

# UCSF

## UC San Francisco Previously Published Works

### Title

Survivorship care planning in neuro-oncology.

### Permalink

<https://escholarship.org/uc/item/0f7567x0>

### Journal

Neuro-oncology practice, 5(1)

### ISSN

2054-2577

### Authors

Leeper, Heather E  
Acquaye, Alvina A  
Bell, Susan  
et al.

### Publication Date

2018-03-01

### DOI

10.1093/nop/npx034

Peer reviewed

## Survivorship care planning in neuro-oncology

Heather E. Leeper, Alvina A. Acquaye, Susan Bell, Jennifer L. Clarke, Deborah Forst, Nadia N. Laack, Michael J. Link, Jennie W. Taylor, and Terri S. Armstrong

*Department of Neurology, NorthShore University Health System, Evanston, IL (H.E.L.); National Institutes of Health, Bethesda, MD (A.A.A.); The Ohio State University Werner Medical Center, Department of Neurological Surgery, Columbus, OH (S.B.); Departments of Neurology and Neurological Surgery, University of California (UCSF), San Francisco, CA (J.L.C. and J.W.T.); Massachusetts General Hospital Cancer Center, Boston, MA (D.F.); Department of Radiation Oncology, Mayo Clinic, Rochester, MN (N.N.L.); Department of Neurologic Surgery, Mayo Clinic, Rochester, MN (M.J.L.); National Institutes of Health, Bethesda, MD (T.S.A)*

**Corresponding Author:** Heather E. Leeper, MD, MS, Department of Neurology, NorthShore University Health System, 2650 Ridge Ave, Evanston, IL 60201 ([heatherleeper@gmail.com](mailto:heatherleeper@gmail.com)).

### Abstract

Cancer patient survivorship has become a significant topic within oncology care for both adult and pediatric patients. Starting in 2005, the Institute of Medicine recommended the use of survivorship care plans to assist patients transitioning from active treatment to the posttreatment phase of their cancer care, a critical time for many patients. Since 2014 there has been a mandate within the United States for adult cancer patients treated with curative intent to receive survivorship care plans comprised of a treatment summary and a follow-up plan to facilitate a better understanding among patients of what to expect after treatment. In addition to a general oncology survivorship care plan, specific care plans have been created for breast, lung, prostate, and colon cancers, as well as lymphoma. A survivorship care plan specific to adult neuro-oncology has been developed by a multidisciplinary and interprofessional committee, with approval from the Society for Neuro-Oncology Guidelines Committee. It has been published in compendium with this review of survivorship care planning and available as a fillable PDF on the Society of Neuro-Oncology Guidelines Endorsement web page ([https://www.soc-neuro-onc.org/SNO/Resources/Survivorship\\_Care\\_Plan.aspx](https://www.soc-neuro-onc.org/SNO/Resources/Survivorship_Care_Plan.aspx)). Implementation of this survivorship care plan provides a unique opportunity to begin addressing the range of survivorship issues our neuro-oncology patients navigate from diagnosis to end of life.

### Keywords

Neuro-oncology | patient care planning | survivorship care planning

Cancer patient survivorship was initially conceived as a movement by patient advocacy groups seeking to reframe the role of the cancer patient from a mere passive recipient to one of active participant. In acknowledgment of the lived experience unique to the individual, the National Coalition for Cancer Survivorship (NCCS) was founded in the United States (U.S.) in 1986, with the mission to advocate for quality cancer care. As a result of these efforts and increased awareness of cancer patient experiences, there was an eventual shift in the vernacular towards cancer patients being referred to as survivors, rather than victims,

navigating a range of “survivorship issues related to living with, through and beyond a cancer diagnosis.”<sup>1,2</sup> The term “cancer survivor” was inspired by Dr. Fitzhugh Mullan – a physician and one of the founders of NCCS – upon his use of the term survival in describing his own cancer experience at age 32:

*“Actuarial and population-based figures give us survival estimates for various cancers, but those figures do not speak to the individual patient, whose experience is unique and not determined or described by aggregate*

*data. Many patients are 'cured' long before they pass the five-year mark, and others go well beyond the five-year point with overt or covert disease that removes them from the ranks of the 'cured,' no matter how well they feel. Survival is a much more useful concept, because it is a generic idea that applies to everyone diagnosed as having cancer, regardless of the course of the illness. Survival, in fact, begins at the point of diagnosis, because that is the time when patients are forced to confront their own mortality and begin to make adjustments that will be part of their immediate, and to some extent, long-term future."*<sup>3</sup>

