



Clinical Study

Patient experiences of decision-making in the treatment of spinal metastases: a qualitative study

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Received 7 August 2019; revised 21 November 2019; accepted 27 December 2019

Abstract

BACKGROUND: In the treatment of spinal metastases the risks of surgery must be balanced against potential benefits, particularly in light of limited life-expectancy. Patient experiences and preferences regarding decision-making in this context are not well explored.

PURPOSE: We performed a qualitative study involving patients receiving treatment for spinal metastatic disease. We sought to understand factors that influenced decision-making around care for spinal metastases.

STUDY SETTING: Three tertiary academic medical centers.

PATIENT SAMPLE: We recruited patients presenting for treatment of spinal metastatic disease at one of three tertiary centers in Boston, MA.

OUTCOME MEASURES: We conducted semistructured interviews using a guide that probed participants' experiences with making treatment decisions.

METHODS: We performed a thematic analysis that produced a list of themes, subthemes, and statement explaining how the themes related to the study's guiding questions. Patients were recruited until thematic saturation was reached.

RESULTS: We interviewed 23 participants before reaching thematic saturation. The enormity of treatment decisions, and of the diagnosis of spinal metastases itself, shaped participant preferences for who should take responsibility for the decision and whether to accept treatments bearing greater risk of complications. Pre-existing participant beliefs about decision-making and about surgery interacted with the clinical context in a way that tended to promote accepting physician recommendations and delaying or avoiding surgery.

CONCLUSIONS: The diagnosis of spinal metastatic disease played an outsized role in shaping participant preferences for agency in treatment decision-making. Further research should address strategies to support patient understanding of treatment options in clinical contexts—such as spinal metastases—characterized by ominous underlying disease and high-risk, often urgent interventions. © 2019 Elsevier Inc. All rights reserved.

FDA device/drug status: Not applicable

Author disclosures: **ECL:** Nothing to disclose. **JNK:** Grant: NIH (G). **JAB:** Nothing to disclose. **ATC:** Nothing to disclose. **GSS:** Nothing to disclose. **JHS:** Consulting: Stryker (C). **TAB:** Grant: NIH (G). **EL:** Grant: NIH (G), Pfizer (C), Samumed (C), Flexlon (C); Consulting: REgeneron (C); Scientific Advisory Board/Other Office: JBJS (C). **AJS:** Grant: NIH-NIAMS (G), OREF (F), DoD (H), CMS-OMH (F); Royalties: Wolters-

Kluwer (B), Springer (A); Scientific Advisory Board/Other Office: JBJS (D).

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Keywords: Spinal metastases; Decision making; Provider communication; Surgical management; Radiation oncology; Qualitative research

Introduction

The treatment of patients with spinal metastases is challenging and requires the expertise of providers from different disciplines, including oncologists, surgeons, radiation oncologists, and pain management specialists.¹ Although the benefits of nonoperative management are well characterized, some evidence suggests that patients may experience superior maintenance of function, less pain, and improved cognition if treated with an approach that incorporates surgery [1–6].

The risks of surgery must be balanced against potential benefits, particularly in light of limited life-expectancy [1,2]. Patients may prefer gradual deterioration with nonoperative treatment over surgical risks and a longer recovery time. Patient preferences have been examined for treatment decisions in certain primary cancers that present tradeoffs between survival and functional status [7–12]. For example, McNeil et al. reported that one in five patients with laryngeal carcinoma would choose a treatment that offered shorter survival in order to preserve an important aspect of their life (in this case, voice) [7]. We are not aware of similar research involving treatment choices for metastatic disease. A better understanding of patient preferences in the context of spinal metastases can inform discussions with patients and their families at the time of treatment initiation and improve shared-decision making.

In this context, we performed a qualitative study involving patients receiving treatment for spinal metastatic disease. Using semistructured interviews, we sought to better understand patient preferences for the treatment of spinal metastases and factors that influence decision-making around medical care. Qualitative methods may be better suited to explore the subjective nature of decision making in the treatment of spinal metastases. This approach allows patients to describe their decision-making experiences in their own words, as opposed to predetermined choices or restricted language as may be the case with questionnaires [13,14].

Materials and methods

Participants and recruitment

We recruited patients presenting for evaluation and treatment of spinal metastatic disease at three academic tertiary care centers in the Departments of Orthopedic Surgery, Neurosurgery, or Radiation Oncology. Additional inclusion criteria were age >18 and ability to speak English. Potentially eligible participants received a letter inviting them to enroll in the study and providing a chance to opt out. Those who had not opted out within 10 days were contacted by a research assistant who gauged interest, confirmed eligibility, and for those wishing to participate, obtained verbal

consent. All study activities were approved by our Institutional Review Board.

