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Authors

Page, Margaretta S
Chang, Susan M

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Creating a caregiver program in neuro-oncology

Margaretta S. Page and Susan M. Chang

University of California San Francisco Neuro Oncology Gordon Murray Caregiver Program, 400 Parnassus A808, SF CA 94143

Corresponding Author: Margaretta S. Page, RN, MS, UCSF Neuro Oncology 400 Parnassus A 808 SF CA 94143 (Margaretta.Page@ucsf.edu).

Abstract

Background. Neuro-oncology caregivers face unique challenges. Caring for a patient who has a catastrophic, life-threatening diagnosis combined with progressive neurological decline can produce great distress. Experts agree that a formalized plan of care to address the needs of the neuro-oncology caregiver is needed.

Methods. In 2013, the Division of Neuro-Oncology at the University of California, San Francisco initiated a program designed to provide additional services to address the needs of the neuro-oncology caregiver. Records have been kept outlining program development, the caregivers seen, their identified needs, and services provided.

Results. From October 2013 through August 2015 staff met with 334 “new to clinic” caregivers, 90 of whom were caring for patients with newly diagnosed glioblastoma. One hundred ninety-eight caregivers were deemed at high risk for distress due to transitions in patient care that were occurring. One hundred forty-nine caregivers of former patients received bereavement services for up to 6 months. The areas of highest need were emotional support and advocacy issues. The number of caregiver needs increased as patients moved along the disease trajectory. The program was able to identify resources that were lacking. Dedicated staff allowed for improvement in the kinds of caregiver-specific support services offered.

Conclusion. Dedicated caregiver staff allows for developing relationships with caregivers across the disease trajectory and appears to be important in being able to offer individualized assessments and tailored care plans. Evaluation of caregiver and patient outcomes is the next step in understanding program effectiveness.

Key words

caregiver needs | caregiver stress | caregiver program | primary malignant brain tumor | quality of life

In the last 10 to 15 years there has been more awareness surrounding the specific challenges faced by caregivers of patients with primary malignant brain tumors. These caregivers are supporting someone with a catastrophic and life-threatening illness and, in many cases, this person is suffering from rapid changes in neurologic, neuro-psychiatric, and physical condition. At diagnosis these cognitive changes present in both subtle to profound ways. Symptoms progress across the disease trajectory, regardless of the tumor type, and it is well documented that caregivers of neuro-oncology patients have multiple needs.^{1,2} They are at high risk for distress and many suffer from high levels of anxiety, depression, and reduced quality of life.^{3–5}

It has been documented that caregivers of patients with neuropsychiatric symptoms are at higher risk for increased levels of distress, more so than those caring for patients without neuropsychiatric symptoms.⁶

It is important to recognize that a patient with a primary malignant brain tumor is part of a family system and attending to the needs of the caregiver is important, not only for the health and well-being of the caregiver, but for the patient as well. The quality of care that the patient receives is intrinsically related to the capacity of the caregiver to provide the necessary care at home.^{1,7} Experts readily agree that a formalized system of structured caregiver support would benefit both the patient

and the caregiver,^{3,8} but further study is needed to better understand the expectations and specific kinds of support needed by the caregivers.

In 2013, the Division of Neuro-Oncology at the University of California, San Francisco (UCSF), with support from the Gordon Murray Brain Tumor Initiative, created a program to provide an additional layer of care to the neuro-oncology patient by providing specialized staff to assess and attend to the needs of the caregiver across the disease trajectory. The program was designed with knowledge that there are high needs for information early in the illness, that stress levels rise as the symptom burden increases, and that caregivers report high needs at times of transition.¹ The program also accounted for needs that are constantly changing by offering several opportunities for connection with the caregiver over the trajectory of the illness. An additional goal was to address any deficiencies in resources that could help meet those needs. In this report, we describe steps taken to develop and activate this program and the very early findings of the program.

Methods

Program Development

A mission statement (Box 1) for the Caregiver Program was developed. It was based on findings in the literature and feedback from former caregivers. Early work also included developing a plan for implementing the program. Dedicated, caregiver-focused personnel were appointed to the program, including a medical director, an expert neuro-oncology nurse clinician, an experienced neuro-oncology social worker, and an administrative program coordinator to facilitate the activities of the program. Job descriptions were created for each member of the team (Table 1). The program was formally named the UCSF Neuro-Oncology Gordon Murray Caregiver Program and approved by the legal, risk, and privacy regulatory committees of the UCSF Medical Center.

