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ORIGINAL REPORT

"IN MY BEFORE LIFE": RELATIONSHIPS, COPING AND POST-TRAUMATIC GROWTH IN ADOLESCENT SURVIVORS OF A TRAUMATIC BRAIN INJURY

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Objective: **Explore the individual, adolescent phenomenology of quality of life after traumatic brain injury.**

Subjects/Patients: **Adolescent survivors of traumatic brain injury.**

Methods: **Qualitative interviews with 10 adolescents, mean age at assessment 17.09 years (SD 1.81). Mean time since injury 4.62 years (SD 2.89). Data were analysed using a primarily interpretative phenomenological analysis approach.**

Results: **Two major findings: (1) perceived quality of life was not automatically impacted by a traumatic brain injury, but when it was, the directionality of impact (positive, negative) varied depending on the life-domain; (2) changes in ability post-traumatic brain injury were attributed to the injury (more often cognitive and physical changes) or to a sense of normal maturation processes (72% and 28%, respectively). Attribution processing permeated themes of personal and social discrepancies, which also yielded themes of: altered family and relationships, roles, responsibilities, independence, coping and post-traumatic growth. All participants reported a happy life at the time of interview.**

Conclusion: **The adolescents' appraisal of their identity from pre- to post-injury life was related to their current sense of well-being. Most notably was the sense of balance; participants addressed the negative and positive consequences of brain injury to qualify their sense of wellbeing.**

Key words: brain injuries; adolescent; quality of life; adjustment, psychological; qualitative research.

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INTRODUCTION

Traumatic brain injury (TBI) is a leading cause of morbidity and mortality in children and adolescents in first world nations (1). In recent years there has been a move to assess sequelae of TBI beyond the cognitive domains (such as executive function) into internalizing states including mood and quality of life (QoL). The majority of research in pediatric and adolescent QoL has focused on parent or clinician proxy assessment (2), using a health-related QoL (HRQoL) model (2, 3). Proxy reporting (4, 5) and HRQoL models (6) have been criticized in the broader psychological literature due to the disconcordance between parent and youth reports ("The Proxy Problem" (7)), yet parental proxy of HRQoL remains the most often used method of assessment in pediatric TBI research (2). The reliance on traditional quantitative measurement systems with a history of insensitivity to TBI-related issues (8, 9) may limit our understanding of coping, adjustment and resilience processes, owing to the containment of scope inherent in Likert-type scales (e.g. symmetric agree–disagree scales specific to question asked).

The focus of development for the adolescent, even after TBI, is centered on the growth of a sense of identity – a sense of self; but information about the young person's experiences of QoL post-TBI is lacking. There is a small qualitative literature focused on psychosocial adjustment after TBI (10–12), and while this is important areas of investigation it does not capture the widely accepted multidimensional concept of QoL (6, 13). What is clear from these studies is that friendships are extremely important to adolescents' sense of self and relevance in their worlds and, implicit in these concepts, their sense of well-being. Work with survivors of adult TBI has included qualitative assessments of the process of understanding – and updating – a sense of self after TBI (14, 15). Research on these processes in adolescents is currently lacking.

The overall aim of this study was to explore individual, adolescent phenomenology relating to life after a TBI using an in-depth qualitative model. Aspects of communication, daily living (e.g. self-care), relationships (family and friends), school performance, happiness and future goals were investigated. These domains were chosen to explore how adolescents engage and react to domains regularly included in the broader QoL outcome literature. Given the lack of consideration of patient-focused QoL outcomes in the literature for adolescent survivors of TBI, the documented over-reliance on parent proxy reporting of HRQoL, and the need for patient relevant data to inform clinical and rehabilitative practice, an assessment of the adolescent experience of QoL post-TBI is warranted.

