An electronic survey about college experiences after traumatic brain injury

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Abstract. For many with traumatic brain injury (TBI), going to college is a realistic goal; however there is little documentation of the challenges faced by those with TBI who attend college. The primary purposes of this study were to document the academic challenges (studying, in-class experiences, time management, psychosocial aspects) reported by adults with TBI, and to investigate relationships between these challenges and the physical, cognitive and psychosocial consequences of TBI. An electronic anonymous survey was distributed. Of the 35 respondents with TBI, nearly all reported the need to review material more and a majority reported that others do not understand their problems. In-class experiences of being nervous before tests, forgetting what is said in class, and getting overwhelmed in class were also reported by a majority. Those who reported more physical, cognitive and psychosocial consequences of their injury also identified more academic challenges as well, although cognitive consequences alone predicted academic challenges better than all of the consequences combined. Psychosocial aspects also predicted academic challenges to a lesser extent. In spite of these findings, nearly half of the respondents had not heard of or had never accessed campus disability services. To develop effective on-campus service delivery models, additional research is needed to understand why students do or do not make use of existing services.

Keywords: College, post-secondary education, study skills, cognition, psychosocial, services, higher education

1. Background

Prior to the 1970’s, relatively few students with moderate-to-severe TBI attended college. Due in large part to passage of the Individuals with Disabilities Education Act (IDEA, Public Law 108–446), the Americans with Disabilities Act (ADA), Section 504 of the Rehabilitation Act of 1973, and their international equivalents, many students with TBI now have the opportunity to pursue post-secondary education. These laws require colleges and universities that receive federal assistance to provide accommodations and auxiliary aids and services that will allow students with disabilities to participate fully in academic life. As a result, students who sustained TBI before, during, or after college have the potential to attend. There are, however, no empirically based guidelines for how to educate college students with TBI. As a first step in developing guidelines, this paper reports the findings of an electronic, anonymous survey that was designed to: 1) elicit descriptive academic information about the impact that TBI has on adults who go to college, and; 2) to describe the services that adults have utilized prior to or while attending college after a TBI.

1.1. Challenges faced by students with TBI

Students who attend college with brain injury can be divided into three groups: those who were injured as children or adolescents and enter college as freshmen; students injured while attending college; and adults who cannot return to their pre-injury work and need to retool or switch careers [16]. Although these three groups are diverse in their needs and characteristics,
and the injury itself results in heterogeneous impairments, there is preliminary evidence that cognitive impairments and poor post-injury adjustment are in general associated with lower academic performance [1,2, 5,12,13]. Johnstone et al. [6] described six young students with TBI. Among this group, those with significantly impaired cognition had limited academic success as they transitioned to college. Similarly, Stewart-Scott and Douglas [15] found that 10 young adults with severe TBI who were in college reported a variety of academic challenges that were related to their cognitive, psychosocial and physical problems. The majority reported expending more effort in studying, a reduction in extracurricular activities, changes in relationships with peers, and a lower grade point average than prior to their injury. This occurred even after waiting to return to school an average of 11 months while receiving rehabilitation services that included a hospital to school transition team.

It is not only students with severe TBI who face challenges returning to college. Studies of college students with mild TBI (mTBI) show that some effects linger and may interfere with academic performance. From a written survey of 1079 college students, LaForce and Martin-McLeod [7] found that 39% had sustained a mTBI. Among these students there was a higher incidence of physical symptoms (e.g. headaches, fatigue), cognitive impairments (e.g., memory, attention) and psychosocial problems (e.g., aggression, depression, reduced frustration tolerance). In a large epidemiological study, Gerberich et al. [3] compared 99 college students with TBI (most with mTBI) to students who had been hospitalized for disorders not affecting the brain. Fewer female students with TBI returned to college than those without injury and than male students with TBI, and had lower GPAs compared to others when no-pass credits were included. In another study that included testing and self-report, cognitive impairments resolved relatively quickly for 79 college freshmen who had sustained mTBI as children or adolescents, although these students reported more emotional distress than non-injured students [10]. Thus, whereas cognitive abilities are likely predictors of academic performance in college, psychosocial factors appear to play an important role as well, even for those with mTBI.