Data collection

Individual interviews were conducted on the phone or in person at BWH. Participants were not known to the interviewer before participation. Participants received 25 USD to thank them for their time. The conversations followed a semistructured interviewer guide (Table 1) that probed the following: participants' goals for treatment, the people and sources of information they consulted, their valuation of different health states, and their understanding of the tradeoffs involved in choosing operative or nonoperative management. Enrollment continued until we achieved thematic saturation, defined as the point at which further data collection was not anticipated to lead to new insights or additional critical information [13]. The study team operationalized this criterion by meeting regularly during enrollment to assess the novel content added by each new interview as compared with previously existing interviews; only when no new relevant insights were being added did we consider thematic saturation achieved and stop enrollment. Informed consent was obtained from all participants. Demographic and clinical information was obtained before, or at the time of, the interview.

Analysis

Interviews were audio-recorded with permission and transcribed verbatim. All transcripts were deidentified. We conducted a thematic analysis [13–16] of all transcript data. Thematic analysis is a widely used form of qualitative analysis, and we followed the procedures delineated by Braun and Clarke [13]. We selected a thematic approach due to this technique's flexibility, the ability to apply the process across a range of epistemologies and the fact that the approach can be utilized by researchers without individual experiences in the clinical context [13]. In the first phase, two investigators independently coded the transcript text by attaching codes (words or phrases) to the most basic segments of data bearing on the guiding questions of the study: *How do individuals with spinal metastases make decisions to undergo operative versus nonoperative treatments? How do patients come to understand the different health and functional outcomes that might result from each treatment, and what role does this knowledge play in the treatment decision?* The two coders (ECL, AJS) met to align their coding practices and finalize the coding scheme, after which one investigator (ECL) coded the remaining data using the qualitative analysis software Dedoose (Dedoose.com).

In the second phase, investigators independently searched the transcripts for themes, which express broader patterns in the data in relation to the guiding questions.

Table 1
Topics addressed in interviewer guide

Overview and treatment history	<ol style="list-style-type: none"> 1. When were you first diagnosed with cancer and what type of cancer were you diagnosed with? 2. When did you first become aware that the cancer had spread to the spine? Were other parts of your body involved as well? 3. At what point did you start receiving cancer treatments in the Boston area? 4. What treatments have you received for the cancer up until now? <ol style="list-style-type: none"> a. How about for the cancer involving your spine? 5. What treatments for the cancer do you plan to receive in the future, if any? <ol style="list-style-type: none"> a. How about for the cancer involving your spine? 6. How did you decide upon the treatments you have been receiving for the cancer involving your spine?
Sources of advice and information	<ol style="list-style-type: none"> 1. How important was the advice of your health care providers (surgeon, oncologist, radiation oncologist, primary care provider, etc.) in your decision of what treatments to have for the cancer involving your spine? <ol style="list-style-type: none"> a. If they mention trust: <ol style="list-style-type: none"> i. How did you develop trust in your physician? ii. Do you feel you can ask them questions or contradict them? 2. How important was advice from other people and sources of information, such as: <ol style="list-style-type: none"> a. Family and friends? b. Written materials? c. Online information? d. Other?
Weighing treatment options	<ol style="list-style-type: none"> 1. Did your physicians discuss with you the pros and cons of various treatment choices? Did you feel that you had alternatives, or that there was really only one choice? <ol style="list-style-type: none"> a. If you had different options, what led you to choose the treatment you ultimately received? <ol style="list-style-type: none"> i. What were you told about the possible health states that might result down each “pathway”? ii. Did you have a sense of urgency about beginning some kind of treatment? What timeframe did you think would be best for making your decision? 2. What were your goals in choosing the treatment for your spine cancer? <ol style="list-style-type: none"> a. What was most important to you? <ol style="list-style-type: none"> i. Probe: Lessen pain, improve ability to walk or do activities, avoid a fracture or other complication? b. Did you feel that one treatment would be better than another in helping you meet these goals? 3. Please tell me about the process of deciding on the type of treatment you would receive. <ol style="list-style-type: none"> a. Were you undecided for a long time? How close were the two options in your evaluation? b. Can you reflect on a particular moment in which you decided which type of treatment (operative/nonoperative) you wanted to receive?
The future	<p>You made the decision to undergo treatment. What were your expectations around treatment?</p> <ol style="list-style-type: none"> 1. What did you expect the benefits of treatment would be? <ol style="list-style-type: none"> a. Did you expect that it would be painful or that it would not be painful? b. How long did you think it would take until you were able to recover fully (returning to the activities you could do before treatment for spinal cancer), or walk as much as you wanted? c. Has the treatment worked out the way you hoped it would? <ol style="list-style-type: none"> i. Probe: Are you better or worse than you were when you started treatment? 2. What adjustments to your daily activities did you have to make following your treatment? 3. Were there any parts of the treatment experience that you found frustrating?
Reflection	<ol style="list-style-type: none"> 1. If you could change one thing about your treatment, what would it be? 2. If you had to do it all over again, would you make the same treatment choices? 3. If you were speaking to someone considering treatment for this same condition and you had to give them advice: <ol style="list-style-type: none"> a. What would you say? b. What should they be sure to speak with their surgeons/oncologists about? c. How can surgeons/oncologists be more helpful to a patient when making decisions regarding treatment?

