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# Maladaptive behavior and communication disorders following tbi: Survivor, caregiver and speech-language pathologists' perspectives

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Maladaptive Behavior and Communication Disorders Following TBI: Survivor Caregiver and  
Speech-Language Pathologists' Perspectives

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An Honors College Project Presented to  
the Faculty of the  
College of Health and Behavioral Sciences  
James Madison University

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by Marena Shelby Jones

May 2017

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Accepted by the faculty of the Department of Communication Sciences and Disorders, James Madison University,  
in partial fulfillment of the requirements for the Honors College.

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PUBLIC PRESENTATION

This work was presented at the American Speech-Language-Hearing Association Convention on November 18<sup>th</sup>,  
2016 and is accepted for presentation at the Speech-Language-Hearing Association of Virginia Convention on  
March 25<sup>th</sup>, 2017.

# MALADPTIVE BEHAVIOR AND COMMUNICATION DISORDERS

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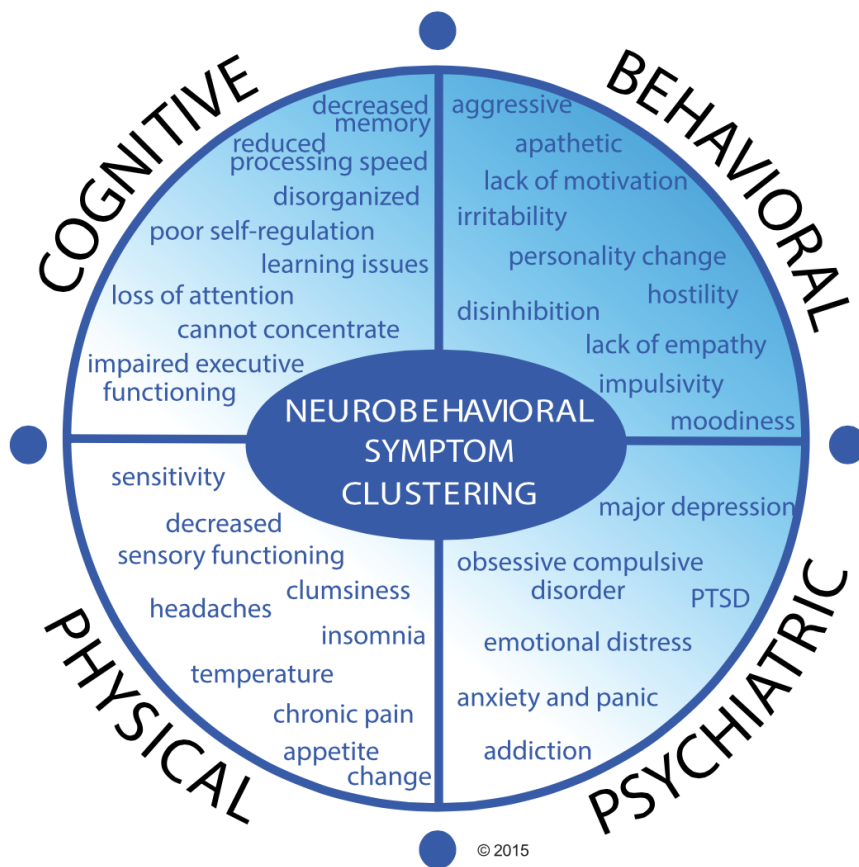
Finally, thank you to Vickie Ho and Leslie Walker, M.S. Speech-Language Pathology graduate students at James Madison University, for their contributions to this project.

### **Abstract**

Following traumatic brain injury (TBI), individuals often face neurobehavioral challenges (e.g., aggression) that hinder treatment. Research on the relationship between communication disorders and maladaptive behaviors is limited. Participants from a convenience sample of two survivors of TBI, a caregiver, and a speech-language pathologist were interviewed about their experiences and perspectives. The interviews reflected focused questions that were congruent across participants. Interviews were recorded, transcribed, and coded. Each coder coded the transcriptions individually, they were then compared using consensus coding for reliability, and finally analyzed for emergent themes. The two most referenced themes were “Communication challenges” and “Changes through rehab”. “Communication challenges” served as an umbrella to the themes “Others to understand” and “Learn to talk”. As for “Changes through rehab”, “Independence” and “Talking” were most reported. “Impulsive” was the most referenced theme under “Behavior”. Other themes emerged but are tangential to the research question. The results from this pilot investigation provide an enriched insight to the experiences surrounding TBI. The promise of this concentrated sample size is a prelude to an expansive understanding of the relationship between communication and behavior.

**Introduction**

The number of individuals living with traumatic brain injury (TBI) is growing, with 2.5 million occurrences reported in the U.S. (CDC, 2016). These individuals often suffer from neurobehavioral challenges that alter cognition, behavior, physical, and psychiatric health (Anson & Ponsford, 2006; Arnould, Dromer, Rochat, Van der Linden, & Azouvi, 2016; Asloun et al., 2012; Harmsen, Geurts, Fasotti, & Bevaart, 2004; McAllister, Flashman, McDonald, & Saykin, 2006; O’Donoghue, Meixner, & Hawk-Sanchez, 2015; Williams, Evans & Wilson, 2003). Subsequently, patients with TBI, and their caregivers, face a plethora of barriers to recovery. Figure 1 depicts these possible barriers and the common sequelae that contribute to neurobehavioral challenges following brain injury.



