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Identifying research priorities and essential elements of palliative care services for people facing malignant brain tumors: A participatory co-design approach

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Abstract

Background. Primary malignant brain tumors (ie, brain cancer) impact the quality of life (QoL) for patients and care partners in disease-specific ways involving cognition and communication. Palliative care (PC) addresses patient/care partner QoL, but it is not known how PC may address the unique needs of brain cancer patients. The purpose of this project was to identify brain cancer PC research priorities using participatory co-design methods.

Methods. Participatory co-design included the formation of a longitudinal, collaborative advisory group, engagement frameworks, design-thinking processes, and social media-based engagement over a 1-year period. Community-identified brain cancer QoL needs and research priorities were mapped to proposed "essential elements" of brain cancer PC services.

Results. We engaged an estimated 500 patients, care partners, healthcare professionals, and others with an interest in QoL and PC services for people with malignant brain tumors. Research priorities included testing the early introduction of PC services designed to address the unique QoL needs of brain cancer patients and care partners. Essential elements of brain cancer PC include: (1) addressing brain cancer patients' unique range of QoL needs and concerns, which change over time, (2) tailoring existing services and approaches to patient needs and concerns, (3) enhancing the involvement of interprofessional care team members, and (4) optimizing timing for PC services. This was the first participatory research effort exploring brain cancer patient and care partner QoL needs and PC services.

Conclusions. The brain tumor community calls for research testing PC service models for patients that incorporate the "essential elements" of palliative care.

Keywords

community engagement | malignant brain tumors | palliative care | participatory co-design | quality of life

According to the Central Brain Tumor Registry of the United States (CBTRUS), there were over 25 000 people (henceforth "patients") per year diagnosed with a malignant brain tumor between 2016 and 2020.[1] Gliomas represent 81% of malignant brain tumors, 60.2% of which are glioblastoma.[1] Five-year survival rate for these patients is 35.7%, while for those with glioblastoma, the 5-year survival rate is only 6.7%, the poorest prognosis.[1] Although there are promising therapies to treat people with low-grade gliomas,[2] there are fewer options for high-grade glioma, and curative therapies for all brain malignancies, regardless of grade, remain elusive.[3] Over the last 40 years, only 4 therapies for malignant brain tumors have been approved by the US Food & Drug Administration (FDA).[4] Patients commonly experience physical and/or cognitive decline, personality and behavior change, and suffer chronic exposure to stress, grief, and anxiety.[5] Symptom burden for these patients is high and substantially impacts the quality of life (QoL) of both patients and care partners.[6] In addition,

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prognostic awareness differs between patients, their care partners, and treating clinicians, making goal-concordant discussion of treatment more complex.[7] Throughout this manuscript we use the terms "brain cancer" and "malignant brain tumor" interchangeably; our focus was on primary rather than metastatic brain tumors.

Healthcare services focused on improving QoL are needed for brain tumor patients and their care partners. Palliative care (PC) has been shown to improve QoL (and sometimes extend life) for people facing serious illness.[8] The Center to Advance Palliative Care defines PC as "specialized medical care for people living with a serious illness. It focuses on providing patients with relief from the symptoms and stress of the illness. The goal is to improve QoL for both the patient and the family."[9] Using a team-based, interprofessional approach, PC addresses patient and care partner QoL needs and serves as a complement to treatment, importantly, even when therapy is considered curative.[10] A specialist PC service involves an interprofessional team (physicians, advanced practice providers, pharmacists, nurses, social workers, and chaplains) with advanced training.[10] Specialist PC interventions improve outcomes in both malignant and nonmalignant life-limiting conditions.[10] These studies reveal a survival advantage in those receiving early PC intervention and are recommended by the American Society for Clinical Oncology,[11] the European Society for Medical Oncology,[12] and the National Institute for Health and Clinical Excellence.[13] In studies specific to patients with stage IV non–small-cell lung cancer,[14] acute myeloid leukemia,[14–16] and pancreatic cancer,[17–19] early PC integration along with standard of care versus standard of care alone showed improved QoL and extended overall survival.

