

Existential distress among caregivers of patients with brain tumors: a review of the literature

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Background. Attention to existential needs is a component of comprehensive oncologic care, and understanding these needs among informal caregivers of patients with brain tumors is necessary to provide them with comprehensive psychosocial care. The purpose of this systematic review was to synthesize the literature on existential distress experienced by these informal caregivers to inform the development of psychotherapeutic interventions for this population.

Methods. A systematic review was conducted using electronic medical databases. Studies that examined any element of existential distress among informal caregivers of patients with brain tumors were included. A final sample of 35 articles was reviewed.

Results. Six existential themes emerged: identity; isolation; responsibility and guilt; death anxiety; deriving meaning and personal growth; and spirituality and religion. The unique existential experience of parenting a patient with a brain tumor also emerged. Existential distress in all areas was identified as experienced early in the cancer trajectory and as a critical, unmet need.

Conclusions. Existential distress is well documented among informal caregivers of patients with brain tumors and is a significant driving force of burden. Awareness and acknowledgement of this distress, as well as interventions to ameliorate this suffering, are needed. More candid communication between health care providers and caregivers about brain tumor prognosis and caregivers' existential distress may improve their psychosocial outcomes.

Keywords: brain tumors, burden, existential distress, informal caregivers, palliative care.

Informal caregivers provide uncompensated care for ill loved ones that involves significant time and energy and requires the performance of tasks that may be physically, emotionally, socially, existentially and financially demanding. In 2009, 65.7 million Americans served as informal caregivers, 4.6 million of whom were caregivers to cancer patients,^{1,2} a population at risk for a range of psychological (eg, anxiety, depression, hopelessness^{3,4}) and physical (eg, increased mortality, cardiovascular disease, poor immune functioning, sleep difficulties^{5,6}) complications.

Informal caregivers of patients with malignant brain tumors are at particular risk for burden due to the devastating neurologic and oncologic sequelae of these diseases. Burden has been described as a "multidimensional biopsychosocial reaction resulting from an imbalance of care demands relative to caregivers' personal time, social roles, physical and emotional states, financial resources, and formal care resources given the other multiple roles they fulfill."^{7,8}

Personality changes, mood disturbances, and cognitive limitations are ubiquitous in the course of the illness and make caregiving

particularly challenging.⁹ The care needs of brain tumor patients are complex due to cognitive and language deficits,¹⁰ diminished decision-making abilities, and progressive personality changes; this places tremendous responsibility on informal caregivers to attend increasingly over time to activities of daily living¹¹ and to engage in treatment decision making and end-of-life planning.¹²

A growing body of literature documents existential distress as a significant component of burden among informal caregivers who care for cancer patients generally.^{13–16} While no one definition of existential distress exists, it has been described as including feelings of hopelessness, demoralization, loss of personal meaning and dignity, feelings of burden towards others, and the desire for death or the decreased will to continue living.^{17–19} Studies examining the experience of caring for brain tumor patients specifically indicate that existential concerns comprise a considerable domain of unmet need, more so than among other informal caregivers.²⁰ Caregivers of patients with brain tumors commonly struggle with the following: (i) guilt regarding their responsibility to care for

Received 27 August 2015

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themselves in addition to meeting the patient's needs²¹; (ii) changes in their sense of identity²²; (iii) changes in and loss of their relationship with the patient because of the effect of brain tumors on patients' personalities⁹; and (iv) fears regarding the impending death and need to continue life after the patient has deceased.²² Importantly, these caregivers report turning to spirituality to find meaning and purpose amid the challenges of caregiving,²³⁻²⁵ and having a strong desire to receive palliative care services that attend to these existential needs.²⁶ The development of targeted psychotherapeutic interventions for existential distress among informal caregivers of patients with brain tumors is therefore needed.¹⁶ The purpose of this systematic review was to synthesize the literature on spiritual and existential burden. Such a synthesis will inform the development of a tailored psychotherapeutic intervention for this vulnerable population.

Methods

Systematic literature searches following PRISMA guidelines²⁷ were conducted (June 12, 2014) in 6 databases for references written in all languages with no specified sex, age group, or time range included. The databases searched were: MEDLINE (via PubMed), Embase, The Cochrane Library, Web of Science, PsycINFO (via OVID), and CINAHL. For the following databases, both controlled vocabulary and text words were used in the development of the search strategies: PubMed, Embase, The Cochrane Library, PsycINFO, and CINAHL. The Web of Science database does not employ a controlled vocabulary, so this was searched using only text words. All search results were combined in a bibliographic management tool (EndNote) and duplicates were eliminated both electronically—using the capabilities in EndNote—and manually, to detect duplicates missed by the software.

The search strategy included 3 concepts linked together with the AND operator: (i) cancer and brain tumor terms including neoplasms, tumors, gliomas, brain neoplasms; (ii) caregiver terms including spouses, partners, and family; and (iii) unique needs and burden terms including mental health, anxiety, mood, demands, isolation, adaptation, unmet needs, and emotional burden. Controlled vocabularies were searched for and included in the search strategy for the searches in PubMed, Embase, Cochrane, PsycINFO, and CINAHL. The Web of Science search combined the keywords of all three concepts. The search filter of human-only studies was employed in PubMed, Embase, Web of Science, and CINAHL. In Cochrane and PsycINFO, nonhuman species were triaged during the abstract and full text review phases. For a complete list of MeSH and keyword terms used, please refer to the search strategy accompanying this paper.

The titles and abstracts of 10 772 articles were retrieved. Case studies, letters to the editor, abstracts, opinion pieces, and articles written in languages other than English were excluded. Of the remaining articles, 245 titles and abstracts were evaluated for study inclusion. During the article review phase, data were abstracted by a primary reviewer who completed a data abstraction form, and then a secondary reviewer checked the primary review for accuracy and completeness. Two reviewers independently assessed the study's eligibility for inclusion, and unresolved disagreements between reviewers were adjudicated by a third reviewer in the group. The PRISMA flow diagram of this search strategy is presented in Fig. 1.

Results

Thirty-five articles met inclusion criteria for this systematic review (see Table 1). Of the articles included in the review, 2 were retrospective studies, 27 were prospective studies, and 6 were systematic reviews. Articles were divided according to the existential themes addressed.

