Published in final edited form as:
Brain Inj. 2011 ; 25(9): 882–894. doi:10.3109/02699052.2011.581638.

Children's longing for everydayness: life following traumatic brain injury in the USA

Cecelia I. Roscigno, PhD RN[+], **Kristen M. Swanson, PhD RN FAAN**[*], **Monica S. Vavilala, MD FAAP**[‡], and **JoAnne Solchany, PhD ARNP**[†]

[+]College of Nursing, University of Illinois at Chicago; Chicago, IL

[*]School of Nursing, University of North Carolina at Chapel Hill, Chapel Hill, NC

[‡]Anesthesiology & Pain Medicine and Pediatrics at the University of Washington and Harborview Injury Prevention and Research Center, Harborview Medical Center; Seattle, WA

[†]School of Nursing, University of Washington, Seattle, WA

Abstract

Primary Objective—Little is known about life after traumatic brain injury (TBI) from the child's perspective.

Research Design—This descriptive phenomenological investigation explored themes of children's experiences following moderate to severe TBI.

Methods and Procedures—Inclusion criteria: 1) 6 – 18 years of age at injury; 2) moderate to severe TBI; 3) ≤ 3 years since injury; and 4) English speaking and could participate in an interview. Children participated (N = 39) in two interviews at least one year apart. A preliminary model was developed and shared for participants' input.

Main Outcomes and Results—Six themes emerged: 1) it is like waking up in a bad dream; 2) I thought going home would get me back to my old life, but it did not; 3) everything is such hard work; 4) you feel like you will never be like the person you were before; 5) it is not all bad; and 6) some people get it, but many people do not.

Conclusions—Social support was important to how children adjusted to changes or losses. Most children did adjust to functional changes by second interviews. Children had a more difficult time adjusting to how others defined them and limited their possibilities for a meaningful life.

Introduction

There are no qualitative investigations examining how social interactions within children's ecological environments affect their emotional adjustment, recovery, and community reintegration following traumatic brain injury (TBI). Children can both affect and be affected by the multi-layered social environments within which they live and interact on a daily basis (i.e. family, friends, neighborhood, church, school, the broader society, and the world) [1,2]. In order to be inclusive and capture the factors which affect children's experiences following TBI, studies of their outcomes must incorporate a more ecological perspective and integrate children's physical, emotional, psychological, behavioural, spiritual, and social realities from their perspective as well [3–5].

Cecelia I. Roscigno PhD RN CNRN 845 South Damen Avenue MC 802 Chicago, IL 60612 Tel: 312-996-5801 Fax: 312-996-8871 roscigno@uic.edu.

Previous investigators have laid a strong framework in which to ground understanding of the individual functional and behavioural factors that affect children's outcomes following TBI. Evidence exists regarding: 1) the efficacy and effectiveness of existing acute care interventions; 2) acute care predictors of global or functional outcomes; and 3) descriptions of negative symptoms [6]. Some investigators have also attempted to understand aspects of children's social conditions following TBI by soliciting the perspectives of parents or significant others as a proxy for children's perspectives [7–9]. Results of these approaches highlight noteworthy changes in children's functioning that oftentimes prove challenging to others. Yet prior studies continue to limit insight into the quality of life for children following TBI because they relegate children's perspectives to the background. In recent years, some investigators have attempted to describe aspects of children's social environments following TBI. Findings from these investigations have shed light on the nature of recovery, contributors to disability, and promoters or inhibitors to community reintegration post-TBI [10–12].

A more comprehensive analysis of outcomes following TBI, however, would also consider children's quality of life or well-being as not only a state of their functioning, or a state of their mind, but also as a state of their social world and social interactions [3]. This necessitates inclusion of children's narratives when conceptualizing life following TBI. To date, there are no published phenomenological investigations including children following TBI that lend insight into their perspectives. Therefore, gaps exist in our understanding of factors which influence children's recovery, social integration, and quality of life after TBI. Including their perspective will facilitate more socially relevant research designs, suggest meaningful items for quality of life outcome measurement tools, and enhance future healthcare provider interactions and interventions with this population and their families.

The specific aim of this investigation was to portray the common themes describing experiences of a socially heterogeneous group of English-speaking children (defined in this article as from 6 to 18 years of age at time of injury), from across the USA and within the first five years following a moderate to severe TBI. For the purposes of this article and ease of communication, the word `children' also includes those who were 18 years or older when interviewed and whom might otherwise be considered young adults.

Methods

After institutional review board approval, a descriptive phenomenological approach was used as the genre to explore how children experienced and framed their life following moderate to severe TBI. Descriptive phenomenology comes from the interpretive paradigm, which posits that meaning-making is temporally dynamic and influenced by the social environment. The interpretive paradigm values studying human phenomena in their natural setting, flexible research designs, purposeful sampling, personal accounts, and prolonged investigator engagement in the phenomenon of study using empathetic neutrality (understanding without judgment) [13]. Descriptive phenomenology posits that the subjective description of the lived experience is the best means of yielding the broadest understanding of the individual and social factors that define and shape what is common to a given phenomenon. This methodology assumes that before a human phenomenon can be analytically given meaning by an individual, the phenomenon is first experienced. Experiences are then given their significance by way of the individual's sensory perceptions, emotional responses, memories, knowledge, and culture (known as intentionality). Two important strategies in design and analysis differentiate this methodology from other research approaches: 1) to position the person who has experienced the phenomenon as the expert and the investigator instead acts as an instrument to convey the participants' experiences; and 2) the investigator uses a technique called bracketing, which is a conscious and reflective attempt to gain an insider's understanding of the phenomenon by separating out the investigator's usual ways of making sense (e.g. extant theories, prior study conclusions, or accepted clinical practice) [14].

Using this methodology to investigate the narrative accounts of a socially varied group of children following a moderate to severe TBI, and remaining attentive to aspects of narratives that are unique to one child's life context versus common to most, enables discernment of the essential framework that explicates what it is like to be a child who has lived through a TBI. Through phenomenological study, the perspectives of a group that has been left out of the knowledge development process (i.e. children and especially children with impairments) may be heard. This knowledge enables others to heed those factors children perceive to influence their everyday life subsequent to TBI.

