Curr. Treat. Options in Oncol. (2019) 20:80
DOI 10.1007/s11864-019-0681-y

Neuro-oncology (GJ Lesser, Section Editor)

Survivorship and Caregiver Issues in Neuro-oncology

Heather E. Leeper, MD, MSc

Address
Neuro-Oncology Branch, National Cancer Institute, National Institutes of Health,
9030 Old Georgetown Road Bethesda MD 20892 USA
Email: heather.leeper@nih.gov

This article is part of the Topical Collection on *Neuro-oncology*

Keywords Survivor · Caregiver · Survivorship · Supportive care · Primary brain tumor · Neuro-oncology

Opinion statement

As cancer care has evolved so has the awareness of the issues cancer patients, their caregivers and families face during and after treatment, giving rise to the cancer survivorship care initiative. The body of research pertaining to quality of life, health-related quality of life, and multidimensional symptom burden of neuro-oncology patients and their caregivers has grown significantly, yielding a wealth of data and information indicating interventions and actions targeting symptoms and needs are both warranted and desired. The provision of survivorship care aiming to deliver care in a patient-centered, whole-person model offers a means by which these interventions and actions can be actualized. The research specific to survivorship care models and survivorship care plans and their delivery remains a large opportunity, one worth the careful consideration and participation of neuro-oncology healthcare providers for the benefit of their highly deserving patients and their caregivers and families.

Introduction

The number of cancer survivors has been burgeoning both due to significant progress in cancer diagnosis and treatment since the 1970s and increased cancer incidence related to an aging population [1, 2]. It is predicted by 2022 there will be as many as 18 million cancer survivors in the USA alone [3]. There is incontrovertible evidence that survivors have unique and complex needs [1, 2, 4–7]) as recognized by several entities: the European Organisation of Research and Treatment of Cancer (EORTC) Survivorship Task Force, the US's National Cancer Institute (NCI) Office of Cancer Survivorship Research, the National Coalition for Cancer Survivorship (NCCS), the National Comprehensive Cancer Network (NCCN), the American Society for Clinical Oncology (ASCO), the American Cancer

Table 2. Institute of Medicine's recommended cancer survivorship care plan components

Treatment summary	1. Diagnostic tests performed with results 2. Tumor characteristics (site, diagnosis grade/stage, marker information) 3. Dates of treatment initiation and completion 4. Surgery, chemotherapy, radiotherapy or other cancer-directed therapies provided including agent administered, treatment regimen, total dosage, any clinical trial identifying number and title, indicators of treatment response, and toxicities experienced during treatment 5. Psychosocial, nutritional, or other supportive services provided 6. Full contact information of treating institutions and key individual providers 7. Identification of a key point of contact and coordinator of continuing care
Follow-up care plan	1. Likely course of recovery from treatment toxicities, as well as need for ongoing health maintenance/adjuvant therapy. 2. Description of recommended cancer screening and any other periodic testing and/or examinations, including their frequencies and who the ordering provider should be 3. Information on possible late and long-term effects of treatments and resulting symptoms 4. Information on possible signs of recurrence and second cancers 5. Information on possible effects of cancer on marriage/partner relationship, sexual functioning, work, parenting and potential need for psychosocial support 6. Information on potential insurance, employment, and financial consequences of cancer, and referral to counseling, legal aid and financial assistance as needed 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 9. Referrals to specific follow-up care providers including primary care provider and support groups 10. Provide listing of cancer support services and information, local and national

Data from http://www.nationalacademies.org/hmd/~/media/Files/Report%20Files/2005/From-Cancer-Patient-to-Cancer-Survivor-Lost-in-Transition/factsheetcareplanning.pdf

Society, and the American College of Surgeons Commission on Cancer (CoC), the latter having mandated delivery of survivorship care plans as part of their cancer center credentialing process. These survivor needs not only are complex but also span multiple domains (social, emotional, cognitive, psychological, and financial) as were outlined in the seminal Institute of Medicine report "From Cancer Patient to Cancer Survivor: Lost in Transition" [1].