Shifting Identity and Roles

Twenty-two articles addressed the theme of informal caregivers' shifting and unstable sense of identity and of their role in relation to the patient as a source of existential distress. These studies highlighted how, even over the course of days, primary self-identification became overwritten by that of providing care for the patient.²⁸⁻³² The shift of identity is accelerated due to the patient's dynamic neurologic changes, and one review of the impact of a brain tumor on informal caregivers highlighted their incredulity at the pace and magnitude of this shift.³³ For example, McConigley's semi-structured interviews revealed role change occurring almost immediately in the illness, not just from partner to informal caregiver, but in other specific roles, such as from "the driver" to "the driven."³¹ Another qualitative study of 10 informal caregivers of patients with brain tumors suggested that role changes are particularly prominent among spouses, a theme echoed by other studies in this review.^{9,34} For example, in their qualitative study, Strang and Strang found that informal caregiver spouses describe an immediate disintegration of the parity in their marital relationship as a result of the patient's neurologic changes, and that this is an exquisitely painful dimension of the disease to assimilate.³⁴ This disruption of relationship roles and identities is compounded by loss of employment and income and changes in other important social and familial relationships.^{29,35,36}

Other studies emphasized the brain tumor as a disease of the family with impact upon a family's collective identity, not only that of the primary informal caregiver.³⁷ For example, Leavitt et al identified "family life changes" as a critical subtheme that emerged from qualitative interviews.³² After diagnosis, the network of roles within a family is immediately disrupted, with parents caring for adult children, or grandchildren and spouses becoming responsible for family members for whom they previously were not. The transcripts revealed that this upending of longstanding familial relationships is a source of profound distress.

Finally, Passik et al highlighted the impact of changes in the patient's cognition and personality as a result of disease on the identity of the informal caregiver.³⁸ Specifically, informal caregivers reflected upon aspects of themselves that were uniquely elicited by the patient and their relationship but that are now lost in the setting of the patient's deterioration. In this way, the patient's decline leads to a diminished sense of self for the informal caregiver, and this is experienced as a significant loss.

Isolation

Sixteen studies highlighted the experience of profound isolation as another domain of existential distress (see Table 2). For example, one qualitative study with 10 informal caregivers of brain tumor patients described informal caregivers concealing their fears and anxiety about disease progression from other family members, likely out of desire to protect others but at the cost

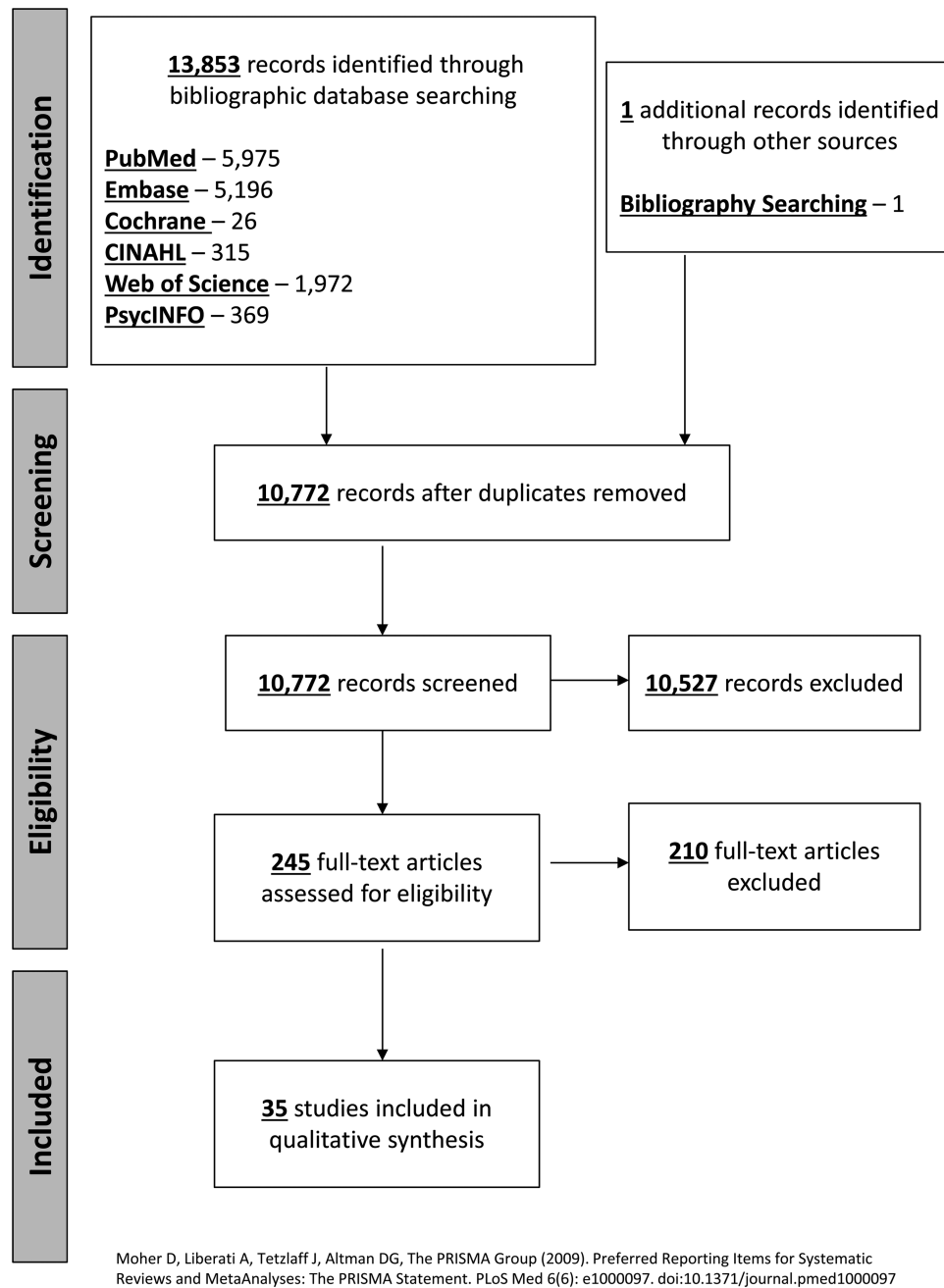


Fig. 1. PRISMA flow diagram.

of their own well-being.³⁹ This isolation is, ironically, compounded by the caregiver's having to field the grief and sadness of other family members and friends but without having someone to turn to for their own support. Another qualitative study indicated that isolation may be exacerbated in part by friends and family withdrawing from the patient in the face of progressive changes in his or her personality and behavior. This leads to the informal caregiver's social isolation, as well as further decreased psychological and logistic support as the disease progresses, and it is precisely then when this support is most critical.¹⁰