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METHODS

Subjects

Subjects were selected using the purposive sampling technique (16), based on audit of medical records of children presenting to the Emergency Department of The Royal Children's Hospital (RCH), Melbourne, Australia. Eligible subjects were mailed letters and followed up with phone calls to determine interest in the study. All participants and/or their parents provided informed consent. Participants met the following inclusion criteria: 1) adolescents (10–25 years), TBI sustained at least 12 months before assessment; 2) medical records sufficient to determine injury severity; 3) no pre-injury history of neurological, developmental, or psychiatric disorder; 4) English speaking; and 5) IQ > 70. Interviews were conducted in a private room at The RCH. A total of 10 cases were selected for Interpretative Phenomenological Analysis (IPA) analysis. All participants were Caucasian Australians, residing in urban areas proximal to the hospital. Mean age at injury was 12.48 years (SD 3.06; range: 4.33–16.0) and mean age at assessment was 17.09 years (SD 1.81; range: 13.92–19.50). Mean time since injury was 4.62 years (SD 2.89; range: 1.92–10.75). The majority of the sample (64%) was male, consistent with TBI prevalence in the general population. At the time of assessment 54.5% of participants were enrolled in high school, 27.3% in university studies, 9.1% in a non-university course. One participant (9.1%) was employed full-time. Injury details for participants are presented in Table I.

TBI severity was classified according to the Mayo Classification System for Traumatic Brain Injuries (17) as it permits TBI injury severity classifications in instances where data relating to the injury (e.g. post-traumatic amnesia duration (PTA), loss of consciousness (LOC), duration, etc.) may be missing. This system maximally uses the available information to classify TBI severity: (a) Moderate-Severe (Definite) TBI, (b) Mild (Probable) TBI, (c) Symptomatic (Possible) TBI. The majority of participants (63.6%) were 'moderate-severe TBI definite' ($n=7$), 2 were mild (probable) TBI and 2 were symptomatic (possible) TBI. Participant characteristics are presented in Table I. The study was approved by The RCH Human Research Ethics Committee.

Measures

The interviews were semi-structured. The novel semi-structured interview, the *iQoL: Adolescent TBI* (Table II) (18), included domains used in the broader psychological literature on QoL and the World Health Organization Disability Assessment Schedule II (19). The interview reflected TBI and adolescent-appropriate content: 1) Understanding and Communicating; 2) Getting Around; 3) Self-Care; 4) Getting Along with People; 5) Participation in Society; 6) School Performance; and 7) How do you Feel? The interview also contained questions to determine when changes occurred, for example, before or after the TBI; to determine pre-morbid vulnerabilities and/or pre-existing concerns. The questions were open-ended, with prompts available. The concluding question for each section asked the adolescent to "rank the impact/importance of any changes" they experienced on a Likert-Type scale of 0–5, with 0 being 'no impact' to