There are no consensus definitions nor guidelines for brain cancer PC. Patients and their care partners face significant burdens due to neurocognitive effects created by the tumor and its treatment, which leads to increased dependency and social isolation. A 2022 Cochrane systematic review of early PC for people with malignant brain tumors showed that no trials have assessed the impact of specialist PC teams on outcomes for brain cancer patients or carers.[20] Despite evidence that patients, care partners, and clinicians benefit from working within interprofessional oncology teams in other cancer states, currently, there exists no evidence-based models of PC specific to people with brain cancer.[20]

Given the intricate treatment requirements across various fields for brain cancer patients (eg, neurosurgery, neuro-radiation oncology, neuro-oncology, and neuropsychology)—distinct from general cancer cases—there is a compelling need for a customized PC model specifically designed to address these complex needs. For this project, we used participatory methods to co-design a brain cancer PC model. Participatory methods are used to engage people with lived healthcare experiences and others with a vested interest in the products of research, and are useful for developing models of care that meet the needs of patients and families and assessing the feasibility of implementation in real-world care settings.[21] Deverka and colleagues defined multistakeholder engagement as "an iterative process of actively soliciting the knowledge, experience, judgment, and values of individuals selected to represent a broad range of direct interests in a particular issue, for the dual purposes of creating a shared understanding and making relevant, transparent and effective decisions."[22] While involving patients and care partners as collaborators in cancer research is not new,[23–25] there are few examples of engagement with those facing malignant brain tumors.

The goals of this project were to engage patients, care partners, and other stakeholders with a vested interest in brain cancer PC to: First, gain an understanding of what QoL means to people facing malignant brain tumors—both patients and their care partners; and next, discover what brain tumor community members view as research priorities for improving QoL through delivery of brain cancer-specific PC services.

Materials and Methods

We used multiple participatory co-design methods: Engagement of a multistakeholder advisory group (the Brain Cancer Quality of Life Collaborative, henceforth "the Collaborative"[26]) that met monthly throughout the 1-year project; design thinking (a human-centered design approach that included a literature review, ethnographic interviews, and a day-long, in-person workshop); social media-based engagement activities; facilitated special interest group meetings; and hosted several serendipitous interactions with people working in neuro-oncology and PC (Figure 1). Activities were conducted between December 2017 and September 2018. We previously reported results of Twitter-based engagement (the social media platform now referred to as "X") to understand what QoL means for those facing malignant brain tumors (including patients, care partners, and clinicians).[27]

Two engagement frameworks guided this process: the 7Ps of Stakeholder Engagement[28] and the Analytic-Deliberative Model for Stakeholder Engagement.[22] The 7Ps framework specifies key groups to involve that would be responsible for or have a direct interest in an area of research, including: Patients and the public, providers, purchasers, payers, policymakers, product makers, and principal investigators.[28] The Analytic-Deliberative Model articulates a process by which community partners gather input in the form of personal and professional knowledge and experience and research evidence, use quantitative and/or qualitative methods to combine evidence (eg, facilitated workshops), and make joint decisions that yield more stakeholder- and partner-centered research that ultimately improve health (eg, directing research priorities).[22]

This project was determined to be Non-Human Subjects Research by the (Colorado Multiple Institution Review Board).

Forming a Core Collaborative Advisory Group

First, we formed an advisory group of 16 individuals interested in improving QoL for people facing malignant brain tumors and PC. (Table 1) The members of this community were primarily invited to join the Collaborative based on LS' relationships developed via established patient communities on social media.

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Table 1. Brain Cancer Quality of Life Collaborative Members by Perspective Type

Perspective	No. of members
Brain tumor patients	2
Brain tumor care partners	3
Social psychologist/health services researcher (PhD)*	1
Oncology and palliative care social worker (MSW)	1
Nurse scientist (PhD, RN)	1
Neuroscience nurse (RN)	1
Neuro-oncologist (MD)	1
Neuro-surgery nurse specialist (RN)*	1
Palliative care physician (MD)	1
Physician informaticist (MD)*	1
Research coordinator, advocacy organization	1
Representative from insurer*	1
Research assistant (MSW)	1
Total community members	16

* = also have personal connections to people with a brain tumor

The Collaborative first convened via Zoom for a 90-minute introductory video call in December 2017, for community members to get to know one another and to articulate what they hoped to accomplish through the partnership. To prepare for the introductory call, a clinician-researcher with expertise in neuro-oncology nursing prepared an annotated bibliography of key literature on PC, malignant brain tumors, and QoL. (Supplementary Material 1–2) This bibliography was distributed to the Collaborative for reference and pre-reading. A second call in January 2018 prepared the group for an in-person workshop to be held the following month. The Collaborative met monthly via Zoom through September 2018 for about 1 hour/month to analyze inputs from other parallel engagement activities (Tables 2–3) and deliberate and make decisions about research priorities, which included developing and testing brain cancer PC services. Attendees were offered $50 per meeting.

