Evaluation of Cognitive-Communication Deficits Following Treatment of Primary Brain Tumor Patients

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Kylee Marie Haller

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Jessica A. Brown, Ph.D., CCC-SLP

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Acknowledgements/Dedication

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with relentless support. My interest in speech-language pathology and desire to research impairments related to brain tumors and their subsequent treatments, stemmed from my grandfather, Donald Haller, Sr., whom was diagnosed with a glioblastoma in 2006. Therefore, I would like to dedicate this project to him.

Abstract

In 2016, the Central Brain Tumor Registry of the United States reported an incidence of 379,848 for primary brain and other central nervous system (CNS) tumors. It is well understood that brain tumors and their subsequent treatments lead to a variety of impairments pre-, during, and post-treatment. In turn, these impairments ultimately lead to changes in quality of life and daily functioning. However, this is a limitedly studied topic, specifically from a speech-language pathology perspective. The goal of this study was to address the lack of data regarding deficits of importance to speech-language professionals (i.e., cognitive and linguistic impairments), by documenting common symptomology and deficits experienced within the brain tumor population through self-report and standardized assessment measures. Furthermore, we sought to determine the impact of such deficits on daily functioning.

We obtained patient self-report and standardized assessment results from 28 adult participants with a diagnosis of a primary brain tumor, completion of at least one cycle of treatment (e.g., tumor resection/biopsy, chemotherapy, and/or radiation), and self-reported cognitive, linguistic, and/or socio-emotional deficits. Results indicated that following treatment, individuals with brain tumors self-report more deficits in cognitive, linguistic, physical, and socio-emotional domains than are objectively identified on standardized assessments. Participants provided qualitative descriptions of their symptoms within their daily lives to further describe the frequency, severity, and functional impact. Cognitive symptoms were the most commonly endorsed within this study population.

As a result, development and testing of appropriate, effective assessment and treatment methods are important next steps. The model utilized within this study, including self-reported data, determining functional impact of deficits, and standardized assessments, allows rehabilitation professionals to focus on patient-centered care, where an individual's participation should be a primary focus of intervention. We encourage the use of the *Mayo-Portland Adaptability Inventory* (*MPAI*) as an appropriate measurement tool for this population—when used in conjunction with in-depth interviewing—as it correlated with self-reported symptomology in people with primary brain tumors and provides a standardized score. The other cognitive-linguistic assessments (i.e., *Cognitive Linguistic Quick Test* and *Comprehensive Aphasia Test*) utilized within this study do not appear to be sensitive enough to thoroughly document the functional impact of post-treatment deficits in the brain tumor population. Further research is required to determine appropriate assessment and treatment options at different points throughout the continuum of care that individuals with brain tumors experience.

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Introduction/Review of Literature

Brain tumors and their subsequent treatment result in a variety of temporary and/or chronic physical, sensory, and cognitive deficits. Although research exists to document a variety of impairments experienced by individuals with brain tumors, understanding how such deficits impact daily functioning and quality of life is an important, yet underdeveloped area of study.

High health-related quality of life is an important outcome for patients with cancer, and specifically patients with brain tumors (Taphoorn, Sizoo, & Bottomley, 2010). As a result, several tools exist to assess quality of life in this population (e.g., MD Anderson Symptom Inventory Brain Tumor Module and Functional Assessment of Cancer Therapy; Taphoorn et al., 2010) and are readily used in cancer treatment centers across the United States. Specifically, the majority of treatment centers utilize patient self-report as a mechanism to gain information regarding symptomatology and quality of life (Bottomley et al., 2016); however, in circumstances where individuals with brain tumors are not accurate or adequate self-historians, caregiver or spouse report has been documented to correlate well with patient report and real-world functioning (Sneeuw, Sprangers, & Aaronson, 2002; Taphoorn et al., 2010).

Patients with brain tumors who self-report higher quality of life scores tend to demonstrate longer survival rates (Brown et al., 2006). Thus, quality of life, and the factors that hinder it, are important clinical concerns when attempting to improve patient outcomes and enhance survival for individuals with current or historic brain tumors.

Factors documented to significantly decrease quality of life in people with brain tumors include cognitive function—either assessed objectively or subjectively—

depression, increased fatigue, motor deficits, and high seizure frequency (Giovagnoli, Silvani, Colombo, & Boiardi, 2005; Klein et al., 2001; Pelletier, Verhoef, Khatri, & Hagen, 2002; Taphoorn et al., 2010). Of particular concern, are the cognitive and communicative impacts of brain tumors as their presence can negatively affect occupation and social functioning; subsequently, decreased quality of life and increased overall stress and distress are noted (Hodgson et al., 2013). Cognitive and communicative factors impacting quality of life manifest in a variety of ways dependent on the individual and their tumor characteristics. However, deficits in driving skills, following directions, keeping track of and pay bills (i.e., money management skills), and decreased job performance or productivity are common for individuals post-brain tumor diagnosis and treatment (Adams, Sullivan, & Vitaz, 2015; Feuerstein, Hansen, Calvio, Johnson, & Ronquillo, 2007). For example, Feuerstein and colleagues (2007) noted that 65% of work limitations experienced by survivors of brain tumors result from personal, modifiable factors including, cognitive impairments, depression-like symptoms, fatigue, and sleep disturbances. Such modifiable factors exceeded the effects of non-modifiable factors (e.g., tumor type, location, and treatment). It stands to reason then, that factors significantly impacting daily, independent productivity and functionality can and should be addressed by medical and rehabilitation professionals with the attempt to improve symptomatology and overall function.

Brain Tumor Facts and Figures

In 2016, the Central Brain Tumor Registry of the United States reported an incidence for all primary malignant and non-malignant brain and Central Nervous System (CNS) tumors of 379,848 tumors—119,674 malignant and 260,174 non-malignant

(2016). In the United States, brain tumor incidence is higher in females (i.e., 213,174 tumors) than it is in males (i.e., 154,816 tumors; Central Brain Tumor Registry of the United States, 2016). Following diagnosis of brain tumor, the average five-year survival rate in the United States after a diagnosis is approximately 34.9% for primarily malignant or other CNS tumors and 90.47% for individuals with non-malignant brain or other CNS tumor (Central Brain Tumor Registry of the United States, 2016).

The prognosis for individuals diagnosed with primary brain tumors remains poor; however, many recent medical discoveries have led to increased survival rates among diagnosed patients (Newton & Otero, 2015); however, differences in survival rates exist dependent on tumor grade—that is, the level of tissue abnormality. The current median survival rate for a high-grade brain tumor (i.e., a tumor classified as grade III or IV; Kieffer, 2015) is approximately 12 to 16 months and the median survival rate for low grade tumors (i.e., a tumor classified as grade I and II; Louis et al., 2016) is approximately six to ten years (Newton and Otero, 2015; Ostrom et al., 2014). However, regardless of tumor grade, it is generally accepted within the medical community that approximately 76% of patients with a primary brain tumor whom survive two-years after diagnosis will survive another three years on average (Newton & Otero, 2015). The median age of primary brain tumor diagnosis is between 54 and 58 years old (Newton & Otero, 2015), as a result, the percentage of individuals with brain and other CNS tumors whom are diagnosed between 55 and 64 have the following survival rates: 51.1% for one year, 29% for two years, 17.7% for five years, and 13% for ten-year survival (Ostrom et al., 2014). These data provide evidence to support the notion that many adults with diagnosed brain tumors will potentially seek avenues for return to engagement in pre-

diagnosis roles and responsibilities. As a result, understanding symptoms resultant from brain tumors before, during, and after treatment, as well as subsequent effect on quality of life and daily living are vital to enhancing outcomes for patients surviving years after diagnosis.

Pre-Treatment Symptoms & Side Effects

Prior to receiving treatment, over 90% of patients with brain tumors report experiencing at least one cognitive or linguistic deficit and almost 71% experience three or more deficits (Tucha, Smely, Preier, & Lange, 2000). These reported deficits may result from tumor location or size, side effects post-surgery and/or biopsy, steroids, and anti-epileptics medications (DeMonte, Gilbert, Mahajan, McCutcheon, Buzdar, & Freedman, 2006; Taphoorn & Klein, 2004). In regard to tumor location, patients may experience changes in mood; increased intracranial pressure; ataxia; sensory, visual, and/or language deficits; headaches; seizures; focal weakness; and impairments in cognitive or executive functioning (Amidei & Kushner, 2015; DeMonte et al., 2006). Patients with localized tumors tend to experience increased focal cognitive deficits; whereas, patients with diffuse tumors experience global cognitive deficits due to the infiltrating nature of their tumor (Anderson, Damasio, & Tranel, 1990; Hahn, Dunn, Logue, King, Edwards, & Halperin, 2003; Scheibel, Meyers, & Levin, 1996; Taphoorn & Klein, 2004).

Tucha and colleagues (2000) assessed various aspects of executive functions including verbal fluency, figural fluency—the ability to generate nonsense figures within an allotted time (Tucha, Smely, & Klaus, 1999), concept formation, and abstract thinking via standardized psychometric testing and patient report in individuals with primary brain

tumors pre-treatment. Results indicated that deficits in executive functioning—that is, high order cognitive encompassing skills required for goal directed and purposeful behaviors and are essential when responding to unfamiliar or novel situations (Izaks, Joosten, Koerts, Gansevoort, Slaets, 2011)—appear to be the most prominent symptom experienced with cognitive or linguistic domains (Tucha et al., 2000). Specifically, among their 139 participants, 78% demonstrated impairment of executive functions, including difficulties with abstract thinking, concept formation, and divergent thinking, based on their neuropsychological testing. Based on the classification of ability levels, 91% of their participants had impairments in at least one cognitive area, with results of 71% of participants' neuropsychological testing identifying three or more areas of impairment. Approximately 64% exhibited impairment on one or more memory function tests. Attention deficits were found in more than 60% of participants and visuoconstructive skills were impaired in approximately half of the participants. Finally, they found language impairments, specifically with reading and writing, in 22% of participants. Although these results provide evidence for cognitive and linguistic functioning in this population, it is likely that symptomology changes with regards to treatment initiation.

Within Treatment Symptoms & Side Effects

Treatments prescribed for patients with brain tumors may result both in substantial benefits and side effects and produce varying symptoms. While results of clinical trials provide information regarding known, global deficits post-treatment, determining or predicting negative treatment impacts on an individual level is difficult. This is particularly true as most patients complete multiple treatment options

simultaneously or within a brief timeframe. Typical post-treatment symptoms include: cognitive changes, motor weakness, sensory deficits, difficulties producing speech, decreased vision, hearing loss, and visual-spatial disorders (Lovely, 2004). See Table 1 for further factors that contribute to subsequent physiological, cognitive, linguistic, and socio-emotional deficits in the brain tumor population.

Patients diagnosed with brain tumors may encounter treatments such as tumor resection and/or biopsy, steroids, anti-epileptic medication, radiation therapy, and chemotherapy (Taphoorn and Klein, 2004). Each of these treatments, either administered simultaneously or in isolation, lead to potential cognitive-linguistic impairments. Each treatment and potential side effects will be discussed below.

Table 1.

Contributing factors to post-treatment deficits (adapted from DeMonte et al., 2006).

Disease-Related Factors	Patient-Related Factors	Treatment-Related Factors		
		Radiation Therapy	Chemotherapy	Supportive Agents
• Tumor Location • Tumor Type • Tumor Growth Speed • Tumor-Related Epilepsy • Tumor Volume	• Age • Sex • Education • Race • Handedness • Sociocultural Variables • Premorbid Personality • Current Psychological Status • Mental Health History • Developmental Disorders • History of Head Trauma • Chronic illness • Medication Side Effects	• Brain Swelling • Demyelinating Diseases • Brain Tissue Death • Progressive Neurological Decline, including Dementia • Dose per Fraction of 2 Gy or Larger	• Acute Brain Swelling • Chronic Brain Swelling • Central Nerve Degeneration • Peripheral Nerve Degeneration • Cerebellar Symptoms	• Steroids • Bipolar Medications • Migraine Medications • Seizure Medications • Opioids

Surgical Resection. Routine care following brain tumor diagnosis first includes tumor resection and/or biopsy (DeAngelis, 2001). Surgery to resect or biopsy the tumor is essential to documenting tumor characteristics and determining a histological diagnosis. In turn, surgical resection can result in reduced tumor size or tumor elimination (DiPatri, Pham, & Muro, 2009; Taphoorn & Klein, 2004). Several studies have documented that the extent of tumor resection significantly correlates to survival rates and patient quality of life (Duffau et al., 2003; Keles, Lamborn, & Berger, 2001). While this is an important step in treatment, surgery carries a high risk for permanent neurological damage to adjacent brain structures (Duffau et al., 2003; Frontczak-Baniewicz, Chrapusta, & Sulejczak, 2011). However, deficits experienced after surgery are primarily focal in nature typically resolve within a three-month period (DiPatri et al., 2009; Taphoorn & Klein, 2004). Unfortunately, long-term effects from surgery are difficult to isolate as the majority of patients subsequently participate in additional treatments (DiPatri et al., 2009).

Pharmacological Treatments. Steroids and anti-epileptic drugs are frequently prescribed to patients with brain tumors as preventative treatment measures. Steroid treatment in particular has been widely used to treat brain tumors for approximately the last 50 years (Dietrich, Rao, Pastorino, & Kesari, 2011). Such drugs are used to treat potential edema, which is an abnormal accumulation of fluid in connective tissue (Klatzo, 1973), and its associated neurological deficits. Steroids are often prescribed to address headaches and intracranial pressure (Lovely, 2004). Large doses of steroids are frequently used in acute phases when neurological symptoms are present due to the brain tumor (Dietrich et al., 2011). It is well documented, however, that steroids are associated

with serious side effects (Newton & Ray, 2015; Koehler, 1995). The severity of these side effects is primarily dependent on steroid duration and dose (Dietrich et al., 2011). Some side effects include, immunosuppression, cataracts, blurred vision, gastrointestinal bleeding, myopathy, and increased appetite. Furthermore, steroids mediate patient symptoms associated with nausea and vomiting, decreased appetite, and pain management (Dietrich et al., 2011).

Anti-epileptic drugs are also frequently prescribed for this population. This is likely due to the fact that epileptic seizures are the first noticeable symptoms in 30-90% of patients eventually diagnosed with a brain tumor (Taphoorn & Klein, 2004). Approximately 71% of patients with low-grade gliomas are prescribed at least one anti-epileptic drug to prevent occurrence of future seizures (Klein et al., 2003). Both anti-epileptic drugs and potential subsequent seizures are documented to decrease cognitive function (Taphoorn & Klein, 2004).

Radiation. Radiation therapy is another common form of brain tumor treatment (Shih, Loeffler, & Tarbell, 2009). Two current forms of radiation therapy include photon beam radiation therapy, which is a type of radiation therapy that uses gamma rays or x-rays and radiation is delivered at the surface of the body and goes into the tumor (National Cancer Institute Dictionary of Cancer Terms, n.d.), and proton beam radiation therapy, which is a type of radiation therapy that uses protons to kill tumor cells and this type of treatment has been found to reduce the amount of damage from radiation to healthy tissue (National Cancer Institute Dictionary of Cancer Terms, n.d.).

Radiation doses required to control brain tumors are often close to or higher than doses which are toxic to healthy brain tissue, thus, damage to neighboring healthy tissues

often occurs (Taphoorn & Klein, 2004). As post-diagnosis survival rates improve, chronic effects from radiation therapy are evident with the scientific focus placed on furthering understanding of such deficits, developing symptom management techniques, and minimizing long-term effect (Laack & Brown, 2004; Shih et al., 2009). Existing data on the specific, functional manifestations of neurocognitive injury, beyond cognitive screening and solely quantitative data from neuropsychological assessments, after radiation therapy in adults is lacking (Brown et al., 2003; Laack et al., 2003). Yet, this is an area of much needed study to determine the relative benefits of radiation therapy to quality of life, independent completion of daily activities, and return to pre-diagnosis roles (Shih et al., 2009).

Chemotherapy. Finally, patients diagnosed with brain tumors may undergo chemotherapy within their treatment plan. Chemotherapy improves outcomes for patients with brain tumors, however, it can also result in chronic organ damage. Subsequently, this may lead long-term survivors to decreased independent daily and poor quality of life (Gururangan, 2009). Chemotherapy has significant consequences on the healthy brain tissue and colloquially, has been termed “chemo brain.” Acute damage frequently manifests as encephalopathy and hallucinations (Gururangan, 2009). Chemotherapy is shown to improve survival, however there are significant concomitant acute and chronic side effects.

Post-Treatment Symptoms & Side Effects

Regardless of tumor type, grade, or prescribed treatment, 80% of individuals face difficulty with cognition post-care (Mukand, Blackinton, Crincoli, Lee, & Santos, 2001). Specifically, 74.5% of patients report experiencing three or more neurological deficits

and 39.2% experience five or more deficits (Mukand et al., 2001). The neurological deficits experienced post-treatment are often similar to those experienced prior to and during treatment and specifically include: cognitive changes, hemi/tetraplegia, visual-perceptual deficits, sensory loss, neurogenic bowel/bladder, cranial nerve palsy, dysarthria, dysphagia, aphasia, ataxia, and diplopia (Mukand et al., 2001). Additionally, in a review of recent cognitive assessment studies it was found that brain tumor survivors exhibit deficits in the areas of: cognitive flexibility, planning, attention, working memory, visual scanning, and processing speed (Gehrke, Baisley, Sonck, Wronski, & Feuerstein, 2013).

Mukand and colleagues further documented the effects of treatment on individuals with brain tumor post-treatment. Specifically, each participant had a detailed neurological examination and documented Functional Independence Measure (FIM) scores both from admission and at time of discharge. At admission, the average FIM score was 67.2 (range: 34 – 100) and at discharge the average FIM score was 87.1 (range: 37 – 121), with an average gain of 19.9 points. Following discharge from inpatient rehabilitation, Mukand and colleagues noted that the majority (i.e., 68.6%) of individuals were released to the home environment. Overall, the post-treatment deficits documented by Mukand and colleagues are similar to studies that compare brain tumor patients with the stroke (Huang, Cifu, & Keyser-Marcus, 1998) and traumatic brain injury populations (O'Dell, Barr, Spanier, & Warnick, 1998).

Of note, to derive the previously reported findings, Mukand and colleagues completed a retrospective chart review of 49 adults admitted to an inpatient rehabilitation center after undergoing cancer treatment (e.g., surgery, chemotherapy, or radiation) to

document such impairments. Although such a procedure provides beneficial information, it also results in an incomplete understanding of the issues patients faced. Specifically, relying solely on chart reviews fails to incorporate the patient's perspective and does not allow for evaluation of objective data regarding the presence/absence or extent of the patient's impairments. Understanding differences in symptomology post-treatment allows clinicians to provide appropriate services throughout the continuum of care for individuals with brain tumors. However, it should be noted that the provided post-treatment symptomatology does not isolate experiences following the culmination of specific treatment types. As such, post-treatments impact resulting from specific treatments are outlined below.

It should be noted within the present study that all participants were recruited via Mayo Clinic's radiation oncology department; however, many of these individuals might have received other treatments or therapies throughout their treatment, thus we felt it was important to discuss all of these areas.

Surgical Resection. Following surgical resection or biopsy, patients are likely to experience a variety of cognitive and neurological deficits. Duffau and colleagues (2003) found 40% of cases experienced contralateral motor deficits and 29% experienced speech disorders after tumor resection. All tumors occurred in the left hemisphere when speech deficits were present. Seventy-five percent of left hemisphere tumors had incomplete resection due to the development of speech deficits during surgery. In the left hemisphere tumor group, 32% experienced mild speech disturbances, while one experienced improvement of preoperative aphasia. Overall, Duffau et al. (2003) found that majority of cases are able to resolve within a few months, but that some will continue to have mild

deficits. This study did not take into account the compounded side effects to cognition and language as the individual continues to seek other types of treatment for their brain tumor.

It is well-recognized that location specific, focal neurological deficits can develop post-resection. For example, after surgical resection of brain tumors, 15-70% of patients experience seizures (DiPatri et al., 2009). Additional deficits encompass all aspects of brain functioning such as language processes, cognitive changes, nerve dysfunction, change in smell and/or taste, changes in hearing, visual and motor disturbances (DiPatri et al., 2009). Overall, surgical resection greatly improves survival rates, but the risk of subsequent cognitive and neurologic deficits remains substantial.

Pharmacological Treatments. Seizures are common side effects of tumors and its treatments. It is estimated that 30-80% of patients with a brain tumor experience epilepsy (Ray, Maschio, & Newton, 2015). This leads care providers to prescribe anti-epileptic drugs to manage seizure activities. While seizures themselves have significant cognitive side effects, anti-epileptic drugs prescribed to reduce seizure occurrence do as well (Dewan, Thompson, Kalkanis, Barker, & Hadjipanayis, 2017; Lovely, 2004). Potential symptoms experienced with the use of anti-epileptics include, ataxia, dizziness, blurred vision, drowsiness, fatigue, nausea, nystagmus, and changes in behavior (Lovely, 2004). All of these side effects, have potential to interfere with cognitive and linguistic function and overall quality of life for patients with brain tumors.

Radiation. Radiation therapy has been associated with high-level cognitive function deficits, which can result in the loss of skills, such as the ability to pay bills, drive, follow directions, and perform on the job (Adams, Sullivan, & Vitaz, 2015).

Damage to brain tissue from radiation may occur acutely but occurs more commonly months or years following treatment (Monje & Wen, 2009). Radiation induced encephalopathy, or swelling of the brain, is one of the most common side effects. The onset of post-radiation encephalopathy is characterized in phases—that is, acute, early-delayed, and late-delayed encephalopathy (Sheline, Wara, & Smith, 1980). Acute encephalopathy occurs within two weeks of commencing radiation and often further impairs a patient's pre-existing neurological deficits. Early-delayed encephalopathy develops between one to six months after radiation is complete. This continues to negatively impact neurological deficits and impacts cognition at an exponential rate as time goes on. Typically, encephalopathy improves and returns to baseline within one year of radiation treatment; however, for some individuals, encephalopathy is irreversible (i.e., late-delayed encephalopathy). This occurs several months to years after radiation is completed and creates diffuse brain tissue atrophy or focal tissue death. The hallmark symptom of late-delayed encephalopathy is cognitive impairments (Béhin & Delattre, 2003). Resultant cognitive impairments are initially mild to moderate and often lead to continued deterioration, including dementia (Taphoorn & Klein, 2004). Existing data on neurocognitive injury after radiation therapy in adults is poor (Shih et al., 2009). Subtle changes in cognitive function after radiation are easily missed on insufficiently sensitive tests and can have significant effects on the individuals (Shih et al., 2009). Frequent monitoring of cognition through use of self-report, standardized, and functional measures may help to reduce this risk and identify post-radiation encephalopathy at earlier time frames.

