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# A Comparison of Palliative Care Perceptions Across Metastatic Spine Patients and the General Population

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## Abstract

**Background:** Palliative care (PC) has been shown to benefit patients with metastatic cancer by managing symptoms, improving quality of life, and facilitating advance care planning. Despite this, PC is often misunderstood and underutilized.

**Objective:** To deepen our understanding of PC barriers seen among the spine metastasis population.

**Design/Setting:** Between March 2021 and August 2022, people with metastatic spine tumors (MSTs) at a multidisciplinary oncology clinic were administered a survey on PC prior to their scheduled appointment. These responses were compared with the Health Information National Trends Survey 5 (HINTS 5), which is a validated survey created by the National Cancer Institute between February and June of 2020. Chi-squared statistical analysis was used.

**Results:** Fifty-six people with MST were compared with 3795 patients from the HINTS 5 database. People with MST reported a significantly higher baseline understanding of PC when compared with the general population (GP) (chi-squared = 34.4,  $p < 0.0001$ ). People with MST had a higher frequency of disagreement with the statement “PC is equivalent with death” when compared with the GP (chi-squared = 12.8,  $p = 0.0124$ ). Over 25% of the MST group reported no understanding of PC.

**Conclusion:** MST patients are often referred to PC services due to the extreme symptom burden of their disease. Based on this study, in comparison to the GP, people with MST tended to have a more accurate and well-adjusted perception of the goals and functions of PC. Although reassuring, there remains a high proportion of patients who have no knowledge of PC, and groups erroneously associated PC with hospice status.

**Keywords:** palliative care; perceptions; physician patient communication; metastatic spine; spine tumor; surgery

## Key Message

This study investigates perceptions of PC among patients with MST, revealing a greater familiarity with PC among patients with MST when compared with the GP. Despite this, significant misconceptions persist, highlighting the need for improved education and utilization of PC.

## Introduction

Patients with metastatic spine tumors (MSTs) experience severely debilitating symptoms.<sup>1–3</sup> Studies estimate that 40%–70% of patients with cancer will develop a spine metastasis at some point during their clinical course with the associated

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symptoms of medically refractory pain, paresthesia, weakness, myelopathy, bowel/bladder incontinence, and even complete or partial paralysis.<sup>4,5</sup> Given the overall incidence and severity of this condition, interventions that can either curtail or better manage the symptom burden are warranted to preserve quality of life.

PC can help people with MST to address symptoms, care planning, and support; PC can reduce depression, patient distress, caregiver burden, and health care expenditures while also improving overall patient-reported health-related quality of life and survival.<sup>6-11</sup> Furthermore, current National Comprehensive Cancer Network guidelines recommend that PC consultation be considered for any patient with metastatic disease.<sup>12</sup> Despite these guidelines and the potential benefits, PC utilization remains low.<sup>13,14</sup> Notably, one study demonstrated that 86% of people who are eligible for PC do not utilize it.<sup>15</sup> There are a number of hypotheses that have been postulated to explain these findings including poor public awareness, cultural and social barriers about pain and dying, insufficient health care resources, and overly restrictive regulations for opioid pain relief.<sup>16,17</sup>

Given the symptomatic burden, shortened life expectancy, and complex decision making associated with this population, people with MST are ideally suited for PC consultation.<sup>18,19</sup> However, the perceptions of PC in the MST population are poorly understood. Evaluating the possible knowledge gaps and stigmas associated with PC would allow spine oncology providers to better focus efforts to increase utilization. Therefore, the goal of this study was to compare the perceptions of PC in people with MST at our institution to the general population (GP). We hypothesized that people with MST would have a greater understanding regarding the existence of PC but would experience a greater stigma toward the utilization of PC when compared with the GP.

