effectiveness of palliative radiation and chemotherapy on their life expectancy and chances for cure.<sup>8,9</sup> This is concerning, as it has been established that patients are willing to accept more invasive treatments if there is even a small chance for cure; however, if patients understand that the treatment goal is palliative, their willingness to accept an invasive treatment decreases significantly.<sup>9</sup> It is therefore crucial for physicians to determine what patients hope to achieve from therapy and guide them toward realistic expectations before initiating treatment. Currently, there is a lack of validated instruments to systematically evaluate patient expectations, expectations regarding treatment outcomes remaining thus largely unknown.<sup>10</sup>

We therefore conducted a multistage research project to develop a patient-derived expectations questionnaire for individuals with spinal metastases. First, we explored how physicians communicate information on treatment options and outcomes to patients with metastatic spinal disease.<sup>11</sup> Second, a qualitative study was conducted to establish patient expectations on outcomes of treatment after surgery and/or radiation therapy for spinal metastases.<sup>12</sup> This study represents the final phase of this research project and presents the development of a patient-reported expectations questionnaire regarding outcomes of surgery and/or radiation therapy for spinal metastases.

## METHODS

An international qualitative and quantitative multiphase research study was conducted to develop the Patient ExPectations in Spinal Oncology (PEPSO) questionnaire. After institutional review board approval, this study was initiated in 2 tertiary spine centers, located in Canada and The Netherlands. Written informed consent was obtained from participating patients, family members, and health care providers.

### Phase I: Identifying Patient Expectations

Individual semistructured interviews were conducted with patients, family members, and health care providers involved in the care of patients with spinal metastases. Patients were eligible to participate if they required surgery and/or

radiotherapy for the treatment of symptomatic spinal metastases. Patients with a diagnosis of primary spinal or spinal cord tumor were excluded. Individuals undergoing repeat treatment were also included to permit transferability of the questionnaire in patients who may need repeat surgery or radiation. Patients were excluded if they required emergency intervention that prohibited scheduling of an interview. Close family members were also invited to participate in individual semistructured interviews. Health care providers were invited to participate if they were directly involved in the management of patients with spinal metastases.<sup>11,12</sup>

Patient and family member interviews were conducted pretreatment (0-7 days) and post-treatment (6 weeks +/- 1 week) using a semistructured interview guide with broad and open-ended questions. Patients and family members were asked about their expectations regarding treatment outcomes and the information provided by physicians. In the post-treatment interviews, patient experiences and fulfillment of pretreatment expectations were discussed. Health care providers were interviewed once and were asked broad and open-ended questions regarding the information they provide to patients and how they verify patient expectations. Patients, family members, and health care providers continued to be enrolled until no new information was abstracted from the interviews (content saturation).<sup>11,12</sup>

The interviews were analyzed using a standardized qualitative thematic analysis.<sup>13</sup> Two researchers independently analyzed the interview scripts. Using an iterative process, interview data were grouped into codes. The codes were then categorized into subthemes and overarching themes. Detailed methods and results based on the Consolidated Criteria for Reporting Qualitative Research guidelines from the patient and physician interviews were previously reported.<sup>11,12,14</sup>

### Phase II: Item Development and Response Scale

Two researchers independently developed items and the response scale for the preliminary version of the questionnaire based on the subthemes and themes identified in the first phase of the study. All items were initially developed in English. Items were phrased in multiple ways using terminology used by patients in the first phase of the study. The items and the response scale options for the preliminary version of the questionnaire were selected after a consensus meeting with the research team including experienced qualitative researchers, physicians, and a language specialist. The preliminary English version of the PEPSO questionnaire was translated to Dutch involving an expert committee including a language specialist.

### Phase III: Selecting Final Items and Content Validity

An additional sample of patients was enrolled in this study to validate the content and language used in the questionnaire. Individual cognitive interviews with patients were conducted to investigate the response process. Patients were asked whether items were clearly worded and whether they felt items were relevant to them. In addition, patients were asked to clarify their responses to evaluate whether patients' answers reflected the construct of interest. Detailed summary notes were taken during the cognitive interviews and analyzed independently by 2 researchers. The items and response scale were revised during a meeting with the research team based on the results of the cognitive interviews. Finally, another sample of patients was enrolled in the study to verify the revised item pool and response scale.

