

The views of patients with brain cancer about palliative care: a qualitative study

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ABSTRACT

Background Palliative care, a specialty aimed at providing optimal care to patients with life-limiting and chronic conditions, has several benefits. Although palliative care is appropriate for neurosurgical conditions, including brain cancer, few studies have examined the views of brain cancer patients about palliative care. We aimed to explore the thoughts of brain cancer patients about palliative care, their opinions about early palliative care, and their preferred care setting.

Methods Semi-structured interviews and the qualitative research methodologies of grounded theory were used to explore perceptions of palliative care on the part of 39 brain cancer outpatients.

Results Seven overarching actions emerged:

- Patients would prefer to receive palliative care in the home.
- Increased time with caregivers and family are the main appeals of home care.
- Patients express dissatisfaction with brief and superficial interactions with health care providers.
- Patients believe that palliative care can contribute to their emotional well-being.
- Patients are open to palliative care if they believe that it will not diminish optimism.
- There is a preconceived idea that palliative care is directly linked to active dying, and that supposed link generates fear in some patients.
- Patients prefer to be educated about palliative care as an option early in their illness, even if they are fearful of it.

Conclusions Overall, when educated about the true meaning of palliative care, most patients express interest in accessing palliative care services. Although the level of fear concerning palliative care varies in patients, most recognize the associated benefits.

Key Words

Brain cancer; brain tumours; palliative care, home-based; palliative care, in-facility; qualitative research; palliative care, early

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INTRODUCTION

Palliative care is an inter-professional initiative that aims to provide optimal and specialized care to patients with life-limiting illnesses who are progressively dying¹. It can be introduced at any point during illness, given that it is not solely meant for the stages of active dying². Care can be provided in a facility, such as a hospital-based palliative care unit, or a community-based hospice where clinician-focused care is provided; or in a home-based setting, where care is provided primarily by family members or informal

caregivers with clinician support. The management of a healthy social life and regular interaction are more probable in the home setting.

Palliative care is especially effective when introduced early to the patient. Various authors have reported that, in addition to standard therapies, early palliative care is successful in maximizing quality of life and even extending life in oncology patients²⁻⁶. The benefits for oncology patients and their families of early introduction of palliative care are believed to substantially outweigh the potential ramifications^{6,7}. In addition, early implementation

of palliative care can aid in providing individualized and effective care for the patient, which promotes patient satisfaction and fulfils their needs^{6,8}. Palliative management also proves suitable in various neurosurgical conditions, including traumatic head injuries, massive intracranial hemorrhages, and brain tumours³. The beneficial value of neuro-palliative care has also been manifested in several situations, and many of its advantages have been explored^{3,9}. Importantly, patients receiving neuro-palliative care have expressed satisfaction with their care³. Although underutilized in the past, the practice of neuro-palliative care is on the rise, corresponding with an escalating number of trained facilitators⁹.

Compared with patients having many other forms of cancer, patients with malignant brain tumours often have a very poor prognosis and do not live for an extended period after diagnosis^{3,10–12}. Their care can be delivered in a hospice, where a comfortable and home-like facility is provided¹³, or alternatively, in the patient's own home.

The diagnosis of a malignant brain tumour is a profoundly frightening and jarring life event. Coping with this illness is likely to summon extreme stress, in turn leading patients to seek and depend on emotional support and companionship. In the terminal stage of an illness, it is important for dying individuals to maximize their remaining time with family and loved ones¹⁴. Sharing time with family is much more feasible in a home-based environment, because home-based palliative care provides the opportunity to be surrounded by family members and loved ones more often and at any time of day. Interactions are more likely to be insufficient in palliative care facilities because the chance of having varying caretakers is greater, multiple patients are being treated in one location, and patients are living away from their loved ones. Research has shown that patients dying in facility settings spend a large amount of time alone and that family visits average only 13 minutes daily¹⁵. Approximately 75%–85% of all palliative care is conducted in the home and is provided by unpaid family members¹⁶. Karen Rook¹⁷ differentiates between social support and companionship, stating that social support is merely a transaction in which assistance is provided and which is more likely to occur in a palliative facility, and describing companionship as shared leisure and enjoyment, which is more likely to occur among family caregivers. Compared with social support, companionship was deemed more important to well-being, promoting the home environment as a place for emotional well-being.

