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**Themed Section: The Patient Journey**

# Patient Expectations About Palliative Treatment for Symptomatic Spinal Metastases: A Qualitative Study

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## ABSTRACT

*Objectives:* Patients with spinal metastases often receive palliative surgery or radiation therapy to maintain or improve health-related quality of life. Patients with unrealistic expectations regarding treatment outcomes have been shown to be less satisfied with their post-treatment health status. This study evaluated expectations of patients with spinal metastases scheduled for surgery and/or radiation therapy.

*Methods:* Individual semistructured interviews were conducted with patients with symptomatic spinal metastases before and 6 weeks after surgery and/or radiation therapy. Expectations regarding treatment outcomes were discussed before treatment, and level of fulfillment of these pretreatment expectations was discussed after treatment. Interviews were recorded, transcribed and analyzed according to the thematic analysis method to identify themes.

*Results:* Before treatment, patients thought they were not, or minimally, informed about (expected) treatment outcomes, but they felt well informed about treatment procedures and possible complications. Although patients expected pain relief and improvement in daily functioning, they found it difficult to describe any recovery timeline or the impact of these expected improvements on their daily life. Patients generally understood that treatment was not curative, but lacked insight into the impact of treatment on life expectancy given that this was hardly discussed by their surgeon and/or radiation oncologist. Pretreatment expectations regarding pain and daily functioning were only partially met in most patients post-treatment.

*Conclusions:* Patients thought they were not, or only minimally, informed about expected outcomes after surgery and/or radiation therapy for symptomatic spinal metastases. Improvements in patient-physician communication and counseling could help guide patients toward realistic pretreatment expectations.

*Keywords:* palliative treatment, patient expectations, spinal metastases, treatment outcomes.

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## Introduction

Health-related quality of life (HRQOL) is a subjective and multidimensional construct largely depending on patients' perception of their current health status.[1] Surgery and radiation therapy for the treatment of symptomatic spinal metastases have been shown effective to improve specific domains of HRQOL including physical, social, and mental function and overall HRQOL.[2-5] Pretreatment expectations about treatment effectiveness have been shown to influence post-treatment HRQOL.[6] Expectations may be defined as beliefs about future outcomes, formed through cognitive processes and influenced by previous knowledge and past experiences.[7] Hope for improvement in symptoms may lead to unrealistic expectations about treatment outcomes, especially when patients are poorly informed about expected outcomes by their physicians.[8] When pretreatment expectations regarding treatment outcomes are not met after treatment, patients have shown to be less satisfied with their post-treatment health status.[9] Moreover, patients with unrealistic expectations may give consent for a treatment that they might have refused had they had realistic expectations regarding treatment outcomes and their prognosis. Therefore, creating realistic pretreatment expectations is crucial.

In a systematic review, we showed that patients who underwent spinal surgery for noncancer-related conditions and patients with advanced cancer had overly optimistic expectations regarding treatment outcomes including pain and symptom relief, lower functional disability, (complete) recovery, and prognosis.[10] To date, little is known about expectations of patients with symptomatic spinal metastases planned for palliative surgery and/or radiation therapy.

Therefore, the purpose of this study was to explore patient expectations regarding treatment outcomes after surgery and/or radiation therapy for the treatment of symptomatic spinal metastases.

## Methods

Patients were recruited from 2 tertiary centers (Departments of Orthopaedic Surgery and Radiation Oncology, University Medical Center Utrecht [UMCU], The Netherlands, and Vancouver General Hospital [VGH], Canada). Patients who were aged ≥ 18 years, were able to speak and understand Dutch (The Netherlands) or English (Canada), and planned for surgery and/or radiation therapy for symptomatic spinal metastases were eligible. The research protocol was approved by the institutional review boards of both participating hospitals. A written informed consent was obtained from all patients.

### *Procedure*

Individual semistructured interviews were conducted within 1 week before surgery and 6 weeks (±14 days) after surgery and/or radiation therapy. Pretreatment interviews were held at the hospital or at the patients' home. When it was not possible to conduct the post-treatment interview in person, it was conducted over the phone.

An interview guide containing broad and open questions was used to structure the interview to ensure completeness and consistency across interviews. Pretreatment topics included (1) expectations regarding treatment outcomes including factors influencing expectations, (2) information provided by physicians, (3) patient perception of information provided, and (4) the role of close relatives in the development of expectations. Post-treatment interviews addressed (1) review of pretreatment expectations, (2) fulfillment of pretreatment expectations, and (3) patient perception of completeness of the information provided by the physician before treatment. In case clarification was needed, interviewers asked additional questions. Patient enrolment proceeded until no new information was retrieved from the interviews (data saturation).

