

Comparing Knowledge and Perceptions of Palliative Care Among Neuro-Oncology Patients, Caregivers, and Providers to a Representative U.S. Sample

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Abstract

Background: Primary brain tumors (PBTs) pose a significant health challenge, affecting patients and their caregivers. While early integration of palliative care (PC) has shown benefits in advanced cancer, its integration for PBT patients, particularly glioblastoma (GBM) patients, remains complex. We hypothesized that our previous PC integration efforts may have failed due to knowledge-gaps and misconceptions among patients, caregivers, and providers. **Objective:** This study aimed to identify knowledge gaps and misconceptions about PC among patients with primary brain tumors (PBTs), their caregivers, and their medical providers. **Method:** An electronic survey was distributed to PBT patients, caregivers, and medical providers, that included questions regarding PC from the Health Information National Trends Survey (HINTS). Survey responses were analyzed; comparisons were made between the 3 groups as well as the general population. **Results:** Of 141 respondents (59 patients, 57 caregivers, and 25 providers), each group held perspectives on PC differing from the general population. While all groups had an improved understanding of PC's role in symptom management, uncertainty persisted among patients and caregivers regarding life-prolonging treatment and certain PC goals like caregiver support or end-of-life care. **Conclusion:** Understanding gaps in knowledge and perceptions of PC among PBT patients and caregivers is crucial for effective intervention, with caregivers playing a vital role in advocating for PC. Future research should explore factors influencing these perceptions and development of targeted education to improve early PC referrals for patients with PBTs.

Keywords

primary brain tumors, palliative care, glioblastoma, knowledge gaps, misconceptions, patients, caregivers, medical providers

Introduction

In 2022, an estimated 93 470 new cases of primary brain tumors (PBTs) were diagnosed in the United States.¹ PBTs, such as glioblastoma (GBM), are a devastating diagnosis, causing significant symptom burden and having a median overall survival of 12 to 21 months.² Throughout the disease course, patients may experience a decline in neurologic function, leading to substantial distress for both patients and caregivers.³

Palliative care (PC), as defined by the World Health Organization (WHO), aims to improve the quality of life (QoL) of patients and their families facing life-threatening illnesses through early identification, assessment, and treatment of pain and other problems—physical, psychosocial, and spiritual.⁴

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Early integration of PC into oncology care for advanced cancer patients may improve QoL and reduce psychosocial distress.⁵⁻⁷ For example, an early collaboration between hematology and PC units significantly reduced symptoms like pain, anorexia, and anxiety.⁸ The impacts of early integrated PC can also positively impact caregivers of patients with advanced lung or gastrointestinal cancer patients, by significantly reducing their psychosocial distress.⁹ A retrospective analysis of PBT patients showed 46% of high-grade glioma patients reported a National Comprehensive Cancer Network (NCCN) distress score of 4 or higher in the first month of diagnosis.¹⁰ NCCN guidelines recommend prompt consultation with a PC specialist for high distress levels.¹¹ However, no prospective evidence demonstrates the value of early PC in PBT patients, and no validated model for delivering integrated PC in newly diagnosed GBM patients exists.

To address gaps in PC delivery, we initiated a pilot project in August 2016 to assess the feasibility and acceptability of integrating early PC for patients with GBM.¹² This single-arm study referred patients to PC at diagnosis and followed them prospectively until death or the study period's end. However, challenges with enrollment were observed: 32 patients were offered participation, only 12 consented, and 4 later withdrew. We concluded that early PC, at the time of diagnosis was not feasible or acceptable to patients with GBM. In 2018, we developed a PC screening tool to improve outpatient PC referrals for patients with GBM. However, even when indicated, some providers did not make PC referrals and some patients were resistant to receiving them.¹³ We hypothesized that our 2 separate interventions may have failed due to inaccurate knowledge and perceptions of PC and/or suboptimal timing of discussing PC intervention in the disease trajectory.