Studies concerning the palliative management of neurosurgical patients are limited^{3–4,18–20}, and few focus on and examine the effects of at-home palliative care^{1,21}. Although patients have expressed general satisfaction with neuro-palliative care, no study has qualitatively evaluated the emotional effects of at-home compared with inpatient hospice palliative care from the patient perspective, and how the patient experience relates to quality of life.

The purpose of the present study was therefore to understand the views of patients about the emotional and social benefits of at-home neuro-palliative care compared with in-facility neuro-palliative care. We also aimed to explore patient perspectives about whether early introduction of palliative care is beneficial. We intended to

obtain a clear view of whether patients believe that needs for companionship and interaction can be fulfilled through at-home neuro-palliative care, and how home care might contribute to a high quality of life.

METHODS

Study Design

Qualitative semi-structured interviews were conducted with outpatients having malignant brain tumours. Semi-structured interviews differ from structured interviews in being less restrictive and letting interviewees explore a wider range of topics and themes than might be possible during a structured interview²².

Setting and Participants

The participating malignant brain tumour patients were recruited during May–August 2016 from the neuro-oncology clinic at Princess Margaret Cancer Centre. They were not newly diagnosed patients; they were attending at least their 2nd clinic appointment, and they had been judged by a neuro-oncologist to be unlikely to die within the following 6 months. Patients were excluded from the study if they lacked proficiency in English, if they were experiencing a large amount of distress or were in an unstable psychiatric state, or if they had significant cognitive impairment.

Sample Size

Of 55 patients who were approached, 39 were eligible for the study, provided consent, and underwent a qualitative semi-structured interview. A sample size of 39 was sufficient for achieving adequate data saturation. Data saturation is a concept in qualitative research describing a point after which successive interviews do not present any novel concepts or actions²³. The 16 patients who declined interviews most commonly did so because of lack of time.

Data Collection

All interviews were conducted in English. A single investigator (MV) conducted the interviews after each participant's appointment with the neuro-oncologist (WPM). The interview questions were administered verbally and were audio-recorded. Recordings were transcribed verbatim. Before each interview, the definition of palliative care was explained to each participant. Interviews were administered in a way that allowed participants to share as much information as they pleased and to recount any additional experiences or stories that they desired.

Data Analysis

The audio recordings of the interview responses were analyzed by open coding, which classifies the data into like ideas, and by axial coding, which pieces information together based on overarching trends²³. The analysis conformed to the grounded theory procedures described by Strauss and Corbin. Although theory-building was not an objective in the data analysis, grounded theory techniques were used to form and process comprehensive actions that unfolded from the data. Grounded theory approaches were

used to understand patient perceptions and to explore their thoughts about the idea of palliative care. Use of those techniques allowed the authors to take an inductive stance and to delve deeper into the true meaning of the information shared, gaining an all-encompassing view of patient opinions and developing those opinions into descriptive actions with various dimensions.

Code collection was executed throughout the entire duration of the study, with theoretical sampling being the central method used. Theoretical sampling is a data acquisition process in which code collection and data analysis occur jointly and are then followed by the analyst's decision about which data to collect next²³. Concepts derived from the early data points were used to refine the research process and interview guide, because data collection and analysis occur concurrently in grounded theory²³. The refinement process served as a method of validation for the resulting actions, because suggested concepts were substantiated in subsequent interviews. The process also allowed for refinement of the categories generated by data analysis and provided direction for the subsequent interviews so as to develop theory. Theory development was evident in the regular modification of the interview questions used in the study. Concepts were formulated using a manifest approach to analyze the verbatim content of the interview transcriptions (which means describing what the informants shared). Transcriptions were directly analyzed for commonalities in the participant responses. Overarching findings were then distilled by linking similar concepts using both manifest content (referring to broad surface analysis) and latent content (referring to analysis of a more in-depth underlying meaning in the transcriptions). Inferences made included a consideration of context, which is defined as the conditions or circumstances affecting the responses of participants²³.

