Fall 2008

Educating the general public about brain injuries

Jesse Edwards Williams
University of New Hampshire, Durham

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Educating the general public about brain injuries

Abstract
The purpose of this investigation is to determine if exposure to educational materials regarding acquired brain injuries (ABI) can have a positive impact on the attitudes and beliefs of the general public. The findings of this research will help determine the values of educating the general public and help determine future methods for educating the public about ABI.

Misconceptions about ABI are still present today. The results of this investigation demonstrate that responses significantly differed depending on what methods of instruction respondents received.

Keywords
Health Sciences, Speech Pathology, Biology, Neuroscience, Health Sciences, Rehabilitation and Therapy

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EDUCATING THE GENERAL PUBLIC ABOUT BRAIN INJURIES

BY

JESSE EDWARDS WILLIAMS
B.A., University of Vermont, 2006

THESIS

Submitted to the University of New Hampshire
in Partial Fulfillment of
the Requirements for the Degree of

Master of Science
in
Communication Sciences & Disorders

September, 2008
This thesis has been examined and approved.

Michael Fraas, Ph.D., Assistant Professor
Communication Sciences & Disorders

Stephen Calculator, Ph.D., Chairperson of
Communication Sciences & Disorders

Frederick C. Lewis, Ph.D., Associate Professor
Communication Sciences & Disorders

July 30, 2008
Date
DEDICATION:

To the one I love.
ACKNOWLEDGEMENTS:

To my parents who I model my life after; my brother who lives life to the fullest; the speechies who kept me sane; all the professors in the Communication Sciences Department that taught me the world of speech & language; my thesis review committee; Dr. Calculator for my AAC drive; Dr. Fraas for not only being my mentor but a friend; my husband who is also my best friend.
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ABSTRACT

EDUCATING THE GENERAL PUBLIC ABOUT BRAIN INJURIES

BY

JESSE EDWARDS WILLIAMS

University of New Hampshire, September, 2008

The purpose of this investigation is to determine if exposure to educational materials regarding acquired brain injuries (ABI) can have a positive impact on the attitudes and beliefs of the general public. The findings of this research will help determine the values of educating the general public and help determine future methods for educating the public about ABI.

Three hundred and eleven respondents from the general public answered survey questions about general brain injury and stroke knowledge, the effects of coma, memory deficits resulting from ABI, the ABI recovery process and community reintegration for survivors. A chi-square analysis revealed significant statistical differences between the educational groups and the survey group. Findings were also compared to those of previous studies using similar questionnaire items.

Misconceptions about ABI are still present today. The results of this investigation demonstrate that responses significantly differed depending on what methods of instruction respondents received.
Chapter I:

Introduction

Statement of the Problem

Acquired brain injuries (ABI) occur in 1.4 million people a year (Thurman, 1999; Langlois & et al, 2004). Approximately 5.4 million individuals in the United States live with the long-term effects of ABI (Center for Disease Control, 2001). It is estimated that every 21 seconds an ABI occurs. The wars in Iraq and Afghanistan have caused a rapid increase in this number. New explosives and roadside bombs have made TBI the most common injury for U.S. troops serving in the Middle East. This combined with heightened war survival rates have caused 60 to 83% of those soldiers injured in explosions to be diagnosed with TBI (Okie, 2005; Zoroya, 2005).

Acquired brain injuries are defined as any damage to the brain from changes in the brain's neuronal activity due to a traumatically induced physiological disruption of brain function (American Congress of Rehabilitation Medicine, 1993). An ABI can occur in a variety of ways including falls, assaults, motor-vehicle accidents, being struck by objects and various forms of stroke and tumors (CDC, 2006).

Despite the prevalence of ABI, the general public continues to have misconceptions, negative attitudes and a lack of knowledge with regard to the
ramifications of acquiring a brain injury (Hux, 2006). The general public underestimates the overall severity, range and the effects of brain injury (Gouvier, Uddo-Crane & Brown, 1988; Mackenzie & McMillian, 2005). As a result, survivors receive inappropriate and ineffective treatments (Tervo, Palmer, & Redinius, 2004), they are continually discriminated against by the general public (Swift & Wilson, 2001), and they don’t receive the necessary resources to help them effectively integrate back into their communities (McCabe et al., 2007). Several studies have suggested that further information and education of the general public about brain injury may be beneficial (Mackenzie & McMillian, 2005; Hux, 2006).

This study will investigate the effects of various tools used to educate the general public about ABI. It is hoped that these methods of education will result in increased knowledge of, improved attitudes toward, and decreased misconceptions about ABI.
CHAPTER II:

ACQUIRED BRAIN INJURY

Types of ABI

Traumatic brain injury.

The most common type of acquired brain injury is a traumatic brain injury (TBI), more specifically the result of an accident to a person's head or neck from striking an object. Motor vehicle accidents, falls and sports injuries are the most common forms of TBI (Jaiswal, 2006; Coronado et al., 2006). Other forms of TBI may include poisoning, toxic exposure, infections, insufficient oxygen, and electrical shock, along with near-drowning experiences (BIAUSA, 2006). The risk of brain injury is highest among adolescents, young adults and individuals over the age of 75. Adults over the age of 75 are more susceptible to TBI due to falls.

Recent surveys have shown that males are twice as likely as females to sustain a TBI. This is thought to be a result of males participating to more risky behaviors (O'Jile & et al., 2004; Good & et al., 2008). It has been concluded that women are much safer behind the wheel of an automobile than men. Men are more likely to drive while intoxicated, drive faster and out of control, take risks for pleasure, and are more likely to consciously discard their seatbelts (Courtenay, 1998).
Vascular pathologies.

Strokes, aneurysms, heart attacks, and arteriovenous malformations can cause an acquired brain injury. ABI due to stroke is a result of disruption of a person's vascular supply to the brain (Sohlberg & Mateer, 2001). Every three minutes somebody dies of a stroke. Strokes account for one in every 15 deaths in the United States, making strokes ranked as the third leading cause of mortality. Strokes affect over 700,000 people each year in the United States. It is estimated that a stroke occurs every 45 seconds. Strokes affect 40,000 more women than men. This can be due to the fact that women live longer than men. The United States has over 13 million people who have had a silent stroke; a stroke that causes brain damage that does not exhibit the classic symptoms of a stroke (CDC, 2006). Strokes are the leading cause of long-term disability in the United States with a prevalence of more than 4 million people (CDC, 2006).

Impact of ABI on Survivor's Life

Depending on the severity of the brain injury and the location of the pathology, an ABI can severely impact an individual's lifestyle. The effects of a brain injury are life-long and can be very costly for many individuals. In the United States in the year 2000, the direct and indirect medical costs of TBI totaled an estimated $60 billion (Finkelstein, 2006). The mean lifetime cost associated with stroke is estimated between $90,000 and $228,000 depending on the type of stroke (e.g., subarachnoid hemorrhage, intracerebral hemorrhage, or ischemic stroke) (Taylor et al., 1996). For TBI,
this figure is estimated between $600,000 and $1,875,000 per person (Dorset, 1998).

Brain injuries can cause a wide range of deficits and symptoms. Specific deficits associated with brain injury are dependent on the site of lesion. Examples include behavioral, physical and cognitive dysfunction (Lefebvre & et al., 2005). Every individual with a brain injury is unique from the next in that combinations of disabilities may occur. In addition, individuals may experience variability in the type and severity of their disabilities (Swift & Wilson, 2000).