Many of the studies reviewed also highlighted isolation from professional support networks.^{10,34,40} For example, the interviews

conducted by Strang et al revealed that informal caregivers feel estranged and isolated from medical professionals who avoid discussing how the patient's illness is impacting them and their family.³⁴ Furthermore, these caregivers made a direct link between this feeling of isolation, from the support of even their health care providers, and their symptoms of depression. Indeed, in the only quantitative study reviewed in this section, unmet supportive care needs (as assessed by the Supportive Care Needs Survey, SCNS-34) were indeed associated with significantly higher anxious and depressive symptomatology (via the HADS).⁴¹

Such isolation and lack of professional support was reported even among informal caregivers currently in receipt of palliative

Table 1. Key characteristics of articles reviewed

Article	Author	Country	Participants	Disease Trajectory	Study Design		Scales Used
					Qualitative	Quantitative	
Prospective studies							
A family's perspective on living with a highly malignant brain tumor ⁴²	A. K. Wideheim, et al.	Sweden	3 Patients and 8 Family Members	≤6 mo from diagnosis	+	-	
Being the next of kin of a person with a low-grade glioma ⁴⁰	T. Edvardsson and G. Ahlstrom	Sweden	28 Unspecified ICs	Unspecified	+	+	Quantitatively coded semi-structured interviews
Brain tumor as a threat to life and personality: The spouse's perspective ⁹	P. Salander	Sweden	24 Unspecified ICs	Unspecified	+	-	
Care and support needs of patients and carers early post-discharge following treatment for non-malignant brain tumour: Establishing a new reality ²⁸	P. Cornwell et al.	UK	5 Unspecified ICs	≤3 mo from diagnosis	+	-	
Caring for loved ones with a brain tumour ⁴⁴	C. S. Poon	Canada	14 Unspecified ICs	Unspecified	+	+	Caring Burden Scale, The Home Caregiver Needs Survey, Caregiver Reaction Assessment, The Affects Balance Scale, Caregiving Competence Scale
Caring for someone with high-grade glioma: A time of rapid change for caregivers ³¹	R. McConigley, et al.	Australia	21 Unspecified ICs	Unspecified	+	-	
Caring for the brain tumor patient: Family caregiver burden and unmet needs ³⁷	J. R. Schubart, M. B. Kinzie and E. Farace	USA	25 Unspecified ICs	Multiple timepoints throughout the disease trajectory	+	-	
Changes in caregiver perceptions over time in response to providing care for a loved one with a primary malignant brain tumor ³⁹	A. Hirick, et al.	USA	10 Unspecified ICs	≤1 mo from diagnosis	+	-	
Death anxiety in brain tumour patients and their spouses ⁵⁰	S. Adelbratt and P. Strang	Sweden	20 Patients and 15 Family Members	Unspecified	+	-	
Evaluation of an online peer support network for fathers of a child with a brain tumor ³⁵	D. B. Nicholas, et al.	Canada	21 Fathers	6 mo to 5 y from diagnosis	+	+	Coping Health Inventory for Parents, Multi-Dimensional Support Scale, Mean of Illness Questionnaire

Existential support in brain tumour patients and their spouses ³⁴	S. Strang, et al.	Sweden	20 Patients and 16 Unspecified ICs	Unspecified	+	+	-	
Finding the right kind of support: A study of carers of those with a primary malignant brain tumour ¹⁰	A. Arber, et al.	England	22 Unspecified ICs	Unspecified	+	+	-	
Forgotten voices: Lessons from bereaved caregivers of persons with a brain tumour ⁴⁵	P. R. Sherwood, et al.	Germany	43 Unspecified ICs	Post-mortem	+	+	-	
Identifying family members who are likely to perceive benefits from providing care to a person with a primary malignant brain tumor ⁸¹	A. Newberry, et al.	USA	89 Patients and Unspecified ICs	2 timepoints \leq 4 mo of diagnosis	-	-	+	Positive Aspects of Caregiving
Informal caregiving in patients with brain tumors ⁵²	M. Whisenant	USA	20 Patients and Unspecified ICs	Unspecified	+	+	-	
"Now we have to cope with the rest of our lives." Existential issues related to parenting a child surviving a brain tumour ²⁹	U. Forinder and A. Lindahl Norberg	Sweden	11 Parents	Survivorship	+	+	-	
Palliative care of children with brain tumors: A parental perspective ³⁶	S. Zelcer, et al.	England	25 Parents	Post-mortem	+	+	-	
Psychosocial care for the caregivers of primary malignant brain tumor patients ⁴⁷	M. Wasner, P. Paal and G. D. Borasio	Germany	27 Patients and Unspecified ICs	Unspecified	+	+	+	Mini Mental Status Exam, Hospital Anxiety and Depression Scale, Schedule for the Evaluation of Individual Quality of Life-Direct Weighting, Burden Scale for Family Caregivers, Numeric 0-100 QOL scale
Sleep loss and its effects on health of family caregivers of individuals with primary malignant brain tumors ⁵³	J. D. Pawl, et al.	USA	133 Unspecified ICs	\leq 2 mo of diagnosis	+	+	+	Interpersonal Support Evaluation List, Mastery Scale, Goldberg Adjective Scale, Marital Adjustment Scale, Neurobehavioral Cognitive Status Examination, Medical Outcomes Study 35-Item Short Form (SF-36), Positive Aspects of Caregiving Scale
Social, psychological and existential well-being in patients with glioma and their caregivers: A qualitative study ¹⁴	D. Cavers, et al.	UK	26 Patients and 23 Unspecified ICs	4 timepoints \leq 6 mo from diagnosis	+	+	-	

