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Addressing Death Distress in Caregivers of Patients with Malignant Glioma

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ADDRESSING DEATH DISTRESS IN CAREGIVERS OF PATIENTS WITH MALIGNANT GLIOMA

A dissertation submitted in partial fulfillment of the requirements for the Doctorate in Philosophy of Psychology at Virginia Commonwealth University

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Acknowledgement

Let us touch the dying, the poor, the lonely and the unwanted according to the graces we have received and let us not be ashamed or slow to do the humble work.

-Mother Teresa

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Abstract

ADDRESSING EXISTENTIAL DISTRESS IN CAREGIVERS OF PATIENTS WITH MALIGNANT GLIOMA

By Kelcie Daelynn Willis, M.S.

A dissertation submitted in partial fulfillment of the requirements for the degree of Doctorate in Philosophy of Psychology at Virginia Commonwealth University.

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The field of psychosocial oncology seeks to improve the quality of life of patients and families affected by cancer. This task becomes increasingly important when there are limited, non-curative treatment options, a high probability of recurrence, and rapid functional decline, such as in the case of a malignant glioma (MG). Indeed, the diagnosis of a MG is associated with negative sequalae that often translates to higher caregiver burden. Caregivers—who must manage the functional decline of the patient, changes within the family, and a complicated medical system—often feel overwhelmed, isolated, and ill-equipped to handle these myriad responsibilities. While they also report significant depression and anxiety, caregivers specifically endorse death distress (i.e., fear, despair, or preoccupation with the patient’s inevitable mortality). Few evidenced-based interventions exist for ameliorating caregiver psychological distress, despite their stated desire for increased professional support., and none targets death distress in caregivers. Managing Cancer and Living Meaningfully (CALM) is a brief, evidence-based, supportive-expressive psychotherapy developed to address the practical and profound issues associated with advanced cancer and may benefit caregivers’ death distress. However, the suitability of CALM has yet to be evaluated in caregivers specifically. Therefore, the overarching purpose of the current study was to evaluate the suitability of CALM in caregivers of patients diagnosed with MG by collecting the foundational data necessary to enhance the intervention to meet the unique needs of this population. To achieve this goal, the current study recruited 22 bereaved caregivers to complete a focus group and subsequent questionnaires. During the focus groups, caregivers learned about the standard CALM intervention and provided feedback/recommendations to improve its suitability, feasibility, and acceptability. Their responses were qualitatively analyzed by a team of coders using thematic, deductive, latent analysis (Kappa = 0.86). The results suggest that the CALM intervention is highly relevant to the caregiving experience and might benefit caregivers emotionally, make them feel more prepared/effective, improve their communication with the patient, and provide a unique opportunity to receive specialized care specific to neuro-oncology. Potential hurdles for caregivers' participation included not having sufficient time and energy, not feeling emotionally ready, fearing they would burden the patient with their emotionality, and believing their loved one would not be emotionally or cognitively capable to participate. Participants also provided recommendations for additional content areas (e.g., caregiver burden and bereavement), how to introduce services, when to initiate treatment, when to participate as an individual versus as a dyad, and how to address logistical concerns. Although CALM might be only one of many necessary interventions to support caregivers’ needs, participants’ feedback was largely positive. Their recommendations will be valuable in developing a final, optimized CALM protocol that addresses the needs of the forgotten patient in cancer care: the caregiver.

Addressing Death Distress in Caregivers of Patients with Malignant Glioma

"All of a sudden now, in a lot of ways, you're the patient. And I think that you get sort of forgotten because once that person dies, they're moving onto something else."
-Focus Group Participant

Cancer is among one of the leading causes of death globally.[1] In the United States alone, the National Institute of Health (NIH) estimates almost 2 million individuals received a cancer diagnosis in 2020, and 600,000 ultimately died from the disease – placing cancer as the second leading cause of mortality in the United States.[1,2] Furthermore, as cancer treatments continue to advance, so do the number of cancer survivors: it is estimated that there are currently 17 million cancer survivors living in the United States alone.[2] Given the advancements in life-extending treatments and ubiquity of the disease, cancer care has evolved to be more comprehensive, such that the psychosocial aspects of the disease are receiving more attention.

The biopsychosocial model of illness challenges the traditional biomedical model by acknowledging the reciprocal relationship between social/psychological processes and health (see Figure 1).[3] Under the biopsychosocial theoretical framework exists the field of psychosocial oncology, which attempts to address the emotional, behavioral, and psychological aspects of a cancer diagnosis and its treatment – ultimately, to improve a patient's overall quality of life.[3] Psychosocial oncology emerged alongside patient-centered, holistic medical care and argues that good psychosocial care *is* quality cancer care. Systematic reviews and meta-analyses suggest that psychosocial treatment cannot only alleviate emotional distress in patients diagnosed with cancer,[4] but might also impact the patient's physical functioning as well.[5] Therefore, an interdisciplinary care team of psychiatrists, psychologists, social workers, chaplains, and other medical staff are often involved in patients' care across the cancer continuum, from diagnosis to end-of-life.[6] The role of these professionals becomes even more critical when there are limited biomedical treatment options, such as in the case of a primary brain tumor (PBT).

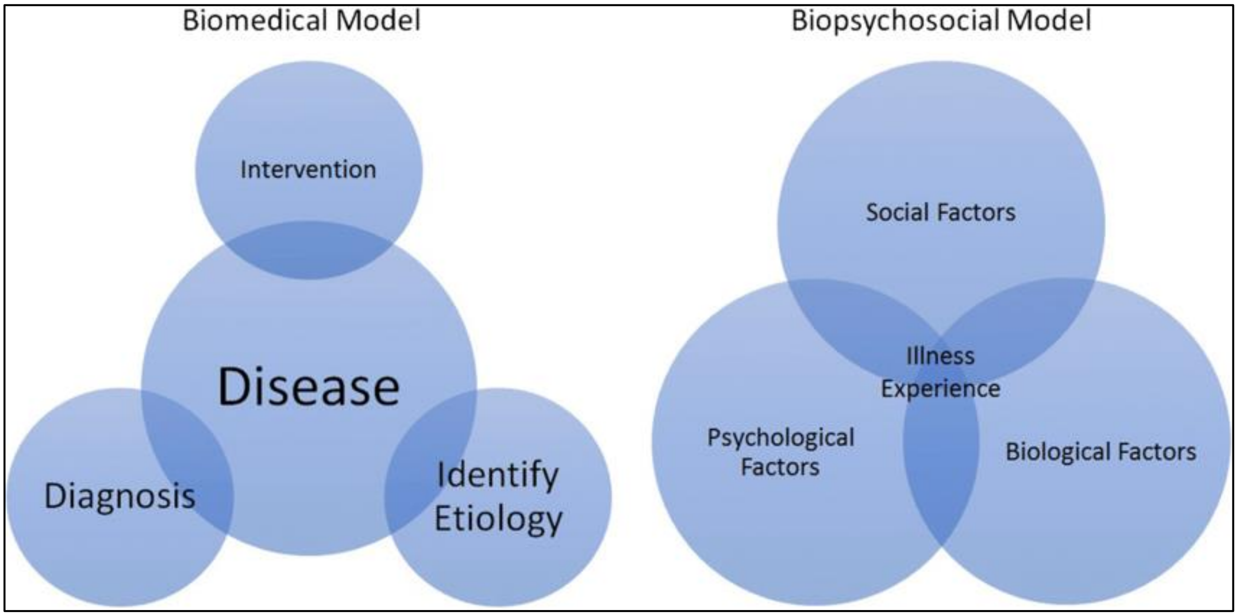

Figure 1. *Biomedical Versus the Biopsychosocial Model of Disease.*

Diagnosis of a Primary Brain Tumor

Brain cancer may either be primary (originating in the cells of the brain) or metastatic (originating from cells of another body part and spreading to the brain). Metastatic brain tumors are the most common type of brain tumor in adults, frequently originating from lung, breast, or skin cancer.[7] On the other hand, a PBT is one of the rarest forms of cancer, comprising of 1.4% of all new cancer diagnoses.[8] The National Brain Tumor Society estimates that over 84,000 Americans will be diagnosed with a PBT in 2021, and approximately 700,000 Americans are already living with a PBT.[9] With over 120 different types of tumors – each named from the cellularity or location they originate from – there is significant heterogeneity in a PBT diagnosis.[10]

PBTs are classified by the World Health Organization (WHO) by grade (I-IV);[11] as such, PBTs can be either benign (grades I & II; about 70% of all cases) or malignant (grades III & IV; about 30% of all cases).[9] The most common type of benign PBT is a meningioma, where after receiving surgery, the five-year survival rate is quite high (74-84%).[12] Malignant PBTs, on the other hand, tend to be much more aggressive and do not have the same favorable outcomes (five-year survival rate = 21.5%).[9] The most common malignant PBT is a glioma, which includes the diagnoses of astrocytoma, oligodendroglioma, and glioblastoma multiforme (GBM). These three types of tumors are the focus of the current review. Although the survival rate depends on several factors (e.g., genetics, tumor location, access to care), malignant astrocytoma and oligodendroglioma have a median survival rate of 24 and 50 months respectively.[13,14] The most common and aggressive type of glioma is GBM (45.2% of malignant primary brain tumors[15]), which has a five-year survival rate of 7.2% and a median length of survival of only 8 months. The average length of survival of a GBM with treatment is still only 15 months.[12] These dismal prognostic statistics are a direct consequence of the lack of curative treatments currently available for a malignant glioma (MG).

Treatment of a Malignant Glioma

Treatment of a MG is particularly challenging compared to other cancers, given the necessary hurdle of permeating the blood-brain barrier and the need to maintain as much healthy brain tissue as possible for quality of living.[16] The most common treatments are neurosurgical debulking (partial or gross total), cranial irradiation, and chemotherapy, all of which can cause nondiscriminatory damage to surrounding brain tissue.[17–19] Patients are often also prescribed a number of other pharmacological medications (e.g., corticosteroids, anticonvulsants, psychostimulants, psychotropics) throughout their treatment to alleviate symptoms, yet these drugs produce a myriad of their own negative side effects.[20] Unfortunately, the last major medical breakthrough for treating a MG occurred over 15 years ago in 2005, with the development of the Stupp Protocol.[21] The Stupp Protocol involves maximum neurosurgical debulking followed by concomitant and adjuvant chemotherapy with standard cranial irradiation and was found to extend life by only a few months.[22] There are currently only five FDA-approved drugs and one cumbersome device (Optune) available for treating MG in the United States,[9] meaning patients have very limited options. Moreover, these available treatments are imperfect: because it is not possible to remove *all* cancer cells in the brain during neurosurgical debulking, tumor recurrence is almost certain in every MG diagnosis.[12,23] This is particularly troublesome given there is currently no standard of treatment for tumor recurrence upon completion of the Stupp Protocol.[23] Thus, patients and families are forced to make difficult treatment decisions (e.g., enroll in a clinical trial or receive palliative care), weighing the potential benefits and costs associated with each. Together, the lack of curative treatment options, almost certainty of tumor recurrence, and known side effects of each treatment inevitably impair the quality of life of patients diagnosed with MG.

Negative Sequalae of a Malignant Glioma Diagnosis

Both the tumor itself and its various treatments are responsible for a variety of negative side effects that impair quality of life, including consequences that are neurological, cognitive, behavioral, social, and psychological in nature:

Neurological Symptoms. Most obviously, given its location within the brain, a MG and its treatment can cause various neurological symptoms. Commonly reported neurological symptoms include headaches, seizures, impaired balance, gross and fine motor impairment, muscle weakness, sensory issues, and visuospatial problems.[24–26] Mukand and colleagues found that 75% of patients had at least three concurrent neurological deficits; 40% had five or more.[27] As will be discussed, these neurological issues can severely impact daily functioning and thus quality of life. Rehabilitation in the form of physical and occupational therapy might reduce the burden of these symptoms.[28] Pharmacological drugs such as anticonvulsants, corticosteroids, and psychostimulants are also used to assuage neurological problems yet can cause their own negative sequalae (e.g., changes in mood, appetite, sleep).[28]

Cognitive Dysfunction. Most patients diagnosed with a MG demonstrate subjective (self-reported) and objective (neuropsychological evaluation) cognitive changes, with estimates as high as 91% and 83%, respectively.[29,30] Reported and observed deficits commonly include slowed processing speed, reduced attention/concentration, executive dysfunction, language difficulties, and memory impairment; the type of impairment may vary depending on tumor size/location (focal insult) as well as the dose/type of neurotoxicity (diffuse insult).[31] There is also heterogeneity in the severity of cognitive impairment. Some patients only report subtle changes and others demonstrate impairments that significantly impact their daily funtioning.[32] In these cases, patients may be unable to drive, work, and/or care for themselves or others.[33,34] Unfortunately, cognitive impairment in patients with MG may be chronic, even after treatment ends, and often results in an eventual, drastic decline.[35]

Sleep Disturbance and Fatigue. Sleep-wake disturbance and fatigue are two of the mostly commonly reported changes and severe symptoms of patients with MG.[36] Over 60% demonstrate poor sleep quality, and about a quarter meet the clinical cut-off for insomnia.[37]

Many also report excessive daytime sleepiness and fatigue, especially during cranial irradiation treatment.[38] Corticosteroids and anticonvulsants—which are commonly prescribed in patients with MG—are also known to aggravate sleep disturbance.[39,40] Unfortunately, despite the high prevalence and known negative impact on daily functioning, most patients do not feel their sleep disturbances are well-managed by their neuro-oncology care team.[37]

Exercise and Motor Impairment. Though exercise is highly recommended to patients diagnosed with cancer to combat cognitive impairment and fatigue,[5,41] many patients with a MG are either physically limited or too afraid to engage in exercise due to the risk of seizures and falls.[42] Indeed, motor deficits occur in 10-44% of patients depending on the stage of treatment.[43] Previous analyses have found significant muscle weakness, myopathy, and reduced cardiorespiratory fitness due to cancer-related treatment.[44,45] Given these challenges, it is perhaps not surprising that a longitudinal study of patients with MG reported a steady decrease in physical activity and functioning over time, which inevitably impairs patient quality of lfie.[46]

Changes in Diet. Patients also report changes in their diet. Contrary to that of other cancer populations, patients with MG are more likely to *gain* weight due to corticosteroid use: one study found that patients endorsed significant increases in appetite and weight (37% and 23%, respectively).[47] However, some patients do report decreases in appetite, typically as a result of chemotherapy and cranial irradiation.[48–50] Depressed mood, nausea, and/or dysphagia—which are three common symptoms among patients with MG—can also affect appetite.[43]

Sexual Functioning. Patients diagnosed with a MG may report changes in sexual behavior and sexual functioning. One qualitative study found that patients reported decreased intimacy in their relationships following the physical and emotional changes of the diagnosis.[51] They may lose sexual attraction to their partner and notice a change in their intimacy due to their increased dependency on their loved one.[52] Relatedly, patients undergoing chemotherapy may have future issues with fertility, and many are encouraged to pursue fertility preservation prior to treatment should time allow, if of child-bearing age.[53,54] These changes to sexual functioning may have important implications for the quality of patients' relationships.

Social Changes. Patients may also perceive shifts in their social relationships over the disease trajectory, including their interactions with their primary caregiver, other family members, friends, romantic partners, and co-workers.[55,56] Unfortunately, some relationships deteriorate as a result of the diagnosis and subsequent stress. For example, patients often worry about being a "burden" to others due to the amount of assistance required;[57,58] others may have difficulties connecting cognitively due to ongoing treatment effects or neurocognitive deficits.[52] Still, some patients seek social support but find that old friends, "avoid them or avoid talking about the illness" (p. 385).[52] Nevertheless, some individuals find that the stress of the disease serves to strengthen pre-existing relationships or provides them the opportunity to forge new ones through advocacy or peer support.[59–61] Proper social support is crucial as it has been found to correlate with heightened quality of life.[62]

Occupational Impacts. The MG and its treatment may also impact the patient's occupational capacity. A review of cancer survivors found that the highest risk of unemployment was in those diagnosed with CNS cancers.[63] In terms of employment, only 12-18% of patients with a MG return to either part- or full-time work within three months of their surgery, according to the Glioma Outcomes Project.[64] The neurocognitive changes, inability to drive, physical burden of tumor or treatment (e.g., seizures, fatigue, vision loss), and amount of time required to receive treatment might prevent a patient from continuing employment.[31,34] This often has a negative financial impact, which can significantly decrease quality of life, including a reduced sense of self-efficacy.[65] Nevertheless, some patients do decide to return to work, yet they frequently report significant challenges with meeting the demands on their workplace (e.g., difficulties with organization, sustained attention for eight hours, pace of work, remembering tasks).[34,66]

Psychological Distress.

Personality Changes. Tumor location, size, and associated edema of a MG can cause changes to a person's personality.[67–69] For some, this may even be the first indication of the disease.[70] There is great variability in the type of personality change in patients with MG: for example, frontal lobe damage is associated with confusion and dementia, right frontal damage specifically is associated with mania, irritability, and impulsivity, and damage to the thalamus and hypothalamus is associated with emotional lability, hypersexuality, and garrulousness.[71] These changes in personality can improve, persist, or even worsen after treatment.[68] For example, both corticosteroids and anticonvulsants are known to increase agitation, irritability, and suicidal ideation.[67]

Depression. Most patients (93-95%) report experiencing symptoms of depression during their disease trajectory.[25,72] In fact, the rate of clinical depression is higher in patients with MG (22-41%) than that of both the general population (7%) and patients diagnosed with other cancers (13%).[72–76] Although depression is, to some extent, a normative response given the psychological weight of a MG diagnosis, depression in patients with MG can also be a neurochemical consequence of treatment.[77] Nearly half of patients with MG are prescribed psychotropic medications,[72] yet these medications can cause the patient additional issues (e.g., lowering the seizure threshold, fatigue, cognitive impairment).[78]

Anxiety. Similarly, symptoms of anxiety are commonly reported and somewhat normative in the context of a MG. Moderate-to-severe symptoms of anxiety are apparent in 17-32% of patients, with symptoms frequently transient throughout the disease trjectory.[79,80] Symptoms are especially common before regular Magnetic Resonance Imaging (MRI) scans, a phenomenon known as "scanxiety."[81,82] However, it is important to note that these symptoms of anxiety are related to, but separate from existential distress.[80]

Existential Distress. Give the unfavorable prognostics and high likelihood of tumor recurrence for MGs, it is perhaps no surprise that patients struggle with existential concerns, such as fear of cancer recurrence and death distress (death anxiety, death depression, death obsession).[83] Indeed, patients report that existential distress is one of their greatest, unmet psychosocial needs.[59,84] Fear of cancer recurrence, a form of existential distress related to the tumor coming back or progressing is common: A study by Braun et al.[84] found a slightly higher endorsement of fear of cancer recurrence in patients with PBT compared to that of other non-CNS cancer populations.[85] Another form of existential distress is death distress, which refers to fear, sadness, despair, and loneliness that occurs in response to thoughts about death and dying.[86] Recent studies have found that 81% of patients with PBT endorse moderate-to-severe symptoms of death anxiety on a screener of death distress,[80] and 48% of patients endorse moderate-to-severe symptoms on a more comprehensive measure specific to oncology.[58] Moreover, compared to other types of psychological distress, patients endorsed death distress at a much higher frequency: using latent class analysis, Loughan and colleagues[80] found the majority of patients reported high death distress but low depression and generalized anxiety, suggesting death distress is a separate yet important construct of distress. Both components of existential distress are important considerations in patients with MG, as their severity may impact overall quality of life.[73]

Caring for a Patient with a Malignant Glioma

The aforementioned negative sequalae does not affect the patient alone; the overall burden of the disease and its treatment also inevitably weighs heavy on close loved ones, especially the primary caregiver. A primary caregiver – most frequently a spouse, adult offspring, parent, sibling, or other closed loved one[87] – is defined as the person responsible for the patient, who provides ongoing care but is not financially compensated.[88,89] Given the significant challenges of a MG, caregivers often assist with the functional, financial, emotional, and medical needs of the patient over the course of the disease.[90] Caring for a patient with a malignant glioma (subsequently referred to as PwMG) is quite unique, as it translates to the challenges of both an incurable cancer *and* a neurodegenerative disease.[91] Previous qualitative interviews of caregivers from all stages of the disease (i.e., diagnosis, stable, progression, death) describe four main categories of caregiving challenges: 1) overseeing changes within the family system, (2) managing challenging patient behaviors and symptoms, (3) dealing with one's own personal feelings and reactions, and (4) navigating the medical system and care of the patient.[92]

Changes within the Family System. Given the relatively short course of a MG prognosis, roles and responsibilities within the family can change rapidly. For example, the caregiver may be suddenly required to help with activities of daily living while also managing household responsibilities, finances, and other relationships. In sharing their time with the patient and other family members, caregivers feel "sandwiched," finding it difficult to care for other loved ones and/or share worrisome information about the patient with others.

Challenging Patient Behaviors and Symptoms. Secondly, caregivers feel responsible for comforting the patient, despite encountering various tumor-related problem behavioral symptoms, including aggression, impulsivity, reduced attention, memory problems, and depression. Some caregivers understand the reasons for personality and neurocognitive changes more than others. Nonetheless, many caregivers feel, “torn between patience and guilt” as they interact with their loved one with MG (p. 591)[93]

Caregivers’ Personal Feelings and Reactions. The exhibited changes in their loved one often contribute to caregivers’ personal feelings and reactions, the third domain of challenges. Most commonly, caregivers describe feeling both overwhelmed and isolated.[94] One caregiver explained that the uniqueness of their role created stigma, where non-caregivers did not know what to say or how to help. Caregivers also report honest emotional reactions such as denial, resentment, depression, anger, guilt, and anxiety—directed at the situation, patient, and sometimes the medical team. As the disease unfolds, caregivers do their best to make sense of the diagnosis amidst uncertainty, balancing hope with despair.

Navigating Medical Systems and Patient Care. Within this final category of challenges, caregivers describe difficulties understanding the medical system, scheduling appointments, physician-caregiver communication, disability insurance, medical decision-making, and advance care planning. Their new, yet necessary role as a nurse/patient advocate is emotionally burdensome for some; for example, medical staff often ask caregivers to administer medications based on their personal discretion and/or complicated instructions.[95] The ambiguity in making the “right” versus “wrong” decision is particularly heavy in the context of a noncurative disease, as caregivers must choose to "prolong life" or "prolong death" in their loved one, who often lack capacity to understand and make decisions themselves.[96] Perhaps not surprisingly, caregivers report feeling untrained and unprepared to manage these myriad tasks. Moreover, caregivers express frustration that the medical system as whole lacks formal structures to support caregivers, adding to their overall feelings of distress and burden.[92]

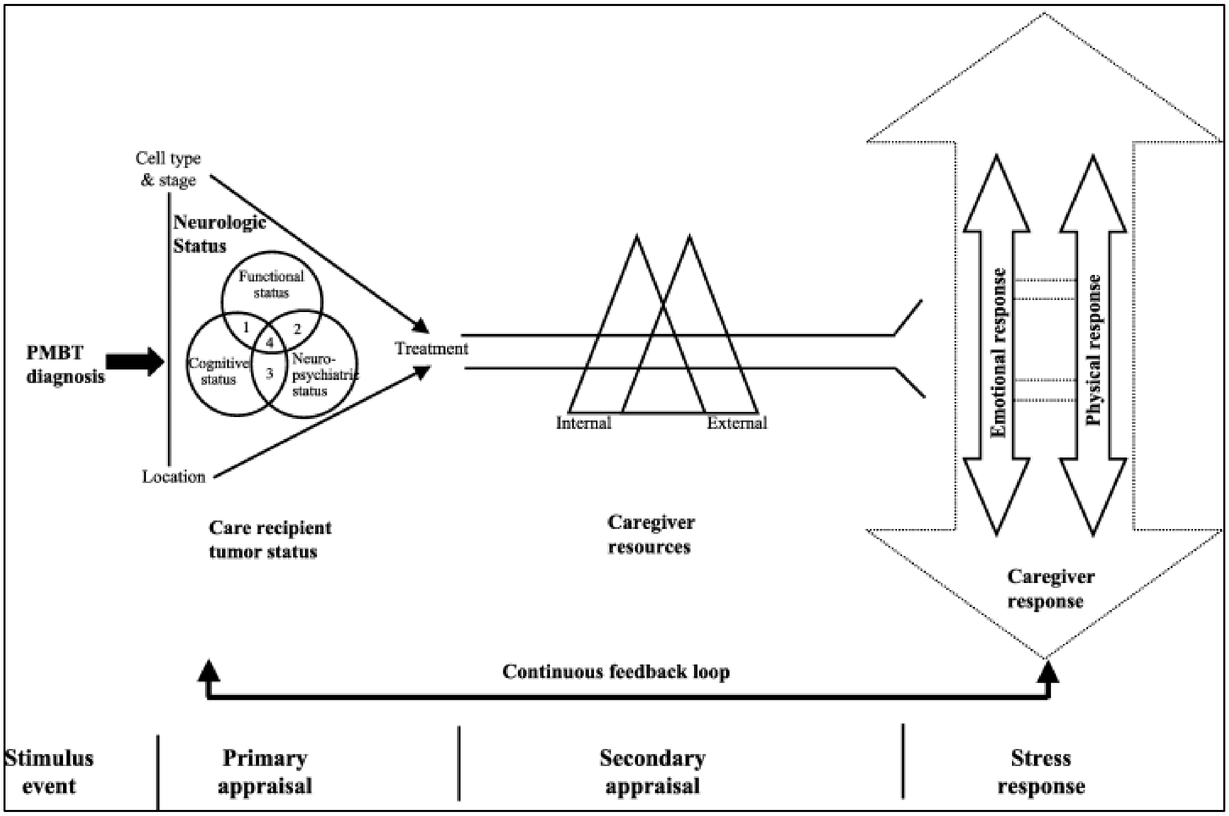

Figure 2. *Conceptual Model of Caregiver Stress.*

Associated Distress in Caregivers

Although some caregivers report positive changes as a result of the diagnosis (e.g., stronger relationships between family members, increased inner strength, resilience),[97,98] which might serve to buffer burden,[99] most experience significant stress as a result of the aforementioned challenges and accumulating responsibilities.[100] Sherwood and colleagues' conceptualize burden as a function of the caregiver's appraisal of the patient's needs in relation to the caregiver's appraisal of available resources, both internal and external (see Figure 2).[99] Under this model, burden surges when the patient's needs are greater than the available caregiving resources, and as described in the case of a MG, the patients' needs are often high. The burden of caregiving can become problematic, with financial, social, physical, and psychological implications:

Financial Implications. Caregiving can lend itself to economic hardship. One study of caregivers found that half of the sample was not employed as a direct result of the diagnosis, especially if the patient was dependent on another to manage instrumental tasks of daily living.[101] Even for those caregivers who remain employed, the expense of formal patient care (e.g., institutional or at-home support)—which many PwMG require—is quite high.[102] The cost of medical treatment is also extraordinary; brain cancer has the highest per-patient initial cost of care (≈$150,000) and the highest annualized mean net costs for last-year-of-life care ($135,000 - $210,000) compared to any cancer group.[103] This level of economic hardship was correlated with both anxiety and depression over time.[104]

Social Implications. Although some caregivers report adequate social support,[105] others believe their roles lead to social deficits**.**[57] In fact, caregivers of PwMG, compared to their low-grade or non-CNS cancer peers, demonstrate poorer social functioning (i.e., inability to pursue normal social activities, social withdrawal) and are at risk for experiencing social isolation as a result of their anticipated reactions of others.[106] For example, family members and friends frequently do not know how to approach the caregiver, misunderstand changes within the patient, and/or react negatively to updates in the patient's disease or response to treatment.[56,107] The lack of adequate social support can impact caregiving functioning: A study found that those with poorer social networks demonstrated greater subjective caregiver burden.[102]

Physical Health Implications. The burden and substantial role requirement of caregiving can also impact physical health. Caregivers are at a risk for systemic inflammation (e.g., increased C-reactive protein and IL-1ra), and those who report low self-esteem from caregiving are at an even greater risk.[108,109] Increased fatigue and sleep disturbance are also commonly reported, especially when patient functioning is low.[110,111] Lastly, studies of bereavement—a probable experience in caregivers of PwMG—suggest decreased immune functioning, increased healthcare utilization, and higher rates of mortality in caregivers following the loss of their loved one;[112–114] however, there exists no such study specific to caregivers of PwMG at this time.

Emotional Implications. Perhaps most of the available literature on caregivers of PwMG focuses on the emotional burden associated with caregiving. The overarching trend in this area suggests the following: 1) caregivers endorse high emotional distress compared to the general population, 2) caregivers' reported distress is greater than patients', and 3) symptoms of distress are highest at diagnosis but may ebb and flow with the course of the disease.[115–117] The type of emotional symptomatology might include depression, anxiety, and existential distress (e.g., death anxiety and fear of cancer recurrence):

Depression. Numerous studies document increases in depression. Approximately 40% of caregivers scored above the clinical cut-off as measured by the Hospital Anxiety and Depression Scale (HADS) in a recent systematic review.[118] Interestingly, caregivers not only endorse greater depressive symptoms than that of the general public, but they also report greater symptoms than the patients themselves.[94,119] Risk factors for depression include lower caregiver age, income, social support, and patient functioning.[116,120,121] Moreover, symptoms are correlated with increased burden and decreased quality of life.[94] The prevalence of depression translates to a higher use of antidepressants; one study estimated that 21-29% of spouses of PwMG were prescribed an antidepressant compared to 8-10% of their matched peers in the general public.[122]

Anxiety. Caregivers also report significant symptoms of stress and anxiety, with estimates ranging from 12% to 40% (determined by the DSM-IV SCID-IV[123] and HADS,[124] respectively). Symptoms of anxiety follow a similar trend as symptoms of depression; caregivers endorse greater symptomatology than that of both the general public and patients.[119,123,125] Specifically, compared to patients, caregivers report a higher rate of sleeping issues, decreased concentration, restlessness, irritability, tenseness, fatigue, and loss of appetite related to their anxiety.[123] Female caregivers and those with lower social support are at a greater risk for increased anxiety, and symptoms have been shown to correlate with other consequential outcomes, such as increased bodily pain, difficulties in their new role, and changes to their schedule and health.[94,116,119] One study assessed the content of caregivers' worries and found that the diagnosis, surgery, side-effects, and fear that their loved one is suffering were all highly-endorsed concerns;[123] however, this study did not independently assess existential distress, a related, yet separate construct.

*Existential Distress***.** Because caregivers must face the same reality of a MG diagnosis (i.e., lack of curative treatments, high rate of recurrence), caregivers similarly experience existential issues such as death distress and fear of cancer recurrence.[57,126,127]

Indeed, in one qualitative investigation, caregivers described their fear of the patient's inevitable death as an *all-consuming preoccupation*.[127,128] This death distress may be easily triggered by even minor neurological symptoms in the patient or by environmental cues of death (e.g., hospital bed).[59] A recent systematic review of existential concerns in neuro-oncology caregivers noted that qualitative studies consistently point to death distress as a *significant, unmet need* and *opportunity for psychosocial care*,[127] especially given the fact that conversations about death rarely take place with the medical team, patient, or the family.[129,130] Nevertheless, quantitative investigations of death distress are severely lacking due to a dearth of appropriate, validated measures for caregivers of PwMG. A preliminary, unpublished investigation suggests that the prevalence of death distress is much higher in caregivers compared to patients affected by brain tumors; moreover, this same investigation found that caregivers reported more symptoms of death distress than symptoms of depression and generalized anxiety.[131] In terms of fear of cancer recurrence, only one study to date has investigated existential distress in neuro-oncology caregivers; results were on par with other measures of distress, in that caregivers feared recurrence to a greater degree than patients.[132] In sum, existential distress seems to be a significant, yet unaddressed, concern of caregivers of PwMG. Therefore, more attention to this type of distress is warranted.

In sum, the combined financial, social, physical, and emotional morbidity of caregiving negatively impacts overall quality of life.[124] Indeed, this specific population demonstrates poorer quality of living than both the general population and caregivers of other diseases.[133,134] Yet because the focus of treatment is normally on the PwMG, caregivers' needs are often pushed to the side, forgotten, or outright neglected.[92] The above review reveals that caregivers report considerable distress, warranting more attention to this often-overlooked population. Although the needs of caregivers should be addressed for these facts alone, addressing caregiver distress may also benefit the patient.

The Caregiver and Patient Dyad

Though the distress may manifest differently, both the patient and the caregiver demonstrate significant challenges. These experiences do not exist in isolation; instead, research suggests that each partner has a reciprocal effect on the other, such that the experience of a MG serves as a "dyadic stressor" for both the patient and caregiver (p. 162).[117] Using the actor-partner interdependence model (APIM), a recent study revealed that patients' and caregivers' coping style influenced both their own quality of life and that of their partner; for example, a patient's use of avoidance was found to decrease the caregiver's quality of life, and the caregiver's use of social support was associated with higher patient quality of life.[117] A follow-up, longitudinal study found that this interdependence may also have a temporal component; for example, the patient's use of positive-thinking and problem-solving at baseline predicted improved caregiver quality of life three-months later, and the caregiver's use of social support at baseline predicted improved patient quality of life three-months later.[135] There also appears to be an interdependency in regard to existential outcomes: Braun and colleagues revealed a significant partner effect; specifically, increased depressive symptoms and death distress in caregivers predicted *decreased* fear of cancer recurrence in the patient, suggesting the emotional well-being of one partner depends on the emotional well-being of the other.[132] One study considered how certain caregiver characteristics influence patients longevity; astonishingly, the results revealed that for every increase in a caregiver's feeling of mastery, there was a 16.1% risk reduction in patient death. In this way, addressing caregiver concerns has important implications not just for the caregiver, but also for the patient. Although our current medical system is designed to make the patient the priority,[136] increased attention to the caregiver should also benefit the patient in light of this identified circularity.

Supportive Care Needs of Caregivers

Sherwood's conceptual model (Figure 2) suggests that adequate support—both internal and external—can ameliorate caregiver burden.[99] Some caregivers possess innate traits or coping skills that buffer distress, such as spirituality or religious coping.[137,138] Others rely more heavily on both formal and informal external resources. Although there is a clear need for external support, the optimal type and method of delivery is still in question. Caregivers summarize three preferred *sources of external support*:[90] professional support from the medical team, social support from friends and family members, and community-based support from other caregivers. Although all avenues are important, healthcare professionals, under the biopsychosocial model, should play a key role in addressing caregiver concerns.

A closer examination of professional support reveals three main *categories of intervention* desired by caregivers.[92,139,140] First, caregivers are interested in informational or educational interventions from professionals, in which they learn what changes to expect in their loved one, the various side effects of treatment, or how to be an effective caregiver. Secondly, caregivers desire skills-based or rehabilitative support, which can teach them how to increase communication with the healthcare team or better manage patient symptoms. Lastly, caregivers frequently request psychosocial support, including counseling, to discuss their emotions, improve their coping, enhance the caregiver-patient relationship, and prepare for end-of-life. This last request is not surprising given the results of a longitudinal study, which found that the caregivers' psychosocial needs remain high over the entire disease trajectory.[141] Yet despite both their stated desire for counseling, *and* the Institute of Medicine's strong advocacy for increased psychosocial care in oncology,[142] psychosocial treatment for caregivers is severely lacking.

Available Psychosocial Interventions for Caregivers of PwMG

Abundant studies have highlighted the psychosocial needs of caregivers, yet there is a dearth of evidence-based interventions tailored to address them. Indeed, a 2019 systematic review and meta-analysis identified only eight randomized controlled trials (RCTs) with samples comprised of at least 20% neuro-oncology caregivers.[140] Of these, four interventions were explicitly designed for caregivers, whereas the remaining four were created for the patient-caregiver dyad. Although interventions varied in content and style, the authors highlighted overarching limitations of all reviewed RCTs: sample composition (e.g., mixed cancer samples, pediatric and adult cancer samples), sample size (i.e., small total sample, small proportion of neuro-oncology caregivers), research design (e.g., quasi-RCT, multiple interventions tested at once), and attrition were all concerns of the reviewed studies.

Only three studies in this review were comprised of 100% neuro-oncology caregivers: The first intervention (n = 31) involved six 50-minute, biweekly cognitive behavioral therapy (CBT) sessions on topics such as setting aside time for self, epilepsy, contact with the patient and other close loved ones, and practical needs.[143] This intervention targeted caregiver mastery and quality of life. The second intervention (n = 9) was for caregiver-patient dyads and included six 50-minute cognitive rehabilitation sessions (e.g., strategies to improve memory) and six 50-minutes problem-solving sessions (e.g., stress management), both delivered over a two-week period.[144] This study aimed to improve quality of life and distress in caregivers. The final intervention (n = 30) was a one-time, 15-minute, online activity that sought to increase the caregiver's awareness of their social network, with the intention of ultimately improving quality of life and distress.[145] The results of all three studies provided a low or very low grade of certainty for the estimate of effects and exhibited high rates of attrition (43%, 33%, and 20%, respectively). With this, it is evident that more attention to intervention development and design is needed for caregivers of PwMG.

There are other interventions in development with psychosocial components that have not yet reached the stage of a RCT. First, several nurse-led interventions have been found to alleviate caregiver distress; in these studies, nurses make regular contact with the family, assess their needs, and either make referrals to psychological care or provide emotional support themselves.[146–150] However, the specific type of psychosocial care provided is not detailed in these studies. Two interventions have utilized yoga and meditation in PwMG and their spouses.[151,152] Although patients seem to benefit, no improvements have been found in caregivers at this time. Another couple-based intervention asked each partner to create three goals and then discuss as a dyad for eight minutes.[153] At least one of these goals had to be unrelated to the patient's health. Qualitive interviews conducted after the intervention suggest both partners found this communication and emotional disclosure activity beneficial. Finally, two preliminary interventions seek to address existential concerns by asking *patients* to complete a life legacy document (Dignity Therapy)[154] or a spiritual life legacy document (Hear My Voice)[155] prior to their cognitive decline. Caregivers, who do not actively participate but review the document afterwards, provided positive evaluations of the interventions. Caregivers in the Hear My Voice intervention also showed significant increases in spiritual well-being one-month later.[156] The effect of these two interventions on other caregiver outcomes, such as death distress, is unknown.

Together, these studies highlight the exceptionally limited availability of psychosocial interventions for caregivers of PwMG. Yet it is important to acknowledge that there are likely several potential barriers to care, thus explaining the lack of evidenced-based interventions. First, caregivers may believe they do not have time to participate in a trial as they provide an average of 11.2 hours of care per day, 6.7 days per week.[150] Secondly, caregivers often see their own psychological needs as separate and not as important as the needs of the patient.[98] Lastly, formal structures for psychosocial care of caregivers are extremely lacking,[92] and caregivers report that appropriate support often comes in a form that is limited or too late.[94] These potential barriers are underscored in a study of treatment preferences. Keir assessed caregivers' interests in a stress-reduction program and found that although the majority (72%) reported significant levels of stress, only 44% were interested in participating in an intervention.[157] The majority (90%) preferred an intervention that could be completed at home, and most (63%) wanted to complete the intervention alongside their loved one instead of alone.[157] In terms of intervention frequency, the most popular endorsement was weekly care (30%) for approximately 30 minutes (42%).[157] In a second study, caregivers expressed interest in both traditional *and* impromptu, drop-in counseling services.[141] It is critical that future intervention studies take into account these barriers and assess caregivers' preferences for treatment in order to produce suitable interventions and trials with proper adherence and low attrition.