Brain injuries can result in deficits in communication, such as expressive and receptive language impairments. The individual may experience difficulty understanding spoken communication and written communication along with difficulties in spelling, reading and writing (Coelho, 2007; Reuffer, 2007). Weakness and motor problems with the speech muscles can result in a variety of issues for the individual, such as difficulty moving the articulators to speak resulting in impaired intelligibility. In addition, it is not uncommon to see decreased respiratory vital capacity which is necessary for speech. Social communication skills are also effected in individuals with ABI because individuals may not be able to maintain a conversation, stay on topic, comprehend turn taking skills or understand others facial expressions (Fraas & Calvert, 2007; Turkstra, 2007). Swallowing disorders are also a major complication seen with individuals who have ABI (Brown, 2007; Morgan & Mackay, 1999).
Individuals with brain injuries may or may not have a visible disability. ABI patients who have no physical disabilities are often referred to as the ‘walking wounded’ (Ruff, 2005). This leads to an unrealistic expectation in performance from their family and peers. This lack of awareness may lead the general public to believing that a person is “normal” if there are no visible signs of disability.

Cognitive deficits that result from brain injuries can significantly impair an individual’s life depending on the severity of the injury and where the trauma occurred. The most common areas affected are attention, memory and executive function (BIR). Short-term memory and selective attention deficits may make it difficult for survivors to concentrate and multi-task (ASHA, 2008). Attention deficits may affect the client’s rate of processing and response to simultaneous stimuli, along with increased distractibility. Individuals who have sustained a brain injury have difficulty retaining new information as efficiently as before their trauma (Sohlberg & Mateer, 2001).

Sensory deficits are another area affected by ABI. Individuals with ABI may experience visual problems that effect vision in different fields, along with the difficulty of identifying colors. Some patients with ABI have sustained trauma to the auditory pathways, causing sensorineural hearing loss and/or tinnitus (McIntosh, 1997; Lew & et al., 2007). Veterans with ABI have a higher percentage of hearing loss and reported tinnitus due to blast-related injuries, which result in middle and inner ear damage (Lew & et al., 2007).
Impact of ABI on the family.

Sustaining a brain injury is not only difficult for the patient to adapt to, but for their family as well. Sometimes an injury can disrupt the equilibrium of the whole family and cause a burden for families (Lefebvre, 2004). Many families have a difficult time adapting to their family member’s brain injury. Even many years after the trauma, the disability and hardship persists, affecting the entire family nucleus (Inzaghi, et al., 2005). Families of survivors of brain injury complain that the lack of psychological support and rehabilitation for their loved ones plays a negative role in their adaptation process (Kendall, et al., 2000). Families have reported that the disabilities associated with ABI are not only demanding for the survivor but for the members of their family as well (Lefebvre, 2004). Family members have often experienced isolation from social groups following the survivor’s injury (Inzaghi & et al., 2005). Some of the most difficult aspects for significant others of individuals with ABI is the breakdown of intimate relationships, self-centered behavior by the survivor, and the ambiguous loss they have experienced (Landau & Hissett, 2008; Fleminger, 2008). It has been found that nearly 50% of relationships of persons with TBI have ended in divorce or separation (Wood & Yurdakul, 1997). This collapse of the familial network has a harmful impact on the ABI survivor.

Financial Burdens.

A financial burden is placed on many individuals with ABI and their families because many do not have the ability to return to work, are working
only at a part-time capacity, or have been demoted to lower paying jobs (McCrimmon & Oddy, 2006; Kosciulek, 1991). Reported unemployment rates vary considerably for individuals with ABI, anywhere from as low as 7% to as high as 76% (Johnstone, 2003; McCrimmon & Oddy, 2006). This variability is impacted by such factors as demographics (e.g., gender and age), pre-injury factors (e.g., education level and work history), injury severity, level of impairment in executive functioning, amount of care and rehabilitation, and family support (McCrimmon and Oddy, 2006; Johnstone et al., 2003). Returning to work is one of the main goals for brain injury survivors (McCrimmon & Oddy, 2006). Reintegration into the workplace allows individuals with ABI the ability to regain their identity and independence, feel a sense of purpose, provide them with the opportunity for social interaction, and relieve emotional distress from financial burden (Kreutzer et al., 2003). Individuals with ABI that were not able to reintegrate into the work force were reported to have more symptoms of fatigue, depression and mood disturbances (McCrimmon & Oddy, 2006). Family members whose loved ones did not return to work reported more difficulties than families who had loved ones that did return to work (McCrimmon & Oddy, 2006). In a 2005 study, few patients with ABI fully achieved reinsertion into the work force. On average 50% of the subjects returned to their jobs from pre-injury, however most of them were found to be performing at a lower level (Inzaghi & et al., 2005). Psychological sequel is more likely to occur when an individual with
ABI is experiencing social and/or financial problems in their lives (Fleminger, 2008).
CHAPTER III:

ABI MISCONCEPTIONS, ATTITUDES, AND BELIEFS

**Misconceptions about ABI**

There are many misconceptions held by the general public about ABI. The persistence of these misconceptions leads to a lack of resources and support to assist survivors (Hux, 2006). Education of the public about the impact of ABI is essential in order to eliminate misconceptions and help survivors improve their quality of life (Swift & Wilson, 2001).

There is a lack of general public awareness regarding the implications of ABI. This includes the cognitive, emotional, behavioral and physical symptoms associated with ABI, along with the recovery process and rehabilitation procedures (Hux & et al, 2006; Gouvier & et al, 1998). The general public has many misconceptions about brain injuries, demonstrating a lack of knowledge in this area (Swift & Wilson, 2000). It is estimated that one in four lay people respond inaccurately to statements regarding the effects of brain damage, period of unconsciousness, and the amnesia and memory loss that is associated with brain injury (Gouvier & et al, 1988). Many members of the general public do not understand the process of recovery for individuals with brain injury; and they were unaware that survivors suffer long term consequences (Swift & Wilson, 2000).

The media portrayal of ABI has led many people in the general public to believe that individuals with brain injuries can have severe memory
impairments and not recall previous life events before their brain injury but are normal in every other way (Hux & et al., 2006). These types of misconceptions have been precipitated by such films as “The Bourne Identity” and “50 First Dates”. Many individuals believe that the recovery from brain injuries is parallel with the recovery of physical injuries (Swift & Wilson, 2000). Individuals with brain injuries can not recover completely; the general public was not able to recognize this (Hux & et al., 2006).

Another area of concern is that the general public does not understand the diverse symptoms that are associated with brain injury (Swift & Wilson, 2000). Lack of education about ABI for the general public can lead to a lack of support and resources for survivors. Educators and rehabilitation specialists were also surveyed about their knowledge regarding brain injuries. Although educators knew more about ABI than the previously surveyed general public, in comparison to rehabilitation staff the educators demonstrated misconceptions about the cognitive impairments, emotional control management, and factors influencing recovery after brain injury (Farmer & Johnson-Gerard, 1997).

Current Attitudes and Beliefs about Brain Injury

General public.

The need for heightened awareness and public education exists to ensure that citizens have the ability to understand what people with an ABI are going through (Swift & Wilson, 2001; Lefebvre & et al., 2005). This is especially true for those whose symptoms are mainly cognitive, social, or
emotional. The general public may overlook these injuries because they are not visually evident. Survivors have said that their ability to function in society is normally overestimated because of these intangible injuries or underestimated in cases where physical injuries have occurred (Swift & Wilson, 2001). These negative attitudes towards people can create obstacles preventing individuals from fulfilling their life goals and feeling as contributors to society (Antonak & Livneh, 2000). Survivors, as a result, have experienced many forms of anxiety and depression disorders, which make the recovery process even more difficult (Lefebvre & et al., 2005). Survivors are often isolated from their social counterparts causing an increase in anxiety and depression, which in turn compromises their adaptation processes and recovery process (Lefebvre & et al., 2005).

Health and human service professionals and students.

Misconceptions along with inaccurate and inadequate knowledge about brain injuries are not only common amongst the general public but for health professionals as well (Swift & Wilson). Misconceptions held by practicing clinicians can have a severe impact on a patient's recovery process. Believing that a client will never attain a certain level of functioning can negatively impact goal setting and has been shown to result in lowered levels of motivation both for the clinician, the client and the client's family (Tervo & et al, 2004).

