

“I won’t be around forever”: Understanding the decision-making experiences of adults with severe TBI and their parents

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There is growing recognition of the right of all individuals, including those with cognitive impairment, to make decisions about their own lives. However, little is known about how the process of decision making is experienced after severe traumatic brain injury (TBI). This study used constructivist grounded theory to explore processes used by adults with severe TBI and their parents in making decisions about life after injury. Data consisted of 18 individual, in-depth interviews with four dyads (consisting of an individual with severe TBI and his or her parent). The overlying construct emerging from the data was a process of *reimagining the future*, which influenced how participants approached and participated in making decisions. In line with this construct, two central themes described processes of joint decision making within parent–adult child relationships after severe TBI over time: (1) making decisions with parental support, and (2) reducing parental involvement. These findings emphasise the complexity of supporting decision making after injury, and illustrate that both parents and their adult children with TBI use explicit and implicit

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strategies to facilitate increased participation in making decisions. This study also underscores the need for brain injury clinicians to consider the needs of parents who find themselves in this role.

Keywords: Qualitative; Decision making; Parents; Caregivers; Brain injury.

INTRODUCTION

Traumatic brain injury (TBI) is a significant public health issue internationally (Corrigan, Selassie, & Orman, 2010). The peak incidence of TBI is generally in adolescence and young adulthood, for example, in Australia, TBI-related hospitalisation rates peak between the ages of 15 and 24 years (Australian Institute of Health and Welfare, 2007).

Young adults who sustain TBI are often in the process of becoming independent and developing their decision-making skills. They may be starting to individuate from their parents and relying on them less for support and guidance (Shorland & Douglas, 2010). However, the wide range of sequelae associated with severe TBI, including changes across cognitive, behavioural and psychosocial domains, may mean that individuals with TBI require significant care and support after injury (Blais & Boisvert, 2005; Colantonio et al., 2004; Ponsford et al., 2014; Sloan, Winkler, & Anson, 2007). In relation to decision making, changes in an individual's cognitive functioning are particularly significant and often reflect aspects of executive dysfunction (such as impulsivity, reduced idea generation, and impairments in reasoning and working memory) (Bechara & Van Der Linden, 2005; Dreer, DeVivo, Novack, Krzywanski, & Marson, 2008; McHugh & Wood, 2008). It is common that parents find themselves in the role of providing support to their adult children (Perlesz, Kinsella, & Crowe, 2000), and this support may extend to assistance with making decisions. This may signify a major shift in the nature of the relationship and result in a sense of ongoing parental responsibility (Degeneffe, 2001; Douglas & Spellacy, 2000; Florian & Katz, 1991).

For decades, researchers have investigated the impact of TBI on the family as well as on survivors (Anderson et al., 2009; Brooks, 1991; Douglas & Spellacy, 1996; Ergh, Rapport, Coleman, & Hanks, 2002; Ponsford, Olver, Ponsford, & Nelms, 2003; Sander, Maestas, Clark, & Havins, 2013; Watts & Perlesz, 1999). Understanding the experience of family caregivers is of particular significance because there is strong evidence that improved recovery following TBI is associated with the well-being and adjustment of the primary caregiver and positive family functioning (Rotondi, Sinkule, Balzer, Harris, & Moldovan, 2007; Sander et al., 2002). Previous research in relation to family caregivers has predominantly been concerned with the

measurement of constructs such as psychological distress and family functioning (Schönberger, Ponsford, Olver, & Ponsford, 2010).

There is debate in the literature as to the differential impact of TBI depending on the relationship between individuals with TBI and their caregivers, with several authors proposing that TBI has a more negative impact on spousal caregivers than parental caregivers (Ennis, Rosenbloom, Canzian, & Topolovec-Vranic, 2013; Perlesz, Kinsella, & Crowe, 2000; Serio, Kreutzer, & Gervasio, 1995). The range of reasons provided by researchers for this disparity include clinical observations that mothers are better able to cope with caregiving demands compared to wives (Thomsen, 1984), that the social implications of caregiving are more significant for spouses than for parents (Lezak, 1988), and that spousal caregivers do not have the support of a partner with whom to share the burden (Serio, Kreutzer, & Gervasio, 1995).

In a recent systematic review of depression and anxiety in parent and spousal caregivers, Ennis et al. (2013) concluded that the literature did not suggest a difference between spouses and parents, but rather that there is clear evidence of increased rates of anxiety and depression among family caregivers, irrespective of their relationship to the individual. A range of studies has identified that stress and burden are often increased for both parent and spousal caregivers, although the groups may face different challenges and respond to these challenges in different ways. Of particular significance for parents is the return to their previous role as caregiver when they are in the process of moving into a new phase in their life and were expecting fewer parenting responsibilities (Degeneffe, 2001; Ennis et al., 2013).

For the most part, our current understanding of outcomes for adult children with TBI and their parent caregivers has derived from quantitative studies. However, a growing number of researchers have used qualitative methods in order to gain an in-depth understanding of the relationship between adult children and their parent caregivers after TBI. Most studies have focused on the experience of being a parent to an adult child with TBI, by investigating the parent's perspective in isolation (Carson, 1993; Ishikawa, Suzuki, Okumiya, & Shimizu, 2009; Tabata, 1998; Wongvatunyu & Porter, 2005, 2008a, 2008b). Fewer have included both the parent and adult child perspectives (Kao & Stuijbergen, 2004; Karpman, Wolfe, & Vargo, 1986), and the perspectives of each participant group (parent or child) have often been presented separately, allowing only limited insight into the relational nature of their experiences.

