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RESEARCH PAPER

"I've never been a yes person": Decision-making participation and self-conceptualization after severe traumatic brain injury

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ABSTRACT

Purpose: Although adults who sustain a severe traumatic brain injury (TBI) require support to make decisions in their lives, little is known about their experience of this process. The aim of this study was to explore how participation in decision making contributes to self-conceptualization in adults with severe TBI.

Method: We used constructivist grounded theory methods. Data included 20 in-depth interviews with adults with severe TBI. Through a process of constant comparison, analysis involved open and focused coding until clear categories emerged and data saturation was achieved.

Results: Self-conceptualization emerged as a complex and multifaceted process, as individuals with TBI aimed to reestablish a sense of autonomy. We describe a recursive relationship in which decision-making participation assists the dynamic construction of self, and self-concept contributes to the experience of making decisions. The role of an individual's social support network in acting as a bridge between participation and self-conceptualization is presented.

Conclusions: Findings emphasize that contributing to decisions about one's own goals across a range of life areas can reinforce a positive self-concept. It is vital that supporters understand that participation in decision making provides a pathway to conceptualizing self and aim to maximize the person's participation in the decision-making process.

➤ **IMPLICATIONS FOR REHABILITATION**

- Previous research has identified that the experience of sustaining TBI has a significant impact on a person's conceptualization of self.
- This study identified that decision-making experiences play an important role in the ongoing process of self-conceptualization after injury.
- Decision-making experiences can reinforce a person's self-concept or lead them to revise (positively or negatively) their sense of self.
- By maximizing the person's decision-making participation, those around them can support them to develop positive self-attributes and contribute to shaping their future goals.

Introduction

Self-concept has been defined as a "multi-dimensional, internal representation of the individual".[1] It consists of the collective characteristics we consider our own, including our thoughts and feelings about who we are.[2] It is dynamic and continuously under revision, and both influences and is influenced by the decisions we make and the goals we set for ourselves.[3] There is a growing consensus that major and unexpected life events, such as traumatic brain injury (TBI), resonate in one's personal narrative.[4–8] The subsequent changes in an individual's self-concept are then reflected in the decisions they make and act upon. This study explores the interface between the experience of decision making and the process of self-conceptualization after TBI.

The impact of TBI on decision making

TBI is a high-prevalence injury [9] and has been described as a significant public health concern internationally.[10,11] Young people

are at particular risk of injury, with a peak in occurrence among those aged 15 to 24-years old.[12–14] TBI is, therefore, often a source of lifelong disability,[15] with resulting economic and social costs to the individual, family, and community. Individuals who have sustained TBI frequently experience changes in their physical, cognitive, behavioral, emotional, and/or psychosocial functioning, leading to longer-term disability.[16–18] Decision-making impairment is a common neurobehavioral consequence of severe TBI.[19]

Decision-making difficulties primarily relate to damage to the prefrontal areas and frontal systems, which are particularly vulnerable to injury in TBI.[20–23] As a result, individuals with TBI may experience issues both formulating goals and persisting in goal-directed behavior.[24,25] Furthermore, as TBI may lead to significant changes in an individual's life course,[26] adults with TBI may be faced with a range of new and/or unanticipated decisions relating to, for example, health and financial matters, rehabilitation goals, and decisions about their employment, relationships, and living arrangements.[25,27]

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In practical terms, we all make decisions through the course of each day. Our decisions reflect who we are and what we value.[28,29] Some of our decisions may appear minor or inconsequential, such as what we eat or what we wear. Others may have greater consequences for our lives, such as where we choose to live or with whom we enter into a relationship.

In Western societies, decision making is generally perceived as a self-generated process. Autonomous decision making is predominantly understood as a process whereby decisions are driven by the self,[30] and made with intention and without undue interference from others.[31] A consistent finding across the literature is that people with TBI are at risk of having reduced participation in their own life decisions.[8,32–34] It has been argued that this is, at least in part, due to the failure of others to recognize the ability of individuals with a disability to make decisions about their lives.[35]

Self-conceptualization after TBI

There is a growing body of literature investigating the self after TBI.[1,6,36–41] Researchers have noted a lack of agreement relating to how the self is defined and conceptualized, including imprecise distinctions between a number of related terms and concepts (such as sense of self, self-identity, self-knowledge, and self-concept).[42] Despite this, literature within psychological and sociological fields generally describes two separate characterizations of self.[43,44] First is the multiple selves perspective, in which identity consists of several selves which are situational and dependent on context and environment. Second is the dispositional perspective, in which the self is stable and consistent across situations and over the life course. There is evidence that chronic illness can alter both situational and dispositional self-concept.[37,45] Changes to self-concept occur in a dynamic and cyclical fashion after TBI, as the person develops awareness of the consequences of the injury and adapts to new experiences and challenges.[1,38,46] A person's social environment and their interactions with others plays a crucial role within this context.[1,36,39] In particular, those in the person's support network may both provide feedback about injury-related impairments, and offer support and opportunities to manage these impairments.