**Figure 1.** Neurobehavioral Issues following Brain Injury (O’Donoghue, Meixner, & Hawk-Sanchez, 2015).

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One significant challenge is maladaptive behavior (e.g., aggression, impulsivity, disinhibition, etc.). Research supports interventions like functional-communication training and cognitive-behavior therapy for treating maladaptive behaviors, in addition to other comorbid conditions. Conversely, there are few reports of the barrier that communication disorders present when implementing these behavioral interventions.

This qualitative pilot study focuses on maladaptive behaviors commonly exhibited by individuals with TBI, as well as communication disorders that result from cognitive impairments (DePompei, Zarski, & Hall, 1988). Individuals were interviewed about their perceptions with respect to these barriers based on their experiences with TBI. The participants included two TBI survivor, a caregiver of a survivor, and a speech-language pathologist with professional experience in TBI. This study received approval from the James Madison University Institutional Review Board (IRB, 17-0007). The researcher employed scripted questions for the semi-structured personal interviews to explore the connection between communication disorders and maladaptive behaviors.

### **Literature Review**

Maladaptive behavior, both verbal and physical, is commonly reported for individuals following TBI (Walker et al., 2010; Arnould et al., 2016). Harmsen et al. (2004) reported a high correlation between individuals who had experienced post-traumatic amnesia and the presence of maladaptive behavior. Patients commonly exhibit such challenging behaviors across treatment environments (Ducharme, 1999). These behaviors pose obstacles for speech-language pathologists (SLPs) providing rehabilitation (Harmsen et al., 2004), caregivers' relationships (Anderson et al., 2009; DePompei et al., 1988; Walker et al., 2010), and patients reaching their goals (Arnould et al., 2016; Tam, McKay, Sloan, & Ponsford, 2015; Vakil, 2005).

The literature reports different intervention strategies for maladaptive behaviors - two prominent strategies are Functional Communication Training (FCT) and Cognitive-Behavior Therapy (CBT). FCT is a conceptual framework derived from a behaviorist theory (Wood & Alderman, 2011). Contrarily, CBT is a psychotherapeutic focused intervention (Hsieh, Ponsford, Wong, & McKay, 2012a; Topolovec-Vranic et al., 2010; Walker et al., 2010).

#### *Functional Communication Training*

Many intervention strategies for challenging behaviors in patients with TBI are derived from the concept of "functional equivalence" (Ducharme, 2000; Mirenda, 1997; Rahmen, Oliver, & Alderman, 2010). Functional equivalence assigns maladaptive behavior to a certain function, meaning that individuals behave in a manner to gain attention or escape a situation. Individuals learn that their behaviors can influence their environment, promoting access to desired reinforcements (Ducharme 1999; Vollmer & Smith, 1996; Yody et al., 2000). To ascertain which factors underlie the problem behaviors, as well as the existing reinforcements, functional behavior analysis (FBA) is undertaken (Vollmer & Smith, 1996).



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A FBA assists clinicians to identify what appropriate behaviors they can teach patients in order for them to acquire access to reinforcements. SLPs may employ functional communication training (FCT) interventions to bridge communication barriers. Remedial behavioral approaches focus on teaching individuals how to use facial expressions, gestures, symbol boards, and other facilitators as means to provide these patients with appropriate communication alternatives (Ducharme, 2000). An obstacle to FCTs for individuals following TBI is memory deficits (Asloun et al., 2008; McAllister, Flashman, McDonald, & Saykin, 2006; Smith, Okiyama, Thomas, Claussen, & McIntosh, 1991; Vakil, 2005). Because of working memory deficits (Vakil, 2005), reinforcing positive behaviors through functional training is compromised. With memory issues, cognitive-behavior therapy is an alternative approach for TBI patients (Williams et al., 2003).

### *Cognitive-Behavior Therapy (CBT)*

CBT uses adaptive thinking and behavior strategies to modify an individual's thinking (Anson & Ponsford, 2006; Hsieh et al., 2012b). CBT has proven to be a successful treatment for mood disorders post-TBI, including posttraumatic stress disorder, anxiety, and aggression (Hsieh et al. 2012a; Walker et al., 2010; Williams et al., 2003). Williams et al. (2003) studied the results of a CBT program in a neurobehavioral environment; their report emphasized the success of CBT to treat comorbid conditions following TBI. However, few articles address the implications communication disorders have on CBT outcomes.

Progress in CBT is dependent on having effective communication (Harmsen et al., 2004; Hsieh et al., 2012a). Combating this obstacle involves strategies that rely on visual representations and prompting (Hsieh et al., 2012b). These strategies may include forms of augmentative and alternative communication (AAC) since individuals with communication impairments often rely on such devices (Campbell, Balandin, & Togher, 2002). Fager, Hux, Beukelman and Karantounis (2006) studied the use of AAC with brain injury and noted that these devices may bridge the gap between behavior training interventions and

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the challenges of perception, comprehension and expression (Wood & Alderman, 2001). Again, the research addressing outcomes of alternative communication devices assisting with maladaptive behavior is lacking (Mirenda, 1997).

This missing evidence highlights the lack of knowledge about the relationship between maladaptive behaviors and communication disorders (Schlosser, 1997). This pilot study seeks to explore and further understand the relationship between these sequelae of TBI.

