

## ORIGINAL ARTICLE

# 'The biggest thing is trying to live for two people': Spousal experiences of supporting decision-making participation for partners with TBI

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### Abstract

*Primary objective:* To understand how the spouses of individuals with severe TBI experience the process of supporting their partners with decision-making.

*Design:* This study adopted a constructivist grounded theory approach, with data consisting of in-depth interviews conducted with spouses over a 12-month period. Data were analysed through an iterative process of open and focused coding, identification of emergent categories and exploration of relationships between categories.

*Participants:* Participants were four spouses of individuals with severe TBI (with moderate–severe disability). Spouses had shared committed relationships (marriage or domestic partnerships) for at least 4 years at initial interview. Three spouses were in relationships that had commenced following injury.

*Main outcome and results:* Two main themes emerged from the data. The first identified the saliency of the relational space in which decision-making took place. The second revealed the complex nature of decision-making within the spousal relationship.

*Conclusions:* Spouses experience decision-making as a complex multi-stage process underpinned by a number of relational factors. Increased understanding of this process can guide health professionals in their provision of support for couples in exploring decision-making participation after injury.

### Keywords

Caregivers, couples, marital relationship, qualitative research, relationships after TBI, traumatic brain injury

### History

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## Introduction

Severe traumatic brain injury (TBI) is associated with a range of changes across physical, cognitive, emotional and behavioural domains, resulting in functional impairments that necessitate the provision of support in the daily lives of individuals who have experienced the injury [1–7]. Where individuals have a spouse or intimate partner, it is likely that they will provide much of this support, requiring a substantial shift within the relationship, including the roles and expectations of the non-injured partner [8–10]. As such, severe TBI necessitates adjustment not only for the person, but also for their family members [11–13].

### Intimate relationships after brain injury

There is a growing literature on the impacts of TBI on intimate relationships. To date, researchers exploring the impact of TBI on spousal relationships have principally focused on the quality and stability of relationships after injury [14]. Evidence regarding the stability of marital relationships after TBI has

been equivocal, with researchers identifying a wide variability in the rate of relationship dissolution after injury. Some researchers have proposed that relationship breakdown is no more common among married couples where one partner has TBI [15], although divorce rates ranging from 15–78% have been reported in the literature [16–18]. However, the comparison of studies is made difficult by the range of methodological approaches taken by researchers and the inclusion of participants with injuries across the severity continuum and at different time periods post-injury [14].

Increasingly, researchers have investigated the factors associated with marital quality following injury. The importance of understanding marital quality is underlined by a growing body of evidence from the sociological and public health literature which suggests that, although the marital relationship holds the greatest significance for individual wellbeing, being in a poor quality relationship may be worse for health than being in no marriage at all [19–21]. Researchers have demonstrated that TBI is associated with a range of factors that may lead to diminished marital quality after injury. These include increased levels of stress and strain, reduced shared social activity, poorer mental health and significant changes in previously held role expectations [8, 9, 15, 22–24]. In addition, the quality of communication within the relationship (particularly within conflict situations) has been

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associated with marital satisfaction [25, 26] and it has been documented that this may be negatively impacted by TBI [27, 28]. Given the impact of injury on spousal relationships and their implications for health [29], identifying and reducing sources of strain should be an important target for health professionals working within these contexts after TBI.

A critical review of the literature examining marriage after brain injury [14] identified that there remains much to be learnt about the characteristics associated with positive marital quality after TBI. However, within the context of TBI, it is well understood that spouses are often the main providers of support and frequently act as the vehicle through which people are able to participate in society [30, 31]. Further, there is significant evidence that many spouses experience increased levels of burden after TBI [32] and that this burden may increase over time [33]. In order to address factors that may contribute to this, it is critical to continue to develop understanding of the spousal experience.

Despite the wide range of spousal relationships in contemporary society, previous research exploring relationships after TBI has focused primarily on the experiences of heterosexual couples in marital relationships. Less is known about the experiences of same-sex or cohabitating couples who are not married. Similarly, there is a dearth of published literature on the quality of spousal relationships formed after an individual has sustained a TBI and the factors that may influence the success and/or longevity of these relationships. While it has been proposed that relationships formed after injury may be less susceptible to breakdown [34], this assumption appears to be based on anecdotal evidence and there is little published data to support this being the case.

### Decision-making after brain injury

Traditionally, decision-making has been conceptualized as a process undertaken by an individual in isolation [35]. There is significant evidence that severe TBI is associated with a range of impairments that may impact on decision-making abilities at the individual level, although the complexity of decision-making processes means that cognitive deficits may manifest in a number of ways [36]. However, newer conceptualizations of disability emphasize that decision-making is a relational process involving both the person and those around them, who may need to provide support and accommodation for the person with disability to participate in the decision-making process [37].

### Decision-making within marital relationships

There is a long history of research into the decision-making processes utilized within dyadic relationships [38–40]. Dyadic decision-making varies from individual decision-making in that it tends to be less orderly and more than one perspective needs to be taken into account [41]. Additionally, the relationship between members of the dyad is of primary importance in structuring the decision-making process. Long-term marital and marriage-like relationships represent a commitment by two people towards a life together, therefore requiring contributions by both towards a range of shared goals [42]. Within these relationships, decision-making may be considered a binding activity in which individual partners

consider each other's needs and work together as a couple. However, in contrast to other relationships, which may be formed for the primary purpose of making decisions, it is not the sole focus of intimate relationships, but rather serves a necessary function in maintaining the relationship [43].

Many of the studies exploring the nature of dyadic decision-making provide only limited insight into the way that couples make decisions in their daily lives. In particular, many studies are experimental and rely on hypothetical scenarios and decisional outcomes are judged against objective criteria [43]. In contrast, dyadic decision-making generally occurs in the context of other activity, topics are emotionally laden and outcomes are frequently relational in nature [44]. Despite these limitations, research has highlighted that couples with close and satisfying relationships use co-operative and constructive decision-making processes based on open and supportive communication, joint goal-setting and consideration of each other's needs [44, 45].