Chemotherapy. Finally, chemotherapy commonly causes a variety of significant post-treatment side effects. Common side effects directly relate to cognitive and linguistic impairments include, seizures, fatigue, encephalopathy, agitation, depression, and sensorineural hearing loss (Gururangan, 2009; Janelsins, Kesler, Ahles, & Morrow, 2014). Just like radiation therapy, chemotherapy is often given at toxic levels, thus causing acute and chronic damage. Delayed damage and encephalopathy manifests as spasticity, dementia, severe neurocognitive impairment, especially in patients whom previously received radiation therapy, and in severe cases coma (Gururangan, 2009).

Chemotherapy related cognitive impairment is commonly reported in all cancer patients (Hodgson, Hutchinson, Wilson, & Nettelbeck, 2013; Janelsins et al., 2014; Myers, 2009). Hodgson and colleagues conducted a meta-analysis of the cognitive effect of chemotherapy documenting that the most frequent impairments involve attention, clarity of thought, executive functioning, memory, and speed of information processing (2013). Other areas of smaller statistical significance were in language skills, memory, and verbal function. Finally, Hodgson and colleagues found extremely small statistical significance—with effect sizes of less than -0.12—for concept formation and reasoning, construction, orientation, and perception (2013). These documented cognitive impairments manifested in functional difficulties with everyday tasks such as, paying bills, meal preparation, and requiring additional time to complete simple tasks (Boykoff, Moieni, & Subramanian, 2009; Hodgson et al., 2013). Because of these deficits, patients often distanced themselves from others to hide their impairments, thus causing strain on relationships (Myers, 2009). Therefore, evidence exists to support that chemotherapy induced cognitive impairment decreases quality of life and increases personal stress.

Assessing & Treating Cognitive-Linguistic Functions in Individuals with Brain Tumors

Documenting the nature and extent of cognitive-linguistic impairments in patients with brain tumors is vital in ensuring that adequate follow-up care and rehabilitation services are initiated. This is particularly important given the high rate in which both cognitive and communicative deficits occur following brain tumor diagnosis and treatment. Additionally, decline in cognition can potentially be an initial sign of tumor recurrence (Armstrong, Goldstein, Shera, Ledakis, & Tallent, 2003; Meyers & Hess, 2003). Knowing this, cognitive changes should be well monitored to assist in recognizing such possibilities.

Rehabilitation professionals have access to a variety of assessment methods from which to choose when testing both cognitive and communicative functions in adult populations. Measures commonly utilized include patient and caregiver interviews; self-report questionnaires and interviews; screening tools; and standardized, neurocognitive assessment batteries. Relative benefits and potential challenges for each assessment option exist and are discussed below.

Self-Report Questionnaires and Interviews. As patient-centered care becomes standard for many medical facilities, the use of self-report and interview measures increases (Bottomley et al., 2016). Patient-centered care is not only becoming the norm for medical professionals but is currently suggested by the literature and medical teams as best practice (Davis, Schoenbaum, & Audet, 2005; Levinson, Lesser, & Epstein, 2010; Rathert, Wyrwich, & Austin Boren, 2012). Self-reported data allows individuals to

provide information across time, settings, and contexts, whereas a standardized assessment can only measure a snapshot of the skills being assessed (Benítez -Silva, Buchinsky, Man Chan, Cheidvasser, & Rust, 2004). Self-report measures are inherently person-centered. Such measures include the perspective of the patient with a focus on listening to patient concerns and needs, rather than documenting only what can be evaluated by a therapist via formal, lengthy, standardized assessment protocols. The most beneficial way to gather patient-centered data, seems to be via patients reporting on their perceived changes in symptoms and function (Cella et al., 2010). This allows for patient perspective to be considered, when an individual could score within normal ranges on a standardized assessment (e.g., 2 SD below or above the mean) and still report deviation from normal functioning. Patients, and potentially their caregivers, are the natural choice for documenting functional, life altering changes in symptomatology.

Contrary to these perceived benefits, there remains downfalls to interviews and self-reported data. Primary challenges to patient reported outcomes are their accuracy and objectivity. Specifically, patients often exaggerate the severity of their symptoms when perceived impairment gains them support in some manner (Benitez-Silva et al., 2004). Conversely, patients may under-report their deficits to maintain a positive, normal image of themselves on a questionnaire or within an interview (Van de Mortel, 2008). Both of these scenarios obscure the realities of their deficits. Overall, interview and self-reported data have benefits and challenges requiring consideration prior to their use and as such, likely should not be implemented in isolation.

Screening Tools. Neuropsychological screening and assessment tools are widely used to document cognitive functioning within cancer-related clinical trials. Typically,

these researchers opt for screeners rather than complete cognitive batteries often due to the advantageous decrease in cost of screening tools compared to comprehensive assessments (Meyers & Wefel, 2003). While screening tools are cost effective, time saving, and simple to administer, they are not sensitive to subtle changes, nor do they yield insightful information about cognitive dysfunction. Subsequently, screening tools do not effectively measure cognitive functions that are impacted by brain tumors and its treatments and may not even serve to diagnose presence or absence of an impairment. There are data supporting the use of brief neurocognitive assessments within the brain tumor population, yet these practices are not universally employed within research or clinical settings (Meyers & Wefel, 2003). Furthermore, utilizing screening tools as the only measure of cognitive function is insufficiently sensitive and results in misleading, inaccurate information (Meyers, 2003).

Furthermore, several studies have found that results from neuropsychological assessments when used in conjunction with prognostic variables can predict survival better than the variables alone in individuals with brain tumors (Meyers, Hess, Yung, & Levin, 2000). Continued research in the use of standardized tests and screening tools is needed to determine the most appropriate assessment measures. The best option for accurate, easily accessible measures of cognitive change in individuals with brain tumors is still highly contested (Meyers & Brown, 2006).

Standardized Neurocognitive Assessments. Standardized assessments allow for evaluation of performance on a pre-determined, constant scale in the hopes to determine or classify scores into a category (Phelps, 2005) and provide a myriad of benefits to rehabilitation and medical professionals. The use of such tools allows medical

professionals to accurately diagnosis impairments and document deficit severity if a sensitive, effective standardized measure is selected. However, regardless of the assessment chosen, all standardized tests offer advantages over self-report measures alone, such that these tests provide medical professionals with objective data to document change in functioning through formal measures, rather than relying on patients' or clinicians' self-perceived change.

In ideal circumstances, scores on standardized measures are consistent across administrators and can be administered repeatedly to assess progress or change over time. This correlates to the assessment's reliability and validity. Interrater reliability is typically high with standardized assessments, as there is a set, standardized administration of the assessment. Neurocognitive assessments are often evaluated to determine individual levels of test-retest reliability (Franzen, 2000). However, test-retest reliability is different for each assessment. Ecological validity—that is, the ability of the assessment to evaluate performance similar to naturally occurring function—within neuropsychological assessments is a major limitation (Ch. 2, Parsons, 2016). In 1996, ecological validity was redefined for neuropsychological testing in an attempt to replicate everyday demands of the individual and tasks within contrived assessment environments (Franzen & Willhelm, 1996). This practice is notable as it allowed for better prediction of everyday functioning via formal, standardized assessment protocols.

Challenges of standardized assessments are widespread. Assessments are often insufficiently sensitive to detect the subtle changes experienced by individuals with brain tumors, even though these changes may be life altering (Shih et al., 2009). Additionally, standardized, neuropsychological testing does not often provide sufficient data to

adequately identify deficits that are experienced within natural contexts and settings (Hodgson et al., 2013). However, it is widely acknowledged that rehabilitation professionals rely on, and are often required to complete, standardized assessments fulfilling mandates set by third party payment sources (United States of America, Center for Medicare and Medicaid Services, Office of Financial Management). Thus, the need for appropriate, sensitive assessments for the brain tumor population is great.

Treatment Methods. Once deficits have been identified, various treatment options exist to address noted concerns. Cognitive rehabilitation was first mentioned in individuals with brain tumors in 1983 (Rao & Bieliauskas). In this study, large improvements were documented after a four-month treatment program. Since then, several studies have found that the use of general strategies can be implemented to support cognition, vocation, and psychologic wellbeing (Meyers & Boake, 1993; Sherer, Meyers, & Bergloff, 1997). Sherer and colleagues (1997) applied rehabilitation techniques and programs from the traumatic brain injury population to patients with primary brain tumors and found improvements in productivity and independence. More recently, Gehring and colleagues (2009) assessed cognitive rehabilitation in patients with gliomas. Individuals were randomly assigned to either the intervention group or the control group. The intervention included compensatory skills training the areas of attention, executive functioning, and memory, as well as computer-based attention retraining. To begin, participants completed a neuropsychological battery and self-report questionnaires. The neuropsychological battery consisted of subtests from standardized assessments in the domains of attention, executive functions, and cognitive symptoms. The questionnaires related to cognitive function, community reintegration, fatigue and

mental health related quality of life. These researchers documented significant effects immediately post-treatment in subjective cognitive function and perceived burden of cognitive function; however, no significance emerged related to objective neuropsychological assessment findings. However, at the six-month follow-up, the intervention group scored significantly better on the neuropsychological battery than the controls in verbal memory and attention. The intervention group also reported less mental fatigue. Results from this initial study provide evidence that early cognitive intervention has the ability to improve long-term cognitive function both objectively and subjectively in individuals with brain tumors.

Regardless of medical or rehabilitative discipline, there is little consensus on treatment options for this population. The two primary treatment options for individuals with cognitive decline secondary to a brain tumor are pharmacological approaches and/or neuropsychological approaches (Gehring, Sitskoorn, Aaronson, & Taphoorn, 2008). Physicians often look towards prescription medications and current drug trials to improve cognitive function (Meyers & Brown, 2006). Pharmaceutical interventions often base their arguments in dementia research to show that similar medications can be used in patients with brain tumors to improve mood, cognitive function, and overall quality of life (Gehring et al., 2008). However, success of pharmacologic approaches is not definitive. Development of cognitive and linguistic interventions specific to treating individuals with primary brain tumors is a vital next step in clinical research endeavors for this population.

Role of Speech-Language Pathologists

Limited research exists to support the role of speech-language pathologists (SLPs)

in the assessment and treatment of cognitive-linguistic deficits in patients with brain tumors (Davies, Hall, & Clarke, 2003; Sherer, Meyers, & Bergloff, 1997). As outlined in the American Speech-Language-Hearing Association's (ASHA) Scope of Practice for SLPs (2016), "service delivery areas include all aspects of communication, swallowing and related areas including, but not limited to: speech production, fluency, language, cognition, voice, resonance, feeding, swallowing, and hearing" (pg. 1). Thus, a primary purpose of SLPs is to assess and address communication and its related disorders. The objective is to improve functional communication skills with the goal of allowing an individual to fully participate in all aspects of communication which subsequently includes educational, social, and vocational domains (ASHA, 2003). Additionally, the World Health Organization (WHO) has begun to stress the importance of maximum participation being a goal of medical and rehabilitative treatment (Stucki, 2005). Thus, if an individual is experiencing deficits that interfere with maximum participation, therapists should address these concerns through effective, evidence-based assessment and treatment. As more people are surviving from head and neck cancers, SLPs are likely to encounter these patients and serve as primary providers of rehabilitation services (Mayer, 2008; Mukand et al., 2001).

Of note, brain tumors are not an etiology specifically addressed within ASHA guidelines at this time; however, patients with brain tumors and subsequent cognitive-communication and swallowing deficits are frequently seen in acute, subacute, and long-term rehabilitation contexts (Greenberg, Treger, & Ring, 2006; Mayer, 2008; Mukand et al., 2001)—settings in which speech-language pathologists commonly assess and treat individuals with cognitive and communicative deficits. While participating in

rehabilitation services, patients with brain tumors will likely encounter SLPs within their medical team. The initial role of SLPs is to assess the current function of the patient and, if necessary, to diagnose cognitive-linguistic deficits and determine deficit severity. This will ideally lead to selection and creation of functional, attainable therapy goals and interventions. Thus, in rehabilitation settings, SLPs are one of the primary clinicians who provide cognitive-linguistic assessment, therapy, or support services for people with benign and malignant brain tumors experiencing subsequent cognitive and communication problems (ASHA, 2005; 2014).

When reviewing speech-language pathology journals (e.g., the Journal of Speech, Language, and Hearing Research and the American Journal of Speech-Language Pathology), a total of 11 peer-reviewed articles were found to pertain to individuals with brain tumors. In the Journal of Speech, Language, and Hearing Research, there were nine articles relating to brain tumors—three articles related to hearing impairment secondary to a brain tumor (Callan, Lasky, & Fowler, 1999; Fowler & Noffsinger, 1983; Mencher, 1967). Additionally, one article addressed each of the following: dysphagia (Logemann, Pauloski, Colangelo, Lazarus, Fujiu, & Kahrillas, 1995), psychogenic stuttering (Mahr & Leith, 1992), dysarthria (Darley, Aronson, & Brown, 1969), apraxia of speech (Duffy & Josephs, 2012), respiratory changes (Murdoch, Chenery, Stokes, & Hardcastle, 1991), and verbal language (Bonkowski, 1967) and stated that some or all participants had a diagnosis of brain tumor. However, no articles directly studied individuals with brain tumors as the primary population of interest nor did any studies evaluate cognitive or linguistic performance.

In the American Journal of Speech-Language Pathology, two articles emerged

related to brain tumors (Fraas & Calvert, 2009; Odekar & Hallowell, 2005). One article discussed narrative characteristics after acquired brain injury, where brain tumors were an included etiology for an acquired brain injury (Fraas & Calvert, 2009). The other article addressed scoring for language comprehension in aphasia, where brain tumors were included as an etiology for the aphasia (Odekar & Hallowell, 2005). Unfortunately, the most recently published study occurred in 2012. Additionally, none of these studies solely and directly addressed individuals with primary diagnoses of brain tumors. Even though, there are no publications directly studying the brain tumor population from a speech-language pathology perspective, several national presentations have addressed this topic.

Over the past four years, nine presentations relating to brain tumors were presented at the American Speech-Language-Hearing Association National Convention. At the 2014 convention, no presentations given related to brain tumors. In 2015, three presentations related to brain tumors. One discussed dysphagia, another regarding patient-centered goals, and finally brain tumor related aphasia (Longnecker, 2015; Maier, Coles, Carson, Dukelow, & Stavisky, 2015; McGrady, 2015). The convention in 2016 had two presentations related to brain tumors. One discussed the need for sensitive measures of language function for patients with brain tumors and another discussed improving cognition through SLP intervention in individuals with brain tumors and other cancer diagnoses (Antonsson, Longoni, & Hartelius, 2016; Stoffel, 2017). Finally, in 2017, four presentations discussed brain tumors. One provided an overview of brain tumors, their treatments, rehabilitation considerations, and treating speech, language, and cognition after brain tumors (Payne, 2017), another discussed rehabilitation outcomes for

pediatric patients with brain tumors (Witt & Pavone, 2017), the third reported on a case study of a child with anomia after tumor resection (Lemke, Jordan, & Serper, 2017), and finally the fourth presentation discussed the preliminary data from this study (Haller et al., 2017).

Since brain tumors are a relatively new area being explored by the field of speech-language pathology, SLPs are not explicitly trained within their graduate level education to work with this population (Council on Academic Accreditation [CAA] in Audiology and Speech-Language Pathology, 2017). Rather, SLPs are extensively trained to work with cognitive, social aspects of communication, and receptive and expressive language deficits in patients after stroke or traumatic brain injury (CAA in Audiology and Speech-Language Pathology, 2017; Clinical Topics and Disorders in Speech-Language Pathology, n.d). With the thorough training received and significant research regarding cognitive-linguistic deficits in these populations that is available to SLPs, an argument can be made that assessing and treating similar deficits in the brain tumor population falls within the scope of practice for an SLP. The current scope of practice for SLPs does not discriminate based on etiology, rather it states that SLPs can provide services in prevention, counseling, assessment, and intervention for cognitive-communication deficits (ASHA, 2016). Thus, speech-language pathologists working with the brain tumor population would benefit from more specific information to incorporate with the education received about similar deficits in other populations. This includes the most commonly reported symptoms, the severity and frequency of occurrence, and impact on daily functioning for clients with brain tumors. Additionally, inclusion of standardized and self-reported measures to fully assess cognitive and linguistic deficits may prove

useful to therapists. This is because within the role of a SLP, he/she will be required to initially assess for deficits then plan and implement treatment. This in turn may lead to the creation of therapeutic guidelines in the future, to support best-practice cognitive treatments for individuals in this population.

Current Study and Hypotheses

Rehabilitation professionals need information regarding the functional impact of cognitive-linguistic deficits post-treatment in individuals with brain tumors. Various methods exist to define those deficits including self-reported measures, patient and/or caregiver interview, and standardized assessments. These can be used in conjunction with one another to provide a holistic (i.e., objective, and subjective) profile of the individual with a brain tumor. Furthermore, SLPs are uniquely situated for involvement in care of these individuals because of their thorough education on assessment and treatment methods of cognitive-linguistic deficits after other acquired brain injuries.

The aim of this study was to address the lack of data regarding brain tumor treatment-related impairment from a speech-language pathology perspective. This was completed by documenting symptomology and areas of deficit specific to the treatment of brain tumors. A long-term goal is to establish a definitive role for speech-language pathologists within the rehabilitation team as it relates to cognitive and communicative assessment and treatment. This goal will be reached by using a variety of methods, such as patient self-report and standardized assessments.

The primary research questions served to address these aims:

1. What are the most commonly experienced cognitive-linguistic symptoms experienced by individuals with brain tumors after treatment of their tumor?
2. What is the self-reported impact of cognitive-linguistic symptoms on functional daily activities in individuals with brain tumors after treatment of their tumor?
3. Does self-reported survey data accurately correlate with standardized test scores assessing cognitive-linguistic deficits in individuals with brain tumors?

It is anticipated that adults with histories of primary brain tumors resulting in treatment will demonstrate highly variable, individualized cognitive and linguistic symptoms. Results of self-report symptomology measures are expected to reveal novel information regarding cognitive-communication deficits experienced following tumor treatment, which affect daily living activities. It is also hypothesized that at least some scores on standardized assessments will correlate with patient demographic and treatment related information as well as with self-report and symptomology measurement tools.

Method

Recruitment and Eligibility

Recruitment. Participant involvement was on a voluntary basis and no compensation was provided for completion of the research study. One member of the research team recruited all study participants via her position at Mayo Clinic, Rochester, MN. Participants meeting the eligibility criteria described below were approached regarding their potential study involvement.

Study Eligibility. The target group of participants was adults diagnosed with a benign or malignant brain tumor(s) either as a primary diagnosis or recurrent means who self-reported cognitive-linguistic deficits following treatment. We determine positive self-report of cognitive-linguistic deficits through answers on the *Functional Assessment of Cancer Therapy – Brain* (*FACT-Br*) survey (Lai et al., 2014; Lien et al., 2011). The *FACT-Br* is a quality of life and symptom index measure used standardly in clinical care at Mayo Clinic. Questions Br1, Br3, Br4, Br8, and Br9 from the *FACT-Br* relate to cognitive and linguistic deficits (Lai et al., 2014). Specifically, the questions are written as the following: (Br1) "I am able to concentrate," (Br3) "I can remember new things," (Br4) "I get frustrated that I cannot do things I used to do," (Br8) "I am able to find the right word(s) to say what I mean," and (Br9) "I have difficulty expressing my thoughts." The potential responses included "0 – Not at all," "1 – A little bit," "2 – Some-what," "3 – Quite a bit," and "4 – Very much." These questions are seen in detail in Figure 1.

The additional inclusion criteria for participants in this study were as follows:

- be between 18 to 89 years old;
- have undergone at least one cycle of a cancer treatment regimen (e.g.,

chemotherapy, radiotherapy, surgery);

- have completed at least one cycle of a cancer treatment regimen within five years of enrollment in the study;
- be native speakers of American English;
- have obtained a minimum of a high school education.

Figure 1. *FACT-Br* inclusion criteria questions.

	ADDITIONAL CONCERNS	**Not at all**	**A little bit**	**Some-what**	**Quite a bit**	**Very much**
Br1	I am able to concentrate	0	1	2	3	4
Br3	I can remember new things	0	1	2	3	4
Br4	I get frustrated that I cannot do things I used to	0	1	2	3	4
Br8	I am able to find the right word(s) to say what I mean	0	1	2	3	4
Br9	I have difficulty expressing my thoughts	0	1	2	3	4

Study Consent. All participants retained power of attorney and completed consent prior to enrollment. Participants demonstrated consent via the *Informed Consent for Research: A Guide to Assessing Participant's Understanding* (Mayo Clinic IRB, 2016). This document is available only for Mayo Clinic studies and is not readily available to the public (See Appendix 1).

Participants

At the time of consent, initial survey, and standardized testing, all participants were current patients at Mayo Clinic's Radiation Oncology department in Rochester, Minnesota. Twenty-eight total individuals comprised the participant sample (i.e., 18 males and 10 females). Participants ranged in age from 23 to 63 years (M = 45.67, SD = 10.43) and reported completing a minimum of a high-school education (range: 12 –

Graduate degree, *M* = 15 years, *SD* = 2.26 years). The racial and ethnic background of the participants was limited, and all participants were Caucasian. All participants lived within the continental United States and at the time of the initial survey and standardized testing were residing in Minnesota. Table 2 provides individual participant data regarding gender, age, education, current living situation, employment status, diagnosis, tumor location, and radiation type.

Table 2.

Demographic characteristics for participants.

Participant	Gender	Age (years)	Education (years)	Current Living Situation	Employment Status	Diagnosis	Tumor Location	Radiation Type
1	M	43	14	Independently	Full Time	Glioblastoma Multiforme	Right – Temporal	Photon
2	M	55	16	Independently	Full Time	Atypical meningioma	Midbrain – Bifronto-parietal	Photon
3	F	48	16	With Support	Part Time	Meningioma	Left – Spheno-orbital	Proton
4	M	61	12	With Support	Retired	Anaplastic ependymoma	Left – Temporal	Proton
5	M	38	16	Independently	Full Time	Diffuse astrocytoma	Left – Temporal	Proton
6	F	31	16	Independently	Unemployed	Anaplastic Glioma	Right – Frontal	Proton
7	M	30	16	Independently	Full Time	Astrocytoma	Left – Temporal	Proton
8	F	50	16	With Support	Full Time	Oligodendroglioma	Left – Frontal	Proton
9	M	23	12	With Support	Student	Mixed germ cell	Left – Frontal	Proton
10	F	47	16	With Support	Full Time	Glioblastoma Multiforme	Left – Temporal	Photon
11	M	42	14	With Support	Full Time	Astrocytoma	Right – Frontal	Proton
12	M	37	16	Independently	Full Time	Recurrent oligodendroglioma	Right – Temporal	Proton
13	M	50	16	With Support	Full Time	Oligodendroglioma	Left – Frontal	Photon

14	M	35	16	With Support	Full Time	Infiltrating astrocytoma	Right – Frontal	Proton
15	M	50	16+	Independently	Volunteer	Anaplastic astrocytoma	Left – Frontal	Proton
16	M	51	14	With Support	Full Time	Meningioma	Left – Parietal	Proton
17	F	37	16+	With Support	Full Time	Anaplastic oligodendroglioma	Left – Temporal	Proton
18	F	38	16+	With Support	Volunteer	Oligodendroglioma	Left – Parietal	Proton
19	F	56	14	Independently	Full Time	Glioblastoma Multiforme	Left – Frontal	Photon
20	M	32	16	Independently	Full Time	Craniopharyngioma	Left – Sella-Supracellar	Proton
21	F	62	12	With Support	Volunteer	Meduloblastoma	Right – Cerebellum	Proton
22	M	53	12	Independently	Full Time	Glioblastoma Multiforme	Left – Occiptal-Parietal	Photon
23	M	50	16	With Support	Full Time	Anaplastic astrocytoma	Right – Temporal	Proton
24	F	54	12	Independently	Full Time	Meningioma	Left – Cavernous Sinus	Proton
25	M	52	16+	Independently	Full Time	Meningioma	Right – Orbital Area	Proton
26	M	37	16+	Independently	Full Time	Oligodendroglioma	Right – Frontoparietal	Proton
27	M	60	12	Independently	Volunteer	Gliosarcoma; Anaplastic Oligodendroglioma	Right – Frontal	Photon
28	F	57	16+	With Support	Full Time	Meningioma	Left – Temporal	Proton

Materials

Study materials included a researcher-developed Cognitive Communication Survey and three standardized assessment tools.