Design Thinking to Conceptualize Research Opportunities for Brain Cancer Quality of Life and PC

Design thinking is a human-centered design approach that encourages a focus on "the end users" of solutions being generated, ultimately leading to more human-centered (or in this case, specifically, patient-centered) services and processes.[29–31] When used in the context of healthcare, the design-thinking process is an iterative problem-solving method, and consists of 4 design stages: Inspiration, ideation, implementation, and prototyping.[32] During the inspiration stage, we conducted a literature search on QoL and PC for brain cancer. An expert facilitator conducted ethnographic interviews with 7 individuals about their existing knowledge and views on PC for people with brain tumors, including: One patient, 2 care partners, and 3 clinicians (a neuro-oncologist, PC physician, and neuro-pathologist); and one group interview that included a neuro-oncologist, a neuro-oncology nurse, and an oncology social worker (Figure 1). The Collaborative then met at a community center for a 1-day, 8-hour meeting in February 2018. The intended product of the meeting was to develop initial brain cancer-PC "prototypes" that could serve as the basis for empirical research. As the first and only in-person activity hosted by the Collaborative, the meeting agenda was organized as a workshop focused on the ideation phase of design thinking. Workshop activities were oriented around the central design challenge question, "How might we learn to best deliver palliative care to brain cancer patients and their care partners?" The workshop facilitator anchored the day by first sharing insights gained from the ethnographic interviews. Next, the facilitator guided participants through a structured process that (1) established "a common language" (or, group consensus) for brain cancer PC, and (2) discovered what community members believed the highest priorities for brain cancer QoL research should be.

The consensus conclusion of the design-thinking workshop was that there is an urgent need for a randomized trial of an early PC intervention for people with malignant brain tumors and their care partners—ie, a "brain cancer PC study" akin to the Temel study of early PC for lung cancer.[8] In discussion with experts in PC, neurology, and neuro-oncology, it became clear further work was needed to conceptualize what and how PC services should be provided for the brain tumor community given the unique patient and care partner challenges and experiences—that is, the next question was, what are the essential elements of brain cancer PC services? To do this required a better understanding of QoL and PC communication needs and experience among the brain tumor community.

Social Media-Based Engagement

The Collaborative engaged 2 established Twitter social media communities organized around interest in brain tumors (#BTSM) and hospice and palliative medicine (#HPM).[27] (Table 2) Reflecting on the design-thinking activities and advisory group discussions, the group developed prompts for 2 interactive, asynchronous discussions using Twitter ("tweet chats") that focused on QoL and PC in the winter and spring of 2018. The #BTSM tweet chat focused on QoL needs for people facing brain tumors, and the #HPM tweet chat focused on communication about PC for people facing neurological conditions. The #BTSM tweet chat prompts were phrased to be broadly relevant to any brain tumor type, not just those that are malignant. The transcripts from these tweet chats were qualitatively analyzed for key themes related to QoL and communication about PC. These themes formed the basis for our ultimate objective: Defining elements of PC services for people with malignant brain tumors and their care partners.

Identifying Elements of Brain Cancer PC Services

The Collaborative then mapped 22 discrete QoL domains to corresponding PC service components (eg, seizure