In this phase, the investigators analyzed the codes and considered how they related to each other [13]. This phase was followed by peer debriefing and ended with a list of themes, subthemes, and proposed statements that explain how the codes and themes may bear on the guiding questions. One investigator compiled the supporting transcript data for each theme and hypothesis. We developed a thematic map to visually portray the themes and their relationships to each other and to the guiding questions. All investigators met again to refine the thematic scheme and map with

disagreements resolved by consensus until full agreement was achieved.

Results

Participants

Seventy-seven potentially eligible patients were sent recruitment letters, and 23 (30%) consented to participate. All who agreed to enroll completed interviews. The

percentage of patients that agreed to participate was similar when stratified by sex (30% of eligible males and 29% of females) and somewhat higher for nonoperative cases (38% of eligible nonoperative patients versus 24% of surgical patients). Eleven participants (48%) had undergone operative treatment for spinal metastases, whereas 12 (52%) had received only nonoperative management. Forty-three percent of the sample was female, and the mean age was 62 (SD 10.5; Table 2). Fourteen participants (61%) were interviewed at the time of their first diagnosis with metastatic disease, whereas 9 (39%) had previously been diagnosed with metastases. Seven patients (30%) had a solitary metastatic process, whereas 16 (70%) had multiple sites of involvement. We conducted interviews from June 2018 through March 2019, primarily by phone (2 in person).

Results of thematic analysis

We identified three themes and 13 subthemes (Fig. 1). Below, we list each theme (I-III) and subtheme (capital letters) along with select associated findings suggested by the transcript data and the supporting quotes (noted with Arabic numerals). This framework is outlined in Table 3, and a comprehensive list of supporting quotations is found in Appendix 1. In the quotations below, the number in parentheses indicates the participant's study-specific number.

I. Diagnostic context

Participants made their treatment decisions in the context of diagnoses of advanced, metastatic cancer, which

Table 2

Clinical and sociodemographic characteristics of study participants. Note that percentages are rounded

Variable	Number (%) n=23
Sex	
Female	10 (44)
Male	13 (57)
Age (Mean, SD)	62 (11)
Race	
White	23 (100.0)
BMI (Mean, SD)	28.0 (6)
Charlson Comorbidity Index (Mean, SD)	2.1 (1)
Primary tumor	
Breast	1 (4)
Kidney	6 (26)
Lung	4 (17)
Prostate	2 (9)
Thyroid	1 (4)
Head and neck cancer	1 (4)
Multiple myeloma/lymphoma	4 (17)
Testicular	1 (4)
Uterine	1 (4)
Paranganglioma	1 (4)
Pancreatic	1 (4)
Treatment	
Operative	11 (48)
Surgery alone	2 (9)
Surgery and radiation therapy	1 (4)
Surgery and chemotherapy	3 (13)
Surgery, radiation therapy, and chemotherapy	5 (22)
Nonoperative	12 (52)
Radiation therapy alone	2 (9)
Radiation therapy and chemotherapy	10 (44)

