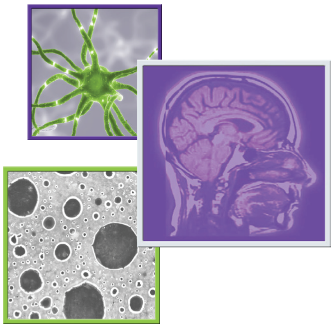
REVIEW

CNS Oncology



Neuro-oncology family caregiving: review and directions for future research

Paula R Sherwood*,1, Maureen Cwiklik2 & Heidi S Donovan2

Practice points

- Rates of depressive symptoms ranged from 10 to 50% and were reported to be higher than population normative values.
- Rates of caregiver anxiety ranged from 40 to 75%, and moderate-to-high burden was found to be present in 79% in another sample of caregivers of persons with a primary malignant brain tumor.
- Increased distress in neuro-oncology caregivers has been linked to younger age; higher levels of economic burden and unmet needs; and lower levels of social support, spirituality and caregiver mastery.
- Overall, studies have underscored the strong need caregivers have for information as well as the fact that caregivers are either not receiving or retaining information or they are not finding information they do receive to be useful.
- Although most caregivers may believe that stress reduction techniques may be beneficial, less than half say they would participate in a stress reduction technique and the majority of caregivers prefer that programs be delivered in the home.
- Healthcare providers exposed to a video on neuro-oncology caregivers are likely to have a greater understanding of the caregivers' role and potential distress and are more likely to involve a social worker in the healthcare team.
- Cognitive behavioral therapy can increase caregivers' feelings of mastery.

Vast research has underscored negative psychological and physical effects of providing care for someone with a chronic illness. Unfortunately, caregivers of persons with a primary malignant brain tumor have received very little attention in the research literature. The purpose of this article is to review what is known regarding descriptive and interventional work in neuro-oncology caregiving and to suggest avenues for future research. A total of 36 descriptive and six intervention studies were identified for this review. Increased distress in neuro-oncology caregivers has been linked to younger age; higher levels of economic burden and unmet needs; and lower levels of social support, spirituality and caregiver mastery. Intervention research suggests that educational programs and cognitive behavioral therapy may decrease neuro-oncology caregiver distress.

First draft submitted: 12 June 2015; Accepted for publication: 26 October 2015; Published online: 17 December 2015

---

[1] Acute and Tertiary Care Department, School of Nursing, School of Medicine, University of Pittsburgh, 336 Victoria Bldg, Pittsburgh, PA 15260, USA
[2] School of Nursing, University of Pittsburgh, 336 Victoria Bldg, Pittsburgh, PA 15260, USA
*Author for correspondence: Tel.: +1 412 624 4802; prs11@pitt.edu

Future Medicine part of fsg

10.2217/cns.15.43 © 2016 Future Medicine Ltd

KEYWORDS
- brain tumor
- burden• caregiver • family
- neuro-oncology

Over four decades of research in the area of family caregiving have underscored negative psychological and physical effects of providing care for someone with a chronic illness [1,2]. Family caregivers have been shown to be at risk for depression, anxiety, burden, inefficient sleep, increased tobacco and alcohol use, hypertension, poor antibody response to vaccines and increased morbidity [1,3–4]. The majority of research in the area of caregiving has been done with caregivers of persons with either Alzheimer's disease or cancer. These disease types tend to have very different trajectories. Caregivers of persons with Alzheimer's disease typically face a slow onset and progression that leads to neuropsychological (NP) symptoms such as memory loss, delusions and emotional lability. NP symptoms are a primary predictor of caregiver distress, independent of physical dysfunction. Caregivers of persons with cancer typically face a much faster onset of disease followed by intensive complex treatment regimens that produce symptoms such as fatigue, vomiting, neuropathy and sleep disturbances. Interestingly, the disease trajectory of patients with a primary malignant brain tumor (PMBT) includes characteristics of both cancer (rapid onset and complex treatment regimen) and Alzheimer's disease (disease progression that includes NP symptoms). Unfortunately, caregivers of persons with a PMBT have received very little attention in the research literature.