Recognizing the complex issues faced by cancer survivors within the U.S. health care system, the federally funded Institute of Medicine (IOM) published a detailed report in 2005, titled "From Cancer Patient to Cancer Survivor: Lost in Transition," which provided both analysis and recommendations about how the care of cancer survivors can and should be improved. The report called for "health care providers, patient advocates and other stakeholders...to raise awareness of the needs of cancer survivors, establish cancer survivorship as a distinct phase of cancer care and act to ensure the delivery of appropriate survivorship care."<sup>4</sup> The report also

recommended each cancer patient receive a survivorship care plan (SCP) to facilitate a better understanding among patients of what to expect in the posttreatment period. The IOM report defined a "cancer survivor" as an individual "from the time of cancer diagnosis through the balance of his or her life," thus seeking broad inclusivity of the ever-growing number of individuals diagnosed and treated for cancer.<sup>4,5</sup>

The SCP consists of a comprehensive treatment summary and a follow-up care plan pertaining to long-term effects from treatment, cancer recurrence monitoring, and psychosocial issues prevalent among cancer patients (see [Table 1](#) for IOM's recommended SCP contents). The American Society for Clinical Oncology developed a general SCP for any cancer – in addition to specific SCPs for lymphoma and breast, lung, prostate, and colorectal cancers – via a broad consensus process, which included patients. The Children's Oncology Group has created comprehensive organ system-based screening recommendations within its Long-Term Follow-Up Guidelines for Survivors of Childhood, Adolescent and Young Adult Cancers.<sup>6</sup>

In an effort to begin addressing the survivorship care needs within the adult neuro-oncology patient population, an adult neuro-oncology patient SCP has been developed by a multidisciplinary and interprofessional ad hoc committee of the

**Table 1** Institute of Medicine cancer survivorship care planning recommendations

Elements of a Survivorship Care Plan:

Treatment Summary

1. Diagnostic tests performed and results.
2. Tumor characteristics (site, diagnosis, grade/stage, marker information).
3. Dates of treatment initiation and completion.
4. Surgery, chemotherapy, radiotherapy...or other therapies provided, including agents used, treatment regimen, total dosage, identifying number and title of clinical trials (if any), indicators of treatment response, and toxicities experienced during treatment.
5. Psychosocial, nutritional, or other supportive services provided.
6. Full contact information on treating institutions and key individual providers.
7. Identification of a key point of contact and coordinator of continuing care.

Follow-Up Care Plan

1. The likely course of recovery from treatment toxicities, as well as need for ongoing health maintenance/adjuvant therapy.
2. A description of recommended cancer screening and other periodic testing and examinations, and the schedule on which they should be performed (and who should provide them).
3. Information on possible late and long-term effects of treatment and symptoms of such effects.
4. Information on possible signs of recurrence and second tumors.
5. Information on possible effects of cancer on marriage/partner relationship, sexual functioning, work, and parenting, and the potential future need for psychosocial support.
6. Information on potential insurance, employment, and financial consequences of cancer and, as necessary, referral to counseling, legal aid, and financial assistance.
7. Specific recommendations for healthy behaviors (e.g. diet, exercise, healthy weight, sunscreen use, virus protection, smoking cessation, osteoporosis prevention).
8. As appropriate, information on genetic counseling and testing to identify high risk individuals who could benefit from more comprehensive cancer surveillance or risk reducing surgery. When appropriate, recommendations that first degree relatives be informed about their increased risk and the need for cancer screening.
9. Referrals to specific follow up care providers, support groups, and/or the patient's primary care provider.
10. A listing of cancer-related resources and information (Internet-based sources and telephone listing of major cancer support organizations).

Society for Neuro-Oncology (SNO) Guidelines Committee. The development of an SCP specific to pediatric neuro-oncology is in process. The adult neuro-oncology patient SCP (Fig. 1) was designed to address the broad range of World Health Organization (WHO) diagnoses and possible treatments, with the goal of being as inclusive as possible of variable patient needs while maintaining brevity. This SCP, published in compendium with this review and available as a fillable PDF on the SNO Guidelines Endorsement web page, is intended to be applicable to all patients with primary central nervous system tumors regardless of diagnosis or WHO grade ([https://www.soc-neuro-onc.org/SNO/Resources/Survivorship\\_Care\\_Plan.aspx](https://www.soc-neuro-onc.org/SNO/Resources/Survivorship_Care_Plan.aspx)). Beyond the IOM's recommended elements for all care plans, the committee incorporated fields for responses regarding pathology,

surgery, radiation, chemotherapy, and symptom management specifically adapted to neuro-oncologic diagnoses and their treatment. Also included were an expanded section on supportive care services most often utilized by neuro-oncology patients and detailed follow-up plan options for laboratory testing, imaging, and postradiation monitoring. The SCP is designed to be used as is or to serve as a core element to be adapted into survivorship care plans developed by individual institutions or health care systems.