Exploring decision-making participation in the context of the self

The relationship between participation in decision making and self-conceptualization after brain injury has not previously been explicitly explored. However, three key findings from the research suggest a potential interface between decision-making experiences and the post injury self-narrative. These include (1) evidence of the relationship between an individual's goals and self-concept after injury, (2) loss of autonomy as a common experience for adults with TBI, and (3) the role of support in empowering (or disempowering) adults with TBI to make decisions and act autonomously.

Goals have been described as both arising from and contributing to self-concept.[3] While goals are conceptualized in a narrow sense within a rehabilitation context, evidence suggests that each of us holds life goals that exist in a complex hierarchy.[47] Life goals can be thought of as a collective representation of an individual's decisions across multiple domains, in reflecting the life they would like to lead and the person they would like to become.[48] In exploring the dynamic evolution of the self for adults with severe TBI, Douglas [1] illustrated the important role that goals and goal achievement played in this process, therefore,

highlighting a potential relationship between goal determination, decision making, and self-conceptualization.

Several researchers have provided evidence that adults with TBI experience a loss of autonomy following injury.[7,49,50] This experience may be directly related to injury-related impairments, including experience of "loss of connection between one's mind and body",[51] which negatively impact on an individual's sense of agency.[8,39,42,46] These findings point to the potential role of decision-making participation in providing a means to overcome the loss of autonomy described by adults with TBI.

Finally, while the self emerges through activity, it also exists in social relationships.[52] Adults with TBI have reported how their self-concept is shaped through their interactions with others, noting that their individuality is overlooked by others [41] and that they are perceived to be "marginalized and dependent".[53] Freeman et al. [54] described the impact of social interactions in shaping self-concept and its potential implications for decision making. In response to feelings of guilt and shame resulting from their interactions with others, participants in their study described that they withdrew from social interactions and/or followed the lead of others rather than feeling that they were able to exercise autonomy in their own lives. Other authors, such as Lawson, Delamere, and Hutchinson,[55] identified a failure of brain injury rehabilitation programs to offer personally meaningful decision-making opportunities, and highlighted how this threatens a person's self-concept. In contrast, personal autonomy and dignity were enhanced by support in social relationships that reflected love, respect, and understanding [7].

Research purpose

In recognizing that adults with TBI are at risk of developing a negative self-concept [36,56] and the importance of finding ways to intervene in this process, the objective of this study was to explore the role that participating in decision making plays in self-conceptualization after severe TBI. In addition, we aimed to use participant exemplars to illustrate this process in action. This study is part of a larger research project that aims to develop an understanding of the process of decision making after severe TBI, by exploring the experiences of individuals with TBI and those they identify as participating in decision making with them (including their spouses, parents, friends, and support workers). Institutional approval to conduct this study was granted by the La Trobe University Human Ethics Committee prior to its commencement.

Methodology, methods and data analysis

Guba and Lincoln [57] argue that "questions of method are secondary to questions of paradigm". Within a constructivist paradigm, this study utilized grounded theory methodology in order to develop a deep understanding of the subjective experiences of adults with severe, chronic TBI in making decisions about their lives since injury. Grounded theory has been defined as "the discovery of theory from data systematically obtained from social research".[58] It emphasizes "explication and emergence",[59] with the researcher using an iterative process of data generation, analysis, and conceptual theorizing in order to allow concepts to emerge from data.[60] In comparison to more traditional versions of the method, constructivist grounded theory differs in relation to assumptions regarding the position of the researcher.[61] Charmaz [62] describes a number of principles central to contemporary constructivist research practice, including the importance of treating the research process as a social construction, scrutinizing the direction of research, and ensuring that sufficient data are

collected to enable the researchers to build an understanding of how participants construct meaning in their lives.