To date, the experience of couples making decisions following TBI has not been explicitly researched and remains poorly understood. However, several studies exploring other aspects of life for couples following TBI have suggested a significant change in the way that decision-making is approached and negotiated within these relationships. In a study exploring relationship and sexual quality after TBI, Gosling and Oddy [10] reported that female spouses described that they had taken on a parental role with 'total decision-making responsibility' post-injury (p. 785). In their study of intimacy in couples after TBI, Gill et al. [28] reported that uninjured spouses found it difficult to balance both their partner's need for support and their need to make some decisions alone. Increased awareness of the spousal experience of supporting their partner is necessary to ensure that health professionals working with people across all service contexts are able to respond to changes in the dynamics of the relationship in a meaningful way.

### Research purpose

This study is part of a larger research project that aims to develop an in-depth understanding of the experience of making decisions about life after severe TBI from the perspective of people with TBI and those who support them with decision-making. This study aimed to capture the unique perspective of spouses in the context of living with a partner with severe TBI and develop an initial model, grounded in participants' experiences, of the process of supporting their partners with decision-making after severe TBI. Better understanding the spousal perspective is significant as experience guides the spouse's actions within the relationship. Thus, it was hoped that exploration of the spousal experience would produce insights that could be used to support the ongoing adjustment of couples living with the consequences of TBI. Although the authors have chosen to focus on the spousal perspective in this study, further exploration of dyadic experiences of decision-making remain essential in order to better understand how this process is experienced and remain a priority for future research. Ethical approval to conduct this study was granted by the La Trobe University Human Ethics Committee prior to the commencement of the study.

## Methodology, methods and data analysis

Given the aim of this research was to develop an understanding of decision-making grounded in the experiences of the spouses of adults with severe TBI, the researchers adopted a qualitative design utilizing elements of a constructivist grounded theory approach [46]. Grounded theory has been defined as ‘the discovery of theory from data systematically obtained from social research’ ([47], p. 2). Rather than attempting to verify an existing theory or hypothesis, researchers using a grounded theory approach allow their findings to emerge through an iterative process of data generation, analysis and conceptual theorizing [48]. Grounded theory is a methodological approach that has been used widely across the health and social sciences [49]. It has been argued that it is particularly useful when trying to develop an understanding of ‘social interactions or experiences’ ([50], p. 103) and was selected as this research incorporated both an exploration of the spousal experiences of making decisions and the social processes and interactions that surround these experiences.

The epistemological position of grounded theory has been described as a continuum, with popular versions of the method incorporating positivist and post-positivist through to constructivist assumptions [51]. The ontological position in this research was informed by a constructivist–interpretivist paradigm [52]. Constructivism is the view that there are multiple social realities and that knowledge about these realities is mutually constructed by the viewer and the viewed through a process of interaction within the world and with others [53]. In adopting a constructivist grounded theory approach in this study, the researchers acknowledged the relationship between researcher and participant as central to the research process. Further, the individual and unique characteristics of participants are valued and this study aimed to build relationships with participants that allowed the development of a deeper level of understanding that extended beyond surface meanings [54]. This study was set out to build an understanding of participants’ experiences via a series of unstructured interviews. By interviewing participants over a period of at least 12 months, the researcher was able to develop a relationship with participants that facilitated an in-depth understanding of their experiences and an exploration of the temporal and relational factors that impacted on their experiences.

## Procedure

A series of in-depth interviews was conducted with spouses of people with severe TBI. Interviews were conducted by the first author, a speech pathologist with clinical experience working with individuals and families following brain injury. Data generation occurred over an 18-month period, with each participant taking part in two interviews. This study draws on a total of eight interviews with four spouses. Interviews lasted between 50–150 minutes and were audio-recorded and later transcribed verbatim by the interviewer for analysis.

Initial interviews with spouses were based around a broad topic guide developed by the researchers to explore the experience of being involved in decision-making with a partner with TBI. In the first interview, the participant was

asked to tell the researcher about themselves and their partner and describe some of the decisions that they had made together since their injury. Participants were prompted to talk about ‘significant’ life decisions (topics covered included purchasing a home and having children) and everyday decisions. Subsequent interviews provided participants with the opportunity to build on previous discussions and focus on more recent decisions, with the interviewer asking the participants, ‘Can you tell me about some of the decisions you have made recently? How did that decision come about? Can you describe the approach you took in relation to that decision?’ The researcher also used subsequent interviews to discuss codes and categories that had emerged through the process of data analysis and explore whether these resonated with participants and, if not, explore how their own experiences may have differed. In this way, prolonged engagement with participants was used as a form of member checking. Participants were also provided with copies of their interview transcripts and invited to contact the researcher if there was anything they wished to amend or additional comments they wished to add, although none of the participants did so.

## Participants

Four spouses participated in this study (see Table I for demographic details). They were provided with information about the research by their partners (who are central participants in the larger study) and invited to contact the researcher if they wished to participate. Their partners with TBI had all sustained a severe TBI and were recruited across the eastern states of Australia through community-based services and service provider networks for people with acquired brain injury. All four spouses who were provided information by their partners agreed to participate in the research and participated in a series of interviews after written consent was provided.

All of the participating spouses had been in a committed relationship with their partners with TBI for at least 4 years (mean = 12.5, range = 4–24 years). Two of the couples were married and two were in domestic partnerships (unmarried, long-term cohabitation). A decision was made by the researchers to include spouses in domestic partnerships in order to reflect a fuller range of contemporary relationships. Three of the couples were in heterosexual relationships and one was in a same-sex relationship. It was noteworthy that the first three couples recruited to the study had commenced their relationship after their partner had sustained their injury. The fourth couple recruited to the project had been in a relationship prior to the wife sustaining a severe TBI and provided the opportunity to review the theme structure in light of this difference. A brief description of each of the couples is provided below. Participants have been assigned pseudonyms in order to maintain confidentiality.

### *Couple 1: Jeff and Anna*

Jeff and Anna are not married but have been living together for over 10 years and have three children under the age of 10. Jeff and Anna commenced their relationship after Anna’s first TBI. Although her first TBI was classified as severe, Anna returned to employment after the injury and both report that

Table I. Demographic details of spouses and their partners with TBI.