Psychosocial Treatment for Existential Distress

None of the reviewed, available interventions have demonstrated effectiveness in treating existential distress. As previously discussed, caregivers endorse an exorbitant amount of fear of cancer recurrence and death distress—higher than the rate of patient's existential distress and greater than their own rate of depression and anxiety.[58,131] Caregivers also explicitly state a desire for psychosocial support from their healthcare team to address their existential and end-of-life concerns.[56,59,141] A systematic review of end-of-life needs concluded that families were satisfied, "with medical treatment but not with existential support" (p. 151), as it was left unaddressed by their medical team.[158] Consequently, without proper support or information, bereaved caregivers regretted not creating an advanced care plan and not, "sharing meaningful goodbyes" with their loved one prior to their cognitive decline and passing (p. 73).[159] It is important to note that these same caregivers desired continued support after the patient's death.[160] Yet despite these myriad requests, there are a dearth of resources for the end-of-life concerns.[92,161] It is critical that more attention is given to the terminal or end-of-life stage of psychosocial treatment in light of these findings.

There are three ongoing trials in neuro-oncology that target existential concerns and may be worthy avenues of further exploration: Making Sense of a Brain Tumor, Meaning-Centered Therapy for Cancer Caregivers, and Managing Cancer and Living Meaningfully (CALM). Although each intervention includes caregivers, the results of caregiver participation are not reported. However, there is reason to believe these interventions are promising for caregivers in light of the patient findings. The Making Sense of a Brain Tumor program aims to improve participants' sense of coherence in 10 one-hour, modular sessions.[162] Patients showed lower depression, better existential well-being (as measured by the McGill Quality of Life scale), functional well-being, and global quality of life compared to the waitlist control group.[162] Caregiver data have been collected but is not yet published.[162] Meaning-Centered Psychotherapy for Cancer Caregivers seeks to extend the benefit of this seminal existential psychotherapy to caregivers.[163] Although data specific to neuro-oncology are not yet available, patients with advanced cancer have reported increases in spiritual well-being, increased personal meaning, and lower anxiety as a result of the seven hour-long sessions.[164] Data collection in caregivers of PwMG is currently underway (NCT03454295). Lastly, preliminary data from an ongoing CALM trial in neuro-oncology suggest that patients endorsed significantly less depression and death distress upon completion of this six-session intervention.[165] Results from an RCT of advanced cancer patients outside of neuro-oncology mirror these findings.[166] It is important to note that of all aforementioned interventions, CALM is the only existential intervention to specifically measure and report reductions in death distress in patients. The other studies, on the other hand, show changes in existential well-being. Therefore, an investigation of CALM in caregivers of PwMG—a population with extremely high death distress— is warranted.

Managing Cancer and Living Meaningfully (CALM) Therapy

Managing Cancer and Living Meaningfully (CALM)[167] shows potential for reducing existential distress in caregivers of PwMG, though this has yet to be specifically investigated. CALM is a brief, individual or couples-based, supportive-expressive, psychotherapeutic intervention developed by palliative care physicians and psycho-oncologists to provide hope, manage distress, increase death preparedness, and improve meaning and quality of life for patients with advanced cancer. CALM was founded on relational, attachment, and existential theory, and optimally consists of 3-6 sessions of 45-60 minutes, delivered over a 3–6-month period by a certified CALM interventionist. CALM sessions address four broad and interrelated domains found to be relevant to the experience of advanced cancer: (1) symptom management and communication with healthcare providers, (2) changes in self and relationships with close others, (3) meaning, purpose, and spirituality and (4) the future, hope, and mortality (see Figure 3). These domains are addressed with all patients during the intervention, although the sequence and relative emphasis on each domain vary, depending on the urgency and importance to each patient. CALM also reinforces processes such as double awareness (i.e., the capacity to balance presence in life with preparation for death[168]) and mentalization (i.e., the capacity to distinguish feelings versus facts and appreciate the possibility of multiple perspectives[169]). Lastly, CALM allows and encourages caregivers to participate in therapy alongside the patient with advanced cancer, though this is not required.

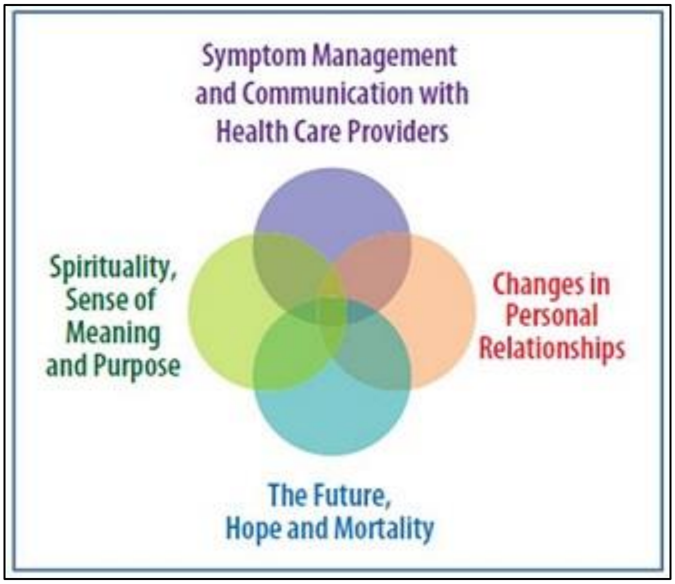

Figure 3. *The Four Domains of CALM.*

Research over the last decade provides an evidence-base for use of CALM in advanced cancer. First, two preliminary Phase II and Phase III trials have shown CALM to be a feasible and acceptable intervention with small-to-medium effect sizes.[170,171] The first non-randomized pilot trial found improvements in depression, death distress, and spiritual well-being at both 3- and 6-months post-intervention.[170] The second randomized feasibility trial found additional improvements in attachment security.[171] Next, data from a qualitative study of 10 patients who underwent the intervention described unique benefits of CALM not experienced elsewhere.[172] First, patients described CALM as a safe place to process the experience of advanced cancer; secondly, patients felt permitted to talk about death and dying, an often taboo topic of discussion; third, patients received assistance in managing their illness and navigating the healthcare system; fourth, patients saw improvements in relational strain; and lastly, patients felt, "seen as a whole person" within the healthcare system as a result of their participation in CALM (p. 716).[172] Finally, perhaps the strongest evidence in support of CALM comes from a recent large RCT.[166]

This RCT compared the CALM intervention (*n* = 151) to usual care (*n* = 154) in patients with various advanced cancers on a variety of outcomes at both 3- and 6-months post-intervention. The primary outcome was depression; secondary outcomes included generalized anxiety, death distress, spiritual well-being, quality of life, attachment security, couples' communication, posttraumatic growth, and demoralization.[166] The results revealed that CALM was effective in treating and preventing depression in advanced cancer patients at both 3- and 6-months post-intervention compared to usual care. There were also improvements in secondary outcomes including death distress, preparation for the end-of-life, demoralization, spiritual well-being, couples' communication, generalized anxiety, and attachment security, suggesting CALM might increase the psychological well-being of advanced cancer patients.

There are three important notations from this body of research: (1) CALM is the only intervention shown to decrease death distress significantly in advanced cancer patients, (2) Previous trials of CALM did not include patients with brain cancer, a common trend in oncology research due to suspected cognitive impairment or other discriminatory exclusion criteria,[83] and (3) The efficacy of CALM has only been evaluated in patients; *the effect of CALM in caregivers has not yet been evaluated despite the option for caregivers to participate in the trial.* These last points highlight the gaps in research evaluating CALM, and highlight the need to assess the suitability of CALM in the context of both neuro-oncology—a rare, yet vulnerable type of cancer—and in caregivers—a population shown to exhibit significant distress. Although other interventions might also offer potential to reduce death distress in caregivers of PwMG, CALM has already shown to be effective in research with patients, highly encourages caregiver participation, and allows for the patient and caregiver to share a dyadic experience. The domains of CALM and its perceived benefits also map nicely onto the reported challenges and requests of caregivers of PwMG. Therefore, the current study collected necessary foundational data reflecting caregivers' perceptions of CALM that will eventually contribute to an enhancement of this intervention for caregivers of PwMG.

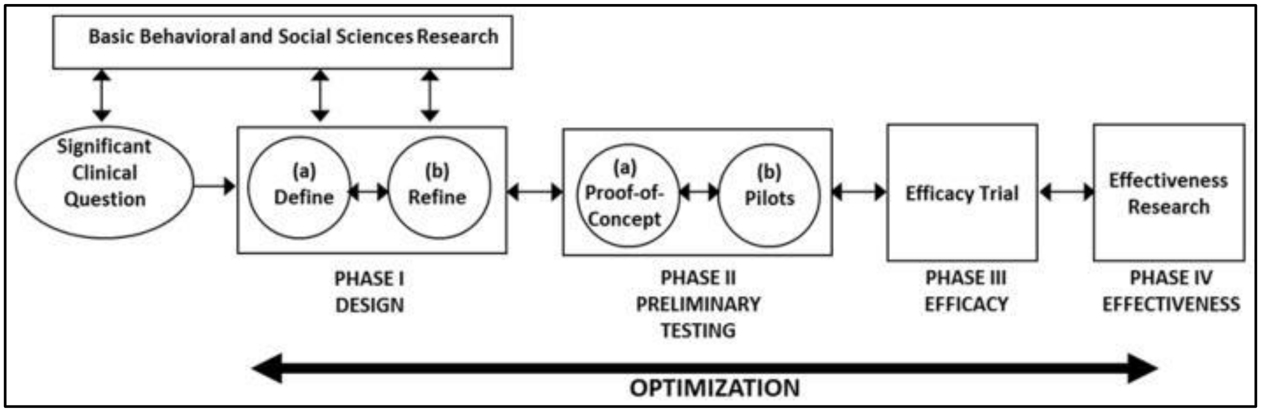

Figure 4. *The ORBIT Model for Behavioral Treatment Development.*

Statement of the Problem

A cancer diagnosis has psychosocial impacts for both the patient and their loved ones; the diagnosis of a MG further provides unique negative sequalae that often translate to higher caregiver burden. Because there are no curative treatments available, progression is likely, loss of cognitive or physical functioning is highly probable, and the overall prognosis is poor, caregivers face significant challenges and associated psychological distress, including that which is existential in nature. In sum, caregivers of PwMG consistently endorse death distress and the desire for support, yet there is not currently a suitable psychosocial intervention available for addressing death distress in this population. CALM represents a promising avenue for exploration and should be evaluated in caregivers, especially as they are already highly encouraged to participate in the intervention. In accordance with the NIH Science of Behavior Change ORBIT model for developing behavioral interventions (see Figure 4),[173] it is important that foundational data are collected *first* in order to determine what, if any, enhancements to the CALM protocol are required before piloting and assessing the feasibility, acceptability, and efficacy of the intervention with caregivers of PwMG. Therefore, the overarching purpose of the current study was to collect the necessary, foundational data on caregivers' perspectives of CALM to inform future pilot studies of the optimized intervention. The specific aims of the current study were as follows:

Aim 1. The first aim of the current study was to assess caregivers' perspective of the standard CALM intervention, including the relevance of the CALM domains and processes and suitability of the format/delivery. Caregivers were first informed about the standard CALM intervention, and then participated in qualitative focus groups, generating responses and personal examples to semi-structured questions as applicable.

Aim 2. The second aim of the current study was to determine caregivers' recommendations to improve the feasibility, acceptability, and effectiveness of the standard CALM intervention, including any adaptations to tailor the content, format/delivery, or assessments to the specific needs of caregivers of PwMG. Caregivers were asked to describe any potential facilitators or barriers to engagement with CALM in the qualitative focus groups.

Aim 3. The last aim was to learn more about caregivers' unique experience of death distress, including ways in which death distress is exacerbated or could be alleviated through psychosocial intervention. Caregivers were invited to share their experiences and ideas during qualitative focus groups.

METHODS

Participants

The current study enrolled bereaved caregivers of deceased patients diagnosed with malignant glioma. The study completed four focus groups of 4-8 caregivers (*N* = 22). This group size was selected as it strikes an optimal balance between being both small enough to promote anonymity of responses and large enough to elicit adequate dialogue to collect a breadth of experiences.[174] According to Fugard and Potts, a sample size of 18-24 participants would provide at least five examples of themes that are only 30-35% prevalent in the population.[175] This target sample size is also appropriate for a *Phase 1a Define Trial*, which relies on depth of data over breadth to define treatment components, target subjects, and outcomes.[173]

In this study, a "caregiver" refers to the primary person who provided ongoing support to the patient; however, it is not necessary that the caregiver lived with the patient or was biologically or legally related.[101] The choice to recruit bereaved rather than current caregivers is because this population is better suited to answer research questions on the feasibility and suitability of CALM; bereaved caregivers have more experience with caregiving over the entire cancer continuum, from patient diagnosis to after death. Thus, the current study recruited caregivers who have lost a loved one in the last six months to three years in accordance with what is typical of previous research of bereaved caregivers of PwMG.[160] Additional inclusion criteria were: (1) fluency in English, (2) aged 18 and older, and (3) access to a reliable internet connection and video capable device (e.g., desktop, tablet, smartphone). Professional caregivers who received financial compensation for their services were deemed ineligible.

Recruitment and Screening. Bereaved caregivers were recruited locally (e.g., associated with VCUHealth) and using online brain cancer bereavement support groups. These groups were identified through prior knowledge and google searches. Electronic advertisements were distributed to support group members in two ways. For support groups with an email listserv, we first asked permission from the administrator to join the listserv and then sent a recruitment email (see Appendix A) using the email associated with the LiveNOW Lab (livenow@vcu.edu). For support groups with a social media page, we first asked permission to join the group and then posted a study announcement (see Appendix B) using the social media accounts associated with the LiveNOW Lab (http://facebook.com/LiveNOWlab and @LiveNOWLab). We will also relied on word-of mouth and the snowball method to recruit other bereaved caregivers, and participants were given recruitment flyers to distribute to their own circles following their completion of the study.

For all recruitment methods, interested caregivers contacted study staff via the listed telephone number or email. A trained research assistant (RA) screened for eligibility via telephone using a screening form and script (see Appendix C and D, respectively). If eligible, the RA described the study to potential participants and emailed the study information sheet (see Appendix E); because this study was deemed exempt, a formal consent process was not necessary. Once all questions were answered, interested caregivers were enrolled and assigned a subject number. Recruitment was ongoing until a sample of 18-24 was achieved.

Design and Procedure

This study has been designed in accordance with the NIH Science of Behavior Change ORBIT model for developing behavioral interventions (see Figure 4).[173] It specifically represents a *Phase 1a Define Trial* as this study aims to define potential treatment components, identify appropriate subjects, and assess barriers to feasibility and acceptability. The current study is funded by the American Psychological Foundation's Alice F. Change Cancer Wellness grant and has received ethical approval by Massey Cancer Center's Protocol Review and Monitoring Committee (PRMC) and VCU's Institutional Review Board (IRB; HM20022584). Participants enrolled in the current study were asked to complete a 90-minute, semi-structured focus group and subsequent online questionnaires. Both components were completed in April 2022.

Focus Group. Upon enrollment, the RA scheduled the date and time of participants' assigned focus group and invited them to the Zoom meeting via email. The RA also asked participants to complete a brief survey on their sociodemographic characteristics (e.g., age, gender, and race/ethnicity), the deceased patients' medical characteristics (e.g., tumor diagnosis, grade, treatment), and their caregiving role (e.g., relationship to patient, duties) ahead of their scheduled focus group (see Appendix F). Participants completed this brief survey via REDCap, a secure online data collection system, and it took an estimated five minutes to complete. The RA emailed a URL link to the REDCap survey immediately following enrollment. The link automatically provided up to three reminders for completion.

During the virtual focus groups, participants first learned about the standard CALM intervention by means of an emailed information packet (see Appendix G). The facilitator reviewed this information and answered any questions about the CALM intervention before asking open-ended, semi-structured questions regarding their opinions and recommendations for the standard treatment (see Table 1 for sample interview questions for each study aim). Each focus group lasted approximately 90 minutes. The group facilitator was the first author (KDW), who has previous experience as a process observer of a focus group in neuro-oncology. For each question, the facilitator allowed time for each participant to respond, reflecting back what is stated. When additional, clarifying information was needed, the facilitator asked appropriate follow-up questions, allowing time for each participant to speak should they wish. A process observer also attended each focus group (ARL); her main task was to take note of verbal and non-verbal responses, all while maintaining a neutral presence.

Participants were asked to join with their cameras on for ease of dialogue but were also asked to use first names only to protect confidentiality. Sessions were both audio and video recorded with closed captioning, an accessibility and transcription feature of Zoom. After the focus group ended, the audio, video, and closed captioning files were saved a secure network server. Following the focus group, participants received a copy of our study flyer via email to share with other bereaved caregivers should they so choose. They also received a $20 Amazon e-gift card as compensation for their participation in the focus group.

Table 1.
Example Questions for the Focus Group by Study Aim.

AIM 1. **To assess caregivers' perspective of the standard CALM intervention, including the relevancy and application of the four CALM domains, format/delivery, and assessment.**

- In what way are each of the CALM domains relevant and/or irrelevant to your experience as a caregiver and your psychological needs? Please provide an example for each domain as well.
    - Domain 1 = Symptom Management & Communication with Healthcare Providers
    - Domain 2 = Changes in Self & Personal Relationships
    - Domain 3 = Spirituality, Sense of Meaning and Purpose
    - Domain 4 = The Future, Hope, Mortality
- Do you think the standard CALM intervention would be beneficial to caregiver? In what way?
- Do you think the format (3-6 60-minute sessions delivered over 3-6 months) would be feasible for you? Why or why not?
- What would it be like to talk about these issues alongside your loved one?
- What would make participating in CALM easier or more challenging?
- Would you be willing/able to complete a battery of surveys (which take about 30 minutes to complete) before the intervention, immediately following, and three months after?
- Would you be willing/able to complete brief 5-minute satisfaction questionnaires after each session?

AIM 2. **To determine recommendations to improve the feasibility, acceptability, and effectiveness of the standard CALM intervention, including any adaptations to tailor the content, format/delivery, or assessments to the needs of caregivers of patients of with malignant glioma**.

- What other topics relevant to caregivers do you feel are left out and why?
- At what point during the disease trajectory would you prefer to talk about each of these topics?
- When should caregivers of brain tumor patients start and end counseling more generally? Would you be interested in continuing or starting care after your loved one's passing?
- How often would you need to or be able to engage in services while caring for a patient with malignant glioma?
- Would you want to participate individually, alongside your loved one, or both? Why?
- What is the best way format for caregivers to receive an intervention?
- Are there any other logistical concerns to consider when designing an intervention for caregivers in this context?
- If you were a scientist, what other things would you measure or track in caregivers participating in this program?

AIM 3. **To learn more about caregivers' unique experience of death distress, including ways in which death distress is exacerbated or could be alleviated through psychosocial intervention.**

- Many caregivers report experiencing death distress, or fear/despair/preoccupation with their loved one's impending death. Did you experience this phenomenon? And if so, when did you begin to notice these feelings?
- How did you cope with this distress?
- What made this type of distress worse?
- What resources do you wish you received to address this distress?
- How do you believe therapy or counseling could alleviate this distress?
- Is there anything else you would like to talk with us about regarding this type of distress or recommendations for treatment for future caregivers?

Post Focus Group Questionnaires. Immediately following the focus group, caregivers were invited to complete online questionnaires on their current psychological functioning (e.g., depressive symptoms, anxiety symptoms, posttraumatic growth; see Appendices H-K) using a secure online data collection system: REDCap. These questionnaires took approximately 15-30 minutes in total to complete (see Table 2). The RA emailed a link to the REDCap survey immediately following the participant's scheduled focus group. The link automatically provided up to three reminders. If participants completed this portion of the study, they received an additional $20 in the form of an Amazon e-gift card as compensation.

Table 2.
Quantitative Measures of Psychological Functioning.

Variable	Measurement	Completion Time
Depression	Patient Health Questionnaire – 9 Item (PHQ-9)*	2 – 5 min.
Generalized Anxiety	Generalized Anxiety Disorder – 7 Item (GAD-7)*	2 – 5 min.
Attachment	Experiences in Close Relationships Inventory (ECR-M-16)*	5 – 10 min.
Spiritual Well-Being	FACIT-Spiritual Well-Being Scale (FACIT-Sp)*	5 – 10 min.
Belief in the Afterlife	Belief in Afterlife Scale, Form B (BAS-B)	2 – 5 min.
Posttraumatic Growth	Post Traumatic Growth Inventory (PTGI)*	5 – 10 min.
Bereavement	Two-Track Bereavement Questionnaire for Complicated Grief (TTBQ-CG31)	5 – 10 min.
Quality of Death	Quality of Dying and Death Questionnaire – 17 Item (QODD – 17 Item)	5 – 10 min.

Note: *Measures used in the CALM RCT

Measures

Caregiver and Patient Characteristics Form. This form includes questions about the caregiver's demographics, questions about the deceased patient's demographics and medical characteristics, and questions about the caregiver's role and relationship to the patient.

Patient Health Questionnaire-9 (PHQ-9).[176] This nine-item self-report inventory measures depressive symptoms. Derived from the validated full Patient Health Questionnaire, the PHQ-9 asks participants to rate frequency of various depressive symptoms (e.g., *little interest or please in doing things*, *feeling down, depressed, or hopeless*) over the previous two weeks. Each item is measured on a 4-point scale, with responses ranging from 0 (not at all) to 3 (nearly every day). All items are summed to produce a total score ranging from 0-27. Guidelines for score interpretation suggest 0-5 indicates minimal depression, 5-9 indicates mild depression, 10-14 indicates moderate depression, 15-19 indicates moderately severe depression, and >20 indicates severe depression. Developed specifically for use in healthcare settings, the PHQ-9 has demonstrated clinical utility and validity as a screener for depression and is recommended by the American Society of Clinical Oncology.[177,178]

Generalized Anxiety Disorder-7 (GAD-7).[179] The GAD-7 assesses generalized anxiety symptoms within a two-week period. Participants rate how often they experienced various anxiety symptoms (e.g., *feeling nervous, anxious, or on edge*, *not being able to stop or control worrying*) using a 4-point scale: 0 (not at all) to 3 (nearly every day). The seven items are summed to produce a total score ranging from 0-21. Scores of 0-4 indicate minimal anxiety, 5-9 indicate mild anxiety, 10-14 indicate moderate anxiety, and 15-21 indicate severe anxiety. The American Society of Clinical Oncology recommends the GAD-7 as a valid assessment of anxiety symptoms.[177]

Experiences in Close Relationships Inventory (ECR-M-16).[180] The ECR-M-16 is modified version of the larger ECR,[181] a measure of attachment insecurity for both romantic and platonic relationships. It measures two types of attachment insecurity: attachment anxiety (i.e., fear of abandonment; 8 items) and attachment avoidance (i.e., defensive independence; 8 items).

Sample items for each respective subscale include, “I worry a lot about my relationships” and, “I try to avoid getting too close to other people.” All items are assessed on a seven-point scale (1 = strongly disagree; 7 = strongly agree). For each subscale, the associated items are summed, and scores range from 8 to 58. Higher scores indicate greater attachment insecurity. The ECR-M-16 demonstrated good internal consistency, test-retest reliability, and validity in a sample of advanced cancer patients.[182]

The Functional Assessment of Chronic Illness Therapy-Spiritual Well-Being Scale (FACIT-Sp).[183] The FACIT-Sp is a 12-item measure of spiritual well-being that was developed and created for those affected by cancer. The FACIT-Sp has demonstrated good reliability and validity across many ethnic groups and religious traditions, including those who identify as not religious.[184] All items are rated on a 5-point scale from 0 (not at all) to (4) very much. Two items are reverse coded, and two items were slightly reworded to reflect the patient’s illness instead of a personal illness following the precedent by Colgrove and colleagues.[185] The FACIT-Sp produces three subscales of spiritual well-being: Meaning (e.g., *I have a reason for living*; 4 items), Peace (e.g., *I feel a sense of harmony within myself*; 4 items), and Faith (e.g., *I find strength in my faith or spiritual beliefs*; 4 items). It also produces a total score, ranging from 0 to 48. Higher scores reflect greater spiritual well-being. Although there are no specific cut-off points, a large study of mixed-cancer caregivers identified a mean of 35.65 (*SD* = 8.77).[185]

Belief in Afterlife Scale, Form B (BAS-B).[186] The BAS-B is a 10-item measure that assesses the degree to which individuals believe in life after death. For example, participants consider to what extent they agree that “there is supportive evidence for the existence of an afterlife” on a 5-point scale: 1 (strongly disagree) to 5 (strongly agree).

Six items are reversed scored. To calculate a total score, all items are summed; higher scores indicate a stronger belief in the afterlife. This scale was originally validated in American undergraduates, but it can be used for individuals of diverse faiths.[187]

Post Traumatic Growth Inventory (PTGI).[188] The PTGI is a 21-item self-report measure that assesses the positive changes that might have occurred following a stressful event, such as the loss of a loved one to a MG. Participants rate items such as, "I accept needing others" and, "I established a new path for my life" on a six-point scale: 0 (I did not experience this change) to 5 (I experienced this change to a very great degree). The PTGI is comprised of five subscales: Relationship with Others (7 items), New Possibilities (5 items), Appreciation of Life (3 items), Spiritual Change (2 items), and Personal Strength (4 items). The score for each subscale is created by averaging its associated items. Subscale scores >3 suggest moderate-to-high posttraumatic growth in that specific domain.[189] Additionally, a total PTGI score may be calculated by adding all items; scores range from 0 to 105. Previous literature proposes that a score of 46 and above indicates moderate-to-high overall posttraumatic growth.[190] The PTGI was originally validated in breast cancer survivors, yet has demonstrated satisfactory internal consistency, test-retest reliability, and validity in cancer caregivers as well.[191]

The Two-Track Bereavement Questionnaire for Complicated Grief (TTBQ-CG31).[192] The TTBQ-CG31 is derived from the larger TTBQ,[193] a measure of bereavement informed by Rubin's seminal two-track model.[194] The TTBQ-CG31 was designed as a brief measure that specifically taps into symptoms of complicated grief. Each of the 31 items are rated on a 5-point scale. Similar to the TTBQ, the TTBQ-CG31 assesses Biopsychosocial Dysfunction (Track I) and Relationship to the Deceased (Track II). Four subscales may be calculated. *Dysfunction* (9 items, Track I) reflects problems with emotion regulation and coping; *Relational*

Active Grief and Trauma (15 items, Track II) assesses symptoms of trauma and separation anxiety; *Conflicted Relationship with the Deceased* (5 items, Track II) measures the negative or complicated aspects of the relationship; and *Close and Positive Relationships with the Deceased* (2 items, Track II) taps into positive or uplifting aspects of the relationship. The items associated with each subscale are averaged to produce four subscale scores, ranging from 1 to 5. A total score is calculated by averaging the four subscale scores. The authors suggest that symptoms are significant if the total score, Relational Active Grief and Trauma subscale, and Dysfunction subscale scores are greater than 3.40, 4.10, and 3.10, respectively.

The Quality of Dying and Death Questionnaire-17 Item (QODD-17 item).[195] This scale was adapted from the original 31-item version of the QODD[196] and asks bereaved respondents to rate the quality of the dying experience during the descendant's last seven days. If the descendant was not conscious the last seven days, then respondents are asked to consider their last month of life. Each of the 17 items is answered in two parts. First, in Part A, respondents answer how frequently certain end-of-life events occurred (e.g., how often did the patient appear to feel at peace with dying, have their pain under control, breathe comfortably) on a six-point scale: 0 (none of the time) to 5 (all of the time). In this way, respondents can indicate if an event was not applicable. Next, in Part B, respondents are asked to evaluate each of these events on a 11-point scale: 0 (terrible experience) to 10 (almost perfect experience). A total score is calculated by summing the responses to Part B (the evaluation of the experience) and dividing by the number of items that were answered/applicable. This mean is then multiplied by 10, such that total scores may range from 0 to 100. Higher scores indicate a greater quality of death and dying. The 17 item version was validated sample of intimate associates of terminally ill hospice patients and demonstrated good internal consistency and construct validity.[195]

Data Analytic Plan

Quantitative Analyses. Quantitative data from the questionnaires were analyzed using SPSS Version 28. The current study calculated the descriptive statistics (means and standard deviations) and frequencies of each study variable to understand the demographic and psychological characteristics of the sample. This information provided context for the subsequent qualitative analyses.

Qualitative Analyses. The majority of analyses of the current study were qualitative, which reflects the type of data analytic strategy of many *Phase 1a Define Trials*.[173] The research team for these analyses comprised of the first author (KDW), four hired coders (KL, SB, AF, & LT), and the process observer (AL). The coding team included two medical students, two clinical psychology doctoral trainees, and a trained post-baccalaureate student in psychology. All work was supervised by Dr. Ashlee Loughan, who has experience conducting focus groups with samples of patients with primary brain tumors.[197] Most members of the coding team had previous experience and training in qualitative coding under Dr. Loughan. Furthermore, each member of the research team: (1) received additional training from the first author (KWD) and the supervisor (Dr. Loughan), (2) had relevant experience in neuro-oncology, and (3) were members of the LiveNOW research lab.

Data Transcription. The research assistant first transcribed each focus group verbatim using the closed captioning transcript as a starting point and the audio/video recordings to ensure accuracy. The four transcripts were de-identified before uploaded to NVivo version 12, a qualitative data analysis software. NVivo keeps a transparent, electronic record of the coding process that details the researchers' process (i.e., *dynamic audit trail*), including how text is coded, any coder queries, and a separate location for who the responders are; therefore, NVivo supports increased reliability and credibility of findings.[198,199]

Coding Approach. The overarching aim of the focus groups was to understand bereaved caregivers' preferences for treatment. Thus, the current study utilized thematic analysis to examine themes in their responses and recommendations. Thematic analysis is described as a "foundational" type of qualitative research that seeks to identify, analyze, and report patterns within descriptive data.[174] According to Braun and Clarke, thematic analysis is appropriate for examining the perspectives of research participants and summarizing the similarities and differences in responses. To achieve this, the data are grouped by codes, defined as the smallest unit of meaningful data that reflect an overarching theme.[174] Themes are defined as patterns or through-lines in the data in light of the research questions.[174] Additionally, the current study used a primarily deductive, theoretical, top-down approach to analyze the focus group transcriptions;[174,200] this decision was based on the expectation that certain themes would arise in the data (e.g., themes related to suitability, feasibility, acceptability, recommendations), given the framing of the questions, specific research aims, and previous literature in psychosocial interventions. Lastly, data were analyzed at the latent, constructivist level, meaning the research team *interpreted* bereaved caregivers' responses in the context of previous literature, examined any underlying ideas, and did not rely solely on what was explicitly stated.[174]

Coding Procedure. The coding team was trained in the Braun and Clarke method of thematic analysis, which includes the following, iterative steps: (1) familiarize yourself with the data by reading and re-reading the transcriptions; (2) systematically generate initial codes; (3) search for themes by collating codes into themes; (4) review themes by revisiting the data; (5) name, define, and identify final themes; (6) produce the final report by providing examples of each theme and relating each to the research questions.

Specifically, each member of the research team was required to read all four transcripts *twice* before meeting as a group to discuss potential codes. The coding team met on three different occasions to develop the codebook, re-reading the four focus groups transcripts each time in light of the suggested themes to ensure data integrity. Following the third coding meeting, the first author created and distributed a codebook that included the names, definitions, and examples of each code and theme. Subsequently, each of the four coders were randomly assigned to one of the four focus groups to code using the finalized codebook. Each paid member of the coding team coded one transcript in NVivo, and the first author coded all four focus groups transcript for reliability. All major, relevant responses were coded, and responses could receive multiple codes if appropriate. After one round of coding, the kappa value among all coders indicated moderate reliability: 0.55 (range = 0.38 - 0.68). Subsequently, the first author met with each coder to discuss and resolve any identified discrepancies in coding; while Dr. Loughan was designated to resolve any stalemates in this process, this ultimately was not needed. The final reliability kappa among all coders was 0.86 (range = 0.80 - 0.94) and deemed adequate. Throughout this process, to promote data integrity, the first author and research assistant took detailed notes of all activities and decisions (i.e., audit trail[201]) and these were shared with the supervisor.

Results

Participant and Patient Characteristics

For this study, 53 bereaved caregivers showed interest in participating. Of these, 28 completed screening; 14 were unable to be reached; and 11 were not contacted because the target sample size was achieved. Of the 28 screened, 25 met eligibility criteria. The top reason for ineligibility was due to patient's time of death being outside the specified bereavement eligibility window (*n* = 3). All eligible participants consented to the study and completed the initial Caregiver Information Survey. However, two did not complete the focus group or subsequent questionnaires due to scheduling issues. Moreover, one participant was excluded from all qualitative and quantitative analyses due to suspected ineligibility (i.e., not a bereaved caregiver). Therefore, the total sample size for all portions of the study was 22 bereaved caregivers.

Most participants were female (77%), non-Hispanic White (68%), middle aged (M_{age} = 47.27 years; *SD* = 14.98; range = 25-73 years), widowed (41%), had at least one child (68%) and were college educated (77%). Most participants were employed either full-time (27%) or part-time (32%), made at least $75,000 annually, and had employer-based insurance (55%). Full participant sociodemographic characteristics can be found in Table 3.

Table 3.
Participant Characteristics

Demographic Variable		***N***	**%**
Sex	Male	5	23%
	Female	17	77%
Race/Ethnicity	Non-Hispanic White	15	68%
	Non-Hispanic Black	5	23%
	Hispanic White	1	5%
	Mixed Race	1	5%
Relationship Status	Married	7	32%
	Single	4	18%
	Widowed	9	41%
	Partnered	2	9%
Children	0	7	32%

	1	2	9%
	2	10	45%
	3	1	5%
	4	2	9%
Education	High school or GED equivalent	1	5%
	Some college of associate degree	4	18%
	Bachelor’s degree	11	50%
	Graduate or professional degree	6	27%
Employment Status	Full-time	6	27%
	Part-time	7	32%
	Self-employment	3	14%
	Retired	5	23%
	Unemployed	1	5%
Annual Income	Less than $20,000	3	14%
	$20,000 to $34,999	4	18%
	$35,000 to $49,999	1	5%
	$50,000 to $74,999	2	9%
	$75,000 to $99,999	3	14%
	Over $100,000	8	36%
	Missing	1	5%
Current Insurance	Employer-based	12	55%
	Medicaid/Medicare	6	27%
	Private plan	3	14%
	Marketplace	1	5%
Age	Range: 25-73 years	*M* = 47.27	*SD* = 14.98

In terms of the deceased patient’s sociodemographic and medical characteristics, most patients were men (82%) diagnosed with a glioblastoma multiforme (77%), Grade 4 (82%). During the course of the disease, most patients received gross total surgical resection (64%), radiation therapy (86%), and chemotherapy treatment (82%). Average age of the patient at the time of their death was 54.14 years (*SD* = 13.79; range = 30-77 years), and the average time that had elapsed since the patient’s passing was 19.14 months (*SD* = 8.73; range = 6-36 months). Patients lived an average of 36.20 months (*SD* = 36.29; range = 4-117 months). See Table 4 for detailed information about the deceased patient.

Table 4.
Deceased patient characteristics.

Variable		***n***	**%**
Patient gender	Man	18	82%
	Woman	4	18%
Tumor diagnosis	Glioblastoma multiforme	17	77%
	Astrocytoma	1	5%
	Oligodendroglioma	1	5%
	Other	3	14%
Tumor grade	Grade 3	4	18%
	Grade 4	18	82%
Surgical resection?	Gross total	14	64%
	Subtotal	3	14%
	Biopsy only	5	23%
Radiation therapy?	Yes	19	86%
	No	2	9%
	Unsure	1	5%
Chemotherapy?	Yes	18	82%
	No	2	9%
	Unsure	2	9%
Patient age at passing	Range: 30-77 years	*M* = 54.14	*SD* = 13.79
Time since passing	Range: 6-36 months	*M* = 19.14	*SD* = 8.73
Patient lifespan	Range: 4-117 months	*M* = 36.20	*SD* = 36.91
Time since diagnosis	Range: 20-140 months	*M* = 54.35	*SD* = 36.29

Lastly, participants described their relationship to the patient and their caregiving duties. Participants were mostly spouses (45%) and lived with the patient (73%). Many provided care for less than two years (73%) and experienced a change of employment as a result of their caregiving duties (50%). Participants noted a variety of caregiving duties (see Table 5), with the most frequently endorsed responsibilities including completing household chores (95%), communicating with providers (91%), organizing or administering medications (86%), and helping with toileting and bathing (86%).

Table 5.
Previous Caregiving Duties.

Variable		***n***	**%**
Relationship to patient	Spouse	10	45%
	Child	3	14%
	Parent	3	14%
	Other family	4	18%
	Non-relative	2	9%
Live with patient?	Yes	16	73%
	No	4	18%
	Other	2	9%
Length of care	Less than 1 year	5	23%
	1-2 years	11	50%
	2-3 years	2	9%
	3-5 years	1	5%
	More than 5 years	3	14%
Employment change?	Yes	11	50%
	No	10	45%
	Other	1	5%
Managed finances?	Yes	16	73%
	No	6	27%
Managed appointments/calendar?	Yes	18	82%
	No	4	18%
Communicated with providers?	Yes	20	91%
	No	2	9%
Medical decision-making?	Yes	17	77%
	No	5	23%
Organized or administered medications?	Yes	19	86%
	No	3	14%
End-of-life planning?	Yes	16	73%
	No	6	27%
Assisted with driving?	Yes	18	82%
	No	4	18%
Completed household chores?	Yes	21	95%
	No	1	5%
Cared for the patient’s children or pets?	Yes	10	45%
	No	12	55%

Helped with grooming, dressing, and undressing?	Yes	18	82%
	No	4	18%
Helped with toileting and bathing?	Yes	19	86%
	No	3	14%

Psychological Questionnaire Data

On average, the sample demonstrated mild symptoms of both depression and generalized anxiety. Participants demonstrated a relatively strong belief in the afterlife, yet total spiritual well-being—including the three subscale scores—was considered low relative to a comparison sample of neuro-oncology caregivers.[156] In terms of attachment style, participants were slightly more anxiously attached than avoidantly attached. Participants' total posttraumatic growth score was high, yet only two of the five domains were in the moderate-to high range: Personal Strength and Appreciation of Life. In this way, participants' scores for New Possibilities, Spiritual Change, and Relationships with Others were all in the low range. The results of the TTBQ suggest that participants, on average, did not meet the suggested clinical cutoff for complicated grief. Lastly, the mean score of the QODD scale was 47.89, though scores ranged significantly (*SD* = 21.91); participants were most distressed by symptoms of incontinence and the patient's concern for family members/being a burden at the end-of-life. The distress profiles of the sample are provided in Table 6.

Table 6.
Distress Profiles of Bereaved Caregivers.