Sample

Recruitment took place between 2005 and 2007 using several recruitment strategies: personal solicitation at a northwest children's rehabilitation clinic; national advertisements through two TBI related websites; posters placed in public settings; classified advertisements; mailed invitations to participants in a regional brain and spinal cord injury programme in Florida State; and via a Pacific Northwest hospital's pediatric trauma registry. This later approach was used to target children in specific age groups, or from racially and ethnically under-represented groups, so that the final sample might be more representative of the population of children with TBI.

Children were included if they were: 1) 6 – 18 years of age at time of injury; 2) categorized with moderate to severe TBI (Glasgow Coma Scale (GCS) score < 13); 3) able to participate in an interview process; 4) between 4 months and 3 years post-TBI; 5) still dependents of parents or guardians; 6) conversant in English; 7) able to assent or consent as appropriate; and 8) their parent(s) or legal guardian(s) consented. Because data pertaining to parents' experiences were also gathered, at least one parent had to be willing to participate in an interview (findings pertaining to parents' experiences are not reported in this article). Children were excluded if they had an additional diagnosis of spinal cord injury or significant developmental disability prior to injury. Recruitment continued until the sample reflected heterogeneity in developmental levels, injury severity, family income, urban and rural settings, and racial and ethnic backgrounds, and themes were saturated (table 1).

The final sample consisted of 39 children recruited from 13 states across the USA. The majority came from across Washington ($n = 15$) and Florida ($n = 11$) States. Participants were heterogeneous in ages, family incomes, injury severity, injury circumstances, and living settings (table 1). Despite a recruitment protocol that was intended to be inclusive and maximize the racial and ethnic diversity, the final sample did not mirror the population's racial and ethnic diversity.

Procedures

Once parents or adult children expressed interest in the study, arrangements were made for a phone appointment at a time when both the parent(s) and child would be available. During the phone appointment, study procedures were explained, questions were answered, and the child's willingness and ability to participate were evaluated. Verbal informed consent was obtained at this time in order to proceed with plans to travel to the family's place of residence. Written informed consent was obtained in-person prior to initiation of first interviews.

Parent(s) completed a questionnaire that focused on family/child demographics, circumstances surrounding the injuries, and the child's acute care and rehabilitation history.

Injury severity was confirmed in several ways: GCS score at admission to intensive care unit (ICU) as reported by referring clinician ($n = 17$), trauma registry GCS scores as screened by the PI ($n = 3$), parent's copies of medical reports voluntarily shared ($n = 15$), or unsubstantiated parental report ($n = 4$). Children participated in two tape-recorded semi-structured interviews, which lasted at least 90 minutes each and took place 12 to 15 months apart. Children's responses to open-ended questions were the primary source of data. For the first interview, arrangements were made to interview children in person. All but one of the first interviews took place in the child's home. To assure that the child's version of events were held as the gold standard, children were interviewed prior to the parent(s) and in a private location of the child's choosing. Interviews began with an opening question: `What is the first thing you remember after your injury'? Follow-up probes included: `tell me what rehabilitation was like'; `tell me about when you first went home'; `tell me what it was like when you went back to school'. Children were encouraged to elaborate on their stories with probes such as: `tell me what that was like'; `how did that feel'; `why was that important to you'. During each interview, children were also asked for their advice on `what things would make it better for kids' and `what doctors, nurses, therapists and the public needed to understand about living with TBI'.

Interviews were tape-recorded and transcribed verbatim. Transcripts were checked by the PI (first author) against the recordings for fidelity to the original interviews. Extensive field notes were kept, which included observations as well as information volunteered by children via phone, email, or in person after the tape-recorder was turned off. All data were de-identified.

Second interviews took place over the phone or in person 12 to 15 months after the first interview with 31 of the 39 children. Eligibility for a phone versus in-person interview was determined based on the child's development and maturity, degree of cognitive impairment, speech impairments, ability to maintain attention on the phone versus in an in-person meeting, prior rapport with the child, and the child and family's personal preferences. This decision was made collaboratively between the researcher, the parent(s), and the child. The second interview had a dual purpose: 1) gathering accounts of children's experiences since the first interview; 2) soliciting child feedback on the investigator's preliminary descriptive themes, which were primarily developed from first interviews, but further expanded during the second interview to reflect the entirety of their experiences. Children were compensated with a $50.00 gift card or check for each interview they participated in to thank them for sharing their time. Of the eight children lost to follow-up, four families did not return any of three phone calls requesting a second interview, three families moved with no forwarding information, and one mother declined for fear that the second interview would stir up too many negative emotions for her child. Children's second interviews were in person ($n = 7$) or by phone.

To address the concern of potential adult/investigator versus child/participant power imbalances in conceptualizing the final themes describing children's experiences, participants were instructed, `I am going to tell you what I think everyone was trying to tell me life is like for children following TBI. Remember, that you are my boss and you are the one who is the expert in being a kid/young adult and living with TBI, if I say something that doesn't seem right to you, then you correct me and tell me how it was different for you. When you do that, it helps me to understand your experience better and how some things might have been different for you. I will then ask you to explain this some more so that you can help me and others to understand it better'. The preliminary summary of descriptive themes were then revised and expanded based on the collective feedback and later narrative accounts of daily life garnered in the second interviews. Using this system of member checks enhanced the credibility of findings [15].

Analysis

Transcripts were hand coded and analyzed using Collaizi's [16] descriptive phenomenological framework. The steps included: 1) reading and re-reading all participants' entire story until the investigator had a sense of each person's whole experience; 2) pulling out significant descriptions (emic accounts) from each participant's narratives, which captured the behaviors or a beliefs they described as meaningful; 3) collapsing and/or aligning individual's emic accounts to find overlapping themes and discern against emic accounts that were contextually specific to an individual, but not the group; 4) classifying themes, defining each theme, and relating how themes were associated with each other; 5) integrating findings into a preliminary summary of descriptive themes that described and defined participants' early experiences (prior to first interviews); 6) getting feedback on the investigator's preliminary summary of early experiences in the second interviews, while also expanding the descriptive summary to capture experiences between first and second interviews; and 7) revising the preliminary summary based on feedback and new information from second interviews to create a final descriptive summary of common experiences.

To assure rigor and obtain critique for potential bias or premature foreclosure on findings, the PI consulted several times with two colleagues, one an expert in phenomenological methods and the other a counselor who works with children and families following TBI. During these in-person meetings, the PI shared individual transcripts and drafts of the emerging model. This consultation process allowed for peer debriefing and assured the credibility of the investigator's interview techniques, data fidelity, and analysis process [15].