In 2014 the American College of Surgeons Commission on Cancer mandated adult cancer patients treated with curative intent receive SCPs.<sup>7</sup> In pediatric and adult oncology alike, the SCP was intended to function as the cornerstone in facilitating the transition from the active treatment phase to the posttreatment phase, a critical juncture in every

## NEURO-ONCOLOGY PATIENT SURVIVORSHIP PLAN



### Cancer Survivorship

#### **Resources and Tools for the Multidisciplinary Team**

Your survivorship care plan is a summary of your tumor treatments and recommendations for follow up care. It also provides you with some information about what to expect and where you can find answers to questions about survivorship. This plan is intended to assist patient and caregivers with many different types of tumors. Any aspects of the plan that do not apply can be left blank.

**Fig. 1** Neuro-oncology patient survivorship care plan. Developed by a multidisciplinary and interprofessional ad hoc committee of the Society for Neuro-Oncology Guidelines and Committee [https://www.soc-neuro-onc.org/SNO/Resources/Survivorship\\_Care\\_Plan.aspx](https://www.soc-neuro-onc.org/SNO/Resources/Survivorship_Care_Plan.aspx).

patient's care. The primary premise of the SCP is to provide crucial information about the patient's care for the benefit of both the patient and her or his primary health care provider, thereby better informing both parties about what to expect in terms of medical and supportive service needs while promoting healthful lifestyle choices. However, the Commission on Cancer mandate was not accompanied by any guidelines or evidence-based practice on how to implement the SCPs, or by any evidence of the SCP's efficacy to achieve the intended goals. To date, there remains little evidence supporting the utility of SCPs with a large knowledge gap necessitating much more research addressing the impact, if any, on survival outcomes, SCP dissemination and implementation, as well as SCP content.<sup>8,9</sup> An interesting perspective on the research about SCP efficacy, which in the existing literature has largely focused on breast and gynecologic oncology, is that the negative or null results may reflect poor or inconsistent SCP implementation rather than nonefficacy of the SCP itself.<sup>10</sup> Cancer survivorship care planning is recognized to require specific, coordinated, and collaborative research efforts and agendas with participation by all stakeholders, including patients and their families, to develop requisite science to inform the necessary care processes.<sup>11</sup>

The feasibility of completing and delivering SCPs, in terms of both appropriate clinical staff and the availability to engage in this time intensive work, has presented considerable implementation challenges, if not barriers, at the local level. Further compounding the logistical challenges of implementation are those of reimbursement: there are no survivorship-specific billing codes and procedures. As reflected by the American Society for Clinical Oncology's Practice & Guidelines regarding coverage and reimbursement for survivorship care services within the U.S. health care system, physicians may be able to bill for the total time spent examining and/or counseling the patient and follow-up visits are routinely covered by payers; however, not all nonphysician survivorship providers are able to report and bill in all states. The billing procedures for encounters pertaining to survivorship care planning are best determined locally in relation to what programs, resources, and measures are in place.<sup>12,13</sup>

Setting the issues of cancer survivorship care planning within the larger field of oncology aside, an opportunity to begin addressing survivorship care for our unique patient population exists within neuro-oncology. The lack of implementation guidelines and mandates need not be barriers or limitations to developing survivorship care within neuro-oncology. The mutual aspiration of those involved in developing the neuro-oncology patient-specific SCP, compliant with the current requisite SCP content recommendations, was to create a tool to catalyze addressing survivorship in neuro-oncology and to foster collaborative research on survivorship care planning via the SCP's dissemination within our community. Indeed, there is a myriad of potential opportunities to engage with our patients and their caregivers about survivorship. As health care providers to neuro-oncology patients and their caregivers, we are acutely aware of the many unmet psychosocial needs and high symptom burden experienced by our patients. There has been growing interest and awareness about the efficacy of symptom management, whether in the form of palliative care services or increased symptom surveillance and management between and prior to oncology clinic visits as validated in randomized clinical

trials to improve overall survival by clinically meaningful time amounts.<sup>14,15</sup> By directly engaging with our patients and their caregivers about survivorship issues contained within the SCP, an opportunity for dialogue about symptom management and other needs will arise, which can be clinically meaningful and beneficial, prospectively. Furthermore, one could also argue there is a strong element of self-empowerment and self-advocacy to have a comprehensive overview of one's medical care, with emphasis of including a basic plan to move forward from the active treatment phase.