Several common themes are evident across the research into parental experience of caregiving after TBI. Changes in the parents' own relationships have been a frequent finding, including an increased sense of closeness to their adult child, significant changes (both positive and negative) in the dynamics of the family unit, and a reduction in the size of their own social networks (Carson, 1993; Curry, 2006; Kao & Stuijbergen, 2004; Karpman

et al., 1986; Leathem, Heath, & Woolley, 1996; Wongvatunyu & Porter, 2008a). Other shared themes have included parents' difficulties in understanding their child's brain injury and, as time post-injury lengthens, an increased focus on maximising the independence of their adult child (Carson, 1993; Kao & Stuifbergen, 2004).

The critical role played by parent caregivers in making decisions with and for their adult children has emerged in a number of studies. These studies have also highlighted some of the challenges faced by parents during this process. A descriptive phenomenological study of seven parents caring for a young adult with TBI identified "Considering my child's safety" as one of five phenomena that characterised their experience (Wongvatunyu & Porter, 2005, p. 51). This phenomenon highlights the challenge faced by mothers in trying to protect their children from risky situations while also acknowledging that they need to provide them with opportunities to make decisions and live their own lives.

Carson (1993) used a grounded theory approach to investigate parents' experiences of living with a young adult with moderate to severe TBI. She proposed a three-phase theory, "Investing in the comeback", to explain participants' experience, and demonstrate how parents acted in ways that enhanced their child's achievement of "optimal functioning" (p. 167). The challenging role faced by parents when acting as a decision-making supporter for their adult children was highlighted in the second phase, "Fostering independence", with parents describing an inner struggle between the desire to protect their adult children and supporting them to make their own decisions. This struggle was articulated by one parent participant who said: "The last year I've really had to come to grips with the fact that being protective of him because of his accident is not doing him any favours. It's really important to me to care about him . . . but I need to let him make his own decisions" (Carson, 1993, p. 170). This dilemma also emerged in a phenomenological study of the experience of having a TBI or having an adult child with TBI (Kao & Stuifbergen, 2004), with the data revealing a struggle between dependence and autonomy in the mother-child relationship. Similarly, themes of "overprotectiveness" and being the "provider of guidance and advice" also arose in a qualitative case study of 10 parents of young adults with TBI (Karpman et al., 1986, p. 32), although the data in this study did not suggest a dilemma for parental caregivers around the negotiation of independence with their adult child.

Participating in making decisions about one's own life is recognised as a human right that is enshrined in the United Nations Convention on the Rights of Persons with Disabilities (2007). However, it is unclear how individuals with severe TBI who require support to exercise their rights, and those who support them, experience the process. While there have been no detailed explorations of the experience of parental caregivers supporting their adult children to make decisions, previous studies suggest that there is

a range of challenges associated with this process. Understanding this experience will provide insights into the processes used in informal supported decision-making arrangements and the barriers to maximising participation in making decisions. The relational nature of autonomy (Hunt & Ells, 2011; Schipper, Widdershoven, & Abma, 2011) also emphasises the need to explore the decision-making process from the perspective of a range of individuals engaged in the process. Accordingly, this study explores both the adult child and parent perspective in understanding the experience of making decisions after severe TBI.

Given our limited knowledge, the aim of this qualitative study was to explore the processes used by adults with severe TBI and their parents in making decisions about life after injury. This study is part of a larger research project that aims to develop an understanding of the process of decision making after severe TBI. As part of the larger project, the researchers have sought to understand the perspective of individuals with TBI and those they identify as participating in decision making with them, including their spouses, parents, friends and support workers, and develop a model grounded in their experience. Institutional approval to conduct this study was sought from and granted by the La Trobe University Human Ethics Committee prior to the commencement of the study.

METHODS

Crotty (1998) contends that qualitative research is underpinned by four elements: (1) the researchers' epistemology, (2) their theoretical perspective or philosophical stance, (3) their methodology, and (4) their methods. Table 1 outlines the application of these four elements to the current study.

TABLE 1
Application of Crotty's elements to this research

<i>Element</i>	<i>Approach taken</i>
Epistemology <i>What did the researchers consider to be knowledge in this study?</i>	Constructionism
Theoretical perspective <i>What is the philosophical stance underpinning the research methodology?</i>	Symbolic interactionism
Methodology <i>What was the strategy or plan of action?</i>	Constructivist grounded theory
Methods <i>How was information about participants' knowledge and experience generated?</i>	Series of unstructured in-depth interviews

As the aim of this research was to develop an understanding of the process of decision making within the parent–adult child relationship after severe TBI, a constructivist grounded theory approach (Charmaz, 2006) was adopted. Grounded theory provides a suite of systematic strategies for undertaking qualitative research, and is particularly useful as an exploratory strategy when conducting research in areas where there is limited knowledge (Grbich, 2007). Constructivist grounded theory allows the researchers to develop an understanding of how meaning is developed by individuals through interactions within a shared social context (Kennedy & Lingard, 2006). This was essential given that the purpose of this study was to explore how shared meaning is created between adults with TBI and their parents when making decisions about life after injury.