Cognitive Communication Survey. The 155-question researcher-generated survey included four major components: (a) relevant demographic, social, and medical history information (n = 5); (b) current living status information (n = 13); (c) symptomology including physiological, cognitive, linguistic, and socio-emotional challenges experienced by the participant (n = 4); and (d) change in function exhibited during daily activities since brain tumor treatment (n = 132). The survey utilized conditional logic such that no participants provided responses to all 155 questions. A description of each section follows. See Appendix 2 is the entirety of the Cognitive-Communication Survey.

Demographics. The survey begins with questions regarding demographic and medical history information. This included data on how the participant completed the survey, the participant's gender, age, level of education, and ethnicity/race. Multiple-choice and short response text format was used for all questions in this section.

Current living status. Secondly, the survey probed for information about current living arrangements, performance of independent living activities, money management and financial skills, performance of daily self-care activities, transportation needs, employment, volunteer status, description of social interactions and social contact, and involvement in leisure and recreational activities. Current living arrangements multiple-choice options follow: "Resides at home independently;" "Reside at home with spousal or caregiver support;" "Reside in an assisted living facility;" and "Reside in a nursing

home facility." Performance of independently living activities, money management and financial skills, and transportation needs response options are in a similar format that follows: Independent, without supervision; Independent but other have concerns; Require a little assistance/supervision; Require moderate assistance/supervision; Require extensive assistance/supervision. Finally, performance on daily self-care activities options for response follow: "Independent in all modes of transportation;" "Independent in all modes of transportation but others; cannot drive;" "Require a little assistance or supervision from others; cannot drive;" "Require moderate assistance or supervision from others; cannot drive;" and "Require extensive assistance or supervision from others; cannot drive."

Additionally, participants disclosed if they were employed full time, part time, full or part time with support, or unemployed. If they selected an employed option, a branching logic question appeared asking them to provide their current vocation in short response text format. The same holds true for volunteer status. They selected from full time, part time, full or part time with support, or no, then through branching logic provided the environment and capacity they volunteer in.

Finally, participants responded to questions regarding their social/family relationships. Questions asked participants to describe their social interaction with family/close friends with response options that follow: "Normal stress within family or other close network of relationships;" "Mild stress that does not interfere with family functioning;" "Mild stress that interferes with family functioning less than 25% of the time;" "Moderate stress that interferes with family functioning 25 - 75% of the time;" "Severe stress that interferes with family functioning more than 75% of the time." Next,

participants responded to questions about their social contact with friends or associates and their involvement in leisure and recreational activities with response options that follow a similar pattern of: Normal; Mild difficulty but maintain normal involvement/participation; Mild difficulty/limited participation; Moderately limited involvement/participation; and No or rare involvement/participation.

Symptomatology. The next sections queried participants regarding current symptomology. Researchers categorized potential symptoms across four domains: physiological (n = 12), linguistic (n = 11), cognitive (n = 10), and social-emotional (n = 11). There were 44 potential symptoms to report (See Table 3). The list of symptoms was developed by researchers based on a list previously created for a study addressing symptomology of individuals after traumatic brain injuries (Brown, Hux, Hey, and Murphy, 2017). The specific prompt for each of these sections was "Select which of the following symptoms you are experiencing post-surgery and/or treatment."

Table 3.

Cognitive Communication Survey symptoms.

Physiological	Linguistic	Cognitive	Social-Emotional
Dizziness	Abnormal Clearness or Rate of Speech	Problems Remembering Information Learned in School or on the Job	Anxiety
Headaches	Talking Too Much or Not Enough	Difficulty Keeping Track of Multiple Activities at One Time	Depression
Sensitivity to Light	Difficulty Understanding Words or Phrases You Hear	Problems Learning or Recalling New Information	Irritability/Anger/ Emotional Outbursts
Impaired Strength or Coordination in One or Both Hands	Difficulty Understanding/Following Conversations	Memory Problems for Information about Self or Family from Years Ago	Increased Sensitivity to or Focus on Physical or Emotional Problems
Sensitivity to Sound	Difficulty Reading	Slow Thinking	Flashbacks
Pain	Difficulty Writing	Difficulty Solving Problems	Panic Attacks
Balance or Coordination Problems	Difficulty Expressing Words/Phrases	Attention Problems	Mood Swings
Reduced Mobility	Difficulty Expressing Yourself/Participating in Conversation	Difficulty with Planning or Organization	Lack of Recognition of Problems
Problems Hearing	Difficulty Using Gestures or Facial Expressions	Problems Starting or Finishing Tasks	Inappropriate Social Interactions
Problems Seeing	Stuttering	Concentration Problems	Difficulty with Relationships
Excessive Fatigue	Missing Nonverbal Cues		Apathy or Loss of Interest
Visuospatial Problems			

A participant endorsed any and all symptoms that he/she experienced. Questions incorporated branching logic such that for each symptom a participant endorsed, additional questions related to symptom severity/frequency/impact on activities of daily living emerged. Subsequent questions included multiple-choice options related to self-perceived symptom frequency and severity. Open-ended prompts required the participant to "Briefly explain or provide an example of how your <symptom> impacts your daily life." For this short answer question, functional examples of the symptom were provided to help participants determine what the question was asking of them. For example: Reduced mobility – "Unable to exercise, difficulty navigating dense environments such as the grocery store;" Excessive fatigue – "Can no longer perform tasks at your job efficiently, require sleep during the day;" Difficulty reading words, sentences, or paragraphs – "No longer able to read for job requirements, require assistance for medication or financial management issues;" Difficulty expressing words or phrases – "Stress on self or close relationships, withdrawal or social isolation;" Problems learning or recalling new information – "Difficulty learning new household routines, unable to manage timely completion of tasks;" Slow thinking – "Others become frustrated with your need for increased time, unable to follow conversations easily;" Anxiety – "Lack of desire to leave the house, constant worry about health and safety;" and mood swings – "Hinder ability to complete socially appropriate tasks, put stress on close relationships."

Mayo-Portland Adaptability Inventory (Malec & Lezak, 2008). The Cognitive Communication Survey utilized branching logic questions to incorporate the *MPAI* questions. The question probing for severity of problems had multiple-choice options modeled after the Likert-type scale of the *MPAI* Part A: Abilities and Part B: Adjustment.

The options were as follows: “Mild problem, does not interfere with daily activities,” “Mild problem, interferes with activities less than 25% of the time,” “Moderate problem, interferes with activities 25-75% of the time,” and “Severe problem, interferes with activities more than 75% of the time.” The researchers chose to include additional symptoms within the survey beyond which are probed by the MPAI. The multiple-choice options for the additional symptoms participants could select were in the same format as those from the *MPAI*. See Figure 2 for a screenshot of the Cognitive Communication Survey as an example of the branching logic questions for symptom.

Figure 2. Cognitive Communication Survey symptom branching logic questions example.

How often do you experience difficulty expressing words or phrases?

Less than once a month	Once a month	2-3 times per month	Once a week	2-3 times per week	Daily

On average, how severe is your difficulty expressing words or phrases?

- Mild problem, does not interfere with daily activities
- Mild problem, interferes with activities less than 25% of time
- Moderate problem, interferes with activities 25-75% of the time
- Severe problem, interferes with activities more than 75% of the time

Briefly explain or provide an example for how your difficulty expressing words or phrases impacts your daily life (examples: stress on self or close relationships, withdrawal or social isolation)

A research team member reviewed all survey responses within one week of completion. When participants self-reported negative social-emotional symptoms of depression during completion of the initial survey, a study coordinator disclosed this response to a member of the participant's care team. They then determined whether the individual needed a referral for additional support.

Standardized Assessments. The standardized assessment battery consisted of two tests with multiple subtests targeting linguistic and cognitive domains. When selecting assessments for this study, researchers looked for an assessment that would provide the most amount of information from a functional, clinical view rather than attempting to determine a diagnosis for the participants. We selected the *Cognitive-Linguistic Quick Test* (*CLQT*; Helm-Estabrooks, 2001) to briefly assess the major cognitive domains, provide severity of each, and an overall severity rating for cognitive-linguistic deficits. We selected the *Comprehensive Aphasia Test* (*CAT*; Swinburn, Porter, and Howard, 2004*)* to assess individuals without the diagnosis of aphasia, because the *CAT*'s primary purpose is not to determine normal vs. aphasic or to categorize aphasia types. Rather, it is to determine areas of strength and weakness in different language tasks. For this study, we did not require individuals to have a diagnosis of aphasia, nor was it expected that all individuals with brain tumors would be aphasic.

Cognitive Linguistic Quick Test. The *Cognitive-Linguistic Quick Test* (CLQT; Helm-Estabrooks, 2001) provides information regarding five major domains, attention, memory, executive functions, language, and visuospatial skills, as well as a cognitive composite rating. For each testing domain, the achieved raw scores are converted so that

total domain scores provide an indication of deficit severity (i.e., 4 = within normal limits, 3 = mild, 2 = moderate, or 1 = severe) for individuals eighteen to eighty-nine years old. The overall severity rating scale is as follows: 4.0 - 3.5 within normal limits, 3.4 - 2.5 mild, 2.4 - 1.5 moderate, and 1.4 - 1.0 is severe. Multiple subtests contribute to each domain score. Subtests probe for information regarding: symbol cancellation (i.e., visual neglect, visual processing, attention), confrontation naming, clock drawing, story retell (i.e., verbal memory), auditory comprehension, symbol trails (i.e., trail making), generative naming (i.e., oral fluency), design memory (i.e., nonverbal visual spatial skills and nonverbal memory), mazes (i.e., nonverbal visual spatial skills and problem solving), and design generation (i.e., nonverbal visual spatial skills and problem solving). See Table 4 for the subtests that correlate to each cognitive domain. The *CLQT* allowed the researchers to determine the overall severity of each individual's cognitive profile and an average level of impairment faced by the target population.

Table 4.

CLQT domains and correlating subtests.

Cognitive Domains				
Attention	Memory	Executive Functions	Language	Visuospatial Skills
Symbol Cancellation	Personal Facts	Symbol Trails	Personal Facts	Symbol Cancelation
Story Retelling	Story Retelling	Generative Naming	Confrontation Naming	Symbol Trails
Symbol Trails	Generative Naming	Mazes	Story Retelling	Design Memory
Design Memory	Design Memory	Design Generation	Generative Naming	Mazes
Mazes				Design Generation
Design Generation				

***Comprehensive Aphasia Test* (*CAT*; Swinburn, Porter, and Howard, 2004)**. The *CAT* assesses the performance of language-based measures across various complexity levels of comprehension and expression in oral and written forms. Comprehension subtests include: understanding spoken words, sentences, and paragraphs; and understanding written words and sentences. Expressive language subtests include: repetition of words, non-words, digits, and sentences; naming objects and actions; spoken picture description; reading aloud words and nonwords; copying words; writing to dictation and writing a picture description (See Table 5). The test provides normed information regarding scores for individuals with and without aphasia, thus, it allowed researchers to measure the severity of language deficits across a variety of complexity levels and compare results to norms. The *CAT* was normed on fifty-four adults, twenty-seven aphasics and twenty-seven normal individuals. They were matched

were all aspects that affect language, except for gender. Approximately 46% of the normal sample were spouses of individuals with aphasia, thus, a bias towards women exists for this sample.

Table 5.

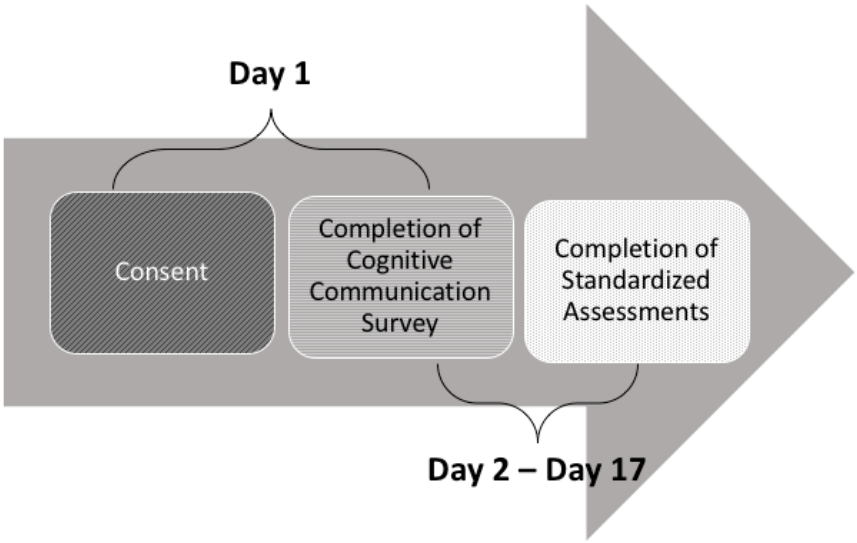
CAT sections and subtests.

Comprehension of Spoken Language	**Comprehension of Written Language**	**Repetition**	**Naming**	**Reading**	**Writing**
Comprehension of spoken words	Comprehension of written words	Repetition of words	Naming objects	Spoken picture description	Writing: copying
Comprehension of spoken sentences	Comprehension of written sentences	Repetition of complex words	Naming actions	Reading words	Writing: picture names
Comprehension of spoken paragraphs		Repetition of nonwords		Reading complex words	Writing to dictation
		Repetition of digit strings		Reading function words	Written picture description
		Repetition of sentences		Reading nonwords	

Procedure

The study consisted of two parts: (1) completion of the Cognitive Communication Survey and (2) performance on a battery of standardized cognitive and language assessments. On the first day, participants completed the consent process to enroll in the study and subsequently completed the Cognitive Communication survey. A researcher then scheduled an appointment for standardized assessment completion.

Figure 3. Timeline of study procedure.



Screening. To participate in the study, the individual had to meet all previously stated inclusion criteria. A research team member at Mayo Clinic completed chart reviews of current patients within the radiation oncology department diagnosed with primary brain tumors to determine appropriate potential participants.

Cognitive Communication Survey. The survey was administered at Mayo Clinic immediately after consent. Initial survey completion took between 14.50 minutes to 2.80 hours (*M* = 58.00 minutes, *SD* = 42.43). Three participants (i.e., P1, P10, and P21) had inaccurately recorded durations, including completion times of nearly five hours to 24

hours. The durations inaccurately recorded were likely due to the final submit button not being pressed by the participant when they completed the survey. We queried participants regarding survey completion (i.e., independently, completed by a caregiver/relative only, or both the participant and the caregiver/relative). Twenty-six participants reported completing the survey independently, one participant completed with support, and one participant did not respond to the question.

Participants took breaks or discontinued survey completion or study participation if desired. The survey was administered using Qualtrics© Survey Software which was accessed online via a Mayo Clinic iPad. Data was stored securely on the Qualtrics© Survey Software and was built and hosted by the University of Minnesota.

Standardized Assessments. The standardized testing protocol was administered and completed within one month of consent at Mayo Clinic in Rochester, Minnesota. The mean length of time between survey completion and assessment was 7.73 days (range: 2 – 17 days, *SD* = 4.43). Participants took breaks as desired and no participants complete testing over multiple sessions.

Assessment completion occurred at Mayo Clinic's campus in quiet, consultation rooms. We administered standardized assessments in a consistent order for each participant—that is, (1) *Cognitive Linguistic Quick Test* then the (2) *Comprehensive Aphasia Test*. Administration of standardized assessments followed precise, standardized instructions and was scored by the first author of this paper immediately following completion.

Results

The results of each section of this study (i.e., Cognitive Communication survey, standardized testing) are thoroughly described in the following sections. Additionally, statistical analyses are provided and explained.

Cognitive Communication Survey

Symptom Endorsement across Categories. On average, participants endorsed 7.46 of 44 potential symptoms (range: 0 – 21, *SD* = 6.12). The most endorsed category was cognitive symptoms with an average endorsement of 2.36 out of ten possible symptoms (range: 0 – 9, *SD* = 2.57). This was followed by physiological symptoms (*M* = 2.11, range: 0 – 7, *SD* = 1.87). Participants endorsed linguistic and socio-emotional complaints equally with an average rate of 1.50 symptoms (Linguistic – range: 0 – 7, *SD* = 2.22; socio-emotional – range: 0 – 7, *SD* = 1.86). Figure 5 depicts the percentage of endorsed symptoms for each category across all participants. See Table 6 for individual participant symptom endorsement.

Figure 4. Percent of endorsed symptoms for each category across participants.

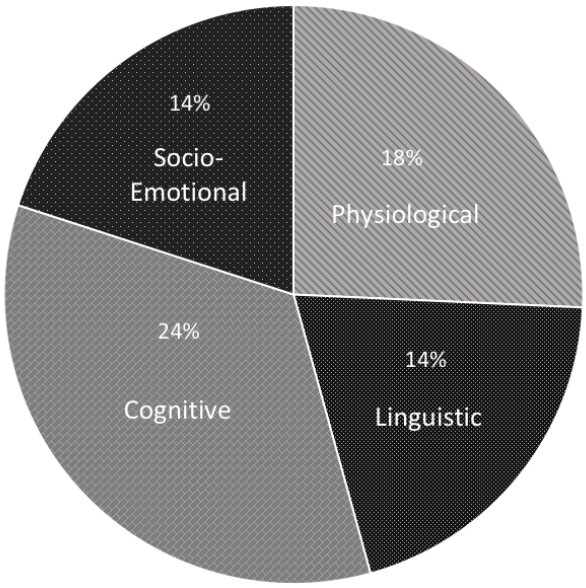


Table 6.

Self-reported symptoms across categories.

		Symptom Categories			
Participant	Total (n = 44)	Physiological (n = 12)	Linguistic (n = 11)	Cognitive (n = 10)	Socio-Emotional (n = 11)
1	2	2			
2	7	2	1	2	2
3	17	7	7	2	1
4	6	3	1	2	
5	18	2	5	9	2
6	2			2	
7	10	4	2	2	2
8	11	3	4	4	
9	21	4	1	8	8
10	11	3		3	5
11	1	1			
12	7	2		2	3
13	4		2	2	
14	6	3			3
15	5	1	2	1	1
16	1		1		
17	11	2	6	3	
18	20	3	7	6	4
19					
20	1	1			
21	7	4	1		2
22					
23	5			3	2
24	5			3	2
25	10	2		6	2
26	1				1
27	6	5			1
28	14	5	2	6	1

Symptom Endorsement for each Category. Within physiological symptoms, participants endorsed headaches the most (i.e., 11 participants, 39%) and visuospatial problems the least (i.e., 2 participants, 7%). Participants endorsed difficulty expressing words or phrases the most (i.e., 12 participants, 43%) and missing nonverbal cues from others (i.e., 1 participant, 4%) the least within linguistic symptoms. Within cognitive symptoms, participants endorsed difficulty keeping track of multiple activities at one time the most (i.e., 13 participants, 46%) and memory problems for information about self or family from years ago the least (i.e., 1 participant, 4%). Finally, participants endorsed anxiety the most (i.e., 12 participants, 43%) and flashbacks, panic attacks, difficulty with relationships, and inappropriate social interactions the least (i.e., 1 participant each, 4% for each symptom) within socio-emotional symptoms.

Symptom Frequency. Participants reported the highest average frequency for visuospatial problems within physiological symptoms. Two participants endorsed this symptom, both reporting daily occurrence (M = 1.00; SD = 0.00). Participants reported the lowest average reported frequency for reduced mobility within physiological symptoms, one participant reported daily occurrence and two participants reported less than one time per month (M = 4.22; SD = 2.89). The most commonly endorsed physiological symptom was headaches (i.e., 11 participants, 39%). Participants frequency report included four participants with daily occurrence, four with two-to-three times per week, and one for each one time per week, two-to-three times per month, and one time per month (M = 2.18; SD = 1.32).

The linguistic symptoms with the highest reported average frequency all had only daily occurrence reported. The symptoms included difficulty reading words, sentences, or

paragraphs (i.e., 5 participants, 18%), difficulty writing words, sentences, or paragraphs (i.e., 4 participants, 14%), talking too much or not enough (i.e., 2 participants, 7%), and missing nonverbal cues from others (i.e., 1 participant, 4%). Participants reported the lowest average reported frequency for stuttering within linguistic symptoms, where one participant reported two-to-three times per week and one participant reported one time per month (*M* = 3.50; *SD* = 0.71). The most commonly endorsed linguistic symptom was difficulty expressing words or phrases (i.e., 12 participants, 43%). Participants frequency report included six participants with daily occurrence, five with two-to-three times per week, and one with one time per month (*M* = 1.75; *SD* = 1.14).

Participants reported the highest average frequency for attention problems within cognitive symptoms, where three participants reported daily occurrence and one participant each for two-to-three times per week and one time per week (*M* = 1.60; *SD* = 0.89). Participants reported the lowest average frequency for problems remembering information learned in school or on the job, one participant reported two-to-three times per week and one for two-to-three times per month (*M* = 3.00; *SD* = 1.41). Participants endorsed difficulty keeping track of multiple activities at one time the most commonly among cognitive symptoms (i.e., 13 participants, 46%). Participants frequency report included six with daily occurrence, five with two-to-three times per week, and two with one time per week (*M* = 1.69; *SD* = 0.75).

Participants reported the highest average frequency for difficulty with relationships within socio-emotional symptoms, where the only participant reported daily occurrence (*M* = 1 - daily; *SD* = 0.00). Participants reported the highest average frequency, with more than one participant endorsing the symptom, for lack of recognition

of problems (i.e., others tell you there is a problem, but you don't agree), where two participants reported daily occurrence, and one each for two-to-three times per week and one time per week (*M* = 1.75; *SD* = 0.96). Participants reported the lowest average frequency for apathy or loss of interest in previously enjoyed activities within socio-emotional symptoms, where one participant reported two-to-three times per month and one for less than one time per month (*M* = 5.00; *SD* = 1.41). Participants most commonly endorsed anxiety within the socio-emotional domain (i.e., 12 participants, 43%), where four participants reported daily occurrence, six with two-to-three times per week, and one participant each for one time per week and two-to-three times per month (*M* = 1.92; *SD* = 0.92).

