# A GROUNDED THEORY STUDY OF THE PROCESS OF ACCESSING INFORMATION ON THE WORLD WIDE WEB BY PEOPLE WITH MILD TRAUMATIC BRAIN INJURY

by

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A DISSERTATION

Presented to the Faculty of

The Graduate College at the University of Nebraska

In Partial Fulfillment of Requirements

For the Degree of Doctor of Philosophy

Major: Human Sciences

Under the Supervision of Professor Roger Bruning

Lincoln, Nebraska

August, 2008

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The purpose of this grounded theory study was to examine the process by which people with Mild Traumatic Brain Injury (MTBI) access information on the web. Recent estimates include amateur sports and recreation injuries, non-hospital clinics and treatment facilities, private and public emergency department visits and admissions, providing approximately 3.8 million MTBIs annually (CDC, 2007c). Equal access has gained attention of policy-makers in both disability rights and web development worlds. Inequity on the web currently exists for all individuals with disabilities, including a growing population of MTBI survivors.

In this study, both the Glaser and Strauss and Strauss and Corbin models of the Grounded Theory research tradition informed data analysis. Nine MTBI survivors were interviewed as they visited websites. Data analysis provided five core themes. MTBI Users: (a) have personal preferences about how content is organized and positioned; (b) finds that colors and images, including those applied to text, impacts attempts to access and comprehend information; (c) chooses to either react or respond to initial interaction;

(d) encounters circumstances that impact success; and (e) is surrounded by circumstances that impact technology or the web. A common theme weaving through four of these five (number 5 excluded) are informed by the MTBI User's emotionality, that is, the role of the User's emotions such as frustration of pleasure to create a pleasing or dissatisfying experience.

The information access process that emerged from this study includes three stages: User Meets the Web, User Assesses Page, and User Persists. In each stage, the User may either continue or exit the page depending on interference of emotionality or of persistence. If the User successfully passes through all three stages, the desired information has been accessed and the User may either exit the web or begin the process again with a new page.

Copyright Page

## Dedication

I wish to dedicate this work to my parents, Helen White and Riley Blodgett, who taught their daughters the value of education. They lovingly encouraged us to reach for our dreams and work diligently for success. Thank you Mom and Dad.

I also dedicate this research to all individuals who are experiencing the effects of Mild Traumatic Brain Injury. We are on a continuing journey and someday may see a light at the end of this dark tunnel.

## Acknowledgements

The completion of this dissertation is the result of extraordinary support and guidance from my advisor, Dr. Roger Bruning. For the past 14 years, he has observed my development, and has advocated for me so I could have extra time to heal from my accident and still complete this project. His friendly encouragement and critical eye have helped me, especially during the final stages. I am deeply grateful to him.

I also wish to thank Dr. Ellen Weissinger who has approved the necessary time to complete this project. She taught my first research course during my Masters program. Her academic career has been an inspiration to me.

Special thanks go to those who served on my committee: Dr. John W. Creswell, Dr. Christy Horn, and Dr. Karen Hux. You have been most patient over the years. My former chair, Dr. John Dirkx, who moved to Michigan State University at the beginning of my doctoral program, contributed immeasurably to my academic experiences.

The participants in this study deserve my gratitude. They each gave of their time to provide rich transcripts for this analysis. I gained an appreciation for the experiences of others with brain injuries.

My family deserves my deepest gratitude and appreciation for years of encouragement and support. My sisters, Blue Olson and Linda Hansen, have lovingly encouraged me through the most difficult times with love and support. My children, who have grown up and had babies of their own during my doctoral program, have unfailingly trusted that I would be done with this dissertation someday. To my friends and family of choice, I thank you with all my heart.

Terry, I thank you for your challenge that I couldn't "make it like you did." I held to this challenge to the completion of years of study. I thank you, Jason. Even though our marriage failed after my accident, you inspired my motivation to complete this project.

Finally, I would like to thank two icons who came into my life during the final writing of this project: Andrea Bocelli and Sarah Brightman. (This may sound silly.) Having closeted myself for what turned out to be years, teaching internationally from my own corner, a friend sent a friendly url and turned me on to YouTube, my new link to the world of online entertainment. *Time to Say Goodbye* was my Christmas wish to my international students in 2007. Late one night as words began to edit themselves, I heard Andrea sing to me, *"like stars across the sky."* Easily distracted, I turned to listen, and he sang: *"We were born to shine…Like stars across the sky we were born to shine."* He was singing to me and to all other people who have survived Mild Traumatic Brain Injury.

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# CHAPTER I

This study is about people with Mild Traumatic Brain Injury (MTBI) who try to engage with the World Wide Web (referred to in this report as the web). Whether injured by a motor vehicle accident, assault, fall, explosive, or playing sports, the survivor is faced with sometimes surprising and unpredictable impairments that challenge day-to-day functioning. Cognitive change can especially bewilder the survivor who is accustomed to "complex, tactical, and strategic tasks that require the assimilation of increasing amounts of new knowledge…and high workloads" (Gorden, cited in Brown, 1998, p. 3).

> Access to information on the web is essential to the MTBI survivor because:
>
> [e]ach year, being digitally connected becomes evermore critical to economic and educational advancement and community participation. Now that a large number of Americans regularly use the Internet to conduct daily activities, people who lack access to these tools are at a growing disadvantage.
>
> (U.S. Dept. of Commerce, Executive Summary, 2000)

Emphasis on technological tools and skills directs attention to the importance of technology access but away, however, from the importance of cognitive skills that serve as the basis of critical thinking, problem solving, and learning. It is these cognitive skills that become compromised in the split second required for a brain injury to occur (Centre for Neuro Skills [CNS], 2006; McCrea, Kelly, Randolph, Cisler, & Berger, 2002).

Considerable effort has been devoted to creating awareness of the importance of accessible web pages for persons with mobility, vision, hearing, and other physical

disabilities. Mention has been made as to the implications for persons with learning and cognitive disabilities, primarily for stroke victims (W3C, 1999, 2006, 2007). Emphasizing the importance of accessible web design, Waddell reported, "The transformation of the Internet from a text-based medium to a robust multi-media environment has created a crisis – a growing digital divide in access for people with disabilities" (1999, p. 4).

## What is MTBI?

Used interchangeably with the term concussion (CDC, 2003, 2006a; Warden, Helmick, Ryan, Sparling, & Stevens, 2007), MTBI presents symptoms that include headache, nausea, vomiting, balance problems, seizures, visual problems, dizziness, irritability, fatigue, light and noise sensitivity, depression, problems with emotional control, problems with concentration, and problems with memory and reasoning, confusion (CDC, 2003; 2006a; 2007b; 2007d; DVBIC, 2007; Parker, 1996; Warden et al., 2007; Zasler, 1998), and many other manifestations that are not readily visible to the outside world. While these symptoms may speak to other illnesses and syndromes, the Centers for Disease Control and Prevention recommends that these be attributed to MTBI when the symptom was not present before an injury or was made worse by an injury (CDC, 2003).

"In recent decades, public health and health care communities have become increasingly aware that the consequences of mild traumatic brain injury (MTBI) may not, in fact, be mild" (CDC, 2003, Preface). Epidemiologic research has identified MTBI as a public health problem of large magnitude, while clinical research has provided evidence that these injuries can cause serious, lasting problems in 10 to 20 percent of all MTBI

survivors (CDC, 2003; Ruff, 2005). MTBI does not leave telltale evidence of physical damage that can be detected by standard CT scans and MRIs, and not all people who seek treatment receive such scans (CDC, 2006a; Dalphonse, 2007; Ruff, 2005). Diffusion tensor imaging that does show damage to white matter caused by MTBI (Bazarian, Zhong et al, 2007; Kraus et al., 2007) is not a routine diagnostic test provided in emergency departments (Bazarian, McClung, Cheng, Flesher, & Schneider, 2005; Borg et al., 2004).

No longer diagnosed by presence or absence of measurable damage to brain structures, MTBI is increasingly understood as

> a complex pathophysiologic process affecting the brain induced by traumatic biomechanical forces secondary to direct or indirect forces to the head…that disrupts the function of the brain….typically associated with normal structural neuroimaging findings (i.e., CT scan, MRI). MTBI results in a constellation of physical, cognitive, emotional and/or sleep-related symptoms and may or may not involve a loss of consciousness (LOC). Duration of symptoms is highly variable and may last from several minutes to days, weeks, months, or even longer in some cases. (CDC, 2007d, p. 2)

The neuropathophysiological process involves "a complex cascade of ionic, metabolic and physiologic events. Clinical signs and symptoms of MTBI such as poor memory, speed of processing, fatigue, and dizziness result from this underlying neurometabolic cascade" (CDC, 2007d, p. 3).

## What are the Numbers?

Statistics point to a profound and devastating health crisis that just begins to illuminate the personal and economic devastation that is MTBI today (CDC, 2003). To illustrate urgency, most reports on brain injury include a lengthy list of numbers and causes, a dry representation of real people. Recent focus on MTBI as a major public health problem has encouraged research to bring to light the extent of the problem. Table 1 demonstrates the impact of MTBI on health in the United States compared with other diseases that receive a great deal of public attention.

*Table 1. Public Health Problems*

| Health Issue | Annual Incidence | Source |
|---|---|---|
| MTBI (sports & recreation) | 3,800,000 (2004) | CDC (2007c) |
| MTBI (hospital & ER) | 1,800,000 (2004) | WHO (2004) |
| TBI (hospital & ER) | 1,400,000 (2003) | Langlois et al. (2006) |
| Heart attacks | 1,200,000 (2004) | Am. Heart Assn (2007) |
| Stroke | 750,000 (2004) | Carandang, et al. (2006) |
| Alzheimer's disease | 438,000 (2007) | Alzheimer's Assn (2007) |
| Breast cancer | 180,510 (2007) | Am. Cancer Society (2007) |
| AIDS | 41,000 (2005) | CDC (2007d) |
| HIV/AIDS | 37,000 (2005) | CDC (2007d) |

One method of identifying MTBI cases has been to sort mild from moderate and severe brain injuries in overall statistics statements. Frequently reported annual overall TBI incidence is either 1.4 million (from Langlois, Rutland-Brown, & Thomas, 2006) or 1.5 million (from Kraus & McArthur, 1996). An estimated 75% to 90% of these (1.1 to

1.35 million) are new MTBIs, mainly derived from sorting diagnoses according to recent CDC criteria (Cassidy et al., 2004; CDC, 2007d; Langlois et al., 2006). A startling figure released by the CDC (2007c) in a pamphlet for physicians states, "[a]pproximately 1.6 – 3.8 million sports- and recreation-related TBIs occur in the United States each year. Most of these are MTBIs that are not treated in a hospital or emergency department" (p. 2). Note that this figure refers to injuries incurred while engaging in sports and recreation. The addition of sports and recreation to the mix of falls, assault, and vehicle accidents indicates that MTBI is far more prevalent than the 75% to 90% of 1.4 million, and that severe TBIs may be more prevalent as well.

These annual figures in the United States are very likely grossly underreported as they do not include injuries treated in doctors' offices, outpatient settings, or federal, military, or Veterans Administrations hospitals (Langlois et al., 2006). "The literature on this area is of varying quality and causal inferences are mistakenly drawn from cross-sectional studies" (Carroll et al., 2004, p. 84). MTBI outranks heart attack, stroke, Alzheimer's disease, breast cancer, AIDS, and HIV as public health problems (see Table 1), yet MTBI is still the "silent epidemic" (CNS, 2006; DVBIC, 2007). Survivors look fine, bearing invisible injury.

This silent epidemic is gaining voice as the tragic prognosis of MTBI is being felt as military personnel return home from tours in Iraq and Afghanistan. MTBI is the signature injury from the current wars (CNS, 2006; DVBIC, 2007), where "28% of those with battle injury severe enough to require evacuation to Walter Reed Army Medical Center, were found to have sustained at least a mild TBI" (Warden et al., 2007, p. 2).

> More than 20,000 U.S. military personnel have been wounded in the war through mid-September (2007)….but nobody knows exactly how many…have suffered traumatic brain injuries....The impact of a missing leg or arm is clear to anyone meeting an amputee. But changes in the brain that result from a soldier being thrown around in a bomb blast aren't always immediately obvious, even to the soldier. When the wound is invisible, it can be easy to dismiss. (Carroll, 2007)

Whereas MTBI had been easily shoved aside by clinicians who only respond to the overtly observable, war veterans who return home damaged and changed have brought the plight of all victims and survivors of MTBI to the fore of public awareness.

## So What?

> The digital economy is moving our Nation toward greater prosperity. Our goal … is to ensure that all Americans – regardless of age, income, race, ethnicity, disability, gender or geography – gain access to … tools and skills needed in the new economy. (U.S. Dept. of Commerce, 2000, p. i)

MTBI is a disability that can lead to a lifetime of struggle. Cognitive and visual challenges can be especially troublesome (NORA, 2001a), especially now in the digital economy as the survivor utilizes the web (Information society, 2008). Because it is a disability, provisions of the Americans with Disabilities Act of 1990 (U.S. Department of Justice, 2007) apply to MTBI survivors. Accommodations developed for people with physical disabilities should be extended to meet the physical and cognitive needs of MTBI survivors. Ability to access but also to manage information may be the

determining cognitive requirements standing between success and failure in post-injury recovery in 21st century society.

## Purpose of the Study

The purpose of this grounded theory study was to examine how people with MTBI access information on the web. This researcher had identified a gap in the literature regarding the web as an information access issue for MTBI survivors. Applying grounded theory methodology, this inquiry investigated MTBI survivors as they navigated both through familiar and unfamiliar web pages.

## Grand Tour Question

The Grand Tour question asks, "What is the process by which people with Mild Traumatic Brain Injury access information on the web?" The following questions informed the intent of the observations and interviews that comprised data collection.

1. How do MTBI survivors feel about the web in general?
2. What strategies do MTBI survivors utilize to navigate through a front page?
3. What do MTBI survivors do to make the medium "work" for their purposes?
4. What do MTBI survivors do if the visual content does NOT "work" for them?
5. Does the graphical layout of web pages influence a survivor's perception of written material?
6. Does the graphical layout of web pages influence how a survivor chooses what content to focus on or to ignore?

## Significance of the Study

How well MTBI survivors access information on the web is a disability accessibility issue. This topic is timely because the "growth and success of the emerging digital economy requires that attention be paid to the mechanism for enabling dynamic participation" (Waddell, 1999, p. 2). American society has transitioned from one based on material production to one where "the majority of employees work in information jobs, i.e. they have to deal more with information, signals, symbols, and images than with energy and matter" (Otto & Sonntag, 1985, cited in Information society, 2008, p. 2). MTBI survivors who live and work in this information society, this network society where "networks have become the nervous system of society" (van Duk, 2006, cited in Information society, 2008, p. 2), may be at risk because of the very nature of their injuries.

Web pages are created with intent to deliver information to an audience. With the rise of commercial use of the web, intent includes sales and marketing of goods and services to include retail, medical, and educational services. It is feared that

> [w]ithout the application of ADA requirements to the Internet, new barriers to effective communication and global commerce will be erected that will have a discriminatory impact upon individuals with disabilities. Accessible web design should be mandated so that everyone, regardless of age or disability, or the limitations of their computer equipment, can participate in the benefits of the World Wide Web. (Waddell, 1998, p. 4)

This statement represents the needs for MTBI survivors who seek to share the same experiences as others with and without disabilities.

With the rise of the web as a tool for education, research, and commerce, it would seem reasonable to believe that both the web user and website owner would benefit from a site designed for maximum access and comprehension of information (Sydik, 2007). Unfortunately, Waddell's warning holds true nearly ten years later as the National Federation for the Blind recently sued Target Corporation for refusing to make its website accessible to the blind (ICDRI, 2008).

A brief scan of web pages reveals information presented in multiple colors, animations, background designs, small text, large text, different fonts, short and long lines, high and low contrast, short and long scrolls, frames, no frames, and other variations (see, for example, http://www.webpagesthatsuck.com). One consistent characteristic of web page design is the presence of text as the primary delivery mode of information. Text is surrounded by colors, graphics, and movement.

> Whether the digital barrier is the inaccessible design of the Internet/Intranet web sites, Internet Service Provider 'portals,' incompatible browsers, or inaccessible web-based platforms for on-line business, the trend is growing and must be addressed at the infancy of the digital economy….Unless functionality solutions for accessibility are addressed today, the state of the digital divide tomorrow may be impossible to overcome. (Waddell, 1999, p. 5)

If survivors cannot visually and cognitively negotiate elements to understand how to find what they seek, all content contained within a web page or web site is, essentially, inaccessible.

## Delimitations and Limitations of the Study

"Two or more parameters for a research study establish the boundaries, exceptions, reservations, and qualifications inherent in every study: delimitations and limitations" (Castetter & Heisler, 1977, cited in Creswell, 2003, p. 147).

### *Delimitations*

Delimitations are those decisions that narrow the study (Creswell, 1994; 2003). This study is narrowly focused and was delimited by the type of research design and by criteria for selecting participants. The research design is grounded theory, which includes specific procedures for inquiry and analysis. Participants who qualified for this study had acquired MTBI, diagnosed or undiagnosed with proof of insult, reached the age of majority, and were able to communicate both verbally and in writing.

### *Limitations*

While there was a large pool from which to draw participants with MTBI, this study was limited by availability of persons who were willing and able to participate in this inquiry. The nine participants were fewer than the suggested number for grounded theory. They were heterogeneous in terms of their personal profiles, including age, gender, type of injury, number of injuries, occupation, and education. This was purposeful with the intent to isolate specific data that emerged across these profiles rather than representing a demographic element; however, a greater number of participants may have provided more clarity as analysis progressed. This limited the study by moving study of other populations into the realm of further study.

The qualitative design and purposive sampling of this study contribute to the investigative nature of basic research. As is the nature of qualitative research where the

researcher is the primary instrument, data may be interpreted differently by other researchers. A limitation, then, is that this study is not generalizable to all persons with MTBI, but is, however, transferable to inform further study.

## Definition of Terms

For the ease of the reader, there are a number of words specific to disability, accessibility, and brain injury that require definition. As well, terms that address the social and environmental lifescape in which the MTBI web user functions are also defined here.

Access: The extent to which persons with disabilities can perceive, understand, navigate, and interact with the web (W3C, 2007).

Acquired Brain Injury (ABI): injury to the brain which is not hereditary, congenital or degenerative (BIA, n.d.).

Cognitive-Communications Skills: Ability to use language and underlying processes such as attention, memory, self-awareness, organization, problem solving, and reasoning to communicate effectively (Blosser & DePompel, 1996).

Cognitive disability: "a disability that impacts and individual's ability to access, process, or remember information" (Center on Human Policy, Syracuse University, n.d., p. 1).

Digital Economy: Generally references the information technology industry and all aspects of personal and commercial life that interfaces with it. By participating on the web, one is participating in the digital economy (U.S. Department of Commerce, 2003).

The digital economy "focuses on trading bits in cyberspace rather than atoms in physical space" (Information society, 2008, p. 4).

Executive Functions: Many distinct functions presumed to be mediated by neuronal systems that include prefrontal cortex, including organization, higher order thinking, goal accomplishment, problem solving, sequencing, and multitasking (Raskin, 2000, p. 113).

Information Society: The term has no agreed-upon definition, however various economists and social scientists have offered definitions that share similar concepts. It is generally agreed that the information society, also termed the information economy or postmodern society, is one in which knowledge is a commodity and more than half of the GNP and work force is employed in the knowledge industry (Information society, 2008). There are five specific areas of the knowledge society: "education, research and development, mass media, information technologies, and information services" (Machlup, 1969, cited in Information society, 2008, p. 1). The information society, as a social construct, is also attributed to fostering the Grand Narrative, presentation of society and culture in hegemonic terms.

Mild Traumatic Brain Injury (MTBI): An occurrence of injury to the head resulting from blunt trauma or acceleration or deceleration forces with one or more of the following conditions attributable to the head injury: any period of loss of consciousness lasting 20 minutes or less; transient confusion, disorientation, or impaired consciousness; dysfunction of memory (amnesia) around the time of injury; signs of other neurological or neuropsychological dysfunction, such as a) seizures immediately following head injury; b) irritability, lethargy, or vomiting among infants and very young children

following head injury; c) headache, dizziness, irritability, fatigue, or poor concentration among older children and adults. When identified soon after injury these can be used to support the diagnosis of mild TBI but cannot be used to make the diagnosis in the absence of loss of consciousness or altered consciousness (CDC, 2003, p. 16-17).

Survivor: A person who has survived a traumatic brain injury, whether mild, moderate, or severe. This is a positive, empowering term that is used in place of negative, disempowering terms such as *victim* or *patient*.

Traumatic brain injury (TBI)—Moderate to severe: An injury to the brain, not of degenerative or congenital nature, caused by an external physical force that may produce a diminished or altered state of consciousness, which results in an impairment of cognitive abilities or physical functioning. It can also result in the disturbance of behavioral or emotional functioning (BIA, n.d.; Parker, 1996). May include (a) loss of consciousness lasting longer than 30 minutes, (b) post-traumatic amnesia lasting longer than 24 hours, or (c) penetrating craniocerebral injury.

User: In this study, the term "User" with a capital U refers to web users with MTBI and participants in this study. References to "user" in lower case refers to the generic web user. The purpose of referring to the User as a proper noun, as a name, is to maintain their individuality, their specialness as unique beings with, or regardless of, MTBI.

World Wide Web (web): An extensively interlinked computer network consisting of a collection of internet sites that offer documents, text, graphics, sound, and animation resources through the hypertext transfer protocol (WordNet, 2007).

## Audience

This study offers insight into information access implications of web page design to MTBI survivors. Because little research has been pursued in this specific area, results of this study will be of use to any educator or website designer who is charged with creating a website that will serve as an information gateway accessible to all users. Administrators charged with implementing ADA accommodations for persons with disabilities have opportunity to offer informed accommodations for those with brain injury. MTBI advocates may find the results of this study useful, because the web is a rich source of information for survivors, clinicians, advocates, and families. Data that inform accessible web page design specific to the MTBI population will enable TBI information sites to be accessible on a broader scale. TBI and MTBI survivors, by reading the stories of the anguish, challenges, and successes experienced by the participants, may gain insight toward managing their own experiences.

# CHAPTER II

## Review of the Literature

Little literature review is demanded at the outset of a grounded theory study except to establish the relevance of the study. For this study, existing literature was examined previous to finalizing the research question. Existing literature was woven within the presentation of the data to elaborate on participant voices regarding their experiences with web pages.

### *MTBI Research Background*

The Traumatic Brain Injury Act of 1996 was a Federal response to traumatic brain injury as the leading cause of death and disability among children and young adults in the U.S. It charged the Centers for Disease Control and Prevention (CDC) to reduce the incidence of traumatic brain injury. This legislation launched a much-needed, coordinated, nationwide, effort to identify and research TBI. One of the primary mandates was to develop uniform reporting procedures for traumatic brain injury so the CDC proceeded to authorize state surveillance systems to gather information on the number, causes, and severity of MTBI. Initial studies of state data were reported in "Traumatic Brain Injury in the United States: A Report to Congress" (CDC, 1999). Previous to this effort there was no consistent definition, thus no accurate measure of prevalence.

In 2000, the Children's Health Act directed the CDC to study the incidence and prevalence of MTBI. In 2003 the CDC published the findings: "Report to Congress on mild traumatic brain injury in the United States: Steps to prevent a serious public health

problem." With this information, Congress supported further timely and aggressive investigation into MTBI.

*Prevalence Underestimated*

Kraus and McArthur's comprehensive review of published data estimates a ratio of mild to moderate to severe brain injuries at 8:1:1 (1996, p. 444). "Sports-related injuries accounted for 20 percent (306,000) of the…TBIs in the United States in 1991" (Sosin, Sniezek, & Thurman, 1996, p. 10). Of those, only 12 percent were hospitalized (35,000), suggesting that in 1991 alone, 271,000 remaining children suffered sports-related brain injuries in the mild to moderate category. This suggests that in the 16 years since that study, approximately 4.6 million children have been affected by MTBI from sports injuries alone. Prior to the CDC surveillance statistics, reports estimated 1 to 1.5 million people were treated annually for TBI and released from emergency rooms (Guerreo, Thurman, & Sniezek, 2000; Kraus & MacArthur, 1996; Sosin et al., 1996). Undoubtedly, those released from emergency rooms are not the severe brain injuries that require hospitalization and life support to stabilize the patient. Kraus and McArthur (1996) cautioned that

> many mild injuries to the head may never be brought to medical attention and, therefore, are missed by researchers who rely on conventional case-finding methods. Supporting this concern is the substantial percentage of head-injured persons treated in emergency departments or admitted to hospitals who do not have neurologic involvement and the many mild or trivially brain-injured persons who may not seek medical treatment or obtain care through clinics or physicians' offices. The implication is that a significant undercounting of true brain injuries

> exists, possibly as large as 85%. Most of this underestimation of brain trauma, however, likely consists of milder forms of brain injury (p. 436).

As state surveillance data reported TBI statistics and trends, a profound finding was that "MTBI accounts for at least 75% of all traumatic brain injuries in the United States. However, it is clear that the consequences of MTBI are often not mild" (CDC, 2003, Preface). Estimates of MTBI at that time were underestimated for a number of reasons:

> The existing Centers for Disease Control and Prevention definition for TBI surveillance is designed to identify cases of TBI that result in hospitalization, which tend to be more severe. MTBI is most often treated in emergency departments or in non-hospital medical settings, or not treated at all. Few states conduct emergency department-based surveillance, and current efforts do not capture data about persons with MTBI who receive no medical treatment. Additionally, neither hospital- nor emergency department-based data can provide estimates of the long-term consequences of MTBI (CDC, 2003, p. 1).

*Children's Health Act of 2000*

These MTBI statistics reflect a major health problem. To address this, Congress passed the Children's Health Act of 2000 under which the CDC was to gather data on the incidence and prevalence of MTBI. To accomplish this, the CDC established the Mild Traumatic Brain Injury Work Group, comprised of experts in the field, to "determine appropriate and feasible methods for assessing the incidence and prevalence of MTBI in the United States" (CDC, 2003, p. 1). The resulting report, "Report to Congress on Mild

Traumatic Brain Injury in the United States: Steps to Prevent a Serious Public Health Problem" (CDC, 2003) focused specifically on MTBI.