These negative attitudes arise from many differences between clinicians and their clients during evaluations. Most clients feel that they are
more capable than their clinicians have rated them, especially when it comes
to cognitive and emotional functioning (Fischer & et al, 2004). It has been
documented that there is a higher level of motivation brought to a therapy
session when clinicians and clients share the same level of awareness of
deficits and abilities (Fleming, Strong & Ashton, 1998). Inappropriate
attitudes of health professionals towards the individual with an ABI can
negatively affect survivor’s self-esteem, give them a sense of hopelessness,
and impair the recovery process (Lefebvre, 2005; Tervo & et al, 2004).

Inappropriate attitudes held by allied health professionals towards their
patients has been found to be the foremost barrier to their successful
recovery (Tervo, et al., 2004). Positive attitudes, in turn, can help individuals
with disabilities lead a normal lifestyle as productive community members
(Tervo, et al., 2004).
CHAPTER IV:

ABI EDUCATION

**Educating the General Public**

Understanding the general public's knowledge, attitudes and beliefs about ABI is essential in developing an effective education approach. In addition, it is important to assess the effects of the educational tools used in order to provide appropriate intervention to modify negative attitudes towards individuals with disabilities (Antonak & Livneh, 2000). Effective educational tools can be useful in developing intervention programs that help modify negative attitudes towards individuals with disabilities and allow them to more effectively integrate into their communities (Antonak & Livneh, 2000; Yuker, 1988).

Attitudes are regarded as latent or inferred psychological tendencies that are expressed by evaluating a particular entity with either a degree of favor or disfavor (Eagly & Chaiken, 1993; Antonak & Livneh, 2000). Attitudes are acquired from previous experiences accumulated over time and can be influenced by the values and judgments held by an individual's peers and family (Antonak & Livneh, 2000; McConell & et al, 2008).

Attitude measurements are beneficial in identifying a respondent's behavior towards a referent and can help determine the socialization process and events contributing to it (Antonak & Livneh, 2000). Direct methods are a form of attitude measurement that have been widely used to measure
perceptions towards individuals with disabilities. This measurement technique is used when respondents are either aware that their attitudes are being measured or become aware due to the nature of the measurement technique (Antonak & Livneh, 2000). A structured opinion survey allows individuals to express their feelings through a series of selected responses about the referent. Evaluative responses of beliefs can help play a significant role in understanding and predicting social behavior and identifying the underlying evaluative reactions that cause a respondent's behavior (Gawronski, 2007; Friedrich & Verive, 1991).

**Educational Methods**

Public education can be accomplished through many forms of media. Many not-for-profit medical/recovery based programs use main stream advertising on television and radio to reach a large number of people. An awareness campaign developed by the National Diabetes Education Program and Center for Disease Control and Prevention was able to access individuals with diabetes through multiple forms of media, such as television and radio, and see a positive trend in testing and awareness since the campaign began (Gallivan & et al., 2007). This can be expensive. Many health organizations have had to find more inexpensive means to educate the public. For example, interviews, oral histories, and other such narratives have been used to educate patients and the general public about psychiatric issues (Cohen, 2005). Identifying effective and efficient forms of education are increasingly
important when funds are limited and dwindle over time for health organizations (Houghton & et al., 1994). Another benefit to health education materials is that there is no need for face-to-face counseling, which can be comprehensive, time consuming and expensive (Clayton et al., 1995).

Pamphlets are a common form of public education that is inexpensive and can easily be used as a preventative or intervention measure (King, 1999; Wilt & et al., 2001). Printed interventions are a low-cost and efficient way to provide validated and standardized information to a variety of individuals. Individuals have the ability to access pamphlets in multiple environments, particularly medical offices where patients can read them while they are waiting for their appointments. Mailed pamphlets have the advantage of allowing individuals from different geographic areas to receive certified information away from clinical encounters (Placek, 1974). Another benefit to pamphlets is that they can be read by multiple individuals and recycled to others over time.

Health educators rate videotapes as highly effective education materials, particularly for patients with lower educational levels (Clayton, et al., 1995; Solomon & Dejong, 1989; Funnell, et al., 1992). A randomized clinical trial for a sexually transmitted disease (STD) clinic found that exposure to video-based patient education helped improve knowledge amongst their patients about prevention and was associated with reduced rates in STD infections (O'Donnell, et al., 1998). An additional study found that individuals with written educational materials and those that viewed a
videotape learned roughly the same amount of information (Clayton, et al., 1995). A major benefit to using the videotape as an educational tool is that it can be used for individuals that are less comfortable with written information (Clayton, et al., 1995).

A possible tool for educating the general public about the impact of ABI is listening to oral histories. An oral history is defined as, ‘A method of gathering and preserving historical information through recorded interviews with participants in past events and ways of life’ (Oral History Association, 2002). Oral histories allow the public to ascertain information about a particular population directly, in turn eliminating secondary reports and receiving information that is more direct and valid. Oral histories can have a powerful influence on an individual’s current beliefs and help change their existing misconceptions. It was found that oral histories provided by subjects with psychiatric disorders improved understanding in the general public and provided clinicians and patients with insight into treatment effectiveness (Cohen, 2005).

A recent investigation has shown that oral histories were effective in changing the attitudes and beliefs of practicing speech-language pathologists, along with graduate and undergraduate students studying the field of communication disorders. Fraas and Calvert (2007) found that undergraduate students demonstrated the greatest change in attitudes and beliefs about ABI following their exposure to oral histories. The authors
suggest that because undergraduate students have the least amount of exposure to patients with ABI they mirror the knowledge of the general population. Therefore, it was suggested that oral histories may be useful in changing the attitudes of the general public towards ABI.

Purpose

The purpose of this investigation is to determine which method of educating the general public is the most effective. The present-day study’s results offer updated information about the knowledge and attitudes of the general public regarding ABI and determine the level of existing misconceptions. The findings of this research will help determine the values of educating the general public and aim at decreasing the misconceptions of ABI in the future. This research can potentially help determine prospective treatment for individuals with ABI. In addition, findings of this study can potentially show us what type of demographic variables influence attitudes towards individuals with brain injury using the background information that was collected from the survey responses.
CHAPTER V: METHODS

Participants

Three hundred and eleven participants responded to requests to engage in this investigation. Participants were recruited through 'word of mouth'. Initial recruitment consisted of 100 emails being sent to a random selection of My Space users. Emails asked the participants to complete an online survey about acquired brain injury.

Twenty-five percent of the emails asked the participant to read an informative pamphlet, another 25% were asked to watch a video interview of ABI survivors, and another 25% were asked to listen to an audio compilation of interviews of ABI survivors before completing the survey. The remaining 25% were asked to complete only the survey. The participants were then asked to forward the email to as many people as possible. This method of participant selection makes it impossible for us to determine an actual response rate. However, links to the survey were available for a 6 month period.

The 311 participants consisted of 264 females (85%) and 47 males (15%). Forty-four respondents (14%) were under the age of 20, 142 participants (46%) were between the ages of 20 and 29, 30 (10%) were between the ages of 30 and 39, 44 (14%) were between the ages of 40 and
49, 44 (14%) were between the ages of 50-59, and 7 (2%) were above the age of 60 years.

Participants reported varied educational backgrounds. Sixty-five (21%) of the participants had received a high school or GED education, 104 (33%) reported having some post-secondary schooling (e.g. some college), 89 (29%) reported having a college degree, and 53 (17%) reported acquiring an advanced degree (e.g. M.S. or PhD).

The participants were next asked to classify themselves into one of the following categories that described their experience with ABI best. The responses indicate that 10 (3%) of the respondents had sustained an ABI, 23 (7%) cared for someone with an ABI, 136 (44%) knew someone with an ABI, and 15 (5%) worked in an environment with substantial numbers of people who had sustained an ABI. One hundred and twenty-seven (41%) reported that they did not know anyone who had sustained an ABI.