Table 7 outlines each symptom individually regarding the frequency ratings reported by participants.

Table 7.

Symptom endorsement, frequency, and severity

Symptoms	# of people endorsed	Frequency						Severity			
		Daily	2 - 3x per week	1x per week	2 - 3x per month	1x per month	<1x per month	Mild, does not interfere	Mild, interferes <25%	Moderate, interferes 25 - 75%	Severe, interferes >75%
Physiological (n = 12)											
Dizziness	5 (18%)	1	2	1	1	0	0	4	0	1	0
Headaches	11 (39%)	4	4	1	1	1	0	3	8	0	0
Pain	4 (14%)	1	1	0	2	0	0	3	1	0	0
Sensitivity to light	3 (11%)	2	1	0	0	0	0	2	1	0	0
Sensitivity to sound	3 (11%)	1	1	0	1	0	0	3	0	0	0
Reduced mobility	3 (11%)	1	0	0	0	0	2	2	0	1	0
Balance or coordination problems	6 (21%)	3	1	1	1	0	0	4	0	2	0
Impaired strength or coordination in one or both hands	5 (18%)	2	1	1	0	0	1	3	0	1	1
Problems hearing	4 (14%)	2	1	0	0	0	1	4	0	0	0
Problems seeing	4 (14%)	3	1	0	0	0	0	2	0	2	0
Excessive fatigue	9 (32%)	6	1	0	1	0	1	3	3	3	0
Visuospatial problems	2 (7%)	2	0	0	0	0	0	1	0	1	0
Linguistic (n = 11)											
Abnormal clearness or rate of speech	3 (11%)	1	2	0	0	0	0	3	1	0	0
Stuttering	2 (7%)	0	0	1	1	0	0	1	1	0	0

Difficulty understanding words or phrases you hear	3 (11%)	1	0	0	2	0	0	1	2	0	0
Difficulty understanding/ following conversations	5 (18%)	1	2	1	1	0	0	2	2	1	0
Difficulty reading words, sentences, or paragraphs	5 (18%)	5	0	0	0	0	0	2	2	0	1
Difficulty writing words, sentences, or paragraphs	4 (14%)	4	0	0	0	0	0	2	1	1	0
Difficulty expressing words or phrases	12 (43%)	6	5	0	0	1	0	9	2	1	0
Difficulty expressing yourself/participating in conversations	5 (18%)	2	2	0	1	0	0	1	3	1	0
Difficulty using gestures or facial expressions	N/a	N/a	N/a	N/a	N/a	N/a	N/a	N/a	N/a	N/a	N/a
Talking too much or not enough	2 (7%)	2	0	0	0	0	0	1	1	0	0
Missing nonverbal cues from others	1 (4%)	1	0	0	0	0	0	0	0	1	0
Cognitive (n = 10)											
Memory problems for information about self	1 (4%)	0	1	0	0	0	0	1	0	0	0

or family from years ago											
Problems remembering information learned in school or on the job	2 (7%)	0	1	0	1	0	0	1	1	0	0
Problems learning or recalling new information	9 (32%)	2	3	3	0	1	0	4	5	0	0
Slow thinking	8 (29%)	5	2	0	1	0	0	5	2	1	0
Difficulty with planning or organization	6 (21%)	1	3	2	0	0	0	3	3	0	0
Difficulty solving problems	4 (14%)	1	1	2	0	0	0	0	3	0	1
Attention problems	5 (18%)	3	1	1	0	0	0	2	2	1	0
Concentration problems	11 (39%)	5	4	1	1	0	0	6	2	3	0
Problems starting or finishing tasks	5 (18%)	1	2	2	0	0	0	3	1	1	0
Difficulty keeping track of multiple activities at one time	13 (46%)	6	5	2	0	0	0	6	4	3	0
Socio-Emotional (n = 11)											
Anxiety	12 (43%)	4	6	1	1	0	0	8	3	1	0
Depression	3 (11%)	0	0	2	1	0	0	1	1	1	0
Flashbacks	1 (4%)	0	0	1	0	0	0	1	0	0	0
Panic attacks	1 (4%)	0	1	0	0	0	0	1	0	0	0

Difficulty with relationships	1 (4%)	1	0	0	0	0	0	0	0	1	0
Apathy or loss of interest in previously enjoyed activities	2 (7%)	0	0	0	1	0	1	1	0	0	0
Irritability/anger/ emotional outbursts	6 (21%)	0	5	0	0	1	0	2	3	0	0
Mood swings	6 (21%)	1	4	0	1	0	0	4	2	0	0
Increased sensitivity to or focus on physical or emotional problems	6 (21%)	2	1	1	1	1	0	3	2	0	1
Inappropriate social interactions	1 (4%)	0	0	0	1	0	0	0	0	0	0
Lack of recognition of problems (others tell you there is a problem but you don't agree)	4 (14%)	2	1	1	0	0	0	1	1	2	0

Symptom Severity. Participants reported the lowest average severity for sensitivity to sound and hearing problems within physiological symptoms. For sensitivity to sound, all three participants reported mild—does not interfere (*M* = 1; *SD* = 0.00). For hearing problems, all four participants reported mild—does not interfere (*M* = 1; *SD* = 0.00). Participants reported the highest average severity for impaired strength or coordination in one or both hands, excessive fatigue, and visuospatial problems within physiological symptoms. For impaired strength or coordination in one or both hands, three participants reported mild—does not interfere and one each for moderate—interferes 25 - 75% of the time, and severe—interferes with more than 75% of the time (*M* = 2.00; *SD* = 0.87). For excessive fatigue, three participants reported for each mild—does not interfere, mild—interferes less than 25% of the time, and moderate—interferes 25 - 75% of the time (*M* = 2.00; *SD* =1.41). Finally, for visuospatial problems, one participant reported for each mild—does not interfere and moderate—interferes 25 - 75% of the time (*M* = 2.00; *SD* =1.41). Participants most commonly endorsed headaches within the physiological domain (i.e., 11 participants, 39%), where three participants reported mild—does not interfere and eight reported mild —interferes less than 25% of the time (*M* = 1.73; *SD* = 0.47).

Participants reported the lowest average severity for abnormal clearness or rate of speech within linguistic symptoms, where three participants reported mild—does not interfere and one reported mild—interferes less than 25% of the time (*M* = 1.66, *SD* = 0.58). Participants reported the highest average severity for missing nonverbal cues from others within linguistic symptoms, where the only participant reported moderate—interferes 25 - 75% of the time (*M* = 3.00; *SD* = 0.00). For symptoms that more than one

participant endorsed, participants reported the highest average severity for difficulty reading words, sentences, or paragraphs and difficulty expressing yourself/participating in conversations. For difficulty reading words, sentences, or paragraphs, two participants reported mild—does not interfere, two reported mild—interferes less than 25% of the time, and one reported severe—interferes more than 75% of the time (*M* = 2.00; *SD* = 1.22). For difficulty expressing yourself/participating in conversations, one reported mild—does not interfere, three reported mild—interferes less than 25% of the time, and one reported moderate—interferes 25 - 75% of the time (*M* = 2.00; *SD* = 0.71). Participants most commonly endorsed difficulty expressing words or phrases within the linguistic domain. Severity report for this symptom included nine participants with mild—does not interfere, two with mild—interferes less than 25% of the time, and one with moderate—interferes 25 - 75% of the time (*M* = 1.33; *SD* = 0.65).

Participants reported the lowest average severity for memory problems for information about self or family from years ago within cognitive symptoms, where the only participant reported mild—does not interfere. Of the cognitive symptoms endorsed by more than one participant, problems remembering information learned in school or on the job, slow thinking, and difficulty with planning or organization had the lowest average reported severity. For problems remembering information learned in school or on the job, one participant reported mild—does not interfere and the other reported mild—interferes less than 25% of the time (*M* = 1.50; *SD* = 0.71). For slow thinking, five participants reported mild—does not interfere, two reported mild—interferes less than 25% of the time, and one reported moderate—interferes 25 - 75% of the time (*M* = 1.50; *SD* = 0.76). Finally, for difficulty with planning or organization, three participants

reported for mild—does not interfere and three for mild—interferes less than 25% of the time (*M* = 1.50; *SD* = 0.55). Participants reported the highest average severity for difficulty solving problems within cognitive symptoms, where three participants reported mild—interferes less than 25% of the time and one reported severe—interferes more than 75% of the time (*M* = 2.50; *SD* = 1.00). Participants most commonly endorsed difficulty keeping track of multiple activities at one time within the cognitive domain (i.e., 13 participants, 46%). Severity ratings for this symptom included six participants' reports of mild—does not interfere, four with mild—interferes less than 25% of the time, and three with moderate—interferes 25 - 75% of the time (*M* = 1.77; *SD* = 0.83).

Participants reported lowest average severity for flashbacks, panic attacks, and apathy or loss of interest in previously enjoyed activities within socio-emotional symptoms. For flashbacks, the only participant to endorse the symptom reported a severity of mild—does not interfere (*M* = 1.00; *SD* = 0.00). For panic attacks, the only participant to endorse this symptom reported mild—does not interfere (*M* = 1.00; *SD* = 0.00). For apathy or loss of interest in previously enjoyed activities, only one of two participants who endorsed this symptom reported severity and they reported mild—does not interfere (*M* = 1.00; *SD* = 0.00). Within the category of socio-emotional symptoms, one participant endorsed the symptom, inappropriate social interactions, and did not report a severity. Participants reported highest average severity for difficulty with relationships within socio-emotional symptoms, where the only participant to endorse the symptom reported moderate—interferes 25 - 75% of the time (*M* = 3.00; *SD* = 0.00). Lack of recognition of problems (others tell you there is a problem but you don't agree) had the highest average severity rating for a socio-emotional symptom with more than

one participant endorsement. For this symptom, one participant reported mild—does not interfere, one with mild—interferes less than 25% of the time, and two with moderate—interferes 25 - 75% of the time (*M* = 2.25; *SD* = 0.96). Participants most commonly endorsed anxiety within the socio-emotional domain (i.e., 12 participants, 43%). Severity ratings included eight participants reporting mild—does not interfere, three with mild—interferes less than 25% of the time, and one with moderate—interferes 25 - 75% of the time (*M* = 1.42; *SD* = 0.67).

Table 7 outlines each symptom individually regarding the severity ratings reported by participants.

Qualitative Description of Symptom Impact. Participants provided qualitative descriptions of how the endorsed symptom impacted their daily life. The descriptions for some of the most commonly endorsed, most frequent, and most severe symptoms are discussed. Participants most commonly endorsed headaches within physiological symptoms, some of the descriptions of functional impact included: "Stay away from loud places. Rest" (P3); "Headache keeps me from work" (P7); "Mostly avoiding bright or loud areas" (P9); "More rest time, impacts ability to concentrate and focus" (P10); "Some sleep difficulty" (P12); "Need to still take Tylenol to reduce, the headaches cause a little bit of headache and harder to maintain reading and thinking during the minor headaches" (P17); and "Must nap" (P18).

Participants endorsed the highest frequency for visuospatial problems within physiological symptoms, with functional impact descriptions including: "Shooting pool" (P4) and "Need help red [reading] or ritig [writing]" (P18). Participants endorsed impaired strength or coordination in one or both hands, excessive fatigue, and

visuospatial problems as the most severe physiological symptoms. Functional impact descriptions for impaired strength or coordination in one or both hands included: "Reduced efficiency in completing daily tasks, sometimes requires assistance" (P8) and "Tremor in right hand, difficulty writing" (P21). For excessive fatigue, functional impact descriptions included: "Feel tired daily towards end of day. Go to bed earlier than I used to" (P3); "Sometimes requires sleeping during the day" (P7); "Need sleep a lot and am not very active anymore" (P9); "Makes it hard to get motivated to do things. Makes it difficult to concentrate and formulate clear thoughts. Contributes to word finding problems" (P10); "Require sleep or resting during the day" (P12); and "Not able to do the daily activities without taking breaks. Often times not able to accomplish all that I used to" (P28). Participant 25 provided one of the most thorough descriptions of how his excessive fatigue changed over the course of treatment and altered his functional abilities stating: "Following radiation I go home and sleep for a couple of hours, this especially started after Day 15. I limit my activity most days, but have traveled each weekend and taken about 6 - 7 hour trips. My ability to focus has been affected. As a dentist, I feel I could have worked full days my first week of radiation. The second and third week, at most a half day. At this point at Day 21 I feel like I will have to recover some and regain strength and focus before I go back to working on patients--though I could probably do administrative work for an hour or two."

Participants most commonly endorsed difficulty expressing words and phrases within linguistic symptoms with functional impact descriptions including: "Tend the be more quiet at times mostly in large crowds" (P3) "Social isolation" (P15); "A little frustrating, but not a big deal" (P16); "Only vist [visit] with famly [family]" (P18); and

“Difficulty expressing myself and thoughts at work” (P28). Participants endorsed the highest frequency for difficulty reading words, sentences, or paragraphs, difficulty writing words, sentences, or paragraphs, and talking too much or not enough within linguistic symptoms. For difficulty reading words, sentences, or paragraphs, functional descriptions included: “Takes longer to read than before due to deceased vision” (P3); “Just hit and miss on analysis of reading from time to time, doesn't impact anything critically” (P17); and “Can not read forms boks [books] or finaces [finances]” (P18). For difficulty writing words, sentences, or paragraphs, functional impact descriptions included: “Takes longer to write due to vision loss” (P3); “More time is required for writing” (P13); and “Husband does med [medications] can not mange [manage] money or shop alon [alone]” (P18). For talking too much or not enough, the description of functional impact stated: “Just more talkative than I used to be. Interrupt spouse more frequently” (P10). Participants reported the highest frequency and severity for missing nonverbal cues from others within linguistic symptoms. The functional impact description stated: “Have some peripheral vision loss on left which causes some problems” (P3).

Participants most commonly endorsed difficulty keeping track of multiple activities at one time within cognitive symptoms, with functional impact descriptions including: “If asked to get directions on my phone I will get distracted and forget what I'm doing when a text message comes through” (P6); “Can't talk to spouse and do any other activity. I need to focus entirely on the conversation, otherwise I don't retain the information” (P10); “Difficulty multi tasking and keeping track of items” (P12); “Multi-tasking is still possible, but requires written notes for organization” (P13); “Can't talk and

do other things at same time" (P15); "Hard to cook help kids or read and help oters [others]" (P18); "Difficulty multi tasking" (P23); "Multi tasking less" (P24); and "This has been since anti-seizure Ned's [meds] started 11years ago. Has been worse since treatment. Fatigue plays a role" (P25). Participants endorsed the highest frequency for attention problems within the cognitive domain, with functional impact descriptions including: "Can't stay on task for more than 20 min without significant exertion of effort" (P10); "Multitasking struggles...get distracted easily" (P24); and "Fatigue plays a role in this" (P25). Participants endorsed the highest severity for difficulty solving problems within cognitive symptoms with descriptions of functional impact including: "Difficulty with multitasking" (P6); "Talk myself in circles regarding important family decisions and evaluation of treatment options" (P10); and "Husband does all [problem solving]" (P18).

Participants most commonly endorsed anxiety within socio-emotional symptoms, with descriptions of functional impact including: "Worry about the future & future health issues related to tumor" (P3); "Anxiety to return to work and keep my current job" (P7); "Makes it difficult to sleep, gives me racing thoughts, and feels like I'm constantly worrying" (P10); "Stressful thoughts requiring breathing exercises and/or medication" (P12); "Is my tumor coming back" (P14); "Worry bout [about] heath [health]" (P18); "Don't like large crowds. Cry a lot" (P21); "Rather stay at home" (P24); and "I am anxious before my radiation treatments. Being cinched down with a helmet over it is difficult for me. Harder as time goes on" (P25). Participants reported difficulty with relationships as the most frequent and most severe symptom. The participant described functional impact stating: "Have difficulty communicating with my spouse. we have a lot of misunderstandings" (P10).

Standardized Assessments

All participants received a score for the *Mayo-Portland Adaptability Inventory – Fourth Edition* (*MPAI*), through the test's incorporation into the Cognitive Communication survey. However, six of 28 participants (21%) did not complete the remaining standardized assessments (i.e., the *Cognitive Linguistic Quick Test* and the *Comprehensive Aphasia Test*).

Mayo-Portland Adaptability Inventory – Fourth Edition (MPAI). All participants received raw scores and corresponding T-scores. Participants scored an average raw score of 12.29 (range: 1 – 36, *SD* = 9.71) out of 111. All participants scored below the mean of the standardized data T-scores (*M* = 50, *SD* = 10). Participants scored an average T-score of 16.71 (range: -42 – 44, *SD* = 19.30). The lower the T-score the closer to normal participation and symptoms not interfering with daily life. Two participants (i.e., P10 and P18) received scores closest to the mean of the normative sample, with both scoring a raw score of 36 and T-score of 44. These participants scored closest to the average score of people with acquired brain injuries. One participant (i.e., P22) obtained the lowest score possible on the assessment, a raw score of 0 and a T-score of -42. See Table 8 for raw scores and T-scores for each participant.

Table 8.

Mayo-Portland Adaptability Inventory scores.

Participant	Raw Score	T-Score
1	2	-4
2	9	18
3	22	33
4	10	21
5	16	28
6	11	21
7	15	27
8	17	29
9	21	33
10	36	44
11	5	9
12	8	16
13	6	12
14	6	12
15	10	20
16	2	-7
17	10	20
18	36	44
19	1	-19
20	2	-4
21	22	34
22	0	-42
23	22	34
24	5	9
25	20	32
26	3	0
27	9	18
28	18	30

Cognitive Linguistic Quick Test (CLQT). The mean composite score of the *CLQT* was 3.79 out of 4.0 (range: 2.4 – 4.0, *SD* = 0.48). The scores correlate to severity ratings of "4.0 - 3.5 – Within Normal Limits," "3.4 - 2.5 – Mild;" "2.4 - 1.5 – Moderate;" "1.4 - 1.0 – Severe." Of the 22 participants, 19 participants (86%), obtained scores within normal limits. One participant (i.e., P5) obtained a score within the mild range. Two participants (i.e., P4 and P18) obtained scores in the moderate range. No participants obtained severe scores.

The assessment is broken into six domains, attention, memory, executive functions, language, visuospatial, and a clock drawing. Numeric scores as well as a severity rating are calculated for each domain. Participants achieved an average attention domain score of 191 out of 215 (range: 62 – 210, *SD* = 30.82). Nineteen of the 22 participants (86%) obtained attention scores within normal limits. Two participants (i.e., P6 and P7; 9%) obtained a mild rating and one participant (i.e., P20) obtained a moderate attention rating. Participants achieved an average memory domain score of 162.55 out of 185 (range: 130 – 184, *SD* = 14.69). Seventeen of 22 (77%) participants obtained scores within normal limits. Two participants (i.e., P2 and P16; 9%) obtained a mild severity rating for memory. Three participants (i.e., P4, P5, and P28; 14%) obtained moderate severity ratings for memory. Participants achieved an average executive functions domain score of 30.45 (range: 15 – 39, *SD* = 5.85) out of 40. Twenty of 22 participants (91%) obtained executive functions scores within normal limits. No participants obtained mild ratings for executive functions. One participant (i.e., P4) obtained a moderate severity rating for executive functions. One participant (i.e., P18) obtained a severe rating

for executive functions. Participants achieved an average language domain score of 31.54 (range: 22 – 36, *SD* = 3.42) out of 37. Twenty of 22 participants (95%) obtained severity ratings within normal limits for the language domain. No participants obtained mild severity ratings. One participant (i.e., P4) obtained a moderate severity rating for their language domain. No participants obtained a severe severity rating. Participants achieved an average visuospatial domain score of 93.05 (range: 40 – 104, *SD* = 13.24) out of 105. Twenty of 22 participants (91%) obtained a visuospatial severity rating within normal limits. One participant (i.e., P4) obtained a mild severity rating for the visuospatial domain. No participants obtained a moderate severity rating. One participant (i.e., P18) obtained a score that correlated to a severe severity rating for visuospatial skills. Finally, participants achieved an average clock drawing domain score of 12.05 (range: 8 – 13, *SD* = 1.40) out of 13. Nineteen of 22 participants (86%) obtained clock drawing severity ratings within normal limits. Two participants (i.e., P5 and P17) obtained a mild rating for the clock drawing. Two participants (i.e., P15 and P18; 9%) obtained a moderate severity rating for their clock drawing.

Table 9 shows results for composite and domain scores for each participant who completed the *CLQT*. Table 10 shows the correlating severity ratings for each domain score and composite score.

Table 9.

Standardized testing information – *Cognitive Linguistic Quick Test (CLQT)*.

Participant	Composite Score (__/4.0)	Attention (__/215)	Memory (__/185)	Executive Function (__/40)	Language (__/37)	Visuospatial Skills (__/105)	Clock Drawing (__/13)
1	4.0	199	157	32	34	93	13
2	3.8	200	146	34	33	92	13
3	4.0	191	165	28	32	91	12
4	2.4	161	136	17	22	76	13
5	3.4	179	139	32	25	97	11
6	4.0	205	173	37	35	100	13
7	4.0	200	164	28	31	96	13
8	4.0	201	163	31	30	98	13
9	4.0	201	176	34	33	100	13
10	4.0	198	157	27	29	96	12
11	4.0	202	169	29	31	97	13
12	4.0	210	173	39	35	104	12
13	4.0	202	178	37	35	101	13
14	4.0	197	166	31	33	95	11
15	4.0	205	170	31	32	99	8
16	3.8	197	152	29	29	97	13

17	4.0	208	184	32	36	98	11
18	2.4	62	181	15	33	40	9
19	4.0	191	169	28	31	93	11
25	4.0	186	155	30	32	89	13
26	4.0	210	173	39	35	104	13
28	3.6	197	130	30	28	91	12

Table 10.

Standardized testing information – *CLQT* – Severity ratings.

