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- 59 **Purpose:** A mixed-method approach was used to investigate the lived experiences of adults with
- 60 mild traumatic brain injury (mTBI). The study aimed to understand the perceived relationship of
- 61 cognitive-communication problems, thinking and communication concerns, and neurobehavioral
- 62 symptoms. We hypothesized that individuals with cognitive-communication problems would
- attribute their problems with communication to their mTBI history and their self-perceived
- problems would be correlated with symptomatology.
- 65 **Method:** The Neurobehavioral Symptom Inventory (NSI) and an online cognitive-
- 66 communication survey was used to conduct a study of participants with mTBI history.
- 67 **Results:** Thirty participants were included in the final sample. Quantitative survey and NSI
- scores were analyzed. The average NSI Total score was 17 with the following subscale score:
- somatic (5), affective (8) and cognitive (3.9). Participants reported problems with expressive
- 70 communication (56%), comprehension (80%), thinking (63%) and social skills (60%). Content
- analysis revealed problems in the following areas: Expression (e.g., verbal, and written
- 72 language), Comprehension (reading and verbal comprehension), Cognition (e.g., attention,
- 73 memory and speed of processing, error regulation) and Functional Consequences (e.g., academic
- work, and social problems, and anxiety and stress). A Pearson correlation indicated a statistically
- 75 significant relationship (p<0.01) between the Communication Survey Total and the NSI Total,
- 76 Somatic, Affective and Cognitive subscales.
- 77 **Conclusion:** This study highlights a multi-factorial basis of cognitive communication in adults
- 78 with mTBI. We show those with mTBI history perceive difficulties with cognitive-
- 79 communication skills: conversations, writing and short-term memory/attention. Furthermore,
- 80 those with mTBI perceive their cognitive-communication problems after injury has impacted
- 81 their vocational, social, and academic success.

## Introduction

Traumatic brain injury (TBI) is a global health concern, affecting an estimated 10 million individuals worldwide (Levack et al., 2010). TBI can dramatically disrupt quality of life and present significant challenges for the injured persons due to long-term physical, cognitive, emotional and social consequences (Jumisko et al., 2005). Mild traumatic brain injury (mTBI), or concussion, accounts for 80-90% of all TBI (Skandsen et al., 2019). Despite its high prevalence, a diagnosis of mTBI is often elusive due to transient symptomatology and absent radiological evidence (Lange et al., 2012). While post-mTBI symptoms typically resolve after 3-6 months of injury onset, about 25-35% of individuals with mTBI experience persistent symptoms (Schneider et al., 2022). Individuals with mTBI often report cognitive, affective, and physical sequelae post-injury (Borgaro et al., 2003), as commonly measured by the neurobehavioral symptom inventory (NSI). The severity and frequency of these symptoms is critical to identify, as it frequently guides clinical decision-making and helps medical providers prioritize post-mTBI care (Scholten et al., 2017).

One area that has been overlooked in this body of work has been the status of communication skills after injury. To date, literature concerning mTBI-related communication disorders is very limited, but preliminary studies have noted that adults with mTBI demonstrate some deficits in tasks involving narrative discourse, confrontation naming, sentence comprehension, category-naming, verbal fluency, reading and writing (Barrow et al., 2006; Blyth et al., 2012; King et al., 2006; LeBlanc et al., 2020; Norman et al., 2019a, 2019b). Much like communication problems after moderate to severe TBI, deficits concerning language after mTBI have been attributed to changes in cognition after injury and thus they are labeled "cognitive-communication" deficits (American Speech-Language Hearing Association, 1993). Experimental

studies of mTBI have shed some light on the performance of individuals with cognitive-communicative deficits. However, there is still a gap in our understanding of how these impairments impact an individual's life and their personal experiences and how high levels of neurobehavioral symptoms correlate with language performance.

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It is necessary to further examine the lived experiences of individuals with mTBI because of two compelling reasons: 1) the nature of symptoms after TBI is subtle and 2) existing clinical assessments are not sufficiently sensitive for this population (Duff et al., 2002; Valovich McLeod et al., 2017). Qualitative studies may provide an important shift in assessment practices as many individuals with mTBI report cognitive-communication difficulties that are difficult to capture using existing assessments. One area in which the qualitative approach has shown promise in examining mTBI has been in the study of personal adjustment following injury (Nalder et al., 2013). Well-established qualitative research methods such as structured interviews have been utilized to gain insight into the life-altering psychosocial consequences of brain injury. In these studies, adults with TBI described disruption to sense of identity, grief from the loss of former life roles, socioemotional consequences, and psychiatric disturbances (Freeman et al., 2015; Knight et al., 2020; Levack et al., 2010). However, current studies exploring the qualitative aspects of recovery after TBI, such as Levack's (2010) meta-synthesis have focused mainly on moderate to severe TBI, leaving the experiences of adults with mTBI, relatively unexplored.