Materials

Survey.

A 50-item survey was developed to assess knowledge about acquired brain injuries held by the general public. The survey was divided into several sections. Participants were asked to make judgments on their amount of exposure to survivors of ABI, attitudes about ABI, factual knowledge about ABI, and aspects of blame related to ABI. In addition participants were asked about issues related to the ABI recovery process including: the effectiveness of rehabilitation, the length of time survivors are able to demonstrate
recovery, the ability to live meaningful occupational and social lives, and the importance of community interaction in the recovery process. In addition the survey asked questions revolving around the definition and the effects of stroke, as this can be a major cause of ABI. The survey was distributed to clinicians working with acquired brain injury patients for validation and feedback for appropriateness of variables.

The initial section of the survey asked participants to provide demographic background information (e.g., gender, age, ethnicity, and educational level) and included a question regarding the participant’s occupation. In addition, respondents specified their background experience in the area of ABI.

In section two, participants responded to 13 true/false questions that assessed their general knowledge about ABI. Section three asked participants to respond to 5 questions related to the recovery process following ABI. These questions were Likert-scaled with five points ranging from ‘Strongly Disagree’ (1) to ‘Strongly Agree’ (5). In the fourth section of the survey, participants responded to six questions related to their feelings towards survivors of ABI. These questions were also on a 5 point Likert scale.

Pamphlet.

An informative pamphlet highlighting the facts and common misconceptions about brain injury was developed by the researchers to cover the particular topics that were to be addressed in the survey. The pamphlet contained information relevant to stroke and traumatic brain injury. The
information in the pamphlet was gathered following a review of literature on
ABI and stroke, along with past research in those areas. The pamphlet was
then read by practicing clinicians in the area of brain injury rehabilitation to
ensure that the information in the pamphlet was valid and up to date.

The pamphlet was designed to provide educational information about
the effects of brain injury in a manner that a lay person could easily
understand. The information in the pamphlet was then compared to the other
two forms of educational tools used for this study (video and audio) by three
clinicians in order to verify that the same amount of relevant information that
was needed to answer the questionnaire items was captured.

Video interviews.

Interviews with survivors of ABI were previously recorded at The
Krempels Brain Injury Foundation in Portsmouth, NH, a non-profit
organization dedicated to improving the lives of individuals living with an ABI.
A video documentary of these interviews was created that highlights the
needs and challenges of survivors. In addition, it provides the viewer with
informative knowledge about ABI and its impact on survivors and
communities. The documentary can be viewed online at:

www.seacoastonline.com/braininjury.

Oral interviews.

Oral history interviews of survivors of ABI were recorded at The
Krempels Brain Injury Foundation in Portsmouth, NH. Members of this
community-based day program for adults with acquired brain injury
interviewed each other following a semi-structured format. Interview questions included information about the member's life before their accident, their injury, their rehabilitation, and their recovery and life following their injury (Calvert & Fraas, 2006). Oral histories that contained relevant information that would be needed for participants to answer questionnaire items correctly, contained the same information as the pamphlet, and that could possibly help eliminate misconceptions were chosen for this study. Interviews were edited down to a ten minute summary of responses that provided the listener with insight into ABI.

Statistical Analysis

These data were used to perform chi-square analyses between participant subgroups. Participant groupings included: a. Method of education: survey (N = 111), pamphlet (N = 93), video (N = 62), and audio (N = 45); b. age: < 20 years (N = 44), 20-29 years (N = 142), 30-39 (N = 30), 40-49 (N = 44), 50-59 (N = 44), and 60 or more years (N = 7); c. years of education: high school diploma/GED (N = 65), post-secondary degree/some college (N = 104), college degree (B.A./B.S.) (N = 89), and advanced degree (M.A./Ph.D.) (N = 53); and d. ABI experience: survivor (N = 10), care for someone with a brain injury (N = 23), know someone with an ABI (N = 136), work in setting which includes survivors of ABI (N = 15), do not know anyone with an ABI (N = 127).

A chi-square analysis was performed between the results from this current study and Hux et al.'s research (2006). Thirteen of the fifty statements
included on the questionnaire were developed by Hux et al. and used for comparison purposes.
CHAPTER VI:

RESULTS

Misconceptions about brain injury continue to exist among the general public. For comparison purposes, Table 1 shows the correct response percentages from the participants enrolled in the current study, who only completed the survey with no educational tool, compared with participants from the Hux et al. (2006) investigation. While there were some discrepancies between the current investigation and the findings of Hux et al., the general trend in response accuracy was the same between studies.
Table 1: Percentage of Participants who Responded Accurately to ABI Items: Comparison with Findings from Hux et al., (2006).

<table>
<thead>
<tr>
<th>Questionnaire Item (correct answer in parentheses)</th>
<th>Hux et al.</th>
<th>Williams</th>
</tr>
</thead>
<tbody>
<tr>
<td>1 Most people with an acquired brain injury look and act disabled. (F)</td>
<td>98.74</td>
<td>86.50</td>
</tr>
<tr>
<td>2 When people are knocked unconscious, most wake up shortly with no lasting effects. (F)</td>
<td>51.89</td>
<td>45.0</td>
</tr>
<tr>
<td>3 Even after several weeks in a coma, when people wake up, most recognize and speak to others right away. (F)</td>
<td>76.42</td>
<td>81.10</td>
</tr>
<tr>
<td>4 People in a coma are usually not aware of what is happening around them. (T)</td>
<td>40.25</td>
<td>36.0</td>
</tr>
<tr>
<td>5 After a head injury, people can forget who they are and not recognize others, but be normal in every other way. (F)</td>
<td>6.60</td>
<td>13.5</td>
</tr>
<tr>
<td>6 Sometimes a second blow to the head can help a person remember things that were forgotten after a first blow to the head. (F)</td>
<td>71.38</td>
<td>90.1</td>
</tr>
<tr>
<td>7 People with amnesia for events before the injury usually have trouble learning new things too. (T)</td>
<td>51.89</td>
<td>27.0</td>
</tr>
<tr>
<td>8 After a head injury, it is usually harder to learn new things than it is to remember things from before the injury. (T)</td>
<td>51.52</td>
<td>42.3</td>
</tr>
<tr>
<td>9 How quickly a person recovers depends mainly on how hard they work at recovering. (F)</td>
<td>47.48</td>
<td>62.4</td>
</tr>
<tr>
<td>10 People who have had one head injury are more likely to have a second one. (T)</td>
<td>32.08</td>
<td>32.4</td>
</tr>
<tr>
<td>11 A person who has recovered from a head injury is less able to withstand a second blow to the head. (T)</td>
<td>70.13</td>
<td>77.5</td>
</tr>
<tr>
<td>12 It is good advice to rest and remain inactive during recovery. (F)</td>
<td>60.06</td>
<td>64.9</td>
</tr>
<tr>
<td>13 Complete recovery from a severe head injury is not possible, no matter how badly the person wants to recover. (T)</td>
<td>27.99</td>
<td>25.2</td>
</tr>
</tbody>
</table>
Comparisons to Previous Studies

Accurate perceptions.

Greater than 80% of the current study's respondents gave correct responses to 3 of the 13 survey items that appeared on both studies (Question items 1, 3, & 6). Question item #6 in comparison to Hux et al.'s study had the greatest percentage of improvement with an increased response accuracy of 18.8%, demonstrating that people have a greater understanding that "a second blow to the head will not lead to remembering things that were previously forgotten". In comparison to the previous study participants showed an increase of 14.92 % regarding the ability to identify that "how quickly a person recovers depends mainly on how hard they work at recovering" is a false answer. The other question with a greater correct percentage of 80% was down in comparison to the previous study, demonstrating that in three years 12.24% more of the general public has the belief that "people with brain injuries look and act disabled". Seven of the thirteen questions from the current study that appeared on both studies had higher percentages than the previous. It must be noted however that with a true/false question there is a 50% chance of getting an answer correct strictly by chance; this factor may impact the study's results.