**Methods**

**Study population**

This study involved a retrospective review of prospectively collected PC perception surveys between the dates of March

2021 and August 2022. Our study population included people with MST at Duke Cancer Institute and data for these patients were collected using a pregenerated Research Electronic Data Capture System (REDCAP)<sup>TM</sup> survey. Ethical approval for the delivery of these surveys was obtained under institutional review board (IRB) protocol 00101198 and IRB protocol 00090883. Before giving patients the survey, informed consent was obtained according to the guidelines of IRB protocols. Demographic information including race, gender, educational status, and age at cancer diagnosis was collected. Patients were asked about their overall understanding of PC, their perception of the goals of PC, and whether or not they equate PC with death. These results were compared against the GP through the use of the Health Information National Trends Survey (HINTS) database. The HINTS is distributed and collected through random-digit dialing of households, focusing on a nationally representative sample of adults in the United States. It comprises questions regarding health-related behaviors, attitudes, and knowledge, validated through rigorous testing and methodological research to ensure reliability and validity. Specifically, we accessed the HINTS 5 Cycle 2 survey on December 1, 2022, and retrieved health information from January 2018 to October 2020.<sup>20</sup>

**Statistical analysis**

To determine the average response score, we utilized a Likert scale and one-sample *t* test with respect to GP to test for significance in our survey responses. Therefore, participants with lower response scores had a greater degree of agreement with the survey question. All statistical analysis was conducted using Graph Pad Prism statistical software and statistical significance was determined to be *p* < 0.05.

**Survey codification**

Initially, when patients were asked to describe their level of knowledge about PC, answers could range from “Never Heard

TABLE 1. PATIENT CHARACTERISTICS

Characteristic	Spine mets (n = 56)	HINTS (n = 3795)	p-Value
Age at cancer diagnosis	60.5 (1.14) <sup>a</sup>	55.0 (0.97) <sup>a</sup>	
Gender			0.316
Male	27 (48.2%)	1561 (41.1%)	
Female	28 (52.8%)	2204 (58.8%)	
Race			0.04
Hispanic	0 (0.0%)	596 (15.7%)	
Non-Hispanic White	44 (78.6%)	2133 (56.2%)	
Non-Hispanic Black	7 (12.5%)	481 (12.6%)	
Non-Hispanic American Indian or Alaska Native	0 (0.0%)	15 (0.3%)	
Non-Hispanic Asian	2 (3.6%)	161 (4.2%)	
Non-Hispanic Native Hawaiian or Pacific Islander	0 (0.0%)	10 (0.2%)	
Multiple races	1 (1.8%)	94 (2.5%)	
Highest level of education			0.45
Elementary	1 (1.8%)	173 (4.5%)	
High school	8 (14.3%)	705 (18.6%)	
Vocational	7 (12.5%)	264 (6.9%)	
College	22 (39.3%)	1796 (47.3%)	
Graduate school/professional degree	11 (19.6%)	684 (18.0%)	
Unknown	2 (3.6%)	143 (3.7%)	

<sup>a</sup>Median (SD); No (%).  
HINTS, Health Information National Trends Survey.

of It” to “I know a little bit” to “I know PC and could explain it” and were codified using a Likert scale as a 1, 2, and 3, respectively. In this schema, higher scores indicate greater agreement with the statement. For the remaining questions about the goals of PC and general misunderstandings of PC, the range of possible responses included “Strongly Agree,” “Somewhat Agree,” “Somewhat Disagree,” “Strongly Disagree,” and “Don’t know.” These responses were codified using a Likert scale from 1 to 5 with a score of 1 corresponding to “strongly agree,” 2 indicating “Somewhat Agree,” 3 indicating “Don’t Know,” 4 indicating “Somewhat Disagree,” and 5 corresponding with “Strongly Disagree.” In this schema, lower scores indicated a stronger agreement with the statements

## Results

### Patient demographics

Overall, we identified 3795 participants from the HINTS 5 database and 56 patients that we consented from our institution’s spine metastasis population. Between the two populations, we observed one significant difference in race when comparing the HINTS Hispanic population to the study population (HINTS 15.7% Hispanic responders to 0.0% Hispanic responders at study institution [ $p = 0.0363$ ]). Non-Hispanic White, Non-Hispanic Black, Non-Hispanic American Indian or Alaska Native, Non-Hispanic Asian, Non-Hispanic Native