In the absence of a mandate at the present time, we have the freedom to exercise the opportunity to design and conduct the crucial research regarding SCP implementation and efficacy in our own patient population, which is largely comprised of many rare cancer types and thus unlikely to be included in SCP implementation or efficacy research conducted within the larger field of oncology. The National Cancer Institute, among others, has encouraged the development of care processes via accurate documentation within organizations and institutions performing the survivorship care planning to build the requisite scientific evidence and inform the contents of a successful implementation process.<sup>16</sup> Indeed, even if there were evidenced-based practice guidelines regarding SCP implementation, they would have likely been developed with minor if any involvement of patients with primary central nervous system neoplasms, thus raising concerns about the validity of the evidence for neuro-oncology patients. Additional potential options to address barriers to the implementation of neuro-oncology SCP locally include conducting the implementation as a quality improvement or systems-based practice project, possibly to address symptom management, quality of life, reducing patient and caregiver distress, or cancer patient resource navigation; and establishing relationships with local oncology care providers to collaborate on optimizing survivorship care planning services.

The hope is that the SCP can become an instrument for communication with our patients and caregivers who face many complex survivorship issues. These include the potential for high neurologic and constitutional symptom burdens that are often progressive over time;<sup>17</sup> social and role issues related to living with a cancer diagnosis;<sup>18</sup> the need for coordination of health care within a single or among multiple institutions, which may be remote from their home and local primary care providers; need for supportive medical care, financial, and psychosocial resources; need for illness understanding and coping strategies for the fear of recurrence; and many others. In order to assess the current awareness of cancer patient survivorship care planning among the neuro-oncology health care provider community, a survey was conducted by the SNO Guidelines Committee using the SNO membership email list. The survey was approved by the NorthShore University Health System IRB as being IRB exempt and HIPAA compliant. Participants received an email invitation on May 23, 2017 and June 27, 2017. The survey closed on July 14, 2017 with 225 total responses. As reflected in the results from the recently conducted SNO Guidelines Committee survivorship awareness survey (Table 2), there is significant interest among neuro-oncology health care providers to continue to learn more about survivorship and improve access to information and resources pertaining to survivorship.

**Table 2** Responses from the recently conducted Society for Neuro-Oncology Guidelines Committee survivorship awareness survey