### **Methodology**

This IRB-approved qualitative pilot investigation employed focused, structured interviews that targeted the topics of interest. The interviewees reflect a convenience sample including two TBI survivors, a family member of a survivor, and a speech-language pathologist with professional experience in TBI. These interviews query the participants' experiences with maladaptive behavior and communication disorders in TBI through core questions that were congruent across all interviews. Interviews were recorded digitally and with supporting field notes. Recordings were transcribed, with data uploaded into NVIVO-11 for coding, theming, and integration. A blinded and then consensus coding methodology was employed for reliability. First, each coder used NVIVO-11 to code each individual interview. Once completed, the coded interviews were compared side-by-side. Using the represented codes, along with the descriptive responses of the participants, a consensus was formed. Following consensus coding, all coded interviews were aggregated and data were analyzed for emergent themes across the responses of the participants. The aggregate coding was then analyzed by theme, by how often themes were referenced, and by how many sources each theme was referenced (refer to Appendix C). Using these criteria, the most prevalent themes were determined.

**Results and Discussion**

Each of the core questions yielded themes across the participants’ responses; these are listed in Table 1:

Table 1

*Core Questions and Corresponding Themes*

<b>Core Question</b>	<b>Emergent Theme(s)</b>
What are some challenges or obstacles you faced when recovering?	Communicating: Others to understand, Learn to talk
Did these challenges change as you progressed/improved? If so, how?	Independence, Talking
How did you communicate when/if you had limited means to do so?	Devices
Were/are there certain behaviors or actions that you used/use to communicate certain things?	Impulsive
Did your relationships with others (family, service providers etc.) change? If so, how?	Family Support

The most prevalent themes were merged into hierarchy charts through NVIVO-11. The size of the squares represents the saturation of coded themes in correspondence with the core question they answered. Figure 2 depicts codes that emerged under the categories of “communication challenges” and “behavior”. “Communication challenges” was saturated across interviews, serving as home to the themes: “Others to understand” and “Learn to talk.” “Impulsive” was the most common behavior descriptor recounted.

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CHALLENGES-COMMUNICATING		BEHAVIORS		
<p><b>Others to understand</b> (References-21)</p> <p>“He’s all there...so sometimes I feel like he’s just screaming it in his head but he can’t get it out.”</p> <p>“Just because I am in a wheelchair, I do not speak, I do not get taken seriously.”</p> <p>“Communicating is hard. It can be frustrating. Especially when I can’t understand what he wants or needs.”</p>	<p><b>Learn to talk</b> (References-10)</p> <p>“...speech was really a big issue. He just can’t communicate.”</p>	<p><b>Impulsive</b> (References-8)</p> <p>“They may be impulsive in what they say, in what they do.”</p> <p>“...they’ll be impulsive about getting up when they shouldn’t, sometimes they have to be restrained in their chairs for their own safety...”</p>		
	<p>“But it is a trade off-pain versus talking. I won’t have him be in pain.”</p>	<p>“You can have some people who are dysarthric at first who clear very quickly. And others who you never really understand, even years later.”</p>	<p><b>Yell</b> (References-2)</p>	<p><b>Inappropriate</b> (Ref.-2)</p>
			<p><b>Throwing</b> (References-2)</p>	<p><b>Hit</b> (Ref.-1)</p>
		<p><b>Tenses-Tightens</b> (References-2)</p>		

**Figure 2.** Challenges-Communicating and Behavior Thematic Hierarchy Chart

The researchers queried whether and how challenges changed or evolved across the rehabilitation process. As depicted in Figure 3, themes were “Independence” and “Talking”.

CHANGES THROUGH REHAB		
<p><b>Independence</b> (References-17)</p> <p>“His PT is working a lot on walking and all of those things increase his independence which makes him happy.”</p> <p>“He’s the happiest when he is independent and can do a task by himself.”</p> <p>“Well I got to walk down to her house and that was quite a bit, gave me quite a lot more freedom and she just helped me out.”</p> <p>“But you try to give them autonomy so they’re making decisions and gradually making better decisions and more effective decisions.”</p>	<p><b>Talking</b> (References-12)</p> <p>“Well, that just helped me out quite a bit because I could speak and tell everybody what was happening.”</p> <p>“They kind of evolve. In fact many times they do sort of evolve from something that’s very severe to something that still looks problematic but you can see that there’s a process happening.”</p>	<p><b>Cognition</b> (References-7)</p>
	<p><b>Paralysis</b> (References-6)</p>	<p><b>Motivation Differences</b> (References-4)</p>
	<p><b>Walking</b> (References-5)</p>	<p><b>Behavior</b> (References-2)</p>

**Figure 3.** Changes Through Rehab Thematic Hierarchy Chart

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Plausibly, “independence” and “talking” -core to rehabilitation- may mitigate communication challenges and maladaptive behaviors. This observation constructs an overarching theme emphasizing the importance of communication (e.g., independent decision-making) and its role in recovery following TBI. In relation to the overall research question, these findings reinforce the impact that communication challenges present, with or without the presence of maladaptive behaviors.

Other themes secondarily related to the research question include “Devices” being the most referenced communicative form, “Frustration” representing a significantly reported negative emotion, and an overall limited presence of positive emotions. “Family support” also emerged, with little distinction between parent or sibling support.

**Future Directions**

The results of this qualitative research, while lacking in generalizability due to small sample size, help sensitize SLPs to the lived experiences of persons with TBI. Insights gained through this pilot investigation provide new understanding of the connection between maladaptive behaviors and communication. The pilot findings merit expansion to a larger sample size to further inform this topic and generate ideas for novel pathways to working with individuals with TBI exhibiting communication disorders and maladaptive behaviors.