Variable	***N***	**Min.**	**Max.**	***M***	***SD***
GAD-7	22	0	21	7.95	5.59
PHQ-9	22	0	23	9.49	6.75
BAS-B	22	25	48.8	38.08	7.2
FACIT-Sp Total	22	19	43	28.46	7.88
FACIT-Sp Meaning	22	5.82	16	11.72	3.25
FACIT-Sp Peace	22	2	16	8.36	3.33
FACIT-Sp Faith	22	0	16	8.37	4.81

ECR-M-16 Anxious	22	10	44	28.48	11.67
ECR-M-16 Avoidant	22	13	38	26.84	8.69
PTGI Total	22	13	97	63.06	22.32
PTGI Relationships	22	1	5	2.95	1.12
PTGI New Possibilities	22	0	4.8	2.79	1.49
PTGI Life Appreciation	22	1.33	5	3.82	0.99
PTGI Spiritual Change	22	0	4.5	2.59	1.32
PTGI Personal Strength	22	0.25	5	3.09	1.34
TTBQ Total	22	1.81	4.31	2.93	0.72
TTBQ Dysfunction	22	1.14	4.33	2.56	0.87
TTBQ Relational Active Grief & Trauma	22	1.77	4.85	3.04	0.86
TTBQ Conflicted Relationships	22	1	4.4	2.58	1.04
TTBQ Close & Positive Relationships	22	2.5	5	4.39	0.79
QODD Total	21	14.12	88	47.89	21.91

Thematic Content Analysis

The coding team identified four major themes: 1) caregiver's reaction to the CALM intervention; 2) the relevance of the current CALM domains to the experience of caregiving; 3) caregivers' recommendations to improve CALM to better suite their needs; 4) potential new CALM domains for caregivers. Each theme is further organized by subthemes and codes, which are discussed in greater detail below.

Caregivers' Reactions to CALM

Throughout the focus groups, participants described their reactions to the standard, evidence-based CALM intervention. Many of the caregivers believed they would have experienced benefits from CALM, including increased communication with their loved one and the opportunity to receive the emotional support they desperately desired. Others noted potential concerns or hurdles regarding their participation in the standard CALM intervention, such as not having enough time/energy to participate as well as emotional readiness. The frequency and kappa estimates for each code are listed in Table 7.

Positive Reactions to CALM. Most of the feedback about CALM was positive. Participants consistently stated that participation in CALM might have improved their communication with the patient, supported them emotionally, and/or prepared them for the future, rendering them more effective in their role as a caregiver. Many appreciated that CALM would provide very specialized care specific to advanced cancer that they might not have been able to find in the community; in the same vein, many emphasized that cancer in the brain is unique compared to other advanced cancers. Furthermore, some caregivers believed that even if they had not participated, they might have still experienced benefit through their loved one's participation. In this way, many wished that their loved one had the chance to have some of these discussions with a trained professional. See a sampling of quotes for each code below:

> ***Allows Caregivers to Feel Supported.***
> Woman 3 V: I think it would help me in that I don't talk about my problems with my friends or my kids. It would have helped me to have someone else there, basically just to know what I was going through… I have to tell you, I'm super jealous of those of you who had that because I didn't, and you both sound so calm for lack of a better word over what happened.
>
> Man 2 M: I think the program will be so helpful to talk to someone and let them know how you feel. This will bring some relief, because we need someone who can listen and understand.
>
> Woman 1 T: I have panic disorder, so I know what a panic attack feels like, and it was very similar, but different. It was... It's so hard to explain it was... I thought it was triggering a panic attack in me when we got the definitive, 'yes, the biopsy came back, it's GBM.' And it was just, you know…my husband was extremely supportive and so helpful throughout the whole process. I couldn't have done it without him, but he would have a hard time understanding why I was so afraid for my dad, and I think it would have been helpful to have someone to talk to, you know, about my own fear and my own, you know, just the anxiety over the this. Like I said, the term is new to me, death distress. That's definitely something I would have found helpful.
>
> Woman 3 C: Someone who has all of that experience, and it can just reassure, and I think for me, like making me feel like I wasn't alone, because I think that's a huge thing in this is that Glioblastoma is rare…So I think just the whole idea of not being alone and having the [therapist] have information and knowledge and expertise of cancers is to be supremely helpful.

Allows Caregivers to be Better/More Prepared.

Woman 4 M: Yeah, I think I was one of the very lucky ones, because we went to VCU while my husband was first hospitalized for having the seizure, and then they saw the mass, and then they did all the testing and biopsy. We were offered therapy services while still in the hospital. Could that be because the CALM program was already set in place with Dr. Loughan up, probably…So since this was patient-centered, I think that she modified it as we went through each session for me, too, as a caregiver so I felt very prepared. There's no way she could have told us everything that could have happened and answered every question I had, you know, any given moment, because there was just so many variables. But I feel like I was very lucky to have this setup, and it made a horrible situation a little bit easier. A little bit better to manage through the end.

Woman 1 A: It flip flopped in a nanosecond. Just ahh, and it was how do I respond? How do I react? Hold on. Hold on. Okay, this is, this is, what we're presented with right now. [CALM] would have been… That would have been really helpful.

Woman 2 K: Well, since this is really my first go round with such intense grief and such a big loss, it would have just better prepared me. And maybe, you know, I wouldn't feel wouldn't have felt so lost in all of this. You know, grief is coming, but what is that? You know, every day is a surprise.

Improves Communication.

Woman 2 K: So not only that communication is helpful, but I think that it presents almost a forcing function to have some of those conversations that are hard to have. I think when you're in sort of that caregiving triathlon era, it's like one appointment after the next, after you're sort of like going from one thing to the next, and you don't always prioritize sitting down and diving into these things. And so, I think it's it does act as a forcing function for something that would then be beneficial in the long term.

Woman 3 C: I would think looking back on things, we didn't talk enough about stuff like this.

Woman 2 K: I do wish that we had had more conversations about even like his wishes or things that he wanted the kids to know…having some of those facilitated conversations, I think, would have been nice.

Man 3 C: The fact that the patients and their caregivers will have a chance to communicate and communicate how they feel, what is actually going on, and the skillful communication… it will help. I think it will help.

Provides Personalized Care Specific to Brain Cancer.

Woman 3 C: I think there's a fine line between offering it and kind of being persistent. I don't know if I would have made a call myself, but somebody called me to offer it. I probably would have listened to what it was how I think the main selling point of CALM is that it's people who have experience with neuro-cancers.

> Woman 1 A: I have a lovely therapist who I have been seeing since my first child was born but she's not skilled in GBM and so I wasn't getting a lot out of it.
>
> Woman 5 R: I don't know. CALM, can it be the end-all-be-all-fixe? No. But there's no end-all-be-all-fix. But could it be an absolutely integral part of helping people manage? It's interesting we all say such unique things, but then they're all still the same, but this cancer is unique. I will say this. So that's something that I think needs to be acknowledged when people deal with GBMs. It's not the same as having bladder cancer or breast cancer, and they're all different but something that takes on the brain like it does is a totally different beast.

Provides Benefit by Proxy.

> Woman 4 T: I so wish this... I would have known and been able to get my husband in something like this...For my husband, because he was unrealistic the whole time. He, you know, like I said, I loved that he was positive. He didn't want to know prognosis. He didn't want anybody to give him a time limit on his life and I honored that, but I also did my own research. And when you're reading about treatments like Optune, I mean, you're bound to run across those prognoses, and we eventually kind of learned that, but he never accepted it, even when it was so bad. So, you know, bathroom accidents weren't GBM related. He just couldn't get there in time. Headaches weren't GBM related, they were just headaches. Him getting lost at the cancer center was not GBM related, so all of those types of things. I think it would have helped for someone to like help him understand that those were, and that things were getting more serious. And not the finances are the most important thing, but we lived in XXX, and we were a blended family, and one thing that we didn't have is a will, living or otherwise, because if we talked about that, that meant him accepting that he was going to die, and he couldn't do that.
>
> Woman 2 K: I think I would have wanted to hear like [domain] three and four. You know, from her perspective, because I had to extrapolate a fair amount of that.

Negative or Ambiguous Reactions to CALM. Nevertheless, participants noted important concerns that the coding team classified as negative or ambiguous reactions to CALM. Primary of these concerns was the lack of time or energy to participate in psychotherapy given caregivers ‘high burden of responsibilities.’ Others noted that they might not have been ready to have some of these conversations or, alternatively, their loved one would not have been emotionally ready or cognitively capable of having these conversations. Lastly, for those that would have been ready to participate in CALM, they still worried that sharing their feelings would have burdened the patient. Some of these concerns were later addressed in their recommendation to improve the logistics/format/content of CALM for caregivers. See a sampling of quotes for each code below:

> ***Not Enough Time/Energy to Participate.***
> Woman 2 K: So, I think that is the time I would have benefited the most from this kind of thing. But that's also the time that I had the least amount of time, and that wasn't the time I would have been like, ‘I'm going to take some me time and figure these things out.’ I think we were just in total survival mode.
>
> Woman 1 M: I think, yeah, I think when you're busy and in the thick of it, the last thing you want to think of is one more task or one more thing on the to do list.
>
> Woman 2 J: I hope that this doesn't sound disrespectful, but the CALM therapy to me, while I was going through all of this, I wouldn't have had time. A glioblastoma to us was like this high-stakes game of whack-a-mole. Constantly, it was something, and it was if it wasn't the medicines and the treatments and the treatment options, and he was very able to take care of himself initially, but when he was awake, I would be tending to him, and when he was asleep, I would be researching what else is out there. There really wasn't time for me or any of this. So, the PTSD that she mentioned is relevant because all of this emotional stuff for me got packed in a corner until afterwards.
>
> ***Emotional Readiness of Caregiver and/or Patient***
> Woman 3 C: However, I liked living in denial and having these conversations would have brought me out of the denial that I was happily in.
>
> Woman 5 D: That was also when they told him he couldn't drive, and he got really pissed, so he didn't want to participate in the counseling, but I did, and I was hoping that he would be nosy enough to like participate over my shoulder and learn something at the same time.
>
> Man 1 G: So actually, there's some conversations, which I used to not even to invite him around. Yeah, maybe you should deal with the mortality so that I don't bring that kind of fear in him…In 2014 we went to therapist. And the therapist started talking about mortality, about the issue of death. Yeah, he was so stressed out. I think even though we went through all this session, I think he was like, you didn't even understand anything. The mental strength was not there. Like, yeah, everything was just like, not normal to him.
>
> ***Scared to be a Burden to Patient***
> Woman 1 M: Talking about the struggles with caregiving and what it does to you, both psychologically and emotionally and spiritually and then physically, you know, some of that would be hard to talk about with them because to your point, earlier, you know, the last thing you want is for them to feel like a burden or for them, you know, to take that message from that when that's not the case at all.

> Woman 4 T: You mentioned that, like, would you want to do it alone together or, you know, separate. For me personally, I would want both options. There were so many times that I wanted to say things to doctors or nurses, but felt like I would hurt my husband's feelings or, you know, deflate his positivity and so I had to, like, sneak phone calls and so that that just throws in a whole other basket of emotions, you know, guilt and things like that like, why am I… I shouldn't have to hide things from my husband.

Patient Would have Been Unable to Participate.

> Woman 2 K: And I think those are conversations that by the time I realized we needed to have them, or I wanted to have them, it was already, you know, he was to a point where he wouldn't have really been able to engage in those.
>
> Woman 5 D: While I was participating in counseling, he was declining significantly, and never got to participate. So, it was very much geared toward what I needed.
>
> Woman 3 C: Well, yeah, I mean, I keep imagining these conversations or this happening when he was, you know, on the decline in 2020, when he was, you know, mostly not bed ridden but mostly in bed. But really, you're right, though it would have been it would have been harder when he was, you know, healthier or they would have had a different spin, I guess. Maybe. But it would have been harder for him to have the time to do this when he was declining because then he wasn't able to communicate so.

Ambiguous or Neutral Reaction

> Woman 3 C: Possibly, I mean, I don't know. Maybe, I mean, I wouldn't be opposed to [CALM], I probably wouldn't seek it out, but if it was offered, I probably would take advantage of it. I mean, that's just my personality, I think.
>
> Woman 1 M: I don't know, so maybe those conversations right from the get-go would have been helpful for me? I'm not sure it would have been helpful for my husband.

Table 7.

Reactions to CALM: Frequency and Kappa Values.

Positive Reactions to CALM	**Frequency**	**Kappa**
Allows caregivers to feel supported	16.01%	0.93
Allows caregivers to be better/more prepared	9.17%	0.88
Provides personalized care specific to brain cancer	5.86%	0.93
Improves communication	5.41%	0.92
Provides benefit by proxy	2.11%	0.67
Negative Reactions to CALM	**Frequency**	**Kappa**
Not enough time/energy to participate	4.66%	0.84
Emotional readiness of caregiver and/or patient	3.25%	0.65
Scared to be a burden to patient	2.01%	0.56
Patient would have been unable to participate	1.84%	0.80

Ambiguous or neutral reaction	1.49%	1.00

Relevancy of CALM for Caregivers

Beyond their initial reactions to the intervention, the participants provided myriad examples of how the domains and processes (i.e., double awareness) of CALM were relevant to their experience as caregivers. The coding team was familiar with the domains of CALM and classified their experiences to the appropriate domain, creating subcodes for each. See Table 8 for frequency and kappa values for each code.

Domain 1: Symptom Management and Relationships with Health Care Providers. The majority of codes suggested that the participants struggled most with obtaining medical knowledge about the disease. Some relied on providers and others used online resources; most wanted more information about the disease and what to expect, yet a handful wanted to know less. Related, participants documented difficulties with communicating with providers in order to obtain this information. Hurdles included access to providers, the complexity of the information, providers’ reliance on the patient for accurate updates, and concern that honest communication would negatively impact the patient’s hope. Participants shared memories of both positive and negative encounters with their medical team. A small proportion of the codes reflected the challenges and confusion of medical decision-making, and the fact that caregivers were often forced to make difficult decisions between a rock and a hard place. Lastly, given the eligibility requirements of the current study, many of the participants served as caregivers during the COVID-19 pandemic. Consequently, they explained how the pandemic made navigating the healthcare system even more challenging.

Medical Knowledge.

> Woman 3 V: I also think that the neuro-oncologists were not well equipped to really tell us what the outcome would be in terms of what kind of behaviors is going to happen between now and then. They basically jump right to oh, the deaths will be painless and

not easy but that they would just go to sleep but there wasn't anything about all of the stuff that comes beforehand, and that I think there was a lot of grief to that, because I was finding it out as it was happening.

Woman 5 R: I'm looking at non-methylated, methylated, you know, different. Yeah, I mean, I was I was on every website I could trying to crack this darn code, and I'd be like, ‘No, no, I got it. I'm fine.’ I stayed up to three o'clock in the morning every morning trying to figure this out for her.

Woman 3 C: But I think, you know, I wouldn't allow myself to look at the online stuff. I just wouldn't allow it but when I finally did, even the list of symptoms was so vague, right? Like agitation. What does agitation look like? I think for all of us that look different, right?

Communication with Providers.

Woman 6 S: But one of my issues was the doctors want to talk to the patient. They don't check with the caregiver that what the patient is telling them…because my husband would go in there and pretend like everything was okay, because he was afraid, and I discovered this through just you know friends helping me find out as much as I could, that they don't want to go in and appear to be sick because they're afraid of what the doctor might put them on like you know, extra medication or something. So, I think the doctors need to talk to the caregivers more, but I think the caregivers should have like from the beginning more access, to be able to ask questions to somebody who knows.

Woman 5 R: So, I would go to these doctors, and they would show me something of her MRI and I'd be like, ‘that's all lit up, that's more cancer,’ and they'd be like, ‘let me go talk to the radiologist.’ I don't, you know, I just felt like no one ever gave me a straight answer, I felt like I was an oncologist, or was finding out more than any... and I every time I tried to ask a question, of course, my mom was in the room, and I don't know. I felt like there was no support or anybody really connected with what a GBM was, or just give me the truth. So, I got to tell you, I feel a lot of, I don't know, not that I was lied to, I just felt like I was overlooked a lot.

Negative Relationships with Providers.

Woman 1 A: I remember the E.R. doctor who delivered the news was very matter of fact. There was very little compassion. He had to move on. They were short staffed. They were in in this terrible time that, you know, they hadn't experienced before, and so he was very curt about it, and I was by myself.

Woman 3 R: Well, the nurses on his step-down unit called me a bulldog or a pit-bull, something to that effect, because I had to get the director of nursing involved in his case. They left him in a diaper, restrained for 14 hours. This was a man that walked the day after surgery, so they just didn't want any possibility of a fall. Things like that went on and on and on.

Woman 5 R: We had hospice, literally the last week she died, of course, nothing was working, so they tried Avastin and Avastin rotted out her guts, and somehow she made it through it, you know, getting a colostomy bag and piecing her intestines back together and finally, the doctor said, I think she needs to be on hospice, and hospice said she's not dying in the next two days, so we're sending her home. Well, she died five days later, but just with COVID I mean, we had we just had no clue.

Positive Relationships with Providers.

Woman 3 C: The hospice nurse, who was just like I said before, an angel and he really, he was one step ahead of me, and I trusted him early on for some reason, and he was one step ahead of me. So, when he saw that we needed to order up a hospital bed and a wheelchair and a bedside commode, he somehow talked me into doing that and he made that happen. So, it was sitting in the garage when we needed it. He made sure that we had funeral arrangements, mainly because it's very hard to navigate death.

Woman 1 A: I remember sitting in a doctor's office talking to him on the phone, totally about something no relation to the other, and I said, ‘no matter what this is this is going to be what it is.’ And he said ‘I've studied brains. I work on brains; I try to make brains healthy. I know nothing about what you are going through.’… And I needed that validation from somebody who I kind of had put on a pedestal, not necessarily to make things better, but to just give me something.

Woman 4 M: But then as things got a little bit harder, I felt that Dr. Loughan would reach out to us to touch base more like in that crisis mode time. Either I could email her and kind of get in the books a little bit quicker and she would figure out a time for us or she would reach out to me because she knew that I was too busy to even think about it.

Medical Decision-Making.

Woman 1 A: I went outside and kind of tried to process this, and made phone calls to my immediate, you know, my husband, my brother and... and then, again, I don't know if anybody felt like this. It was this rush of decisions. ‘We have to do this. We recommend surgery. She's going to have to go to rehab.’ It was... It was all of this like planning. And there wasn't really a chance to digest it.

Woman 3 R: I needed support at the onset because, oh my God, like [Woman 1 A] said, all the decisions and everything that happened, it has to happen right now.

Man 3 C: And some of this consent is quite crucial, talking about, you know, you are consenting to your father being exposed to radiation, you know, these conditions will at some point, cause some problems maybe that were not some stuff that he was suffering from so, you know, you are like taking the load. If at all if anything happens to him, it will be you who is going to be asked about it. You're going to carry the load like it was you who consented to it, and you know it will be quite distressing.

Effect of COVID-19.

> Woman 5 M: And in my situation, I don't know if you guys felt this, but I didn't even know what questions to ask. I mean, besides the obvious one like, okay, how much longer does he have, which neither one of us wanted that answer, but I didn't... I had, and we went through our entire thing on COVID, so we never even met the oncologist in person, not once, the nurses we didn't need. He saw I didn't... He was diagnosed by himself in the emergency room because I had to drop him off. Like, which still haunts me...just the personal, the personal touch. I think of our hospice nurse, what I craved that so much because nothing was personal in COVID, let alone this, you know, glioblastoma experience.
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> Woman 2 N: You kind of formed your own little support group in radiation waiting rooms or in doctors waiting rooms as much as you could do so during COVID. I mean, I think the COVID thing added another layer of complexity for all of us because it seems like most of you dealt with at some point COVID as well, but I think it's nice to know, not that it matters, but it's nice to know you're not alone, and I joined a Facebook group and got some very valuable information as well.

Domain 2: Changes in Self and Relations with Close Others. The majority of codes for Domain 2 were about the caregiver's relationship with the patient, followed by their relationship with other family members and friends. It was clear that the dynamic between caregiver and patient was dampened by fears of being a burden as well as changes in personality and cognition. Moreover, caregivers consistently expressed difficulty juggling their relationship with the patient with other relationships with friends and family. A large proportion of codes also described how lonely and isolated caregivers felt in their roles. They felt isolated from family, friends, and providers, though some found comfort in connecting to other caregivers on social media groups. Lastly, participants discussed their relationship with themselves, including how their identity changed as a result of the diagnosis and how they came to both appreciate and question their new identity.

Relationship with Patient.

> Woman 1 M: They feel like a burden. Oh my gosh, you're not a burden. You're the best thing that's ever happened to me.
>
> Woman 2 K: And so probably the last like four or five months of his life, he started dealing with sort of personality changes, memory issues, things that hadn't been a part of

our brain tumor journey up until that point. And this maybe bleeds into that second category on relationships, but it, and that it becomes almost this like mind game, it's hard when your person is changing in ways, and you don't know. You know that probably some of it is symptoms, but you don't know that. It's hard to sort of draw those lines and navigate that.

Woman 4 T: And those are all things that we've read about come to realize or talk with other people about since his passing. No one ever told us, these are the things that you could experience with GBM, and I know every case is different, you know, that lack of empathy. Nothing physical to see. You see these changes, that agitation like crazy spending, having to tell my husband, “No, we can't buy you a car because you don't have driving privileges,” you know, besides the fact that we can't afford one. Those types of things were so horrible, but... and we argued, and what it's left my daughter and myself with is all this regret for the hurt and anger that we felt towards him when he acted that way.

Woman 2 K: But I do think it intersects with CALM, because a lot of like here's what to expect from a symptom decline perspective that is very related to how do I handle those things when they happen and how do I handle it when I can't have conversations with my spouse anymore? How do I handle it when, you know, my husband wasn’t able to find his words the whole time and was just living in his own world? He would say things to people that, you know, they'd be like, ‘Oh, cool, that sounds like a great day,’ and I'm like, ‘none of that happened’ like he was just drawing his brain was all over the place. Then having somebody telling me that that might happen as a symptom is one thing, but then somebody helping me. Like, how do you navigate continuing to have a meaningful relationship with that person and helping your children have a meaningful relationship with that person? It seems like that could intersect with the CALM side of things.

Relationship with Themselves (Identity).

Woman 1 A: I think I always joke like if you would have met me two years ago I... think that that person is so different than the person I am today and so there has just been this significant shift. Right, it's kind of like you lose yourself and you have to kind of reinvent your whole person.

Woman 1 M: I know when my husband was sick and declining and I thought it sometimes felt like the line was blurred between he and I.

Woman 3 R: No, you know, and I ended up almost being like a helicopter parent, when he would go into another room, ‘What are you doing? What are you doing?’

Woman 5 D: So, I think that there, I think that's a lot of what helped me with the CALM thing is realizing, first of all, that it is a really hard job to be a caregiver and someone to give you support that you're doing a great job. You're doing a really important job that most people could never do.

Relationship with Other Family Members.

Woman 1 A: It has a huge effect on your relationships personally within your family or, you know, my parents and sister are the ones that passed, well not my mom, but my dad and sister are the ones passed away. So, you know, I've got two small children. I've got a husband; I've got a mom who's also sick. So how to juggle all of that and how to not have that guilt, but how to really deal too with like the relationship shifts that are happening? Where you have to be everything for everyone, and that's, I mean, that's tough, so for me, it would be domain two I think that would be the most important.

Woman 4 T: Being busy, not being able to find the time, I didn't have any help from family at all. My eighteen-year-old daughter was my biggest help, and especially with my younger [child].

Woman 2 K: I had a hard time navigating… my husband has a very involved family, which is wonderful, and everyone wanted to be present at everything, but you know, you caregivers all have different relationships with their person and different goals. So, his mom's goal for him and getting better is very different than my goal for him and getting better. When we're going to OT, PT, SLP appointments together, she wants him to just feel safe and comfortable. And if you get better, you get better but take your time, you know, and I'm looking at him as my partner and my spouse and like, we've got this like, we are working through this, we are pushed into the next thing, and that then starts to affect my relationship with his family. If you have these different goals. So, it's this whole ecosystem of things happening that. I didn't even really have the time to sit down and realize what it was and think through those things. But now in hindsight, it. It would have been useful, I think, to have somebody sort of prompting me through those discussions and realizing sort of the landmines that we were stepping around in all of those different phases.

Relationship with Friends.

Woman 2 K: There were just there were a lot of interpersonal relationship-based things that we were navigating and sort of flying blind, because a lot of our peer group that you would normally look to and have these conversations with were doing these things in a very different way and having very different conversations than we were.

Woman 1 A: I lost the ability to have conversations with people, because your life has just simply been surrounded by this for so long that that's how you know how to talk about. Yeah, and now you're like, 'oh, what do we talk about?' Like the weather? Like, it's almost like you have to teach yourself how to have those conversations.

Woman 3 V: Well, and sometimes [friends] think they know what's going to help you and it doesn't help you. It just adds burden.

Loneliness/Isolation.

Woman 4 T: I joined so many groups on Facebook and you know, you hate that anybody else is going through it, but it's also such a comfort that somebody understands it because there's nobody that can understand it, I don't think. And even each of us can't understand each other's own individual stories, because they're all so different, but there is something

> similar there that we can understand how shattering it is to lose someone you love before you lose them, with children in the mix. I just felt so stretched thin and like I, I had no help. And if it made it more difficult for me to be the mother, I wanted to be the wife, the caregiver, all of those things, but I was so overloaded and stressed and couldn't get help and didn't know who else to ask for help.
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> Woman 2 N: I think one of the probably one of the hardest things for both the patient and the caregiver is sort of the isolation that you end up with because of the disease itself, because of the demands of whatever treatment you've chosen to pursue, and because of what happens to other friends and family in the process of the course of the disease.
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> Woman 3 V: I felt like I was adrift by myself, because nobody could give me any kind of answers, or how to deal with somebody who was literally disappearing for years.
>
> Woman 1 A: I don't know how others are feeling, but I am still very much coping with the trauma of that loneliness. And that isolation felt like that there was nothing that I could do, or anybody could do to reverse this. It’s been a year and a half, and I'm still trying to figure it out.

Domain 3: Spirituality, Sense of Meaning and Purpose. Under the umbrella of Domain 3, participants spoke about how they made sense of the disease as well as how they were able to find a new sense of meaning and purpose during the process. This included success stories and difficulties. They struggled to find ways to live in the present given their concern of disease progression (i.e., double awareness). They also discussed this from the perspective of the patient and explained how the two processes often differed. Lastly, participants demonstrated both positive and negative experiences as it related to spirituality and religiosity.

Caregiver's Sense of Meaning and Purpose.

> Woman 1 M: For me, my sense of meaning and purpose during that time was I was wholly just focused on him and my children, of course, because they are grieving this loss even just while he was still alive. So, I felt like my purpose during that time was very different kind of from his.
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> Woman 1 A: It was my role in that, so to have some flexibility, especially ongoing because the symptom management, there's sort of a definitive, I think, time frame around that. Then you get down to sort of the end where there's purpose. Those last couple purpose and hope and that kind of thing. I don't know if you all felt the same way that it has taken me a long time to figure out now. I meant something, even though it was it was terrible. Oh my God, I wouldn't wish this on anybody. I had something every single day,

all night and then it was it was gone. So, I was mourning the loss of my mother but I'm also mourning that role.

Woman 2 J: Early on after diagnosis, I was distressed about the prognosis for glioblastoma, but quickly I put the death fear aside because it wasn't serving me or my husband, and I quickly decided that any of us could die at any day, any time and feeling like that made me feel that every day that we have is a blessing.

Patient's Sense of Meaning and Purpose.

Woman 1 M: I think that sense of meaning and purpose is very different for the caregiver than it is for the person, the person with the brain tumor… I don't know, because I wasn't the patient, from his perspective, but I would imagine, you know, my husband was somebody who lit up a room. You know, his whole life when he walked in the door and even when he was sick, and even when he was messing up his words, he still lit up the room. So, I would imagine that part of his purpose and sense of meaning also would come from continuing to do that for the people that he loved and cared about, just to continue to sort of bring that joy.

Woman 1 A: [The doctor] said it, ‘I can't do anything for you,’ and what that shifted to was well, now I have time. She's alive today. What purpose can she and I work on together?

Woman 5 R: My mother was practicing real estate, multimillion dollar, closing houses until the day she died, five and a half months from her diagnosis—and shouldn't have been and she just she wouldn't give it up.

Double Awareness.

Woman 2 N: You’re caught in that situation where you want to be supportive and positive for them, but you also know that this is not going to end well, and that's probably the biggest struggle that I have is trying to put up the front and support her, but then deal with, ‘Gee, we've got to make sure that we get the will done. We've got to make sure that we do the estate planning. We've got to think about all these things.’…So, it was that whole thing of trying to support her and be positive while I in my heart knew that this wasn't going to go well.

Woman 3 C: I also found it was really hard to kind of prepare for death while still having hope. We wanted to stay positive, because he handled his surgery so well. He handled radiation and chemo really, really well. He handled the Optune really well. It wasn't until he had a seizure that we started seeing some of the deficits and then as the tumor was growing, the deficits obviously increased. We made it until about a month before he passed away until he finally kind of accepted that we were... he wasn't going to get better, but it is really hard to and stay positive and hopeful and prepare for death at the same time.…But I think there has to be a cross between like a little bit of comfort, a little bit of reality, a little bit of, little bit more comfort, a little bit... There just has to be this perfect balance of pulling you out of your denial enough to see what's really happening in front of you, even though you don't want to see it. That has to be part of the CALM…. It’s the

> hope and the reality that just they don't go together and it’s kind of black and white. It has to be one or the other. For me, I never found the middle place until probably, you know, he was non-responsive for days before he passed away.
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> Woman 2 N: Well, I think, you know, some of you had very short times, and I know you think that's terrible, but having a very long time has its downsides too, and we had almost three years, and so, as you progress through, you personally start to lose hope as you get toward the end, you're in this terrible conflict between, you're hoping they will die, but you will hope they don't. And that's like the very worst feeling.

Spirituality/Religiosity.

> Woman 2 K: The biggest existential crisis I've ever been in, like I'm a daily meditator and prayer and I was like, F you God, go to hell!
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> Woman 3 V: I think one of the sections that didn't work for me necessarily was the spirituality piece of it. My husband and I, we are not religious. But there is a lot of focus for people to do prayer and that sort of thing for somebody in lieu of anything else, right? I mean, I do meditation and that sort of thing, but it's very Christian based a lot of times, and there doesn't seem to be any room for other kinds of beliefs.
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> Woman 1 T: My dad was seen locally because he didn't like having to have me drive him into XX, you know, every day. And the local center had a chaplain, and she was amazing, but we didn't meet her until towards the very end, and I really wish she had been introduced sooner. I think it would have been very helpful.

Domain 4: The Future, Hope, and Mortality. The majority of codes under Domain 4 were related to the experience of death distress and anticipatory grief. Caregivers expressed validation by the term “death distress” and explained how the feeling manifested and persisted. While they reported often receiving prognostic information from providers, they did not know what to expect at the micro-level towards the end-of-life. Caregivers reported frequently being uncertain about the future and what choices to make; they wanted to know how to prepare themselves and their loved one for death, both practically and emotionally. Nevertheless, they also discussed the important role of maintaining hope, even at the end. A small minority described providing reassurance to their loved one of their future well-being. In terms of financial and legal affairs, participants stated that they not only wanted practical help, but they also desired emotional support, as many of their loved ones refused to complete a will due to their own death distress.

> ***Death Distress/Anticipatory Grief.***
> Woman 3 R: The fear, of course, hit immediately but I had to keep that inside, and I called this, what is the term you were using again, Kelcie? I called it basically anticipatory grief, because technically, I lost my husband during that surgery.
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> Woman 2 K: You know I think this goes back to part of what you were saying that there are different. You know, the patient's fear of death might be the death itself whereas my fear of death is like, what does our life look like after that? Like, how does our life continue on and what does it look like with this big hole in it? … I mean, at that point in time when you know that your person is declining and likely dying soon, you're sad.
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> Woman 1 T: I just I keep coming back to I'm just looking at it up on my screen here, the death distress. I'd never heard of that, but I can attest that it happens… I think it would have been helpful to have someone to talk to, you know, about my own fear and my own, you know, just the anxiety over the this. Like I said, the term is new to me, death distress… I think just being able to verbalize those feelings (death distress) would have helped. And to have them understood. I knew enough about GBM that there wasn't going to be a miracle at the end. You know, so I knew it was coming. But I think it would just help to have been able to say it out loud. These particular feelings and have them kind of more validated, I guess.
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> Woman 1 A: I feel for me. I feel like I was I've always been in death distress like the minute things happened I've just like, that's just become a part of who I am at this point in time. I'm a functioning adult, but I am constantly thinking about it.
>
> Woman 2 N: As a final thought. I'd like to suggest maybe a semantics change: you talk about alleviating death distress. I don't think that's possible. I think you should substitute the word accepting or adapting to rather than alleviate because it can't be alleviated.
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> ***End-of-Life Preparation.***
> Woman 4 T: If I don't know if CALM offers that type of, you know, in that accepting death, how to prepare for it, that would be wonderful.
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> Woman 1 T: About halfway through his disease, he'd just gone in for a regular checkup and his primary doctor had given him just a pamphlet of questions. You know, the five questions at the end of life, and it was great. You know, it took us several more months to kind of pick away at that, you know, a little bit at a time.
>
> Woman 2 K: I know this doesn't speak to what you said, but what calmed me actually was I had this list from hospice, and it described all the things that happen to the body and spiritually, emotionally, and physically when they're dying in the last like months, weeks, days, hours, and it's not linear. You can't check them all off, but I could start

identifying them. So, it helped me recognize where we were in the process, which maybe gave me some peace because it's already been said we knew what the end game was going to be.

Woman 3 C: Our culture doesn't do a great job navigating death and taking care of people who are dying, or caregivers is what I found but we really need someone to kind of show us the ropes because when you're in it, you’re caretaking, it is hard to just take care of business.

Preparing for Financial/Legal Affairs.

Woman 5 D: So, to me, if you don't have somebody helping you with those kind of things, you're really missing out. I had lawyers and financial advisers and people to get all that information from. But if it if everything you need came from, you know, your support counselor, that'd be amazing.

Woman 2 J: We had the opportunity to have free wills done and he didn't want to do it, because to do that would mean to acknowledge that he was going to die, and he wasn't going to go there. And it was not until it took me probably four months of gentle persuasion to just persuade him that we both needed this, it is something we need to do anyway. We have no children. You know, if something happens to me, you're going to need somebody who can take care of you in the way that you would like, so let's both get it done and we did we were lucky that we got it done before he was before he had some big deficit and may not have been considered of sound mind to do it.

Woman 2 K: So, in our case, hospice forced us the DNR. I had already done and the will and the power of attorney but then it's like, you don't understand, it's going down fast. We need her good brain to decide this now, and I will say this it gave us some relief to have those questions settled, and my sister knew all the way until like nine days before she died, she could change her mind on those, and she asked about that and so she had her own power still, she felt like she was still empowered. So, I think DNRs earlier the better, because then you don't have to worry so much about these big, giant monster questions you've got to come up against.

Uncertainty of Future.

Woman 1 T: And it's every, you know, every journey is different. Every GBM timeline is so different it's hard to say, you can't say okay at six months, then, because some people don't get six months.

Woman 3 R: I had huge guilt, I guess, over kind of going along with the people at the hospital saying, ‘let's do the surgery,’ not knowing, you know, I use the famous phrase, ‘if I knew, then what I know now.’ There are many things and I've even talked to the surgeon about the since then and it's two years since my husband passed because I'm still dealing with that guilt, would his quality of life been better had we not have the surgery? It would certainly have been quicker. But either way, he would not have understood what was going on.

Woman 3 C: I also learned that you don't get answers to questions you don't ask, and so there's no additional information given about your situation unless you ask the questions. And in my situation, I don't know if you guys felt this, but I didn't even know what questions to ask. I mean, besides the obvious one like, ‘Okay, how much longer does he have,’ which neither one of us wanted that answer.

Hope of Future.

Woman 2 K: When you're in that situation, you're like, ‘Fight it, fight it, fight it.’ We're going to be the good news story role. That is important in that hope does keep you going.

Man 3 C: And the last two domain was about the future, hope, and mortality--yes, if at all, you're going to have a person to share with you what the future holds for you, to at least tell you there is hope in living in this world. It would be quite beneficial and important.

Woman 2 J: I decided that glioblastoma can take an awful lot from me, but it can only take my happiness if I let it, and so, pretty quickly, I discarded that and we went on to fight to win and decided we were going to be one of the five percent to go through the eye of the needle, and that's what we did. He succumbed after fourteen and a half months, but only in the last month would I say did he reconcile himself to that he was going to pass and we had many what I can only call angelic visitations, which put us both at ease, put him at ease that he was... that he was going somewhere good and put me at ease, that he was going to be okay.

Information about Prognosis/Progression.

Woman 1 M: For me, I don't know what you all's experience was, but I felt like no one was ever really talking about medical providers particularly talking about what to expect. You know, and I know no one has a crystal ball, no one can predict the future. You know, we have our numbers and our research and our data and, you know, our median age or, you know, time of survival and all of that. But I feel like nobody really talks about, you know, when the decline starts, here are some things you might be wanting to think about, or here are some things that you might want to sort of, you know, prepare for or nobody really talks about that you know.

Woman 1 T: Our neuro-oncologist was great. She was very, very knowledgeable, and knew what to do... but I don't feel prepared us at all for some of the decline, or any of the decline really, I mean, she kept saying that, you know, six months away from now after having your last seizure you can drive again, and there was absolutely no way that he could never drive again. Am I right? I mean yeah, I really do wait and the same I had that same experience with the asking on the message boards, you know, about delusions, I mean all of a sudden, he's very delusional and seeing things, and everybody was kind of silent about it was very strange, because I mean, you know, from my own research, I have found that's very common. So, I don't know, I get that it's a fine line between, you know, scaring a caregiver with what could or could not happen. But you know it's just as scary when it's kind of thrust upon you with no forewarning.

Reassurance to Patient.

Woman 2 N: I know she struggled with the idea of the future and mortality, she worried a great deal about what her father and I were going to do without her…Your kids never think that you're competent to the degree that they would like you to be. So, I think she was really worried that if she wasn't here to keep an eye on us and to make sure that, you know, we were doing what she thought we should be doing, that that things would just fall apart.

Woman 4 M: Yeah, we had those conversations because, again, almost all of our sessions were together and so the focus was me being able to say that I was going to be okay and not making plans, just I'm going to be okay…I think it was important for me to know that my husband knew that I was going to be okay, and it was, that was enough. Did we need to discuss what I was going to do and had this plan? No, I didn't need to add more to his plate, and I also didn't need to add more to my plate. I didn't need to have a plan other than just the things that needed to happen for him, the immediate things the lawyers, the will, all that kind of stuff. But yes, knowing that it was going to be okay, I was going to be okay.

Table 8.

Relevancy of CALM: Frequencies and Kappa Values.

