

Caring for Caregivers: Exploring Beneficial Intervention Features for Caregivers of
Traumatic Brain Injuries

by

Brittany Tate

December 2022

Presented to the

Division of Science, Information Arts, and Technologies

University of Baltimore

In Partial Fulfillment

of the Requirements for the Degree of

Master of Science

Approved by: _____

Bridget Blodgett, Thesis Advisor

[Greg Walsh, Committee Member]

Abstract

52% of Traumatic Brain Injury recipients suffer from extended effects of these injuries that affect not only cognitive, but emotional and behavioral well-being, for years after initial onset. Caregivers of these individuals are often informal, meaning they possess no medical professional background and are not being paid for their assistance. These individuals dedicate significant hours and effort to education and performing care duties, often leading to experiencing instances of significant stress. This study explored the question of what features would be beneficial in an intervention tool for Caregivers of Individuals with Traumatic Brain Injuries. A Traumatic Brain Injury Quality of Life (TBI-QOL) Caregiver Strain - Short Form Questionnaire was administered to participants, followed by a prototyped intervention highlighting three (3) proposed features. Participants were given task-based scenarios to interact with each feature of the prototype, followed by a survey for feedback. Successful task completion was achieved by at least 80% of participants, in each scenario. The Symptom Tracker was cited most often as the most beneficial feature. In terms of what features were most desired that were not currently existing: Suggestions of next actions to take to help the care recipient and a means for communication with medical professionals, tied. The implications of this study are concurrent with literature findings that caregivers desire and would positively receive interventions that assist with informational needs, record organization, and give them supportive tools to perform their duties more autonomously. These findings have implications for creating new interventions both within Medical Institutions and Health and Wellness focused companies. This proposed intervention has potential to impact and integrate with environments such as medical record systems, discharge instructional material, and web and mobile applications.

Acknowledgments

First and foremost, I'd like to thank my parents, who have encouraged and supported me endlessly in any endeavor I took on, any challenge I faced, and any dream I dreamed. Without their unfailing love, guidance, and encouragement I would have never achieved all that I have thus far, nor would I be as confident in where I am going in the future.

I would also like to thank my family, friends, and faculty who have also supported me throughout not only this thesis, but my entire graduate school experience. This has been one of the most challenging periods of my life and every time it seemed utterly impossible to make it through to the finish line, I was supported, loved, and inspired in so many ways – both big and small – but always greatly meaningful.

I dedicate this work to not only them, but also to myself; as my reminder that my dreams may be big, but they are never too big to not become reality.

Table of Contents

Table of Contents	v
List of Tables	vii
List of Figures	viii
Introduction	9
Literature Review	11
Caregiver Stress	11
Healthcare Information Seeking Behaviors	13
Health Information Literacy & Quality.....	14
Mobile Health Technology.....	15
Medical Imagery	17
Relevant Findings.....	17
Methodology.....	18
Research Question.....	18
Survey	18
Design	19
Prototype	19
Data	21
Data Collection.....	21
Reliability and Validity	21
Results	23
Task Performance	24
Post-Test	33

Conclusion.....	35
Implications.....	36
References	38
Appendix A: Traumatic Brain Injury Quality of Life (TBI-QOL) Caregiver Strain - Short	
Form Questionnaire.....	42

List of Tables

Table 1. Neuro-QOL Caregiver v2.0 TBI-Care QOL Caregiver Strain – Short Form 6a Participant T-Scores 23

Table 2. Task Success Rates and Times.....33

List of Figures

Figure 1. Learning Center Screen.....	25
Figure 2. Learning Center Screen with Heatmap.....	26
Figure 3. App Home Page Screen.....	28
Figure 4. App Home Page Screen with Heatmap.....	29
Figure 5. Symptom Track Screen with Heatmap.....	31

Introduction

The Centers for Disease Control and Prevention (CDC) recorded approximately 223,135 traumatic brain injuries (TBI) in 2019 ("TBI Data", 2022). These injuries and disabilities are not just temporary instances, with a long-term study showing that approximately 52% of those with moderate or severe traumatic brain injuries had similar or worsening outcomes in the 5 years following injury (Centers for Disease Control, 2022). Only 42% of patients receive educational materials at discharge and only 44% follow-up with another health care provider after discharge ("Brain Injury Awareness", 2022). With over half of patients not recovering from traumatic brain injuries, and less than half receiving educational material, there is a need for a source of information for education and guidance on the long-term health journey. Lack of education on proper care methods can exacerbate existing patient health issues as well as have a detrimental effect on their personal and professional lives.

Study and research in prevention, diagnosis, and treatment are continually expanding fields. The biggest advancements and publicity have come from initiatives such NFL Concussion Protocols and state of the art diagnostic technology, like Rapid Blood Tests, which measure the number of specific proteins in the blood, that are released when a brain injury occurs ("Finally, A Blood Test for Traumatic Brain Injury", 2021). Prior methods of TBI diagnosis include neurological tasks and CT scans which can take varying lengths of time to perform and be evaluated, not including the wait time to have these tests administered.

However, for those who may be removed from a medical or professional athletics background, the journey to recovery may be more difficult, as they may rely on themselves or caregivers who cannot fully dedicate their time and energy solely to this intensive recovery effort. In a review of public health data from 2015 to 2017 performed by the CDC of caregivers 45 years and older, it was reported that "One in three caregivers (31.3%), provided 20 or more hours per week of care and over half (53.8%) have given care or assistance for 24 months or more" ("Caregiving for Family and Friends — A Public Health Issue", 2022).

Studies into the effects of traumatic brain injuries have transcended delving into solely the physical effects of the injured party, to include social and emotional effects on the

caregivers of these patients as well. There is an increasing awareness in research that this population, particularly those who are serving as caregivers, are directly affected by TBIs.

The caregivers who support TBI patients through the day-to-day part of their recovery are often informal caregivers; meaning they receive no pay for their work and dedication, and often no professional experience in a medical background ("Definitions - Family Caregiver Alliance", 2022). Informal caregivers present a unique set of challenges faced, and methodologies used in relation to caring for a TBI patient, when compared to professional caregivers with medical backgrounds. Informal TBI caregivers have gained some research attention, but it is still evident, based on available literature, that this area requires further research.

This study will begin with a review of the relevant literature and then outline the methodology used, before delving into analysis of the data and the conclusions made from the findings.