### *Data Analysis*

All interviews were digitally recorded and transcribed verbatim. Identifiable information was removed from the interviews to ensure participant confidentiality. Transcripts were analyzed by 2 researchers (RG, psychologist and epidemiologist, and AV, orthopedic surgery resident and epidemiologist) using the qualitative analysis software program NVivo 11 according to the thematic analysis method.[11] An initial list of codes and themes was developed by the 2 researchers based on the interview guide and first 5 interviews. Codes and themes were added based on the information from additional interviews until data saturation occurred. The 2 researchers independently generated codes by assigning labels to text fragments of the interviews that were regarded as meaningful information. Consensus about generated codes was reached by discussion. Codes with similar topics were grouped independently by the researchers into subthemes and overarching themes.

## Results

Data saturation was obtained after 15 interviews in The Netherlands and 9 interviews in Canada. Interviews were conducted between November 2018 and May 2020. Two patients in The Netherlands and 3 patients in Canada refrained from the post-treatment interview. Reasons for withdrawal from participation in the second interview included admission to the hospital and feeling too fatigued or too sick. Median time between the pretreatment interview and treatment was 1 day (range 0-7), and pretreatment interviews lasted on average 34 minutes (SD 10, range 10-50) (Table 1). Median time between (start of) treatment and post-treatment interviews was 43 days (range 35-56), and post-treatment interviews lasted on average 22.5 minutes (SD 9.1, range 13-44). Mean age of the included patients was 59.5 years (SD 15.0) and 42% was female. A total of 10 patients (42%) had spinal metastases involving multiple spinal regions. A total of 13 patients were planned for surgery (54%), whereof 10 patients also for adjuvant radiotherapy. Almost half of the patients (42%) received previous treatment for spinal metastases.

In the interviews before treatment, all patients reported back and/or neck pain. Most patients used opioid pain medications and experienced side effects, for example, fatigue, constipation, and confusion. Some patients reported weakness in arms and/or legs. Most patients experienced limitations in daily and physical functioning (eg, shorter walks, less/not being able to do household chores and/or social activities outside the house).

### *Expectations of Treatment Outcomes*

In general, patients thought they were not or minimally informed about (expected) treatment outcomes. Some patients mentioned that their physician indicated that treatment outcomes are hard to predict.

> "I do not expect anything. I do not know what to expect. He [the physician] could not promise me anything. (NL14)"

Most patients believed that the treatment goal was to relieve pain, whereas some patients believed that improvement in quality of life, prevention of spinal instability, or prolonging life expectancy was the goal of treatment.

When asking patients about their expectations of treatment outcomes, all patients expected improvement in their symptoms. Most patients expected a significant reduction or complete resolution of pain. In addition, most patients indicated to expect significant improvements in daily and physical functioning, for example, self-care, walking or biking for longer periods of time, and performing household chores.

> "Well, I think that it is going to be okay. I just think that it will work what they are planning to do and that it will ultimately be successful. And that the outcomes will be positive. (NL03)"

Most patients did not expect to return to their predisease level of daily functioning. Nevertheless, some patients did expect to return to predisease functioning.

> "So I expect to not be in pain. And then because of that, I expect to be [back to] normal. (CA02)"

Most patients were aware that recovery after surgery takes time. Nevertheless, patients expressed a wide range in expected recovery time, ranging from days (from hospital discharge) to 4 months. Most patients expected recovery time to be between 1 and 2 months.

> "I never had thought about it [recovery], but I mean in my mind I know it's not going to be a couple of weeks. I imagine it's going to take time. So I don't know. I would think maybe a month. (CA04)"

Almost all patients experienced constipation caused by opioid pain medications, but they expressed no specific expectations regarding post-treatment bowel functioning. Nevertheless, they hoped for improvement.

Some patients stated that they expected their mood to improve post-treatment, because of reduction in pain. Others did not expect any changes in their mood given that they did not experience any mood problems at baseline.