Continued

Table 1. Continued

Article	Author	Country	Participants	Disease Trajectory	Study Design		Scales Used
					Qualitative	Quantitative	
Spiritual thoughts, coping and "sense of coherence" in brain tumour patients and their spouses ⁴⁶	S. Strang and P. Strang	Sweden	20 Patients and Unspecified ICs	Unspecified	+	-	
The attitudes of brain cancer patients and their caregivers towards death and dying: a qualitative study ²⁶	N. Lipsman, et al.	Canada	7 Patients and 22 Unspecified ICs	Unspecified	+	-	
The brain tumor experience and quality of life: A qualitative study ⁴³	S. Fox and C. Lantz	USA	23 Patients and 21 Spouses	Unspecified	+	-	
The experience of mothers caring for a child with a brain tumour ⁴⁸	R. I. Shortman, et al.	Europe	6 Mothers	Unspecified	+	+	Impact on Families Scale
The quality of life of patients with malignant gliomas and their caregivers ⁵¹	C. Munoz, et al.	USA	20 Patients 17 Unspecified ICs	Prior to tumor recurrence	+	+	Mini Mental Status Exam, Functional Assessment of Cancer Therapy-Brain, Quality of Life Scale/ Cancer Patient Cancer Survival, Caregiver Quality of Life Cancer Supportive Care Needs Survey (SCNS-34), Hospital Anxiety and Depression Scale, Supportive Care Needs Survey-Short Form 34, Supportive Care Needs Survey-Partners & Caregivers 44, Functional Assessment of Cancer Therapy-General, Functional Assessment of Cancer Therapy-General Population, FACT-Br
Unmet supportive care needs and interest in services among patients with a brain tumour and their carers ⁴¹	M. Janda, et al.	Australia	75 patients and 70 Unspecified ICs	Unspecified	-	+	
When a family member has a malignant brain tumor: The caregiver perspective ³⁰	C. Schmer et al.	USA	10 Unspecified ICs	≤6 mo from diagnosis	+	-	
Retrospective Studies							
Brain tumor support group: Content themes and mechanisms of support ³²	M. B. Leavitt, S. A. Lamb and B. S. Voss	USA	37 Unspecified ICs	Unspecified	+	-	
Together and apart: Providing psychosocial support for patients and families living with brain tumors ²¹	C. Kanter et al.	Canada	137 Patients and 238 Unspecified ICs	Unspecified	+	+	Quantified themes from transcribed group support meetings

Table 2. Existential theme

Existential theme	Study Design	Key Findings
Identity and Role Change	Qualitative 21 Quantitative 7	<ul style="list-style-type: none"> • ICs quickly become enmeshed with the patient and lose a sense of their own identity. • The patient’s ongoing loss of cognitive function and unique personality leads to dominance of the IC’s role and loss of reciprocity in the relationship. This, too, impacts ICs’ sense of identity.
Isolation	Qualitative 10 Quantitative 2	<ul style="list-style-type: none"> • ICs become rapidly isolated as patients’ cognitive and personality changes lead to a deterioration in the IC-patient relationship. Isolation increases over time. • Isolation and loneliness are exacerbated when medical professionals avoid discussing how the disease impacts the family and the IC-patient relationship.
Responsibility and Guilt	Qualitative 18 Quantitative 6	<ul style="list-style-type: none"> • Responsibilities of ICs of brain tumor patients are greater than those of other cancer patient ICs due to patients’ significant limitations. • Paradoxical experience of complete responsibility for patient yet feeling complete powerlessness. • ICs experience guilt when they acknowledge their own limitations and needs; as a result, their self-care appears to be extraordinarily poor.
Death	Qualitative 16 Quantitative 3	<ul style="list-style-type: none"> • Death anxiety is experienced as “existential crisis” for ICs. • Loss of personality and cognitive capacity are experienced as ongoing and repeated “mini-deaths.” • Medical professionals are generally avoidant of EOL discussions, while ICs desire information to manage expectations.
Growth, Meaning and Purpose	Qualitative 17 Quantitative 7	<ul style="list-style-type: none"> • ICs experience feelings of increased closeness, love, and admiration for the patient. • Providing care allows ICs to derive meaning, purpose, and personal growth from their experience. • Providing care is seen as an opportunity to reframe priorities and values, and to find inner strength and courage.
Spirituality and Religion	Qualitative 12 Quantitative 7	<ul style="list-style-type: none"> • Spirituality and religion facilitate coping and meaning-making and are sources of comfort, hope, optimism and strength. • Attention to spiritual and religious beliefs are identified as a critical unmet need among ICs. • Spirituality and religion are often evoked when asking, “Why did this happen?”

IC: informal caregiver.

Table 3. Caring for a child with a brain tumor

Area of interest	Study Design	Key Findings
The Child with a Brain Tumor	Qualitative 5 Quantitative 2	<ul style="list-style-type: none"> • A significant challenge for parents is facing the disconnect between the perceived harshness of instilling pain/discomfort associated with treatment vs the protective instinct of parenthood. • The brain tumor creates an even larger gap in authority than naturally exists between parent and child.

patient also emerged in narratives of mothers of children with brain tumors.⁴⁸ Guilt was also identified as resulting from losing patience with the patient⁴⁵ and when trying to maintain one’s own life and meeting one’s own needs while providing care.²¹

Death Anxiety

Nineteen of the reviewed articles highlighted the existential theme of informal caregivers’ anxiety regarding patients’ inevitable death. Several qualitative studies suggested that this fear is uniquely intense and inescapable in the context of brain tumors,^{22,49} in part because the patient’s progressive neurologic and behavioral deterioration are experienced as relentless reminders of what the future holds.⁵⁰ One qualitative study suggested that death anxiety is an “all-consuming” preoccupation for informal caregivers from the time of diagnosis,⁴² and another indicated that this anxiety is one that “shakes the foundation of

their lives and family.”³⁴ Adelbratt et al performed a qualitative study of 15 informal caregivers, focusing specifically on the experience of death anxiety, demonstrating the common experience of “trigger phenomena,” referring to the fact that witnessing a minor symptom (eg, headache), or even being in the health care setting, can by association precipitate death anxiety.⁵⁰

Several studies indicated that support for informal caregivers’ death anxiety is an unmet need and an opportunity for improvement in medical and psychosocial care. For example, in a qualitative study by Fox et al, 21 informal caregivers of brain tumor patients reported that discussing the patient’s death with health care providers would have ameliorated grief and anxiety but such discussions rarely took place.⁴³ Rather than candidly discussing death anxiety, health providers emphasized a “take one day at a time” approach, which was perceived as avoidant of acknowledging the undeniable future and therefore unsupportive.⁴² Similarly, another qualitative study of 16 informal caregivers

highlighted that physicians were frequently viewed as retreating from discussing death anxiety into focusing on technical medical factors, and that this was felt as a failure of comprehensive care.³⁴ One study of support groups for patients and informal caregivers suggested that therapeutic interventions should take place without the patient present to allow informal caregivers to explore their fears surrounding the patients' disease more fully.²¹

Deriving Meaning and Personal Growth

In 23 studies, a favorable dimension of the existential experience emerged: the opportunity for personal growth and deriving meaning through providing care for the patient. Alongside the isolation, anxiety, and guilt described above, informal caregivers reported an intensification of their love and admiration for the patient, and in 3 qualitative studies, described the illness as a catalyst for increased connectedness with their loved one, especially in earlier phases of the disease.^{30,39,51} The informal caregivers interviewed in Lipsman et al described the rewarding feeling of discovering resilience and inner strength despite the adversity of the disease.²⁶ In a qualitative study of 20 informal caregivers, Whisenant et al highlighted the sense of growth felt through the knowledge and skills gained in caregiving, and the increased sense of purpose derived from providing care.⁵² Similarly, a mixed methods study by Wasner et al of 27 informal caregivers highlighted the meaning derived from taking responsibility for the patient's well-being and in providing them with the best care. Awareness and affirmation of meaning-making and purpose appeared to be particularly facilitated through group psychotherapy.⁴⁷