The Health Information National Trends Survey (HINTS), sponsored by the National Cancer Institute, has uncovered knowledge gaps and misconceptions about PC in the general population.¹⁴ A recent study using HINTS data found PC programs are relatively new, and awareness among the general public is low, leading to common misperceptions.¹⁵ The study also demonstrated that members of the general public who perceived themselves to have a high level of knowledge about PC actually exhibited inaccurate knowledge or held negative beliefs.¹⁵

At our high-volume, tertiary, brain tumor center, we aimed to explore potential differences in knowledge and perceptions of PC among our patients, their caregivers, and their medical team. We distributed a survey utilizing identical questions from the publicly available HINTS survey ([Supplemental Material 1](#)), allowing us to not only analyze their responses, but also compared our findings with a nationally representative sample.¹⁵

Methods

This IRB-exempt study involved an online anonymous questionnaire, utilizing questions from the HINTS survey, that could be completed in under 5 minutes during a routine clinic

visit ([Supplemental Material 1](#)). Participants included in the study were (1) self-identified established patients receiving care for their PBT, (2) self-identified caregivers of established patients receiving care for their PBT, and (3) medical providers from the treating clinical teams.

Recruitment strategies included signage in clinic as well as verbal prompts from clinic staff (check-in desk, medical assistants (MAs), nurses, advanced practice providers (APPs), and physicians). Posters were displayed in multiple locations, including patient waiting areas, the nurse's station, individual patient rooms, and clinic work rooms.

Study data were collected and managed using Research Electronic Data Capture (REDCap) electronic data capture tools hosted at The Preston Robert Tisch Brain Tumor Center, Duke University.^{16,17} REDCap is a secure, web-based software platform designed to support data capture for research studies. For all respondents (patients, caregivers, medical providers), the REDCap survey was accessed by a single QR code or shortened URL. The QR code was generated by using the following website: <https://www.qr-code-generator.com>. We used a customized URL - eg, bit.ly/DukeBTC that participants could access through any browser on their mobile device.

To avoid the risk of people incorrectly identifying themselves, the online survey ([Supplemental Material 1](#)) had a confirmatory question before an individual respondent could proceed. For example, "Are you a patient with a brain tumor receiving medical care at The Preston Robert Tisch Brain Tumor Center in clinic 3-1?" If the response was NO, they could not proceed. To prevent duplicate responses, we also asked, "Have you completed this survey before?" If the answer was YES, they could not proceed. To ensure participant privacy, no protected health information from any of the 3 study groups was collected, and identifiable personal information was not gathered.

The study commenced in August 2020, with enrollment spanning approximately 3 months. To ensure the successful launch of the survey that did not impair the workflow of the front desk staff or the medical assistants, we had dedicated logistical support from a clinical research coordinator for the first week. Participation was voluntary for patients ≥ 18 years old, receiving care from one of our brain tumor center healthcare providers. Caregivers ≥ 18 years old were also eligible to participate, provided they identified themselves as a caregiver to an established brain tumor center patient. Additionally, medical providers with titles of MD, DO, PA, NP, and RN, who regularly care for patients with PBTs as part of their practice, were included.

A validated instrument of 9 questions was used, with the first 6 questions addressing knowledge of PC, and the last 3 questions addressing perceptions about PC ([Figure 1](#)). Since this was an IRB-exempt, we did not create unique identifiers to link patients with their caregiver's responses. Hence, patients, caregivers, and providers were treated as 3 independent groups in analyses.

1. To me, the goal of palliative care is to help friends and family cope with a patient's illness.
2. To me, the goal of palliative care is to manage pain and other physical symptoms.
3. To me, the goal of palliative care is to offer social and emotional support.
4. To me, the goal of palliative care is to give patients more time at the end of life.
5. Palliative care is the same as hospice.
6. If you accept palliative care, you must stop other treatments.
7. Accepting palliative care means giving up.
8. When I think of "palliative care", I automatically think of death.
9. It is a doctor's obligation to inform all patients with cancer about the option of palliative care.

Figure 1. Survey questions addressing knowledge and perceptions of PC.

HINTS 5, Cycle 2 data from 3504 respondents are available from the NCI (<https://hints.cancer.gov/data/download-data.aspx>) in SAS datasets.¹⁵ These data have been more recently updated. However, we used the dataset analogous to the time frame for our survey.

The percentage of patients, caregivers, providers, and members of a national sample who indicated that they had heard about PC was computed. An exact chi-square test compared groups (patients, caregivers, providers, and a national sample) with respect to the percentage of patients who had heard about PC. Among those participants who had heard about PC, frequency distributions within participant groups were generated for each survey question. We compared patient, caregiver, and clinician responses to the outcomes observed within the national sample.