Literature Review

Caregiver Stress

Starting from the moment of injury, a caregiver is tasked with navigating immediate and continuing emergent situations and environments while the patient undergoes initial intake, evaluation, and treatment. Once the patient is ready for discharge, a caregiver enters a new environment where they need to be prepared to shoulder the care of the patient in an informal setting. Tests administered to informal caregivers for TBI patients experiencing Post-Traumatic Amnesia (PTAS) evaluated the hours per week spent on completing a myriad of caregiver duties (Lieshout, Oates, Baker, Unsworth, Cameron, Schmidt, and Lannin., 2020). 20 hours a week were spent on shopping, organizing help, adaptations, and additional aid, 19 hours a week preparing meals, 18 hours a week cleaning, 17 hours a week giving social support, and 15 hours a week providing personal care (Lieshout et al., 2020). The cumulative number of hours spent on these caregiving tasks totals 89 hours (about 3 and a half days). For reference, there are 168 hours in a week, leaving only 79 hours total for the informal caregiver's own personal responsibilities, such as work, self-care, and chores for their own household. It can be surmised that some of these tasks may be performed in tandem, but even at the lower estimations of time spent per week on duties, the dedicated hours to caregiving nears, if not equates, taking on and completing maximum hours of a part-time job. This considerable time commitment does not include time to learn about and gain skills to deal with not only the physical and environmental obstacles, but also the emotional and behavioral changes in the patient.

The Neuropsychiatric Inventory Questionnaire (NPI-Q) “[...] assesses 12 symptoms of behavioral disturbances in patients [...]” (Devi, Khan, Rana, Dhandapani, M, Ghai, Gopichandran, and Dhandapani, S., 2020). Researchers found the most prevalent symptoms of TBI patients was agitation (40%), appetite disturbances (32%), depression (24%), anxiety (18%), and irritability (16%). A significant positive correlation was found between the TBI patient’s NPI-1 score and the caregiver burden score, indicating the increased prevalence of symptoms of behavioral disturbances increased the caregiver burden score (Devi et al., 2020). In addition, lower scores of cognition in TBI patients were significantly negatively correlated with a caregiver’s burden scores (Devi et al., 2020). The decreased presence of cognitive functioning abilities of TBI patients increases the stress experienced by caregivers (Devi et al., 2020). Lieshout et al.

(2020)'s study did not discover significant feelings of unpreparedness for performing caregiving duties, however, caregivers were least prepared to find information and help through the healthcare system or manage the stress that comes from these duties.

Beyond behavioral and cognitive changes, changes to motor skills and new environmental considerations must also be made and provide yet another obstacle for caregivers to determine how to overcome. Depth perception, coordination, balance, and changes in muscular tone are often manifestations of TBI impacts on mobility (Oyesanya, Aruselvam, Thompson, Norelli, and Seel, 2021). Both indoor and outdoor spaces must be seen with a new lens and the environment adjusted to re-arrange the home or search for accessibility features when outside of the home.

Even with a dedicated intervention method, post-discharge plans are a source of frustration, despite these processes often containing explicit procedural guidelines. Medication management comes with dosage and frequency requirements printed right on the label, as well as often, other material explaining the instructions and interactions in greater detail. Still, unsuccessful, and unsafe medication intake has been reported by patients and caregivers alike, citing reasons such: deliberate resistance, physical discomfort taking the medication, or, as to be expected with TBIs, difficulty remembering which medication and amounts to take at what time (Oyesanya et al., 2021). While caregivers are thought to be the de-facto appointee of medication management, it is pertinent to remain aware that caregivers may not live full time, or at all, with the patients; additionally, they may be balancing their own household and family duties and work responsibilities. A caregiver from Oyesanya et. al., (2021) noted how their recipient missed medication "...multiple times every week, sometimes". Considered in conjunction with the personal duties and responsibilities of caregivers, a contextual image can be formed of how this regimented step of care can easily fall apart and go from being a point of decision-making relief to another stressor for a caregiver.

With an influx of new responsibilities and dynamic, critical information, it is important to understand not only what causes stressors in caregivers, but how those stresses manifest physiologically. A caregiver experiencing diminished health and capabilities due to stress will not be able to provide health care to their fullest capacity to their care recipients. Schwabe and Wolf (2010) introduced novel words to experimental test participants with instructions to try to

remember them. The experimental group of participants were subjected to stress during the learning period; the presence of stress was verified through salivary cortisol levels, blood pressure, and a subjective evaluation measurement (Schwabe and Wolfe, 2021). Recognition and recall abilities of the words were evaluated after a 24-hour period (Schwabe and Wolfe, 2021). Irrespective of the level of contextual relevance or emotional connotations of the words provided, those who were subjected to stress at the time of learning performed worse on both recognition and recall (Schwabe and Wolfe, 2010).

Stress is one detractor from learning relevant caregiving material; however, it is also of importance to evaluate the availability and comprehensiveness of material itself and the barriers to successful caregiving that exist there.

Healthcare Information Seeking Behaviors

It is valuable to understand a caregiver's motivations to reach a subjectively determined level of competency, to contextualize the examination of how caregivers engage in healthcare information seeking behaviors.

Self-Determination theory is a psychological theory regarding the psychological needs and growth tendencies of the individual (Cherry, 2021). The theory postulates that there is an innate desire for growth that drives an individual's behavior. To achieve this growth, people need to experience 3 things: Connection, Competence, Autonomy. A sense of belonging relates to Connection / Relatedness. Gaining a strong proficiency in related skills is Competence. Being able to "...take direct action that will result in real change..." is Autonomy (Cherry, 2021). It is feasible to deduce that that an individual is motivated, at least in part, by the same factors of this theory. The desire to become knowledgeable (Competence) and perform quality care outside of medical settings (Autonomy) is the basis of a caregiver position. The definition of an informal caregiver is one that is not medically trained or monetarily compensated, and thus has a more personal relationship – (Connectedness) to the care recipient.

A conceptual study sought to predict health information seeking behaviors (HISBS) through three sources of information: the internet, doctors, and family members (Yang, Chen, and Wendorf, 2017). The study concluded that the perception of trust of a source was positively associated with the corresponding HISBS (Yang et. al., 2017). The level of support perceived by a

caregiver from family members had a positive correlation to the amount of trust those caregivers had in the information provided and the behaviors used to gain that information (Yang et. al., 2017). In turn, that level of trust positively predicted the behaviors of individuals to seek information from not only family, but the internet and doctors as well (Yang et. al., 2017).