Overall, patients found it difficult to describe factors that influenced the development of their expectations. Most patients

**Table 1.** Demographic characteristics of patients with spinal metastases who were interviewed about their expectations of the treatment outcome.

| Variable | Total | The Netherlands | Vancouver, Canada |
|---|---|---|---|
| N | 24 | 15 | 9 |
| Gender (female), n (%) | 10 (42) | 9 (60) | 1 (11) |
| Time between pretreatment interview and treatment in days, median (range) | 1 (0-7) | 1 (0-7) | 2 (1-4) |
| Number of patients for post-treatment interview | 19 | 13 | 6 |
| Time between treatment and post-treatment interview in days, median (range) | 44.5 (35-57) | 43 (35-56) | 49 (35-57) |
| Age, mean (SD) | 59.5 (15.0) | 61.5 (11.7) | 56.2 (18.8) |
| Education, n (%) | | | |
| Primary or (post)secondary school | 12 (50) | 10 (67) | 2 (22) |
| College or university | 11 (46) | 5 (33) | 6 (67) |
| Unknown | 1 (4) | — | 1 (11) |
| Marital status, n (%) | | | |
| Married or lived with partner | 15 (63) | 10 (67) | 5 (56) |
| Single | 9 (38) | 5 (33) | 4 (44) |
| Primary tumor, n (%) | | | |
| Prostate | 6 (25) | 5 (33) | 1 (11) |
| Breast | 5 (21) | 4 (27) | 1 (11) |
| Lung | 2 (8) | 2 (13) | — |
| Renal cell | 2 (8) | — | 2 (22) |
| Other | 9 (38) | 4 (27) | 5 (56) |
| Level of spinal metastases, n (%) | | | |
| Cervical | 1 (4) | 1 (7) | — |
| Thoracic | 9 (38) | 4 (27) | 5 (56) |
| Lumbar | 3 (13) | 2 (13) | 1 (11) |
| Sacral | 1 (4) | — | 1 (11) |
| Multiple spinal regions | 10 (42) | 8 (53) | 2 (22) |
| Treatment history of spinal metastases, n (%) | | | |
| No previous treatment—primary tumor recently diagnosed | 5 (21) | 4 (27) | 1 (11) |
| No previous treatment—primary tumor >1 year ago diagnosed | 9 (38) | 8 (53) | 1 (11) |
| Previous treatment | 10 (42) | 3 (20) | 7 (78) |
| Planned treatment for spinal metastases, n (%) | | | |
| Surgery | 3 (13) | 1 (7) | 3 (33) |
| Radiation therapy | 9 (38) | 8 (53) | 1 (11) |
| Surgery, followed by radiation therapy | 10 (42) | 5 (33) | 5 (56) |
| Radiation therapy, followed by surgery | 2 (8) | 1 (7) | — |

*Note:* Other primary tumors included gynecological cancer, multiple myeloma, sarcoma, bone cancer, and gastrointestinal cancer (including colorectal and liver cancer).

stated that they mainly developed their expectations based on the information provided by their spine surgeon or radiation oncologist, but that the information they received regarding expected treatment outcomes was limited. Some patients indicated the internet as an information resource, whereas others were critical about the internet because of many inconsistencies and information being not specific to patients with cancer. In addition, experiences of family or friends also served as information source for some patients for the development of expectations.

Overall, patients did not actively discuss expectations regarding treatment outcomes with close relatives or their spouse. Despite this, some patients believed that their close relatives had similar expectations, whereas some other patients did not know whether their expectations matched.

## *Life Expectancy and Cure*

When asking patients what they have been told regarding the chance of cure with surgery and/or radiation therapy, all Dutch patients stated to be aware that cure is not possible, whereas some of the Canadian patients expressed hopes for cure. When reflecting on life expectancy, almost all patients mentioned that their life expectancy or the impact of treatment on their life expectancy was not discussed by their spine surgeon or radiation oncologists. Some patients stated that they did not want to receive information regarding their life expectancy.

> “That was never mentioned and I do not ask for that [information about their life expectancy]. (NL03)”

Patients acknowledged that it is hard to predict life expectancy. When asked, patients expressed a wide range in subjective life expectancy, varying between months and years.

> “It may be well that it will last a few months, but it also may last a few years. (NL09)”

## *Patient Perceptions of the Information Provided by the Physician*

Patients thought that they were well informed about the procedural aspects of the upcoming treatment. Most patients found that the information was complete and properly explained; they were satisfied with the information provided by the physician. Most patients stated that information included risks and possible complications of spine surgery (including paralysis, numbness, continued pain, wound infection, cement leakage, spinal cord injury because of malplacement of hardware, and bowel or bladder dysfunction) and radiation therapy (including nausea, fatigue, and problems with the esophagus). Nevertheless, some indicated that risks and possible complications were not discussed. To note, some patients preferred not to be informed about treatment risks and complications.