The few studies available regarding mTBI have largely focused on the experience of sports-related concussion (SRC). A study on the perceived effects of SRC on psychosocial effects found that most adolescent participants noted significant symptoms that influenced their physical, emotional, school, and social well-being (Valovich McLeod et al., 2017). This

investigation urged for management practices to progress toward adequate evaluation using a holistic approach to include all domains of health status, beyond simply monitoring cognitive impairments. Another study interviewed young adults with sports-related concussion to examine the continuum of care after injury (Brown & Knollman-Porter, 2020). Results from this study demonstrated that among parents, coaches, physicians, friends and athletic trainers, participants reported their concussive events to their parents most frequently, supporting the well-established notion that mTBI places an increased burden on family members and caregivers. Notably, both studies revealed that young athletes with concussion often masked their symptoms for fear of judgement from peers, restricted participation of activities, and/or lack of understanding about post-injury consequences (Brown & Knollman-Porter, 2020; Valovich McLeod et al., 2017). The adolescent participants in the study described a perceived need to preserve a sense of normalcy in their lives. The authors posited that ideas such as these may hinder individuals from seeking and receiving appropriate treatment.

While the young adult and adolescent studies descibed above provide some insight regarding the lived experiences of individuals with mTBI, there is still a lack of evidence to suggest that these results can be extended to all adults with mTBI. Studies exploring empirical outcomes after injury and qualitative outcomes are very much needed as healthcare systems shift to individualized, whole-person approaches to rehabilitation and managed care. Studies that highlight the subjective experience of TBI can reveal and highlight the gaps that exist in our current approaches and this would deepen our understanding of this vulnerable and undertreated population. In summary, more evidence is needed to explore mTBI and to further define the complexities and nuances of the post-injury experience on an individual. This knowledge can

help advance the development of mTBI-specific management strategies as well as clinical tools for assessment and interventions that support the needs of individuals with mTBI.

As we consider how best to manage the long-term effects of mTBI, it is necessary to address cognitive-communication difficulties after injury. Communication is a skill that contributes to successful community reintegration after injury and employment in the 21<sup>st</sup> century (Meulenbroek et al., 2022; Ruben, 2000). Furthermore, impairments in communication function negatively affect an individuals' ability to self-advocate, socially integrate, and develop meaningful work, resulting in reduced quality of life (Galski et al., 1998). Current evidence does not adequately address cognitive-communication disorder as a potential etiology contributing to an individuals' affective disturbances (e.g., anxiousness, feeling sad or depressed, irritable, or frustrated) post-injury. Further exploration of the meaningful experiences of individuals with mTBI can deepen the understanding of cognitive-communicative sequelae following injury. This knowledge can help advance the management strategies as well as clinical tools for assessment and intervention to support the needs of individuals with mTBI. Therefore, the purpose of this study is to explore self-perception of cognitive-communication problems of adults living with mTBI. Using an online survey approach, we aimed to answer the following research questions:

- 1) Do adults with mTBI attribute their current cognitive and communication problems to their history of mTBI?
- 2) What are some of the concerns adults with mTBI have related to their cognitive-communication skills?
- 3) Is level of self-reported post-concussion neurobehavioral symptomatology associated with participant self-perception of cognitive-communication skills post-injury?

#### Methods

The study consisted of a cross sectional survey design using an online survey method.

Design and reporting of the study was guided by the Checklist of Reporting Results of Internet E-Surveys (CHERRIES) (Eysenbach, 2004) to ensure adequate description of the electronic survey. The survey was piloted amongst two research teams at UTHSCSA and UTSA to test electronic functionality and question clarity.

Recruitment and Screening

The study survey was advertised through a variety of media outlets. Mass, campus-wide e-mails to all students, faculty, staff, and alumni about the study opportunity was approved and sent across the following local colleges and universities: the University of Incarnate Word, Our Lady of the Lake College, the University of Texas at San Antonio and the local Area Alamo College system. Social media posts were made on the following platforms: Facebook, Twitter and Instagram. Facebook was used to contact lead organizers of brain injury support groups. Paper flyers were posted on approved sites at the University of Texas at San Antonio Campus (see Appendix, Figure 1). The survey was also advertised through two public, open-access websites. A post was made on the UTHSA Find-A-Study website: <a href="https://vpr.uthscsa.edu/findastudy/">https://vpr.uthscsa.edu/findastudy/</a>. Potential participants from the community can access the site to view a listing of all applicable studies, a search bar, study information and links to contact the study team. An additional post was published on the UTSA Wicha, Brain, Language and Cognition Lab website: <a href="https://www.utsa.edu/biology/faculty/WichaLab/">https://www.utsa.edu/biology/faculty/WichaLab/</a>, under the "Participate" section.