The analysis used the lens of grounded theory's philosophical underpinning of symbolic interactionism. From that perspective, individuals are understood to impose subjective meanings on ideas, objects, and events²³. Essentially, beliefs dictate an individual's thoughts and behaviours. That design was appropriate for the study because of the criticality of exploring the beliefs of brain cancer patients so as to understand their thoughts and actions surrounding palliative care. To understand the way in which patients react to the idea of palliative care, it was crucial to recognize the social constructs and stigmas that might have played a role in influencing patient perceptions. Additionally, various analytical tools were used in the operation of analysis. Those tools included constant comparison (in which incidents are compared to classify data), context consideration (in which a set of conditions might have affected a certain outcome), and identification of the negative case (in which outliers help with the further understanding of concepts)²³.

Analysis of the data was a dynamic process, which began with the collection of the first pieces of data²³. The data analysis involved identification of codes from interview transcriptions and the gathering of those codes to generate concepts. Concepts were then compared, contrasted, and joined to yield 7 overarching actions. The gathered information was analyzed by two of the authors (MV, MB).

Finally, to ensure trustworthiness and accuracy in the reported findings, the analysis also took into account qualitative rigour. To avoid researcher influence on the research process, credibility and verbatim transcription of all interviews were used to obtain truth value. Applicability was achieved by the collection of demographics and the use of direct quotations. Consistency was achieved by recognizing and understanding any sources that might have caused variability. Neutrality was maintained by upholding researcher objectivity²⁴.

Compliance with Ethics Standards

All participants provided informed consent, and participation was completely voluntary. Strict confidentiality was upheld for all participants. All data obtained were kept private, and audio recordings were kept in a secure location. The study received approval from the University Health Network's research ethics board.

RESULTS

Demographic Characteristics

Mean age of the 39 participants was 51 years (range: 32–75 years). The male-to-female ratio was 1.6:1. All participants had tumours located in the brain, and approximately 54% had been diagnosed with glioblastoma multiforme. Of the latter group, 50% were long-term survivors (4 or more years) of a brain tumour, possibly reflecting a less-aggressive diagnosis in the past. Two of the interviewees had brain tumours resulting from hematologic malignancies. All participants had received or were then receiving chemotherapeutic or radiation treatment, and most had undergone surgical resection. Table 1 summarizes the participant demographics.

Findings

Analysis of the transcripts yielded 7 overarching actions, which are outlined in the subsections that follow and are supported by quotes from the participants. Some of the processes showed variation in terms of participant age; however, the views of participants did not differ by sex.

Patients Would Prefer to Receive Palliative Care in the Home

Most participants indicated that they would prefer to receive care in the comfort of their own home. Participants also believed that their needs for companionship and interaction could be fulfilled through care in the home.

I think everybody would prefer to receive it at home.
— Interview 29, female, 54

I can be as comfortable as I can be in my home. My family is at home, my friends would be more at ease visiting my home. I feel strong when they're there.
— Interview 1, male, 68

Participants also indicated that being at home would produce a sense of normality and allow them to feel less of a patient, which would, overall, be conducive to a greater sense of well-being.

It's home. Everything's there that you're familiar with. It's a lot easier to take. People, material, furniture. And it's little things—even the cats and stuff. Just these little things. Because at the end of the day, it's still normal. And that's the thing, we want to be normal.