Partner	SP1, Jeff	SP2, Anthony	SP3, Karen	SP4, Keith
Relationship status	Unmarried/cohabitating	Unmarried/cohabitating	Married	Married
Relationship length (years)	10	12	4	24
Children from relationship	3 (school-aged)	No	1 (infant)	No
Employment status	Part-time	Not in paid employment	Part-time	Not in paid employment
Supports (formal/informal)	Mother	Limited	FT; members of spiritual community; mother	NP
Age at injury	CP1, Anna 30	CP2, Mick 23	CP3, Peter 38	CP4, Rose 29
Time post-injury (years)	17 (7)	19	8	14
Cause of injury	Sporting accident	Motor vehicle accident	Motor vehicle accident	Motor vehicle accident
Hospitalization (months)	12	Unknown	5	6
Current level of disability (GOSE) [45]	SD–	SD+	MD–	SD–
Relationship status at injury	Single	Single	Married (different partner)	De facto (same partner)
Employment status at injury	Full-time	Not employed	Full-time	Full-time
Current employment status	Not in paid employment	Not in paid employment	Casual employment	Not in paid employment
Supports (formal/informal)	CP, SW, mother, close friends, brain injury support group	Small group of close friends	FT	Parents, NP

*Level of Disability:* SD+, Upper severe disability; SD–, Lower severe disability; MD–, Lower moderate disability.

*Formal supports:* FT, family therapist; NP, neuropsychologist; CP, clinical psychologist; SW, support worker.

she required only minimal support in her daily life. Approximately 3 years into their relationship and subsequent to the birth of their children, Anna sustained a second brain injury. Both Jeff and Anna report that the impact of this injury has been significant and has magnified her cognitive deficits. Anna is now unable to be left alone other than for short periods of time. Both describe the challenge that these cognitive changes have contributed to in their relationship. Jeff is employed in a semi-professional role in a part-time capacity and reports that his employment options are limited by his caring responsibilities. Both Jeff and Anna report that they have significant concerns about their financial future.

#### *Couple 2: Anthony and Mick*

Anthony and Mick are a same-sex couple who have been living together for 12 years. They met and started their relationship after Mick had sustained a severe TBI when he was aged 23. Neither are currently employed; until recently, they ran a business together but decided to sell the business in order to spend time travelling together. Anthony and Mick both report that they have limited contact with their families but do have a small, shared network of close friends. They report that they have had limited support from rehabilitation or brain injury service providers.

#### *Couple 3: Helen and Peter*

Helen and Peter met through a mutual friend ~5 years ago when attending a retreat in Peter's home country. They have since married and had a child. Peter also has two teenage children (who live overseas) from a previous marriage. Helen is a healthcare professional and has recently returned to part-time work after a period of maternity leave. She reports that she 'knew there was something wrong with (Peter)' when she met him, but felt that they had a strong connection when they met. They settled in Helen's home country, Australia, just over 3 years ago.

#### *Couple 4: Keith and Rose*

Keith and Rose are a married couple in their forties. Although they were not married at the time of Rose's TBI 14 years ago, they married shortly after. They do not have children and both report that they had made a decision not to have children prior to Rose's injury. Although they were both in full-time employment at the time of Rose's injury, Keith is now Rose's full-time carer and unable to maintain paid employment. Following her TBI, an independent financial administrator was appointed to manage Rose's financial affairs. Both Keith and Rose report that this has placed significant restrictions on their lifestyle and ability to make decisions for the future.

#### **Data generation and analysis**

Methods of data generation included a series of in-depth interviews and field notes. Although alternative methods of data generation such as dyadic interviews of couples in the process of making decisions were considered, interviews were chosen as the primary method of data generation as they aligned most closely with the aim of the study: to develop a deep and detailed understanding of how individuals in the position of providing decision-making support perceived and made sense of their individual experiences. Field notes provided a record of observations made by the researcher and discussions not captured via audio recording and also helped to place the data within a broader socio-demographic context.

Data was entered into NVivo 9 to aid data management [55]. All transcripts were read independently by the first two authors during the process of data analysis. Initially, textual data was read line-by-line and provisional codes reflecting action developed. The researchers were particularly interested in the presence of *in vivo* codes. Through a process of constant comparison, whereby the researchers asked how the data reflected similar and/or different experiences reported by participants, focused codes developed. Alongside the coding

process, memos were written in an electronic journal, initially as a summary of the researchers' thoughts, ideas and questions and later as a process to identify and clarify emerging categories and explore issues requiring further analysis. This process was followed until clear categories and sub-categories emerged and concluded when no new themes were evident.

A range of criteria have been suggested in order to assess the quality of qualitative research, with specific strategies being suggested to be applied to grounded theory research. Charmaz [46] has argued that researchers using constructivist grounded theory consider the criteria of credibility, originality, resonance and usefulness. In this study, credibility was established through a number of strategies including prolonged engagement with participants and through discussions with the research team during fortnightly meetings. Additionally, in order to demonstrate the emergent theory is grounded in participants' experiences and reflects their narratives, illustrative quotes are presented throughout this article. Resonance was established through discussions with other researchers and health professionals working with people with brain injury and the presentation of the emerging themes at conferences both in brain injury rehabilitation and supported decision-making.

## Results

As evident from the descriptions above, participating spouses differed across a range of variables, including gender, sexuality, marital status, length of relationship (and whether the relationship was formed pre- or post-injury), parenthood, employment and availability of support. Despite these differences, two major common themes emerged from the data. The first reflected the crucial role of the spousal relationship itself. The second focused on the spouses' experience within the decision-making process.

### Features of the spousal relationship

The data provided clear evidence that decision-making is a process embedded in the context of the spousal relationship. The nature of the relationship in which decision-making occurs, therefore, shapes and is itself shaped by the experience of decision-making. Although the relationships that participating spouses were part of varied across a range of factors, their experiences reflected a consistent range of features that supported the relationship, so that decision-making can then take place. These are presented in Figure 1 and are discussed below.