Results

Survey Respondent Characteristics

141 participants responded to the survey, including 25 providers, 59 patients, and 57 caregivers. Among the 56 patients who reported an age, the median age was 48.3 (SD = 13.1; range 21-74); whereas the median age among the 54 caregivers who provided an age was 49.6 years (SD = 12.1; range 24-73). More than half of the caregivers were female (64.9%) and identified themselves as spouses or domestic partners (68.4%). Additional characteristics of patient and caregiver survey respondents can be found in [Tables 1](#) and [2](#).

Among the providers surveyed, years of experience were evenly distributed between those with more than 10 years and those with less than 10 years of experience. Due to the number of providers (25), we did not ask them to report their specific title (MD, DO, NP etc.), since the study team could potentially identify them.

Self-Reported Knowledge of PC

All respondents who identified as neuro-oncology providers reported they have at least some knowledge of PC. The group

with the next highest self-reported knowledge of PC was PBT caregivers, at 84.2%. Conversely, PBT patients had a higher rate of response to "no knowledge of PC" at 33.9%, when compared to caregivers (15.8%). Finally, PBT patients, caregivers, and neuro-oncology providers all had a higher self-reported knowledge of PC when compared to the national sample to which only 33.0% responded "some knowledge of PC" ($P < 0.001$). ([Table 3](#)).

Patients Compared to a U.S. Sample. Subsequent analyses were conducted among those participants who had heard about PC. The distribution of PBT patient responses to the HINTS survey differed significantly from the national sample for 3 of the 9 survey items: coping with a patient's illness ($P < 0.001$), pain management ($P = 0.03$), and accepting PC means giving up ($P = 0.008$). Patients more often somewhat agreed (43.6% vs 34.4%) or somewhat disagreed (18.0% vs 3.2%) that a goal of PC is to help friends and family to cope with a patient's illness, when compared to the national sample. All PBT patients either strongly agreed (61.5%) or somewhat agreed (38.5%) that a goal of PC is to manage pain and other physical symptoms, which is significantly higher than nationally reported rates. Not a single PBT patient from our site agreed with the statement that "accepting palliative care means giving up" ([Table 4](#)). Notably, 23.1% of PBT patients responded "don't know" to the survey item regarding stopping other treatments if one accepts PC ($P = 0.09$; [Table 4](#)).

Caregivers Compared to a U.S. Sample. The distribution of responses of Caregivers of PBT patients to the HINTS survey differed significantly from the national sample for 5 of the 9 survey items: (1) coping with a patient's illness ($P < 0.0001$), (2) pain management ($P < 0.0001$), (3) PC gives patients more time at the end of life ($P = 0.02$), (4) PC means giving up ($P = 0.02$), and (5) MD obligation to inform patient of PC ($P < 0.0001$). Caregivers more often "somewhat disagreed" or "strongly disagreed" with the statements that goals of PC included (1) to help friends and family cope with a patient's illness, and (2) give more patients more time at the end of life. Caregivers also

Table 1. Overview of Patient Survey Respondents.

	N	%
Race		
White	48	81.4
Black or African-American	4	6.8
Asian	3	5.1
Prefer not to answer	1	1.7
Missing	3	5.1
To which gender identity do you most identify?		
Female	28	47.5
Male	27	45.8
Prefer not to answer	1	1.7
Missing	3	5.1
The 'grade' of my brain tumor is a grade?		
4	22	37.3
3	11	18.6
2	12	20.3
"I Don't know"	7	11.9
Missing	7	11.9
What is your highest level of education?		
High school	6	10.2
Vocational	6	10.2
College	25	42.4
Graduate school/Professional degree	19	32.2
Missing	3	5.1

responded with higher rates of "strongly disagree" or "don't know" to both the statement that accepting PC means giving up, and that a goal of PC is to manage pain and other physical symptoms. The final survey item that differed significantly between caregivers and the national sample was that it is a doctor's obligation to inform all patients with cancer about the option of PC, to which caregivers more often somewhat agreed (40.0% vs 25.4%) or responded, "don't know" (20.9% vs 7.0%). Similar to PBT patients, more than a quarter of caregivers (27%) responded "don't know" to the survey item regarding stopping other treatments while receiving PC ($P = 0.11$).