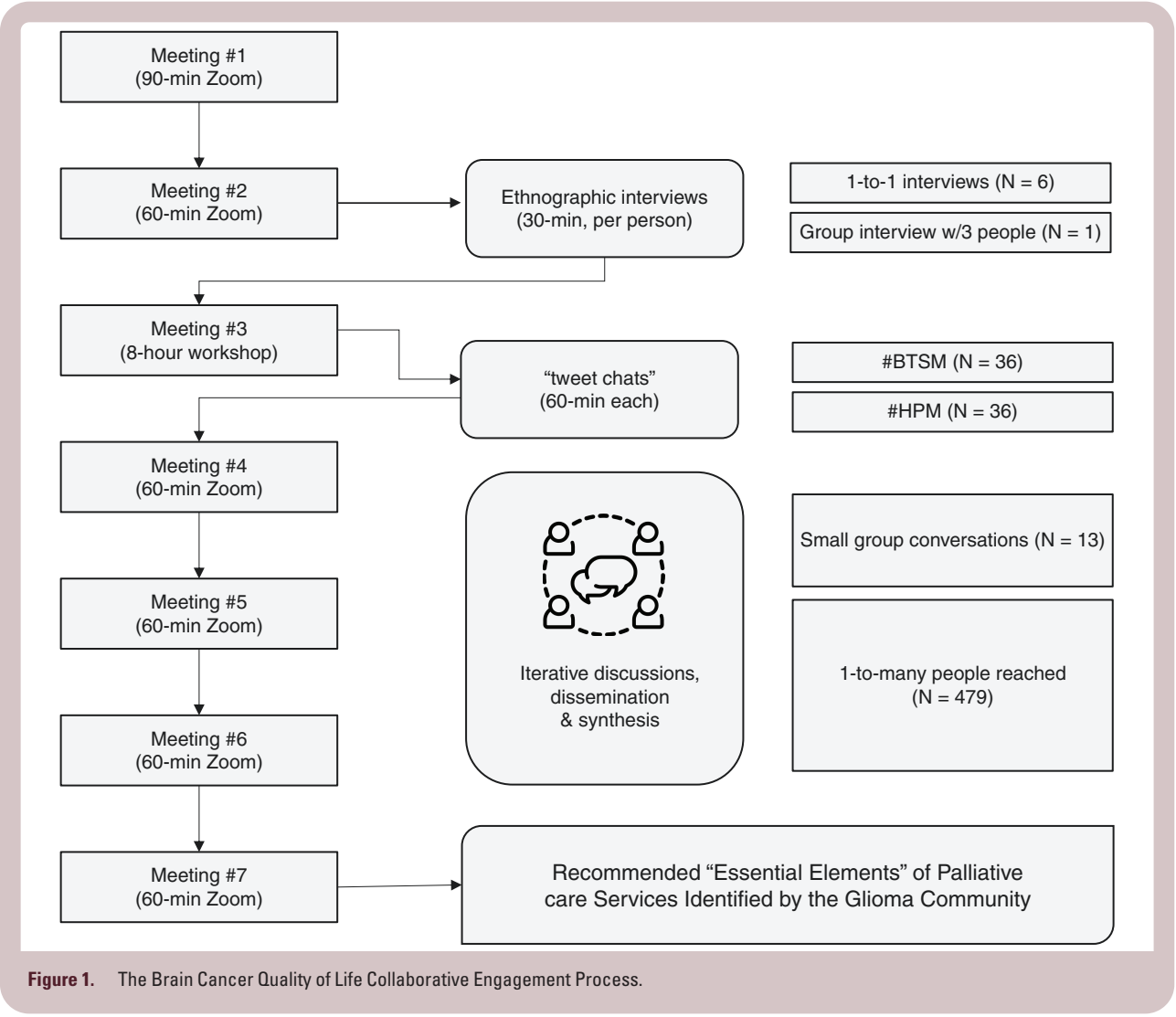

Figure 1. The Brain Cancer Quality of Life Collaborative Engagement Process.

management, pain, anxiety, functional limitations, cognitive challenges, identity and existential distress, survivorship, healthcare navigation distress, intimacy and close relationships, legal and financial challenges, etc.). (Table 4) Both clinical experts and patient and care partner members of the Collaborative accessed a shared spreadsheet to contribute their thoughts on which types of services and/or care team members may be best suited to address each domain. Specifically, "Patient & Care Partner Needs & Concerns" were first identified by the patient/care partner participants; "Existing Services, Approaches, and/or Care Team Members to Address Needs" or "No, or Limited, Services & Approaches" were identified by all involved. We then met virtually as a group to begin synthesizing this input into a general framework for the elements of brain cancer PC. (Figure 2).

As concepts for brain cancer PC services began to emerge, members of the Collaborative participated in dissemination and community engagement activities by attending outside special interest group meetings, presenting posters on works in progress, and serving on panels at conferences and as invited speakers at local and national meetings. Collaborative members presented to more than 300 brain tumor advocates as part of a public policy day in Washington, D.C., and at 2 special interest group gatherings organized at the Society for NeuroOncology Annual Meeting, where additional feedback was gathered. (Table 3) Through an iterative process, insights gained from these additional community engagement efforts helped refine the framework for the elements of brain cancer PC services.

Results

In total, these efforts engaged more than 500 individuals representing diverse personal and professional perspectives, including: People with malignant brain tumors, care partners, clinicians and trainees (neuro-oncology, neurology, PC, oncology social work, other allied health professionals), health services researchers (including PC and neuro-PC researchers), brain tumor community advocates, and health policy professionals. (Tables 1–3)

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Table 2. #BTSM and #HPM Tweet Chat Participants

Community member type	# of brain tumor tweet chat participants	# of hospice and palliative care tweet chat participants
Patient	12	4
Care partner	3	2
Clinician (neuro-oncology clinicians)	5 (3)	15 (1)
Researcher	5	5
Other healthcare professional	2	3
Advocacy or other healthcare organization	6	7
Unknown	3	1
Total Twitter chat participants	36	36

Design-Thinking Insights

The ethnographic interviews with patients, care partners, and clinicians highlighted diverse perspectives:

- PC clinicians believed they should be part of the team providing care for malignant brain tumor patients at every stage of illness, rather than being consulted near the end of life (ie, pre-hospice),
- Patients and care partners did not clearly understand what PC is and commonly associated it with hospice; and
- Neuro-oncology clinicians reported they provided care attentive to QoL needs as part of standard of care, and additional PC services were unnecessary.