A Pearson correlation found that the responses between Hux et al., (2006) and the current investigation were similar. See table 2.
Table 2: Correlation between Accurate Responses from Hux et al., (2006) and Current Study.

<table>
<thead>
<tr>
<th></th>
<th>Accurate Responses from Hux et al., (2006)</th>
<th>Accurate Responses from Current Study</th>
</tr>
</thead>
<tbody>
<tr>
<td>Pearson Correlation</td>
<td>1</td>
<td>.892**</td>
</tr>
<tr>
<td>Significance (2-tail)</td>
<td>.892**</td>
<td>.000</td>
</tr>
<tr>
<td>N</td>
<td>13</td>
<td>13</td>
</tr>
<tr>
<td>Person Correlation</td>
<td>.892**</td>
<td>1</td>
</tr>
<tr>
<td>Significance (2-tail)</td>
<td>.000</td>
<td></td>
</tr>
<tr>
<td>N</td>
<td>13</td>
<td>13</td>
</tr>
</tbody>
</table>

** Correlation is significant at the .01 level (2-tailed)
Inaccurate perceptions.

For the remaining ten question items, the percentage of respondents getting correct answers that appeared on both studies from the current study ranged from 13.5-77.5%. Five of the thirteen questions had correct percentages lower than the correct percentages from Hux et al.'s study, demonstrating that misconceptions about ABI still exist in the general public.

The question with the least correct response percentage was Item #5, people still believe that after a head injury, “people can forget who they are and not recognize others, but be normal in every other way”. Only 13.5% of the participants in this study knew that this item was false. This finding was more than twice that from Hux et al.’s study (6.60%). Regardless, this finding is quite low; indicating a substantial misconception by the general public.

Other memory survey items (items 7 & 8) showed a disturbing increase in misconceptions since the previous study. Rather than improving in the area of memory and identifying that it is usually harder to learn new things than it is to remember things from before the injury is correct, a decrease in correct responses of 24.89% was shown. Another decrease of 9.22% correct responses was shown when asked if people with amnesia for events before the injury usually have trouble learning new things too was correct.

The questionnaire items corresponding with comatose symptoms also revealed a low response accuracy. Of the respondents 64% were incorrect when believing that individuals in a coma are aware of what is going on around them, this number has stayed primarily stable since the previous
study. Approximately 45.0% of patients were able to identify that the statement “when people are knocked unconscious, most wake up shortly with no lasting effects” as a fallacy, this percentage has stayed consistent in comparison to Hux et al.’s study.

Another area of concern is with regard to the general public’s misconceptions about the recovery process following ABI. The study found that 64.9% of participants believed that it is not good advice to remain inactive during the recovery process in comparison to the previous study where 60.06% believed this to be true.

High misconceptions among the general public persist regarding the statement “complete recovery from a severe brain injury is not possible, no matter how badly the person wants to recover”. Only 25.2% of individuals believed this to be true; this number of correct responses remained stable in comparison with the results from the previous study.

Regarding a second blow to the head, only 32.4% of respondents knew that people who have had one head injury are more likely to have a second. These results remained consistent since the last time the general public had been surveyed. Inaccurate perceptions remain regarding how quickly a person with head injury recovers; many individuals still believe that it depends on how hard the individual works on recovering. Fortunately this misconception has diminished since the last study, 62.4% of the respondents found this question to be a fallacy. The response accuracy for this question item is up by 14.92%. The other recovery item question, a person who has
recovered from a head injury is less able to withstand a second blow to the head, has significantly increased by 18.72% of respondents identifying this correctly with a rate of 90.1%.

**Education Methods Used to Inform the General Public**

The second part of the analysis examined which methods of education were most effective in reducing misconceptions among the general public. The four groups compared were: 1. those who only responded to the survey (i.e. no education); 2. those who read an informative pamphlet; 3. those who watched interviews of brain injury survivors; and 4. those who listened to audio recordings of interviews with brain injury survivors.

In addition, survey questions were divided into categories in order to determine what types of information is the easiest to educate. The five categories included: 1. General TBI information; 2. general stroke information; 3. coma information; 4. information about memory; and 5. information about the recovery process.

Finally, analysis was conducted to determine if there was any impact on these responses based on age, level of education, and previous experience with ABI. Each category is discussed and chi-square tables are provided.

**Educating the general public about traumatic brain injury.**

Table 3 displays the response accuracy for each group when asked the general TBI knowledge question, “Acquired brain injuries are the leading cause of brain injury world wide”. A chi-square analysis revealed a statistically
significant difference between groups (those receiving ABI education and those not receiving education) on the questionnaire item stating that acquired brain injuries are the leading cause of death and disability worldwide \(X^2 (3, n = 311) = 20.79, p < .05\]. The survey group had the lowest percentage correct of 22.5% followed by the movie group with 38.7%, the pamphlet group with 45.2% and the audio group with 57.8% correct. This indicates that those who received education were more accurate in their response to the general TBI question compared to those without education (i.e. those who responded to the survey only). The participants who listened to the audio sample were most accurate in their response to this question.
Table 3: Response accuracy between groups on general knowledge about TBI.

<table>
<thead>
<tr>
<th>Questionnaire Item</th>
<th>Survey</th>
<th>Pamphlet</th>
<th>Video</th>
<th>Audio</th>
<th>( X^2 )</th>
</tr>
</thead>
<tbody>
<tr>
<td>GTBI7 Acquired brain injuries are the leading cause of death and disability worldwide. (Y)</td>
<td>22.5%</td>
<td>45.2%</td>
<td>38.7%</td>
<td>57.8%</td>
<td>*20.79</td>
</tr>
</tbody>
</table>

Critical Value = 7.81
Educating the general public about the effects of stroke.

Table 4 shows the response accuracy rate between groups for general stroke knowledge. There were seven stroke questions from the survey, four of which were found to be statistically significant (where the critical value was equal or greater to 7.81). The question with the largest critical value of 24.21, asked participants to identify if “stroke patients are able to retain their ability to read and write despite their inability to speak”. Only 19.8% of survey participants were able to identify that this question was a fallacy, followed by the pamphlet group with a correct percentage of 33.8%, the video group with 38.7% and the audio group with 60.0% correct. Backgrounds with ABI, educational level and age influenced the attitudes of respondents for this question. The second stroke question asked respondents whether or not they believed that “most stroke survivors retain the ability to engage in new learning.” A chi-square analysis revealed a statistically significant result \[X^2 (3, n = 311) = 15.20, p < .05\] between groups. The pamphlet showed to be the least effective material when educating the general public about this particular question, with a response accuracy of 78.5%, while the other studied groups were all <90.0% accurate. As shown in Table 4, the questionnaire item regarding a “stroke results in the acquisition of Alzheimer’s disease,” had a statistically significant result \[X^2 (3, n = 311) = 13.01, p < .05\]. In this question the audio group had 100% accuracy and the survey group had 97.3% accuracy, with the pamphlet group and the video group trailing behind, although still being effective not as effective as the other two groups.
Respondents with a background in higher education had fewer stroke misconceptions than those who were not, possibly impacting the outcome of this question. The last stroke question found to be statistically significant focused on respondents identifying the misconception "A long-term consequence of stroke is loss of vision" as false. The educational tool that had the best response accuracy was the video with 61.3% correct, then the pamphlet with 47.3% correct and the audio with 46.7% correct. Surprisingly, the survey group using no educational tool had the best percentage correct with 65.8%. It was found that those respondents who obtained a higher educational level and were older in age were more likely to answer to this question correctly.
Table 4: Response accuracy between groups on general stroke knowledge.