Symbolic interactionism provided a theoretical perspective for the research, in line with the view that individuals are active agents in their lives who constantly adapt as a result of their interactions with others.[63] Adopting a symbolic interactionist perspective, therefore, required the researchers to explore the ways in which individuals view the world and how their past experiences and interactions shape their actions.[64] Grounded theory provided a systematic means for doing this.[65]

Participants

Potential participants were identified and invited to participate through community-based rehabilitation clinicians, brain injury services, and support groups in the eastern states of Australia. A selective sampling approach was initially adopted based on five inclusion criteria: severe TBI (defined as more than 7 days of post-traumatic amnesia); TBI acquired at 16 years or older; aged between 18 and 55 years at the time of initial interview; living in the community; and able to communicate responses verbally or in writing during a 30-min interview. As the study progressed, theoretical sampling was used to explore emerging categories through the recruitment of participants with similar and divergent experiences and follow up interviews with participants.[66]

Eight adults with TBI agreed to participate (see Table 1 for demographic details). Each had sustained a severe TBI resulting from a fall, sporting accident or motor vehicle accident. All were in the chronic phase (7–29 years) post-injury. Participants presented with moderate-severe levels of disability, as measured on the Extended Glasgow Outcome Scale (GOSE).[67] All were able to provide consent to participate in the study. Seven of the eight participants were born in Australia. The remaining participant was born overseas and moved to Australia after sustaining a TBI.

At the time of their first interview, four participants were single and four had a spouse. Three of the four partnered participants had commenced a relationship with their current spouse after sustaining a TBI. All the participants lived in the community: four with their spouses, one with a sibling, two lived alone with formal and informal support, and one participant lived in a large supported accommodation facility for people with a range of cognitive and psychosocial disabilities. Seven of the eight participants were engaged in full-time work or study at the time of their injury. At the time of initial interview, two participants were employed on a part-time basis and the remaining six participants were not in paid employment. As noted in Table 1, each

participant has been assigned a pseudonym in order to meet requirements in relation to confidentiality.

Data generation and analysis

This study draws on a total of 20 individual in-depth interviews. All interviews were conducted by the first author, a speech pathologist with experience in brain injury rehabilitation. None of the participants were known to the interviewer prior to participation in the study. Data generation occurred in the period between August 2012 and May 2014, with each of the eight participants taking part in either two or three interviews over a 12-month period. Interviews ranged from approximately 45 to 155 min in length. The interview format was largely unstructured, with an emphasis on participants being able to discuss issues of primary importance to them. In initial interviews, participants were asked to reflect on decisions that they had made since injury. Topics explored included types of decisions, reasons and/or triggers for these decisions, identification of decision-making support, and decision-making processes used. Second and subsequent interviews began with a review of the previous interview and discussion of concepts that had emerged from the analysis process to date. The interviewer explored whether these concepts resonated with participants and how their own experiences may have been similar or different. In this way, prolonged engagement with participants was used as a form of member checking. Participants were also asked to describe more recent decisions they had participated in and how these decisions had taken place. All interviews were digitally recorded and later transcribed verbatim by the first author. Interview transcripts were augmented by the interviewer's field notes which captured her observations and placed the data within a socio-demographic context.

Data were entered into NVivo 9 to assist data management.[68] Each transcript was read independently by the first two authors, with an initial focus on the development of provisional codes using gerunds.[69] Where discrepancies arose, the researchers returned to the original transcripts and achieved consensus through discussion and comparison across transcripts. Using a process of constant comparison whereby similarities and differences in participants' experiences were compared and contrasted, the researchers then developed focused codes. Alongside and throughout this process, memos were written by the first author. Memos served as a means of exploring emerging codes, identifying any issues that required further analysis, and summarizing previous notes. This process was repeated until clear categories and sub-categories emerged, and concluded when no new themes were evident (i.e. data saturation was apparent).

Table 1. Demographic details of participants.

Name[a]	Age at interview (range)	Cause of injury	Years post injury	Impairments reported by participant	Level of disability (GOSE)[b]	Status when included in study
John	50–59	Motor vehicle accident	29	Physical/mobility, speech	SD−	Single, living in supported accommodation, not in paid employment
Anna	40–49	Sporting accident	17	Cognitive, speech	SD−	Living with spouse and children, not in paid employment
Mick	40–49	Motor vehicle accident	19	Memory	SD+	Living with spouse, not in paid employment
Peter	40–49	Motor vehicle accident	8	Memory, speech	MD−	Living with spouse and child, not in paid employment
Beau	30–39	Fall	7	Physical, memory, speech	MD−	Single, living alone with support, not in paid employment
Rhys	20–29	Motor vehicle accident	10	Physical weakness, speech	MD+	Single, living alone with support, part-time employment
Cameron	30–39	Fall	9	Memory	MD+	Single, living with family, part-time employment
Rose	40–49	Motor vehicle accident	14	Physical/mobility	SD−	Living with partner, not in paid employment

[a]Please note that pseudonyms have been assigned to each of the participants.
[b]Level of disability [67]: SD+: upper severe disability; SD−:lower severe disability; MD+: upper moderate disability; MD−: lower moderate disability.