The PI's preliminary summary of common themes was based on accounts from children's first interviews. Since the time since injury varied between children at first interviews, the PI was able to use a preliminary theme developed from a subset of the children who were further out from injury and test it's transferability to the rest of the children who were interviewed at a much earlier period following their injury (e.g. `it is not all bad', which described how time affected children's appraisals). The preliminary summary was presented to the children during their second interviews thus providing participants an opportunity to validate or refute any portions of the first draft. The second interviews also enabled the investigator to learn what recovery was like over time by hearing stories and reflections that took into account events that occurred since the first interviews. Summaries of second interview narratives were discussed prior to the conclusion of the second interviews. The final descriptive summary of themes contained more emphasis on how the passage of time enhanced psychological healing, and how children reconciled the responses of others to their impairments, than would have ever been possible had the study been cross sectional [15].

Results

Children's narratives varied based on their cognitive development prior to TBI, severity of cognitive injury, and time since injury. Older children were more reflective about their experiences and more inclined to share detailed accounts of incidents. Children with more functional impairments experienced unexpected responses from peers and friends and therefore, had to work harder to find their new identity and position in their social world. At first interviews, children with greater cognitive impairments provided a less nuanced account and struggled as they tried to recall earlier phases of their recovery (e.g. inpatient rehabilitation).

At second interviews, all but two of the children recovered more cognitive capacity, so they were more reflective and articulate at sharing what it meant to feel different, dismissed as unworthy, and feeling unfamiliar to themselves and others during the earlier phase of recovery. The two children who had recovered less cognitive ability were still able to share their appraisals, but at times in the interviews they continued to be less descriptive in their experiences and less reflective about what it felt like (i.e., it sucked or I don't know why all my friends don't come around anymore). Despite their less detailed accounts, we felt their narratives still provided important information as they also represented the most marginalized of all the children (kept out of mainstream classes, avoided or rejected by peers and friends, and one was wheelchair bound and found his physical environment also became more restrictive). Their two stories still provided important accounts of how the environment shaped their experiences and meaning post TBI. The other 23 children with severe TBI touched on profound issues such as the meaning of life and what it is to be human, which will be shared in more depth in another manuscript.

Six main themes illustrated the common experiences of life following TBI over time: 1) It is like waking up in a bad dream; 2) I thought going home would get me back to my old life, but it did not; 3) Everything is such hard work; 4) You feel like you will never be like the person you were before; 5) It is not all bad; and, 6) Some people get it, but many people do not. The six themes are defined in Table 2. Exemplars of the narratives are presented in the text to contextually illustrate the themes. At times there is more than one narrative presented to illustrate the similarities or differences between children due to injury severity, development, or some other factor. Following the themes, narratives are also presented to illustrate how children described their adjustment process (longing for everydayness) and children's insight into what they thought others needed to understand.

It is like waking up in a bad dream

> **Female, 10 years, moderate TBI:** My grandpa came to visit me, and he was on the phone, and he was like, `I'm visiting my granddaughter. She had just got hit by a car'. And I'm sitting up there, I was staring at him, like, `Are you sure'?….`Who's he talking about'?….. And I was like, `Me? I didn't get hit by a car. What are you talking about'? …. I thought I was dreaming and everything, because everything looked like a cartoon to me. It looked fake to me. It felt fake to me. I didn't really think I had got hit by a car. And so, I was just like, `I didn't get hit by a car; you guys are crazy'! But as the days and weeks went by, I realized, `I got hit by a car. Deal with it'.

I thought going home would get me back to my old life, but it did not

> **Male, 10 years, moderate TBI:** Well, when I first got home, I just remember going in my house and seeing my brothers and stuff, and they were all happy to see me and everything, and I was happy because I was finally back in my own house…. I kind of just sat around and I think I played a couple video games and stuff. [Everybody was treating me] just normal.

> **Male, 12 years, severe TBI:** `I was so happy. I just wanted to run around and go, `Yeeesss'! and run and jump so I could go home and…be like…be like, get myself back…back on track….[then as more time passed] I would cry and cry and cry and ask where did [my brother and our friends] go? And then, my mom was like, `Well, you can go with them in the wheelchair'. I'm like, `No'! It didn't make me feel better at all!

Everything is such hard work

> **Female, 9 years, moderate TBI:** `But I was supposed to go to my friend's'! and you have to cancel some stuff that you like, just because you have to go to therapy.

> **Female, 13 years, severe TBI:** Going to a different school, going through a transition programme, meeting new people, getting different teachers, adjusting to a new school. Just everything. Just basically starting a new life.

You feel like you will never be like the person you were before

> **Female, 20 years, severe TBI:** I'm slower; I know I'm slower than I used to be…. like before I might have been really smart, and been the first person to turn the test in and get a hundred percent. And now I might be the last one. I still get a good grade, but it's frustrating.

It is not all bad

> **Male, 13 years, severe TBI:** It brought me a lot closer to God and a lot closer to my family…because God saved my life and I feel like I'm more spiritual, spiritually attached to him. And I feel like, more like attached to my life, my mom, my dad and my sisters and brothers because I've been spending more time with them and gotten to know a little bit more about them. And, a little bit more than I never would have known…so that's been really good actually.

> **Female, 19 years, severe TBI:** I think the accident has changed me by; I straightened up my life a lot. I'm going to graduate high school, go to college, <u>be somebody</u> in life. And my mom's my best friend. And most people don't actually become friends or are able to talk to their mother `til they are way older, have their own family, and made many mistakes without their mother in their life.

Some people get it, but many people do not

> **Male, 10 years, moderate TBI:** I couldn't remember the work, and all—and the teacher was like, `You know it; you just can't remember it. Try as <u>hard</u> as you can'. And I was like, `I <u>am</u> trying as hard as I can'. And she's like, `Just try harder', and I'm like, `I'm trying harder. I'm trying to go as <u>hard</u> as I can, and I still can't figure out fifteen divided by four'. It made me feel sort of weird. It made me feel my brain was, like—the brain cell was, like, checking all file cabinets, and couldn't find nothing. I was getting irritated again.'

> **Female, 14 years, severe TBI:** Yeah, [my friends came over at first] but then they saw me, and they saw the way I acted, and then they didn't come over anymore. I think it happened pretty fast. [I knew by] the way they avoided me at church. Like, they would always like, I would be talking to someone, and then one of the other friends would say, `Oh, come on, so-and-so, let's go do this! Bye, see you later'! And I was always kind of naïve of why they didn't bring me, but yeah, later, I understood it all.