*Lack of Common Definition*

A major reason for lack of accurate MTBI statistics has been lack of a uniform definition that would allow for a uniform diagnosis. The Work Group was faced with finding a solution for the problem that plagued the medical community: There was no consistent diagnosis for MTBI because there was no consistent definition. The solution, then, was to recommend a definition of MTBI that could be used by the state surveillance teams to gather the data required by Congress. The Working Group recommended a conceptual definition for new incidents of MTBI as

> an injury to the head as a result of blunt trauma or acceleration or deceleration forces that result in one or more of the following conditions:
>
> 1. Any period of observed or self-reported
>
>  a) transient confusion, disorientation, or impaired consciousness;
>
>  b) dysfunction of memory around the time of injury;
>
>  c) loss of consciousness lasting less than 30 minutes.
>
> 2. Observed signs of neurological or neuropsychological dysfunction, such as
>
>  a) seizures acutely following injury to the head;
>
>  b) among infants and very young children: irritability, lethargy, or vomiting following head injury;
>
>  c) symptoms among older children and adults such as headache, dizziness, irritability, fatigue, or poor concentration, when identified soon after injury can be used to support the diagnosis of mild TBI, but cannot be

> used to make the diagnosis in the absence of loss of consciousness or altered consciousness. (CDC, 2003, p. 2)

The Working Group also defined conceptual and operational definitions for prevalent cases:

> The conceptual definition of a prevalent case of MTBI is any degree of neurological or neuropsychological impairment, functional limitation, disability, or persistent symptom attributable to an MTBI…. The operational definition of a prevalent case of MTBI-related impairment, functional limitation, disability, or persistent symptoms is any case in which current symptoms are reported consequent to MTBI or make worse in severity or frequency by the MTBI, or in which current limitations in functional status are reported consequent to MTBI. (CDC, 2003, p. 2-3)

With these definitions, diagnostic codes were identified that fit, and the CDC-sponsored research proceeded to search databases, hospital records, and the medical community for updated data MTBI data.

### *Research Progression*

MTBI statistics have been extrapolated from (a) hospitalization records that include all brain injuries but not all clinic and emergency department visits (see Kraus & McArthur's excellent 1996 report, for example), (b) emergency department data that did not include hospitalizations or doctor office visits (see Bazarian et al., 2005), and (c) emergency department and hospitalizations data but not from doctors offices or outpatient clinics (see Langlois et al., 2006). The CDC (2007c) reported on injuries

sustained by amateur athletes, reflecting that most of the MTBIs were "not treated in a hospital or emergency department" (p. 2).

When analyzing numbers, the reader must consider if statistics presented were gathered before the CDC studies or if they reflect data gathered with definitions recommended by the Mild Traumatic Brain Injury Work Group in 2003. Literature reviews can become confusing if this is not made clear. Kraus and McArthur (1996) and Sosin et al. (1996) were on the early end of the recent data, reporting on data from the early 1990s. Later studies have reviewed literature, medical records, and databases with the CDC's diagnostic protocols for MTBI and have provided very recent profiles of MTBI, treated and untreated (Bazarian, McClung, Cheng et al., 2005; Bazarian et al., 2005; Carroll, Cassidy, Peloso, Garritty, & Giles-Smity, 2004; Carroll et al., 2004; Cassidy et al., 2004; Langlois et al., 2006). Because studies offer varying conclusions, in part due to whether the research was done before or after the definitions were developed, one must exercise caution when drawing conclusions about MTBI.

*Centers for Disease Control and Prevention Surveillance*

The Centers for Disease Control and Prevention conducted a study of TBI-related emergency room visits, hospitalizations, and deaths in the United States between 1995 and 2001 (Langlois et al., 2006) and updated for 2002 and 2003 (CDC, 2007a). Three databases were analyzed: the National Hospital Ambulatory Medial Care Survey (NHAMCS) conducted by CDC's National Center for Health Statistics (NCHS), the National Vital Statistics System, and the National Hospital Discharge Survey (NHDS). All three databases contain data on traumatic brain injury-related deaths, hospitalizations, and visits to hospital emergency departments.

The unit of study was diagnostic codes that fit the CDC's definition for TBI. Diagnostic codes measured included those for (a) fracture of the vault or base of the skull; (b) other and unqualified multiple fractures of the skull; (c) intracranial injury, including concussion, contusion, laceration, and hemorrhage; (d) other open wound to the head; (e) late effect of fracture of skull and face bones; (f) head injury, unspecified; (g) open wound of the head; (h) fracture of skull and facial bones; (i) injury to optic nerve and pathways; (j) intracranial injury; (k) crushing injury of head; (l) open wounds involving head with neck; (m) fractures involving head with neck; (n) crushing injuries involving head with neck; (o) injuries of brain and cranial nerve with injuries of nerves and spinal cord at neck level; and (p) sequelae of injuries of head. Patient charts from emergency department visits, hospitalizations, and deaths provided the data (Langolis et al., 2006).

Data from this 7-year time frame were averaged to provide a stable report that included the most recent data possible. Annual averages during the 7-year span from 1995 – 2001 (Langolis et al., 2006) are reported in Table 2. The report states that these numbers may be misleading

> because data for an estimated 439,000 TBIs treated by physicians during office visits and 89,000 treated in outpatient settings were not included in this report…. TBI for which no medical advice was sought, an estimated 25% of all mild and moderate TBIs, were not included. Also, both NHDS and NHAMCS do not include data from federal, military, or Veterans Administration hospitals. (p. 49)

*Table 2: Traumatic Brain Injury Treatments*

| Category | Average |
|---|---|
| Traumatic Brain Injury (overall) | 1.4 million |
| Treated and released from emergency departments (mild/moderate) | 1.1 million |
| Deaths | 50,000 |
| Hospitalizations | 235,000 |
| Treated at physician office visits (mild/moderate-not included in CDC report) | 439,000 |
| Treated at outpatient settings (mild/moderate-not included in CDC report) | 89,000 |
| No medical advice sought | 25% of all mild and moderate TBIs |
| Federal, military, or VA hospitals | not included |

*Hospital Ambulatory Medical Care Survey*

Bazarian et al. (2005) reexamined the Hospital Ambulatory Medical Care Survey for 1998 through 2000 specifically for diagnostic codes identified by the CDC that point to MTBI and reported that the incidence of MTBI is higher than previously reported. Kraus and McArthur (1996) had reported that the annual incidence of all types of head injuries that occurred in the U. S. was approximately 220 per 100,000 people in 1992 (1996), but almost a decade later Bazarian's team found the average incidence of MTBI was more than double at 503.1 per 100,000 population.

*World Health Organization*

An international team with the World Health Organization Collaborating Center for Neurotrauma at the Karolinska Institute in Stockholm, Sweden, examined the MTBI literature from 1980 to 2002 (Carroll, Cassidy, Peloso, Garritty et al., 2004). In this massive study, they

> screened 38,806 abstracts, critically reviewed 169 studies… accepted 121 (72%) [and reported that] 70-90% of all treated brain injuries are mild….[however] much mild traumatic brain injury is not treated at hospitals, and the true population-based rate is probably above 600/100,000. (Cassidy et al., 2004, p. 1)

Table 3 compares the rates of the three studies over a span of 10 years. No matter how the data are turned or the population measured, millions of American children and adults suffer and live the tragic results of MTBI.

*Table 3: MTBI per 100,000 persons*

| Research teams | Estimate/100,000 | Date of Data |
|---|---|---|
| Kraus & McArthur (1996) | 220 | 1992 |
| Bazarian, McClung, Shah et al. (2005) | 503.1 | 1998 - 2000 |
| WHO Collaborating Center for Neurotrauma (2004) | 600 | 1980 - 2002 |

## Web Accessibility

When the web was introduced in 1990 by Timothy Berners-Lee (W3C, 2004) the Internet had already been in existence for 15 years and was primarily used as a medium for academic and scientific information sharing. In the early years, the Internet was principally text, therefore was less of an access barrier (Waddell, 1998). Since then, the web has become home to extensive graphics and media, especially during the past few years as bandwidth and computer capabilities have dramatically increased. Accessibility was not initially an issue because the web was unencumbered by markup and graphical additions that interfered with communication. With the rise of the web there came to be conflicts between technology and information access for persons with a wide range of

disabilities. Audio and video-streaming, Portable Document Format (PDF) documents, graphics, and links all represent barriers to accessibility that must be addressed (Waddell, 1998). This, then, has become an accessibility concern, because

> the web is an increasingly important resource in many aspects in life: education, employment, government, commerce, health care, recreation, and more. It is essential that the Web be accessible in order to provide equal access and equal opportunity to people with disabilities. (World Wide Web Consortium [W3C], 2007)

### *What is Web Accessibility?*

Waddell (1998) reported that a university student with a disability had complained that the university had not provided the student Internet access. This complaint led to a discussion by the Office of Civil Rights, United States Department of Education (OCR) of what it means to have access. "[T]he issue is not whether the student with the disability is merely provided access, but the issue is rather the extent to which the communication is actually as effective as that provided to others" (OCR, 1996, p. 1). The OCR further stated that the "three basic components of effective communication are: 'timeliness of delivery, accuracy of the translation, and provision in a manner and medium appropriate to the significance of the message and the abilities of the individual with the disability'" (1997, p. 1).

The definition of effective communication and access has evolved to apply to web accessibility: "persons with disabilities can….perceive, understand, navigate, and interact with the web" (W3C, 2007, p. 1). Web accessibility concerns apply to all disabilities, including speech, visual, physical, auditory, neurological, and cognitive, that can affect

interaction with the web. People with temporary disabilities, such as those with broken arms or, perhaps, the 80 to 90 percent of MTBI survivors who fully recover within six months (Ruff, 2005), benefit from accessibility as well. Even problems such as slow internet connections that often occur in remote geographical areas benefit from the technology behind accessibility (W3C, 2007).

### *World Wide Web Consortium Web Accessibility Initiative*

The Web Accessibility Initiative (WAI), introduced in 1997 by the World Wide Web Consortium (W3C), was charged with development of a framework for creating an accessible web. In 1999, the Web Content Accessibility Guidelines 1.0 (WCAG 1.0) were approved and became a recommended set of guidelines for the web design industry (W3C, 1999, 2006). It remains stable (2006) and is the document that is "most often referred to when discussing general principles of web accessibility" (Sydik, 2007, p. 246). "[I]t is still a fairly decent model that I expect will continue to remain the gold standard of guidelines for some time" (p. 54).

WCAG 1.0 presents a series of 14 guidelines, each with multiple subheads, or checkpoints. Some of the guidelines make intuitive sense to the non-technological user. Others are clearly for the web authoring community. Each checkpoint is assigned a priority level, an indication of priority or necessity. Priority 1 indicates a checkpoint is required. A website that meets Priority 1 checkpoints meets the minimum requirement for accessibility. "A Web content developer must satisfy this checkpoint. Otherwise, one or more groups will find it impossible to access information in the document. Satisfying this checkpoint is a basic requirement for some groups to be able to use Web documents" (W3C, 1999, p 5). Checkpoints that are assigned Priority 2 "should" be satisfied (p. 5).

"Satisfying this checkpoint will remove significant barriers to accessing Web documents (p. 5). Sydik describes Priority 2 as "a mixed bag….some…essential….Others should be done as part of being a good host to your visitors or as good content development principles" (2007, p. 246). WCAG 1.0 describes Priority 3 as practice that a web content developer may follow. "Otherwise, one or more groups will find it somewhat difficult to access information in the document. Satisfying this checkpoint will improve access to Web documents" (W3C, 1999, p. 5). Conformance ratings indicate which Priority level is built into a site. Sydik describes the goal as the "Double-A, where all Priority 1 and 2 checkpoints are satisfied: This is the sweet spot for WCAG 1.0 compliance. At this level, you're doing the things that are most likely to improve the experience of users visiting your site" (Sydik, 2007, p. 247).

*WCAG 1.0 Guidelines*

The 14 guidelines include the following:

1. Provide equivalent alternatives to auditory and visual content.
2. Don't rely on color alone.
3. Use markup and style sheets and do so properly.
4. Clarify natural language usage.
5. Create tables that transform gracefully.
6. Ensure that pages featuring new technologies transform gracefully.
7. Ensure user control of time-sensitive content changes.
8. Ensure direct accessibility of embedded user interfaces.
9. Design for device-independence.
10. Use interim solutions.

11. Use W3C technologies and guidelines.
12. Provide context and orientation information.
13. Provide clear navigation mechanisms.
14. Ensure that documents are clear and simple. (W3C, 1999, 5-15)

It is beyond the scope of this review to detail all of the web accessibility guidelines and checkpoints set forth by WCAG 1.0. Guidelines that pertain to neurological and cognitive disabilities are directly relevant, however, and will be discussed within the context of MTBI sequelae.

*WCAG 1.0 Checkpoints and MTBI*

Only the Priority 1 Checkpoints are required by WCAG 1.0 to be implemented. Comparison of common cognitive sequelae and the Guidelines and Checkpoints that apply directly to MTBI survivors reveals that most are Priority 2 and Priority 3.

1. Checkpoint 2.2: Ensure that foreground and background color combinations provide sufficient contrast when viewed by someone having color deficits or when viewed on a black and white screen [Priority 2 for images, Priority 3 for text] (W3C, 1999, p. 7).
2. Checkpoint 3.6: Mark up lists and list items properly [Priority 2] (W3C, 1999, p. 8).
3. Checkpoint 3.4: Use relative rather than absolute units in markup language attribute values and style sheet property values [Priority 2] (W3C, 1999, p. 7).
4. Checkpoint 4.2: Specify the expansion of each abbreviation or acronym in a document where it first occurs [Priority 3] (W3C, 1999, p. 8).

5. Checkpoint 7.1: Until user agents allow users to control flickering, avoid causing the screen to flicker [Priority 1] (W3C, 1999, p. 10).
6. Checkpoint 7.2: Until user agents allow users to control blinking, avoid causing content to blink (i.e., change presentation at a regular rate, such as turning on and off) [Priority 2] (W3C, 1999, p. 10).
7. Checkpoint 7.3: Until user agents allow users to freeze moving content, avoid movement in pages [Priority 2] (W3C, 1999, p. 10).
8. Checkpoint 10.1: Until user agents allow users to turn off spawned windows, do not cause pop-ups or other windows to appear and do not change the current window without informing the user [Priority 2] (W3C, 1999, p. 12).
9. Checkpoint 13.1: Clearly identify the target of each link [Priority 2] (W3C, 1999, p. 14).
10. Checkpoint 13.2: Provide metadata to add semantic information to pages and sites [Priority 2] (W3C, 1999, p. 14)
11. Checkpoint 13.3: Provide information about the general layout of a site (e.g., a site map or table of contents) [Priority 2] (W3C, 1999, p. 14).
12. Checkpoint 13.4: Use navigation mechanisms in a consistent manner [Priority 2] (W3C, 1999, p. 14).
13. Checkpoint 13.5: Provide navigation bars to highlight and give access to the navigation mechanism [Priority 3] (W3C, 1999, p. 14).
14. Checkpoint 13.6: Group related links, identify the group (for user agents), and, until user agents do so, provide a way to bypass the group [Priority 3] (W3C, 1999, p. 14).

15. Checkpoint 13.7: If search functions are provided, enable different types of searches for different skill levels and preferences [Priority 3] (W3C, 1999, p. 14).
16. Checkpoint 13.8: Place distinguishing information at the beginning of headings, paragraphs, lists, etc [Priority 3] (W3C, 1999, p. 15).
17. Checkpoint 14.1: Use the clearest and simplest language appropriate for a site's content [Priority 1] (W3C, 1999, p. 15).
18. Checkpoint 14.2: Supplement text with graphic or auditory presentations where they will facilitate comprehension of the page [Priority 3] (W3C, 1999, p. 15).
19. Checkpoint 14.3: Create a style of presentation that is consistent across pages [Priority 3] (W3C, 1999, p. 15).

Of the 19 Checkpoints that are obviously and directly applicable to survivors of MTBI with cognitive and visual disability, only two WCAG 1.0 Checkpoints are Level 1, therefore required. Checkpoint 14.1: "Use the clearest and simplest language appropriate for a site's content" might be considered a *no-brainer* for any web developer with a message to present to any audience. Checkpoint 7.1: "Until user agents allow users to control flickering, avoid causing the screen to flicker," applies to the many users who are susceptible to seizures. Ten Checkpoints are Priority 2 and eight are Priority 3, neither of which is required for web pages. Under the guidelines, it is possible for even government and business websites to avoid building websites that allow MTBI survivors equal access to information.

## The Human Experience

Numbers and statistics are an impressive but callous prelude to a discussion of the human cost of MTBI. The "Report to Congress on Mild Traumatic Brain Injury in the United States: Steps to Prevent a Serious Public Health Problem," published by Centers for Disease Control and Prevention (2003), estimated that MTBI costs the US $17 billion annually. This statistic is misleading, however, in part because it is based on 1985 data. At that time the total lifetime cost of TBI was estimated at $37.8 billion and 44%, or $16.5 billion was attributed to MTBI. The CDC later adjusted these data to inflation, applied 1995 figures, and estimated a total TBI cost of $56 billion with $16.7 billion attributed to MTBI (p. 11). This figure only included costs from hospitalizations and deaths, but stops there:

> it does not include injuries treated in EDs [emergency departments]. This omission is significant, given the decreasing trend to hospitalize persons with TBI….it excludes injured persons treated in other, non-hospital medical care settings, such as private physicians' offices; the costs of lost productivity and lost quality of life, and indirect costs borne by family members and friends who care for persons with MTBI. (p. 11)

In 2000, estimates for direct and indirect costs of TBI increased to $60 billion in the United States (CDC, 2006b). The enormity of these numbers can only be comprehended within the context of the stories of survivors and their families (Denton, 1999; Long, 2005; Osborn, 1998; Quinn, 1998; Russell & Sharratt, 1992; Senelick & Ryan, 1998; Swanson, 1999).

## *MTBI: The Silent Epidemic*

MTBI has been called the silent epidemic because damage is not readily apparent (Langolis et al., 2006, p. 1; DVBIC, 2007). As a result, MTBI does not command awareness among the general public. To provide a better understanding of social awareness of TBI in the United States, a Harris Poll survey was conducted on behalf of The Brain Injury Association (Harris Interactive Inc, 2000) as part of a five-year plan to increase public awareness. Five years of public education followed the study, during which follow-up polls were conducted to measure effectiveness of the public awareness campaign (BIA, 2000).

### *Harris Poll Findings*

The study revealed that there is a very low incidence of public awareness of TBI. Despite statistics that estimate 75% to 90% of all TBIs are mild (CDC, 2003, 2007d; Kraus & McArthur, 1996), and that great numbers of MTBIs exist outside of the parameters of those studies, this study reveals social ignorance of this public health problem. To appreciate the findings of this fascinating study, one must understand that while it is possible to sustain a head injury without injuring the brain, such as with facial injuries, it is not possible to sustain a brain injury without injury to the head.

A brief summary of findings from the Harris survey (2000) highlights American public lack of awareness, accurate information, or both. Approximately:

1. 15% say they are ‘very familiar’ with the term ‘brain injury.’ (p. 2)
2. 19% say they are ‘very familiar’ with the term ‘head injury.’ (p. 4)
3. 53% say they are ‘somewhat familiar’ with the term ‘brain injury.’ (p. 2)
4. 50% say they are ‘somewhat familiar’ with the term ‘head injury.’ (p. 4)

5. 21% say they are ‘not very familiar’ with the term ‘brain injury.’ (p. 2)
6. 18% say they are ‘not very familiar’ with the term ‘head injury.’ (p. 4)
7. 12% say they are ‘not familiar at all’ with the term ‘brain injury.’ (p. 2)
8. 12% say they are ‘not familiar at all’ with the term ‘head injury.’ (p. 4)
9. 4% say ‘they themselves have sustained a brain injury.’ (p. 2)
10. 25% say they ‘have personally sustained a head injury.’ (p. 4)
11. 35% say ‘they know someone who has sustained a brain injury.’ (p. 2)
12. 53% say ‘they know someone who has sustained a head injury.’ (p. 4)
13. 56% say ‘a concussion is a brain injury.’ (p. 2)
14. 74% believe ‘there is a difference between a brain injury and a head injury.’ (p. 4)
15. 38% say they ‘can detect a person with a brain injury’ in a room by observation. (p. 3)
16. 8% say that ‘all or most people who sustain head injuries experience learning and memory problems.’ (p. 5)
17. 7% say that ‘all or most people who sustain head injuries experience behavior problems.’ (p. 5)

The findings continue with percentages regarding cause, recovery, lifestyle, and frequency. The findings report, “Most adults [83%] who think there is a difference between a head injury and a brain injury [74%] believe that when a person sustains a concussion, they also sustain a head injury” (p. 5).

Comparing awareness of brain injury and head injury statistics, it is reasonable to conclude that not only is the American public less aware of brain injury in general, that

they would also be less aware of MTBI. The invisibility of MTBI is tragic as statistics reveal that millions of adults and children in the U.S. live with the results.

*Cogito, ergo sum [I Think, Therefore I am]*

Regardless of the variety of brain injuries and the range of damage that can be incurred, one cognitive result seen in almost all brain injury survivors is damage to executive functioning (BIA, n.d.; Cassidy, 1991; CDC, 2003; Guerreo et al., 2000; Langolis et al., 2006; Parker, 1996; Vieth, Johnstone, & Dawson, 1996).

> This is considered by many the cruelest blow of all. More than any other cognitive factor, executive functioning is at the heart of all our endeavors. It is the fuel that feeds the executive in the corner office. It is the spark that fires the writer in front of the word processor. It is the link that turns a concept into a reality for anyone, at any place, and in any walk of life. It involves the way we talk to people, deal with people, and carry out our daily lives. (Cassidy, 1991, p. 56)

It is executive functioning that allows a person to be a manager, teacher, or coach as well as be CEO of one's own life. Damage to executive functioning impairs abilities to organize, perform daily operations such as using a daily calendar, remember appointments, perform tasks and sequence, track telephone conversations, the little gifts that are taken for granted during day-to-day life. MTBI strikes the low blow, impacting the survivor's standard of living and quality of life.

*Organization*

To facilitate the MTBI survivor's work on the web, several of the WCAG 1.0 guidelines for web accessibility involve designing and programming pages that are

organized in very specific ways, intended to improve information access. One example, Guideline 2 reads: “Don’t rely on color alone” (W3C, 1999, p. 7). Design issues such as color usage, color combinations, and contrasts can affect how well, if at all, the user is able to organize information on a page and, therefore, have access to page content. When colors indicate organization or navigation, meaning is lost when color is not available, as with black and white or grayscale monitors or with visual color deficits. Specifically, Checkpoint 2.2 reads: “Ensure that foreground and background color combinations provide sufficient contrast when viewed by someone having color deficits or when viewed on a black and white screen [Priority 2 for images, Priority 3 for text]” (p. 7).

Sorting information may not rest at the top of the MTBI survivor’s skillset after injury to executive functioning (CDC, 2003; Russell & Sharratt, 1992). Guideline 3, “Use markup and style sheets and do so properly” (W3C, 1999, p. 7), speaks to the underlying programming of the web page in such a way that the page is organized and helpful for the user to understand. Checkpoint 3.6 states: “Mark up lists and list items properly. [Priority 2]” (W3C, 1999, p. 8). Lists are a visual organizer, a helpful accommodation for persons with cognitive disabilities.

Checkpoint 3.4 is specific to programming for pages with an accommodation strategy for users who prefer larger text: “Use relative rather than absolute units in markup language attribute values and style sheet property values. [Priority 2]” (W3C, 1999, p. 7). This guideline is relevant to MTBI survivors who choose to change the size of the text on a page. Relative values allow a page to adjust itself to the new positioning while fixed values do not and result in pages that are difficult to read. An aging population of users who are not disabled may still prefer larger text. MTBI survivors with

visual challenges also may prefer larger text. Relative attribute values will rearrange page elements when text is resized, preventing the problem of messy and disorganized layouts that are difficult to decipher.

*Distracting Pop-Ups*

One almost universal symptom of MTBI is distractibility. Guideline 10, "Use interim solutions," (W3C, 1999, p. 11) suggests that developers may use stop-gap measures when approved solutions are not applicable. Checkpoint 10.1 states: "Until user agents allow users to turn off spawned windows, do not cause pop-ups or other windows to appear and do not change the current window without informing the user. [Priority 2]" (W3C, 1999, p. 12). Pop-up windows can be a source of distraction and annoyance for any user, including the MTBI survivor who is susceptible to distraction. Interjecting the emotive aspect, MTBI also can lead to difficulty with handling frustration and other emotional responses to circumstances (Parker, 1996) including those encountered on the web.

*Navigation*

WCAG 1.0 Guideline 13 specifically addresses navigation: "Provide clear navigation mechanisms" (W3C, 1999, p. 14). "Provide clear and consistent navigation mechanisms – orientation information, navigation bars, a site map, etc. – to increase the likelihood that a person will find what they are looking for at a site" (p. 14). This guideline and checkpoints apply directly to persons with cognitive disabilities, including MTBI. They point to specific techniques as well as general usability.

Checkpoint 13.3 states: "Provide information about the general layout of a site (e.g., a site map or table of contents). [Priority 2]" (W3C, 1999, p. 14). Sydik asks, "What

is wrong with the standard navigation that makes [a site map] necessary?" (2007, p. 259). This question is well taken. If a site does not provide navigation that a user with MTBI can readily understand, a site map provides another option for information access. Some users benefit from seeing the "big picture," others, perhaps not.

The remaining Checkpoints for Guideline 13 address strategies for handling specific navigation and instruction functions. Each serves to support the MTBI survivor to better access information on the web.

> Checkpoint 13.4: Use navigation mechanisms in a consistent manner [Priority 2].
>
> Checkpoint 13.5: Provide navigation bars to highlight and give access to the navigation mechanism [Priority 3].
>
> Checkpoint 13.6: Group related links, identify the group (for user agents), and, until user agents do so, provide a way to bypass the group [Priority 3].
>
> Checkpoint 13.7: If search functions are provided, enable different types of searches for different skill levels and preferences [Priority 3].
>
> Checkpoint 13.8: Place distinguishing information at the beginning of headings, paragraphs, lists, etc. [Priority 3]. (W3C, 1999, p. 15)

*Links*

Checkpoint 13.1 states: "Clearly identify the target of each link. [Priority 2]" (W3C, 1999, p. 6). "Link text should be meaningful enough to make sense when read out of context -- either on its own or as part of a sequence of links. Link text should also be terse" (W3C, 1999, p. 14). Sydik comments, "This is one of the most self-explanatory checkpoints in WCAG 1.0: don't use links with titles such as 'Click here'" (2007, p.

259). “Click here” gives a command but does not connect an action with a destination. Users with memory or language challenges may find this to be a barrier.

### *Information Management*

With the onslaught of information unleashed by the web upon users in schools and homes, higher order problem solving and critical thinking skills are needed to effectively manage all this information (ALA, 1998). Volumes of information traditionally housed within the musty realm of libraries are now available in massive quantity on the web. The web is also an unsupervised medium for dissemination of varying degrees of content quality from false information (see http://www.snopes.com for example) to the latest medical research (see http://www.sciencedirect.com for example). When a search engine returns hundreds or thousands of *hits* from even correctly formed search procedures, higher order thinking is required to sort through and make appropriate decisions about the value of information available. Conversely, when a search returns no *hits*, the user must think through hierarchical word constructions to search again. Checkpoint 13.2 speaks to “providing metadata to add semantic information to pages and sites (W3C, 1999, p. 13)” to assist with searching, while Checkpoint 13.7 discusses search functions within pages.