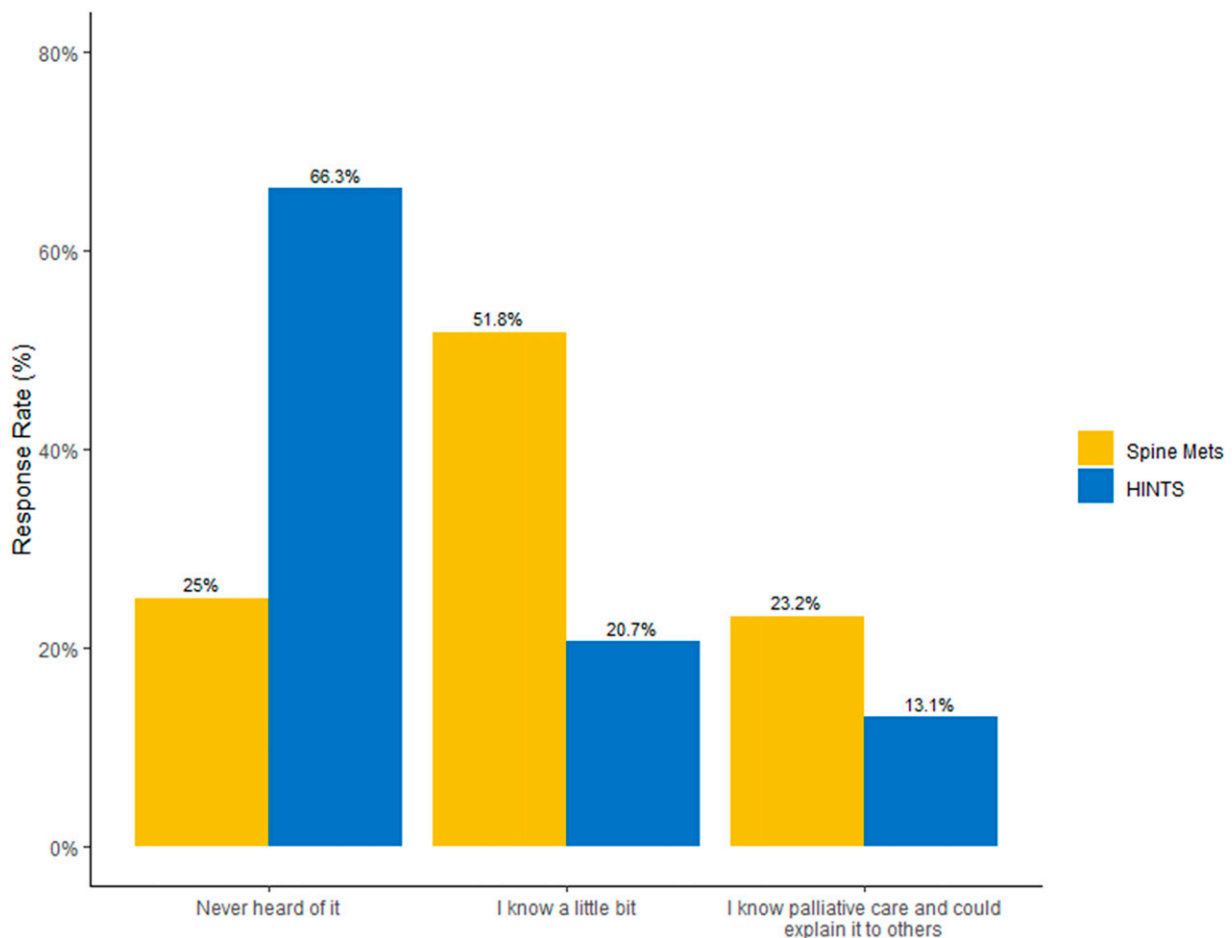
Hawaiian or Pacific Islander populations were similar across both the general and MST populations ( $p = 0.85$ ). Gender and highest level of education were both similar between groups ( $p = 0.25$ ,  $p = 0.45$ ) (Table 1).

### Baseline understanding of PC

We observed a significant difference between MST and GP responses relative to a basic understanding of PC ( $p \leq 0.001$ ) (Fig. 1, Table 2). Within the GP 66.3% had never heard of it, whereas, within the MST population, only 25% had never heard of it.