Shifting priorities and values emerged as a critical theme. Specifically, providing care for a patient with a brain tumor afforded individuals the opportunity to reappraise their values and priorities in a lasting and meaningful way. One expression of this new perspective was a caregiver's learning to "value every day" in the face of the patient's limited survival, an appreciation that was generalized beyond the patient's illness into the caregiver's overall worldview.⁵² Likewise, informal caregivers observed that this experience highlighted what was most important to them and elements of their lives for which they were thankful, despite the loss they were experiencing.³⁵

Spirituality and Religion

Spirituality and religion were examined in 15 studies reviewed. Several studies identified spirituality as an important component of quality of life.^{43,53} Indeed, Pawl et al found that spiritual well-being, as measured by the Functional Assessment of Chronic Illness Therapy- Spiritual Well-Being (FACIT-Sp), was positively correlated with quality of life in a sample of 133 informal caregivers surveyed within 2 months of their loved one's diagnosis.⁵³

While traditional religious beliefs were not clearly distinguished by most studies from spirituality, spirituality overall was identified as one of the greatest areas of need⁴⁴ and an important source of coping for many informal caregivers of patients with brain tumors.^{21,26,36,51} Spirituality was identified as helping to find purpose and meaning in the changed reality brought about by their loved one's illness.^{26,46} Hope and inner strength emerged for some through religious faith and related activities, such as prayer, blessing rituals, and church attendance,^{40,44,51} but for others through more secular spiritual approaches,

including belief in a power beyond oneself, life after death, destiny, goodness of life, and grandness of nature.^{43,46}

Religious beliefs and/or spirituality were identified as a predominantly positive element of the coping process,²⁶ with one qualitative analysis of a focus group discussion indicating that comments about spirituality were 88% positive.⁵¹ One study suggested, however, that spirituality also had the potential to increase a sense of meaninglessness resulting from the existential struggle of the perceived injustice of the patient's illness (eg, "Why did this happen to a good person?"), even for those without a specific religious tradition.⁴⁶

The Experience of Parenting a Patient with a Brain Tumor

In addition to the 6 above-mentioned existential themes, the review highlighted the unique existential themes that arise for parents of patients with a brain tumor (See Table 3). Parents of pediatric brain tumor patients are a subset of informal caregivers who face a unique set of existential concerns. Five studies focused on informal caregivers of children with brain tumors. Fear of responsibility for the child's disease emerged and many parents believed that others could not understand the depth of pain and sadness they felt as a result of their child's illness.³⁵ Interestingly, one qualitative study found that there was less frequent citing of heartache and sadness among informal caregivers whose child's disease had a medium or high impact on family life, based on the Impact on Families Scale (IFS). The IFS measures the extent to which a chronic childhood illness impacts the family in terms of financial burden, restrictions in social life and decreased interactions with significant others and other family members, subjective distress, as well as positive mastery and coping. It is possible that this result was due to increased cohesion and acceptance in the families examined.⁴⁸

Several qualitative studies reported that parents felt conflicted by having to meet both their child's medical and emotional needs.³⁶ Additionally, responsibilities outside of caregiving, such as employment, financial stressors, and care of other children challenged parents' ability to spend quality time with their sick child³⁶ and introduced tensions in other familial relationships.^{29,35} Due to serious developmental, cognitive, and psychosocial treatment sequelae, parents of children in remission from a brain tumor were concerned about potential obstacles to their child's independence as an adult and experienced additional burden by having to arrange school accommodations for their child.²⁹ Two studies reported that parents found social support, such as family⁴⁸ and peer support groups,³⁵ helpful in coping with the challenges of caring for their sick child.

Forinder et al suggested that some parents struggled to address their child's own existential reflections and resulting anxiety and depression,²⁹ while Zelcer et al reported that several children accepted their disease before their parents, and took responsibility for guiding their family to acceptance.³⁶ Some children's lack of understanding of the gravity of their disease and potential resulting conversations about death were a significant source of parental distress, and many parents experienced guilt if they were unable to speak to their children about death.³⁶

Discussion

The goal of this systematic review was to synthesize the literature on existential distress experienced by informal caregivers of

patients with brain tumors. Despite only 15 studies identifying existential distress of any kind as a key outcome of interest, six existential themes emerged in the 35 studies reviewed: identity, isolation, responsibility and guilt, death anxiety, deriving meaning and personal growth, and spirituality and religion. Additionally, the review highlighted the unique existential themes that arise in the setting of parenting a patient with a brain tumor.

Informal caregivers experience a rapid shift in identity at pace with changes in their loved one's health and neurologic function.^{28,31,38} It is also likely that the life-threatening nature of the brain tumor and the unique experience of living with the knowledge of the patient's limited lifespan contributes to disintegration of parity in the patient-caregiver relationship, especially partnered/marital relationships. While intimacy and sexuality were not addressed specifically in the articles reviewed, our clinical experience is that these domains of the relationship are heavily compromised in the brain tumor context. In cancer generally, sexuality and intimacy suffer in conjunction with shifts in identity and in interpersonal bonds,⁵⁴ but this requires more focused research in neuro-oncology. We propose that health care providers proactively acknowledge the painful reality of shifting identity in its many manifestations, and that therapeutic interventions should promote adaptive strategies for informal caregivers of brain tumor patients to remain grounded to the extent possible in their sense of themselves.

Isolation, in many dimensions, emerged in this review as a fundamental source of sadness for informal caregivers of patients with brain tumors.^{10,34} This isolation is in relation to the patient because of her or his cognitive and personality changes, and also from friends and social support.³⁹ It is for these reasons that both peer and professional support is so critical to informal caregivers' well-being, and social support should be evaluated and enhanced from the point of diagnosis. Medical professionals can mitigate isolation by acknowledging the presence of informal caregivers during medical appointments, requesting their feedback and participation during the medical decision-making process, and by proactively asking how they are coping and acknowledging their important role.^{10,48,55} Additionally, support groups that specifically promote shared experience among informal caregivers of patients with brain tumors will help them to feel validated, more understood, and less isolated.³⁵

Intermixed responsibility and guilt emerged as common existential themes. The narratives reviewed highlighted informal caregivers taking full responsibility for their loved ones' well-beings, with the patient's neurologic impairment rendering this responsibility particularly heavy.⁴² Taking full responsibility was also described as a method to mitigate informal caregivers' guilt—guilt that they cannot cure their loved one's cancer or do more for them.³⁷ Not surprisingly, guilt as a result of taking responsibility for their lives—through self care, for example—was also a common experience. While previous studies have emphasized the need for rapid delivery of psychoeducation early on in the caregiving trajectory,⁵⁶ psychotherapeutic interventions that target guilt and facilitate informal caregivers taking responsibility for their lives despite the pull to devote all their energy to the patient are needed to enhance their resilience.