—Children with either moderate or severe TBI who continued to have positive and supportive interactions from others while they reintegrated back into their community felt that they were cared about, and that nothing of essence was different about them (table 3).

The critical objectives of this investigation were met because this approach allowed first person perspectives of the children to be positioned in the forefront of knowledge building and others' perspectives or extant theories to be critically analyzed against this group of children's experiences and appraisals. This approach allowed the researchers to present a deeper and more nuanced understanding to the readers how experiences influenced meaning. The findings illustrated that changes in ability or functioning were initially interpreted as a defining feature of the meaning children made of their experiences, but over time and especially when they received support from others, children were able to reconcile their changes and find new meaning that gave them a sense of purpose and belonging. The average time span of the first interviews ($M = 15$ months) and the year or more time span between the first and second interviews enabled a deeper understanding of how the quality of support from others influenced how children saw themselves and how quickly they were able to transition to find new meaning. Many of the older participants remarked that their first interview had left them contemplative about their lives and that the second interview was experienced as `really good for me' because they realized that others like them were experiencing and feeling similar things. Children also commented that they felt good about helping others to understand what it is like, so that improvements could be made to help out other children in the future. This approach also allowed the presentation of positive appraisals and accomplishments, which are typically pushed to the background of other research on TBI.

Longing for everydayness

Most children at the time of the second interviews reported that they were either back to their `everydayness' or getting there. Everydayness was inductively defined by the researchers based on the children's descriptions of their adjustment process. It is defined as a psychological state when children felt comfortable with their self, so they no longer had to think and rethink why others did not understand or accept them. They described a relative harmony between their perceived self (body, mind, and spirit) and their social world. Children discussed that when they reached this point, they could then choose to ignore others if they responded negatively towards them and they were more likely to be successful:

> **Female, age 13, severe TBI:** And as I was getting through it and the days were going by, I kept comparing myself to the person I used to be. And I was thinking to myself, I'm never going to be this girl again. I'm not going to be the same person and so then I might not have the same friends…. I realize I have pretty much become that same girl. I am that same girl, just somewhat different. And I have lost a friend, a couple of friends because of this, but, it doesn't really bug me that much because I've made new friends now too. And so it doesn't bug me a whole lot and I realize that I'm that same girl, just a couple things have changed.
>
> **Female, age 19, severe TBI:** It really has been a process, like little steps along the way….every day I would maybe make a new realization about little things, or I would think about things differently…. just this process has brought me to this point of the journey where I am just so much more comfortable with myself than I was and just, I mean everything's not perfect, of course, but it's just so, so, so much better than it was. I decided that I'm going to be comfortable with who I am and, you know, ignore if I have people who are making me uncomfortable or things are different, that I'm just going to make the best of this life.

Children's Insight—Children suggested a variety of things to improve care of children following TBI, which have been paraphrased: allowing the parents 24 hour access in the ICU; teaching health care providers what it is like to emerge from a coma; teach healthcare providers and community members more about TBI from the survivors' perspectives; make the work of recovering fun and balance it with social activities; and have more emotional support in the community. In response to the question `what do you think is most important for others to understand about what it is like to have a TBI?' Children with moderate TBI stated that `it gets better', while children with severe TBI overwhelmingly stated that others need to understand that, despite any functional impairment they might have following TBI, they were still the same person in essence. They stressed they still had the same needs to belong, to be important to others, to find meaning and purpose, and to be seen as a unique individual. They often believed that they knew what others were thinking and why they were behaving the way they did because they, too, once thought the same things about people with impairments of any kind:

> **Female, age 14 years, severe TBI:** I think before the accident, I really didn't know what it was like, and I was, like, basically blowing them off; being like, `whatever'….. `Whatever,' you know, `you're in a wheelchair'… And now I feel better that I actually think about people and how they feel. I think that you should explain to people what really happens when, you know, something happens to somebody that's really bad; only so that they know what it's like… how emotional it is…. And just to let people know that if you went through that, you would feel the same way. And people [who have had a TBI] aren't any different than you are.

> **Female, age 14 years, severe TBI:** As people get to know me, they can see what I can do…. But a lot of people just on the grounds that…I'm different. Not necessarily in a good way, they just don't bother even taking the time to find out who's the face behind the mask. And, and part of that is they go, like, "Oh, she's brain-injured," like that almost puts up a wall for them to even try to get to know you.

Discussion

This is the first published investigation providing an in-depth first person account of children's appraisals of experiences and life quality after TBI. It shifts our understanding of quality of life to children's perspectives. The main findings are: 1) children with severe TBI and some children with moderate TBI experienced profound sudden changes in their ecological environments (self, family, school, neighborhood, other social organizations, and their broader communities); 2) children were not always prepared for the negative responses or misunderstandings of others to their changes; 3) all children initially grieved their changes and losses, but when children lacked social support they spent a longer time grieving their changes than those children who perceived good social support; 4) by second interviews, all but two children learned ways to adjust to their changes and find positive meaning in their lives, but many continued to experience environmental barriers (physical or attitudinal) that they explained were more difficult to adjust to; 5) many children with TBI can participate in qualitative interviews and the information they can provide us may challenge existing knowledge about life quality after TBI and the factors that contribute to the meaning of life for children following TBI.

Experienced profound sudden changes in their ecological environments

Children with severe TBI and some children with moderate TBI experienced profound sudden changes in their ecological environments that initially placed them in a state of turmoil (`it is like waking up in a bad dream') and continued when they reintegrated into their communities (`I thought going home would get me back to my old life, but it did not', `everything is such hard work', and `you feel like you will never be like the person you were before'). While in the acute care setting, all children reported receiving a great deal of social support. They assumed that in their most vulnerable time, they would continue to be supported by those around them, but they realized that many had a difficult time enduring along with their recovery process and accepting chronic changes.