Participants

Members of four parent–adult child dyads participated in this study (see Table 2 for demographic details). Interviews were first conducted with

TABLE 2
Demographic details of central participants and their parents

	<i>CP1 (Anna)</i>	<i>CP2 (Brad)</i>	<i>CP3 (Cam)</i>	<i>CP4 (Rhys)</i>
Age	47	36	32	27
Length of PTA (days)	>21	90	42	51
Level of disability (GOSE) ¹	SD–	MD–	MD+	MD+
Living arrangement at injury	Living alone	Living with friends	Living with parents	Living with parents
Current living arrangement	Living with spouse	Living alone (formal support)	Living with brother	Living alone (informal support)
Current relationship status	De facto	Single	Single	Single
Employment/student status at injury	FT	FT	FT	FT
Current employment status	Not in paid employment	Not in paid employment	PT	PT
Parent	PP1 (Helen)	PP2 (Derek)	PP3 (Daphne)	PP4 (Julie)
Relationship to CP	Mother	Father	Mother	Mother
Marital status	Widowed	Married	Married	Married
Employment status	Retired	FT	FT	PT

¹Level of Disability (Wilson et al., 1998): SD– = lower severe disability, MD+ = upper moderate disability, MD– = lower moderate disability. PTA = post-traumatic amnesia; GOSE = Extended Glasgow Outcome Scale; CP = central participant. FT = full-time; PT = part-time.

central participants with severe TBI, who were identified and invited to participate through community-based rehabilitation clinicians, brain injury services and support groups in the eastern states of Australia. During the initial stage of participation, central participants were asked to identify the people in their lives who participated in decision making with them. Four central participants identified a parent as fulfilling this role. Participants were asked to provide information about the research to their identified parent, and parents were then invited to contact the researcher if they wished to participate. All four parents who were identified agreed to participate and subsequently took part in a series of interviews with the researcher.

Central participants (CPs) were three males and one female aged 27–47 years at the time of initial research participation. Each had a severe TBI resulting from a fall, sporting accident or motor vehicle accident. All were in the chronic phase (7–17 years) post-injury and presented with moderate to severe levels of disability, as measured on the Extended Glasgow Outcome Scale (GOSE) (Wilson, Pettigrew, & Teasdale, 1998). All participants were aged 17 years of age or older when they sustained their TBI, and therefore had some experience of independent decision making prior to their injury. At the time of initial interview, two CPs lived alone (with paid formal support or informal family support) and two lived with other family members (a spouse and a sibling). Apart from one participant who lived in a domestic partnership, the remaining CPs were single.

Parental participants (PPs) were three mothers and one father aged 50–76 years. All lived in the same city as their adult children with TBI. Three were married and one was widowed. One was retired and the remainder were employed, either full-time (2 participants) or part-time (1 participant). Pseudonyms have been allocated to both central and parental participants and certain identifying data have been withheld in order to address requirements in relation to confidentiality.

Procedure

This study draws on a total of 18 individual in-depth interviews. All interviews were conducted by the first author, a speech pathologist with clinical experience in brain injury rehabilitation. The interviewer had no previous clinical relationship with any of the participants. Participants each took part in two to three interviews over a 12-month period. Interviews ranged from 45 to 155 minutes in length (mean = 72 mins). Each interview was digitally recorded and later transcribed verbatim by the interviewer. Information contained in interview transcripts was augmented by field notes and a reflective journal kept by the first author.

Although interviews were interactive and unstructured in format to provide participants with control over the interview process and allow them to fully

explore issues of importance to them (Corbin & Morse, 2003), a broad topic guide was used to facilitate discussion. For central participants, questions initially centred on their experiences of both major and day-to-day decisions, including the type of decisions they made, how those decisions came about, and the support processes they used in making decisions. A range of general and specific communication strategies, including those outlined by Douglas (2013), were utilised to enhance communication and support the participation of individuals with TBI. These included ensuring that interview location had minimal distractions and that communication breakdowns were managed proactively through the provision of scaffolding strategies. In interviews with parental decision-making supporters, participants were asked to discuss their adult children, their relationship with them, and then to talk about some of the decisions that they had made since the injury, including describing their involvement in the decision-making process. In subsequent interviews, individuals were asked to describe recent decisions they had participated in and how these decisions had taken place. Interview questions during these later interviews were also designed to explore codes and categories that were emerging from the data.

Data analysis

Management of the data was assisted by entry of interview data into the NVivo 9 software package (QSR International Pty Ltd., 2010). Each transcript was read independently by the first two authors. Data analysis commenced following the first interview, in line with the methods described by Charmaz (2006). Initially, coding was undertaken on a word-by-word and line-by-line basis. At this stage, the authors were particularly interested in “in vivo” codes that allow experience to be coded in participants’ own words (Corbin & Strauss, 2008). Additionally, the use of gerunds during the coding process ensured the researchers remained focused on the actions and processes that were experienced and described by participants (Charmaz, 2008). Constant comparative methods were used to compare codes within and between interviews. Memos were written in order to clarify and explore emerging categories and identify issues for further investigation. Diagramming was used as an additional strategy to explore the relationships between codes and categories. Memos, codes, diagrams and relevant literature formed the basis of discussion during fortnightly meetings between the research team. Through this process, focused codes and theoretical categories emerged, leading to development of the model presented in this paper.