Domain 1	**Code**	**Frequency**	**Kappa**
	Medical knowledge	16.16%	0.88
	Communication with providers	9.76%	0.79
	Negative relationships with providers	7.41%	0.90
	Positive relationships with providers	6.52%	0.84
	Medical decision-making	4.30%	0.94
	Effect of COVID-19	8.22%	0.81
Domain 2	**Code**	**Frequency**	**Kappa**
	Relationship with patient	19.64%	0.88
	Relationship with themselves (identity)	6.53%	0.66
	Relationship with other family members	9.86%	0.88
	Relationship with friends	5.06%	0.50
	Loneliness/isolation	11.87%	0.91
Domain 3	**Code**	**Frequency**	**Kappa**
	Caregiver's sense of meaning/purpose	5.20%	0.49
	Patient's sense of meaning/purpose	4.50%	0.65
	Double awareness	15.52%	0.87
	Spirituality/religion	5.44%	0.80
Domain 4	**Code**	**Frequency**	**Kappa**
	Death distress/anticipatory grief	13.18%	0.85
	End-of-life preparation	11.91%	0.72

	Preparing for financial/legal affairs	5.55%	0.93
	Uncertainty of future	5.55%	0.87
	Hope of future	3.97%	0.81
	Information about prognosis/progression	2.88%	0.99
	Reassurance to patient	1.76%	1.00

Caregivers' Recommendations to Improve CALM

Although there were many examples that the domains of CALM were relevant to their experience, participants, nevertheless, made suggestions to improve the timing, content, format, and logistical concerns. For each of these categories, there was not always a clear consensus, but rather, ideas for the study team to consider when introducing services, recommending joint versus separate sessions, initiating services in the disease course, and overcoming logistical barriers (e.g., scheduling, travel). In addition, caregivers shared novel ideas for supportive care services outside the scope of CALM, such as a 24-hour caregiver hotline. See Table 9 for frequency and kappa values for each code.

Recommendations for Timing of CALM in Disease Course. Participants often asked the facilitator "when" CALM is usually offered in the disease course because of their timing concerns. While many reported that they would have been too overwhelmed or not emotionally ready to have these discussions initially, many also noted they would run out of time to participate in CALM due to the patient's rapid decline if the intervention was offered later in the disease course. They also noted the discrepancy between their emotional readiness and the patient's readiness, and how the content of sessions would depend on where they were in the disease course. The most common, clear recommendation was to offer CALM at diagnosis—or very soon after—and to continue to offer it until the patient and/or caregiver was ready.

> Woman 2 K: I like the idea of it being offered from the beginning and consistently, I think that anything offered in the beginning, you know, like everybody else said, your head is spinning and a million different directions and you're just trying to figure out

> what's up and what's down. But that's often the time that a lot of services are offered. And then it goes radio silent for a while when there are down times that you could think about them a little bit more. So, I think, the more touch points you can get like, ‘hey, we're still here. These are the kinds of things we do,’ would be helpful.
>
> Woman 4 T: So, I would have loved to have the resource or say, ‘okay, this is what's available, this is what's out there.’ And then also, maybe have like a follow-up, I don't know, like four, six, eight weeks check-in: ‘Okay, how are you doing with these types of things?’ And for the caregiver to be able to lead it, like it would be tough to say, ‘okay, I want to do this, but I will have to commit every so often’... I know it'd be difficult, but I'm kind of an as needed basis, I guess.
>
> Woman 1 M: Maybe this therapy is something that should go run the spectrum. It should be something that starts off, you know, relatively in the beginning when you're being bombarded with trying to process this new diagnosis and you take it through till the end.
>
> Woman 1 T: I found that you need to have those hard conversations sooner with GBM patients, you know, or at least with my dad, you know, just like I said, everything moves so fast when the decline begins that you know you need to do it while they're cognizant and aware, and before the symptoms really kick in... It's so overwhelming at the beginning, I do agree that it would be highly beneficial, but I just don't even know how you would work it into it, you know? I mean, yes, in hindsight, it would be fantastic, but everything is just hitting you all at once that any more overload. I just don't know that it's practical. I would say for sure towards the end, I mean, any time that palliative is even introduced, I would say at that time would be perfect.

Recommendations for Content of Sessions. Beyond the four domains of CALM, there were several patterns regarding recommendations for the content of sessions. Participants indicated that the domain that would take precedence would vary throughout the disease course; yet they often argued that difficult conversations were essential to CALM. Others recommended that CALM include more tangible, skills-based components for stress management, coping, finances/legal affairs, and caregiving itself.

> Woman 4 M: Yeah, I think the therapist should prompt those types of questions, because there were times that I certainly didn't want to go into a session and just say the things that I was afraid of... afraid of because of course, he was with me in those sessions, but even now, like sometimes I just don't want to go there. But I think if you're prompted, then you can get there, and you feel safe already because you've established a relationship, but then you can have those difficult discussions. But, just my personality, I won't generally initiate those conversations.

> Man 1 G: Okay, can we talk about stress management? I think it is fundamental because it is very critical to both...Yeah, because a lot of challenges and it brings a lot of stress. So, if you can have that kind of program, maybe to be added that can be among the domains there so that we can have something for dealing with the stress.
>
> Woman 1 M: Well, you know, sometimes life gets very practical, even in the emotional realm. And you want to you want some tools in the toolbox.
>
> Woman 1 A: I hate the term, but I will use it: self-care. It's so important and I had to get really good at taking care of myself so that I could take care of everybody else but allowing yourself permission to do that, I think, was really hard for me to, you know, enact and so I think bringing that. into the conversation as well, like you can't help, you can't help anybody else.

Recommendations for How to Introduce Services. This code largely overlapped with participants' aforementioned recommendations for when to initiate CALM in the disease course, with a few additional components. The majority indicated that they would have liked to become aware of CALM earlier than later, even if they would have waited to begin therapy. In addition, participants emphasized the importance of including the medical team in introducing CALM and that CALM should be presented as a holistic approach to care. Lastly, many recommended that the team *persistently* recommended services, as this would improve access to the caregivers who would not seek treatment on their own but would benefit, nevertheless.

> Woman 1 T: Yeah. I think they should have like a middle ground, you know, like you said after the initial shock, and you know, first learning about everything when things kinda somewhat settle down. If there is an introduction of CALM then and kind of, you know, like a strong introduction, but not like, if you want it, it's here. If not, call us, but then a reintroduction towards, you know, towards the end or just before. And every journey is different. Every GBM timeline is so different, it's hard to say, you can't say, 'okay at six months,' then, because some people don't get six months.
>
> Woman 2 K: I agree, I wouldn't have taken extra time to find it. But I think presenting it as a part of a holistic treatment plan, like we are treating this person's body and the disease, but this is also a hard journey and you guys are already stressed. This is like this is a part of, you know, treating the mind and like trying to make this as gentle of a journey as possible.
>
> Woman 3 C: You'd ask, I think, if I would have participated, I guess I don't know that I would have thought it out if it was like a flier on the back of the doctor's door. I probably

> wouldn't have been like, ‘Oh, I need that.’ But if it was presented by the doctor or presented by my spouse, if the doctor or therapist presented it to him and then he presented it to me, I probably would have or if it was reached out that way. So, I guess that's just me, I wouldn't have probably sought it out, but I would have taken advantage if it was offered.

> Woman 2 J: We got wads of paperwork about, you know, about brain tumors and, you know, all this stuff to read, and to get a handout in there [about CALM] would have been helpful for me because at night I would sit and read this stuff, and I still have most of it, actually. And to be able to, you know, like to have it in the back of your mind and at the time that it pops up, that you read, oh, I read something about that in that yellow folder, right?

Recommendations for Independent/Joint/Combo Sessions. There were different opinions on if CALM should be delivered as a dyadic versus individual intervention. Most commonly, participants articulated that there were some conversations that they would have benefitted having as a dyad and others that they would have preferred to have alone without their loved one present. Time was a factor to consider in having separate sessions. When participants recommended separate sessions, it was usually due to the sensitive nature of the topic (e.g., the future or mortality).

> Woman 2 K: I think there is probably in each of these domains, a space to have a solo conversation that's more caregiver focused as well as a group conversation. I think different things would be or sort of different angles of the same things would be discussed...Along with the mortality again, together conversations are fine, but I think also separate conversations would be very much warranted. You know, you have very different fears.

> Woman 5 D: For me, I would have definitely appreciated it being separately, because we are very different. He is an eternal optimist, and I'm an eternal plan for dooms-dayer. and we would add very different focus.

> Woman 1 T: I agree, I think it would have made the hard conversations a little bit more easily facilitated. You know, if there was a, you know, an opportunity for both, you know, at least even midway through. But you know, towards the end I would say just, you know, just for myself.

> Woman 4 M: If we did it separately, I don't think there would have been enough time for both of us. You know, him at one time me at another, even if it were back-to-back, because we were already together, or I had to drive him somewhere.

Recommendations for Improving Logistical Concerns. In order to improve the likelihood of caregiver participation, the participants of the focus group made suggestions regarding logistical concerns. Many strongly recommended the option of telehealth visits to save time. Others suggested scheduling appointments in advance that align with patient scans or offering times after normal hours. Lastly, caregivers noted the importance of meeting with the same therapist to avoid repeating their story.

> Woman 4 T: And so, if there were virtual options for CALM, that would be probably most beneficial to give people that option, and if people do have the great benefit of having help and could get away, it's probably great to offer in-office as well.
>
> Woman 3 C: If you have a place to privately talk...I was worried about him overhearing conversations that I had too. So, there's that, but I think that the tele-visits would be for sure, a lot less time consuming. Because there's not the, you know, the driving and the parking and the getting presentable.
>
> Woman 3 R: Into late evening, possibly after that patient has been put to bed and is comfortable and hopefully sleeping for a while.
>
> Woman 2 K: I feel like there is so much wasted downtime for caregivers during appointment days. When the patient is going in and out of blood draws and vitals and scans and sitting and getting treatment. We are often there twiddling our thumbs, chatting, looking at whatever is, you know, gabbing on the TV, whatever they have up like that. I know that can probably be a scheduling nightmare too, but that is a great time to pull caregivers into some of these things since they already have taken the day off work. They are already there; those waiting rooms are filled with people sitting around nervous. So, I feel like that would be a good time to integrate some of these things.

Novel Ideas/Recommendations. Participants brainstormed ways of implementing supportive services that extended beyond the scope of CALM. Examples of these ideas included creating a psychological and educational support hotline for caregivers after hours, creating handouts for caregivers or a list of homework questions for both patients and caregivers to answer in their own time, and scheduling services during patient MRIs.

> Woman 6 S: There were sleepless nights, and in the end when he was going to die, I had nobody to talk to until I found my own people to talk to. So, a 1-800 number when you're awake at two o'clock in the morning if you have a question or some worries.

> Woman 2 N: I don't know that I would have been receptive to in the in terms of the frame of mind, I might have even been actually annoyed by someone trying to put me in something that I was constantly looking at my watch and thinking about what was coming next, I don't think that would have been the right frame of mind when I really needed that was like at 3:00 in the morning after the 15th time I had put her back to bed and the 12th time that I had changed the sheets and that sort of thing when I was ready to just lose my mind and walk out the door, but knew I couldn't.
>
> Woman 3 C: I was just thinking, I wish somebody had kind of...even if it wasn't in a setting, if we had like a list of homework questions sort of to go through.... maybe like homework, you know, things to discuss together without a third party or things to discuss with your children or your parents or siblings or… And almost of it's like a task, like if it if it's an assignment, you know, it somehow makes it easier then then coming up then then just having conversations that are that are hard, I guess, if you know, but if you're like, 'Oh, well, my therapist or the counselor said that we need to talk about this,' then you know, I don't know. It's just a little bit easier.
>
> Woman 1 T: I mean, if you could schedule the sessions for the caregiver at the same time the patient is in the MRI. I mean, there's so many MRIs, you know?
>
> Woman 2 J: Or even a kitchen magnet, a magnet to stick on your kitchen with the phone number and the website.

Table 9.

Recommendations to CALM: Frequency and Kappa Values.

Caregivers Recommendations to Improve CALM	Frequency	Kappa
Recommendations for timing of CALM in disease course	22.22%	0.93
Recommendations for content of sessions	15.51%	0.82
Recommendations for how to introduce services	11.14%	0.91
Recommendations for independent/joint/combo sessions	10.24%	0.90
Recommendations for improving logistical concerns	8.51%	0.82
Novel ideas/recommendations	5.92%	0.86

Potential New Domains for Caregivers

Beyond the four domains of CALM, the participants of the current study described other areas of concern that specifically reflect the caregiving experience: that is, 1) the burden they experience in their unique caregiving role and 2) their experience of bereavement following patient's passing. These two topics are not currently captured in the standard CALM intervention; therefore, the coding team classified these two topics as “potential new domains of CALM for caregivers” and noted the various subcomponents of both.

Caregiver Burden. First, participants consistently described the significant burden they incurred as a result of their special role. As seen in their experience of Domain 2, the participants believe that caregiving comes with unique stressors that are not experienced by the patient, other family members, or friends. Consequently, their burden was emotional, physical, functional, financial, and cognitive. The stress of caregiving greatly interfered with their overall well-being, and caregivers either felt overlooked or unsure of how others outside their role could help manage their experience of burden. See Table 10 for frequency and kappa values for each code related to caregiver burden.

Emotional Stress of Caregiving. The majority of codes centered on the emotional stress of caregiving. Participants reported complicated emotions, such as feeling shocked, overwhelmed, powerless, and guilty. Caregivers also reported a variety of anxious thoughts about taking care of their loved one. All together, these emotions added to their experience of significant stress.

> Woman 3R: It was initial shock and disbelief and then I very quickly transitioned over to caregiver, I suppose, and very strongly into advocate. The fear, of course, hit immediately but I had to keep that inside.
>
> Woman 1 A: It was this rush of decisions. We have to do this. We recommend surgery. She's going to have to go to rehab. It was... It was all of these like planning. And there wasn't really a chance to digest it. Truly, until we got her home with us, and then it set in that how... How am I going to cope with my mother dying in my home?
>
> Woman 2 N: And so, as you progress through and you, you personally start to lose hope as you get toward the end, you're in this terrible conflict between, you're hoping they will die, but you will hope they don't. And that's like the very worst feeling.
>
> Woman 2K: I don't know if everyone's loved one had seizures, but in general that's a pretty stressful thing to witness in a human being...There's just a lot of like mental acrobatics that's happening on the caregiver side to try and be helpful, but not like over

> dictate the patient's life. And, you know, you're also stressing...we're on a boat like what's going to happen? If this person had a seizure and we're on a boat. I think stuff that's sort of always in the back of your head.

Personal Needs, Health, and Other Responsibilities. Beyond the emotional stress of caregiving, participants explained that their role impacted their ability to take care of themselves physically and functionally. They noted impairments in health, including impairments in sleep, energy levels, and strength. They also discussed how their role meant personal/alone time was a rare experience. Lastly, they described how being a caregiver interfered with other important responsibilities, such as their job, completing household chores, and parenting.

> Woman 2 J: At the end, I was so sleep deprived that I just needed some sleep, and I needed someone to come and be with him for a couple of hours so I could get some solid sleep, and the only way I could get it would be if in the respite care where they take him away and put him in a nursing home. And I said, ‘I can't do that.’ I just need somebody to be with him in case he needs to use the urinal.... He had a lot of deficits, and he needed a lot of physical help, and it was really... I could barely keep up with the physical demands of the situation and it was really all I could do to keep cheerful with him and take care of those needs. Any of my only need that I needed met was sleep. I needed sleep. I couldn't get help.

> Woman 4 T: If people do have the great benefit of having help and could get away, it's probably great to offer in-office [appointments] as well, because when I could do that, it was nice to get away from the house and nice to sit in the car and drive and listen to the radio and not have the responsibilities for a little while.

> Woman 3 R: During the day, [caregivers] are either trying to work or they're running after this patient trying to make them comfortable, entertain them as best they can, and keep up with being a wife or a mother, and keep up with your household duties.

Financial Burden. The extent of caregiving responsibilities also created a financial burden. Participants explained this burden was a result of leaving their jobs to become full-time caregivers and paying for medical equipment near end-of-life or their loved one’s medical bills.

> Woman 1 T: I did take several leaves of, I mean, a few leaves of absences from my job to help care for him.

> Man 4 B: So, at that time I was the only person who was able financially to come through for him and his medical bills...I was lacking funds because, you see, I was using most of my savings to take care of my uncle because he was also, let's say, demoted from his work.
>
> Man 2 M: We went to seek help, but we had no money at the moment, because he was the bread winner. That's when I realized how desperate of help...I would like to give money...made me powerless, and I just cried not knowing what to do about the situation.
>
> Woman 4 T: I had went and bought hundreds of dollars' worth of equipment, bedside commode and things like that because nobody was offering that kind of help and home health…One thing that we didn't have is a will, because if we talked about that, that meant him accepting that he was going to die and he couldn't do that. We didn't have a will because if we talked about that, that meant him accepting that he was going to die…All these additions that we added and worked on together in our home. I'm now entitled to one sixth because we didn't have a will. One sixth. So even everything that I brought to the marriage is no longer mine, and I can get one sixth and so having someone help the patients understand the reality would be beneficial in that aspect.

Trouble Asking for Help. Though their burden was high, many caregivers described that they were unable to ask for the help that they desperately needed. There were various reasons for this, including: 1) the inability to articulate what they needed at the time because they were too overwhelmed or focused on the patient and 2) believing their unique role as a caregiver could not be replicated by anyone else.

> Woman 1 M: You know, and sometimes you don't even know what you need, you know? You know, it's kind of like one of the things I learned about going through the process. I have learned now, if I have a friend or know someone or they're in a hard time, you don't ask what they need. Because a lot of times, people don't know what they need, you know, and they can't necessarily tell you. Nobody's going to say, 'Oh, well, I need this and this and this and this,' you know, especially sitting in a in an appointment that you're already doing, you know, you don't know what you need.
>
> Woman 3 C: I didn't want to leave him because nobody could take care of him as well as I could, and it was really my greatest privilege to take care of my husband. But nobody was going to do it as well as I could. Not only that, but just how the experience was so private, and so I just wouldn't want anybody else to see him in the state he was in. That was a challenge for me. Was letting people help, you know.

Feeling Overlooked. The extent of caregiver burden was exacerbated without proper support. Many described feeling overlooked, especially by medical teams. They wanted to be acknowledged, even though the focus was primarily on the patient. Moreover, they continued to feel this way throughout the bereavement period.

> Woman 3 V: So, you know, everything was about my husband, all everything. There was no real attention to me or my kids, you know, as adult children. And so, I think that that would have been helpful just to have that... all of a sudden now you're. in a lot of ways, you're the patient now. And I think that that you get sort of forgotten because once that person dies, you're moving onto something else and, you know, we have a short bereavement kind of view in America, I think, and it's not short and it continues to roll on through your life for quite a long time.
>
> Woman 5 R: I felt like there was no support or anybody really connected with what a GBM was, or just give me the truth. So, I got to tell you, I feel a lot of... I don't know. I felt like--not that I was lied to--I just felt like I was overlooked a lot.
>
> Woman 5 R: Anything that you could just give any support, I think, to acknowledge a caregiver would be huge because I don't even think that was acknowledged from the doctors.

Table 10.
Caregiver Burden: Frequency and Kappa Values.

Possible New Domain: *Caregiver Burden*	**Frequency**	**Kappa**
Emotional stress of caregiving	19.40%	0.79
Personal needs, health, and other responsibilities	3.97%	0.65
Financial burden	1.88%	1.00
Trouble asking for help	2.08%	0.68
Feeling overlooked	4.02%	0.87

Bereavement. The current study's sample composition of bereaved caregivers allowed for conversation on how the patient's death continues to impact their emotional state. Participants explained their emotional grief reactions and how their identity, beliefs, and relationships have all changed as a result of the loss. Consequently, participants also indicated they would benefit from continued psychological support during the bereavement period, a theme that overlapped with their recommendations for the timing of CALM. There was little evidence of posttraumatic growth, though caregivers were able to express gratitude for their unique role in the patient's life and to one another. See Table 11 for frequency and kappa values.

Emotional Manifestations of Grief. Participants described a wide range of negative emotions during their bereavement period. Beyond feelings of sadness, loss, and yearning, there was evidence of guilt and trauma, where caregivers attempted to make sense of the disease and their role. Caregivers also described feeling isolated and forgotten. These feelings were still strong years following the death of the patient.

> Woman 1 A: I don't know how others are feeling, but I am still very much coping with the trauma of what that loneliness and that isolation felt like -- that there was nothing that I could do, or anybody could do, to reverse this. You know, again, it's been a year and a half, and I'm still trying to figure it out.
>
> Man 1 K: Unfortunately, for some of us, the pain never goes away. I can imagine for myself, I'm at this age of mine. I've lost my dad to... who succumbed to the disease. It's been three years ago, but I still feel as if it was just the other day and memories won't disappear.
>
> Woman 3 R: But then again, I have huge guilt, I guess, over kind of going along with the people at the hospital saying, ‘Let's do the surgery,’ not knowing, you know, I use the famous phrase, if I knew, then what I know now. There are many things and I've even talked to the surgeon about the since then and it's two years since my husband passed because I'm still dealing with that guilt, what his quality of life been better had we not have the surgery? It would certainly have been quicker. But either way, he would not have understood what was going on.
>
> Woman 2 J: So, the PTSD that she mentioned is relevant because all of this emotional stuff for me got packed in a corner until afterwards.

Loss of Meaning/Identity after Patient Death. Many described that after their loved one had passed away, their life lacked the same meaning and purpose. Not only did their relationship with the patient provide meaning, but their identity as a caregiver was source of meaning that quickly vanished after the patient’s death. Some were able to discuss their process of discovering their new identity without their loved one.

> Woman 2 J: So, the after the aftermath of it, when I struggle with the why am I still here, and that I am still here, so there must be a reason for it. So, I just keep plugging along one day at a time.
>
> Woman 1 A: When mom died, I didn't have anything. I'm a mother, I'm a wife, I'm a professional. I love being outdoors. I have pets. I have friends, and yet all of that just sort of became this sort of grey sort of I hate to say nothing, because I don't want to make it sound like my children are nothing. My husband's not nothing...I meant something, even though it was it was terrible. Oh my God, I wouldn't wish this on anybody. I had something every single day, all night, and then it was it was gone. So, I was mourning the loss of my mother but I'm also mourning that role.
>
> Woman 5 D: We did a lot of talking about the future and what to do after [Woman 5 D's partner] died and how to basically find myself again and find my new identity, which wasn't as a caregiver. Going back to the gym, going back to like, I retired the day, the month after. Actually, he died on the 19th of December. I retired January 1st, so I went back to work part time and just like figuring out how to kind of pick up the pieces and get on with my life in a meaningful way.

Desire for Continued Psychological Support. Related to their recommendations for the timing of CALM, caregivers indicated that they would have appreciated continued psychological support after the patient’s passing. This would not only serve to help them feel less ‘forgotten’ by medical systems, but it would also provide validation, a place to process their loss, and coping skills, when appropriate, particularly around significant dates (e.g., the patient’s birthday, death day).

> Woman 4 A: Sometimes we forget that after people pass away, we still need the support and so having a booster session or having those additional sessions after could be helpful because we get kind of forgotten about after people die like, ‘oh they're dead, okay.'
>
> Woman 1 M: Some coping skills, preparation for things, you know, like, post loss, for example. Okay, I'm preparing for his birthday. You know, I don't know how I'm going to feel on that day, but I'm guessing I'm going to feel terrible. And I talked about this with a therapist like, what are the tools that you need, okay? Well, you know, you're anticipating this, so maybe on that day, what would you find helpful? Would you find it helpful to work or not? Or would you find it helpful to, you know, get together with people that he loved? Or would you rather, you know, experience that day sort of on your own? Sort of just to be thinking ahead because that day is likely to be hard for you, you know? I know that's a that's a post loss example.

> Woman 1 A: It would just be nice to know that it's there when caregivers, certainly myself in this role needed it, especially after mom died... Now I'm like going through the five stages of grief and like, my story's over. I have been going through a complicated grief cycle for two years and I'm still going through it. I'm going to keep going through it and so just talking about that, I think and having that validation that you're going to and it's okay and I think that would be helpful.

Changed Perceptions of Death Itself. After watching their loved one pass, several caregivers noted that their view of death had changed. Specifically, they felt less fearful of death and were more likely to accept death as a natural part of life.

> Woman 2 K: It made me face the reality that we all die, and we don't know of what yet, but we will. That is just like a part of our condition, the condition of all living beings and we're so afraid to address. I guess I'm not as afraid to address that now and like knowing that and having a better understanding of my own mortality now and the mortality of everyone around me hasn't detracted from my hope and other things.

> Woman 2 J: I will say that I do not fear death after going through this experience. For a while after [Woman 2 J's husband] died, it was like I held his hand when he went through the portal, and I could see how fake all of this is that this world is, you know, it is but a play and s the world is a stage, and we are the players.

Changes to Social Relationships after Patient Death. Many of the participants' relationships changed after the loss of their loved one. These changes were described as negative, such as losing friends who are partnered, feeling detached from others, difficult navigating a relationship with the patient's side of the family, and losing interest in social interactions.

> Woman 3 C: I am struggling to manage and maintain relationships of all kinds because I go from not even just wanting to be around anybody to what do I have in common with people anymore, especially our couple friends? You know, it feels weird to be included with the couples, but it would feel even more weird not to be included with the couples, right?

> Woman 2 J: Relationships were strange and still were after [Woman 2 J's husband] died because the mundane things like the weather. Who gives a crap? I could not sit and talk silly stuff with people, because it was just so irrelevant and so for a long time, I was no fun...I don't have time for B.S. and drama that kind of stuff anymore. I mean, I can enjoy a joke now, and I can laugh and have fun, but when I hear people complaining about little stuff that's not a big deal. I say, man, 'I'd trade ya in a heartbeat.'

Evidence of Posttraumatic Growth. There were very few instances of posttraumatic growth that were explicitly stated; moreover, these examples were only identified by one coder. One caregiver discussed the new relationships she gained from meeting other caregivers online. Another discussed an opportunity to become closer to her husband and learn a new side of him. Lastly, caregivers expressed gratitude to one another at the end of each focus group.

> Woman 4 T: And so, like I said, connecting with those or other wives is the only, you know, I've had so many other people reach out to me, and I've made new friends because nobody else gets it. Someone I've never met will send me messages and say, 'I had a hard day today. I know you're the only one that will understand.'
>
> Woman 2 J: When he said, 'My name's [Woman 2 J's husband], and I'm twelve years old' when he's really 61, I kind of took it as an opportunity to o meet my 12-year-old husband. It was sad, but it was also a unique opportunity because I didn't know him when he was 12, so I sat and talked with 12-year-old husband, it was fascinating.
>
> Woman 5 R: We're all in the same club, but y'all are lovely club members.

Table 11.
Bereavement: Frequency and Kappa Values.

Possible New Domain: *Bereavement*	**Frequency**	**Kappa**
Emotional manifestations of grief	7.89%	0.89
Loss of meaning/identity after patient death	7.84%	0.83
Desire for continued psychological support	10.25%	0.86
Changed perceptions of death itself	1.48%	0.79
Changes to social relationships after patient death	3.10%	1.00
Evidence of posttraumatic growth	1.67%	0.00

Discussion

The burden of a brain tumor often weighs heavily on the caregiver, and extant research highlights the discrepancy between the stated needs of caregivers compared to the available, evidence-based interventions for this at-risk population.[140] One specific challenge that caregivers face is death distress.[202] Although an evidenced-based treatment for death distress currently exists and encourages caregiver participation,[203] CALM primarily focuses on the needs of the patient and its suitability for any caregiving population has not been assessed. The current research program, ultimately, seeks to optimize CALM therapy for caregivers of PwMG. As a first step, this investigation conducted a *Phase 1a Define Trial* of qualitative focus groups, using a sample of bereaved caregivers of PwMG, to enhance understanding of their impressions and recommendations to optimize CALM for caregivers in neuro-oncology.

The results suggest that the CALM intervention is highly relevant for the caregiving experience. Moreover, participants felt that CALM would support caregivers emotionally, make them feel more prepared/effective, improve their communication with the patient, and provide a unique opportunity to receive specialized care specific to neuro-oncology. However, participants in the current study also identified potential hurdles for caregivers' participation. Their concerns included time and energy restrictions, not feeling emotionally ready to engage in such discussions, fearing they would burden the patient with their emotionality, and believing their loved one would not have been psychologically or cognitively capable of participating.

To address some of these concerns, the caregivers provided recommendations for content, timing, and format of CALM to better serve the needs of caregivers. Specifically, they recommended additional content areas for discussion, suggested here as two new domains: 1) *Caregiver Burden* and 2) *Bereavement*. Relatedly, many supported the idea that CALM should be introduced to families at diagnosis, reintroduced throughout treatment by the medical team, and continued even after the patient’s passing. Caregivers might benefit from the option to have both joint and individual therapy sessions. Lastly, participants shared novel ideas to improve logistical concerns, including offering telehealth appointments, after-hours appointments, or scheduling appointments during patients’ routine brain scans. Overall, the participants provided feedback about CALM that was largely positive, and their opinions provide an important foundation to optimize the CALM intervention for caregivers.

Sample Characteristics: Bereaved Caregivers of PwMG

Although this study's sample size was sufficient,[175] the sample make-up was fairly homogeneous. Most participants were non-Hispanic, White, female spouses, who were highly educated, relatively affluent, and insured. Though homogenous, this sample is often typical of caregiving research in neuro-oncology due to: 1) systematic barriers and 2) the prevalence rates of malignant glioma.[204,205] Specifically, older, non-Hispanic White males are more likely to be diagnosed with a malignant glioma,[206] so it is perhaps not surprising that our sample of bereaved caregivers were mostly non-Hispanic White, female, widows. However, it should be acknowledged that caregivers of minoritized backgrounds face additional hurdles. For example, results from a recent systematic review in neuro-oncology highlighted the increased distress found in younger caregivers and those of lower SES.[205] Patients in neuro-oncology who identify as racial/ethnic minorities also have greater delays in treatment and symptom burden,[207] which inevitably affects the experience of the caregiver. Evidence of these inequalities in the current study included poignant examples of economic hardship from the five Black male participants. Without fuller representation of individuals from disadvantaged or systematically minoritized backgrounds, the current study's results should be interpreted as recommendations that might be most generalizable to relatively privileged, female spousal caregivers.

The quantitative data collected following the focus groups also provided important contextual information about the emotional functioning of the sample. Overall, following the patient's passing, caregivers report ongoing challenges to their psychological well-being, including increased depression and anxiety as well as reduced spiritual well-being and low posttraumatic growth. The results are consistent with the very limited, available research in bereaved caregivers of PwMG: In fact, a 2019 systematic review identified only four studies published between 2005-2015, and all were qualitative.[208] Nevertheless, a recent 2023 mixed-methods, longitudinal study of caregivers in neuro-oncology ($N = 25$) found that there were improvements in depression and anxiety symptoms during the bereavement period ($M = 18$ months bereaved) compared to the time of initial diagnosis; however, some did report stable or worsening symptoms following the patient's death.[209] Even still, during the bereavement period, 40% and 20% of the Lobb et al. (2023)[209] sample had subclinical-to-clinical symptoms of anxiety and depression, respectively, similar to what has been found in active neuro-oncology caregivers.[205] In terms of bereavement symptoms, Lobb et al. (2023) used a different outcome measure than our current study, the Core Bereavement Items (CBI), and found that approximately 30% of the sample endorsed clinical levels of bereavement-related distress.[209] Although on average, participants in the current study did not meet the clinical cutoff, 9-32% did meet criteria for clinical symptoms of complicated grief as measured by the TTBQ.

No previous studies have examined any of the other outcome variables in bereaved neuro-oncology caregivers; however, research in *active* neuro-oncology caregivers reveals similar impacts to both spiritual well-being and posttraumatic growth. Compared to a longitudinal study of both patients and caregivers in neuro-oncology, bereaved caregivers in the current study demonstrated less spiritual well-being across all domains.[156] Interestingly, the prevalence of posttraumatic growth appears higher in the current study's bereaved sample compared to a preliminary investigation of active caregivers of PwMG, though only two of the five domains were found to be in the moderate-to-high range on average in the current study.[210] Overall, it is clear that this population continues to experience psychological distress, months and years following the patient's passing. Moreover, these quantitative results were echoed throughout the qualitative findings.

The Relevancy of CALM for Caregivers

Throughout the focus groups, the participants provided myriad examples of how the existing structure of CALM is relevant to the experience of caregiving. Moreover, their reported experience is consistent with previous qualitative and quantitative research of current caregivers of PwMG:

Domain 1: Symptom Management and Relationships with Health Care Providers

First, the participants of the focus group recollected the challenges of navigating the patient's diagnoses and the medical system at large. Their greatest concern was the lack of medical knowledge about the patient's symptoms and treatment. Indeed, previous research in current neuro-oncology caregivers reverberates this challenge of obtaining medical knowledge, leaving caregivers feeling very unprepared in their roles.[92,95,96,118,211,212] Participants highlighted the barriers to receiving information, including the inability to access providers, provider's dependency on the patient's report alone, and the complexity of medical information as it pertains to malignant glioma. These widescale barriers in healthcare have prompted the Caregiver Advise Record Enable (CARE) ACT, which requires hospitals to document caregivers and provide them with adequate education and training; however, the CARE Act is not routinely implemented across the United States and varies state-by-state.[213] Consequently, caregivers often turn to online sources of information (e.g., WebMD, social media), which often provide unreliable or inapplicable information.[214,215] Further, without access to adequate information, caregivers struggled to make difficult medical decisions, reinforcing subsequent feelings of guilt, inadequacy, and powerlessness.[90,92]

This large-scale issue of navigating healthcare requires multiple levels of intervention beyond CALM therapy. Nevertheless, CALM can be useful in navigating these concerns in several ways. First, although the CALM therapist is traditionally not an oncologist, CALM can offer space to process their feelings regarding the medical system and providers, both positive and negative. In addition, CALM provides the space for the caregiver to clarify points of confusion and create an action plan for obtaining answers. The integration of the CALM therapist in the hospital system promotes increased communication with the medical team and the ability to point families to resources they might not have otherwise received. Interestingly, caregivers of the current study often felt they could not disagree with their loved one's report of their medical status in front of providers, out of fear of diminishing the patient's hope. These interpersonal dynamics are also particularly well-suited for CALM and could be addressed either as a dyad or in individual therapy.

Effect of COVID-19. Given the study's inclusion criteria (i.e., date of the patient's passing), participants also offered insight into how the COVID-19 pandemic provided additional challenges to navigating the healthcare system. Specifically, they discussed their frustrations with visitor restrictions, the inability to meet providers in person/lack of a personal touch, and the inadequate care they received as COVID-19 absorbed many of the hospital's limited resources. One recently published 2021 study interviewed 20 caregivers in neuro-oncology and found evidence for higher caregiver burden during the pandemic, due to factors such as fear of infecting the patient and reduced social support.[216] Medical providers in oncology also observed challenges to communication and supporting caregivers during the pandemic, and 43% of providers believed patient care experienced atypical delays.[217] Without the support of healthcare, caregivers in the United States were forced to shoulder more of the burden of care than normal, causing them to feel even more isolated in their roles.[218] With this, the pandemic highlighted the fractures in our current healthcare system and the importance of supporting/educating caregivers, who are essentially unpaid extensions of the medical team.[219] These findings were echoed throughout the focus groups and highlight the myriad challenges caregivers in neuro-oncology face related to Domain 1.

Domain 2: Changes in Self and Relations with Close Others

Next, it was evident from the focus groups that the caregiving role naturally creates new and often challenging relational dynamics—with the patient, with other family members, with peers, and within themselves. The most discussed relationship was that of the caregiver and patient dyad, a dynamic often challenged by the personality changes and cognitive decline customary in this population. Consequently, in many ways, this relationship often began to reflect that of a parent and child dyad. This result was also echoed in the Caregiver Information Survey, where the majority of participants endorsed taking over tasks such as finances, appointments, household chores, grooming, and toileting/bathing of the patient. Interpersonal challenges between the caregiver and patient have been previously identified by myriad qualitative studies, and navigating the changes within the patient is consistently reported to be one of the most distressful aspects of caregiving.[92,212,220,221] Above and beyond this changing dynamic, the participants also alluded to the idea that both parties were fearful of being a burden to one another. In a dyadic therapeutic context, these aforementioned concerns could be addressed in CALM therapy directly; as both members of the dyad (caregivers and patients) could be challenged to “mentalize” from the each other’s perspective.[222]

In addition, the participants discussed relationship challenges with other family members and friends. Often, they felt that they were not fully supported or seen by these individuals during their time of caregiving. This contributed to their feeling of isolation, as no other person had the same, unique relationship they had with the patient. These interpersonal challenges and feelings of isolation have been documented in many qualitative studies of neuro-oncology caregivers.[90,116,127,212,223] Additionally, consistent with previous research, participants explained how difficult it was to juggle these other relationships in their lives, such that they felt "sandwiched" between multiple responsibilities, especially if they had young children or an older parent to take care of on top of their neuro-oncology caregiving duties.[92,220,224] To address these concerns, the therapeutic process of "mentalization" (e.g., the process of considering the possibility of multiple perspectives[169)] would allow the caregivers to consider multiple viewpoints from the perspective of other family members/friends and/or how to navigate these evolving relationships.[222] It is unclear at this time if other family members (e.g., spouses or children) or friends should be included in an optimized version of CALM for caregivers. If so, the optimized intervention might draw from family therapy approaches developed for advanced cancer, which seek to improve communication, family cohesion, and conflict resolution in palliative care settings, both before and following the patient's passing.[114,225] In addition, to support caregivers in their feelings of isolation, the CALM therapist may draw upon a recent web-based app known as eSNAP developed by Reblin and colleagues (2022), which seeks to increase a caregiver's perception of social support and support-seeking behaviors.[226]

Lasty, participants discussed changes within themselves and their identity, both positively and negatively. Sometimes, they "lost" who they were, or they found that their identity became enmeshed with the patient's and/or the patient's disease. Factors such as quitting their jobs, spending less time with friends and other family members, and providing around-the-clock care stripped them of their identity. Nevertheless, some participants gained a new identity that felt empowering, such as *advocate*, *resilient*, or *special*. The participants' discussion is consistent with a previous qualitative study in advanced cancer, which found that caregivers often reported a change or loss to their self-identity.[227] In light of these findings, navigating a caregiver's changing identity would be appropriate to address CALM therapy, both individually and as a dyad.[222] Because identity often shifts to focus on providing care to the PwMG, caregivers can use CALM to revisit who they once were prior to the diagnosis in order to effectively reclaim themselves. Although they might not be able to shed their new "caregiver" identity entirely, they can learn to hold multiple selves at once through the process of mentalization.[203]

Domain 3: Spirituality, Sense of Meaning and Purpose

Compared to the other domains, there was less evidence of Domain 3 discussions in the focus groups. This could be for two reasons: First, capturing ideas like "meaning" and "purpose" might be more diffuse and less concretely identifiable by the coding team. Secondly, given the sample was of the bereaved, most discussions focused on how they are finding meaning/purpose (or lack thereof) at this stage, after the patient's death. Nevertheless, the participants still connected with this domain, finding purpose in their new roles, and capitalizing on the time they had left with the patient. A previous systematic review similarly found that caregivers in neuro-oncology often derive new meaning from their role of ensuring the patient's well-being and striving to "value every day," despite the limited time they may have left with their loved one.[228] In addition, this review highlights that priorities of the caregiver and patient often shift during the course of the disease, such that the diagnosis serves as an opportunity to re-evaluate what is most important to both parties.[127] In the current study, participants highlighted that the caregivers' and patients' identified meaning did not always perfectly align (e.g., one may be focused on joy and the other may be focused on survival). Moreover, many found it challenging to aide their loved one in finding a new a sense of meaning/purpose given the number of cognitive/physical impairments.