1.2. Services for students with TBI

In theory, students with TBI-related disabilities may receive the same kinds of academic accommodations available to other students with disabilities, such as note-takers, additional time to complete assignments and exams, a quiet room to take exams, and the ability to audio-record lectures. Only one study to date, however, has provided empirical data on how these services are delivered to college students with TBI. Harris and DePompei [4] conducted a telephone survey of the Office of Disability Services (ODS) in each of 74 colleges and universities in Ohio. Less than 9% of colleges identified TBI as a diagnostic category in disability services manuals, 38% identified students with TBI as a specific group, 39% had counselors who were qualified to work with students with TBI, and the route for students with TBI to access services was unclear based on their review of disability manuals and interviews. A reduced course load was the most common recommendation, which extends the time to complete the degree and increases the cost of education. Like other students with disabilities, students with TBI had to self-identify and advocate for themselves to access services, something with which they might have no prior experience. Furthermore, counselors reported that students with TBI were very likely to need specific academic and psychological support or counseling. Thus, the majority of campuses were ill-equipped to provide services for the unique needs of students with TBI and the route for accessing services on campus was unclear. To develop appropriate and accessible programs there is a need for more information from the students’ perspective about use of and satisfaction with campus services.

1.3. Purposes of the present study

The primary purpose of this study was to elicit information from students with TBI about their college experiences. We were particularly interested in how students perceived their academic skills and performance, and if they thought these were related to the effects of their injury. We hypothesized that those who reported more lingering effects of TBI would also report more changes in academic skills and performance. A secondary purpose was to document the support and services that students received. Our experience suggested that many students would have had no experience with campus-based disability services.
2. Methods

2.1. College Survey for Students with Brain Injury (CSS-BI)

To test the two study hypotheses we created a survey of 8 sets of questions that could be anonymously accessed on-line through the survey engine surveymonkey.com. The first and second authors drafted the survey’s questions and the third author provided feedback. To create the questions, the authors drew on over 35 years of combined clinical experience with TBI and the experiences of college students with TBI with whom they had worked. Additionally, other surveys including The Awareness Survey [14] and the Mayo-Portland Adaptability Inventory [9] were reviewed for content to ensure that the present survey included physical, cognitive, and psychosocial domains that are known to be problematic after TBI. Disability student service specialists who work with students with brain injury also provided input on the survey. Finally, two university students with brain injury provided early feedback on the content and clarity of the questions, and indicated that the survey should take no longer than 20 minutes to complete.

The eight sets of questions on the CSS-BI include yes/no, multiple choice, open-ended and Likert rating scale answer formats. Questions 1 and 2 asked about the type and history of the brain injury (e.g., traumatic brain injury, tumor, stroke) and the age when the injury occurred. Respondents also answered questions about the circumstances surrounding their injury (e.g., were you unconscious at the time of your injury, were you hospitalized).

Questions 3 and 5 were designed to elicit perceptions of the effects of the brain injury. For Question 3, respondents indicated if they had experienced any of the 16 physical, cognitive and psychosocial symptoms listed, and if they had received therapy for that effect. For Question 5, they indicated the degree to which they agreed with statements about their academic college challenges since brain injury using a 5-point Likert rating scale from strongly disagree (1) to strongly agree (5). They were also asked about their interest in getting academic help from a brain injury specialist and their interest in meeting other students with brain injury. The 13 statements could be organized into 4 categories: studying, time management, in-class experiences, and psychosocial experiences. Items in Questions 3 and 5 were presented randomly to guard against order effects, and had no topic headings (e.g., physical consequences, studying) so as not to bias responses.

Three sets of questions were designed to obtain information about the therapy and services that students had received both as patients and as students. In Question 4, respondents were asked if they had completed, were currently in, or had ever received individual therapy types, including physical therapy (PT), speech or language therapy (ST), occupational therapy (OT), vocational counseling (voc rehab), psychological counseling or a support group (counseling), or other counseling/therapy. Question 6 asked, “Since you have been in college (or when you were in college) did you use the following services because of your brain injury?” Respondents used a 7-point Likert scale to identify their use of services (never heard of it, heard of it but never used, once, occasionally, sometimes, pretty often, all of the time). Nine service organizations were listed: Campus Disability; Campus Veterans; Campus Counseling and Campus Medical Services; the VA Medical Center; a local outpatient rehabilitation program; the State Brain Injury Association; State Vocational Rehabilitation Services and; other hospital or rehabilitation services. Question 7 asked, “For any service that you have used at least once, please tell us how useful you found the service;” and allowed respondents to rate each service using a 4-point Likert scale (completely useless, somewhat useless, somewhat useful, and extremely useful).