#### Understanding the functional implications of the brain injury on their partner

The first feature that emerged as shaping the relationship context on the part of the spouses was a deep understanding of the implications of their partner's injury. This understanding was developed through their interactions with their partners and reflections on these interactions. The process of developing understanding took considerable time, particularly for spouses who had commenced their relationships after injury, as they attempted to construct a sense of continuity regarding

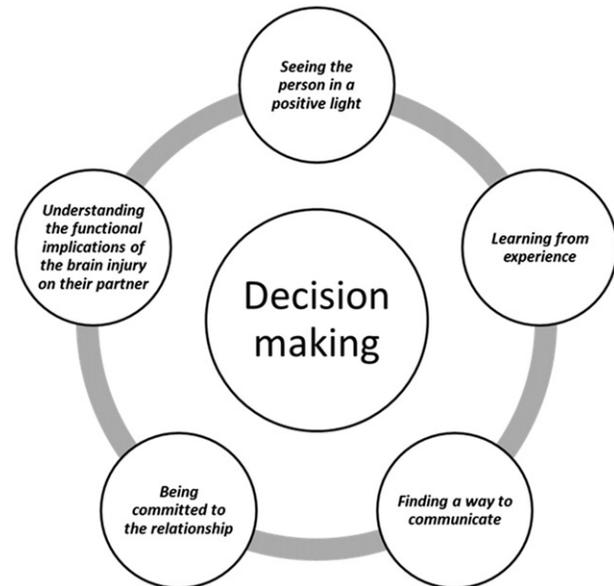


Figure 1. Features of the relationship space.

the unique characteristics and qualities of their partners pre- and post-injury. For example, one spouse said that it had 'taken (him) years and years and years to really understand the depth of (the brain injury)' (Anthony). In these situations, spouses described a parallel process of simultaneously getting to know the person and developing an understanding of TBI. This process was made even more difficult by a dearth of professional support and advice relating to brain injury. In the absence of professional support and advice, one spouse described that she sought advice from people who knew her husband pre-injury to try and make sense of its impact on him: 'I actually sent his ex-wife an email... 'What was he like before the accident? Because he keeps telling me how different he is'' (Karen). Similarly, the spouse who had been in a relationship prior to his wife sustaining a TBI reported a need to balance this sense of discontinuity regarding the implications of his partner's injury against the personal and relationship characteristics which had endured: 'Still my partner and just kept going on. When she got better, we take her home and work it out from there, you know' (Keith).

#### Seeing the person in a positive light

Seeing the person in a positive light also emerged as a key feature of relationships in which the partner with brain injury was at the centre of the decision-making process. Spouses who had met their partner since injury described the positive personal characteristics that they noted about them when they first met: 'When I met him, I thought there is a guy here who has got a life, has got something to say, has got a voice...' (Karen). They also described the many positive personal characteristics that they had come to learn about the person over the course of their relationship: 'He's a highly gregarious person, he's got a lot of friends...' (Anthony).

Spouses expressed their desire to share their life together, including sharing the process of decision-making. Keith described that the relationship that he and his partner enjoyed had always been based in friendship and that this feeling had

transcended the injury: ‘We were good friends before the accident, not just partners but we were friends, and it’s always been that way . . . we can still just sit down and just talk or whatever or we can go off camping by ourselves’. Spouses who had met their partner following injury described the attributes that attracted them to the person. One spouse saw their partner as someone with significant potential and someone who was different to how they were viewed by others: ‘From the day I met (my partner), I’ve always had this really strong belief that . . . he wasn’t who everyone said he was. He wasn’t this guy that couldn’t do anything because of his brain injury . . . it’s just not what I saw, it’s not who I saw’ (Karen). This understanding of their partner’s potential, despite their physical or cognitive limitations, was a key driver in the way that spouses approached the decision-making process with their partners.

### Being committed to the relationship

Spouses described a strong sense of commitment to their partners and the lives that they had created with them. This commitment varied from spouse to spouse and took many forms. Sometimes it was based in feelings of love for their partner or in having endured difficult times together: ‘I will always be here for her, no matter what. I mean, we’ve had some hard bloody times . . . I’m not going anywhere’ (Keith). For some spouses, their commitment had a more pragmatic basis, such as a desire to provide a stable home for their children, despite the presence of difficulties within the relationship: ‘I’m there for the kids and I pay the mortgage and pay the bills . . . (but) our personal relationship’s crap’ (Jeff). A strong sense of needing to maintain the relationship for the sake of the children was reported in both cases where children had resulted from the relationship. Even when interpersonal difficulties existed, the data provided evidence that spouses adapted their approach to decision-making in order to maintain the relationship. In the case of one participant, a joint approach to decision-making was generally avoided in order to minimize the frequency of difficult interaction and disagreement within the relationship in order to maintain the longer-term viability of the relationship: ‘I tend to keep out of (those decisions) because it’s not worth the argument’ (Jeff).

### Finding a way to communicate

Each of the spouses described how communication played a significant role in their relationships and how they had to develop strategies to support communication with their partners. Data from spouses indicated that they came to develop an awareness of their partners’ communication impairments over time and were sometimes surprised to learn that the way their partner communicated was a result of their TBI: ‘I thought, “Well, you’re sitting there in the room, there are people talking”. Obviously he’s got the ability to speak. “Why can’t you just talk?” . . . It’s been quite a learning curve for me to understand that’ (Karen). Spouses also described that they generally had limited access to information regarding communication impairment after brain injury, even in situations where their partner had participated in rehabilitation, and limited knowledge about what strategies

they could use to support their partner’s communication. Instead, spouses found ways to communicate within the relationship through a process of trial and error. One participant, whose partner had participated in a communication intervention trial, described how it was the only formal input that they had received and that it had been particularly beneficial because they had both developed their understanding of his communication impairment through this work:

The work that (the speech pathologist) did with him in terms of communication and teaching him how to analyse what’s frustrating for him and then telling me how to help him through that and handle this (was) really, really good . . . the only formal stuff we’ve had and it was in a study rather than, ‘This how you do it’ (Anthony).

From a spousal perspective, communication with their partners proved extremely challenging at times and the same participant (Anthony) described that he had to ‘learn a different language . . . a different way of speaking’ in order to involve his partner in any meaningful way in making decisions.

### Learning from experience

Spouses described that their relationships evolved over time in response to previous experiences that they had as a couple. The dynamic nature of the relationship was particularly salient when considering the interaction between the relationship and the spouse’s approach to decision-making. Past experiences that spouses perceived as having been positive (in terms of either process or outcome) reinforced a particular approach to decision-making. For example, Karen described how her partner had taken on the role as being the ‘sounding board’ in decision-making and this was something that worked well for her:

I got to the point where I went, ‘Oh gosh, what have I done’ and I was really going into a bit of a panic thinking I’d made a big mistake and (he) was the one saying, ‘No, I think you’ve done the right thing and it’s going to be okay . . .’. It’s good to have that reassurance.