Initial contact was made to potential participants, who expressed interest in participating via e-mail, requesting a phone number and desired time for a screening call appointment. The informed consent process included both verbal and electronic components. During the screening

call, participants were verbally provided with details regarding the length of the study, the primary investigator, and data storage. The following questions were administered during the screening call:

- 1) Do you have a history of mild traumatic brain injury or concussion? Yes\*
- 2) Do you have any history of neurological diseases or disorders affecting the brain? This can include any stroke, epilepsy, or learning disabilities. No\*
- 3) Are you currently taking any medications that may affect the brain? No\*
- 4) Are you a native English speaker, meaning English was the first language you heard and spoke? Yes\*
  - 5) Do you have any hearing problems? No\*

Eligibility was determined by whether potential participants provided the appropriate response to the screening questions above as indicated by the (\*). Those eligible were asked to provide their e-mail address and were scheduled to complete the survey on a date within their convenient timeframe. The survey e-mail, sent to only those who were verified through the screening call, contained instructions, a description of the survey, study team contact information and a unique link to access the study survey. Participants were notified through a disclosure statement prior to accessing the study that the link was specific to them and should not be forwarded to others. A monetary incentive was offered for completion of the study through a prepaid \$10 ClinCard Mastercard that was mailed via the United States Postal Service upon completion of the survey.

Sample

Respondents were asked to report their demographics information, including sex, age, race/ethnicity, and educational level. All participants included in the present study were invited

to participate in the study based on their self-report of injury, which is considered a standard clinical practice (Marshall et al., 2015; Scholten et al., 2017) in confirming a history of mTBI or concussion, based on the following criteria: loss of consciousness for less than 30 minutes (0 minutes - 30 minutes); or, alteration of consciousness/mental state up to 24 hours; or, post traumatic amnesia up to 1 day; or, results in Glasgow Coma Scale Score (best available score in the first 24 hours) of 13-15.

The survey was open, and participants were actively recruited fromJuly to December 2020. A total of 31 participants completed the survey during this time. Of the 31 participants, nine individuals were returning participants, meaning they had previously participated in another research study led by the principal investigator and contacted using the existing information in the study team database. The remaining 23 participants were recruited from the community using various advertisement procedures. One participant was excluded from the final analysis because they indicated that they did not have a self-reported history of mild traumatic brain injury or concussion based on the mTBI definition included on the first question of the study. Participants were excluded based on the following criteria:

- History of pre-injury medical or neurological disease affecting the brain (other than mTBI) or language disability
- 2) Non-native English speaker as indicated by self-report
- 3) Hearing within normal limits per self-report
- 4) Indication of a health-care surrogate on medical record or by self-report
- 5) Uncorrected vision impairment

6) Currently taking medication(s) other than those specifically prescribed for TBI that could impair their cognitive abilities

# **Procedures**

All procedures were approved by the University of Texas Health San Antonio (UTHSCSA) Institutional Review Board (IRB). Study data was collected and managed on a highly secure and Health Insurance Portability and Accountability Act (HIPAA) compliant webbased application called Research Electronic Data Capture (REDCap). The application is hosted through a partnership with the Department of Epidemiology and Biostatistics (DEB) and Information Management Systems (IMS) at UTHSCSA.

## Data Protection

All data captured was hosted on the local institution UTHSCSA server, and personal information was collected and stored in a REDCap MySQL database. The password-protected database could only be accessed by UTHSCSA-affiliated users who are added to the User Whitelist through a local REDCap administrator to protect against unauthorized access. Additionally, if an activity such as the typing or moving of the mouse was not detected an autologout default setting time of 30 minutes was employed. The logging and audit trail feature were used to monitor all user activity and actions. Data export was limited to select users and advanced export features were used to automatically remove fields tagged as identifiers to prevent sensitive data from being exported from the system. All user data is filtered for any harmful markup tags, sanitized and escaped prior to being displayed on a web page. A new "nonce" or secrete user specific token is generated on each web page that a user views during a session to prevent cross-site request forgery attacks (CSRFs).

## Survey

The electronic survey was administered through a unique embedded link within an e-mail that was sent directly to the pre-screened participant. Survey completion was voluntary. The

items and questionnaires within the survey were not randomized or alternated. The survey is comprised of four sections and was presented in the following order: (1) electronic consent, (2) communication survey, (3) Neurobehavioral Symptom Inventory (NSI), which is a 22-item self-report questionnaire, (4) participant information. The adaptive questioning survey presentation technique was used in the survey to enable subsequent questions to be presentated on the basis of the response choice of a participant on a previous question.

. For the nine returning participants, the data collection process was streamlined by using adaptive questioning. If we already had demographic information that does not change (race, ethnicity, etc.) from a prior session we did not request this information during the virtual study session and acquired the information from our database from an existing intake record. Questions regarding their personal, academic, vocational, medical and brain injury history were made available only if participants indicated that an update was required. For non-returning participants, all questions were presented.

Upon entering the study, participants were presented with a total of 12 pages or screens for the electronic consent section of the survey. The first six of the pages contained the scanned consent documents that the UTHSCSA IRB previously approved. The remainder of the pages contained information regarding instructions, authorization and electronic signature capture. The documents contained information about the purpose of the study, investigator, length of time, incentives and data storage. A back button was available on each page of the electronic consent to allow participants to review each page prior to providing an electronic signature using their finger or a mouse, and date on the final page of the consent document sequence. Participants were also presented with an opportunity to download the full signed consent documents upon completion.