	Europe n = 41	United States n = 139	Total <sup>1</sup> n = 225
<b>Role in healthcare team?</b>			
Nurse	—	7 (5.0%)	8 (3.6%)
Nurse Practitioner	2 (4.9%)	15 (10.8%)	17 (7.6%)
Physician's Assistant	1 (2.4%)	3 (2.2%)	4 (1.8%)
Physician	<b>35 (85.4%)</b>	<b>96 (69.1%)</b>	<b>173 (76.9%)</b>
Psychotherapist/Psychologist	2 (4.9%)	8 (5.8%)	11 (4.9%)
Social Worker	—	1 (.7%)	1 (.4%)
Trainee (Resident or Fellow)	1 (2.4%)	9 (6.5%)	11 (4.9%)
<b>Clinical field of practice</b>			
Medical Oncology	3 (7.3%)	4 (2.9%)	8 (3.6%)
Neuro-Oncology	<b>11 (26.8%)</b>	<b>63 (45.3%)</b>	<b>85 (37.8%)</b>
Neurosurgery	8 (19.5%)	25 (18.0%)	51 (22.7%)
Pediatric Oncology	1 (2.4%)	4 (2.9%)	9 (4.0%)
Pediatric Neuro-Oncology	10 (24.4%)	18 (12.9%)	33 (14.7%)
Supportive Services	1 (2.4%)	2 (1.4%)	4 (1.8%)
Radiation Oncology	5 (12.2%)	15 (10.8%)	25 (11.1%)
Other	2 (4.9%)	8 (5.8%)	10 (4.4%)
<b>Years in current role</b>			
1–5 years	4 (9.8%)	39 (28.1%)	54 (24.0%)
6–10 years	13 (31.7%)	26 (18.7%)	50 (22.2%)
10+ years	<b>24 (58.5%)</b>	<b>74 (53.2%)</b>	<b>121 (53.8%)</b>
<b>Practice setting</b>			
NCI-designated cancer center	—	51 (36.7%)	51 (22.7%)
Academic/tertiary	<b>29 (70.7%)</b>	<b>59 (42.4%)</b>	<b>122 (54.2%)</b>
Academic-affiliated	5 (12.2%)	14 (10.1%)	25 (11.1%)
Community hospital	5 (12.2%)	6 (4.3%)	12 (5.3%)
Private practice	2 (4.9%)	9 (6.5%)	15 (6.7%)
<b>How familiar with care plans?</b>			
Not at all familiar	2 (4.9%)	8 (5.8%)	14 (6.2%)
Slightly familiar	11 (26.8%)	29 (20.9%)	49 (21.8%)
Somewhat familiar	<b>14 (34.1%)</b>	<b>56 (40.3%)</b>	<b>91 (40.4%)</b>
Very familiar	<b>14 (34.1%)</b>	46 (33.1%)	71 (31.6%)
<b>Are plans provided at institution?</b>			
Yes	<b>26 (63.4%)</b>	<b>111 (79.9%)</b>	<b>165 (73.3%)</b>
No	15 (36.6%)	28 (20.1%)	60 (26.7%)
<b>Awareness of mandate</b>			
Not at all aware	<b>29 (70.7%)</b>	30 (21.6%)	<b>86 (38.2%)</b>
Slightly aware	3 (7.3%)	34 (24.5%)	44 (19.6%)
Somewhat aware	6 (14.6%)	<b>50 (36.0%)</b>	65 (28.9%)
Very aware	3 (7.3%)	25 (18.0%)	30 (13.3%)
<b>Awareness of services at institution</b>			
Not at all aware	3 (7.3%)	11 (7.9%)	23 (10.2%)
Slightly aware	13 (31.7%)	34 (24.5%)	56 (24.9%)
Somewhat aware	11 (26.8%)	44 (31.7%)	66 (29.3%)
Very aware	<b>14 (34.1%)</b>	<b>50 (36.0%)</b>	<b>80 (35.6%)</b>



Table 2 Continued

	Europe n = 41	United States n = 139	Total <sup>1</sup> n = 225
<b>SNO providing education</b>			
Not at all interested	—	4 (2.9%)	8 (3.6%)
Somewhat interested	5 (12.2%)	21 (15.1%)	37 (16.4%)
Moderately interested	<b>20 (48.8%)</b>	45 (32.4%)	74 (32.9%)
Extremely interested	16 (39.0%)	<b>69 (49.6%)</b>	<b>106 (47.1%)</b>
<b>Which platforms at SNO would be beneficial?<sup>2</sup></b>			
Published materials	23 (56.1%)	83 (59.7%)	134 (59.6%)
Online material to download	33 (80.5%)	114 (82.0%)	180 (80.0%)
Workshops and round table discussion	16 (39.0%)	58 (41.7%)	93 (41.3%)
Lectures at annual meeting	23 (56.1%)	86 (61.9%)	130 (57.8%)
Web-based forums or other interactive formats	8 (19.5%)	49 (35.3%)	73 (32.4%)
Other	4 (9.8%)	5 (3.6%)	9 (4.0%)

<sup>1</sup>Includes responses from Europe (18.2%) and the United States (61.8%) along with the following geographical locations: Africa (1; 0.4%), Asia (14; 6.2%), Australia or New Zealand (5; 2.2%), Canada (13; 5.8%), Mexico, Central or South America (12; 5.3%).

<sup>2</sup>Participants could check all that applies for this question, the results for each platform could reflect more than one response from each participant.

As neuro-oncology dedicated health care providers, we are well aware that the goal of much of our medical care is maintenance of neurologic function and quality of life, yet significant knowledge gaps remain regarding how our patients experience their symptoms throughout their lives, including at the end of life, and how to optimize their quality of life.<sup>19,20</sup> We can start to address these knowledge gaps if we are willing to collaborate with each other, and by creating opportunities for dialogue with our patients and their caregivers about what their viewpoints, opinions, and needs are. These collaborations can arise at the local level, followed by collaborations with neighboring institutions as well as across larger distances so as to be mindful of cultural preferences, a critical factor in providing patient-centered care. Implementation of this SCP provides a unique opportunity to begin addressing the range of survivorship issues our neuro-oncology patients navigate from diagnosis to end of life. Exactly such efforts are already underway for patients with other cancer types. Our neuro-oncology patients deserve equitable survivorship care, which we can now start working towards, equipped with an appropriately designed SCP specific to neuro-oncology and our continued dedication to the optimization of our patients' care and well-being.