Similarly, Keith described that he and his partner had developed a consistent pattern of interaction regarding decisions (particularly in relation to relatively minor purchases): ‘We have always sort of been like that. She will tell me if she is going out to buy something or whatever . . . or if I am going to buy something, I will tell her’. However, negative experiences also provided grounds for the spouse not to repeat a particular course of action. In response, the spouses described taking one of two courses of action. The first involved modifying their approach to decision-making to accommodate their partner’s difficulties. This often resulted in minimizing their partner’s input into decision-making processes which they predicted might result in a negative interaction, as articulated by Anthony: ‘The most important thing is that if he doesn’t want to make a decision I just don’t force it any more . . . it used to be, if I try and force him to make a decision, then that blocks everything else, so there are some things he just can’t decide’.

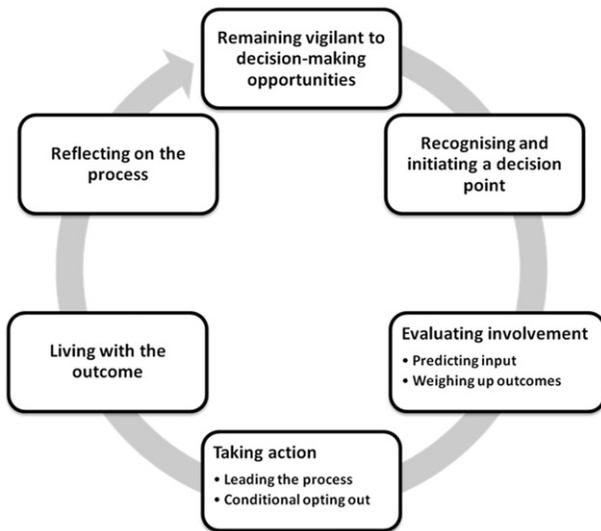


Figure 2. Decision-making in spousal relationships after severe TBI.

The second involved withdrawing from particular decision-making processes, as reported by Jeff: ‘She runs the house. I tend to keep out of it because it’s not worth the argument, basically . . . I’ve just thrown my hands in the air and thought, “Whatever”’.

### The process of decision-making

The second major theme emerging from the data related to the complex nature of the spouse’s experience of making decisions with their partners with TBI. The rich insights provided by spouses revealed that decision-making played out as a complex process that was ordered through multiple phases or stages within the context of the relationship (see Figure 2). Six key stages were evident: (1) *Remaining vigilant to decision-making opportunities*, (2) *Recognizing and initiating a decision point*, (3) *Evaluating involvement*, (4) *Taking action*, (5) *Living with the outcome* and (6) *Reflecting on the process*. This multi-stage process took the form of an experiential feedback loop, with past and current decision-making experiences modulating spouses’ future attitudes and approaches.

#### Stage 1: Remaining vigilant to decision-making opportunities

Spouses held the primary responsibility in the relationship for remaining vigilant to decision-making opportunities. These opportunities existed across the decision-making continuum and included decisions about mundane aspects of life, such as deciding what to have for dinner: ‘She doesn’t really cook a lot anymore and when she does she gets flustered about it so I usually make the decisions about what we’re going to have’ (Jeff). It also reflected significant decisions including those involving a major financial commitment, such as the purchase of a house: ‘This house just came up on the internet, and I saw it and it was a good price, and we went and had a look at it, and I really liked the house and we went ahead and did it’ (Karen). As evident in the examples provided above, being responsible for identifying decision-making opportunities meant that spouses needed to develop skills and knowledge

across multiple life domains and were often required to operate outside of traditional gender roles.

Spouses indicated that their partners with TBI experienced difficulty responding to these opportunities as a result of their cognitive impairments, particularly due to difficulties planning: ‘He has this fragmented thing and because he, I’ll say procrastinates because it’s a description of what happens, I don’t know that he actually does procrastinate’ (Anthony) and initiating action: ‘definitely lack of initiative, lack of drive . . .’ (Karen). As a result, spouses acknowledged that they took the lead role in decision-making, even though, in many cases, they were keen to ensure that their partner with TBI was involved in some capacity. Despite this, the impact of this additional responsibility was often keenly felt by spouses. As one participant described ‘the biggest thing is trying to, I suppose, live for two people . . . it’s draining. It drains you like you would not believe . . . trying to make all the decisions’ (Keith). The data also supported the notion that the more strongly a bond to their partner was felt, the greater the level of stress and strain that was placed on them as decision-maker, as their actions were governed by a sense of wanting to do the right thing by their partner.

The spouse’s level of vigilance relied on a range of personal and environmental factors, including their cognitive and emotional reserves and the demands of their partner with TBI. Spouses described that they often sought to minimize their decision-making opportunities by ‘routinizing’ many aspects of their life (and their partner’s life). This act, as described by Anthony, allowed him to retain some energy for other tasks or decisions: ‘He’s got a routine set . . . and once that comes to the point where he needs to make a decision about what he’s going to do, he’ll make a decision based on routine . . . that side of things actually is fairly easy, because it’s a structured thing’. This adoption of routine was particularly important, as spouses reported that it was not their responsibility for making major decisions that they found burdensome, but rather the constant pressure of having to make all of the household decisions with limited support: ‘The little decisions about, “What do you want to eat tonight?” and he’ll say, “Whatever”, I find really frustrating because it’s like, well, “What do you want?”’ (Anthony).

#### Stage 2: Recognizing and initiating a decision point

In many cases, the spouse recognized the need for a decision and then initiated a decision-making process to meet this identified need. Both internal and external drivers were implicated in determining that a decision was required. Examples of internal drivers included acknowledging frustration at their partner for spending most of their time at home with little to do. External drivers included factors such as financial hardship and processes imposed by external bodies.

Regardless of the drivers of the decision-making process, initiation of decision-making was almost always undertaken by the uninjured spouse. As one spouse reported, ‘he is rarely very pro-active about things . . . if someone else gives him a task then it’s very difficult for him to conceptualize and act on that and develop a plan’ (Anthony). Another acknowledged

their role as the driver of decisions: ‘I probably drive things in the initiation side of things, like I’ll sit there and come up with the idea’ (Karen).