Table I. *Participant characteristics*

ID	Gender	Age at injury, Age at assessment	Time since injury	Cause of injury	Type of injury	GCS scene; GCS lowest	PTA (days, hours)	LOC	Surgical intervention (Yes, No)	Cerebral topography	Neurological signs	TBI severity
1	Male	16 y 17 y, 9 m	1 y, 11 m	MVA (occupant)	Acceleration/deceleration	NA; GCS = 4	21 days	NA	No	Abnormal	Present	Moderate-severe definite
2[a]	Female	11 y, 9 m 13 y, 11 m	2 y, 2 m	Sports-related head collision with stationary object	Direct impact, head against object. Skull fracture.	NA; GCS = 12	24 hours	< 1 min	Yes	Abnormal	Present	Moderate-severe definite
3	Male	14 y, 10 m 17 y, 1 m	2 y, 3 m	Sports-related head collision with ground	Direct impact, head against object	NA; GCS = 13	NA	< 1 min	No	Normal	Present	Mild probable
4	Male	13 y, 3 m 15 y, 5 m	2 y, 2 m	Sports-related head collision with ground	Direct impact, head against object	NA; NA	NA	Short duration	No	Normal	Present	Mild probable
5	Male	12 y, 10 m 17 y	4 y, 2 m	MVA (occupant)	Acceleration/deceleration	NA; GCS = 3	NA	NA	Yes	Abnormal	Present	Moderate-severe definite
6	Female	15 y 18 y, 5 m	3 y, 5 m	Violence/assault	Direct impact, blow to the head	NA; NA	NA	NA	No	Normal	Present	Symptomatic possible TBI
7	Male	12 y, 3 m 19 y, 2 m	6 y, 11 m	Violence/assault	Direct impact, head against object	NA; NA	NA	NA	No	Normal	Present	Symptomatic possible TBI
8	Male	4 y, 4 m 15 y, 1 m	10 y, 9 m	MVA (occupant)	Acceleration/deceleration	NA; GCS = 7	NA	NA	Yes	Abnormal	Present	Moderate-severe definite
9	Female	11 y, 3 m 18 y, 6 m	7 y, 3 m	MVA (occupant)	Acceleration/deceleration	NA; NA	NA	Short duration	No	Abnormal	Present	Moderate-severe definite
10	Female	12 y, 9 m 19 y, 6 m	6 y, 7 m	MVA (pedestrian)	Direct impact, head against object	NA; GCS = 13	NA	NA	No	Abnormal	Present	Moderate-severe definite
11	Male	13 y 16 y	3 y	Sports-related head collision with ground	Direct impact, head against object	NA; NA	NA	Short duration	No	Normal	Present	Mild probable

[a] Participant 2 did not participate in the interview component of the study; therefore data from this participant do not appear in this publication. "Short duration" verbatim recorded LOC from patient medical file. GCS: Glasgow Coma Scale; PTA: post-traumatic amnesia; LOC: loss of consciousness; CT: cerebral topography; TBI: traumatic brain injury; NA: not available.

Table II. *Example of iQoL Semi-Structured Interview Content*

Understanding and communicating	Since your injury, have you found that you've had any trouble concentrating on things, at school or at work? If YES: what have you found to be difficult to concentrate on? How often do you find this happens? (If unsure, probe with: many times a day, once a day, all day, couple of times a week). Do you find that being sleepy affects your concentration at all? If YES: how so? Is this different to how you were able to concentrate before the injury? If YES: how so? How does your trouble with concentration make you feel?
Getting around	Have you found that you experience a lot of fatigue ("tiredness") when you are moving about, like walking or trying to catch a tram? If YES: Are there particular types of physical activities that are hard to do? If YES: what physical activities are difficult? How often do you find this happens? (If unsure, probe with: many times a day, once a day, all day, couple of times a week). Do you find that being sleepy affects your ability to do physical things? If YES: how so? Is this different to how you were able to participate in physical activities before the injury? If YES: how so? How does your trouble with physical abilities make you feel?
Self-care	Has anything changed in terms of your ability to get ready for the day, for instance, needing help to get dressed, bathe, eat, brush your teeth or go to the toilet? If YES: What areas have changed? Do you need a personal aid to help you with these things? How does needing help/changes in your abilities make you feel?
Getting along with people	Has anything changed in your relationship with your friends since the injury? If YES: What do you feel has changed? Is this different to the relationship you had before the injury? If YES: how so? What would you rate as the most important change to your relationship with your friends since your injury? How does this change in relationships make you feel?
Participation in society	Have you had any problems being a part of social activities (with family or friends) after your injury? If YES: What do you feel has changed? Is this different to how things were before the injury? If YES: how so? What would you rate as the most important change to your previous involvement in social activities. How does this change in relationship/ability make you feel? Do you ever wish things were the way they were before the injury?
School performance	Have you found any differences in how you are keeping up at school? Do you have any experience with it being difficult to concentrate when in class? If YES: Do you find that your concentration is worse at any point in the day? Do you experience any difficulty with handing in assignments on time? If YES: Is this different from your ability to hand in assignments before? Do you have any difficulty with timed exams? If YES: what do you find difficult? Do you feel confident answering questions in class? Is this any different to how you felt before your injury?
Open section: How do you feel?	Has your injury changed how you plan for the future? do not provide prompts unless participant seems unsure; prompt with: "For example, what you plan on doing after high school? The job you'd like to get? Whether or not you want to go to college or university? How does this make you feel? Is there anything you wish you could change? What have you found has made the biggest difference to you and how you have coped with life after the injury?