The number of questionnaire items per page varied based on the corresponding section of the survey. Each item within the communication survey section was presented on a single page, and the eight questions with instructions were distributed across 12 pages or screens. The NSI section was administered across three pages, with one page of instructions, one single page of all 22 items were presented, and the last a transition page. The final section of the survey contained participant information across five pages. The number of items varied based on branching logic for returning and non-returning participants with the number of items per page ranging from six to twenty items. The total survey across all four sections was distributed across 32 pages.

Since this was a closed survey, the view rate was not calculated because the survey was not made available to view until eligibility had been determined. Therefore, the number of unique visitors to the first page equals the number of site visitors. A total of 31 people visited the first page that contained the survey instructions. The participation rate was 100%, which was calculated by the number of people who filled in the first survey page. The completion rate was 100%, calculated by dividing the number of people that submitted the last survey page by the number of people who submitted the first survey page. Each survey access link provided to participants is unique and valid for only one submission, which prevents response modifications or multiple submissions. Once a user completed a survey section, the survey was never displayed a second time. However, if a user was unable to complete a section of the survey due to a technical issue (i.e., internet connectivity), they were instructed to contact a member of the study team and to refrain from reentering their responses into the same form. No technical issues were reported, and only the first entry was used for analysis. User cookies, IP address, and log file analysis were not used.

Upon final submission, a member of the research team was automatically notified. Survey completeness was checked automatically after the submission and missing mandatory items were highlighted. Additionally, the status of each survey section was denoted by a color indicator; red – incomplete; yellow – unverified; green – complete. All sections, apart from the participant intake section, included a non-response option such as "None" or "Not Applicable" or "0" on a Likert scale rating. Only a text version of the Likert scale response was presented to participants and the associated Likert scale numerical value was not visible.

Responses were only enforced on questions in the intake section related to mild traumatic brain history or information required for payment processing. Respondents were able to review responses though a back button. A review step where respondents were provided a summary of their responses and acknowledgement of response correctness was not used. However, respondents could view their overall progress for each of the four sections of the survey.

All participants were provided unlimited time to complete the survey and were notified that their participation would take about an hour. The exact time needed to complete the full study was not measured because the collection system does not provide an option to collect an onset timestamp. Only the offset time or time that the response for a section was submitted is generated. Therefore, the time it took participants to review and submit the eConsent section is unknown. The time needed to complete the experimental sections (communication survey, NSI, and participant information) of the study was calculated by subtracting the completion time of the last section (participant information) with the completion time of the eConsent section. The average completion time for the survey was 28 minutes (range 6 - 41 minutes). Responses were not excluded if they were submitted quickly.

The survey instruments for each of the four sections were built using the Online

Designer tool. Field or question types were selected from a drop-down selection list, the field
label was specified, and choices for each question were entered when required. Fields that
required the entry of personally identifiable information (PII) were marked to allow for the
participant's personal data to be protected through user access controls that would enable only
select members of the study team to download and export PII.

# Survey Question Development

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The electronic survey was developed on REDCap. An introduction to the purpose of the survey and instructions served to orient the participant to the questionnaire interface. Question 1 included the diagnostic definition of mTBI and consisted of a simple yes-or-no question regarding participant's mTBI history. Questions 2-6 were written to carefully address deficits within the domain of cognitive-communication, including but not limited to language, attention, pragmatic, and cognitive deficits. Each question was presented with a blanket statement about a deficit and supporting examples that describe its consequential impact on life. Participants were required to provide a response to these questions from a five-point Likert scale; almost always, often, sometimes, seldom, or never. Question 7 was a free-response question that prompted the participant to share any additional information about how their cognitive and communicative abilities have been impacted by their history of concussion. Considering the nature of a virtual survey, Question 8 was included as a yes-or-no to address whether the participant experienced issues of any type during their participation. Question 9 allowed the participant to describe the issues experienced. A brief thank you and transitional statement to the next component of the study was presented upon survey completion.

#### Statistical correction

Items were not weighed to adjust for sample.

