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Becoming a decision-making supporter for someone with acquired cognitive disability following traumatic brain injury

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ABSTRACT

Despite an increased awareness of society's obligation to ensure that people with cognitive disabilities have access to decision-making support, little is known about how this support should be provided. For people with traumatic brain injury, informal support mechanisms may provide the primary means of support but there is limited understanding of how this aids participation. As part of a larger project using constructivist grounded theory to explore processes used by adults with severe traumatic brain injury in making decisions after injury, the authors explored a single-case study, presented in this article. In particular, the study aimed to build an understanding of the evolution of decision-making support over time from multiple perspectives. Data consisted of seven in-depth, individual interviews with three participants: the central participant, Beau, and two participants whom he nominated as his decision-making supporters. Analysis of the data revealed several key themes relating to both the nature of the decision-making process and the factors that underpinned decision-making support. Relational factors included: (a) knowing who I am and what I value; (b) understanding the nature of the relationship; and (c) working with each other. Process factors included: (a) sharing a vision; (b) adjusting process to decisional circumstances; and (c) developing a supportive network. Findings emphasised that knowing the person well and sharing a focus on maximising autonomy contributed to positive decision-making support. However, the data also highlight potential challenges associated with the role of decision-making supporter and the importance of support for those who take on this role.

Acquired brain injury has been identified as a leading cause of death and disability internationally (Hyder, Wunderlich, Puvanachandra, Gururaj, & Kobusingye, 2007). In Australia, almost 440,000 people identified as having an acquired brain injury resulting in disability (Australian Institute of Health and Welfare, 2007). Traumatic brain injury is the most common form of acquired brain injury, and has its peak incidence among adolescents and young adults (National Institute of Neurological Disorders and Stroke, 2011).

Severe traumatic brain injury is associated with a range of changes, across cognitive, behavioural, and psychosocial domains, which means that increased support is often required to maximise decision-making participation (Blais & Boisvert, 2005; Colantonio et al., 2004; Fellows, 2012; Ponsford et al., 2014; Sloan, Winkler, & Anson, 2007). Compromised social relationships may further affect participation. Research has identified that people with traumatic brain injury frequently experience changes in the nature of their existing relationships, a reduction in the size of their social networks, and increased communication and interpersonal difficulties (Douglas, 2004; Hawthorne, Gruen, & Kaye, 2009; Jumisko, Lexell, & Söderberg, 2005; Morton & Wehman, 1995). These changes may have significant implications in terms of the support available to the person to make decisions and put his or her decisions into practice (Knox, Douglas, & Bigby, 2013), and emphasise the importance of better understanding the nature of support relationships that can maximise the individual's participation in decision-making.

Despite an increased awareness of society's obligation to ensure that people with cognitive disabilities have access to decision-making support, relatively little is known about what ideal support looks like in practice. While there have been several calls for a stronger evidence base regarding the theory and application of formal supported decision-making practices (Browning, Bigby, & Douglas, 2014; Carney, 2014; Kohn & Blumenthal, 2014), there is also a need to better understand how informal support mechanisms may contribute to the goal of maximising an individual's autonomy. This is particularly important because informal mechanisms are the means through which the majority of people with traumatic brain injuries access support (Perlesz, Kinsella, & Crowe, 2000). Further, the interdependent nature of autonomy (Hunt & Ells, 2011; Schipper, Widdershoven, & Abma, 2011) highlights the need to explore decision-making from the perspectives of the range of individuals who participate in the process.

Purpose

This research is part of a larger project aimed at building an understanding of the experience of making decisions after severe traumatic brain injury (Knox, Douglas, & Bigby, 2015a, 2015b). Participants in the larger project included eight adults with severe traumatic brain injury (central participants) and those they identified as supporting them with decision-making. In this article, we explore a single case from the broader study to develop an understanding of the evolution of decision-making support over time from multiple perspectives (individual with traumatic brain injury, parent, and friend). This case was chosen as participants described a number of factors that were of interest. Despite having sustained a severe traumatic brain injury, the central participant and his supporters described a shared and singular focus on achieving independence. This provided an opportunity to explore the "active ingredients" of support and how these factors contributed to a positive outcome for the central participant.