Quality

It has been argued that grounded theory research should be assessed both in terms of the process used by researchers and whether or not the emergent

findings are grounded in the data (Tweed & Charmaz, 2012). In this study, the concepts of credibility, originality, resonance and usefulness were adopted as measures of quality (Charmaz, 2006). Credibility was achieved through audio recording and transcription of interviews, prolonged engagement with participants including seeking feedback from participants about emerging codes and categories, and regular joint analysis and discussion meetings. Originality and resonance were confirmed through conference presentations and discussions with other clinicians working in brain injury rehabilitation.

RESULTS

In all four participating dyads, participants with TBI nominated only one of their parents as being a primary decision-making supporter. In two of four cases, central participants acknowledged the important role of the other parent in their lives, but did not identify them as participating in decision making with them. The remaining two participants had no contact with the other parent (due to death of the parent or ongoing conflict in the relationship). It is important to note that two participants with TBI identified an additional decision-making supporter besides their parent (one a spouse, the other a friend). However, in this study, we have chosen to focus solely on the experiences of decision making within the parent–adult child relationship.

Despite the relational differences described above, two central themes emerged from analysis of the rich insights provided by participants. Together, these themes, shown in Figure 1, describe the process of joint decision making within parent–adult child relationships after severe TBI. The first theme reflected the factors that supported making decisions together. The second captured the strategies used by participants to reduce parental involvement in decision making.

A guiding construct of *reimagining the future* was evident in participants' changing approach to decision making over time. This construct underpinned the way that they approached the joint decision-making process, and reflected how individuals with TBI and their parents integrated the brain injury into their lives and developed a revised vision of the future. It also provided motivation for the pursuit of greater levels of independence in decision making for the person with TBI. This is exemplified by one parent:

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. I said, "I'm not going to be here forever and I want to know that come hell or high water you could live by yourself . . ." (Derek – PP2).

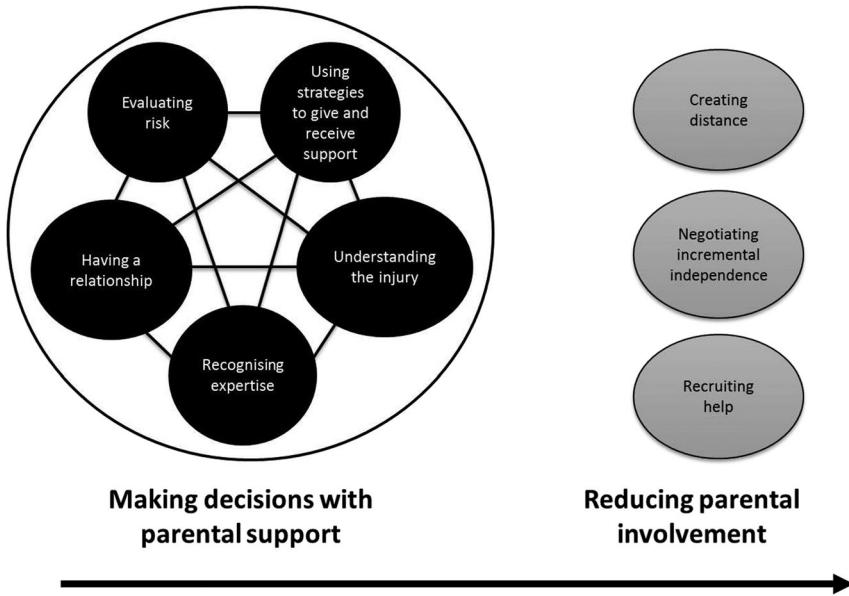


Figure 1. Decision making within parental relationships after severe TBI.

Making decisions with parental support

Participants described a range of factors that supported joint decision making. Five factors emerged as most salient: (1) *Having a relationship*; (2) *Understanding the injury*; (3) *Using strategies to give and receive support*; (4) *Evaluating risk*; and (5) *Recognising expertise*. Shared participation in decision making relied on these five factors being simultaneously present. However, particular factors were more prominent, depending on the nature of the decision being made. For example, the potential outcome of a given decision may lead to the agents involved in the decision-making process placing a greater focus on the risk evaluation, or lead one or both of the parties to adopt a broader range of strategies in attempting to achieve a particular outcome.

Having a relationship. The status and nature of the pre-injury relationship emerged as an important factor in supporting joint decision making. In particular, trust and understanding emerged as critical features of the pre-injury relationship. One participant described his relationship with his mother in his statement, “She’ll only do what’s best for you ...” (Rhys – CP4). Another reported that, “Mum’s been a big support to me all along ... and I’ve been lucky to have someone like that as a mother along the way” (Anna – CP1).

The level of contact pre-injury was also influential. Some dyads had a frequent level of contact prior to the injury. However, this was not always the case, as indicated in the following quote:

I call [my father] by his first name. I met him when I was 12 and I probably only saw him once a month for 12 years . . . (Brad – CP2)

While there was evidence in the data that the pre-injury relationship did not have to be more than at least “good enough”, it was also apparent that the better the pre-injury relationship, the easier it was for participants to enter a joint decision-making process, and take a collaborative approach to managing tensions that arose during the process.