### *Language*

> None of the other losses were as devastating or humiliating or as unacceptable to me as not being able to read or write. I did not just write to earn my living. A writer was WHO I was….When I lost my ability to read and write, I became a non-person, with no worth in my own eyes. (Russell & Sharratt, 1992, p. 64)

Language loss and word-finding challenges are common symptoms of MTBI (NORA, 2001b; Russell & Sharratt, 1992; Zihl, 2000). Language is addressed by Guideline 4: "Clarify natural language usage" (W3C, 1999, p. 8). Natural language is defined as "spoken, written, or signed human languages such as French, Japanese, American Sign Language, and Braille" (W3C, 1999, p.18). Guideline 14, "Ensure that documents are clear and simple" (W3C, 1999, p. 15), also speaks to the need to create visually organized and easy to understand pages.

> Consistent page layout, recognizable graphics, and easy to understand language benefit all users. In particular, they help people with cognitive disabilities or who have difficulty reading….Using clear and simple language promotes effective communication. Access to written information can be difficult for people who have cognitive or learning disabilities. Using clear and simple language also benefits people whose first language differs from your own, including those people who communicate primarily in sign language. (p. 15)

Checkpoints that support these two guidelines specify detailed scenarios to help web designers with text development. Checkpoint 4.2 states: "Specify the expansion of each abbreviation or acronym in a document where it first occurs. [Priority 3]" (W3C, 1999, p. 8). Persons with cognitive disabilities that include memory limitations, so frequently experienced among MTBI survivors, can find that abbreviations and acronyms are stumbling blocks if they do not remember the meaning, even if such are common language. Simply including the full name one time may provide the information for the user to either jog the memory or to have available for reference. Checkpoint 14.1 states: "Use the clearest and simplest language appropriate for a site's content. [Priority 1]"

(W3C, 1999, p. 15);" Checkpoint 14.2 states: "Supplement text with graphic or auditory presentations where they will facilitate comprehension of the page. [Priority 3]" (p. 15);" and Checkpoint 14.3 states: "Create a style of presentation that is consistent across pages. [Priority 3]." (p. 15).

### *Vision*

A century of research has provided information on results of damage to different parts of the brain, impact on memory, cognition, learning, as well as visual disturbances, migraines, and headache. Visual dysfunction as a result of TBI is well documented and is routinely included in discussions about TBI sequelae (BIA n.d.; Chang, Ciuffreda, & Kapoor, 2007; Luria, A. R., 1972/1902; NORA, 2001a; Russell & Sharratt, 1992; Zihl, 2000). About 20% of survivors of acquired brain injury (ABI) suffer from visual problems (Zihl, 2000). (ABI includes damage from stroke.) However, despite millions of dollars and hours of research, little attention has been paid to the full impact of visual dysfunction on information management (Zihl, 2000).

#### *Physical Sequelae*

TBI leaves devastating visual damage in its wake for most survivors (Padula, n.d., cited in Politzer, n.d.). Because visual processes are not a physical function located in a single part of the brain but rather are spread like a web throughout the brain (Zihl, 2000), likelihood of visual damage is great with any TBI. When the visual system is disrupted, even when visual acuity is sharp, repercussions include reduced convergence or flexibility to focus quickly at different distances (BIA, n.d.; NORA, 2001a; Padula, n.d.; Politzer, n.d.; Windsor, n.d.; Zihl, 2000). Visual field loss, double vision, and visual balance disorders are "the three most devastating and intolerable vision problems

resulting from brain injury…" (Politzer, n.d.). Even to track visually across a line of text can become laborious.

*Emotional Fallout*

Visual disruption can lead to loss other than visual perception (Zihl, 2000). Reduced ability to read, write, and interpret textual information correctly brings discouragement and humiliation that can be overwhelming (Blosser & DePompel, 1996; Cassidy, 1991; Osborne, 1997; Russell & Sharratt, 1992; Zihl, 2000). A functioning visual system is critical for interpreting written language, or reading. With the rapid increase of online education, survivors who experience difficulty with reading may find the text-heavy content presentation and online conferences to be arduous. Challenges to reading, a function that is essential to success in a text-based educational system, can be discouraging at best (Russell & Sharratt, 1992).

The survivor becomes caught between having the ability and willingness to read and not having physiological visual ability to make meaning of the written word. For the person who enjoys reading and writing, who has woven a sense of self to include reading and writing, visual disruption can carry far deeper implications.

*Computers and Flicker*

While MTBI sequelae are troubling, annoying, even debilitating, flashing lights can be dangerous. Survivors frequently complain of visual discomfort with computer screens and televisions. This phenomenon is related to a technological phenomenon known as *flicker* (Singh, Bhalla, Lehl, & Sachdev, 2001; Sydik, 2007; Turner, 1968). Screens redraw images multiple times per second, and even overhead fluorescent lights have a flicker. Seizures can result from exposure to light sources that include flicker.

Critical flicker frequency (CFF) is defined as "the fastest rate at which a flickering source of light appears to be flickering as opposed to being steady" (p. 245).

*Video Games*

Video game-induced seizures are a unique phenomenon related to flicker. Recently seen in children and teenagers, Singh et al (2001) explain this reflex epilepsy as

> …the commonest form of epilepsy in which seizures are provoked by specific external stimulus. Photosensitive reflex epilepsy is provoked by environmental flicker stimuli. Video game epilepsy is considered to be its variant or a pattern sensitive epilepsy. The mean age of onset is around puberty and boys suffer more commonly as they are more inclined to play video games. (p. 1)

Recent studies of critical flicker frequency show that while there is no significant difference between MTBI survivors and non-injured subjects across age groups, "the majority of [M]TBI subjects manifested both light and motion sensitivity," leading researchers to conclude that critical flicker frequency is "related to the reported degree of light and motion sensitivity in individuals with MTBI. Neurological disinhibition as a result of brain injury [may be the cause of] hypersensitivity to light and motion in the presence of normal CFF" (Chang et al., 2007, p. 1).

*Medication Side-Effects*

Sensitivity to medication creates a risk even for persons with MTBI who do not have a seizure disorder. MTBI drug treatments include anti-epileptics that are effective for multiple problems, including seizures resulting from brain injury and mood control. Drugs administered to treat otherwise debilitating problems commonly have visual

disturbances as a side effect (Hilton, Hosking, & Betts, 2004; Turner, 1968), including susceptibility to flicker (Chang et al., 2007).

*2012 Olympics Logo*

A flicker-related phenomenon that occurred in 2007 in the broadcast industry drew much attention (Press Dispensary, 2007). The 2012 Olympics logo, broadcast on television and on the internet, triggered "the largest number of TV induced epileptic seizures ever seen in the UK [United Kingdom]" (p. 1). The Harding Flash and Pattern Analyser revealed that the video "was found to contravene the OfCOM [FederalOoffice of Communications] guidelines on at least 126 frames [indicating that the risk factor] was off the scale" (p. 1).

*WCAG Flicker Guidelines*

Guidelines to protect susceptible users seek to prevent flicker and blinking by eliminating flicker or by allowing the user to assume control over presence and rate. Guideline 7 states: "Ensure user control of time-sensitive content changes" (W3C, 1999, p. 10). "Ensure that moving, blinking scrolling, or auto-updating objects or pages may be paused or stopped" (p. 10.). This guideline attempts to place the user in control of flicker, blinking, and other motion on the screen. Checkpoint 7.1 states: "Until user agents allow users to control flickering, avoid causing the screen to flicker. [Priority 1]" (W3C, 1999, p. 10); Checkpoint 7.2 states: "Until user agents allow users to control blinking, avoid causing content to blink (i.e., change presentation at a regular rate, such as turning on and off). [Priority 2]" (p. 10); Checkpoint 7.3 states: "Until user agents allow users to freeze moving content, avoid movement in pages. [Priority 2]" (p. 10). These three Checkpoints, if applied, could improve the online experience for the MTBI survivor.

## Summary

MTBI is a major health issue that has captured attention at the highest levels of government in the United States. Considerable focus has been directed toward physical disabilities and stroke, but there has been no close-up study of information access among survivors of MTBI which, in fact, has enjoyed an official definition only since 2003. Research is beginning to address physiology and sequelae, and social systems are slowly moving toward understanding.

When the Children's Health Act of 2000 authorized further study, an intensive research effort by the CDC to educate the public and reduce incidence of MTBI began. The first step was to develop a common definition. As a result, reporting could be more accurate. Since 2000, estimates have moved from percentages of documented TBIs to prevalence of MTBI itself. The relatively short period of time since this intense effort began, coupled with sensible first steps of establishing definition and prevalence, leaves a gap in the literature about MTBI and information access on the web. One would expect that, given sufficient funding, future research will venture into information processing in much greater detail.

MTBI survivors function and participate in a vast variety of resources available on the web. Whether shopping, participating in online education, interacting with others, or many other choices, the person with MTBI is interfacing with web pages in search of information. The WCAG 1.0's 14 Guidelines and Checkpoints have guided web accessibility development since 1999. These Guidelines are measurably focused on physical disabilities. Aware of cognitive disabilities that result from stroke and other illness-related incidents, WCAG 1.0 presents 19 Checkpoints that address cognitive

needs. Unfortunately, only two of these—flicker control and simplified language—are rated Priority 1 (required). The other 17 are either Priority 2 (would improve experience but not required), or Priority 3 (primarily for developers and not generally applied). It appears that accessible website development that meets the needs of survivors of MTBI is in the hands of developers.

The human cost of MTBI is disturbingly high. Lost productivity and quality of life related to damage to executive function, compromised vision, emotionality, and command of language is enough to impact employment as well as daily living. The cost borne by family and friends speak to the immense tragedy that is MTBI. This *silent epidemic* must find its voice. Meanwhile, the need for an accessible web remains apparent for all individuals with disabilities.

# CHAPTER III

## Research Design and Methods

### *About Qualitative Methodology*

In a world characterized by multiple realities and contextual truth, where researchers ask how people make sense of their lives and offer opportunities to discover new attitudes and beliefs, a priori hypothesis testing does not always afford appropriate results. "No a priori theory could anticipate the many realities that the inquirer will inevitably encounter in the field, nor encompass the many factors that make a difference at the micro (local) level" (Lincoln & Guba, 1985, p. 205). When reality has presented a question that must be explored to discover meaning, then qualitative research is the paradigm of choice. Qualitative methods and strategies have evolved through a process of rigorous refinement. From today's perspective, "there seems to be some consensus as to what constitutes qualitative inquiry and such a discussion is not needed" (Creswell, 2003, p. 180). A brief discussion here will, hopefully, provide sufficient background to better understand this study.

*Characteristics of qualitative research*

Qualitative research involves a number of characteristics that are distinguished from quantitative perspectives (Bogdan & Bicklen, 1992; Creswell, 2003; Creswell 2007, Lincoln & Guba, 1985). Creswell (2003) outlined commonly adopted characteristics that are included in this section.

*Natural setting*. Qualitative research involves fieldwork conducted within the natural setting, or context, of the participant. Studying people in their natural setting

offers a rich picture of phenomena and interaction within familiar conditions. Removing the participant from the life context under study can result in missed opportunity to observe phenomena that are present only within the natural setting.

*Multiple methods of data collection.* Data is gathered through of a variety of sources, including interviews, observation, pictures, diaries, and others. While the qualitative researcher, as the primary data collection instrument (Bogdan & Biklen, 1992; Creswell, 2003; Erlandson, Harris, Skipper, & Allen, 1992; Lincoln & Guba, 1985), takes notes, listens to stories, then weaves what is heard, seen, felt, and so on, into a pattern of intricate detail to draw theory from data, the "investigator and respondent together *create* the data of the research" [emphasis in the original] (Lincoln & Guba, 1985, p. 100).

*Emergent.* Qualitative, naturalistic inquiry traditions look for emerging meaning that lurks within human stories by exploring experiences or phenomena. Participant experiences each speak to part of a story that unfolds into a greater picture.

*Interpretive.* As the primary instrument, "the researcher filters the data through a personal lens that is situated in a specific sociopolitical and historical moment" (Creswell, 2003, p. 182). Bogdan and Biklen comment that "choices of codes and grouping of data into codes, is influenced by the researcher's social values and ways of making sense of the world" (1992, p.172).

*Reflexivity*. Interpretive work requires that the researcher be fully aware of one's personal filters. Steps should be taken to assure that a study does not become a statement of the researcher's personal opinion. Researcher bias is an unavoidable factor to grapple with in any attempt to understand accurately and communicate another person's way of making meaning in life (Bogdan & Bicklen, 1992; Creswell, 2003). It is impossible for a

qualitative study to be free from researcher interpretation, so it is essential for the researcher to have studied personal assumptions and experiences. "This introspection and acknowledgement of biases, values, and interests (or *reflexivity*) [emphasis in the original] typifies qualitative research today….It also represents honesty and openness to research, acknowledging that all inquiry is laden with values" (Creswell, 2003, p. 182).

*Complex reasoning.* Data are analyzed inductively; that is, research is not driven by preexisting hypotheses but seek to discover new theory or new questions. Inductive processing begins with details and moves to more general thought. Inductive processing is used to tease theory from data and move from specific to broad, whereas deductive thought, Sherlock Holmes style, starts with the general idea, examines details, until one detail becomes the answer. Modern interpretation of qualitative analysis indicates that deductive as well as inductive reasoning is present (Creswell 2003).

*Strategies of inquiry.* Traditions that have emerged from the general description of naturalistic inquiry include, but are not limited to, ethnography, phenomenology, narrative inquiry, biography, grounded theory, and case study (Clandinin & Connelly, 2000; Creswell, 2003, 2007; Lincoln & Guba, 1985). Theory orientation, question structure, amount of detail, and specificity of the end product differ according to tradition and the fields from which the traditions emerge.

*Holistic.* Qualitative research explores the broad picture, the process of lives. "This explains why qualitative research studies appear as broad, panoramic views rather than micro-analyses. The more complex, interactive, and encompassing the narrative, the better the qualitative study" (Creswell, 2003, p. 182). It is through process that we make

meaning of our lives. "Qualitative researchers are concerned with process rather than simply with outcomes or products" (Bogdan & Bicklen, 1992, p. 31).

*Research Design: Grounded Theory*

The intention of the grounded theory tradition is to structure data collection and analysis so that a working theory, derived from the data, will emerge (Lincoln & Guba, 1985, Strauss & Corbin, 1990). "Grounded theory allows the relevant social organization and socialpsychological organization of the people studied to be discovered, to emerge – in their perspective!" (Glaser, 1992, p. 5). Glaser and Strauss explain their philosophy that "the adequacy of a theory…cannot be divorced from the process by which it is generated….It is likely to be a better theory to the degree that it has been inductively developed from social research" (1967, p. 5). As such, it is "an inductive, constant comparative method in which the researcher ultimately attempts to generate a theory of human experience grounded in the data which summarizes the phenomenon being studied" (Babchuk, Courtney, & Jha, 1994, p. 3). The researcher "tries to give his data a more general sociological meaning, as well as to account for or interpret what he found" (Glaser & Strauss, 1967, p. 4). Glaser and Strauss further explain that

> since the categories are discovered by examination of the data, laymen involved in the area to which the theory applies will usually be able to understand it, while [researchers] who work in other areas will recognize an understandable theory linked with the data of a given area….Theory based on data can usually not be completely refuted by more data or replaced by another theory….it is too intimately linked to data…destined to last despite its inevitable modification and reformulation. (Glaser & Strauss, 1967, pp. 3-4)

Grounded theory presented by Strauss and Corbin diverged from the original model created by Glaser and Strauss (Charmaz, 2007). In his grounded theory collection, Glaser has strongly objected to changing grounded theory into a new method involving layers of coding that are *forced* into categories. Glaser structured his 1992 book, "Basics of Grounded Theory Analysis: Emergence vs. Forcing," to match the organization of Strauss and Corbin's 1990 "Basics of Qualitative Research." Chapter by chapter, Glaser speaks to various levels of departure:

> Basics of Qualitative Research just puts out an old method in new terminology, ignoring the true contribution of Discovery of Grounded Theory [Glaser, 1967] and Theoretical Sensitivity [Glaser, 1978]. Without this scholarship, which accounts for changes past to present, the authors can say and claim anything. It asks others to figure out the changes if they can even formulate them. (1992, p. 7).

Glaser further predicts a bleak future for researchers who embrace the practice of forcing codes into categories:

> the more the analyst practices the use of this model [forced coding] the more he will exclude forever his ability to respond to any theoretical code that may emerge and become relevant. He will always just see a condition or a consequence irrespective of relevance and state his professional identity on it. (1992, p. 63-64)

Glaser continued to counter his colleagues with the original model. He reminded his colleagues that grounded theory analysis consists of "three major components: (1) data collection, which soon becomes intricately involved in (2) the methods analysis, that

soon generate the concepts, hypotheses and their integration which result in the production of (3) written and verbal presentations" (Glaser, 1992, p. 13).

This grounded theory study of MTBI survivors and the web was informed by both *camps*: the original grounded theory as developed by Glaser and Strauss in 1965 and the divergent method espoused by Strauss and Corbin that informs much research instruction today. In a lengthy process, data were coded and grouped, recoded and regrouped, until Theoretical coding was attained. Analysis of codes and categories was informed more by the flexible original method than by the forced highly structured method.

Charmaz, a student of both Glaser and Strauss, clearly discusses grounded theory as originally developed while presenting Strauss and Corbin's departure—evolution perhaps—in clear terms (2007).

### *Brief Coding Overview*

#### *First Phase: Strauss and Corbin*

Strauss and Corbin (1990) assert that five steps be considered. First is study of causal conditions that "lead to the occurrence or development of a phenomenon" (p. 100). These are specific properties of the phenomenon as well as conditions that influence the fourth step, action/interaction. The second step, study of a phenomenon, asks what the data refer to and what emerges from the causal condition. Context, the third step, "represents the specific properties that pertain to a phenomenon … location of events or incidents" (p. 101). Intervening conditions are similar to causal conditions but are broad conditions that are brought to bear on the action/interaction step. Finally, action/interaction strategies can be studied in terms of sequences and purpose, informed by causal and intervening conditions, context and the phenomenon itself. As the steps of

this model bear out, consequences of action/interaction strategies may become conditions in another step of analysis.

Grounded theory data collection involves three steps of *theoretical sampling* where data are gathered "on the basis of concepts that have proven theoretical relevance to the evolving theory" (Strauss & Corbin, 1990, p. 176). *Proven theoretical relevance* "[i]ndicates that concepts are deemed to be significant because they are repeatedly present or notably absent when comparing incident after incident, and are of sufficient importance to be give the status of categories" (p. 176). The first step, *open sampling,* finds that "openness rather than specificity guides the sampling choices….can be done purposively or systematically, or occur fortuitously" (p. 176).

*First Phase: Glaser*

Conversely, Glaser states that

> [i]n grounded theory we do not [emphasis in the original] link properties and categories in a set of relationships denoting casual conditions, phenomena, context, intervening condition, action/interactional strategies and consequences. This would be preconception and forcing theoretical coding concepts to the max. The grounded theorist simply codes for categories and properties and lets whatever theoretical codes emerge where they may. To use this model…teaches the analyst to force a full conceptual description on data with no questions about whether the links are relevant to any emerging theory that really explains how the participants process their main concerns. (Glaser, 1992, p. 63)

"Open coding is the initial step of theoretical analysis that pertains to the initial discovery of categories and their properties….the analyst starts with conceptual

nothing—no concepts. Open coding comes to an end when it yields a core category" (Glaser, 1992, p. 39). How coding systems develop is influenced as the researcher asks a set of questions of the data: "What are these data pertinent to, what do they indicate, etc?" (Babchuk et al., 1994, p. 4). Types of codes, not all inclusive, as discussed by Glaser (1998) and Bogdan and Biklen (1992), view data from a number of different perspectives. "Certain words, phrases, patterns of behavior, subjects' ways of thinking and events repeat and stand out" (p. 166). Codes can be as straightforward as demographic or physical description of context, or as abstract as theoretical or socio-political orientation of either the researcher or the participants.

*First Phase: Charmaz*

Charmaz (2007) starts with initial coding, moving to focused coding, then theoretical coding. "Coding means naming segments of data with a label and simultaneously categorizes, summarizes, and accounts for each piece of data. Coding is the first step in moving beyond concrete statements in the data to making analytic interpretations" (Charmaz, 2007, p. 43). "Initial coding should stick closely to the data" (p. 47).

*Second Phase: Strauss and Corbin—Axial*

Relational and variational sampling, "associated with axial coding…[aims] to maximize the finding of differences at the dimensional level….[and] can be done deliberately or systematically" (p. 176). Finally, *discriminate sampling* "associated with selective coding….[aims] to maximize opportunities for verifying the story line and relationships between categories and filling in poorly developed categories" (Straus &

Corbin, 1990, p. 176). Discriminate sampling is also integral to the verification process (Creswell, 1998).

*Second Phase: Glaser—Substantive*

> To selectively code means to cease open coding and to delimit coding to only those variables that relate to the core variable….selective coding starts after and only when the analyst is sure that she has found a core variable. The core category simply emerges from the constant comparative coding and analyzing the data. The core variable then becomes a guide to further data collection and theoretical sampling. (Glaser, 1992, p. 75)

Glaser (1998) discusses substantive coding as "the categories and properties of the theory which images the substantive area researched" (p. 163).

*Second Phase: Charmaz—Focused*

Charmaz (2007) discussed focused coding as "the second major phase in coding [and examines codes on a more] directed, selective, and conceptual" basis (p. 57). Focused coding "means using the most significant and/or frequent earlier codes to sift through large amounts of data….requires decisions about which initial codes make the most analytic sense to categorize your data incisively and completely" (p. 57).

*Saturation*

Theoretical saturation is essential for theory to be conceptually representative of the data (Strauss, 1990). The general rule in grounded theory research is to sample until theoretical saturation of each category is reached. When theoretical saturation is attended to during data collection, the amount of data can be lessened, because the researcher does not need to continue collecting data that already speaks to a code or category (Charmaz,

2007). Sampling continues until (a) no new or relevant data emerges from the data that would strengthen categories, (b) all paradigm variations and processes are accounted for, and (c) the relationships between categories are well established and validated (Strauss, 1987/1995).

*Third Phase: Strauss and Corbin—Selective*

Strauss and Corbin define selective coding as "the process of selecting the core category, systematically relating it to other categories, validating those relationships, and filling in categories that need further refinement and development" (1990, p. 116). As we can see, grounded theory selective coding serves in a different capacity than that presented by Glaser. Strauss states that selective coding is in search of the core category, while Glaser states that selective coding comes only after the core category has emerged.

*Third Phase: Glaser—Theoretical*

Following substantive coding, Glaser states that theoretical codes "implicitly conceptualize how the substantive codes will relate to each other as interrelated, multivariate hypotheses in accounting for resolving the main concern. They are emergent and weave the fractured story turned into concepts back to an organized whole theory" (Glaser, 1998, p. 163). Further, it "is the interaction between substantive and theoretical coding which characterizes grounded theory [as] an analytic inductive research methodology rather than conceptual journalism" (165). Theoretical coding is "a property of coding and constant comparative analysis that yields the conceptual relationship between categories and their properties as they emerge….Theoretical codes are conceptual connectors to be used implicitly and explicitly in the way and style in which

the analyst writes" (Glaser, 1992, p. 38). Categories emerge as the researcher compares "incident to incident and/or to concepts" (p. 40).

*Third Phase: Charmaz—Theoretical*

"Theoretical coding is a sophisticated level of coding that follows the codes you have selected during focused coding" (Charmaz, 2007, p. 63). Charmaz strongly references Glaser in her discussion of theoretical coding. Charmaz further explains that theoretical codes "are integrative; they lend form to the focused codes….These codes may help you tell an analytic story that has coherence,….conceptualize how your substantive codes are related,…[and] move your analytic story into a theoretical direction" (p. 63).

## *Pre-existing Assumptions*

Pre-existing assumptions do exist in the qualitative research world in a manner that is very different from that of quantitative research. That data *can* be collected in the natural setting (in participant's homes and on familiar computers), that participants *should* have a forum for expressing their voice, and that guidelines for conducting qualitative research evolve as the research progresses, depict how pre-existing assumptions manifest in qualitative work. Such assumptions represent this researcher's "social values and ways of making sense of the world that can influence which processes, activities, events, and perspectives researchers consider important enough to code" (Bogdan & Biklen, 1992, p. 172). Pre-existing assumptions can also be influenced by academic training (Bogdan & Biklen, 1992), cultural background, even personal experience (Strauss 1987/1995), thus serving as an information filter that affects data collection and analysis (Bogdan & Biklen, 1992). Naturalistic researchers generally agree

that the researcher is the primary research instrument (Bogdan & Biklen, 1992; Erlandson, Harris, Skipper & Allen, 1992; Lincoln & Guba, 1985). Considering that the grounded theory researcher is the primary research instrument, pre-existing assumptions and personal experiences emerge with clarity, and the researcher emerges as a participant in the study, providing clear information for the reflexivity process.

### *Reflexivity*

> If the unexamined life is not worth living, the inquirer who persists in remaining ignorant of contextual values is at best not worth listening to, and, at worst, may generate findings positively inimical to both the cause of science and the well-being of the respondents. (Lincoln & Guba, 1985, p. 177)

I became interested in this topic as a result of experiencing Mild Traumatic Brain Injury (MTBI) just three days after completing my doctoral comprehensive exams. I could no longer comprehend my dissertation research that I had been working with for many months. As I proceeded with rehabilitation, I soon learned that there was very little understanding of my loss among the rehabilitation team and even less among my co-workers, friends and family. This was especially a problem in my workplace. From the outside, I appeared quite fine. On the inside, I no longer felt competent in my work.

My attempts at library searches were futile for many months but slowly began to unveil a literature that addressed Traumatic Brain Injury. There had been some work in the outcomes of college students with TBI, but only one article had surfaced that addressed the issue of cognitive loss among "intellectuals." As I was newly interested in the phenomenon that had happened to me, I decided to change my dissertation topic to study how highly educated people handle their learning experiences following a TBI.

I have been a student of research in the field of adult education for many years. I hold a masters degree in the field and have conducted several studies in the areas of adult literacy and critical thinking. Moving toward an adult learning focus seemed a natural fit to unify my study into my own state with research into how others have experienced learning following the brain injury. As this topic developed, I became aware that the old adult literacy focus on access to technology had evolved to include access to information that technology provides. I also realized that I, as a competent computer user, experienced constant difficulties with both reading and photosensitivity. I learned that the strange sensations I experienced when I read anything and when I worked on the computer were photosensitive seizures. I had suspected that a combination of my eyes moving back and forth across lines and the light from the monitor was very bad for me. Yet, I was employed in a position that required constant computer usage and my research required considerable reading and keyboarding.

My biases and beliefs at the time of this study were that the personal and economic loss for a highly educated person is greater than for a person of average intelligence and skill. Right or wrong, this belief came to me because of the great potential that, I felt, is lost in the person of advanced skill or intelligence. As the years have gone by, my own personal and economic loss has been profound. Often the greatest skill a person has to offer society is cognitive ability to manage information, think critically about issues, and multitask. With one skill destroyed, another vocational skill ideally emerges to take its place, but no skill replaces the ability to think.