At the end of the survey, participants were asked about changes since their brain injury in six domains: employment, academic status, academic major, career goals, the college attended, and living arrangements. These were yes/no questions, followed by a request for an explanation of each “yes” response.

2.2. Distribution and consent

The first page of survey was the consent form approved by the Institutional Review Board for Human Subjects at the University of Minnesota. At the end of the consent form, participants were asked comprehension questions about the survey, its use, and anonymity of responses. Only surveys from individuals who indicated that they had authorization to sign legal documents were kept and analyzed. Individuals were given the opportunity to provide an email address if they were wanted to participate in a drawing for an Amazon.com $30 gift card.

The CSS-BI was distributed on-line through several electronic avenues, including the University of Min-
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Minnesota Disability Student Offices monthly electronic newsletter, the Brain Injury Associate of Minnesota (BIA-MN) Headlines electronic newsletter, as well as links sent to researchers and clinicians in Kansas and Wisconsin. All responses were anonymous.

3. Results

3.1. Sample population: Reported type and history of injury

Forty-seven individuals began the on-line survey. Data from eight individuals were excluded because: 1) the participant answered no questions or only the first question after consenting, or; 2) the participant indicated that he or she did not have authorization to sign legal documents. Of the 39 students who responded to the survey, 35 (89.7%) reported having a TBI, of whom 8 (22%) reported having a TBI plus other neurological problems (e.g., stroke, encephalitis, brain tumor) or learning disabilities. Of the four individuals who reported something other than TBI, three reported having a brain tumor and one reported having brain surgery for an Arnold Chiari malformation. Only the responses from the 35 respondents with TBI were included in the remaining data analyses.

Twenty-five of the respondents with TBI (71.4%) reported that they had sustained their injury after age 18 years. Seven (20%) were injured between ages 12 and 18 years and 2 were injured between birth and age 11 years. Thirty two (91%) reported being hospitalized post-injury, and the average estimated length of stay was 80 days ($SD = 96.3$). Eighty percent (28) reported being unconscious, 5 said they were not unconscious, and 2 were uncertain. The average loss of consciousness (LOC) was 25 days ($SD = 31.7$), though two participants reported LOCs of 30 and 90 minutes respectively, and 2 reported "other". Twenty eight participants (80%) reported having received therapy after their TBI for an estimated average of 202 days ($SD = 141.2$), or 29 weeks. Seven (20%) reported that therapy was ongoing and one reported “other”. The vast majority (85%) reported having taken a break from college or work post-injury and the average break was 295 days ($SD = 237.2$), just over 9 months. Thirty participants (90.9%) reported that their primary disability was due to brain injury.

Individuals were also asked if they had received services from the six disciplines listed above. A majority of respondents (84.8%) had received at least one type of therapy and nearly half of respondents (45.5%) reported receiving four or five types of therapy. Seventy-six percent reported receiving OT, whereas PT, ST, voc rehab, and counseling were reported by 63 to 69% of respondents. An expected trend occurred between hospital-based rehabilitation (PT/OT/ST) and community-based services (voc rehab/counseling/other): PT, OT, and ST were each reported by more than 50% of respondents as being “past/completed,” with fewer reporting “current/ongoing” use of those therapies. Greater proportions of respondents (27% to 42%) reported the community-based rehabilitation services as “current/ongoing,” with smaller proportions (12% to 36%) stating that they had completed voc rehab, counseling, or other therapies in the past.

3.2. General effects of TBI

Individuals were asked to report their perceptions about the effects of their injury and whether or not they received therapy for that effect (see Table 1, question 3). The average number of effects was 9.69 ($SD = 3.79$, range 2 to 15). Although presented randomly to respondents, these effects are organized into three broad categories of physical/medical, cognitive, and psychosocial. Of physical/medical effects, a majority indicated that they had experienced fatigue, headaches and difficulty with their legs, whereas nearly half indicated that dizziness had occurred. Fewer than half reported getting therapy for dizziness, fatigue or headaches.

A variety of cognitive effects of TBI were reported by the majority of individuals (83% to 66%). Memory impairments and difficulty with academics were reported with the highest frequency, followed closely by organizational difficulty, problems making decisions, and impaired attention. Fewer than half perceived that they had received therapy to address these problems with the exception of therapy for memory, of which 52% reported receiving therapy.