Of course, differences in meaning could be addressed in an intervention such as CALM, as well as caregivers' evaluation of their priorities at various stages of the disease. For example, because caregivers often feel overwhelmed with their number of responsibilities,[229] they might benefit from processing which tasks are most important to them—and how their pursuit of joy and self-care fits into this— with a trained CALM therapist. Additionally, as a dyad, they might safely explore how each of their values have changed (e.g., from achievement to companionship) so that they may negotiate together what is most important to the caregiver-patient unit.

However, most prevalent under this domain was caregivers' difficulty to find meaning/purpose in the face of the patient's impending decline. In this way, caregivers in the current study demonstrated difficulty with *double awareness*, or the capacity to balance presence in life with preparation for death.[168] Not only did participants feel validated to learn the term, but the results also demonstrated myriad manifestations of this therapeutic process. For example, many described difficulties with remaining positive versus realistic, staying in the present moment versus preparing for death, and even hoping for the patient to live versus feeling relieved for them to die given their anticipatory grief. No other study has explicitly studied "double awareness" in this group; however, one study found that caregivers often have trouble balancing "hope with realistic expectations" during the "long haul," period of caregiving in neuro-oncology.[230] The ability to balance both the present and the future; hope and fear; living in the present while preparing for their death is inevitably an iterative process. The CALM therapist is particularly well-suited to help caregivers find/return to that balance, as this is core therapeutic process of the intervention.[203]

Spirituality was discussed as both a struggle and a source of strength in the current study. Many stated they felt angry at God as they made sense of their experience. Others noted their faith was a source of hope during the course of the disease and thereafter. The quantitative results suggest that the current study's sample demonstrated a high belief in the afterlife, but lower spiritual well-being compared to prior studies of active neuro-oncology caregivers.[231] Previous qualitative research in both patients and caregivers in neuro-oncology mirrors this pattern of mixed findings.[232] Although spirituality may serve different roles in caregivers' lives, ultimately, it is an important access point of identifying personal meaning.[97,233] In this way, whatever the response is to spirituality, a CALM therapist can promote meaning-making as an adaptive coping mechanism. Furthermore, though some did not connect to spirituality at all, it is important to note that not every domain must be discussed in CALM and there are other ways for caregivers to make sense of the experience.[203,232]

Domain 4: The Future, Hope, and Mortality

Lastly, the bereaved caregivers provided many examples of how their experience fit under the umbrella of Domain 4, including their experience of death distress—the most prevalent theme under this category. Participants were first validated that there was a term for their experience: *death distress*. They specified that their experience of death distress looked differently from that of the patient, a point that has been demonstrated in previous psychometric studies of the Death and Dying Distress Scale.[58,202] Some described this feeling as both a "fear" and "sadness" related to their loved one's impending death; others described their death distress as a type of "anticipatory grief," where the decline of the patient triggered both their fear of death and their grieving process.[59] In this way, caregivers experienced "two deaths," one physical and the other emotional following the patient's decline.[127] According to participants, death distress was experienced early in the disease course and persisted. Because of this, one participant suggested that death distress cannot be “alleviated” but, instead, it can only be “accepted.” When asked what would have helped them manage these feelings, participants agreed that talking to someone about their death distress would have been beneficial—an idea echoed in a previous qualitative study of caregivers in neuro-oncology.[97] Given CALM is the only intervention shown to specifically reduce death anxiety in patients in oncology, it may be well-suited to address this type of distress in caregivers.[166] Overall, it is clear from both the qualitative and quantitative literature that death distress is indeed a ubiquitous, unmet need in this group, warranting intervention.[202,234]

The next most prevalent theme was preparation for the end-of-life. In sum, participants recalled feeling very unprepared and uncertain of the future, and desired more support during this stage of the disease. They specifically wanted more than just statistics from their medical teams; they needed emotional, practical, financial, and legal support. These themes were echoed in a recent 2023 qualitative study[209] of bereaved caregivers of patients with high-grade gliomas: in addition to desiring emotional support during the patient’s decline, caregivers in this study also wanted more useful, concrete information about what to expect regarding the patient’s prognosis, disease progression, and end-of-life care; practical and financial support at the end-of-life was also a need in this study.[209] In order to receive this type of support, caregivers hoped to remain in contact with the patient’s oncology team; yet many found that this relationship ended suddenly when the patient was transitioned to palliative care.[209] Moreover, a recent survey suggest that approximately one-half of providers in neuro-oncology feel uncomfortable talking about death with patients and families.[235] With this, CALM might be an especially useful therapeutic space for caregivers to process what questions they should ask their medical teams, the pros and cons between difficult treatment decisions, and how to prepare themselves both emotionally and practically for the patient's passing. Connecting caregivers to peer-to-peer support may also be useful for end-of-life preparation,[236] though as recognized by the focus group participants, no malignant glioma journey is the same.

Lastly, participants spoke of positive experiences related to Domain 4, including their hope for the future and the reassurance they provided to their loved one at the end-of-life. Participants reiterated how important it was for them to have hope during this process; however, they needed help balancing their hope with the reality of the disease (i.e., double awareness). Their hope also changed over the course of the disease; while many initially hoped that their loved one would be one of the rare, "five percent" that survive, they often would gradually transition to hoping for more time, or relief in the patient's suffering. Similar themes of hope can be found in qualitative analyses of both caregivers and patients in neuro-oncology.[59,237,238] Lastly, participants found it meaningful to provide their loved one with reassurance that they would be okay after the patient's passing, though this theme was less prevalent than others. This concern also arose in participants' evaluation of the patient's death and dying (QODD), as sampled caregivers were most distressed about the patient's fear of being a burden. Together, these two topics—finding the balance with hope and providing reassurance to the patient—are often areas of exploration in the standard CALM protocol,[222] providing further evidence that the domains of CALM may adequately address many of the participants' stated needs.

Perceived Benefits of CALM for Caregivers

Given the demonstrated relevancy of the established domains of CALM, it is perhaps no surprise that focus group participants generally had a positive impression of the intervention. First, they believed participating in CALM would allow them to feel more emotionally supported. Caregivers consistently demonstrate exorbitant rates of emotional distress.[118,124,202] Therefore, the importance of opportunities to provide psychological support to this at-risk group cannot be overstated. Moreover, dyadic statistical models suggest that improving caregiver distress could also improve the patient's well-being[84,239] as well as the caregiver's feelings of mastery.[240] With this literature in mind, there is an ethical obligation to support caregivers emotionally for the benefit of both parties.

Secondly, many believed that participating in CALM would make them better caregivers—allowing them to feel more prepared and effective in their roles. Previous qualitative research in neuro-oncology highlights that caregivers often feel unprepared to manage the changes in patient's disease, cognition, emotional well-being, and personality.[95,241] By addressing some of the practical issues of caregiving, CALM might support caregiver self-efficacy, mastery, and preparedness. Again, the importance of this cannot be overstated: preliminary research from Boele et al. (2017)[242] found that for every one unit increase in caregiver mastery, there was a 16.1% risk reduction in patient mortality while controlling for patient age, KPS (Karnofsky Performance Status) score, surgical outcome, and postsurgical treatment.

Related to this idea, participants reiterated that receiving psychotherapy from someone knowledgeable in *neuro-oncology* specifically would be especially valuable. They explained that community providers often do not understand the unique challenges of a brain tumor and noted that cancer in the brain is different from other malignancies. Previous qualitative research in caregivers of PwMG echoes this sentiment; many point to the cognitive and personality (neurological) changes that occur as the major difference.[97] A trained psychotherapist with expertise in neuro-oncology would not only allow caregivers to feel more understood and emotionally validated, but would also provide a direct link to important resources that would make caregivers more effective in their roles.

In terms of the dyad, participants also believed that CALM could have improved their communication with their loved one. Many discussed how CALM provides the necessary structure and safety to approach "difficult conversations" that patients and caregivers may otherwise avoid. Interestingly, participants also believed that insight into the patient's thoughts/feelings, or simply seeing the patient's emotional well-being improve, was a strong benefit of CALM—apart from any direct benefits to the caregiver. Again, given the known bidirectional relationship between patient-caregiver well-being,[239] this finding is not surprising.

These perceived benefits mirror those of previous qualitative investigations conducted with patients regarding CALM. Specifically, patients noted that CALM provided *unique* benefits unlike anything else in their medical care.[172] These benefits included having a safe space to discuss difficult, often taboo topics; feeling supported in navigating the healthcare system; noticing improvements in relationships; and being seen as a whole person—a critical point for caregivers who often feel overlooked.[172] Overall, in tandem with CALM's relevancy, these identified benefits provide strong support for optimizing CALM for caregivers. Nevertheless, although participants affirmed the value in the intervention, they also voiced their concerns and recommendations.

Perceived Challenges of CALM for Caregivers

If CALM is to be optimized to serve the interests of caregivers better, there are a few concerns that must be addressed. First, participants stated that they may not have had the time or the energy to participate in any additional medical appointments. Research by Dionne-Odom and colleagues (2021) shows that neuro-oncology caregivers spend an average of 11.2 hours, 6.7

days a week caring for the patient.[150] Further evidence from Jeon et al. (2021) affirms that caregivers of PwMG are at risk for poor sleep, especially when burden is high.[243] To address this real and expressed concern, participants recommended that appointments are offered at non-traditional times, including during patient routine brain scans and after normal business hours. This is a similar finding to Halkett et al. (2018), which found that 12% of sampled caregivers of PwMG wanted impromptu, drop-in counseling services, should they find an extra hour in their day.[141] Secondly, participants recommended that both in-person *and* teletherapy sessions are offered, in order to save on travel time—a point echoed in previous research.[141,150,157] Lastly, caregivers' lack of time/energy could be significantly improved with better policies and/or access to respite care. Research in dementia suggests that respite care, such as daycare services, can decrease caregiver burden,[244] though research specific to neuro-oncology is needed to better understand how to best support caregiver time and energy.

Another major concern was the timing and dyadic nature of CALM. Participants noted that there were often discrepancies between caregiver-patient emotional readiness. Sometimes, caregivers were not ready to approach topics covered in CALM; other times, they worried that their loved one was not ready, or that they would burden the patient with their negative emotions should they participate together. To address this concern, the participants recommended that providers offer and re-offer services consistently over the course of disease. This would allow for more windows of opportunities for the dyad to join at the correct time for them, as each experience is unique. In CALM's program of research with patients, there exists a "tipping point," whereby patients become ready to engage in this type of psychotherapy.[222] This is usually around the time when treatments have failed, or progression has occurred, prior to the patient becoming too ill to participate.[203] More research is needed to identify if this "tipping point" is earlier for caregivers and how to best accommodate discordance between the dyad. Secondly, participants recommended that CALM is also offered as individual therapy, to both the patient and the caregiver, should some topics be too sensitive to talk about as a dyad. Individual treatment for the caregiver may also help in cases where the patient is too cognitively impaired to participate, something that is an almost certainty and unique feature of neuro-oncology. However, in order to offer services to the caregiver, medical systems must first identify them as recommended by the CARE act—yet again, this is not consistently implemented across the United States.[245]

Lastly, there was a small minority of participants who expressed that they would likely never participate in an intervention like CALM because of other personality factors and preferences. Some suggested they would not seek out psychotherapy generally or that they preferred "living in denial." This theme of denial has been replicated in previous qualitative studies in neuro-oncology, where some were only able to reduce their denial during the patient's rapid decline or after the patient's death.[229] With this, it is important to note that even if these aforementioned hurdles are addressed, CALM will still not be for everyone, and other types of interventions *might* better serve these caregivers (e.g., medical training, respite care, grief counseling).

Recommended Additions to CALM for Neuro-Oncology Caregivers

The results of the current study suggest that CALM may be optimized for caregivers if two new additional domains are added to the CALM protocol: 1) Caregiver Burden and 2) Bereavement.

Caregiver Burden

Given that CALM was developed primarily to address the needs of patients with advanced cancer,[166] it is understandable that there is not a domain that touches on caregiver burden, specifically, at this time. Caregiver burden is defined in the literature as a multi-faceted construct that encompasses physical, psychological, emotional, social and financial stress related to the caregiving role.[246] In neuro-oncology, a study by Choi and colleagues (2012)[116] found that 79% of caregivers experienced moderate-to-high levels of burden as measured by Burden Scale for Family Caregivers. Burden is high when the caregiver's needs outweigh the available resources.[99] Certainly, caregiver burden is related to each of the four domains of CALM and might even be a result of navigating healthcare, interpersonal challenges, questions of meaning/purpose, and end-of-life issues; yet the extent of burden described in the current study suggests that an additional domain is warranted to best support this group.

The types of caregiver burden reported in the current study can also be found in previous literature. Specifically, participants described caregiver burden as overwhelming emotional stress, the inability to take care of oneself and/or juggle multiple roles, and financial strain. Previous literature in neuro-oncology documents the exorbitant levels of depression and anxiety among caregivers, with prevalence estimates higher within this group than in both the general population and patients diagnosed with malignant glioma.[115,239,247] Moreover, caregivers consistently report poorer sleep[110,248] and greater systemic inflammation,[108,109] pointing to participants' stated difficulty with taking care of themselves physically. Active caregivers in a previous qualitative study in neuro-oncology similarly described difficulty navigating changes within the family system and juggling multiple roles.[229] Lastly, the financial stress of caregiving is well documented, as this diagnosis is not only costly, but often necessitates leaving one's full-time job to provide care.[101–104] In fact, brain cancer has the highest initial and annualized mean net cost of care compared to any cancer group.[103] Half of the current study's sample reported a change in employment as a result of their caregiving role. Taken together, it is evident from this study and others that caregiver burden is a significant issue in this population and, therefore, deserves closer and more specific attention in a therapeutic context.

CALM for caregivers could address caregiver burden in several ways. First, the participants in the current study explained that the inability to articulate what they need and/or ask others for help—coupled with feeling of being overlooked—served to exacerbate their experience of burden. The reflective space provided in CALM[203] might give caregivers a place to process their needs and create an action plan to advocate for themselves, despite the fact that they are indeed overlooked. Because previous research suggests that poor social support is highly correlated with burden,[102] CALM could also help caregivers identify those they could safely ask for help, whether practical or emotional. Alternatively, CALM may serve as a type of formal social support for these caregivers. Lastly, because participants recommended the option for both individual and joint sessions, providers might consider using individual sessions to address issues related to caregiver burden. This safe space may reduce caregivers' feelings of guilt and shame that participants often described in the current study. Moreover, it may provide the opportunity to learn concrete stress management skills, yet another recommendation from participants in the current study.

Bereavement

Although some topics of bereavement may be explored in Domain 4 (e.g., providing reassurance to the patient about the caregiver's future), the results of the current study suggest that continued psychotherapy after the patient's passing is warranted. As explicitly stated by one participant, "some things should be discussed after." The current study found that during the bereavement period, caregivers face new challenges yet lack appropriate support.[212] First, many have difficulty managing their emotional experiences of grief. This has similarly been described in other qualitative studies in neuro-oncology, in which caregivers endorsed lengthy grieving periods and complex feelings of inadequacy, guilt, regret, confusion, anger, gratitude, and depression.[208] Moreover, participants specifically cited a loss of identity when their caregiving role abruptly ended, accompanied by a loss of meaning and even changes in the way they perceived death. These types of concerns are reflected in Domain 3, though caregivers' responses or struggles to find meaning might be slightly different in the bereavement phase. In the same vein, related to Domain 2, participants' bereavement also affected their social relationships. Indeed, three out of the four qualitative studies from the Piil systematic review[208] found that neuro-oncology caregivers often lose their social networks while the patient is ill and have difficulty reconnecting. With all of this, it is apparently important that caregivers are followed into the bereavement period, and participants believed that even offering a few "booster" sessions post-loss could be extremely beneficial to their emotionality and overall well-being.

If CALM is continued during the bereavement phase, there is an opportunity for caregivers to process the loss with a provider who already knows their story. Similar to Meaning-Centered Grief Therapy,[249] which is an extension of Meaning-Centered Psychotherapy, CALM could assist bereaved caregivers in navigating their difficult emotions, making sense of the loss/death, connecting to new sources of meaning, and finding ways to stay connected to their loved one.[249] Indeed, many participants in the current study described the loss as "traumatic," which is a known risk factor for developing complicated grief.[250] Unfortunately, there were few examples of posttraumatic growth in the focus groups, and participants were, on average, low in three out of five PTGI domains. The two subscales on which this sample scored highest were: 1) Personal Strength and 2) Appreciation of Life. Similarly, previous qualitative research suggests that some caregivers of PwMG may feel closer to their loved one, a sense of inner strength, or increased self-worth as a result of their roles, [97,251,252] suggesting posttraumatic growth might be achievable for certain caregivers. Addressing these challenges associated with the bereavement period would not only support caregivers' emotional well-being and physical health outcomes[112–114] but would also address their expressed concern of being "forgotten" once the patient passes.

Other Recommendations to the Format, Presentation, and Timing of CALM

In addition to the aforementioned recommendations, participants provided many other valuable, creative ideas that would optimize the standard CALM intervention to the unique experience of caregiving. First, participants recommended that the medical team introduces CALM persistently, in multiple ways, to improve caregiver engagement. At diagnosis, they suggest providing a brochure, handout, or even a refrigerator magnet with information about supportive care services. These physical reminders of CALM were recommended at diagnosis because caregivers commonly report feeling inundated with information at this stage of the disease.[253] Once the dust slightly settles, participants recommended that the medical team begins to approach families about CALM, presenting the service as a holistic approach to treatment and standard-of-care. The advice and authority of medical providers would have increased caregivers' participation, despite the aforementioned constraints. Lastly, they recommended that at every stage of the disease, CALM is re-introduced to families. This is because every journey and timeline of a malignant glioma is different, and therefore, the previously discussed tipping point for each family may come at different points of the disease course. Overall, participants believed they would have benefited from CALM, but many reported feeling too overwhelmed to initiate services themselves for their own, singular benefit. In this way, the need for integrated, comprehensive care is clear.

As mentioned previously, participants saw value in offering both individual and joint CALM sessions when possible, though time and scheduling difficulties were significant concerns. CALM was ideally designed to have the caregiver participate in at least 1-2 sessions in order to allow for another perspective, bolster cohesion, and support the relational unit; however, dyadic treatment is not always possible if one party is unwilling or incapable.[222] In such cases, it is possible that individual sessions with the caregiver or patient alone could be a foot-in-the-door technique to prepare the individual for future dyadic sessions. In addition, providing the caregiver and patient with a list of "homework questions" to answer on their own time—a recommendation from the focus group—might be an alternative solution to circumvent the differences in emotional readiness and time constraints. Although the current study provides strong support for individual sessions to address topics such as caregiver burden and bereavement, it is important to note that the billing and documentation system in the United States does not currently support this.[219]

In terms of content, participants highlighted the essential components of CALM while also making suggestions for new content areas. First, many believed that CALM should consistently encourage "difficult conversations" between the dyad and between the caregiver-therapist. The CALM manual, indeed, suggests that the therapist promotes difficult conversations by modulating care based on the patient's affect, protecting the patient from both hyperarousal and emotional detachment.[203] Yet, above and beyond having difficult conversations, participants suggested that CALM include very tangible, skills-based components as well. For example, they recommended stress management strategies, caregiver education and skills training, financial and legal counsel, as well as 24-hour access to medical information in the form of a caregiver hotline. This is not the first study to document these supportive care needs.[92,139–141,157] Although CALM is well-suited to address many of these topics, formal resources and handouts are currently not included in intervention materials. With this, it will be important that future iterations of the CALM protocol address these practical needs while also staying true to the original intent of the supportive-expressive intervention.

Taken as a whole, participants' recommendations for CALM point to a desire for integrated, comprehensive care. To these bereaved neuro-oncology caregivers, improved quality-of-life is an essential component of medical care,[97] and they prefer a one-stop shop for receiving multiple levels of intervention. Of course, there are many barriers to this in the United States; namely, billing and documentation for caregivers is not straightforward.[254] Nevertheless, these recommendations provide valuable information about how to optimize CALM and where CALM fits into the larger picture of supportive care services for caregivers more generally.

Clinical Implications

The results of this study provide valuable clinical insights to optimize the CALM intervention and to support caregivers more broadly. It is important to recognize that CALM might be only one of multiple approaches to address caregivers' needs.[139,140] Indeed, the themes identified in the current study reveal that educational interventions, family therapy, social support, stress management, early palliative care, and grief counseling might all be important, additional components of comprehensive care for caregivers. Both nationally and internationally, hospital systems are beginning to develop clinics dedicated to the needs of cancer caregivers.[255,256] Even more relevant, the University of California San Francisco (UCSF) created the first caregiver clinic specific to neuro-oncology, known as the Gordon Murray Caregiver

Program.[257] It provides interdisciplinary support across multiple domains, including educational resources, peer-to-peer counseling, individual psychotherapy with a trained health psychologist, and referrals to palliative care and hospice. Caregivers are screened at initial appointments using a standardized checklist, and those caring for a patient with GBM are contacted ever four months by a different provider (e.g., nurse, social worker) to address their varying supportive needs at that point in the disease trajectory. Although the efficacy of this clinic's approach has not yet been formally evaluated, the results of the current study suggest that a multi-dimensional, comprehensive clinic specific to the needs of caregivers in neuro-oncology— like the Gordon Murray Caregiver Program—should be the gold standard.

Nevertheless, participants in the current study recognized that CALM, specifically, provides a service unique from any other currently offered. More importantly, the results of the current study suggest that CALM might be a good option for addressing caregiver death distress, a highly prevalent form of emotional distress.[202] Not only has CALM shown to reduce death distress in patients with primary brain tumors, but participants in this study (and others[97]) stated that they would benefit from having a safe space to talk about their death distress—specifically, with a member of the medical team in an integrated, neuro-oncology setting. Thus, if slight adjustments are made to CALM's delivery to better suit the needs of caregivers, CALM is a promising avenue for helping this group "accept" their persistent feelings of death distress. Non-specific to CALM, at minimum, caregivers appear to need (and desire) clinical intervention for end-of-life concerns. As simply summarized by a bereaved caregiver in a recently published qualitative study: "A psychologist should have been provided to us through palliative care" (p. 4).[209] Until CALM is formally optimized to the needs of this group, clinicians should work together to address the aforementioned support needs of caregivers—including their ubiquitous death distress.

Future Directions

This current study is the first step of many to optimize CALM for caregivers and to address caregiver death distress. In accordance with the NIH ORBIT model,[173] the next steps of a *Phase 1a Define Trial* include a *Phase 1b Refine Trial, Phase 2 Preliminary Testing Trials* (i.e., proof-of-concept and pilot trials), efficacy trials, and effectiveness trials. The immediate next steps include gathering similar data from current neuro-oncology caregivers; ideally, both those who have and have not participated in the standard CALM intervention. Data from current caregivers can be synthesized with the current study to produce an optimized CALM protocol. This optimized intervention can be tested and amended (if necessary) in subsequent proof-of-concept, feasibility/acceptability, and pilot trials, prior to any RCT. Each step of intervention development is critical for ensuring that the intervention is not only efficacious, but practical in real-world settings. After a successful RCT, long-term future directions include: 1) investigating the efficacy and implementation of CALM for neuro-oncology caregivers in caregiver clinics; 2) understanding how this intervention fits into a larger, quality-of-life initiatives and comprehensive care for this group; and 3) extending these results to other caregivers with advanced cancers and/or neurological diseases.

In addition to this intervention development, more quantitative exploration into the mental and physical well-being of bereaved caregivers is warranted. Only five studies to date have investigated this group, and most are qualitative analyses.[160,209] Future investigation of other outcome variables known to be affected during the bereavement phase is warranted (e.g., global health and health behaviors).[112–114] Moreover, a closer examination of how these outcome variables are related to one another as well as the risk/protective factors of bereavement will provide valuable information for future intervention development. For example, future studies might explore if caregiver death distress during the patient's lifetime impacts caregiver well-being during the bereavement phase. Although important, these questions were outside the scope of the current study.

Strengths and Limitations of the Current Study

The current study represents an important first step in discovering how CALM therapy might be optimized to fit the needs of caregivers in neuro-oncology, as well as identifying other needed supportive care services. As a *Phase 1a Define Trial*, the current study possesses many strengths. First, it is one of the very few studies to investigate the experience of bereaved caregivers both qualitatively and quantitatively.[160] By elevating bereaved caregivers' voices, the current study provides strong evidence that continued support/attention in this group is warranted. Moreover, the perspective of *bereaved* caregivers, specifically, allowed for a more holistic account of their experiences and needs. The study also had a large sample size for this type of trial, comprised of 27% racially/ethnically minoritized caregivers, and allowing for data saturation. Participants were recruited from both within and outside of VCUHealth, and a small handful received therapeutic services from VCUHealth Neuro-Oncology and LiveNOW, previously. This allowed for natural comparing and contrasting of experiences during the focus group, creating fruitful discussion and highlighting how appropriate support of caregivers might lead to better outcomes during the bereavement phase.[258] Lastly, the rigorous qualitative methodology, including double coding for reliability and inclusion of both medical and psychological trainees in the coding process, was a strength of the study.

Nevertheless, the current study is not without its limitations. First and foremost, the current study does not include current caregivers, and until this data are synthesized, it is unclear whether these recommendations will be feasible for those actively providing care, given hindsight is not always an accurate method of evaluation. In a similar vein, because the caregiver experience does not exist in a vacuum, it is unclear how these recommendations are viewed by the patients with malignant glioma. Nevertheless, the results of the Loughan et al. (2021) qualitative study suggests that patients with primary brain tumors strongly advocate for increased caregiver support and are in favor of both independent and joint therapy sessions.[197] Next, while the current study included a small number of racially and ethnically minoritized caregivers, as noted before, more attention to non-affluent White, spousal caregivers is needed. Specifically, future studies should address the needs of younger adult children, who often shoulder more financial consequences as a result of the disease.[259] Related to the sample, it is possible that there was a selection bias, and those who were more distressed self-selected to participate in the current study, especially as the recruitment method included online support groups. Lastly, while the coding methodology was rigorous, there were eight codes with kappa values under 0.70. However, reliability estimates were above 0.80 across all coders and codes collectively. Although there was not always consensus across recommendations, the current study provides valuable insight on the supportive care needs of caregivers that can be addressed to improve their overall quality-of-life and functioning.

Conclusions

Caregivers have extensive emotional, practical, and physical needs that are continuously left unaddressed by our medical systems. The current study found that death distress is a common area of concern for neuro-oncology caregivers, yet evidence-based treatments addressing it are severely lacking. CALM therapy, which has been found to reduce death distress in patients with advanced cancer, might be a viable treatment for addressing this need and others in caregivers. Indeed, the bereaved caregivers of the current study mostly had positive impressions of the intervention as they reflected on their experience. Themes identified from the focus groups suggest that the domains of CALM are not only relevant to their needs, but CALM might also provide unique benefits not found elsewhere in their care. Nevertheless, they also shared important concerns that should be addressed in future optimizations of CALM. Their recommendations highlighted the importance of being persistent in offering services, providing the opportunity for individual sessions that accommodate their demanding care schedule, and discussing topics such as burden and bereavement following the patient's passing. Although CALM might not be a magic wand for supporting all care needs, the feedback captured by the current study is an important first step in addressing an unmet need and significant point of distress in caregivers of PwMG. These data will be synthesized with the perspective of current caregivers in order to create a final, optimized protocol that can be tested in future pilot and randomized controlled trials. This study and the ones that follow are significant strides to support the forgotten patient in cancer care: the caregiver.

References from Proposal

1. Sung H, Ferlay J, Siegel RL, et al. Global Cancer Statistics 2020: GLOBOCAN Estimates of Incidence and Mortality Worldwide for 36 Cancers in 185 Countries. *CA Cancer J Clin*. 2021;71(3):209-249. doi:10.3322/CAAC.21660
2. Cancer Statistics - National Cancer Institute. Accessed August 22, 2021. https://www.cancer.gov/about-cancer/understanding/statistics
3. Suls J, Rothman A. Evolution of the Biopsychosocial Model: Prospects and Challenges for Health Psychology. *Health Psychology*. 2004;23(2):119-125. doi:10.1037/0278-6133.23.2.119
4. Rehse B, Pukrop R. Effects of psychosocial interventions on quality of life in adult cancer patients: meta analysis of 37 published controlled outcome studies. *Patient Educ Couns*. 2003;50(2):179-186. doi:10.1016/S0738-3991(02)00149-0
5. Meyer TJ, Mark MM. EMPIRICAL ARTICLES Effects of Psychosocial Interventions With Adult Cancer Patients: A Meta-Analysis of Randomized Experiments. Published online 1995.
6. Jacobsen PB, Wagner LI. A New Quality Standard: The Integration of Psychosocial Care Into Routine Cancer Care. *Journal of Clinical Oncology*. 2012;30(11):1154-1159. doi:10.1200/JCO.2011.39.5046
7. Fox BD, Cheung VJ, Patel AJ, Suki D, Rao G. Epidemiology of Metastatic Brain Tumors. *Neurosurgery Clinics*. 2011;22(1):1-6. doi:10.1016/J.NEC.2010.08.007
8. Siegel RL, Miller KD, Jemal A. Cancer statistics, 2016. *CA Cancer J Clin*. 2016;66(1):7-30. doi:10.3322/CAAC.21332
9. National Brain Tumor Society. Quick Brain Tumor Facts.
10. Villa C, Miquel C, Mosses D, Bernier M, Di Stefano AL. The 2016 World Health Organization classification of tumours of the central nervous system. *Presse Medicale*. 2018;47(11-12P2):e187-e200. doi:10.1016/J.LPM.2018.04.015
11. Louis DN, Ohgaki H, Wiestler OD, et al. The 2007 WHO Classification of Tumours of the Central Nervous System. *Acta Neuropathologica 2007 114:2*. 2007;114(2):97-109. doi:10.1007/S00401-007-0243-4
12. Ostrom QT, Cioffi G, Gittleman H, et al. CBTRUS Statistical Report: Primary Brain and Other Central Nervous System Tumors Diagnosed in the United States in 2012-2016. *Neuro Oncol*. 2019;21(5):1-100. doi:10.1093/neuonc/noz150
13. Shin DW, Lee S, Song SW, et al. Survival outcome and prognostic factors in anaplastic oligodendroglioma: a single-institution study of 95 cases. *Scientific Reports 2020 10:1*. 2020;10(1):1-8. doi:10.1038/s41598-020-77228-2
14. Dong X, Noorbakhsh A, Hirshman BR, et al. Survival trends of grade I, II, and III astrocytoma patients and associated clinical practice patterns between 1999 and 2010: A SEER-based analysis. *Neurooncol Pract*. 2016;3(1):29-38. doi:10.1093/NOP/NPV016
15. Thakkar JP, Dolecek TA, Horbinski C, et al. Epidemiologic and Molecular Prognostic Review of Glioblastoma. Published online 2014. doi:10.1158/1055-9965.EPI-14-0275
16. Bhowmik A, Khan R, Ghosh MK. Blood Brain Barrier: A Challenge for Effectual Therapy of Brain Tumors. *Biomed Res Int*. 2015;2015. doi:10.1155/2015/320941
17. Lara-Velazquez M, Al-Kharboosh R, Jeanneret S, et al. Advances in brain tumor surgery for glioblastoma in adults. *Brain Sci*. 2017;7(12):166. doi:10.3390/brainsci7120166

18. Cramer CK, Cummings TL, Andrews RN, et al. Treatment of Radiation-Induced Cognitive Decline in Adult Brain Tumor Patients. *Curr Treat Options Oncol*. 2019;20(42):1-16. doi:10.1007/s11864-019-0641-6
19. Wardill HR, Mander KA, Van Sebille YZA, et al. Cytokine-mediated blood brain barrier disruption as a conduit for cancer/chemotherapy-associated neurotoxicity and cognitive dysfunction. *Int J Cancer*. 2016;139(12):2635-2645. doi:10.1002/ijc.30252
20. Drappatz J, Schiff D, Kesari S, Norden AD, Wen PY. Medical Management of Brain Tumor Patients. *Neurol Clin*. 2007;25(4):1035-1071. doi:10.1016/j.ncl.2007.07.015
21. Stupp R, Mason WP, van den Bent MJ, et al. Radiotherapy plus Concomitant and Adjuvant Temozolomide for Glioblastoma. *New England Journal of Medicine*. 2005;352(10):987-996. doi:10.1056/nejmoa043330
22. Davis ME. Glioblastoma: Overview of Disease and Treatment. *Clin J Oncol Nurs*. 2016;20(5):S2. doi:10.1188/16.CJON.S1.2-8
23. Gallego O. Nonsurgical treatment of recurrent glioblastoma. *Current Oncology*. 2015;22(4):e273. doi:10.3747/CO.22.2436
24. Liu R, Page M, Solheim K, Fox S, Chang SM. Quality of life in adults with brain tumors: Current knowledge and future directions. *Neuro Oncol*. 2009;11(3). doi:10.1215/15228517-2008-093
25. Fox SW, Lyon D, Farace E. Symptom clusters in patients with high-grade glioma. *J Nurs Scholarsh*. 2007;39(1):61-67.
26. Hottinger AF, Yoon H, Deangelis LM, Abrey LE. Neurological outcome of long-term glioblastoma survivors. *J Neurooncol*. 2009;95(3). doi:10.1007/s11060-009-9946-9
27. Mukand JA, Blackinton DD, Crincoli MG, Lee JJ, Santos BB. Incidence of neurologic deficits and rehabilitation of patients with brain tumors. *Am J Phys Med Rehabil*. 2001;80(5). doi:10.1097/00002060-200105000-00005
28. Vargo M. Brain tumor rehabilitation. *Am J Phys Med Rehabil*. 2011;90(SUPPL.5). doi:10.1097/PHM.0B013E31820BE31F
29. Tucha O, Smely C, Preier M, Lange KW. Cognitive deficits before treatment among patients with brain tumors. *Neurosurgery*. 2000;47:324-333; discussion 333-334. doi:10.1097/00006123-200008000-00011
30. Påhlson A, Ek L, Ahlström G, Smits A. Pitfalls in the assessment of disability in individuals with low-grade gliomas. *J Neurooncol*. 2003;65(2). doi:10.1023/B:NEON.0000003727.09448.dd
31. Allen DH, Loughan AR. Impact of Cognitive Impairment in Patients with Gliomas. *Semin Oncol Nurs*. 2018;34(5):528-546. doi:10.1016/J.SONCN.2018.10.010
32. Mahalakshmi P, Vanisree AJ. Quality of life measures in glioma patients with different grades: A preliminary study. *Indian J Cancer*. 2015;52(4):580-585. doi:10.4103/0019-509X.178395
33. Salander P, Bergenheim AT, Henriksson R. How was life after treatment of a malignant brain tumour? *Soc Sci Med*. 2000;51(4):589-598. doi:10.1016/S0277-9536(00)00002-2
34. Feuerstein M, Hansen JA, Calvio LC, Johnson L, Ronquillo JG. Work productivity in brain tumor survivors. *J Occup Environ Med*. 2007;49(7):803-811. doi:10.1097/JOM.0B013E318095A458
35. Burg MA, Adorno G, Lopez EDS, et al. Current unmet needs of cancer survivors: Analysis of open-ended responses to the American Cancer Society study of cancer survivors II. *Cancer*. 2015;121(4):623-630. doi:10.1002/cncr.28951

36. Armstrong TS, Shade MY, Breton G, et al. Sleep-wake disturbance in patients with brain tumors. *Neuro Oncol*. 2017;19(3):323-335. doi:10.1093/neuonc/now119
37. Willis KD, Ravyts SG, Lanoye A, Loughan AR. Sleep disturbance in primary brain tumor: prevalence, risk factors, and patient preferences. *Supportive Care in Cancer 2021*. 2021;1:1-8. doi:10.1007/S00520-021-06476-3
38. Powell C, Guerrero D, Sardell S, et al. Somnolence syndrome in patients receiving radical radiotherapy for primary brain tumours: A prospective study. *Radiotherapy and Oncology*. 2011;100(1):131-136. doi:10.1016/j.radonc.2011.06.028
39. Valko PO, Siddique A, Linsenmeier C, Zaugg K, Held U, Hofer S. Prevalence and predictors of fatigue in glioblastoma: A prospective study. *Neuro Oncol*. 2015;17(2):274-281. doi:10.1093/neuonc/nou127
40. Armstrong TS, Gilbert MR. Practical strategies for management of fatigue and sleep disorders in people with brain tumors. *Neuro Oncol*. 2012;14(Suppl 4):iv65. doi:10.1093/NEUONC/NOS210
41. Puetz TW, Herring MP. Differential effects of exercise on cancer-related fatigue during and following treatment: A meta-analysis. *Am J Prev Med*. 2012;43(2):e1. doi:10.1016/j.amepre.2012.04.027
42. Blaney JM, Lowe-Strong A, Rankin-Watt J, Campbell A, Gracey JH. Cancer survivors' exercise barriers, facilitators and preferences in the context of fatigue, quality of life and physical activity participation: a questionnaire–survey. *Psychooncology*. 2013;22(1):186-194. doi:10.1002/PON.2072
43. IJzerman-Korevaar M, Snijders TJ, de Graeff A, Teunissen SCCM, de Vos FYF. Prevalence of symptoms in glioma patients throughout the disease trajectory: a systematic review. *J Neurooncol*. 2018;140(3):485-496. doi:10.1007/s11060-018-03015-9
44. Dietrich J, Rao K, Pastorino S, Kesari S. Expert Review of Clinical Pharmacology Corticosteroids in brain cancer patients: benefits and pitfalls. Published online 2014. doi:10.1586/ecp.11.1
45. Jones LW, Friedman AH, West MJ, et al. Quantitative Assessment of Cardiorespiratory Fitness, Skeletal Muscle Function, and Body Composition in Adults With Primary Malignant Glioma. doi:10.1002/cncr.24808
46. K P, J J, KB C, 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). doi:10.1111/ECC.12806
47. Armstrong TS, Ying Y, Wu J, et al. The relationship between corticosteroids and symptoms in patients with primary brain tumors: Utility of the Dexamethasone Symptom Questionnaire-Chronic. *Neuro Oncol*. 2015;17(8):1114-1120. doi:10.1093/neuonc/nov054
48. Bitterlich C, Vordermark D. Analysis of health-related quality of life in patients with brain tumors prior and subsequent to radiotherapy. *Oncol Lett*. 2017;14(2):1841-1846. doi:10.3892/ol.2017.6310
49. Erharter A, Giesinger J, Kemmler G, et al. Implementation of Computer-Based Quality-of-Life Monitoring in Brain Tumor Outpatients in Routine Clinical Practice. *J Pain Symptom Manage*. 2010;39(2):219-229. doi:10.1016/j.jpainsymman.2009.06.015
50. 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 Oncol*. 2016;18(2):252-260. doi:10.1093/neuonc/nov166