### Patient perceptions of the goals of PC

Initially, we asked patients if they agree that the goal of PC was to help friends and family cope with a patient’s illness. We observed an average score of 1.71 (confidence interval [CI]: [1.65–1.77]) for GP group and an average score of 2.39 (CI: [2.02–2.76],  $p < 0.0001$ ) for people with MST (Table 3). We asked patients whether they thought the goal of PC was to manage pain and other physical symptoms. We observed an average score of 1.41 (CI: [1.36–1.46]) for GP and an average score of 1.8 (CI: [1.48–2.12],  $p = 0.0022$ ) for people with MST (Table 3). Finally, we asked patients whether they thought the goal of PC was to “Offer social and emotional support.” We observed an average score of 1.59 (CI: [1.53–1.65])



**FIG. 1.** Palliative care baseline understanding. A comparison of spine metastasis and Health Information National Trends Survey (HINTS) responses when questioned about their baseline understanding of palliative care.

TABLE 2. SURVEY QUESTIONS AND RESPONSES

Characteristic	Spine mets	HINTS <sup>2</sup>	p-Value
Baseline understanding of palliative care			
(a). How would you describe your level of knowledge about palliative care?	(n = 56)	(n = 3445)	<0.001
Never heard of it	14 (25.0%)	2283 (66.3%)	
I know a little bit	29 (51.8%)	712 (20.7%)	
I know palliative care and could explain it to others	13 (23.2%)	450 (13.0%)	
Perceptions of palliative care goals			
(a). To offer social and emotional support	(n = 56)	(n = 1142)	<0.001
Strongly agree	19 (33.9%)	693 (60.7%)	
Somewhat agree	20 (35.7%)	350 (30.7%)	
Don't know	11 (19.6%)	27 (2.4%)	
Somewhat disagree	2 (3.6%)	18 (1.6%)	
Strongly disagree	4 (7.1%)	54 (4.7%)	
(b). To manage pain and other physical symptoms	(n = 56)	(n = 1156)	0.004
Strongly agree	33 (58.9%)	862 (74.6%)	
Somewhat agree	12 (21.4%)	214 (18.5%)	
Don't know	5 (8.9%)	25 (2.2%)	
Somewhat disagree	1 (1.8%)	6 (0.5%)	
Strongly disagree	5 (8.9%)	49 (4.24%)	
(c). To help friends and family cope with a patient illness	(n = 56)	(n = 1150)	<0.001
Strongly agree	20 (35.7%)	617 (53.6%)	
Somewhat agree	16 (28.6%)	403 (35.0%)	
Don't know	5 (8.9%)	38 (3.3%)	
Somewhat disagree	8 (14.3%)	32 (2.8%)	
Strongly disagree	7 (12.5%)	60 (5.2%)	
Misconceptions of palliative care goals			
(a). If you accept palliative care, you must stop other treatments	(n = 55)	(n = 1177)	0.03
Strongly agree	4 (7.3%)	57 (4.8%)	
Somewhat agree	10 (18.2%)	112 (9.5%)	
Don't know	11 (20.0%)	191 (16.2%)	
Somewhat disagree	5 (9.1%)	266 (22.6%)	
Strongly disagree	25 (45.5%)	551 (46.8%)	
(b). Palliative care is the same as hospice care	(n = 56)	(n = 1173)	0.96
Strongly agree	5 (8.9%)	99 (8.4%)	
Somewhat agree	11 (19.6%)	278 (23.7%)	
Don't know	10 (17.9%)	197 (16.8%)	
Somewhat disagree	13 (23.2%)	265 (22.6%)	
Strongly disagree	17 (30.4%)	334 (28.47%)	
(c). When I think of palliative care, I automatically think of death	(n = 56)	(n = 1182)	0.01
Strongly agree	4 (7.1%)	114 (9.6%)	
Somewhat agree	8 (14.3%)	362 (30.6%)	
Don't know	6 (10.7%)	75 (6.3%)	
Somewhat disagree	11 (19.6%)	276 (23.4%)	
Strongly disagree	27 (48.2%)	355 (30.03%)	

for the GP and an average score of 2.14 (CI: [1.84–2.43],  $p < 0.0001$ ) for people with MST (Figure 2, Table 3).