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**Appendices**

**Appendix A: Approved IRB**

James Madison University  
Human Research Review Request

FOR IRB USE ONLY:			
Exempt:	<input type="checkbox"/>	Protocol Number:	1 <sup>st</sup> Review: _____ Reviewer: _____
Expedited:	<input checked="" type="checkbox"/>	IRB: <u>17-0007</u>	2 <sup>nd</sup> Review: _____ Reviewer: _____
Full Board:	<input type="checkbox"/>	Received: <u>05/05/16</u>	3 <sup>rd</sup> Review: _____

<b>Project Title:</b>	<u>Barriers to Treatment in TBI: Maladaptive Behavior and Communication Disorders</u>
<b>Project Dates:</b> (Not to exceed 1 year minus 1 day)	From: <u>07/1/16</u> To: <u>05/06/17</u> MM/DD/YY MM/DD/YY

<b>Responsible Researcher(s):</b>	<u>Marena Jones, Cynthia O'Donoghue, Cara Meixner</u>	
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<b>Department:</b>	<u>CSD</u>	
<b>Address (MSC):</b>	<u>4304</u>	
<b>Please Select:</b>	<input checked="" type="checkbox"/> Faculty	<input checked="" type="checkbox"/> Undergraduate Student
	<input checked="" type="checkbox"/> Administrator/Staff Member	<input type="checkbox"/> Graduate Student

*(if Applicable):*

<b>Research Advisor:</b>	<u>Dr. Cynthia O'Donoghue</u>
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<b>Minimum # of Participants:</b>	<u>3</u>
<b>Maximum # of Participants:</b>	<u>6</u>
<b>Funding:</b>	<p><b>External Funding:</b> Yes: <input type="checkbox"/> No: <input checked="" type="checkbox"/> If yes, Sponsor: _____</p> <p><b>Internal Funding:</b> Yes: <input type="checkbox"/> No: <input checked="" type="checkbox"/> If yes, Sponsor: _____</p> <p><b>Independently:</b> Yes: <input checked="" type="checkbox"/> No: <input type="checkbox"/></p>
<b>Incentives:</b>	<p><b>Will monetary incentives be offered?</b> Yes: <input type="checkbox"/> No: <input checked="" type="checkbox"/></p> <p><b>If yes: How much per recipient?</b> _____ <b>In what form?</b> _____</p>
<b>Must follow JMU Financial Policy:</b>	<a href="http://www.jmu.edu/financemanual/procedures/4205.shtml#.394IRBApprovedResearchSubjects">http://www.jmu.edu/financemanual/procedures/4205.shtml#.394IRBApprovedResearchSubjects</a>
<b>Institutional Biosafety Committee Review/Approval:</b>	<p><b>Use of recombinant DNA and synthetic nucleic acid molecule research:</b>  <input type="checkbox"/> Yes <input checked="" type="checkbox"/> No</p> <p><b>If "Yes," approval received:</b> <input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Pending</p> <p><b>IBC Protocol Number(s):</b></p> <p><b>Biosafety Level(s):</b></p>
<b>Will research be conducted outside of the United States?</b>	<p><input type="checkbox"/> Yes <input checked="" type="checkbox"/> No</p> <p><b>If "Yes," please complete and submit the International Research Form along with this review application:</b>  <a href="http://www.jmu.edu/researchintegrity/irb/forms/irbinternationalresearch.docx">http://www.jmu.edu/researchintegrity/irb/forms/irbinternationalresearch.docx</a>.</p>

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**Certain vulnerable populations are afforded additional protections under the federal regulations. Do human participants who are involved in the proposed study include any of the following special populations?**

- Minors
- Pregnant women (*Do not check unless you are specifically recruiting*)
- Prisoners
- Fetuses
- My research does not involve any of these populations

**Some populations may be vulnerable to coercion or undue influence. Does your research involve any of the following populations?**

- Elderly
- Diminished capacity/Impaired decision-making ability
- Economically disadvantaged
- Other protected or potentially vulnerable population (*e.g. homeless, HIV-positive participants, terminally or seriously ill, etc.*)
- My research does not involve any of these populations

**Investigator: Please respond to the questions below. The IRB will utilize your responses to evaluate your protocol submission.**

1.  **YES**  **NO** Does the James Madison University Institutional Review Board define the project as **research**?

The James Madison University IRB defines "research" as a "systematic investigation designed to develop or contribute to *generalizable knowledge*." All research involving human participants conducted by James Madison University faculty and staff and students is subject to IRB review.

2.  **YES**  **NO** Are the human participants in your study **living** individuals?

"Individuals whose physiologic or behavioral characteristics and responses are the object of study in a research project. Under the federal regulations, human subjects are defined as: living individual(s) about whom an investigator conducting research obtains: (1) data through intervention or interaction with the individual; or (2) identifiable private information."

3.  **YES**  **NO** Will you obtain data through **intervention** or **interaction** with these individuals?

"Intervention" includes both physical procedures by which data are gathered (*e.g.*, measurement of heart rate or venipuncture) and manipulations of the participant or the participant's environment that are performed for research purposes. "Interaction" includes communication or interpersonal contact between the investigator and participant (*e.g.*, surveying or interviewing).

4.  **YES**  **NO** Will you obtain **identifiable private information** about these individuals?

"Private information" includes information about behavior that occurs in a context in which an individual can reasonably expect that no observation or recording is taking place, or information provided for specific purposes which the individual can reasonably expect will not be made public (*e.g.*, a medical record or student record). "Identifiable" means that the identity of the participant may be ascertained by the investigator or associated with the information (*e.g.*, by name, code number, pattern of answers, etc.).