All sections close with the question: How much, on a scale of 0 (being not at all) to 5 (being terrible) does this interfere with your day to day life?, except for "Open Section: How do you feel?"

5 representing a 'significant impact' on life. The data on importance and impact are the topic of a separate paper[1].

A qualitative approach encourages purposive sampling, which uses a sample group for whom the research question will be of particular relevance, best represents the criteria of the study and allows for in-depth examination and processing of the information provided (20–22). A purposive sample is a non-representative subset of some larger population, and is constructed to serve a very specific need or purpose (23), in this case, adolescents with a history of TBI. The principle of data saturation reflects the idea of quality over quantity, where there is a point at which additional observations, interviews and data offer no new insights (24, 25). Upon reaching saturation, further expansion of the sample size is contraindicated (25, 26). In the current study, data were considered saturated when no additional emerging themes were found in the data set with the addition of new participants. Data saturation was reached at $n=10$ interviews.

Data analysis

Data were analysed using an IPA; (22) and Multi-threaded DNA (mDNA) (27) approach. IPA explores the process of attribution and sense-making at an individual level, through analysis of the respondents' account of their personal experiences (28). IPA was used to assess the data provided by the adolescents about their life experiences post-TBI. IPA is especially useful when research questions target complexity, process or novelty (22); the approach is used to determine how individuals perceived situations and how they made sense of their personal and social world after experiencing an event (22). The IPA method was a particularly good fit with the study's goals. IPA requires that researcher remain self-aware and engage in a checking process between the reflections of the participant and those of the researcher (22). This process prevents tainting the data with assumptions or biases of the researcher. The primary researcher was a Clinical Neuropsychology intern with experience working with patients and their families in child health settings and also as a consumer of child health services due to chronic illness. Co-authors were all experienced clinicians and researchers within the child health and mental health domain. They provided additional insight into the data, and the method of cross-checking themes ensured that the themes were grounded in the data. The final interpretation of the data represented an integration of all perspectives.

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[1] Di Battista A., Catroppa C., Soo C., Godfrey C., Anderson V. Does what we measure matter? Quality of life defined by adolescent traumatic brain injury survivors. Brain Injury (under review).

The mDNA (27) was used alongside the IPA process. mDNA allowed for content to be classified into themes which represent the thematic entity of the content. The combined data analysis process was as follows: All interviews were recorded then transcribed verbatim and entered into Ethnograph 6.0 (29) for coding. Coding was performed by the first author (A.D.). The first transcript was read line-by-line noting comments on the right hand side (e.g., summaries, paraphrasing, questions, contradictions, amplifications, minimizations). The same transcript was then re-read from the beginning, with emerging and content themes coded on the left hand side. This process was terminated once the reviewer was satisfied that all relevant data had been extracted and commented upon. During the second stage these initial notes were

Table III. *Emergent themes*

		Emergent themes		
Interview domains	Major components of interview domain	Psychological concepts	Medical/physical symptoms	Other
Understanding and communicating	Concentration	Distractibility	Fatigue	Music
		Trouble in classroom setting	Headache	
		Annoyance with Self		
		Personal discrepancy		
		Hopelessness		
		Worthiness		
		Emotional distress		
		Avoidant coping		
		Procrastination		
		Change due to age (attributions)		
		Boredom		
		Change TBI related (attributions)		
		Memory		
		Negative attributions		
		Non-negative effect		
	New learning	Personal discrepancy	Headache	
		Emotional distress	Fatigue	
		Threat to self		
		Hopelessness		
	Memory	Responsibility		
		Change TBI related (attributions)		
		Personal discrepancy		
		Safety		
		Threat to self		
		Negative changes		
		Emotional distress		
		Low mood		
	Communication	Concentration	Fatigue	
		Memory		
		Isolation (social)		
Getting around	Fatigue	Change TBI related (attributions)	Headaches	
		Age related change (attributions)		
		Low mood		
	Physical ability	Personal discrepancy	Sport	
		Positive change		
		Independence		
		Age related change (maturation)		
		Responsibilities (new responsibilities)		
	Sport	Changes (less participation)		
		No change (same participation as pre-injury)		
Self-care	Activities of daily living (ADL)	Personal discrepancy	Physical ability	
		Employment		
	Independence	Wishful thinking (wish different)	ADL	
		No negative effect		
		Posttraumatic growth		
		Positive change		
		Personal philosophy		
		Increased independence		
		Personal discrepancy		
		Social discrepancy		
		Responsibility		