51. Lovely MP, Stewart-Amidei C, Page M, et al. A new reality: Long-term survivorship with a malignant brain tumor. *Oncol Nurs Forum*. 2013;40(3):267-274. doi:10.1188/13.ONF.267-274
52. Sterckx W, Coolbrandt A, Clement P, et al. Living with a high-grade glioma: A qualitative study of patients' experiences and care needs. *European Journal of Oncology Nursing*. 2015;19(4):383-390. doi:10.1016/j.ejon.2015.01.003
53. Velez MP, Richardson H, Baxter NN, et al. Risk of infertility in female adolescents and young adults with cancer: a population-based cohort study. *Human Reproduction*. 2021;36(7):1981-1988. doi:10.1093/HUMREP/DEAB036
54. Nordan T, Thomas AM, Ginsburg ES, et al. Fertility preservation outcomes in women with gliomas: a retrospective case-control study. *J Neurooncol*. 2020;147:371-376. doi:10.1007/s11060-020-03429-4
55. Cubis L, Ownsworth T, Pinkham MB, Foote M, Legg M, Chambers S. The importance of staying connected: Mediating and moderating effects of social group memberships on psychological well-being after brain tumor. *Psychooncology*. 2019;28(7):1537-1543. doi:10.1002/pon.5125
56. Janda M, Eakin EG, Bailey L, Walker D, Troy K. Supportive care needs of people with brain tumours and their carers. *Supportive Care in Cancer 2006 14:11*. 2006;14(11):1094-1103. doi:10.1007/S00520-006-0074-1
57. 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. *Can Med Assoc J*. 2012;184(7):373-382. doi:10.1503/cmaj.111622
58. Loughan AR, Husain M, Ravyts SG, et al. Death anxiety in patients with primary brain tumor: Measurement, prevalence, and determinants. *Palliat Support Care*. Published online 2021:1-9. doi:10.1017/S1478951521000808
59. Adelbratt S, Strang P. Death anxiety in brain tumour patients and their spouses. *Palliat Med*. 2000;14(6):499-507. doi:10.1191/026921600701536426
60. Ownsworth T, Chambers S, Hawkes A, Walker DG, Shum D. Making sense of brain tumour: A qualitative investigation of personal and social processes of adjustment. *http://dx.doi.org/101080/096020112010537073*. 2010;21(1):117-137. doi:10.1080/09602011.2010.537073
61. Self-Identity after Brain Injury - Tamara Ownsworth - Google Books. Accessed December 14, 2020. https://books.google.com/books?hl=en&lr=&id=FxosAwAAQBAJ&oi=fnd&pg=PP1&dq=Self-identity+after+brain+injury&ots=pzMBKup4Fc&sig=FCnF_Z2FAfUSGRIS2DJY3ioVNr0#v=onepage&q=Self-identity after brain injury&f=false
62. Troschel FM, Ahndorf F, Wille LM, et al. Quality of life in brain tumor patients and their relatives heavily depends on social support factors during the covid-19 pandemic. *Cancers (Basel)*. 2021;13(6). doi:10.3390/cancers13061276
63. de Boer AGEM, Taskila T, Ojajärvi A, van Dijk FJH, Verbeek JHAM. Cancer survivors and unemployment: a meta-analysis and meta-regression. *JAMA*. 2009;301(7):753-762. doi:10.1001/jama.2009.187
64. Anderson FA. The Glioma Outcomes Project: a resource for measuring and improving glioma outcomes. *Neurosurg Focus*. 1998;4(6):E10. doi:10.3171/FOC.1998.4.6.11

65. Halkett GKB, Lobb EA, Rogers MM, et al. Predictors of distress and poorer quality of life in High Grade Glioma patients. *Patient Educ Couns*. 2015;98(4):525-532. doi:10.1016/J.PEC.2015.01.002
66. Silvaggi F, Leonardi M, Raggi A, et al. Employment and Work Ability of Persons With Brain Tumors: A Systematic Review. *Front Hum Neurosci*. 2020;0:452. doi:10.3389/FNHUM.2020.571191
67. Lupton A, Abu-Suwa H, Bolton GC, Golden C. The implications of brain tumors on aggressive behavior and suicidality: A review. *Aggress Violent Behav*. 2020;54. doi:10.1016/j.avb.2020.101416
68. Madhusoodanan S, Ting MB, Farah T, Ugur U. Psychiatric aspects of brain tumors: A review. *World J Psychiatry*. Published online 2015. doi:10.5498/wjp.v5.i3.273
69. Madhusoodanan S, Opler MG, Moise D, et al. Brain tumor location and psychiatric symptoms: Is there any association? A meta-analysis of published case studies. *Expert Rev Neurother*. Published online 2010. doi:10.1586/ern.10.94
70. Keschner M, Bender M, Strauss I. Mental symptoms associated with brain tumor: A study of 530 verified cases. *JAMA*. 1938;110:714-718.
71. Loughan AR, WKD, LA, ADH, RM, RS, BR, BJ. Psychosocial Issues in Cancer Patients with Neurological Complications. In: Newton H, Malkin M, eds. *Neurological Complications of Systemic Cancer and Antineoplastic Therapy*. 2nd ed. Elsevier; 2021.
72. Litofsky NS, Farace E, Anderson F, et al. Depression in Patients with High-grade Glioma: Results of the Glioma Outcomes Project. *Neurosurgery*. 2004;54:358-367. doi:10.1227/01.NEU.0000103450.94724.A2
73. Pelletier G, Verhoef MJ, Khatri N, Hagen N. Quality of life in brain tumor patients: The relative contributions of depression, fatigue, emotional distress, and existential issues. *J Neurooncol*. 2002;57(1):41-49. doi:10.1023/A:1015728825642
74. Wellisch DK, Kaleita TA, Freeman D, Cloughesy T, Goldman J. Predicting major depression in brain tumor patients. *Psychooncology*. 2002;11(3):230-238. doi:10.1002/pon.562
75. Arnold SD, Forman LM, Brigidi BD, et al. Evaluation and characterization of generalized anxiety and depression in patients with primary brain tumors. *Neuro Oncol*. 2008;10(2):171-181. doi:10.1215/15228517-2007-057
76. Linden W, Vodermaier A, MacKenzie R, Greig D. Anxiety and depression after cancer diagnosis: Prevalence rates by cancer type, gender, and age. *J Affect Disord*. 2012;121(2-3):343-351. doi:10.1016/j.jad.2012.03.025
77. Litofsky NS, Resnick AG. The relationships between depression and brain tumors. *J Neurooncol*. 2009;94:153-161. doi:10.1007/s11060-009-9825-4
78. Rooney A, Grant R. Pharmacological treatment of depression in patients with a primary brain tumour. *Cochrane Database of Systematic Reviews*. 2013;5:1-19. doi:10.1002/14651858.CD006932.pub3
79. Tibbs MD, Huynh-Le MP, Reyes A, et al. Longitudinal Analysis of Depression and Anxiety Symptoms as Independent Predictors of Neurocognitive Function in Primary Brain Tumor Patients. *Int J Radiat Oncol Biol Phys*. 2020;108(5):1229-1239. doi:10.1016/j.ijrobp.2020.07.002
80. Loughan AR, Aslanzadeh FJ, Brechbiel J, et al. Death-related distress in adult primary brain tumor patients. *Neurooncol Pract*. 2020;7(5):498-506. doi:10.1093/nop/npaa015

81. Rosenblum ML, Kalkanis S, Goldberg W, et al. Odyssey of hope: A physician's guide to communicating with brain tumor patients across the continuum of care. *J Neurooncol*. 2009;92(3 SPEC. ISS.):241-251. doi:10.1007/s11060-009-9828-1
82. Tyldesley-Marshall N, Greenfield S, Neilson S, English M, Adamski J, Peet A. Qualitative study: patients' and parents' views on brain tumour MRIs What is already known on this topic? *Arch Dis Child*. 2020;105:166-172. doi:10.1136/archdischild-2019-317306
83. Loughan AR, Lanoye A, Aslanzadeh F, et al. Fear of Cancer Recurrence and Death Anxiety: Unaddressed concerns for adult neuro-oncology patients. *J Clin Psychol Med Settings*. Published online 2019:1-15.
84. Braun, SE., Aslanzadeh, F., Thacker, L., & Loughan AR. Examining Fear of Cancer Recurrence in Primary Brain Tumor Patients and Their Caregivers Using the Actor-Partner Interdependence Model. *Psychooncology*.
85. Humphris GM, Watson E, Sharpe M, Ozakinci G. Unidimensional scales for fears of cancer recurrence and their psychometric properties: The FCR4 and FCR7. *Health Qual Life Outcomes*. 2018;16(1):30. doi:10.1186/s12955-018-0850-x
86. Abdel-Khalek AM. THE DEATH DISTRESS CONSTRUCT AND SCALE. *Omega (Westport)*. 2011;64(2):171-184. doi:10.2190/OM.64.2.e
87. 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. *Journal of Neuro-Oncology 2018 140:2*. 2018;140(2):367-375. doi:10.1007/S11060-018-2962-X
88. PR S, BA G, CW G, et al. Predictors of distress in caregivers of persons with a primary malignant brain tumor. *Res Nurs Health*. 2006;29(2):105-120. doi:10.1002/NUR.20116
89. Adashek JJ, Subbiah IM. Caring for the caregiver: a systematic review characterising the experience of caregivers of older adults with advanced cancers. *ESMO Open*. 2020;5(5):e000862. doi:10.1136/ESMOOPEN-2020-000862
90. D C, J Z, Q X, et al. The role of informal caregivers for patients with glioma: a systematic review and meta-synthesis of qualitative studies. *Ann Transl Med*. 2021;9(12):1020-1020. doi:10.21037/ATM-21-2761
91. 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. doi:10.1002/nur.20116
92. JR S, MB K, E F. Caring for the brain tumor patient: family caregiver burden and unmet needs. *Neuro Oncol*. 2008;10(1):61-72. doi:10.1215/15228517-2007-040
93. Francis SR, Hall EO, Delmar C. Ethical dilemmas experienced by spouses of a partner with brain tumour: *https://doi.org/101177/0969733019857790*. 2019;27(2):587-597. doi:10.1177/0969733019857790
94. Wasner M, Paal P, Borasio GD. Psychosocial Care for the Caregivers of Primary Malignant Brain Tumor Patients. *https://doi.org/101080/155242562012758605*. 2013;9(1):74-95. doi:10.1080/15524256.2012.758605
95. Mohammed S, Swami N, Pope | Ashley, et al. "I didn't want to be in charge and yet I was": Bereaved caregivers' accounts of providing home care for family members with advanced cancer. Published online 2018. doi:10.1002/pon.4657
96. McConigley R, Halkett G, Lobb E, Nowak A. Caring for someone with high-grade glioma: a time of rapid change for caregivers:

http://dx.doi.org/101177/0269216309360118. 2010;24(5):473-479. doi:10.1177/0269216309360118

97. 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(1):7. doi:10.1186/1472-684X-6-7
98. Ownsworth T, Goadby E, Chambers SK. Support after Brain Tumor Means Different Things: Family Caregivers' Experiences of Support and Relationship Changes. *Front Oncol*. 2015;0(FEB):33. doi:10.3389/FONC.2015.00033
99. Sherwood P, Given B, Given C, Schiffman R, Murman D, Lovely M. Caregivers of persons with a brain tumor: a conceptual model. *Nurs Inq*. 2004;11(1):43-53. doi:10.1111/j.1440-1800.2004.00200.x
100. ST K, AB G, KE C, LC B, L G, HS F. Differential levels of stress in caregivers of brain tumor patients--observations from a pilot study. *Support Care Cancer*. 2006;14(12):1258-1261. doi:10.1007/S00520-006-0090-1
101. Sherwood PR, Donovan HS, Given CW, et al. Predictors of employment and lost hours from work in cancer caregivers. *Psychooncology*. 2008;17(6):598-605. doi:10.1002/PON.1287
102. E B, F LD, M P, K HX, ME J, JY D. The multidimensional burden of informal caregivers in primary malignant brain tumor. *Support Care Cancer*. 2017;25(1):245-253. doi:10.1007/S00520-016-3397-6
103. Mariotto AB, Robin Yabroff K, Shao Y, Feuer EJ, Brown ML. Projections of the Cost of Cancer Care in the United States: 2010–2020. *JNCI: Journal of the National Cancer Institute*. 2011;103(2):117-128. doi:10.1093/JNCI/DJQ495
104. Bradley SE, Sherwood PR, Kuo J, et al. Perceptions of economic hardship and emotional health in a pilot sample of family caregivers. *Journal of Neuro-Oncology 2009 93:3*. 2009;93(3):333-342. doi:10.1007/S11060-008-9778-Z
105. Ownsworth T, Henderson L, Chambers SK. Social support buffers the impact of functional impairments on caregiver psychological well-being in the context of brain tumor and other cancers. *Psychooncology*. 2009;19(10):1116-1122. doi:10.1002/pon.1663
106. Boele FW, Heimans JJ, Aaronson NK, et al. Health-related quality of life of significant others of patients with malignant CNS versus non-CNS tumors: a comparative study. *Journal of Neuro-Oncology 2013 115:1*. 2013;115(1):87-94. doi:10.1007/S11060-013-1198-Z
107. Salander P, Spetz A. How do patients and spouses deal with the serious facts of malignant glioma?: *http://dx.doi.org/101191/0269216302pm569oa*. 2016;16(4):305-313. doi:10.1191/0269216302PM569OA
108. Dunn LB, Aouizerat BE, Langford DJ, et al. Cytokine gene variation is associated with depressive symptom trajectories in oncology patients and family caregivers. *European Journal of Oncology Nursing*. 2013;17(3):346-353. doi:10.1016/J.EJON.2012.10.004
109. Sherwood PR, Price TJ, Weimer J, et al. Neuro-oncology family caregivers are at risk for systemic inflammation. *Journal of Neuro-Oncology 2016 128:1*. 2016;128(1):109-118. doi:10.1007/S11060-016-2083-3
110. JD P, SY L, PC C, PR S. 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. doi:10.1002/NUR.21545

111. MS J, HM D, MR A. Sleep disturbance of adults with a brain tumor and their family caregivers: a systematic review. *Neuro Oncol*. 2017;19(8):1035-1046. doi:10.1093/NEUONC/NOX019
112. Ferrario SR, Cardillo V, Vicario F, Balzarini E, Zotti AM. Advanced cancer at home: caregiving and bereavement: *http://dx.doi.org/101191/0269216304pm870oa*. 2016;18(2):129-136. doi:10.1191/0269216304PM870OA
113. Stroebe MS, Hansson RO, Stroebe W, Schut H. Introduction: Concepts and issues in contemporary research on bereavement. *Handbook of bereavement research: Consequences, coping, and care*. Published online October 27, 2004:3-22. doi:10.1037/10436-031
114. Lichtenthal WG, Prigerson HG, Kissane DW. Bereavement: A Special Issue in Oncology. *Psychooncology*. Published online January 4, 2013:537-543. doi:10.1093/MED/9780195367430.003.0076
115. GK H, EA L, T S, 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):887-893. doi:10.1007/S00520-016-3478-6
116. Choi CWJ, Stone RA, Kim KH, et al. Group-Based Trajectory Modeling of Caregiver Psychological Distress Over Time. *Annals of Behavioral Medicine*. 2012;44(1):73-84. doi:10.1007/S12160-012-9371-8
117. Baumstarck K, Leroy T, Hamidou Z, et al. Coping with a newly diagnosed high-grade glioma: patient-caregiver dyad effects on quality of life. *Journal of Neuro-Oncology 2016 129:1*. 2016;129(1):155-164. doi:10.1007/S11060-016-2161-6
118. 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. doi:10.1093/NEUONC/NOR229
119. Petruzzi A, Finocchiaro CY, Lamperti E, Salmaggi A. Living with a brain tumor. *Supportive Care in Cancer 2012 21:4*. 2012;21(4):1105-1111. doi:10.1007/S00520-012-1632-3
120. Russell B, Collins & A, Dowling & A, et al. Predicting distress among people who care for patients living longer with high-grade malignant glioma. doi:10.1007/s00520-015-2739-0
121. 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. doi:10.1002/nur.20116
122. Jansson MRN, von Heymann-Horan A, Rasmussen BK, et al. Risk for use of antidepressants, anxiolytics, and hypnotics in partners of glioma patients—A nationwide study covering 19 years of prescriptions. *Psychooncology*. 2018;27(8):1930-1936. doi:10.1002/PON.4744
123. Goebel S, von Harscher M, Mehdorn HM. Comorbid mental disorders and psychosocial distress in patients with brain tumours and their spouses in the early treatment phase. *Supportive Care in Cancer 2010 19:11*. 2010;19(11):1797-1805. doi:10.1007/S00520-010-1021-8
124. 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*. 2007;63(6):617-623. doi:10.1016/j.jpsychores.2007.06.018

125. M J, S S, J D, D L, D W, E 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. doi:10.1016/J.PEC.2008.01.020
126. K M, HS P. Needs for everyday life support for brain tumour patients' relatives: systematic literature review. *Eur J Cancer Care (Engl)*. 2011;20(1):33-43. doi:10.1111/J.1365-2354.2010.01184.X
127. Applebaum AJ, Kryza-Lacombe M, Buthorn J, DeRosa A, Corner G, Diamond EL. Existential distress among caregivers of patients with brain tumors: a review of the literature. *Neurooncol Pract*. 2016;3(4):232-244. doi:10.1093/NOP/NPV060
128. A Family's Perspective on Living With a Highly Malignant Bra... : Cancer Nursing. Accessed August 11, 2021. https://journals.lww.com/cancernursingonline/Fulltext/2002/06000/A_Family_s_Perspective_on_Living_With_a_Highly.12.aspx?casa_token=wr_WJXUwaqAAAAAA:iD4uDdgzq5Sigp1vM8y0PU13W8z8dnNRCcj1d8FG1sFNQIuzTr51jIn8eCEiHMZmM9V5ugNzf3KQwa-tjl3IV2gP
129. Fox S, Lantz C. The brain tumor experience and quality of life: a qualitative study. *Journal of Neuroscience Nursing*. 1998;30(4):245-251.
130. C K, NM D, M D, A S, K E. Together and apart: providing psychosocial support for patients and families living with brain tumors. *Support Care Cancer*. 2014;22(1):43-52. doi:10.1007/S00520-013-1933-1
131. Willis KD, Braun SE, Boutte R LAr. Death anxiety in caregivers of primary brain tumor patients: Prevalence and correlates. In: *American Psychosocial Oncology Society Annual Meeting*. ; 2020.
132. SE B, FJ A, L T, AR L. Examining fear of cancer recurrence in primary brain tumor patients and their caregivers using the Actor-Partner Interdependence Model. *Psychooncology*. 2021;30(7). doi:10.1002/PON.5659
133. Finocchiaro CY, Petruzzi A, Lamperti E, et al. The burden of brain tumor: a single-institution study on psychological patterns in caregivers. *Journal of Neuro-Oncology 2011 107:1*. 2011;107(1):175-181. doi:10.1007/S11060-011-0726-Y
134. SM A, K D, D H, G L. Exploring the Support Needs of Family Caregivers of Patients with Brain Cancer Using the CSNAT: A Comparative Study with Other Cancer Groups. *PLoS One*. 2015;10(12). doi:10.1371/JOURNAL.PONE.0145106
135. Baumstarck K, Chinot O, Tabouret E, et al. Coping strategies and quality of life: A longitudinal study of high-grade glioma patient-caregiver dyads. *Health Qual Life Outcomes*. 2018;16(1):157. doi:10.1186/s12955-018-0983-y
136. Kuluski K, Kokorelias K, Peckham A, Goldhar J, Petrie J, Alloway CA. Twelve principles to support caregiver engagement in health care systems and health research. *Patient Exp J*. 2019;6(1):141-148. doi:10.35680/2372-0247.1338
137. AG N, CW C, HS D, et al. Exploring spirituality in family caregivers of patients with primary malignant brain tumors across the disease trajectory. *Oncol Nurs Forum*. 2013;40(3). doi:10.1188/13.ONF.E119-E125
138. PJ S, B T, B K, G F. Religious/spiritual concerns of patients with brain cancer and their caregivers. *Ann Palliat Med*. 2021;10(1):964-969. doi:10.21037/APM-20-813
139. K P, M J, J J, M J. Controlled rehabilitative and supportive care intervention trials in patients with high-grade gliomas and their caregivers: a systematic review. *BMJ Support Palliat Care*. 2016;6(1):27-34. doi:10.1136/BMJSPCARE-2013-000593

140. FW B, AG R, H B, P S. Interventions to help support caregivers of people with a brain or spinal cord tumour. *Cochrane Database Syst Rev*. 2019;7(7). doi:10.1002/14651858.CD012582.PUB2
141. GKB H, EA L, T S, et al. Do carer's levels of unmet needs change over time when caring for patients diagnosed with high-grade glioma and how are these needs correlated with distress? *Support Care Cancer*. 2018;26(1):275-286. doi:10.1007/S00520-017-3846-X
142. NE A, AEK P. Cancer Care for the Whole Patient: Meeting Psychosocial Health Needs. Published online April 19, 2008:1-429. doi:10.17226/11993
143. 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. *Journal of Neuro-Oncology 2012 111:3*. 2012;111(3):303-311. doi:10.1007/S11060-012-1012-3
144. Locke DEC, Cerhan JH, Wu W, et al. Cognitive rehabilitation and problem-solving to improve quality of life of patients with primary brain tumors: A pilot study. *Journal of Supportive Oncology*. 2008;6(8):383-391.
145. Reblin M, Ketcher D, Forsyth P, et al. Outcomes of an electronic social network intervention with neuro-oncology patient family caregivers. *Journal of Neuro-Oncology 2018 139:3*. 2018;139(3):643-649. doi:10.1007/S11060-018-2909-2
146. D T, M D, S G, M M, S D. Intracranial Tumors: A Nurse-Led Intervention for Educating and Supporting Patients and Their Caregivers. *Clin J Oncol Nurs*. 2019;23(3):315-323. doi:10.1188/19.CJON.315-323
147. Halkett GKB, Lobb EA, Miller L, et al. Feasibility Testing and Refinement of a Supportive Educational Intervention for Carers of Patients with High-Grade Glioma — a Pilot Study. *Journal of Cancer Education 2017 33:5*. 2017;33(5):967-975. doi:10.1007/S13187-017-1175-X
148. GK H, EA L, L M, et al. Protocol for the Care-IS Trial: a randomised controlled trial of a supportive educational intervention for carers of patients with high-grade glioma (HGG). *BMJ Open*. 2015;5(10). doi:10.1136/BMJOPEN-2015-009477
149. Philip J, Collins A, Staker J, Murphy M. I-CoPE: A pilot study of structured supportive care delivery to people with newly diagnosed high-grade glioma and their carers. *Neurooncol Pract*. 2019;6(1):61-70. doi:10.1093/NOP/NPY010
150. JN DO, GR W, PP W, et al. Implementing a Clinic-Based Telehealth Support Service (FamilyStrong) for Family Caregivers of Individuals with Grade IV Brain Tumors. *J Palliat Med*. 2021;24(3):347-353. doi:10.1089/JPM.2020.0178
151. Milbury K, Weathers SP, Durrani S, et al. Online Couple-Based Meditation Intervention for Patients With Primary or Metastatic Brain Tumors and Their Partners: Results of a Pilot Randomized Controlled Trial. *J Pain Symptom Manage*. 2020;59(6):1260-1267. doi:10.1016/j.jpainsymman.2020.02.004
152. Milbury K, Mallaiah S, Mahajan A, et al. Yoga Program for High-Grade Glioma Patients Undergoing Radiotherapy and Their Family Caregivers: *https://doi.org/101177/1534735417689882*. 2017;17(2):332-336. doi:10.1177/1534735417689882
153. Ketcher D, Ellington L, Baucom BRW, Clayton MF, Reblin M. "In Eight Minutes We Talked More About Our Goals, Relationship, Than We Have in Years": A Pilot of Patient–Caregiver Discussions in a Neuro-Oncology Clinic: *https://doi.org/101177/1074840720913963*. 2020;26(2):126-137. doi:10.1177/1074840720913963

154. MB K, J E, J M, et al. Dignity therapy for patients with brain tumours: qualitative reports from patients, caregivers and practitioners. *Ann Palliat Med*. 2021;10(1):838-845. doi:10.21037/APM-20-553
155. Piderman KM, Radecki Breitkopf C, Jenkins SM, et al. The Feasibility and Educational Value of Hear My Voice, a Chaplain-Led Spiritual Life Review Process for Patients with Brain Cancers and Progressive Neurologic Conditions. *Journal of Cancer Education 2014 30:2*. 2014;30(2):209-212. doi:10.1007/S13187-014-0686-Y
156. Piderman KM, Radecki Breitkopf C, Jenkins SM, et al. The impact of a spiritual legacy intervention in patients with brain cancers and other neurologic illnesses and their support persons. Published online 2015. doi:10.1002/pon.4031
157. ST K. Levels of stress and intervention preferences of caregivers of brain tumor patients. *Cancer Nurs*. 2007;30(6). doi:10.1097/01.NCC.0000300174.18584.F9
158. G M, A C, C B, 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. doi:10.1016/J.PEC.2012.11.002
159. A C, C L, C B, et al. The challenges and suffering of caring for people with primary malignant glioma: qualitative perspectives on improving current supportive and palliative care practices. *BMJ Support Palliat Care*. 2014;4(1):68-76. doi:10.1136/BMJSPCARE-2012-000419
160. K P, S N, A L, M J. Bereaved caregivers of patients with high-grade glioma: a systematic review. *BMJ Support Palliat Care*. 2019;9(1):26-33. doi:10.1136/BMJSPCARE-2017-001386
161. I S, N H, T L, et al. Quality of online self-management resources for adults living with primary brain cancer, and their carers: a systematic environmental scan. *BMC Palliat Care*. 2021;20(1). doi:10.1186/S12904-021-00715-4
162. Ownsworth T, Chambers S, Damborg E, Casey L, Walker DG, Shum DHK. Evaluation of the making sense of brain tumor program: A randomized controlled trial of a home-based psychosocial intervention. *Psychooncology*. 2015;24(5):540-547. doi:10.1002/pon.3687
163. Applebaum AJ, Kulikowski JR, Breitbart W. Meaning-Centered Psychotherapy for Cancer Caregivers (MCP-C): Rationale and Overview. *Palliat Support Care*. 2015;13(6):1631-1641. doi:10.1017/S1478951515000450
164. Breitbart W, Poppito S, Rosenfeld B, et al. Pilot randomized controlled trial of individual meaning-centered psychotherapy for patients with advanced cancer. *Journal of Clinical Oncology*. 2012;30(12):1304-1309. doi:10.1200/JCO.2011.36.2517
165. Loughan A, Willis K, Lanoye A, et al. Exploring CALM in Patients with High-Grade Glioma. In: *Society for Neuro-Oncology Conference*. ; 2021.
166. Rodin G, Lo C, Rydall A, et al. Managing Cancer and Living Meaningfully (CALM): A randomized controlled trial of a psychological intervention for patients with advanced cancer. *Journal of Clinical Oncology*. 2018;36(23):2422-2432. doi:10.1200/JCO.2017.77.1097
167. Hales S, Lo C, Rodin G. Managing Cancer and Living Meaningfully (CALM) Therapy. In: Holland JC, Breitbart WS, Butow PN, Jacobsen PB, Loscalzo MJ MR, ed. *Psycho-Oncology*. Third edit. Oxford Press; 2015:487-491. doi:10.1093/med/9780199363315.003.0062

168. Rodin G, Zimmermann C. Psychoanalytic reflections on mortality: A reconsideration. In: *Journal of the American Academy of Psychoanalysis and Dynamic Psychiatry*. Vol 36. ; 2008. doi:10.1521/jaap.2008.36.1.181
169. Shaw C, Chrysikou V, Lanceley A, Lo C, Hales S, Rodin G. Mentalization in CALM psychotherapy sessions: Helping patients engage with alternative perspectives at the end of life. *Patient Educ Couns*. 2019;102(2). doi:10.1016/j.pec.2018.10.001
170. Lo C, Hales S, Jung J, et al. Managing Cancer and Living Meaningfully (CALM): Phase 2 trial of a brief individual psychotherapy for patients with advanced cancer. *Palliat Med*. 2014;28(3):234-242. doi:10.1177/0269216313507757
171. Lo C, Hales S, Chiu A, et al. Managing cancer and living meaningfully (CALM): Randomised feasibility trial in patients with advanced cancer. *BMJ Support Palliat Care*. 2019;9(2):209-218. doi:10.1136/bmjspcare-2015-000866
172. Nissim R, Freeman E, Lo C, et al. Managing Cancer and Living Meaningfully (CALM): A qualitative study of a brief individual psychotherapy for individuals with advanced cancer. *Palliat Med*. 2012;26(5):713-721. doi:10.1177/0269216311425096
173. Czajkowski SM, Powell LH, Adler N, et al. From ideas to efficacy: The ORBIT model for developing behavioral treatments for chronic diseases. *Health Psychology*. 2015;34(10):971-982. doi:10.1037/hea0000161
174. Braun V, Clarke V. Successful Qualitative Research a practical guide for beginners.
175. Fugard AJB, Potts HWW. Supporting thinking on sample sizes for thematic analyses: a quantitative tool. *http://dx.doi.org/101080/1364557920151005453*. 2015;18(6):669-684. doi:10.1080/13645579.2015.1005453
176. Kroenke K, Spitzer RL, Williams JBW. The PHQ-9: Validity of a brief depression severity measure. *J Gen Intern Med*. 2001;16(9):606-613. doi:10.1046/j.1525-1497.2001.016009606.x
177. Andersen BL, DeRubeis RJ, Berman BS, et al. Screening, assessment, and care of anxiety and depressive symptoms in adults with cancer: An American Society of Clinical Oncology guideline adaptation. *Journal of Clinical Oncology*. 2014;32(15):1605-1619. doi:10.1200/JCO.2013.52.4611
178. Thekkumpurath P, Walker J, Butcher I, et al. Screening for major depression in cancer outpatients. *Cancer*. 2011;117(1):218-227. doi:10.1002/CNCR.25514
179. Spitzer RL, Kroenke K, Williams JBW, Löwe B. A brief measure for assessing generalized anxiety disorder: The GAD-7. *Arch Intern Med*. 2006;30(8):772-779. doi:10.1001/archinte.166.10.1092
180. Fraley RC, Heffernan ME, Vicary AM, Brumbaugh CC. The Experiences in Close Relationships-Relationship Structures Questionnaire: A Method for Assessing Attachment Orientations Across Relationships. *Psychol Assess*. 2011;23(3):615-625. doi:10.1037/a0022898
181. Brennan KA, Clark CL, Shaver PR. Self-report measurement of adult attachment: An integrative overview. In: Simpson J, Rholes W, eds. *Attachment Theory and Close Relationships*. Guilford Press; 1998:46-76.
182. Lo C, Walsh A, Mikulincer M, Gagliese L, Zimmermann C, Rodin G. Measuring attachment security in patients with advanced cancer: psychometric properties of a modified and brief Experiences in Close Relationships scale. *Psychooncology*. 2009;18(5):490-499. doi:10.1002/PON.1417

183. Peterman AH, Fitchett G, Min D, Brady MJ, Hernandez L, Cella D. Measuring Spiritual Well-Being in People With Cancer: The Functional Assessment of Chronic Illness Therapy-Spiritual Well-Being Scale (FACIT-Sp). Published online 2002.
184. Munoz AR, Salsman JM, Stein K, Cella D. Reference Values of the Functional Assessment of Chronic Illness Therapy – Spiritual Well-Being (FACIT-Sp-12): A Report from the American Cancer Society's Studies of Cancer Survivors. *Cancer*. 2015;121(11):1838. doi:10.1002/CNCR.29286
185. Leighanna A, Colgrove MPH, Kim Y, Thompson N. The Effect of Spirituality and Gender on the Quality of Life of Spousal Caregivers of Cancer Survivors. *Ann Behav Med*. 2007;33(1):90-98. Accessed September 24, 2021. https://academic.oup.com/abm/article/33/1/90/4569341
186. Osarchuk M, Tatz SJ. Effect of induced fear of death on belief in afterlife. *J Pers Soc Psychol*. 1973;27(2):256-260. doi:10.1037/H0034769
187. Hill P, Jr RH. MEASURES OF RELIGIOSITY. Published online 1999. Accessed September 24, 2021. https://www.researchgate.net/profile/Bob-Lew/post/Does-anyone-have-good-indicators-for-spirituality/attachment/59d63b9879197b8077998a18/AS%3A411545008918529%401475131384835/download/Measures+of+Religiosity%2C+Hill+%26+Hood+%281999%29%2C+pp+01-50.pdf
188. Tedeschi RG, Calhoun LG. The Posttraumatic Growth Inventory: Measuring the Positive Legacy of Trauma. *Journal of 7t'aumatic Stress*. 1996;9(3).
189. Jansen L, Hoffmeister M, Chang-Claude J, Brenner H, Arndt V. Benefit finding and post-traumatic growth in long-term colorectal cancer survivors: prevalence, determinants, and associations with quality of life. *British Journal of Cancer 2011 105:8*. 2011;105(8):1158-1165. doi:10.1038/bjc.2011.335
190. Mazor Y, Gelkopf M, Mueser KT, Roe D. Posttraumatic Growth in Psychosis. *Front Psychiatry*. 2016;0(DEC):202. doi:10.3389/FPSYT.2016.00202
191. Moore AM, Gamblin TC, Geller DA, et al. A Prospective Study of Posttraumatic Growth as Assessed by Self Report and Family Caregiver in the Context of Advanced Cancer. *Psychooncology*. 2011;20(5):479. doi:10.1002/PON.1746
192. Rubin SS, Bar-Nadav O. The Two-Track Bereavement Questionnaire for Complicated Grief (TTBQ-CG31). *Techniques of Grief Therapy: Assessment and Intervention*. Published online September 25, 2015:111-122. doi:10.4324/9781315692401-25
193. Rubin SS, Nadav OB, Malkinson R, Koren D, Goffer-Shnarch M, Michaeli E. The Two-Track Model of Bereavement Questionnaire (TTBQ): Development and validation of a relational measure. *Death Stud*. 2009;33(4):305-333. doi:10.1080/07481180802705668
194. Rubin S. A TWO-TRACK MODEL OF BEREAVEMENT: Theory and Application in Research. *American Journal of Orthopsychiatry*. 1981;51(1):101-109. doi:10.1111/J.1939-0025.1981.TB01352.X
195. Downey L, Curtis JR, Lafferty WE, Herting JR, Engelberg RA. The Quality of Dying and Death Questionnaire (QODD): Empirical Domains and Theoretical Perspectives. *Journal of Pain and Symptom Management*. 2010;39(1). doi:10.1016/j.jpainsymman.2009.05.012
196. Patrick DL, Engelberg RA, Curtis JR. Evaluating the quality of dying and death. *Journal of Pain and Symptom Management*. 2001;22(3). doi:10.1016/S0885-3924(01)00333-5

197. Loughan, A. R., Reid, M., Willis, K. D., Davies, A., Boutté, R. L., Barrett, S., & Lo K. The burden of a brain tumor: guiding patient centric care in neuro-oncology. *Journal of Neuro-Oncology*. 2022;157(3):487-498.
198. Bringer JD, Johnston LH, Brackenridge CH. Maximizing Transparency in a Doctoral Thesis1: The Complexities of Writing About the Use of QSR*NVIVO Within a Grounded Theory Study. *Qualitative Research*. 2004;4(2). doi:10.1177/1468794104044434
199. Houghton C, Murphy K, Meehan B, Thomas J, Brooker D, Casey D. From screening to synthesis: using nvivo to enhance transparency in qualitative evidence synthesis. *J Clin Nurs*. 2017;26(5-6). doi:10.1111/jocn.13443
200. Transforming qualitative information: Thematic analysis and code development. - PsycNET. Accessed September 24, 2021. https://psycnet.apa.org/record/1998-08155-000
201. Rodgers BL, Cowles K v. The qualitative research audit trail: A complex collection of documentation. *Res Nurs Health*. 1993;16(3):219-226. doi:10.1002/NUR.4770160309
202. Willis K, Ravyts SG, Lanoye A, et al. Measuring and understanding death anxiety in caregivers of patients with primary brain tumor. *Palliat Support Care*. Published online 2022:1-8.
203. Rodin, G., & Hales S. *Managing Cancer and Living Meaningfully: An Evidence-Based Intervention for Cancer Patients and Their Caregivers.* Oxford University Press; 2021. doi:10.1093/med/9780190236427.001.0001
204. Hunt GG, Longacre ML, Kent EE WRL. Cancer caregiving in the US: an intense, episodic, and challenging care experience. National Alliance for Caregiving. Published 2016. https://www.caregiving.org/wp-content/uploads/2020/05/CancerCaregivingReport_FINAL_June-17-2016.pdf
205. Sherwood PR, Cwiklik M, Donovan HS. Neuro-oncology family caregiving: review and directions for future research. *http://dx.doi.org/102217/cns1543*. 2015;5(1):41-48. doi:10.2217/CNS.15.43
206. Ostrom QT, Cote DJ, Ascha M, Kruchko C, Barnholtz-Sloan JS. Adult glioma incidence and survival by race or ethnicity in the United States from 2000 to 2014. *JAMA Oncology*. 2018;4(9). doi:10.1001/jamaoncol.2018.1789
207. Porter AB, Chukwueke UN, Mammoser AG, Friday B, Hervey-Jumper S. Delivering Equitable Care to Underserved Neuro-oncology Populations. *American Society of Clinical Oncology Educational Book*. 2021;(41). doi:10.1200/edbk_320803
208. Piil K, Nordentoft S, Larsen A, Jarden M. Bereaved caregivers of patients with high-grade glioma: a systematic review. *BMJ Support Palliat Care*. 2019;9:26-33. doi:10.1136/bmjspcare-2017-001386
209. Lobb, E. A., Halkett, G. K., McDougall, E., Campbell, R., Dhillon, H. M., Phillips, J. L., & Nowak AK. Bereavement outcomes of carers of patients with high grade glioma: Experiences of support before and after the death. *Death Studies*. Published online 2023:1-10.
210. Kelcie Willis, Autumn Lanoye, Christopher Kleva, Morgan Reid, Amber Fox, Jaclyn Sadicario, Julia Brechbiel AL. SILVER LININGS: THE EXPERIENCE OF POSTTRAUMTIC GROWTH IN NEURO-ONCOLOGY CAREGIVERS. In: *Society of Neuro-Oncology*. ; 2022.
211. Jones D, Pinkham MB, Wallen MP, et al. Benefits of supportive strategies for carers of people with high-grade glioma: a systematic review: Strategies for addressing the needs of

high-grade glioma carers. *Supportive Care in Cancer*. 2022;30(12):10359-10378. doi:10.1007/s00520-022-07419-2