## Measures collected

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A widely used and psychometrically validated (Belanger et al., 2010; Soble et al., 2014) self-report measure of post-concussive symptoms after mTBI called the Neurobehavioral Symptom Inventory (NSI) was administered. In this questionnaire, individuals rate their current symptoms with regard to how much the symptoms disturbed them in the last 2 weeks on a scale from 0 to 4 that includes severity and frequency (0 = symptom is rarely present or not a symptom)at all, 4 = symptom is very severe and almost always present) across a total of 22 items. The NSI total score can be calculated by taking the sum of the 22 items (range 0 to 88). Symptoms can categorized be into three sub-scales: cognitive, somatosensory, and affective. The cognitive subscale score calculated by taking the sum 4 items (poor decision making, forgetfulness, difficulty making decisions and slowed thinking) for a sub-scale score range of 0-16. The somatosensory sub-scale score is calculated by summing the scores from 11 items (dizzy, poor balance, poor coordination, nausea, vision problems, sensitivity to light, hearing difficulties, sensitivity to noise, numbness, change in taste, loss of appetite). The somatosensory sub-scale can range from 0-44. The affective sub-scale score is comprised of 7 items (headaches, fatigue, difficulty falling asleep, feeling anxious, feeling depressed, irritability, poor frustration tolerance). The affective sub-scale can range from 0-28. A higher score is associated with greater severity of symptom reporting for the total and sub-scale scores. In the current study, because of pragmatic circumstances surrounding the COVID-19 pandemic which limited in-person contact with participants, the NSI was administered online. Previous research on the psychometric properties of the NSI refer to in-person and telephone administration.

# Analysis

Only completed questionnaires were included in the analysis. In this instance, the participant information section was re-administered through a new form to include only the missing field. The participant was not exposed to the full completed survey components more than once, and only the most recent data for the previously missing fields was included for analysis.

# Content analyses procedures

To analyze open-ended questions, the study team used an adapted content analysis method (Creswell & Tashakkori, 2007). Each response was read by three study team members (RN, EP and SC). Study team members conducted their analysis independently and did not discuss content or subcontent areas until content areas had been identified independently. Final categorization of main and subcontent areas was conducted in consensus via discussion. Some participants provided free text responses that included more than one main content or subcontent area. In cases such as these, for example, Participant 1 reported both word-finding and fatigue in their response, the response was counted separately in both the fatigue and word-finding subcontent areas.

#### **Results**

## Demographic Variables

A total of 30 adults with mTBI participated in the study. Table one includes participant demographic information including age and self-reported race and ethnicity, level of education, time post-injury, mechanism of injury, history of loss of consciousness and number of mTBI/concussions. Total Neurobehavioral Symptom Inventory scores, as well as somatosensory, affective and cognitive subscale scores are included. The majority of the study sample were of

White race (n=21). Four individuals identified as Black, two identified as Asian and one participant identified as Native American/Alaskan Native, one participant identified as Other and one participant did not disclose race or ethnicity. Seventeen (56.6%) of the participants were female and 13 (43%) were male. Average age of participants was 25.53 years old with a range of 18 to 50 years old. Highest education level reported was the following among the participants: 13 reported High School, three participants reported an Associate's degree, 10 reported attaining Bachelor's degrees and four participants reported attaining a Master's degree or higher. *Injury Variables* Most individuals (n=16) self-reported a history of two or more concussions (range 1 - 8). The average time post injury was 4.67 years with a range of 11 months to 11 years. The most common mechanism of injury was a fall or hit related to sports, affecting 24 (76%) participants, five participants (~17%) reported motor vehicle accidents, one participant reported injury secondary to assault. A self-reported history of loss of consciousness varied across the sample. A portion of the sample reported no history LOC in their lifetime (n=13). Eight participants reported a history of LOC following their most recent concussion event with an LOC ranging from less than a minute (n=5) to greater than 1 minute but not exceeding 30 minutes (n=3). For other participants in the sample their history of LOC was unclear. Some participants did not report LOC (n=6), while others were unsure of the LOC duration following their most recent concussion (n=3). NSI Symptom Variables The average NSI total score was 17.31 (range of 6-39). Total NSI scores and somatosensory, affective, and cognitive subscale scores were also included in Table 1. Average NSI

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424 somatosensory subscale score was 5.2 (range 1-16), average affective subscale score was 8.26 425 (range 1-17) and the average cognitive subscale score was 4 (range 0-9). 426 Survey Results 427 Appendix A shows the results of the survey by participant. 428 Within Participant Responses 429 When considering pattern of responses within participants, only one of the thirty participants 430 rated themselves as never experiencing any of the five symptom areas, although did identify that 431 a week's break was required from school and electronic devices. Half (15/30) of the participants 432 rated themselves as having symptoms only NEVER, SELDOM and SOMETIMES across the 433 five symptom areas. Three participants rated frequencies of the five symptoms as either 434 SOMETIMES, OFTEN or ALWAYS. In the remaining eleven participants, the degree to which 435 each symptom element affected them varied, with item ratings ranging from NEVER to 436 ALWAYS across items. Participants who experienced symptoms less frequently, still reported 437 the impact the symptoms had on their life e.g. word-finding, reading comprehension and memory 438 difficulties. 439 Content areas requiring a response regarding the frequency of the problem on a Likert-440 scale included: expressive communication (including speaking and writing), comprehension 441 skills (including reading), thinking skills (e.g., organizing, completing multi-step tasks), social 442 skills and whether participants felt that fatigue after brain injury had affected their 443 communication and thinking skills. Participants viewed the communication survey questions one 444 at a time and were required to select frequency of occurrence i.e. Never, Seldom, Sometimes, 445 Often, Almost Always and Always for each of the problem areas. The total percentage of

participant reporting each symptom area was calculated for each participant who indicated the

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symptom was present in their response (Seldom, Sometimes, Often, Almost Always and Always) over the total number of participants in the study. Since their injury, twenty-five participants (83%) reported problems with expressive communication skills, 24 participants (80%) reported problems with comprehension skills, and 19 participants (63%) reported problems with their thinking skills. 12 participants (40%) reported problems with social skills and 23 (76%) reported that fatigue negatively impacts their communication and thinking skills.