Method

As the aim of this research was to explore the experience of decision-making, the researchers adopted a qualitative design utilising elements of constructivist grounded theory (Charmaz, 2014). The emphasis of this methodology is allowing findings to emerge through an iterative process of data generation, analysis, and conceptualisation, rather

than setting out to verify an existing theory or hypothesis (Dey, 1999). Further, the focus is on developing an understanding of how individuals construct meaning through interactions within a shared social context (Charmaz, 2008; Kennedy & Lingard, 2006). Constructivist grounded theory was selected as it allowed the researchers to explore how social interactions contribute to the decision-making process and influence the provision of decision-making support. It also provided an opportunity to gain a deeper understanding of the experiences of participants from their own perspective and in their own words. Ethical approval to conduct this study was granted by the La Trobe University Human Ethics Committee prior to the commencement of the study.

Participants

Three participants took part in this study. Each has been provided with a pseudonym in order to maintain confidentiality. The central participant, Beau, was a young man who had sustained a severe traumatic brain injury in his twenties. Following his injury, he participated in an inpatient rehabilitation program for approximately 12 months. He continued to have sporadic contact with community-based health professionals in relation to specific rehabilitation goals he had identified. Beau described himself as a risk taker prior to his traumatic brain injury and reported that he had been "doing drugs and alcohol and all the rest of it". Beau also reported that his family relationships had always been complex and difficult and, although he had had a large social network prior to his injury, he currently reflected that "I thought I had hundreds [of friends] … but they probably weren't friends, they were just people. I've only got two close friends [now]."

Beau nominated two people as his primary decision-making supporters. The first was his father, Malcolm. Beau reported that he did not have a strong relationship with Malcolm prior to his injury. His parents had divorced when he was a child, and he spent little time with his father when he was growing up. However, since his injury, Beau reported that their relationship had changed: "I'm close with him now but I don't call him Dad, I call him by his first name." When Beau was discharged from inpatient rehabilitation, he went to live with Malcolm and reported that he often looked to Malcolm for support.

The second decision-making supporter that Beau identified was his friend of more than 15 years, Adrian. Beau described Adrian as "a good person, a good friend … I speak to him probably every couple of days but I see him weekly and he's a good, he's a bit older than me so he can sort of give his outlook on life and I take that in a fair bit." Beau initially met Adrian as his neighbour when he was a teenager and, at the time of his injury, Beau was living with Adrian. Beau reported that Adrian had helped him to arrange his finances and find part-time employment. Although they had had a close relationship prior to his injury, Beau reported that he currently "tells [Adrian] everything I do, like everything".

Procedure

This study draws on a total of seven individual in-depth interviews. All interviews were conducted by the first author, a speech pathologist with experience in working with people following acquired brain injury. The central participant, Beau, took part in 3 interviews over a 12-month period. His nominated decision supporters each took part in two interviews over the same time period. Interviews ranged from 45 to 105 minutes in length, and were digitally recorded and later transcribed verbatim. The interview format was

largely unstructured and interactive in order to enable participants to discuss issues of primary importance to them (Corbin & Morse, 2003). In the initial interviews, participants were asked to reflect on decisions that the central participant had made since injury, including decision-making processes used, and how support was initiated and enacted. Participants were also asked to describe their relationships. In subsequent interviews, individuals were asked to describe more recent decisions in which they had participated and how these decisions had taken place. Interview questions during these later interviews were also designed to explore emergent codes and categories.

Data analysis

Methods of data generation included a series of in-depth interviews and field notes. Interview data were entered into the NVivo 9 software package (QSR International Pty Ltd, 2010) to assist with data management. Analysis of data commenced following the first interview. Initially, coding was undertaken on a word-by-word and line-by-line basis (Charmaz, 2014). Constant comparative methods were used to compare codes within and between interviews. Memos, codes, and diagrams emerging during the process formed the basis of discussion during regular meetings of the research team.

Results

Several themes emerged during the process of analysis that reflected both the nature of the decision-making process and the factors that underpinned decision-making support for Beau. The overarching theme to emerge was that *decision-making is a dynamic and interactional process*. It was clear that the relationship provided the backdrop for this process. Three themes that reflected the relationship in which decision-making occurred for these participants were evident (relational factors). In addition, three themes that characterised how the decision-making process took place emerged (process factors). An overview of these factors is provided in Table 1.