A room in the clinic was designated for meeting with the caregiver to offer a quiet, relaxing, and soothing space. The room's interior was designed with comfortable furnishings and soft lighting. The goal of the interior design was to

avoid the cool and sterile decor typically associated with a doctor's office.

With the mission of providing optimal care across the disease trajectory in mind, a multi-dimensional plan was developed. The plan included creating a system to offer direct care to the caregiver, collaborating with other groups vested in the care of the caregiver and improving our resources, and identifying areas where we were not sufficiently meeting caregiver needs.

Direct Care of the Caregiver

In order for the team to screen and assess each caregiver consistently, the program created a screening and needs assessment tool (see Supplementary Material online). The tool was developed for this program to identify the primary caregiver, their social and medical support network, and the context of their caregiving situation, with a focus on unmet needs, problems, or potential risks. As we used the assessment tool, we learned that some caregivers found the interview process to be intrusive, particularly during times of crisis. A decision was made to use the assessment as more of a guideline for our interactions with the caregivers, rather than a form to be completed. This allowed us to remain attentive to the caregivers' primary concerns. Occasionally, several contacts were needed with the caregiver to produce a full understanding of the situation. The assessment tool served as a pseudochecklist for the team to continually assess for a holistic understanding of the informational, emotional, practical, and social needs of the caregiver, in addition to their overall well-being.

Information gathered from each assessment was captured in two places. For programmatic efforts and data purposes all caregiver assessment information collected, beginning at the first interaction with the Caregiver Program, was entered on an Excel spreadsheet. For communication with and among the caregiver team and the health care team, the patient's electronic medical record was used. A caregiver assessment flowsheet function was created to allow the caregiver team to input detailed assessments in the patient's medical record. This allowed for enhanced communication with the patient's primary care team, tracked the number of caregivers who had been provided with services, and documented the caregiver's reported needs and subsequent interventions. The caregiver team met weekly to review the team's caseload, assessments, and triage care to the caregivers.

At the outset, a decision was made to target four specific groups of caregivers (see Table 2) with the knowledge that we would not be able to care for every caregiver prospectively. The four groups were designed so that we could provide care across the disease trajectory. Our intent was to offer services, gather data, and learn more about caregiver needs at different stages in the illness.

The "new to clinic" caregiver group included caregivers of patients who were being evaluated by the UCSF Neuro-Oncology Clinic for the first time. Prior to meeting with the physician, information about the clinic and an introduction to the Neuro-Oncology Gordon Murray Caregiver Program was provided to the caregiver/patient dyad. General educational materials such as the brain tumor information book from the American Brain Tumor Association⁹ and the

Box 1. Mission Statement

The UCSF Gordon Murray Caregiver Program is a complementary service designed for all families and/or caregivers of adult patients undergoing care for primary brain tumor at the UCSF Neuro-Oncology Program. The purpose of the program is to provide integrated care that includes the caregivers across the trajectory of the illness with the goal of optimizing the quality of life for both the patient and the caregiver. The program is designed to support the caregiver in the treatment of the patient's disease by providing education, information, access to disease and caregiver resources, as well as information and referral to peer and professional counseling and support groups.

Table 1 Job duties of members of neuro-oncology caregiver team

Team Member	Role
Medical Director	Leadership, vision, oversight of program development. Offers prioritization of program elements and progress, develops national and international agendas by creating policy initiatives for long-term goals to improve caregiver outcomes, leads caregiver research initiatives, and evaluates program and caregiver outcome data. Financial oversight and fiscal support.
Expert neuro-oncology nurse	Operational development and day-to-day management of the Caregiver Program. Provides clinical expertise and direct care to caregivers and families of neuro-oncology patients. Offers education about the disease and needs of neuro-oncology caregiver to caregivers and other health professionals involved with caring for brain tumor patients along the disease trajectory. Serves as consultant to others in the department, medical center, and community at large. Participates in application of and evaluation of evidence-based solutions in the care of the caregiver. Participates in clinical research.
Neuro-oncology social worker	Provides psychosocial assessments, crisis intervention, consultation, education, and linkage to supportive services and community resources that are specifically offered and intended for the neuro-oncology caregiver. Participates in program goal setting and outcome evaluations. Offers monthly neuro-oncology caregiver support group.
Administrative coordinator/analyst	Provides administrative support to the Caregiver Program. In addition to day-to-day administrative details, collaborates with caregiver team to create necessary documentation and understanding of goals, outcomes, outcome measurement, implementation strategies, and program evaluation procedures. Serves as main point of contact for all program communications. Meets all caregivers at first visit to the Neuro-Oncology clinic. Develops plan of care with clinical team. Responsible for program marketing and communications.