Of psychosocial effects, nearly three quarters of the sample reported that anger and depression were effects of their injury. Broader effects of mood changes and difficulty with relationships were reported by about one-half of the respondents, whereas fewer reported difficulty maintaining friendships and very few reported substance/alcohol abuse as an effect of their injury.
Reported physical/medical, cognitive and psychosocial effects reported by adults with TBI who attended college who answered “What have been some effects of your brain injury? Please check all that apply, and indicate whether you have received therapy for each effect” (question 3) N = 35

<table>
<thead>
<tr>
<th>Effect Description</th>
<th>Experienced the effect</th>
<th>Had therapy for the effect</th>
</tr>
</thead>
<tbody>
<tr>
<td>Physical/Medical</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Fatigue</td>
<td>26 (74.3%)</td>
<td>8 (30.8%)</td>
</tr>
<tr>
<td>Headaches</td>
<td>24 (68.6%)</td>
<td>8 (33.3%)</td>
</tr>
<tr>
<td>Physical impairment: legs (e.g., walking)</td>
<td>21 (60%)</td>
<td>16 (76.2%)</td>
</tr>
<tr>
<td>Dizziness</td>
<td>17 (48.6%)</td>
<td>7 (41.2%)</td>
</tr>
<tr>
<td>Physical impairment: arms/hands (e.g., writing)</td>
<td>14 (40%)</td>
<td>12 (85.7%)</td>
</tr>
<tr>
<td>Cognitive</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Memory problems</td>
<td>29 (82.9%)</td>
<td>15 (51.7%)</td>
</tr>
<tr>
<td>Difficulty with academics</td>
<td>29 (82.9%)</td>
<td>7 (24.1%)</td>
</tr>
<tr>
<td>Organization problems</td>
<td>27 (77.1%)</td>
<td>10 (37%)</td>
</tr>
<tr>
<td>Problems making decisions</td>
<td>24 (68.6%)</td>
<td>11 (45.8%)</td>
</tr>
<tr>
<td>Attention problems</td>
<td>23 (65.7%)</td>
<td>8 (34.8%)</td>
</tr>
<tr>
<td>Psychosocial</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Anger</td>
<td>25 (71.4)</td>
<td>12 (48%)</td>
</tr>
<tr>
<td>Depression</td>
<td>25 (71.4)</td>
<td>16 (64%)</td>
</tr>
<tr>
<td>Mood changes</td>
<td>20 (57.2%)</td>
<td>11 (55%)</td>
</tr>
<tr>
<td>Difficulty with relationships</td>
<td>17 (48.6%)</td>
<td>2 (11.8%)</td>
</tr>
<tr>
<td>Difficulty maintaining friendships</td>
<td>10 (28.6%)</td>
<td>2 (2%)</td>
</tr>
<tr>
<td>Substance/alcohol abuse</td>
<td>3 (8.6%)</td>
<td>2 (66.7%)</td>
</tr>
<tr>
<td>Other (please specify)</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

More than half of those who reported depression reported receiving therapy for it, and about half of those who reported mood changes and anger reported receiving therapy for it. Very few who reported having trouble with relationships or friendships reported having received therapy for these problems, although two of the three who reported substance abuse problems received therapy.

3.3. College academic challenges after TBI

The thirteen statements about academic challenges were presented randomly to each individual (see Table 2, question 5). Respondents used a 5-point Likert rating scale to report the degree to which they agreed or disagreed with each statement. Eleven respondents used 5 different ratings, 13 used 4 different ratings, and 9 used 3 different ratings, demonstrating that no one used the scale in a binary manner.

To determine if respondents generally agreed or disagreed with each statement, “strongly agree” and “agree” were combined into “agree”, and “disagree” and “disagree strongly” were combined into “disagree” and treated in a binary manner. Respondents reported an average of 7.72 (SD = 2.85, range 2 to 12) academic challenges, with some reporting very few and others reporting many. Nearly all respondents (97%) reported that they had to review material more than they had pre-injury, and about three-fourths indicated that others did not understand their problems. More than half reported being nervous before tests, being overwhelmed when studying, having trouble paying attention in class or studying, procrastinating, not understanding assignments, forgetting what was said in class, having trouble managing time, and having fewer friends.

We also inquired about respondents’ interest in receiving academic assistance and meeting other students with brain injury. Two-thirds indicated that they would be interested in getting assistance and just over half indicated that they would be interested in meeting other students with brain injury.