## RESULTS

### Phase I: Identifying Patient Expectations

A total of 24 patients were enrolled between November 2018 and May 2020, 13 patients were scheduled to undergo surgery

with or without adjunctive radiation therapy, and 11 patients were scheduled for treatment with radiotherapy alone. The mean age was 59.5 years (SD = 15.0), and 58% of the patients were male. Before treatment, all patients experienced spinal pain and limitations in daily activities and physical functioning.

Patients commonly reported that they felt minimally or not informed by their physicians regarding expected treatment outcomes. Furthermore, patients stated that they felt generally overwhelmed by the information provided by their physicians. Expected treatment outcomes indicated by patients include improvements in pain, daily functioning, physical functioning, and decreased use of analgesics. In addition, patients mentioned a wide range of expected recovery times and goals of treatment.

A total of 22 physicians were enrolled, including spine surgeons, radiation and medical oncologists, and physiatrists. Physicians indicated the importance of patient expectations but acknowledged that they mostly fail to verify patients' expectations regarding treatment outcomes. Physicians also reported that patients are generally too optimistic regarding treatment outcomes and often underestimate the recovery time. Importantly, most physicians also noted that they believe a substantial number of patients do not fully understand the palliative treatment intent.

### Phase II: Item Development and Response Scale

Items for the preliminary version of the questionnaire were based on the overarching themes and subthemes identified during the interviews with patients, family members, and health care providers. Items were reviewed and selected during a consensus meeting with the research team, resulting in a preliminary version of the questionnaire which included 34 items. The questionnaire was initially divided into 4 sections: (1) consultation with the physician (15 questions), (2) patient expectations regarding outcomes (11 questions), (3) timeline of expectations (4 questions), and (4) life expectancy (4 questions). Likert response options were assigned for all questions except for the ones regarding life expectancy. The life expectancy questions were assigned individual response options.

### Phase III: Selecting Final Items and Content Validity

Ten patients were enrolled to verify the content, relevance, and language of the items. One-on-one cognitive interviews were conducted with patients who were either scheduled to undergo surgery and/or radiation therapy or had recently finished treatment.

From the 34 items in the preliminary version, 22 items were retained in the final version of the PEPSO questionnaire (Figure). Items were retained if they were endorsed by patients and were considered clinically relevant. Several items that addressed similar themes but with alternative wording were either combined or omitted based on patient feedback. The final questionnaire is divided into 3 parts: (1) patient expectations of treatment outcomes (13 questions), (2) prognosis (3 questions), and (3) consultation with my physician (6 questions). Depending on the timing of questionnaire administration (preconsultation or postconsultation with their physician), part C may be administered or omitted.

For the items regarding expected outcomes, patients are asked "Please indicate what you expect (not hope), followed by when you expect (not hope) this change after surgery/radiation" to assess both the expected outcome and the timing of the expected outcome. The items cover expectations related to pain, analgesia requirements, daily and physical functioning, and overall quality of life. For the items regarding prognosis, patients are asked "The following statements are about how you feel about your prognosis. Please indicate which option(s) best describe your answer." Items cover the overall goal of treatment, life expectancy, and chances for cure. For items regarding the consultation with their physician, patients are asked "To what extent, do you agree or disagree with these statements?" Items cover patient understanding regarding the information provided by the physician and shared decision making.

Based on the results of the interviews, 2 separate versions of the questionnaire were developed: one for patients waiting for surgical intervention (Figure) and another for patients waiting for radiotherapy (Appendix 1, <http://links.lww.com/NEU/D883>). The contents of the 2 versions are the same; however, the questionnaire instructions are different in that "surgery" is replaced with "radiation therapy," and in the questions, "spine surgeon" is replaced with the "radiation oncologist." Final wording of the items was checked with the patients and the research team.

Finally, an additional 6 patients were enrolled for cognitive interviews to evaluate the revised questionnaire. Patients verified the content and the language, and no further adjustments were suggested. Table presents the baseline characteristics of patients included in the interviews in Phases 1 and 3. Appendix 2, <http://links.lww.com/NEU/D884>, presents information regarding the scoring of the questionnaire.