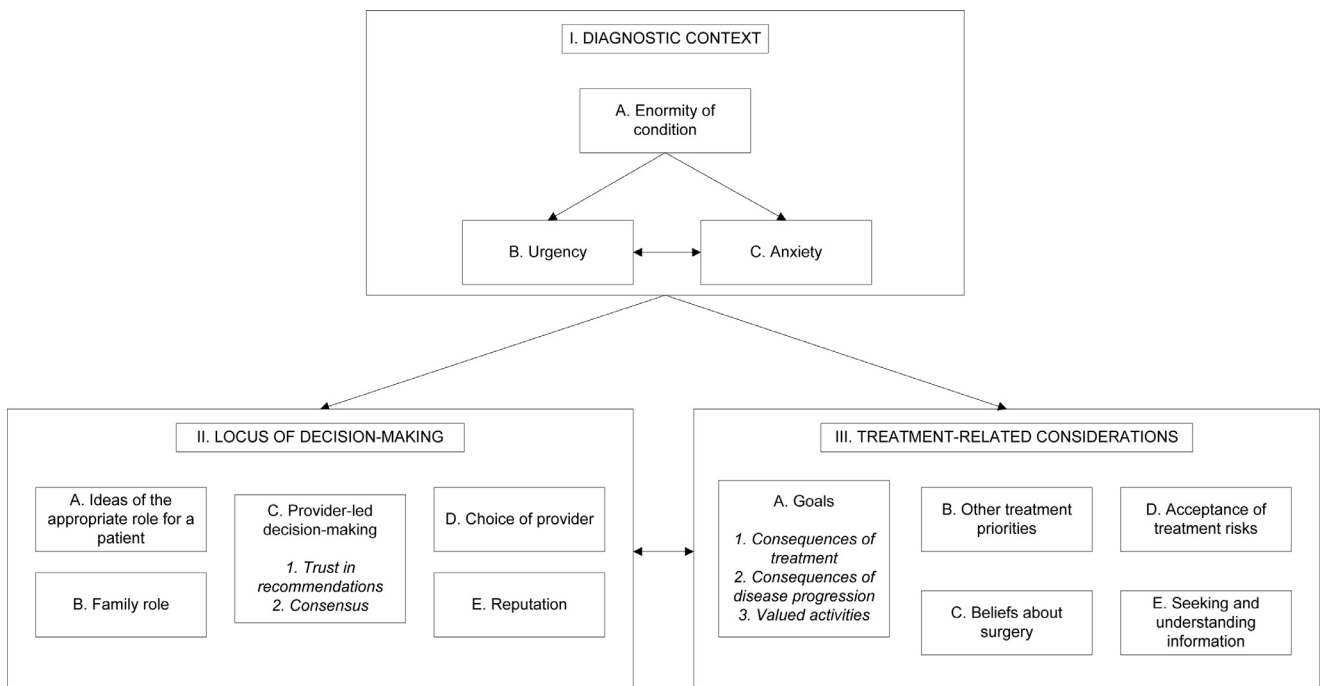


Fig. 1. Our thematic map that visually portrays the themes and subthemes identified in this study and their relationships.

