

REVIEW

Considering the student perspective in returning to school after TBI: A literature review

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Abstract

Primary objective: This paper aims to (i) present a systematic review of the literature exploring students' perspectives of their educational experiences following TBI and (ii) identify important themes arising from this material which may assist clinicians and educators in improving support services and outcomes for their clients.

Methods and procedures: A systematic search was conducted of appropriate databases as well as manual searches of key references and expert authors. Search criteria included: (i) presence of TBI and (ii) student as informant. No restrictions were placed on severity or age at injury, type of schooling, time since injury or return to school.

Main outcomes and results: Search results identified over 400 articles, eight of which met the relevance criteria. These studies showed large variations across informant characteristics and research designs. Despite this, a number of recurring themes outlining the students' perspectives were evident. These included: 'difficulties identified', 'impact of difficulties on study', 'things that helped' and 'things that were not helpful'.

Conclusions: Whilst some aspects of the students' stories resonated with the expert opinions widely published, there were further important insights. In particular, themes related to the concept of identity suggest that clinical approaches need to broaden and include tools that can assist students in the reconstruction of their lives.

Keywords: Education, rehabilitation, community integration, outcome

Introduction

Rehabilitation workers and educators have long recognized the importance of school participation for young people. School age, particularly in the secondary and tertiary years, is a period of high risk for sustaining a serious TBI. Males are estimated to be twice as likely to be injured as females, perhaps reflecting their risk-taking behaviour at this stage of life [1]. Within the US each year, more than 124 000 people sustain a TBI severe enough to expect long-term disabilities [2]. In the 15–24 year old age group, incidence of TBI causing hospitalization is 135 per 100 000 persons, although at least 75% of these injuries are classified as mild [3]. Australian data shows a similar incidence of moderate and severe

injury estimated to be 11–12 cases per 100 000 persons. This incidence rate results in ~325 new cases of moderate or severe injuries each year within the secondary and tertiary education age group [4–6].

School participation trends in western societies reflect an increasing social pressure to remain within the educational system for longer periods. Across Australia, data from the Australian Bureau of Statistics [7] shows that between 2000 and 2010, the proportion of 25–64 year olds with a beyond high school qualification rose from 49% to 63% of the population. Coupling the high rate of serious TBI within the school age population with the increasing likelihood of needing to return to the education

system following injury underlines the importance of ensuring that support systems adequately address students' needs for school re-entry and their ongoing participation within the education sector.

The literature describing outcomes after TBI for both paediatric and adult survivors shows that TBI is a complex injury which results in a mixture of well-defined common problems but with heterogeneity in its impact on individuals [8]. Longitudinal studies consistently show a range of persisting difficulties spanning cognitive, behavioural, emotional, social and physical consequences for those who sustain moderate or severe injuries. Factors such as pre-injury demographics, personality, intellectual function and academic skills will affect the long-term impact of the injury. In addition other factors such as injury severity, age of injury and the individual pattern of persisting difficulties will affect the person's ability to resume participation in life roles across academic, sport and leisure, community, social, family and work activities [9–16]. Given this complexity, it is not surprising that the process of returning to school after TBI continues to provide challenges in understanding how the multiple factors may affect an individual student's participation.

The journey for students returning to school crosses many disciplinary boundaries. Early management requires a focus on medical intervention and rehabilitation but then moves on to an educational framework potentially involving both mainstream and special education resources. As described by Ylvisaker et al. [8], the early approach to school re-entry was seen as a 'time limited, hospital-to-school transition' (p. 101). Recent approaches, however, encourage workers in the field to adopt a more holistic view that includes collaboration across all sectors to provide ongoing assistance to students over time [17]. Incorporating the perspectives of both rehabilitation staff and educators has enabled a comprehensive set of management principles to be established [18].