Table 2 Target groups of caregivers that received care from October 2013 to August 2015 and types of services offered

Caregiver Group	Service Provided
Caregivers of New Patients to the Clinic (N=334) Caregivers of all new patients coming to the UCSF Neuro-Oncology Clinic	At first visit received caregiver introduction packet: American Brain Tumor Association primer, UCSF Brain Tumor Caregiver Handbook, support group information, information about caregiver program services, and an assessment for additional needs.
Caregivers of Newly-diagnosed Glioblastoma Patients* (N=90) Caregivers of all patients with newly diagnosed glioblastoma (patients have received no treatment other than initial surgery)	Received 4 proactive telephone check-ins (1 call per time point), 1 from each member of the caregiver team, during the first 4 months of illness. Emotional support and needs assessments were offered at each time point.
Caregivers of High-risk/Transition Patients (N=198) Caregivers of patients with increased symptom burden, progressive disease, those transitioning to hospice care, those dealing with changes in type of illness or changes in location of care.	At time of referral, received telephone or in-person assessments and interventions were provided based on needs.
Bereaved Caregivers: Caregivers of Patients who passed away (N= 149)	Received telephone check-in at 1 and 6 months after patient's death; assessments and interventions offered, if needed.

*subset of New to Clinic group.

UCSF Brain Tumor Caregiver Orientation Handbook,¹⁰ and information about the Caregiver Program, were shared. In addition, information about community-based patient and caregiver support groups specific to the home address of the patient was provided. The goal of this initial orientation was not only to provide all new patients and caregivers with a baseline level of accurate information and support available, but also to introduce the Caregiver Program.

The second group to receive an intervention was the caregivers of patients with newly diagnosed glioblastoma (GBM). Due to the terminal nature of disease and potential for rapid progression, it was assumed that caregivers of this disease group have high needs for information,

practical support, connection to resources, and emotional support. The program offered scheduled, proactive outreach at prescribed intervals during the first 4 months after the patient's initial visit to the clinic. Caregivers of newly diagnosed GBM patients received the introductory information offered to all new patients as well as follow-up telephone outreach at 2 weeks, 4 weeks, 8 weeks, and 4 months after their initial visit. Over the course of the 4 months, these caregivers received calls from each member of the team: the social worker, the neuro-oncology nurse, and the program coordinator. The calls facilitated an opportunity for check-in directed to the caregiver with inquiry specifically about how they were coping and ongoing screening

for needs, with emphasis on all 4 of the domains assessed at the initial clinic visit. These connections also provided an opportunity to offer support and build relationships.

The third group of caregivers was called the “high-risk transition” group. This group broadly included caregivers of any patient who was in some state of transition with his or her treatment plan or care and, therefore, at higher risk for distress. Common transitions in illness include transition from active treatment to hospice care, transition of care from one location to another (eg, hospital or skilled nursing facility to home), or a change in treatments. Transition care may include referral for hospice care or referral back to a local oncologist after being taken off of a clinical-trial treatment due to disease progression. Finally, the treating physician could choose to make a referral to the caregiver team for any transition in patient condition (particularly increased symptom burden) that would put the caregiver at risk for distress. In most cases, individuals in the high-risk transition group were contacted by telephone or assessed in the caregiver meeting room.

The fourth group was known as the “bereavement” group and was made up of bereaved caregivers of our former patients. Literature supports connecting with the bereaved after the death of the patient. Although this was often done at UCSF, it was not done in a formal or consistent manner with an intentional assessment of caregiver needs. The bereavement group received a personal handwritten card from the entire neuro-oncology staff involved in their care as well as a personal phone call from the neuro-oncology caregiver nurse at 1 and 6 months following death. During bereavement check-in, caregivers were screened for overall well-being and current connection to local resources, including the local hospice team that provided care to the patient. If the caregiver acknowledged emotional difficulty the caregiver nurse contacted the local hospice that was following the patient to request additional outreach. Caregivers were also offered information about additional community bereavement services.