Table III. *Contd.*

		Emergent themes		
Interview domains	Major components of interview domain	Psychological concepts	Medical/physical symptoms	Other
Getting along with people	Friendships	Social discrepancy		
		Post-traumatic growth		
		Personal discrepancy		
		Self-esteem		
		Confidence		
		Suicidal ideation		
		Blame (attribution)		
		Change due to age (attributions)		
		Social inclusion		
		Inter-personal discrepancy		
		Change TBI related (attributions)		
		Wishful thinking		
		New perspective		
		Posttraumatic growth		
	Family relationships	Improvement		Confidants
		Posttraumatic growth		
		Positive change		
		Change due to age (attributions)		
		Catastrophic reactivity (attributions) social discrepancy		
		Responsibility		
		Independence		
		Interpersonal discrepancy		
	Relationships (e.g. boyfriend, girlfriend)	New perspective		
		No change		
Participation in society	Social activity	Social inclusion		
		Sport		
		Coping		
		Annoyance		
		Social discrepancy		
		Confidence		
		Change TBI related (attributions)		
		Inter-personal discrepancy		
	School activity	Memory		
	Employment	----	Fatigue	
School Performance	Keeping up at school	Change due to age (attributions)		
	Concentration in class	Memory		
	Handing in assignments on time	No change		
	Difficulty timed exams			
	Confidence to answer questions in class			
Open Section: How do you Feel?	Future goals	Hopelessness		
	Future planning	Personal philosophy		
	Changed plans?	Threat to self		
	Life now?	Willpower		
	Anything wish could change?	Post-traumatic growth		
	Biggest difference to you and how you coped post-injury?	Social discrepancy (driving)		
		Self-esteem		
	Goals for the future	Loss		
	Have your goals changed? College? University? Family? Marriage? Driver's license?	Personal discrepancy		
		New perspective		
		No change		
		Positive change		

This table plots the content and emergent themes provided through the semi-structured interview, the iQoL: Adolescent TBI. The content themes represent those domains contained in the semi-structured interview. The emergent themes represent those topics of conversation that were volunteered by the adolescent being interviewed in response to the content domain questions. Activity of Daily Living (ADL); those elements of daily life, e.g. brushing teeth, getting dressed, preparing a meal. TBI: traumatic brain injury.

transformed into consolidated statements that reflected the underlying essence of the segment of text. As emerging themes developed, linkages between these were also noted. This process was repeated for all subsequent transcripts. During the active process of noting themes, those which developed across the transcripts were compiled into an "emerging themes" list (Table III). This table was used to reference clusters of themes across and within cases. In order to ensure that the themes were grounded in the data and well validated, C.G. (blinded to previous extraction and coding,) separately coded 10% of the transcripts. Discussion, conferral and consensus of coding were applied.