In comparison to the extensive body of 'expert' literature documented from the perspectives of teachers, parents and rehabilitation workers, there are relatively few published studies where students have been invited to share their own experiences and perspectives of their school participation following TBI. It was not until Todis et al. [19] described the educational experiences of students that these perspectives were examined. In a book chapter the authors presented rich and detailed data from a range of informants including students, parents and a variety of school professionals. In describing their research, Todis et al. [19] relied heavily on detailed observational reports to provide insights into students' everyday school life. However, apart from these descriptions, the students' voices were only

directly presented in one concluding quote. This representation of the student perspective by a single quote was in marked contrast to the representation of the 'expert' perspective, which was captured in 26 quotes: 16 from educational professionals and 10 from family members. At that time, this under-representation of the students' direct perspective may have reflected a general tendency of authors to exclude this perspective in reporting research findings.

Since 1997, qualitative studies exploring student experiences have increasingly appeared. This change is perhaps related to two factors: (1) the scientific community's increasing acceptance of research methods, which are able to 'obtain a more detailed and flexible understanding of individuals' beliefs, perceptions and accounts' ([20], p. 1386); and (2) the recognition that despite well-documented guiding principles to assist students with TBI in returning to school, clinicians and educators continue to be challenged by how best to support students in their ongoing participation. A rigorous review of themes arising from the students' own experiences may provide further clarity on this complex matter.

Aim

The aim of this paper is first to present a systematic review of the literature which explores students' perspectives of their educational experiences following TBI. Second, this paper aims to identify important themes arising from this material, which may assist clinicians and educators in improving support services and outcomes for their clients.

Method

Identification of relevant literature commenced with a systematic search of appropriate databases for material from 1980 to Nov 2010: OVID (including Medline, Embase, PsycInfo); CINAHL; CSA Illumina (ERIC, Linguistics and Language) Proquest, Informit Health and Education. Additional manual searches of reference lists of key journal articles and articles from expert authors in the area were completed. Further checks were made by using the 'find similar' search on Ovid databases for previously identified articles.

Initial searches were conducted using two broad categories/concepts using subject headings and keyword searches. The first was to identify the presence of traumatic brain injury using search terms related to brain injury. No restrictions were placed on (i) severity of injury, (ii) age of injury onset and (iii) timing of data collection in relation to time

post-injury or time since return to school. The second search area focused on the student role using variants of student, school, education, school re-entry, return to study. No restrictions were placed on student age, type of educational institution or phase of study process. A third search criteria/concept was introduced to filter for the student perspective including alternatives of student participation, student experience, student engagement, student perception, student attitude. Finally, no restrictions were placed on study design. All searches were further filtered to exclude those published in languages other than English. Journal titles were scanned and abstracts retrieved for further scrutiny where appropriate. The abstracts of articles identified through the search strategy were then screened for compliance with search criteria. Articles that met these criteria were retrieved in full text and reviewed.

Results

Search results identified over 400 articles. Medline revealed 434, PsycInfo 36, Embase 11, with only single results from ERIC and Informat. After screening of titles and review of abstracts, seven articles [18, 21–26] met the relevant criteria. One further article [27] was identified after hand searching from the reference lists of included publications.

The eight identified studies showed large variations across informant characteristics, range of informants and research designs. Each of the studies is briefly described below in order of publication and a summary of comparative features is shown in Table I. Publications span a range of 13 years from 1998–2010, with more than half of these occurring in the last 5 years.

Stewart-Scott and Douglas [25] in 1998 were the first to publish research reporting predominantly on students' experiences. They completed a single semi-structured telephone interview with 13 students; three in mainstream secondary education and 10 in post-secondary settings. The student sample was drawn from consecutive admissions to a metropolitan brain injury unit in Melbourne, Australia. Only students were interviewed and data collection took place ~3 years or more post-injury. All participants sustained their injuries during their schooling years, with an age range of 15–26 years. Nine males and four females were interviewed.

Backhouse and Rodger [21] used focus groups to examine the experiences of students and/or parents about school participation and the transition into employment. The convenience sample was accessed through Brain Injury clinics of two major hospitals in Brisbane, Australia. Students in this group were 6–13 years of age at the time of injury. At the time of

data collection, four students had progressed to mainstream secondary school and three were completing secondary level distance education. Two male and four female students agreed to participate and a further five parents, whose children declined, also participated in focus groups.