By reading books written by brain injury survivors, I found that the experiences described by writers were so similar to mine that I felt I could have written the books

myself. I developed a bias that other survivors share the same experiences and understandings that I have. At the time, I believed that other survivors had similar learning experiences and shared the same meanings that I had. Because I know now that each injury is unique, and sequelae, though predictable, also are unique, I have made every effort to identify and set aside these biases as I analyzed the data so that I could hear voices that speak to experiences that are different from my own.

### *Role of the Researcher*

The role of the researcher in qualitative research is to be fully cognizant of personal lenses and how involved the researcher will be with the topic of study. For example, the personal lens must be explored and set aside so that the data could be approached with a fresh perspective. The research team discusses the lenses through which researchers view research. The internal researcher must continually examine personal biases in all research conducted within the project, utilizing research methodology and content knowledge but setting aside personal and political perspectives.

How involved the researcher will be with the participants is also to be considered. Level of relationship with participants can range from deep immersion, such as for ethnography, to relative distance, such as for phenomenology.

It is the researcher's responsibility to protect confidentiality and well being of study participants. Being aware of one's personal lens—the researcher's point of view and perspectives—helps ensure that participant voices are reflected fairly and accurately portrayed.

*Validity*

"Verification in grounded theory research is an active part of the process of research and becomes part of the standards one should use to judge the quality of the study" (Creswell, 1998, p. 209). Grounded theorists hold that it is the researcher who is responsible for establishing verification in a study (Creswell, 1998; Erlandson et al, 1992; Strauss, 1987/1995; Strauss & Corbin, 1990; Bogdan & Biklen, 1992). Qualitative researchers direct considerable care to the process of ensuring that findings honestly and authentically reflect the data. While the actual term for this process varies, the intent is consistent. Strauss discusses verification, induction, and deduction, stating that "deduction without verification or qualification or even negation of an hypothesis or set of hypotheses is truncated inquiry" (Strauss, 1995/1985, p. 11-12). Further, "verification cannot occur without deduction….for data collection without reference to implications of theoretical hypotheses are useless" (p. 12). Merriam suggests that the "accuracy of the information and whether it matches reality" informs the issue of internal validity (cited in Creswell, 1994, p. 158).

Regarding bias, Glaser indicated, "the fear of bias perspective, which forces data and renders it unfaithful to reality analyses, is not unfounded …. Grounded theory has several methods which reduce and forestall this bias… such as constant comparison and saturation and core relevance" (1992, p. 14). A generative question is raised and brought to the data to answer, where linkages are explored (Strauss, 1987/1995). Verification is solidified through this process. "Only that which is repeatedly found to stand up against reality will be built into the theory" (Strauss 1987/1995; Strauss & Corbin, 1990).

"At the same time that we're looking for evidence in the data to verify our statements of relationship, we are also looking for instances of when they might not hold up" (Strauss & Corbin, 1990, p. 108). Questions are raised at the presence of contradictory evidence. Should a transcript not support a statement or question, does this mean that original understanding of meaning is wrong? Contradictory findings may represent error, reality shifts, state of transition, as well as possible variations that add depth of understanding (Erlandson et al, 1992; Strauss & Corbin, 1990). When a variation appears, it becomes very important to "trace back and try to determine what conditions are causing this particular variation" (Strauss & Corbin, 1990, p. 140). Views are unique to each individual, so the data is examined, not from the point of view of comparing with each others experiences or those found in the literature, but only within the experience of each person, and about whether the data collected from each person accurately reflects their actual experience (Creswell, 1994).

While validity in grounded theory is heavily directed toward constant comparison—spiraling findings back to the original data to see if they authentically represent the data—in this study validation procedures as outlined by Creswell (2003) were also followed.

*Triangulation*

Multiple data sources were utilized for this study. Participants were observed as they visited websites. They also had their Idea Books in which to write any notes as they went along. Talk-Aloud was a third source. Their conversations were tape recorded for transcription.

*Rich, Thick, Description*

Creswell (2003) listed rich, thick, description as a validity strategy. Language used in a study is critical. This study included words from the participants as they described their experiences.

*Bias*

Researcher bias is a question as findings emerge from the data. Self-examination aids the researcher to distinguish between self and other. One of the first steps by this researcher was to review personal journal notes and compile a statement of my personal lens and include it in the final report.

*Prolonged Time in the Field*

Unlike ethnography where the researcher spends considerable time in the field, this study consisted of in-depth interviews. Each interview was a discrete experience requiring from 2-4 hours. However, interviews were collected over the course of several weeks. Contact was maintained with some of the participants, and relationships that grew from the interview experience did, in a sense, prolong the experience long past the official end of data collection. No notes were taken, but observation allowed this researcher to continue to see how MTBI affected their lives.

*Peer Debriefing*

This researcher had the opportunity to discuss this study at length with Dr. Roger Bruning, the advisor on this project. Dr. Bruning is well-versed in quantitative research, therefore, he ensured that this researcher could clearly present this grounded theory study in a meaningful way.

*Member-checks*

Due to the great length of time between data collection and writing the findings, several participants moved or became socially and geographically unavailable. Two participants reviewed the final report.

The first participant who agreed to review the study was J. She commented that the categories all made sense and that it was interesting to her to read the analysis and findings. She felt that it was a good idea to have had participants who represented different ages, genders, employment, and education. She liked the tables. As she read through the findings about vision, she was happy to learn that she experienced the same vision problems as other participants. Overall, J was pleased with the report.

LH, the second participant who reviewed the study, found the findings to be well-developed and accurate according to her experiences as a web user with MTBI.

## *Ethical Dilemmas*

During data collection, treatment of participants is of utmost concern. If a participant should choose to withdraw after providing valuable data, a researcher could be tempted to use the data, regardless. Dissemination of data must continue to protect participant confidentiality. Without appropriate care, anonymity may be compromised if the study is published. Control over data may be jeopardized. Should the researcher become excessively involved with the issue—*go native* in the research vernacular—when the tradition does not support a high level of involvement, the distinction between data and researcher's interpretation may be blurred.

*Participants*

The nature of MTBI is such that, while it is impossible to pinpoint exactly how a person may be handling life as a survivor, there are common sequelae shared by many survivors. The following criteria were followed when recruiting participants for this study:

1. alert (not in a coma),
2. able to communicate in some manner both in written and verbal modalities,
3. at or above the age of majority in their state of residence,
4. able to comprehend the nature of the study,
5. competent to legally sign the Institutional Review Board consent form, and
6. at least minimal experience with web browser function and web page use.

Advertising for this study included letters to doctors (Appendix A), word-of-mouth, and business-size cards posted in public places (Appendix B). Candidates for this study contacted this researcher with an interest in sharing their own experiences. This study was viewed as relevant to their personal circumstances. Candidates were screened to query the nature of the reported TBI, length of time since injury, any medications that may have influenced this study, computer experience, extent of rehabilitation, known persistent problems, and susceptibility to movement or flashing lights on the computer screen (Appendix C). Individuals who qualified for this study were asked to sign a consent form (Appendix D).

*L Overview*

L is a 33-year-old married female who worked as a legal secretary at the time of her car accident but at the time of the interview was providing child care for her nieces

and nephews at home at the time of this interview. For this study, she spoke of results of the car accident in February, 2001. She reported that she was not unconscious at any time, did not have a concussion, and that she was taken to the hospital where she was given instructions on how to care for herself. During the interview she revealed that she has also suffered whiplash five times in the past, although she denies ever suffering a concussion.

Lingering symptoms included pain in her neck, mainly when sitting at her computer and driving. She also continued to have headaches that she attributed to the muscles in her neck. She was not told that she had a brain injury.

L spoke casually about her Internet experience. She stated that she knew how to launch a browser and access the web. The browser she used was Internet Explorer and, although she stated that she did not spend much time on the web, considered herself somewhat experienced with the browser. She denied that flashing lights or movement on the computer screen caused her any difficulty. Her favorite game site was pogo.com, entertainment that afforded her the choices and security that she preferred. She and her husband are avid Nascar fans and she visits the Nascar home page daily to view in-depth information.

*T Overview*

T, a 33-year-old single female, was an office receptionist at a university at the time of the interview. She also had had a car accident approximately four years before this interview, when she was a telephone customer representative for a retail company. She reported that although she suffered whiplash and remembered hitting her head, she

did not tell the police officer that she hit her head as she was quite shaken. She was taken to the hospital where she was given instructions and released.

Lingering symptoms included pain in her back and shoulders. She also had been told she had PTSD and experienced difficulty driving at times. Both as a driver and passenger in a moving vehicle, motion to the right continues to cause her to jump noticeably.

Changing self-directed work to a supervised position requiring another person to monitor focus and productivity can be a voluntary move or a difficult, involuntary one. T stated that she had been employed in telephone customer service but when she changed jobs she moved into a position of greater responsibility but with less independence. “I have more responsibilities now than I did then. More and more type tasking.” Yet, she reported that detail and organizing were compromised as a result of her injury.

She considered her online experience to be moderate. At the time of this interview, she stated that she did not spend much time on the web, primarily because she did not have reliable internet access at home. She did enjoy sites that were related to her personal interests, mainly on pagan topics. When she used a search engine she was focused and tenacious. She started by going to the first *hit* on the search page, viewed the page, then used the browser back arrow to go back to the search engine page, where she would open the next link in sequence. She was very methodological about sequentially opening websites according to their order in the list.

*SE Overview*

SE was a 46-year-old married female who was trained as a truck driver. During the interview her story unfolded to include numerous injuries that occurred as far back as

when she was in grade school. When she was nine years old, she fell on her forehead. She had two black eyes for about a month. In 1970, while still in grade school, she fell on ice. When she was in the range of seven to twelve years old, she was hit with a baseball bat between her eyes. In 1982 she suffered a vehicle accident. She was driving an ATV three-wheeler vehicle that flipped over, leaving her with a concussion, two broken vertebra and skull fractures. In 1983 she hit the front of her forehead on a beam. In 1986 she suffered a leg injury in a crash with her Harley Davidson motorcycle. In 1998 she suffered a whiplash when her car was rear-ended in a street collision. The injury she initially alluded to for the interview was the whiplash in 1998.

Lingering symptoms she reported included forgetfulness. She became aware of this in her early 20s when she would forget where she put something and also experienced difficulty remembering in conversations. She still needed to write information down in order to remember. She continued to experience fatigue, sleep interruption, and frequent need for a nap during the day. She recalled when she was in school that her teacher would catch her "daydreaming" and accused her of not paying attention. As an adult she wondered if she was having absence seizures when she was young. Also at that time, she described conversations would sound like gibberish, "like the teacher in the Charlie Brown cartoon."

Due to considerable eyestrain, headaches, and difficulty coping with flashing lights on a computer screen, SE changed her line of work to truck driving. She reported, "Now that I'm not working on computers, that I'm working asphalt and driving truck and stuff, I'm using my glasses less and less and using my safety glasses at work which are just as good at distance." Her eye-strain ended with computer-free employment.

She described her internet use as primarily email, games, and children's activity sites. Children's activity sites were often a focus of web exploration. Her pre-school grandson inspired this interest.

*F Overview*

F was a 20-year-old man who was a high school student and part-time employee at a restaurant at the time of his car accident in 1998. He continued employment in the food service industry. He reported that the accident was on an icy road when he was first hit from behind and slid to hit the car ahead of him. This resulted in his head snapping back and forward. He reported having talked with an officer but was taken to the hospital later by his parents due to a deep cut on his lip. He also bumped heads with his brother shortly before this interview. He reported that "it hurt a lot." He had never been told that he has a head injury or brain injury.

Lingering symptoms included having headaches for about three years following the accident. During our conversation, he also appeared to be frustrated when he could not provide an answer to an interview question.

F was a high school student working at a grocery store at the time of his injury and he reported that at the time of this interview (after graduating high school) he still worked in food service, but in a position of greater responsibility. He had sought neither post-secondary education nor a better paying job.

While he knew how to access the web by clicking on a button, he described himself as a person who does not spend much time on the World Wide Web. He enjoyed going to websites about his favorite band: Tool.

*K Overview*

K was a 30 year-old-single male who worked in industrial maintenance at the time of his most recent injury. Since that time his employment had changed to being a production foreman. He reported that he had never had a concussion; however, he suffered whiplash in a car accident three and one-half years before this interview. He did not go to the hospital nor did he receive any other medical treatment. He stated he was OK now.

During the interview his story unfolded to reveal numerous additional injuries. He said that he fell and hit his head 13 times in 1992 or 1993. He reported that he was not unconscious, but was "really dizzy for a while." When asked what he did when he fell, he replied that he "laid there." He took care of himself by going inside and lying down.

He reported that he "hits his head a lot." He also said that he had been "electrocuted a lot" on the job, with a shock three years ago after a car accident and again one year ago. He remains employed in the electronics industry where he continues to be at risk of further exposure to electricity.

K's lingering symptoms manifested in awareness that the "past is a haze." He also reported experiencing trouble at work with details, names, and faces.

As a high-end internet user, K considered himself an expert in computer and browser use. He knew how to access the web and used Internet Explorer as his browser of choice. His favorite sites were those that focused on technology, "geek sites" to coin a phrase, directed toward the sophisticated heavy user, such as CNET.com. Lights and movement on the screen bothered him, although it depended on which colors are

involved. Red and yellow were "bad" for him and worse when those colors flicker. He felt that general page design did not affect him.

*E Overview*

E was an 18-year-old female who reported an injury when she was in 9th grade. She was a student at a major university at the time of this interview. She suffered a concussion on August 19, 1999 when she fell while playing soccer at a summer camp. She was unconscious for less than a minute, was taken to the hospital where she had an MRI. She was in the hospital for one and one-half days where she reported being "in and out" of consciousness during that time.

As she continued to expand on personal history, she spoke of two additional accidents. When she was ten years of age she hurt herself while performing a back flip on the family trampoline. She reported that she did not hit her head on the rim but sustained a whiplash. In addition, when she was nine she fell out of her treehouse. There were stairs, and she missed most of them.

E described her lingering symptoms to include depression from her daily post-concussive headaches. She reported that at school she continued to have an overall hard time focusing, sitting still, and coping with eye fatigue. She described difficulty with her eyes to include increased effort needed to focus. Thus, when she was relaxed her vision was out of focus.

She considered herself moderately experienced with browser software. She knew how to log on to a browser and accessed the web through America Online. She reported that flashing lights and page design did not affect her. During the school year her use of

the computer to access the web was limited to once a day, approximately half an hour to an hour, and less in the summer when school was not in session.

*J Overview*

J was a 40-year-old woman who reported lingering symptoms from two separate incidents. In 1979, when she was in high school, she was hit in the head by the hatchback door on her car when the door supports gave out and the door fell. She had a "good knot." About three hours later, while she was at work, she fell. She felt spinning, no memory for a while, and her employer took her to the hospital with a severe concussion and possible skull fracture. She was sent home and was "flat on her back" for about two weeks.

The 1992 incident was domestic abuse. Her now ex-husband hit her in the head. She went to the emergency room and had a headache for about two weeks. She reported that she did not lose consciousness.

Lingering symptoms include having trouble with focus and studying. In 1979 following the hatchback incident, when she returned to school, she couldn't study because of ongoing headaches. She currently experienced difficulty with her eyes tracking across a line while she read. She stated that her migraines didn't start until after the head traumas. Strobe lights and bright lights "really bother me." J noted that over the years her speech has changed. "Sometimes I can't get the words out." Another incident that may be considered a lingering symptom, or unrelated, was a car accident 2002 when she "blacked out" and hit another car at low speed. She reported to this researcher that she has experienced occasional seizures that are unconfirmed by her doctor.

J considered herself as having moderate experience with a computer and browser software. She spent approximately 2-3 hours per week on the web checking mail and exploring retail sites. She likes to knit and crochet so she lingered on craft sites.

She is a nurse but is disabled with bipolar disorder and PTSD.

*LH Overview*

LH, now in her mid 50s, reported having experienced multiple head and brain injuries since she was 12 years old. Over the years she has been employed in low paying jobs including being a laundry worker. She has an associates degree in business but remains unemployed. When she was 12 she suffered an accident at school. She recalled that the doctors did not look at her head because her back was injured. She was in traction due to the back injury. At some point in the 1960s she was in a car accident. She was unconscious with a skull fracture behind her ear and a hurt back. In the 1970s and 1980s she suffered domestic abuse. She was taken to the hospital with severe bruises. She stated that she looked like a different person. As the violence continued, she reported that her now ex-husband knocked her across the room with a fist and she hit a wall. She also reported being held down and pummeled.

She summarized her ongoing problems to include attention deficit, distractibility, and emotional scarring. She believed that the attention deficit began with her accident when she was 12. As she grew older and suffered more abuse, her life seemed to be like "chasing rabbits." She disclosed that she was easily distracted and that she couldn't "get stuff done." Staying on task remains a challenge. Her economic loss has been profound, as she had not been able to get or hold a job. She felt that the abuse "scarred my whole

life." She stated, "I lived the better part of my life thinking it was inherent or personal and thought I can change."

While LH knew how to access the internet by clicking on the Explorer icon, she considered herself to have little or no experience with browser software. She did not spend much time on the web at home. When afforded the opportunity to spend time on the web, LH searched for specific information having to do with starting a business as an online consultant.

## Data Collection

### *Multiple Approaches*

This grounded theory study explored how MTBI survivors interact with web pages to find their way around, into, and access information with a website. Data collection involved asking participants to launch their favorite page, then navigate as they preferred. The final activity included viewing a pre-selected group of web pages. They were directed to the Section508.gov website, to a search engine to locate Bobby™ approved sites, and to choose two or three sites from the search engine page. The final step was to go to an Australian metro website. As they moved from page to page, they engaged in an interactive dialogue with the researcher, answering questions and commenting on the process.

This researcher chose not to include urls or copies of web pages in this report because of the possibility that by viewing the sites, readers would find themselves comparing participant's comments with their own interpretations. Doing so would establish a barrier between the reader and the data in the form of comparison. It was felt

that by viewing the sites, readers could focus too heavily on the visual data. This researcher attempted to "hear what they saw" as much as observe the experience. During the interviews participants were encouraged to describe what they viewed in their own words. They expressed how they felt as well. Viewing the websites would not have assisted the reader to understand participant experiences, simply because of the added layer of the reader's personal filters.

## *Seven Stages of Data Collection*

### *Reflexivity*

Data collection began as this researcher engaged in reflexivity to develop a sense of personal lens. This process took place over time and was revisited in the research journal and memos. Understanding this personal lens cleared the way for authentic listening and critical thinking during data collection and analysis.

### *Idea Book*

Following screening and consent, the next step was to introduce the note-taking aspect of data collection. Participants were given a small notebook – the Idea Book (Appendix E). Specific questions were listed on each notebook page for the Participant to answer about each web page visited: (a) Briefly describe this page. (b) What did you like about this page? and (c) What didn't you like about this page?

### *Interviews*

In keeping with qualitative tradition, participants were interviewed in a casual conversational style within the comfort of their own homes or in a familiar location. They also chose websites where they wanted to begin the web page examination stage of the study before being directed to examine sites chosen by the interviewer. One interview

was conducted over three sessions due to a participant's sensitivity to the computer screen. The researcher took copious notes during the interview process (see Appendix F for Interview procedures as included in IRB protocol).

*Talk-Aloud*

Talk-Aloud involved the participant talking through the interview process. This running dialogue with the interviewer was recorded and transcribed, providing the written data for analysis. The combination of the Idea Book and the Talk-Aloud data was intended to provide details and fill in any "blanks" that may have remained in the researcher's notes.

*Observations*

As interviews proceeded, documentation included observation of participant behavior, formal visual note of body language, facial expressions, hand movements, hesitation, moments of frustration or comfort, and any other indications of influence of a web page on their overall experience.

*Final Debriefing*

Finally, a debriefing interview included participant commentary on a direct comparison of viewed pages. The debriefing interview consisted of three questions:

1. What features worked best for you?
2. What features did not work for you?
3. Any other comments?

*Researcher Data*

Grounded theory procedures include considerable use of memos, or researcher notes, about specific incidents. Beyond memos are "observer comments" in the field—

more elaborate than memos—that offer opportunity for the researcher to document questions and breakthroughs in thought (Bogdan & Biklen, 1992).

## Data Analysis

Analysis is a picture that is painted as data are gathered, examined, and as time is spent with study participants (Bogdan & Biklen, 1992). On a pragmatic level, inductive data analysis involves making sense of field notes (Bogdan & Biklen, 1992; Lincoln & Guba, 1985). Clarifying grounded theory approach, Glaser explained:

> The whole notion of inductive vs deductive studies is an oversimplification of the very complex thinking patterns involved in grounded theory….grounded theory is an inductive methodology, but there is some deduction in grounded theory. Theoretical sampling is deductive. It is the carefully grounded deduction from an inducted category or hypothesis of where to go next….or what data one might find to induce further a growing theory….Deductions for theoretical sampling fosters better sources of data, hence better grounded inductions. (1998, p. 43)

For this study, data were analyzed using procedures outlined by Strauss (1967) and Glaser (1992, 1967, 1995, 1998), with attention to the divergent method presented by Strauss and Corbin (1990). This researcher felt that grounded theory, as a method, presented a choice to proceed with the original concepts developed by Glaser and Strauss while examining the divergent method proposed by Strauss and Corbin. This analysis presents the extended open coding phase to include theoretical coding, refraining from axial coding to the extent outlined by Strauss and Corbin. Charmaz explained that "[t]hose who prefer simple, flexible guidelines—and can tolerate ambiguity—do not need

to do axial coding" (2007, p. 61). As a validation measure, categories are viewed from both perspectives.

# CHAPTER IV

## Results

### *Spiral Analysis*

Transcript analysis can be conceived of as flowing in a spiral through the different stages of analysis of each transcript. Analysis, then, finds that data in one phase informs analysis in another. In this study, as more transcripts entered analysis, codes were arranged and rearranged until a set, completely informed by the data, was established.

The first three transcripts for this study were first read through and hand-coded in the margins. Data were deconstructed for line-by-line coding (Charmaz, 2007) and copied into a spreadsheet worksheet. Hand-written remarks were transcribed into the worksheet next to corresponding text. Transcripts were read again, adjusting the preliminary concepts as informed by cumulated understanding to that point. This focused coding process continued for an extended period of time, each time further clarifying participants' experiences as reported in the transcripts.

As codes emerged, definitions were developed to guide further use during coding of additional transcripts (Appendix G). Codes consisted of dozens of descriptive words and phrases that were grouped and regrouped into preliminary categories.

Next, the fourth transcript was coded using the code structure developed during analysis of the first three. With addition of the new transcript, data were further reduced to 62 codes. Some codes appeared to be approaching saturation, that is, additional codes were not providing fresh insight. These were observed closely as further analysis continued.

### *Verification*

For verification of the process thus far, the codes were taken back to the data to evaluate for fit. Two transcripts that had already been analyzed were chosen to recode, applying the reduced codes and categories. The exercise revealed that the codes and categories fit the data presented in the two transcripts. Recoding the first two transcripts validated the sorting process previously conducted on the first three. No new codes emerged.

With the 62 codes established as a reasonable summary, a fifth transcript was deconstructed using the established and defined codes. The same steps were followed. Codes that appeared to approach saturation were examined for meaning and were reassigned as necessary. Frequency tables also were created to add examples from each additional participant. The purpose, then, of the layers of data analysis was to ensure the best possible interpretation of the experience of the participants as they visited websites to address the purpose of this study.

As recommended by qualitative methodology procedures, the data were allowed to rest. Returning with fresh perspective, this researcher proceeded to deconstruct the four remaining interviews proceeded following the same procedures.

### *Preliminary Analysis: Strauss and Corbin Model*

Twelve categories emerged from codes, each presenting a facet of the multiple aspects of the participants' experiences with this exercise. Some codes within these categories shared meanings but were applied to separate contexts; therefore, the same section of transcript may have been located within more than one code, and that code may have been renamed and located in another category. The 12 categories, reduced

from the wide range of codes and listed alphabetically, are *Advertisement, Content, Focus and Distraction, Graphic Design, Links, Physical, Purpose, Reading, Self, Site, Technology, and Thinking and Learning.* Definitions for the categories were also developed to inform the code groupings (Appendix H). Appendix I displays codes grouped by category with frequencies.

In examining the conversations between the interviewer and the participant, as recorded by the transcripts, it became apparent that the responses of brain injury survivors often required some prompting due to memory and word-finding problems, distractibility, and other cognitive events that result from brain injury. Thus, researcher's questions and comments were noted along with participant statements. Prompting generally took the form of repeating previous comments or concepts expressed by the participant. Word-finding was especially difficult for some participants, but a single word used as a prompt often allowed them to proceed as intended.

Participants' comments were combined to develop a story that expressed their thoughts and feelings about each category. Comments often varied, reflecting the unique experiences of each participant.

*Advertisement Category*

The *Advertisement* category reflects the sometimes aggressive marketing of goods and services prevalent on websites. Visually, advertisements display colors and layouts that differ in size, message, and use of animation. Codes attributed to the *Advertisement* category reflect distraction, annoyance, assumptions about value, and descriptions of coping behaviors. While participants references to advertisements were less frequent than with other categories, their verbal expressions were louder and primarily negative, as

shown in Table 4.

Advertisements are created to draw attention, thus distracting the participant's focus. T found ads to be “annoying because they always blink.” S stated, “sometimes at the top of the page they have this one thing that used to say ‘if this is flashing you are a winner’ and it’s like, go away. I’ve been there and you’re not really a winner. They’re just annoying.” Advertisements placed within the layout or programmed as pop-ups may be perceived as pervasive and invasive, evoking feelings of annoyance and frustration, particularly with popup boxes and animated graphics. K, technologically experienced, expressed the intensity of his perception:

> they’re very annoying. I mean they’re just more than I can handle. What I hate is pop up ads on popup ads on popup ads. They’re some that you close and it pops up another popup ad.

*Table 4: Advertisement*

| Category | Code | Comment Frequency |
|---|---|---|
| Advertisement | Annoyed | 7 |
| | Pervasive | 7 |
| | Wastes Time | 3 |
| | Ignore | 3 |
| | Assumptions | 1 |
| | Distract | 1 |
| Advertisement Total | | 22 |

The User may assume that the advertisement lacks value and is a waste of time rather than consider that it may be useful to their personal lives.

*Content Category*

The web is an extensive source of information. Each page is a visual production created to engage the user with the site's message. The User responds to how text and colors are arranged on a page and how information is organized. The two codes that comprise the *Content* category are *Organize/Layout* and *Information*. Compared to other categories, Participants spoke often and consistently about layout, organization, and their relationship with knowledge. Table 5 illustrates how often these concepts were referenced in the transcripts.

Lists, for example, organize information to strengthen data-gathering. LH liked bullets, "and then there's stuff that goes under that. I mean it's organized. It has clearly identifiable sections." L assessed, "I like how it's categorized … so they're easy to find."