Caregivers of persons with a PMBT often face a rapid trajectory of illness and accompanying NP and physical dysfunction in the care recipient. At 5 years post diagnosis of a primary malignant brain or CNS tumor, only 33% of those diagnosed are still alive [5]. In addition, the diagnosis and subsequent treatment of a PMBT often lead to NP and physical dysfunction. NP deficits can include working memory, cognitive processing, visual searching, planning and foresight, and general attention [6,7]. Physical dysfunction can result from the location of the tumor, surgery, radiation, edema and radiation necrosis, among others and causes dysfunction in the affected area. NP and physical dysfunction in a person with a PMBT make family involvement in patient care essential, yet the negative consequences of providing emotional, physical and financial support to a friend or family member with a PMBT has received little attention. The purpose of this article is to review what is known regarding descriptive and interventional work in neuro-oncology caregiving and to suggest avenues for future research.

Methods

• Identification & study selection

The purpose of this review was to identify articles whose focus was emotional or physical outcomes for caregivers of persons with a primary malignant brain tumor. Inclusion criteria for this review were articles where caregiver outcomes were the primary variable of interest; caregivers were ≥ the age of 18; the patient population was restricted to CNS tumors (so that the focus of the article was in neuro-oncology, rather than in other cancer types with PMBT representing only a small proportion of the sample); and the patient diagnosis included a PMBT (metastatic disease to the brain from other cancer sites and 'benign' brain tumors were excluded).

The following databases were searched: CINAHL, Google Scholar, PsycINFO and PubMed. Keywords used in the search were 'brain tumor', 'caregiver', 'cancer', 'family', 'glioma' and 'neuro-oncology' in various combinations. Searches were not limited by beginning year in order to gain a comprehensive review of work in the area. The last year of publication included in the search was 2014. Only peer-reviewed and primary articles were considered for inclusion to ensure methodologically sound articles and only those published in English were included. Reference lists of identified articles were also reviewed to identify any articles not found in the original search.

• Review

Analysis of the articles was based on expert review by two of the authors (PS and MC). Any disagreement was settled by discussion and consensus of all three authors (PS, MC and HD). Article review and synthesis was focused on: sample (dyad vs caregiver, tumor type, recruitment rate and retention, and race/ethnicity), setting (community vs tertiary care center, country of origin, year[s] of data collection), design (descriptive vs intervention; quantitative vs qualitative), measurement (construct and specific measures) and results. Because the purpose of this review was not to perform a meta-analysis, statistical analyses were not completed.

• Results

Using the described constraints, a total of 183 articles were identified for potential inclusion.

The primary author (PS) was responsible for applying the following inclusion criteria to these articles for potential inclusion. After these inclusion criteria were applied, 36 descriptive and six intervention preparation/intervention articles were found that were included in the review. Of these, 13 articles were from the same study. Multiple articles from the same study were considered as separate findings as long as the analysis differed significantly from that which had been presented before. When descriptive statistics were generated for the sample of descriptive and intervention studies, only one representative article from the larger study was included to calculate variables such as mean age and sample size. Table 1 presents a summary of the articles reviewed for this manuscript.

• Descriptive studies

A total of 36 descriptive studies were identified for this review. Sample sizes ranged from 5 to 133 (median = 27 participants) and the majority of caregivers in each study were Caucasian female spouses of the patient. Studies were conducted in a number of countries (Australia, Nigeria, Milan, Germany, UK, Canada, USA), with the majority conducted in the USA. Focus groups and cross sectional descriptive mailed surveys were the most common research design. In qualitative studies, content analysis was the most common form of analysis and univariate analyses were most common in quantitative studies.

Qualitative analyses accounted for approximately a third of the descriptive studies on caregivers of persons with a PMBT [8,12,14–16,19–20,27,29,37–39,42–44]. Themes varied from study to study, although there were common themes found among multiple studies. Two such themes were accessing support and changes to the family. Caregivers talked about both social support as well as support from healthcare professionals. Support was considered both positive and negative, depending upon its source and availability. Changes to the family were described as immediate and widespread from renegotiating relationships to adjusting to new roles in the family. Finally, the majority of qualitative studies generated themes of psychological distress.