Health Information Literacy & Quality

Regardless of how a caregiver comes across health information, it becomes irrelevant if the information given is not relevant, current, or understandable. To pass Web Content Accessibility Guidelines (WCAG), reading material must “[...] not require reading ability more advanced than the lower secondary education level”, which approximates to the 8th grade on a U.S. education scale (W3C, n.d. a). An evaluation of search engine results for on traumatic brain injury health information sources was conducted in 2021 on 202 websites and showed that majority of these online sources “required 9–12 years of education ...according to Flesch–Kincaid Grade Level and categorized as “Difficult” on Flesch Reading Ease Score” (Manivannan et. al, 2021). 54% of adults in the US, as of 2022, read at or below the sixth-grade level (Literacy Statistics, 2022). The JAMA Benchmark, is regarded as a reliable indicator of credibility, that inspects “[...] (authorship, attribution, disclosure, and currency) of an online information source”; the DISCERN system scores information on criterion "... including relevancy, and the quality of patient information available. It is widely recognized as a good measure of the quality of information provided in both a health care professional and patient-centric manner” (Manivannan et. al, 2021). Most sources scored 3-4 on the JAMA scale which runs 0-4, showing that the sources provided were current and credible sources. However, on the DISCERN scale, most sites were scored as poor quality (Manivannan et. al, 2021). This recent study highlights the phenomena that despite available information on TBIs being current, credible, and available online, it is not meeting the need of being comprehensive information or accessible.

Further studies support this point as Hahn et. al (2021) studied caregiver health literacy specifically for TBIs and their self-evaluated stress. Lower health literacy caregivers reported more feelings of stress, poor physical health, less connection to the care recipient (Hahn et. al, 2021).

Mobile Health Technology

Discussing the efficacy of mobile technology as a tool for caregivers is a crucial topic to discuss, before designing a new intervention. Hart et al. (2018) concluded from qualitative analysis of TBI literature that discovered an increasing trend in using family members and caregivers in the development and testing of mobile health (miHealth) technologies for TBIs. In addition, the analysis added noted that mhealth technology has been noted to increase reported scores of self-efficacy and investment in rehabilitation. It is cautioned that when mhealth applications are used for patients with long term persistent symptoms, it should be used in conjunction with other psychotherapeutic treatments. Considerations about keeping the information provided up to date and "...helping the patient [or caregiver] separate fact from speculation" should be priority considerations (Hart et al., 2018). Literature also noted the potential benefits of web-based education, as opposed to traditional paper materials, and that a mhealth intervention is not only cost effective but can help provide the worsening of symptoms and identify emergent situations early on that require medical intervention (Hart et al., 2018). Oyesanya et al., (2021) reported "[...] some family caregivers were unsure if the behaviors they observed were due to a true mental health problem or if it was a common occurrence in the TBI recovery process." This unearths a question of "what do potential caregivers, want to know about TBIs?"

Both TBI recipients and their caregivers have mentioned the realities, difficulties and concerns about areas including but not limited to, safety concerns, mobility, sleep / sleepiness, physical activity, cognitive changes and socialization and the methods they use, with varying degrees of success, to address or compensate for their experiences (Oyesanya et al., 2021). Looking into the concerns and both the successful and unsuccessful methodologies of treatment by both caregivers and care recipients, can provide insight into the categories of main concerns an application should address and what types of information the app should provide (i.e., how to mitigate a particular symptom).

Zulman, Piette, Jenchura, Asch, and Rosland (2013) identified barriers to adapting technology in caregiving of adults with chronic conditions. For those using technology for caregiving, the most cited purpose of use was to seek out online health information at 70.6% (Zulman et al., 2013). Accessing records and results, performing medication refills, and

contacting providers were cited less than 15% of the time by users (Zulman et al., 2013). At the time of this study, of Zulman et al.'s (2013) 316 participants, only 34.5% percent stated they use information technology in their out-of-home caregiving, which begets the question of what is the technology not providing, that caregivers would need?

Of those that did not use technology, a majority expressed a potential willingness to use it if the technology helped the recipient. The two biggest use cases identified that would engage nonparticipants were: finding health information (67.8%) and tracking personal health information (53.6%) (Zulman et al., 2013). It can be concluded that having technology to provide additional health information in a home setting is of higher importance to a caregiver than using technology to perform duties that can be accomplished through other means.

Maintaining and having updated information was seen by informal caregivers as important for the reasoning that any outdated information poses a safety risk when communicating and making medical decisions and therefore was the most important and frequently updated category, versus legal or financial (Holden, Karanam, Cavalcanti, Parmar, Kodthala, Fowler, and Bateman, 2018). But "Interestingly, formal caregivers believed household and diagnosis related information was updated more frequently than informal caregivers actually reported" (Holden et al., 2018).

For established mobile technology, there are recommendations and features that have been studied to improve the overall performance and impact of mobile health technologies.

Holden et al. (2018) ascertain that a Health Information Management tool should be capable of addressing "1) information acquisition and integration across multiple sources and records; 2) information maintenance, updating, and use over time; and 3) information sharing and communication..." with the core features being communication and scheduling. Gathering health information from various sources was characterized by caregivers as "[...] demanding and usually performed incrementally over time", thus the authors recommend that "Caregivers should be able to regularly receive and document into the system any updates or changes in information" (Holden et al., 2018). A tool for collecting and organizing information, such as a calendar, is useful but should be capable of integrating the care recipient's medical events and the caregiver's personal events; while they are separate categories of information, there is an interdependence (Holden et al., 2018). Information should be able to be gathered, synthesized,

and easily sharable to other needed parties and be able to be accessible on various digital platforms, if a digital intervention is used (Holden et al., 2018).

Medical Imagery

Phelps, Wellings, Griffiths, Hutchinson, and Kunar (2017) evaluated the efficacy of medical images in aiding understanding of patients with diagnosis in a two-part experimental study. Participants of this study received a hypothetical diagnosis of an illness accompanied by either: A) 2-D images, B.) 3-D images, or C.) no images. After the diagnosis, each participant self-rated via a Likert Scale their feelings on the diagnosis, the trust in the medical information provided, and – if an image was provided to them, additional questions of if the imagery was helpful (Phelps et al., 2017). Use of medical images was found to increase participant’s overall feelings of trust in the diagnosis and feelings of understanding, with 3D images providing a slightly more prevalence of those feelings over 2D (Phelps et al., 2017).

Relevant Findings

After reviewing the literature, the following findings remain the most relevant to the study performed. The first relevant overall finding is that caregivers of traumatic brain injury patients are experiencing stress. Furthermore, this stress often stems from the realms of performing caregiving tasks, as well as performing work to obtain information about the injury and subsequent care. The next relevant finding is that caregivers are engaging in health information seeking behaviors. Caregivers have a desire to feel prepared to successfully perform their duties and use both personal and professional sources to uncover information they deem relevant and helpful. This information collection behavior is not confined to occurring only in a medical environment, such as a doctor’s office. The third relevant finding is that there is a continued lack of resources currently in the market that are meeting the multi-faceted needs and desires of caregivers. Sources often provide some combination of being relevant, comprehensive, recent, or understandable, but rarely, if ever, possess all those qualities. To a much lesser extent these sources are gathered in a single place.