**Patient misconceptions of PC**

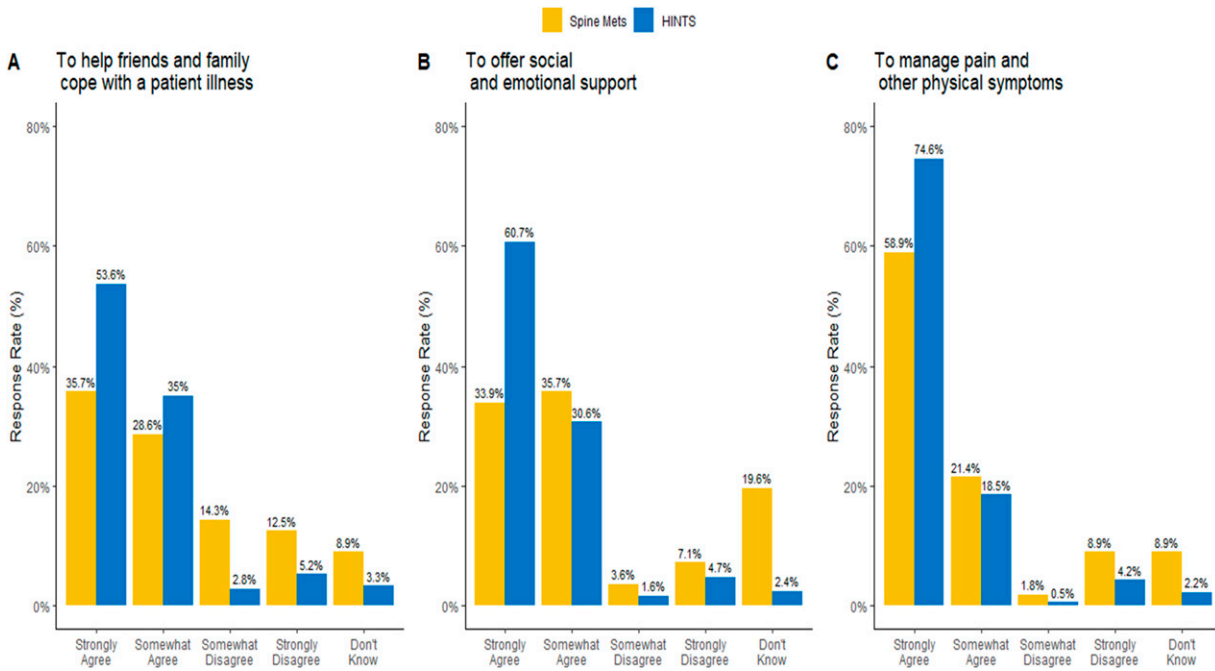
In continuing our investigation into PC perceptions, we also asked patients: “When I think of PC, I automatically think of death.” The average score for the GP was 3.34 (CI: [3.26–3.42]), whereas the average score for the MST group was 3.88 (CI: [3.53–4.23],  $p = 0.12$ ) (Table 3). When asked for agreement to the statement, “If you accept PC, you must stop all other treatments,” the average score for the GP was 3.97 (CI: [3.90–4.04]), whereas the average score for the spine metastasis population was 3.67 (CI: [3.31–4.03],  $p = 0.06$ ) (Table 3). Patients were then asked if they believed that “PC is the same as hospice care.” The average score for the GP was 3.39 (CI: [3.31–3.47]), whereas

the average for MS group was 4.22 (CI: [3.87–4.57],  $p < 0.0001$ ) (Figure 3, Table 3).

**Discussion**

Through this investigation of PC perceptions, we observed that people with MST tend to have a higher baseline understanding of PC compared with the GP. Furthermore, when asked about their understanding of the goals of PC, in all survey prompts, both populations tended to agree with the true goals of palliative intervention. Finally, when asked about common misconceptions of PC, we saw patients from both groups did not equate PC with death, but they did believe other treatments need to stop, which is more consistent with the status of hospice.