In quantitative studies, distress was typically the outcome of interest and was operationalized as depressive symptoms, anxiety, caregiver burden and distress [10,13,15–18,21–22,25,28,30–35,40–41,45–46]. Multiple measures were used, the most common being the Hospital Anxiety and Depression Scale and the SF12 or 36. Other measures included the FACT-GP, perceived stress scale, Caregiving Coping Questionnaire, Neurosurgery Impact Questionnaire, Caregiver Reaction Assessment and the Burden Scale for Family Caregivers. Rates of depressive symptoms ranged from 10 to 50% [13,21,43] and were reported to be higher than population normative values. Rates of caregiver anxiety ranged from 40% to 75% [13,21,43], distress was reported in 35% of one sample [45] and above population normative values, and moderate-to-high burden was found to be present in 79% in another sample of caregivers of persons with a PMBT [13]. These findings underscore the negative psychological outcomes that can occur in neuro-oncology caregiving. Studies that compared neuro-oncology caregivers to population norms provide evidence that these outcomes are higher than the general population. Interestingly, two studies demonstrated positive outcomes, such as a closer relationship to the care recipient and increased feelings of self-worth, in caregivers of persons with a PMBT [29,31]. It is interesting to note that one of the articles [31] was based on the same sample that reported high levels of depressive symptoms in caregivers [13], suggesting that positive and negative outcomes occur concomitantly in caregiving populations. This finding has been reported in other caregiving populations and has the potential to lay rich groundwork for interventions that focus on both decreasing negative outcomes increasing the number and quality of positive outcomes.

Multiple studies also focused on identifying factors that could either increase or decrease caregiver distress. Increased distress in neuro-oncology caregivers has been linked to younger age; higher levels of economic burden [10] and unmet needs [22]; and lower levels of social support [13], spirituality [30] and caregiver mastery [41]. Choi *et al.* found a relationship between higher tumor grades and increased caregiver distress [13], where Keir reported the opposite relationship [24]. Similar to qualitative reports, poor care recipient mental and physical status have also been associated with caregiver distress [13,28,47], although these results have been challenged by others whose findings have failed to support these relationships [35,43]. Reasons for disparate findings include the use of different measures, potential cultural differences in caregivers' perception of providing care and methodological issues such as sample size. These

Table 1. Summary of articles.