Methodology

The purpose of this research aimed to gather information about perceived stressors caregivers of traumatic brain injuries and test the effects of a proposed application focused on educating informal caregivers on what different symptoms and behaviors their care recipient may experience, the causes to those, and any available tips on how they can attempt to address and mitigate those issues. The intervention also provided assistive tools to help learn medical terminology and record symptoms of the patient. The subject focused on the long-term phase of recovery. This phase was chosen because patients and caregivers may experience less understanding regarding what may occur beyond official concussion clearance and find fewer relevant resources on how symptoms may differently manifest continually over extended periods of time.

Research Question

This research sought to address the following question:

What features would be beneficial in an intervention tool for Caregivers of
Individuals with Traumatic Brain Injuries?

From the literature review it has been highlighted that the need for information motivates caregivers. The resources currently available are not meeting the in designs of current websites and applications, which in turn is leading to increased levels of stress. This question is addressed through a pre-survey measuring caregiver levels of stress, a proposed application containing features designed based on information gleaned about caregiver desires and needs in previous studies, and a post-test questionnaire about the participants 'evaluation of said features.

Survey

The survey questions used in the beginning of the test were taken from the Traumatic Brain Injury Quality of Life (TBI-QOL) Caregiver Strain - Short Form Questionnaire (see Appendix A). The TBI-QOL is a measurement specifically designed to assess the health-related quality-of life (HRQL) of a caregiver working with those with traumatic brain injuries (Carlozzi et al.,

2019a). This measurement has the capability to identify specific issues of caregivers, as well as indicate who may benefit from additional services or resource referrals. The developed questionnaire was created using existing, verified health quality of life measures in conjunction with newly developed questionnaire pools. The TBI-QOL was further tested for tool reliability and validity and found to be successful on both criteria (Carlozzi et al., 2020).

Design

Figma was used to design and prototype the application intervention to be used for testing. As a design and prototyping platform used by large name industries, the Figma program is robust and encompasses all the features needed for the purposes of creating the application intervention for this experiment. The survey and test were created and hosted on Maze.co. This website allowed for recruitment in any suitable location, via a link, thus preventing limitation to participants of the host website, as some other services do. Maze also gave the option for respondents to have anonymity for the test preventing unwanted PII from being collected, and therefore prevented the need to encode that information.

Prototype

In terms of design, the intervention tool was designed according to recommendations and information provided by leading groups in the user experience field such as Nielsen Norman Group, and published authors with dedicated expertise in user interfaces. "Designing with the Mind in Mind" (2014), details the Gestalt principles of visual perception such as proximity, similarity, and common fate, among others to highlight that humans seek and use visual structure to break information into distinct sections. These distinct sections make it easier for people to navigate, absorb, and make meaning of the information being presented to them. To create visual hierarchy, designs should use size, prominence, and content relationships for organizing with labels that clearly identify the content inside (Johnson, 2014). It was also advised the labels used, speak to the content to be found within. Thus, for this application design, the three core features were separated into labeled groups on the homepage, that delve more into higher detailed pages once clicked upon.

To support reading and minimize the disruptions to it, Johnson (2014) recommends use of plain backgrounds, using text to create hierarchy and consistent, plain language in content. Given that one of the purposes of this proposed application is to educate caregivers, and thus will present niche medical and/or technical terminology, one feature of the application provides definition to medical words. To support the characteristics and limitations of long-term memory, short-term memory, and attention span addressed by Johnson (2014) and the usability heuristic recognition over recall, the definitions of these words can be stored in a customizable dictionary, as needed by the user.

Each selected task for the experiment was chosen to highlight the three proposed features of the intervention application. Existing literature suggested that caregivers held more importance in mhealth technology providing additional information resources and tracking, thus each task was framed with the caregiver encountering different scenarios where they would need to find, record, and/or learn information.

Data

Data Collection

Data was collected from ten (10) participants over the period of 8 weeks for collection with a starting date of March 22nd to May 19th, 2022. All participants were required to currently be or have been a caregiver, aged 18 years or older at the time of response and cared for an adult patient with a diagnosed traumatic brain injury. Participants were recruited from general social media postings.

The participants took a pre-test survey on levels of strain experienced as a caregiver to gauge baseline level stress before using the intervention and prime the hypothetical context. For social priming to occur, people's mental perceptions of social events, targets or situations must somehow be stimulated (Molden, 2014). Subjects do not need to be unaware of any primer they experience (although they can be) but do need to be unaware of the intentionality or effect it will play in their subsequent responses (Molden, 2014). Priming effects results by causing related information, thoughts, and feelings to become more mentally accessible; in turn the prime receiver will interpret those recalled thoughts and feelings as their own current feelings on the focused matter at hand and respond based on those thoughts and feelings (Molden, 2014). Creating a prime for this study validated the given responses of participants, as more likely to reflect their thoughts and feelings if this intervention was deployed in a real-life situation, versus a testing environment.

Participants were given a hypothetical scenario of care giving for a college student with a traumatic brain injury. Afterwards, they interacted with the proposed assistive software interface that allows the user to seek educational information regarding traumatic brain injuries, to perform 3 tasks. Each task involved using the software tool to seek out information or other functionality. After the test, participants took a brief semi-structured questionnaire about the design of the software.

Reliability and Validity

In this research reliability and validity have been established through several means. Firstly, the survey questions used in the beginning of the study are derived directly from the TBI-QOL measurement tool developed by Carlozzi et al. (2019a). After this tool was developed, it

Traumatic Brain Injuries: Data

underwent a separate study to verify the validity and reliability, which was confirmed for each measure (Carlozzi et al., 2020). Having participants complete this survey serves not only as a verified measurement tool of caregiver stress experiences, but also serves as a primer for caregivers. Priming the caregiver with questions about their own experiences does not put them into a state of stress but brings thoughts and perspectives of their own experience into forethought, while they explore the hypothetical situation (Molden, 2014).

This study adheres to external validity based on the requirements set forth by Neilson Norman Group, a leading consulting firm of user experience and interface research, design, and other user related topics. External validity is established through the participants recruited being representative of the demographics and user goals in which the study is exploring ("Internal vs. External Validity of UX Studies", 2022). Recruiting caregivers for the specific condition of traumatic brain injuries, to provide insight on a hypothetical application to assist caregivers specifically with TBI related circumstance, meets that external validation criteria. The order of the scale used to rate each question of the survey was alternated to further ensure validity of the responses received. Inter-rater reliability was established with an advisor to be a secondary reviewer of the experiment.