Understanding the injury. Data indicated that individuals with TBI and their parents work through a process of coming to terms with the injury and understanding its implications in light of each person’s unique characteristics. Individuals with TBI described an increasing awareness of the cognitive sequelae associated with the injury and their impact on their decision-making abilities, particularly changes in executive function.

Big decisions . . . made on the spur of the moment. Probably due to the head injury, I think . . . without having the opportunity to think things through logically and carefully. (Anna – CP1)

Like, when I am in a money situation, I still don’t know, if it’s big money, I still don’t know . . . what’s reasonable. (Brad – CP2)

Parents and their adult children also described developing a joint understanding of the injury through their everyday interactions and discussions of functional changes they had observed. Julie (PP4) explained how her interactions with her son have made her more aware that he “had this very frontal . . . still has that impulsive [approach], which can be problematic at times.” Another parent, Derek (PP2), reported that his son will sometimes say, “Oh, that’s the injury,” in relation to his behaviour or actions and that this had acted as a means of developing a shared awareness of the impact of the injury in his life. In combination with having a positive relationship, having a shared understanding of the impact of the injury supported the dyad to acknowledge what was most important to the individual with TBI when working through contentious decisions.

Using strategies to give and receive support. Through developing an understanding of the functional implications of injury, strategies to overcome cognitive impairments, and support participation in joint decision making

were developed. The nature of this support was negotiated within the relationship but, from the perspective of the individuals with TBI, these strategies included maintaining very regular contact with their parents so that they acted as a “back up”.

I talk to [my parents] every day. Yeah. They know. They know what’s going on. (Cam – CP3)

When we have a meeting ... [my mother’s] there as a back stop to remember things I don’t remember. (Anna – CP1)

Participants also characterised this support in terms of advice and reassurance.

I get heaps more advice now. Like, before my accident, I’d just do it all myself ... I get advice so I can make the right decision ... make a good decision. (Brad – CP2)

Sort of, once I’ve got my head around stuff, I’ll bounce it off her. She’s sort of the reassurance. (Rhys – CP4)

A strategy frequently described by parents involved redirecting or shaping the decision-making process towards a revised outcome. While shaping might be seen as an attempt to have unnecessary influence over the decision-making process, parents generally utilised this strategy by first attempting to understand what was important to their child in relation to a particular decision and then trying to achieve a similar outcome through a modified course of action.

Redirecting ... We spend quite a bit of time doing that. When he was on and on and on about this house, we sort of thought, “Okay, if he’s going to get a house, let’s guide him to perhaps just buying an established house.” So we found a house and he bought that ... (Julie – PP4)

Evaluating risk. Evaluation of risk emerged as a key driver in regulating the relative contribution of parents and their adult children to the joint decision-making process. The data provided evidence that there were several areas in which risk was most keenly recognised. First, there was an acute awareness of risk in relation to the individual’s physical safety, in particular, the risk of sustaining a further brain injury.

“You cannot ride a bike,” I said. “It’s just insanity, one more knock on your head and that could be it ... If you think we’re going to go through

the two years we went through with rehab because you want to ride a bike when you shouldn't, nup, not going to happen.” (Derek – PP2)

While Derek's quote suggests an underlying level of parental control in the decision-making process, he also indicated that he would not interfere with his son's decision, even if it conflicted with his own assessment of the risk associated with the decision. For example, despite Derek's expressed wishes, he did not intervene when Brad did attempt to ride a bicycle.

Second, an ongoing assessment of risk in relation to financial matters was reported. This risk particularly related to the individual with TBI making poor financial choices or being taken advantage of by others. Central participants reported some awareness of their vulnerability, especially if they had previously been manipulated by others.

My cousin . . . she and her boyfriend convinced me to buy a house in Bali . . . And then I tried that idea with my dad and my dad just laughed at me. (Brad – CP2)

Parents also described being fearful of their child being taken advantage of financially:

It worries me to death and it's just, you know, people will come and stay with him or stuff and they'll promise to pay him board. Then, “No, no, no, not paying board,” and then it's like they'll go and they'll take bits and pieces with them, that sort of thing. [He]'s very kind hearted . . . there are always those people in society that are going to prey on the vulnerable. (Julie – PP4)

As a result of this perceived risk, parents often retained some level of oversight in relation to their adult child's finances. Parents described using a range of measures to minimise potential risk, such as reviewing their adult child's mail (with their knowledge), helping to review and set their child's budget, making agreements that any financial decisions over a certain dollar amount need to be discussed with them, checking in with them about the spending decisions that they had made, and encouraging them towards particular purchases or financial decisions. In most scenarios described by participants, open and honest communication about financial risk was favoured by both members of the dyad and viewed as a learning opportunity.

Finally, there was an acknowledgement of a different form of risk; risk to the individual's sense of self. Several examples emerged where parents acknowledged the presence of physical or financial risk associated with a decision but weighed this against recognition of the importance of their adult child making and acting upon a decision. In these cases, parents

either acknowledged that their child was more informed in relation to the decision and/or identified the importance of allowing the individual to act as an autonomous agent. Parents reported several examples where they actively minimised their influence and involvement in the decision-making process to enable this to occur. For example, one parent acknowledged that the purchase of a particular model of car by her son was not a decision she necessarily supported, but that she decided not to intervene as she knew that the decision was an important one for him.