Table 1. Important National Cancer Institute definitions in survivorship care

Cancer survivor	An individual is considered a cancer survivor from the time of diagnosis, through the balance of his or her life. Family members, friends, and caregivers are also impacted by the survivorship experience and are therefore included in this definition.
Cancer survivorship research	Survivorship research focuses on the health and life of a person with a history of cancer beyond the acute diagnosis and treatment phase. It seeks to both prevent and control adverse cancer diagnosis and treatment-related outcomes such as late effects of treatment, second cancers, and poor quality of life, to provide a knowledge base regarding optimal follow-up care and surveillance of cancer, and to optimize health after cancer treatment.

From National Cancer Institute (NCI) Division of Cancer Control & Population Sciences. Definitions, 2019. http://cancercontrol.cancer.gov/ocs/statistics/definitions.html (accessed April 1, 2019)

Biomedical versus biopsychosocial healthcare models

Cancer survivorship as a healthcare initiative has not been without controversy and survivorship care plans (SCPs) have been met by healthcare providers with skepticism, discussed throughout this review [8, 9]. The NCI's definitions of who is a cancer survivor and what is encompassed within cancer survivorship care and its research were set forth over a decade ago (Table 1) [1]. Despite a lack of systematic trials demonstrating the effectiveness of SCPs to positively impact any outcome, the CoC mandate for the delivery of survivorship care plans in the USA began in 2012, starting with patients treated with curative intent and having completed active treatment (see Table 2 for recommended contents of a SCP). Due to the emphasis of SCPs in the absence of a well-developed survivorship care infrastructure, SCPs may have become erroneously synonymous with survivorship care, though SCPs were only intended to be an element of a whole-person, patient-centered approach to survivorship care [10]. Within this context, many questions have been raised: what are the interventions SCPs can feasibly impact? How can or should that impact be measured? What precisely constitutes "active" or "primary" treatment"? How is "active disease" defined? How much residual disease can a patient have and still be eligible for survivorship care? Does curative treatment intent dictate who can or should receive survivorship care? How and why are the caregivers, families, and friends of cancer survivors to be accommodated within this initiative?

Instead of delineating nuances of ever greater detail to address these definitions, taking a macroscopic view of the healthcare model oncology operates within may provide crucial insights. Oncology, like much of medicine, operates within the biomedical healthcare model, a model based on science and reductionism whose focus is on identifying the biologic etiology of disease and methods of diagnosing disease and developing and implementing treatment of disease [11]. In contradistinction, cancer survivorship more likely optimally operates within the biopsychosocial model. The biopsychosocial healthcare model posits that illness arises from a confluence of biologic, psychological, and social factors (depicted in Fig. 1); illness is a lived experience [11]. In brief, modern medicine is devoted to finding causative agents of disease, to

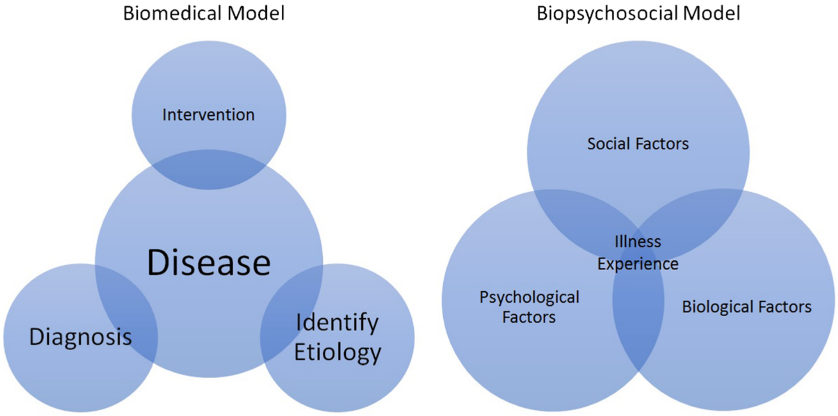

Fig. 1. Depiction of the biomedical and biopsychosocial models of healthcare

diagnosing and treating disease, and omits the patient experience of illness. Illness has been defined within medical anthropology as constellations of disvalued changes in their state of being (namely, symptoms and signs of being sick) and social function [11, 12]. By taking this perspective of how oncology and modern medicine frame clinical questions in reference to the disease process when the actual question within survivorship care being asked is what is the patient's experience, it is apparent how the premise of survivorship as a patient-centered approach endeavoring to provide whole-person care, specifically addressing the physical, cognitive, emotional, psychological, and social factors of the human illness experience, may be better conceptualized and enacted within the biopsychosocial model.