Outputs of the design-thinking workshop reflected: (1) The need to increase awareness and clarify the distinction between hospice and PC; (2) The belief that PC should be an integrated layer of support for people with malignant brain tumors; (3) The need to advocate for policy change at the legislative level to ensure universal access and increased insurance coverage for PC; (4) The value of personalized patient-clinician relationships in the context of QoL discussions; (5) The need to learn more about unmet social and emotional needs patients and care partners have following the initial diagnosis to ensure timely support and access to needed resources and referrals; and (6) The need to learn about effective communication strategies for outreach about PC. These were the topics prioritized for further investigation and community engagement.

Social Media-Based Engagement Participation and Insights

Participants in the Twitter discussions mirrored those of the Collaborative (eg, patients, care partners, clinician, and representatives from brain tumor advocacy organizations). (Table 2) Key themes that emerged from the Twitter chats revealed that QoL for people with brain tumors and care partners was impacted by multiple domains of physical, cognitive, emotional, social, and spiritual/existential functioning.[27] Importantly, QoL needs and concerns *change over time* as the person's symptoms and health change, and the unpredictability, variability, and uncertainty inherent to brain tumors *have their own impact on QoL*. Reaching a consensus position, Twitter chat participants recognized that individuals caring for those with brain tumors require additional support beyond what is typically provided by the health system serving the patient. Patients and care partner participants expressed a desire to talk about QoL needs with their clinical team—though not immediately following the initial diagnosis.

Recommended "Essential Elements" of PC Services Identified by the Glioma Community

As shown in Figure 2, Collaborative members agreed that brain cancer PC services should be defined by: the *needs* patients and care partners have ("Patient & Care Partner Needs & Concerns"), *how* PC services and approaches might address those needs ("Existing Services & Approaches"), *who* in the medical team provides the services to support those needs ("Interprofessional Care Team"), and *when* services should be offered to support patients and care partners (ie, longitudinally over time) ("Optimal Timing of Discussions"). Care partners should be *recognized as crucial participants* in clinician/patient communication. The mapping exercise revealed 4 "Essential Elements" of PC services.

Essential Element 1: Patient and care partner needs and concerns.—Patient and care partner community members identified a range of physical, cognitive, mental health, psychosocial, and existential concerns that may be addressed by brain cancer PC services. Concerns included: the management of physical symptoms (eg, seizures, pain, nausea, constipation); mental health and distress (ie, depression, anxiety, grief, change in identity, existential suffering); cognitive and functional challenges (ie, change in personality, speech, and movement, confusion, memory loss, incontinence); social challenges (ie, changes in close relationships, sexuality, caregiver distress, future planning); and financial toxicity, economic, and legal distress (ie, impact on finances, employment, disability, access to healthcare). Notably, these needs and concerns were reflected by both patients and care partners—a conclusion