Research quality

Strategies to address the concepts of credibility, originality, resonance, and usefulness [70] were embedded in the methodological process in order to enhance the quality of the study. Prolonged engagement with participants increased the study's credibility by improving the researcher's ability to develop a deep understanding of the underlying phenomena [71] and providing opportunities to discuss emerging themes with participants. Credibility was further enhanced through regular meetings of the research team in order to discuss the emerging findings. Originality and resonance were established by presentation of the emerging themes at a number of conferences in brain injury rehabilitation and supported decision making. Additionally, illustrative quotes and participant exemplars are presented in order to demonstrate that the emergent theory is grounded in participants' experiences and reflects their narratives. Feedback provided by people with TBI, their families and professionals following the presentation of these findings, and the implications derived from the findings for maximizing decision-making participation reflect the usefulness of the findings.

Findings

The central finding emerging from the data reflected a process of *reestablishing autonomy* after TBI and revealed a powerful link between the constructs of decision-making participation and conceptualization of self, and the constructs of support and decision-making participation. In presenting the results of this study, these two major categories are described. Three exemplars of this process, drawn from the rich insights of participants, are presented in order to highlight the role of decision-making supporters and the impact of decision-making experiences on shaping future goals.

Conceptualizing self through decision-making participation

The first major category to emerge from the data reflected the dynamic process of self-conceptualization and its relationship to participants' experience of decision-making participation. Data highlighted that decision making occurred in the context of setting and acting on individual goals and priorities after TBI and, as such, provided a medium through which the self is continuously refashioned. Participants described that self-conceptualization and decision making were intricately linked, as their comparison of past, present and future selves drove action and participation in decision making. Within this category, interview data reflected participants' knowledge of self (Who I am) and evaluation of self (How I feel about myself).

Who I am

Knowledge of self reflected participants' attributes and goals for the future. In broad terms, participants' attributes shaped their approach when making decisions and their interactions with others during the decision-making process. Peter described himself as being *"caring and loving"*, and Rhys as someone who worries *"about others before myself"*. Both participants described that these attributes shaped their approach to making decisions in seeking outcomes that reinforced these attributes. However, injury-related impairments sometimes provided a complication, with Peter reporting he sometimes made decisions that he regrets *"for days and weeks afterwards"* because his actions were in conflict with his self-concept.

A common attribute described by participants reflected being a decision maker and exercising autonomy. This was captured in statements by several participants, including *"I'm fairly strong minded"* (Anna), *"I'm fully independent"* (Beau), and *"I've got my own brain … I've never been a yes person, you know what I mean"* (Rose). Participants described that while being a decision maker was a highly valued attribute, it was often in conflict with the way they were perceived by others. Making their own decisions, therefore, provided an opportunity to reinforce this attribute. Equally, for a small number of participants, the experience of having decision-making opportunities removed from them led to a revision of their self-concept as someone who relies on others to make decisions: *"I just walk away and leave it, and go, 'It's up to you'"* (Mick).

Participants also reflected that their goals motivated them in relation to the decision-making opportunities they sought and the approach they adopted when making decisions. While participants described that their goals spanned a range of life domains, the data captured an underlying goal of wanting to exercise autonomy. This goal was described as wanting to become *"a more confident independent person"* (Cameron) and *"trying to get more control back"* (Peter). It related to a desire to exercise greater control in their lives, particularly in specific areas of their life that were most important to them, such as living alone or being viewed as a capable mother. For many participants, goals around their independence grew as they experienced feelings of being autonomous and had the opportunity to make more decisions on their own.

How I feel about myself

The data revealed that how participants felt about themselves influenced their thoughts and actions in decision making. These feelings reflected both their attitudes to self, shaped through interaction and comparison with others, and their previous experiences of success. Together, these factors shaped their motivations for decision making, the types of decisions they made and the support they sought in making decisions.

Participants' statements reflected that their attitudes were shaped by their interactions with others, and self-comparisons against their pre-injury self, their non-injured peers and others with TBI. The attitudes of others provided a source of motivation for participants and guided them towards particular decision pathways. For example, all the participants described situations where they had been treated by others as *"unable to make decisions"* (Anna). Mick described being *"rendered useless"* by others since his injury. Others described being *"treated like a moron"* (John), *"called a robot"* (Peter) and being *"spoken down to"* (Beau). For some, these attitudes were demotivating and imparted a sense of hopelessness, which then pervaded their approach to making decisions. For others, it provided a sense of motivation to overcome or disprove these attitudes. Similarly, participants described that their attitude to self was influenced by comparison against those in their peer group. Cameron reflected that it had been *"a constant theme of my recovery. I just want to be like everyone else"*. Despite highlighting the difference in their life courses, these evaluations supported participants to focus on set goals and make decisions in particular life domains, particularly with regard to relationships.