*Table 5: Content*

| Category | Code | Comment Frequency |
|---|---|---|
| Content | Organize/Layout | 131 |
| | Information | 73 |
| Content Total | | 204 |

T commented, "It's a bullet list so it's very easy to find whatever it was that you are looking for." "The first thing you notice right off the bat," remarked LH, "is that there's a new service because it's over on the left. Then I look at the picture. It's like reading a page. You start at the left and you work right." Rather than search for information within a site, "I personally want to know up front this is how…it works….I

don't want all the fluff first. I want the details first," she continued.

Similar to lists, *menus* and *boxes* provide information and visible cues to information access. Viewing a site for a train station, L commented, "I like … drop down menus for each of the timetables…then it gives you 11 choices so you can narrow your search right away….I like this [site map] because it just makes the whole thing more spacious." LH finds "little boxes that say more …instead of making you go someplace else on the site it gives you [desired information] right on the next column …and like I said I like my information up front."

Color also serves to facilitate or impair information access. In his daily life, K spent a great deal of time seeking information pertaining to computers. He concluded that when "everything's that's different is boxed in with its own little title and pretty much separate from everything else," he could access information more efficiently. "That way you don't have to go by just titles and just arrangement but there's all sorts of visual cues…. you've got stuff separated by not only boxes but also colors which is rather of helpful." L noted that "it's better [with] different colors. It's easier to break up the categories. I think it makes it easier to see."

Position and color arrangement either helped or hindered F's process through a page. As he evaluated an unfamiliar page, F remarked, "there's too much empty space, and the font's too small and the writing is hard to read and there's, there's not enough … enough stuff you can narrow your search." T described her difficulty with an unfamiliar web page that had blue and gray stripes as a background and darker blue or gray text as the page being very difficult to see, "[T]here's three buttons at the top…. all in a row. It's kind of hard to see them because … blue and white striped background with white

writing on the top [is] not easy … for me to see." Interestingly, that web page was Bobby™ approved for accommodating the needs of disabled users.

While some organization strategies are strongly preferred, such as bullets, lists, and alphabetical arrangement, participant responses suggest that even if most effective layout strategies are not presented, some form of organization is essential to access to information.

*Focus and Distraction Category*

Design and layout details both attract and distract, the difference being the intent. An element that *distracts draws the User's attention away* from the task for reasons not necessarily related to the purpose while an element that *attracts draws attention toward* it for purposes of supporting the task at hand. At times, Participants took steps to or avoid the distractions. Three codes that comprise the *Focus and Distraction* category: *Distracts, Attracts User,* and *Self-Training* are presented in Table 6. Participants expressed fewer comments about their own discovery about handling distracters while the other two were more prevalent. Perhaps this discrepancy represents that these Participants are aware of being distracted or attracted to another location but think differently about fixing the problem by themselves.

*Table 6: Focus and Distraction*

| Category | Code | Comment Frequency |
|---|---|---|
| Focus and Distraction | Distracts | 22 |
| | Attracts User | 18 |
| | Self-Training | 5 |
| Focus and Distraction Total | | 45 |

An element that attracts the User's attention may be positioned to assist with information access complementary to the purpose, perhaps to draw attention to navigation instructions or related information presented in a callout box. While attention is diverted, the result is not intended to be a detriment to the User's activity on the page. L found that "headlines that are high contrast attract attention," while T commented that if visuals "are not as flashy, it's easier to see where you are going more quickly." On her favorite game site, S appreciated that "the brighter colors seem to draw my attention more, like the red and the green. The red, of course, would draw your attention. The red on the 'Pocket Cash' where it has the blue background [draws my] attention."

Colors impacted LH's focus: "It didn't work for me to have real bright colors on the side, especially because it split my focus and I wasn't getting what was in the middle." Position directly impacted LH's focus. When in Yahoo, "to look for something, I'd be wanting to look over here (left) first and this (box on the right) draws my attention away from there….it's distracting over here (right)." She continued, "there's movement in there, a flashy thing, I mean I don't like that moving, it's flipping between two different things… it's attention getting but it's distracting."

S didn't "like the flashing stuff. It's distracting to me…. like the flashing sometimes out of the corner of my eye; anything like that would distract me." When playing timed online games, S experienced the downfall of being distracted by flashing graphics. "I focus on that and lose time."

When distracted, the brain-injured User's attention is drawn away to a different point on a page and reading flow and information access is disrupted. The User must

redirect attention back to the page content. Finding one's exact place again can be difficult, possibly leaving the User feeling lost or frustrated. When distracted by flashing or blinking animations, T found, "I have to look again for what I was looking [at]." For example, "if I'm…trying to find something and an ad… flashes or blinks, it gets my attention, which is what I'm sure it's what it's designed to do."

*Graphic Design Category*

Web pages are palates of colors with a variety of designs and combinations that evoke emotions and stimulate interest such that the User may react or respond to content that resides within the colors. Text is often colorfully created, and at times the use of color actually impairs the User's process. Table 7 presents the three codes that grouped to represent Participants perceptions, *Colors, Text Treatment* and *Impairs*.

*Table 7: Graphic Design*

| Category | Code | Comment Frequency |
|---|---|---|
| Graphic Design | Colors | 83 |
| | Text Treatment | 65 |
| | Impairs | 7 |
| Graphic Design Total | | 155 |

Text is a key component on any web page. While unadorned text transmits a message, text becomes design as color and shapes are graphically applied to the message. Different typestyles, colors, and font sizes interplay with background colors to involve the User on dynamic levels, including organization and navigation.

The Participant is acutely aware of typestyle, size and graphic treatment. Quickly

assessing suitability in terms of his personal requirements, F remarked that the text "doesn't work for me" because "the text is really small." Graphic design treatment can dampen the User's experience as well. On an unfamiliar website, F observed that

> the letters are of a strange style of lettering.…the type face is, you know, small, it's a weird style of writing. Some of the letters you can't really understand too well…. the letters that are black with the double red outline are hard to understand, it's a strange font.

He could navigate to another site in search of specific information. Emphatically, he remarked, "I can tell you something I don't like about this page….The size of the font. The font is too small, not readable, very hard for me to read." T detailed her discomfort with a group of similar colors, "sort of tan letters on a buff colored background which is harder to read. It's text is a different color, too….sort of tan color that's …. more … orange than brown but they are close enough that it's not as comfortable." As she sought specific information on a page, T exclaimed, "oh that's really teeny, I didn't see that at first." On a Bobby™ approved website, she discovered a function within the site that allowed her to change size and typestyle. "It made it a lot easier, makes it bigger....not crowded and tiny, it's clear."

Basic use of bold helped T locate her options. She described "a small list …divided up by lines….also has highlighted which sub-set [of] categories I'm looking at … [with] a bold heading with a brief description."

Colors applied to text also serve to guide navigation. "I liked the accessibility … you click on a colored word and it takes you to different sites. That makes it so much easier to navigate," remarked S. Intently observing a more visibly varied treatment, T

described, “as you scroll over and it changes, it lights up, there’s sort of a camouflage green color. And as the icon goes by, the hand, the letters become outlined in blue and inside they are white. They are highlighted.” Likewise, K summarized clearly that “it’s got light blue and then it turns red when you mouse over, which is rather nice.”

Links that change colors are so common that Users now expect the function on frequented websites. Absence of that function is noticed. Understanding the color codes, so to speak, F knew from experience that “blue writing, you can click on it. Black, means you can’t click on it, it’s not a link.” S explained that “black and white printing is something that you can’t click on to go somewhere else, but the colors like blue help you to know that you’re going to find out more, and then when you actually get on there to click on it, it changes to red to let you know that that’s where you’re actually going to go.” K liked a “link that changes color, which is nice.” On another site, K appeared surprised and remarked, “headlines are blue, links are blue and underlined, these links don’t change color though. Hum.”

Background color and visual texture treatment can interfere with content that is presented as text. User color preferences vary, but also share responses and reactions to similar treatments. Colors and combinations that do not produce glare were appreciated, as were text size and color treatment. With her vision affected by her car accident, T found that “it’s kind of hard to see them because … it’s blue and white striped background with white writing on the top. That’s not easy … for me to see with the stripes behind it.” L commented, “I don’t like the red writing on white, [it’s] hard on my eyes.” She preferred a “muted color…it’s not a lot of glare with the text.” Comparing color combinations, she found white text on a blue background “easier to read than the

white on this burnt orange almost…it's not pure orange, it's not yellow, but I think it's harder to see the writing on that than it is on the blue." On a Bobby™ approved site, L remarked, "I like the way they do stuff like this [graphic on a grey background]. It helps free it from the bright white. I just think it's easier on the eyes to read than the stuff in the bright white." LH "noticed that some websites have a bright white background and then the black letters like too black." Conversely, K remarked that "black text is really visible. Black text on white." S preferred "grey tones, black…some geometric designs" for background treatment on her game sites.

Commenting on graphic design choices for menus, LH preferred a menu that "changes color but it doesn't necessarily jump out at you like a whole different, like bright yellow or neon color or anything like that." A purple and green combination appealed to S as she enjoyed her game: "The purple is the regular counting letters and the green with the stars on them are bonus letters so that it's a nice color scheme. I like purple and green, I like purple especially." In contrast, T described her assessment in affective terms, commenting "this one's purple and lavender and pink which I don't like as well, it's kind of annoying." On a frequented website, T again observed, "the Yahoo [logo] stands out because it's red and everything else is more pastel, more gentle."

Graphic design is an aspect of a web page that is immediately noticed and judged. Although there is no single set of colors, backgrounds, and text treatments that are preferred or disliked by Participants, these do affect the overall web experience.

*Links and Icons Category*

A link is a means of transportation from one page to another. Pages may link within a site or between sites, literally between servers worldwide. It is of great

importance to the User for links to be easily located, especially those that are not the standard blue, underlined text. The *Links and Icons* category speaks to participants expectations. Table 8 presents the codes, *Easily Located, Seamless, Hand,* and *Barrier*. Participants spoke specifically of the ease, or lack thereof, of locating a link, and appreciated the presence of the default pointer setting that looks like a hand when the mouse rolls over a "live" link.

Links take the form of text, icons, or stylized graphics. Links that are embedded in text may be difficult to discern, especially if they are not the familiar blue, underlined text. Individual words or text links may be embedded within larger paragraphs or groups of words, or hidden within a graphic or overall layout. Default browser settings change the familiar mouse I-beam to a graphic of a hand when the mouse rolls over a link, a changed familiar to the User. Links located within lines of text may be identified by text that is a different color, underlined, or by the identifiable hand. On his favorite website K noted that "all the links are blue in the text."

*Table 8: Links and Icons*

| Category | Code | Comment Frequency |
|---|---|---|
| Links & Icons | Easily Located | 19 |
| | Seamless | 2 |
| | Hand | 8 |
| | Barrier | 2 |
| Links and Icons | Total | 31 |

An alternative to text-style links are icons. These graphics are pictures that

identify destination either with stylized words or recognizable graphics. By being descriptive in a manner understood by the User, icons served to alleviate the need to read small, crowded text or lists of hot links. This may be a relief for those whose vision is challenged due to brain injury. S described that "the butterfly…takes you back to the main site….Then it has this big gold star that says *Favorites*, and if you click on that it has a list that pops where you can add or organize your favorites."

Where a link is placed on a page, whether a text link or an icon, helps the User identify it. On her main page, S found, "they have the home page over on the left and you can actually click on that and go to that site." Links positioned in the main viewing area, for example, were convenient for her.

Occasionally, page design includes links that are not visible but are identified only when the familiar hand appears. Such invisible links may be confusing for the User, especially the novice. K remarked, "you can just roll your mouse over something that you might not know is a link, like this picture. Your little hand comes up." "I don't know too much about the web," noted F, "but I know that when the arrow turns into the hand that it's a link to some other stuff." When links are hidden within a graphic, closely arranged, or not visible on a page, the User may become confused and frustrated. When links are invisible, appearance of the hand is crucial to successful identification of the exact location.

One feature especially appreciated by Participants for navigation purposes, was the link that changed color when the pointer rolled over it. S explained that she understood that the purpose of designing links to change color is to inform the User that the text is a "live" link, and "to let you know that's where you're actually going to go." T

observed, “as the [hand] goes by…the letters become outlined in blue and inside they are white. They are highlighted.” “Yeah, it helps out because you can just roll your mouse over something that you might not know is a link, like this picture. Your little hand comes up …. I think it’s pretty neat. It does help,” K explained.

Text colors also provide clues to link location. For example, S knew that “black and white printing is something that you can’t click on to go somewhere else, but the colors like blue help you….[to] actually go to a different website which makes it easy to get more information.” Conversely, colored text can be confusing. F expressed confusion when text was colored the familiar blue and phrased to appear to be a link but was not what he expected. He had to move his mouse pointer around the page to find the desired links. “They look like links. Oh wait, ok, just click on a name.”

Links may be designed to serve as a table of contents. Menus present Users with convenience and familiarity. T preferred “the drop down box on the top left corner that was originally there so I can get out anytime I want without having to click the back button and go where I was before.”

The User of the web expects links to work and provide a glitch-free ride to the intended destination. Accurate link programming ensures a seamless change from page to page, site to site, and within a single page. When a link is text or a graphic that indicates function or destination, the User expects the link to provide the connection indicated in the name. Engaged in her game, L appreciated links that do what the name indicated. “If I wanted to put chess over into my favorites I click on it and hit ‘add’ and it will pull it over here into my favorites…if I want to take it back out I put ‘remove.’”

In contrast to seamless functionality, links that do not deposit the User in the

anticipated location, thus requiring the User to continue to search, serve as a challenge and a barrier for some. F commented, "I did not like the fact that … no … no direct links … to … other … pages." How well a link functioned informed F's impression of a site in terms of usefulness and convenience.

*Physical Category*

Physical manifestations of injury vary in symptom and intensity. Common post-injury complaints include fatigue (Sundström et al, 2007), pain in the back, arms, and eyes. As well, visual deficits (Lachapelle et al, 2008), such as Post-Traumatic Vision Syndrome (PTVS) (NORA, 2001a; 2001b), is a common secondary injury sequelae that involves the eye or optic nerve. Because vision is challenged for many brain-injured people, page design that encourages visual comfort benefits the User. Participant comments for this category are relatively low, compared with other categories, as illustrated in Table 9. However, nearly all Participants referred to their eyes during their interviews.

*Table 9: Physical*

| Category | Code | Comment Frequency |
|---|---|---|
| Physical | Eyes | 11 |
| | Injury Related | 1 |
| | Accommodations | 1 |
| Physical Total | | 13 |

Computer screen refresh and flicker rates stress the eyes and may trigger migraines, seizures, or eye fatigue. T noted, "if I were tired I would have a really hard

time… The font is [NOT]… very readable. S shared, "when I was working at [her employment before she changed to truck driving] …my eyes would get real tired." She reported that she would have to lie down in a dark location at her workplace to control her eye pain.

PTVS may manifest with blurred vision in the presence of normal acuity, inability to read across a straight line of text, nystagmus (involuntary oscillation of the eyeball), and many other problems that interfere with. As well, color combinations and animation may aggravate visual problems. L remarked, "I don't like the red writing on white, hard on my eyes….I don't like looking at it…it's almost like my eyes are straining to see it." "The yellow is actually a little hurtful on the eyes," explained K, and LH appreciated a site where "there's not so much contrast. The greater the contrast sometimes the more blurry it seems to be to the eye, to my eye."

Compounded with general injury-related depressed physical energy, the effect of graphic design can increase a feeling of fatigue. Pain also interrupts interaction with the web. L mused, "I haven't been 'playing for awhile' because of my injured back."

The self-directed User develops techniques to manage physical challenges. Accommodations range in complexity from simply scrolling down a page to hide a graphic animation or turning off sound, to purchasing new eyeglasses, or changing employment. For example, S, employed in a position that required constant customer contact by telephone with constant computer use, suffered severe eye pain and headaches. "I really, really, really needed to just lie down and put a cloth over my head to rest my eyes. She took steps to manage her eye pain. She changed the angle through which she looked out of her glasses, "I'm not looking down that much because then it would be like

a closer look and it would be a little blurred when I have my regular glasses on," Aware that her acuity was corrected appropriately but the headaches and eye pain remained, she changed her employment to a position that did not include a computer. "I can read fine. Even that's, you know, that's small print without my glasses. My eyes get tired but my eyes have adjusted since I gotten off the computer." Intent to overcome the interference of physical limitation encourages the User to develop accommodative strategies.

*Purpose Category*

Users utilize the web for a variety of purposes. The web provides a vast playground where millions of people, including the brain-injured User, can interconnect with each other for games, social, and fun interaction, as well as to communicate, be entertained, and seek information. Table 10 illustrates the three codes that make up the *Purpose* category: *Specific Intent, Entertainment*, and *Communication*. All Participants engaged with the web with a specific intent rather than to "surf" and take in the sights, so to speak. Participant comments spoke of a desire to gather information, be entertained, and to communicate in chatrooms and email.

*Table 10: Purpose*

| Category | Code | Comment Frequency |
|---|---|---|
| Purpose | Specific Intent | 25 |
| | Entertainment | 15 |
| | Communication | 10 |
| Purpose Total | | 50 |

Social networks may be disrupted by brain injury, forcing the brain-injured User

to make new friends. The web serves as a communication tool through the use of multiple synchronous and asynchronous vehicles, including chat rooms, blogs, instant messaging, and email. Being in contact with the "outside world" can be difficult for those who are challenged by organizing schedules to travel to libraries or to make phone calls. For those for whom life has reduced interactions with friends as well as for those who are outgoing by nature, internet communication allows time for word-finding and thought formation.

Despite a wealth of opportunity for communication, Users may not be confident or outgoing and may, therefore, limit their social interactions. "Mostly I just use it for reading my e-mail," T said. A busy woman, S shared that "I don't usually go into those (chatrooms). I think I've only been in two different chatrooms."

Communication is integral to entertainment as well as social interaction. The User may seek entertainment to play solo or with other people on the web. Computer games can provide a pasttime activity, stress relief, or mental strength-building for either solitary or social activity. Some web-based entertainment is grounded in social interaction and Users worldwide can play with and compete against each other. There is also a degree of anonymity in internet-based society. When she is in her favorite game site, S can "find out here what other players are doing, what they played and what their average scores are, that kind of thing. So it's like competing with people without having to know them." Games fulfill specific needs. In her favorite game site, L will "play with other people [or] …play against the computer if other people aren't there."

In addition to gaming, entertainment includes music and video. Online music "helps [S] with not being bored and keeping me on my toes." She frequents "MSN music so that [she] can listen to music online. Just sitting here playing games or whatever so I

can be entertained along with getting information so I don't have to play my radio if I don't want to." The decision is hers.

Some Users visit the web with specific intent to build family bonds, gather information, and utilize web resources for personal management. F noted that "If you wanted to get some carpentry work done you can look up this site and see some of the other things that they have done." "I kind of want to know how it works," LH stated bluntly. "I want to know what she's charging, I want to know the basic bare bones of all this stuff."

Shared interests can bring families together with computer activity. L and her husband were racing fans. Their favorite site offered

> everything about racing…. We can find out who's taking a poll. We can find out what times races are, what day they are, who's leading in points, when qualifying is, when the next race is, where it is, what the weather's gonna be like at the race… you can find out who's taken the poll, you can find out what order they're gonna be in going out racing, you can find out what their seeds were in different practices and when the practices are gonna be and get all the good gossip on what the drivers are doing.

Because they balanced their hobby with other life events, the website provided more than just data. Scheduling helped with time management in her busy family. She frequently visited the site to "find out what time the races are going to be this weekend, find out if I'm going to be back in time from church."

Holding her small grandson, S located an educational site for young children. She felt that by including the young child, he would learn that a computer is fun. "They have

prehistoric puzzles. I look for these kind of things because my grandson loves anything dinosaur….He likes that."

The desire to expand personal or professional horizons also inspires the User to visit the web. As she visualized starting a small business, LH searched the web with a search engine to find examples of the service she intended to offer. She also looked for information to help her learn how she could develop a niche for her services. "Well, from my perspective, because I'm considering doing something like this, I would want to know about this, and get information."

The web becomes an information-seeking tool when the User researches a specific topic through the use of search engines and by visiting familiar or recommended websites. Visiting his favorite computer information site, K remarked, "well, if you're here you're definitely looking for something related to computers or computer hardware." On the other hand, he preferred to have control over the web experience,

> and instead of going to that site, which is a discussion site populated by adolescents, juveniles, people that I don't really want to hear, I don't want to read their comments, this video card kicks ass, duh duh duh duh duh, you know, I don't need to read comments like that.

Sometimes the search for desired information requires the User to persist, though reluctantly. In response to a change of design and layout of one of her favorite sites, L decided "if I didn't have to come here to find something out I probably wouldn't just because they make it more difficult than they used to." Websites that F frequented included information specifically about his favorite band, especially concert schedules. "You come here to look for news, of the band, or the lyrics, or pictures…. It is pretty

much the main thing you are looking for at a band site."

Health related and medical information is a strong interest for the information seeker. While L does not prefer to venture out of her familiar set of sites to explore unknown pages on the web, she would venture out with sufficient motivation. "When mom got diagnosed with the cancer….I went to, I don't even remember what it was, yahoo, and we typed in the kind of cancer that she has and it brought up all different sites." With those resources, L and her family could learn about the health crisis and how it would affect them.

*Reading Category*

In a visual environment such as the web, deciphering text is a requirement for successful comprehension of content and navigation. How text and graphic elements are combined can diminish or enhance the User's ability to read text. The presence of PTVS may compromise ability to distinguish letters, color combinations and resulting contrasts, glare, perceived movement, and other challenges to the User's physical text deciphering. Table 11 illustrates four codes that directly address reading ease or difficulty experienced by the Participants. They are keenly aware of the "readability" of a page, specific about what points of design assist or impair reading. Colors, graphics, layout, and organization all contribute to how well the written word is understood.

As text exists on nearly every page on the web, ability to visually discern words and letters is essential. Although all Users have needs that need to be met to maximize reading potential, web pages must serve those needs. Colored text on a black background, "is more visually pleasing …easier to read…because of the contrast," remarked K, while LH stated that she didn't "care for stuff on the black [however] red on the black is easy to

read, easier than the white because there's not such glare kind of. It's not as dramatic." LH preferred a different color scheme. "All in a dark goldenrod and brown on a white background, that works for me, easy to read." "Tan letters on a buff colored background … harder to read," reported T. "If everything's blue, light blue on a dark blue background it's going to be hard to see."

*Table 11: Reading*

| Category | Code | Comment Frequency |
|---|---|---|
| Reading | Readability | 38 |
| | Impairs Reading | 14 |
| | Common Language | 13 |
| | Literacy | 5 |
| Reading Total | | 70 |

Text style and size informs word identification. S wore corrective lenses and preferred large print. A graphic on a game website captured her "attention really well but with the smaller print, of course, you know like normal people who haven't had an injury would probably" read the smaller text with less difficulty. "If the printing is too small, I adjust the size fit on my screen so that I can see it easier" she remarked. F studied a page to make sense of a decorative typeface. He stated he could read the words "but it's not the best type of writing that they are using…and there's this picture of something in the background, I can't quite tell what it is….There's little text at the bottom and that's easily read."

Use of small text over large text may have a negative impact on both the User and

the purpose of the website. Knowing her own needs, S stated that she "might not pay attention to that small of print all the time." This both limits access to information and reducing a website's effectiveness with a potential target market.

In addition to text color and size, how information is organized helps or hinders reading. When lists and call-out boxes organize information, S remarked, "you don't have to be looking through a bunch of information trying to sort it out …. without having to go in reading a bunch of text."

Vocabulary used in the text is also key to reading success. When a person loses language, that is, does not remember words, can no longer spell correctly, or experiences word-finding challenges, understanding formerly familiar text may be out of reach. A User who formerly had an extensive vocabulary and high literacy may be left with reduced but adequate grasp of language; however, a brain-injured person with limited literacy prior to injury may find that literacy is diminished to a disturbingly low level. In general, low literacy affects a person's ability to function in the workplace and in society. When required to read a web page that is not friendly to those with reduced literacy, the User may discover a lack of ability to understand not only meaning but the words themselves. Use of colloquial language and inappropriate literacy levels in content may impair reading, but use of language that is familiar to the User, a common vocabulary, may assist with word -finding difficulties.

*Self Category*

Each User is a unique individual. On the web, the individual interacts with all that the web presents. The User, as an individual person, has feelings, thoughts, and self-knowing that is informed by the external world of the web. Rather than being a passive

traveler, the User may evaluate the experience on a personal level.

Table 12 illustrates the 10 codes that wove together to create the *Self* category. Participant comments that alluded to the individual affective world informed by these codes. Participants were direct and frequent with their statements about likes and dislikes.

Success is empowering, encourages a sense of proficiency, boosts self-confidence, fosters self-efficacy and supports self-directedness. Feelings of empowerment and confidence are strengthened when the User feels a sense of control. Ability to edit a page to suit personal preferences appeared to satisfy S as she noted that "you can customize [the site] so that if you're having problems with it you can change it." On a page that allowed T to change the size and form of text, she expressed that she could "change, with the drop down box…make it bigger." In her favorite game site, L enjoyed "that it lets you edit the place to put the favorite things that you want so that you don't have to look through the whole page when you come on, you've got the area that you like to work in."

New computers are available with useful and entertaining software already loaded to help the new user to gain experience and confidence right away. When S bought her computer system she found that she was introduced to the functions without having to experience any frustration with technology. As she toured her new computer, she noted

> on the left over here I can personalize…to get a weather forecast …and get that all set up. My calendar that I could use like to remind me of different birthdays, anniversaries, doctor appointments. If I wanted to, you can just put it on your computer and it will pop up a little message in your email for you so that it reminds you that you've got an appointment or someone's birthday's coming

up…you can send them an e-greeting card or something like that.

Even though S had some experience with computers, she was very excited and appreciative of the ease with which she became accustomed to the features of her new computer.

*Table 12: Self*

| Category | Code | Comment Frequency |
|---|---|---|
| Self | Personal Preference | 165 |
| | Proficient | 43 |
| | Self-Directed/Self Reliant | 41 |
| | Feelings | 21 |
| | Empower | 19 |
| | Self Aware | 18 |
| | Confidence | 17 |
| | Expectations | 4 |
| | Lost | 3 |
| | Security Conscious | 3 |
| Self Total | | 334 |

*Role of proficiency.* F and K demonstrated their proficiency as well as their expectation that they could monitor their location in a field at either the bottom or top of the browser window. As K checked the address bar at the bottom of the page, he remarked, “I do tend to pay quite a bit of attention to that so I know where I’m going before I get there.” A Participant with little to moderate experience, F “hit the news...and then I came here. It looks like the same thing except it moved over a little bit. How do I

know that this is the page? Because I looked up at the URL and it said the page that I was in was news."

*Role of self-directedness.* The self-directed User may choose to explore an unfamiliar site with a sense of exploration rather than a sense of being lost or not in control. Attempting to open a document from a link, K found that the document was created in Adobe Acrobat™ and that his computer didn't have the Reader™ software to open the document. In the midst of his activity, K was required to locate and download the Reader™. The process began when

> a window pop[ped] up saying that it didn't know what this file is supposed to be for and asked if I wanted Windows to search for the appropriate program. I said sure, and it took me to Adobe site and helped me walk through information and click the link to download…a page that is temporarily unavailable.