Relational factors

Knowing who I am and what I value
The data provided clear evidence that recognising the essential person at the centre of the support relationship was central to the provision of positive decision-making support. This included both knowledge of the personal characteristics of the individual and an understanding of the person's self-narrative, including an understanding of the individual's history, his achievements, and his aspirations for the future. It also revealed an understanding of how those around the person viewed and interacted with him. In the context of an acquired disability, such as traumatic brain injury, this knowledge provided a means for supporters to engage with Beau as a person first, rather than viewing him as a person with a cognitive disability.

In describing Beau, both Adrian and Malcolm expressed that many aspects of who he was before the injury had endured: "You get to know somebody, you know exactly what they're going to do and say and, a lot of that, the underlying things are still the same" (Adrian). Malcolm reported that, in some ways, he thought the "brain injury's actually

Table 1. Emergent themes: relational and process factors.

Category	Theme	Example quotes
Relational factors	Knowing who I am and what I value	• "I've become very independent which is what I pride myself on … my independence." (Beau) • "You get to know somebody, you know exactly what they're going to do and say, and a lot of that, the underlying things are still the same." (Adrian)
	Understanding the nature of the relationship	• "I obviously see more of him. We've got a closer relationship, a lot closer … [but] I didn't want him to get into seeing me as any sort of crutch. I just wanted to be a safety net, not a crutch." (Malcolm)
	Working with each other	• "I didn't tell my dad any of this, I told [Adrian] the whole way through. And I didn't tell my dad because once again … I had worked out that he's got his own agenda." (Beau)
Process factors	Sharing a vision	• "I was determined that the gift that I could give him would be to coach and mentor him to independence. I didn't want him sitting at home in a wheelchair with a rug over him." (Malcolm)
	Adjusting process to decisional circumstances	• "I just let him tell me what was happening everyday. I didn't go to any of the interviews … or I didn't do any of the paperwork, he did it all. I said to him in the beginning, if you are going to do that, you do it yourself. You don't need to ask everybody, or talk to everyone about it, you just do it." (Adrian) • "When I've got a problem I either talk to [friend A] or Adrian. Adrian is cynical about most things. I know how to work him now." (Beau)
	Developing a supportive network	• "After a brain injury, one of the … telling factors is obviously case management and people helping you." (Beau) • "On all sorts of different fronts, I'm teaching him how to create better relationships." (Malcolm)

made [Beau] a better person, he's sort of a better personality now. He was really, really self-absorbed [before]." This intimate knowledge of who Beau was provided them with significant insight into how his traumatic brain injury had affected his decision-making skills: "He can't make an instant decision … or he can't be put on the spot for an answer. I don't speak to him like that, because I know that it's not going to work. But I've seen him in that situation with other people" (Adrian).

Both supporters recognised that many of the goals that Beau was working towards were "related to things he did before the accident" (Adrian). For example, Malcolm reported that Beau had "always been conscious of how he looks" and that this was strongly related to Beau now being "very focused on getting fitter, having a good body image". In providing decision-making support, this knowledge allowed them to see a bigger picture and understand how the goals Beau set were central to his self-narrative.

From Beau's perspective, recognition of his achievements and his goals for the future directed how and when he sought support with making decisions. In particular, an acknowledgment of the complexity associated with particular types of decisions about "girls and money", and the importance of these domains in the future life he imagined for himself, made him more likely to seek advice in relation to these areas. However, it was also clear that self-conceptualisation is shaped by feedback from others. Over time, Beau reported an increasing level of confidence in his own ability to make decisions in response to positive feedback from those around him: "My dad said to me, 'Beau, I'm quite

surprised with how well you're doing … you're just working at it and just putting yourself in the right places, making the right decisions'."

Understanding the nature of the relationship

Beau had established relationships with both Malcolm and Adrian prior to his injury. Although Malcolm and Adrian reflected that this provided a strong foundation for them to transition into their roles as decision-making supporters, they also described significant changes in their relationships since Beau's injury, including an increased sense of closeness and mutual respect: "it's a relationship that [was] redefined by the accident" (Malcolm). Similarly, Beau described a greater sense of trust in his supporters. Both supporters reported a detailed knowledge and understanding of Beau's views and perspective, based partly on their previous knowledge, and described how this guided their actions: "I just try to think what's best for him, which is what I would've done before the accident" (Adrian).