### Stage 3: Evaluating involvement

When considering to what extent the decision-making process would be shared, spouses took a range of factors into account.

*Predicting input.* Non-injured spouses considered the likely effort that would be required to support meaningful participation by their partners in the decision-making process. For example, one spouse described how his partner’s cognitive disability impacted on the amount and type of information that he needed to provide and the modifications he may need to make to support him to process this information: ‘If he’s having trouble understanding why this decision’s important or what the ramifications are for this decision then you know, we’ll go around it two or three different ways’ (Anthony). Time was also a significant factor that spouses identified as needing to take into account. Anthony described that it had taken him ‘a long time to realize . . . that when (his partner) doesn’t immediately make a decision it’s not because he’s being obtuse, it’s because he needs time to process’. Subsequently, spouses reported that supporting their partner to participate in decision-making became difficult when quick decisions were required and/or they felt that their own time was already thinly spread, such as was the case in the spouses who were also caring for children: ‘I had to make decisions on the run I guess . . . maybe I should’ve been a bit more patient about things’ (Karen). In these situations, the result was that, while decisions were made with consideration of their partner’s needs, there was no direct consultation with them about their preferences.

*Weighing up outcomes.* Prior to engaging with their partners, spouses also weighed up the potential outcomes of involving (and not involving) their partners in the decision-making process. Outcomes they considered were many and varied and included potential risks such as injury to their partner, adverse financial implications, stress that decision-making participation may cause and potential inter-personal difficulties that might result from entering into a joint decision-making process. For example, opportunities to extinguish predicted risk to the individual were made easily, as described by Anthony: ‘The decisions that I make for him that take him out of a dangerous situation, I’m happy to do’. Similarly, all spouses reported that financial considerations were central in their deliberations. In particular, uncertainty in relation to their future employment prospects (as a result of their caring responsibilities) and the financial security of their family drove their action at this stage of the process:

The hardest thing is that we can’t better ourselves, you know, we are sort of stuck in a little circle and that’s it. Put in a little box in that corner and that is what you have got, this is what you have for the rest of your life; the money is going to run out here. End of story (Keith).

### Stage 4: Taking action

Following the process of evaluating what involvement to have in the decision-making process, spouses considered a range of possible actions. Their involvement in the decision-making process tended to take one of two forms: (a) leading the process or (b) conditional opting out.

*(a) Leading the process.* The most frequently taken approach by spouses was that of leading the decision-making process. Leading the process took one of two forms. Spouses described that this involved facilitating their partner’s input at a specific point during the decision-making process, when laying out possible options. As a result, the final decision reflected the outcome of a sort of joint process. However, there were occasions where decisions were made by spouses with limited input from their partner with TBI, as articulated by Participant 3: ‘Even when I say we, it was still very much a decision that I made’ (Karen).

Once it had been determined that a decision was required, a process of identifying possibilities commenced. Spouses described this process as one that they generally undertook on their own: ‘It was something that I thought about and came up with for the idea and then I kind of consulted (my partner)’ (Karen). Individuals with TBI were rarely active in this process and, in many cases, were not aware that their spouse was engaged in a decision-making process: ‘the day-to-day stuff is, more or less, I look after that side of things, end of story . . .’ (Keith). During this process, spouses described the importance of recognizing the current context, particularly in determining whether particular options were viable: ‘I’d like some sort of decision-making whereby we can go away and have a holiday, but then that’s a financial consideration’ (Jeff). Most commonly, this process was revealed as being undertaken by the spouse with very limited input from the individual: ‘(It’s) a decision I made for him because I knew he couldn’t do it’ (Anthony).

After the options had been considered, spouses generally defined the means by which the individuals with TBI could participate. At times, this might involve identifying a well-defined ‘section’ of the decision that could be assigned to their partner. For example, Anthony described that he had made a decision about closing the retail outlet he owned with his partner, but had given his partner the responsibility of choosing the final date of operation. Frequently, this process reflected the spouse identifying their preferred decision or course of action and providing the individual with TBI with the opportunity to endorse this course of action: ‘What I’ve done here is lay a task out in front of him and stuff and all he has to do is say yes or no and we’ve got a very structured way about doing that’ (Anthony). Some spouses described the key function of their partner’s participation in the decision-making process as providing reassurance about the decision that they had made: ‘I’m the one who makes decisions and thinks about things to do and things to participate in, and . . . he’s like the personal bounce-off’ (Karen). At times, it appeared that informing their partners of the outcome of the decision-making process was considered a proxy for participation: ‘When it comes down to financial stuff, yeah, I make . . . the main decisions . . . but

she is always informed of any decision I make, or do' (Keith).

Spouses not only made decisions about their life as a couple, but also about actions they identified their partner needed to undertake. In these situations, spouses described that they were responsible for initiating an action plan and then actively supporting their partner with TBI to undertake this action plan by providing practical support and cognitive scaffolding, considering that the individual was often unable to do this independently: 'We've got this end point now . . . I have to take a bit of a gentle pushing to help him along a particular path, and that's . . . the smaller decisions of what to do along the way to the bigger decision, outcome' (Anthony).

*(b) Conditional opting out.* Although spouses took primary responsibility for decision-making, it was also evident that there were certain types of decisions that spouses would initiate and then leave their partner to undertake. For spouses, the decision to 'opt out' of the decision-making process was conditional on a range of factors. Most notably, this course of action was often taken to avoid conflict within the relationship, as spouses reported they had learnt, through previous experience, that their partners with TBI had identified some decisions they wished to maintain as their own. Anthony reported that he had learnt that 'there's a lot of things that I just know I can't influence, because there are some things for him which are out of bounds'. In particular, this participant reported that he had learnt through previous experience that his input regarding his partner's management of money needed careful negotiation and, at times, he chose to opt out of difficult discussions in order to reduce the likelihood of conflict within the relationship. When spouses attempted to offer support in these areas, it was actively resented by their partners: '(My partner says), "That's my job, you do your job". Keep out of it, sort of thing . . . ' (Jeff).

The decision for spouses to 'opt out' was not always made to avoid conflict. At times, spouses saw that it provided opportunities for their partners to make decisions without their input and was a way of reinforcing their partner's sense of autonomy. However, choosing this course of action was also conditional on the spouse's determination of the likelihood of a negative outcome if they did so. As Keith reflected, 'I'll tell her I don't agree with her . . . and I just say . . . if it's not going to affect us in any major way, well, I say, "Look, you make your own decision and you do it". You know, if you think you have got to go and do something . . . '.