Author (year)	Caregivers enrolled	Methodology	Variables of interest	Country	Ref.
Arber *et al.* (2013)	22	Qualitative	Support needs	UK	[8]
Boele *et al.* (2013)	56	Quantitative intervention	Quality of life and mastery	The Netherlands	[9]
Bradley *et al.* (2009)	33	Quantitative descriptive	Economic hardship	USA	[10]
Cashman *et al.* (2007)	24	Quantitative intervention	Educational needs	Canada	[11]
Cavers *et al.* (2012)	23	Qualitative	Physical, social, psychological and existential distress	UK	[12]
Choi *et al.* (2012)	103	Quantitative descriptive	Psychological distress	USA	[13]
Cornwell *et al.* (2012)	19†	Qualitative	Postsurgical experiences	Australia	[14]
Finocchiaro *et al.* (2011)	17	Qualitative	Communication with the healthcare provider	Italy	[15]
Finocchiaro *et al.* (2012)	100	Quantitative descriptive	Quality of life	Italy	[16]
Flechl *et al.* (2013)	52	Quantitative descriptive	Care recipients' end of life phase	Austria	[17]
Heese *et al.* (2013)	605	Quantitative descriptive	Care recipients' end of life phase	Germany	[18]
Hricik *et al.* (2011)	10	Qualitative	Changes over time in the care situation	USA	[19]
Janda *et al.* (2006)	18	Qualitative	Supportive care needs	Australia	[20]
Janda *et al.* (2007)	70	Quantitative descriptive	Quality of life	Australia	[21]
Janda *et al.* (2008)	70	Quantitative descriptive	Unmet needs	Australia	[22]
Kanter *et al.* (2014)	238	Quantitative descriptive	Issues in support groups	Canada	[23]
Keir *et al.* (2006)	60	Quantitative descriptive	Psychological stress	USA	[24]
Lageman *et al.* (2015)	22	Quantitative descriptive	Educational and support preferences	USA	[25]
Lucas (2011)	33	Quantitative intervention	Reactions to implementation of a list serve	USA	[26]
McConigley *et al.* (2010)	21	Qualitative	Information and support needs	Australia	[27]
Mezue *et al.* (2011)	66	Quantitative descriptive	Impact of caregiver stress on care recipient	Nigeria	[28]
Munoz *et al.* (2008)	17	Qualitative	Quality of life	USA	[29]
Newberry *et al.* (2013)	50	Quantitative descriptive	Spirituality	USA	[30]
Newberry *et al.* (2012)	89	Quantitative descriptive	Benefits from providing care	USA	[31]
Parvataneni *et al.* (2011)	83	Quantitative descriptive	Caregiver needs	USA	[32]
Pawl *et al.* (2013)	133	Quantitative descriptive	Sleep loss and health	USA	[33]
Pawl *et al.* (2013)	133	Quantitative descriptive	Sleep characteristics	USA	[34]
Petruzzi *et al.* (2013)	72	Quantitative descriptive	Psychological distress and physical health	Italy	[35]
Rabow *et al.* (2010)	20 providers and 12 caregivers	Quantitative intervention	Provider attitudes	USA	[36]
Schmer *et al.* (2008)	10	Qualitative	Caregiver perspectives while the care recipient is receiving chemotherapy	USA	[37]
Schubart *et al.* (2007)	25	Qualitative	Challenges from caring for someone with neuropsychological dysfunction	USA	[38]
Sherwood *et al.* (2004)	43	Qualitative	Bereaved caregivers' perspectives	Multiple countries	[39]
Sherwood *et al.* (2008)	95	Quantitative descriptive	Employment and lost hours from work	USA	[40]
Sherwood *et al.* (2007)	95	Quantitative descriptive	Mastery and depression	USA	[41]
Strang *et al.* (2001)	16	Qualitative	Existential support	Sweden	[42]
Wasner *et al.* (2013)	27	Mixed methods descriptive	Quality of life and psychological distress	Germany	[43]
Whisenant (2011)	20	Qualitative	Caregiver experiences	USA	[44]

†Care recipients had a nonmalignant brain tumor.

inconsistencies underscore the need for a common set of measures, larger sample sizes and methodologic rigor.

A number of studies focused on identifying the unmet needs of caregivers. In fact, there have been several systematic reviews of the needs of caregivers of persons with a PMBT [48,49]. Studies have reported that between 29 and 50% of caregivers were dissatisfied with the information they had been provided [17,32,43]. This may be due to a mismatch in the type of information neuro-oncology clinicians believe is important versus the information caregivers desire. It is also possible that caregivers are unable to grasp and retain all the information provided in a clinic visit. For example, Finocciaro *et al.* [15] reported that only 76% of caregivers were able to provide the correct diagnosis after meeting with their neuro-oncology provider. Overall, studies have underscored the strong need caregivers have for information as well as the fact that caregivers are either not receiving or retaining information or they are not finding information they do receive to be useful.

Additional concepts that have been studied in caregivers of persons with a PMBT include economic burden and implications for caregiver employment [10,17,40], sleep [33,34], mastery [41] and biomarkers of caregiver distress [46]. Although extensively studied in other caregiving populations, these concepts are just beginning to be explored in neuro-oncology. Caregiver issues that have been addressed in other populations that warrant attention in neuro-oncology include cultural and gender influences on mental health, attention to nonwhite, nonspousal and male caregivers, and understanding how caregiver distress changes over time and in response to the care situation. There is also a lack of understanding of the impact that caregiver distress has on physical health, morbidity, mortality and health services utilization.

Findings from this review highlight that caregivers of persons with a PMBT display high levels of distress and that certain factors place caregivers at higher risk for distress. Inconsistencies among study findings and concepts not yet explored in neuro-oncology underscore the need for larger, longitudinal descriptive research trials that will allow interventions to target the groups of caregivers most at risk for distress with the right kind of support and information to improve emotional and physical outcomes.