## DISCUSSION

The Patient Expectations in Spine Oncology (PEPSO) questionnaire was developed to evaluate expectations regarding treatment outcomes for patients requiring surgery and/or radiation therapy for spinal metastases. The items in the PEPSO questionnaire were developed based on information provided by patients, family members, and health care providers using a rigorous qualitative research method. The PEPSO questionnaire is unique because it is the first instrument to evaluate expectations specific to patients with spinal metastases undergoing surgical and/or radiation therapy. Implementation of this instrument in the clinical setting may help to further improve patient-centered care for this population. The questionnaire provides both patients and physicians with an opportunity to discuss goals of treatment and adjust unrealistic outcome expectations whenever necessary. In addition, it will further enhance the shared decision making process because it allows for a more in-depth and tailored discussion on the effects of treatment on their symptoms. Finally, the questionnaire provides physicians and researchers with a standardized method to investigate patient expectations and compare these expectations with other patient-reported outcome measures, including HRQOL and patient satisfaction.

## Patient ExPectations in Spine Oncology (PEPSO) questionnaire

- Surgery -

### A: Patient expectations of treatment outcomes

The following questions are about your expectations on how surgery will have an effect on the symptoms caused by your spine tumor. Please first indicate **what you expect (not hope)**, followed by **when you expect** (not hope) this change after surgery (i.e., in the first 2 weeks, between 2-6 weeks or more than 6 weeks after surgery). There are no right or wrong answers.

Compared to your symptoms one week ago, what do you anticipate surgery will do for the following?

|   | Much worse            | Somewhat worse        | No change             | Somewhat better       | Much better               | Do not know           | Not applicable        | <2 weeks              | 2-6 weeks             | >6 weeks              | Do not know           |
|---|-----------------------|-----------------------|-----------------------|-----------------------|---------------------------|-----------------------|-----------------------|-----------------------|-----------------------|-----------------------|-----------------------|
| 1. The pain in your back/neck?  | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/>     | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| 2. Fatigue?   | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/>     | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| 3. The strength in your arms?   | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/>     | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| 4. The strength in your legs?   | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/>     | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| 5. Your ability to do 15 minutes of mild to moderate physical activities? (e.g. walk, bicycle ride)                       | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/>     | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| 6. Your ability to drive yourself?  | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/>     | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| 7. Your ability to care for yourself? (e.g. bathing, showering, dressing)   | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/>     | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| 8. Your ability to independently perform moderate daily activities? (e.g. vacuuming, window cleaning, carrying groceries) | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/>     | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| 9. Your ability to engage in social activities with family/friends/groups outside your house?                             | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/>     | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| 10. Bladder problems? (e.g. incontinence, retention)  | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/>     | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| 11. Bowel problems? (e.g. incontinence, constipation)   | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/>     | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| 12. Your overall quality of life?   | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/>     | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
|   | No pain medication    | Less pain medication  | No change             | More pain medication  | Much more pain medication | Do not know           | Not applicable        | <2 weeks              | 2-6 weeks             | >6 weeks              | Do not know           |
| 13. The amount of pain medication that you take?  | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/>     | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |

**FIGURE.** Preoperative version of the Patient Expectation in Spinal Oncology questionnaire.

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**B: Prognosis**

The following statements are about how you feel about your prognosis. Please indicate which options best describe your answer. There are no right or wrong answers.

1. I expect that surgery will have the following outcomes (more than one answer possible):
  - Reduce my pain
  - Improve my quality of life
  - Improve my mobility
  - Remove my tumor in my spine
  - Improve my chance of cure
  - Improve my life expectancy
  
2. I have had a discussion with my healthcare provider (e.g. spine surgeon, radiation oncologist, medical oncologist, nurse practitioner) about my life expectancy.
  - No (please select which applies)
    - Not discussed by my physician
    - I prefer not to discuss my life expectancy
  - Yes (select all that apply)
    - Medical oncologist
    - Radiation oncologist
    - Spine surgeon
    - Other: \_\_\_\_\_
  
3. What do you feel are the chances that your cancer can be cured with surgery for your spine?
  - Not curable
  - Less than 50% chance of cure
  - 50% chance of cure
  - More than 50% chance of cure
  - Do not know
  - Prefer not to answer

**C: Consultation with my spine surgeon**

The following statements are about your consultation with your spine surgeon about the tumor in your spine. Please indicate to what extent you agree or disagree with these statements.