Table 3

Themes and key findings resulting from the thematic analysis

Theme or subtheme	Findings	Sample of supporting text from transcripts
I. Diagnostic context		
A. Enormity of condition	Magnitude of diagnosis impaired patients' capacity to participate in shared decision making, ask questions, and communicate concerns.	"You don't know the questions to ask, because I had no idea I was gonna have tumors on my spine. If I had known that, I would have come in and said. . . are we gonna do surgery, or are we gonna do radiation..."
B. Urgency	The feeling of necessity to move forward with treatment as soon as possible promoted unquestioned acceptance of the treatment plan offered.	"Whenever you have something in you that's growing—it's a growth—you probably want it—outta there as soon as possible. [Surgery] was scheduled pretty quickly."
C. Anxiety	Researching on one's own was seen as psychologically unhealthy or unwise. Anxiety around expediting treatment initiation so that something is being done to 'treat' the metastatic disease.	"If I go down that rabbit hole it just leads to an uncomfortable place." "Any surgery can go bad and I knew that. But I was just. . . anxious to get it over and done with..." "When it's time to pull a Band-Aid off, you pull it quick. You don't pull it slow." "...I didn't think there were any options other than [surgery], because it seemed like if this wasn't dealt with then I could definitely end up with some deficit... I was anxious to get it fixed. . ."
II. Locus of decision-making		
A. Ideas of appropriate role for a patient	Determination to endure treatments was strengthened by time spent dealing with cancer. The belief that patients' role is more to cope with treatments than to decide on them encouraged acceptance of recommendations.	"I guess what also made the decision easier for me was having gone through all those previous operations. So, I guess, if you're committed to the process, once you commit to the process, don't step out of the last—at the end. Does that make sense?" "They know a lot more than me, so you go with—it's like goin' to an auto mechanic."
B. Family role	Some participants valued making decisions on their own to remove burden from their families. Many participants relied on family members to ask questions. Several expressed the notion that family members were better situated to be less emotional, and more 'level-headed.'	"That's a pretty hefty decision-making thing to do. My wife and I. . . work it out, but in the end I relieve her or the doctors or anybody else of [the decision]" "You're in a bit of a fog. I just wanted to get done—whatever needs to be done get done. The other person who's not feeling that is saying, 'Well, hold on a second.' They had more questions than I had."
C. Provider-led decision-making		
1. Trust in recommendations	Reputation and perception of physicians' expertise increased the tendency to accept recommendations. The sense that a treatment was the recommended protocol tended to foreclose other options (conflation of recommendation with decision).	"It just never occurred to me to second guess them. . .I'm going to the best I can find in the country; how foolish would it be of me to be second guessing them[?]" "They decided—they recommended, and I agreed—to go with radiation."
2. Consensus	The perception of consensus among physicians increased trust in recommendations.	"She said that...the oncologists, the radiologists, the surgeons. . .meet and they actually look at the spine . . . working together to make the decision . . . when you hear things like that it's very reassuring."
D. Choice of provider	Participants exercised their choice and spent considerable effort choosing a provider, after which they tended to trust in providers' opinions.	"I trust my doctors, so if my surgeon. . .or my radiation oncologist said. . . see if you think this might be helpful to you, I would do it."
E. Reputation	Physician and/or hospital reputation was seen as a guarantee that treatment recommendations would be sound.	"I look more at the person that's giving me the advice, at their background and their knowledge. . . . then I go on their advice."
III. Treatment-related considerations		
A. Goals		
1. Consequences of treatment	Treatments with less recovery time were valued more highly by patients. Provider conversations were the main source of information that shaped patients' expectations of side effects and risks.	"... I obviously was looking for the treatment that would give me the least amount of down-time. That was probably the radiation."
2. Consequences of disease progression	Consequences of disease progression (neurological problems, pain) motivated patients to take action. Surgery was often preferred when the fear of disease progression was strong enough.	"...I just wanted to stop the progression. And avoid being paralyzed."

Table 3 (Continued)

Theme or subtheme	Findings	Sample of supporting text from transcripts
3. Valued activities	A driving goal was to be around for family events and to see the next generation; treatments were evaluated for their ability to help achieve this.	“My son is getting married in October and I’m part of his wedding party, and I don’t wanna do wheelchairs. I’d rather walk him down the aisle.”
B. Other treatment priorities	Receiving other treatments or being in a trial was sometimes the primary goal, and a spinal metastasis treatment would not be chosen if it interfered.	“... I’ve been vying for this CAR T-cell for the past couple of years... So I didn’t have a chance to research, however, even if I had, the overriding decision maker was getting in to the trial...”
C. Beliefs about surgery	Patients viewed surgery as a last resort and something to be avoided for as long as possible.	“I just wanted to give the other options an opportunity to work first. If they don’t, it’s nice to have the surgery option as a backup plan.”
D. Acceptance of treatment risks	Acceptance that something might go wrong was necessary for participants who chose a treatment option with greater risks.	“I’m comfortable enough at this point with dying, that if I make a mistake, it’s just my mistake. I did it, so nobody will feel like, ‘...I made the wrong decision for him.’”
E. Seeking and understanding information	Understanding required the time to ask questions and process; urgency can interfere. Understanding all pathways required a willingness and ability to ask questions. Difficulty in reaching the care team or fears of aggravating providers produced confusion and prevented patients from asking questions. A second, ‘down the road’ option was often not thoroughly explained, understood, or explored.	“You get home, and then you start researching, and then all the questions come. They’ve been really good about doing follow-up answers to my questions, but I’d rather be prepared.” “They just don’t have the time. [You can’t] take up half of their... day so that you and everybody in your family can understand what [is] going on.” “They didn’t really mention surgery... I mean, they did when I went for my [radiation] consult... and they kinda just glazed over the surgery. Or maybe I glazed it over.”

profoundly influenced how decisions were made. This diagnostic context, including illness uncertainty, shaped participant preferences for how much agency to take in their own decision process and sometimes limited participants from fully engaging in the decision through independent research and critical conversations with their health-care providers.