The data reflected that an additional benefit of having an established relationship for decision-making supporters was having previous experience of working through disagreements. This experience provided a platform for openness and honesty within the relationship. Adrian reported that he drew on his previous knowledge in communicating with Beau: "I think my level of giving him a mouthful probably hasn't changed. It's probably still the same." Equally, both supporters described times when they recognised that a particular decision was important to Beau and they were unlikely to influence his course of action. In these situations, both supporters acknowledged their difference of opinion and provided Beau with space to work through the decision independently: "I ease off. I said what I have to say, and then I leave him … [to] do it" (Malcolm).

Working with each other

A key finding to emerge from the data reflected the different ways in which Beau engaged with his supporters and the ways that his supporters worked with each other. As a group, Beau, Malcolm, and Adrian used a range of informal mechanisms to work through decisions together (e.g., by going out for dinner together once a fortnight). However, there were also times when Beau reported that he sought support from only one of his supporters (or from neither of them), depending on the nature of the decision he was making. He acknowledged that each of his supporters had specialist expertise in at least one domain and he particularly valued their input when making decisions that enabled him to call upon this expertise. For example, Beau particularly valued Adrian's advice in financial matters: "I was in debt when I was living with him, and doing drugs and alcohol and all the rest of it but he got me out of debt … then he put together all my accounts, and like he's really good with money, extremely good with money, so I've sort of learned from [that]." However, Beau described times when he actively withheld information from his supporters if he was not sure that their advice primarily reflected what would be best for him: "I didn't tell my dad any of this. I told Adrian … [but] I didn't tell my dad because I had worked out about a year earlier that he's got his own agenda."

Malcolm and Adrian also reported that there were times when they would discuss or plan their approach to decisions while not in Beau's presence. For example, Malcolm explained that he would occasionally call Adrian to check his opinion in relation to a particular decision: "Sometimes I'll ring [Adrian] and I'll say, 'This is on,' and he'll say, 'He's

already spoken to me about it.' 'What did you say?' 'I told him he was a f..n' idiot.' 'Yeah, so did I, okay good.' " This example highlights several important factors about decision-making support that is provided by more than one person. First, support is interactional and may be influenced by the words and actions of other supporters. Second, at times, supporters may feel they need assistance in determining how best to provide support for the person towards a longer-term goal.

Process factors

Sharing a vision

An important factor associated with the positive outcomes resulting from Beau's support relationship was a shared long-term goal. This goal was defined by participants as "independence". Beau described himself as being "a big fan of independence … being independent and looking after myself." The supporters' actions reflected that they wanted to maximise Beau's autonomy, rather than supporting him to be independent. Their focus was Beau being able to live the life he wanted and to make decisions aligned with this aim. Although both Malcolm and Adrian said that they had reduced their level of support over time, both expected to play some role in supporting Beau with making decisions into the future. Both reported that they were motivated to encourage Beau to make decisions on his own in situations where he was able to do so, and "not [to] see [his supporters] as any sort of crutch … a safety net, not a crutch" (Malcolm). They explained that at times they had advised Beau that he could make particular decisions on his own: "I said to him … if you are going to do that, you do it yourself. You don't need to ask everybody, or talk to everyone about it, you just do it" (Adrian).

Beau's supporters maintained alertness to risk but had learnt that maximising his autonomy required accepting a level of risk. On occasions, particular risks were acknowledged but balanced by awareness that risk provided learning opportunities, as exemplified in the following quote from Malcolm:

> [In the past] I was far more concerned about people taking advantage of him … it wouldn't surprise me if he came to me and said, "Oh, I met this fabulous person and they needed to borrow $500, so I've given it to them." That wouldn't surprise me. But, we all fall for that … And in one way I hope it happens because the lesson is then learnt … the best way to learn a lesson is to have it happen and [think], "Shit, I didn't like that."