Collaborations with Other Groups Interested in Improving the Care of the Caregiver

The second major effort of the program implementation involved the promotion of the Caregiver Program and improving visibility to others within UCSF and from external institutions who had similar interests in improving the care of the caregiver. The caregiver team fostered collaboration with other health providers to form and lead a new group aimed at meeting the needs of caregivers of patients with diverse neurological disorders. The Neuro-Caregiver Collaboration met regularly to share ideas and resources for caregivers across the specialties of dementia, brain tumors, and traumatic brain injury. Although the disease entities are different, there are similarities in the experiences and needs of this group of caregivers. For the last 3 years, the Neuro-Caregiver Collaboration has sponsored a free, annual caregiver workshop. The workshops provided caregivers opportunities to learn more about brain anatomy and function, behavioral changes and how to manage them, parenting when a spouse is impaired, methods for self care, and practical advice on safe driving, legal

matters, and decision-making. Caregivers were offered free lunch, short chair massages, and opportunities to connect with others in similar situations. Evaluations from these conferences were unanimously positive and highlighted the need not only for an educational forum but also for a dedicated time to share concerns and strategies for coping. In addition, the caregiver team worked with the Medical Center’s palliative care team. A member of the caregiver team regularly attended interdisciplinary rounds to discuss cases as well as worked with the Palliative Care Fellowship Training Program, the inpatient neurosurgery provider teams, and community agencies to offer education about the needs of the neuro-oncology caregiver.

Improving Available Resources

The third goal of the program was to identify gaps in the resources for caregivers and to quickly implement strategies to address these deficiencies. New services implemented in response to the expressed needs of caregivers included a 6-week telephone caregiver support group to provide information and access to resources for caregivers who are unable to travel to UCSF; an ongoing monthly, in-person, caregiver-specific support group; and a peer-to-peer matching program in which experienced, trained caregivers provide one-on-one peer support to newer caregivers.

In collaboration with the Palliative Care Service at UCSF, the neuro-oncology caregiver team produced 2 educational manuals focused on symptom management and palliative care for the neuro-oncology patient.^{11,12} The first manual was tailored for the patient and caregiver and provided, in lay terms, information about the clinical changes that would occur as the tumor progressed and about preparing for the transition to hospice. The second manual was tailored to health professionals and outlined the disease-specific signs and symptoms experienced by patients as the tumor progresses, the challenges in managing care for these patients, and suggestions for medical interventions.

Results

The Gordon Murray Neuro-Oncology Caregiver Program was officially launched in October 2013. Between that time and August 2015, 334 “new to clinic” caregivers were offered information packets and received an initial screening for caregiver needs. Ninety caregivers of newly diagnosed GBM patients received 4 outreach calls at prescribed time intervals to assess their needs. One hundred ninety-eight caregivers of patients deemed at high risk by the provider were contacted to address areas of need, and 149 caregivers of our former patients were contacted by phone at 1-month and 6-month intervals after the patient’s death. These caregivers were assessed for bereavement needs during those points of contact.

Based on the individualized screening and assessments of caregiver needs the following interventions have been offered: disease-specific information, direct connection with disease and caregiver resources, emotional support, and opportunities for caregivers to establish connections

with other caregivers in similar situations (Box 2). Fig. 1 summarizes the percentage of needs documented in each category of the newly diagnosed GBM group and the high-risk transition group. Our data show that there are a variety of needs expressed and that caregivers of patients in transition report a higher percentage of needs in each category when compared to the caregivers of patients with newly diagnosed GBM in the first 4 months of illness. These findings suggest that the needs of caregivers do vary and that the number of caregivers with needs increases as transitions occur. Both groups had highest needs around emotional support and advocacy issues, which include legal, financial, employment, school, Family and Medical Leave Act, and insurance and disability. The second-largest group of high-need areas included family dynamics, such as marital concerns and parenting, and procuring home health services. Compared with caregivers of patients in early stages of the illness, caregivers of patients undergoing

some sort of transition (ie, progressive disease, increased symptom burden, or transition to hospice) had higher numbers of needs for services in every category.