— Interview 12, female, 55

By stating that the home setting is a lot easier to take, the participant implied that a non-home setting would likely be overwhelming. When taking the context of illness into account, the “overwhelming-ness” of an unfamiliar setting compounded with the general “overwhelming-ness” that accompanies being a brain cancer patient disfavours the thought of an in-facility setting for

TABLE I Demographic information for all study participants

Age (years)	Sex	Diagnosis	Time elapsed since diagnosis	Ever seen a palliative care doctor?
32	Male	Glioblastoma multiforme	2 Years, 1 month	No
33	Male	Glioblastoma multiforme	6 Years	No
36	Female	Oligodendroglioma	8 Years	No
37	Male	Anaplastic oligodendroglioma	1 Year	No
37	Female	Glioblastoma multiforme	3 Years	No
37	Male	Glioblastoma multiforme	3 Years	Yes
38	Male	Anaplastic oligodendroglioma	1 Year	No
38	Female	Glioblastoma multiforme	6 Years, 3 months	No
39	Female	Oligodendroglioma	6 Years	No
41	Male	Low-grade glioma	13 Years	No
42	Female	Gliomatosis cerebri	10 Months	No
43	Female	Astrocytoma	7 Years	No
44	Female	Glioblastoma multiforme	15 Years	No
46	Male	Glioblastoma multiforme	3 Years, 9 months	Yes
46	Female	Glioblastoma multiforme	4 Years, 6 months	No
46	Male	Glioblastoma multiforme	10 Years	No
47	Male	Anaplastic oligodendroglioma	12 Years	No
48	Female	Oligodendroglioma	11 Years	No
51	Female	Glioblastoma multiforme	7 Months	Yes
51	Male	Glioblastoma multiforme	3 Years	No
51	Male	Glioblastoma multiforme	4 Years, 2 months	Yes
53	Male	Glioblastoma multiforme	9 Years, 1 month	No
53	Female	Astrocytoma	11 Years	No
54	Female	Oligodendroglioma	9 Years, 9 months	No
55	Female	Glioblastoma multiforme	1 Year, 6 months	Yes
56	Male	Astrocytoma	5 Years, 11 months	No
56	Female	Anaplastic oligodendroglioma	10 Years	No
60	Male	Glioblastoma multiforme	1 Year, 10 months	No
60	Male	Glioblastoma multiforme	19 Years, 2 months	No
62	Female	Anaplastic astrocytoma	1 Year	No
64	Male	Glioblastoma multiforme	28 Years, 6 months	No
65	Male	Glioblastoma multiforme	2 Months	No
68	Male	Anaplastic astrocytoma	2 Years	Yes
68	Male	Glioblastoma multiforme	6 Years, 11 months	No
68	Male	Glioblastoma multiforme	8 Years	No
69	Male	Diffuse large B-cell lymphoma	1 Year, 3 months	No
72	Male	Glioblastoma multiforme	10 Months	Yes
72	Male	Non-Hodgkin lymphoma	2 Years	No
75	Male	Glioblastoma multiforme	2 Years	Yes

palliative care. The avoidance of an overwhelming situation advocates for the home setting.

However, when considering the negative case, it should be noted that younger participants were not as agreeable with the notion of home care and, in fact, were often unsure of their optimal palliative care setting. That uncertainty was especially apparent in participants who spoke of having young children.

The Ability to Spend Increased Time with Caregivers and Family Are the Main Appeals of Home Care

Participants placed paramount value on interaction and time spent with their caregivers, such as family and friends. One of the central reasons that participants indicated a preference for home-based palliative care as opposed to in-facility palliative care was the fact that family and friends are more accessible in a home setting.

My family and friends are everything to me. These interpersonal relationships are so important. Having them can truly make or break you. The interaction with people who wish you well is invaluable, irreplaceable.

— Interview 6, female, 62

My friends would be there caregiving, and it's much easier and more pleasant for them to be at home and my place as opposed to coming to the hospital.

— Interview 3, male, 38

The foregoing statement implies that not only is the home setting favourable for patients, but it is preferred by friends and visitors as well. Because access to family and friends is of great value to brain cancer patients, that participant expressed the need to prioritize the preference and comfort of visitors as well. It is important that the setting in which the patient is located is optimal for others as well, which further incentivizes the home as an appealing setting.

Familiarity in the home is also a major factor in daily comfort and coping for brain cancer patients.

When you're already not feeling well, the creature comfort of being at home is very important. You feel better, sleep better, and eat better in a familiar setting. You have your own bed, own fridge, own books, own belongings.