Results

Participants first responded to questions from the “Neuro-QOL Caregiver v2.0 TBI-CareQOL Caregiver Strain – Short Form 6a” (Carlozzi e. al., 2019b). Scores were calculated using The Health Measures Scoring Service (HM-SS); “[...] a software application which automates and facilitates IRT calculated scoring of short form data...” from the Neuro-QOL measurement system (Cella, Gershon, Bass & Rothrock, 2020). TBI-QOL scores should be presented as T-Scores with the standard mean given by Neuro-QOL as a score of 50 with a Standard Deviation of 10. The mean was derived from sampling of a clinical population of individuals in the reference group of caregivers of individuals with TBI. (Interpret & Scores, 2022). The calculated T-scores for participants of this study were as follows:

Table 1

Neuro-QOL Caregiver v2.0 TBI-Care QOL Caregiver Strain – Short Form 6a Participant T-Scores

Participant	T-Scores
Participant 1	49.7
Participant 2	53.4
Participant 3	59.6
Participant 4	50.9
Participant 5	60.4
Participant 6	59.6
Participant 7	54.7
Participant 8	56.6
Participant 9	59.9
Participant 10	58.6

In raw scores, the mean for this study’s sample set was 19 and the median was 19.5. Given the established mean from Neuro-QOL, study participants fell within one standard deviation of the average, barring one participant (who was above one deviation by 0.4). It is of interest to note that all participants who scored within one deviation, all except one, had scores

Traumatic Brain Injuries: Results

above the mean. This would indicate that they are currently experiencing strain. This individual who scored 1 standard deviation above appeared to be experiencing notable amounts of strain at the time of answering. These questions were effective as a primer for the scenario, as the quantitative results show that participants scored where expected in terms of caregiver strain when compared to the mean from a clinical reference population.

Task Performance

Every participant was presented with the same fictional background story and three tasks to provide context in which to search for information on the proposed application.

Task 1. Background: Hanna has been sleeping through most of their classes. You frequently tell them to go to bed earlier, but you often hear them walking around the house in the middle of the night. They are constantly tired and confused during the day and fall asleep at inappropriate times. You want to find out what is causing Hanna's sleepiness.

Task: Please search the application to find more information on this sleeping issue and what you can do at night to help them sleep.

Figure 1. App Home Page Screen



Traumatic Brain Injuries: Results

Figure 2. App Home Page Screen with Heatmap

[← Learning Center](#)

Sleep Problems

After a TBI, you might find that the patient is sleepy throughout the day, but restless at night.

How Common is This Issue?

[Insomnia](#) and [drowsiness](#) typically go together and are both common long-term effects of mild traumatic brain injury.

What Causes This Issue?

The Hypothalamus 

The hypothalamus contains groups of neurons that act as control centers for regulating sleep and wakefulness.

Inside the hypothalamus, is the suprachiasmatic nucleus (SCN) – clusters of thousands of cells that receive information about light exposure directly from the eyes and control your behavioral rhythm.

Some people with damage to the SCN sleep erratically throughout the day because they are not able to match their circadian rhythms with the light-dark cycle.

[Read more...](#)

How To Address This Issue?

Daytime Activities

- Set alarms to wake up at the same time every day.
- Create a daily schedule with meaningful activities.
- Exercise regularly.

Did you know? Those with TBI who exercise regularly report fewer sleep problems.
- Limit daytime naps to no more than 20 minutes.

Nighttime Activities

- Follow a Bedtime Routine
- Try to go to bed at the same time every night.
- Avoid Caffeine, Nicotine, Alcohol, Sugar for 5 hours prior to bed.
- Avoid eating prior to sleep to allow time to digest.

But do not go to bed hungry, as it can wake them from sleep.
- Do not exercise within 2 hours bed time.

But stretching or meditation may help with sleep.
- No eating, reading, or TV in bed.

Natural Remedies

- Herbal tea
- Melatonin

Herbal tea and melatonin can help relax your mind and get your sleep cycle back on track.

Be sure to tell the health care provider if you use or intend to use these, in case of any drug interactions or side-effects.

Medication

Medications are available to help.

If nothing else works, your doctor can prescribe medications that will help you sleep.

However, these should only be used as a last resort because some drugs cause daytime drowsiness and cognitive problems.

Consult your health care provider to see if this is an appropriate choice.

While the feedback of some participants included positives about the helpfulness and intuitiveness of the proposed application, it is important to examine their actions during performance of the test tasks.

For the first task, 8 of the 10 users did not successfully complete the task. Each user who did not complete this task attempted to complete it by utilizing the “Symptom Tracking Feature” when the correct pathway was under “Learning Center”. Even for the 2 participants who were successful, they also first initially attempted to complete the task by accessing “Symptom Tracker”.

The website used to host the test and prototype creates heat maps showing where participants hovered. In this task, all heat maps for all participants were around their initial guess “Symptom Tracker”. 2 participants focused on the iconography before making their selection, 4 focused on the text, and 2 focused on both.

With 100% of users first attempting to solve the problem to finding remedies through the symptom tracker, this could allude to the framework of how caregivers' problem-solve and associate words. Searching for the cause of sleepiness, which had been framed as a symptom of the traumatic brain injury, could have created an association to any reference of “symptoms”.

Further studying word associations may be of benefit to delve further into the mental framework caregivers are creating and utilizing in their information searching and task performing habits.

The second and third tasks were successfully completed with much greater rates of success.

Task 2. Scenario 2: You have found the information on sleepiness you’re looking for, but there’s some medical words you’re not familiar with. You want to find out what these words mean and keep track of them.

Task 2: Discover what “hypothalamus” is and add this word to your personal dictionary.