A. Enormity of condition

While speaking with providers about treatment decisions, most participants were simultaneously adjusting to the reality that they had spinal metastatic involvement. Emotional reactions to the gravity of their diagnoses, combined with illness uncertainty, made it difficult for participants to fully engage in the conversation and formulate questions:

“You don’t know the questions to ask, because I had no idea I was gonna have tumors on my spine. If I had known that, I would have come in and said... are we gonna do surgery, or are we gonna do radiation...” [9]

The magnitude of the decision also contributed to a limited ability to imagine alternatives:

“I didn’t think there were any options other than [receiving the treatment offered], because it seemed like if this wasn’t dealt with then I could definitely end up with some deficit including paralysis.” [17]

B. Urgency

Participants described a perceived need to move forward quickly with treatment whether or not this was articulated directly by their clinicians. This sense of urgency was not solely limited to those who opted for surgical intervention. Visceral disgust toward the tumor sometimes compounded this sense of urgency:

“Whenever you have something in you that’s growing—it’s a growth—you probably want it—outta there as soon as possible. [Surgery] was scheduled pretty quickly.” [13]

C. Anxiety

Participants experienced anxiety around the prospect of what the diagnosis of spinal metastases meant for their future, the potential for functional decline and the need for treatments with substantial complication profiles such as surgery or radiation therapy. Many were concerned about the burden that this would place on their families and cited anxiety as a factor driving them to accept more aggressive treatments. The desire to take decisive action was a way of coping with the anxiety of diagnosis and treatment:

“Any surgery can go bad and I knew that. But I was just... anxious to get it over and done with...” [5]

To avoid exacerbating anxiety, some participants declined to research treatment options on their own:

“If I go down that rabbit hole it just leads to an uncomfortable place.” [8]

II. Locus of decision-making

Inherent in participants’ decision-making processes was an initial choice: Who will serve as the decision maker(s)? That choice was shaped by the magnitude of the treatment decision (Theme I) and guided by personal beliefs and values that varied among individuals.

A. Ideas of the appropriate role for a patient

Some participants expressed the notion that their role was not to decide on treatments but to work hard on recovery. A common belief was that the patient’s role is to defer to the doctor’s expertise and ask few questions. Conveying this more passive role through analogy, participants spoke of doctors as experts that they came to for service:

“They know a lot more than me, so you go with—it’s like goin’ to an auto mechanic.” [13]

B. Family role

Many participants relied on family members to ask questions and develop further clarity around treatment options on their behalf. Several expressed the notion that family members were better situated to be less emotional, and more “level-headed,” when asking for additional information around treatment options.

“You’re in a bit of a fog. I just wanted to get done—whatever needs to be done get done. The other person who’s not feeling that is saying, ‘Well, hold on a second.’ They had more questions than I had.” [13]

This role differed, however, when it came to deciding on the ultimate course of treatment. Several participants expressed a desire to decide on their own precisely because of the magnitude of the decision, sparing their families from responsibility for complications or unsatisfactory outcomes:

“That’s a pretty hefty decision-making thing to do. My wife and I . . . work it out, but in the end I relieve her or the doctors or anybody else of [the decision]” [6]

C. Provider-led decision-making

1. Trust in recommendations

A particularly salient trend involved acceptance of the treatments recommended by physicians. Recommendations weighed heavily; in fact, participants sometimes conflated a recommendation with the decision itself [*“They decided—they recommended, and I agreed—to go with radiation.” [12]*]. When describing reasons for agreeing with the recommended treatment, participants cited the reputation

and expertise of their doctors, especially in contrast to the participants’ own knowledge.

“It just never occurred to me to second guess them. . . I’m going to the best I can find in the country; how foolish would it be of me to be second guessing them[?]” [12]

2. Consensus

A powerful factor that encouraged participants to trust in—and accept—treatment recommendations was the sense that several physicians had reached consensus.

“She said that...the oncologists, the radiologists, the surgeons . . . meet and they actually look at the spine . . . working together to make the decision . . . when you hear things like that it’s very reassuring.” [2]

D. Choice of provider

Choosing a provider was often a defining first step in treatment decision-making. Many participants focused their research not on the treatment approach, but on selecting a provider in whom they could place their trust:

“I trust my doctors, so if my surgeon . . . or my radiation oncologist said . . . see if you think this might be helpful to you, I would do it.” [10]

E. Reputation

Reputation, referrals from other providers, and the recommendation of family/friends played a key role in provider choice. Being under the care of renowned hospitals and clinicians gave the participants confidence in (a) accepting the recommended treatment and (b) undergoing complex surgeries:

“I look more at the person that’s giving me the advice, at their background and their knowledge . . . then I go on their advice.” [7]

“My brother . . . knew of Dr. [last name], and they gave him a very high recommendation. That was pretty much all I needed was somebody that . . . knew him and said that he was very, very good.” [5]

III. Treatment-related considerations

A. Goals

Participants considered three main categories of goals: minimizing negative consequences of treatment, minimizing disease progression, and protecting the ability to engage in valued activities.