Neuro-Oncology Providers Compared to a U.S. Sample. The distribution of Neuro-oncology provider responses to the HINTS survey differed significantly from the national sample for 5 of the 9 survey items: (1) coping with patient's illness ($P < 0.001$), (2) PC means more time at end of life ($P < 0.001$), (3) PC is same as hospice care ($P < 0.0001$), (4) PC implies patient must stop other treatments ($P < 0.003$), and (5) PC means giving up ($P = 0.03$). Providers more often somewhat disagreed (40.0% vs 17.8%) or strongly disagreed (36.0% vs 13.9%) that a goal of PC is to give patients more time at the end of life). Additionally, providers more often strongly disagreed with the survey following survey items: PC is the same as hospice care (72.0% vs 28.2%), accepting PC requires stopping other treatment (88.0% vs 46.7%), and accepting PC means giving up (92% vs 57.7%).

Table 2. Overview of Caregiver Survey Respondents.

	N	%
Race		
White	46	80.7
Black or African American	2	3.5
Asian	1	1.8
Prefer not to answer	6	10.5
Missing	2	3.5
To which gender identity do you most identify?		
Female	37	64.9
Male	16	28.1
Prefer not to answer	2	3.5
Missing	2	3.5
How are you related to the patient?		
Spouse	37	64.9
Child	6	10.5
Sibling	5	8.8
Parent	4	7.0
Domestic partner or significant other	2	3.5
Other family member	1	1.8
Missing	2	3.5
What is your highest level of education?		
High school	2	3.5
Vocational	3	5.3
College	28	49.1
Graduate school/Professional degree	21	36.8
Prefer not to answer	1	1.8
Missing	2	3.5

Discussion

Due to the impact of brain tumors on patients and families, the PBT population is uniquely well-suited for PC interventions. However, knowledge and perceptions about PC are important to understand prior to designing a successful PC intervention. Our study revealed that PBT patients, their caregivers, and neuro-oncology providers responses deviated from the national sample on various survey items. While some of these responses demonstrated that these groups had a better understanding of PC compared to the national sample, others highlighted the need for tailored interventions to increase awareness of the goals of PC among patients, caregivers, and providers in the context of PBTs.

PBT patients demonstrated a strong consensus on the role of PC in managing physical symptoms, as evident by high rates of agreement on the survey. However, both PBT patients and their caregivers expressed uncertainty regarding the implications of accepting PC, particularly concerning the cessation of other treatments. This is a critical differentiating factor between PC and hospice care, and this perception held by PBT patients and their caregivers may contribute to delayed integration of PC after a patient's diagnosis.¹⁸ Patients and their caregivers should be educated on the role of PC, particularly that it is

Table 3. Self-Reported Knowledge of PC by Different Groups.

		No Knowledge of PC	Some Knowledge of PC	N (Total)	P-value
Group	Patients	20 (33.9%)	39 (66.1%)	59	<0.0001 ^a
	Caregivers	9 (15.8%)	48 (84.2%)	57	
	Providers	0%	25 (100%)	25	
	National sample	2283 (67%)	1162 (33%)	3445	

^aThe P-value compares all 4 groups (patients, caregivers, providers, and national sample) with respect to the percentage of group that have some knowledge of PC.

Table 4. PBT Patient Responses Compared to a U.S. Sample.

Survey questions	National Survey (N = 1162)	PBT patients (N = 39)	P-value
	N (%)	N (%)	
If you accept palliative care, you must stop other treatments			0.091
Strongly agree	56 (4.8%)	1 (2.6%)	
Somewhat agree	107 (9.2%)	2 (5.1%)	
Somewhat disagree	260 (22.4%)	3 (7.7%)	
Strongly disagree	543 (46.7%)	24 (61.5%)	
Don't know	167 (14.4%)	9 (23.1%)	
Missing data	29 (2.5%)	0	
Accepting palliative care mean giving up			0.008
Strongly agree	28 (2.4%)	0	
Somewhat agree	141 (12.1%)	0	
Somewhat disagree	242 (20.8%)	6 (15.4%)	
Strongly disagree	670 (57.7%)	28 (71.8%)	
Don't know	46 (4.0%)	5 (12.8%)	
Missing data	35 (3.0%)	0	

additive, and patients can continue life-prolonging or curative therapies while also receiving symptom management and initiating conversations regarding advanced care planning.