At times, opting out of the decision-making process was also used as a strategy by spouses to avoid a decision being made. Although the sole female spousal participant (Karen) did not identify that there were decisions that were outside the scope of her interest or responsibility or that she was motivated to avoid conflict, her partner's cognitive impairment, including his profound difficulty planning and initiating action, meant that he rarely made decisions without her input. In acknowledging that her partner needed significant support to make a decision and follow through on it, Karen described taking a step back from a decision that would involve a significant investment of resources and disruption to the family. In this case, she had taken a different approach by handing sole responsibility for decision-making over to

her partner: 'I've actually deliberately taken a step back from that situation. And I've gone, "Well, these people are your family, and it's something that you need to figure out . . . you need to figure out what's going on"'.

#### *Stage 5: Living with the outcome*

Regardless of the role taken by the spouse, the next stage described in the decision-making process was living with the process. Despite initiating decisions and generally managing the decision-making process, spouses' overall reflections on decision-making indicated a feeling of having limited control in their lives. This feeling reflected a sense of having made many sacrifices and adjustments in their lives to maintain their relationship with their partner: 'I feel like I'm just sort of along for the ride half the time' (Jeff). Financial limitations also contributed to this sense of having limited control over the future, due to restrictions on their ability to maintain paid employment: 'I can't work. If I get someone in to look after (my partner) and work, they get paid more than what I do . . . so I can't do it that way' (Keith).

#### *Stage 6: Reflecting on the process*

Finally, individuals described undertaking an evaluation process after the decision had been made and enacted. The evaluation process included consideration of two factors: (1) the outcome of the decision-making process, as articulated by Anthony: 'All I care about is that the outcome was good' and (2) the implications of the decision-making process for their relationship. Karen describes how she felt a combination of frustration at having to be involved in all decisions involving her partner, while also acknowledging that this process acted to reinforce their relationship: 'I think, "Why can't he just do it on his own?" but then I think, "That's marriage, isn't it?" That's marriage, that's not brain injury. That's marriage, you know, you complement each other, you support each other, you do things for each other'.

## **Discussion**

From this study, an initial model of decision-making grounded in the experiences of spouses supporting their partners with severe TBI has been developed. While the critical role that spouses play in driving action and supporting participation in the lives of their partners after TBI has been highlighted previously [56, 57], the findings of this study provide evidence of the crucial role that spouses also play in supporting decision-making. Analysis of the data demonstrated that non-injured spouses are generally the lead decision-maker in the relationship, both for everyday and major life decisions. Further, it emerged that spouses led the process, regardless of whether the decision primarily affected themselves, the couple or family or their partner.

The spouses' relationships with their partners were central to their experiences. Not surprisingly, the features that contributed to the quality of the spousal relationship also played a substantial role in maintaining a relational context within which the decision-making process could function. The relational characteristics important to the experience of spouses had much in common with those that have been

identified as exerting a positive influence on intimate relationships generally [58] and following TBI [28]. These features reflected a desire on the part of spouses to maintain the relationship by finding strategies to work through challenges that they faced as a couple together. Where these factors were absent and the relationship space was poor, decision-making was often also poor. For example, where joint participation in decision-making led to conflict, spouses tended to either exclude themselves from future decision-making or sought to covertly control the outcome of the decision-making process. Three of the five factors that emerged in this study, particularly being committed to the relationship, finding a way to communicate and seeing the person in a positive light, are similar to a number of the factors identified by Gill et al. [28] as supporting the maintenance of intimate relationships. Further, the important role of communication in mediating intimate relationships after TBI was evident in this study and has now been highlighted by a number of authors [9, 22, 27, 28, 59]. The findings of this study add further weight to previous calls emphasizing the need for couples intervention to include a focus on building the spouse's repertoire of communication skills and strategies, particularly when faced with negative or frustrating interactions [25, 27].

From the perspective of spouses, decision-making emerged as a process involving discernable phases. Identification of a process model can be useful in developing an understanding of the stages that individuals in a similar situation are likely to experience [60]. The phases identified in this study underline the complexity of the decision-making process and highlight the scope and intensity of demands upon spouses of individuals with severe TBI. All spouses in this study reported that they found the role as 'the decision maker' burdensome, particularly when it resulted in an inability to share day-to-day household responsibilities. This sense of 'living for two people' echoes the experiences of spouses in Douglas and Spellacy's [24] study, who reported that they found the challenge of 'living, and living with a brain injured person' overwhelming (p. 85). In this study, spouses described a process in which they attempted to proceduralize or routinize as many decisions as possible in order to reduce the burden that they felt in response to having to make decisions for both partners. Although the use of routines reduced spouses' feeling of 'living for two people', it also left them reporting a lack of decision-making opportunities and a sense of disempowerment in their own lives. Professionals working with couples after TBI should consider how they can support spouses to find a balance between reducing the demands placed upon them and maintaining a sense of control and to identify areas and ways in which they may more easily share decision-making with their partner.

The findings of this study also help to highlight the unique challenges faced by spouses who commence a relationship with a partner with severe TBI. Although some recent studies [9, 28] have included couples who have commenced their relationship or married since injury, the unique challenges faced by this group have received comparatively little attention in the literature. Whilst it has been suggested that these relationships may be more stable [34], the spouses in this study reported their own unique challenges in

maintaining their relationships. In particular, they reported a strong desire to understand what their partner was like prior to TBI in order to understand the impact of the injury and a need to feel a sense of continuity in relation to their partner's life narrative. However, as they were not present during the early stages of rehabilitation when the majority of brain injury education is provided, they were often reliant on their own research and observation in understanding TBI in the context of who their partner is now. Gill et al. [28] reported that spouses who had formed relationships with an individual after TBI described difficulties in knowing where to set boundaries in their caregiving role, possibly reflecting a lack of confidence in their understanding of the impact of the brain injury on the individual. The findings of this study add to the existing literature which has emphasized the important role that support and education plays in supporting the development and maintenance of relationships for individuals with TBI and their close others across the recovery continuum [9, 27, 28, 49, 61]. It also highlights the importance of rehabilitation clinicians taking a couple-centred approach, to ensure that the education they provide regarding TBI is relevant and meaningful.