I was concerned but it was his passion ... so I don't think I felt that I could step in and say, "Well, you're not doing that," because that's not my passion. (Julie – PP4)

Recognising expertise. The data indicated that parents were particularly active in the joint decision-making process in relation to matters where they felt most comfortable or had particular knowledge and experience that they could offer. Equally, central participants recognised their parents' specialist expertise and highly valued their input in these areas. This perspective was illustrated in an example from one participant whose mother was heavily involved in health and medical affairs, "My grandfather was a doctor, so mum's pretty cluey in terms of medical things ... " (Anna – CP1).

For another participant, his father's experience in starting his own business meant that he viewed him as an expert mentor and guide when he developed a desire to start a business himself.

Starting a business ... my dad helped me out ... [he] sat down and put some more stuff together. He's a bit of a mentor ... he can sort of send me in the right direction. (Brad – CP2)

Reducing parental involvement

The second major theme captured the process of reducing parental involvement in decision making. Individuals with TBI and their parents used a range of strategies in working towards more independent decision making over time. They reported a range of motivations for doing so, including the pursuit of increased independence for individuals with TBI. Parents also reported a desire to reclaim the life they had imagined for themselves prior to their child's injury and recognised that there would be a time in the future when they are unable to support their adult child in the same way as they do at present. This is exemplified by Julie (PP4), who stated: "Certainly other parents have also said to me, 'I'm not going to be around forever' ... that's something [we] really have to think about." Participants described three actions that they used in order to reduce parental involvement in making decisions: (1) *Negotiating incremental independence*, (2) *Creating distance*, and (3) *Recruiting help*.

Negotiating incremental independence. The data reflected that both groups of participants used a range of strategies in negotiating increased independence over time. These included parents testing their child's potential for independence by withdrawing support for a period of time or providing a reduced level of decision-making support within defined limits. Several parents described that going on an overseas holiday was an opportunity for them to test their child's independence. Doing so meant that their children had to manage on their own for that period of time, including making their own decisions without the input of their parents.

We went away last year and ... [my son] said, "I remember, mum, you said to me that when you went on holidays last year, that this was a big test because I had to do all that." (Daphne – PP3)

I went to Vietnam a couple of years ago. It was for two weeks ... I don't get in contact with [my daughter] at all. (Helen – PP1)

One participant described that he now had responsibility for managing his day-to-day budget on his own, but was required to seek a second opinion on decisions exceeding a particular amount of money he had agreed with his father.

Able to budget ... But if it involves big money, I have to get [my father's] opinion. (Brad – CP2)

Brad's father described that he viewed this process of encouraging independent decision making within negotiated limits being similar to "a set of running rails which are defined to some extent by the brain injury and his current situation ... those running rails can change as he progresses" (Derek – PP2).

Creating distance. Both parents and their adult children described creating distance in their relationship, with the aim of individuals with TBI achieving greater independence. Parents adopted a range of approaches to create distance, including reducing the amount of contact they had with their child.

I've had to detach ... I don't ring him every day. 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. (Derek – PP2)

Alternatively, they put boundaries around the contact they had with their adult children, requiring them to make decisions independently, or with alternative supporters, when the parents were not available.

[My married daughter] was ringing me at night ... I now don't answer the phone after 6 o'clock. (Helen – PP1)

Individuals with TBI engaged in a parallel process whereby they sought to achieve independence from their parents. This was a complex process with individuals acknowledging an appreciation of their parents' support on one hand but also reporting a desire to be more like their peers in making independent decisions about their lives.

I did need that [support from my mother] for a while but . . . I want to wean away from that. (Cam – CP3)

As a result, participants described that they had started to make more active choices about when, and in what contexts, they wanted their parents' support with decision making. In some situations, they had chosen to withhold information from their parents in order to exercise autonomy and avoid entering a joint decision-making process.

More recently, I've been holding back on information . . . I sort of don't tell her too much because she sort of gets pretty worried and starts to limit my activities and things. (Anna – CP1)

Recruiting help. The third strategy used by participants involved identifying and recruiting others who could take the place of parents in participating in joint decision making with the individual with TBI. Both participants with TBI and their parents reported that there were a range of people that were able to take on a more active support role. Parents often described that the individual's siblings were being primed to take on the role of decision-making supporter.

[His sister] and her husband will probably be the ones that will take that role on . . . When we're too old and had-it to do anything, they'll be the ones that step up. (Julie – PP4)

Because he is sharing with his brother, [his brother] makes sure that the bills and things are paid. (Daphne – PP3)

However, siblings were not always willing or able to move into this role. In several cases, participants with TBI identified that they had enlisted friends to provide support. For these participants, having access to a range of different people that they could seek support from provided a greater sense of choice and control.

So any big decisions I have to make, I try and get a second opinion . . . whether it be [friend 1] or [friend 2], and less [my father]. (Brad – CP2)
I've kind of been selective . . . but the girls have been really helpful in being supportive in being able to talk to. (Anna – CP1)

DISCUSSION

Following TBI, many parents find themselves once again in a role of providing significant care and support to their adult child. This study sought to build an initial understanding of the experience of decision making within these relationships by exploring the perspectives and experiences of both parents and their adult children with severe TBI.