Furthermore, the biopsychosocial model of healthcare provides a more appropriate framework for the goals, needs, and constructs within survivorship care research initiative aiming to benefit survivors and their caregivers. Indeed, the biopsychosocial model has been well-validated as an innovative healthcare model; can be incorporated into research on interventions for complex, chronic health conditions; and has been used in some clinical guidelines [11, 13]. The overarching premise of cancer survivorship care and that of its research initiative have many similarities with other fields of medicine, for example, rehabilitative medicine, hospice and palliative medicine, and family medicine, that have embraced the biopsychosocial model in favor of its capacity for whole-person, patient-centered care [11, 14, 15]. The World Health Organization's International Classification of Functioning, Disability and Health initiative in fact explicitly employed the biopsychosocial model because of its accommodation of the psychological and social aspects of our human experience in confluence with biology [16].

Survivorship care in neuro-oncology

Survivorship has been gaining interest in both the clinical and health outcome research arenas, which have pragmatically yet grossly divided survivorship by cancer type and/or by age group (pediatric, adolescent and young adult, and adult). Herein lies the opportunity for neuro-oncology healthcare providers to address survivorship care for their own patient population. Not only should we become engaged because we have the expert medical knowledge of the 130 or more tumor diagnoses comprised within neuro-oncology or because we have an understanding of the scope and scale of our patients' and caregivers' needs and high symptom burdens, but also because there is a moral imperative to ensure neuro-oncology survivors and their caregivers receive equitable survivorship care relative to other cancer survivors [17, 18].

Increased interest in evaluating health-related quality of life (HRQoL), in and of itself a complex patient-assessed concept crossing physical, social, cognitive, and emotional domains, in neuro-oncology patients has yielded new information and data, informing how impactful survivorship care could be. For example, a recently published prospective cross-sectional single institutional cohort study of 291 post-operative WHO grade I meningiomas, 71% status post gross total resection, used the EORTC Quality of Life Questionnaire-30 to assess HRQoL. The authors found patients reported more than 120 months after surgery to have persistent impairments in cognitive, social, and emotional functions accompanied by substantial sleep impairment and fatigue as compared with the normative reference population [19]. In addition, a systematic review of 19 articles measuring HRQoL via several instruments also in meningioma patients found that overall meningioma patients reported "clinically relevant worse HRQoL than healthy controls" without improvement years following tumor-directed treatment [20]. These data illustrate the biomedical model's inadequacy to fully accommodate the post-operative meningioma patients' survivorship care needs: these patients have been diagnosed and fully treated with no further disease-directed interventions warranted yet remain highly symptomatic and unwell. The biopsychosocial model would account for their persistent illness as experienced by dysfunction across multiple domains, warranting a comprehensive patient-centered assessment to identify symptom-focused interventions.

As a means to catalyze the discussion and development of survivorship care within neuro-oncology, a neuro-oncology patient-specific survivorship care plan has been created per the guidelines outlined in Table 2 and is intended to accommodate survivors across the diagnostic spectrum. The care plan is available as a downloadable PDF from the Society of Neuro-Oncology's "Resources" webpage and is able to be utilized in part or in its entirety for those healthcare practitioners interested in including neuro-oncology patients' participation at their local institutions. The research agenda for survivorship care in neuro-oncology is still early in its formation and will need to identify reliable instruments and tools to be validated enabling the assessment of survivorship care outcomes, symptom management, and burdens in neuro-oncology survivors and their caregivers as interventions are planned. Several tools (Quality of Life in Adult Cancer Survivors, Impact of Cancer, Brief Cancer Impact Assessment) to assess psychological issues and life concerns within the general survivor population have been already developed and may be of consideration for validation [21].