In addition to documenting types of needs and interventions provided, following the launch of the program, efforts were made to assess participants' knowledge of the program, satisfaction with the services, and information about whether or not the program was meeting caregiver needs. Surveys were sent to the first 197 caregivers who received services from the program. Of these, 24.8% responded. In summary, the survey results indicated that caregiver needs vary, the timing in which individuals desire intervention varies and that repeated outreach improves knowledge of the program and satisfaction with care provided.

Discussion

The conceptual model by Sherwood and colleagues for providing care for a person with a primary malignant brain tumor guided the development of a dedicated Neuro-Oncology Caregiver Program at UCSF.¹³

Their model draws on Lazarus¹⁴ and Folkman's¹⁵ work on stress and coping. The Sherwood et al model suggests that the stress response experienced by the caregiver is based on 2 appraisals. The stress stimulus is the diagnosis of the primary brain tumor. The caregiver's primary appraisal takes place when the caregiver assesses the patient's situation (type and location of tumor; cognitive, physical, and neuropsychiatric sequelae; and treatment required) and the demands that the patient's condition and treatment will place on him/her. The caregiver then assesses the external and internal resources available, the secondary appraisal, to meet these demands. It is this process of evaluating demands vs available resources that determines both the emotional and physical stress responses experienced by the caregiver.

Using this model, the caregiver program has been working to identify and meet caregiver needs across the trajectory of the disease. The staff work with caregivers to identify their needs and assist caregivers in obtaining access to the external resources available as well as provide connections to opportunities to strengthen their internal resources. It is hoped that strengthening the internal and external resources available to caregivers will not only decrease the distress they experience, but improve caregiver self-efficacy and, subsequently, patient care.

Systematically providing and tracking care offered to the caregiver has documented the variety of supportive care needs and helped identify the most common needs of the caregiver of a patient with primary malignant brain tumor. Common needs include emotional support and help with practical matters, followed by concerns with family dynamics and procuring help in the home (Fig. 1). The data regarding caregiver needs reinforce findings previously reported in the literature.^{6,8,16,17} Caregivers need assistance in accurately making primary appraisals of the patient's situation as well as support in accessing and strengthening their internal and external resources to meet care demands.

As care was provided over the first 2 years of the program, it became clear that in addition to the commonalities about

Box 2. Interventions offered to caregivers

- Disease-specific information
 - Disease counseling about what to expect, symptoms, side effects, coaching, and health navigation
 - Caregiver workshops
- Direct connection with disease and caregiving resources
 - Home health referrals to physical therapy/occupational therapy/speech therapy, home care, respite care
 - Referral of patient or caregiver to psycho-oncologist, community based mental health services, or neuro-psychological assessment and counseling
 - Referral of patient to palliative care or hospice services and additional coaching and communication amongst agencies
- Practical Support
 - Counseling and/or connection to resources for concerns of legal resources, family and medical leave, finances, insurance, disability benefits, employment and school
 - Connection to resources for lodging and transportation
- Emotional support
 - Active listening
 - Counseling on parenting strategies and resources
 - Counseling and support around marital and family dynamics and coordination to counseling professionals as necessary
 - Coaching on coping skills and self-care
- Opportunities for caregivers to establish connections with other caregivers in similar situations
 - Peer-to-peer support program
 - UCSF Neuro-Oncology Caregiver Support group
 - Telephone support groups
 - Caregiver workshops

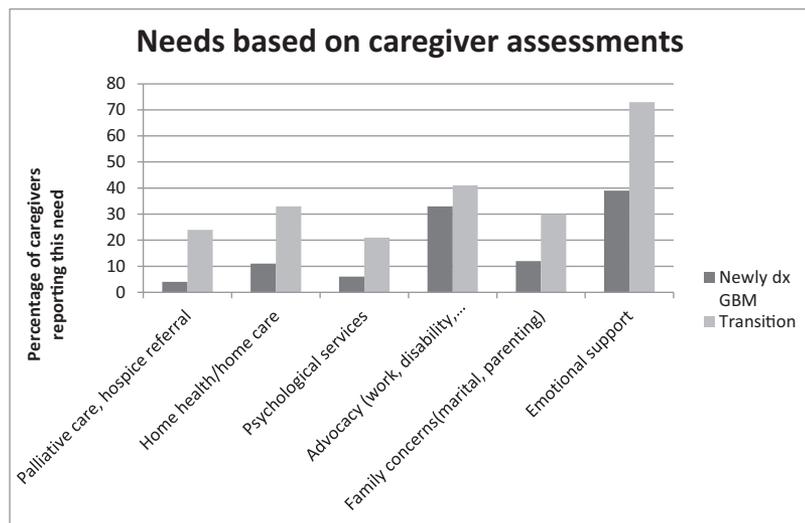


Fig. 1 Categories of needs identified by caregiver group.