Vaidya [26] completed separate in-depth interviews with four secondary students, their parents and teachers. All students were aged between 16–17 years at the time of injury and were interviewed ~1 year post-injury. Three male and one female student were interviewed. Students were approached to participate through their connection with a rehabilitation facility in Delaware.

Sharp et al. [24] interviewed eight parent and student pairs using in-depth interviews. These participants were selected due to their status as students, from a larger sample of families recruited for research from three brain injury units in metropolitan Sydney, Australia. Five students were male and three female. All students were adolescents and at mainstream secondary school at the time of injury (14–19 years) and were first interviewed ~1 year after their injury. Some parent/student pairs participated in repeated interviews between 2–5-times over a period of up to 2 years.

Kennedy et al. [23] produced an internet survey for post-secondary students who were recruited from advertisements through Disability Student Officers, a Brain Injury Association, researchers and clinicians in Kansas and Wisconsin. Students completed the questionnaire anonymously but reported their age of injury occurring from 2–19 years of age. There were 35 respondents.

Todis and Glang [27] followed a cohort of students over a period of 8 years, completing repeated in-depth interviews, observations and quantitative measures. A range of informants were interviewed including students, parents and 'knowledgeable others', with all interviews being held separately. The 33 students completing the qualitative aspect of this research study were a sub-set of a larger sample of youths with TBI living in Oregon and Washington. At the time of entry into the study, students ranged in age from 17–23 years and were transitioning from secondary school into work or post-secondary education. Age of injury ranged from 6–18 years; 18 students were male, 15 were female.

Hux et al. [22] engaged students, parents and teachers separately in single in-depth interviews to explore the study skills and accommodations used by college students. At the time of interview, the students were aged between 20–28 years. Age of TBI for these students was in the range of 14–17 years of age. Two students were male and two were female. Recruitment occurred through contact with

Table I. Summary of research papers.

Year of publication		Study	
Stewart-Scott and Douglas 1998	Consecutive admissions to metro brain injury rehab unit, Melbourne, Australia.	Backhouse and Rodger 1999	Convenience sample approached through ABI clinics of two major hospitals in Brisbane, Australia.
Recruitment of student participants		Vaidya2002	Convenience sample approached through DuPont Hospital for Children rehab facility. Delaware.
		Sharp et al. 2006	Sub-set of student participants selected from a larger sample of families recruited from three brain injury units in metro Sydney, Australia.
		Kennedy et al. 2008	Responses received following on-line distribution and advertising including Uni of Minnesota Disability Student Offices newsletter, Brain Injury Assoc of Minnesota newsletter, researchers and clinicians in Kansas and Wisconsin.
		Todis and Glang 2008	Sub-set of student participants selected from a larger sample of youth with TBI living in Oregon and Washington.
		Hux et al. 2010	Convenience sample known to researcher based at University of Nebraska-Lincoln.
		Mealings and Douglas 2010	Convenience sample approached through metro brain injury rehab unit, Melbourne, Australia.
Range of informants	Students only interviewed.	Students and family members interviewed together.	Students, parents and teachers interviewed separately.
	Students and parents included in focus groups. Mostly parents and students in separate groups.	Students and family members interviewed together.	Students, parents and 'knowledgeable others' interviewed separately.
no of student participants	13 9 male, 5 female	8 5 male 3 female	35 no gender specified
age of TBI	15–26 years	14–19 years	6–18 years
		16–17 years	2–19 years
		4 3 male 1 female	33 18 male 15 female
		7 2 male 4 female	6–13 years
		4 3 male 1 female	14–17 years
		8 5 male 3 female	14–19 years
		4 3 male 1 female	16–17 years
		4 2 male 2 female	14–17 years
		3 2 male 1 female	13–17 years