Children were not always prepared for the negative responses or misunderstandings of others

When children returned home and began reintegrating into their social environments, they realized the individual and social impacts of their injuries (`I thought going home would get me back to my old life, but it did not', `you feel like you will never be like the person you were before', `some people get it, but many people do not'). Children were very dependent on others for assistance and physical and emotional support in the early period of recovery (`everything is such hard work'). Yet not all children experienced consistent empathetic responses from others, or the emotional support they needed or expected during their recovery (`some people get it, but many people do not'). When children experienced avoidance or negative responses from others, this added to their sense of loss, which caused them to continue to fluctuate between longing for their old self and social life, and trying to move forward with a new self and new social life [17,18]. Children then had a vulnerable sense of self due to their own realization of changes and their fears that they would be viewed as different and unworthy of being a part of their social networks (`you feel like you will never be like the person you were before'). Such social isolation and negative interactions from others could make some children vulnerable to depression and place them at risk for suicidal ideation or further delays in other areas of their entire development due to a lack of motivation or inactivity [2,19,20]. Although children eventually gained a new sense of self and ultimately adjusted to their functional challenges (`it is not all bad'), they reported that it was often difficult for others to adjust and accept them (`some people get it, but many people do not') and this was the factor they reported as most difficult to adjust to.

When children lacked social support they spent a longer time grieving their changes

Children grieved their changes and losses, but when children perceived they lacked social support they spent a longer time grieving their changes than those children who perceived good social support (`you feel like you will never be like the person you were before'). Social reactions reported by participants seemed to be related to their injury severity, but there were a few cases in both moderate and severe TBI groups where this was not true and these unique cases illustrated that despite injury severity, children's appraisals had more to do with the nature of their perceived social support than with their injury severity (table 3). For instance, all but two children with moderate TBI reported that others were supportive and accepting of them when they returned home. Thus, most from this group were able to redefine their self without being in a long state of identity crisis. Across injury severity categories, those children who had more negative reactions (avoidance or rejection) from those whom they expected to be compassionate and supportive found themselves deeply reflecting on their new disconnectedness from others, and its meaning in relation to their identity and their purpose in life. The timing of the first interviews ($M = 15$ months) seemed to catch many children at the point where they were in the midst of this deep emotional and spiritual struggle (fractured self and grieving). Children described how they were keenly aware of how some others saw them and defined their life as having a lesser quality than non-disabled persons. Many children admitted that they too had thought that way about persons with disabilities prior to this experience. They recognized the uncomfortable, avoiding, or rejecting behaviours that some peers or community members projected towards them.

Children learned ways to adjust and find positive meaning in their lives, but many continued to experience environmental barriers

Although children with moderate TBI reported experiencing the same themes as those with severe TBI, they typically recovered and reintegrated socially in days, weeks, or months versus the weeks, months, or years that children with severe TBI took. Children in this sub-group had only minor cognitive impairments and these were not always obvious to others, so they likely appeared to be unimpaired to others. Yet children in this sub-group also reported some unique social misunderstandings and responses. They noted that it was commonly assumed by others that because they looked well and it was several months since their TBI, that they were at this point in time `healed' from their TBI. Any functional (i.e. memory, attention, or cognitive) or behavioural problems (i.e. fatigue, headaches, impulsivity) present in the child were instead reasoned by others to be willful choices by the child according to children's accounts (e.g. just not trying hard enough, just trying to get attention, just using brain injury for an excuse to get out of doing work). These assumptions injured the child's sense of self because these reactions disputed the child's impairment experience, personal integrity, and their efforts to adapt to their impairments.

Most children learned ways to adjust and find positive meaning in their lives (`it is not all bad'), but many continued to have difficulties with how others defined them or their life quality subsequent to their TBI. They reported difficulties with the physical or attitudinal limitations that others placed on their future opportunities. By second interviews, most children had transitioned from seeing their self in terms of how society and others define a life with quality (functioning and peer social status) to primarily defining their life quality in terms of their heightened spirituality (a sense of peace and purpose, that there is a meaning to life that is outside of our self, and related to a connectedness with others) [21,22]. Children's narratives clarified that most eventually adapted overall to limitations in their physical and cognitive functioning, and rejection from previous significant relationships (friends and peers). This did not mean that children did not still have days when they would revert back to a period of grieving for their old self or old social life after experiencing additional negative responses from others, but in essence they described a personal satisfaction with who they were as a person, the purpose they believed their life held, and their attitudes regarding their future. This new knowledge calls into question how we measure quality of life in this population, primarily by functional capacities or descriptions of the quantity of social friendships.

Positive appraisals by persons with TBI (`it is not all bad') are often explained as merely a forced coping mechanism for loss, but this explanation may simply be the investigator's inability to understand something that is so foreign to their conceptualization of adaptation to impairments or a life with quality [23,24]. Rejections of persons' ability to embrace their new life and find positive meaning in their experiences as a real and valid appraisal following TBI may have more to do with healthcare providers' training, which is dominated by the biomedical perspective alone [25,26]. Most healthcare providers have a deficient appreciation of the social attitudes and barriers that are strong contributors to persons' co-creation of meaning regarding disability and the personal and social attributes that can counter social barriers. The biomedical viewpoint has been repeatedly shown to bias healthcare provider appraisals of a life with quality for persons labeled with disabling conditions [23,24,27–37]. In addition, positive accomplishments, contributions, and personal appraisals are captured far less in current research investigations evaluating life after TBI [38–43]. Thus, by capturing only participants' difficulties, we are left with the impression that these children lead meaningless lives, are a drain to their family, their community, and society as a whole.

Many children with TBI can participate in qualitative interviews and the information they can provide us may challenge existing knowledge about life quality after TBI

Current quality of life instruments used in this population typically ask a child about their physical, cognitive, or behavioural functioning and the number of friends they now have; a child may answer objectively that they have limited functioning or a decrease in the number of friends, but this may not be the factors that they are using to appraise their life quality [44]. Measuring functional capacity in the early period following TBI may capture the child's recognition of changes and fractured self (grieving of losses and changes). Later on, however, measures of functional capacity may capture the child's realization of how others are responding to them and their life quality (i.e. `I have fewer friends' or `I cannot do what they do'), but not necessarily how children themselves feel about their life quality. By the second interviews, children countered the notion that functioning or number of friends was of primary importance to their appraisal of the quality of their life post-TBI and this was related to the finding that children adjusted and found positive meaning in their lives. The fact that children had adapted to their changes and the quality of existing or new supportive relationships was reported as more important to them than the quantity of such relationships. Children explained that many of their prior friendships were more superficial and that they previously took their relationships with family members for granted, but now they had more meaningful friendships and relations with family members, which they explained were with people that cared about them unconditionally. Others have pointed out that impairments only influence some aspects of an individual's appraisal of quality of daily life because the individual is appraising their life much more holistically (body, mind, spirit, and their relationship within their social environments) [21,23]. The children with severe TBI in this study felt that in essence (holistically) they were still the same person, even though they were aware of their differences in functioning, so they often grappled to understand why others could not get past their impairments to see the person they still were and the person they were becoming. This was related to the finding that even though children adjusted to their impairments, they continued to have difficulties with how others defined them or their life quality subsequent to their TBI. They also had difficulties with the limitations others placed on their future opportunities (e.g. `you'll never be able to…'). The disconnect that children described between the way they saw their self holistically (their essence) and the way they felt that others focused only on their disability (their differences) has been described as a common disconcerting component of living with any disability [22].