Participants described that their achievements spanned a range of life roles and domains. Over time, achievements became attributes and shaped the decisions they made. Across a range of life domains, participants highlighted their achievements in incrementally rebuilding a sense of autonomy. Making decisions provided a vehicle for them to exert control in their lives, and gradually develop their independence, as captured in the following quote by Peter: *"For the first 5 years post-accident, my wife basically done*

everything for me … From 2008 onwards I started to crawl back and take more control". For many participants, early achievements reflected making simple or mundane decisions with less support. These achievements grew over time as they developed a sense of achievement in making decisions: "I feel like I'm more capable of making decisions. I lost confidence in myself years ago … I thought, you know, "I can't do it," but now I know I can do it" (Cameron).

In addition to demonstrating the link between decision making and self-concept, data also revealed that the bridge to self-conceptualization through decision-making was manifested through support. Those around the person with TBI provided a buffer against negative social comparisons and provided feedback that supported participants to recognize their achievements. Participants also described that their social network played a direct role in facilitating their participation in making decisions.

Experiencing support through participation

The second major category captured the relationship between making decisions and social support. Interview data highlighted the vital role that the people around the person with TBI have in supporting their decision-making participation and, in turn, influencing the conceptualization of self. Participants described the varied sources of social support that shaped their decision-making experiences. Additionally, the support process took many forms which shaped the level of active involvement that the person with TBI had in making decisions.

The data revealed that people in a variety of roles around the individuals acted as decision-making supporters. Participants noted that family members were the primary providers of this support. In particular, parents and domestic partners were identified as most often taking on this role with siblings providing support to some participants. Cameron described that his father had "[helped] my other brothers … [but] he's had to go that next step with me". Rose reflected that "[having support] is very important. I don't know how I would have survived without [my partner]". Friends played an essential role for others, particularly where family relationships were less positive. Several participants described that paid professionals, such as rehabilitation clinicians and disability support workers, were an important source of social support and provided both emotional and practical support. For example, Peter described that "there [were] quite a few things [his psychologist] has been instrumental to", including supporting him to make decisions around employment, family relationships, and leisure.

Despite the different sources of support, the data signaled that support was necessary to commence the decision-making process. Participants valued supporters who had an understanding of their self-concept, and demonstrated an ongoing commitment to the relationship. One participant, John, reported that a lack of understanding about his brain injury was a barrier to forming and maintaining relationships, which impacted on the support he had available to him: "There's not too many people who can understand brain damage, and the results of it. And so they're a bit wary about … me". John's situation highlighted the importance of not only having people in your social network, but having people who understand brain injury, are willing to act as supporters and know the person well.

In addition to their varying sources of social support, participants described that the nature of the support provided to them shaped their decision-making opportunities and the extent to which they were involved in the process. Four distinct methods of support provision were evident in the data: creating decision-making opportunities, providing expert advice, acting on my

behalf, and motivating and providing encouragement. The first, creating opportunities, could involve generating an idea, as described by Beau, "[My friend] sort of came up with the initial idea, but then we worked on it together". Some supporters took a more active role in creating opportunities: "[Mum] went up to the Human Resources manager and just sort of asked … So I was put on three months' work experience" (Rhys). A second approach taken by supporters was to provide expert advice to participants during the decision-making process. Some participants described the value of being able to seek advice from different supporters with varied expertise, as reported by Anna: "I've kind of been selective … There are people who are good at certain things, and you just pick out". More commonly, participants indicated that they had a small number of supporters whose advice they sought and valued for a variety of decisions, as described by Cameron: "I've got a lot from his way of thinking, you know, and sometimes I think well that [is] something that I sort of aspire to". The third method of support reflected that there were times when participants would withdraw from the decision-making process and their supporters would act on their behalf. This type of support was used when a more dogged or sophisticated approach was required, as described by Rose:

> One good thing, I'm really proud of [my partner] (for) was when we were with [trustee]. They've got to send us out a thing and tell us how much money I've got and all that. For about the first two years that we [were] with them they just had my money sitting like in an account that wasn't earning interest or anything like that. So [my partner] … sued [trustee], we got 300-something dollars out of them for loss of interest.