Caregiver issues

The myriad of issues faced by caregivers has increasingly become the subject of research interest as reflected in the recent literature. Research has aimed to gain a better understanding of the scope of caregiver role: what are the impacts on the caregiver's psychological state and quality of life (QoL); how does the role of caregiving evolve across the illness trajectory; and what are the various facets of caregiver burden. Additionally, studies have sought to understand more about caregivers' information needs, what supportive care resources might be desired, and how caregivers might prefer to be assisted across the illness trajectory.

Initial investigations into the caregiver role elucidated high distress levels in many of the caregivers of neuro-oncology patients, stimulating research seeking to determine in greater detail what psychosocial issues and psychological symptoms are associated with the role of caregiving across the illness trajectory. There is ample evidence in the literature regarding the adverse effects on caregiver QOL due to the patient's course of disease and treatment [22–25]. Research employing a range of methodologies has yielded detailed information about this particular aspect. For example, in a prospective cohort study of 45 matched high-grade glioma patient-caregiver dyads, the psychological status of the caregivers was found to be significantly impaired and a third of the caregivers displayed major depressive symptoms. As a result of the severity and prevalence of these psychological symptoms, the authors found caregiver QoL was strongly negatively impacted [26]. Not only investigators have found high burdens of emotional and psychosocial distress, but also their studies have consistently revealed high rates of anxiety and depression in caregivers [26, 27•, 28–30]. A cross-sectional survey of 49 caregivers of primary malignant brain tumors completing the Hospital Anxiety and Depression Scale (HADS) found 49% met criteria for anxiety and 20% reported depression symptoms [30]. Further, the authors of this study compared their results with those from 11 studies also utilizing HADS to assess anxiety and depression in caregivers of patients with several other cancer types (lung, breast, ovarian, prostate, and multiple myeloma among others), and nearly all had reported lower rates of both anxiety and depression [30]. Other researchers have replicated these findings of higher caregiver burden in caregivers of primary brain tumor patients relative to other cancer caregivers [27•, 31–34]. Healthcare providers who have dedicated their professional lives to caring for the neuro-oncology patient and caregiver population can readily attest to the high burdens born by their patients and their respective caregivers and families alike, which is further exacerbated by the rapidity of these cancers in causing significant neurologic decline.

To gain insight about how caregiver psychological issues and supportive care needs evolve over the illness trajectory, several studies followed caregiver cohorts over a specified time course with two particularly detailed studies discussed here. Halkett et al. and Piil et al. conducted longitudinal cohort studies seeking to evaluate how caregiver distress, anxiety, and depression changed over time [27•, 35]. Halkett et al. initiated their quantitative study at the commencement of chemoradiation with repeat assessments 3 and 6 months later, while Piil et al. collected qualitative data from 33 caregivers for 1 year starting at the time of diagnosis. Both studies ultimately aimed to identify specific caregiver needs and preferences including for supportive care. In Halkett et al.'s study, 70 caregivers completed all 3 assessments with 62% scoring within the moderate to high distress range using the Distress Thermometer scale at their first assessment. These scores remained essentially unchanged in 61% at their 3-month assessment and 58% were persistently scoring in the moderate to high distress range at their 6-month assessment. Using the General Health Questionnaire-12 to measure psychological distress in these same caregivers, Halkett et al. reported 41% had severe psychological distress or signs of psychological stress at the initial assessment followed by 48% at the 3-month assessment and 37% at the 6-month assessment. This persistence of caregiver psychological symptoms has been found by others researchers; thus, there is strong evidence that much of caregiver distress, anxiety, and depression do not dissipate throughout the illness trajectory [29, 36•]. Piil et al. enrolled 33 caregivers who in summation reported their initial distress related to the unpredictability of the future and the patients' poor prognoses; hence, their early information needs pertained to learning about the disease and its course and treatment options [35]. As patient symptom burden increased and physical morbidity worsened, the caregivers' burden concomitantly increased, causing their information needs to shift towards management of the patients' symptoms, means to accommodate the physical limitations, and their needs for supportive care resources increased [37, 38]. Overall, this study's caregiver cohort expressed preferences and needs for interventions from supportive care individualized to meet their psychosocial needs, from family and friends to help them manage their caregiving burdens across emotional and social domains as well as by aiding materially or logistically [37, 38].