Figure 3. App Home Page Screen

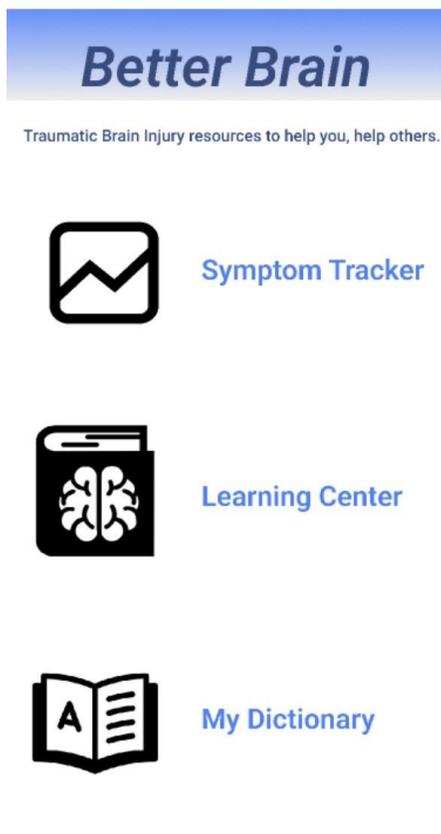
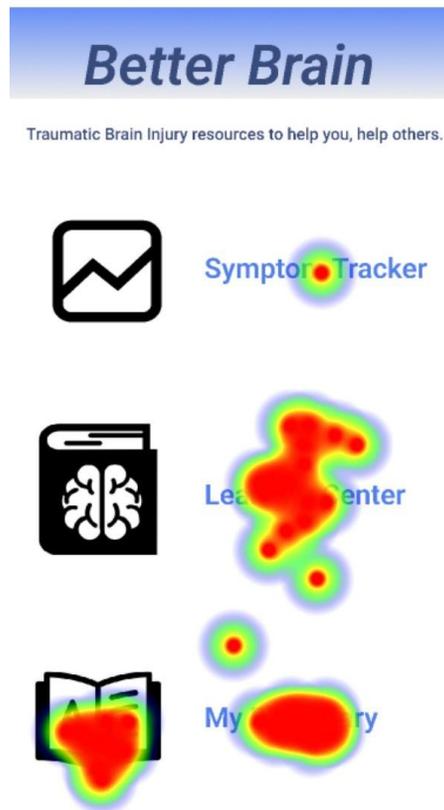


Figure 4. App Home Page Screen with Heatmap



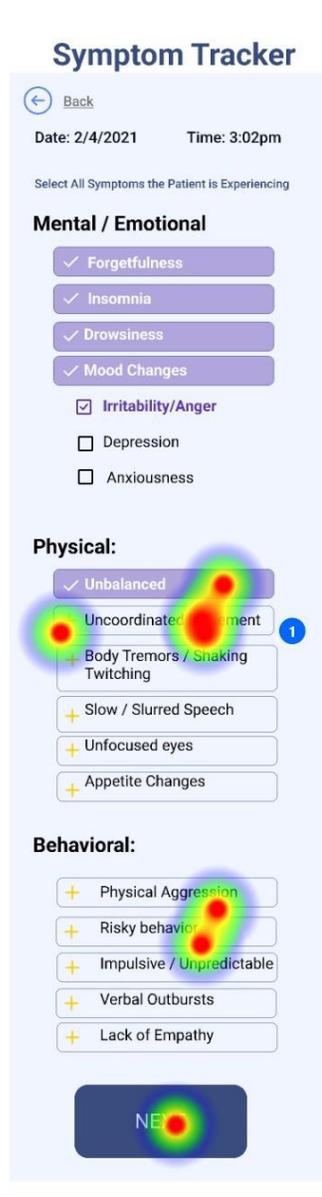
The second task was completed with 80% success by participants. The ability to look interactively and save words to a custom dictionary followed Norman Nielsen's 7th heuristic which calls for flexibility and ease of use, and to allow for customization where possible. In attempting to follow Web Content Accessibility Guidelines (WCAG)'s success criterion of not only using color to convey meaning, the interaction words, were distinguished with a different font weight, style, and color. However, for one of the participants who did not successfully complete task 2, they did initially follow the correct path, but did not take notice of the targeted word, which may be indicative of a need to re-examine the conventions used to call out interactive text ("Understanding Success Criterion 1.4.1: Use of Color", 2022).

Task 3. Scenario 3: Today has been a tough day. First, Hanna forgot their backpack for school and lost their phone. Later, you asked them to wash their dishes, and Hanna suddenly got very angry and started screaming at you about their chores. Finally fell over after standing up from a chair and broke a vase over.

You want to make sure you remember the issues they experienced to talk about later with their Doctor.

Task 3: Use the app to keep track of these new issues.

Figure 5. Symptom Tracker with Heat Map.



The third task was also completed at a success rate of 80%. The additional instructional text and use of a “Call to Action” button may have assisted participants in having a higher success rate than Task 1. These features, respectively, explicitly communicate what the user is

expected to do as well as indicate there are additional steps to complete the task in full. For the participants that failed the task, one individual attempted to complete the task by navigation to the section labeled “Learning Center”. The second individual who failed chose the correct pathway but did not complete the task. This may be due to possible technical errors, but the specific reasoning cannot be determined due to the anonymity of the test administration. S

With such greater success rates for the second and third task, as well as a considerable time difference in the average time it took users to complete the first task versus the latter, it begets the question of what caused these differences. Is there a design flaw in terms of the first feature? Did the order of the tasks and/or time for users to familiarize themselves with the application play a role? Further studies would be needed to delve into those inquiries.

Traumatic Brain Injuries: Results

Table 2

Task Success Rates and Times

	Task 1 Pass/Fail	Task 1 Time (seconds)	Task 2 Pass/Fail	Task 2 Time (seconds)	Task 3 Pass/Fail	Task 3 Time (seconds)
Participant 1	Fail	452.6s	Pass	33.1s	Pass	207.9s
Participant 2	Fail	11.7s	Pass	11.9s	Fail	15.5s
Participant 3	Fail	104.0s	Fail	28.7s	Pass (I)	64.8s
Participant 4	Fail	114.9s	Pass	19.4s	Pass	33.2s
Participant 5	Fail	69.4s	Pass	9.1s	Pass	25.8s
Participant 6	Fail	11.3s	Pass (I)	8.6s	Pass	43.7s
Participant 7	Pass (I)	310.0s	Fail	126.1s	Pass	25.8s
Participant 8	Pass (I)	104.6s	Pass	4.2s	Pass	40.3s
Participant 9	Fail	100.9s	Pass	14.4s	Fail	35.3s
Participant 10	Fail	256.9s	Fail	267.0s	Pass	35.3s

Key: (I) = Indirect

Post-Test

When asked about which features participants found most beneficial, while all options were cited, the most frequent answer was the Symptom Tracker (70%). One participant

commented “Symptom tracker was great for keeping a historical record of occurring issues/symptoms.” The application was noted by multiple users as intuitive or easy to navigate.

In terms of what users would further desire from an application such as this, a couple of users (20%) expressed the desire for suggestions on how to help their patient with the issues being experienced. This was a feature of the application within the Learning Center Feature and noted by another user as a beneficial one; however, based on the feedback, this sub-feature may need to be re-designed in a way to amplify its visual prominence and/or discoverability. Another user expressed wanting guidance based on levels of severity of symptoms. Communication abilities between the caregiver and medical professionals was also requested by 20% of participants.

These suggestions came in the form of providing numbers of hotlines to speak to various medical professionals and being able to take notes and observations and send them to a medical reviewer for comments and to have questions answered. Other suggestions included: diagnoses, suggested medications, medical specialist recommendations, and integrations with smart technology to monitor heart rate, sleep habits, etc. These requests support relevant findings from previous literature, that caregivers hold strong importance in being able to be connected to a variety of resources.