Finally, participants described a method of decision making support in which their supporters provided motivation for them, with several participants describing that their supporters often gave them an extra "push": "I wanted to do it and obviously you get encouragement from your immediate circle" (Cameron). Supporters provided important feedback, which played a critical role in emphasizing participants' achievements. For example, Cameron described that his mother's acknowledgment of his increased independence "makes me feel good". At times when the outcome of a decision was not what the participant had hoped for, feedback from supporters provided a means of maintaining a positive self-concept.

Shaping self-concept through decision making: participant exemplars

Three exemplars from participant data are presented in order to highlight the interaction between decision-making experience and self-conceptualization, and illustrate the role that a person's support network can play in supporting the development of a positive self-concept.

Beau: "becoming that independent person … decision making is involved"

Beau's experience emphasizes the importance of a strong support network in maximizing decision-making participation which, in turn, has a positive impact on the evolution of self-concept. Independence is an important personal attribute for Beau: "[I'm a] big fan of independence"; "I pride myself on my independence"; "I love being independent". However, he describes that he has worked hard to rebuild his independence since his injury and has developed a different understanding of the meaning of independence. For Beau, independence now means having the opportunity to make decisions in all aspects of his life: "It just gives me total independence, decisions I can make for myself". Crucially, Beau

acknowledges the importance of those around him in identifying and taking up decision-making opportunities that support him to do so: *"After a brain injury, one of the… telling factors is … people helping you"*. Having a stable social network around him that offers ideas, encouragement and practical support has supported Beau to set himself new goals that act to further expand his independence, such as moving into his own unit and learning to drive. In Beau's case, it is not only this support but the feedback he is given that confirms his achievements and reinforces his personal attributes: *"My dad said to me, 'You're just working at it and just putting yourself in the right places'"*. These experiences have reinforced his conceptualization as someone who is *"fully independent"*.

Mick: "when all is said and done, I probably make one percent of the decisions"

Mick's experience highlights how the support around a person can both expand and constrain their decision-making opportunities, and the implications this has for self-conceptualization. Mick described how a number of cognitive difficulties resulting from his injury made decision making more difficult. He reported that he often withdrew from the decision-making process as a result: *"What's good about someone making decisions for you? Nothing. Because you should be able to make them yourself… I should be able to do it but I can't"*. Despite his frustration, Mick expressed his relief at being able to rely on his partner's active assistance for many decisions. He described that his partner *"knows how [he] works"* and used his knowledge of Mick to guide his interactions and behavior. As such, his partner was able to suggest strategies that allowed him to maintain his involvement in the decision-making process such as carving out a manageable portion of a decision. Mick reported that there were times when he was happy for his partner to act as a proxy decision-maker, such as when dealing with a service provider that caused them both significant irritation: *"I don't deal with [service provider] anymore, [my partner] does. He's a lot more stubborn, where I'll just get annoyed, he'll sit down and be logical"*. However, Mick recounted that there were times when he had made a decision that was subsequently overridden by his partner. This experience both frustrated him and reinforced a sense of being unable to make decisions: *"Participate in a decision? The last one… probably my laptop. I told [my partner] what I wanted. He made the decision to get this one. And that's the one I got"*.

John: "they couldn't give that to everyone here… so, I just have to put up with no option"

John's situation illustrates the results of an impoverished support space for decision-making opportunities and self-conceptualization. John has a chronic TBI and lives in a large congregate care facility. He identified the proprietors of the care facility as his only support network. While they had an amiable relationship, John reported that he needed to initiate the support process which resulted in a dearth of decision-making opportunities: *"If I need help, I need to go and see them, and they're only too willing to help… but it's up to me. And I don't"*. John reported feelings of isolation and exclusion due to his brain injury. The negative perceptions of brain injury held by those around him impeded his decision-making opportunities. For example, he described that *"when my parents died, my brother… got the most say because he's never had brain damage or anything…"*. His interactions with others reinforced a lack of control in his life. His contact with support professionals (both inside and outside the facility) reinforced a perception of incompetence and sense of isolation: *"I mostly just play it by ear now… most of the plans that I make, the authorities just come in and say, 'This is how you're going to do it… what you're going to do'"*. An administrator with whom he has limited contact had been appointed to manage his finances: *"They're supposed to send me out once a year an account of my money and what it's being used for but they don't anymore… They don't bother telling me where it is or how much I've got or anything like that"*. He reported limited opportunities to effect change in his daily routine: *"There's a suggestion box somewhere or other, where we can put in idle thoughts and suggestions… but, um, I don't know where it is"*. John described that he had now come to conform to the *"stock-standard routine"* of his environment. His self-concept was characterized by a distinct lack of goals and vision for the future. By seeing himself as someone who has limited influence in any aspect of his life, he described that he now *"just let [things] happen, rather than contributing or thinking about them"*. He reports, *"I just have basically given up. I just live each day as it comes instead of planning [for the future]"*.