Limitations

A limitation of this sample was that children self-selected to participate in the study. Despite attempts to get a sample that was representative to the population in ethnicity and race, this sample was primarily Caucasian and non-Hispanic. They were also English speaking only. These cultural factors could explain experiences or the appraisal of experiences that are not generalizable. In addition, there were only 14 moderately impaired participants and all but three in this sub-group were under the age of 11 years at enrollment. The smaller number, their cognitive development at the time of these interviews, and their less severe injuries may have together limited the depth of information this sub-sample provided. Overall, this sub-group had less obvious impairments and their narratives suggested they had more support in their community. Descriptive phenomenology is intended to give deeper insight into the contextual factors experienced by the participants that influenced the meaning made of the phenomenon, but it is not intended to make generalizations. Children's narratives also illustrated that important differences existed between participants in family visitation policies, and the nature of support services provided in the following areas: acute care; inpatient and outpatient rehabilitation; community transitioning coordination; returning to school; and in their community. These between participant differences become minimized by use of descriptive phenomenology, but would also be important to explore in more depth in future investigations.

Implications

The addition of children's perspectives to conceptualizations of a life with quality following TBI allows others to gain a deeper understanding of the nuances of recovery and community reintegration. The suggestions voiced by the children in this investigation can be used to supplement strategic policy changes for professionals that work with this population (table 4). Continuing to include and heed children's voices in future research will enable investigators to capture important developmental and contextual factors which children perceive and report as affecting their life quality following TBI. This additional knowledge will facilitate a more comprehensive understanding of the variety of socio-cultural factors affecting adjustment and reintegration, which will make clinical practices and social policies more germane to children's and families' needs post-TBI. Novel efforts need to be made to include children in future studies who are in the youngest age group (< 12 years) with severe TBI. Children with racial, ethnic, and language variation also need to be included in future studies to understand how these cultural factors might also play a role in experiences and appraisals of life quality following TBI.

Conclusion

Qualitative research is not being conducted with children following TBI. Yet, this study demonstrates that many children with TBI can effectively relate their experiences after injury. Because their accounts differ from extant theories accounting for life quality following TBI, it will be important to conduct more research that builds their perspectives into our theories. Clinical and social programmes and future research investigations should consider children with TBI as primary sources of data to drive information about them and evaluate services provided for them.

Acknowledgments

The author would also like to acknowledge the following for their assistance with recruitment: the Rehabilitation Department at Seattle Children's; the University of Washington's Rehabilitation Department; the Florida Department of Health's Brain and Spinal Cord Injury Program (Ft. Lauderdale Region); the Harborview Medical Center Pediatric Trauma Registry; and the Brain Injury Association of USA. The author would like to acknowledge Pamela Mitchell for her participation on the author's dissertation committee. Most of all, the author would like to thank the children who shared their insights about living with TBI.

Declaration of interest The first author received grant funding from Integra LifeSciences Corporation, but the authors alone are responsible for the research and content this paper.

The study received funding support from: a NINR Ruth L. Kirschstein Predoctoral Research Fellowship (1 F31 NR009599-02); a Psi Chapter of Sigma Theta Tau Grant; a 2006 American Nurses Foundation Martha E. Brill Scholars Award; a University of Washington School of Nursing Hester McLaws Scholarship Fund; a University of Washington LEND Training Grant (TG # 6 T73 MC 00041-11-03); the University of Washington Gatzert Child Welfare Fellowship; and an Integra LifeSciences Grant. The first author's postdoctoral training, in which this manuscript was written, was funded by the Irving B. Harris Foundation Faculty Scholars Initiative.

References

1. Bronfenbrenner U. Toward an experimental ecology of human development. American Psychologist. 1977; 32:513–531.
2. Thomasgard M, Metz WP. Promoting child social-emotional growth in primary care settings: Using a developmental approach. Clinical Pediatrics. 2004; 43:119–127. [PubMed: 15024435]
3. Griffin, J. Well-being: Its meaning, measurement, and moral importance. Oxford University Press; New York, New York: 1986.
4. Ravens-Sieberer U, Patrick PD, Benz B, Calaminus G, Flechtner H, Melchers P, Patrick P, Schäfer B, Suhr L, Schrod L, et al. Quality of life in children with traumatic brain injury--basic issues, assessment, and recommendations. Restorative Neurology and Neuroscience. 2002; 20:151–159. [PubMed: 12454363]
5. World Health Organization. Measurement of quality of life in children. Division of Mental Health, World Health Organization; Geneva, Switzerland: 1993.
6. Haley SM, Graham RJ, Dumas HM. Outcome rating scales for pediatric head injury. Journal of Intensive Care Medicine. 2004; 19:205–219. [PubMed: 15296621]
7. Chisholm J, Bruce B. Unintentional traumatic brain injury in children: The lived experience. Axone. 2001; 23:12–17. [PubMed: 14621498]
8. Hawley CA. Saint or sinner? Teacher perceptions of a child with traumatic brain injury. Pediatric Rehabilitation. 2005; 8:117–129. [PubMed: 16089252]