## Supplementary Material

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

## Funding

No targeted funding to report.

**Conflicts of Interest:** None

## References

1. National Coalition for Cancer Survivorship. Our Mission. <https://www.canceradvocacy.org/about-us/our-mission>. Accessed September 21, 2017.
2. National Coalition for Cancer Survivorship. Defining Cancer Survivorship. *Cancer Policy Matters Blog*. July 24, 2014. <https://www.canceradvocacy.org/news/defining-cancer-survivorship>. Accessed September 21, 2017.
3. Mullan F. Seasons of survival: reflections of a physician with cancer. *N Engl J Med*. 1985;313(4):270–273.
4. Hewitt M, Greenfield S, Stovall E, eds; Institute of Medicine and National Research Council of the National Academies. *Cancer Survivors. From cancer patient to cancer survivor: Lost in transition*. Washington, DC: The National Academies Press; 2006:9–186.
5. Nekhlyudov L, Ganz PA, Arora NK, et al. Going beyond being lost in transition: a decade of progress in cancer survivorship. *J Clin Oncol*. 2017;35(18):1978–1981.
6. Children's Oncology Group. Long-Term Follow-Up Guidelines for Survivors of Childhood, Adolescent, and Young Adult Cancers. <http://www.survivorshipguidelines.org>. Accessed December 5, 2017.
7. American College of Surgeons. Accreditation Committee Clarifications for Standard 3.3 Survivorship Care Plan. <https://www.facs.org/publications/newsletters/coc-source/special-source/standard33>. Published September 9, 2014. Accessed September 21, 2017.
8. Mayer DK, Birken SA, Check DK, et al. Summing it up: an integrative review of studies of cancer survivorship care plans (2006–2013). *Cancer*. 2015;121(7):978–996.
9. Birken SA, Ellis SD, Walker JS, et al. Guidelines for the use of survivorship care plans: a systematic quality appraisal using the AGREE II instrument. *Implement Sci*. 2015;10:63.

10. Mayer DK, Birken SA, Chen RC. Avoiding implementation errors in cancer survivorship care plan effectiveness studies. *J Clin Oncol*. 2015;33(31):3528–3530.
11. Alfano CM, Smith T, de Moor JS, et al. An action plan for translating cancer survivorship research into care. *J Natl Cancer Inst*. 2014;106(11):pii: dju287. doi: 10.1093/jnci/dju287.
12. American Society of Clinical Oncology. Coverage & Reimbursement for Survivorship Care Services. <https://www.asco.org/practice-guidelines/cancer-care-initiatives/prevention-survivorship/survivorship/survivorship-8>. Accessed September 21, 2017.
13. Parman C. Billing challenges for survivorship services. *Oncology Issues*. 2013;28(3):8–12.
14. Temel JS, Greer JA, Muzikansky A, et al. Early palliative care for patients with metastatic non-small-cell lung cancer. *N Engl J Med*. 2010;363(8):733–742.
15. Basch E, Deal AM, Dueck AC, et al. Overall survival results of a trial assessing patient-reported outcomes for symptom monitoring during routine cancer treatment. *JAMA*. 2017;318(2):197–198.
16. Garcia SF, Kircher SM, Oden M, et al. Survivorship care planning in a comprehensive cancer center using an implementation framework. *J Community Support Oncol*. 2016;14(5):192–199.
17. Armstrong TS, Vera-Bolanos E, Acquaye AA, et al. The symptom burden of primary brain tumors: evidence for a core set of tumor- and treatment-related symptoms. *Neuro Oncol*. 2016;18(2): 252–260.
18. Pace A, Dirven L, Koekkoek JAF, et al.; European Association of Neuro-Oncology palliative care task force. European Association for Neuro-Oncology (EANO) guidelines for palliative care in adults with glioma. *Lancet Oncol*. 2017;18(6):e330–e340.
19. Walbert T, Khan M. End-of-life symptoms and care in patients with primary malignant brain tumors: a systematic literature review. *J Neurooncol*. 2014;117(2):217–224.
20. Thier K, Calabek B, Tinchon A, et al. The last 10 days of patients with glioblastoma: assessment of clinical signs and symptoms as well as treatment. *Am J Hosp Palliat Care*. 2016;33(10): 985–988.