Age of student at research	18–29 years	14–19 years	16–17 years	14–19 years	18–25 years	17–23 years	20–28 years	14–20 years
Type of schooling student experienced post-TBI	3 mainstream secondary school, 10 post-secondary.	4 mainstream secondary school, 3 distance education.	All mainstream secondary school.	All mainstream secondary school.	All college (post-secondary) students.	All secondary school but 6 within self-contained programmes and 18 using Learning Resource Centres.	All post-secondary: 2 public uni, 1 community college, 1 private uni.	All mainstream secondary.
Data collection methods for student participants	Single phone interview using a 44 item structured questionnaire-quantitative and descriptive items.	Single focus groups: 1 for distance ed students, 1 for secondary students, 1 a mix of a student and parents.	Single semi-structured, in depth interview.	Repeated in depth interview between 1–5 times over a period of up to 2 years.	Single internet survey.	Repeated in-depth interviews (initially unstructured and becoming more focused as study progressed) and participant observation as well as quantitative data; over a period of up to 8 years.	Single semi-structured, in depth interview.	Single semi-structured, in depth interview.
Area of school focus	Participation	Transition	Participation	Participation	Participation	Transition	Participation	Participation

the main researcher in her role at University of Nebraska.

Mealings and Douglas [18] interviewed three male adolescent students in a single in-depth interview. The students were all secondary students at the time of their injury (13–17 years) and were interviewed at least 6 months after returning to school, which was at least 1-year post-injury. Students were recruited through a metropolitan brain injury unit in Melbourne, Australia.

Despite the methodological heterogeneity of these investigations, a number of recurring themes outlining the students' perspectives were evident across the studies. A summary of results is shown in Table II.

Student perspectives—difficulties identified

Included in all but one of the eight studies were students' self-reports of TBI-related difficulties, which continued to impact on their schooling. From the remaining seven studies, four main categories of changes emerged: cognitive, emotional, physical and psychosocial.

Cognitive difficulties. Most commonly reported cognitive changes included memory impairments [18, 22–25, 27], difficulty paying attention or concentrating [18, 22–25] and cognitive fatigue [18, 23–25]. Cognitive-communication difficulties related to understanding complex instructions, reading and listening were noted by some students [22, 24, 25]. Less commonly reported difficulties included reduced organization skills [25], difficulties making decisions [23] and unpredictability of thinking skills from day-to-day [27].

Emotional difficulties. Students often described ongoing emotional issues related to feelings of loss and difficulty adjusting to their changed situation [18, 22, 24, 27]. Reduced self-confidence or lowered self-esteem was also noted in four studies [18, 21, 24, 25]. Generalized changes to mood including mood swings or being upset more easily were reported [22, 24, 25], whilst other students described specific changes such as depression [23, 24], difficulties managing anger [18, 23], anxiety and reduced motivation [25].

Physical difficulties. The most frequently reported physical difficulty for students at school was difficulty using their dominant arm/hand [18, 22, 23, 25] followed by persisting headaches [23–25] and reduced balance [18, 22, 24]. General changes to mobility were described as an issue in two studies [23, 24]. A range of other physical difficulties

including changes to speech quality [18, 22], reduced co-ordination [25], physical scarring, sensory changes [24], dizziness and pain [22] were also noted.

Psychosocial difficulties. Feelings of being misunderstood and treated differently by others were frequently described by students across studies [18, 21–24]. These feelings were closely related to students' descriptions of difficulties finding and fitting in with friends [18, 23–25]. Some students described difficulties maintaining friendships as their pre-injury peers had moved on [22, 25] and some students raised issues of bullying and teasing [21, 24]. Other changes noted included reduced participation in extra-curricular activities [25] and substance abuse issues caused by their injury [23].

Student perspectives—impact of difficulties on study

Following on from their TBI-related difficulties; students described a range of effects on their ongoing participation at school. In relation to their course, students from within all eight of the selected articles reported that they had to change their course and/or their educational or vocational goals after their injury [18, 21–27]. At times this meant attending special education programmes either at different schools or within specialized streams at the students' existing schools [18, 21, 24, 26, 27]. Another frequently experienced issue was a need to engage in a reduced course load as a way to maintain successful participation [18, 22–27]. Some students reported wanting to leave school earlier due to their difficulties [18, 21, 24] and school avoidance [21]. For students who were injured in later stages of their educational process, a number also described a general decrease in the grades they achieved post-injury [18, 22, 24, 25].