<table>
<thead>
<tr>
<th>Questionnaire Item</th>
<th>Response Accuracy (% Correct)</th>
<th>X² Critical Value = 7.81</th>
</tr>
</thead>
<tbody>
<tr>
<td>Stroke1</td>
<td>Stroke can cause paralysis to one side of the body. (Y)</td>
<td>100 100 100 100 .00</td>
</tr>
<tr>
<td>Stroke2</td>
<td>Most stroke survivors retain the ability to engage in new learning. (Y)</td>
<td>95.5 78.5 90.3 91.1 *15.20</td>
</tr>
<tr>
<td>Stroke3</td>
<td>Stroke can cause an impaired ability to produce or understand speech. (Y)</td>
<td>99.1 98.9 100 100 1.08</td>
</tr>
<tr>
<td>Stroke4</td>
<td>A stroke results in acquisition of Alzheimer's disease. (N)</td>
<td>97.3 88.2 87.1 100 *13.01</td>
</tr>
<tr>
<td>Stroke5</td>
<td>Stroke patients usually retain their ability to read and write despite an inability to speak. (N)</td>
<td>19.8 33.3 38.7 60.0 *24.21</td>
</tr>
<tr>
<td>Stroke6</td>
<td>A long-term consequence of stroke is loss of vision. (N)</td>
<td>65.8 47.3 61.3 46.7 *9.39</td>
</tr>
<tr>
<td>Stroke7</td>
<td>A long-term consequence of stroke is hearing loss. (N)</td>
<td>75.7 61.3 74.2 68.9 5.59</td>
</tr>
</tbody>
</table>
Educating the general public about the effects of a coma.

Table 5 displays information regarding the response accuracy amid groups on general coma knowledge. One out of three questions was found to be statistically significant (where the critical value was equal or greater than 7.81) by performing a Chi Square analysis \[X^2 (3, n = 311) = 13.91, p < .05\]. Three groups were able to correctly identify that “even after several weeks in a coma, when people wake up, most recognize and speak to others right away” was a false response with 80% or greater accuracy. The group that did surprisingly the worst was the audio group with 60% of the respondents answering this question incorrectly. After reviewing the audio sample, it was found that the information was not provided for participants to answer this question correctly. This question did not appear to be impacted by the factors of age, education or experience with ABI by the respondents.
### Table 5: Response accuracy between groups on coma knowledge

<table>
<thead>
<tr>
<th>Questionnaire Item</th>
<th>Response Accuracy</th>
<th>( \chi^2 )</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Survey</td>
<td>Pamphlet</td>
</tr>
<tr>
<td><strong>Coma1</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>When people are</td>
<td></td>
<td></td>
</tr>
<tr>
<td>knocked unconscious, most wake up shortly with no lasting effects. (F)</td>
<td>45.0</td>
<td>47.3</td>
</tr>
<tr>
<td><strong>Coma2</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Even after several weeks in a coma, when people wake up, most recognize and speak to others right away. (F)</td>
<td>81.1</td>
<td>84.9</td>
</tr>
<tr>
<td><strong>Coma3</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>People in a coma are usually not aware of what is happening around them. (T)</td>
<td>36.0</td>
<td>48.4</td>
</tr>
</tbody>
</table>
Educating the general public about memory deficits due to ABI.

As shown in Table 6, two questionnaire items (Memory2 & Memory3) revolving around memory deficits were found to be statistically significant (where the critical value was equal or greater than 7.81). The most significant memory question asked participants from the four groups to identify “People with amnesia for events before the injury usually have trouble learning new things too” as true, with a Chi Square analysis of \(X^2 (3, n = 311) = 14.68, p < .05\]. Respondents exhibited hefty amounts of knowledge deficits on this questionnaire item with the audio group having the highest correct percentage of 53.3%, followed by the pamphlet group with 49.5%, the video group with 43.5%, and the survey group with 27.0% correct. This question was found to be impacted by the variables of education level, age and experience with ABI. The second memory questionnaire item found to be statistically significant asked participants to identify this statement as false: “Sometimes a second blow to the head can help a person remember things that were forgotten after a first blow to the head.” A chi-square analysis revealed a significance of \(X^2 (3, n = 311) = 7.38, p < .05\]. The educational tool to impact respondent’s correct answers the most was the video with 82.3%, followed by the pamphlet with 80.6% and the audio with 73.3%. The survey group had the greatest percentage of accurate responses with 90.1% correct. This question was found to be impacted by the one variable of education. Individuals with a higher education level answered this question more accurately than those who had less.
Table 6: Response accuracy between groups on memory knowledge

<table>
<thead>
<tr>
<th>Questionnaire Item</th>
<th>Response Accuracy</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Survey</td>
<td>Pamphlet</td>
</tr>
<tr>
<td>Memory1</td>
<td>13.5</td>
<td>6.5</td>
</tr>
<tr>
<td>After a head injury, people can forget who they are and not recognize others, but be normal in every other way. (F)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Memory2</td>
<td>90.1</td>
<td>80.6</td>
</tr>
<tr>
<td>Sometimes a second blow to the head can help a person remember things that were forgotten after a first blow to the head. (F)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Memory3</td>
<td>27.0</td>
<td>49.5</td>
</tr>
<tr>
<td>People with amnesia for events before the injury usually have trouble learning new things too. (T)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Memory4</td>
<td>42.3</td>
<td>40.9</td>
</tr>
<tr>
<td>After a head injury, it is usually harder to learn new things than it is to remember things from before the injury. (T)</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Educating the general public about the ABI recovery process.

Table 7 lists the response accuracy between groups on ABI recovery process. Out of five questionnaire items regarding ABI recovery process, four were found to be statistically significant. Despite using educational tools, all groups continue to have misconceptions about the recovery process for individuals with brain injuries. A critical value of 20.48 was found for the questionnaire item stating: “Complete recovery from a severe head injury is not possible, no matter how badly the person wants to recover.” The pamphlet group was able to accurately identify this statement as true by 55.9% of respondents, followed by 44.4% in the audio group, 37.1% by the video group and 25.2% by the survey group. All educational procedures were found to be effective in educating the general public about this particular question. This question was found to be impacted by the variables of age and education. Participants had to identify the following statement as false: “It is good advice to rest and remain inactive during recovery.” A Chi Square analysis revealed a statistically significant difference between groups \[X^2 (3, n = 311) = 9.93, p < .05\]. The group that was most impacted by an educational tool was the video group with 87.1% correct responses, followed by the audio group with 73.3% and the pamphlet with 71.0%. The survey group who had no educational resources had 64.9% responses correct. A Chi Square analysis revealed a statistically significant difference between groups regarding the statement of “How quickly a person recovers depends mainly on how hard they work at recovering” \[X^2 (3, n = 311) = 16.89, p < .05\]. The
survey group was found to have the greatest response accuracy with 79.3%, followed by the next closest the video group with 67.7%. The last statistically significant recovery question with the true statement "A person who has recovered from a head injury is less able to withstand a second blow to the head" was found to be consistent across groups in response accuracy (73.1%-77.5%) except for the video group who had the lowest response accuracy of 56.5%. This question was impacted by the amount of experience the participant had with regards to ABI.
Table 7: Response Accuracy between Groups on ABI Recovery Process

<table>
<thead>
<tr>
<th>Questionnaire Item</th>
<th>Survey</th>
<th>Pamphlet</th>
<th>Video</th>
<th>Audio</th>
<th>X² Critical Value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Recovery1</td>
<td>79.3</td>
<td>62.4</td>
<td>67.7</td>
<td>46.7</td>
<td>*16.89</td>
</tr>
<tr>
<td>Recovery2</td>
<td>32.4</td>
<td>28.0</td>
<td>17.7</td>
<td>17.8</td>
<td>6.323</td>
</tr>
<tr>
<td>Recovery3</td>
<td>77.5</td>
<td>73.1</td>
<td>56.5</td>
<td>73.3</td>
<td>*8.97</td>
</tr>
<tr>
<td>Recovery4</td>
<td>64.9</td>
<td>71.0</td>
<td>87.1</td>
<td>73.3</td>
<td>*9.93</td>
</tr>
<tr>
<td>Recovery5</td>
<td>25.2</td>
<td>55.9</td>
<td>37.1</td>
<td>44.4</td>
<td>*20.48</td>
</tr>
</tbody>
</table>
CHAPTER VII:
DISCUSSION

Misconceptions about brain injuries are still present in today's general public. When comparing the results of this current study to the previous results of Hux et al., it can be concluded that these misconceptions have either remained stable or increased over time. The results of this investigation demonstrate that responses significantly differed depending on what methods of instruction respondents received. The audio sample, oral histories told by survivors of ABI, was the most influential educational tool used in this study. Some of the questionnaire items were influenced by the other educational materials indicating that a multifaceted approach to educating the general public may be the best educational mode to inform individuals about brain injuries.