Considering these results further we observe that the MST group has a significantly higher average score for their



**FIG. 2.** Palliative care goals. A comparison of spine metastasis and HINTS survey responses when questioned about the goals of palliative care.

self-reported baseline understanding at 1.98 when compared with the GP group at 1.47. This indicates that responders from the spine metastasis population felt they had a greater understanding of PC when compared with the GP. This is in line with our initial hypothesis, as we anticipated these patients to have a higher baseline understanding of PC due to their greater exposure to supportive and health care-related services.<sup>21,22</sup>

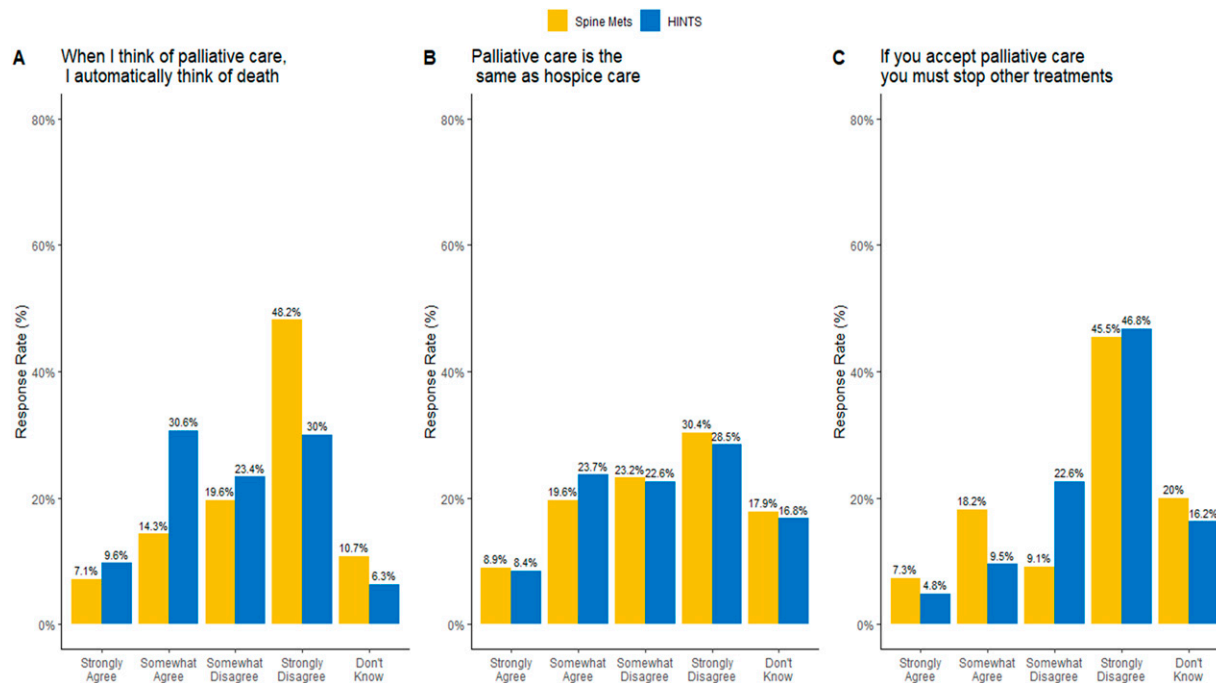
In our analysis of the goals of PC, we asked patients if the goal of PC was to manage pain and other physical symptoms, help friends and family cope with an illness, or offer social and emotional support. Interestingly, participants from the GP tended to agree with the stated goals of PC at a greater rate than the MST population, which is evidenced by their lower overall average scores from the goals survey. This directly contradicts our initial hypothesis and observed results that patients with spine metastasis will have a greater true

understanding of PC, though interestingly the group felt as though they understood the topic. This discrepancy could indicate several possibilities, including that perhaps the MST population has a false sense of confidence when it comes to their baseline knowledge of PC or confusion inherent in how the question is presented. This likely comes as a result of previous experience with either a health system or palliative care (PC). Although this could be a significant factor influencing our participant’s response, the HINTS database did not collect information regarding the participants’ previous experience with PC. Therefore, a meaningful comparison between prior experience cannot be made for these two populations using the current databases.