3.4. Relationships between reported TBI effects and academic challenges

Relationships between the physical, cognitive and psychosocial effects of TBI and academic challenges were examined with regression analyses. The total number of effects was regressed against the number of academic challenges reported (1 = strongly agree/agree, 0 = disagree/strongly disagree), revealing that the total number of effects accounted for 33% of the variance of academic challenges [F(1, 31) = 15.47, p = 0.0004] (see Fig. 1). That is, there was a significant positive correlation between injury effects and academic challenges. Additionally, the total number of effects was regressed against the sum of Likert ratings (strongly disagree = 1; disagree = 2, neither agree nor disagree = 3; agree = 4; strongly agree = 5), a measure of the certainty with which they agreed.
Table 2
College academic experiences reported by adults with TBI who answered “To what extent do you agree with each of the following statements about your experience as a college student since your brain injury?” (question 5) N = 33

<table>
<thead>
<tr>
<th>Study</th>
<th>Strongly disagree</th>
<th>Disagree</th>
<th>Neither agree nor disagree</th>
<th>Agree</th>
<th>Strongly agree</th>
</tr>
</thead>
<tbody>
<tr>
<td>Strongly Disagree</td>
<td>Neither agree</td>
<td>Agree</td>
<td>Strongly</td>
<td>disagree</td>
<td>nor disagree</td>
</tr>
</tbody>
</table>

Studying
I have to review material more than I used to. | 1 (3.0%) | 0 | 0 | 12 (36.4%) | 20 (60.6%) |
I get overwhelmed when studying. | 1 (3.0%) | 3 (9.1%) | 7 (21.2%) | 15 (45.5%) | 7 (21.2%) |
I have trouble paying attention in class or while studying. | 4 (12.1%) | 2 (6.1%) | 7 (21.2%) | 13 (39.4%) | 7 (21.2%) |
I don’t always understand instructions for assignments. | 3 (9.1%) | 5 (15.2%) | 4 (12.1%) | 10 (30.3%) | 11 (33.3) |

Time Management
I procrastinate on things I need to do. | 3 (9.1%) | 6 (18.2%) | 2 (6.1%) | 14 (42.4%) | 8 (24.2%) |
I have trouble managing my time. | 2 (6.1%) | 5 (15.2%) | 8 (24.2%) | 9 (27.3%) | 9 (27.3%) |
I have trouble prioritizing assignments and meeting deadlines. | 4 (12.1%) | 6 (18.2%) | 9 (27.3%) | 8 (24.2%) | 6 (18.2%) |
I am late to class. | 15 (45.5%) | 8 (24.2%) | 6 (18.2%) | 3 (9.1%) | 1 (3.0%) |

In Class Experiences
I get nervous before tests. | 1 (3.0%) | 2 (6.1%) | 7 (21.2%) | 13 (39.4%) | 10 (30.3%) |
I forget what has been said in class. | 1 (3.0%) | 3 (9.1%) | 8 (24.2%) | 11 (33.3) | 10 (30.3%) |
I get overwhelmed in class. | 4 (12.1%) | 4 (12.1%) | 9 (27.3%) | 11 (33.3) | 5 (15.2%) |

Psychosocial
Others do not understand my problems. | 1 (3.0%) | 2 (6.1%) | 6 (18.2%) | 14 (42.4%) | 10 (30.3%) |
I have fewer friends than before. | 5 (15.2%) | 4 (12.1%) | 7 (21.2%) | 10 (30.3%) | 7 (21.2%) |

Interests
I would be interested in getting individualized academic help from a brain injury specialist. | 1 (3.0%) | 4 (12.1%) | 6 (18.2%) | 8 (24.2%) | 14 (42.4%) |
I would be interested in meeting other college students with brain injury on campus. | 2 (6.1%) | 1 (3.0%) | 12 (36.4%) | 8 (24.2%) | 10 (30.3%) |

Other (please specify)

Fig. 1. The relationship between the total number of effects related to TBI (physical, cognitive and psychosocial) and the reported number of academic challenges.

with statements about academic challenge. There was a similar, highly significant relationship between the two [R² = 0.33, F (1, 31) = 14.96, p = 0.0005]. That is, students who reported more effects tended to agree more strongly with the academic statements.