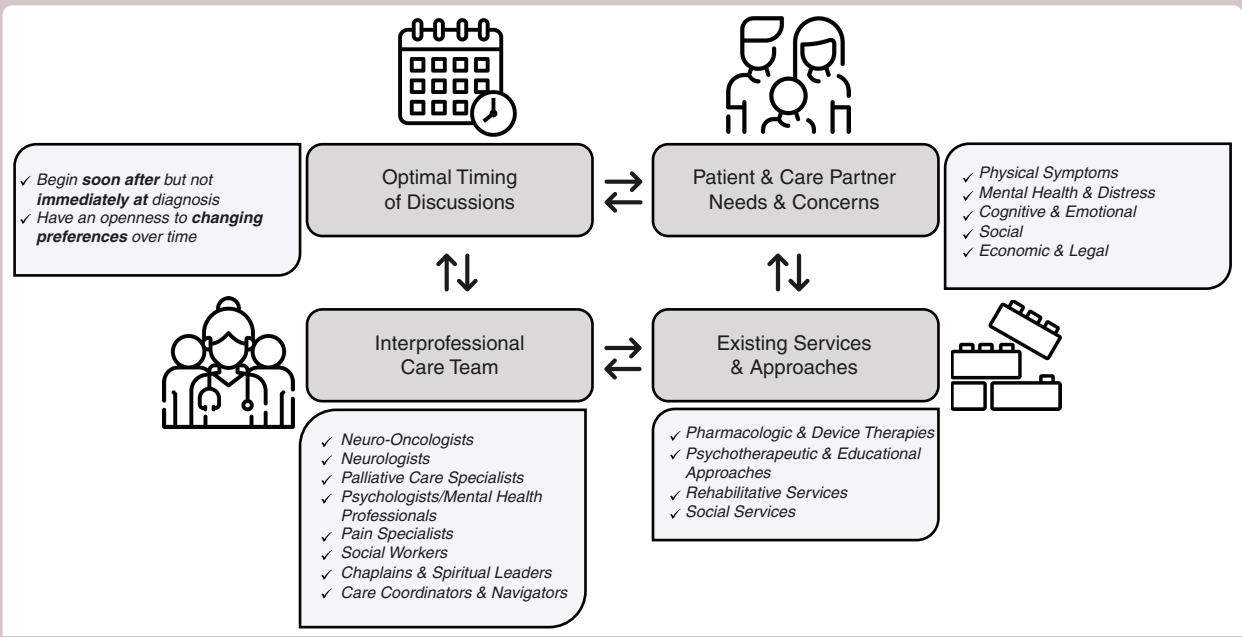

Figure 2. Recommended "Essential Elements" of Palliative Care Services Identified by the Glioma Community.

Table 3. Dissemination and Community Engagement Activites

Activity	# of community partners reached
Voice, video, and in-person conversations	
CEO, patient advocacy organization	1
Neuro-oncologists/oncologists (MDs)	5
Palliative care physicians (MD)	3
Palliative social worker (LCSW)	1
Palliative neurologist (MD)	1
Researchers studying QoL in neuro-oncology (PhD)	2
Total community members engaged	13
Invited presentations	
December 2017 UC Davis Comprehensive Cancer Center Brain Tumor Support Group presentation (Sacramento, CA)	21 patients & care partners
April 2018 Visiting professor, UC Davis Betty Irene School of Nursing (Sacramento, CA)	22 nursing and PA students
May 2018 National Brain Tumor Society Annual Policy Day presentation (Washington, D.C.)	≈300 patients & care partners
June 2018 Association of Oncology Social Work Annual Conference—PCORI session presentation (Atlanta, GA)	≈30 social workers & researchers
November 2018 Society for NeuroOncology Annual Meeting –palliative care/neuro-oncology meet-up (New Orleans, LA)	17 neuro-oncology specialists
January 2019 Palliative Care Alliance in Research & Education 4th Annual Conference, UC Davis (Sacramento, CA)	~50 palliative care clinicians
November 2019 Society for NeuroOncology Annual Meeting –palliative care/neuro-oncology meet-up (Phoenix, AZ)	14 neuro-oncology specialists
November 2019 Society for NeuroOncology Annual Meeting—poster session (Phoenix, AZ)	~25 neuro-oncology specialists/researchers
Approximate number of presentations/meeting attendees reached	479

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Table 4. Community Mapping Activity: Services, Approaches, and/or Care Team Members

Patient and care partner needs and concerns	Existing services, approaches, and/or care team members to address needs	No, or limited, services and approaches
Care partner distress and satisfaction	Caregiver support programs, individualized assessments, tailored interventions based on needs, access to therapists and/or social workers	—
Challenging behaviors (eg, personality changes, frontal lobe disinhibition, tangentiality, circumlocution)	Care partner support, cognitive behavioral therapy, care partner education, neuro-psychology baseline testing	—
Changes in close relationships, including the change in relationship between patient and care partner, and the need for additional dependence on a broader social network for support	Communication interventions, discussion about social network resources and additional needs, connections with social workers	—
Changes in sexuality	—	Not addressed
Complementary and alternative/integrative medicine (eg, cannabinoids), nutrition	Palliative care clinicians	—
Diagnostic and prognostic awareness	Palliative care physician	—
Epilepsy/seizure management	Neuro-oncologists, and/or neurologists, anti-epilepsy medications (including medications for break-through seizures), seizure emergency planning, patient/care partner seizure education	—
Existential distress, lack of preparation for the end of life, mortality awareness	Advance care planning, legacy planning, spirituality support	—
Financial toxicity	—	Not addressed
Functional limitations: Cognitive (eg, confusion, memory loss, language/speech)	Neuro-psychological evaluation, cognitive remediation, care partner education, fatigue management, energy conservation	—
Functional limitations: Physical (eg, speech, movement, ADLs, urinary incontinence)	Physical therapy, occupational therapy, rehabilitation	—
Grief and loss of identity (eg, work, meaningful experiences, driving/independence), returning to activities one previously enjoyed or were able to do (patient, care partner, family)	Palliative care physician, social worker, legacy planning	—
Headaches	Neuro-oncologists, neurologists pain management specialists	—
Healthcare navigation distress	Care coordination	—
Intimacy loss	—	Not addressed
Legal challenges	—	Not addressed, may be mentioned as part of advance care planning
Mood (depression and anxiety)	Neuro-oncologists, neurologists, neuro-psychologists, therapists trained in managing anxiety related to life threatening/life-limiting illness, medication management if needed	—
Pain	Palliative care physicians, pain management specialists, neuro-oncologists, neurologists	—
Psycho-spiritual distress, existential suffering, mortality salience ("terror management")	Palliative care physicians, chaplains, social workers, neuro-oncologists	—
Resilience, coping, post-traumatic growth (including dyadic coping with care partner)	Palliative care physicians, therapist, social worker, chaplain	—
Survivorship (eg, adjusting to life, preparing for change over time)	Survivorship care plans, medical psychologists that focus on how mental, emotional, and social factors affect physical well-being	—
Treatment-related symptoms (eg, nausea, vomiting, constipation)	Neuro-oncologists	—