Intervention studies

Six intervention preparation/intervention studies were found in the literature. Prospective study sample sizes (n = 3) ranged from 24 to 61 and no power analyses were included. Two of the studies were retrospective reviews of interventions that had been in place over time and one was designed to identify intervention preferences. Caregivers were recruited from major cancer centers and there were few common measures between studies. Measures of interest were primarily psychological distress and included the SF-36 mental functioning component, mastery and perceived stress. Box 1 presents suggestions for clinical practice based on evidence to date.

• Intervention preparation studies

Kanter *et al.* [23] reviewed past support groups and found that 59% of caregivers attended a support group more than once. Themes of discussion were similar to data generated from descriptive qualitative studies and included cognitive problems in the care recipient, practical issues and caregiver burden. Lucas *et al.* [26] reviewed an on-line support group for caregivers of persons with a PMBT. They reported that at three years after implementation, on-line exchanges became more regular and thoughtful and were one of the only studies to include a discussion of the cost of the intervention. The other study considered within this group was that of Keir [45], who queried caregivers regarding their preferences for interventions. The investigators found that although the majority of participants believed stress reduction techniques may be beneficial, only 44% stated they would participate in a stress reduction technique and almost all of the caregivers preferred that the programs be delivered in the home.

Data from these three studies suggest that caregivers feel that interventions are warranted. There is some discrepancy, however, between the interventions that have been trialed and caregivers' receptivity. Support groups, either on-line or in person, may be effective for some caregivers although there is some question regarding the depth and regularity of their participation. Findings suggest that caregivers may be less interested in participating in interventions that are directed solely toward the caregiver, rather than including interventions aimed at helping the caregiver provide care. Overall, the studies provide foundation for planning and implementing longitudinal prospective interventions with high methodologic rigor.

Three prospective interventions were found in the literature. The first was completed by Rabow *et al.* [36], who developed a short film concerning neuro-oncology caregivers which was watched by 61 healthcare providers. Using a pre–post test design, the healthcare providers indicated a greater understanding of the caregivers' role and potential distress and were more likely to involve a social worker in the healthcare team. The other two interventions

Box 1. Recommendations based on research to date.

- Social support is a vital component of caregiver well-being
- Feeling supported by the healthcare team is important to caregivers
- Healthcare professionals need to direct interventions and support to the entire family, not simply the patient, as the diagnosis causes major changes in family structure and relationships
- Family caregivers of persons with a primary malignant brain tumor are at risk for psychological distress including high levels of depressive symptoms, anxiety and caregiver burden
- Caregivers who are younger, have more economic burden and unmet needs and have lower levels of social support, spirituality and feelings of mastery are at risk for poor mental health
- Neuro-oncology caregivers consistently report having unmet needs
- The insufficient number of intervention trials in neuro-oncology have not provided sufficient information to substantiate evidence based interventions to improve caregiver outcomes

were directly aimed at improving caregiver outcomes. Cashman *et al.* [11] developed an educational program based on caregiver and expert opinion and reported improved knowledge at the end of the intervention (4 weeks), although scores decreased at 6 weeks, suggesting that information retention may be an issue.

Only one randomized controlled trial was identified. Boele *et al.* [9] compared an intervention using six 1-h sessions of cognitive behavioral therapy (CBT) with a psychologist to a care-as-usual control group. Boele *et al.* reported that mental health of the intervention group remained stable across time while mental health in the control group declined and that there was an increase in caregiver mastery in the intervention group following CBT. These findings have been seen in other caregiver populations as well.

Conclusion & future perspective

These studies set the groundwork for future intervention research to alleviate the distress of neuro-oncology caregivers. The abundance of caregiver interventions in the fields of cancer and dementia in particular need to be reviewed for applicability in neuro-oncology. Researchers should begin to focus on accruing larger samples, which would allow for more detailed evaluations of critical components of interventions and hypothesized mechanisms of intervention effects. Conducting these studies in neuro-oncology is extremely challenging, given the lower incidence rate of PMBTs compared with other cancers. Multicenter trials and a higher degree of collaboration between sites may be required to generate a sufficient sample for analysis. Common measures across intervention studies would also improve our understanding of the impact of different types of interventions. The Patient Reported Outcomes Measurement Information System (PROMIS) funded by the NIH has developed a set of standardized, valid, reliable and flexible outcome measures that could be implemented and would enhance our ability to compare intervention effectiveness across studies. In addition, measures of patient status should be objective when possible, rather than relying on the caregiver to provide information on the patient, particularly regarding patient neurological status (a significant predictor of caregiver distress) and patient symptoms.