— Interview 15, male, 68

Experiencing Brief and Superficial Interactions with Health Care Providers Evokes Dissatisfaction in Patients

Participants deemed emotional connection and bonding to be extremely important for emotional well-being, and indicated that they often feel that they cannot achieve such connection with health care providers. Participants recognized that health care providers are busy and cannot always tend to their emotional needs, but nevertheless expressed distaste.

It's their job, it's tiring. Not every health care person has the time to be empathetic to everyone. But as a patient it's very difficult when that's all you get.

— Interview 2, male, 32

Participants believed that they have more of these surface-level interactions in a facility setting than at home.

The level of "TLC" in a facility just wouldn't be the same. You're not getting deep interactions or long conversations.

— Interview 3, male, 38

Patients Believe That Palliative Care Can Contribute to Their Emotional Well-Being

Even if unnerved by the thought of palliative care, most participants indicated that palliative care would most likely contribute to their emotional well-being. They conveyed their appreciation for the services that palliative care can provide and its ability to assist with things that they might not be able to do on their own. With regard to at-home palliative care, participants especially believed that their emotional well-being would be increased because of the presence of loved ones.

I believe it would contribute because I would be in a home setting. I have my friends and family to help me through it and keep my spirits up.

— Interview 38, male, 69

Patients Express Openness to Palliative Care If They Believe It Will Not Diminish Optimism

When participants believed that palliative care might put them in the mindset that they are on a journey to death, they were dismissive of the idea of palliative care.

At this stage, I don't want to think about that. I don't want to be "palliative" and have that drilled into my mind.

— Interview 37, female, 36

That opinion can be linked back to the philosophical underpinning of symbolic interactionism. The participant has stated that she does not want to be "palliative" and have that thought drilled into her mind, which suggests that there is a stigma or social construct surrounding palliative care. Although it might not be possible to fully deduce what the social construct is, its negativity is apparent. That negative belief feeds into the patient's thoughts surrounding loss of optimism.

However, when individuals are aware that "palliative" does not carry that negative meaning and that palliative care aims to improve quality of life, they open to it.

I do not believe that once you've accepted palliative care that you've given up.

— Interview 11, male, 47

Optimism is of much importance to brain cancer patients in order to heal, positively cope, and live an

enjoyable life of high quality. Many patients, both newly-diagnosed and long-term, remain optimistic in their illness, despite the terminal nature of brain cancer.

The statistics are just numbers. They don't mean anything about me and my own illness. People have beat the odds.

— Interview 20, male, 46

There's no cure for it right now, but who knows what can happen in the future. I could get cured.

— Interview 12, female, 55

Having a Preconceived Idea That Palliative Care Is Directly Linked to Active Dying Generates Fear in Some Patients

Most participants felt that the word “palliative” carries stigma, which leads many patients to believe that palliative care is only for patients at the stage of active dying. That link causes some patients to be frightened of and closed off to the idea of palliative care. That fear was especially pronounced in newly diagnosed patients. Once educated about the true definition of palliative care, patients expressed less fear, but still acknowledge that the stigma could be difficult to ameliorate.

Now that I know what it means, I'm not so scared of it. However I don't think that fear can fully go away with just the flick of a light switch.

— Interview 32, female, 37

Interestingly, that participant has actually recognized that an existing social construct has influenced her thoughts about palliative care, which is a prime example of symbolic interactionism. However, her comment also explains the challenge in transitioning to an objective view on palliative care, because the negative belief associated with the social construct remains.

Some participants even recommended that palliative care be rebranded to avoid that false preconception.

It's a lot of negative. You should change “palliative” to just “nice people.” Change the word “palliative care” to something different, and I think the message will be different and received differently. Palliative care to me when I heard about it is end of life.

— Interview 12, female, 55

The fear was increasingly pronounced in younger participants, especially those less than 39 years of age.