# Free Response Text

Table 2 demonstrates the free text responses for each participant, organized by main content areas and subareas. When asked if there were "any other concerns about your thinking or communication skills?" or "Has your brain injury impacted other areas of your life?" all participants provided a response.

Resolved Symptoms

Five participants indicated that their symptoms did exist at one point in time after the injury but had resolved e.g., Participant 10 stated "I was affected negatively by all of the questions answered when I suffered my concussions. I am not affected the same way today, years after my injury. But months after the injury, I had trouble with critical thinking, my social life, and positivity." One person stated explicitly that their lack of symptoms at the time of testing was a result of treatment and time "for a short period of time after my concussion I had a hard time finding words and forming sentences, but with therapy and overtime I was able to regain this skill." (Participant 22)

Affirmation of survey questions

Two participant's free text responses seemed to affirm that the areas identified in the questions were areas they had difficulty with. For example, "I think these questions highlight my

main concerns when I think of how I am now versus prior to receiving the mild concussions" (Participant 18)

No additional problems

Six participants reported that there were not any additional concerns relating to their communication or thinking, nor on other aspects of their life. Interestingly, two of these participants appeared to reply with a degree of reflection on their conscious awareness or perception of the issues. For example, Participant 9 "not that I'm consciously aware of" (never and seldom).

Language Problems: Expressive Language

Within the main content area of expression, 11/30 participants included in this study reported problems with expressive language including verbal and written language. Extracted meaning units included difficulty with responding to others, difficulties during conversation and general difficulties in expression, word-finding problems, and speech articulation, with several participants reporting anxiety, feeling "flustered" and panic during these expressive communication difficulties.

Specifically, three participants desc337-ribed more general difficulties with expressing themselves in conversation and connected speech "carrying a conversation" (Participant 27) and describing situations or feelings (Participant 26). Five participants specifically noted issues of word finding difficulties, resulting in pauses and being flustered (Participant 28), the need to circumlocute to find a different word when talking with others (Participant 29), and also semantic and phonological paraphasias e.g., "Sometimes, I say a word that sounds like the word that I want to say, but it is a made-up word." [Participant 8]. One of these participants also described struggling to produce words correctly in a written format, "I often write words with the

letters out of order now. For instance, when writing the word "idea" I will write the letter d first, and then the I, and then I will stop and have to fix it. I do this very often when handwriting notes, and it gets worse when I'm tired or stressed" (Participant 28).

Speech motor difficulties were reported by four participants, and these ranged from stuttering-like disfluencies, pauses or slurred speech. Stuttering was the most commonly reported motor speech difficulty reported by participants. Three participants used the word "stutter" to explain their expressive communication difficulties, which one participant (Participant 6), reported was associated with moments of anxiety. The remaining participant clearly outlined characteristics of dysarthria that resulted in slurred speech and difficulty saying words (Participant 18).

Language Problems: Receptive Language

Three out of 30 respondents reported receptive language symptoms including difficulties with comprehension in conversation by one participant "There are times in the day I completely can't respond to a question or process what was asked of me." (Participant 1) and two participants reported problems with reading and writing down what they understood from a reading passage or a verbal lecture. Specific problems cited included both transcription of the material as well as more expressive elements of spelling unfamiliar and familiar words.

## Cognitive Problems Reported by Participants

Five participants reported challenges in cognitive areas such as processing, focus and attention. Two participants in this subgroup reported difficulties with short-term memory, and the rest reported problems with attention and concentration. In addition, one participant reported long pauses in sentences due to processing issues during speaking and two participants reported difficulties with error regulation "I have to double and triple check for errors."

# Functional Consequences of Reported Problems

Six participants reported functional consequences as a result of fatigue, mental health and socialization limitations attributed to their brain injuries. Cognitive fatigue related to stressful environments (e.g., a fast-paced clinical environment) as well as the injury exacerbating previous symptoms (e.g., attentional difficulties, headaches) also emerged as categories for participants reporting cognitive symptoms. Mental health challenges included identifying anxiety related to speech problems (Participant 6) as well as being unable to put feelings into words (Participant 26). Social challenges reported included participants feeling anxious, upset, engaging in self-isolating behaviors and acting differently in public than in private. Participants reported these social behaviors as a result of cognitive challenges and other people "being unable to understand" them. Recreational challenges reported by participants included difficulty with playing sports and video games.