Participant	Composite Score	Attention	Memory	Executive Function	Language	Visuospatial Skills	Clock Drawing
1	WNL	WNL	WNL	WNL	WNL	WNL	WNL
2	WNL	WNL	***MILD***	WNL	WNL	WNL	WNL
3	WNL	WNL	WNL	WNL	WNL	WNL	WNL
4	***MOD***	***MILD***	***MOD***	***MOD***	***MOD***	***MILD***	WNL
5	***MILD***	***MILD***	***MOD***	WNL	WNL	WNL	***MILD***
6	WNL	WNL	WNL	WNL	WNL	WNL	WNL
7	WNL	WNL	WNL	WNL	WNL	WNL	WNL
8	WNL	WNL	WNL	WNL	WNL	WNL	WNL
9	WNL	WNL	WNL	WNL	WNL	WNL	WNL

10	WNL	WNL	WNL	WNL	WNL	WNL	WNL
11	WNL	WNL	WNL	WNL	WNL	WNL	WNL
12	WNL	WNL	WNL	WNL	WNL	WNL	WNL
13	WNL	WNL	WNL	WNL	WNL	WNL	WNL
14	WNL	WNL	WNL	WNL	WNL	WNL	WNL
15	WNL	WNL	WNL	WNL	WNL	WNL	***MOD***
16	WNL	WNL	***MILD***	WNL	WNL	WNL	WNL
17	WNL	WNL	WNL	WNL	WNL	WNL	***MILD***
18	***MOD***	***MOD***	WNL	***SEVERE***	WNL	***SEVERE***	***MOD***
19	WNL	WNL	WNL	WNL	WNL	WNL	WNL
25	WNL	WNL	WNL	WNL	WNL	WNL	WNL
26	WNL	WNL	WNL	WNL	WNL	WNL	WNL
28	WNL	WNL	***MOD***	WNL	WNL	WNL	WNL

Subtests. There are nine subtests within the *CLQT* that correlate to each domain. They include personal facts, symbol cancellation, confrontation naming, story retell, symbol trails, generative naming, design memory, mazes, and design generation. Participants achieved an average personal facts subtest score of 7.91 (range: 7 – 8, *SD* = 0.29) out of 8. Participants achieved an average symbol cancellation subtest score of 11.14 (range: 0 – 12, *SD* = 2.55) out of 12. For confrontation naming, participants achieved an average subtest score of 9.86 (range: 8 – 10, *SD* = 0.47) out of 10. Participants achieved an average story retell subtest score of 7.32 (range: 5 – 10, *SD* = 1.91) out of 10. For symbol trails, participants achieved an average subtest score of 9.41 (range: 6 – 10, *SD* = 1.10) out of 10. Participants achieved an average generative naming subtest score of 6.45 (range: 3 – 9, *SD* = 1.87) out of 9. For design memory, participants achieved an average subtest score of 5.68 (range: 4 – 6, *SD* = 0.65) out of 6. Participants achieved an average mazes subtest score of 7.32 (range: 0 – 8, *SD* = 1.86) out of 8. Participants achieved an average design generation subtest score of 7.27 (range: 4 – 12, *SD* = 2.76) out of 12.

Cognitive Communication Survey & CLQT. Since the CLQT measures broad cognitive domains that correlate to symptoms potentially endorsed by participants, we looked at whether participants with self-reported deficits also obtained abnormal scores on the *CLQT*.

Participant 2 self-reported memory difficulties on his Cognitive Communication survey. He reported memory difficulties occurred 2 - 3 times per week with a severity of mild—does not interfere with daily activities. This correlated with a mild severity rating of the memory domain on his *CLQT*. Participant 5 self-reported attention problems on his

Cognitive Communication survey. He reported it occurred 2 - 3 times per week with a severity of mild—does not interfere with daily activities. This correlated to his *CLQT* attention domain score of a mild severity rating. Participant 18 self-reported difficulty solving problems on her survey. She reported this occurred daily and was a severe impairment—interfering with more than 75% of activities. This correlated with her *CLQT* executive function severity rating of severe. Participant 4 self-reported difficulty expressing words or phrases. He reported this as a daily problem with a severity of mild—does not interfere with daily activities. This correlated with his language score on the *CLQT*. He received a severity rating of moderate on his *CLQT*. He also reported visuospatial problems on his survey with these difficulties occurring daily and a severity rating of mild—does not interfere with daily activities. This correlated with his visuospatial domain on the *CLQT*, where he received a severity rating of mild. Finally, participant 18's visuospatial domain severity rating on the *CLQT* of severe, correlated with her self-report on her Cognitive Communication survey. On the survey, she reported this difficulty occurring daily with a severity of moderate.

The Comprehensive Aphasia Test (CAT). This assessment is broken into six sections, comprehension of spoken language, comprehension of written language, repetition, naming, reading, and writing. Additionally, there are two picture description scores, spoken and written.

Participants achieved an average spoken language score of 61.91 (range: 53 – 66, *SD* = 3.10) out of 66. One participant (i.e., P18) scored below the cut-off of 56 for a normal score; achieving a score of 53/66. Participants achieved an average comprehension of written language score of 57.59 (range: 38 – 62, *SD* = 5.11) out of 62.

Two participants (i.e., P5 and P18; 9%) obtained scores below the cut-off for written language; achieving respective scores of 52/62 and 38/62. Participants achieved an average repetition score of 72.91 (range: 70 – 74, *SD* = 5.24) out of 74. No participants scored below the cut-off for repetition. Participants achieved an average naming section score of 48.64 (range: 30 – 54, *SD* = 5.24). All participants obtained scores below the cut-off of for naming. Participants achieved an average reading score of 68.86 (range: 59 – 70, *SD* = 2.70) out of 70. One participant (i.e., P18) scored below the cut-off for reading; achieving a score of 59/70. Participants achieved an average writing section score of 72.14 (range: 51 – 76, *SD* = 5.62) out of 76. Two of 22 participants (i.e., P4 and P18; 9%) scored below the cut-off for writing; achieving respective scores of 62/76 and 51/76.

Participants achieved an average spoken picture description score of 33.68 (range: 19 – 68, SD = 12.13). 13 of 22 participants (59%) obtained scores below the cut-off for spoken picture description. Participants achieved an average written picture description score of 30.86 (range: 13 – 67, *SD* = 13.88). Three of 22 participants (i.e., P5, P11, and P18; 14%) scored below the cut-off for written picture description; achieving respective scores of 16, 13, and 18. These scores were diminished, because participants narratives included many decreased syntactic complexity and variety within their sentences, incomplete sentences—when initially prompted to use full sentences—and utilized many indefinite terms. A culmination of all of these factors led to limited verbal and written output, in turn lowering subtest scores.

Table 11 shows scores for individual participants for each section of the *CAT* and indicates scores below the cut-off for that particular section.

Table 11.

Standardized testing information – *Comprehensive Aphasia Test (CAT)*.

Participant	Comprehension of Spoken Language (___/ 66)	Comprehension of Written Language (___/62)	Repetition (___/ 74)	Naming	Spoken Picture Description	Reading (__/ 70)	Writing (__/ 76)	Written Picture Description
1	60	56	72	52*	23*	70	56	19
2	64	54	72	48*	31*	70	54	25
3	65	61	74	54*	34	70	61	27
4	57	57	70	30*	47	68	57*	28
5	59	52	72	46*	23*	66	52	16*
6	63	59	74	50*	28*	70	59	24
7	59	60	74	50*	21*	64	60	17
8	63	61	72	50*	35	70	61	24
9	64	58	72	52*	28*	68	58	32
10	63	62	74	54*	26*	70	62	20
11	63	58	70	52*	19*	70	58	13*
12	65	62	74	48*	68	70	62	67
13	64	61	74	52*	27*	70	61	28
14	63	54	74	53*	31*	70	54	30
15	62	59	74	50*	56	70	59	44

16	63	59	72	50*	41	70	59	33
17	63	58	74	44*	47	70	58	48
18	53*	38*	70	46*	27*	59*	38*	18*
19	61	61	74	50*	39	70	61	39
25	64	60	74	50*	23	70	60	60
26	66	58	74	48*	28*	70	58	30
28	58	59	74	41*	24*	70	59	37

*indicates an achieved score below the cut-off for a particular subtest

Correlations

Pearson correlation tests were completed, and results analyzed on a variety of categories and subtests. Table 12 provides data describing the correlations between demographics, symptoms, and standardized assessments. The only significant correlations between self-reported symptoms and demographic information included tumor grade correlating to the endorsement of socio-emotional symptoms (r = -0.511; p = 0.021) and to total number of symptoms endorsed (r = -0.475; p = 0.034) and tumor laterality correlating to endorsement of linguistic symptoms (r = -0.532; p = 0.011). Additionally, tumor laterality significantly correlated to the *CLQT* executive function domain score (r = 0.426; p = 0.048). Participant gender significantly correlated to *MPAI* total score (r = -0.470; p = 0.027) and the *MPAI* ability subscale (r = -0.572; p = 0.005).

Table 12.

Demographic information correlations.

	Age	Tumor Grade	Tumor Laterality	Linguistic Symptoms	Socio-Emotional Symptoms	Total Symptoms	*MPAI* Total Score	*MPAI* Ability Subscale	*CLQT* Memory Domain	*CLQT* Language Domain	*CLQT* Executive Functions Domain
Gender	*r* = -0.117	*r* = -0.095	*r* = 0.372	*r* = -0.052	*r* = 0.140	*r* = -0.040	***r* = -0.470**	***r* = -0.572**	*r* = -0.142	*r* = -0.046	*r* = 0.258
	p = 0.605	*p* = 0.690	*p* = 0.088	*p* = 0.817	*p* = 0.535	*p* = 0.860	***p* = 0.027**	***p* = 0.005**	*p* = 0.527	*p* = 0.838	*p* = 0.246
Age		*r* = 0.155	*r* = -0.073	*r* = 0.152	*r* = -0.238	*r* = -0.051	*r* = -0.115	*r* = 0.063	***r* = -0.561**	***r* = -0.470**	*r* = -0.318
		p = 0.514	*p* = 0.747	*p* = 0.499	*p* = 0.287	*p* = 0.823	*p* = 0.610	*p* = 0.782	***p* = 0.007**	***p* = 0.027**	*p* = 0.149
Tumor Grade			*r* = -0.072	*r* = -0.383	***r* = -0.511**	***r* = -0.475**	*r* = -0.109	*r* = -0.202	*r* = 0.143	*r* = 0.012	*r* = -0.061
			p = 0.764	*p* = 0.095	***p* = 0.021**	***p* = 0.034**	*p* = 0.646	*p* = 0.392	*p* = 0.547	*p* = 0.960	*p* = 0.800
Tumor Laterality				***r* = -0.532**	*r* = 0.109	*r* = -0.252	*r* = -0.355	*r* = -0.420	*r* = -0.027	*r* = 0.403	***r* = 0.426**
				***p* = 0.011**	*p* = 0.628	*p* = 0.258	*p* = 0.105	*p* = 0.052	*p* = 0.905	*p* = 0.063	***p* = 0.048**

Many significant correlations were found between self-reported symptoms and *MPAI* scores. Correlations between the *CLQT* and *CAT* and self-reported symptoms are not reported, because no significant correlations were found. Table 13 provides data describing the correlations between self-reported symptoms and *MPAI* scores. Significant correlations between self-reported symptom categories included endorsed physiological symptoms to endorsed socio-emotional symptom ($r = 0.431$; $p = 0.045$) and linguistic symptom endorsement to cognitive symptom endorsement ($r = -0.532$; $p = 0.011$). All symptom categories, except linguistic, and total symptoms endorsed significantly correlated to the *MPAI* total scores (physiological – $r = 0.470$, $p = 0.027$; cognitive – $r = 0.622$, $p = 0.002$; socio-emotional – $r = 0.503$, $p = 0.017$; and total symptoms – $r = 0.646$, $p = 0.001$). *MPAI* T-scores significantly correlated to endorsement of physiological ($r = 0.611$; $p = 0.003$), cognitive ($r = 0.803$; $p = 0.000$), socio-emotional ($r = 0.527$; $p = 0.012$), and total symptoms ($r = 0.810$; $p = 0.000$). *MPAI* adjustment subscale scores significantly correlated to physiological ($r = 0.447$; $p = 0.037$), cognitive ($r = 0.436$; $p = 0.042$), socio-emotional ($r = 0.715$; $p = 0.000$), and total symptoms endorsed ($r = 0.566$; $p = 0.006$). Additionally, the *MPAI* ability subscale significantly correlated to endorsement of linguistic ($r = 0.471$; $p = 0.027$), cognitive ($r = 0.645$; $p = 0.001$), and total symptoms ($r = 0.630$; $p = 0.002$).

Table 13.

Symptom category correlations.

	Linguistic Symptoms	Cognitive Symptoms	Socio-Emotional Symptoms	Total Symptoms	*MPAI* Total Score	*MPAI* T-Score	*MPAI* Ability Subscale	*MPAI* Adjustment Subscale	*MPAI* Participation Subscale
Physiological Symptoms	$r = 0.211$ $p = 0.347$	$r = 0.399$ $p = 0.066$	$\boldsymbol{r = 0.431}$ $\boldsymbol{p = 0.045}$	$r = 0.705$ $p = 0.000$	$\boldsymbol{r = 0.470}$ $\boldsymbol{p = 0.027}$	$\boldsymbol{r = 0.611}$ $\boldsymbol{p = 0.003}$	$r = 0.405$ $p = 0.062$	$\boldsymbol{r = 0.447}$ $\boldsymbol{p = 0.037}$	$r = 0.289$ $p = 0.191$
Linguistic Symptoms		$\boldsymbol{r = -0.532}$ $\boldsymbol{p = 0.011}$	$r = 0.060$ $p = 0.791$	$r = 0.653$ $p = 0.001$	$r = 0.233$ $p = 0.297$	$r = 0.356$ $p = 0.104$	$\boldsymbol{r = 0.471}$ $\boldsymbol{p = 0.027}$	$r = -0.004$ $p = 0.987$	$r = 0.130$ $p = 0.565$
Cognitive Symptoms			$r = 0.321$ $p = 0.145$	$r = 0.797$ $p = 0.000$	$\boldsymbol{r = 0.622}$ $\boldsymbol{p = 0.002}$	$\boldsymbol{r = 0.803}$ $\boldsymbol{p = 0.000}$	$\boldsymbol{r = 0.645}$ $\boldsymbol{p = 0.001}$	$\boldsymbol{r = 0.436}$ $\boldsymbol{p = 0.042}$	$\boldsymbol{r = 0.485}$ $\boldsymbol{p = 0.022}$
Socio-Emotional Symptoms				$r = 0.653$ $p = 0.001$	$\boldsymbol{r = 0.503}$ $\boldsymbol{p = 0.017}$	$\boldsymbol{r = 0.527}$ $\boldsymbol{p = 0.012}$	$r = 0.257$ $p = 0.248$	$\boldsymbol{r = 0.715}$ $\boldsymbol{p = 0.000}$	$r = 0.244$ $p = 0.274$
Total Symptoms					$\boldsymbol{r = 0.646}$ $\boldsymbol{p = 0.001}$	$\boldsymbol{r = 0.810}$ $\boldsymbol{p = 0.000}$	$\boldsymbol{r = 0.630}$ $\boldsymbol{p = 0.002}$	$\boldsymbol{r = 0.566}$ $\boldsymbol{p = 0.006}$	$r = 0.403$ $p = 0.063$

Discussion

Individuals with primary brain tumors experience extensive symptoms pre-, during, and post-treatment, that negatively impact their full participation in daily activities and quality of life (Liu, Page, Solheim, Fox, & Chang, 2009). These deficits encompass physical, cognitive, linguistic, and socio-emotional domains (Heimans & Taphoorn, 2002; Osoba, Brada, Prados, & Yung, 2000). A significant burden is faced by individuals with brain tumors due to the symptoms experienced—particularly in the cognitive and linguistic domains as such deficits, along with patient demographic, tumor factors, and treatment outcomes all play a substantial role in decreasing an individual's overall engagement in pre-diagnosis roles and responsibilities (Liu et al., 2009).

To date, little evidence exists supporting effective, efficient methods of alleviating cognitive deficits for individuals with brain tumors. Medications have been found to provide some improvement in cognitive function as evidenced by maintenance or improvement of cognitive assessment scores and quality of life questionnaires (Gehring, Sitskoorn, Aaronson, & Taphoorn, 2008). However, non-drug related interventions (e.g., cognitive rehabilitation) show promise to improve quality of life and functional outcomes (Willis et al., 2006). Yet, cognitive rehabilitation has been limitedly studied in the brain tumor population (Gehring, Sitskoorn, Aaronson, & Taphoorn, 2008; Khan, Amatya, Ng, Drummond, & Olver, 2013; Kirshblum, O'Dell, Ho, & Barr, 2001; Sherer, Meyers, & Bergloff, 1997; Zuchella et al., 2013). Rehabilitation has been found to be beneficial at improving cognitive function in other populations including traumatic brain injury (TBI) and stroke (Coelho, DeRuyter, & Stein, 1996; Dignam, Copland, O'Brien, Khan, & Rodriguez, 2017; Murray, 2012; Peach, 2013). Thus, applying this knowledge to the

brain tumor population may prove to be a viable alternative aimed at improving cognitive and linguistic function following treatment.

As a necessary first step, this study aimed to gather information regarding the general cognitive-linguistic symptomology of individuals after treatment, the self-reported impact of cognitive-linguistic symptoms on functional daily activities and explore relations among self-reported data and performance on standardized cognitive-linguistic assessments. We hypothesized that study participants would a) demonstrate highly variable cognitive and linguistic symptoms, b) self-report deficits affecting independent completion of daily living activities, and c) demonstrate adequate performance on standardized measures.

Study results indicated that post-radiation treatment, individuals with brain tumors report experiencing between zero and 21 total symptoms across cognitive, linguistic, physical, and socio-emotional domains. Cognitive symptoms were the most commonly endorsed overall, followed by physiological, linguistic, and socio-emotional symptoms respectively. Commonly endorsed symptoms across domains included headaches, problems expressing themselves accurately, difficulty with multitasking, and anxiety.

In regard to standardized testing performance, we collected *Mayo-Portland Adaptability Inventory* (*MPAI*) scores on all participants. T-scores ranged from -42 to 44 with lower T-scores indicating no interference of symptoms on daily life. All participants scored below the mean T-score for the normative sample, indicating that the participants in this study are participating at a level greater than normal for individuals with other acquired brain injuries. Similarly, the majority of participants (i.e., 86%) who completed the *Cognitive Linguistic Quick Test* (*CLQT*) obtained overall scores within normal limits.

One participant scored in the mild range and two in the moderate range for overall composite scores. Memory was the domain where the least number of participants obtained a score in the normal range. Only 17 out of 22 participants obtained a normal score, with two participants obtaining a mild severity rating and three obtaining a moderate severity rating within the memory domain.

Conversely, scores obtained on the *Comprehension Aphasia Test* (*CAT*) were not within normal limits. Specifically, all participants who completed the formal assessments obtain scores below the normal cut-off on the naming subtest. One participant obtained a score below the cut-off for spoken language and two participants scored below the cut-off for written language. On the reading subtest, two participants obtained a score below the cut-off. Finally, on the spoken picture description thirteen participants obtained scores below the cut-off and three participants scored below the cut-off for the written picture description.

Based on correlation results from this study, we cannot assume that everyone with a brain tumor should be referred to speech-language pathology services. Demographic factors did not significantly correlate to self-reported symptoms, so it cannot be used as a factor for determining need for referral. However, tumor grade significantly correlated to self-reported socio-emotional symptoms and total symptoms endorsed. Thus, screening based on tumor grade may be an effective method for referral. Individuals with brain tumors have an increased number of self-reported symptoms that can be further assessed with a speech-language pathology referral and based on increased socio-emotional deficits individuals may require additional referrals. Additionally, tumor laterality should

indicate a referral to speech-language pathology, as it significantly correlated with self-reported endorsement of linguistic symptoms.

A significant correlation was also noted between endorsement of linguistic and cognitive symptoms. It stands to reason then, that based on tumor laterality, medical professionals should consider referring individuals for treatment which may include both linguistic and cognitive domains. Finally, there was a significant correlation between endorsement of physical symptoms and socio-emotional symptoms. This is important to note as this finding would encourage referrals to other professions solely based on patient self-report. Thus, individuals with increased physical deficits may benefit from a referral to psychology departments for management of potential socio-emotional deficits.

Cognition

As we found in the results of the Cognitive Communication Survey and the cognitive standardized assessments, many individuals with brain tumors experience a variety of cognitive impairments as a result of treatment for their brain tumor. The most common symptoms were difficulty with multitasking, problems concentrating, difficulty with new learning and recalling this information, and slow thinking. Approximately 30 – 40% of participants reported changes in these areas. However, fewer participants were identified by the formal assessments compared to the self-report survey. This leads to further questions regarding appropriate assessment models for individuals with brain tumors. Specifically, only four participants were identified as having deficits in attention and five demonstrated deficits in memory on the *CLQT*.

The most common cognitive deficit experienced by individuals with brain tumors was difficulty with multitasking. Participants' examples of functional impact from their

problems multitasking, included getting distracted by messages or alerts when attempting to complete a task on their phone, inability to talk to their spouse when completing another activity because they cannot retain the information without completely focusing, and inability to cook, help their children, or read at the same time. Attention emerged as the most frequently experienced cognitive symptom. Participants provided functional examples, such as getting easily distracted, being unable to focus on a task for more than twenty minutes without excessive effort, and decreased attention secondary to fatigue. In terms of severity, problem solving deficits emerged as most severe. Functional examples of problem solving deficits included spouses having to take on all roles that require problem solving and talking themselves in circles when making important family or treatment decisions. All of these common symptom complaints within the brain tumor population have extensive research backing their assessment and treatment within other etiologies. Furthermore, these examples provide a better understanding of the deficit and can guide therapists as they create a patient-centered treatment plan and functional outcomes for return to pre-treatment life.

All of the reported cognitive deficits and those identified on standardized assessments for individuals with brain tumors are common with many etiologies, including TBI and stroke (Jokinen et al., 2015; Kirshblum, O'Dell, Ho, & Barr, 2001; Levine et al., 2015; Rabinowitz and Levin, 2014). The field of speech-language pathology already has substantial research, assessments, and evidence-based treatment options for cognitive impairments in individuals after TBI and stroke (Cherney, Patterson, Raymer, Frymark, & Schooling, 2008; Coelho, DeRuyter, & Stein, 1996; Holland & Fridriksson, 2001; Riedeman & Turkstra, 2018; Wall, Isaacs, Copland, &

Cumming, 2015). By understanding and utilizing the vast information from these etiologies, there is nothing seen commonly among individuals with brain tumors that is drastically different from subsequent cognitive deficits following TBI and stroke. This allows speech-language pathologists (SLPs) to build on their current understanding of other etiologies as a basis for treating individuals with brain tumors. Incorporating examples of symptom manifestations assist SLPs in focusing their treatment on functional outcomes to improve cognitive function and quality of life.

Communication

Similar to cognitive symptoms, individuals with brain tumors may experience linguistic symptoms comparable to individuals post-stroke and TBI (Brady, Kelly, Godwin, Enderby, & Campbell, 2016; Fridriksson, 2010; Hatfield, Millet, Coles, Gassaway, Conroy, & Smout, 2005; Hunting-Pompon, Kendall, & Bacon Moore, 2011). Once again, the crossover between etiologies, allows SLPs to start their assessment and treatment of brain tumors with their current knowledge of similar deficits commonly seen following other types of brain injury.

Naming. The results of the *Comprehensive Aphasia Test*'s (*CAT*) found that all participants received scores below the cut-off score for being within normal limits on the naming subtest. This outcome invites several questions related to potential issues with the assessments and whether anomia is a common side effect of brain tumors and their subsequent treatment. The *CAT*'s naming subtest may be inappropriate for the brain tumor population. All of these questions require further research and assessment of naming abilities in this population to determine precisely the rational for all participants to be identified with naming deficits. Additionally, comparisons of scores on a variety of

naming tests from individuals with brain tumors would provide further evidence for which assessments are the most efficacious to determine naming abilities in the brain tumor population.