Conclusion

The findings of the study show positive indication that features provided in the intervention, which were designed with the recommendations gleaned from the literature review, are on the correct path towards addressing issues and desires of TBI caregivers. The purpose of the study was to discover which features could potentially be beneficial to caregivers of TBIs. As surmised by the results and previous research, features that allow a caregiver to learn, find actionable items, and keep detailed historical records are all beneficial. Designs of healthcare applications should focus on amalgamating information in a way that can be summarized and tailored to specific, user-prompted inquiries. Especially true for caregiver focused interventions, applications should operate from the basis of “Recall over Recognition. In concurrence with prior studies, when presenting information, closely related visualizations accompany that information to aid understanding. This includes using iconography to aid wayfinding from the homepage. Titles closely related to the information and actions within improve likelihood of successful task completion. Users indicate preference for tracking care-recipients behavior, over periods of time. These records should allow for free-form text input opportunities. For an app focused on helping the facilitation of caregiving, information should be paired with actionable steps and/or further resources that move the user further towards their objective; whether this goal is retaining information, establishing connections, or otherwise.

While this study has shown that there are some strong hints as to what specific features a caregiver is looking for, the important takeaways go beyond that. This study, in a zoomed-out view, has reaffirmed indications that there is an underserved need for technology for caregivers, that is focused on addressing their needs, at least in addition to – if not separate from, their patients. Additionally, this is an intervention that would be welcomed by this population, if intuitive and implemented carefully.

Limitations

One limitation of the study was the sample size used for the study. With ten (10) participants, the findings of this test are not generalizable to the population or act as an indication of larger wide-spread trends. Another study limitation was the study focused on the

Traumatic Brain Injuries: Conclusion

pilot of the design features to be used in this application rather than if the tool itself was useful to alleviate some of stressors experienced by TBI caregivers. Thus, further research would need to be explored into if tools such as this have an influence on self-reported stress or feelings of caregiver efficacy.

Another study limitation is due to the unmoderated, anonymous nature of the test, there can be no exact clarification of why or how failures occurred, only educated guesses. This becomes especially relevant when viewing examples of heatmaps of some participants who did not successfully complete a given task but progressed to the correct area before the failure was marked. Additionally, while participants could take a specific action to give up on the task, any instance of “bouncing” which is leaving the current page through the browser, is marked also as a failure, and results do not distinguish which exact instance occurred, on this platform.

Implications

This study focused on addressing needs related to caregiving duties, but the literature review as well as the TBI-QOL survey of this study has shown that stress is still a consistent feature for this demographic; so, application designers can and should invest efforts in creating tailored applications for not only duties, but wellness as well to address unique challenges and needs.

Caregiver healthcare applications have a unique position in the healthcare market. Currently, explorations into caregiver interventions are limited if existent. Instructional applications for care activities that do exist, are designed with a scope of guiding and interacting with the recipient directly, under the assumption they oversee their care. Re-framing focus to the caregivers provides multiple opportunities for healthcare application expansion. Caregiver applications can, in the future, become a de facto mediator and source of truth between the caregiver and a medical practitioner. This would relieve the documented desire among this population for more support and access to professional advice, as well as the expressed goal of becoming more informed and competent in caregiving duties.

The digitization of medical records and services have grown exponentially in the past decade and have already solved many of the initial hurdles to taking a medical environment to

Traumatic Brain Injuries: Conclusion

various online platforms. Therefore, there is a strong, established environment for innovation and integration of this intervention. Caregiver provided records can synchronize with the Electronic Medical Records of the care recipient. Integration can not only suit medical institutions, but consumer faced entities focused on Wellness.

In future iterations, this application can move beyond providing informational material but take on an instructional role - providing recommended actions, instructional steps, and in-person resources dynamically, based on user inputs and records. The scope of this study was caregivers of Traumatic Brain Injuries; however the foundational framework of this proposed intervention can be translated to suit caregivers of various illnesses and injuries.

Researchers in turn should delve into this seldom-touched avenue of discovering what components are needed to take a well-documented problem and make a robust solution that can be applied in various mediums. This could be in the form of testing interventions or looking into the psychology and behaviors of this demographic in various realistic settings.

It is well known that the better a support system someone has while recovering from illness or injury, the better their chances of a successful recovery. Thus, while research goes forward in its endeavors to learn and combat the complex effects of Traumatic Brain Injuries, we must make sure we are providing dedicated effort, in both design and scientific endeavors, to support those who are caring for others.

References

- Brain Injury Awareness. (2022). <https://www.biausa.org/public-affairs/public-awareness/brain-injury-awareness>
- Caregiving for Family and Friends — A Public Health Issue. (2022). Caregiving for Family and Friends — A Public Health Issue. *CDC*.
<https://www.cdc.gov/aging/caregiving/caregiver-brief.html>
- Carlozzi, N., Kallen, M., Hanks, R., Hahn, E., Brickell, T., & Lange, R. et al. (2019). The TBI-CareQOL Measurement System: Development and Preliminary Validation of Health-Related Quality of Life Measures for Caregivers of Civilians and Service Members/Veterans With Traumatic Brain Injury. *Archives Of Physical Medicine And Rehabilitation*, 100(4), S1-S12. doi: 10.1016/j.apmr.2018.08.175
- Carlozzi, N., Boileau, N., Kallen, M., Nakase-Richardson, R., Hahn, E., & Tulsy, D. et al. (2020). Reliability and validity data to support the clinical utility of the Traumatic Brain Injury Caregiver Quality of Life (TBI-CareQOL). *Rehabilitation Psychology*, 65(4), 323-336. doi: 10.1037/rep0000295
- Carlozzi, N.E., Kallen, M.A., Ianni, P.A., Hahn, E.A., French, L.M., Lange, R.T., Brickell, T.A., Hanks, R., Sander, A.M. (2019). The Development of a New Computer-Adaptive Test to Evaluate Strain in Caregivers of Individuals With TBI: TBI-CareQOL Caregiver Strain. *Archives of Physical Medicine And Rehabilitation*, 100(4s), doi:10.1016/j.apmr.2018.05.033
- Cella, D., Gershon, R., Bass, M., & Rothrock, N. (2020). *Assessment Center Scoring ServiceSM User Manual*. Assessment Center.
https://www.assessmentcenter.net/ac_scoring/service/templates/UserManual.pdf
- Cherry, K. (2021, March 15). Self-Determination Theory and Motivation. *Very Well Mind*. <https://www.verywellmind.com/what-is-self-determination-theory-2795387>
- Family Caregiver Alliance. (2022). Definitions. *Family Caregiver Alliance*.
<https://www.caregiver.org/resource/definitions-0/>
- Devi, Y., Khan, S., Rana, P., Dhandapani, M., Ghai, S., Gopichandran, L., & Dhandapani, S. (2020). Cognitive, Behavioral, and Functional Impairments among Traumatic Brain Injury Survivors: Impact on Caregiver Burden. *Journal of*

Neurosciences in Rural Practice, 11(4), 629–635. <https://doi.org/10.1055/s-0040-1716777>

Finally, A Blood Test for Traumatic Brain Injury. (2021). *Finally, A Blood Test for Traumatic Brain Injury*. Abbott.