Not surprisingly, anxiety about the patient's inevitable death is a source of intense distress for informal caregivers throughout the illness trajectory.^{22,49} This anxiety can be triggered or intensified by seemingly innocuous events or symptoms, and furthermore it

is challenging for informal caregivers to discuss these feelings in the presence of the patient. A growing body of literature indicates that having accurate prognostic awareness is not associated with poor psychosocial outcomes, but that instead, the reverse is true.⁵⁷⁻⁶¹ As such, though completely unavoidable, death anxiety may be mitigated through physicians' more open communication with caregivers, especially at the point where they become the proxy for patients, whose cognitive and personality changes limit their ability to advocate for themselves. Moreover, providers can address death anxiety through independent conversations with informal caregivers, ideally in the event of "triggers" described above, when worry about a symptom appears disproportionate. These ostensibly minor events may serve as a juncture for health providers to acknowledge and support informal caregivers more comprehensively.

Despite the challenges and distress, the caregiving experience is also an opportunity for meaning-making and growth, which may buffer against burden.⁶² The addition of meaning-based coping⁶² to Lazarus and Folkman's original model of stress and coping was based on the reports of caregivers of men with AIDS,⁶³ which highlighted their experience of suffering but also of making meaning in the context of providing care. Indeed, a growing number of studies have documented the experience of posttraumatic growth^{64,65} as a result of stressful experiences, and finding meaning has been proposed as one mechanism through which positive outcomes can be achieved.⁶⁶⁻⁷² The studies reviewed here highlighted the concurrence of meaning and suffering, and the caregiving experience as one that enhanced caregivers' sense of values,^{26,47} as well as clarified what was important to them and the elements of their lives for which they were thankful, despite the multiple losses they were experiencing.³⁵ The studies reviewed also identified spirituality and religion as a mechanism through which such meaning-making occurs. While studies highlighted the struggle of many informal caregivers to understand the existential questions of why this happened, others highlighted that the expression of love and care for the patient with the brain tumor led to increased spirituality.⁵¹

Finally, this review highlighted the unique existential concerns of parents of children with brain tumors: the threat of losing their child, uncertainty about the present and the future, and feelings of loss more globally.²⁹ Shortman et al note that it is essential for clinicians to make efforts to understand the experience of parents in order to provide them with effective support and empower them to facilitate adaptation to the child's illness and consequences.⁴⁸ Moreover, the studies reviewed identified childhood cancer as a catalyst for children to mature and become more thoughtful. Therefore interventions for children and adolescents with brain tumors should also consider the possibility of meaning-making and growth.

Limitations

Limitations of this review must be acknowledged. First, spiritual and existential themes were not the *a priori* concern of many of the articles reviewed; rather they were gleaned retrospectively and therefore they were not examined in a manner dedicated or specific to these constructs. Second, the prevailing methodology in the articles reviewed is qualitative, and therefore we cannot strongly describe a quantifiable degree of existential distress or a demonstrable association between distress and constructs such as quality of life or caregiver burden. Despite these

limitations, it is compelling that these themes emerged recurrently and consistently in qualitative studies, albeit through a *post hoc* analysis. Therefore, the results strongly suggest that systematic and prospective study is needed. Finally, our exclusion of studies published in languages other than English may have biased the results, though the studies were conducted in a variety of countries and hence some heterogeneity of contexts is represented.

Conclusions and Future Directions

Existential distress is a devastating source of burden experienced by informal caregivers of patients with brain tumors. As such, interventions that mitigate existential suffering in this vulnerable group of caregivers are essential. While interventions have been developed to target caregiver burden generally, those addressing existential distress among informal caregivers of patients with cancer are limited.¹⁶ Our group has developed Meaning-Centered Psychotherapy (MCP),⁷³⁻⁷⁵ an existential therapeutic model originally developed to ameliorate suffering, guilt, and death anxiety among patients with advanced cancer. MCP has been adapted for cancer caregivers generally⁷⁶ and randomized controlled trials are currently underway to evaluate the preliminary efficacy of MCP-C in decreasing burden and enhancing meaning-making among caregivers of patients with any cancer type. Based on the results of this review, the adaptation of MCP-C for the unique experience of informal caregivers of patients with brain tumors is one avenue of intervention development supported by evidence in the oncology context.

Additionally, interventions that incorporate elements of psychoeducation, problem-solving, and communication skills training are also needed across the caregiving trajectory. The benefits of all psychotherapeutic interventions will likely be greatest when delivered early in the caregiving trajectory, as a result of the often rapid decline in multiple domains of functioning among patients. In the specific context of brain tumors, in which informal caregivers may be limited in their ability to travel because of caring for the patient, interventions by way of telephone or Internet-based platforms may be especially useful.^{77,78} Finally, since few studies captured in this review focused specifically on evaluating existential distress among informal caregivers of patients with brain tumors, and the majority included were qualitative studies in which existential themes emerged in the discussion of caregiver burden generally, there is a critical need for rigorous, prospective studies to evaluate and define the nature of existential distress among this vulnerable group of caregivers.

Funding

There is no funding source to disclose.

Conflict of interest statement. None declared.

References

1. National Alliance for Caregiving. *Caregiving in the U.S.* 2009. 1–79.
2. Biegel DE, Sales E, Schulz R. *Family caregiving in chronic illness: Alzheimer's disease, cancer, heart disease, mental illness, and stroke.* Thousand Oaks, CA, US: Sage Publications, Inc; 1991.