Seeking to better understand the psychological facets of caregiver burden, researchers have also explored caregiver emotions about their role and coping. In one cohort study 70% of 45 caregivers reported they felt unable to cope and only 50% reported having the ability to sufficiently support the patient at home [26]. Caregivers who reported high levels of confidence in caring for the patient were noted by Halkett et al. to have some incremental improvement in their distress levels over the course of 6 months whereas those reported feeling less than highly confident in their caregiving reported mean distress levels that increased over the 6-month study period [27•]. Baumstarck et al. conducted a cross-sectional study of 42 patient-caregiver dyads at the time of new high-grade glioma diagnosis and determined their QoL highly correlated with coping strategy use [39]. This and other studies have suggested that targeted individualized interventions should be offered to help patients and caregivers implement effective coping strategies [26, 36•, 39]. The value of this high-intensity caregiving for their loved ones within individual families is beyond conception; however, the financial cost is not inconsequential. Bayen et al. calculated the uncompensated caregiving hours for only personal care activities provided by 38 caregivers in France had a mean monetary value of €677 to €1683/month or €8124 to €20,196/year, equivalent to $765–$1900/month or $9183–$22,828/year [40]. This data makes the healthcare economic argument to provide comprehensive support to caregivers who so readily assume their roles and provide such loving and dedicated care more salient.

Barriers and research opportunities

Despite the endorsement of SCP delivery by the ASCO and the American Cancer Society in conjunction with the CoC mandate, the rate of participation in delivering SCPs has been low as determined by survey [41, 42]. There are multiple factors underlying this lack of participation [43••]. Because codes for the billing of an ambulatory clinic visit specifically to deliver a SCP or of the time spent in SCP preparation have not been created, the reimbursement for survivorship clinic visits necessitates planning and savvy navigation of existing billing and coding systems [44, 45]. Furthermore, the capacity to dedicate staff to work in survivorship clinics and to allocate pre-visit time to prepare SCPs is significant issues [46]. Across the USA, there is an evolving shortage of physicians, especially oncologists; thus, the feasibility within many healthcare systems for physicians to participate in SCP preparation and delivery is low [47]). Oncology advanced practice providers as existing, deeply impactfu,l and highly knowledgeable members of many oncology practices are ideal participants in the delivery of survivorship care and SCPs [47]. Indeed, professional nursing societies have embraced survivorship care and have been providing education and resources about SCPs and survivorship care as well as proposing models of survivorship care delivery [47, 48, 49].

However, perhaps the most significant underlying factor preventing the uniform adoption of SCPs has been the lack of support from healthcare providers who are withholding their engagement pending definitive research evidence of the effectiveness of SCPs to positively impact survivor outcomes. The ability to draw conclusions from the body of research pertaining to this topic has been problematic due to widely varied methods and findings, as succinctly discussed in a recent expertly conducted systematic review of 24 studies published in English and seeking to evaluate disease outcomes, healthcare use, and patient-reported outcomes following SPC delivery [43••]. There is considerable heterogeneity across these 24 studies with regard to the various cancer populations assessed, what information was contained within the SCP, who the SCPs recipients were, when and how the SCPs were delivered, what outcomes were assessed, and whether counseling was concurrently delivered with the SCP. Consequently, only a qualitative synthesis without a concurrent quantitative meta-analysis was feasible. The review's analysis employed the Cochrane Risk of Bias Tool for Randomized Controlled Trials and the Quality Assessment Tool for Quantitative Studies for the nonrandomized studies. The authors summarized that the 11 nonrandomized studies focused primarily on how SCPs were accepted by recipients and SCP feasibility and therefore lacked any planned outcomes on impact. Further, though the 13 randomized studies aimed primarily to effect patient-reported outcomes and perceptions of care via SCP delivery, the authors reported a lack of any substantive findings regarding any impact on perceptions of care, healthcare use or delivery, or patient-reported outcomes. These expert reviewers offered several recommendations for future survivorship care research. They advised more standardization of SCP delivery, SCP content, and specific outcomes or targeted effects to be assessed, thereby creating similar SCP practices within the same survivor populations to enable meaningful research collaboration. Secondly, the reviewers recommended randomized studies of high methodologic quality would provide much needed high-quality data. Lastly, they recommended a core set of proximal outcomes including measures of provider and survivor knowledge, understanding of care provider roles and communication quality, and means to optimize SCP delivery. The reviewers also reiterated SCPs are a vehicle, not the entire provision, of survivorship care and called for further development and research of survivorship care and models for its delivery and implementation [43••].