Patients were positive about the way physicians provided information. They felt that the physician took time for the consultation; the consult felt not rushed and they appreciated repetition of information.

Despite being well informed, patients indicated to have received a lot of information, felt overwhelmed, and did not retain all the information.

> "You receive so much information, that at some point you think, does it still makes sense? I remember the advantages. And the disadvantages... I do not want to know them. (NL08)"

Some patients stated that they were informed about different treatment options for their spine tumor including surgery, radiation therapy, or no treatment. Although others stated they were only informed about the treatment they were offered by their physician. Patients indicated that physicians gave a treatment recommendation (ie, surgery and/or radiation therapy), with only the recommended treatment being discussed with the patient.

Patients experienced that the final treatment decision was a shared decision. Nevertheless, patients indicated that they did not question the treatment recommendation because they believed the treatment was required to relief their pain (instead of choosing no treatment or alternative treatment options). Patients indicated that they trusted their physician when making treatment decisions.

### *Post-treatment*

Overall, patients were positive about treatment outcomes. Most patients felt that treatment outcomes partly met their pretreatment expectations and stated not to experience any unexpected treatment outcomes. Expectations regarding pain reduction were met for most patients, and most patients required lower doses of opioid pain medications after treatment. Still, 2 patients found the treatment effect on their pain level disappointing.

Most patients experienced improvements in daily functioning and physical functioning 6 weeks after surgery (ie, walking longer distances); nevertheless, they did not return to predisease level of physical functioning. Some patients reported side effects after radiation therapy, including fatigue, nausea, and increased pain, yet indicated that they were informed about these side effects.

Pretreatment expectations were not fulfilled for all patients. Patients indicated that they were informed about an extended recovery period; nevertheless, they expected earlier and more improvement in physical functioning than what they experienced. Despite most patients experiencing improvements in physical function, patients still experienced limitations in their physical functioning 6 weeks after the treatment (eg, feeling stiff and reduced strength in the arms and/or legs) compared with predisease level of functioning.

## Discussion

This qualitative study explored patient expectations regarding treatment outcomes after surgery and/or radiation therapy for the treatment of spinal metastases. Patients with symptomatic spinal metastases planned for spine surgery and/or radiation therapy reported to be not or minimally informed about (expected) treatment outcomes, but felt well informed about the treatment procedure and possible complications. Patients expressed to expect improvements in pain and daily functioning after treatment, but they found it difficult to estimate time to recovery or the impact of expected improvements on their daily life. Despite the lack of information regarding expected outcomes, patients indicated that the information from the physician was the most important source for the development of their expectations. Patients were mostly aware of the palliative nature of the treatment. Some patients expected prolongation of life, but the impact of the treatment on their life expectancy or prognosis was hardly discussed by the spine surgeon and/or radiation oncologist. Although patients found it difficult to describe their expectations in detail previous treatment, expectations regarding pain were met for most patients 6 weeks after treatment, whereas expectations regarding physical functioning were not met for all patients. Patients underestimated time to recovery and increased stiffness and weakness in the arms and/or legs at 6 weeks after treatment.

Pretreatment expectations are important for post-treatment satisfaction and HRQOL. A study among 4709 individuals undergoing primary lower limb (ie, hip or knee) joint replacement showed that post-treatment patient satisfaction was determined by meeting preoperative expectations (odds ratio 2.62, 95% confidence interval 2.24-3.07) and satisfaction with pain relief (odds ratio 2.40, 95% confidence interval 2.00-2.87).[12] In addition, another study showed that patients were more satisfied after total hip or knee replacement when more expectations were fulfilled 1 year after surgery.[13]

In the absence of literature about expectations of patients with spinal metastases planned for surgery and/or radiation therapy, we conducted a systematic review to explore expectations regarding treatment outcomes in patients who had spinal surgery for noncancer-related conditions and from patients with advanced cancer, under the assumption that these 2 populations share some characteristics with patients with symptomatic spinal metastases.[10] In line with this systematic review, we found in the current study that some patients had overly optimistic expectations regarding impact of treatment on physical functioning. In contrast, expectations regarding pain were partially met for most patients, whereas the systematic review showed overly optimistic expectations regarding pain.