9. Kao HF, Stuifbergen AK. Love and load--the lived experience of the mother-child relationship among young adult traumatic brain-injured survivors. Journal of Neuroscience Nursing. 2004; 36:73–81. [PubMed: 15115361]
10. Morris PG, Prior L, Deb S, Lewis G, Mayle W, Burrow CE, Bryant E. Patients' views on outcome following head injury: A qualitative study. BMC Family Practice. 2005; 6:30. [PubMed: 16048645]
11. Pierce CA, Hanks RA. Life satisfaction after traumatic brain injury and the World Health Organization model of disability. American Journal of Physical Medicine and Rehabilitation. 2006; 85:889–898. [PubMed: 17079961]
12. Prigatano GP, Gupta S. Friends after traumatic brain injury in children. Journal of Head Trauma Rehabilitation. 2006; 21:505–513. [PubMed: 17122681]
13. Patton, MQ. Stategic themes in qualitative inquiry. In: Patton, MQ., editor. Qualitative research and evaluation methods. 3rd ed.. Sage Publications; Thousand Oaks, California: 2002. p. 37-73.
14. Husserl, E. Phenomenology and the crisis of philosophy: Philosophy as a rigorous science, and Philosophy and the crisis of European man. Harper & Row; New York: 1965.
15. Lincoln, YS.; Guba, EG. Naturalistic inquiry. Sage; Beverly Hills, CA: 1985.
16. Colaizzi, PF. Psychological research as the phenomenologist views it. In: Valle, R.; King, M., editors. Existential-phenomenological alternatives for psychology. Oxford University Press; New York, New York: 1978. p. 48-71.
17. Gracey F, Palmer S, Rous B, Psaila K, Shaw K, O'Dell J, Cope J, Mohamed S. “Feeling part of things”: Personal construction of self after brain injury. Neuropsychological Rehabilitation. 2008; 18:627–650. [PubMed: 18609024]
18. Marris, P. Loss and Change Garden City. Anchor Press/Doubleday; New Jersey: 1975.
19. Simpson G, Tate R. Suicidality after traumatic brain injury: Demographic, injury and clinical correlates. Psychological Medicine. 2002; 32:687–697. [PubMed: 12102383]
20. Simpson G, Tate R. Suicidality in people surviving a traumatic brain injury: Prevalence, risk factors and implications for clinical management. Brain Injury. 2007; 21:1335–1351. [PubMed: 18066936]
21. Dunn DS, Brody C. Defining the good life following acquired physical disability. Rehabilitation Psychology. 2008; 53:413–425.
22. Wright, BA. Physical disability: A psychological approach. Harper & Row; New York, New York: 1960.
23. Albrecht GL, Devlieger PJ. The disability paradox: High quality of life against all odds. Social Science and Medicine. 1999; 48:977–988. [PubMed: 10390038]
24. Wright, BA. Attitudes and the fundamental negative bias: Conditions and corrections. In: Yuker, HE., editor. Attitudes towards persons with disabilities. Springer Publishing Company, Inc.; New York, New York: 1988. p. 3-21.
25. Fox RC. Cultural competence and the culture of medicine. New England Journal of Medicine. 2005; 353:1316–1319. [PubMed: 16192475]
26. Longmore PK. Medical decision making and people with disabilities: A clash of cultures. Journal of Law, Medicine and Ethics. 1995; 23:82–87.
27. Bach JR, Tilton MC. Life satisfaction and well-being measures in ventilator assisted individuals with traumatic tetraplegia. Archives of Physical Medicine and Rehabilitation. 1994; 75:626–632. [PubMed: 8002759]
28. Blaymore Bier JA, Liebling JA, Morales Y, Carlucci M. Parents' and pediatricians' views of individuals with meningomyelocele. Clinical Pediatrics. 1996; 35:113–117. [PubMed: 8904483]
29. Cooley WC, Graham ES, Moeschler JB, Graham JM Jr. Reactions of mothers and medical professionals to a film about Down syndrome. American Journal of Diseases of Children. 1990; 144:1112–1116. [PubMed: 2144943]
30. Cushman LA, Dijkers MP. Depressed mood in spinal cord injured patients: Staff perceptions and patient realities. Archives of Physical Medicine and Rehabilitation. 1990; 71:191–196. [PubMed: 2317136]

31. Gerhart KA, Koziol-McLain J, Lowenstein SR, Whiteneck GG. Quality of life following spinal cord injury: knowledge and attitudes of emergency care providers. Annals of Emergency Medicine. 1994; 23:807–812. [PubMed: 8161051]
32. Goode, D.; Holm, P.; Holst, J.; Perlt, B. Quality of life for persons with disabilities international perspectives and issues. Brookline Books; Cambridge, MA: 1994.
33. Janvier A, Leblanc I, Barrington KJ. Nobody likes premies: The relative value of patients' lives. Journal of Perinatology. 2008; 28:821–826. [PubMed: 18633422]
34. Siperstein GN, Wolraich ML, Reed D. Professionals' prognoses for individuals with mental retardation: search for consensus within interdisciplinary settings. American Journal of Mental Retardation. 1994; 98:519–526. [PubMed: 8148128]
35. Siperstein GN, Wolraich ML, Reed D, O'Keefe P. Medical decisions and prognostications of pediatricians for infants with meningomyelocele. Journal of Pediatrics. 1988; 113:835–840. [PubMed: 3183837]
36. Wolraich ML, Siperstein GN, O'Keefe P. Pediatricians' perceptions of mentally retarded individuals. Pediatrics. 1987; 80:643–649. [PubMed: 3670966]
37. Wolraich ML, Siperstein GN, Reed D. Doctors' decisions and prognostications for infants with Down syndrome. Developmental Medicine and Child Neurology. 1991; 33:336–342. [PubMed: 1710585]
38. Adams N. Positive outcomes in families following traumatic brain injury. The Australian & New Zealand Journal of Family Therapy. 1996; 17:75–84.
39. Hawley CA, Joseph S. Predictors of positive growth after traumatic brain injury: a longitudinal study. Brain Injury. 2008; 22:427–435. [PubMed: 18415723]
40. McGrath J. Beyond restoration to transformation: Positive outcomes in the rehabilitation of acquired brain injury. Clinical Rehabilitation. 2004; 18:767–775. [PubMed: 15573833]
41. Thomsen IV. Late outcome of very severe blunt head trauma: a 10–15 year second follow-up. Journal of Neurology, Neurosurgery and Psychiatry. 1984; 47:260–268.
42. Thomsen IV. Late psychosocial outcome in severe traumatic brain injury. Preliminary results of a third follow-up study after 20 years. Scandinavian Journal of Rehabilitation Medicine. Supplement. 1992; 26:142–152. [PubMed: 1488637]
43. Wood RL, Rutteford NA. Psychosocial adjustment 17 years after severe brain injury. Journal of Neurology, Neurosurgery and Psychiatry. 2006; 77:71–73.
44. Cremeens J, Eiser C, Blades M. A qualitative investigation of school-aged children's answers to items from a generic quality of life measure. Child: Care, Health and Development. 2007; 33:83–89.