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triangulated by design thinking, consideration of the published literature, and insights gained through social media engagement.

Essential Element 2: Existing services, approaches, and/or care team members to address needs.—Neuro-oncology and PC community members identified existing services and approaches that could address the needs identified by patient and care partner concerns and could work in tandem with a neuro-oncologist. Services and approaches included: person-centered care assessments; pharmacologic and device therapies (eg, pain and seizure management, neuro-psychological testing); psychotherapeutic and educational approaches (eg, counseling and psychotherapy, anticipatory guidance, seizure planning and training, caregiver education, and survivorship planning); rehabilitative services (eg, physical, speech, and occupational therapies); and social services (eg, advance care planning, care coordination, financial and legal resource navigation, resources for the patient/care partner extended support network, such as a "meal train").

Essential Element 3: Identifying and including an expanded interprofessional care team.—The Collaborative identified disciplines within interprofessional care teams who should be consulted as part of brain cancer PC services—or those who may have been helpful if services had been offered to the patient and/or care partner. These included: care coordinators and navigators; chaplains and other faith leaders; general neurologists; nurse specialists; pain specialists; PC clinicians; psychologists, social workers, and other mental/behavioral health professionals; and physical medicine and rehabilitation specialists.

Essential Element 4: Optimal timing of PC service introductions and adjustments.—The Collaborative discussed at great length the optimal timing of conversations focused on the topic of QoL, and how PC discussions may be confused/conflated with discussion about hospice. The groups reached consensus that discussions about QoL and brain cancer PC services should begin *soon after* but *not immediately at* diagnosis, and be introduced in the context of trusted care relationships.[27] Given their symptoms, a patient's needs and concerns ebb and flow over time, sometimes quickly. Thus, an important component of PC timing is adjustments over time in both types and intensity of services, approaches, and the care team members involved as needs and concerns may rapidly change.

Discussion

This work demonstrates that diverse perspectives and knowledge bases can be brought together for the purposes of meaningful co-design in advancing the care of people facing malignant brain tumors. Across partner types—neuro-oncologists, nurses, PC clinicians, patients and care partners, and social workers—all wanted to see a multi-site randomized trial of early PC for brain cancer patients and their care partners. This research priority was inspired by a study of early PC for people with metastatic non-small-cell lung cancer, and the Collaborative advocated that future work might mirror this study. Yet discussion with experts in PC, neurology, and neuro-oncology felt a brain cancer-specific PC intervention would need to be developed before such a study could be conducted.

To address this limitation, the Collaborative outlined the elements necessary in designing brain cancer PC services. As previously identified by Stec and Walbert, patient and care partner QoL needs might be addressed based on the stage of disease, area of the brain affected, treatment-related symptom burden, the individual's tolerance to therapy, and patient and care partner preferences.[33,34] The Recommended "Essential Elements" of PC Services Identified by Glioma the Community (Figure 2) could be used as a framework to better understand the many personas, approaches, and specialties involved in a brain cancer PC model. We heard in our engagement efforts that the brain tumor experience is unique among cancers, and that patient/care partner-identified preferences expressed at the onset of disease change over time, often in parallel with changes in a patient's functional status. Consistent with the findings of Sharma et al, there is discordance between the prognostic awareness of people with malignant brain tumors, their care partners, and their clinicians.[7,35] As such, it is important to check in at key moments to see if the goals of a patient-care partner dyad have shifted since the initial diagnosis.