5.  **YES**  **NO** Does the study present **more than minimal risk** to the participants?

"Minimal risk" means that the risks of harm or discomfort anticipated in the proposed research are not greater, considering probability and magnitude, than those ordinarily encountered in daily life or during performance of routine physical or psychological examinations or tests.



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### **Purpose and Objectives**

#### *Background and Overview*

Following traumatic brain injury (TBI), patients may face a variety of neurobehavioral issues. Many of these issues create hindrances to favorable treatment outcomes. One of the most common sequelae of TBI is maladaptive behavior. There are many strategies for treating maladaptive behavior and comorbid conditions like PTSD, depression and post-traumatic amnesia in patients with TBI. However, there is a lack of research dedicated to the interface of treating patients with TBI for maladaptive behavior and communication disorders.

#### *Purpose*

This investigation seeks to further understand the relationship between maladaptive behavior and communication disorders within the TBI community. These conditions are often comorbid in individuals with TBI. **Through an in-depth case study, this project will explore the influence of communication disorders on maladaptive behavior treatments in patients with TBI.**

### **Procedures/Research Design/Methodology/Timeframe**

This qualitative study will employ focused, semi-scripted interviews with three individuals: a survivor of TBI who exhibits/has exhibited maladaptive behavior and has been diagnosed with a communication disorder, a family member of a survivor, and a speech-language pathologist with professional experience working in the TBI community. These participants will be recruited through a convenience sample. Using contacts with area providers of TBI services and the Shenandoah Valley Brain Injury Support group, we will share our project with them and extend the opportunity to volunteer to participate. Providers will be informing patients of the study and how they may participate if so inclined. Participants will be at least 18 years of age. All recruiting efforts will be HIPPA compliant.

Potential volunteers will be identified and communicated with through email, phone, or both. Once participants are confirmed, interviews will be conducted through face-to-face interviews or by video conference call. Participants will be asked to provide verbal consent to participate in the video conference call interview. The interview will be conducted at a mutually agreed upon location. Interviews will be digitally audio recorded with the participants' consent, and then transcribed. The participants' identities will be coded to ensure confidentiality and the collected data, along with the transcriptions, will be secured on a password protected drive. If the participants decline to be recorded, the interview will still be conducted but the information gained will not be used for any part of this study. All subject files will be compliant to HIPPA regulations.

This study will involve interviews with at least one survivor of TBI. This individual may have experienced cognitive impairments as a result of the TBI. However, the identified participant will have the cognitive capacity to consent to participate individually and actively participate in the interview.

## MALADPTIVE BEHAVIOR AND COMMUNICATION DISORDERS

Interviews will query the participants' experiences with maladaptive behavior and communication disorders in TBI and how those experiences impact their perceptions surrounding these topics. Interview questions will vary across individuals but will ultimately address maladaptive behavior and communication disorders and how their experiences impact their perceptions surrounding these topics including but not limited to, impact on rehabilitation, family function, and community reintegration.

There is little direct benefit for the participants. However, their participation and responses will contribute to a greater understanding of interactions between comorbid issues like maladaptive behavior and communication disorders within the field of TBI. There is no more than minimal risk with participation in this study.

Interviews will be conducted throughout the summer, July-August. Once complete, interviews will be transcribed and analyzed.

### **Data Analysis**

Interviews will be digitally audio recorded with a handheld recorder and then transcribed by the primary researchers. Transcription will be completed by either using TranscribeMe or manually by the principal investigators. Audio recordings and completed transcriptions will be secured on a password protected drive with access only available to the researchers. Once the transcriptions are completed, they will be uploaded to Nvivo, a software tool for qualitative data analysis, where it will be coded and analyzed for trends across the responses of the interviewees.

Upon completion of the study, all identifiable data that connects the participants to the study will be destroyed. The principal investigator will destroy data according to University policy. Papers will be shredded or discarded of in secured discarding bins. Any recorded data will be destroyed in a similar manner.

### **Reporting Procedures**

Findings will be analyzed and compiled into a paper, which will serve as the final product of an Honors Project, and may be submitted to an undergraduate peer review journal. Findings may also be presented at conferences. Participants may also request the results of the study.

### **Experience of the Researcher (and advisor, *if student*):**

As a student, this is my (Marena Jones') first study. However, Dr. Cynthia O'Dongohue and Dr. Cara Meixner have experience working with human subjects as well as qualitative study experience. Both individuals will guide me in this study.



## **Consent Form to Participate in Research**

### **Identification of Investigators & Purpose of Study**

You are being asked to participate in a research study conducted by Marena Jones (James Madison University), Dr. Cynthia O'Donoghue (James Madison University) and Dr. Cara Meixner (James Madison University). The purpose of this study is to further explore the relationship between maladaptive behaviors and communication disorders during rehabilitation for patients with traumatic brain injuries.

### **Research Procedures**

If you decide to participate in this research study, you will be asked to sign this consent form once all of your questions have been answered to your satisfaction. This study entails an individual face-to-face interview that will either be administered in person or by video conference call. The interview will be conducted at a mutually agreed upon location. You will be asked to provide answers to a series of questions about your experiences with TBI, maladaptive behavior, communication disorders and your perceptions surrounding these topics. The interview will be audio-recorded with your permission and then later transcribed.