Patients Prefer to Be Educated About Palliative Care as an Option Early in Their Illness, Even If They Are Fearful of It

Although the thought of introducing palliative care provokes fear and discomfort in some patients, participants indicated that there is value in patient education about palliative care and its services in the early stages of illness. Participants had an appreciation for how education can

ease their ability to make use of certain palliative services as required during their illness.

Even if I may not want to use it yet, knowing about it is like having a special card in the back of your wallet. It's there and ready to use when you need it.

It's good to know about these things beforehand.

— Interview 2, male, 32

By stating that education about palliative care allows for its services to be ready to use, the participant has implied that he might likely someday require those services. That admission is reasonable in the context of brain cancer. However, fear of accepting palliative care is also evident, especially considering that the patient is fairly young. Willingness to seek education about palliative care shows the delicate balance in brain cancer between optimism and considering the reality of the illness.

DISCUSSION

In this study, we set out to explore the views and thoughts of brain cancer patients about palliative care and its perceived benefits, as outlined in the 7 actions presented in the Results section. Numerous findings emerged from the study.

When discussing palliative care with the study participants, fear or an unnerved demeanour was commonly observed. There is a prevailing misconception that there is no difference between end-of-life care and palliative care. People generally believe that palliative care means death and dying, a misperception that might be attributable to the alarming lack of public education in this area²⁵. Throughout the study interviews, numerous participants had, notably, experienced palliative care as provided to family members during their final days. In high-income countries, 69%–82% of the actively dying population require palliative care²⁶. It is therefore likely that, at some point during their lifetime, most people will encounter palliative care as provided to a friend or loved one. It was evident that this acquaintance with palliative care on part of our participants contributed to a negative association with dying. The memories that were discussed typically encompassed solely the end stage or even the final days of life. Such memories could also feed into the misperception of palliative care.

Our interviewees included multiple long-term survivors, some having lived with brain cancer for 4 or more years, and all had been deemed to be unlikely to die within 6 months. A large fraction of the group was expectedly resistant to the idea of palliative care, because they understood themselves to be unlikely to be drawing near the end of life. Long-term survivors and those in remission recognized the benefits of palliative care, but did not believe that they required additional assistance because they had been in an unflinching state for an extended period of time. Their belief demonstrates the undoubted disconnect in the way that palliative care is defined from a medical standpoint and in how patients understand palliative care. “Palliative care” is an umbrella term: it includes end-of-life care, but it also includes care

that is designed to increase quality of life and that can be introduced at any time during the course of a life-limiting illness²⁷. Thus, the diagnosis of brain cancer made all interviewees potential candidates for palliative care. However, as expressed in the finding about an individual's openness to palliative care if optimism is not diminished, it is of supreme importance to reinforce with patients that receiving palliative care does not conduce giving up or loss of optimism. Ultimately, a patient is, by definition, palliative when they have chosen to accept palliative care, not when they have chosen to accept death.

The study findings show that brain cancer patients are increasingly drawn to the supportive aspects of palliative care, including social relationships, meaningful interactions, emotional well-being, and comfortable surroundings, and less to the functional aspects such as reduction in symptom burden and amelioration of pain. The study participants considered the supportive aspects to be most substantial for achieving a high quality of life. Although palliative care is formally defined as treatment that encompasses many facets, including pain management and physical, psychosocial, and spiritual support²⁸, it should be noted that palliative care has to be individualized and tailored to the specific needs of patients. Although pain and physical suffering can be symptoms of brain cancer, a myriad of other symptoms are cognition-based and unique compared with those in other cancers²⁹. Thus, brain cancer patients are in need of other forms of support. It is crucial to mend the disconnect between the support that patients require and the services that can be provided through palliative care.

When asked to describe their feelings at the time of the initial diagnosis compared with their current feelings in living with brain cancer, most participants explained that they had come to a degree of acceptance of living with their illness and felt stable. The feeling of shelter created by that stability could have played a role in the mindset toward palliative care in our participants. Human beings display a natural resistance to change³⁰. If patients feel secure and accepting of their life conditions, especially after a dynamic and shocking experience (diagnosis), they typically would not be in favour of introducing change. Resistance to change could, therefore, translate into resistance toward palliative care.