Discussion

There is widespread acknowledgment of the right of all adults, including those with a cognitive disability, to participate in making decisions in their lives. This stance reflects a need to respond to the historical experiences of many people with disabilities in being excluded from decision making [72] and research highlighting the role of decision-making participation in identity development and personal well-being.[73–75] By exploring the experiences of adults with severe TBI, this study provides further evidence of the importance of decision-making participation through its contribution to the dynamic process of self-conceptualization after injury.

The overarching finding to emerge from the study was a desire on behalf of participants to re-establish a sense of autonomy in their lives. This finding brings together previous literature identifying that people with TBI report being positioned by others as being passive and dependent [53,54,76] and that acting independently is, therefore, central to rebuilding a positive identity [38] and living a productive life.[77] Participants in this study described that being independent was both an attribute, which they demonstrated through participation in decision making, and a goal. Within the context of rehabilitation, independence has traditionally been defined in a functional sense (e.g., being independent in personal care).[78,79] However, the participants in this study conceptualized independence as being autonomous: making decisions and exercising control in their lives. In the process of gradually building their autonomy over time, they recognized that they were interdependent and described the important role that others played in supporting them to work towards their life goals. This finding aligns with previous calls for rehabilitation practice to shift its focus away from assisting clients to maximize their physical independence towards enhancing participation and autonomy.[55,80,81] There is a growing body of research illustrating the impact of TBI on self-conceptualization.[1,37,38,42,53,54,82,83] Based on the findings of previous research, several possible links between decision-making participation and self-conceptualization were identified. The findings of this study provide evidence that the process of decision making affords a medium through which a person fashions the self. The findings also reveal the role of an individual's social support network in acting as a bridge between participation and conceptualization of self.

Researchers have previously described that the self consists of knowledge components and evaluative components.[1,84,85]

In this study, self-concept was described in relation to two central components: knowledge about self (who I am) and feelings about self (how I feel about myself). There is noteworthy overlap between this finding and the model of self-concept described by Douglas.[1] Interestingly, while Douglas explicitly sought to explore how adults with TBI conceptualized self, self-conceptualization organically emerged as central to the substantive area of exploration in this study, participants' experience of participation in decision making.

In line with previous studies, conceptualization of self emerged as a dynamic and cyclical process.[1,38,42] An individual's experiences of decision-making participation were deeply embedded in this process as decision-making participation and self-conceptualization interacted in a recursive manner. This finding aligns with Gracey et al.'s [39] contention that one of the central ways in which people understand themselves after TBI is via their subjective experience of activity. Through an ongoing process of engaging in decision making and evaluating the outcomes of those decisions, participants fashioned their self-concept. There were times when the process reinforced their views of self, and others when it forced them to revise their self-concept (in either a positive or negative fashion). As a result of these changes, participants developed new goals.

There is growing evidence of the role that those around the individual play in supporting them to develop a positive and coherent self-concept after injury.[55,77,82] The findings of this study suggest that there are several ways that those in an individual's social support network can influence their self-concept through the process of decision making, including through their interactions with the person, in giving feedback, and through the provision of support directly aimed at enhancing the individual's participation in decision making.

Increasing attention has been paid to the influence of social identity in influencing conceptualization of self. Social identity theory proposes that we define ourselves in personal terms as well as in social terms.[86] When individuals share a social identity, this provides a basis for common expectations about the nature and provision of support as well as for mutual trust, respect, and communication.[87] The application of social identity theory to the current exploration highlights the importance of considering how a person's social relationships impact on their conceptualization of self and supporting the development and maintenance of positive and valued relationships for adults with TBI in which optimal support may be provided.

Implications for practice

The findings of this study suggest several potential implications for clinical practice. In particular, the findings highlight that intervention after TBI should aim to maximize autonomy rather than functional independence, be based upon knowledge of an individual's self-concept, and focused on the development and support of social relationships.

For close to two decades, there have been calls for a significant shift in the way rehabilitation is conceptualized and delivered in order to refocus its efforts around maximizing autonomy.[80,88–91] While a paradigm shift may be the most effective way of wholly achieving this aim,[92] clinicians may consider immediate steps that support increased decision-making participation in their practice. The findings of this study suggest several possible avenues. First, rehabilitation teams need to ensure that their processes and structures create real opportunities for engagement and decision making by clients. Several participants in this study reported feeling unable to make decisions within the

rehabilitation structures they experienced because of their complexity and lack of responsiveness to an individual's needs. Additionally, while the predominant tools used to measure outcomes in rehabilitation are disability rating scales that remain tied to the measurement of impairments,[93] goal attainment scales measuring change against personally determined goals provide an alternative that position the individual at the center of intervention decision making.