### **Time Required**

The interview will require 30 minutes to 1 hour of your time.

### **Risks**

There are no perceived risks to your participation in this study, that is, no risk beyond the risks associated with everyday life.

### **Benefits**

There are no direct benefits to you by participating in this research study. However, the responses you provide will contribute to the purpose of this study and will be pertinent in guiding future research for understanding the interactions between maladaptive behaviors and communication disorders in patients with TBI.

### **Confidentiality**

The results of this study will be compiled and integrated into academic forums to be published and presented at conferences. The results will be coded and your identity will not be attached to the final product. All identifying information will be omitted and/or disguised. The researchers retain the right to use and publish non-identifiable data. While individual responses are confidential, data will be integrated and presented showing the trends apparent throughout the responses. All data will be stored in a secure location where only the researchers may access it. Once the study is complete, all information that connects individual participants with their responses will be destroyed.

## Participation & Withdrawal

Your participation is entirely voluntary. Should you choose to participate, you may withdraw at any time without consequences of any kind.

## Questions about the Study

If you have any questions or concerns about the study, whether during or after its completion, or if you would like to receive a copy of the final results, please contact:

### ***Marena Jones, Undergraduate., Principle Investigator***

*James Madison University*

[jones2ms@dukes.jmu.edu](mailto:jones2ms@dukes.jmu.edu)

or

### ***Cynthia O'Donoghue, Ph.D., CCC-SP., Co-Principal Investigator***

*James Madison University, Department of Communication Sciences and Disorders*

*MSC 4304*

*Harrisonburg VA 22802*

[odonogcr@jmu.edu](mailto:odonogcr@jmu.edu)

Questions about Your Rights as a Research Subject

### ***David Cockley, Ph.D.***

Chair, Institutional Review Board

James Madison University

(540) 568-2834

[cocklede@jmu.edu](mailto:cocklede@jmu.edu)

### Giving of Consent

I have read this consent form and I understand what is being requested of me as a participant in this study. I freely consent to participate. I have been given satisfactory answers to my questions. The investigator provided me with a copy of this form. I certify that I am at least 18 years of age.

I give consent to be audiotaped during my interview.

\_\_\_\_\_  
Name of Participant (Printed)

\_\_\_\_\_  
Name of Participant (Signed)

\_\_\_\_\_  
Date

\_\_\_\_\_  
Name of Researcher (Signed)

\_\_\_\_\_  
Date

## **Verbal/Oral Consent Form to Participate in Research**

### **Barriers to Treatment in TBI: Maladaptive Behavior and Communication Disorders**

Oral consent serves as an assurance that the required elements of informed consent have been presented orally to the participant or the participant's legally authorized representative.

Verbal consent to participate in this telephone survey has been obtained by the participant's willingness to continue with the telephone survey by providing answers to a series of questions related to what the participant has experienced with TBI, maladaptive behavior, and communication disorders.

\*You are being asked to participate in a study conducted by Marena Jones, Dr. Cynthia O'Donoghue, and Dr. Cara Meixner of James Madison University that seeks to explore the interactions of maladaptive behavior and communication disorders throughout the rehabilitation of patients with TBI. If you decide to participate, you will be asked to verbally agree once all of your questions have been answered to your satisfaction. Your participation entails an interview conducted through a video conference call at a mutually agreed upon time. You will be asked to respond to a series of questions about your experiences with TBI, maladaptive behavior, and communication disorders and your perceptions surrounding these topics. With your permission, the interview will be digitally audio recorded and then later transcribed. The interview will require 30 minutes to 1 hour of your time.

There are no perceived risks to your participation in this study, that is, no risk beyond the risks associated with everyday life. There are no direct benefits to you by participating in this study. However, the responses you provide will contribute to the purpose of this study and will lead future research in this topic.

The results of the study will be compiled and integrated into academic forums to be published and presented at conferences. All identifying data will be omitted/disguised and will not be attached to the final product. Your individual responses will be confidential, but data will be integrated and presented showing trends present throughout all responses. All data will be secured where only the researches can access it. Once this study is complete, identifiable information that connects participants to their responses will be destroyed. Your participation is entirely voluntary and you may withdraw at any time without consequences of any kind.

If you have any questions or concerns about the study, whether during or after completion, please feel free to contact myself, Marena Jones, or Dr. Cynthia O'Donoghue.

I attest that the aforementioned written consent has been orally presented to the human subject and the human subject provided me with an oral assurance of their willingness to participate in the research.

---

Surveyor's Name (Printed)

---

Surveyor

**Appendix B: Interview Template**

Background Information: age, education, job, experience with TBI.

Information about injury.

What was your role before the injury and after throughout the rehabilitation process?

What should speech-language pathologists know?

---

What are some challenges or obstacles you faced when recovering?

Did these challenges change as you progressed/improved? If so, how?

How did you communicate when/if you had limited means to do so?

Were/are there certain behaviors or actions that you used/use to communicate certain things?

Did your relationships with others (family, service providers etc.) change? If so, how?

Do you have a favored treatment approach?