RESULTS

The focus of this study was to ask participants about their QoL, in order to inform the clinical and rehabilitative practice through direct patient narratives. Qualitative analyses revealed two major findings: (1) having experienced a TBI does not automatically impact perceived QoL, and when it does, the directionality of impact (positive, negative) can vary depending on the life-domain; (2) when changes in ability post-TBI were identified, reasons for change were attributed to a) the injury itself (such as cognitive and physical changes), or b) normal maturation processes (72% and 28%, respectively). Attributions for changes to abilities post-injury were made to either normal age-related attributions (e.g., more responsibilities at school) or the TBI sequelae. For example, concentration abilities following TBI were attributed to age-related attributions: "…these days 'cos I got more work really, but you can't really relate that to the injury…." (ID 4) and "…before the injury I think it's because I've been in the younger year level … now I'm a senior, so I'm so tired I can't do anything" (ID 3). The changes in responsibilities, expectation and workload were responsible for changes in concentration, rather than the TBI. For others, changes were directly attributed to the brain injury: "When it was recently after the concussion I found it really hard to concentrate. Nowadays it's just if I'm really tired [I] find it hard to concentrate… I just felt like my mind was a bit slower, didn't comprehend things as quickly or easily as I did before" (ID 11). For some, the cause for changes were less clear: "I gave [piano] up… the piano was like a huge part of my life and I sort of moved on to academics but I don't know whether that's just me growing up or me after a car accident…"(ID 9).

The results explore the two major findings in response to changes identified in 4 areas: 1) Personal and Social Discrepancies; 2) Family Relationships, Roles, Responsibilities and Independence; 3) Coping and Post-traumatic Growth; 4) Happiness Now. Processes of self, social and inter-personal discrepancies are identified, and emotional consequences and attributions are explored A full list of themes and sub-themes which emerged from the interview, in response to specific content domains, is presented in Table III.

Personal and social discrepancies – "In my before life"

Personal and social discrepancy processes were identified. This process is defined as the labeling of differences, and providing insights between life "before" (e.g. pre-injury) and life "after" (post-injury), for example:"…'cos in the before life, …I had the freedom to ride my bike like to the [service station] with my friends …and I feel like because my brain injury I can't do that anymore and sometimes …I want to just cry…" (ID 5). The impact of perceived post-injury differences was often framed in a social context: "… before the incident in uh like primary school I used to be quite vocal about things…more confident… [in] high school…due to that the incident… I became very quiet, shy…" (ID 7); which compared pre- to post- injury social interactions. The social and self discrepancy process also included maladaptive coping processes, which were identified in response to perceived post-injury changes: "I used to be more confident I guess…like I kind of more now like not include myself in things …like if I get involved then people won't like me.." (ID 6).

Post-injury social differences reflected how adolescents understood themselves in the context of their peers; e.g. driven by comparison between what they the individual were able to do (personal discrepancy) and what their friends were able to do (social discrepancy): "'cos like soon they [friends] can be able to …just drive wherever, like parties, like wherever they're goin', they can just like drive and … I can't" (ID 5).

Enduring support from friends had a powerful effect on how pre and post-TBI life were processed: "…every single one of my friends in my before life are still here in this life now… they haven't left me, and they never would" (ID 5).

Family relationships, roles, responsibilities and independence

Post-injury changes resulted in altered family dynamics; e.g. how the adolescent saw themselves as part of the family system, their role within the family and their perceived responsibility for those changes: "… when that incident happened [my parents] thought aw he's a goner he's dead he's brain-dead … so I dunno it always plays in their mind aw we could have had a disabled or dead son…ever since then I think they've been very thankful that nothing's happened and basically it's all turned out very well" (ID 7).

Perceived independence was impacted when there was a post-injury reliance on family members: "… mum has to help me with a lot more, she's got to help me with a whole lot more in my life… [like] getting changed…" (ID 5). Increased independence post-TBI also occurred, and was in some instances attributed to the injury itself: "Well I can make pancakes now because of the injury… I had to have complete cognitive rest so I made pancakes … and I can make sauces which I invented at the same time so indirectly, it was – it made me more independent" (ID 11) and "immediately after [the TBI] yes, [lost independence] 'cos I was home a lot of the time… I think I've become more independent because of it" (ID 9).