3. Dumont S, Turgeon J, Allard P, Gagnon P, Charbonneau C, Vézina L. Caring for a loved one with advanced cancer: Determinants of psychological distress in family caregivers. *J Palliat Med.* 2006;9(4): 912–921.
4. Kissane DW, Bloch S, Burns WI, McKenzie D, Posterino M. Psychological morbidity in the families of patients with cancer. *Psychooncology.* 1994;3(1):47–56.
5. Christakis NA, Allison PD. Mortality after the hospitalization of a spouse. *N Engl J Med.* 2006;354(7):719–730.
6. 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.* 2009;27(18):2909–2915.
7. Given B, Kozachik S, Collins C, DeVoss D, Given CW. Caregiver role strain. In: Maas M, Buckwalter K, Hardy M, eds. *Nursing Care of Older Adult Diagnoses: Outcome and Interventions.* St. Louis, MO: Mosby; 2001:679–695.
8. Given B, Wyatt G, Given C, et al. Burden and depression among caregivers of patients with cancer at the end of life. *Oncol Nurs Forum.* 2004;31(6):1105–1117.
9. Salander P. Brain tumor as a threat to life and personality. *J Psychosoc Oncol.* 1996;14(3):1–18.
10. 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 of Oncol Nurs.* 2013;17:52–58.
11. Khalili Y. Ongoing transitions: The impact of a malignant brain tumour on patient and family. *AXON.* 2007;28(3):5–13.
12. Sherwood PR, Given BA, Given CW, et al. Predictors of distress in caregivers of persons with a primary malignant brain tumor. *Res Nurs Health.* 2006;29(2):105–120.
13. Applebaum AJ, Farran CJ, Marziliano AM, Pasternak AR, Breitbart W. Preliminary study of themes of meaning and psychosocial service use among informal cancer caregivers. *Palliat Support Care.* 2014; 12(02):139–148.
14. Cavers D, Hacking B, Erridge S, Kendall M, Morris P, Murray S. Social, psychological and existential well-being in patients with glioma and their caregivers: A qualitative study. *CMAJ.* 2012;184(7):373–383.
15. Deshields TL, Applebaum AJ. The time is now: Assessing and addressing the needs of cancer caregivers. *Cancer.* 2015;121(9): 1344–1346.
16. Applebaum AJ, Breitbart W. Care for the cancer caregiver: A systematic review. *Palliat Support Care.* 2013;11(3):231–252.
17. Chochinov HM, Krisjanson LJ, Hack TF, Hassard T, McClement S, Harlos M. Dignity in the terminally ill: Revisited. *J Palliat Med.* 2006; 9(3):666–672.
18. Henery N. Constructions of spirituality in contemporary nursing theory. *J Adv Nurs.* 2003;42(6):550–557.
19. Henoeh I, Danielson E. Existential concerns among patients with cancer and interventions to meet them: An integrative literature review. *Psychooncology.* 2009;18(3):225–236.
20. Catt S, Chalmers A, Fallowfield L. Psychosocial and supportive-care needs in high-grade glioma. *Lancet Oncol.* 2008;9:884–891.
21. Kanter C, D'Agostino NM, Daniels M, Stone A, Edelstein K. Together and apart: Providing psychosocial support for patients and families living with brain tumors. *Support Care Cancer.* 2014;22(1):43–52.
22. Ford E, Catt S, Chalmers A, Fallowfield L. Systematic review of supportive care needs in patients with primary malignant brain tumors. *Neuro Oncol.* 2012;14(4):392–404.
23. Pesut B. A conversation on diverse perspectives of spirituality in nursing literature. *Nurs Philos.* 2008;9(2):98–109.

24. Bingham V, Habermann B. The influence of spirituality on family management of Parkinson's disease. *J Neurosic Nurs*. 2006;38(6):422–427.
25. 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*. 2013;40(3):E119–E125.
26. Lipsman N, Skanda A, Kimmelman J, Bernstein M. The attitudes of brain cancer patients and their caregivers towards death and dying: A qualitative study. *BMC Palliat Care*. 2007;6:7.
27. Moher D, Liberati A, Tetzlaff J, Altman DG. Preferred reporting items for systematic reviews and meta-analyses: the PRISMA statement. *PLoS medicine*. 2009;6(7):e1000097.
28. 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*. 2012;20(10):2595–2610.
29. Forinder U, Lindahl Norberg A. "Now we have to cope with the rest of our lives". Existential issues related to parenting a child surviving a brain tumour. *Support Care Cancer*. 2010;18(5):543–551.
30. Schmer C, Ward-Smith P, Latham S, Salacz M. When a family member has a malignant brain tumor: The caregiver perspective. *J Neurosci Nurs*. 2008;40(2):78–84.
31. McConigley R, Halkett G, Lobb E, Nowak A. Caring for someone with high-grade glioma: A time of rapid change for caregivers. *Palliat Med*. 2010;24(5):473–479.
32. Leavitt MB, Lamb SA, Voss BS. Brain tumor support group: Content themes and mechanisms of support. *Oncol Nurs Forum*. 1996;23(8):1247–1256.
33. Sterckx W, Coolbrandt A, de Casterle BD, 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*. 2013;17(1):107–117.
34. Strang S, Strang P, Ternstedt BM. Existential support in brain tumour patients and their spouses. *Support Care Cancer*. 2001;9:625–633.
35. Nicholas DB, Chahauer A, Brownstone D, Hetherington R, McNeill T, Bouffet E. Evaluation of an online peer support network for fathers of a child with a brain tumor. *Soc Work Health Care*. 2012;51(3):232–245.
36. Zelcer S, Cataudella D, Cairney AEL, Bannister SL. Palliative care of children with brain tumors: A parental perspective. *Arch Pediatr Adolesc Med*. 2010;164(3):225–230.
37. Schubart JR, Kinzie MB, Farace E. Caring for the brain tumor patient: Family caregiver burden and unmet needs. *Neuro Oncol*. 2008;10(1):61–72.
38. Passik SD, Malkin MG, Breitbart WS, Horowitz S. Psychiatric and psychosocial aspects of neurooncology. *J Psychosoc Oncol*. 1994;12(1–2):101–122.
39. 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*. 2011;38(2):149–155.
40. Edvardsson T, Ahlstrom G. Being the next of kin of a person with a low-grade glioma. *Psychooncology*. 2008;17(6):584–591.
41. 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 tumour and their carers. *Patient Educ Couns*. 2008;71(2):251–258.
42. Wideheim AK, Edvardsson T, Pahlson A, Ahlstrom G. A family's perspective on living with a highly malignant brain tumor. *Cancer Nurs*. 2002;25(3):236–244.
43. Fox S, Lantz C. The brain tumor experience and quality of life: a qualitative study. *J Neurosci Nurs*. 1998;30(4):245–252.
44. Poon CS. Caregiving for loved ones with a brain tumour. Dissertation Abstracts International: Section B: The Sciences and Engineering. 2005. <http://ovidsp.ovid.com/ovidweb.cgi?T=JS&PAGE=reference&D=psyc4&NEWS=N&AN=2005-99024-110>. Accessed August, 2014.
45. Sherwood PR, Given BA, Doorenbos AZ, Given CW. Forgotten voices: Lessons from bereaved caregivers of persons with a brain tumour. *Int J Palliat Nurs*. 2004;10(2):67–75.
46. Strang S, Strang P. Spiritual thoughts, coping and 'sense of coherence' in brain tumour patients and their spouses. *Palliat Med*. 2001;15(2):127–134.
47. Wasner M, Paal P, Borasio GD. Psychosocial care for the caregivers of primary malignant brain tumor patients. *J Social Work End Life Palliat Care*. 2013;9(1):74–95.
48. Shortman RI, Beringer A, Penn A, Malson H, Lowis SP, Sharples PM. The experience of mothers caring for a child with a brain tumour. *Child Care Health Dev*. 2013;39(5):743–749.
49. Moore G, Collins A, Brand C, 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):141–153.
50. Adelbratt S, Strang P. Death anxiety in brain tumour patients and their spouses. *Palliat Med*. 2000;14(6):499–507.
51. Munoz C, Juarez G, Munoz ML, et al. The quality of life of patients with malignant gliomas and their caregivers. *Soc Work Health Care*. 2008;47(4):455–478.
52. Whisenant M. Informal caregiving in patients with brain tumors. *Oncol Nurs Forum*. 2011;38(5):373–381.
53. 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*. 2013;36(4):386–399.
54. Rubio-Aurioles E. The Impact of Cancer on the Partner's Sexuality. In: *Cancer and Sexual Health*. Mulhall JP, Incrocci L, Goldstein I, Rosen R, eds. Springer; 2011:383–395.
55. Lund L, Ross L, Petersen MA, Groenvold M. The interaction between informal cancer caregivers and health care professionals: A survey of caregivers' experiences of problems and unmet needs. *Support Care Cancer*. 2015;23(6):1719–1733.
56. 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*. 2013;111(3):303–311.
57. Chochinov HM, Tataryn DJ, Wilson KG, Ennis M, Lander S. Prognostic awareness and the terminally ill. *Psychosomatics*. 2000;41(6):500–504.
58. Dunn SM, Patterson PU, Butow PN, Smartt HH, McCarthy WH, Tattersall MH. Cancer by another name: A randomized trial of the effects of euphemism and uncertainty in communicating with cancer patients. *J Clin Oncol*. 1993;11(5):989–996.
59. Innes S, Payne S. Advanced cancer patients' prognostic information preferences: A review. *Palliat Med*. 2009;23(1):29–39.
60. Applebaum AJ, Kolva EA, Kulikowski JR, et al. Conceptualizing prognostic awareness in advanced cancer: A systematic review. *J Health Psychol*. 2014;19(9):1103–1119.
61. Diamond EL, Corner GW, De Rosa A, Breitbart W, Applebaum AJ. Prognostic awareness and communication of prognostic information in malignant glioma: A systematic review. *J Neurooncol*. 2014;119(2):227–234.