1. Consequences of treatment

Pain and risk of complications were commonly cited reasons to avoid surgery. Treatments with less recovery time or fewer limitations were often preferred:

“... I obviously was looking for the treatment that would give me the least amount of down-time. That was probably the radiation.” [9]

2. Consequences of disease progression

Another key quality of a treatment was its perceived ability to halt disease progression and prevent neurological problems, including paralysis. Surgery was often preferred when the fear of disease progression was strong enough:

“... I just wanted to stop the progression. And avoid being paralyzed.” [16]

3. Valued activities

A driving goal for several individuals was the ability to participate in important events in the lives of family members. This included the desire to maintain specific functional abilities:

“My son is getting married in October and I’m part of his wedding party, and I don’t wanna do wheelchairs. I’d rather walk him down the aisle.” [4]

B. Other treatment priorities

In some cases, a key criterion in considering treatments was their effect on the treatment plan for the primary cancer. Some participants would only consider treatments that maintained the possibility to remain in a clinical trial:

“... I’ve been vying for this CAR T-cell for the past couple of years... So I didn’t have a chance to research, however, even if I had, the overriding decision maker was getting in to the trial...” [20]

C. Beliefs about surgery

It was very common for participants to prefer putting off surgery as long as possible and to evince the belief that surgery was a “last resort.” Occasionally, participants explicitly stated that surgery was the last resort because it was unpleasant, painful, and carried risks of complications. Often, reasons for this belief were implicit:

“I just wanted to give the other options an opportunity to work first. If they don’t, it’s nice to have the surgery option as a backup plan.” [4]

D. Acceptance of treatment risks

Some participants selected a treatment that was considered the riskier option. This required accepting the possibility that something might go wrong:

“I’m comfortable enough at this point with dying, that if I make a mistake, it’s just my mistake. I did it, so nobody will feel like, ‘... I made the wrong decision for him.’” [6]

E. Seeking and understanding information

The interviews revealed wide variation in preferences for seeking information to guide decision-making. Some placed value on knowing all their options and understanding what each treatment entailed. Others preferred less thorough information-gathering. Barriers existed both to performing independent research and to engaging in conversations with providers. Together, these factors tended to perpetuate a limited understanding of treatment options.

Achieving a full understanding of the options required the time, desire, and ability to do research and ask pertinent questions of physicians. Within physician-patient encounters, many participants felt overwhelmed by the diagnosis and unable to process the information in real time:

“You get home, and then you start researching, and then all the questions come. They’ve been really good about doing follow-up answers to my questions, but I’d rather be prepared.” [9]

If one approach was viewed as the first-line treatment, secondary options were not fully explored:

“They didn’t really mention surgery... I mean, they did when I went for my [radiation] consult... and they kinda just glazed over the surgery. Or maybe I glazed it over.” [9]

It was common to defer to the physician’s recommendation without trying to understand the clinical rationale:

“I can’t remember anything specific about the reasoning... But I’m the kind of person that has full faith in these guys... So, I’m pretty much gonna do whatever they suggest.” [15]

Independent research was assigned a limited role – only to supplement the advice of the physician. Research was additionally viewed as unhealthy when it contributed to anxiety:

“... sometimes you’re not always getting accurate information that’s specific to your circumstance... And then, [it] can just cause you more angst or anxiety.” [8]

There was also a sense that participants and their families might be imposing too much on the physician’s time if they aimed to have all their questions answered:

“They just don’t have the time. [You can’t] take up half of their... day so that you and everybody in your family can understand what [is] going on.” [18]

Discussion

We conducted semistructured interviews among patients with spinal metastases to learn about factors influencing their decision-making regarding treatment. The enormity of the diagnosis of spinal metastases coupled with the implications for treatment selection shaped participant preferences

for who should take responsibility for the decision and what level of complication risk to accept. In this context, many participants participated actively in selecting a provider and then preferred to cede decision authority to their physician. Due to this and other factors, many participants did not engage in the thorough explication of risks and benefits that typically characterizes shared decision-making as seen in the setting of elective spine surgical procedures.

Participant beliefs about decision-making and about surgery interacted with the clinical context in a way that tended to promote 1) acceptance of physician recommendations and (2) delaying or avoiding surgery. Our findings indicate that patients with spinal metastases are likely to accept the treatment plan proposed by their care teams, frequently conflating recommendations with management decisions. Similar challenges have previously been described in treatment decision-making for prostate cancer [10]. The role of anxiety and heightened distress in driving patients with end-stage cancer diagnoses to rely heavily on clinicians' recommendations for treatment has also been previously described in other clinical contexts [17]. Previous qualitative research regarding shared-decision making in oncology identified uncertainty around treatment options, concerns regarding adverse events and poor physician communication as the most important barriers [11]. These factors were also expressed by our study participants although some, such as physician communication, feature less prominently.