Another possible reasoning for all individuals doing poorly on the naming subtest of the *CAT*, could be a similar effect to the Hawthorne effect. The Hawthorne effect is a phenomenon where an individual alters their behavior due to their awareness that they are being watched (Adair, 1984). In a research context, individuals are aware that they are actively participating in research and this in turn may alter results or outcomes. During the standardized assessment sessions, we subjectively observed that the majority of individuals provided quick responses ultimately leading to incorrect answers. Responding to probed items quickly may have resulted from participants' awareness of the testing environment (e.g., we were reporting scores for research and some test items are timed). All of these factors may have played a role in the outcomes for the naming subtest of the *CAT*.

Picture Description. On the spoken picture description subtest of the *CAT*, 13 of 22 participants obtained scores below the cut-off for normal limits. This finding may indicate a notable deficit in organization of language, specifically narrative discourse, within the brain tumor population. Overall, organization of language and narrative discourse deficits are frequently seen following diffuse damage from other acquired etiologies. This includes TBI and specifically damage within the right hemisphere, resulting in right hemisphere dysfunction (Biddle, McCabe, & Bliss, 1996; Davis, O'Neil-Pirozzi, & Coon, 1997; Tucker & Hanlon, 1998; Marini, 2012; Marini, Carlomagna, Caltagirone, & Nocentini, 2005).

Narrative discourse after TBI is often inefficient and diminished (Davis & Coehlo, 2004; Marini, Galetto, Zampieri, Vorano, Zettin, & Carlomagno, 2011). Similar outcomes were seen in the picture description narratives provided by the participants within this study such that the majority of participants provided narratives with limited microlinguistic variation. Microlinguistic abilities signify the morpho-syntactic and lexical aspects of language (Coehlo, Grela, Corso, Gamble, & Feinn, 2010; Peach, 2013). Participants narratives included the use of many indefinite terms, incomplete sentences, and decreased syntactic complexity within their sentences. All together, these aspects lead to overall limited verbal output and lower subtest scores.

Assessment Methods

World Health Organization International Classification of Functioning, Disability, and Health (WHO ICF) Model. Utilizing multiple methods of assessment for cognitive and linguistic impairments provides a broader understanding of the problems an individual is experiencing. Regardless of the quantitative data that is obtained by individuals with brain tumors, we should be interested in how these individuals are participating in their daily lives. The impact on daily functioning is something that should always be considered during assessment and treatment. In this study, we utilized a researcher-developed Cognitive Communication Survey as a way to gain quantitative and qualitative data on participants' participation levels. We primarily collected this data via the incorporation of the *MPAI* and the functional impact statements provided by participants regarding each endorsed symptom.

Since 2005, the World Health Organization (WHO) has made an important shift to focus on the importance of decreasing the burden that is associated with health

conditions (Nieburg, 2005). This better aligns with the mission of rehabilitative medicine, which focuses on reducing the burden and aiming to achieve and/or maintain best functioning (Stucki, 2005). In conjunction with the overall mission of WHO, the International Classification of Functioning, Disability, and Health (ICF) framework was created to provide a standardized method of classifying and describing health and health-related states to create a framework of health outcome measures (Stucki, 2005). The current practical tool available to determine ICF outcomes is the WHO Disability Assessment Schedule Version II (WHODAS II), which focuses on activity and participation (WHO Mental Bulletin, 2000). It includes six domains: getting around, getting along with others, household and work activities, participation in society, self-care, and understanding and communicating. All of these areas should be the focus of an interdisciplinary rehabilitation team.

Additional clinical tools include the ICF Checklist and the ICF Core Sets. The ICF Checklist consists of 125 categories where information from direct observation, informant report, primary report, and written records may be used (International Classification of Functioning, Disability, and Health, 2017; Stucki, 2005). The ICF Checklist takes approximately one hour to complete but may take longer if there are multiple medical conditions/impairments, limitations, and restricted participation—making it less than optimal for clinical practice. The ICF Core Sets were developed with Physical Medicine and Rehabilitation in mind. ICF Core Sets have been created for 12 chronic conditions, acute hospitalizations, and post-acute rehabilitation stays (Cieza, Ewert, Ustun, Chatterji, Kostanjsek, & Stucki, 2004; Grill, Ewert, Chatterji, Kostanjsek, and Stucki, 2005; Stucki, Ustun, & Melvin, 2005). The purpose of the Core Sets is to

define what should be measured for each condition to assess and standardize clinical examination, functional observation, history, measures of functional independence, occupation, or overall handicap, and self-report patient questionnaires (Stucki, 2005).

Khan and Amatya (2013) used the ICF to describe patient-reported disability in primary brain tumors and compare them to TBI and stroke. They utilized components of the ICF Checklist and ICF qualifiers to link participant rated activities, participation, and environmental factors. These responses were then compared with ICF Core Set categories for TBI and stroke. Khan and Amatya's sample consisted of 106 participants with a mean age of 51 years old, a median time since diagnosis of 2.1 years; over one third of the participants had high grade brain tumors. Participants reported headaches, ataxia, seizures, cognitive impairment, visual impairment, aphasia, dysarthria, sensory-perceptual deficit, and dysphagia. These deficits correlated to significant issues in the following ICF categories: learning and applying knowledge, general tasks and demands, communication, mobility, self-care, domestic life, and interpersonal interaction and relationship.

Khan and Amatya (2013) found that individuals with brain tumors identified less categories in activities and participation than in the existing ICF Core Sets for stroke and TBI. Additionally, they found that there were more commonalities between individuals with brain tumors and those with a documented TBI than individuals post-stroke, where there were 56 categories in common between the two populations. There were only 51 common categories between brain tumors and stroke core sets. The use of the TBI and stroke ICF Core Sets and ICF Checklist reflect and incorporate the complexity of change and impairments post-treatment of brain tumors. Thus, speech-language pathology

services provided to individuals with brain tumors should follow the WHO ICF guidelines, potentially including the incorporation of core sets and checklist.

Assessments. The array of cognitive-linguistic deficits reported and experienced by individuals post-treatment for brain tumors leads to a need for appropriate assessment measures. A variety of potential tools exist for such assessments, however, the majority of these assessments are normed specifically for other acquired brain injuries, such as stroke and TBI (Hersh, Wood, & Armstrong, 2017; Spreen & Risser, 2004; Turkstra et al., 2005). These tests may be used with the brain tumor population to look at the symptoms commonly experienced between the etiologies. The *Comprehensive Aphasia Test* (*CAT*) and *Cognitive Linguistic Quick Test* (*CLQT*), which were used in this study, are assessments designed to assess cognitive and linguistic deficits after acquired brain injuries. The *CAT* was normed solely on individuals post-stroke and the *CLQT* was normed on individuals post-stroke and TBI (Helm-Estabrooks, 2001; Swinburn, Porter, and Howard, 2004). During evaluation, more than one assessment is needed to assess a variety of areas and skills, thus this study utilized two assessments (e.g., the *CLQT* and *CAT*) to evaluate participants.

Currently, the only cognitive and communication assessments available are normed solely on etiologies other than brain tumors. These assessments focus on symptoms commonly experienced within the other populations and may be useful to professionals currently working with individuals with brain tumors. However, there are likely nuances of deficits experienced by individuals with brain tumors due to the differences in treatment practices and the potential for both focal and diffuse neurological injuries. Having measurement tools that capture the unique impairments of these

individuals would provide rehabilitation professionals with assessment results which can be interpreted and normed on this population. Thus, there is potentially a need for etiology specific tests (Archibald et al., 1994). Creation of etiology specific assessments would require further, extensive research regarding cognitive and linguistic changes during and after treatment of brain tumors to ensure the tests are appropriately assessing the areas of deficit this population commonly experiences. Additionally, there is a high likelihood of acquired neurodegenerative disease after radiation therapy (Butler, Rapp, & Shaw, 2006; Greene-Schloesser & Robbins, 2012; Greene-Schloesser, Robbins, Peiffer, Shaw, Wheeler, & Chan, 2012). Thus, additional assessments may be required to measure progressive impairments, similar to dementia and other neurodegenerative diseases, if current progressive impairment assessments are deemed inappropriate for the brain tumor population.

Results from the study presented herein indicated that use of the *Mayo-Portland Adaptability Inventory* (*MPAI*), a standardized questionnaire, significantly correlated with self-reported symptoms. This assessment takes into account a variety of self-reported deficits across multiple domains, adjustment to impairments, and detriment to full participation. We advocate for the use of the *MPAI* because it provides standard scores and can be used as a formal measure within assessment. However, we do encourage therapists to incorporate additional in-depth interviewing to find specific descriptions of functional impact within the individual's life and supplementary details they find important to note about their life and symptoms. Until we know how the impairments affect a person in their specific situations, we cannot develop effective, individualized

treatments (Begley, Pritchard-Jones, Biriotti, Kydd, Burdsey, & Townsley, 2014; Robin et al., 2014).

Limitations

The use of a model that includes a combination of self-report scales, screening measures, objective tests, and open-ended functional impact discussion is likely optimal for determining holistically how the patient with a brain tumor is functioning and adjusting with their daily life, including their diagnosis, tumor location, and treatments received. Our model created and followed for this study, including our screening via the *FACT-Br*, Cognitive Communication Survey including description of functional impact, and standardized assessments serves as a starting point for creating such a testing model. However, limitations exist which must be considered.

Our population only included those individuals who were screened through specific questions on the *FACT-Br*. We utilized the screener as a way to exclude individuals who were not self-reporting deficits in cognition, language, socio-emotional, or physical domains. Study results may have differed if inclusion and exclusion criteria were altered or had all individuals with brain tumors been included. Conversely, pre-determined inclusion criteria did not specify tumor type, grade, laterality, or previously completed treatments. Thus, our population included a number of variables which may have influenced outcomes.

Understanding that the point where participants were recruited and assessed for this study only encompassed a fixed point during treatment, is critical to the interpretation of the results. This is a snapshot of deficits experienced after the individual had completed at least one cycle of treatment for their tumor. At this point, deficits are not

progressive. If individuals were assessed across the continuum of care, their experienced deficits may differ and possibly change across time, in regard to type, frequency, and severity. Evaluating deficits across the continuum of care may impact decisions regarding treatment initiation, suggested strategies and supports, and involvement of particular rehabilitation professionals. At this time, no such guidelines exist.

A final limitation relates to the small sample size included within the study. In total, we collected survey data on 28 participants and standardized assessment data on 22 individuals. With this limited amount of data, we are only able to make observations and determine potential common symptoms experienced during treatment. However, it is difficult to generalize this data to all individuals being treated for brain tumors, given our limited and heterogeneous population. Large-scale studies documenting cognitive and linguistic deficits in individuals with a variety of demographic variables could prove highly beneficial.

Future Directions

Follow-Up Survey. We are currently collecting data as an extension to the study presented herein. As a next step, we have initiated completion of a Follow-Up Cognitive Communication Survey. The follow-up survey is modeled after the Cognitive Communication Survey but differs in that it probes for information regarding education about speech-language pathologists (SLPs) and their services, whether a patient sought therapy for cognitive-linguistic deficits, and, if applicable, what areas were addressed within therapy. With this information, we are hoping to document change in symptomatology across time. Additionally, it will provide us with information on whether this population is receiving education about SLPs, their services, as well as how

many individuals seek out treatment for their deficits. This will give us a better understanding of how to better educate physicians about screening for referrals and the frequency individuals with brain tumors are being seen by speech-language pathologists.

Treatment. After determining common symptomology, frequency, severity, functional impact, and the most efficacious ways to assess for these symptoms, we need to determine the most appropriate treatments. This leads us to several questions that require further research related to potential use of current treatments from other populations with the brain tumor population and determining the most appropriate health professionals to implement treatment with individuals with brain tumors, whether that be SLPs, neuropsychologists, or other allied health professionals. Other considerations regarding treatment is whether these symptoms resolve, come back, or are progressive. These factors would play a substantial role in how therapy would be formatted and what the ultimate goal of therapy would be. Additionally, we need to consider whether cognitive-linguistic treatment is necessary for an individual post-treatment of a brain tumor to return to pre-treatment life. To return to pre-treatment functioning, including work productivity, family, and household responsibilities, treatment may be beneficial. It could assist in decreasing the impact of symptoms and utilizing appropriate strategies to adjust to the changes in cognition and language since treatment of their brain tumor.

The option that we hope to investigate further is treatment completed by SLPs in a short-term, triage type format. This would allow SLPs to understand the problems faced by the individual, the functional impacts of the symptoms, then determine appropriate strategies to put into place to ameliorate symptoms. This would be implementation of cognitive-linguistic rehabilitation after an initial assessment session, where individuals

are required to implement strategies into their daily lives, track its effectiveness, and then report back to their SLP to refine the use of strategies in their life. Furthermore, early intervention may be the best option to improve symptoms and slow the potential progression.

Zuchella and colleagues (2013) evaluated the effectiveness of early intervention for cognitive rehabilitation in post-surgical individuals with brain tumors. They found a significant improvement in cognitive function in the treatment group when compared to controls. The treatment group performed significantly better on all of their neuropsychological assessments after sixteen, one-hour sessions. The areas of greatest improvement were the verbal memory and visual attention domains. Zuchella et al. also found that the control group had mild improvement, but it was not statistically significant (2013). This study continues to provide evidence for the efficacy of early intervention for cognition in the brain tumor population (Kim, Yoo, Ko, Park, Kim, & Na, 2009; Petersen, Van Mier, Fiez, & Raichle, 1998; Robertson, 2005). Our future goal is to continue to refine the treatment process to provide the greatest improvement of cognitive-linguistic deficits to all individuals with brain tumors.

Conclusions

Researchers have documented the negative impact cancer and its subsequent treatments have on quality of life. For individuals with primary brain tumors, burden on quality of life is also impacted by symptoms resulting from the tumor itself. Results from the study confirm the presence of self-reported and objectively documented cognitive-linguistic impairments in this population. As a result, development and testing of appropriate, effective assessment and treatment methods are important next steps.

Within the last several years, the WHO ICF model has been adapted and its use has been encouraged to make a shift in all medical care to provide patient-centered care (PCC). Within this model and the focus on PCC, medical professionals, including speech-language pathologists, should incorporate the patient's participation in life, and how their deficits may hinder them from full participation, within their plan of care. In this study, components of the *Mayo-Portland Adaptability Inventory* (*MPAI*) were found to correlate with self-reported symptomology in people with primary brain tumors—as such, a standardized score derived from this survey measure may serve as an appropriate measurement tool for this population. The other cognitive-linguistic assessments utilized in this study do not appear sensitive enough to fully document the functional nature of cognitive-linguistic deficits experienced by this population, however, it appears that some subtests may provide objective information regarding impairments. Additional in-depth interviewing, in combination with self-report surveys and standardized testing, is advised to determine functional manifestations of symptoms.

Finally, with the information gained via this study further research is required. Brain tumor treatment may cause long-term progressive decline that requires cognitive-linguistic function to be monitored and assessed over time. The future of this study aims to reassess participants 6-months post-treatment to document symptomology change, change in functional impact, and information regarding received cognitive-linguistic intervention. With this information we, and other researchers, can look further into potential treatment methods for cognitive-linguistic deficits in the brain tumor population.

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Appendix 1.

Informed Consent for Research: A Guide to Assessing Participant's Understanding.

INFORMED CONSENT FOR RESEARCH: A GUIDE TO ASSESSING A PARTICIPANT'S UNDERSTANDING

Does the participant:

1. Understand the purpose of this study?
   Yes ☐ No ☐

2. Know they do not have to be in this study if they don't want to participate?
   Yes ☐ No ☐

3. Understand what will happen to them in this study if they agree to participate?
   Yes ☐ No ☐

4. Understand the possible risks of participating in this study?
   Yes ☐ No ☐

5. Understand the possible benefits of participating in this study?
   Yes ☐ No ☐

6. Have reasons for wanting to participate in this study that are consistent with study goals?
   Yes ☐ No ☐

7. Understand it is possible they won't benefit directly from participating in this study?
   Yes ☐ No ☐

8. Understand what alternative(s) are available if they choose not to participate in this study?
   Yes ☐ No ☐ N/A ☐

9. Know it is okay for them to change their mind at any time about participating in this study?
   Yes ☐ No ☐

10. Know they will not lose access to medical care at Mayo Clinic if they withdraw from this study?

Yes ☐ No ☐

Appendix 2.

Cognitive-Communication Survey.

Q170 Participant ID Code:

_____

Q23 Please answer the following demographic questions:

Q168 Please indicate how you will complete this survey:

- ○ Independently (patient only)
- ○ Caregiver/relative only
- ○ Both patient and caregiver/relative

Q1 Gender:

- ○ Male
- ○ Female

Q3 Age:

_____

Q22 What is your highest level of education completed?

- ○ High school education or equivalent
- ○ 2-year associates/professional degree
- ○ 4-year bachelors degree
- ○ Graduate degree

Q8 What is your ethnicity?

- ○ Hispanic or Latino
- ○ Not Hispanic or Latino

Q10 What is your race?

- ○ American Indian or Alaska Native
- ○ Asian
- ○ Black or African American
- ○ Native Hawaiian or other Pacific Islander
- ○ White
- ○ Bi-racial or Multi-racial

Q21 Please answer the following questions relating to your current living status:

Q13 Which of the following best describes your current living arrangements?

- ○ Reside at home independently
- ○ Reside at home with spousal or caregiver support
- ○ Reside in an assisted living facility
- ○ Reside in a nursing home facility

Q15 How would you classify your performance of independent living activities (example: home repairs, meal preparation, medication management)?

- ○ Independent, living without supervision or support
- ○ Living without supervision but others have concerns about my independence
- ○ Require a little assistance or supervision from others
- ○ Require moderate assistance or supervision from others
- ○ Require extensive assistance or supervision from others

Q17 How would you classify your money management and financial skills?

- ○ Independent, manage all money and finances without supervision
- ○ Independent but others have concern about my money management skills
- ○ Require a little supervision or assistance with large financial matters; independent with small purchases
- ○ Require moderate supervision or assistance with large financial matters; need some help with small purchases
- ○ Require extensive supervision or assistance with large financial matters; frequent help with small purchases

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Q14 How would you classify your performance of daily self-care activities (example: eating, dressing, bathing, hygiene)?

- ○ Independent completion of self-care activities
- ○ Mild difficulty completing self-care activities (example: complete with extended time or use of assistive device)
- ○ Require a little assistance or supervision from others
- ○ Require moderate assistance or supervision from others
- ○ Require extensive assistance or supervision from others

Q16 How would you classify your transportation needs?

- ○ Independent in all modes of transportation
- ○ Independent in all modes of transportation but others have concerns
- ○ Require a little assistance or supervision from others; cannot drive
- ○ Require moderate assistance or supervision from others; cannot drive
- ○ Require extensive assistance or supervision from others; cannot drive

Q20 Please answer the following questions relating to your current work or volunteer experience:

Q4 Are you currently employed?

- ○ Yes, full time (i.e., more than 30 hours per week without support)
- ○ Yes, part time (i.e., 3 to 30 hours per week without support)
- ○ Yes, full time or part time with support
- ○ No

Display This Question:
If Are you currently employed? = Yes, full time (i.e., more than 30 hours per week without support)
Or Are you currently employed? = Yes, part time (i.e., 3 to 30 hours per week without support)
Or Are you currently employed? = Yes, full time or part time with support

Q7 Current vocation:

_____

Q11 Do you currently volunteer?

- ○ Yes, full time (i.e., more than 30 hours per week without support)
- ○ Yes, part time (i.e., 3 to 30 hours per week without support
- ○ Yes, full time or part time with support
- ○ No

Display This Question:
If Do you currently volunteer? = Yes, full time (i.e., more than 30 hours per week without support)
Or Do you currently volunteer? = Yes, part time (i.e., 3 to 30 hours per week without support
Or Do you currently volunteer? = Yes, full time or part time with support

Q12 In what type of environment/in what capacity do you volunteer?

_____

Q19 Please answer the following questions regarding your social/family relationships:

Q18 Which of the following best describes your social interactions with your family/close friends?

- ○ Normal stress within family or other close network of relationships
- ○ Mild stress that does not interfere with family functioning
- ○ Mild stress that interferes with family functioning less than 25% of the time
- ○ Moderate stress that interferes with family functioning 25-75% of the time
- ○ Severe stress that interferes with family functioning more than 75% of the time

Q24 Which of the following best describes your social contact with friends or associates who are not family?

- ○ Normal involvement with others
- ○ Mild difficulty in social situations but maintain normal involvement
- ○ Mild difficult in social situations with mildly limited involvement
- ○ Moderately limited involvement with others
- ○ No or rare involvement with others

Q25 How would you describe your involvement in leisure and recreational activities?

- ○ Normal participation for age
- ○ Mild difficult in activities but maintains normal participation
- ○ Mildly limited participation
- ○ Moderately limited participation
- ○ No or rare participation

End of Block: Demographic Information

Start of Block: Symptom Block

Q26 Select which of the following symptoms you are experiencing post surgery and/or treatment (check all that apply):

- ☐ Dizziness
- ☐ Headaches
- ☐ Pain
- ☐ Sensitivity to light
- ☐ Sensitivity to sound
- ☐ Reduced mobility
- ☐ Balance or coordination problems
- ☐ Impaired strength or coordination in one or both hands
- ☐ Problems hearing (examples: hearing loss or ringing in the ears)
- ☐ Problems seeing (examples: double vision, problems focusing your eyes)
- ☐ Excessive fatigue
- ☐ Visuospatial problems (example: problems drawing or assembling things)
- ☐ None of the above.

Display This Question:
If Select which of the following symptoms you are experiencing post surgery and/or treatment (check... = Dizziness

Q31 How often do you experience dizziness?

- ○ Less than once a month
- ○ Once a month
- ○ 2-3 times per month
- ○ Once a week
- ○ 2-3 times per week
- ○ Daily

Display This Question:
If Select which of the following symptoms you are experiencing post surgery and/or treatment (check... = Dizziness

Q32 On average, how severe is your dizziness?

- ○ Mild problem, does not interfere with daily activities
- ○ Mild problem, interferes with activities less than 25% of time
- ○ Moderate problem, interferes with activities 25-75% of the time
- ○ Severe problem, interferes with activities more than 75% of the time

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Display This Question:
If Select which of the following symptoms you are experiencing post surgery and/or treatment (check... = Dizziness

Q123 Briefly explain or provide an example for how your dizziness impacts your daily life (examples: nausea, inability to exercise, inability to participate in social activities)

_____

_____

_____

_____

_____

Display This Question:
If Select which of the following symptoms you are experiencing post surgery and/or treatment (check... = Headaches

Q33 How often do you experience headaches?

- ○ Less than once a month
- ○ Once a month
- ○ 2-3 times per month
- ○ Once a week
- ○ 2-3 times per week
- ○ Daily

Display This Question:
If Select which of the following symptoms you are experiencing post surgery and/or treatment (check... = Headaches

Q34 On average, how severe are your headaches?