In addition to the course changes reported above, students provided descriptions of how their TBI difficulties, in particular cognitive changes, affected their daily study-related activities. Of these the most frequently reported impact was the need to put in more effort and work harder to get the same result, making study less enjoyable [22–25, 27]. Many study activities were affected by difficulties with memory. Students described forgetting what was said in class [22, 23], needing to review material more often to remember it [23, 27] and getting into trouble including detentions due to forgetting [27]. Concentration and processing speed difficulties also affected student participation causing students to 'listen harder' and pay more attention in class [22, 23] to become overwhelmed or overloaded by information [23, 27] as well as having difficulty understanding complex information [25].

Table II. Summary of student perspectives.

Student perspectives		Stewart-Scott and Douglas	Backhouse and Rodger	Vaidya	Sharp et al.	Kennedy et al.	Todis and Glang	Hux et al.	Mealings and Douglas
Difficulties identified: Cognitive	Memory	×			×	×	×	×	×
	Attention or concentration	×			×	×		×	×
	Cognitive fatigue	×			×	×			×
	Cognitive-communication	×			×			×	
	Organization	×							
	Making decisions					×			
	Unpredictability						×		
Difficulties identified: Emotional	Feelings of loss and difficulty adjusting				×		×	×	×
	Reduced self-confidence	×	×		×				×
	Mood swings/upset more easily	×			×			×	
	Depression				×	×			
	Difficulty managing anger					×			×
Difficulties identified: Physical	Reduced motivation	×							
	Decreased use of dominant hand/arm	×				×		×	×
	Persisting headaches	×			×	×			
	Reduced balance				×			×	×
	Reduced mobility				×	×			
	Reduced coordination	×							
	Reduced speech quality							×	×
	Physical scarring				×				
	Sensory changes				×				
	Dizziness							×	
	Pain							×	
Difficulties identified: Psycho-social	Feeling misunderstood or treated differently		×		×	×		×	×
	Difficulty finding friends and fitting in	×			×	×			×
	Difficulty maintaining prior friendships	×						×	
	Bullying and teasing		×		×				
	Decreased extra-curricular activities	×							
	Substance abuse					×			
Impact of difficulties on study	Change in course, educational or vocational goals	×	×	×	×	×	×	×	×
	Special education programme		×	×	×		×		×
	Reduced course load	×		×	×	×	×	×	×
	Wanting to leave school or school avoidance		×		×				×
	Decrease in grades	×			×			×	×
	Need to put in more effort/work harder	×			×	×	×	×	
	Forgetting what was said, what to do, what was read					×	×	×	
	Having to 'listen harder'					×		×	
	Getting overwhelmed by complex information	×				×	×	×	
	Procrastination or poor time management	×				×			
	More nervous of tests					×			
	Difficulty with oral presentations	×							
	Too tired for homework				×				
	Reluctance to disclose TBI at school				×	×	×	×	
Things that were helpful	Special accommodations or consideration	×		×	×		×	×	×
	Individual strategies	×		×	×		×	×	

(continued)

Table II. Continued.

Student perspectives		Stewart-Scott and Douglas	Backhouse and Rodger	Vaidya	Sharp et al.	Kennedy et al.	Todis and Glang	Hux et al.	Mealings and Douglas
	Individual help-tutoring/aide	×		×	×		×	×	×
	Transition programme		×	×	×		×		×
	Effective planning		×	×	×		×		×
	Teacher knowledge of ABI			×	×		×		×
	Involvement in school meetings			×					×
	Student goals			×			×		×
	Strong teacher relationships			×	×			×	×
	Personal characteristics	×			×		×	×	×
	Positive attitude to school				×				×
Things that were not helpful	Not receiving help requested		×	×	×		×		
	Lack of understanding		×	×	×	×	×	×	×
	Unreasonable expectations			×	×		×		
	Difficult accessing info		×				×		

Difficulties with organization were described as procrastinating [23] and having trouble managing time [23, 25]. Students described a range of other impacts including getting more nervous before tests [23], difficulty giving oral presentations [25] and being too tired at the end of the day to get homework done [24].