Data from intervention studies highlight additional issues for future work. Lucas [26] described the cost of implementing and maintaining an online support group; future intervention studies should include a cost analysis to inform translation into clinical practice. Findings from Keir's [45] work emphasize that although caregivers are distressed, they may not take advantage of opportunities to relieve that stress. It is the researcher's, and ultimately the practitioner's, responsibility to educate caregivers that decreasing their own stress may prevent health problems that could interfere with their ability to provide high quality care to their loved one. Caregiver mastery, defined as feeling in control of the care situation, appears to be an important concept for reducing caregiver distress, although it's not clear whether caregiving-specific mastery or general mastery improves caregivers' mental health. Finally, preliminary findings from these small intervention studies underscore that researchers may be limited in their ability to reduce distress, but may better aim at preventing escalation of distress over time in caregivers of patients with PMBT. Statistical analyses and methodologic approaches should plan interventions allowing for this possibility. Researchers should consider targeting patients at higher levels of distress in order to increase the power of relatively small sample studies.

Studies to date have laid rich groundwork for future descriptive and intervention research in neuro-oncology caregiving. Levels and types of distress have been well-described and interventions are now needed to preserve caregivers' emotional and physical health and, in turn, improve the care delivered to persons with a PMBT. Multiple directions for future research have been identified with an emphasis on increasing methodologic rigor. Large, longitudinal, descriptive and intervention studies are required to advance the science and answer the key questions identified by researchers in this field. In addition, it is imperative that caregiver research beyond the field of neuro-oncology be reviewed for its relevance and potential application.

Financial & competing interests disclosure

The authors have no relevant affiliations or financial involvement with any organization or entity with a financial interest in or financial conflict with the subject matter or materials discussed in the manuscript. This includes employment, consultancies, honoraria, stock ownership or options, expert testimony, grants or patents received or pending, or royalties.

No writing assistance was utilized in the production of this manuscript.

References

Papers of special note have been highlighted as:
•• of considerable interest

1 Northouse LL, Katapodi MC, Schafenacker AM, Weiss D. The impact of caregiving on the psychological well-being of family caregivers and cancer patients. *Semin. Oncol. Nurs.* 28(4), 236–245 (2012).

2 Hiel L, Beenackers MA, Renders CM, Robroek SJ, Burdorf A, Croezen S. Providing personal informal care to older European adults. *Prev. Med.* 70, 64–68 (2014).

3 Fredman L, Cauley J, Hochberg M, Ensrud KE, Doros G. Mortality associated with caregiving, general stress, and caregiving-related stress in elderly women. *J. Am. Geriatr. Soc.* 58(5), 937–943 (2010).

4 Schulz R, Beach SR. Caregiving as a risk factor for mortality: the Caregiver Health Effects Study. *JAMA* 282(23), 2215–2219 (1999).

5 *SEER Cancer Statistics Factsheets: Brain and Other Nervous System Cancer.* National Cancer Institute, MD, USA.

6 Sterckx W, Coolbrandt A, Dierckx de Casterie B *et al.* The impact of a high-grade glioma on everyday life: a systematic review from the patient's and caregiver's perspective. *Eur. J. Oncol. Nurs.* 17(1), 107–117 (2013).

7 Gehrke AK, Baisley MC, Sonck AL, Wronski SL, Feuerstein M. Neurocognitive deficits following primary brain tumor treatment: systematic review of a decade of comparative studies. *J. Neurooncol.* 115(2), 135–42 (2013).

8 Arber A, Hutson N, de Vries K, Guerrero D. Finding the right kind of support: a study of carers of those with a primary malignant brain tumor. *Eur. J. Oncol. Nurs.* 17(1), 52–58 (2013).

9 Boele FW, Hoeben W, Hilverda K *et al.* Enhancing quality of life and mastery of informal caregivers of high-grade glioma patients: a randomized controlled trial. *J. Neurooncol.* 111(3), 303–311 (2013).