- ○ Mild problem, does not interfere with daily activities
- ○ Mild problem, interferes with activities less than 25% of time
- ○ Moderate problem, interferes with activities 25-75% of the time
- ○ Severe problem, interferes with activities more than 75% of the time

Display This Question:
If Select which of the following symptoms you are experiencing post surgery and/or treatment (check... = Headaches

Q124 Briefly explain or provide an example for how your headaches impact your daily life (examples: requiring more rest time, keeping you from loud environments)

_____

_____

_____

_____

_____

Display This Question:
If Select which of the following symptoms you are experiencing post surgery and/or treatment (check... = Pain

Q35 How often do you experience pain?

- ○ Less than once a month
- ○ Once a month
- ○ 2-3 times per month
- ○ Once a week
- ○ 2-3 times per week
- ○ Daily

Display This Question:
If Select which of the following symptoms you are experiencing post surgery and/or treatment (check... = Pain

Q36 On average, how severe is your pain?

- ○ Mild problem, does not interfere with daily activities
- ○ Mild problem, interferes with activities less than 25% of time
- ○ Moderate problem, interferes with activities 25-75% of the time
- ○ Severe problem, interferes with activities more than 75% of the time

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Display This Question:
If Select which of the following symptoms you are experiencing post surgery and/or treatment (check... = Pain

Q125 Briefly explain or provide an example for how your pain impacts your daily life (examples: reduces mobility, limits interactions)

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Display This Question:
If Select which of the following symptoms you are experiencing post surgery and/or treatment (check... = Sensitivity to light

Q37 How often do you experience sensitivity to light?

- ○ Less than once a month
- ○ Once a month
- ○ 2-3 times per month
- ○ Once a week
- ○ 2-3 times per week
- ○ Daily

Display This Question:
If Select which of the following symptoms you are experiencing post surgery and/or treatment (check... = Sensitivity to light

Q38 On average, how severe is your sensitivity to light?

- ○ Mild problem, does not interfere with daily activities
- ○ Mild problem, interferes with activities less than 25% of time
- ○ Moderate problem, interferes with activities 25-75% of the time
- ○ Severe problem, interferes with activities more than 75% of the time

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Display This Question:
If Select which of the following symptoms you are experiencing post surgery and/or treatment (check... = Sensitivity to light

Q126 Briefly explain or provide an example for how your sensitivity to light impacts your daily life (examples: limitations on community places you visit, cannot watch television or movies)

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Display This Question:
If Select which of the following symptoms you are experiencing post surgery and/or treatment (check... = Sensitivity to sound

Q39 How often do you experience sensitivity to sound?

- ○ Less than once a month
- ○ Once a month
- ○ 2-3 times per month
- ○ Once a week
- ○ 2-3 times per week
- ○ Daily

Display This Question:
If Select which of the following symptoms you are experiencing post surgery and/or treatment (check... = Sensitivity to sound

Q40 On average, how severe is your sensitivity to sound?

- ○ Mild problem, does not interfere with daily activities
- ○ Mild problem, interferes with activities less than 25% of time
- ○ Moderate problem, interferes with activities 25-75% of the time
- ○ Severe problem, interferes with activities more than 75% of the time

Display This Question:
If Select which of the following symptoms you are experiencing post surgery and/or treatment (check... = Sensitivity to sound

Q127 Briefly explain or provide an example for how your sensitivity to sound impacts your daily life (examples: causes you to remain in quiet/isolated environments, causes additional symptoms such as headache)

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Display This Question:
If Select which of the following symptoms you are experiencing post surgery and/or treatment (check... = Reduced mobility

Q42 How often do you experience reduced mobility?

- ○ Less than once a month
- ○ Once a month
- ○ 2-3 times per month
- ○ Once a week
- ○ 2-3 times per week
- ○ Daily

Display This Question:
If Select which of the following symptoms you are experiencing post surgery and/or treatment (check... = Reduced mobility

Q43 On average, how severe is your reduced mobility?

- ○ Mild problem, does not interfere with daily activities
- ○ Mild problem, interferes with activities less than 25% of time
- ○ Moderate problem, interferes with activities 25-75% of the time
- ○ Severe problem, interferes with activities more than 75% of the time

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Display This Question:
If Select which of the following symptoms you are experiencing post surgery and/or treatment (check... = Reduced mobility

Q128 Briefly explain or provide an example for how your reduced mobility impacts your daily life (examples: unable to exercise, difficulty navigating dense environments such as the grocery store)

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Display This Question:
If Select which of the following symptoms you are experiencing post surgery and/or treatment (check... = Balance or coordination problems

Q44 How often do you experience balance or coordination problems?

- ○ Less than once a month
- ○ Once a month
- ○ 2-3 times per month
- ○ Once a week
- ○ 2-3 times per week
- ○ Daily

Display This Question:
If Select which of the following symptoms you are experiencing post surgery and/or treatment (check... = Balance or coordination problems

Q45 On average, how severe are your balance or coordination problems?

- ○ Mild problem, does not interfere with daily activities
- ○ Mild problem, interferes with activities less than 25% of time
- ○ Moderate problem, interferes with activities 25-75% of the time
- ○ Severe problem, interferes with activities more than 75% of the time

Display This Question:
If Select which of the following symptoms you are experiencing post surgery and/or treatment (check... = Balance or coordination problems

Q129 Briefly explain or provide an example for how your balance or coordination problems impact your daily life (examples: reduced independence for everyday activities, requiring assistive aids for walking)

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Display This Question:
If Select which of the following symptoms you are experiencing post surgery and/or treatment (check... = Impaired strength or coordination in one or both hands

Q46 How often do you experience impaired strength or coordination in one or both hands?

- ○ Less than once a month
- ○ Once a month
- ○ 2-3 times per month
- ○ Once a week
- ○ 2-3 times per week
- ○ Daily

Display This Question:
If Select which of the following symptoms you are experiencing post surgery and/or treatment (check... = Impaired strength or coordination in one or both hands

Q47 On average, how severe is your impaired strength or coordination in one or both hands?

- ○ Mild problem, does not interfere with daily activities
- ○ Mild problem, interferes with activities less than 25% of time
- ○ Moderate problem, interferes with activities 25-75% of the time
- ○ Severe problem, interferes with activities more than 75% of the time

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Display This Question:
If Select which of the following symptoms you are experiencing post surgery and/or treatment (check... = Impaired strength or coordination in one or both hands

Q130 Briefly explain or provide an example for how your impaired strength or coordination in one or both hands impacts your daily life (examples: cannot complete

morning routine activities such as dressing/grooming, cannot lift everyday objects such as a grocery bag)

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Display This Question:
If Select which of the following symptoms you are experiencing post surgery and/or treatment (check... = Problems hearing (examples: hearing loss or ringing in the ears)

Q48 How often do you experience problems hearing?

- ○ Less than once a month
- ○ Once a month
- ○ 2-3 times per month
- ○ Once a week
- ○ 2-3 times per week
- ○ Daily

Display This Question:
If Select which of the following symptoms you are experiencing post surgery and/or treatment (check... = Problems hearing (examples: hearing loss or ringing in the ears)

Q49 On average, how severe are your problems hearing?

- ○ Mild problem, does not interfere with daily activities
- ○ Mild problem, interferes with activities less than 25% of time
- ○ Moderate problem, interferes with activities 25-75% of the time
- ○ Severe problem, interferes with activities more than 75% of the time

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Display This Question:
If Select which of the following symptoms you are experiencing post surgery and/or treatment (check... = Problems hearing (examples: hearing loss or ringing in the ears)

Q131 Briefly explain or provide an example for how your problems hearing impact your daily life (examples: difficulty understanding conversation in noisy environments, problems hearing spouse or child call your name)

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Display This Question:
If Select which of the following symptoms you are experiencing post surgery and/or treatment (check... = Problems seeing (examples: double vision, problems focusing your eyes)

Q50 How often do you experience problems seeing?

- ○ Less than once a month
- ○ Once a month
- ○ 2-3 times per month
- ○ Once a week
- ○ 2-3 times per week
- ○ Daily

Display This Question:
If Select which of the following symptoms you are experiencing post surgery and/or treatment (check... = Problems seeing (examples: double vision, problems focusing your eyes)

Q51 On average, how severe are your problems seeing?

- ○ Mild problem, does not interfere with daily activities
- ○ Mild problem, interferes with activities less than 25% of time
- ○ Moderate problem, interferes with activities 25-75% of the time
- ○ Severe problem, interferes with activities more than 75% of the time

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Display This Question:
If Select which of the following symptoms you are experiencing post surgery and/or treatment (check... = Problems seeing (examples: double vision, problems focusing your eyes)

Q132 Briefly explain or provide an example for how your problems seeing impact your daily life (examples: easily fatigued when reading large amounts of print, can no longer drive safely)

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Display This Question:
If Select which of the following symptoms you are experiencing post surgery and/or treatment (check... = Excessive fatigue

Q52 How often do you experience problems excessive fatigue?

- ○ Less than once a month
- ○ Once a month
- ○ 2-3 times per month
- ○ Once a week
- ○ 2-3 times per week
- ○ Daily

Display This Question:
If Select which of the following symptoms you are experiencing post surgery and/or treatment (check... = Excessive fatigue

Q53 On average, how severe is your excessive fatigue?

- ○ Mild problem, does not interfere with daily activities
- ○ Mild problem, interferes with activities less than 25% of time
- ○ Moderate problem, interferes with activities 25-75% of the time
- ○ Severe problem, interferes with activities more than 75% of the time

Display This Question:
If Select which of the following symptoms you are experiencing post surgery and/or treatment (check... = Excessive fatigue

Q133 Briefly explain or provide an example for how your excessive fatigue impacts your daily life (examples: can no longer perform tasks at your job efficiently, require sleep during the day)

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Display This Question:
If Select which of the following symptoms you are experiencing post surgery and/or treatment (check... = Visuospatial problems (example: problems drawing or assembling things)

Q54 How often do you experience visuospatial problems?

- ○ Less than once a month
- ○ Once a month
- ○ 2-3 times per month
- ○ Once a week
- ○ 2-3 times per week
- ○ Daily

Display This Question:
If Select which of the following symptoms you are experiencing post surgery and/or treatment (check... = Visuospatial problems (example: problems drawing or assembling things)

Q55 On average, how severe are your visuospatial problems?

- ○ Mild problem, does not interfere with daily activities
- ○ Mild problem, interferes with activities less than 25% of time
- ○ Moderate problem, interferes with activities 25-75% of the time
- ○ Severe problem, interferes with activities more than 75% of the time

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Display This Question:
If Select which of the following symptoms you are experiencing post surgery and/or treatment (check... = Visuospatial problems (example: problems drawing or assembling things)

Q134 Briefly explain or provide an example for how your visuospatial problems impact your daily life (examples: getting lost in previously familiar locations, difficulty writing or filling out forms)

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Q28 Select which of the following symptoms you are experiencing post surgery and/or treatment (check all that apply):

- ☐ Abnormal clearness or rate of speech
- ☐ Stuttering
- ☐ Difficulty understanding words or phrases you hear
- ☐ Difficulty understanding/following conversations
- ☐ Difficulty reading words, sentences, or paragraphs
- ☐ Difficulty writing words, sentences, or paragraphs
- ☐ Difficulty expressing words or phrases
- ☐ Difficulty expressing yourself/participating in conversations
- ☐ Difficulty using gestures or facial expressions
- ☐ Talking too much or not enough
- ☐ Missing nonverbal cues from others
- ☐ None of the above.

Display This Question:
If Select which of the following symptoms you are experiencing post surgery and/or treatment (check... = Abnormal clearness or rate of speech

Q56 How often do you experience abnormal clearness or rate of speech?

- ○ Less than once a month
- ○ Once a month
- ○ 2-3 times per month
- ○ Once a week
- ○ 2-3 times per week
- ○ Daily

Display This Question:
If Select which of the following symptoms you are experiencing post surgery and/or treatment (check... = Abnormal clearness or rate of speech

Q57 On average, how severe is your abnormal clearness or rate of speech?

- ○ Mild problem, does not interfere with daily activities
- ○ Mild problem, interferes with activities less than 25% of time
- ○ Moderate problem, interferes with activities 25-75% of the time
- ○ Severe problem, interferes with activities more than 75% of the time

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Display This Question:
If Select which of the following symptoms you are experiencing post surgery and/or treatment (check... = Abnormal clearness or rate of speech

Q135 Briefly explain or provide an example for how your abnormal clearness or rate of speech impact your daily life (examples: others become frustrated with you during conversations, choosing to speak less due to lack of understanding)

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Display This Question:
If Select which of the following symptoms you are experiencing post surgery and/or treatment (check... = Stuttering

Q58 How often do you experience stuttering?

- ○ Less than once a month
- ○ Once a month
- ○ 2-3 times per month
- ○ Once a week
- ○ 2-3 times per week
- ○ Daily

Display This Question:
If Select which of the following symptoms you are experiencing post surgery and/or treatment (check... = Stuttering

Q59 On average, how severe is your stuttering?

- ○ Mild problem, does not interfere with daily activities
- ○ Mild problem, interferes with activities less than 25% of time
- ○ Moderate problem, interferes with activities 25-75% of the time
- ○ Severe problem, interferes with activities more than 75% of the time

Display This Question:
If Select which of the following symptoms you are experiencing post surgery and/or treatment (check... = Stuttering

Q136 Briefly explain or provide an example for how your stuttering impacts your daily life (examples: avoidance of topics or conversations for which you struggle, increased fatigue during normal conversation)

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Display This Question:
If Select which of the following symptoms you are experiencing post surgery and/or treatment (check... = Difficulty understanding words or phrases you hear

Q60 How often do you experience difficulty understanding words or phrases you hear?

- ○ Less than once a month
- ○ Once a month
- ○ 2-3 times per month
- ○ Once a week
- ○ 2-3 times per week
- ○ Daily

Display This Question:
If Select which of the following symptoms you are experiencing post surgery and/or treatment (check... = Difficulty understanding words or phrases you hear

Q61 On average, how severe is your difficulty understanding words or phrases you hear?

- ○ Mild problem, does not interfere with daily activities
- ○ Mild problem, interferes with activities less than 25% of time
- ○ Moderate problem, interferes with activities 25-75% of the time
- ○ Severe problem, interferes with activities more than 75% of the time

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Display This Question:
If Select which of the following symptoms you are experiencing post surgery and/or treatment (check... = Difficulty understanding words or phrases you hear

Q137 Briefly explain or provide an example for how your difficulty understanding words or phrases you hear impacts your daily life (examples: no longer listen to radio or watch television, increased fatigue during normal interactions)

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Display This Question:
If Select which of the following symptoms you are experiencing post surgery and/or treatment (check... = Difficulty understanding/following conversations

Q62 How often do you experience difficulty understanding/following conversations?

- ○ Less than once a month
- ○ Once a month
- ○ 2-3 times per month
- ○ Once a week
- ○ 2-3 times per week
- ○ Daily

Display This Question:
If Select which of the following symptoms you are experiencing post surgery and/or treatment (check... = Difficulty understanding/following conversations

Q63 On average, how severe is your difficulty understanding/following conversations?

- ○ Mild problem, does not interfere with daily activities
- ○ Mild problem, interferes with activities less than 25% of time
- ○ Moderate problem, interferes with activities 25-75% of the time
- ○ Severe problem, interferes with activities more than 75% of the time

Display This Question:
If Select which of the following symptoms you are experiencing post surgery and/or treatment (check... = Difficulty understanding/following conversations

Q138 Briefly explain or provide an example for how your difficulty understanding words or phrases you hear impacts your daily life (examples: no longer attend noisy environments, difficulty participating in family social gatherings)

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Display This Question:
If Select which of the following symptoms you are experiencing post surgery and/or treatment (check... = Difficulty reading words, sentences, or paragraphs

Q65 How often do you experience difficulty reading words, sentences, or paragraphs?

- ○ Less than once a month
- ○ Once a month
- ○ 2-3 times per month
- ○ Once a week
- ○ 2-3 times per week
- ○ Daily

Display This Question:
If Select which of the following symptoms you are experiencing post surgery and/or treatment (check... = Difficulty reading words, sentences, or paragraphs

Q66 On average, how severe is your difficulty reading words, sentences, or paragraphs?

- ○ Mild problem, does not interfere with daily activities
- ○ Mild problem, interferes with activities less than 25% of time
- ○ Moderate problem, interferes with activities 25-75% of the time
- ○ Severe problem, interferes with activities more than 75% of the time

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Display This Question:
If Select which of the following symptoms you are experiencing post surgery and/or treatment (check... = Difficulty reading words, sentences, or paragraphs

Q139 Briefly explain or provide an example for how your difficulty reading words, sentences, or paragraphs impacts your daily life (examples: no longer able to read for job requirements, require assistance for medication or financial management issues)

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Display This Question:
If Select which of the following symptoms you are experiencing post surgery and/or treatment (check... = Difficulty writing words, sentences, or paragraphs

Q67 How often do you experience difficulty writing words, sentences, or paragraphs?

- ○ Less than once a month
- ○ Once a month
- ○ 2-3 times per month
- ○ Once a week
- ○ 2-3 times per week
- ○ Daily

Display This Question:
If Select which of the following symptoms you are experiencing post surgery and/or treatment (check... = Difficulty writing words, sentences, or paragraphs

Q68 On average, how severe is your difficulty writing words, sentences, or paragraphs?

- ○ Mild problem, does not interfere with daily activities
- ○ Mild problem, interferes with activities less than 25% of time
- ○ Moderate problem, interferes with activities 25-75% of the time
- ○ Severe problem, interferes with activities more than 75% of the time

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Display This Question:
If Select which of the following symptoms you are experiencing post surgery and/or treatment (check... = Difficulty writing words, sentences, or paragraphs

Q140 Briefly explain or provide an example for how your difficulty writing words, sentences, or paragraphs impacts your daily life (examples: cannot complete simple daily tasks such as creating a grocery list, require assistance for medication or financial management issues)

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Display This Question:
If Select which of the following symptoms you are experiencing post surgery and/or treatment (check... = Difficulty expressing words or phrases

Q69 How often do you experience difficulty expressing words or phrases?

- ○ Less than once a month
- ○ Once a month
- ○ 2-3 times per month
- ○ Once a week
- ○ 2-3 times per week
- ○ Daily

Display This Question:
If Select which of the following symptoms you are experiencing post surgery and/or treatment (check... = Difficulty expressing words or phrases

Q70 On average, how severe is your difficulty expressing words or phrases?

- ○ Mild problem, does not interfere with daily activities
- ○ Mild problem, interferes with activities less than 25% of time
- ○ Moderate problem, interferes with activities 25-75% of the time
- ○ Severe problem, interferes with activities more than 75% of the time

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Display This Question:
If Select which of the following symptoms you are experiencing post surgery and/or treatment (check... = Difficulty expressing words or phrases

Q141 Briefly explain or provide an example for how your difficulty expressing words or phrases impacts your daily life (examples: stress on self or close relationships, withdrawal or social isolation)

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Display This Question:
If Select which of the following symptoms you are experiencing post surgery and/or treatment (check... = Difficulty expressing yourself/participating in conversations

Q71 How often do you experience difficulty expressing yourself/participating in conversations?

- ○ Less than once a month
- ○ Once a month
- ○ 2-3 times per month
- ○ Once a week
- ○ 2-3 times per week
- ○ Daily

Display This Question:
If Select which of the following symptoms you are experiencing post surgery and/or treatment (check... = Difficulty expressing yourself/participating in conversations

Q72 On average, how severe is your difficulty expressing yourself/participating in conversations?

- ○ Mild problem, does not interfere with daily activities
- ○ Mild problem, interferes with activities less than 25% of time
- ○ Moderate problem, interferes with activities 25-75% of the time
- ○ Severe problem, interferes with activities more than 75% of the time

Display This Question:
If Select which of the following symptoms you are experiencing post surgery and/or treatment (check... = Difficulty expressing yourself/participating in conversations

Q142 Briefly explain or provide an example for how your difficulty expressing yours/participating in conversations impacts your daily life (examples: stress on self or close relationships, withdrawal or social isolation)

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Display This Question:
If Select which of the following symptoms you are experiencing post surgery and/or treatment (check... = Difficulty using gestures or facial expressions

Q73 How often do you experience difficulty using gestures or facial expressions?

- ○ Less than once a month
- ○ Once a month
- ○ 2-3 times per month
- ○ Once a week
- ○ 2-3 times per week
- ○ Daily

Display This Question:
If Select which of the following symptoms you are experiencing post surgery and/or treatment (check... = Difficulty using gestures or facial expressions

Q74 On average, how severe is your difficulty using gestures or facial expressions?

- ○ Mild problem, does not interfere with daily activities
- ○ Mild problem, interferes with activities less than 25% of time
- ○ Moderate problem, interferes with activities 25-75% of the time
- ○ Severe problem, interferes with activities more than 75% of the time

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Display This Question:
If Select which of the following symptoms you are experiencing post surgery and/or treatment (check... = Difficulty using gestures or facial expressions

Q143 Briefly explain or provide an example for how your difficulty gestures or facial expressions impacts your daily life (examples: frustration for often being misunderstood, difficulty with humor or telling jokes)

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Display This Question:
If Select which of the following symptoms you are experiencing post surgery and/or treatment (check... = Talking too much or not enough

Q75 How often do you experience difficulty with talking too much or not enough?

- ○ Less than once a month
- ○ Once a month
- ○ 2-3 times per month
- ○ Once a week
- ○ 2-3 times per week
- ○ Daily

Display This Question:
If Select which of the following symptoms you are experiencing post surgery and/or treatment (check... = Talking too much or not enough

Q76 On average, how severe is your difficulty with talking too much or not enough?

- ○ Mild problem, does not interfere with daily activities
- ○ Mild problem, interferes with activities less than 25% of time
- ○ Moderate problem, interferes with activities 25-75% of the time
- ○ Severe problem, interferes with activities more than 75% of the time

Display This Question:
If Select which of the following symptoms you are experiencing post surgery and/or treatment (check... = Talking too much or not enough

Q144 Briefly explain or provide an example for how your talking too much or too little impacts your daily life (examples: loss of previously close friends, withdrawal from group social interactions)

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Display This Question:
If Select which of the following symptoms you are experiencing post surgery and/or treatment (check... = Missing nonverbal cues from others

Q77 How often do you experience missing nonverbal cues from others?

- ○ Less than once a month
- ○ Once a month
- ○ 2-3 times per month
- ○ Once a week
- ○ 2-3 times per week
- ○ Daily

Display This Question:
If Select which of the following symptoms you are experiencing post surgery and/or treatment (check... = Missing nonverbal cues from others

Q78 On average, how severe is your experience with missing nonverbal cues from others?