# MALADPTIVE BEHAVIOR AND COMMUNICATION DISORDERS

## Appendix C: Thematic Frequency Table

Name	Sources	References
Behavioral occurrences	1	12
Communication	2	3
Needs	3	6
Behaviors	3	18
Feces	1	1
Hit	1	1
Impulsive	2	8
Inappropriate	1	2
Tenses-tightens	1	2
Throwing	1	2
Yell	1	2
Challenges	5	66
Behavior	2	5
Breathing	3	4
Caregiver-Job	1	1
Challenges - Communicating	4	13
Learn to talk	3	10
Others to understand	5	21
Cognition	2	7
Coma	2	2
Coordination	3	8
Financial or Insurance issues	2	2
Frontal Lobe	1	2

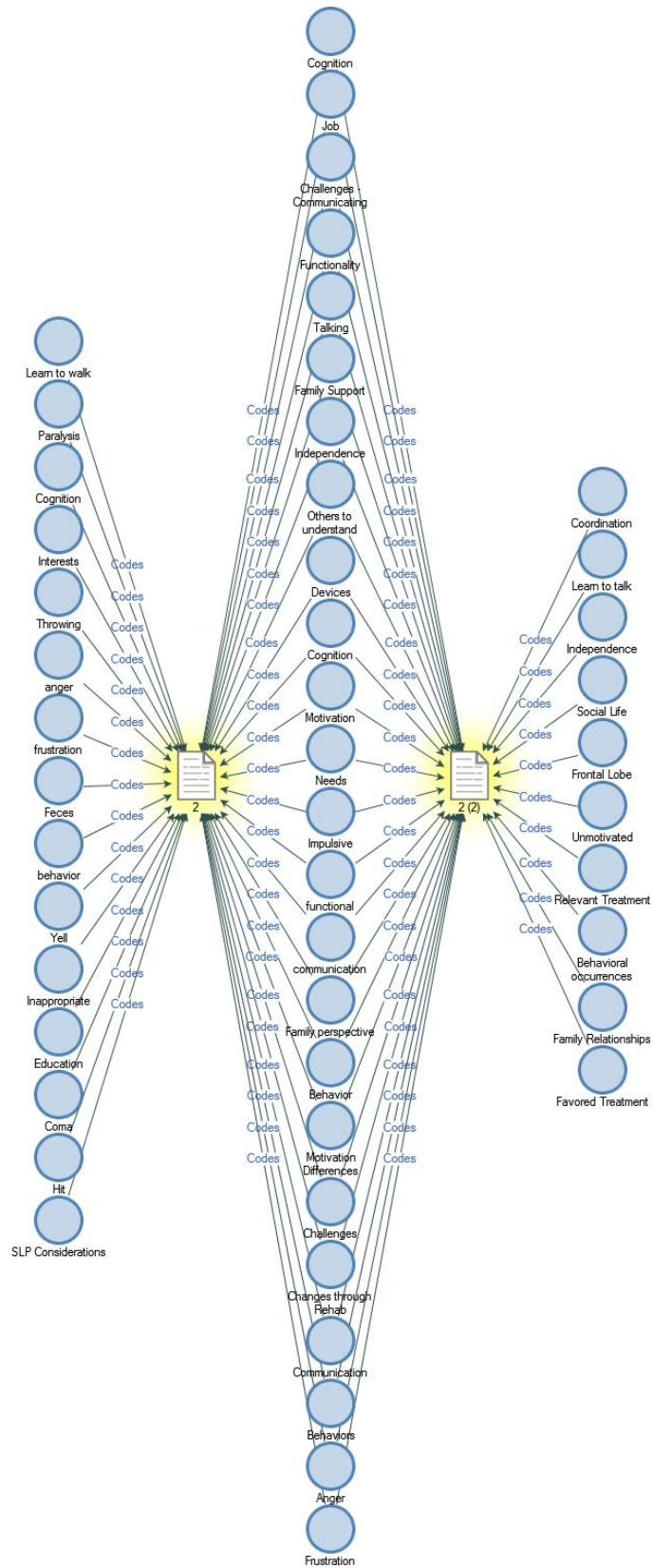
## MALADPTIVE BEHAVIOR AND COMMUNICATION DISORDERS

Functionality	3	5
Independence	1	1
Hard Road	2	3
Learn to walk	2	3
Motivation	2	2
Pain	1	1
Social Life	1	1
Swallowing-Eating	3	4
Vision	1	1
Weight	1	1
Changes through Rehab	5	54
Behavior	1	2
Cognition	2	7
Independence	5	17
Functional	2	3
Job	3	10
Motivation Differences	3	4
Paralysis	2	6
Talking	5	12
Walking	3	5
Communication	6	20
Body Language	1	1
Devices	3	13
Gestures	3	5
Verbal	1	1
Emotions	3	14

## MALADPTIVE BEHAVIOR AND COMMUNICATION DISORDERS

Negative Emotions	2	6
Positive Emotions	2	8
Family Relationships	1	1
Education	1	3
Family perspective	3	4
Family Support	5	16
Life in background	1	3
Favored Treatment	4	12
Promote Independence	1	2
Relevant Treatment	1	2
Walking	3	8
SLP Considerations	4	8
Appreciate Life	1	1
Family Involved	1	1
Independence	1	1
Interests	1	3
Patience	1	1
Speech	1	1
Supports From Others	1	6
Teacher	1	6

Appendix D: Sample Consensus Coding





Appendix E: Poster presented at ASHA 2016 Annual Convention

Maladaptive Behaviors and Communication Disorders Following TBI: Survivor, Caregiver and Speech-language Pathologists' Perspectives

Marena Jones, B.S. Candidate  
Communication Sciences & Disorders, Honors College

Cynthia R O'Donoghue, Ph.D., CCC-SLP  
Professor and Head, Communication Sciences & Disorders  
James Madison University