•• **A randomized controlled intervention trial aimed at reducing caregiver distress.**

10 Bradley SE, Sherwood PR, Kuo J *et al.* Perceptions of economic hardship and emotional health in a pilot sample of family caregivers. *J. Neurooncol.* 93(3), 333–342 (2009).

11 Cashman R, Bernstein LJ, Bilodeau, *et al.* Evaluation of an educational program for the caregivers of persons diagnosed with a malignant glioma. *Can. Oncol. Nurs. J.* 17(1), 6–15 (2007).

12 Cavers D, Hacking B, Erridge SE, Kendall M, Morris PG, Murray SA. Social psychological and existential well-being in patients with glioma and their caregivers: a qualitative study. *CMAJ* 184(7), E373–E382 (2012).

13 Choi CW, Stone RA, Kim KH *et al.* Group-based trajectory modeling of caregiver psychological distress over time. *Ann. Behav. Med.* 44(1), 73–84 (2012).

14 Cornwell P, Dicks B, Fleming J, Haines TP, Olson S. Care and support needs of patients and carers early post-discharge following treatment for non-malignant brain tumour: establishing a new reality. *Support. Care Cancer* 20(10), 2595–2610 (2012).

15 Finocchiaro CY, Botturi A, Lamperti E *et al.* Privacy-solidarity conflict: the communication with the support group. *Neurol. Sci.* 32(Suppl. 2), S225–S227 (2011).

16 Finocchiaro CY, Petruzzi A, Lamperti, *et al.* The burden of brain tumor: a single-institution study on psychological patterns in caregivers. *J. Neurooncol.* 107(1), 175–181 (2012).

17 Flechl B, Ackerl M, Sax C *et al.* The caregivers' perspective on the end-of-life phase of glioblastoma patients. *J. Neurooncol.* 112(3), 403–411 (2013).

18 Heese O, Vogeler E, Martens T *et al.* End-of-life caregivers' perception of medical and psychological support during the final weeks of glioma patients: a questionnaire-based survey, *Neuro Oncol.* 15(9), 1251–1256 (2013).

19 Hricik A, Donovan H, Bradley SE *et al.* Changes in caregiver perceptions over time in response to providing care for a loved one with a primary malignant brain tumor. *Oncol. Nurs. Forum* 38(2), 149–155 (2011).

20 Janda M, Eakin EG, Bailey L, Walker D, Troy K. Supportive care needs of people with brain tumors and their carers. *Support. Care Cancer* 14(11), 1094–1103 (2006).

21 Janda M, Steginga S, Langbecker D, Dunn J, Walker D, Eakin E. Quality of life among patients with a brain tumor and their carers. *J. Psychosom. Res.* 63(6), 617–623 (2007).

22 Janda M, Steginga S, Dunn J, Langbecker D, Walker D, Eakin E. Unmet supportive care needs and interest in services among patients with a brain tuour and their carers. *Patient Educ. Couns.* 71(2), 251–258 (2008).

23 Kanter C, D'Agostino NM, Daniels M, Stone A, Edelstein K. Together and apart: provding psychosocial support for patients and families living with brain tumors. *Support. Care Cancer* 22(1), 43–52 (2014).

24 Keir ST, Guill AB, Carter KE, Boole LC, Gonzales L, Friedman HS. Differential levels of stress in caregivers of brain tumor patients: observations from a pilot study. *Support. Care Cancer* 14(12), 1258–1261 (2006).

25 Lageman SK, Brown PD, Anderson SK *et al.* Exploring primary brain tumor patient and caregiver needs and preferences in brief educational and support opportunities. *Support. Care Cancer* 23(3), 851–859 (2015).

26 Lucas MR. A private caregiver ListServ: maximum benefit for minimum cost. *J. Psychosoc. Oncol.* 29(2), 168–174 (2011).

27 McConigley R, Halkett G, Lobb E, Nowak A. Caring for someone with high-grade glioma: A time of rapid change for caregivers. *Palliat. Med.* 24(5), 473–479 (2010).

28 Mezue WC, Draper P, Watson R, Mathew BG. Caring for patients with brain tumor: the patient and caregiver perspectives. *Niger. J. Clin. Pract.* 14(3), 368–372 (2011).