62. Folkman S, Chesney MA, Richards CA. Stress and coping in caregiving partners of men with AIDS. *Psychiatr Clin North Am.* 1994;17(1): 35–53.
63. Lazarus RS, Folkman S. *Stress, Appraisal, and Coping.* New York, NY: Springer Pub. Co; 1984.
64. Hudson PL, Hayman-White K, Aranda S, Kristjanson LJ. Predicting family caregiver psychosocial functioning in palliative care. *J Palliat Care.* 2006;22(3):133–140.
65. Pinquart M, Sorensen S. Differences between caregivers and noncaregivers in psychological health and physical health: A meta-analysis. *Psychol Aging.* 2003;18(2):250–267.
66. Ayres L. Narratives of family caregiving: The process of making meaning. *Res Nurs Health.* 2000;23(6):424–434.
67. Bauer-Wu S, Farran CJ. Meaning in life and psycho-spiritual functioning: A comparison of breast cancer survivors and healthy women. *J Holist Nurs.* 2005;23(2):172–190.
68. Calhoun LG, Tedeschi RG. *Handbook of Posttraumatic Growth: Research & Practice.* New York: Lawrence Erlbaum Associates Publishers; 2006.
69. Farran CJ, Keane-Hagerty E, Salloway S, Kupferer S, Wilken CS. Finding meaning: An alternative paradigm for Alzheimer's disease family caregivers. *Gerontologist.* 1991;31(4):483–489.
70. Manne S, Ostroff J, Winkel G, Goldstein L, Fox K, Grana G. Posttraumatic growth after breast cancer: Patient, partner, and couple perspectives. *Psychosom Med.* 2004;66(3):442–454.
71. Pargament KI, Ano GG. Spiritual resources and struggles in coping with medical illness. *South Med J.* 2006;99(10):1161–1162.
72. Park CL, Folkman S. Stability and change in psychosocial resources during caregiving and bereavement in partners of men with AIDS. *J Pers.* 1997;65(2):421–447.
73. Breitbart W, Rosenfeld B, Gibson C, et al. Meaning-centered group psychotherapy for patients with advanced cancer: A pilot randomized controlled trial. *Psychooncology.* 2010;19(1):21–28.
74. Breitbart W, Poppito S, Rosenfeld B, et al. Pilot randomized controlled trial of individual meaning-centered psychotherapy for patients with advanced cancer. *J Clin Oncol.* 2012;30(12):1304–1309.
75. Breitbart W, Rosenfeld B, Pessin H, Applebaum A, Kulikowski J, Lichtenthal WG. Meaning-centered group psychotherapy: An effective intervention for improving psychological well-being in patients with advanced cancer. *J Clin Oncol.* 2015;33(7):749–754.
76. Applebaum AJ, Kulikowski JR, Breitbart W. Meaning-centered psychotherapy for cancer caregivers (MCP-C): Rationale and overview. *Palliat Support Care.* 2015. Epub ahead of print.
77. Applebaum AJ, DuHamel KN, Winkel G, et al. Therapeutic alliance in telephone-administered cognitive-behavioral therapy for hematopoietic stem cell transplant survivors. *J Consult Clin Psychol.* 2012;80(5):811–816.
78. Andrews G, Davies M, Titov N. Effectiveness randomized controlled trial of face to face versus Internet cognitive behaviour therapy for social phobia. *Aust N Z J Psychiatry.* 2011;45(4):337–340.
79. Flechl B, Marosi C. Austrian patients with glioblastoma multiforme and their families: Socioeconomic aspects. *Eur Assoc Neuro Oncol Mag.* 2013;3(2):46–48.
80. Madsen K, Poulsen H. Needs for everyday life support for brain tumour patients' relatives: Systematic literature review. *Eur J Cancer Care.* 2011;20(1):33–43.
81. 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.* 2012; 39(3):E226–E232.