To explore the possibility that physical, cognitive and psychosocial effects contributed uniquely to academic challenges, regression analyses were conducted by type of effect. The number of cognitive effects accounted for 46% of the variance of academic challenges [F (1, 31) = 25.98, p = 0.0002], and the number of psychosocial effects accounted for 16% of the variance in academic challenges [F (1, 31) = 5.87, p = 0.02]. The relation of physical effects to academic challenges was not significant [R² = 0.05, F (1, 31) = 1.58, p = 0.22] .

3.5. Use and evaluation of services and support

Respondents were asked about their use of on- and off-campus resources, which was followed up with a question about the usefulness of each resource (see Ta-
Table 3
Reported Therapy and Other Services after TBI of those who answered “How often have you used the following services BECAUSE of your brain injury”? (question 6)

<table>
<thead>
<tr>
<th>Service</th>
<th>Never heard of it</th>
<th>Heard of it but never used</th>
<th>Once</th>
<th>Occasionally</th>
<th>Sometimes</th>
<th>Pretty often</th>
<th>All the time</th>
</tr>
</thead>
<tbody>
<tr>
<td>Campus Disability Services (29)</td>
<td>7 (24.1%)</td>
<td>6 (20.7%)</td>
<td>1 (3.4%)</td>
<td>3 (10.3%)</td>
<td>4 (13.8%)</td>
<td>1 (3.4%)</td>
<td>7 (24.1%)</td>
</tr>
<tr>
<td>Campus Veterans Services (31)</td>
<td>15 (48.4%)</td>
<td>16 (51.6%)</td>
<td>9 (29.0%)</td>
<td>15 (48.4%)</td>
<td>3 (9.7%)</td>
<td>2 (6.5%)</td>
<td>2 (6.5%)</td>
</tr>
<tr>
<td>Campus Counseling Services (31)</td>
<td>7 (22.6%)</td>
<td>17 (54.8%)</td>
<td>1 (3.2%)</td>
<td>5 (16.1%)</td>
<td>1 (3.2%)</td>
<td></td>
<td>1 (3.2%)</td>
</tr>
<tr>
<td>Campus Medical Services (31)</td>
<td>6 (19.4%)</td>
<td>24 (77.4%)</td>
<td>15 (48.4%)</td>
<td>16 (51.6%)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>VA Medical Center (31)</td>
<td>6 (19.4%)</td>
<td>24 (77.4%)</td>
<td>15 (48.4%)</td>
<td>16 (51.6%)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Local rehabilitation program (32)</td>
<td>7 (21.9%)</td>
<td>16 (50.0%)</td>
<td>1 (3.1%)</td>
<td>3 (9.7%)</td>
<td>2 (6.5%)</td>
<td>1 (3.1%)</td>
<td>4 (12.5%)</td>
</tr>
<tr>
<td>State Brain Injury Association (30)</td>
<td>6 (20.0%)</td>
<td>7 (23.3%)</td>
<td>2 (6.9%)</td>
<td>4 (13.8%)</td>
<td>2 (6.9%)</td>
<td>3 (10.3%)</td>
<td>5 (16.7%)</td>
</tr>
<tr>
<td>State vocational rehabilitation services (29)</td>
<td>5 (17.2%)</td>
<td>7 (24.1%)</td>
<td>3 (9.7%)</td>
<td>10 (30.0%)</td>
<td>3 (10.0%)</td>
<td>1 (3.1%)</td>
<td>6 (20.7%)</td>
</tr>
<tr>
<td>Other hospital or rehabilitation services (23)</td>
<td>4 (17.4%)</td>
<td>9 (39.1%)</td>
<td>2 (8.7%)</td>
<td>1 (4.3%)</td>
<td>2 (8.7%)</td>
<td>5 (21.7%)</td>
<td></td>
</tr>
</tbody>
</table>

Nearly half of respondents (13 of 29, 44.8%) had never used campus disability services, and 24.1% (7 of 29) reported using them “all the time.” None of the survey’s respondents had used campus veterans’ services, though one did report using the local VA medical center “pretty often.” Use of campus counseling and campus medical services was reported by 22.7% (7 of 31) of respondents each; of those, most contacts were infrequent. A greater distribution occurred for community services: 28% (9 of 32) of respondents reported using a local rehabilitation service, with 12.5% (4) stating they used it “all the time.” The state brain injury association and vocational rehabilitation were also more widely used, with 56.7% (17 of 30) and 58.6% (17 of 29) of respondents respectively using these resources at some point; 33% (10 of 30) and 31.0% (9 of 29) either “pretty often” or “all the time”. Other hospital and rehabilitation services were also used by 43.4% (10 of 23) of respondents, 21.7% (5) of whom used these services “pretty often”. Overall, respondents appeared to be better informed about community services than campus services: on average, 31% of participants had “never heard of” each campus service, while only 19.2% had “never heard of” each community resource.