Summary

The awareness of what patients and their caregivers and families experience as cancer is diagnosed and treated has greatly increased thanks to patient advocacy and a wealth of research evaluating the range of issues and concerns impacting quality of life/health-related quality of life as well as symptom burdens within non-physical domains of emotional, cognitive, psychological, and social factors. Survivorship care as a healthcare initiative was conceptualized to address this multicity of issues, from which neuro-oncology patients and their caregivers and families would likely significantly benefit. They should be afforded equitable access irrespective of disease-, diagnosis-, or treatment-specific designations as this is incongruent with the patient-centered, whole-person care of survivorship care. Neuro-oncology inherently encompasses a wide range of tumor types and survival prognoses and this should inform how it develops and engages with survivorship care, to create a provision that is appropriately scaled for the needs of its unique population.

Compliance with Ethical Standards

Conflict of Interest

Heather E. Leeper declares that she has no conflict of interest.

Human and Animal Rights and Informed Consent

This article does not contain any studies with human or animal subjects performed by any of the authors.

References and Recommended Reading

Papers of particular interest, published recently, have been highlighted as:
• Of importance
•• Of major importance

1. Hewitt M, Greenfield S, Stovall E. From cancer patient to cancer survivor: lost in transition. In: Washington DC: National Academies Press. 2006.
2. Alfano CM, Smith T, de Moor JS, Glasgow RE, Khoury MJ, Hawkins NA, et al. An action plan for translating cancer survivorship research into care. J Natl Cancer Inst. 2014;106(11).
3. Denlinger CS, Carlson RW, Are M, Baker KS, Davis E, Edge SB, et al. Survivorship: introduction and definition. Clinical practice guidelines in oncology. J Natl Compr Cancer Netw. 2014;12(1):34–45.
4. Hewitt M, Weiner SL, Simone JV. Childhood cancer survivorship: improving care and quality of life. In: Washington. DC: The National Academies Press; 2003.
5. Adler NE, Page A. National Institute of Medicine (U. S.) Committee on Psychosocial Services to Cancer Patients / Families in a Community Setting. Cancer care for the whole patient: meeting psychosocial health needs. Washington, DC: National Academies Press; 2008.
6. Centers for Disease Control and Prevention, Lance Armstrong Foundation. A national action plan for cancer survivorship: advancing public health strategies. 2004.
7. President's Cancer Panel. Living beyond cancer: finding a new balance. Bethesda, MD: National Cancer Institute; 2004.
8. Birken SA, Mayer DK, Weiner BJ. Survivorship care plans: prevalence and barriers to use. J Cancer Educ. 2013;28(2):290–6.
9. Salz T, McCabe MS, Onstad EE, et al. Survivorship care plans: is there buy-in from community oncology providers? Cancer. 2014;120(5):722–30.
10. Parry C, Kent EE, Forsythe LP, Alfano CM, Rowland JH. Can't see the forest for the care plan: a call to revisit the context of care planning. J Clin Oncol. 2013;31(21):2651–3.
11. Wade DT, Halligan PW. The biopsychosocial model of illness: a model whose time has come. Clin Rehabil. 2017;3(8):995–1004.
12. Kleinman A, Eisenberg L, Good B. Culture, illness, and care: clinical lessons from anthropologic and cross-cultural research. Ann Intern Med. 1978;88:252–8.
13. Hersch F. Meeting the healthcare challenges of the 21st century, http://www.sbs.ox.ac.uk/sites/default/files/Skoll_Centre/Docs/essay-hersch.pdf.
14. Kusnanto H, Agustian D, Hilmanto D. Biopsychosocial model of illness in primary care: a hermeneutic literature review. J Family Med Prim Care. 2018;7(3):497–500.
15. van Dijk-de Vries A, Moser A, Mertens VC, van der Linden J, van der Weijden T, van Eijk JT. The ideal of biopsychosocial chronic care: how to make it real? A qualitative study among Dutch stakeholders. BMC Fam Pract. 2012;13:1.
16. World Health Organisation. Towards a common language for functioning, disability and health. World Health Organisation, 2002, http://www.who.int/classifications/icf/icfbeginnersguide.pdf?ua=1 (accessed 31 March 2019).
17. Armstrong TS, Vera-Bolanos E, Acquaye AA, Gilbert MR, Ladha H, Mendoza T. The symptom burden of primary brain tumors: evidence for a core set of tumor- and treatment-related symptoms. Neuro-Oncology. 2016;18(2):252–60.