Despite recognizing these multiple impacts on their studies, many students noted a reluctance to disclose their TBI and identify themselves as impaired, when first returning to school or moving on to a new programme [22–24, 27]. This reluctance to disclose at times resulted in them choosing not to avail themselves of support services existing within their educational institution.

Student perspectives—things that were helpful

Students across most studies described a range of strategies and programme modifications put into place to assist their school participation. Various forms of special consideration and special accommodations were frequently reported and included a broad range of modifications including smaller class sizes, sitting near the front of the room, provision of extra time to complete work and exams, use of scribes or notetakers and working in a distraction-free environment [18, 22, 24–27]. Students also reported that they benefited from individualized advice on improving study habits and study skills [22, 24–27]. Having a tutor and/or an integration aide was also viewed positively [18, 22, 24–27].

Students commented on a number of helpful factors related to transition periods, whether these were hospital-to-school, within school or school-to-work transitions. Many described positive effects of having organized transition programmes to

introduce them to the new structure, such as visiting friends at school before starting, meeting up with teachers or trialling an alternative programme before moving [18, 21, 24, 26, 27]. Closely-related factors were feeling like the move to school was organized and planned [18, 21, 24, 26, 27] and knowing that teachers had knowledge about TBI and the students' specific needs [18, 24, 26, 27].

In terms of ongoing participation, students reported benefits from being involved in planning meetings such as individual education plans [18, 26]. Students from three studies reported that having relevant individual goals was important [18, 26, 27]. Strong relationships with teachers and, therefore, being able to ask for individual assistance and access teacher support were also helpful [18, 24, 26, 27].

Students also commented on their own personal characteristics in helping them at school. In particular, factors such as having a positive attitude, determination to do well and motivation made a difference [22, 25, 27], as well as generally positive attitudes to being at school and wanting to fit in again [18, 24].

Student perspectives—things that were not helpful

Students identified two major barriers to resuming school participation after TBI. In all but one study, students reported that a general lack of understanding of TBI and more particularly limited awareness of the student's specific needs made being at school more difficult [18, 21–24, 26, 27]. The second significant barrier was students not receiving the help they requested including special accommodations agreed to in planning meetings not being put into place [21, 24, 26, 27]. Students were also concerned

by unreasonable expectations about their work capacity, whether these were too high or too low [24, 26, 27]. In relation to periods of transition, students identified difficulties in accessing important information about courses and where and how to get assistance [21, 27].

Discussion

In addition to the description of student experiences summarized above, several of the studies went on to provide a further level of interpretation of results to identify overarching themes or models to explain the students' participation. Hux et al. [22] found there were five 'noteworthy issues' (p. 24), which emerged from their analyses. There were similarities across students in their 'formal accommodation plans' including the common changes made to classroom settings/work (such as use of note takers, modification of test environments, provision of extra time) and 'determination to pursue goals' describing personality factors such as perseverance and tenacity, as well as having supportive networks across families and educational settings helping to work towards these goals. Significant differences were noted in students' 'use of available support strategies and accommodations', with some students using all available supports and others deciding not to pursue options. They also identified issues with 'disparities in perception between survivors and others' reflecting discrepancies between students' perception of their participation when compared to others, perhaps due to students' limited self-awareness; and 'potential for over-accommodating survivors' where students have been provided too much assistance or modifications which impacted on their ability to assess realistically their readiness for work or higher education.

In a different approach, Sharp et al. [24] presented a framework which conceptualized the return to school experience as a 'fitting in' process for adolescents after TBI. In this model, the period of 'fitting back in at school' is shown as a continuous, adjusted process between 'organizing the school return' (including actions such as teaching the teachers, organizing accommodations, educating the peers, preparing the adolescent student and parental decisions) and 'being back at school' (including consequences such as experiencing teacher responses, evaluating accommodations, experiencing peer reactions, adjusting to personal loss and parental involvement). The process of comparing and managing the 'adequate level of fit' between these two components of organizing and experiencing school is conceptualized as enabling the student to continue on at school or leave to pursue alternative options.