3.6. Life changes after TBI

Six questions were asked about major or significant changes since the participant’s injury. Eighty percent (24 of 30) reported changing their employment since their injury and 56.3% (18 of 32) reported changing their career goals. Academically, 67.7% (21 of 31) reported a change in their academic status, 44.4% (14 of 32) reported changing their academic major and 32.5% (11 of 34) switched colleges. Forty-four percent (14 of 32) reported that they had moved since their injury.

All respondents (100%) provided explanations for each of these changes. As we were interested in determining if the changes were perceived as being related to the TBI, each explanation was coded as “negative and related to brain injury”, “positive”, or “unable to determine or not related to brain injury”. For example, going from “full-time employed to employed part-time or unemployed because of disability” would be coded as “negative and related to brain injury”, whereas “moving across town” would be coded as “unable to determine or not related to brain injury”. The first and second authors independently coded all explanations. Point-by-point inter-rater reliability was 82.4% and disagreements were resolved by discussion. The explanations for switching majors, changing colleges and changing residence were uninterpretable and are not reported here. Negative changes related to brain injury accounted for 69% (18 of 26) of the explanations for changes in work, whereas for 26.9% (7) explanations it was not possible to determine the relation to brain injury. Most respondents reported changing from working full time to working part-time, being unemployed or being unable to work at the same level as prior to their injury. Eighty-one percent (17 of 21) of the explanations for a change in academic status were negative and related to brain injury disability. Most of these changes involved taking a reduced course load, taking time off from college, or attending college part time after the injury. Forty-four percent (8 of 18) of the explanations for changing career goals were clearly related to the participant’s brain injury disability; however for 50% (9) of the explanations we were un-

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*Not all participants responded to each item and items were excluded if respondents rated a service they had not used; this resulted in different numbers of responses for each item, ranging from 23 to 32.*
able to determine if the change was due to brain injury. One individual reported going on to own his/her own company after brain injury, the only response to this question set that was coded as “positive.”

4. Discussion

The purpose of this study was to document the perceived effects of TBI and academic experiences reported by adults who had attended college after sustaining a TBI. An additional purpose was to describe the services these individuals reported having received as college students. Most of the study respondents reported having sustained their injury as adults. Most appeared to have sustained severe injuries, given that the reported average length of hospitalization was 2 1/2 months, the average length of unconsciousness was 25 days, participants had received therapy for an average of 202 days, and they reported taking a break from college and/or work for an average of 9 months. There were no restrictions on participation according to severity, so individuals with mild or moderate injuries also may have been included.

The majority of respondents reported a range of physical, cognitive, and psychosocial effects of their injuries. These were consistent with those of participants in the earlier study by Stewart-Scott and Douglas [15], and also with the TBI outcome literature (e.g. [11]). The most common complaints were of memory problems and academic difficulty, with a smaller but still notable proportion reporting problems with organization, decision making, fatigue, anger, depression, and headaches. Problems that had not been documented in previous research included being nervous before tests, forgetting what was said during class, getting overwhelmed in class, and importantly, that others did not understand their problems.

As hypothesized, respondents who reported more injury effects also reported more academic challenges. This was accounted for primarily by cognitive impairments, which were common among students in earlier descriptive studies as well [5–7,10]. Although it might be expected that cognitive impairments would be associated with specific changes in in-class and study behaviors, this had not been documented empirically in the previous literature. An additional novel finding was that psychosocial factors such as depression, anger, mood changes, and trouble with relationships also were related to academic challenges. This was particularly noteworthy given that psychosocial factors might be less likely to receive attention in both transition planning and campus-based services. How cognitive and psychosocial factors interact and relate to academic challenges should be addressed by further research that documents these factors through formal and informal evaluations and interviews.