18. Lovely MP, Stewart-Amidei C, Page M, Mogensen K, Arzbaecher J, Lupica K, et al. A new reality: a long-term survivorship with a malignant brain tumor. Oncol Nurs Forum. 2013;40(3):267–74.
19. Nassiri F, Price B, Shehab A, Au K, Cusimano MD, Jenkinson MD, et al. International Consortium on Meningiomas. Life after surgical resection of a meningioma: a prospective cross-sectional study evaluating health-related quality of life. Neuro Oncol. 2019;21(Supplement_1):i32–43.
20. Zamanipoor Najafabadi AH, Peeters MCM, Dirven L, Lobatto DJ, Groen JL, Broekman MLD, et al. Impaired health-related quality of life in meningioma patients-a systematic review. Neuro-Oncology. 2017;19(7):897–907.
21. Dirven L, van de Poll-Franse LV, Aaronson NK, Reijneveld JC. Controversies in defining cancer survivorship. Lancet Oncol. 2015;16(6):610–2.
22. Piil K, Jarden M. Bereaved caregivers to patients with high-grade glioma: a qualitative explorative study. J Neurosci Nurs. 2018;50(2):94–9.
23. Madsen K, Poulsen HS. Needs for everyday life support for brain tumour patients' relatives: systematic literature review. Eur J Cancer Care (Engl). 2011;20(1):33–43.
24. Spetz A, Henriksson R, Salander P. A specialist nurse as a resource for family members to patients with brain tumors: an action research study. Cancer Nurs. 2008;31(4):E18–26.
25. Wideheim AK, Edvardsson T, Påhlson A, Ahlström G. A family's perspective on living with a highly malignant brain tumor. Cancer Nurs. 2002;25(3):236–44.
26. Sacher M, Meixensberger J, Krupp W. Interaction of quality of life, mood and depression of patients and their informal caregivers after surgical treatment of high-grade glioma: a prospective study. J Neuro-Oncol. 2018;140(2):367–75.
27.• Halkett GK, Lobb EA, Shaw T, Sinclair MM, Miller L, Hovey E, et al. Distress and psychological morbidity do not reduce over time in carers of patients with high-grade glioma. Support Care Cancer. 2017;25(3):887–93

Extensive evaluation of the psychological and psychosocial burden of high-grade glioma caregivers for 6 months starting at time of chemoradiation initiation in Australia.

28. Russell B, Collins A, Dally M, Dowling A, Gold M, Murphy M, et al. Living longer with adult high-grade glioma: setting a research agenda for patients and their caregivers. J Neuro-Oncol. 2014;120(1):1–10.
29. Seekatz B, Lukasczik M, Löhr M, Ehrmann K, Schuler M, Keßler AF, et al. Screening for symptom burden and supportive needs of patients with glioblastoma and brain metastases and their caregivers in relation to their use of specialized palliative care. Support Care Cancer. 2017;25(9):2761–70.
30. Stieb S, Fischbeck S, Wagner W, Appels J, Wiewrodt D. High psychosocial burden in relatives of malignant brain tumor patients. Clin Neurol Neurosurg. 201.

Jul;170:1–6.