The earlier educational experiences are used, the quicker positive attitudes are enforced and misconceptions decrease (Tervo et al., 2004). Some of the statistically significant questionnaire items showed a better correct response percentage from the survey group that did not attain any educational materials. This may be due in part to the extraneous factors such as the participant's age, personal experience with ABI and educational level. It has been found that individuals with a background in acquired brain injuries held fewer misconceptions about brain injuries, and held more favorable attitudes toward individuals with disabilities (Tervo & et al., 2004). However it is a positive sign that by combing the results of all of the educational tools
from this study reveal an increase in the number of correct responses in the statistically significant questions (8 of 13 questions).

Some of the benefits to being able to access the pamphlet are that it is affordable, easy to grab and can be taken into one's own home. The pamphlet might be best used by educating the general public about general facts of brain injury.

Although the video can be shown to large groups of people fairly quickly, it can also enhance individual biases and provide viewers with inaccurate opinions of the capabilities of a person with ABI. This may be in part due to seeing individuals with brain injuries whose brain injury symptoms are invisible to them, meaning there are no physical signs that anything is wrong with them. Or it can do just the opposite, seeing individuals with visible symptoms may cause the general public to misidentify individuals with ABI as being mentally ill, learning disabled or drunk (Swift & Wilson, 2004; Hux et al. 2006). A video designed for the general public must be carefully planned and designed in order not to illicit these negative attitudes. The video was most successful in this study to educate respondents about the effects of comatose.

The audio allows individuals to access information about brain injuries via the internet or radio freely and quickly. The radio has the ability to dispense material to a wide audience and can be organized for lay people to be easily understood. Another benefit to the audio education is that it does not allow individuals to make biased opinions based on the physical attributes.
of an individual. It is possible that the audio was the best educational tool for this survey because the individual with ABI could not be associated with negative connotations because they were not visually presented to the respondent. Overall, the audio was found to be the most effective material to educate the general public about brain injuries when it stood alone.

A possible explanation for the continued large number of people having misconceptions about brain injury may be due to the popular media (Hux & et al., 2006). For instance the statements "after a head injury, people can forget who they are and not recognize others, but be normal in every other way" and "when people are knocked unconscious, most wake up shortly with no lasting effects" was misconceived by many respondents (13.5% and 45% response accuracy, respectively). The popular media shows individuals recovering from their head injuries, if not immediately, shortly after or with superhuman abilities and strengths. Soap operas and medical dramas such as "Grey's Anatomy" and "ER" can be blamed for such occurrences of patients waking up perfectly fine from a coma with no lasting effects. Blockbuster hits such as "50 First Dates", "The Adams Family" and the "Bourne Trilogy" provide characters that have had head injuries that wake up from their comas with atypical or unrealistic reactions and symptoms (Hux et al., 2006).

The information that the popular media is supplying to the general public about brain injuries is damaging to survivors with brain injuries. People are encouraged to believe that recovery from ABI is within their control,
causing impractical expectations and pressure to perform that realistically they can not achieve (Swift & Wilson, 2001).

A possible weakness of this study is that the respondents provided “socially desirable” answers to the survey questions, answers that they thought were expected to choose (Tervo et al., 2004). Due to the fashion of how the study was carried out, via internet, there was no control over who took part in the study. The small sample size may have limited the significance of the study’s analysis and the conclusions made. Not all groups had equal numbers of participants, educational levels, ages, and experiences with ABI. Participants had access to the internet while taking this survey, which could have skewed results. However, this is most likely not the case due to the results continuing to indicate misconceptions about brain injuries. Another extraneous weakness that could not be controlled was whether the participants really did use the educational tools properly or just took the survey and still checked off that they completed a certain resource. A benefit to this type of survey being available on the internet allows individuals from all over the world to access it at their own convenience, along with being anonymous.

The results from this research study can help encourage educational interventions that can alleviate misconceptions and negative attitudes about individuals with brain injuries. Speech-language therapy clinicians can benefit from these findings by highlighting the issues regarding ABI that are most commonly misunderstood by people to their clients and family’s. It is likely
that a member of the family network of patient’s with ABI will subscribe to several of these misconceptions; the counseling process may help facilitate their knowledge deficits. The results from this study can help assist educators in health professions by means of educating students in their training about misconceptions they may encounter in the workforce, along with alleviating their personal negative attitudes and misconceptions in the process. Increasing public awareness can help impact the lives of individuals with brain injury by empowering them to be proactive about their ABI and help change society’s insurance laws that impact them.

Implications for future research.

The needs for future research in ABI are paramount in making public awareness a reality. Further studies need to collect larger sample sizes in order to generalize the data and attribute it to the general public. Researchers need to look more specifically at the respondent’s age and education in order to deliberately know which subgroups to target in the education process. Research should in addition focus on the possible correlations of the media on the attitudes and misconceptions revolving around ABI.
LIST OF REFERENCES


APPENDIX A: QUESTIONNAIRE

1. What is your gender?
   • a. male;
   • b. female

2. Please indicate your age.
   • a. less than 20 years;
   • b. 21-29 years;
   • c. 30-39 years;
   • d. 40-49 years;
   • e. 50-59 years;
   • f. 60 years or older

3. What is your highest level of education?
   • a. less than eight grade;
   • b. 8-11th grade;
   • c. high school diploma or GED;
   • d. post secondary degree or some college;
   • e. college degree (e.g. B.A., B.S.);
   • f. advanced degree (e.g. M.A., PhD)

4. Please check the box that best applies to you.
   • a. I have sustained a brain injury from trauma or stroke;
   • b. I care for someone with a brain injury from trauma or stroke (e.g. friend or relative);
   • c. I know someone who has sustained a brain injury from trauma or stroke;
   • d. I work in a setting that includes large numbers of people with brain injuries from trauma or stroke;
   • e. I do not know anyone with a brain injury due to trauma or stroke

5. Please indicate your ethnicity.
   • a. African-American;
   • b. Asian-American;
   • c. Hispanic/Latino
   • d. American Indian/Alaska Native;
   • e. White;
   • f. Other
Please indicate whether each of the following statements is true or false.

   • a. true;
   • b. false

7. When people are knocked unconscious, most wake up shortly with no lasting effects.
   • a. true;
   • b. false

8. Even after several weeks in a coma, when people wake up, most recognize and speak to others right away.
   • a. true;
   • b. false

9. People in a coma are usually not aware of what is happening around them.
   • a. true;
   • b. false

10. After a head injury, people can forget who they are and not recognize others, but be normal in every other way.
    • a. true;
    • b. false

11. Sometimes a second blow to the head can help a person remember things that were forgotten after a first blow to the head.
    • a. true;
    • b. false

12. People with amnesia for events before the injury usually have trouble learning new things too.
    • a. true;
    • b. false

13. After a head injury, it is usually harder to learn new things than it is to remember things from before the injury.
    • a. true;
    • b. false

14. How quickly a person recovers depends mainly on how hard they work at recovering.
    • a. true;
    • b. false
15. People who have had one head injury are more likely to have a second one.
   • a. true;
   • b. false

16. A person who has recovered from a head injury is less able to withstand a second blow to the head.
   • a. true;
   • b. false

17. It is good advice to rest and remain inactive during recovery.
   • a. true;
   • b. false

18. Complete recovery from a severe head injury is not possible, no matter how badly the person wants to recover.
   • a. true;
   • b. false

Please indicate your level of agreement for each of the following statements regarding the recovery from acquired brain injury due to trauma or stroke.