|   | Strongly disagree     | Disagree              | Undecided             | Agree                 | Strongly agree        |
|---|-----------------------|-----------------------|-----------------------|-----------------------|-----------------------|
| 1. I feel that I understand the information provided by my spine surgeon.   | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| 2. I feel that I understand the reasons for my spine surgery.   | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| 3. I feel that I understand the benefits of spine surgery.  | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| 4. I feel that I understand the risks of surgery.   | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| 5. I feel that I understand the expected functional outcomes (e.g. pain management, ability for self-care, mobility) after spine surgery. | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| 6. I feel that the spine surgeon involved me in the decision for my treatment.  | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |

**FIGURE.** *Continued.*

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**TABLE. Demographic Characteristics of Patients With Spinal Metastases that were Interviewed**

|   | Phase I                  |                 | Phase III                |                 |
|---|--------------------------|-----------------|--------------------------|-----------------|
|   | The Netherlands<br>N (%) | Canada<br>N (%) | The Netherlands<br>N (%) | Canada<br>N (%) |
| Number of patients                                    | 15                       | 9               | 5                        | 7               |
| Sex (female), n (%)                                   | 9 (60)                   | 1 (11)          | 3 (60)                   | 1 (14)          |
| Age, mean (SD)  | 61.5 (11.7)              | 56.2 (18.8)     | 63.4 (11.8)              | 62 (12.8)       |
| <b>Education, n (%)</b>                               |                          |                 |                          |                 |
| Primary or (post)secondary school                     | 10 (67)                  | 2 (22)          | 2 (40)                   | 4 (57)          |
| College or university                                 | 5 (33)                   | 6 (67)          | 2 (40)                   | 2 (29)          |
| Unknown   | —                        | 1 (11)          | 1 (20)                   | 1 (14)          |
| <b>Marital status, n (%)</b>                          |                          |                 |                          |                 |
| Married or lived with partner                         | 10 (67)                  | 5 (56)          | 2 (40)                   | 5 (71)          |
| Single  | 5 (33)                   | 4 (44)          | 3 (60)                   | 2 (29)          |
| <b>Primary tumor, n (%)</b>                           |                          |                 |                          |                 |
| Prostate  | 5 (33)                   | 1 (11)          | 1 (20)                   | —               |
| Breast  | 4 (27)                   | 1 (11)          | 1 (20)                   | —               |
| Lung  | 2 (13)                   | —               | 3 (60)                   | —               |
| Renal cell  | —                        | 2 (22)          | —                        | 2 (29)          |
| Other   | 4 (27)                   | 5 (56)          | —                        | 5 (71)          |
| <b>Level of spinal metastases, n (%)</b>              |                          |                 |                          |                 |
| Cervical  | 1 (7)                    | —               | —                        | 1 (14)          |
| Thoracic  | 4 (27)                   | 5 (56)          | —                        | 5 (71)          |
| Lumbar  | 2 (13)                   | 1 (11)          | 1 (20)                   | 1 (14)          |
| Sacral  | —                        | 1 (11)          | —                        | —               |
| Multiple spinal regions                               | 8 (53)                   | 2 (22)          | 4 (80)                   | —               |
| <b>Planned treatment for spinal metastases, n (%)</b> |                          |                 |                          |                 |
| Surgery   | 1 (7)                    | 3 (33)          | —                        | 2 (29)          |
| Radiation therapy                                     | 8 (53)                   | 1 (11)          | 4 (80)                   | —               |
| Surgery, followed by radiation therapy                | 5 (33)                   | 5 (56)          | 1 (20)                   | 2 (29)          |
| Radiation therapy, followed by surgery                | 1 (7)                    | —               | —                        | 3 (43)          |

Previously, Mancuso et al developed 2 questionnaires to evaluate patient expectations after lumbar and cervical spine surgery.<sup>15,16</sup> The questionnaires evaluate symptom relief, return to normal physical function, resumption of daily activities, and psychosocial well-being.<sup>15,16</sup> Despite these questionnaires being patient-derived and specific to patients requiring spinal surgery, it is important to acknowledge that patients with spinal metastases

represent a vastly different patient population. First, patients with spinal metastases often have various concerns related to their advanced cancer diagnosis and its (systemic) treatment besides their spinal problems. By contrast, patients requiring surgery for a degenerative or deformity-related spinal condition may have other comorbidities, but at the time of treatment, their spinal condition is almost always their primary concern. Second, patients requiring