The overarching finding that emerged was that action was driven by a vision of the future that had been reimagined in the minds of both individuals with TBI and their parents. The process of integrating the brain injury into their lives and developing a new vision for the future guided how both engaged in joint decision making and the extent to which they were active or passive in the decision-making process at particular points in time. All participants described a vision in which the adult child was as independent as possible, including in making decisions in their life. This finding aligns with previous research, in which parents described being motivated to maximise the independence of their adult children over time (Carson, 1993; Kao & Stuijbergen, 2004).

The findings of this study highlight that adults with TBI perceive that maximising their independence in decision making is an important goal, and an indicator that they have made a satisfactory recovery. In many ways, this process of increasingly seeking to exercise autonomy mirrors a typical developmental process whereby young adults seek to individuate from their parents (Koepke & Denissen, 2012). For most participants in this study, individuation had previously been achieved and they were moving through this process for the second time. This finding emphasises the importance of understanding the impact of TBI on the family life-cycle and being mindful of transition periods where tension is most likely to emerge (Jones & Morris, 2013; Rolland, 1987).

In the course of making decisions, two distinct decision-making processes were described by participants: making decisions with parental support and reducing parental involvement. In the initial period post-injury, participants reported that many decisions about all aspects of the adult child's life were made with parental support. Participants described a number of factors that supported joint participation in this process. The parent-child relationship emerged as playing a critical role.

Although some contact pre-injury facilitated an entry into participating in decisions together, participants also described changes in the parent-child relationship post-injury. Curry (2006) noted that the majority of parents in her study described increased closeness in their relationship with their adult child since injury. Positive relationship changes were reported by both groups of participants in this study. The positive connection between the adult child and parent reinforced an ongoing support-seeking process. From

a clinical perspective, these findings provide evidence for the importance of exploring the parent–child relationship in the early stages post-injury, particularly where it appears likely that the parent will take on the role of decision-making supporter. Additionally, strategies to work constructively through conflict and maintain a positive connection are vital.

The importance of mutual positive regard and development of a shared understanding of the impact of the injury and strategies that reflect this understanding again highlighted the relational underpinnings of decision making between parents and their adult children with TBI. The centrality of a positive relationship between parents and their adult children in this study is not surprising, as individuals with TBI who participated in this research nominated their parent as one of the people who assisted them with making decisions. As noted, two participants with TBI also nominated an additional decision-making supporter, highlighting the potential importance of the parental relationship, even where other supporters may be present. It also emphasises that decision making is a complex process, often involving a number of people in the social network of the person with TBI. These findings also suggest that clinicians can play an important role in supporting the individual with TBI by exploring who is involved in supporting their participation in decision making, what roles each supporter plays, and how the nature of interaction between involved participants influences the process.

Participants described that assessing risk was essential in determining the extent to which a joint decision-making process was used. Previous literature has identified that risk minimisation is often a key factor that influences the outcome of decisions about life after TBI (Andreoli, 2010; Knox, Douglas, & Bigby, 2013; Wongvatunyu & Porter, 2005). In this study, parents described that they shaped the decision process at times in order to reduce risk and/or ensure that the outcome aligned with their perception of what was in their adult child's best interests. The challenges associated with decision-making supporters taking a best interests perspective have previously been detailed (Martin et al., 2012). In particular, it has been noted that supporters often experience difficulty being able to extricate their own interests from those of the person they are supporting. This finding highlights the need for explicit discussion regarding drivers in decision making from both the perspective of the parent and the adult child. Making financial decisions represented one area in which parents were particularly active in shaping the decision-making process. Given the implications of restrictions on financial decisions for all aspects of an individual's life, this may be an important area in which parents and their children would benefit from support to develop strategies to maximise independence and mitigate the risk of being taken advantage of by others.

Analysis of the data indicated that parents were more active in decision processes in which they had particular expertise. For parents who perceived

that they were knowledgeable in health or medical matters, this resulted in a high level of engagement in the rehabilitation process and an ability to act as an advocate for their adult child in accessing rehabilitation services, even many years after injury. From a clinical perspective, it is important to gain a sense of parents' previous experience with health and medical matters, in order to identify situations where parents may have limited experience and thus may need additional support from the clinical team to ensure equitable access to services in both the immediate and long term.

An important finding that emerged from this study is that the nature of the decision-making process changes over time, as both individuals with TBI and their parents work towards increased independence and a time in the future when the parent will "exit" as a decision-making supporter. Parents expressed concern about "not being around forever". Fear of uncertainty about support for their adult children into the future is commonly cited as a concern of parents of adult children with an intellectual disability (Bigby, 2000; Cairns, Tolson, Brown, & Darbyshire, 2013; Weeks, Nilsson, Bryanton, & Kozma, 2009). It has been reported that while a majority of carers in this situation may not take concrete steps towards future planning, they may make informal plans for others to become involved in various ways in their absence (Bigby, 1996; Lunskey, Tint, Robinson, Gordeyko, & Ouellette-Kuntz, 2014). Although concerns about the future of adult children with TBI have been noted less frequently in the brain injury literature, parents were strongly motivated to take action to be less involved in the decision-making process. In particular, they were not only motivated by their future absence but also by a desire to reclaim the life they had envisaged for themselves prior to their child sustaining an injury. In areas where parents remained unsatisfied that their children would be able to manage their affairs independently, they engaged in a process of setting up alternative sources of support, such as siblings or a family friend. Not only do these other individuals share the sense of responsibility felt by parents in the short term, they also provide a source of increased certainty about support into the future.