An unavailable page might be daunting for a novice but K's experience and proficiency became apparent as he explained, "I couldn't actually get it from the Adobe™ site. But what I did, what I'm doing now is go to a site run by www.download.com. This is a bunch of freeware, trialware, shareware, big collection for all sorts of operating systems." Although the search for necessary software led him to two different websites, he successfully located and downloaded the software, then returned successfully to his original site.

The self-directed User may make decisions that inadvertently limit access to desired information by skipping past instructions, not scrolling down the window to additional information, or simply not reading content. T chose to bypass a dense menu of text style links to take advantage of an icon that she assumed would give her what she

wanted. “I don’t usually want to BOTHER with reading all that stuff … it’s easier for me to just click on the little round e-mail thing.” By bypassing the menu, she missed an opportunity to learn what other information was included at the bottom of the page. She continued, “I don’t know…because I didn’t scroll down far enough.”

When asked if she would know how to find information other than email, T indicated that she “would go into the search window and type “belly dancing” [her hobby], and hit search. While this seemingly simple action may be taken for granted by those with slightly more experience, for the novice learner being successful finding information on the web is satisfying and empowering.

*Role of emotions.* “Following brain injury, there is often damage to the area of the brain that controls our more basic impulses such as anger….The individual with a brain injury has often lost this control and may experience rage in situations they used to tolerate or ignore completely” (Brain Injury Association of Queensland, Inc., 2007a, p. 1). Anger may erupt from any of a number of causes, including

1. Being confronted with tasks the person is no longer capable of doing;
2. Other people’s behaviour e.g. driving, insensitive comments;
3. Inaccurate thinking e.g. falsely believing that people are laughing at them;
4. Unrealistic self-expectations;
5. Barriers getting in the way of goals or routines e.g. queues;
6. Build up of stress
7. Too much stimulation, lack of structure, change of routind;
8. Physical state e.g pain, tiredness;
9. Mental state e.g. existing frustration, confusion

10. How well the person is treated by others. (p. 1).

*Role of self awareness.* A common sequelae of TBI and MTBI is compromised self-awareness, although survivors of MTBI appear to have better self-awareness than individuals with moderate or severe TBI (Dirette & Plaiser, 2007). Three types of impairment to awareness have been identified:

1. "Impaired intellectual awareness is where an individual is unable to understand a deficit exists;"
2. "Impaired emergent awareness where an individual knows there is a problem but is unable to realize when the problem is occurring or compensate for the deficits;"
3. "Anticipatory impaired awareness where the individual is aware of the deficit, can recognize when the problem is occurring, but is unable to anticipate the likely situations in which the problems will crop up." (Brain Injury Association of Queensland, Inc., 2007b, p. 1).

In addition, self-centeredness implies that "egocentricity [is] more normally associated with a young child [because] they lose the ability to see the world from another person's perspective" (Brain Injury Association of Queensland, Inc., 2007c, p. 1). In the web environment this phenomenon may arise in relation to an emotional response to the experience.

*Role of self-focus.* A sense of self-centeredness concerning interaction with web pages began to emerge when this group of MTBI Users described experiences using the term "I." These references were coded in the Personal Preference code because they directly indicated what participants liked and didn't like.

The MTBI User engages with different levels of personal direction from self to the web. Comments such as “I am” (S, K, LH), “I am not” (L), “I know” (S, K, LH, T), “I don’t know” (T, K, F, S, L), “I need” (S), I like (L, T, S, K, F, LH), “I hate” (K), “I mean” (LH, T, K), “I think” (LH, T, L, K), and “I thought” (F) were expressions that demonstrated the relationship of the User, as an individual being, with the web.

When the self-directed individuals were empowered by volition, participants expressed definitive comments such as “I do” (K, S, LH), “I did” (K), “I didn’t” (T, L, F, LH), “I don’t” (F, T, K, LH, S, L), “I go” (LH), “I get” (S), “I hit” (K), “I listed” (LH), “I play” (L), “I picked” (LH, K), “I came” (T), I looked (K), and “I said” (K). This is accompanied by a hint of a more tenuous response: “I adjust” (S), “I can” or “could” (T, S, L, K), “I can’t” or cannot” (S, K), “I have” (S, LH, K), “I haven’t” (L), “I tend” (LH), “I try” (S), “I use” (S), “I usually” (K, S), “I want” (S, L, K, LH, F), “I was” (LH, T, F), “I work” (LH), “I would” or “will” (F, T, K, LH, S, L), “I probably” (T, F), “I see” (S) “I guess” (LH, T, K), “I wonder” (LH), and “I just” (S, LH), and “I really” (LH),

Following an action, self-directed or not, the User appears to be aware of results at times, both tangible and intangible, demonstrated by expressions such as “I find” or “found” (L, K), and “I learned” (F).

Overall, MTBI Users in this study engaged with the web in a personal manner that reflected self awareness, self-centeredness, and emotionality.

*Site Design Category*

How a web site is organized impacts the brain-injured User's experience. Visual appeal, general "look and feel," design and layout, and placement all influence whether the User perceives the site as pleasing. Presenting pertinent information about the site on

the home page frees the User from additional navigation. If the contents of a site are not readily understood, the User may choose not to spend sufficient time to stay and seek additional information within a website. Design strategies include information placement to arouse interest and guide the User through the site to a certain extent.

The *Site Design* category addresses the efficacy of the website itself and is comprised of nine codes, illustrated in Table 13. Participants frequently referred to aspects of website design in their dialogue.

Immediate perceptions of a page or site may contribute to a user's decision whether to leave a site or stay and engage. Seeking specific information, when L landed on a site with considerable white space, she surmised that "it just makes it look like there's less information you can find out at this site than at others."

*Table 13: Site Design*

| Category | Code | Comment Frequency |
|---|---|---|
| Site Design | Choices | 43 |
| | Design Strategy | 36 |
| | User Friendly | 20 |
| | Consistent | 16 |
| | Disconnect | 9 |
| | Look & Feel | 8 |
| | Different | 6 |
| | Crammed | 5 |
| | Scrolling | 45 |
| Site Design Total | | 148 |

As F navigated through links on his favorite band site, he assessed a page as designed by an amateur, like

> a page that somebody put up, like some fan in high school put up for a computer assignment in one of their classes and didn't actually spend any time and make it, you know, make links and make information accessible, they just wanted to put up a picture….It's pretty boring.

Moving on, F landed on a page that appeared to be professionally designed, "Oh, here you go! Here's an actual page." However, "You see that's kind of, that's kind of …ridiculous. It's just not, it's just not set up very well." F appeared to hold an expectation of how a professionally designed page should look.

At times, web designers may change the look of a page from small adjustments to a complete overhaul. This may compromise the User's ability to fully utilize a site. L remarked, "Sometimes their old way which is way better than this new one and then other times they make it so it's real easy."

Web design commonly attempts to include as much information as possible on a single page. This provoked varied responses from Users. Some Users prefer the presence of pertinent information spaced in such a manner on a single page that text and graphics are readily available. "Like I said," commented LH, "I like my information up front and here it is." On the other hand, another User may feel as though the page is crowded, and therefore may experience difficulty locating desired information, or evoke feelings of discomfort related to personal space. "What I don't like are the sites that have so much information…with so little room." F expressed

> And then there's [the site] where you have the one page that has everything…it would be better if you would just go to another site and then you could find the information … like have one that says news … go look at all the news, all the breaking news headlines, you know… one that says movies, it will have all the upcoming movies. You want to throw stuff in there, because you know, some people want to have so much stuff that there is no space at all…there is always something to look at…always something new to read just to fill the space. Empty space is bad, too much space.

F prefers the presence of less information on a page and more direct links to information. Clearly, F's preferences were different from LH's.

A possible design compromise is to create a page that is larger than the computer screen, allowing for both visual space and sufficient information to be included "up front," as LH remarked. The larger page requires the User to scroll to see the bottom of the page. Again, Users hold differing preferences regarding scrolling. "I find that that makes me real frustrated [when] I have to scroll back down to where I was," remarked T, who then must "refocus, conscious focus, remember where I was and where I was looking." Likewise, F found "I do not like [scrolling]. I'd rather have a bigger screen. Scrolling doesn't appear to bother J, who, as she pursued specific information on a retail site, remarked "I can enlarge the screen, I just scroll down….and they usually have a picture and tell something about and has a price."

Unfortunately, scrolling and resulting moving colors was problematic for J, who has a seizure disorder. "It's starting to blur, when my um yeah… I'm starting to get little twinges right here and here…Yeah, left eye and right above here. While scrolling is not

an inconvenience for J, the passing colors appeared to have the same effect as flashing colors on a page. She must exercise caution in her travels on the web.

When the purpose of a graphic or design is to attract Users to focus on a different message or advertisement, strategies may include flashing graphics, scrolling text, bold colors, and other distracting designs. While successful, the distractions may evoke a negative response from Users. "There's movement in there, a flashy thing," stated LH. "I mean I don't like that moving, it's flipping between two different things …flashing at me. I mean it's attention getting but it's distracting." Another strategy to distract the User in order to deliver a message is to include pop-up windows with bold designs. "I don't even see what it's about," exclaimed K. "What I hate is pop-up ads on pop-up ads on pop-up ads. There's some that you close and it pops up another pop-up ad."

Many websites are designed with similar features in similar locations from page to page within site. T shared that she

> liked it when the things didn't move. For example, the drop down box on the lottery web site was in the same place no matter where you were looking at. When you were looking at the faq page, the drop down box to find where to move down box was always in the same spot.

Asked if he could decipher a page, K remarked, "Oh yeah! You've got the menu here in the same spot."

A menu on the left or right sides of a page provides a familiar location for t links to information within a site. T described "a small list, there's a list on the right hand side divided up by lines. It also has highlighted which sub-set categories." On the other hand, consistent layout from page to page, like a template design, may result in pages that look

too similar to each other. Trying to determine his location within a site, F referenced the URL to determine if he was on a new page. F described that "because you can't see any of the new text in the window you have to go find it….Yup. The top is exactly the same, except it will say news and then there will be a list of days." Also aware of almost identical page designs with no obviously visible means to determine what menu tab she was in, L found that "one of these doesn't look different so I don't know if I'm in one of those right now or if I'm not in one of those."

Some design features now apply across sites and are expected to be in specific places by Users. Specifically, the menu at the bottom of a page with familiar links, such as home and contact information, is so familiar in content and location that it is missed when absent. When describing a page, L remarked, "seems to me to have kind of normal stuff along the bottom."

How a website is designed contributes to the overall experience as the User attempts to access information on a site. If the design of a site meets the needs of the User, then the User will at least have access to the desired information. If the site design confounds the User, then opportunity is lost.

*Technology Category*

Understanding how the technological side of a website actually works is sometimes a challenge. The experienced User may approach the web experience with knowledge and expectations of how complicated technology behaves, while the novice User may have unrealistic expectations.

The five codes that created the *Technology* category, presented in Table 14, represent subtle messages expressed by the Participants. Some comments were direct, but

some were quite understated.

Links that do not work and pages that are slow to open may evoke frustration and impatience. This, and other "glitches," may contribute to MTBI user's compromised emotional awareness sequelae, presenting the predictable outcome that the MTBI User may be confused and frustrated by not knowing how to work with browser software. Built-in browser features, such as being able to configure text size and color schemes manually are noted by participants as being a benefit of the technology.

*Table 14: Technology*

| Category | Code | Comment Frequency |
|---|---|---|
| Technology | Site Function | 16 |
| | Browser Feature | 11 |
| | Special Needs | 6 |
| | Efficiency | 2 |
| | Software | 2 |
| Technology | Total | 37 |

A browser is the software that creates a visual space for the User to interface with the web. Functions that are included in commonly used browsers may create a more comfortable environment for Users with disabilities. Those who require accommodations may be aware that a browser includes functions programmed to meet some needs. S noted that "they've got it where like if you're handicapped with sight they can enlarge the page so you can see better, that kind of thing, just different things on the computer." As well, L remarked that

> having the ability to change text size helps people [of] all ages be able to read your stuff. Like if I write letters to my grandparents I write them in bigger print than I do if I'm writing to my sister just because I know it makes it easier for them to read.

She does "not mind small print" for her own use but she does "know a lot of people would have to change glasses or…if you're older, some of these make it way easier to read if you make it bigger. I think that's a nice handy thing to have on there." K also noted that a web page included "a TTY number for hearing impaired people, which is nice."

Browser features also help with navigation. "One thing I do is roll over a link [and] it shows what the address is down here," explained K as he directed his attention to a URL navigation bar at the bottom of the browser page. When moving the pointer around a page, when it changes into a hand the User knows that a link has been located.

Technology can fail in several ways. User response varies, as well. One confusing or frustrating experience is when the computer does not have an appropriate software program or plugin required to launch a page. For example, many documents are created in Adobe Acrobat. To open such a document, a computer must have the correct version of the Reader software. Some Users know where to find and how to download the required software, but other Users do not and simply cannot access information contained in such documents. "Oh oh, I don't have pdf. 'Use Windows to find the appropriate program,' Ok" remarked K, an experienced User. "Hey. I'll load Adobe Acrobat™ real quick," he continued. His attempt took him to two websites and the entire process required approximately 10 minutes. Plugins are required for video and audio to be

played. If a required plugin is missing, a window with a message appears to help the User to locate and retrieve said plugin. However, the process often is not smooth and the User who does not spend time to locate, download, and in many cases, reboot the computer will not access the information contained in the videos or audio clips.

Speed is valued by these Participants. "It's not going…It's just loading," remarked T who has limited experience. "Alright, hold on here", she continued, "Ahhh, what's going on? Manual? Well? You'd think that it's locked up for a reason here….OK. OK. So Netscape locked up, the page locked up." "Any time now," complained S as her patience was tested. As she waited for a page to load, L remarked that "there must be a whole bunch of pictures." There were, in fact, more than 35 graphics on the page she was trying to access. LH wondered why a page didn't load, "ok, that's not working either…not a day to do it."

Overall, both how well technology functions and the User's tolerance for technology dysfunction supports or prevents the User from accessing information.

*Thinking and Learning Category*

How the User thinks and learns informs how meaning is made on the web. The *Thinking and Learning* category draws from comments and behaviors that indicated what Participants thought and how they learned while interacting with the web. This category is informed by 10 codes that speak to cognitive processes, decision-making, and problem-solving, presented in Table 15.

Having prior knowledge about navigation or use of information allows the User to transfer knowledge more easily. Complicated websites require the User to problem solve and think critically about how to comprehend, navigate, and understand content.

Page and site designs that require effort for the User to understand how to access information may evoke feelings of frustration that may lead to leaving the site, thereby blocking access to information contained within. This can put the brain-injured User at a disadvantage. Content that is written and presented in such a way that the User can understand both the language and meaning of the message assists with understanding not only the meaning of the text but also the value of the information presented.

*Table 15: Thinking and Learning*

| Category | Code | Comment Frequency |
|---|---|---|
| Thinking & Learning | Comprehend | 63 |
| | Prior Knowledge | 28 |
| | Interested | 27 |
| | Familiarize | 20 |
| | Persistence | 22 |
| | Trial & Error | 17 |
| | Lacks Interest | 17 |
| | Help | 13 |
| | Affect | 10 |
| | Critical Thinking | 5 |
| Thinking and Learning Total | | 215 |

The User who approaches a website with no organized system of operation often will need to learn by trial and error. Discovery describes this trial and error approach to the web in a positive sense. When learning the rules to a game, S found that “it was a matter of discovery, doing different things.” While on the Section 508™ page, S found

that the website was not functional. She "found some interesting stuff on the Section 508™ [site] of registered companies." K was puzzled as he attempted to make sense of a public transit schedule on an Australian website. "Um timetables by number, I wouldn't be able to do that," he mused. As a User who enjoys new experiences, K found the link to

> plan my route. Hey, this is nice. Let's say we go somewhere …. Choose your departure suburb. Which suburb am I in—Greenfield. Hum….oh yeah, … I want to take the number 224 bus…. pick a number, the right number for the bus….what's up with trams? I've not been on a tram. Let's see. I think I might have to click on timetable to find out what time. Timetables to find out what time.

He studied each page that he linked to within the site in an unsuccessful attempt to understand the information and site design.

The desire to learn can lead the User to seek online help and tutorials or to secure "live" assistance via telephone, real time internet chat, or personal support from a trainer or friend. Even the most skilled will experience the need, at some point, to make sense of content, navigation, technology, links, and other categories of experiences. As T attempted to learn how to navigate within a page, she mused, "I suppose you just have to scroll down and see what the rest of the page looks like. There's headings." However, "I find that that makes me real frustrated [when] I have to scroll back down to where I was."

Previous experience with general navigation informed T in her quest to navigate. "When I see a little drop down box I know I can use that," she remarked. Looking at the small menu words at the bottom of the page she was viewing, she said, "It seems like these menus tend to be more for help…at least in other ones I've seen they tend to be more for if you want to tell them something, at least in other web pages that I've found."

F remarked, “I don’t know too much about the web, but I know that when the arrow turns into the hand that it’s a link to some other stuff.” While LH did not enter a website through the home page, having utilized a search engine to locate relevant information, she still knew that to ‘go home,’ she “would only go to the bottom and see if there was a listing at the bottom. “Home. There’s home page there.” Colored text is a broad reminder of the presence of links. As she spoke to her knowledge gained from experience, S remarked, “Well, I know that once you get to the website…they have different colors. Sometimes it’s written in blue and then to get to a different part of the site … it will change colors before you actually click on it.”

Life experience and direct instruction transfer to understanding the web environment. K remarked, “Outlines are something I’m used to working with. I got used to them in school.” F “learned that in school.” Not knowing how to access information on an unfamiliar page, LH “just assumed, to begin with, the [menu buttons labeled] timetables and layouts would have just taken me to timetables and layouts.” K remarked, “it’s like watching TV.”

The User also considers the value of instruction available directly within the website. Tutorials and instructions contribute to comprehension as the User becomes accustomed to new features on the web. On her new computer system, S found that initial training was provided in an easy to understand format that “goes through everything on your computer to let you know how to run the system and the different features and to learn more about your pc by giving your tutorials right there on the computer.” On a game site, S related that she, “went into a ‘tells you how to play area,’ getting started, tips and strategies, game help.” On her favorite game site, L appreciated that “before you play

a game it gives you options [to learn] how to play…and it will go through a whole list of how to play this game….and if you don't know how to do it [it] will tell you."

Attempts to create effective online instruction can be successful, but not all Users connect with the design or content that present the instruction. On a Bobby™ approved Section 508™ website, T conceded that she was

> a little confused. It's still set up in column format but it doesn't really explain what it is, what you are doing. Accessible vendors. … External links after the search…. it's still pretty easy to read, I just don't have any idea what this site is about … it's not labeled. It's section 508. www.section508.gov.

S assumed responsibility for her failure to understand instructions. She said, "I didn't really read that in such a way that I understood what I was doing I guess. "

Personal choice becomes apparent as the User persists in an attempt to reach a goal. Informed by personal interest, the User will remain on a site with the intent either to understand information presented on the site or locate desired information. K persisted in his mission to interpret the bus schedule on a website, even thought it was "not something [he was] used to." Game sites often require the User to learn rules and techniques. S commented:

> took me a while to realize what I was actually doing ….But then after a while it kind of just came to me and I went through and did different things and go through it again and then it made sense.

On an unfamiliar site, F discovered that links were not marked with the familiar color. After he learned about how the links were designed, he exclaimed, "They look like links. Oh wait, ok, just click on a name…'Welcome to Loch Ness.'"

When asked how he would have figured out how to find the tour information on an unfamiliar band site if he had not stumbled upon it, F replied that he "probably wouldn't have." He would have "gone to a different site to look for the [tour] dates."

LH chose to search the web for information to learn how to start a new business. On a promising site she found that she had to navigate past the home page and explore the site to find what she wanted to know. Although frustrated by the extra steps, she chose to stay on the site because

> it was something I wanted to know about. If it was something somebody else wanted me to find out about or just idle curiosity, no, not really. If I want to know about it, I will look and look and look for an hour if it's something I need to know, I want to know if anything I have to pursue.

S explained that "I went through and read all of these and then I went back," a process driven by her high interest and persistence.

A truly negative repercussion of content that does not fulfill the User's purpose is summed up in a single statement, as K stated "That's not even worth playing."

*Category frequency*

Sorting by category as Strauss and Corbin suggest, two core themes emerged from the 12 categories: data spoke to being web page oriented or MTBI User experience oriented.

*Categories that address the User.* The *User* theme is comprised of six categories: *Self* (334), *Thinking & Learning* (222), *Reading* (70), *Purpose* (50), *Focus & Distraction* (45), and *Physical* (13), for a total of 734 User statements. These further diverge into three sub-themes.

The first sub-theme, *Self* and *Thinking & Learning*, speaks to the User's sense of self and making meaning in life. The second, *Reading, Purpose,* and *Focus & Distraction*, speaks to the cognitive interaction with content in pursuit of information that will fulfill the User's purpose for engaging with the Web. The third, *Physical*, stands on its own with the fewest comments by participants. This suggests that although the User is aware of areas in life that remain affected by the injury, there appears to be little focus on these challenges. These themes suggest that the MTBI User's sense of self and making meaning in life, goal-oriented cognitive interaction with content in pursuit of information and awareness. It is beyond the scope of this study to examine how pain and discomfort are experienced and expressed by MTBI survivors.

*Categories that address the web.* The *Web* theme is comprised of six categories: *Content* (205), *Graphic Design* (155), *Site* (148), *Technology* (37), *Links & Icons* (31), and *Advertisements* (22), for a total of 598 statements. These further refocus into two sub-themes.

The first sub-theme includes categories that speak to a web page's appearance in terms of appearance, friendliness, and accessibility. In this theme, this sub-theme holds the greater frequency of relevant participant comments.

The sub-theme, *Technology* and *Advertisements*, contributes considerably fewer statements but evoked strong reactions. Both *Technology* and *Advertisements* impact MTBI User's experience. Advertisements are present in a broad variety of forms, evoke strong negative reactions on an emotional level, and are not related to the User's reasons for being present on the web.. The frequencies of these categories contributed considerably fewer statements than the first group but evoked strong reactions. Both

Technology and Advertisements coexist with the User's interaction with the page or site. Technology is always present and impacts the web experience but is not integral to the apparent design and delivery of a page or site. Advertisements are present in a broad variety of forms and do impact the experience but are not related to the User's reasons for being present on the web.

*Core themes: Phase Three:*

At this point, we see that Strauss and Corbin indicate that it is time to enter the final phase of analysis, that of determining a core category. Glaser, on the other hand, states that the core category is identified during selective coding, before moving into phase three: theoretical coding. For both, the core theme is a choice of a single category, or meta-category, and pursuing further analysis in terms of the core theme.

## *Preliminary Analysis: Glaser and Strauss Model*

*Code Frequency*

In considering of Glaser's instruction to keep data uncompromised, codes were sorted by frequency, apart from category grouping (Appendix J). Reviewing data on this level, codes appeared to fall out into three themes.

*Core Themes: Phase Two*

*First theme.* The first theme is informed by two codes (frequency in parentheses), *Personal Preference (165)* and *Organize/Layout (132)*, that dramatically outrank all others. These share many of the same comments regarding what the User likes and does not like about how information is visually presented and organized. This suggests that the User is decidedly aware of, and has personal preferences about, how content is organized and positioned.

*Second theme.* The second theme included *Colors (83), Information (73), Text Treatment (65),* and *Comprehension (63)*. These paint a picture of the way that colors and images, including those applied to text, impact attempts to gain information and comprehend content.

*Third theme.* The remaining 56 codes with frequencies that ranged from 43 comments to one, further split into two sub-themes. These suggest that two directions of engagement follow initial interaction with a web site or page: to react or respond. The User may react to the appearance with a judgment of whether or not to remain on the site or leave. This pragmatic decision is based on considerations that may be reduced to "like/doesn't like," "works/doesn't work," or other dichotomous assessments evoked by thoughts or feelings.

The User may also respond to a page, rather than react, and engage on cognitive and emotional levels within a framework of prior knowledge and expectations, or with feelings that reach into the User's sense of being. Thus, feelings, in addition to thinking, guide the User.

Should the User choose to remain on a page, despite initial reactions that may encourage otherwise, there is opportunity to redirect from negative reaction to positive response. The choice to delve more deeply into a site, despite negative reactions, opens the User to further possibilities. Cognitively or emotionally involved in the interaction, the User may be motivated to keep going in pursuit of the goal. Cognitively, the User seeks to learn and assimilate new information with the support of prior knowledge. The site may engage mental activity, curiosity, natural competition. Emotionally involved, the User may feel empowered, supported, encouraged, or affirmed. Self-confidence may be

boosted. The User may feel valued, but anger and frustration may also erupt.

### *Emergent Possibilities*

The goal of this research was to identify how people with MTBI access information on the web. Bogdan and Biklen suggest that "qualitative research approach demands that the world be approached with the assumption that nothing is trivial, that everything has the potential of being a clue that might unlock a more comprehensive understanding of what is being studied" (1992, pp. 30-31). As no research efforts were identified that studied people with disabilities and the web, much less individuals with MTBI seeking to access information on the web, this researcher chose to consider results from both the original method presented by Glaser and Strauss and the divergent method presented by Strauss and Corbin. To accomplish this goal, this researcher chose to seek emergent possibilities in more than one set of core themes. By doing so, it became apparent that the MTBI User's success with information access is influenced by more than one set of circumstances, more than one core theme, some seemingly of less influence and others of greater relevance.

After examining the data both from individual code and categorical positions, this researcher chose to depart from both grounded theory models. Rather than choose a single core theme to explore in greater depth, information resident in the codes and categories that was relevant to the goal of this study were allowed to further influence the final theory. Thus, aspects of feeling and thinking, design and organization, web concerns and MTBI User preferences, and the rest of the identified characteristics, were allowed to contribute to conditions that influence information access for the MTBI web User.

Figure 1 illustrates the dual analysis pathways converging together to build theory. The Strauss and Corbin method includes additional steps of forcing data into categories and themes. Glaser steps through a process that begins with raw data, identifies codes, sorts codes by frequency, detects core themes, then develops theory. Strauss and Corbin begin with raw data, move through open coding, develop categories, sorts categories, detects core themes, then present a theory.