212. Coolbrandt A, Sterckx W, Clement P, et al. Family Caregivers of Patients with a High-Grade Glioma: A Qualitative Study of Their Lived Experience and Needs Related to Professional Care. *Cancer Nurs*. 2015;38(5):406-413. doi:10.1097/NCC.0000000000000216
213. Litzelman K, Harnish A. Caregiver Eligibility for Support Services: Correlates and Consequences for Resource Utilization. *Journal of Applied Gerontology*. 2022;41(2). doi:10.1177/0733464820971134
214. Miller TT, Maurer SH, Felker JT. Searching for a cure on Facebook: Patterns of social media use amongst caregivers of children with brain tumors. *Cancer Medicine*. 2022;11(17). doi:10.1002/cam4.4693
215. Salmi L, Lum HD, Hayden A, et al. Stakeholder engagement in research on quality of life and palliative care for brain tumors: A qualitative analysis of #BTSM and #HPM tweet chats. *Neuro-Oncology Practice*. 2020;7(6). doi:10.1093/nop/npaa043
216. J B, C K, F B, et al. Neuro-oncological patients' and caregivers' psychosocial burden during the COVID-19 pandemic-A prospective study with qualitative content analysis. *Psycho-oncology*. Published online 2021. doi:10.1002/PON.5713
217. Edge R, Meyers J, Tiernan G, et al. Cancer care disruption and reorganisation during the COVID-19 pandemic in Australia: A patient, carer and healthcare worker perspective. *PLoS ONE*. 2021;16(9 September). doi:10.1371/journal.pone.0257420
218. Sannes TS, Yeh IM, Gray TF. Caring for loved ones with cancer during the COVID-19 pandemic: A double hit risk for social isolation and need for action. *Psycho-Oncology*. 2020;29(9). doi:10.1002/pon.5466
219. Applebaum AJ. I Was Never "Just" a Visitor. The Hastings Center. Published 2022. https://www.thehastingscenter.org/i-was-never-just-a-visitor/
220. Mcconigley R, Halkett G. Caring for someone with high-grade glioma: a time of rapid change for caregivers. doi:10.1177/0269216309360118
221. PR S, BA G, AZ D, CW G. Forgotten voices: lessons from bereaved caregivers of persons with a brain tumour. *Int J Palliat Nurs*. 2004;10(2). doi:10.12968/IJPN.2004.10.2.12460
222. Managing Cancer and Living Meaningfully: An Evidence-Based Intervention for ... - Gary Rodin, Sarah Hales - Google Books. Accessed September 14, 2021. https://books.google.com/books?hl=en&lr=&id=X8UqEAAAQBAJ&oi=fnd&pg=PP1&dq=Managing+Cancer+and+Living+Meaningfully+book&ots=Jia_JduLwC&sig=RKz5P5CTok-wbCRJ0VsgBfsyg2M#v=onepage&q=Managing Cancer and Living Meaningfully book&f=false
223. Dhandapani M, Gupta S, Dhandapani S, et al. Study of factors determining caregiver burden among primary caregivers of patients with intracranial tumors. *Surgical Neurology International*. 2015;6(1). doi:10.4103/2152-7806.167084
224. C S, P WS, S L, M S. When a family member has a malignant brain tumor: the caregiver perspective. *J Neurosci Nurs*. 2008;40(2):78-84. doi:10.1097/01376517-200804000-00006
225. Kissane D, Lichtenthal WG, Zaider T. Family care before and after bereavement. *Omega: Journal of Death and Dying*. 2007;56(1). doi:10.2190/OM.56.1.c
226. Reblin M, Wells KJ, Otto A, et al. Addressing a critical need for caregiver support in neuro-oncology: development of a caregiver navigation intervention using eSNAP social

resource visualization. *Supportive Care in Cancer*. 2022;30(6). doi:10.1007/s00520-022-06977-9

227. Ugalde A, Krishnasamy M, Schofield P. Role recognition and changes to self-identity in family caregivers of people with advanced cancer: A qualitative study. *Supportive Care in Cancer*. 2012;20(6). doi:10.1007/s00520-011-1194-9
228. Applebaum AJ, Kryza-Lacombe M, Buthorn J, DeRosa A, Corner G, Diamond EL. Existential distress among caregivers of patients with brain tumors: a review of the literature. *Neuro-Oncology Practice*. 2016;3(4):232-244. doi:10.1093/nop/npv060
229. 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. doi:10.1215/15228517-2007-040
230. Leavitt MB, Lamb SA, Voss BS. Brain tumor support group: content themes and mechanisms of support. *Oncology nursing forum*. 1996;23(8).
231. Piderman KM, Radecki Breitkopf C, Jenkins SM, et al. A Chaplain-led Spiritual Life Review Pilot Study for Patients with Brain Cancers and Other Degenerative Neurologic Diseases. *Rambam Maimonides Medical Journal*. 2015;6(2):e0015. doi:10.5041/rmmj.10199
232. Strang S, Strang P. Spiritual thoughts, coping and ‘sense of coherence’ in brain tumour patients and their spouses: *http://dx.doi.org/101191/026921601670322085*. 2016;15(2):127-134. doi:10.1191/026921601670322085
233. Cavers D, Hacking B, Erridge S, Kendall M, CMAJ PM, 2012 undefined. Social, psychological and existential well-being in patients with glioma and their caregivers: a qualitative study. *Can Med Assoc*. Published online 2012. doi:10.1503/cmaj.111622
234. AJ A, M KL, J B, A D, G C, EL D. Existential distress among caregivers of patients with brain tumors: a review of the literature. *Neuro-oncology practice*. 2016;3(4):232-244. doi:10.1093/NOP/NPV060
235. Sizoo EM, Pasman HRW, Buttolo J, et al. Decision-making in the end-of-life phase of high-grade glioma patients. *European Journal of Cancer*. 2012;48(2). doi:10.1016/j.ejca.2011.11.010
236. Angelika D. Geerlings, Marjan J. Meinders BRB& MA van der M. Using former carers’ expertise in peer support for carers of people with Parkinson’s Disease. *Nature*. 2022;8(133).
237. K P, M J, J J, M J. Daily Life Experiences of Patients With a High-Grade Glioma and Their Caregivers: A Longitudinal Exploration of Rehabilitation and Supportive Care Needs. *The Journal of neuroscience nursing : journal of the American Association of Neuroscience Nurses*. 2015;47(5):271-284. doi:10.1097/JNN.0000000000000158
238. J S, S M, D W, et al. Decision making in palliative radiation therapy: reframing hope in caregivers and patients with brain metastases. *Supportive care in cancer : official journal of the Multinational Association of Supportive Care in Cancer*. 2006;14(10):1055-1063. doi:10.1007/S00520-006-0032-Y
239. Baumstarck K, Leroy T, Hamidou Z, et al. Coping with a newly diagnosed high-grade glioma: patient-caregiver dyad effects on quality of life. *Journal of Neuro-Oncology*. 2016;129(1):155-164. doi:10.1007/s11060-016-2161-6
240. PR S, BA G, CW G, et al. The influence of caregiver mastery on depressive symptoms. *Journal of nursing scholarship : an official publication of Sigma Theta Tau International Honor Society of Nursing*. 2007;39(3):249-255. doi:10.1111/J.1547-5069.2007.00176.X

241. McConigley R, Halkett G, Lobb E, Nowak A. Caring for someone with high-grade glioma: a time of rapid change for caregivers: *http://dx.doi.org/101177/0269216309360118*. 2010;24(5):473-479. doi:10.1177/0269216309360118
242. FW B, CW G, BA G, et al. Family caregivers' level of mastery predicts survival of patients with glioblastoma: A preliminary report. *Cancer*. 2017;123(5):832-840. doi:10.1002/CNCR.30428
243. Jeon MS, Dhillon HM, Koh ES, et al. Exploring sleep disturbance among adults with primary or secondary malignant brain tumors and their caregivers. *Neuro-Oncology Practice*. Published online September 2020. doi:10.1093/nop/npaa057
244. Vandepitte S, Van Den Noortgate N, Putman K, Verhaeghe S, Verdonck C, Annemans L. Effectiveness of respite care in supporting informal caregivers of persons with dementia: a systematic review. *International Journal of Geriatric Psychiatry*. 2016;31(12). doi:10.1002/gps.4504
245. Given B. The CARE Act: A model for support for family caregiving. *Psycho-Oncology*. 2018;27.
246. George LK, Gwyther LP. Caregiver well-being: a multidimensional examination of family caregivers of demented adults. *The Gerontologist*. 1986;26(3). doi:10.1093/geront/26.3.253
247. Manne SL, Myers-Virtue S, Kissane D, et al. Group-based trajectory modeling of fear of disease recurrence among women recently diagnosed with gynecological cancers. *Psycho-Oncology*. 2017;26(11):1799-1809. doi:10.1002/PON.4223
248. Jeon MS, Dhillon HM, Koh ES, Nowak AK, Hovey E, Agar MR. Sleep disturbance in people with brain tumours and caregivers: a survey of healthcare professionals' views and current practice. *Supportive Care in Cancer*. Published online July 2020:1-12. doi:10.1007/s00520-020-05635-2
249. Lichtenthal WG, Catarozoli C, Masterson M, et al. An open trial of meaning-centered grief therapy: Rationale and preliminary evaluation. *Palliat Support Care*. 2019;17(1). doi:10.1017/S1478951518000925
250. Morris SE, Sannes TS. Bereavement care for family caregivers of neuro-oncology patients. *Ann Palliat Med*. 2021;10(1). doi:10.21037/apm-20-708
251. A N, J K, H D, 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). doi:10.1188/12.ONF.E226-E232
252. MSW CM, PhD GJ, PhD MLM, et al. The Quality of Life of Patients with Malignant Gliomas and Their Caregivers. *https://doi.org/101080/00981380802232396*. 2008;47(4):455-478. doi:10.1080/00981380802232396
253. JR S, MB K, E F. Caring for the brain tumor patient: family caregiver burden and unmet needs. *Neuro Oncol*. 2008;10(1):61-72. doi:10.1215/15228517-2007-040
254. Applebaum AJ, Kent EE, Lichtenthal WG. Documentation of caregivers as a standard of care. *Journal of Clinical Oncology*. 2021;39(18). doi:10.1200/JCO.21.00402
255. Longacre ML, Applebaum AJ, Buzaglo JS, et al. Reducing informal caregiver burden in cancer: Evidence-based programs in practice. *Translational Behavioral Medicine*. 2018;8(2). doi:10.1093/tbm/ibx028

256. Nissim, R. & Hales S. Caring for the Family Caregiver: Development of a Caregiver Clinic at a Cancer Hospital as Standard of Care. *Journal of Clinical Psychology in Medical Settings*. Published online 2022:1-8.

257. Page MS, Chang SM. Creating a caregiver program in neuro-oncology. *Neuro-Oncology Practice*. 2017;4(2):116-122. doi:10.1093/NOP/NPW019

258. Lichtenthal WG, Nilsson M, Kissane DW, et al. Underutilization of mental health services among bereaved caregivers with prolonged grief disorder. *Psychiatric Services*. 2011;62(10). doi:10.1176/ps.62.10.pss6210_1225

259. Warner EL, Wilson AR, Rainbow JG, Ellington L, Kirchhoff AC. Employment of young adult cancer caregivers, other disease caregivers, and non-caregiving adults. *Int J Environ Res Public Health*. 2021;18(14). doi:10.3390/ijerph18147452

APPENDIX A

Recruitment Email

MASSEY
CANCER CENTER
VCU

HELP US LEARN ABOUT CAREGIVER NEEDS

Hello,

I am a clinical psychology doctoral student at VCU Massey Cancer Center, Division of Neuro-oncology currently recruiting for a research project. My project examines the psychological needs of caregivers who have lost a close loved one to a malignant glioma within the last 6 months to 3 years. I am reaching out to you because I think you might be interested in our project.

Participation involves:

- Speaking with our study team to learn about the study and ask any questions
- Completing a brief 5-minute screening questionnaire to determine if you are eligible.
- If eligible, participating in a ~60-90-minute virtual focus group via Zoom with 5-7 other caregivers where you will provide your opinion on a specific psychotherapy.
- Answering a series of online surveys (15-30 minutes) following the focus group.

There is no cost to participate in the study. We will be compensating you for your time with two Amazon e-gift cards for completing the focus group and questionnaires.

If you are interested, please contact us:
Email (LiveNOW@VCU.edu)
Phone (804-828-6739)

Thank you for your time and consideration!

Kelcie Willis, M.S.
Clinical Psychology Doctoral Student
Virginia Commonwealth University and Massey Cancer Center
www.LiveNOW.lab.vcu.edu

APPENDIX B

Recruitment Social Media Post

CAREGIVERS INVITED TO PARTICIPATE IN RESEARCH – VIRTUAL FOCUS GROUP FOR CAREGIVERS OF BRAIN TUMOR PATIENTS

Virginia Commonwealth University / Massey Cancer Center / LiveNOW Lab

We are interested in learning more about the emotional needs of caregivers and their preferences for counseling. We are conducting virtual focus groups of bereaved caregivers of patients diagnosed with malignant gliomas. The focus group will last approximately 60-90 minutes and consist of 5-7 other bereaved caregivers. You will be asked to share your opinions on a specific psychotherapy and tell us how psychologists can best support caregivers throughout their loved one's disease trajectory. Following the focus group, we will invite you to complete online surveys (approximately 15-30 minutes).

If you served as a caregiver of a patient diagnosed with a malignant glioma (astrocytoma, oligodendroglioma, GBM) and your loved one passed within the last six months – three years, we would appreciate your participation. We will compensate you for your time with two Amazon e-gift cards for completing the virtual focus group and subsequent online questionnaires. There is no cost associated with this study. Participation is voluntary.

If you are interested or have additional questions, please contact us at LiveNOW@vcu.edu or 804-828-6739. Thank you for your time and consideration!

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CANCER CENTER
VCU

liveNOW
neuro·oncology·wellness

APPENDIX C

Screening Form

Date:
Interviewer:
Subject Number:

1. Participant is 18 years of age or older: **Yes** / No

2. Participant is able to understand and read in English: **Yes** / No

3. Participant served as an informal caregiver: **Yes** / No

> **A caregiver is defined as the primary person who provided ongoing support to the patient diagnosed with brain cancer; it is not necessary that the caregiver lived with the patient or was related. Caregivers that were compensated for their services are ineligible.*

4. Participant cared for a patient diagnosed with a malignant glioma: **Yes** / No

   Type of glioma: Grade of glioma:

5. The patient has since passed away in the last 6 months to 3 years: **Yes** / No

   Date of passing:

6. Participant has a stable internet connect in their home. **Yes** / No

7. Participant has a video-capable device (e.g., desktop, laptop, tablet, smartphone): **Yes** / No

Notes on participant availability for a 60-90-minute focus group:

Participant email address:
Participant telephone:

APPENDIX D

Screening Script

Referral and Callback Procedure:

"Hello, may I please speak with (interested caregivers name)? My name is (researcher's name), and I am part of the neuro-oncology research team at the LiveNOW Lab and VCUHealth. I am calling because you expressed interested in a new focus group study. These focus groups ask about your opinions of a specific psychotherapy and ways we could better support caregivers of patients diagnosed with malignant gliomas."

"This study involves participation in a 60-90-minute Zoom focus group with 5-7 other caregivers. Additionally, you will fill out a few online surveys afterwards that take about 15-30 minutes to complete. We will compensate you for your time with two $20 Amazon e-gift cards."

"Your participation is completely voluntary. You may decide not to participate in this study. If you do participate, you may withdraw from the study at any time Your participation will not impact your care at any VCUHealth facility. Does this sound like a research study you might be interested in?"

__________ YES ________ NO

IF YES: "We have a few questions to see if you are eligible for the study. These questions should take less than 5 minutes. Do you agree to us asking you a few questions (about your age, previous caregiving role, and internet access) to see if you are eligible for the study?"

__________ YES ________ NO

If NO: "Would you like us to contact you at a better time?"

__________ YES ________ NO Date / time preference: ____________

[Trained research staff proceeds with screener accordingly using the Screening Form]

IF ELIGIBILITY IS MET:

"You meet our study eligibility. We will now send you an information sheet before we schedule your focus group via ZOOM. We encourage you to read over this information sheet thoroughly; if you have any questions, please do not hesitate to contact us."

IF ELIGIBILITY IS NOT MET:

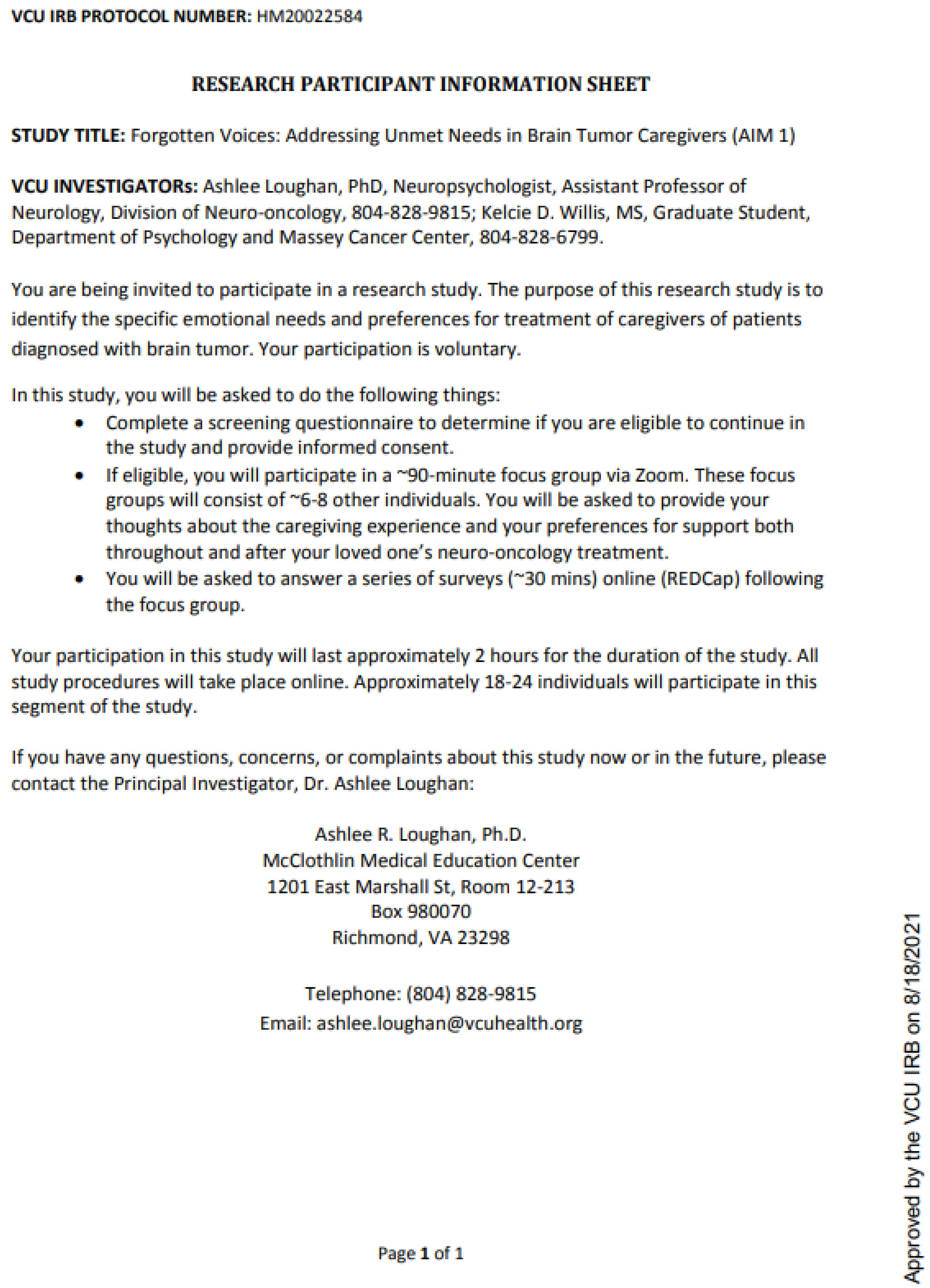
"Unfortunately, you do not meet the requirements to participate in this focus group study. We appreciate your time and interest in our research."

Voicemail Procedure:

"Hi – my name is (researcher's name) with VCUHealth, Massey Cancer Center, LiveNOW Lab, and I am calling for (potential participant name). Please give us a call back at (804) 628-6739."

APPENDIX E

Study Information Sheet



VCU IRB PROTOCOL NUMBER: HM20022584

RESEARCH PARTICIPANT INFORMATION SHEET

STUDY TITLE: Forgotten Voices: Addressing Unmet Needs in Brain Tumor Caregivers (AIM 1)

VCU INVESTIGATORs: Ashlee Loughan, PhD, Neuropsychologist, Assistant Professor of Neurology, Division of Neuro-oncology, 804-828-9815; Kelcie D. Willis, MS, Graduate Student, Department of Psychology and Massey Cancer Center, 804-828-6799.

You are being invited to participate in a research study. The purpose of this research study is to identify the specific emotional needs and preferences for treatment of caregivers of patients diagnosed with brain tumor. Your participation is voluntary.

In this study, you will be asked to do the following things:

- Complete a screening questionnaire to determine if you are eligible to continue in the study and provide informed consent.
- If eligible, you will participate in a ~90-minute focus group via Zoom. These focus groups will consist of ~6-8 other individuals. You will be asked to provide your thoughts about the caregiving experience and your preferences for support both throughout and after your loved one's neuro-oncology treatment.
- You will be asked to answer a series of surveys (~30 mins) online (REDCap) following the focus group.

Your participation in this study will last approximately 2 hours for the duration of the study. All study procedures will take place online. Approximately 18-24 individuals will participate in this segment of the study.

If you have any questions, concerns, or complaints about this study now or in the future, please contact the Principal Investigator, Dr. Ashlee Loughan:

Ashlee R. Loughan, Ph.D.
McClothlin Medical Education Center
1201 East Marshall St, Room 12-213
Box 980070
Richmond, VA 23298

Telephone: (804) 828-9815
Email: ashlee.loughan@vcuhealth.org

Approved by the VCU IRB on 8/18/2021

APPENDIX F

Caregiver and Patient Characteristics Form

Please answer the following questions about yourself

1. **Age:**
2. **Gender identity:**

a. Male
b. Female
c. Other:

3. **Race/Ethnicity:**

a. White/Caucasian, non-Hispanic or Latinx
b. Black/African American
c. Hispanic/Latinx
d. Asian/ Pacific Islander
e. American Indian/Alaska Native
f. Mixed
g. Other:

4. **What is your current relationship status?**

a. Single
b. Living with partner
c. Married
d. Divorced/separated
e. Widowed
f. Other:

5. **Do you have any children? If so, how many:**
6. **What is the highest level of education you have achieved?**

a. Less than high school
b. Some high school
c. High school graduate (or GED equivalent)
d. Some college or associate degree
e. Bachelor's degree
f. Graduate or professional degree

7. **What is your employment status?**

a. Full time employment
b. Part time employment
c. Self-employment
d. Unemployed
e. Student
f. Retired
g. Unable to work/disabled

8. **What is your annual household income level?**

a. Less than $20,000
b. $20,000 to $34,999
c. $35,000 to $49,999

    - d. $50,000 to $74,999
    - e. $75,000 to $99,999
    - f. Over $100,000

9. **What type of health insurance do you currently have?**
    - a. Employer-based
    - b. Private plan
    - c. Marketplace
    - d. Medicaid/Medicare
    - e. Military
    - f. Uninsured

Please answer the following questions about your loved one diagnosed with malignant glioma

1. **Age at passing:**
2. **Gender identity**
    - a. Male
    - b. Female
    - c. Other:
3. **Tumor diagnosis:**
    - a. Astrocytoma
    - b. Oligodendroglioma
    - c. Glioblastoma multiforme (GBM)
    - d. Other:
    - e. Unknown
4. **Tumor grade**
    - a. Grade 3
    - b. Grade 4
5. **Date (month/year) of original diagnosis:**
6. **Date (month/year) of passing:**
7. **Did the patient receive surgery?**
    - a. Gross surgical resection
    - b. Subtotal surgical resection
    - c. Biopsy only
    - d. None of the above
    - e. Unknown
8. **Did they receive chemotherapy?**
    - a. Yes
    - b. No
    - c. Unsure
9. **Did they receive radiation?**
    - a. Yes
    - b. No
    - c. Unsure

Please answer the following questions about your care of this deceased loved one

1. **What was your relationship to this person?**

a. Spouse
b. Parent
c. Child
d. Sibling
e. Other relative
f. Non-relative

2. **Did you and this person live in the same household?**

a. Yes
b. No
c. Other:

3. **How long did you provide care to this person?**

a. Less than 6 months
b. 6-11 months
c. 1-2 years
d. 2-3 years
e. 3-5 years
f. More than 5 years
g. Unsure

4. **Did your employment status change as a result of caregiving duties?**

a. Yes
b. No
c. Other:

5. **Please select your caregiving duties throughout your loved one's disease trajectory:**

☐ Managing finances
☐ Managing the patient's appointments/calendar
☐ Communicating with providers
☐ Medical decision making
☐ Organizing or administering medications
☐ End of life planning
☐ Driving
☐ Household chores such as cooking and cleaning
☐ Taking care of the patient's children or pets
☐ Helping with grooming, dressing, and undressing.
☐ Helping with toileting and bathing
☐ Other:

APPENDIX G

CALM Information Packet

What is CALM Therapy?

<u>CALM stands for Managing **C**ancer **a**nd **L**iving **M**eaningfully.</u> It is a type of psychotherapy (counseling) designed to address both the practical and profound issues most relevant to patients with advanced cancer and their loved ones. Caregivers are allowed to join sessions, but this is not required (some caregivers come to all sessions, other comes to only one). Patients and their loved ones discuss the four CALM "domains" (or topics) with a trained therapist/counselor. These include:

1. Symptom Management & Communication with Healthcare Providers
2. Changes in Self & Personal Relationships
3. Spirituality, Sense of Meaning and Purpose
4. The Future, Hope, Mortality

<u>Format of CALM:</u>
Currently, healthcare professionals refer patients who exhibit emotional distress to a therapist trained in the intervention. CALM optimally consists of *3-6 sessions delivered over a 3-6-month period*, meaning patients and their loved ones normally schedule biweekly or once-monthly sessions. Each of these sessions are approximately *45-60 minutes in duration*. At each session, the patient and their loved one decides which of the four domains they would like to discuss with the therapist and for how long.

<u>Processes of CALM:</u>
The CALM therapist might use these two terms/skills in session to help the patient and their loved one:

- *Double Awareness* = the capacity to balance presence in life with preparation for death
- *Mentalization =* the capacity to distinguish feelings versus facts and appreciate the possibility of multiple perspectives

<u>The Research:</u>
Research in patients with advanced cancer suggests that CALM can both alleviate and prevent symptoms of depression. CALM may also help with anxiety, death distress, preparation for the end-of-life, spiritual well-being, quality of life, posttraumatic growth, demoralization, and other measures of well-being. However, there has been *no research conducted in caregivers* at this time.

<u>Assessment</u>**:**
Patients fill out surveys before starting CALM (baseline), 3-months later, and 6-months later. This takes about 30 minutes to complete each time. Patients also complete a brief 5-minute survey after each session that assesses their satisfaction with that session. This helps the therapist and research team understand the effect of CALM. In order to understand if CALM could benefit caregivers, we would ask them to fill out surveys in a similar manner. Refer to surveys on the next page.

<u>Death Distress:</u>
CALM is the only therapy shown to reduce death distress in patients with advanced cancer. Death distress is commonly reported in caregivers and *refers to the fear, despair, and/or preoccupation of your loved one's impending death and dying*. It is measured by questions 21-35.

Baseline

Please complete the survey below.

Thank you!

---

1) Please provide your email address.

____

2) How old are you?

____

3) What is your ethnicity?

○ White/Caucasian
○ Black/African American
○ Hispanic/Latino
○ Asian
○ American Indian or Alaskan Native
○ Native Hawaiian or Pacific Islander
○ Other

4) What is your relationship to the patient?

○ Spouse/Significant Other
○ Family Member
○ Friend
○ Caretaker

Over the last 2 weeks, how often have you been bothered by the following problems?

		Not at all sure	Several days	Over half the days	Nearly every day
5)	1. Feeling nervous, anxious, or on edge	○	○	○	○
6)	2. Not being able to stop or control worrying	○	○	○	○
7)	3. Worrying too much about different things	○	○	○	○
8)	4. Trouble relaxing	○	○	○	○
9)	5. Being so restless that it's hard to sit still	○	○	○	○
10)	6. Becoming easily annoyed or irritable	○	○	○	○
11)	7. Feeling afraid as if something awful might happen	○	○	○	○

Over the last 2 weeks how often have you been bothered by any of the following problems? (Click the circle to indicate your answer)

12) 1. Little interest or pleasure in doing things

○ 0- Not at all
○ 1- Several days
○ 2- More than half the days
○ 3- Nearly every day

13) 2. Feeling down, depressed, or hopeless

○ 0- Not at all
○ 1- Several days
○ 2- More than half the days
○ 3- Nearly every day

14)	3. Trouble falling or staying asleep, or sleeping too much	○ 0- Not at all ○ 1- Several days ○ 2- More than half the days ○ 3- Nearly every day
15)	4. Feeling tired or having little energy	○ 0- Not at all ○ 1- Several days ○ 2- More than half the days ○ 3- Nearly every day
16)	5. Poor appetite or overeating	○ 0- Not at all ○ 1- Several days ○ 2- More than half the days ○ 3- Nearly every day
17)	6. Feeling bad about yourself -- or that you are a failure or have let yourself or your family down	○ 0- Not at all ○ 1- Several days ○ 2- More than half the days ○ 3- Nearly every day
18)	7. Trouble concentrating on things, such as reading the newspaper or watching television	○ 0- Not at all ○ 1- Several days ○ 2- More than half the days ○ 3- Nearly every day
19)	8. Moving or speaking so slowly that other people could have noticed? Or the opposite -- being so fidgety or restless that you have been moving around a lot more than usual	○ 0- Not at all ○ 1- Several days ○ 2- More than half the days ○ 3- Nearly every day
20)	9. Thoughts that you would be better off dead or of hurting yourself in some way	○ 0- Not at all ○ 1- Several days ○ 2- More than half the days ○ 3- Nearly every day

Please tell us how distressed you felt over the past 2 weeks about each item listed below regarding your loved one. By distress, we refer generally to negative feelings, such as being angry, afraid, sad, or anxious. If you have many different negative feelings about an item, choose your answer based on the strongest negative feeling that you've had. If you did not experience the thought or concern at all, please make it as "0"

0 = I was not distressed about this thought or concern
1 = I experienced very little distress
2 = I experienced mild distress
3 = I experienced moderate distress
4 = I experienced great distress
5 = I experienced extreme distress

Over the past 2 weeks , how distressed did you feel about:

	0	1	2	3	4	5
21)						

	Not having done all the things that they wanted to do	○	○	○	○	○	○
22)	Not having said all that they wanted to say to the people they care about	○	○	○	○	○	○
23)	Not having achieved their life goals and ambitions	○	○	○	○	○	○
24)	Not knowing what happens near the end of their life	○	○	○	○	○	○
25)	Not having a future	○	○	○	○	○	○
26)	The missed opportunities in their life	○	○	○	○	○	○
27)	Running out of time	○	○	○	○	○	○
28)	Being a burden to others	○	○	○	○	○	○
29)	The impact of their death on their loved ones	○	○	○	○	○	○
30)	Their death and dying	○	○	○	○	○	○

0 = I was not distressed about this thought or concern
1 = I experienced very little distress
2 = I experienced mild distress
3 = I experienced moderate distress
4 = I experienced great distress
5 = I experienced extreme distress

Over the past 2 weeks , how distressed did you feel that your loved one's death and dying may:

		0	1	2	3	4	5
31)	Happen suddenly or unexpectedly	○	○	○	○	○	○
32)	Be prolonged or drawn out	○	○	○	○	○	○
33)	Happen when they are alone	○	○	○	○	○	○
34)	Happen with a lot of pain or suffering	○	○	○	○	○	○
35)	Happen very soon	○	○	○	○	○	○

Please answer the following questions by placing a tick in any of the boxes for each of the question.
You do not have to answer these questions if you do not wish. Thank you!

		Not at all	A little	Sometimes	A lot	All the time
36)	I am afraid that my loved one's tumor may recur	○	○	○	○	○

37)

	I am worried or anxious about the possibility my loved one's tumor recurrence	○	○	○	○	○
38)	How often have you worried about the possibility of your loved one getting a tumor again	○	○	○	○	○
39)	I get waves of strong feelings about my loved one's tumor coming back	○	○	○	○	○
40)	I think about my loved one's tumor returning when I didn't mean to	○	○	○	○	○
41)	I examine my loved one to see if they have physical signs of the tumor	○	○	○	○	○

Indicate how often you experience the feelings listed by checking the box that best corresponds to the frequency of these feelings

		Never	Rarely	Sometimes	Quite frequently	Nearly always
42)	Do you feel that because of the time you spend with your relative that you don't have enough time for yourself?	○	○	○	○	○
43)	Do you feel stressed between caring for your relative and trying to meet other responsibilities (work/family)?	○	○	○	○	○
44)	Do you feel angry when you are around the relative?	○	○	○	○	○
45)	Do you feel that your relative currently affects your relationship with family member or friends in a negative way?	○	○	○	○	○
46)	Do you feel strained when you are around your relative?	○	○	○	○	○
47)	Do you feel that your health has suffered because of your involvement with your relative?	○	○	○	○	○
48)	Do you feel that you don't have has much privacy as you would like because of your relative?	○	○	○	○	○
49)	Do you feel that your social life has suffered because you are caring for your relative?	○	○	○	○	○

50)

	Do you feel that you have lost control of your life since your relative's illness?	○	○	○	○	○
51)	Do you feel uncertain about what to do about your relative?	○	○	○	○	○
52)	Do you feel you should be doing more for your relative?	○	○	○	○	○
53)	Do you feel you could do a better job in caring for your relative?	○	○	○	○	○

For each item please write the number that best represents the extent to which you agree or disagree with the statement.

54)	A belief in an afterlife may be useful for some, but I don't believe in one at all.	○ Strongly disagree ○ Disagree ○ Neutral ○ Agree ○ Strongly agree
55)	The life we now lead is but a pebble cast upon the sands of our future lives.	○ Strongly disagree ○ Disagree ○ Neutral ○ Agree ○ Strongly agree
56)	Religiously associated or not, beliefs in an afterlife will never be shown to be true, for after lives are non-existent.	○ Strongly disagree ○ Disagree ○ Neutral ○ Agree ○ Strongly agree
57)	The following statement is true: "Man must enter into some sort of existence after death, for the end of our earthly lives cannot wipe us from existence to nothingness."	○ Strongly disagree ○ Disagree ○ Neutral ○ Agree ○ Strongly agree
58)	When a human dies, that something called "life" dies with him.	○ Strongly disagree ○ Disagree ○ Neutral ○ Agree ○ Strongly agree
59)	The millions killed by Hitler & Stalin passed from life into nothingness.	○ Strongly disagree ○ Disagree ○ Neutral ○ Agree ○ Strongly agree
60)	Many scientists believe in a life after death: they are right, there is one.	○ Strongly disagree ○ Disagree ○ Neutral ○ Agree ○ Strongly agree

---

61) There is supportive evidence for the existence of an afterlife.

○ Strongly disagree
○ Disagree
○ Neutral
○ Agree
○ Strongly agree

---

62) Death ends all forms of life forever.

○ Strongly disagree
○ Disagree
○ Neutral
○ Agree
○ Strongly agree

---

63) The existence of an afterlife can never be scientifically demonstrated for it is impossible to prove a "figment of someone's imagination."

○ Strongly disagree
○ Disagree
○ Neutral
○ Agree
○ Strongly agree

Session satisfaction session 1

Please complete the survey below.

Thank you!

Please provide us feedback on your CALM session today. These questions should take no longer than 5 minutes. We ask that you answer these questions honestly. Your answers will have no bearing on your clinical care or your future research opportunities, and we will not share your answers with your CALM therapist.

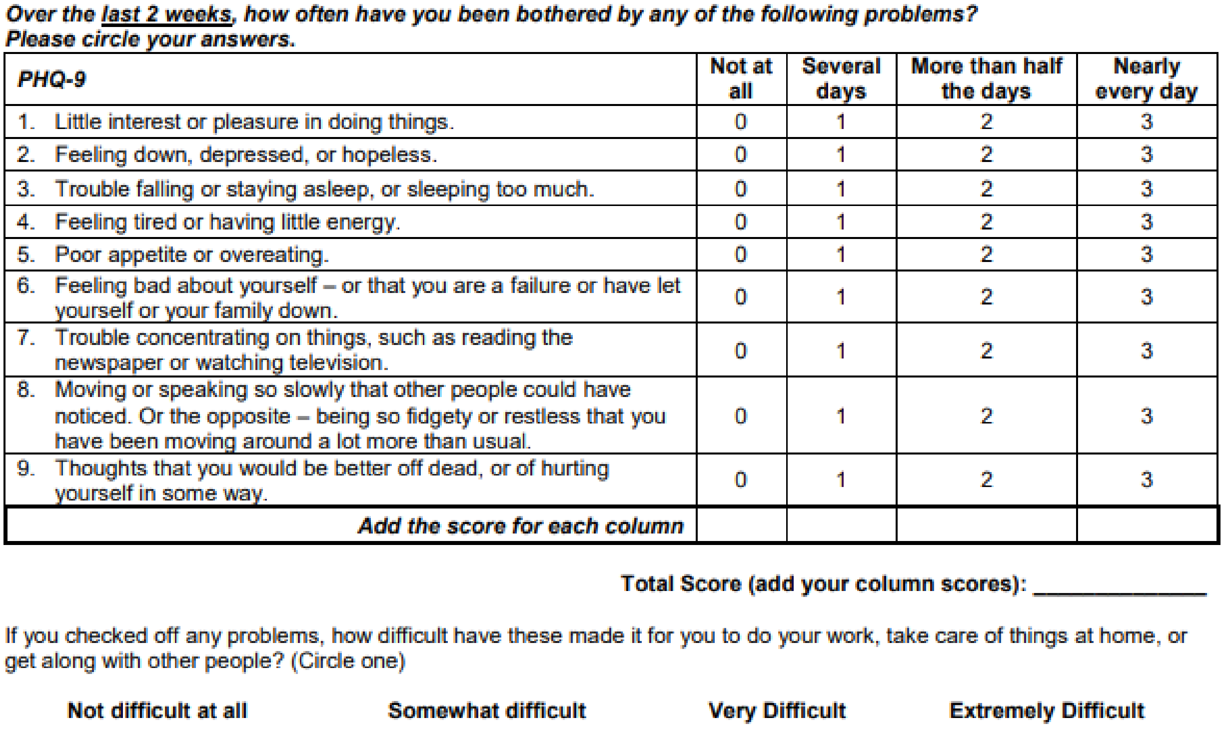
		1 – No benefit	2	3 – Moderate benefit	4	5 – Great benefit
1)	How helpful was today's session?	○	○	○	○	○
2)	How enjoyable was today's session?	○	○	○	○	○
3)	How relevant was today's session to your situation or level of distress?	○	○	○	○	○
4)	How useful was today's session?	○	○	○	○	○
5)	How satisfied were you with today's session?	○	○	○	○	○
6)	How comfortable were you with your therapist today?	○	○	○	○	○

Which CALM topics were discussed in today's session?

7)	Symptom Management and Communication with Health Care Providers	○ Yes ○ No ○ Unsure
8)	Changes in Personal Relationships	○ Yes ○ No ○ Unsure
9)	Spirituality, Sense of Meaning and Purpose	○ Yes ○ No ○ Unsure
10)	The Future, Hope and Mortality	○ Yes ○ No ○ Unsure

APPENDIX H

Patient Health Questionnaire-9 (PHQ-9)



Over the last 2 weeks, how often have you been bothered by any of the following problems? Please circle your answers.