Coping and post-traumatic growth

Narratives provided insights into coping and post-traumatic growth (PTG) processes. Participants reported both internal and external factors for coping: Internal factors – e.g. patience: "Probably my patience. Yes, I had to have a lot of patience to just do nothing for that long I guess" (ID 11) and persistence: "… it's horrible what it (TBI) does to you 'cos it limits you a lot…but with time things become better… if you apply yourself you can achieve great things, move mountains almost…" (ID 7) had a positive effect on coping post-injury.

External factors often included support from friends: "the biggest thing is probably for me is my friends… whatever we're doing they understand now that they gotta help me a little bit more…" (ID 5) and family ""Uh, family, girlfriend [helped]" (ID 1) were seen as an important contributors to coping post-injury.

The PTG processes drew meaning from the TBI: "it [the TBI] sort of concreted my, like my desire to become a doctor" (ID 9) and changed goals, aspirations and life trajectory of the adolescent: "Before in my before life I was nuts for BMXing [bike riding] I would BMX night and day and all I wanted to do was be become a famous BMX star…but now I want to become a motivational speaker and spread my message to the world" (ID 5).

Happiness now

At the end of the interview, participants were asked to describe how they felt about their lives at the time: "Now I'd say good. I've still got a few traces of the symptoms…but it's a lot easier to manage than before" (ID 11); and:"Uh, fantastic! It's really great" (ID 9). None of the adolescents described an unhappy life at the time of the interview.

The direct patient narratives from the adolescent TBI survivors interviewed in this study provide a wealth of information that can be used to inform and enhance the rehabilitative and clinical efforts directed at adolescent TBI survivors.

DISCUSSION

The overall aim of this study was to explore individual, adolescent phenomenology of life after a TBI using an in-depth qualitative model. Ultimately, the individual's appraisal of their identity from pre to post injury life was related to their current sense of well-being. Theories pertaining to the discrepancy process, coping and emotional adjustment to a TBI, the "Y-Model" (14, 30) and Nochi's (15) "loss of self" (the individual that is left after TBI, who has lost a clear self-knowledge, who experiences uncertainty about the role that they can – and will – play in society) served as frameworks to understand the discrepancies described by the adolescents in this study. The Y-shaped model draws from the literature on self-discrepancy theory, goal setting, social and personal identity change, self-awareness and well-being (14), which is appropriate for use in the clinical rehabilitative setting. According to this model, a positive outcome includes an updated, adaptive and realistic self-representation which incorporates the reality of the world in which the individual finds themselves, for example, one in which they must engage in their daily life with a physical or cognitive difficulty after the TBI. A negative outcome occurs when discrepancy analysis identifies a significant shift from pre-injury abilities/experiences without associated benefit, the individual may be rendered in a battle with their perception of themselves. This may lead to feelings of inadequacy or shame and avoidance of situations where skills perceived to have been negatively altered. Such avoidance is ultimately maladaptive and puts the individual at risk of exclusion from the experiences that could re-integrate them into their desired roles. The failure to resolve these discrepancies in a meaningful way puts the individual at risk of ongoing psychological discomfort (14).

In contrast to the Y Model for adults, the current study results suggest that for adolescents, the individual and the social self were not mutually distinctive categories. Personal discrepancies were often described in a social context, suggesting that at this stage of development the individual self is very much entrenched in the social arena (*Results: Personal and Social Discrepancies*). Adolescents are particularly sensitive to social comparison and concerns regarding their status among peers (31, 32). Survivors of pediatric TBI are at elevated risk of social impairment (33), due to deficits in behavioral self-regulation and social-interactive competence (34, 35) which can result in loss of friendships, poor social adjustment and difficulty fitting in (11, 36). In the current study maintenance of social support (e.g., "…every single one of my friends in my before life are still here in this life now…they haven't left me, and they never would" [ID 5]) or loss of social support (e.g., "… like I kind of more now like not include myself in things …like if I get involved then people won't like me.." [ID 6]) greatly impacted on how the adolescents experienced their world post-injury. Interventions targeting friendship acquisition and maintenance for the survivor of pediatric TBI exist (37) and our results support the need for continued efforts to enhance adolescents' social adjustment post-injury.