Adjusting process to decisional circumstances

The decision-making processes described by Beau and his supporters were dynamic and reflected a need to adapt their approach to factors such as the magnitude of the decision being made (and its potential consequences) and how the decision aligned with their shared vision for the future. All three participants described more intensive decision-making support being provided in the early period post-injury. As well as supporting Beau with many of his day-to-day decisions, his supporters reported that they took on an advocacy role to ensure Beau was linked with appropriate services and supports. As time passed, his supporters explained that their focus shifted to providing support that presented Beau with opportunities to further develop his independence.

Beau's supporters also described times when they had taken a more active role in the decision-making process. Indeed, there were some situations where they made decisions

involving Beau with limited input from him, and their approach appeared to align with a version of substitute, rather than supported, decision-making. For example, Adrian reported that Beau had been asking him for years to take him on holiday. In agreeing to go on holiday with Beau, he reflected on what was important about the holiday for Beau, that "all [the] holidays that he'd taken before the accident were always to beach resorts … [and] that's what he loves" and that Beau "wanted to walk on a beach without his brace on". However, rather than actively involving Beau in the decision-making process in choosing a holiday destination, Adrian considered the key factors relevant to the decision: "an easy place to get to, and cheap … for his budget". He then went ahead and "just organised it, and then told [Beau] what we were doing." Beau's supporters explained that they took this approach when they wished to reduce the time or input required to make a decision or to ensure that a decision was made and acted upon.

Developing a supportive network

While acknowledging the important role that his supporters played, Beau described the importance of a network beyond this: "After a brain injury, one of the telling factors is obviously case management and people helping you … You have to know the right people." A key role described by Beau's decision-making supporters was the development of a supportive network around Beau. This network could provide specialist support in relation to a range of decisions, and also create future opportunities for Beau. As a result, Malcolm saw his role as Beau's decision-making supporter as introducing Beau "to the right people at the right time". He also reported that rather than intervening in Beau's interactions with service providers, he had chosen to focus on developing Beau's skills in working with service providers to maximise the outcomes that Beau was able to achieve in these relationships. These skills included encouraging Beau to outwardly express gratitude for the assistance and efforts of others, with Malcolm highlighting the importance of these actions in "creat[ing] connections … people want to help you because you don't take them for granted".

Conclusion

This case study has highlighted several findings that reflect the nature of successful decision-making support for people with cognitive disabilities resulting from severe traumatic brain injury. Success was defined by the participants themselves as a shared long-term vision of maximising Beau's autonomy and increasing his opportunities to live a life that aligned with his own vision for the future.

In the context of an acquired disability, knowledge of the person prior to injury can provide a solid foundation for supporters to transition into the role of decision-making supporter. It can allow them to see the person in terms of who the person is and what he or she values, not in terms of his or her disabilities. Not all individuals may be in the position of having people around them who are able or appropriate to take on this role. In situations where support relationships may be more newly developed, it is critical that supporters build a deep knowledge of the person (including an understanding of his or her self-conceptualisation) in order to provide person-centred support. Further, it is important that supporters recognise that they can shape the person's self-conceptualisation through their interactions with him or her.

The fluid nature of decision-making in this case study was evident from the descriptions of the approaches taken by supporters at different times. In particular, supporters reported that there were times when they took an approach that aligned more closely with substitute decision-making. They chose this approach for a range of reasons including their own convenience and to ensure that a particular outcome was achieved. The capacity for supporters to adopt this approach, even within the context of a positive support relationship, demonstrates the importance of remaining reflective about their role. This case also emphasises the need to unpack the concept of "best interests" within support relationships. Supporters who know the person well may identify that they are acting in accord with what they deem to be the person's best interests, but may actually be referring to a modified version of best interests based on a detailed knowledge of what is important to the person. However, such an approach remains at odds with popular interpretations of supported decision-making and with the intent of the United Nations Convention on the Rights of Persons with Disabilities (United Nations General Assembly, 2007). These potential nuances must be explored within support relationships to ensure the focus remains on maximising autonomy.

Finally, this case study has highlighted a range of possible challenges related to the role of decision-making supporter. It is important that these challenges are acknowledged and that supporters have access to their own support and assistance. Questions must be raised about whether, when there is more than one decision-making supporter, it is appropriate for supporters to work together to devise a shared approach to providing decision-making support and, if not, how supporters may be able to access alternative support in their roles. Further research that aims to understand the experiences of people with cognitive disabilities and those who support them is needed to explore these and other emerging issues.

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