# Associations between survey responses and Neurobehavioral Symptom Inventory Responses

Table 3 depicts results of a Pearson correlation conducted to determine the association between the quantitative survey responses and neurobehavioral symptom inventory responses for the participants in the study. Results indicated that the survey had a strong positive correlation with the NSI Total Score, NSI Affective sub-score and the NSI Cognitive sub-score. The survey and the NSI Somatic Score demonstrated a medium positive correlation.

## **Discussion**

# Key Findings

This study sheds light on an understudied but critically needed area of research in the mTBI literature: self-perception of communication and cognitive skills in adults living with a history of mTBI. An important finding gleaned from online survey responses provided by a

sample of young adults with a history of mTBI was that many report communication problems characterized by problems with expression and comprehension skills, with significant variability on the frequency of these problems among the participants. On the quantitative portion of the survey, about half of the participants reported having difficulties with communication and cognition less often, with a small number (3) experiencing symptoms more frequently across all five symptom areas. However, the remaining 11 had more varied patterns of areas frequently experienced. Therefore, participants experienced a range of symptoms that require probing across all key areas of communication and cognition because of the heterogeneity of reported symptoms in this group. Importantly, our results address Aim 1 by because adults with mTBI attribute their current cognitive and communication problems to their history of mTBI. Furthermore, the relationship between self-reported post-concussion neurobehavioral symptomatology and participant self-perception of cognitive-communication skills post-injury outlined in Aim 3 was explored. The quantitative survey responses correlated strongly with neurobehavioral symptoms which are common after mTBI.

Results of the qualitative free-text portion of the survey supported Aim 2 and highlighted some of the concerns adults with mTBI have related to their cognitive-communication skills. Reported problems centered around cognitive-communication skills, many of which are required and necessary for successful community participation after injury: being able to have conversations with friends, pursuing academic writing, and performing complex tasks accurately. Furthermore, results of our survey reflect the consequences of these perceived deficits; participants reported that reported communication deficits have a significant effect on aspects of coping and mental health including an increase in anxiety symptoms leading to panic attacks and feeling "flustered." A small number of participants reported these symptoms often lead to

socially isolating behaviors, which contribute to difficulties with maintaining friendships and pursuing recreational activities. This finding, a link between emotional consequences and cognitive-communication skills has been identified in the moderate to severe TBI literature (Wang et al., 2021) but has not been identified in the mTBI/concussion population and is important to consider in light of the fact that individuals with mTBI report having an "invisible injury" (DePalma & Hoffman, 2018). Psychological adjustment problems have been found in the literature but the connection to communication skills has not, to our knowledge, been fully explored in mTBI. It has yet to be determined if these psychological adjustment difficulties have a biological basis, or they are a biproduct of the lack of clinical validation of symptoms after injury. Mean NSI scores and results of the correlation between the NSI and the cognitivecommunication survey echo this link between cognitive and behavioral symptoms in adults with mTBI symptomatology and it is important to note that across all NSI subscales, participants in the current study were highly symptomatic when compared to normative samples (Soble et al., 2014).

# Clinical Implications

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To address the symptoms reported by our participants, a radical change to clinical assessment practices will be required of clinicians providing referrals to therapists and to therapists treating patients with mTBI. Currently, referrals to therapy services that address cognitive and communication challenges after injury also often take longer than to any other health care providers (Hardin et al., 2021). Frontline clinicians providing medical TBI evaluations would need to carefully screen and investigate all areas of communication, educate mTBI clients and staff on the benefits of speech language pathology (SLP) care and refer clients

for SLP services, accordingly. Importantly, clinicians should be aware that many clients experience less frequent symptoms that still cause significant impact on their life. Additionally, some clients will present with clear and highly frequent difficulties across many communication areas. Other clients will have areas of difficulty with some communication symptoms but very little in others, making the need for careful case history and assessment important. The use of established referral tools such as the Cognitive-Communication Checklist for Acquired Brain Injury (CCCABI), highly endorsed by both practitioners and individuals with brain injury (MacDonald, 2021) and which screens for 45 communication difficulties across 10 cognitivecommunication areas, could be implemented and adopted into to clinical practice guidelines to effectively capture the needs of those individuals with deficits too subtle to be detected using traditional speech-language measures. In turn, practices such as these would increase referral to speech-language pathology services, access to appropriate intervention and more patientcentered care. Speech-language pathologists accordingly, will need to increase visibility on postconcussion multidisciplinary rehabilitation teams. Currently, the SLP role is clearly defined in settings such as the VA System of Care in the US and in the Department of Defense, however, in civilian settings, the SLP role is more ambiguous and possibly underutilized for post-concussion care (Hardin et al., 2021; Hardin & Kelly, 2019).

Study Design

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There were several advantages of the current study design. First, the virtual format was very cost-effective and facilitated research during a period of time that was otherwise not possible (i.e., during the COVID-19 pandemic). The anonymity offered through this format may have also decreased the likelihood of social desirability bias or the tendency of individuals to respond in a socially acceptable way because participants were not disclosing sensitive

information regarding their injury history and corresponding cognitive communication abilities. We also observed a high completion rate, which may suggest that participants found the study to be engaging. The high level of engagement may be attributed to a combination of short, plain English questions, adaptive questioning and the visual graphics used.