Finally, we assessed common misconceptions of PC such as “PC is equivalent to death” or “if you accept PC you can no longer pursue curative treatment” and “PC is the same as

TABLE 3. AVERAGE RESPONSE SCORES

Characteristic	Spine mets	HINTS <sup>2</sup>	p-Value
(a). To offer social and emotional support	(n = 56)	(n = 1142)	
Average response score	2.14 [1.84–2.43]	1.59 [1.53–1.65]	<0.001
(b). To manage pain and other physical symptoms	(n = 56)	(n = 1156)	
Average response score	1.8 [1.48–2.12]	1.41 [1.36–1.46]	0.002
(c). To help friends and family cope with a patient illness	(n = 56)	(n = 1150)	
Average response score	2.39 [2.02–2.76]	1.71 [1.65–1.77]	<0.001
Misconceptions of palliative care goals			
(a). If you accept palliative care, you must stop other treatments	(n = 55)	(n = 1177)	
Average response score	3.67 [3.31–4.03]	3.97 [3.90–4.04]	0.06
(b). Palliative care is the same as hospice care	(n = 56)	(n = 1173)	
Average response score	4.22 [3.87–4.57]	3.39 [3.31–3.47]	<0.001
(c). When I think of palliative care, I automatically think of death	(n = 56)	(n = 1182)	
Average response score	3.88 [3.53–4.23]	3.34 [3.26–3.42]	0.12



**FIG. 3.** Palliative care misconceptions. A comparison of spine metastasis and HINTS survey responses when questioned about misconceptions of palliative care.

hospice care.” We observed that the spine metastasis population tended to disagree with the statement that “When I think of PC I automatically think of death” at a significantly higher rate when compared with the GP. Despite this, we did not observe significant differences across the other misconception statements with both groups equating the term with more traditionally defined hospice-related terms. This indicates that while the MST population may be more knowledgeable in certain aspects of PC, there is a persistent gap in knowledge when it comes to differentiating PC services from hospice.

In many centers, PC began with a focus on end-of-life care for patients with terminal diagnoses. PC has grown tremendously in the past 30 years and now provides a variety of symptom management and mental health resources that may start earlier in the disease course.<sup>23,24</sup> Additionally, recent legislation such as the PC Information Act has made great strides in facilitating access to PC services for terminally ill patients.<sup>25</sup> Despite these significant changes, patient perceptions of PC services remain outdated and fuel a general misunderstanding of PC services, which ultimately drives its underutilization.<sup>26</sup>

Across the study, there are limitations including the low sample size in our MST group of participants, the wording and interpretation of the questions, and the assumption that we can generalize the perceptions of the GP using the HINTS database. Firstly, our low sample size of people with MST means that our results may not be generalizable to the entire MST population. Importantly, this was given to patients who attended their outpatient surgical oncology appointments and thus may suggest a higher health education and compliance status. Secondly, we could not assess prior experience with PC within the GP as the HINTS survey did not capture this information. Further, the REDCAP survey was given in-

person around surgical health care providers. Accordingly, the results might exaggerate respondents’ projected confidence, feelings of agreement with PC, or even the false impression that their provided answers would in some way direct their surgical decisions by the surgical team. Secondly, with respect to our questions about the goal of PC, the question is worded as “The goal of PC is to X,” which implies that there are not multiple goals of PC and that the answer must be the only goal of PC. Therefore, once a responder has agreed with a goal of PC, they may feel like they have to disagree with the other goals presented. Correcting this statement could improve the accuracy of the data in future renditions.

Overall, this work highlights a distinct gap in health literacy when it comes to perceptions of PC. Although this study represents an important first step in characterizing the perceptions of PC in patients with spine metastasis, future studies are needed to coordinate these perceptions with the actual utilization of PC resources and efforts to improve them. Once this connection is made, we can begin to quantify the influence of these perceptions on PC utilization within the spine metastasis population and focus interventions on the factors that contribute the most to the misunderstanding of PC services.

#### Author Disclosure Statement

The authors have no disclosures relevant to the current work nor any true/perceived conflicts of interest.

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