Several authors have called for the multidisciplinary team to focus their intervention around the concept of self-identity.[37,42,82,84,94] The findings of this study highlight the importance of intervention and interaction with the clinical team being based upon knowledge of an individual's self-concept. As it has been argued that individuals are likely to consider intervention that is not aligned with their self-concept irrelevant,[52] links between specific intervention goals and higher order life goals (and future selves) should be made explicit.[95] Knowledge of the person's self-concept can be developed through observation of the person, discussions with them that aim to appreciate how they understand and feel about themselves (using a framework of self-concept to guide these discussions), and conversations with those around them who are important to them.

Finally, participants' insights provide a call for rehabilitation professionals to integrate support of an individual's social relationships into their intervention. In this study, positive relationships provided a vehicle for participants to re-establish autonomy and exercise control in their lives. Participant exemplars highlighted the need for particular vigilance in responding to the often unmet needs of people with limited social support. Systematic exploration of an individual's social networks (e.g., through use of the tool described by Amado [96]) might assist clinicians in assessing the current status of relationships and identify where opportunities to develop new relationships may exist. Further, given the findings highlighted that participants described seeking "expert advice" in relation to particular decisions, the findings add weight to the call for rehabilitation professionals to remain mindful not only of the availability of support around a person but also of the skills and knowledge of the supporters in carrying out this role.[97]

Implications for training and education for supporters

Given the role that those around the individual with TBI play in supporting their decision-making participation and shaping their experience, the role of rehabilitation professionals may also extend to provide training and education to guide those who take on this role. The findings of the current exploration have highlighted several areas that demand particular attention. First, findings highlight the need for discussion regarding principles of human rights underpinning optimal decision-making support. Recent research has described that those providing decision-making support to people with cognitive disabilities are largely unaware of the United Nations Convention on the Rights of Persons with Disabilities or the concept of supported decision making.[98,99] Without this knowledge, supporters may take on the role of a substitute decision-maker (as described by several participants in this study) without actively considering alternative approaches, such as acting as an advocate alongside the person throughout the decision-making process. Second, findings illustrate the need for supporters to tailor decision-making support according to the decision. This could be achieved by providing information about the different roles fulfilled by supporters and encouraging them to consider these roles along a continuum of support. Supporters could be asked to reflect on where the

support they provide is located along this continuum, and negotiate how support is provided with the person they are supporting. Given the complexity of these tasks and the potential cognitive-linguistic challenges experienced by people with TBI, communication partner training could further develop the skills of those acting as decision-making supporters in developing their communication skills in such situations.[100] Finally, supporters require information about the impact of their support on the way that the individual sees and feels about themselves. The exemplars presented in this article could be used to illustrate this relationship for supporters.

Methodological considerations and future directions

The findings of this study must be considered within its limitations. In particular, the scope of the study was limited in relation to injury severity and chronicity. All the participants in this study had sustained severe to very severe TBI and were living in the community with moderate to severe disability. Although the nature of their cognitive disability and level of support required with decision making was unique to each individual, their experiences may not represent those of TBI survivors with less severe injuries. Further, all the participants in this study had chronic injuries (minimum 7 years post-injury). While many participants described the evolution of their decision-making support since injury, research with individuals in the early post-injury period may reveal different experiences. Additionally, although self-conceptualization is recognized as an ongoing process, it could be assumed that each of the participants had already made significant adjustments in their self-concept. Future research could explore how decision-making experiences contribute to self-conceptualization in the early stages post-injury.

The number of participants in this study, while relatively small, is comparable with similar studies [6,38,40,41,53,54,101]. Further, undertaking multiple interviews with participants supported the generation of rich qualitative data, from which several key themes clearly emerged and the relationship between decision-making participation and self-conceptualization was developed. These findings add further weight to the role of the social context in shaping self and the power of positive support relationships. They highlight the need for evidence-based interventions in establishing and sustaining social relationships in situations where they do not exist and provide clear evidence of the importance of decision-making support.

Conclusions

This study aimed to explore how the decision-making experiences of adults who have sustained severe TBI contribute to their conceptualization of self and develop an understanding of this relationship in order to inform clinical practice. Interview data provided in-depth qualitative evidence of the recursive relationship between making decisions in all aspects of one's life and self-conceptualization. These findings highlight the important nature of the social context in ensuring that adults with TBI are provided opportunities to make decisions in all aspects of their lives and support to enable them to take up these opportunities.

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Disclosure statement

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