#### Limitations

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This study is not without limitations. The highly structured nature of the questions may have forced participants to respond in a way that was based on the preconceptions of the researchers. To address this, we included a free text response question to allow the participants an opportunity to write their perception of their cognitive-communication skills in their own words. We also ensured that the Likert scale was not dichotomous but multiple-choice and allowed participants to respond neutrally to questions. The study questions also required introspective and recall abilities. Factors such as the length of the recall period (time since injury to test date) may have influenced the participant responses. Those with longer time since injury may have experienced a more difficult time recalling relevant behaviors prior to injury. It is also possible that participants lacked introspection, meaning that the participant may not have been able to recognize their own communication problems. Still, others who frequently communicate with the participant could attest to the communication difficulties. Future research should consider these cognitive abilities and include communication partner perspectives. Double barreled questions and/or examples may have also influenced the results. Future investigation should involve investigating constructs separately to avoid response bias. Finally, the communication survey section of the study does not have psychometric properties that have been formally explored, so caution should be exercised when using the results and interpretations from this section.

While the virtual format allowed for us to include participants from various U.S. geographical regions (Colorado, Maryland, South Carolina), majority of the participants (n=27) resided in Texas. Thus, our study and interpretations are limited by a small sample from small geographical location and may not represent views of all individuals with mTBI. The virtual format also limited our ability to control environmental factors (light, sounds, electronic capabilities) encountered during the study session. To address this, we included both verbal and written instructions to participants to minimize environmental factors, but due to the nature of the study design cannot verify that participants followed these instructions. It is also possible that some participants may have found participation in the study to be burdensome, since participation could take up to one hour. However, majority (n=27) of our sample completed the experimental sections of the study in 30 minutes or less, suggesting less participant burden that anticipated. It is important to note that this completion time calculation does not include the time it took participants to review the eConsent forms. We also did not ask the participants directly if they found participation to be a burden. Therefore, the factor of participation burden on participants remains largely unexplored and may have influenced the results.

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Results of our study can be interpreted within the body of existing literature related to the post-mTBI recovery, as it adds to the growing literature exploring the role of affective symptoms and communication and cognition on physical recovery and resuming participation in society after injury. Largely, the existing qualitative studies in mTBI have focused on general recovery patterns and the subjective experience of individuals affected. In Snell et al. (2017) a qualitative case control study investigating patient perspectives on mTBI recovery, the study team found that regardless of recovery status, understanding the injury was important to recovery. Themes such as social support, validation and reassurance were correlated with what they coined as a

"path to wellness" after mTBI. Snell et al. (2020) used a questionnaire and thematic analysis of qualitative interviews to develop a conceptual model of recovery. This study found that individuals with mTBI experienced heightened feelings of uncertainty; this finding correlated with high levels of anxiety and confusion. One participant described mTBI recovery as "up and down, slow and long." The authors posited that one strategy to combat this problem is developing tailored, symptom-specific education about recovery, delivered by responsive clinicians.

Results of our study are also in line with Brunger et al. (2014) qualitative study using semi-structured interviews of 16 military personnel in the UK. Thematic analysis was used to analyze issues related to adjusting to persistent symptoms after injury. The study team described their findings in a linear fashion using the following terms 1) onset, 2) symptom experience 3) recovery and 4) acceptance. Participants in this study reported communication issues similar to those found in the current study. One participant stated, "In conversation, I'd completely forget words, completely forget sentences." Other participants reported difficulty with cognition, characterized by poor concentration, reduction in cognitive capacity and often participants did not realize these shortcomings until they were required to perform a familiar, yet complex cognitive task. So, while this study showed evidence of communication and cognitive report after mTBI, there is limited generalizability due to the specific study sample (military personnel in the United Kingdom) investigated.

Overall Conclusions and Future Directions

Our study adds to the existing literature base because of the unique focus of the survey: cognitive-communication skills after mTBI. The online survey format effectively provided a snapshot view of the experience of individuals living with chronic mTBI however, further, more

in-depth investigation is necessary. Themes such as the effect of communication skills on psychosocial adjustment including the consequences of self-isolating behaviors on employment-related activities and academic performance are important to consider in future study designs. Future studies examining cognitive-communication problems and their functional and psychosocial consequences via in-depth interviews (where symptoms and context can be clarified) is warranted and would greatly complement these preliminary findings. In conclusion, results of this study underscore the importance of monitoring and addressing not only physical but cognitive-communication symptomatology in this vulnerable and underserved population.

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717 DATA AVAILABILITY STATEMENT
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719 The datasets generated during and/or analyzed during the current study are not publicly
720 available due to ethical reasons but are available from the corresponding author on
721 reasonable request.
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