Ours is the first work we are aware of, to explicitly evaluate patient experiences with decision making around treatment for spinal metastatic disease. Our findings have the potential for immediate application to clinical practice and suggest further opportunities for research. In management of spinal metastases, there is often ambiguity as to the best strategy in a particular case. It is important for clinicians to recognize that patients may not be aware of this ambiguity when choosing to defer to treatment recommendations and the context is dramatically different from that encountered with elective spine surgical interventions [1,2,6]. A pivotal finding is that the weight of the metastatic diagnosis itself engenders considerable anxiety and a sense of urgency in defining and initiating a treatment course [18]. This may contribute to incomplete information-gathering on the part of the patient, as well as deference to provider recommendations. Barriers to communication [9,11,18], fears of aggravating providers, and the belief that it is wisest to defer to those with formal training may also prevent a patient from asking questions. Together, these factors appear to perpetuate a limited understanding of available treatment pathways and anticipated outcomes in the setting of spinal metastases. Beliefs about surgery may also predispose participants to delay surgical treatment, with surgery seen as a "last resort," to be considered only when other treatments fail. These factors should be considered directly by clinicians at the time of an initial patient encounter and during the shared decision-making process when deciding on initial treatment.

Our results suggest the need for further focused evaluation on the optimal means of communicating treatment options for patients with spinal metastases, as well as trialing formal interventions that could be deployed in the clinical setting. If our postulates are confirmed in further work, they would point to important directions for clinical practice. For example, barriers to comprehension can be reduced if providers ensure that patients have sufficient time and comfort to ask questions and process answers. The confidence engendered by provider and institutional reputation may be leveraged by clinical care teams to build trust and rapport with patients. Clinicians should also describe a timeline for deciding on a treatment strategy and ensure that all potential strategies are presented. When the treatment strategy results from the consensus of a tumor board or other cross-disciplinary consortium of providers, patients may feel reassured by the consensus but think less critically about the recommendation.

We recognize several limitations, including the fact that participants were drawn from three tertiary referral centers in a single city. The strong reputations of these institutions, and of the individual clinical providers, fostered a level of confidence in providers that would not be replicated in all clinical contexts. Sociodemographic, educational, and vocational characteristics of our participants may differ from those in other health care settings, influencing perceptions around treatments and ways of interacting with the health-care system. The experience and maturity of clinical providers and other caregivers could also influence patient decision-making and the findings in this analysis. Future work should obtain the perspectives of minorities and rural patients receiving treatment for spinal metastases, as well as those of patients treated at nonacademic centers.

Our cohort did achieve a reasonable balance between the number of individuals treated operatively and nonoperatively (11 and 12, respectively). We also achieved an adequate representation of participants receiving treatment for a first time metastatic process, as well as those who had previously been treated for other metastases. The sociodemographic and primary tumor characteristics of the participants in this study are comparable to those of recent investigations in the orthopedic spine and neurosurgical literature. [5,19–21] Of note, only 30% of individuals approached agreed to participate and we recognize a potential bias given this fact. However, clinical and sociodemographic parameters were similar between the patients who participated and those who declined. Furthermore, we continued to interview patients until thematic saturation was achieved. These facts may speak to the generalizability of our findings.

Conclusions

The diagnosis of spinal metastatic disease played an influential role in modulating participant preferences for agency in treatment decision-making and prevented full

engagement with providers. Participants frequently did not achieve a thorough understanding of available options before embarking on a course of care. Our findings suggest that, in patients facing decisions regarding spinal metastases, clinicians might consider more proactively disclosing all potential management strategies, addressing patients' implicit sense of urgency to initiate treatment, describe a timeline for deciding on a treatment strategy and minimize barriers to effective communication.

Acknowledgment

This research was funded by National Institutes of Health (NIH-NIAMS) grants [K23-AR071464](#) to Dr Schoenfeld, [K24-AR057827](#) to Dr Losina and [P30-AR072577](#) to Drs Katz and Losina. The views expressed in this article are those of the authors and do not necessarily reflect the position or policy of the NIH or the Federal government.

Supplementary materials

Supplementary material associated with this article can be found in the online version at <https://doi.org/10.1016/j.spinee.2019.12.018>.

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