Researchers have identified that, in comparison to spousal caregivers, parents are more likely to be motivated by thoughts about the future in the support that they provide (Allen, Linn, Gutierrez, & Willer, 1994; Curry, 2006). Each of the parental participants in this study reported that they were driven to ensure that their adult child was less reliant on them or had alternative sources of support into the future. In comparison with spousal supporters (Knox, Douglas, & Bigby, *in press*), parents are less focused on the "here and now" when working through the decision-making process, placing a greater emphasis on supporting decisions that align with the future life that they have imagined for their adult child.

Methodological considerations and research recommendations

The strength of this research lies in the methods used. Rich, qualitative data were generated through multiple interviews with participants through engagement over a 12-month period and, from these data, an initial model grounded in participants' experience has emerged. In addition, rather than preferencing a single perspective, this study explored the experiences of both parents and their adult children with TBI. Previously, researchers have highlighted the importance of adopting research methods that seek to understand dyadic experience, rather than the views of only one member of the relationship (Bracy & Douglas, 2005; Godwin, Kreutzer, Arango-Lasprilla, & Lehan, 2011; O'Flaherty & Douglas, 1997). The methods used in this study have provided for the development of a richer, more nuanced understanding of the decision-making process as it is experienced by both groups of participants. However, future studies could incorporate interview data generated by the dyad in the process of making decisions. These data may provide additional insights into how tensions are managed during the decision-making process.

One limitation of this study is the relatively small number of participants. However, several key themes strongly emerged from the data, enabling the development of a preliminary model. Nonetheless, further exploration of the key processes and components of shared decision making after severe TBI is recommended. In particular, since this study has highlighted the complex and relationship-bound nature of decision making, exploration of the processes which are similar and different across a diverse range of relationships is needed.

It is important to note that data from this study were drawn from individuals with severe TBI who, when asked to identify those who participated in decision making with them, nominated their parents. Thus, it can be assumed that there was a level of positive connection between the participants for the individuals with TBI to nominate their parents. These results therefore may not be relevant to all parent–adult child relationships after TBI, particularly in those relationships where there appears to be limited positive regard or a lack of connection. Clinicians should be particularly alert to the support needs of adolescents and young adults where this is the case. Additionally, future research could explore how decision making takes place within these relationships. Purposefully sampling for these participants within relationships where there is unresolved conflict may also provide an opportunity to extend or challenge the model proposed in this paper.

Clinical implications

Prior to this study, there has been limited investigation of the parent–adult child relationship that has incorporated both perspectives and attempted to

build a relational perspective of living with severe TBI. This study has explored one driver of the interactions in this relationship, joint decision making. The preliminary model that emerged from the study provides brain injury clinicians with a method of understanding the process of decision making from the perspectives of the individuals with whom they work. The model illustrates that there are several junctures where clinical intervention can support both the growing independence of the individual with TBI and the maintenance of a positive relationship between the individual and his or her parent. First, the overarching construct of *reimagining the future* that has emerged from this study highlights the important role that clinicians can play in facilitating an ongoing conversation between individuals with TBI and their parents about the goals and vision that they each perceive for the individual's future. Where their positions do not align, support to develop a shared vision that reflects what is most important to the individual with TBI is critical.

Second, the model highlights the potential for tension if individuals with TBI and their parents are not moving through the process at the same rate. For clinicians, particular attention needs to be paid to whether there is mutual engagement at the entry and exit points. For example, if parents wish to reduce their level of support while the individuals with TBI remain heavily reliant on their support (or, alternatively, individuals with TBI wish to become more independent while their parents judge that they still require support), this may have negative implications for the relationship. Clinicians need to remain mindful of the potential for this divergence by supporting individuals and their parents to reflect regularly on the level of engagement they feel in a shared process.

Finally, this study highlights that both parents and their adult children are motivated towards the individual being able to be more independent in decision making in the future. Clinicians can support families to negotiate what independence means for them and assist them to develop strategies that can support the growth of independence, such as building a network of supporters who know the individual well.

CONCLUSIONS

This study provides experienced-based qualitative evidence of the complex journey taken by adults with severe TBI and their parents when making joint decisions about life after injury. A preliminary model, grounded in participants' experiences, illustrates how participants' vision of the future for the individual with TBI plays a critical role in shaping their approach to engagement in the decision-making process. The nature of the pre-injury parent-child relationship played an important role in entering a shared decision-

making arrangement. Within this relationship, decision making was conceptualised as a dynamic process with several actions occurring in parallel. However, over time, parents and their adult children used a range of explicit and implicit strategies in order to facilitate more independent decision making. The findings of this study emphasise the need for health and community professionals working with individuals with brain injury to consider the demands that may be placed upon parents who find themselves in this role. It highlights potential conflict points within the decision-making process. Again, as indicated across the literature, the need for support and intervention to be available to families, even many years post-injury, has been reinforced.

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