Mealings and Douglas [18] also described a conceptual model to capture adolescent experiences of school participation. As in Sharp et al.'s [24] model, this framework is presented as an iterative process with a dynamic, interactive relationship between a triad of key areas: 'adolescent student sense of self' (including the students' perception of the role of school, their social, educational and vocational goals and feelings), 'changes' (including internal student changes such as the TBI impairments, changes to goals; and external programme/activity-related changes such as alternative programmes or curriculum modifications, participation restrictions and new roles) and 'supports' (including the quality of relationships amongst the student and family, friends, school and rehabilitation staff; and styles of helping).

A common theme within all three of these analyses of student experiences is the importance of the students' perceptions and responses to being at school flowing from the contribution of individual student factors such as personality, feelings, emotions, personal goals and adjustment. A closer look at the remaining research papers also reveals a remarkable consistency in identifying these factors. Todis and Glang [27] described features of 'positive reframing, flexibility, and determination' as being 'associated with success in post-secondary education' (p. 262). Kennedy et al. [23] found what they described as a 'novel finding' that 'psychosocial factors such as depression, anger, mood changes, and trouble with relationships were related to academic challenges' (p. 518). This point was also made by Stewart-Scott and Douglas [25], who suggested that, although 'not examined in detail in this study', 'emotional and psychosocial changes were an important aspect of educational outcome' (p. 329). Backhouse and Rodger [21] also commented on aspects of student experiences of 'anguish and humiliation, which led to social isolation, low self-esteem' (p. 106). Finally, the students in Vaidya's [26] work identified the need for personally-relevant goals. Although the specific factors identified across these studies show variations in how they have been defined and described, what emerges is the influence of the central role played by the concept of self and related factors and its impact on students' participation at school. Given the broad range of ages sampled across this review, the centrality of this concept of self to the student experience appears to apply, regardless of the age of the student.

Discovering the importance of identity for these students is not surprising when placed in the context of the broader experiences of people with TBI. A significant body of work exists to support the fundamental role that identity construction plays in adjustment and rehabilitation following TBI [28–36].

In particular, Levack et al. [37] completed a metasynthesis of themes describing the ‘enduring experience of TBI’ which identified themes resonant to those arising from the student-related experiences. Two key areas were identified: the experience of loss and the experience of reconstructing life. Themes described to represent the experiences of loss include: ‘mind body disconnect’, ‘disconnect with pre-injury identity’, ‘social disconnect’ and a related theme of ‘emotional sequelae’ resulting from those disconnections. Themes related to the reconstruction process include: ‘reconstruction of self-identity’, ‘reconstruction of a place in the world’ and ‘reconstruction of personhood’, which can be completed using ‘internal and external resources’.

Reflecting on the descriptions of student experiences, the theme of loss identified by Levack et al. [37] is widely represented. Parallels can be drawn with the students’ descriptions of TBI impairments and the theme of mind body disconnect. Disconnections with pre-injury self are shown in students’ descriptions of their loss of educational and vocational goals, difficulty achieving pre-injury academic standards, school avoidance and wanting to leave school. Social disconnections were consistently reported by students shown in their loss of student peers, feeling left out, being misunderstood and having difficulty making friends.

Themes related to reconstruction of self [37] can also be seen in the students’ experiences, particularly emerging from the summaries of ‘things that were helpful’. Reconstruction of self and personhood are reflected in students’ positive descriptions of working toward personally-relevant goals, being a part of programmes that provide them with feelings of success and identifying new educational or vocational goals that allow them to maintain their participation in education. Similarly, themes related to reconstruction in the world occur frequently in students’ positive reflections about successful school participation. These include strong relationships with teachers, feeling supported by family and getting on with school friends.

In summarizing this review of student perspectives of their school participation, it was evident that many aspects of the students’ stories resonated with the expert opinions widely published, particularly in areas related to TBI difficulties and their impact on study skills. However, important insights that extend understanding of the student experience also emerged. Of particular significance were the themes related to the concept of identity. The impact of identity was seen both in understanding the losses for students and in recognizing the opportunities to support reconstruction of self within the educational setting.