19. A person's recovery from an acquired brain injury depends on how much effort they put into getting better.
   • a. strongly disagree;
   • b. mildly disagree;
   • c. neither agree nor disagree;
   • d. mildly agree;
   • e. strongly agree

20. Children are more likely to make a full recovery following an acquired brain injury than adults.
   • a. strongly disagree;
   • b. mildly disagree;
   • c. neither agree nor disagree;
   • d. mildly agree;
   • e. strongly agree

21. Survivors of an acquired brain injury only benefit from treatment right after it occurs (within six months).
   • a. strongly disagree;
   • b. mildly disagree;
   • c. neither agree nor disagree;
   • d. mildly agree;
   • e. strongly agree
22. A person can continue to make improvements five or more years after an acquired brain injury.
   • a. strongly disagree;
   • b. mildly disagree;
   • c. neither agree nor disagree;
   • d. mildly agree;
   • e. strongly agree

23. Age (younger adults) and education (higher education level) help determine how much progress a person makes following an acquired brain injury.
   • a. strongly disagree;
   • b. mildly disagree;
   • c. neither agree nor disagree;
   • d. mildly agree;
   • e. strongly agree

Please indicate your feeling toward each of the following statements regarding acquired brain injury.

   • a. strongly disagree;
   • b. mildly disagree;
   • c. neither agree nor disagree;
   • d. mildly agree;
   • e. strongly agree

25. I would feel uncomfortable riding in an elevator with an individual who has had an acquired brain injury.
   • a. strongly disagree;
   • b. mildly disagree;
   • c. neither agree nor disagree;
   • d. mildly agree;
   • e. strongly agree

26. I feel confident that I would be able to recognize anyone that has sustained an acquired brain injury.
   • a. strongly disagree;
   • b. mildly disagree;
   • c. neither agree nor disagree;
   • d. mildly agree;
   • e. strongly agree
27. I would feel uncomfortable working with someone who has sustained an acquired brain injury.
   • a. strongly disagree;
   • b. mildly disagree;
   • c. neither agree nor disagree;
   • d. mildly agree;
   • e. strongly agree

28. It is his/her fault they sustained an acquired brain injury while riding their bike; they were not wearing a helmet.
   • a. strongly disagree;
   • b. mildly disagree;
   • c. neither agree nor disagree;
   • d. mildly agree;
   • e. strongly agree

Please indicate your level agreement with the following statements.

29. A person can not sustain an acquired brain injury unless they have a loss of consciousness.
   • a. strongly disagree;
   • b. mildly disagree;
   • c. neither agree nor disagree;
   • d. mildly agree;
   • e. strongly agree

30. It is easier for individuals with an acquired brain injury to learn new things than to remember old ones.
   • a. strongly disagree;
   • b. mildly disagree;
   • c. neither agree nor disagree;
   • d. mildly agree;
   • e. strongly agree

31. Insurance covers most costs associated with recovery from an acquired brain injury.
   • a. strongly disagree;
   • b. mildly disagree;
   • c. neither agree nor disagree;
   • d. mildly agree;
   • e. strongly agree
32. Sara is feeling very emotional after sustaining an acquired brain injury but this has nothing to do with the injury itself.

- a. strongly disagree;
- b. mildly disagree;
- c. neither agree nor disagree;
- d. mildly agree;
- e. strongly agree

33. If Bob is feeling back to his 'old self' then his recovery process is complete.

- a. strongly disagree;
- b. mildly disagree;
- c. neither agree nor disagree;
- d. mildly agree;
- e. strongly agree

Indicate your agreement with each of the following statements regarding community re-integration after acquiring a brain injury.

34. Survivors of an acquired brain injury can live meaningful and/or productive lifestyles.

- a. strongly disagree;
- b. mildly disagree;
- c. neither agree nor disagree;
- d. mildly agree;
- e. strongly agree

35. Most survivors of acquired brain injury are able to return to work, school, or volunteer work.

- a. strongly disagree;
- b. mildly disagree;
- c. neither agree nor disagree;
- d. mildly agree;
- e. strongly agree

36. Survivors of acquired brain injury have a higher rate of divorce than those who have not suffered an acquired brain injury.

- a. strongly disagree;
- b. mildly disagree;
- c. neither agree nor disagree;
- d. mildly agree;
- e. strongly agree
37. It is difficult to develop and maintain social relationships for survivors of acquired brain injury.
   - a. strongly disagree;
   - b. mildly disagree;
   - c. neither agree nor disagree;
   - d. mildly agree;
   - e. strongly agree

Please indicate 'yes' or 'no' to each of the following questions about the long-term consequences of stroke.

38. Stroke can cause paralysis to one side of the body.
   - a. yes;
   - b. no

39. Most stroke survivors retain the ability to engage in new learning.
   - a. yes;
   - b. no

40. Stroke can cause an impaired ability to produce or understand speech.
   - a. yes;
   - b. no

41. A stroke results in acquisition of Alzheimer's disease.
   - a. yes;
   - b. no

42. Stroke patients usually retain their ability to read and write despite an inability to speak.
   - a. yes;
   - b. no

43. A long-term consequence of stroke is loss of vision.
   - a. yes;
   - b. no

44. A long-term consequence of stroke is hearing loss.
   - a. yes;
   - b. no
48. What is the annual cost of acquired brain injury in the United States?
   • a. less than 10 billion;
   • b. 20 billion;
   • c. 30 billion;
   • d. 40 billion;
   • e. 50 billion;
   • f. more than 60 billion

49. Acquired brain injuries are the leading cause of death and disability worldwide.
   • a. true;
   • b. false

50. Where have you learned about acquired brain injury? Please type your answer in the following space:

51. Please check each task that you completed.
   • a. completed brain injury survey;
   • b. read informative pamphlet about brain injury;
   • c. viewed movie about brain injury;
   • d. listened to audio sample about brain injury
03-May-2007

Williams, Jesse
Communication Sci.& Dis., Hewitt Hall
70 Webb Place, Apt. 202
Dover, NH 03820

IRB #: 3973
Study: Methods of Educating the General Public About the Impact of Acquired Brain Injuries
Approval Date: 03-May-2007

The Institutional Review Board for the Protection of Human Subjects in Research (IRB) has reviewed and approved the protocol for your study as Exempt as described in Title 45, Code of Federal Regulations (CFR), Part 46, Subsection 101(b) with the following comment(s):

1. In the Data section of the protocol, the researcher should remove the statement, "Anonymity of participants will be maintained throughout the study." This is because for a certain period of time, participants' names will be connected with their responses (the period that their names are on the surveys). As the researcher states, however, once the names are replaced with codes (as long as a list of codes and corresponding names is not maintained), then data can be said to be anonymous.

Researchers who conduct studies involving human subjects have responsibilities as outlined in the attached document, Responsibilities of Directors of Research Studies Involving Human Subjects. (This document is also available at http://www.unh.edu/osr/compliance/irb.html.) Please read this document carefully before commencing your work involving human subjects.

Upon completion of your study, please complete the enclosed pink Exempt Study Final Report form and return it to this office along with a report of your findings.

If you have questions or concerns about your study or this approval, please feel free to contact me at 603-862-2003 or julie.simpson@unh.edu. Please refer to the IRB # above in all correspondence related to this study. The IRB wishes you success with your research.

For the IRB,

Julie F. Simpson
Manager

cc: File
    Fraas, Michael