Between 23% and 64% of patients with advanced cancer have inaccurate expectations regarding the possibility of cure after palliative radiation therapy, chemotherapy, or immunotherapy.[14-17] Few patients in this study had expectations regarding prognosis and life expectancy. Patients mentioned that their life expectancy or the implications of the treatment on their life expectancy were not discussed by the spinal surgeon or radiation oncologist. Some patients stated that they preferred not to think about the future. This is concerning considering the study of Enzinger et al[18] demonstrating that 71.0% of the patients with advanced cancer wanted to be informed about their life expectancy by their physician, but only 17.6% of the patients were informed about their life expectancy. These results indicate that physicians need to more proactively discuss the goals of palliative treatment.[19] Nevertheless, physicians perceive different barriers in effectively discussing goals of care in patients with cancer. Bernacki et al[20] identified the barriers including limited consultation time, uncertainty with regard to prognosis, the physicians' ability to manage patient emotions, and the feeling of insufficient training to discuss goals of care. Therefore, formally educating physicians to discuss goals of care and treatment expectations is important for patients to be able to develop realistic expectations regarding their life expectancy and treatment outcomes.

Patients indicated that they were well informed about the treatment, possible side effects, and complications. In contrast, they felt they were less informed about expected treatment outcomes, for example, what to expect in daily and physical functioning (eg, caring for themselves, walking/biking for longer periods of time, and performing household chores). This might be explained by the fact that patients were preoccupied with, or mainly focused on, the treatment. Patients mentioned that they received large amounts of information before treatment and did not have room to think and process information about the time after treatment. Previous research showed that patients with cancer have more problems with recalling information provided by the physician with increasing amounts of information, especially older patients and patients with a poorer prognosis.[21] In addition, opioid pain medication may impair memory and thinking. Second, patients may not fully understand the information provided by the physician regarding diagnosis, prognosis, and treatment.[22] A third explanation might be that physicians did not verify patients' expectations of treatment outcomes of spine surgery or radiation therapy.[23] In another study within this project, spine surgeons and radiation oncologists acknowledged to not proactively ask patients with symptomatic spinal metastases about their expected treatment outcomes.[23] They indicated that they manage pretreatment patient expectations by giving a broad yet nonspecific overview of treatment outcomes and the most common risks of the treatment not tailored to the individual patient. Rehman et al[24] also concluded that physicians mostly provided information about the surgery and possible complications and less information about prognosis. Moreover, spine surgeons indicated that they have limited allocated amount of time for the pretreatment consultation. Therefore, they may be unable to explore what their patients expect and tend to keep the information more general.

In a previous study, physicians involved in the care of patients with spinal metastases were interviewed and acknowledged the importance to discussing expected treatment outcomes.[23] The interviewed physicians were also asked about recommendations to improve pretreatment expectations of patients. Physicians mentioned tools such as pretreatment education modules about the postoperative period treatment outcomes. Educational classes about the postoperative period up to 12 months for patients undergoing total hip or knee arthroplasty resulted in pretreatment expectations that coincide with physicians' expectations.[25,26] Patients with spinal metastases are a heterogeneous population, often requiring urgent, palliative treatment, which might make discussion about expected treatment outcomes more challenging. Another solution might be use of advanced nurse practitioners, who are well known to have a positive impact in breast cancer care. Breast cancer nurses provide additional counseling and support to patients and the opportunity for patients to discuss unclear issues and ask questions. Patients who received support from a breast cancer nurse were better informed about the treatment and follow-up care and reported a better quality of life up to 1 year after treatment than patients not receiving support.[27] Finally, questionnaires evaluating patient expectations of treatment outcomes might improve patient counseling by verifying patient expectations and, if needed, guidance toward realistic expectations. Future research should explore whether pretreatment discussion and management of realistic expectations will result in improved satisfaction and HRQOL in patients with spinal metastases.

The qualitative study design provides an in-depth insight into patient expectations. Open-ended questions invited patients to share their experiences, and interviews allowed probing for additional information and asking follow-up questions. Patients were enrolled in The Netherlands and in Canada to provide (cultural) diversity and improve generalizability of the results. Nevertheless, in both countries, patients were included from a single center, which possibly affects external validity. In addition, patients were invited by their physician, further limiting generalizability of the results given that it is possible that physicians (unconsciously) exhibited selection bias.

## Conclusions

Currently, patients felt they were not or only minimally informed about expected outcomes after surgery and/or radiation therapy for symptomatic spinal metastases. Considering the association between pretreatment expectations and HRQOL, it is crucial that physicians discuss expected treatment outcomes and guide patients toward realistic pretreatment expectations. Future research studies focused on systematically evaluating HRQOL and patient expectations of treatment outcomes will help to determine the impact of patient expectations on HRQOL and patient satisfaction.

## Article and Author Information

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