The findings of this study also give weight to the need to reconsider how decision-making is conceptualized in rehabilitation practice. Failing to acknowledge decision-making as a relational process may mean that the complex and inter-related motivations and interests which drive decision-making within spousal relationships are overlooked. The results of this study highlight the importance of considering the implications of being reliant on a spouse to initiate decision-making, particularly when this might occur in the absence of explicit discussion of the decision-making process that is underway. It is vital that strategies are put in place to ensure that the needs and wishes of both partners are present in the decision-making process.

### Methodological considerations and research recommendations

The strengths of this study include its qualitative design: using constructivist grounded theory allowed the researchers to develop a deep understanding of the participants' experience and explore decision-making as a dynamic, relational process. Additionally, prolonged engagement with research participants allowed the researchers to explore how decisions were experienced over time and provided a range of opportunities for the primary researcher to make observations relevant to the research.

In line with constructivist beliefs, this research was the result of interactions between the researchers and participants and it must be acknowledged that other researchers may have reached different conclusions in relation to the data. However, the researchers have used a range of procedures in order to ensure the quality of this research, including keeping an audit trail of analysis through a process of coding and memoing, seeking participants' reflections on previous interviews and the emerging analysis and peer debriefing by discussing the results with other professionals working with individuals with TBI and their families. Additionally, the researchers maintained an awareness of their previous experiences and their

potential to influence their actions through the processes of data generation and analysis. In particular, the experiences of the first two authors in speech pathology, neuropsychology and clinical research in TBI gave rise to expectations in relation to the role and motivations of the spouse in the decision-making process. From the commencement of the study, these expectations were made explicit within the research team and were countered by maintaining close attention to the data during discussion in fortnightly meetings and by exploring the data from a range of different perspectives evident in relevant research literature, both inside and outside the fields of disability and acquired brain injury. It is noteworthy that, whilst there was an expectation that the spousal role was unlikely to be an easy one, the magnitude of the demands of the role exceeded expectations with the individual needs of the spouse frequently being given a lower order ranking.

The research must also be considered with regard to its limitations. Despite saturation being apparent within the data across these varied participants, it must be emphasized that the findings have restricted generalizability and are specific to the experiences of these individuals. The use of prolonged engagement contributed to the development of rich insights into the worlds of these participants and afforded an in-depth understanding of the phenomena being explored. Additionally, while this study used a series of in-depth interviews to develop an initial understanding of the spousal experience, it is important to note that there are a range of alternative research methods that are well suited to examination of different aspects of this research topic. For example, including the perspectives of both injured and uninjured partners would allow a comparison of the experiences of giving and receiving support. Similarly, analysis of interview data generated by the dyad in the process of making decisions (for example, using a critical discourse perspective) would provide a fuller picture of the interaction between partners during the decision-making process. These methods could be applied in future research, exploring how meaning is attributed to the decision-making process by both individuals with TBI and their spouses.

All of the couples had been in a relationship for a minimum of 4 years. Although, three of the four couples had begun their relationship subsequent to the individual's brain injury, the length of time spent in a relationship with the individual (whether pre- or post-injury) is clearly an important factor in knowing the individual well. Therefore, the results may have limited application with individuals in newly formed relationships. It is also important to note that partners with TBI had sustained their TBI at least 8 years prior to participation in the study (to a maximum of 19 years prior). This time point is late in the recovery continuum and consequently does not reflect early post-injury experiences.

Finally, as spousal relationships come in a range of forms, this study included participants in a range of relationship types: couples who were married and in domestic partnerships, in heterosexual and same-sex relationships, those whose relationships had endured the injury and those who had commenced their relationship since the injury. The findings of this study align with previous findings that close dyadic relationships frequently work in similar ways, despite

their differences [62]. It is recommended that future research seeks to build understanding of the experience of individuals in a diverse range of relationships after injury.

### Clinical implications

This study is the first to explicitly explore the complex process of decision-making within spousal relationships after TBI. The theory that has emerged from this research can provide a starting point for brain injury clinicians to understand how decision-making takes place within these relationships and to guide their intervention when working with couples after TBI.

Traditionally, assessment of decision-making capacity has involved evaluating the skills and capabilities of an individual on a range of clinical tasks [63]. The findings illustrate that decision-making is a socially mediated and relational process. As such, evaluation of decision-making capacity needs to be considered within the context of the relationships within which it occurs. When working with couples, it would be useful for clinicians to explore the bound nature of the relationship and the nature of the decision-making processes utilized within it. It is also important to understand the range of roles that spouses may play in maximizing the decision-making participation of their partners and tailor support and education to reflect the specific context of that couple at the time of intervention. Further, clinicians can play a critical role in supporting spouses to develop strategies to minimize the burden associated with decision-making and can provide couples with the opportunity to negotiate their priorities for shared decision-making.

Until now, decision-making interventions described in the literature (including goal management training and identity oriented goal intervention) have tended to focus at the level of the individual by attempting to remediate the decision-making impairment through training and/or explicit strategy use [64, 65]. The results of this study emphasize the critical role that key support people around the person with TBI, such as spouses, play in determining and defining goals and following these goals through to action. For clinicians working in this area, it is therefore essential that they ensure that spouses are invited to participate in this process.

### Conclusion

This qualitative study aimed to develop a preliminary model of the experience of decision-making for spouses supporting a partner with severe TBI. Spouses provided a rich insight into their experiences, highlighting how the spousal relationship influences and is influenced by their approach to decision-making. Several key factors that are necessary for shared decision-making were identified. Where these factors were not present and the relationship space appeared poor, decision-making was at risk of representing the conflict between spouses rather than the preferences of members of the couple. Regardless of the nature of the spousal relationship and the type of decision to be made, decision-making was conceptualized as a complex, multi-phase process that was predominantly lead by the non-injured spouse. Despite the limitations associated with this study,

these findings support the importance of therapeutic involvement that is based on a couple-centred approach and provides opportunities for couples to negotiate their preferred approach to decision-making and develop strategies that support both the relationship and the individuals within it.

### Declaration of interest

The authors report no conflicts of interest. The authors alone are responsible for the content and writing of the paper.

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