Table 1

Demographic Characteristics of 39 Child Participants

Variable	***n***	***M* (SD)**	**Range**
Age at first interview (years)		15 3.4	8–20
Gender			
Female	22		
Male	17		
Injury Severity			
Severe TBI	25		
Moderate TBI	14		
Time since injury at first interview (months)		15.5 (9.8)	4–36
Race			
Caucasian	34		
African American	4		
Pacific Islander	1		
Ethnicity			
Non-Hispanic	35		
Mechanism of Injury			
Motor vehicle	18		
Pedestrian	6		
Sports/recreational activity	6		
Recreational vehicle	4		
Blunt force trauma	3		
Firearm	2		
Social Living Setting			
Suburban	19		
Rural	13		
Urban	7		
Reported Family Income (dollars/year)			
< $20,000	7		
$20,000 to <40,000	10		
$40,000 to <60,000	5		
$60,000 to <80,000	5		
$80,000 to <100,000	5		
≥ $100,000	7		

Table 2

Overview of Children's Common Themes of Exueriences Following Moderate to Severe Traumatic

Theme	Definition	Adjustment Process
It is Like Waking Up in a Bad Dream	A surreal experience trying to make sense of what happened when you are not able to remember the events that led up to your injury and hospitalization.	-Trust others as sources of information, even though it conflicted with their sense of reality
I Thought Going Home Would Get Me Back to My Old Life but It Did Not	Children did not always appreciate the impact that their injuries were going to have on their social life. They were excited to go home and believed it would restore them to their former familiar life, but not long after getting home some realized that they and their social life were changed.	-Recognize, grieve, and adjust to their functional changes. -Recognize, grieve, and adjust to how some other people responded to their functional changes.
Everything is Such Hard Work	Rehabilitation, reintegrating into a school, and getting back into life are all hard work. Everything revolved around their brain injury. Children had frequent doctors' appointments, therapies, and many specific interventions that the parents also designed to help their child and these things kept them from staying in touch and being a kid. Children knew everyone was trying to help them, but they explained it was hard having your social life changed so drastically and to not be part of your social networks.	-Recognize the long-term importance of all the work children have to do and adjust to being left out of social networks because of it.
You Feel like You Will Never be like the Person you were Before	Children used their self (how I see me) and social interaction appraisals (how others see me) to gain a sense of who they were and where they fit in to their world after TBI. In the first interview, children had more negative self appraisals because they were adjusting to their changes and losses (grieving) and they sometimes experienced negative interactions with others.	-Compared their present and past abilities and how other's interacted with them before and after their brain injury.
It is Not All Bad	Although all children relayed some negative aspects of life after TBI, they also reflected on the positive things brought about by the TBI in second interviews. The children described that living with TBI caused them to think deeply about who they were as a person, the value and the meaning of their life, and their connectedness with others.	-Time to adjust to so many changes and grieve the changes and losses. -Find a new sense of self (how they present themselves to others) and a new sense of where they fit in their social world (new meanings). -Support and understanding from others helped children adjust sooner.
Some People Get It, but Many People Don't	Some people were very supportive, but many people did not understand what a brain injury was, what to expect in their recovery, or how to be supportive.	-Accept that others do not understand and learn to forgive those that do not meet your expectations. -Accept who you are and find a new meaning in your social life. -Learn ways to help others understand.

Table 3

Comparison Between Children's Subjective Reports of Social Support and Injury Severity Levels

Child's Subjective Report of Overall Support	Injury Severity	Child's Illustrative Narrative
Positive Support	Moderate TBI	**Female, age 9 years, moderate TBI:** [My first day back to class] 'they signed a thing. Like a BIGGGG card. My friend gave me a--a dog that said get well and a card…. my PE teacher and my other teacher came to visit me at my house to give me this TV. We use it for the [X-Box] 360 so that we can play. I was like WHATTTT!'
	Severe TBI	**Male, age 18 years, severe TBI**: I had the, had my soccer team come visit me, the high school baseball team, the high school track team. And that made getting better easier…. Because I have a lot of friends, and friends make all the difference.
Negative Support	Moderate TBI	**Male, age 10 years, moderate TBI:** `I don't know. It just made me feel bad. They weren't my friends, and I'd be like, "Hey, want to play at recess?" and they'd be like, "No; why would I hang out with you?'
	Severe TBI	**Male, age 15 years, severe TBI:** `others were like, "Whatever." They wouldn't talk to me. And I told them—I was like, "We can talk about anything you want to talk about." "Whatever." Made me feel bad; really, really, really, really, really bad.'

Table 4

Clinical and Policy Implications of Children's Experiences

Themes	Implications Inductively Derived from Children's Suggestions
It is Like Waking Up in a Bad Dream	- When children are confused be patient and approach them in a calm, non-threatening manner. Orientate and reassure them that they are safe. - Parents' should be allowed access to their child at all times in the ICU since they were reported to be the most calming and reassuring to children when they began emerging from their coma.
I Thought Going Home Would Get Me Back to My Old Life but It Did Not	- Educate significant others (family members, friends, teachers and classmates) about TBI recovery and dispel myths and fears about impairments. - Provide peer support mechanisms (community support groups or peer mentors) to children while they are reintegrating into their communities.
Everything is Such Hard Work	- Balance rehabilitation work and parent derived interventions with age appropriate social activities. - Make rehabilitation therapies individualized to child's interests, so that child stays motivated and has fun. - Create and fund innovative interventions that engage child's peers in rehabilitation therapies and community reintegration to assist child to stay connected in social networks during recovery.
You Feel like You Will Never be like the Person you were Before	- Include and fund emotional support services to children during rehabilitation and following community reintegration so that children can learn ways to deal with their changes, find alternative ways to process how others may react to their changes, and identify their positive attributes.
It is Not All Bad	- Educate health care providers and the community that positive meaning can be found in life after TBI when the child is positively supported, accepted by others. - Educate health care providers with an ecological understanding of the factors that influence disability.
Some People Get It, but Many People Don't	- Fund and provide mental health services, peer support and/or support group services as a part of children's recovery process. - Incorporate children's perspectives into more research, so that our theories, interventions, policies, and future research is more relevant to their needs.