Adolescents are actively developing their own sense of identity and TBI-related impairments to their independence may put adolescents at risk of emotional distress (14). This study uncovered evidence supporting growth of independence post-injury, suggesting further examination independence in the adolescent TBI survivor could provide meaningful insights into the recovery process.

We identified evidence of post-traumatic growth (PTG) and coping in adolescent survivors of TBI. Coping occurs acutely post-injury, whereas PTG is an incremental, enduring psychological change that develops post-injury (38). The coping processes identified in this study included access to support networks (family and friends) and maintained inclusion in normal, pre-injury activities (e.g., social outings). For some of the adolescents their PTG integrated expectations and limitations on what they can do post-injury (shift in life focus) from pre-injury pursuits and expectations to post-injury reality. Research into PTG after TBI is in its infancy, with preliminary support identified in adults (39, 40). Our study adds evidence in support of strong resilience and PTG in adolescent survivors.

This study contributes insights to current knowledge, addressing factors of relevance to the adolescent sense of well-being post-injury. Social factors and PTG are not generally captured in popular HRQoL methods, particularly information gathered via proxy reported HRQoL methods (2). Retained meaningful social groups provided a rich source of strength to the adolescents who had these supportive networks. Evidence of PTG highlighted the potential for resiliency in adolescent survivors: while difficulties may be experienced, the adolescent need not be defined by them. In support of this view, all participants reported a happy life at the time of the interview, regardless of the difficulties they had endured.

Adolescent narratives provided insight into how the adolescents drew meaning from their TBI, how they attributed changes in life post-injury (TBI or 'normal life' processes). Most notable is the sense of balance; the adolescent was capable of addressing the negative and positive consequences of their brain injury and what it meant to them, their lives and their world post-injury.

Limitations and strengths

All participants were at least one year post injury at the time of the interview; therefore these findings may not be applicable to acute stages of recovery. The sample was predominantly male, consistent with prevalence of TBI. While this study did not directly assess gender effects of the social experience, it would be important for future studies to determine if methods of coping (maladaptive or positive) are different for female survivors. The data presented here can be considered valid representations of the adolescent experienced of those assessed in this study, ensured by the validation of text and coding between the two authors (blinded to each other's coding).

Implications for rehabilitation

Engaging the adolescent survivor of TBI in discussions surrounding their experiences post-injury is an important first step in tailoring psychosocial rehabilitation. Investigation of mood, social experiences, and an exploration of signs of maladaptive coping could help guide the clinician to guide the adolescent towards a more adaptive recovery trajectory. Gaining deeper understanding of what is helpful to the adolescent could be used to scaffold interventions for those who are not faring as well post-injury. Future research could usefully employ focus groups, with adolescents who have succeeded in their post-injury lives, to identify methods that may encourage other adolescents. The richness of data from this study demonstrates the benefit of using a semi-structured interview to assess post-injury life in adolescent TBI survivors. Future longitudinal studies could provide much needed insight into the potential for response shift regarding QoL, as a function of changing needs, desires and responsibilities over time. For instance, do components of QoL and well-being reflect age-specific themes, such as those found in this study about social acceptance and support? Are there particular early-adulthood based needs that have a significant impact on well-being after a TBI, such as acquiring a driver's license, or being able to consume alcohol on social occasions? Adolescents in this study were capable of defining changes to their processes of self, and used insight to identify social and inter-personal discrepancies and the emotional consequences attributed to them. Ultimately, the individual's appraisal of their identity from pre- to post-injury life related to their current sense of well-being. Friendships played an important role in affirming a new identity post-injury. Of particular importance to this study was the identification of post-traumatic growth as a possibility for adolescent survivors of a TBI. These findings have implications not only for research study design, but also for provision and type of clinical services made available to adolescents after a TBI, incorporating the self-identified needs of each individual adolescent TBI survivor.

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