Our study also revealed a notable lack of understanding among patients, their caregivers, and even neuro-oncology providers regarding the scope of PC, particularly its role in supporting patients' friends and families. Included within the definition of PC provided by the National Consensus Project for Quality of Palliative Care, PC improves the quality of life for both patients and their families.¹⁹ Additionally, the National Academy of Medicine core components of quality PC include counseling of the patient and family, as well as family caregiver support.²⁰ The discrepancy as evident by survey responses suggest a potential gap in education in the multidisciplinary nature of PC, and how it extends to address psychosocial support for both patients and their loved ones. Surprisingly, even neuro-oncology providers, who are expected to be well-versed in PC showed similar underestimation regarding this aspect of care. Expanding the awareness of how comprehensive PC could lead to earlier acceptance by patients and their caregivers, and ultimately leading to better patient outcomes.²¹

PC is unique when compared to other medical specialties that patients have previously encountered because it can address many aspects of patient care beyond the management of disease. Healthcare providers that treat patients with PBTs should expect patients and their care partners may need counseling about the role of PC and targeted education to address misconceptions held by patients before placing a referral. When educating PBT patients about PC, providers may need to emphasize that specific goals of PC include helping care partners cope with a patient's illness, symptom management, psychosocial support, and how it differs from hospice.

Addressing knowledge gaps is only one aspect of improving the acceptability of PC interventions among PBT patients and caregivers.^{22,23} An individual's beliefs, attitudes, and personal experience with the healthcare system could significantly shape their perceptions of PC. We note a prior study where patients had various negative reactions to the introduction of PC including feeling shocked, frightened, and a preference to not dwell on the negative.²⁴ These perceptions can be more challenging to address and may require a more nuanced approach that has yet to be defined for the PBT population.

Interestingly, we found that caregivers of PBT patients had a better understanding of PC when compared to PBT patients, but overall, similar attitude profiles. This is not congruent with what is typically found with caregivers, as they often demonstrate similar understanding and perceptions about PC as patients.²⁵ One potential explanation for this difference could be that caregivers take on a role of advocacy and information-seeking behavior when their loved one is diagnosed with a significant illness like a PBT. Additionally, many patients seeking care at our tertiary care institution may have either been referred from other facilities or have self-referred: this could reflect a desire to know “all of their options” and be reflected in the knowledge gained conducting their own research on behalf of their loved one before the appointment. Furthermore, we hypothesize that the PBTs ability to understand and reliably complete the survey may also be impaired by the presence or treatment of their underlying brain tumor. Further research could explore the factors that contribute to the differences in understanding between patients and caregivers, such as education level, facility type (ex. community vs tertiary care center), brain cancer type, and histological tumor grade (ex 1, 2, 3, 4).

One of the limitations of this study was the selection bias introduced by the survey’s availability in English. In addition, those without personal mobile devices were not able to participate. This was a voluntary, anonymous survey that relied on self-selection and self-reporting and did not mandate that all fields be completed. While this increased survey participation and completion, it also led to missing data. There were missing values about self-reported race, ethnicity, gender identify and in the case of the caregivers, the specific relationship to the patients. Additionally, this study was conducted at an academic institution in the southeastern United States and result may not be generalizable: future studies should compare results across multiple institutions for validation.

In conclusion, the findings of this study provide valuable insights into the understanding and perceptions of PC among PBT patients, caregivers, and providers. These results highlight the need for targeted education and intervention strategies to improve the understanding of PC among PBT patients and their caregivers. Additionally, future research should explore the factors contributing to differences in understanding and perceptions between patients and caregivers. Results of our study will further inform the development of PC interventions with the ultimate goal of providing the best care possible for PBT patients and their caregivers.

Author Contributions

JYK, MOJ, KBP contributed to the study conception and design. Material preparation, data collection and analysis were performed by JYK, MOJ, NC, JEH. The first draft of the manuscript was written by JYK, MOJ, and JCD. All authors reviewed and edited subsequent versions of the manuscript. All authors reviewed and approved the

final manuscript. All authors agree to be accountable for all aspects of the work and resolved any issues related to its accuracy or integrity.

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Ethical Consideration

This study was performed in line with the principles of the Declaration of Helsinki. This study received exemption from the Institutional Review Board at Duke University.

Consent to Participate

All participation was voluntary. Survey respondents were not compensated.

Consent for Publication

All surveys were anonymous and were not linked to patient protected health information. This study received exemption from the Institutional Review Board at Duke University and no individual informed consent was required.

Disclaimer

The views expressed in this article are the views of the authors and not the views of affiliated institutions or funders.

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Supplemental Material

Supplemental material for this article is available online. Supplemental Material 1: Survey questions regarding palliative care administered via REDCap to patients, caregivers, and providers.

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