*Emotionality*

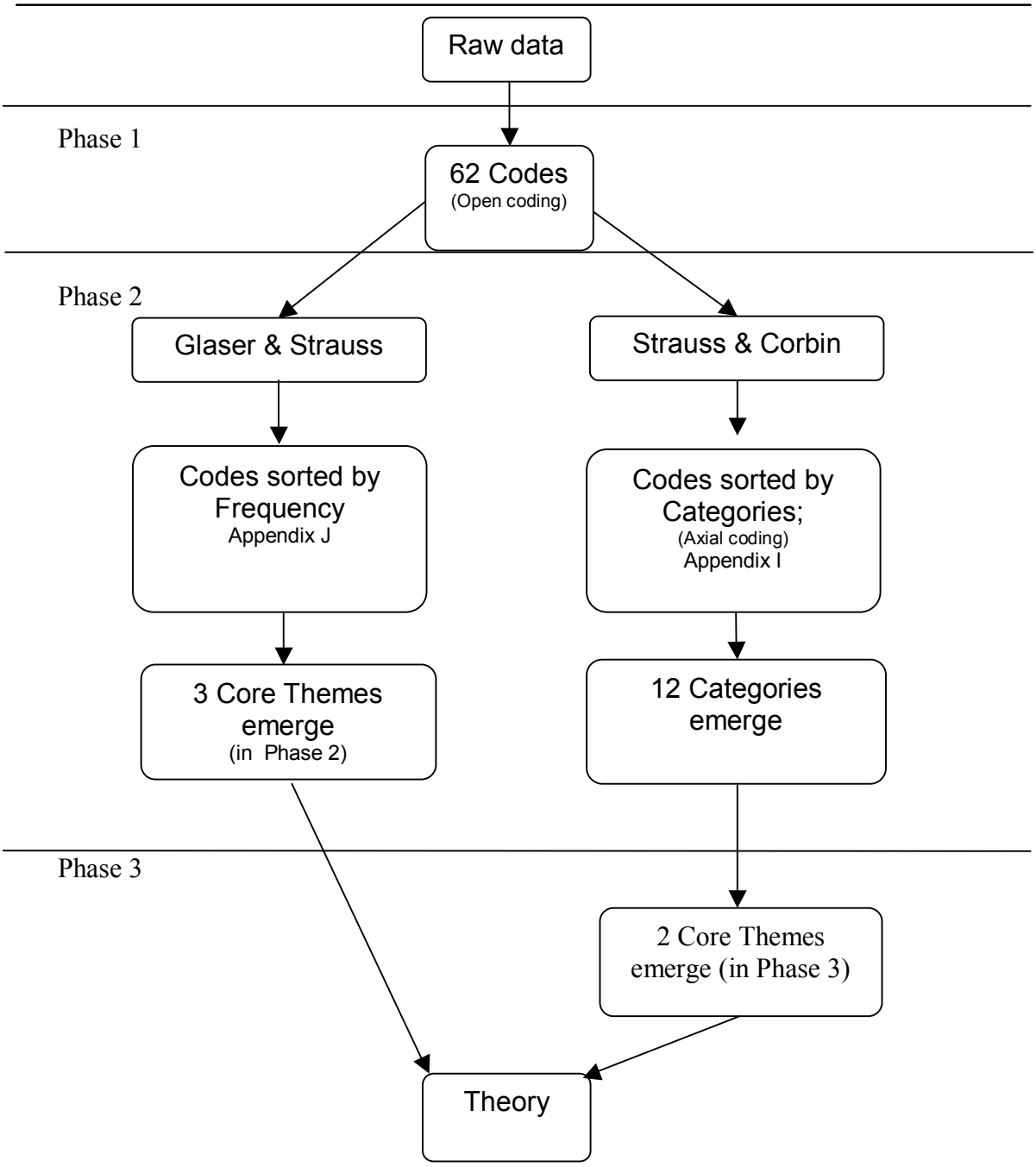
Amid themes that emerged in this study, the effect of emotionality in the MTBI User's web experience stands out. Response to technology dysfunction and presence of advertisements on pages often evoked sudden expressions of frustration and anger, evidenced by raised voices and verbal expressions of displeasure. Further re-examination of emotionality in the data suggested that User's decision-making was influenced by emotional processes than through cognitive processes—feelings over thinking.

*Combined Core Themes*

Analysis of this set of data provided five core themes, two from the Strauss and Corbin method and three from the original method devised by Glaser and Strauss:

1. Users are decidedly aware of how they think and feel about websites, and they have personal preferences about how content is organized and positioned;
2. Colors and images, including those applied to text, impact attempts to gain information and comprehend content; and
3. The User chooses between two directions of engagement that follow initial interaction with a web page: to react or respond.

Figure 1: *Grounded Theory Analysis Process*



4. Circumstances that impact the MTBI User;

5. Circumstances that impact technology or the web;

A common theme weaving through four of these five (number 5 excluded) are informed by the MTBI User's emotionality, that is, the role of the User's emotions, such as frustration or pleasure, to create a pleasing or dissatisfying experience.

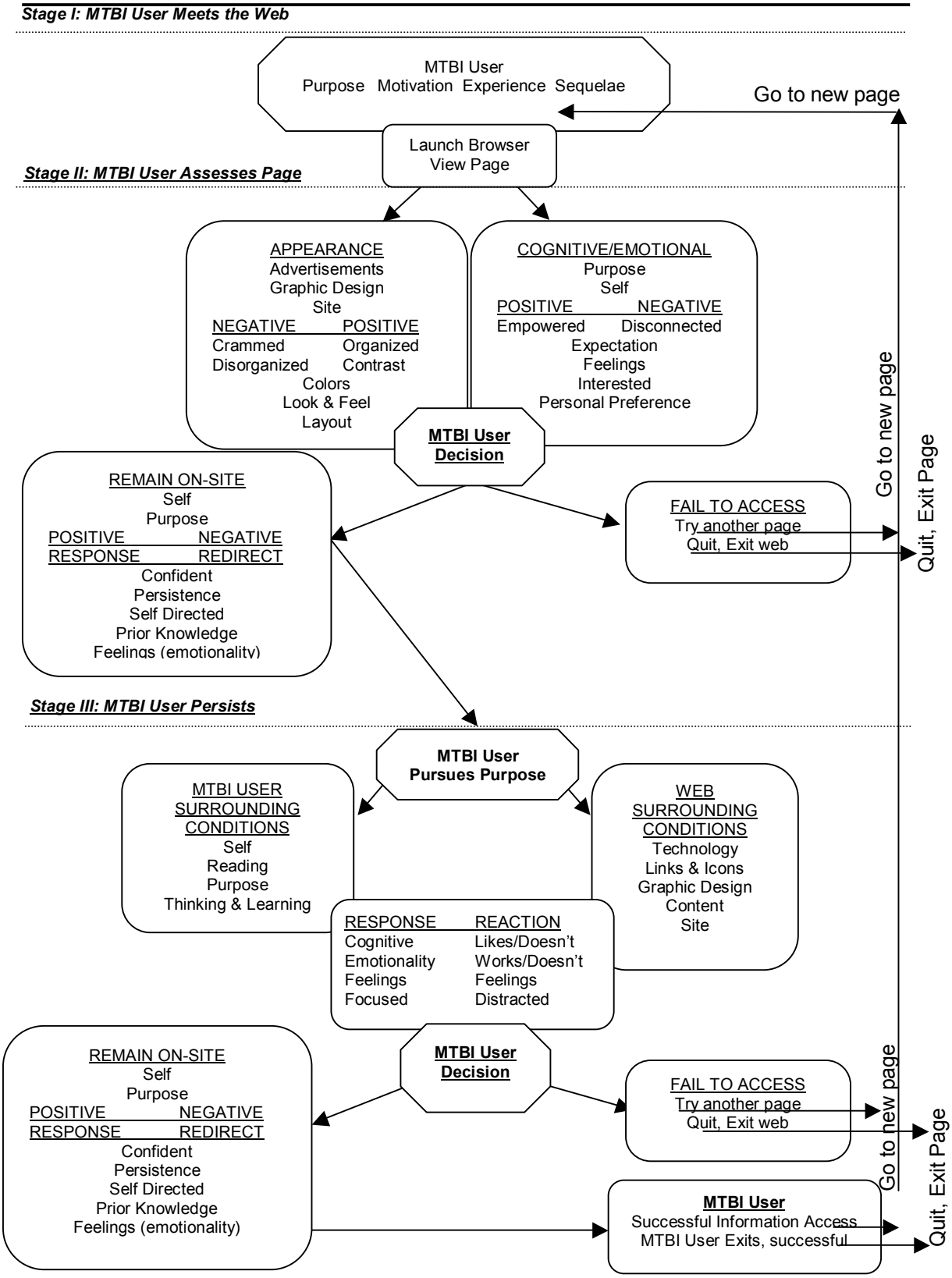
*Visual Model*

A diagram is well suited to present woven details produced by theoretical coding analysis with steps that revolve and evolve. Developed late in the analysis (Strauss & Corbin, 1990), this diagram visually presents the logical links between and within data, so therefore enabled this researcher to tease out a pattern of participant attempts to gain information access. include the Conditional Matrix in the final phase of analysis. In this study, Figure 2 represents a model for the concluding theory. However,rather than the broad Conditional Matrix espoused by Strauss and Corbin, this model speaks to the complexity of the MTBI User's effort to access information on the web.

*Stage 1: User Meets the Web*

The process of accessing information leads the MTBI User through a complex process that includes three stages. As shown in Figure 2, the Theory Model begins with the MTBI User, each of whom is a unique set of physical, mental, and emotional characteristics that vary greatly from person to person. This complex set of personal conditions informs how the User responds and reacts while engaging with a website, including: (a) User's access to a computer with browser software; physical manifestations resulting from injury; (b) purpose and motivation for engaging with the web; (c) self esteem and feelings; (d) technical proficiency; and many other traits.

Figure 2: *Theory*



The web experience begins before sitting down at a computer. A need or desire motivates the MTBI survivor to become a web User. Thus, the User gains physical access to a computer with web capability, then proceeds to launch the browser and begins to interact with the web. When a page appears, the next stage of the process begins.

*Stage 2: User Assesses New Page*

*Cognitive/Emotional.* Thoughts and feelings manifested during this stage lead to, and are informed by, categories that include *Purpose,* and *Self*. One code reflected the positive response to this theme—*Empowered.* One code speaks to negative response—*Disconnected.* Some codes—*Expectation, Feelings, Interested,* and *Personal Preference,* for example—also reflect responses or reactions, depending on the individual User's preferences.

*MTBI User's decision: Positive response.* If a page is (a) appealing, (b) appears to hold promise to meet the User's purpose, and (c) if the User cognitively and emotionally interacts in a positive manner, the User moves into a state of being motivated to make the decision to remain on the site and persist in pursuit of information.

*Redirect negative reaction.* Variation from this sequence results in a number of options. (Recall that heightened emotionality is a common sequelae of MTBI.) If the User experiences a negative reaction to a page's appearance or experiences negative feelings or thoughts about a page for any reason, a different process for interaction unfolds. For example, the User may have a negative reaction to appearance and positive response on a cognitive/emotional level, or vice versa. Codes involved with the User's decision to remain onsite, despite both initial positive responses and negative reactions, include *Confident, Persistence, Self Directed, Prior Knowledge,* and *Feelings* (see

emotionality discussion). These depend on the individual User's preferences. This is a conscious choice that informs the User's decision to either leave the page or remain to explore further.

If a decision is made to remain on the page in the presence of negative signals, the User may find value in an unsatisfactory site and use cognitive awareness to redirect negative perceptions to a more value-informed perspective. If the MTBI User decides to leave the page, two choices present: to go to a new page and begin this process again or to leave the web altogether.

*Stage 3: MTBI User Persists*

*Surrounding conditions.* As categories were examined, two themes emerged: conditions surround the User and aspects of the technical side of the web including web page construction and the underlying presence of the web and computers. Categories that speak to the User's experience on a page include *Self, Purpose, Reading,* and *Thinking & Learning,* references to the User's sense of being and relation with the web on an emotional plane. Categories that reflect the web, from design and arrangement to underlying programming, include *Content, Graphic Design, Links & Icons, Site, and Technology.* Presence of the technology is constant while the User's experience is unique from individual to individual.

*Response or reaction.* A range of codes emerged from the categories that informed the conditions, many focused on feelings and emotionality. Response and reaction interact and inform the next step in the journey though a page. While the User's reactions and responses vary, the underlying presence of the web is faithfully constant.

*Remain on-site.* Interaction between the sets of conditions is a fluid exchange that brings the User, once again, to a point of decision. As the User weaves reaction and response within the context of the web, another point of decision presents. The MBTI User may persist, even in the presence of obstacles, and remain on-site to continue the quest. Contributing categories and codes are similar to this step in Stage 2 when the User assesses a site. The User may tour around a page, decide that it is, after all, insufficient, and exercise the option to exit—to simply leave, unfulfilled.

Should the User persist, the possibility exists to successfully achieve the purpose for being on the web in the first place. At this point—the successful culmination of a complex process of balancing positive and negative thoughts and feelings with decisions to persist or quit—the User has accessed information. This User may leave the page, fulfilled, or choose to begin the process again with another web page.

## Summary

The journey through the layers of coding that began to define this study was revealing in its volume and clarity. Having decided, at the outset, to lean toward grounded theory as it was originally created, this researcher unpacked Glaser's approach from Strauss and Corbin's divergent practices to bring to light both the flexible and forced practices.

The first analysis phase produced 62 codes that were sorted by frequency, and regrouped into:

1. Twelve categories that further grouped into two core themes—conditions that represent the web pages and those that speak to the MTBI web User's experience;
2. Three core themes, (a) that Users have personal preferences of how they think and feel about how content is organized and positioned; (b) colors and images, including those applied to text, impact attempts to gain information and comprehend content; and (c) the User chooses between two directions of engagement—to react or respond—that follow initial interaction with a web page.

Each core theme represents rich interaction between the page and the MTBI User's cognitive and emotional responses. These interactions lead to decisions of whether to persist in the attempt to or exit.

# CHAPTER V

## Conclusion

### *Emergent Theoretical Perspective*

> …post industrial society makes knowledge accessible to the layman because knowledge and information technologies would diffuse into society and break up Grand Narratives of centralized structures and groups. (Lyotard, in Information Society, 2008)

An assertion associated with qualitative inquiry is that all research, positivist and naturalistic, is value-bound (Lincoln & Guba, 1985). Even the "questionnaire maker is being shaped throughout by his or her expectations of what the sample of respondents will be like, and how they are likely to react to whatever instruments he or she may finally send out" (p. 99). Alternatively, positivist inquirers hold that such inquiry is free from values that influence assumptions, theories, hypotheses, perspectives, socio-cultural norms, and personal norms. Those working in qualitative research suggest that such an assertion is, in itself, value-laden.

This study began as grounded theory based in interpretive social science. "Interpretive researchers study meaningful social action, not just the measurable or observable behavior of people" (Neuman, 2006, p. 88). Neuman defines meaningful social action as "social settings to which people subjectively attach significance and that interpretative social science treats as being the most important aspect of social reality" (p. 88). Naturalistic inquiry (Lincoln & Guba, 1985), holds that "realities are multiple, constructed, and holistic; [that the relationship between the] knower and known are

interactive [and] inseparable; [that generalization is not possible as] only time- and context-bound working hypotheses (idiographic statements) are possible; [that it is] impossible to distinguish causes from effects[because] all entities are in a state of mutual simultaneous shaping, [and that] inquiry is value-bound" (p. 37). These tenets served to frame this study.

As data collection proceeded and analysis evolved, it became apparent to this researcher that persons with cognitive disabilities [in this study web users with MTBI] experienced barriers to information access due to design accessibility that is limited to only two Category 1 Guidelines set forth by the W3C. The guidelines were a comprehensive attempt to create an accessible web; however, MTBI is an invisible disability, one that is easy to ignore because of low social awareness (see the Harris Poll results).

To understand the impact of a web with limited access on participants in this study, the premises of critical theory were examined to determine applicability to the process and findings. The themes and theory that emerged from the data were an appropriate fit for naturalistic inquiry and grounded theory; however, awareness that WCAG 1.0 does not support web users with MTBI, swept this study into critical theory. Neuman (2006) states that critical social science or, simply, *critical theory,* "can be best understood within the context of the empowerment of individuals….[and is] connected to an attempt to confront the injustice of a particular society or sphere within the society (p. 95). As such, research and researcher become agents for transformation, "unembarrassed by the label 'political' and unafraid to consummate a relationship with an emancipator consciousness" (p. 95).

To further explain the social impact of brain injury on the individual, Webb argues that:

> social reaction to head injury is testament to the latent eugenicist[1] and mentalist[2] suppositions within modernity[3]. The brain-damaged person cannot readily overcome disability with the assistance of technological aids available to those whose handicapping condition is physical. The consequences that head injury has for the mind and for the 'self' entail the special sequestration of those who are head-injured from modernity's concerns with reflexivity and with the paramount cultural and material importance of the mind….The 'future', around which much of modernity revolves, is denied to those whose catastrophe arose from these same modern times. (1998, p. 541)

Thus, transformation of the social and political order through 'practice' informed by a 'critical theory' … reveal and repudiate the oppressive workings of the status quo" (Marshall, 1943/1993, p. 132).

The web is now a staple in the digital world (Waddell, 1999); it was created and is maintained within the social context that does not place priority on the access needs of users with MTBI. To accommodate maximum information access, WCAG 1.0 must be amended to insist that applicable website construction guidelines be changed from recommendations to requirements. Access to information, framed within a critical theory

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[1] Eugenics is the belief that the human population can be improved by discouraging reproduction between those with negative traits and encouraging reproduction between those with positive traits.
[2] Mentalist refers to the belief that the function of the mind is appropriate for research.
[3] Modernity refers to the concept of being modern. The modernist is one who tends toward the modern way of being.

perspective, becomes a concern for the well-being of people who are cognitively, socially and economically at-risk.

This study, then, became a vehicle to study elements within the emergent web-based social order that are candidates for transformation. Critical theory provides a framework to identify and understand the need for change to existing web policies that do not require elimination of barriers to information access that is currently available to those without cognitive disability: those who have recovered from, or have lived with the good fortune to never have experienced MTBI. In essence, what began as an investigation became a call for action.

### *Initial Motivation*

This topic stemmed from personal interest but as data collection and analysis unfolded, became a project that could possibly inform those with power over regulations for internet design of the needs of a vast population of users. Implications drawn from this study are both broad and narrow; broad because of cognitive constructs that span age, education, and experience; narrow because specific web development guidelines that would support Users with MTBI can be drawn from the findings.

Counts of numbers of survivors vary according to data collection and focus of studies. The commonly seen annual number of TBIs is 1.4 million (Langlois, Rutland-Brown, & Thomas, 2006) and estimates of 75% to 90% are new MTBIs (Cassidy et al., 2004; CDC, 2007d; Langlois et al., 2006). Unfortunately this number draws from a limited number of sources that would present a more accurate statistic for MTBI in the United States (Carroll et al., 2004; Langlois et al., 2006). Recent estimates include amateur sports and recreation injuries, non-hospital clinics and treatment facilities,

private and public emergency department visits and admissions, providing an estimated 3.8 million MTBIs annually (CDC, 2007c). It is difficult to estimate the numbers that are unreported.

### *WCAG 1.0*

In 1999 the W3C developed the WCAG 1.0, a set of guidelines for web development (W3C, 1999, 2006). There are 14 guidelines, each of which covers a set of specific checkpoints. These are intended to create a more accessible web. Disabilities that include vision, hearing, and mobility are addressed in some detail, and WCAG 1.0 indicates that relevant checkpoints are mandatory development features. Cognitive disabilities, such as stroke, receive attention as well but not to the extent of those with disabilities that can be easily observed. Of the 19 WCAG 1.0 Checkpoints, only two are Level 1 and, therefore, required. Other Checkpoints that accommodate MTBI sequelae are listed as Level 2 (recommended but not mandatory) or Level 3 (generally out of reach for current technology). Yet, other Checkpoints intended to accommodate other disabilities also aid MTBI survivors.

Inequity between the W3C's acknowledgement of the needs of persons with different types of disabilities is readily apparent. Web accessibility guidelines that require design accommodations that meet the needs of persons with physical disabilities but ignore the needs of a growing segment of society—persons with MTBI-related disabilities—serve as a barrier to effective information access.

Every MTBI survivor is a unique individual, yet there are shared sequelae that are predictably common. In response to these symptoms, needs, and behaviors, web developers must move beyond the minimum requirements set forth in the WCAG 1.0

Guidelines to attend to access needs of MTBI survivors with cognitive disabilities. This is much less defined than, for example, coding to avoid interfering with a screen reader.

*Codes and Categories*

Participants in this study explored both familiar and unfamiliar web pages. They began with their usual starting page then self-selected web pages for the first hour of the interview. They were then directed to the Section508.gov site, followed by a search for Bobby ™ approved websites, pages approved as having accommodations for disabled web users. (Bobby ™, is a software program that analyzes web pages for accessibility barriers.) Users negotiated the search engine and demonstrated their strategies for selecting which 'hits' to launch.

Data from their experience included observation of each participant's journey by the investigator, talk-aloud recording of their experience, and personal notes from their Idea Book. Data was coded and sorted into 62 codes. These were then analyzed according to both Glaser's guidance toward the original, flexible grounded theory methodology, and by Strauss and Corbin's divergent, forced coding

Glaser's original model grouped the 62 codes into three core themes: what these participants like and dislike about how information is organized, that colors and images impact the MTBI User's attempts to access information, and elements that inform whether the participant chooses to react or respond, therefore remain or exit the site. These three themes together create an image of a journey informed by self-awareness, impacted by appearance, that together determine whether or not the participant successfully accessed information contained within a website.

Strauss and Corbin's model forced the 62 codes into 12 categories representing this group of MTBI Users' experiences: *Advertisement, Content, Focus & Distraction, Graphic Design, Links, Physical, Purpose, Reading, Self, Site, Technology,* and *Thinking & Learning.* Sorted by frequency of the codes within each, the categories grouped into two core themes: the MTBI User's experiences and about aspects of the web pages. Data that emerged about these Users mostly involved how they felt, thought, learned, focused, and how their concept of Self was involved or changed during their interaction with the web. Data that emerged about the web spoke to ways in which the technology and content interacted with the MTBI User.

One category that stood out was Advertisements, not because it carried a high frequency but because every time a participant commented on an advertisement it was emphasized with strong emotion, especially anger and frustration. Even comments that reflected frustration with technology were not nearly as strong as those about advertisements. This emotionality theme informed participants' journeys to a great extent. For example, if a participant landed on a page that evoked frustration or anger, there was a stronger inclination to exit the page, regardless of relevance of the content.

On a personal level, the survivor lives in a world where the web offers entertainment in addition to pragmatic application. Participants in this study all engaged in the web for specific purposes and did not "surf" for the sole purpose of satisfying curiosity. However, social and lifestyle considerations may encourage the survivor to seek out new websites or new gaming applications. In the search to participate in social trends, the MTBI survivor may choose a different course of action.

Participants in this study did not identify a standard set of colors, layouts, or design preferences. They did, however, respond to their dislikes on a highly emotional level, such as their response to graphics with flicker. They also share a common positive feeling of appreciation for clear organization of lists and menus.

### *Implications*

Several considerations inform the potential for success on the web. Basic organizational features such as a site map are not consistently understood as a necessary alternative to menu navigation (see Sydik, p. 259). The survivor may not choose to remain on a site that does not meet information access and aesthetic expectations. The survivor's motivation informs a level of persistence that influences how much attention is dedicated to a web excursion. As well, when using a search engine the survivor may choose to pursue *hits* that are located on the first page or two of several pages of a search return, but investigate no further. To reach this group, web designers who program keywords and tags for search engines could include sufficient identification to have their websites appear within the first page of hits.

Accessible websites are essential for MTBI survivors to cross the digital divide (Waddell, 1999). When the survivor must *figure out* an educational website, for example, the struggle can be overwhelming (Russell & Sharratt, 1992). Whether promoting a workshop or college course, an education-oriented website serves multiple purposes. Access to information about a school provides the survivor with tools for making informed decisions. Online courses themselves may be barriers to information access, as well, depending on the skill of instructional designers and limitations of the software in which courses are built. Because of the large numbers of MTBI survivors in the overall

population, it is reasonable to assume that at least a modest percent are potential students. Educational websites or course design that repel or confound the cognitively-impaired customer may serve to turn away the customer, a disadvantage in a competitive market.

Economic disadvantage reaches both the survivor and the economy (CDC, 2003; U.S. Dept. of Commerce, 2000). Commercial websites that repel the survivor in any way, including educational sites such as colleges and online schools, may find that they do not reach, therefore do not benefit from, a substantial section of potential customers. The seemingly simple process of selecting items to put into an online shopping cart and check out may easily confound the MTBI survivor for whom the web-based shopping experience is more of a challenge.

### *Questions for Further Inquiry*

This investigation studied adults with MTBI of different ages, education, employment, gender, and technology experience. Future investigations could include homogenous groups who share specific characteristics, such as age, technology experience, or education. Questions to inform future studies could investigate how MTBI-induced memory loss affects survivors in an older age group and what happens to their abilities and interests regarding the web. A study of Baby Boomers who are entering retirement would add a perspective that could inform entities who market to people in that age group.

On the younger end, we find the Millennials, people who were born after 1982 and were born after the advent of the Internet. These people have never lived in a world without global access through their computers. They were born wired, so to speak. What happens when a Millennial experiences memory loss and disruption to Executive

Functioning? Does the Millennial lose some ability to manage in a wired world, or is the web technology so ingrained that it serves the user as old knowledge and, therefore, is not disrupted by the MTBI? Further study into the social phenomenon presented by the Millennial generation would inform how information is accessed for decades into the future.

## FINAL REFLECTION

This study has been a journey through time and lives. The experiences of this group of participants with MTBI speak volumes more than words on a page. Each is a living tribute to human spirit.

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# APPENDIXES

# Appendix A

## *Doctor Recruiting Letter Example*

Dr. Kerri Dietz Pillen
1810 Wilshire Dr.
Bellevue, NE, 68005

7-12-02

IRB#2002-01-141-EP

Dear Dr. Pillen:

I am contacting you to request your assistance to locate subjects for my dissertation study. People I seek are those who have sustained mild traumatic brain injury and who have persistent problems after 6 months. The topic of my study is the process of accessing information on the World Wide Web by people with mild traumatic brain injury with persistent problems.

Study procedures are straightforward in nature. I will ask each person to show me a favorite web site and explain what the person likes and doesn't like about the pages. The conversation will be audiotape recorded. There will also be a notebook available for the participant to make written notes. I will then give the person an address to an unfamiliar website that is ADA compliant and repeat the process of discussion and writing notes. In a debriefing interview, the participant will be asked to discuss the pages again, this time comparing and contrasting the favorite pages and the ADA compliant pages.

This study is estimated to take about 90 minutes to two hours. Location of the study will be determined based upon individual needs. Participation is voluntary; there is no monetary compensation for participation at this study at this time.

Candidate comfort is strongly considered when making initial arrangements. Please take a few moments with your patients who may qualify and ask if I may call them to arrange for a screening interview. The interview may take 5 minutes or less. If the person prefers to call me, you may provide my name and telephone number. I can be reached at the following phone numbers:

Cell: 402-304-6336 Home: 402-476-6527

These numbers are Lincoln, Nebraska numbers. If contact with me requires a long distance call, I ask that the person call and allow me to return the phone call so that I may cover the cost of the call.

Thank you very much for your assistance with my dissertation study. I appreciate your time.