Previous research has shown that, in brain cancer patients, there is a trend of struggle to maintain a balance of hope with the reality of the illness³¹. Our study found that patients prefer to remain optimistic in their illness. However, the prognosis and illness trajectory are often not fully known, and health care professionals and patients alike harbour significant uncertainty³². That uncertainty might not only create challenges in being able to adequately plan for palliation, but might also generate a strong sense of fear and anxiety surrounding palliative care. When considering the reality of their illness, patients are aware that they will most likely require such care some day; however, the factors of optimism, hope, and uncertainty might cause them to delay an exploration of palliative options. Given such an irregular trajectory in brain cancer patients, a consideration of palliative care, and especially

its early implementation, could feel more like giving up. Those feelings might also be a component of why referral to palliative care services frequently happens late in the illness course³³.

Although most of our participants favoured home palliative care and postulated that it would be a powerful contributor to emotional well-being, some participants still favoured in-facility palliative care. Overall, most patients with malignant brain tumours have been reported to opt for home care rather than admittance to a hospice³⁴. However, in our study, the main reason that arose for resisting in-home care was the caregiver burden. "Caregiver burden" refers to the stress placed on caregivers from providing home care, which has the potential to cause negative psychological, behavioural, and physiologic effects^{35,36}. Because of the distinct and usually drastic nature of brain cancer, home caregivers for patients with brain cancer experience heightened levels of stress^{35,36}. Substantial loss of independence commonly occurs with the progression of brain cancer²⁹. Studies have shown that brain cancer produces a high degree of symptom burden for patients and caregivers^{36,37}, with caregivers reporting poor physical and emotional health, career sacrifices, monetary losses, and immense strain^{36,37}. Currently, the provision of support and coping therapy for informal carers is lacking, and that lack in turn contributes to a worsening of their stresses^{34,36,38,39}. Patients are panicked and uncomfortable with the idea of shifting the type of relationship they have with their loved ones, and they do not want to impose that type of strenuous responsibility on them.

Study Limitations

Our study has some limitations. First, participants for this project were recruited from a single academic hospital in a socialized health care system, and all came from one clinic where they were seeing the same neuro-oncologist. The level of education about palliative care provided to the participants might not match that provided in other institutions or in different cultures. Additionally, in the participant pool that was interviewed, 50% of the patients had been diagnosed with glioblastoma multiforme, some of whom could have had a diagnosis of a less-aggressive cancer in the past. Those atypical long-term survivors, who had been living with the illness for more than 4 years in some cases, might have therefore developed skewed views about palliative care, perhaps causing them to view it in a less favourable manner. Lastly, given that participation in the study was voluntary and that about 30% of the solicited patients declined, it is possible that participants in the interviews are representative of a more vocal subsample of brain cancer patients. It is impossible to know whether the views of the patients who declined participation would accord with the results of the present study, and so the potential for sampling error—a weakness of essentially all qualitative research—must be considered.

CONCLUSIONS

The findings emerging from the present study convey how brain cancer patients think and feel about palliative

care as management for their illness. Most importantly, patients believe that palliative care would contribute to their emotional well-being. Overall, palliative care in the home setting is the option most preferred by our participants. Although palliative care has proved to be considerably effective for neurologic conditions, our study demonstrates the fear that some brain cancer patients have about palliative care. Our participants also expressed a desire to be aware of palliative care options early in their illness. Thus, health care providers should aim to educate brain cancer patients about palliative care early and in a sensitive manner. Such education might assist in reducing fear and allowing patients to make informed and suitable decisions about their care. Additionally, efforts should be made to tailor palliative care services offered to brain cancer patients, who have indicated that the supportive aspects are of high significance to them. Overall, brain cancer patients recognize the benefits of neuro-palliative care and are opinionated about where and how they would like to receive it, but because of an education gap, show some fear about its implementation.

CONFLICT OF INTEREST DISCLOSURES

We have read and understood *Current Oncology's* policy on disclosing conflicts of interest, and we declare that we have none.

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