Cara Meixner, Ph.D.  
Associate Professor  
Graduate Psychology

**Abstract**

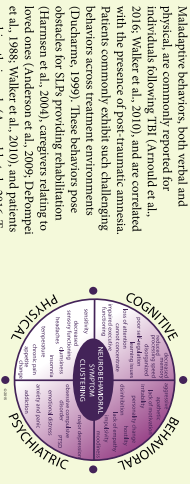
Following traumatic brain injury, survivors often face neurobehavioral challenges (e.g., aggression, impulsivity, disinhibition) that hinder treatment. Research on the relationship between communication disorders and maladaptive behaviors is limited. This qualitative investigation explores the survivor, caregiver, and speech-language pathologist perspectives. Focused interviews are analyzed formulating emergent themes addressing maladaptive behaviors and communication disorders. Emergent themes support a connection between communication (e.g., learning to ask and being understood) and maladaptive behaviors (e.g., impulsivity) that merit further exploration.

**Purpose**

This investigation seeks to further understand the relationship between maladaptive behaviors and communication disorders following TBI. It explores the relationship between influence of communication disorders on maladaptive behaviors and the rehabilitative process from the perspectives of the survivor, the caregiver, and the speech-language pathologist.

**Introduction**

The number of individuals living with traumatic brain injury (TBI) is growing, with 2.5 million occurrences reported in the US (CDC, 2016). These individuals often suffer from neurobehavioral challenges that alter cognition, behavior, physical, and psychiatric health (Arnould, Dromer, Koshak, Van der Linden, & Azouzi, 2016; Aarons et al., 2012; O'Donoghue, Meixner, & Sanchez, 2015; Williams, Evans, & Wilson, 2003). Subsequently, persons with TBI, and their caregivers, face a multitude of barriers to recovery.



Maladaptive behaviors, both verbal and physical, are commonly reported for individuals following TBI (Arnould et al., 2016; Walker et al., 2010), and are correlated with the presence of post-traumatic amnesia. Patients commonly exhibit such challenging behaviors across treatment environments (Ducharme, 1999). These behaviors pose obstacles for SLTs providing rehabilitation (Hartman et al., 2004), caregivers relating to loved ones (Anderson et al., 2009; DeFonpnet et al., 1988; Walker et al., 2010), and patients reaching their goals (Arnould et al., 2016; Han, McKay, Sloan, & Ponsford, 2015; Xaki, 2005).

There is a lack of evidence, however, informing the connection between maladaptive behaviors and communication disorders. This pilot study seeks to explore and further understand the relationship between these sequelae of TBI.

**Methods**

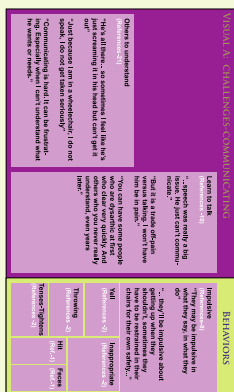
This investigation received approval from the Institutional Review Board of James Madison University. This qualitative pilot study employed structured interviews that targeted the topics of interest. The interviewees reflect a convenience sample including two TBI survivors, a family member of a survivor, and a speech-language pathologist with professional experience in TBI. These interviews query the participants' experiences with maladaptive behaviors and communication disorders in TBI. Interviews were recorded digitally and with supporting field notes. Recordings were transcribed, with data uploaded into NVIVO-11 for coding, theming, and integration. A blinded and then consensus coding methodology was employed for reliability.

**Results**

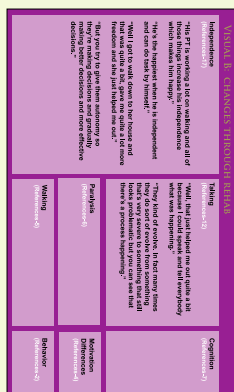
Each of the core questions yielded themes across the participants' responses:

Core Question	Emergent Theme(s)
What are some challenges or obstacles you faced when recovering?	Communicating, Others to understand, Learn to talk
Did these challenges change as you progressed/improved? If so, how?	Independence, Talking
How do you communicate when/ if you had limited progress/improvement?	Devices
Were there certain behaviors or actions that you used/ use to communicate certain things? providers etc.) change? If so, how?	Impulsive Family Support

Visual A depicts codes that emerged under the categories of "communication challenges" and "behavior." "Communication challenges" was saturated across interviews, serving as home to the themes: "Others to understand" and "Learn to talk." "Impulsive" was the most common behavior descriptor recounted.



The researchers queried whether and how challenges changed or evolved across the rehabilitation process. As depicted in Visual B, themes were "Independence" and "Talking".



**Results (continued)**

Plausibly, "independence" and "talking" – core to rehabilitation – may mitigate communication challenges and maladaptive behaviors. This observation constructs an overarching theme emphasizing the importance of communication (e.g., independent decision-making) and its role in recovery following TBI. In relation to the overall research question, these findings reinforce the impact that communication challenges present, with or without the presence maladaptive behaviors.

Other themes secondarily related to the research question include "Devices" being the most referenced coming from frustration representing a significant reported barrier to communication and an overall limited presence of resources. Family support also emerged, with little distinction between parent or sibling support.

**Future Directions**

The results of this qualitative research, while lacking in generalizability due to small sample size, help sensitize SLTs to the lived experiences of persons with TBI. Insights gained through this pilot investigation merit expansion to a larger sample size to further inform this topic and generate ideas for novel pathways to working with communication disorders and maladaptive behaviors.

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