PHQ-9	**Not at all**	**Several days**	**More than half the days**	**Nearly every day**
1. Little interest or pleasure in doing things.	0	1	2	3
2. Feeling down, depressed, or hopeless.	0	1	2	3
3. Trouble falling or staying asleep, or sleeping too much.	0	1	2	3
4. Feeling tired or having little energy.	0	1	2	3
5. Poor appetite or overeating.	0	1	2	3
6. Feeling bad about yourself – or that you are a failure or have let yourself or your family down.	0	1	2	3
7. Trouble concentrating on things, such as reading the newspaper or watching television.	0	1	2	3
8. Moving or speaking so slowly that other people could have noticed. Or the opposite – being so fidgety or restless that you have been moving around a lot more than usual.	0	1	2	3
9. Thoughts that you would be better off dead, or of hurting yourself in some way.	0	1	2	3
Add the score for each column				

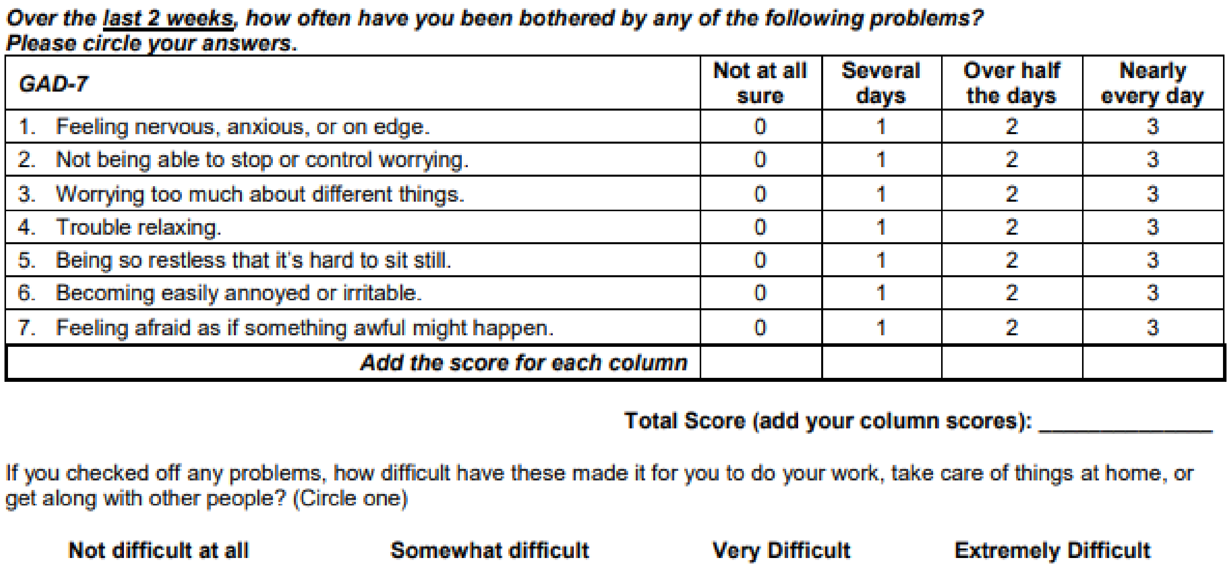
Total Score (add your column scores): _____________

If you checked off any problems, how difficult have these made it for you to do your work, take care of things at home, or get along with other people? (Circle one)

Not difficult at all **Somewhat difficult** **Very Difficult** **Extremely Difficult**

APPENDIX I

Generalized Anxiety Disorder-7 (GAD-7)



Over the last 2 weeks, how often have you been bothered by any of the following problems?
Please circle your answers.

GAD-7	**Not at all sure**	**Several days**	**Over half the days**	**Nearly every day**
1. Feeling nervous, anxious, or on edge.	0	1	2	3
2. Not being able to stop or control worrying.	0	1	2	3
3. Worrying too much about different things.	0	1	2	3
4. Trouble relaxing.	0	1	2	3
5. Being so restless that it's hard to sit still.	0	1	2	3
6. Becoming easily annoyed or irritable.	0	1	2	3
7. Feeling afraid as if something awful might happen.	0	1	2	3
Add the score for each column				

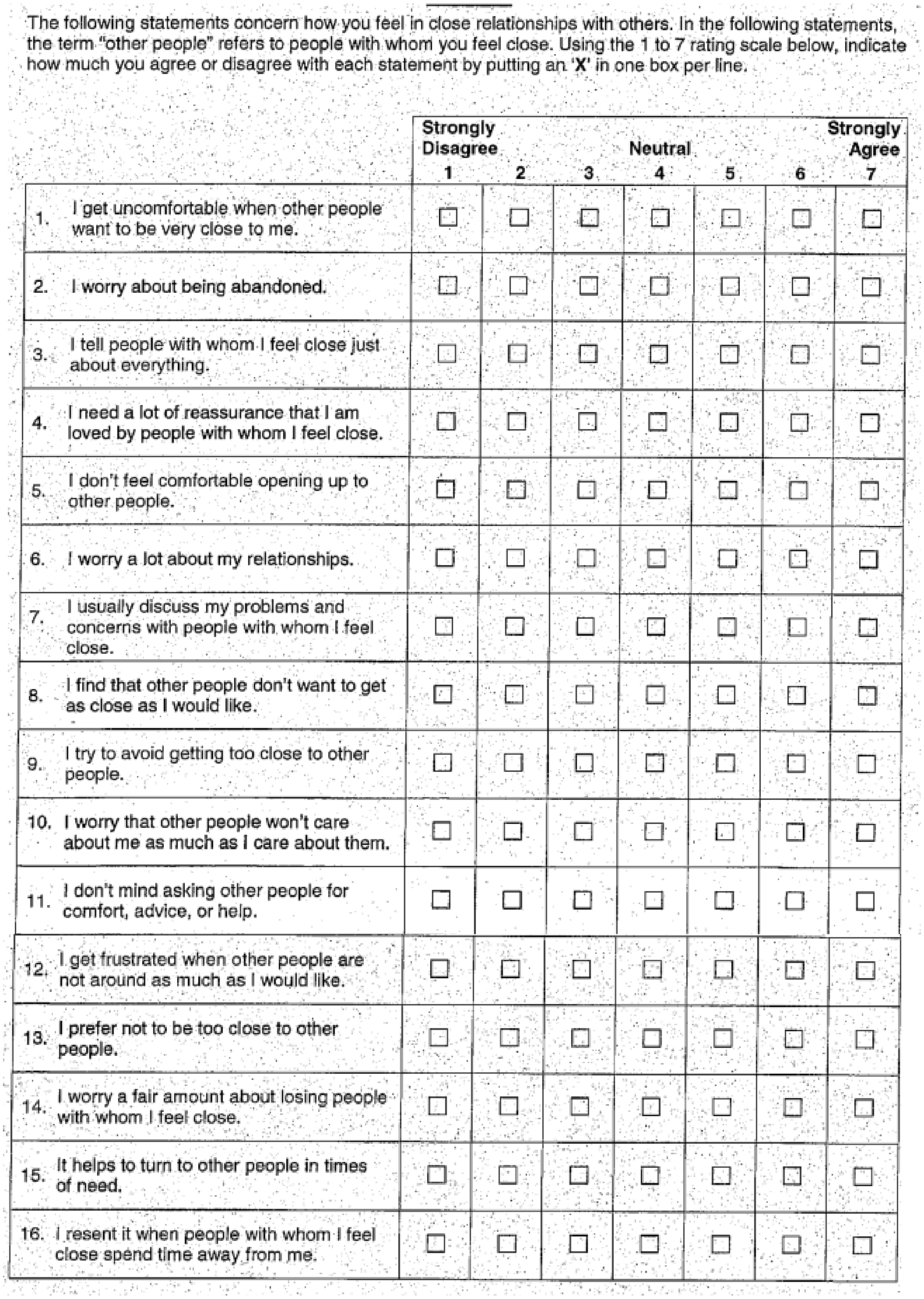
Total Score (add your column scores): ______________

If you checked off any problems, how difficult have these made it for you to do your work, take care of things at home, or get along with other people? (Circle one)

Not difficult at all **Somewhat difficult** **Very Difficult** **Extremely Difficult**

APPENDIX J

Experiences in Close Relationships Inventory (ECR-M-16)



The following statements concern how you feel in close relationships with others. In the following statements, the term "other people" refers to people with whom you feel close. Using the 1 to 7 rating scale below, indicate how much you agree or disagree with each statement by putting an **'X'** in one box per line.

	Strongly Disagree 1	2	3	**Neutral** 4	5	6	**Strongly Agree** 7
1. I get uncomfortable when other people want to be very close to me.	☐	☐	☐	☐	☐	☐	☐
2. I worry about being abandoned.	☐	☐	☐	☐	☐	☐	☐
3. I tell people with whom I feel close just about everything.	☐	☐	☐	☐	☐	☐	☐
4. I need a lot of reassurance that I am loved by people with whom I feel close.	☐	☐	☐	☐	☐	☐	☐
5. I don't feel comfortable opening up to other people.	☐	☐	☐	☐	☐	☐	☐
6. I worry a lot about my relationships.	☐	☐	☐	☐	☐	☐	☐
7. I usually discuss my problems and concerns with people with whom I feel close.	☐	☐	☐	☐	☐	☐	☐
8. I find that other people don't want to get as close as I would like.	☐	☐	☐	☐	☐	☐	☐
9. I try to avoid getting too close to other people.	☐	☐	☐	☐	☐	☐	☐
10. I worry that other people won't care about me as much as I care about them.	☐	☐	☐	☐	☐	☐	☐
11. I don't mind asking other people for comfort, advice, or help.	☐	☐	☐	☐	☐	☐	☐
12. I get frustrated when other people are not around as much as I would like.	☐	☐	☐	☐	☐	☐	☐
13. I prefer not to be too close to other people.	☐	☐	☐	☐	☐	☐	☐
14. I worry a fair amount about losing people with whom I feel close.	☐	☐	☐	☐	☐	☐	☐
15. It helps to turn to other people in times of need.	☐	☐	☐	☐	☐	☐	☐
16. I resent it when people with whom I feel close spend time away from me.	☐	☐	☐	☐	☐	☐	☐

APPENDIX K

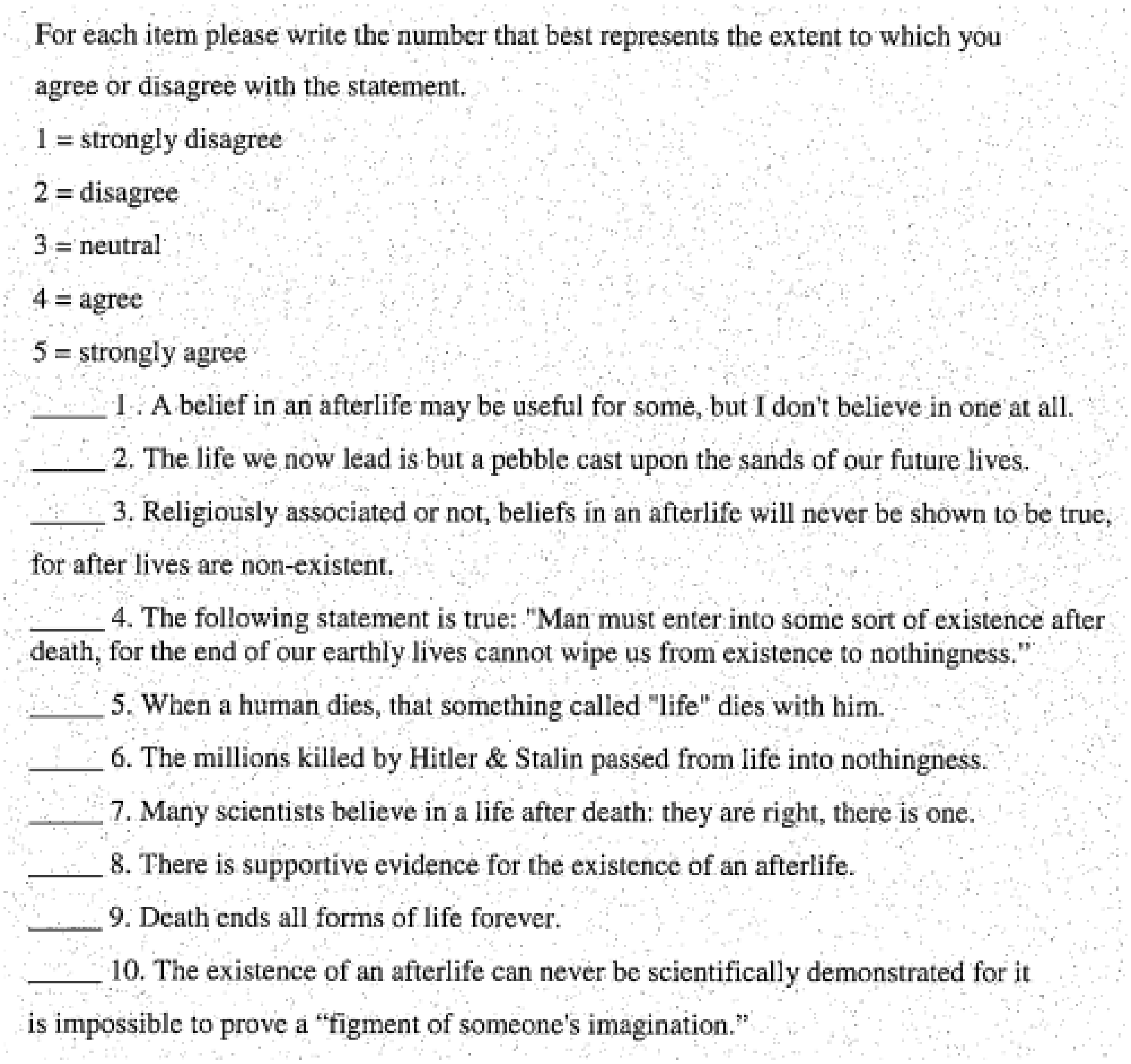
The Functional Assessment of Chronic Illness Therapy-Spiritual Well-Being Scale (FACIT-Sp)

Below is a list of statements that other people have said are important**. Please circle or mark one number per line to indicate your response as it applies to the <u>past 7 days</u>.**

		Not at all	**A little bit**	**Some-what**	**Quite a bit**	**Very much**
Sp1	I feel peaceful	0	1	2	3	4
Sp2	I have a reason for living	0	1	2	3	4
Sp3	My life has been productive	0	1	2	3	4
Sp4	I have trouble feeling peace of mind	0	1	2	3	4
Sp5	I feel a sense of purpose in my life	0	1	2	3	4
Sp6	I am able to reach down deep into myself for comfort	0	1	2	3	4
Sp7	I feel a sense of harmony within myself	0	1	2	3	4
Sp8	My life lacks meaning and purpose	0	1	2	3	4
Sp9	I find comfort in my faith or spiritual beliefs	0	1	2	3	4
Sp10	I find strength in my faith or spiritual beliefs	0	1	2	3	4
Sp11	My loved one’s illness has strengthened my faith or spiritual beliefs	0	1	2	3	4
Sp12	I know that whatever happens, things will be okay	0	1	2	3	4

APPENDIX L

Belief in Afterlife Scale, Form B (BAS-B)



For each item please write the number that best represents the extent to which you agree or disagree with the statement.

1 = strongly disagree

2 = disagree

3 = neutral

4 = agree

5 = strongly agree

_____ 1 . A belief in an afterlife may be useful for some, but I don't believe in one at all.

_____ 2. The life we now lead is but a pebble cast upon the sands of our future lives.

_____ 3. Religiously associated or not, beliefs in an afterlife will never be shown to be true, for after lives are non-existent.

_____ 4. The following statement is true: "Man must enter into some sort of existence after death, for the end of our earthly lives cannot wipe us from existence to nothingness."

_____ 5. When a human dies, that something called "life" dies with him.

_____ 6. The millions killed by Hitler & Stalin passed from life into nothingness.

_____ 7. Many scientists believe in a life after death: they are right, there is one.

_____ 8. There is supportive evidence for the existence of an afterlife.

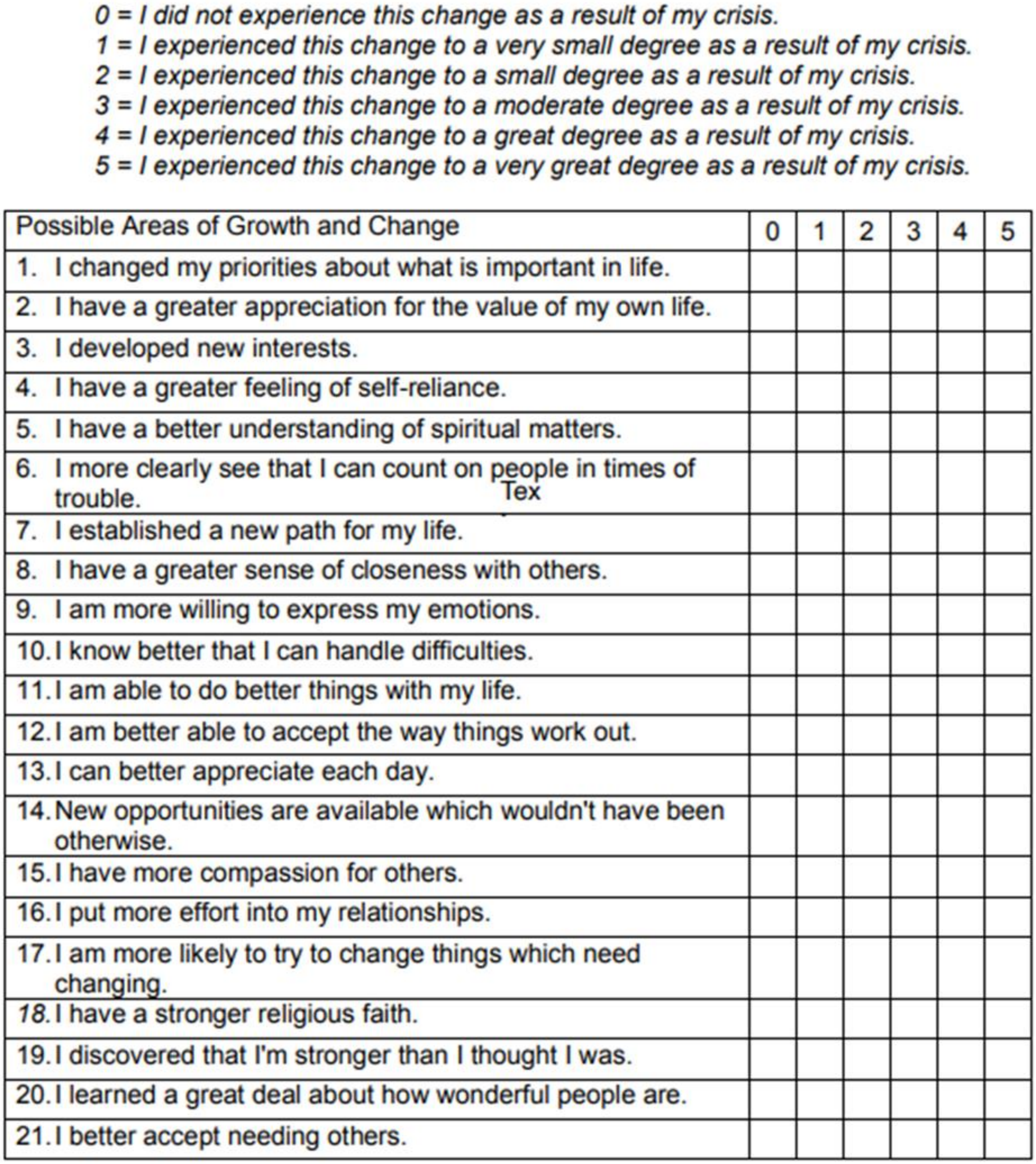
_____ 9. Death ends all forms of life forever.

_____ 10. The existence of an afterlife can never be scientifically demonstrated for it is impossible to prove a "figment of someone's imagination."

APPENDIX M

Posttraumatic Growth Inventory (PTGI)

Indicate for each of the statements below the degree to which this change occurred in your life as result of the crisis/disaster (i.e., loss of your loved one diagnosed with malignant glioma), using the following scale:

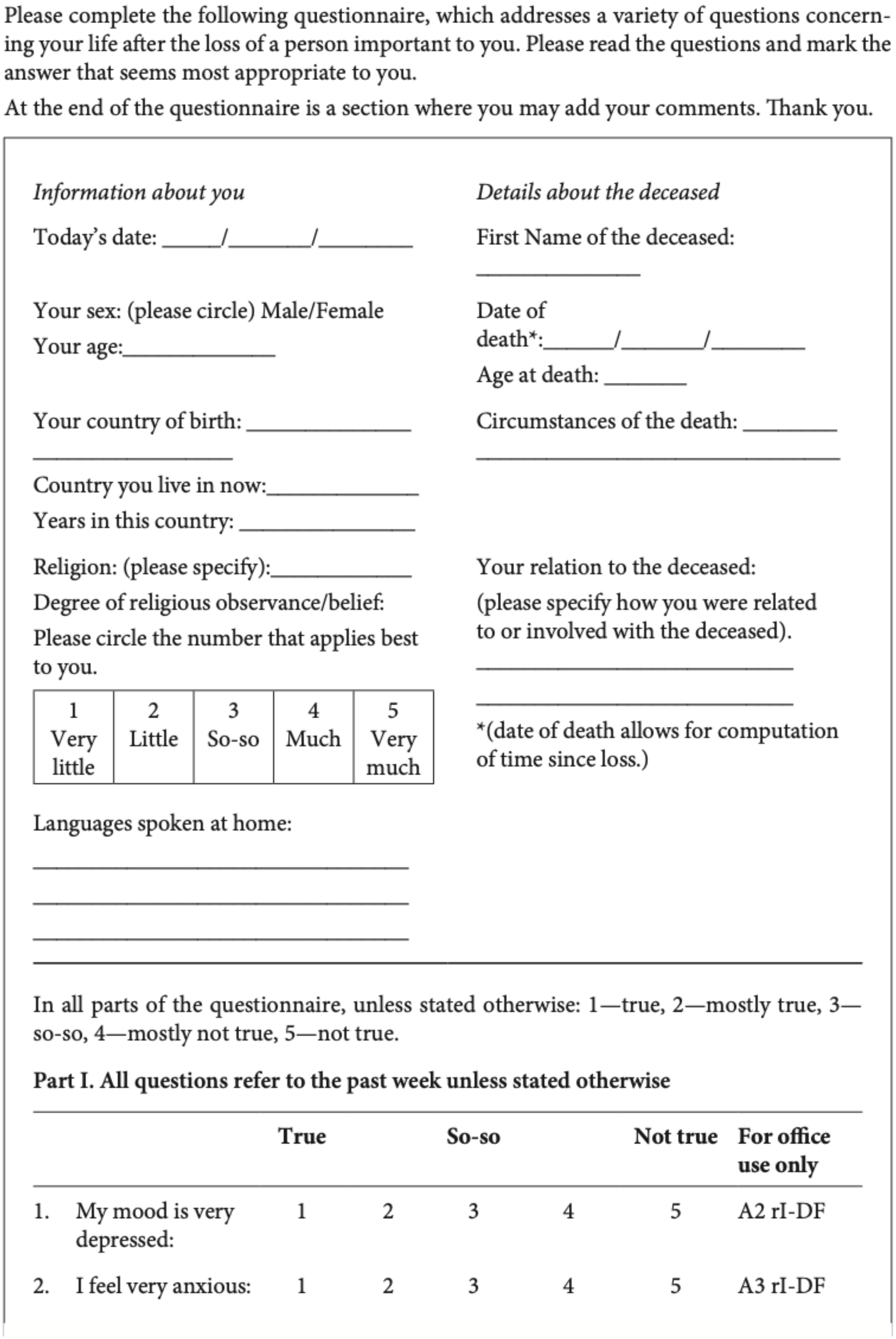


0 = I did not experience this change as a result of my crisis.
1 = I experienced this change to a very small degree as a result of my crisis.
2 = I experienced this change to a small degree as a result of my crisis.
3 = I experienced this change to a moderate degree as a result of my crisis.
4 = I experienced this change to a great degree as a result of my crisis.
5 = I experienced this change to a very great degree as a result of my crisis.

Possible Areas of Growth and Change	0	1	2	3	4	5
1. I changed my priorities about what is important in life.						
2. I have a greater appreciation for the value of my own life.						
3. I developed new interests.						
4. I have a greater feeling of self-reliance.						
5. I have a better understanding of spiritual matters.						
6. I more clearly see that I can count on people in times of trouble. Tex						
7. I established a new path for my life.						
8. I have a greater sense of closeness with others.						
9. I am more willing to express my emotions.						
10. I know better that I can handle difficulties.						
11. I am able to do better things with my life.						
12. I am better able to accept the way things work out.						
13. I can better appreciate each day.						
14. New opportunities are available which wouldn't have been otherwise.						
15. I have more compassion for others.						
16. I put more effort into my relationships.						
17. I am more likely to try to change things which need changing.						
18. I have a stronger religious faith.						
19. I discovered that I'm stronger than I thought I was.						
20. I learned a great deal about how wonderful people are.						
21. I better accept needing others.						

APPENDIX N

The Two-Track Bereavement Questionnaire for Complicated Grief (TTBQ-CG31)



Please complete the following questionnaire, which addresses a variety of questions concerning your life after the loss of a person important to you. Please read the questions and mark the answer that seems most appropriate to you.

At the end of the questionnaire is a section where you may add your comments. Thank you.

Information about you

Today's date: _____/_______/________

Your sex: (please circle) Male/Female

Your age:_____________

Your country of birth: _______________

____

Country you live in now:_____________

Years in this country: ________________

Religion: (please specify):____________

Degree of religious observance/belief:

Please circle the number that applies best to you.

1 Very little	2 Little	3 So-so	4 Much	5 Very much

Languages spoken at home:

____

____

____

Details about the deceased

First Name of the deceased:

____

Date of death*:______/_______/________

Age at death: _______

Circumstances of the death: ________

____

Your relation to the deceased:

(please specify how you were related to or involved with the deceased).

____

____

*(date of death allows for computation of time since loss.)

In all parts of the questionnaire, unless stated otherwise: 1—true, 2—mostly true, 3—so-so, 4—mostly not true, 5—not true.

Part I. All questions refer to the past week unless stated otherwise

	True		**So-so**		**Not true**	**For office use only**
1. My mood is very depressed:	1	2	3	4	5	A2 rI-DF
2. I feel very anxious:	1	2	3	4	5	A3 rI-DF

3.	The direction of the changes in the meaning of my life has been for the worse only:	1	2	3	4	5	A6 rI-DF
		Several times a day	**Almost daily**	**Almost every week**	**Almost every month**	**Almost never**	
4.	Thoughts and feelings flood and confuse me:	1	2	3	4	5	A7 rII-RAGT
		True		**So-so**		**Not true**	
5.	I function very well at work / school (Circle the X on the right if not applicable):	1	2	3	4	5	A9 I-DF X
6.	My self-perception this week has been almost totally positive:	1	2	3	4	5	A11 I-DF
7.	I find it difficult to function socially:	1	2	3	4	5	A12-r I-DF
8.	I believe and trust in my abilities to cope on my own with the tasks of life:	1	2	3	4	5	A19 I-DF
9.	Following the loss, it is fair to describe my current situation as in great need of help:	1	2	3	4	5	A20 rII-RAGT

Part II. Please read the instructions for the next section and proceed

In the following questions, wherever a line (______) appears, please answer as if the name of the deceased was written there. The questions refer to the past week, unless stated otherwise.

	True		**So-so**		**Not true**	**For office use only**
1. Our relationship was such that when I think of ______, I usually remember our disagreements:	1	2	3	4	5	B2*-r II-RC
	Almost never	**Almost every month**	**Almost every week**	**Almost daily**	**Several times a day**	
2. Occasionally, I behave or act emotionally, as if I don't believe that ______ is gone. This happens to me:	1	2	3	4	5	B4 II-RAGT
	True		**So-so**		**Not true**	
3. I think of ______ all the time:	1	2	3	4	5	B6-r II-RAGT
4. I've reached a degree of acceptance of the loss of ______:	1	2	3	4	5	B7 II-RAGT
5. Thoughts about ______ bring up positive feelings in me:	1	2	3	4	5	B9 II RC
	Almost never	**Almost every month**	**Almost every week**	**Almost daily**	**Several times a day**	
6. I remember ______:	1	2	3	4	5	B10 II-RAGT
	True		**So-so**		**Not true**	
7. I avoid things that remind me of ______:	1	2	3	4	5	B11-r II-RC
8. Life without ______ is too hard to bear:	1	2	3	4	5	B13-r II-RAGT

	Almost never	**Amost every month**	**Almost every week**	**Almost daily**	**Several times a day**	
9. I yearn strongly for ______ and miss him/her deeply:	1	2	3	4	5	B15 II-RAGT
	True		**So-so**		**Not true**	
10. I feel pain whenever I recall ______:	1	2	3	4	5	B16-r II-RAGT
11. Now I understand people who think about putting an end to their own life after losing a close person:	1	2	3	4	5	B17-r II-RAGT
12. It's possible to define my situation today, following the loss, as suffering greatly:	1	2	3	4	5	B20-r II-RAGT

Part III. Please read the instructions for this section and proceed

The following questions relate to the last 2 years of the relationship between you and _____ during his/her life.

	True		**So-so**		**Not true**	**For office use only**
1. During his/her life, ______ was a major source of emotional support for me:	1	2	3	4	5	C2-r II-CPR
2. My relationship with ______ had many and strong ups and downs:						C4-r II-RC

3.	My relationship with ______ was characterized by sharp changes between being close to being angry and/or wishing to be distant	C7-r II-RC
4.	______ was the person closest to me:	C8-r II-CPR

Part IV. Please proceed

The next questions ask about your thoughts and feelings today.

		True		**So-so**		**Not true**	**For office use only**
1.	Because of the loss I feel very angry:	1	2	3	4	5	D4-r II-RAGT

Whom are you angry with and why?

(A) __________

(B) __________

		True		**So-so**		**Not true**	
2.	I keep on experiencing the loss as a shocking and traumatic event in my life:	1	2	3	4	5	D7-r II-RAGT

Please explain why:

Thank you for your participation.

For office use only:

The numbers in the right hand column give the item number on the full scale TTBQ2–70. Persons interested in comparing the differences between the TTBQ2–70 to the original TTBQ will find that information on the TTBQ2–70.

Score by adding numbers of relevant scale, and dividing by number of items completed for each score except for X (*r* = reversal where 1 = 5, 2 = 4, 4 = 2, 5 = 1).

- Track I—Dysfunction = I-DF
- Track II—Relational Active Grief and Trauma = II-RAGT
- Track II—Conflict in the Relationship = II-RC
- Track II—Close Positive Relationship = II-CPR
- Total = raw scores of DF + RAGT + RC + CPR divided by number of items completed

Updates and other information regarding the TTBQ can be found at the website: etc.

TTBQ2-CG31 Clinician score sheet

Track II	Relational Active Grief and Trauma (RAGT)	A4R[1] +A9R +B2 +B3R +B4 +B6 +B8R + B9 +B10R +B12R +B13R +D1R + D2R + D3 +D4 +D5	This should be calculated as a mean score (Total score divided by number of items completed).
Track II	Conflict in the Relationship (RC)	B1R +B5 +B7R +C2R +C3R	
Track II	Close and Positive Relationship (CPR)	C1R +C4R	
Track I	Dysfunction (D)	A1R +A2R +A3R +A5 +A6 +A7R +A8 +D6	
Total Score of TTBQ2-CG31		RAGT raw score[2] + CR raw score + CPR raw score + D raw score divided by total number of items completed.	

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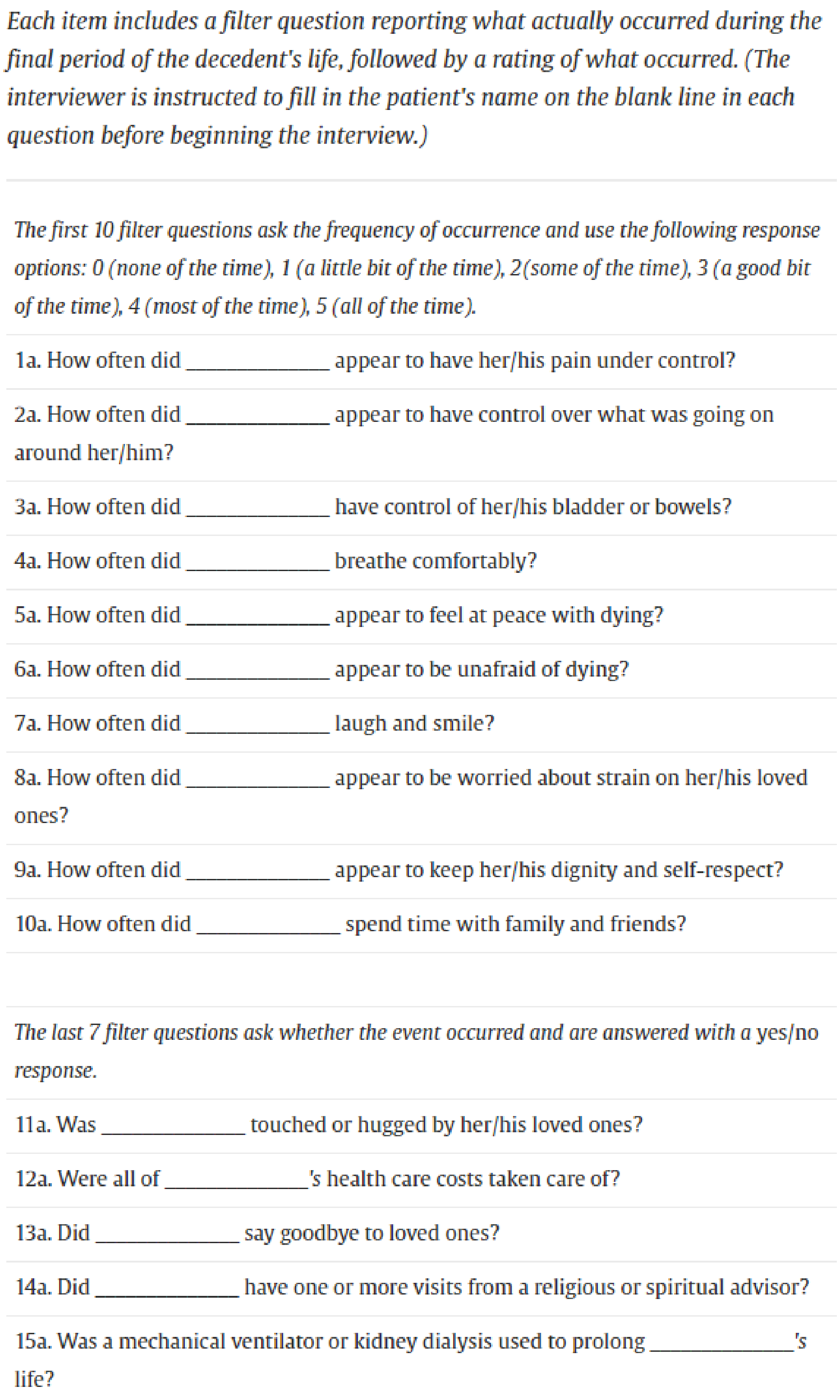
[1] R means to reverse the score so that 1 = 5, 2 = 4, 3 stays the same, 4 = 2, and 5 = 1.

[2] Raw score is the score computed after reversing the items labeled R but before division by number of items per factor.

APPENDIX O

Quality of Dying and Death Questionnaire – 17 Item



Each item includes a filter question reporting what actually occurred during the final period of the decedent's life, followed by a rating of what occurred. (The interviewer is instructed to fill in the patient's name on the blank line in each question before beginning the interview.)

The first 10 filter questions ask the frequency of occurrence and use the following response options: 0 (none of the time), 1 (a little bit of the time), 2(some of the time), 3 (a good bit of the time), 4 (most of the time), 5 (all of the time).

1a. How often did ______________ appear to have her/his pain under control?

2a. How often did ______________ appear to have control over what was going on around her/him?

3a. How often did ______________ have control of her/his bladder or bowels?

4a. How often did ______________ breathe comfortably?

5a. How often did ______________ appear to feel at peace with dying?

6a. How often did ______________ appear to be unafraid of dying?

7a. How often did ______________ laugh and smile?

8a. How often did ______________ appear to be worried about strain on her/his loved ones?

9a. How often did ______________ appear to keep her/his dignity and self-respect?

10a. How often did ______________ spend time with family and friends?

The last 7 filter questions ask whether the event occurred and are answered with a yes/no *response.*

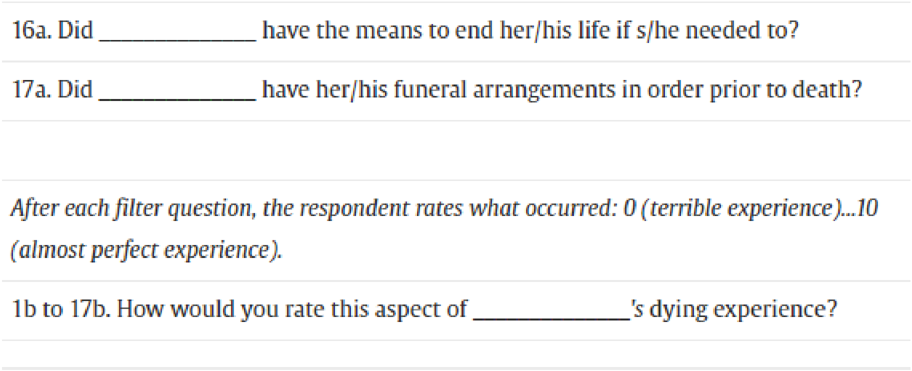
11a. Was ______________ touched or hugged by her/his loved ones?

12a. Were all of ______________'s health care costs taken care of?

13a. Did ______________ say goodbye to loved ones?

14a. Did ______________ have one or more visits from a religious or spiritual advisor?

15a. Was a mechanical ventilator or kidney dialysis used to prolong ______________'s life?



16a. Did _____________ have the means to end her/his life if s/he needed to?

17a. Did _____________ have her/his funeral arrangements in order prior to death?

After each filter question, the respondent rates what occurred: 0 (terrible experience)...10 (almost perfect experience).

1b to 17b. How would you rate this aspect of _____________'s dying experience?

Vita

Kelcie Daelynn Willis was born on December 6, 1993, in Dallas County, Texas. In 2016, she received a Bachelor of Science in Psychology and Bachelor of Arts in Religious Studies from Texas Christian University in Fort Worth, Texas, graduating *summa cum laude*. Subsequently, she earned her Master of Science in Clinical Psychology from Virginia Commonwealth University in 2018 and is on track to earn her doctoral degree in 2023. Additionally, she will soon complete her clinical internship year in the Behavioral Medicine Service at Yale University School of Medicine in New Haven, Connecticut. She looks forward to moving to Boston, Massachusetts to pursue a postdoctoral fellowship at Massachusetts General Hospital/Dana Farber Caner Center, where she hopes to continue developing interventions to improve the quality-of-life of patients and caregivers facing advanced cancer.