A striking finding was the discrepancy between the number of students reporting problems and the number using campus-based services for students with learning disabilities. More than 80% of students reported problems with schoolwork, yet less than half had used campus disability services, and 20% claimed to be unaware of these services. Also, many students appeared to have sought treatment for depression, but few had sought counseling or other services for other changes in psychosocial networks. While the lack of use of campus-based services might be an artifact of the self-report format of this survey, it is consistent with the authors’ experience with individuals who sustain a TBI either just before or during college or university. For many of these individuals, there is a gap of weeks, months, or years between rehabilitation and full- or part-time return to college, so transition planning does not include formal links with disability services at the target institution. Students may enroll with the belief that they will need minimal or no support, and only discover the long-term effects of their injuries when they begin to struggle in class. We often meet these students serendipitously, when they enroll in courses or participate in research studies, and for many this is their first connection with campus services.

The requirement that students with TBI must self-identify and the absence of clear routes to disability services [4] also may contribute to reduced service access, particularly for students with limited awareness of their deficits. However, many with TBI were successful in school prior to sustaining their injuries but may be reluctant to be identified as “impaired,” and to access services that would set them apart from their peers. The question of how best to connect students to available campus resources is an important one for future research. The most obvious points in the clinical process for informing and assisting students in accessing services are at discharge from rehabilitation and at college orientation. Children with TBI are more likely to receive services when there is a transition team in place that guides and assists the family and school professionals in identifying appropriate services. It

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4See Glang and colleagues in this issue for a discussion of educational services and transition programs for children with TBI.
is unclear the extent to which adults receive transition services, but is open for future investigation. Individual differences may also play a role in how students seek support, illustrated by the difference in respondents’ interest in receiving individualized academic help versus meeting with other college students with brain injury. Two-thirds of respondents indicated an interest in receiving individualized academic help, and just over half indicated interest in meeting other students with TBI. Yet it is unclear from this survey whether these responses coincide with preconceived perceptions of academic help versus psychosocial effects of TBI. Additionally, difference in age at the time injury may also be a factor in whether or not students access academic services. Those who are injured as mature adults and who return to college for retraining, may be more likely to self-advocate for services than younger counterparts whose desire is to fit in with peers and have a “typical” college experience.

A final factor that might play a role in access to services is the expertise of disability services providers in the area of TBI. Based on the finding that less than half of college disability specialists were qualified with work with students with TBI and only 9% of programs identified TBI as a unique disability [4], traditional academic accommodations and strategies are not necessarily tailored to the needs to students with TBI. This in turn might discourage students from seeking services more than once, or at all. To develop effective service delivery models, it will be critical to conduct further research into understanding why students do or do not make use of existing services.

The role of off-campus services and support organizations warrants further investigation as well. A relatively high proportion of respondents used services such as the Brain Injury Association (although this may reflect that the survey was distributed through the BIA-MN on-line newsletter), and the majority of respondents rated their experience as useful. These services play a critical role for many individuals with TBI, and if they are useful to students then it might be beneficial to create student-specific services through such community organizations.

4.1. Limitations

As with any survey study, the principal limitation of these data is that there was no objective documentation of participant reports. This could be particularly problematic for individuals with TBI, who may be unaware of their deficits (e.g. [14]). This bias, however, would lead to under-reporting of deficits rather than over-reporting, and the significant correlations between reported cognitive and psychosocial effects and academic challenges suggest these responses were valid. Current research is underway that focuses on the validation of survey responses with standardized testing combined with semi-structured interviews.

A second potential limitation of the study was sample bias. Individuals who were unsuccessful in college or university might be less likely to respond. Those with mild TBI also might not respond, assuming that the questions did not apply to them. We attempted to address this by distributing the survey widely, and respondents gave a wide variety of responses, but it is not possible to avoid this potential for bias in a self-selected sample.

4.2. Summary

The results of this study document some of the challenges faced by students with TBI in post-secondary education, and suggest areas in which future research is needed. In particular, it would be informative to obtain cognitive test data and injury information on participants, to better characterize the sample, and to interview respondents to learn more about their individual experiences. For example, it is possible that depression and anger and not just cognitive and memory impairments contribute to the need for reviewing material more, getting nervous before exams, being overwhelmed in class, or forgetting what is said in lectures. It also would be useful to learn more about existing services at individual college campuses, and which of these benefit students with TBI. Ultimately, this information can lead to the development of systems to keep college students with TBI from “falling through the cracks” and failing courses or dropping out of college altogether. This is especially important considering that unlike ones employment history which can be expunged after 5 years, educational transcripts remain on file forever.

References