the kinds of care that were being requested, there were some areas that the program was not ready to quickly address. Adequate responses needed to be developed. High-need areas for which there were limited resources included a need for connection, information about the disease and caregiving as early as the day after surgery, better mental health resources, family counseling, support around parenting with a spouse who has a brain tumor, and resources about what to expect as the disease progressed. Using this data, specific modules and additional resources have been created by the caregiver team to address these high-volume needs. These include parenting resources; end-of-life information and resources for patients, caregivers, and health professionals involved in home and hospice care; an improved listing of mental health resources; and a new initiative introducing the Caregiver Program and offering resources to caregivers soon after surgery. In addition, to address the expressed need for connection, various opportunities for caregivers to meet and share their experiences were developed.

The systematic tracking of the needs assessments and interventions provided to caregivers support the literature¹⁷ that needs increase over time, and has helped specify areas needing improvement. The surveys reiterate findings that have been reported in the literature.^{8,16,17} People have different ideas and expectations about when care should be provided. It is important to keep this in mind when meeting with a caregiver and calls to mind a concept used in the stroke literature about “timing it right.”¹⁸ It is critical to assess caregiver readiness for information and support. Providing a package of resources at the first visit may not work for many people. Ideally, support should be available when services are needed. Some caregivers want intervention as early as that first day after surgery, while others do not. A dedicated caregiver team allows for flexibility in providing this individually tailored care.

The survey also highlighted the importance of a continued relationship between the caregiver team and the caregiver. All of the caregivers of the newly diagnosed GBM

patients reported that they were familiar with the Caregiver Program service and felt as if their needs were met after four additional outreach calls. In comparison, 20% to 30% of the other groups, who at times had only received introductory information about the program or a one-time assessment and intervention, stated being familiar with the program.

Interestingly, 25% of newly diagnosed GBM caregivers did not access the Caregiver Program for assistance. Perhaps other providers were meeting their needs. It is not uncommon for caregivers of some patients with primary malignant brain tumors to receive attention and care from the treating physicians and nurses. Although, at times more reactionary than proactive, caregivers do receive information, emotional support, coaching, and help with navigating the health care system as part of the patient care received at UCSF. The data discussed here do not account for the care being offered to the caregiver in the patient’s routine clinic appointments and phone calls being handled by the patient’s neuro-oncologist and nurses. The caregiver team offers an extra layer of support to provide consistent complimentary care to the caregiver with the ultimate goal of improving the care of the patient.

The survey data and ongoing anecdotal feedback from caregivers suggest improved satisfaction with care and decreased stress and isolation as a result of the interventions offered by the Caregiver Program. Building on the positive feedback to date, the next phase of the program will focus on conducting a more detailed evaluation of services provided, the impact on caregiver and patient outcomes, as well as continued attention to newly identified high-need areas. We are planning to add a neuro-psychologist to the team to assist caregivers with strategies for the management of challenging behaviors and personality changes, as well as developing educational modules about what to expect and how to best prepare for transition to hospice, and educating hospice professionals about what to expect with this unique patient population. The program plans to facilitate formal interactions with hospice professionals to

provide ongoing educational opportunities regarding end-of-life challenges for brain tumor patients and their families.

Conclusion

Observations from the first 2 years of this innovative Neuro-Oncology Caregiver Program confirm that caregiver needs vary by individual and across the trajectory of the illness. Support is needed at diagnosis and during disease transitions. Developing a relationship with the caregiver and creating a tailored plan based on his or her internal and external resources is needed to successfully support the caregiver. High-need areas include information about the disease and the role of a caregiver, how to manage children in the home when a parent has a brain tumor, a need for connection with others, and improved education in the community about caring for a brain tumor patient at the end of life. This information on high need areas may be useful to other neuro-oncology programs when planning what resources to provide for caregivers. It is hoped that with continued time and effort we will be able to identify which components of our program are most effective in improving caregiver outcomes as well as those that could be replicated and implemented by other neuro-oncology programs.

Supplementary Material

Supplementary material is available at *Neuro-Oncology Practice* online.

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