- ○ Mild problem, does not interfere with daily activities
- ○ Mild problem, interferes with activities less than 25% of time
- ○ Moderate problem, interferes with activities 25-75% of the time
- ○ Severe problem, interferes with activities more than 75% of the time

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Display This Question:
If Select which of the following symptoms you are experiencing post surgery and/or treatment (check... = Missing nonverbal cues from others

Q145 Briefly explain or provide an example for how your missing of nonverbal cues from others impacts your daily life (examples: increased arguments with spouse or caregiver, difficulty understanding humor or romantic gestures)

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Q29 Select which of the following symptoms you are experiencing post surgery and/or treatment (check all that apply):

- ☐ Memory problems for information about self or family from years ago
- ☐ Problems remembering information learned in school or on the job
- ☐ Problems learning or recalling new information
- ☐ Slow thinking
- ☐ Difficulty with planning or organization
- ☐ Difficulty solving problems
- ☐ Attention problems
- ☐ Concentration problems
- ☐ Problems starting or finishing tasks
- ☐ Difficulty keeping track of multiple activities at one time
- ☐ None of the above.

Display This Question:
If Select which of the following symptoms you are experiencing post surgery and/or treatment (check... = Memory problems for information about self or family from years ago

Q79 How often do you experience memory problems for information about self or family from years ago?

- ○ Less than once a month
- ○ Once a month
- ○ 2-3 times per month
- ○ Once a week
- ○ 2-3 times per week
- ○ Daily

Display This Question:
If Select which of the following symptoms you are experiencing post surgery and/or treatment (check... = Memory problems for information about self or family from years ago

Q80 On average, how severe are your memory problems for information about self or family from years ago?

- ○ Mild problem, does not interfere with daily activities
- ○ Mild problem, interferes with activities less than 25% of time
- ○ Moderate problem, interferes with activities 25-75% of the time
- ○ Severe problem, interferes with activities more than 75% of the time

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Display This Question:
If Select which of the following symptoms you are experiencing post surgery and/or treatment (check... = Memory problems for information about self or family from years ago

Q146 Briefly explain or provide an example for how your memory problems for information about self or family from years ago impacts your daily life (examples:

difficulty telling stories or sharing memories, unable to provide history information for health-related matters)

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Display This Question:
If Select which of the following symptoms you are experiencing post surgery and/or treatment (check... = Problems remembering information learned in school or on the job

Q81 How often do you experience problems remembering information you learned at school or on the job?

- ○ Less than once a month
- ○ Once a month
- ○ 2-3 times per month
- ○ Once a week
- ○ 2-3 times per week
- ○ Daily

Display This Question:
If Select which of the following symptoms you are experiencing post surgery and/or treatment (check... = Problems remembering information learned in school or on the job

Q82 On average, how severe are your problems remembering information learned in school or on the job?

- ○ Mild problem, does not interfere with daily activities
- ○ Mild problem, interferes with activities less than 25% of time
- ○ Moderate problem, interferes with activities 25-75% of the time
- ○ Severe problem, interferes with activities more than 75% of the time

Display This Question:
If Select which of the following symptoms you are experiencing post surgery and/or treatment (check... = Problems remembering information learned in school or on the job

Q147 Briefly explain or provide an example for how your problems remembering information learned in school or on the job impacts your daily life (examples: unable to perform at work without support, no longer contributing to family financially)

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Display This Question:
If Select which of the following symptoms you are experiencing post surgery and/or treatment (check... = Problems learning or recalling new information

Q83 How often do you experience problems learning or recalling new information?

- ○ Less than once a month
- ○ Once a
- ○ 2-3 times per month
- ○ Once a week
- ○ 2-3 times per week
- ○ Daily

Display This Question:
If Select which of the following symptoms you are experiencing post surgery and/or treatment (check... = Problems learning or recalling new information

Q84 On average, how severe are your problems learning or recalling new information?

- ○ Mild problem, does not interfere with daily activities
- ○ Mild problem, interferes with activities less than 25% of time
- ○ Moderate problem, interferes with activities 25-75% of the time
- ○ Severe problem, interferes with activities more than 75% of the time

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Display This Question:
If Select which of the following symptoms you are experiencing post surgery and/or treatment (check... = Problems learning or recalling new information

Q148 Briefly explain or provide an example for how your problems learning or recalling new information impacts your daily life (examples: difficulty learning new household routines, unable to manage timely completion of tasks)

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Display This Question:
If Select which of the following symptoms you are experiencing post surgery and/or treatment (check... = Slow thinking

Q85 How often do you experience slow thinking?

- ○ Less than once a month
- ○ Once a month
- ○ 2-3 times per month
- ○ Once a week
- ○ 2-3 times per week
- ○ Daily

Display This Question:
If Select which of the following symptoms you are experiencing post surgery and/or treatment (check... = Slow thinking

Q86 On average, how severe is your slow thinking?

- ○ Mild problem, does not interfere with daily activities
- ○ Mild problem, interferes with activities less than 25% of time
- ○ Moderate problem, interferes with activities 25-75% of the time
- ○ Severe problem, interferes with activities more than 75% of the time

Display This Question:
If Select which of the following symptoms you are experiencing post surgery and/or treatment (check... = Slow thinking

Q149 Briefly explain or provide an example for how your slow thinking impacts your daily life (examples: others become frustrated with your need for increased time, unable to follow conversations easily)

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Display This Question:
If Select which of the following symptoms you are experiencing post surgery and/or treatment (check... = Difficulty with planning or organization

Q87 How often do you experience difficulty with planning or organization?

- ○ Less than once a month
- ○ Once a month
- ○ 2-3 times per month
- ○ Once a week
- ○ 2-3 times per week
- ○ Daily

Display This Question:
If Select which of the following symptoms you are experiencing post surgery and/or treatment (check... = Difficulty with planning or organization

Q88 On average, how severe is your difficulty with planning or organization?

- ○ Mild problem, does not interfere with daily activities
- ○ Mild problem, interferes with activities less than 25% of time
- ○ Moderate problem, interferes with activities 25-75% of the time
- ○ Severe problem, interferes with activities more than 75% of the time

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Display This Question:
If Select which of the following symptoms you are experiencing post surgery and/or treatment (check... = Difficulty with planning or organization

Q150 Briefly explain or provide an example for how your difficulty with planning or organization impacts your daily life (examples: problems organizing the family calendar, often misplacing frequently used items)

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Display This Question:
If Select which of the following symptoms you are experiencing post surgery and/or treatment (check... = Difficulty solving problems

Q89 How often do you experience difficulty solving problems?

- ○ Less than once a month
- ○ Once a month
- ○ 2-3 times per month
- ○ Once a week
- ○ 2-3 times per week
- ○ Daily

Display This Question:
If Select which of the following symptoms you are experiencing post surgery and/or treatment (check... = Difficulty solving problems

Q91 On average, how severe is your difficulty solving problems?

- ○ Mild problem, does not interfere with daily activities
- ○ Mild problem, interferes with activities less than 25% of time
- ○ Moderate problem, interferes with activities 25-75% of the time
- ○ Severe problem, interferes with activities more than 75% of the time

Display This Question:
If Select which of the following symptoms you are experiencing post surgery and/or treatment (check... = Difficulty solving problems

Q151 Briefly explain or provide an example for how your difficulty solving problems impacts your daily life (examples: cannot fully contribute to family decision making, unable to be left alone for non-routine tasks)

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Display This Question:
If Select which of the following symptoms you are experiencing post surgery and/or treatment (check... = Attention problems

Q92 How often do you experience attention problems?

- ○ Less than once a month
- ○ Once a month
- ○ 2-3 times per month
- ○ Once a week
- ○ 2-3 times per week
- ○ Daily

Display This Question:
If Select which of the following symptoms you are experiencing post surgery and/or treatment (check... = Attention problems

Q93 On average, how severe are your attention problems?

- ○ Mild problem, does not interfere with daily activities
- ○ Mild problem, interferes with activities less than 25% of time
- ○ Moderate problem, interferes with activities 25-75% of the time
- ○ Severe problem, interferes with activities more than 75% of the time

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Display This Question:
If Select which of the following symptoms you are experiencing post surgery and/or treatment (check... = Attention problems

Q152 Briefly explain or provide an example for how your attention problems impact your daily life (examples: cannot fully participate in group interactions, cannot complete tasks for longer than 20 minutes)

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Display This Question:
If Select which of the following symptoms you are experiencing post surgery and/or treatment (check... = Concentration problems

Q94 How often do you experience concentration problems?

- ○ Less than once a month
- ○ Once a month
- ○ 2-3 times per month
- ○ Once a week
- ○ 2-3 times per week
- ○ Daily

Display This Question:
If Select which of the following symptoms you are experiencing post surgery and/or treatment (check... = Concentration problems

Q95 On average, how severe are your concentration problems?

- ○ Mild problem, does not interfere with daily activities
- ○ Mild problem, interferes with activities less than 25% of time
- ○ Moderate problem, interferes with activities 25-75% of the time
- ○ Severe problem, interferes with activities more than 75% of the time

Display This Question:
If Select which of the following symptoms you are experiencing post surgery and/or treatment (check... = Concentration problems

Q153 Briefly explain or provide an example for how your concentration problems impact your daily life (examples: increased difficulty in crowded or loud places, easily distracted during less interesting tasks)

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Display This Question:
If Select which of the following symptoms you are experiencing post surgery and/or treatment (check... = Problems starting or finishing tasks

Q96 How often do you experience problems starting or finishing tasks?

- ○ Less than once a month
- ○ Once a month
- ○ 2-3 times per month
- ○ Once a week
- ○ 2-3 times per week
- ○ Daily

Display This Question:
If Select which of the following symptoms you are experiencing post surgery and/or treatment (check... = Problems starting or finishing tasks

Q97 On average, how severe are your problems starting or finishing tasks?

- ○ Mild problem, does not interfere with daily activities
- ○ Mild problem, interferes with activities less than 25% of time
- ○ Moderate problem, interferes with activities 25-75% of the time
- ○ Severe problem, interferes with activities more than 75% of the time

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Display This Question:
If Select which of the following symptoms you are experiencing post surgery and/or treatment (check... = Problems starting or finishing tasks

Q155 Briefly explain or provide an example for how your problems starting or finishing tasks impact your daily life (examples: unable to complete household chores independently, cannot get out of bed in the morning)

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Display This Question:
If Select which of the following symptoms you are experiencing post surgery and/or treatment (check... = Difficulty keeping track of multiple activities at one time

Q98 How often do you experience difficulty keeping track of multiple activities at one time?

- ○ Less than once a month
- ○ Once a month
- ○ 2-3 times per month
- ○ Once a week
- ○ 2-3 times per week
- ○ Daily

Display This Question:
If Select which of the following symptoms you are experiencing post surgery and/or treatment (check... = Difficulty keeping track of multiple activities at one time

Q99 On average, how severe is your difficulty keeping track of multiple activities at one time?

- ○ Mild problem, does not interfere with daily activities
- ○ Mild problem, interferes with activities less than 25% of time
- ○ Moderate problem, interferes with activities 25-75% of the time
- ○ Severe problem, interferes with activities more than 75% of the time

Display This Question:
If Select which of the following symptoms you are experiencing post surgery and/or treatment (check... = Difficulty keeping track of multiple activities at one time

Q154 Briefly explain or provide an example for how your difficulty keeping track of multiple activities at one time impacts your daily life (examples: unable to multi-task, no longer able to take care of children or grandchildren)

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Q30 Select which of the following symptoms you are experiencing post surgery and/or treatment (check all that apply):

- ☐ Anxiety
- ☐ Depression
- ☐ Flashbacks
- ☐ Panic attacks
- ☐ Difficulty with relationships
- ☐ Apathy or loss of interest in previously enjoyed activities
- ☐ Irritability/anger/emotional outbursts
- ☐ Mood swings
- ☐ Increased sensitivity to or focus on physical or emotional problems
- ☐ Inappropriate social interactions
- ☐ Lack of recognition of problems (others tell you there is a problem but you don't agree)
- ☐ None of the above.

Display This Question:
If Select which of the following symptoms you are experiencing post surgery and/or treatment (check... = Anxiety

Q100 How often do you experience anxiety?

- ○ Less than once a month
- ○ Once a month
- ○ 2-3 times per month
- ○ Once a week
- ○ 2-3 times per week
- ○ Daily

Display This Question:
If Select which of the following symptoms you are experiencing post surgery and/or treatment (check... = Anxiety

Q101 On average, how severe is your anxiety?

- ○ Mild problem, does not interfere with daily activities
- ○ Mild problem, interferes with activities less than 25% of time
- ○ Moderate problem, interferes with activities 25-75% of the time
- ○ Severe problem, interferes with activities more than 75% of the time

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Display This Question:
If Select which of the following symptoms you are experiencing post surgery and/or treatment (check... = Anxiety

Q156 Briefly explain or provide an example for how your anxiety impacts your daily life (examples: lack of desire to leave the house, constant worry about health and safety)

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Display This Question:
If Select which of the following symptoms you are experiencing post surgery and/or treatment (check... = Depression

Q102 How often do you experience depression?

- ○ Less than once a month
- ○ Once a month
- ○ 2-3 times per month
- ○ Once a week
- ○ 2-3 times per week
- ○ Daily

Display This Question:
If Select which of the following symptoms you are experiencing post surgery and/or treatment (check... = Depression

Q103 On average, how severe is your depression?

- ○ Mild problem, does not interfere with daily activities
- ○ Mild problem, interferes with activities less than 25% of time
- ○ Moderate problem, interferes with activities 25-75% of the time
- ○ Severe problem, interferes with activities more than 75% of the time

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Display This Question:
If Select which of the following symptoms you are experiencing post surgery and/or treatment (check... = Depression

Q157 Briefly explain or provide an example for how your depression impacts your daily life (examples: lack of desire to leave the house, loss of previously close relationships)

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Display This Question:
If Select which of the following symptoms you are experiencing post surgery and/or treatment (check... = Flashbacks

Q104 How often do you experience flashbacks?

- ○ Less than once a month
- ○ Once a month
- ○ 2-3 times per month
- ○ Once a week
- ○ 2-3 times per week
- ○ Daily

Display This Question:
If Select which of the following symptoms you are experiencing post surgery and/or treatment (check... = Flashbacks

Q105 On average, how severe are your flashbacks?

- ○ Mild problem, does not interfere with daily activities
- ○ Mild problem, interferes with activities less than 25% of time
- ○ Moderate problem, interferes with activities 25-75% of the time
- ○ Severe problem, interferes with activities more than 75% of the time

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Display This Question:
If Select which of the following symptoms you are experiencing post surgery and/or treatment (check... = Flashbacks

Q158 Briefly explain or provide an example for how your flashbacks impact your daily life (examples: lack of desire to leave the house, loss of previously close friends)

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Display This Question:
If Select which of the following symptoms you are experiencing post surgery and/or treatment (check... = Panic attacks

Q106 How often do you experience panic attacks?

- ○ Less than once a month
- ○ Once a month
- ○ 2-3 times per month
- ○ Once a week
- ○ 2-3 times per week
- ○ Daily

Display This Question:
If Select which of the following symptoms you are experiencing post surgery and/or treatment (check... = Panic attacks

Q107 On average, how severe are your panic attacks?

- ○ Mild problem, does not interfere with daily activities
- ○ Mild problem, interferes with activities less than 25% of time
- ○ Moderate problem, interferes with activities 25-75% of the time
- ○ Severe problem, interferes with activities more than 75% of the time

Display This Question:
If Select which of the following symptoms you are experiencing post surgery and/or treatment (check... = Panic attacks

Q159 Briefly explain or provide an example for how your panic attacks impact your daily life (examples: increased fear of being left alone, unable to complete normal routine tasks)

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Display This Question:
If Select which of the following symptoms you are experiencing post surgery and/or treatment (check... = Difficulty with relationships

Q108 How often do you experience difficulty with relationships?

- ○ Less than once a month
- ○ Once a month
- ○ 2-3 times per month
- ○ Once a week
- ○ 2-3 times per week
- ○ Daily

Display This Question:
If Select which of the following symptoms you are experiencing post surgery and/or treatment (check... = Difficulty with relationships

Q109 On average, how severe are your difficulties with relationships?

- ○ Mild problem, does not interfere with daily activities
- ○ Mild problem, interferes with activities less than 25% of time
- ○ Moderate problem, interferes with activities 25-75% of the time
- ○ Severe problem, interferes with activities more than 75% of the time

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Display This Question:
If Select which of the following symptoms you are experiencing post surgery and/or treatment (check... = Difficulty with relationships

Q160 Briefly explain or provide an example for how your difficulty with relationships impacts your daily life (examples: problems maintaining routine family functioning, loss of close friends)

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Display This Question:
If Select which of the following symptoms you are experiencing post surgery and/or treatment (check... = Apathy or loss of interest in previously enjoyed activities

Q110 How often do you experience apathy or loss of interest in previously enjoyed activities?

- ○ Less than once a month
- ○ Once a month
- ○ 2-3 times per month
- ○ Once a week
- ○ 2-3 times per week
- ○ Daily

Display This Question:
If Select which of the following symptoms you are experiencing post surgery and/or treatment (check... = Apathy or loss of interest in previously enjoyed activities

Q112 On average, how severe is your apathy or loss of interest in previously enjoyed activities?

- ○ Mild problem, does not interfere with daily activities
- ○ Mild problem, interferes with activities less than 25% of time
- ○ Moderate problem, interferes with activities 25-75% of the time
- ○ Severe problem, interferes with activities more than 75% of the time

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Display This Question:
If Select which of the following symptoms you are experiencing post surgery and/or treatment (check... = Apathy or loss of interest in previously enjoyed activities

Q162 Briefly explain or provide an example for how your apathy or loss in previously enjoyed activities impacts your daily life (examples: social isolation or withdrawal from friends, no longer spending time independently on hobbies)

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Display This Question:
If Select which of the following symptoms you are experiencing post surgery and/or treatment (check... = Irritability/anger/emotional outbursts

Q113 How often do you experience irritability, anger, or emotional outbursts?

- ○ Less than once a month
- ○ Once a month
- ○ 2-3 times per month
- ○ Once a week
- ○ 2-3 times per week
- ○ Daily

Display This Question:
If Select which of the following symptoms you are experiencing post surgery and/or treatment (check... = Irritability/anger/emotional outbursts

Q114 On average, how severe is your irritability, anger, or emotional outbursts?

- ○ Mild problem, does not interfere with daily activities
- ○ Mild problem, interferes with activities less than 25% of time
- ○ Moderate problem, interferes with activities 25-75% of the time
- ○ Severe problem, interferes with activities more than 75% of the time

Display This Question:
If Select which of the following symptoms you are experiencing post surgery and/or treatment (check... = Irritability/anger/emotional outbursts

Q163 Briefly explain or provide an example for how your irritability/anger/emotional outbursts impact your daily life (examples: increased arguments with spouse or caregiver, noticeable withdrawal from children or grandchildren)

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Display This Question:
If Select which of the following symptoms you are experiencing post surgery and/or treatment (check... = Mood swings

Q115 How often do you experience mood swings?

- ○ Less than once a month
- ○ Once a month
- ○ 2-3 times per month
- ○ Once a week
- ○ 2-3 times per week
- ○ Daily

Display This Question:
If Select which of the following symptoms you are experiencing post surgery and/or treatment (check... = Mood swings

Q116 On average, how severe are your mood swings?

- ○ Mild problem, does not interfere with daily activities
- ○ Mild problem, interferes with activities less than 25% of time
- ○ Moderate problem, interferes with activities 25-75% of the time
- ○ Severe problem, interferes with activities more than 75% of the time

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Display This Question:
If Select which of the following symptoms you are experiencing post surgery and/or treatment (check... = Mood swings

Q164 Briefly explain or provide an example for how your mood swings impact your daily life (examples: hinder ability to complete socially appropriate tasks, put stress on close relationships)

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Display This Question:
If Select which of the following symptoms you are experiencing post surgery and/or treatment (check... = Increased sensitivity to or focus on physical or emotional problems

Q117 How often do you experience increased sensitivity to or focus on physical or emotional problems?

- ○ Less than once a month
- ○ Once a month
- ○ 2-3 times per month
- ○ Once a week
- ○ 2-3 times per week
- ○ Daily

Display This Question:
If Select which of the following symptoms you are experiencing post surgery and/or treatment (check... = Increased sensitivity to or focus on physical or emotional problems

Q118 On average, how severe is your increased sensitivity to or focus on physical/emotional problems?

- ○ Mild problem, does not interfere with daily activities
- ○ Mild problem, interferes with activities less than 25% of time
- ○ Moderate problem, interferes with activities 25-75% of the time
- ○ Severe problem, interferes with activities more than 75% of the time

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Display This Question:
If Select which of the following symptoms you are experiencing post surgery and/or treatment (check... = Increased sensitivity to or focus on physical or emotional problems

Q165 Briefly explain or provide an example for how your increased sensitivity to or focus on physical/emotional problems impacts your daily life (examples: constant worry and fear about health, unable to focus on future)

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Display This Question:
If Select which of the following symptoms you are experiencing post surgery and/or treatment (check... = Inappropriate social interactions

Q119 How often do you experience inappropriate social interactions?

- ○ Less than once a month
- ○ Once a month
- ○ 2-3 times per month
- ○ Once a week
- ○ 2-3 times per week
- ○ Daily

Display This Question:
If Select which of the following symptoms you are experiencing post surgery and/or treatment (check... = Inappropriate social interactions

Q120 On average, how severe are your inappropriate social interaction symptoms?

- ○ Mild problem, does not interfere with daily activities
- ○ Mild problem, interferes with activities less than 25% of time
- ○ Moderate problem, interferes with activities 25-75% of the time
- ○ Severe problem, interferes with activities more than 75% of the time

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Display This Question:
If Select which of the following symptoms you are experiencing post surgery and/or treatment (check... = Inappropriate social interactions

Q166 Briefly explain or provide an example for how your inappropriate social interactions impact your daily life (examples: often interrupting during conversations, receiving negative feedback from others about your actions or words)

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Display This Question:
If Select which of the following symptoms you are experiencing post surgery and/or treatment (check... = Lack of recognition of problems (others tell you there is a problem but you don't agree)

Q121 How often do you experience lack of problem recognition (others tell you there is a problem but you don't agree with them)?

- ○ Less than once a month
- ○ Once a month
- ○ 2-3 times per month
- ○ Once a week
- ○ 2-3 times per week
- ○ Daily

Display This Question:
If Select which of the following symptoms you are experiencing post surgery and/or treatment (check... = Lack of recognition of problems (others tell you there is a problem but you don't agree)

Q122 On average, how severe is your lack of recognition of problems (others tell you there is a problem but you don't agree)?

- ○ Mild problem, does not interfere with daily activities
- ○ Mild problem, interferes with activities less than 25% of time
- ○ Moderate problem, interferes with activities 25-75% of the time
- ○ Severe problem, interferes with activities more than 75% of the time

Display This Question:
If Select which of the following symptoms you are experiencing post surgery and/or treatment (check... = Lack of recognition of problems (others tell you there is a problem but you don't agree)

Q167 Briefly explain or provide an example for how your lack of recognition of problems impacts your daily life (examples: spouse or caregiver becomes frustrated for continually saying the same thing to you, you become frustrated when others don't let you complete tasks independently)

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