Importantly, the Collaborative emphasized that brain cancer PC services would differ from PC for other malignancies due to neurologic symptom burden and must include supporting care partners so that they can fully support patients. Clinicians with board certification in PC (eg, chaplains, physicians, nurses, social workers) have undergone training to specialize in "goals of care" conversations—billable under Medicare—to guide these types of discussions, and would be appropriate to include early in the patient/care partner relationship with the neuro-oncology team.[10] This work corroborates and validates other work in this area focusing on prognostic awareness, symptom burden, financial toxicity, and the early integration of PC.[5,7,34–39]

Through this work, 2 long-term goals emerged. First, to validate brain tumor PC models based on the Recommended Essential Elements endorsed by the community. Next, to rigorously study the early integration of such PC models and their impact on patient and care partner outcomes. Notably, this framework is not a concrete model for care; researchers and care providers are encouraged to develop and test ways of operationalizing these Recommended Essential Elements in PC service models that fit the context of real-world health systems. That is, this research should incorporate principles of "designing for dissemination and sustainability."[40] There are likely health systems that see the PC services they offer as well-aligned with these essential elements. Yet without evidence on the effectiveness of these models, and an understanding of the contexts in which they can be routinely implemented and sustained, we are unable to make claims of evidence-based models of care that are ready for broad scale-up. In parallel, partners engaged in this work emphasized the critical need to advocate for policy

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change and workforce capacity building for PC services, such as increased PC education and training and universal access to needed services and increased insurance coverage for PC.[41]

Until a multi-site randomized trial of early PC for people with malignant brain tumors and their care partners can be conducted, other work can be done now to lay the foundation for such an intervention. This could include optimizing communication about the distinction between hospice and PC, as even patients and care partners engaged in this work often expressed confusion. National public opinion research has demonstrated that it matters how PC is defined when presenting it to both patients and the public: clear messaging about what PC is motivates patients and care partners to engage with PC services.[42] Addressing these issues are foundational to research on effective PC models for people with brain cancer.

Using multiple participatory co-design methods (eg, patient-researcher partnerships, collaborative advisory group, design thinking, social media-based and in-person engagement), frameworks (eg, the Analytic-Deliberative Model,[22] 7Ps framework[28]), and modes of interaction (synchronous and asynchronous), we were able to capture perspectives from a broader spectrum of the brain tumor community than had we focused on one method alone. Community engagement has been happening in other disease states for decades (eg, breast cancer,[43] Parkinson's Disease,[44,45] diabetes,[46] HIV/AIDS[47]), but has only recently been adopted by PC or within the brain tumor community.

Participatory research comes with limitations, including selection bias. While initially building our partnerships through contacts of LS was an effective starting point, in subsequent work we have sought out partnerships with additional patient representative leaders in the brain tumor community who were not connected to LS. For instance, we have purposefully expanded to include patient partners from the Hispanic/Latino community and participants from the International low-grade glioma registry. We used engagement approaches to better elicit the perspectives of the diverse voices representing this community; however, formal qualitative research methods may have reached different conclusions. We felt there was a strength in the participatory approach because it allowed simultaneous, multi-directional integration of perspectives. We recognize that those engaged in these activities are not representative of the entire malignant brain tumor population, as one Twitter discussion was open to people facing all types of brain tumors, and most individuals with whom we partnered were native English speakers, had Internet access, and/or had the ability to attend online or in-person patient advocacy activities. Engagement also needs to be responsive to how and where the community naturally convenes. For instance, using tweet chats as a community engagement method—which were popular when this work began—is no longer as popular among some patients, care partners, clinicians, and research community members. In April 2020, the #HPM Twitter community stopped their monthly tweet chats. Meanwhile, as a result of decreased community participation, the #BTSM tweet chat transitioned to hosting chats every other month.

Following these initial efforts, we took steps toward the sustainability of these established partnerships to advance PC research priorities. In 2019, the Collaborative formed a partnership with the National Brain Tumor Society to create a Quality of Life Research Initiative to build upon this foundation.[48] Support for this Initiative was funded by a PCORI Capacity Building Engagement Award in 2020, with the goal being the development of a QoL research agenda with funding priorities, published in 2023. We anticipate this paper will provide motivation and encouragement to the many investigators we engaged during this work to pursue research and funding on this important topic, and to partner with patients and other community representatives in that work.

In summary, this work is among the first to engage multi-community partner perspectives in the co-design of research on QOL and PC for people facing malignant brain tumors. The 4 recommended "essential elements" of brain cancer PC services identified in this work lay a foundation to inform future clinical trials testing the early integration of PC to improve QoL for people with malignant brain tumors and their care partners.

Supplementary material

Supplementary material is available online at *Neuro-Oncology Practice* (https://academice.oup.com/nop).

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Conflicts of interest statement

LS reports a speaking honorarium from Medscape. All other authors report no conflict of interest.

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Authorship statement

Conceptualized the project and manuscript: L.S. and B.K.. Contributed to writing and editing the manuscript: L.S., B.K., S.O.G., A.H., and L.T.. Analyzed and interpreted the data: L.S. and B.K.. Critically revised the text: L.S., B.K., S.O.G., A.H., M.R., and L.T..

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