29 Munoz C, Juarez G, Munoz ML *et al.* The quality of life of patients with malignant gliomas and their caregivers. *Soc. Work Health Care* 47(4), 455–478 (2008).

30 Newberry AG, Choi CW, Donovan HS *et al.* Exploring spirituality in family caregivers of patients with primary malignant brain tumors across the disease trajectory. *Oncol. Nurs. Forum* 40(3), E119–E125 (2013).

31 Newberry A, Kuo J, Donovan H *et al.* Identifying family members who are likely to perceive benefits from providing care to a person with a primary malignant brain tumor. *Oncol. Nurs. Forum* 39(3), E226–E232 (2012).

32 Parvataneni R, Polley MY, Freeman T *et al.* Identifying the needs of brain tumor patients and their caregivers. *J. Neurooncol.* 104(3), 737–744 (2011).

33 Pawl JD, Lee SY, Clark PC, Sherwood PR. Sleep loss and its effects on health of family caregivers of individuals with primary malignant brain tumors. *Res. Nurs. Health* 36(4), 386–399 (2013).

34 Pawl JD, Lee SY, Clark PC, Sherwood PR. Sleep characteristics of family caregivers of individuals with a primary malignant brain tumor. *Oncol. Nurs. Forum* 40(2), 171–179 (2013).

35 Petruzzi A, Finocchiaro CY, Lamperti E, Salmaggi A. Living with a brain tumor: reaction profiles in patients and their caregivers. *Support. Care Cancer* 21(4), 1105–1111 (2013).

36 Rabow MW, Goodman S, Chang S, Berger M, Folkman S. Filming the family: a documentary film to educate clinicians about family caregivers of patients with brain tumors. *J. Cancer Educ.* 25(2), 242–246 (2010).

37 Schmer C, Ward-Smith P, Latham S, Salacz M. When a family member has a malignant brain tumor: the caregiver perspective. *J. Neurosci. Nurs.* 40(2), 78–84 (2008).

38 Schubart JR, Kinzie MB, Farace E. Caring for the brain tumor patient: family caregiver burden and unmet needs. *Neuro Oncol.* 10(1), 61–72 (2007).

39 Sherwood PR, Given BA, Doorenbos AZ, Given CW. Forgotten voices: lessons from bereaved caregivers of persons with a brain tumor. *Int. J. Palliat. Nurs.* 10(2), 67–75 (2004).

40 Sherwood PR, Donovan HS, Given CW *et al.* Predictors of employment and lost hours from work in cancer caregivers. *Psychooncology* 17(6), 598–605 (2008).

41 Sherwood PR, Given BA, Given CW *et al.* The influence of caregiver mastery on depressive symptoms. *J. Nurs. Scholarsh.* 39(3), 249–255 (2007).

42 Strang S, Strang P, Ternestedt BM. Existential support in brain tumor patients and their spouses. *Support. Care Cancer* 9(8), 625–633 (2001).

43 Wasner M, Paal P, Borasio GD. Psychosocial care for the caregivers of primary malignant brain tumor patients. *J. Soc. Work End Life Palliat. Care* 9(1), 74–95 (2013).

44 Whisenant M. Informal caregiving in patients with brain tumors. *Oncol. Nurs. Forum* 38(5), E373–E381 (2011).

45 Keir ST. Levels of stress and intervention preferences of caregivers of brain tumor patients, *Cancer Nurs.* 30(6), E33–E39 (2007).

46 Rohleder N, Marin TJ, Ma R, Miller GE. Biologic cost of caring for a cancer patient: dysregulation of pro- and anti-inflammatory signaling pathways. *J. Clin. Oncol.* 27(18), 2909–2915 (2009).

47 Sherwood PR, Given BA, Given CW *et al.* Predictors of distress in caregivers of persons with a primary malignant brain tumor. *Res. Nurs. Health* 29(2), 105–120 (2006).

48 Ford E, Catt S, Chalmers A, Fallowfield L. Systematic review of supportive care needs in patients with primary malignant brain tumors. *Neuro Oncol.* 14(4), 392–404 (2012).

49 Madsen K, Poulsen HS. Needs for everyday life support for brain tumor patients' relatives: systematic literature review. *Eur. J. Cancer Care* 20(1), 33–43 (2011).