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spine surgery for non–cancer-related conditions generally have other goals of treatment, such as deformity correction, and improved pain and physical function yet on a different level as compared with patients with metastatic spinal disease. Finally, considering the palliative treatment intent for spinal metastases, it is important for patients to understand that the main goal of treatment is to improve or maintain HRQOL rather than altering their primary tumor course or life expectancy. These differences in treatment goals and outcomes are highlighted by the differences in the content of the items in the PEPSO questionnaire as compared with the questionnaires from Mancuso et al.

In keeping with the palliative treatment intent and often limited life expectancy of patients with spinal metastases, expectations regarding the timing of expected outcomes were included in the questionnaire. Previously, Weeks et al<sup>17</sup> demonstrated that patients with cancer who believed they would survive at least 6 months were 2.6 times more likely to accept invasive treatments than comfort care. Considering the limited life expectancy associated with spinal metastases, patients should be well informed of the recovery process after surgery and radiation and of the time it takes for surgery and/or radiation therapy to affect their symptoms. The PEPSO questionnaire not only asks patients what they expect regarding the effect of treatment on their symptoms but also when they expect the effects to happen. Unrealistic expectations regarding recovery time and effect on their symptoms can therefore easily be identified and discussed with the patient.

With the movement toward value-based and patient-centered health care, patient-reported outcomes and patient satisfaction are increasingly being used to evaluate the effectiveness of cancer care. In a recent systematic review, Witiw et al<sup>7</sup> demonstrated that a smaller discrepancy between expected treatment outcomes and actual perceived outcomes was the most significant predictor of patients' satisfaction after elective spinal surgery. Panda et al<sup>18</sup> examined this “expectation-actuality discrepancy” in a group of 101 patients requiring cancer surgery for solid primary tumors. They found that across all health domains, patients expected better HRQOL than they actually experienced postsurgery. The results of both studies emphasize the importance of pretreatment discussion of outcomes and realigning expectations whenever necessary, as misalignment between expectations and experiences increases the risk of patient dissatisfaction and poorer patient-reported outcomes.

A strength of the PEPSO questionnaire, and this study, is that it was developed using rigorous qualitative research methodology. A heterogeneous patient population representing different primary tumor histology, varying life expectancy and different treatment regimens including treatment with surgery and/or radiotherapy, was included to enhance generalizability of results. Moreover, patients were interviewed using a semistructured interview guide pretreatment and post-treatment. This provided post-treatment patients the opportunity to comment on outcomes they had not considered pretreatment, but now deemed important, based on their experience, to discuss before commencing surgical or radiation therapy. Face and content validation of the items were

secured by developing the items based on input from patients and by verifying the questions and content with repeat cognitive interviews. Finally, by including input from physicians involved in the care of patients with spinal metastases, the PEPSO questionnaire also reflects what health care providers encounter in daily practice.

### Limitations

Despite the multiple strengths of this study, there are some limitations. First, this study was conducted at 2 tertiary spine care centers and may not reflect the expectations of patients in other health care settings. However, considering the complexity of care for patients with metastatic spinal disease, most patients would be treated in tertiary care centers. A future study aimed to evaluate the validity and reliability of the questionnaire will also evaluate the cross-cultural generalizability of the PEPSO questionnaire. Second, the final cognitive interviews evaluating the content of the questionnaire had to be conducted through telephone due to COVID-19 measures preventing in-person interviews. The difference in interview modality may have influenced the responses of patients.

### CONCLUSION

In summary, we developed the PEPSO questionnaire to evaluate patient expectations regarding outcomes after surgery and/or radiotherapy for symptomatic spinal metastases. In addition, the questionnaire evaluates patient expectations around prognosis and understanding of the information provided by spine surgeons or radiation oncologists. A follow-up study is planned to determine the validity, reliability, and cross-cultural generalizability of the questionnaire. In the future, the PEPSO questionnaire will allow for standardized evaluation of patient expectations to facilitate a tailored discussion between physicians and patients regarding expected outcomes after treatment. Unrealistic outcome expectations can be identified and addressed before treatment, thereby reducing the gap between expected and experienced outcomes, ultimately improving patient satisfaction with outcomes of treatment.