Limitations identified in this review

The systematic review undertaken for this article revealed just eight published research studies exploring student perspectives, with none occurring before 1997. This relatively small number of studies suggests that current understanding of this issue has not yet reached saturation/sufficient maturity. Therefore, it is necessary to consider the themes and issues highlighted in this review as preliminary indicators that require further investigation.

Due to the variability in study methods across these studies it is possible that students were limited in their ability to provide relevant information. Data collection in some studies was restricted to more structured responses. This procedure may have influenced either the number of issues raised by these participants or constrained their interpretations of effects upon participation. In addition the large range in student ages and educational contexts from primary through to post-secondary participation suggests that particular issues may be of greater concern for one group of students than another and therefore affect the frequency in which factors were seen within group results. The small sample sizes prevent a more selective investigation of these issues.

Of particular concern for this review was the difficulty of identifying the students’ voices in study designs where a range of informants was used. In particular, results presented by Sharp et al. [24] and Todis and Glang [27] showed a holistic interpretation of issues without separately delineating the informant. Unlike the metasynthesis undertaken by Levack et al. [37], where they were able to eliminate all research projects, which combined informant voices; the very small number of articles available for this review meant that selection criteria were not applied to eliminate this kind of study. Care was taken by the authors of this review to extract the students’ experiences and thoughts where multiple informants were identified, but there may still be some contamination of other perspectives.

Conclusion

From this systematic review considering the students’ perspectives of school participation after TBI it was interesting to note the recurring themes found within the student stories, despite the large variations in several parameters across the studies. Whilst data collected from some investigations were restricted by the structure of questionnaires or online survey, others provided opportunity for students to provide in-depth information through interviews and focus groups. Some studies collected data at a single time point, either whilst the student was studying or as a retrospective review. Other studies allowed

longitudinal engagement. Some studies primarily focused on the transition away from school. However, despite these significant differences, the students' views showed remarkable consistency across all eight studies. More significantly, it was clear that the students' voices were able to provide a further level of detail to inform understanding of the return-to-school experience.

In addition to the well-explored and documented recommendations regarding practical implementation of return-to-school processes available in the literature, the students' own descriptions of their school experiences post-TBI suggest that for participation to be maintained and successful, the clinical approach needs to broaden. Rather than focusing on just the essential practical processes, the students are suggesting that it is time for clinicians to develop tools that can support and enhance factors that assist in the reconstruction of their lives.

Areas to consider for further research

Seeking opinions from students is a relatively new addition to the field of investigating return to school after TBI. Although the first published research identified by the authors of this paper appeared in 1997, five of the eight studies in this review have occurred since 2006. This pattern reflects the increasing acceptance of qualitative research within allied health and acknowledgement that, despite persisting cognitive-communication difficulties, people with TBI can be knowledgeable informants. Recent publications by Lloyd et al. [20], Paterson and Scott-Findlay [38] and Boylan et al. [39] provide prospective researchers with valuable considerations and tools for managing issues, which may affect qualitative interviews with the TBI population. As evidenced by the selection of studies in this review, it is clear that, with preparation, knowledge of TBI and sensitivity to cognitive and/or communication challenges, researchers can enable TBI survivors to contribute rich and valuable information from the insider's perspective.

From the broader perspectives provided by the lived experiences of students, it becomes clear that there are few tools available to workers in the field that allow clinicians to track or evaluate school participation in a meaningful way—encompassing student, clinician and funder needs. Currently gross measures such as the number of subjects a student completes, what special accommodations are used, how much integration aide time or tutoring is needed and school grades are the most common evaluations. However, these measures do not necessarily reflect how the student feels about their school participation, nor do they address the significant factors identified in this review related to issues of

students' sense of identity and their ability to progress toward reconstruction of self.

Development of measures that incorporate and value the student voice and recognize the significant influence of sense of self/identity may also place clinicians into a position where further gaps in understanding of school participation can be explored. In particular, to examine the longitudinal and dynamic process of returning to and being at school, being able to contrast experiences of students with TBI to those of their mainstream peers and providing evidence-based practice that will assist in attracting suitable funding from insurers and educational providers.

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