31. Boele FW, Heimans JJ, Aaronson NK, Taphoorn MJ, Postma TJ, Reijneveld JC, et al. Health-related quality of life of significant others of patients with malignant CNS versus non-CNS tumors: a comparative study. J Neuro Oncol. 2013;115(1):87–94.
32. Jacobs DI, Kumthekar P, Stell BV, Grimm SA, Rademaker AW, Rice L, et al. Concordance of patient and caregiver reports in evaluating quality of life in patients with malignant gliomas and an assessment of caregiver burden. Neuro-Oncol Pract. 2014;1(2):47–54.
33. Petruzzi A, Finocchiaro CY, Lamperti E, Salmaggi A. Living with a brain tumor: reaction profiles in patients and their caregivers. Support Care Cancer. 2013;21(4):1105–11.
34. Moore G, Collins A, Brand C, Gold M, Lethborg C, Murphy M, et al. Palliative and supportive care needs of patients with high-grade glioma and their carers: a systematic review of qualitative literature. Patient Educ Couns. 2013;91(2):141–53.
35. Piil K, Jakobsen J, Christensen KB, Juhler M, Guetterman TC, Fetters MD, et al. Needs and preferences among patients with high-grade glioma and their caregivers - a longitudinal mixed methods study. Eur J Cancer Care (Engl). 201.

Mar;27(2):e12806.

36.• Piil K, Jakobsen J, Christensen KB, Juhler M, Guetterman TC, Fetters MD, et al. Needs and preferences among patients with high-grade glioma and their caregivers - a longitudinal mixed methods study. Eur J Cancer Care (Engl). 2018;27(2):e12806

Extensive assessment of the issues faced by both high-grade glioma patients and caregivers from time of diagnosis for 1 year in Denmark.

37. Piil K, Juhler M, Jakobsen J, Jarden M. Daily life experiences of patients with a high-grade glioma and their caregivers: a longitudinal exploration of rehabilitation and supportive care needs. J Neurosci Nurs. 2015;47(5):271–84.
38. Piil K, Nordentoft S, Larsen A, Jarden M. Bereaved caregivers of patients with high-grade glioma: a systematic review. BMJ Support Palliat Care. 2019;9(1):26–33.
39. Baumstarck K, Leroy T, Hamidou Z, Tabouret E, Farina P, Barrié M, et al. Coping with a newly diagnosed high-grade glioma: patient-caregiver dyad effects on quality of life. J Neuro-Oncol. 2016;129(1):155–64.
40. Bayen E, Laigle-Donadey F, Prouté M, Hoang-Xuan K, Joël ME, Delattre JY. The multidimensional burden of informal caregivers in primary malignant brain tumor. Support Care Cancer. 2017;25(1):245–53.
41. Forsythe LP, Parry C, Alfano CM, et al. Use of survivorship care plans in the United States: associations with survivorship care. J Natl Cancer Inst. 2013;105:1579–87.
42. Salz T, Oeffinger KC, McCabe MS, et al. Survivorship care plans in research and practice. CA Cancer J Clin. 2012;62(2):101–17.

43.•• Jacobsen PB, DeRosa AP, Henderson TO, Mayer DK, Moskowitz CS, Paskett ED, et al. Systematic Review of the Impact of Cancer Survivorship Care Plans on Health Outcomes and Health Care Delivery. J Clin Oncol. 2018;36(20):2088–10.

Comprehensive systematic review of all studies published in English to date seeking to evaluate survivorship care plans, conducted by leaders in the field of survivorship care research. Reviewers also offer specific recommendations for future research.

44. American Society of Clinical Oncology (ASCO). Coverage & reimbursement for survivorship care services. https://www.asco.org/practice-guidelines/cancer-care-initiatives/prevention-survivorship/survivorship/survivorship-8. Accessed 31 March, 2019.

45. Parman C. Billing challenges for survivorship services. Oncology Issues. 2013;28(3):8–12.

46. Dulko D, Pace C, Dittus K, Sprague B, Pollak L, Hawkins N. Barriers and facilitators to implementing cancer survivorship care plans. Oncol Nurs Forum. 2013;40(6):575–80.

47. Corcoran S, Dunne M, McCabe MS. The role of advanced practice nurses in cancer survivorship care. Semin Oncol Nurs. 2015;31(4):338–47.

48. Grant M, Economou D, Ferrell B. Oncology nurse participation in survivorship care. Clin J Oncol Nurs. 2010;14(6):709–15.

49. Haylock PJ. Evolving nursing science and practice in cancer survivorship. Semin Oncol Nurs. 2015;31(1):3–12.

Publisher's note