Sincerely,

Cynthia Blodgett-McDeavitt, M.A., PhD Candidate
University of Nebraska-Lincoln

Appendix B

*Recruiting Card*

---

**Head Injury Study**

Have you ever
- Had a concussion? Suffered a whiplash?
- Had you head snap back and forth?
- Fallen and hit your head?
- Been told that you have a mild brain injury?

If you experienced any of these types of injuries and also noticed that something wasn't quite right afterwards, you may qualify for my dissertation study. Please call **Cynthia at 402-304-6336** for more information.

Appendix C

*Screening Questions*

---

# Candidate Screening Questions

I am looking for people to interview for my study. This study is about how people who have had a brain injury access information on the World Wide Web. I will start by asking you some questions to see if you match the participant group that will work best for this study.

## Part 1.

What name would you like me to use as I make notes?

1. Have you ever had a concussion? [yes] [no] If yes, ask:

    - How long ago?
    - Were you unconscious? How long?
      [if person reports more than 1 hour, discontinue survey. The person sustained greater than a mild tbi]
    - What did you do?
        - Did you go to the doctor or hospital?
          Did the doctor give you any instructions?
        - Did you take care of it yourself?
          What did you do?
    - How are you now? Do you have any problems that still give you some trouble? [Look for answers about: [headaches] [vision] [attention] [fatigue]
    - **If there are persistent problems, ask for Consent.**

2. Have you ever been in a car accident or other situation where you suffered a whiplash or your head snapped back and forth, or you hit your head? [yes] [no] If yes, ask:

    - How long ago?
    - Were you unconscious? How long?
      **[if person reports more than 1 hour, discontinue survey. The person sustained greater than a mild tbi]**
    - What did you do?

*Appendix C (Continued)*

- Did you go to the doctor or hospital?
  Did the doctor give you any instructions?

- Did you take care of it yourself?
  What did you do?

- How are you now? Do you have any problems that still give you some trouble? [Look for answers about: [headaches] [vision] [attention] [fatigue]

- **If there are persistent problems, ask for Consent.**

3. Have you ever fallen and hit your head, for example on ice or on the ground or sidewalk? [yes] [no] If yes, ask:
   - How long ago?
   - Were you unconscious? How long?
     [if person reports more than 1 hour, discontinue survey. The person sustained greater than a mild tbi]
   - What did you do?
     - Did you go to the doctor or hospital?
       Did the doctor give you any instructions?
     - Did you take care of it yourself?
       What did you do?
   - How are you now? Do you have any problems that still give you some trouble? [Look for answers about: [headaches] [vision] [attention] [fatigue]

- **If there are persistent problems, ask for Consent.**

4. Have you ever been told that you had a brain injury or head injury [yes] [no]
   *If yes, ask:*

*Appendix C (Continued)*

- How long ago?
- Were you unconscious? How long?
  [if person reports more than 1 hour, discontinue survey. The person sustained greater than a mild tbi]
- What did you do?
  - Did you go to the doctor or hospital?
    Did the doctor give you any instructions?
  - Did you take care of it yourself?
    What did you do?
- How are you now? Do you have any problems that still give you some trouble? [Look for answers about: [headaches] [vision] [attention] [fatigue]

- **If there are persistent problems, ask for Consent.**

5. Overall, how are you now? Do you have any problems that still give you some trouble? [Look for answers about: [headaches] [vision] [attention] [fatigue]

- **If there are persistent problems, ask for Consent.**

## Part 2.

Ok, now I'll ask some general questions.

1. Do you know how to get to the World Wide Web?

2. How do you typically get to the web?

3. How experienced do you consider yourself with a computer and web browser software like Netscape or Explorer?
   [Not at all] [Some] [Moderate] [Expert]

4. Do flashing lights or movement on a computer screen bother you?

5. Is there anything that I need to know about web page design that affects you?

*Appendix C (Continued)*

Now I'll ask some questions that will help me to group you with other study participants as I analyze the information that you give to me.

6. How old are you?

7. What was your occupation at the time of your injury?

8. Do you do different work now?

9. Do you spend much time on the World Wide Web?

10. Do you have any questions for me?

# Appendix D

## *IRB Approved Consent*

University of Nebraska Lincoln

TEACHERS COLLEGE
Educational Psychology

**INFORMED CONSENT FORM**

IRB#2002-01-141 EP

**Identification of Project:**

Title: *A Grounded Theory Study of the Process of Accessing Information on the World Wide Web by People with Mild Traumatic Brain Injury.*

**Purpose of the Research:**
The purpose of this study is to see how people with mild traumatic brain injury access or manage information on the Internet and World Wide Web. So much information is available on the Internet and it's being used daily as people conduct their lives. You must be 18 years of age or 19 years of age in Nebraska and Alabama to participate in this study. You are invited to participate in this study because you experienced a mild traumatic brain injury and have persistent problems.

**Methods and procedures:**
This study will take about 90 minutes to two hours and will require access to a computer. The study location will be a place that is convenient to you, the participant. It may be conducted at a location where you may use a computer with which you are familiar, or with a laptop computer that the researcher will provide.

You will be asked to go to one or two of your favorite web sites and explain what it is about the pages that you like and don't like. You will be talking with the researcher while you are doing this. Your conversation will be audiotape recorded. There will also be an "Idea Book" for you to write notes to yourself about the pages.

After going through the web sites that you like, you will be asked to go to an unfamiliar website and go through the same process with the audiotaped conversation and the Idea Book.

Following your visits to the web sites, the researcher will do a short interview with you and ask you some questions to compare the pages, describe what you liked and didn't like about the pages you visited.

**Risks and/or Discomforts:**
There are minimal risks or discomforts associated with this research. You may experience some frustration as you surf the web.

**Benefits:**
You may find the learning experience enjoyable and the information may be helpful to you when you use the World Wide Web. The information gained from this study may help us to better understand how a specific group of individuals interact with the web.

initial here _____

114 Teachers College Hall
P.O. Box 880345
Lincoln, NE 68588-0345

*Appendix D (Continued)*

## IRB Approved Consent-Back

IRB#2002-01-141 EP

**Confidentiality:**
At the beginning of the study, you will be asked by what name you would like to be called. The researcher will use that name in any transcripts and reports. Your real name will not be used at any time during data collection or analysis. Consent forms and audiotapes will be kept in the custody of the researcher. The information that comes from this study may be published in educational journals or reported at meetings, but your name will not be revealed. All records will be kept until all future publication is complete.

**Compensation:**
There will be no financial compensation for participating in this research. Costs incurred, such as costs of public transportation to reach the study location, will be reimbursed.

**Opportunity to Ask Questions:**
You may ask any questions concerning this research and have those questions answered before agreeing to participate or during the experiment. Or you may call the investigator, Cynthia Blodgett-McDeavitt at any time:

office phone 402-476-6527 cell 512-826-8181

or call the Department of Educational Psychology at 402- 472-2223. If you have questions concerning your rights as a research subject that have not been answered by the investigator, Cynthia Blodgett-McDeavitt, you may contact the University of Nebraska-Lincoln Institutional Review Board, telephone (402) 472-6965.

**Freedom to Withdraw:**
You are free to decide not to participate in this study or to withdraw at any time without adversely affecting your relationship with the investigators, the University of Nebraska or other participating agent. Your decision will not result in any loss of benefits to which you are otherwise entitled.

**Consent, Right to Receive a Copy:**
You are voluntarily making a decision whether or not to participate in this research study. Your signature certifies that you have decided to participate having read and understood the information presented. You will be given a copy of this consent form to keep.

Signature of Subject:

_____ _____

Signature of Research Participant Date

Name and Phone number of investigator(s)

Cynthia Blodgett-McDeavitt, MA, Principal Investigator Office: (512) 826-8181

Roger Bruning, Ph.D, Secondary Investigator Office: (402) 472-2225

# Appendix E

## *Idea Book*

Your Initials:

URL:

Briefly describe this page.

Your Initials:

URL:

What did you like about this page?

Your Initials:

URL:

What didn't you like about this page?

Appendix F

*Interview Procedures as Included in IRB Protocol*

**2c. Data Collection**

**Task:** Web page exploration

1. To begin to explore how participants engage with the WWW, they will be asked what they normally do on the WWW and to go to a favorite web site. They will be asked a set of baseline questions and to describe
   a) what they like about the pages
   b) what they like about the site

Following this step, a pre-selected ADA compliant website will be toured following the same procedure.

The baseline questions will be consistent throughout data collection.

**Data:** Talk Aloud

As participants "surf" their favorite sites, they will be asked to talk about the sites and speak to the baseline questions. These questions are intended to generate thinking about the pages and encourage further discussion. The baseline questions are as follows:

a) What works for you about this page?

b) What really didn't work for you about this page?

An audiotape recorder will be available to record participant self-talk and dialogue with interviewer. Tapes will be transcribed.

Appendix G

*Code Definitions*

| *Code* | *Definition* |
|---|---|
| Accommodations | User problem-solves and takes action to accommodate challenges presented on a web site or page. For example, if normal glasses prescriptions are not sufficient for computer work, the user chooses an alternative, for example, to get specialized glasses, continue to struggle, or find a different line of work that does not require her to require glasses. Users who experience difficulty with graphic animation may choose to ignore the graphic or scroll down a page to move it out of sight. |
| Annoyed | Messages, layout, art, popup, and excess presence of ads evoke negative emotions, including annoyance |
| Assumptions | Ads located within the layout and popup ads are assumed to be spam, even if they are not spam but part of the website. |
| Attract User | Layout, organization, and graphic or site design strategies that may look the same as distracters are intended to draw attention and assist the user to maintain focus. |
| Barrier | Aspects of link design or placement that hinder navigation through, engagement with, or general experience on the website. |
| Browser Feature | Browsers have features and functions that support the user while visiting the web. These include the ability to change the size of text, windows, pointers, even colors in browser frames. This includes the Hand that appears to indicate presence of a live link. Appearance of the Hand indicates meaning to even the least skilled users. |
| Choices | User is provided with a variety of navigational choices through which to navigate a website. Choices include text links, icons, graphics, menus across top, bottom and left column. |
| Colors | Colors may evoke emotional, cognitive, or physiological responses that influence a user to remain or exit a web page. Includes arrangement of colors and graphical elements, comments on jpgs, and use of animation. |

*(table continues)*

*Appendix G (Continued)*

| *Code* | *Definition* |
|---|---|
| Common Language | User benefits from knowing the meaning of language presented on a website. Standard terminology can confound or clarify, depending upon if the user understands. Not knowing a term that others take for granted prohibits access to information. |
| Communication | User's purpose for interacting with the web is to communicate with others. Communication tools include chat rooms, instant messenger, blogs, etc. |
| Comprehend | Content is not written and/or presented in such a way that the user can readily read and understand meaning. The user is not sure of how to proceed due to lack of sufficient information or instruction provided on a page. |
| Confidence | A confident person is generally self assured of accuracy of decision making. Actions and reactions reflect how well a user may feel regarding personal expertise, despite actual ability. |
| Consistent | Common features are located in similar areas within a web page or site. Location and functionality of features such as a Home button and familiar menus are similar from page to page and site to site. |
| Crammed | Text and page elements are spaced too closely together on a page to be fully comprehended by the User. |
| Critical Thinking | The User demonstrates problem solving and thinking strategies to find solutions, including deriving meaning from associated graphics, neighboring content, application of if-then questionings, and generally piecing together unfamiliar material to make meaning. |
| Design Strategy | Underlying layout and site design decisions intended to guide or lead the user to the desired experience on the site or page. Design strategies may include use of color, sound, and navigation with language or graphics, to stimulate curiosity, evoke feelings, and other desired outcomes. A user can be guided through a website, off a website, and to specific information, as desired by site designers. |

*(table continues)*

*Appendix G (Continued)*

| *Code* | *Definition* |
|---|---|
| Different | At times a website may change the design and layout of a homepage and pages throughout a site. Familiar information and navigation features are relocated or eliminated, replaced with different graphics or information, or both. The user who frequents such a site is aware of the different layout and may experience difficulty orienting to changes. |
| Disconnect | Design, layout, content, or other aspects of a site or page evoke negative response from the user, or user may be confused and dismiss a page as unimportant. |
| Distract | Distraction is loss of focus or inability to gain focus. Any distraction disrupts focus draws eyes away from area of focus on a web page. A distraction is different from a design strategy intended to guide attention. The User loses place on the page when distracted. Speed of an animation, intensity of colors, and changing colors distracts focus. |
| Easily Located | Icons and other graphical elements are located on the page where they are easily visible. |
| Efficiency | When technology does not perform efficiently, ie, pages load very slowly, the computer locks up, or links don't work, a user may express anger or frustration, or may patiently wait for technology problem to resolve. Procedures to address technological difficulties may be time-consuming, such as re-starting the computer, and the laborious task of re-loading programs and finding previous locations. |
| Emotional | Reference to emotional positive or negative memories as related to learning. |
| Empower | User feels a sense of being, or are about to become more in control of one's own life situation. Interaction with website, content, graphics, or other elements influences the User's perspective of personal presence on the web. |
| Entertainment | User uses internet as a source of entertainment, especially with games. |

*(table continues)*

*Appendix G (Continued)*

| *Code* | *Definition* |
|---|---|
| Expectations | The User anticipates that interaction with the web will deliver a predictable experience or perform in a predictable manner. For example, when technology does not function as expected, the User may express anger or frustration, wait for technology problem to resolve, or leave the site. Pages load very slowly, the computer locks up, or links don't work, leading User to express anger or frustration. Difficulties may be time-consuming to correct, such as re-starting the computer or re-loading programs to find previous locations. |
| Eyes | Eye strain, fatigue, and pain as a result of working on a computer. |
| Familiarize | Process whereby user previews information on a page, or process taken to ensure accurate understanding of information. |
| Feelings | A website evokes emotions that are reflected in facial expression or body language. User expresses positive or negative emotions in relation to experience on a page or in a website. Reference to emotion, positive or negative memories as related to learning |
| Hand | The “Hand” is the default setting for the cursor when it rolls over a link on a page. Cursor turns from I-beam or pointer to a hand. This indicates to user that the cursor has located a link. Especially helpful when text is blue, underlined, or invisible |
| Help | Online instruction are sought from online sources provided through links on the website. Help services may be sought from a "live" person instead of technology based Help menus. |
| Ignore | User is aware of presence of advertisements, both pop-up and in the layout design, and chooses to turn attention away from the advertisement in favor of other elements on the page. |
| Impairs | Graphic or site design that lessens the user's ability to process information. This includes sounds, graphics, animations, placement, organization, technical decisions, or anything else that the User encounters when interacting with a page. |

*(table continues)*

*Appendix G (Continued)*

| *Code* | *Definition* |
|---|---|
| Impairs Reading | Any design element or treatment within the body of a page that causes the User to struggle to derive meaning. |
| Information | Presence or absence of information that serves to guide the user around a site and make meaning from the content presented. There may be too much information packed into a page, thus making it difficult to identify needed information. As well, insufficient information may be provided to answer questions, provide instruction, or label links. |
| Injury Related | User attributes discomfort, especially with vision and eye strain, to injury. |
| Interest | Content of the website is of interest to the user, demonstrated by intent focus on a page, exploring links, or showing increased animation when engaged with a page or site. When interested, the user may persist with seeking information or make extra attempts to understand content or layout of a page. |
| Lacks Interest | User may not seek information without prompting, perhaps due to lack of knowledge or interest to seek out information independent of need. User may be aware of needed information, even information that will help to understand a procedure, when playing a game, for example. |
| Literacy | Ability to understand the meaning of words, the definition of words, used on a web page influences whether or not the user can make meaning of the content well enough to access information available on the page or site. |
| Look & Feel | Look & Feel is a subjective description of a User's perception of a page or website that cannot be described more specifically. |
| Lost | User is unsure of bearings within a website. Look and feel of the page in view appears to be unrelated or unfamiliar. |
| Organize/Layout | Content and information on a page is presented in an organized manner, assisting User to scan more quickly, thus locating desired information, including links, more efficiently, with less frustration. |

*(table continues)*

*Appendix G (Continued)*

| *Code* | *Definition* |
|---|---|
| Persistence | Attempt is made, through repeated effort, to locate desired information within a site. Desired information may or may not exist on the site; however, the user focuses attention on the objective, sometimes to great lengths and despite frustration. |
| Personal Preference | A user has personal likes and dislikes in reference to all aspects of a website or page, including color, layout, graphics, and navigation. Direct comments such as, "I prefer," “I don’t like,” "I like," or "personal opinion" identify sentiments of positive or negative preference. |
| Pervasive | Frequency of advertisements appears to be extensive and excessive. Perception of pervasiveness distracts and evokes a sense invasion of the User’s time and purpose. |
| Prior Knowledge | Knowledge that the user draws from to enhance the experience or make efforts more efficient. Knowledge may not be exactly the same as found in the current situation; however, User can compare visual and functional aspects of a page or site to facilitate information transfer to a novel situation. |
| Proficient | Whether confident or not, user demonstrates sufficient knowledge and skill to successfully navigate and/or manage and solve problems. This is apparent when the user interacts with technology. |
| Readability | Design, graphic, or language strategies that do not impair, and may improve, user’s ability to read words on a page. |
| Scrolling | User may be required to scroll down the page to access information not immediately visible. |
| Seamless | Links that tag directly to information within a site move the User directly to desired location within a site or elsewhere on the web. |
| Security Conscious | User is aware of security threats that present on the Web, therefore, takes special precautions, such as steps to prevent identity theft to prevent a security breech. |

*(table continues)*

*Appendix G (Continued)*

| *Code* | *Definition* |
|---|---|
| Self Directed | User independently chooses own action within a site or page, inventing creative solutions to common or unique problems. User is curious and, without prompting, chooses to interact with functions on a page. The self-directed user may decide to remain on a site, or leave a site, based on personal choice. |
| Self Aware | User may not be accurately aware of ability, skills, and needs, and may compare self with others. |
| Self Training | User learns to focus on task at hand by personal volition and without assistance, for example, how to manage distracters or learn to navigate. |
| Site Function | How a website functions is a result of coordination of efforts, including underlying programming and design decisions. |
| Software | To utilize the web, the user must possess at least a basic knowledge of browser software, including features designed to enhance efficiency and enjoyment. |
| Special Needs | Browsers are programmed to include functions that help the user with special needs, such as blindness. User may be aware of such functions, and know how to access them. |
| Specific Intent | The User engages with the www with a specific activity in mind, whether to engage in communication, research, entertainment, or other activity. The User is specific about purpose for engaging with the web. |
| Text Treatment | Text, whether in graphics, content or links, is treated with size, color, and visual contrast. |
| Trial & Error | A User's attempt to interact with a page or site is not informed by an organized plan toward information seeking. The User may click from link to link in a random manner, missing instructions or cues designed to guide the User through meaningful interaction. |

*(table continues)*

*Appendix G (Continued)*

| *Code* | *Definition* |
|---|---|
| User Friendly | A site presents easy-to-use functions, some of which are pre-packaged or pre-programmed, such as an easily located search field or a convenient button to bookmark a favorite page without going into the browser functions. |
| Wastes Time | advertisements are considered to be a waste of time because of distraction potential. User does not perceive following ad links to be of value, therefore a waste of time. |

Appendix H

*Category Definitions*

| Category | Definition |
|---|---|
| Advertisements | Advertisements in pages or as pop-ups are designed with graphic and content to attract the User's attention. Ads affect the emotional, physical, cognitive, and focus of the User. |
| Content | All that is visible and audible is included in the content of a web page . Content may be text about the topic, amount of text in comparison to graphics or space, presence or lack of information or directions that the User expects or desires to be present on the page, arrangement of colors, organization of text, design of graphics, and information presented. |
| Focus/Distraction | The User interacts with a web page by being focused to, or distracted by, the design of a web page or site. Distraction is loss of focus or inability to gain focus; any distraction disrupts focus from reading and draws eyes away from location on web page. |
| Graphic Design | Web pages are artfully developed with colors, pictures, sound, animation, and designs. Graphic Design is the intentional combination of visual and auditory elements to achieve an objective. |
| Links and Icons | Links and icons provide visual cues to guide movement through a page and to move further into a website. Links connect pages on the web. They present as text within sentences, small graphics labeled with the purpose or destination, graphics with images that represent the purpose or destination, or not visible at all, revealed only when the mouse pointer turns into a hand. |
| Physical | Physical challenges resulting from the web experience. For example, problems with arms, hands, vision. |
| Purpose | The User logs on to the web for a purpose, whether for entertainment, general curious exploring, or for a specific reason. |

*(table continues)*

*Appendix H (Continued)*

| *Category* | *Definition* |
|---|---|
| Reading | The text-based nature of the web requires that the User have an ability to read and understand the content, including instructions and cues to link and information location. |
| Self | Descriptions of an individual's personal experience of a web page. |
| Site Design | Overall graphic design and construction of the web site and/or web page. Organization of graphical elements on pages, including menus, arrangement of content and columns, lists, paragraphs and so forth. Placement of any cues to lead user through website and cues to help user to know where they are in cyberspace. |
| Technology | The functionality of technology as experienced by the person visiting a website. Examples are speed of an internet connection, broken links on a website |
| Thinking & Learning | The role of cognition in personal strategies, procedures, and other ways that the User sets into motion in order to learn new content or new skill. The User interacts intellectually, interacting with or without interest, or persisting in an effort to support purpose. Applying prior knowledge to understand or navigate, the User approaches new information with or without a strategy. |

Appendix I

*Categories and Codes with Frequencies*

| *Category* | *Total Frequency* | *Code* | *Frequency* |
|---|---|---|---|
| Advertisements | 22 | Annoyed | 7 |
| | | Pervasive | 7 |
| | | Ignores | 3 |
| | | Wastes Time | 3 |
| | | Distracts | 1 |
| | | Assumptions | 1 |
| Content | 205 | Organize/Layout | 132 |
| | | Information | 73 |
| Focus/Distraction | 45 | Distracts | 22 |
| | | Attracts | 18 |
| | | Self-Training | 5 |
| Graphic Design | 155 | Colors | 83 |
| | | Text Treatment | 65 |
| | | Impairs | 7 |
| Links & Icons | 31 | Easily Located | 19 |
| | | Hand | 8 |
| | | Seamless | 2 |
| | | Barrier | 2 |
| Physical | 13 | Eyes | 11 |
| | | Injury Related | 1 |
| | | Accommodations | 1 |
| Purpose | 50 | Specific Intent | 25 |
| | | Entertainment | 15 |
| | | Communication | 10 |
| Reading | 70 | Readability | 38 |
| | | Impairs Reading | 14 |
| | | Common Language | 13 |
| | | Literacy | 5 |

*(table continues)*

*Appendix I (Continued)*

| *Category* | *Total Frequency* | *Code* | *Frequency* |
|---|---|---|---|
| Self | 334 | Personal Preference | 165 |
| | | Proficient | 43 |
| | | Self Directed | 41 |
| | | Feelings | 21 |
| | | Empower | 19 |
| | | Self-Aware | 18 |
| | | Confidence | 17 |
| | | Expectation | 4 |
| | | Security Conscious | 3 |
| | | Lost | 3 |
| Site Design | 148 | Choices | 43 |
| | | Design Strategy | 36 |
| | | User Friendly | 20 |
| | | Consistent | 16 |
| | | Disconnect | 9 |
| | | Look & Feel | 8 |
| | | Different | 6 |
| | | Crammed | 5 |
| | | Scrolling | 5 |
| Technology | 37 | Site Function | 16 |
| | | Browser Feature | 11 |
| | | Special Needs | 6 |
| | | Efficiency | 2 |
| | | Software | 2 |
| Thinking & Learning | 222 | Comprehend | 63 |
| | | Prior Knowledge | 28 |
| | | Interested | 27 |
| | | Persistence | 22 |
| | | Familiarize | 20 |
| | | Trial & Error | 17 |
| | | Lacks Interest | 17 |
| | | Help | 13 |
| | | Emotional | 10 |
| | | Critical Thinking | 5 |

Appendix J

*Codes Sorted by Frequency*

| *Category* | *Code* | *Frequency* |
|---|---|---|
| [Self] | Personal Preference | 165 |
| [Content] | Organize/Layout | 132 |
| [Graphic Design] | Colors | 83 |
| [Content] | Information | 73 |
| [Graphic Design] | Text Treatment | 65 |
| [Thinking & Learning] | Comprehend | 63 |
| [Self] | Proficient | 43 |
| [Site Design] | Choices | 43 |
| [Self] | Self Directed/Self Reliant | 41 |
| [Reading] | Readability | 38 |
| [Site Design] | Design Strategy | 36 |
| [Thinking & Learning] | Prior Knowledge | 28 |
| [Thinking & Learning] | Interest | 27 |
| [Purpose] | Specific Intent | 25 |
| [Focus/Distraction] | Distracts | 22 |
| [Thinking & Learning] | Persistence | 22 |
| [Self] | Feelings | 21 |
| [Site Design] | User Friendly | 20 |
| [Thinking & Learning] | Familiarize | 20 |
| [Links & Icons] | Easily Located | 19 |
| [Self] | Empower | 19 |
| [Focus/Distraction] | Attract User | 18 |
| [Self] | Self Aware | 18 |
| [Self] | Confidence | 17 |
| [Thinking & Learning] | Trial & Error | 17 |
| [Thinking & Learning] | Lacks Interest | 17 |
| [Site Design] | Consistent | 16 |
| [Technology] | Site Function | 16 |
| [Purpose] | Entertainment | 15 |
| [Reading] | Impairs Reading | 14 |
| [Reading] | Common Language | 13 |
| [Thinking & Learning] | Help | 13 |
| [Physical] | Eyes | 11 |
| [Technology] | Browser Feature | 11 |

*(table continues)*

*Appendix J (Continued)*

| *[Category]* | *Code* | *Frequency* |
|---|---|---|
| [Purpose] | Communication | 10 |
| [Thinking & Learning] | Emotional | 10 |
| [Site Design] | Disconnect | 9 |
| [Links & Icons] | Hand | 8 |
| [Site Design] | Look & Feel | 8 |
| [Advertisements] | Annoyed | 7 |
| [Advertisements] | Pervasive | 7 |
| [Graphic Design] | Impairs | 7 |
| [Site Design] | Different | 6 |
| [Technology] | Special Needs | 6 |
| [Focus/Distraction] | Self Training | 5 |
| [Reading] | Literacy | 5 |
| [Site Design] | Crammed | 5 |
| [Site Design] | Scrolling | 5 |
| [Thinking & Learning] | Critical Thinking | 5 |
| [Self] | Expectations | 4 |
| [Advertisements] | Wastes Time | 3 |
| [Advertisements] | Ignore | 3 |
| [Self] | Lost | 3 |
| [Self] | Security Conscious | 3 |
| [Links & Icons] | Seamless | 2 |
| [Links & Icons] | Barrier | 2 |
| [Technology] | Efficiency | 2 |
| [Technology] | Software | 2 |
| [Advertisements] | Assumptions | 1 |
| [Advertisements] | Distract | 1 |
| [Physical] | Injury Related | 1 |
| [Physical] | Accommodations | 1 |