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### Disclosures

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## REFERENCES

1. Siegel RL, Miller KD, Fuchs HE, Jemal A. Cancer statistics, 2022. *CA: A Cancer J Clin.* 2022;72(1):7-33.
2. Sahgal A, Myrehaug SD, Siva S, et al. Stereotactic body radiotherapy versus conventional external beam radiotherapy in patients with painful spinal metastases: an open-label, multicentre, randomised, controlled, phase 2/3 trial. *Lancet Oncol.* 2021;22(7):1023-1033.
3. Fehlings MG, Nater A, Tetreault L, et al. Survival and clinical outcomes in surgically treated patients with metastatic epidural spinal cord compression: results of the prospective multicenter AOSpine study. *J Clin Oncol.* 2016;34(3):268-276.
4. Versteeg AL, Sahgal A, Rhines LD, et al. Health related quality of life outcomes following surgery and/or radiation for patients with potentially unstable spinal metastases. *Spine J.* 2021;21(3):492-499.
5. Falicov A, Fisher CG, Sparkes J, Boyd MC, Wing PC, Dvorak MF. Impact of surgical intervention on quality of life in patients with spinal metastases. *Spine.* 2006;31(24):2849-2856.
6. Versteeg AL, Sahgal A, Kawahara N, et al. Patient satisfaction with treatment outcomes after surgery and/or radiotherapy for spinal metastases. *Cancer.* 2019; 125(23):4269-4277.
7. Witw CD, Mansouri A, Mathieu F, Nassiri F, Badhiwala JH, Fessler RG. Exploring the expectation-actuality discrepancy: a systematic review of the impact of preoperative expectations on satisfaction and patient reported outcomes in spinal surgery. *Neurosurg Rev.* 2018;41(1):19-30.
8. Chen AB, Cronin A, Weeks JC, et al. Expectations about the effectiveness of radiation therapy among patients with incurable lung cancer. *J Clin Oncol.* 2013; 31(21):2730-2735.
9. Weeks JC, Catalano PJ, Cronin A, et al. Patients' expectations about effects of chemotherapy for advanced cancer. *New Engl J Med.* 2012;367(17): 1616-1625.
10. Waljee J, McGlinn EP, Sears ED, Chung KC. Patient expectations and patient-reported outcomes in surgery: a systematic review. *Surg.* 2014;155(5):799-808.
11. Versteeg AL, Gal R, Charest-Morin R, et al. Expectations of treatment outcomes in patients with spinal metastases; what do we tell our patients? A qualitative study. *BMC Cancer.* 2021;21(1):1263.
12. Gal R, Charest-Morin R, Verlaan J-J, et al. *Patient Expectations About Palliative Treatment for Symptomatic Spinal Metastases: A Qualitative Study.* Value Health; 2022.
13. Barzilai O, Versteeg AL, Goodwin CR, et al. Association of neurologic deficits with surgical outcomes and health-related quality of life after treatment for metastatic epidural spinal cord compression. *Cancer.* 2019;125(23):4224-4231.
14. Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *Int J Qual Health Care.* 2007;19(6):349-357.
15. Mancuso CA, Cammisia FP, Sama AA, Hughes AP, Ghomrawi HMK, Girardi FP. Development and testing of an expectations survey for patients undergoing lumbar spine surgery. *J Bone Joint Surg.* 2013;95(19):1793-1800.
16. Mancuso CA, Cammisia FP, Sama AA, Hughes AP, Girardi FP. Development of an expectations survey for patients undergoing cervical spine surgery. *Spine.* 2013; 38(9):718-725.
17. Weeks JC, Cook EF, O'Day SJ, et al. Relationship between cancer patients' predictions of prognosis and their treatment preferences. *JAMA.* 1998;279(21): 1709-1714.
18. Panda N, Solsky I, Neal BJ, et al. Expected versus experienced health-related quality of life among patients recovering from cancer surgery. *Ann Surg Open.* 2021;2(2): e060.

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**Appendix 1.** Preradiation version of the Patient Expectation in Spinal Oncology (PEPSO) questionnaire.

**Appendix 2.** Scoring guide for PEPSO questionnaire.

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