<https://www.abbott.com/corpnewsroom/products-and-innovation/finally-a-blood-test-for-traumatic-brain-injury.html#:~:text=Our%20i%2DSTAT%20TBI%20plasma,placed%20in%20the%20test%20cartridge.>

Hart, T., Driver, S., Sander, A., Pappadis, M., Dams-O'Connor, K., Bocage, C., Hinkens, E., Dahdah, M. N., & Cai, X. (2018). Traumatic brain injury education for adult patients and families: a scoping review. *Brain injury*, 32(11), 1295–1306. <https://doi.org/10.1080/02699052.2018.1493226>

Holden, R., Karanam, Y., Cavalcanti, L., Parmar, T., Kodthala, P., Fowler, N., & Bateman, D. (2018). Health information management practices in informal caregiving: An artifacts analysis and implications for IT design. *International Journal Of Medical Informatics*, 120, 31-41. doi: 10.1016/j.ijmedinf.2018.09.017

Budiu, Raluca. (2021). Internal vs. External Validity of UX Studies. *Nielsen Norman Group*. <https://www.nngroup.com/articles/internal-vs-external-validity/>

Neuro-QoL. (2022). Neuro-QoL. *Health Measures*.

<https://www.healthmeasures.net/score-and-interpret/interpret-scores/neuro-qol>

Johnson, J. (2010). *Designing with the Mind in Mind: Simple Guide to Understanding User Interface Design Rules*. Netherlands: Elsevier Science.

Lieshout, K., Oates, J., Baker, A., Unsworth, C. A., Cameron, I. D., Schmidt, J., & Lannin, N. A. (2020). Burden and Preparedness amongst Informal Caregivers of Adults with Moderate to Severe Traumatic Brain Injury. *International Journal of Environmental Research and Public Health*, 17(17), 6386.

<https://doi.org/10.3390/ijerph17176386>

Literacy Statistics. (2022). Literacy Statistics. *Think Impact*.

<https://www.thinkimpact.com/literacy-statistics/#:~:text=Nationwide%2C%20on%20average%2C%2079%25,to%202.2>

[%20trillion%20per%20year.](#)

Manivannan, S., Baskaran, R., Fisher, J., Tasker, I., & Zaben, M. (2021). Current Status of Websites Offering Information to Patients with Traumatic Brain Injury and Caregivers: Time for Reform?. *World Neurosurgery*, 153, e419-e427. doi: 10.1016/j.wneu.2021.06.140

Moderate to Severe Traumatic Brain Injury is a Lifelong Condition. (2022). Moderate to Severe Traumatic Brain Injury is a Lifelong Condition. *Centers for Disease Control*.

https://www.cdc.gov/traumaticbraininjury/pdf/Moderate_to_Severe_TBI_Lifelong-a.pdf

Molden, Daniel. (2014). *Understanding Priming Effects in Social Psychology*. United States: Guilford Publications.

Oyesanya, T. O., Arulsevam, K., Thompson, N., Norelli, J., & Seel, R. T. (2021). Health, wellness, and safety concerns of persons with moderate-to-severe traumatic brain injury and their family caregivers: A qualitative content analysis. *Disability and Rehabilitation*, 43(5), 685–695. <https://doi.org/10.1080/09638288.2019.1638456>

Phelps, E. E., Wellings, R., Griffiths, F., Hutchinson, C., & Kunar, M. (2017). Do medical images aid understanding and recall of medical information? an experimental study comparing the experience of viewing no image, a 2D medical image and a 3D medical image alongside a diagnosis. *Patient Education and Counseling*, 100(6), 1120-1127. doi:10.1016/j.pec.2016.12.034

Schwabe, L., & Wolf, O. (2010). Learning under stress impairs memory formation. *Neurobiology Of Learning And Memory*, 93(2), 183-188. doi: 10.1016/j.nlm.2009.09.009

TBI Data. (2022). TBI Data. *Centers for Disease Control and Prevention*.

<https://www.cdc.gov/traumaticbraininjury/data/index.html>

W3C. (n.d. a) Understanding Success Criterion 1.4.1: Use of Color. W3C.

<https://www.w3.org/WAI/WCAG21/Understanding/use-of-color.html>

Yang, Q., Chen, Y., & Wendorf Muhamad, J. (2016). Social Support, Trust in Health

Information, and Health Information-Seeking Behaviors (HISBs): A Study Using the 2012 Annenberg National Health Communication Survey (ANHCS). In *Health Communication*, 32(9), pp. 1142–1150.

<https://doi.org/10.1080/10410236.2016.1214220>

Zulman, D., Piette, J., Jenchura, E., Asch, S., & Rosland, A. (2013). Facilitating Out-of-Home Caregiving Through Health Information Technology: Survey of Informal Caregivers' Current Practices, Interests, and Perceived Barriers. *Journal Of Medical Internet Research*, 15(7), e123. doi: 10.1080/02699052.2018.1493226

Appendix A: Traumatic Brain Injury Quality of Life (TBI-QOL) Caregiver Strain - Short Form Questionnaire

Neuro-QoL Caregiver v2.0 – TBI-CareQOL Caregiver Strain – Short Form 6a

TBI-CareQOL Caregiver Strain – Short Form 6a

Please respond to each question or statement by marking one box per row.

		Never	Rarely	Sometimes	Usually	Always
TBICQ_S46r	I feel that there are not enough hours in the day to get everything done.	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
TBICQ_S27r	I feel stressed when it comes to providing care for the person with the injury.	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
TBICQ_S43r	I feel that stress makes it difficult to start anything new.	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
TBICQ_S32r	I feel drained by my responsibilities as a caregiver.	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
TBICQ_S24r	I cannot handle any more responsibility when it comes to providing care for the person with the injury.	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
TBICQ_S62r	I feel burdened with the responsibility of caring for the person with the injury.	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5

©2019-2021 David Cella on behalf of the National Institute for Neurological Disorders and Stroke (NINDS). Some content used with permission of the PROMIS Health Organization.
Copyright © December 1, 2016 Noelle E. Carlozzi. All rights reserved.

English
January 18, 2021

Page 1 of 1