

ORIGINAL ARTICLE

## The experience of challenging behaviours following severe TBI: A family perspective

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### Abstract

**Primary objective:** Family caregivers play an important role in managing challenging behaviours after TBI. The aims of this study were to understand how family caregivers of individuals with TBI perceive challenging behaviours and their impact on the TBI individual's community integration and family functioning.

**Research design:** A qualitative research design was employed to capture the lived experience of family caregivers of individuals with TBI.

**Methods and procedures:** Face-to-face interviews were conducted on six female family caregivers of individuals with severe TBI (sustained an average of 17 years earlier) and long-standing challenging behaviours.

**Main outcomes and results:** The results revealed that family caregivers adopted a broader definition of challenging behaviour than that used by professionals and these behaviours impacted on the community integration of the individual with TBI, most notably leading to poor social relationships. Challenging behaviours were viewed as a key source of distress and burden for family caregivers and they used many different strategies to manage the behaviours. **Conclusion:** Greater understanding of challenging behaviours from the perspectives of family caregivers may help provide more effective support and interventions to improve quality-of-life for individuals with challenging behaviours after TBI and their families.

### Keywords

Community integration, coping, family experience, thematic analysis, traumatic brain injury

### History

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### Introduction

Moderate-to-severe traumatic brain injury (TBI) is often associated with a range of behavioural changes [1–3]. Increased aggression is recognized as a relatively common behaviour change after TBI, [2, 4–6] however, TBI can also result in inappropriate sexual and social behaviours, perseveration, absconding and lack of initiation [2, 3, 7]. The term ‘challenging behaviours’ is often used to describe these behaviours to highlight the risk they can pose to physical safety, as well as their detrimental impact on community participation [8, 9]. In studies conducted over many years, challenging behaviours have been recognized as posing a greater long-term impediment to community integration after TBI than physical disabilities [2, 4, 7, 10].

While rehabilitation services are vital in addressing behavioural issues in the early stages after TBI, families often become the primary supports for managing challenging behaviours once the person returns to community living [1, 11, 12]. Families are also key to facilitating re-integration into the community by the person with TBI [1, 12–15]. Given this

important role of the family, it is essential to understand the perspective of family caregivers when considering challenging behaviours in the longer term after TBI. Most studies examining challenging behaviours after TBI have been quantitative and have usually included family ratings of behaviour but have done so using scales which are constrained by pre-determined categories of behaviour change based on the perspective of clinicians and researchers who developed them [2–6]. These categories may differ from the conceptualizations of families experiencing challenging behaviour within a naturalistic context. In order to best support families, it is important to understand what behaviours they consider to be challenging and how they see these behaviours as influencing participation in life activities for their family member with TBI.

Qualitative research offers a method for understanding the family experience of challenging behaviour after TBI, without the influence of pre-conceived theories and observations. To date, there has been a lack of qualitative studies focused on families’ perspectives regarding the nature and impact of challenging behaviour after TBI. To the authors’ knowledge, the only qualitative study to focus on behaviour change after brain injury is by Braine [14], who explored the experience of family members living with an individual with challenging behaviours after ABI. The interviews conducted in this study

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highlighted that families may adopt a broader definition of challenging behaviour than what would be used by most clinicians or researchers; for example, they considered cognitive difficulties such as memory problems and slowed processing as challenging behaviours. While the study by Braine [14] provides some insight into the ways in which families categorize challenging behaviours, the absence of detail regarding participant ABI aetiology and time post-injury limits interpretation of findings. Furthermore, this study did not examine the impact of challenging behaviours on community participation. One other qualitative study by Lefebvre et al. [11] did not exclusively focus on challenging behaviours but did look at social integration in individuals with moderate-to-severe TBI. This study identified aggression in the person with TBI as a significant source of stress to family members and as a barrier to social participation [11]. There is no known qualitative research examining a broad range of challenging behaviours and their impact on community participation in TBI.

Increasingly, studies have found that changes in behaviour following TBI are one of the most common and strongest predictors of psychological distress and family functioning [13, 15–17]. Marsh et al. [15] demonstrated that challenging behaviours among individuals with TBI had the most severe and pervasive impact on all aspects of caregiver functioning, with the most distressing behaviours related to emotional control such as aggression. Through path analysis, Anderson et al. [17] examined the effect of neurobehavioural problems on family functioning and psychological distress using the Family Assessment Device [18] in families following severe TBI. They identified chronic stressors including cognitive, physical, behaviour, communication and social problems and established that, of these, behavioural changes were the strongest predictors of poor family functioning.

Whilst previous quantitative research has indicated that challenging behaviours, in particular emotional control changes and aggression, are strong predictors of family burden and distress [13, 15–17] and are viewed by families as more concerning than physical or functional changes [15], few qualitative studies have examined in depth the impact of challenging behaviours on family experience. Qualitative methodology may provide a deeper understanding of the impact of challenging behaviours on the family caregivers themselves, including understanding how families manage the behaviours, than can be obtained from quantitative behavioural scales.

A greater understanding of the subjective and lived experiences of challenging behaviours from the perspectives of family members caring for a relative with TBI would enhance the capacity of healthcare providers to deliver the most effective support in managing challenging behaviours over their lifetime, with the ultimate aim of reducing barriers to community integration and achieving optimal family functioning. The present study, therefore, used a qualitative approach to gain an understanding of the family caregiver experiences of challenging behaviours following severe TBI and the impact on community participation for the TBI individual. Additionally, the aim was to understand the lived experience of family caregivers in the face of challenging behaviours and explore the strategies used by the family to

manage the behaviours. The study focused on individuals with TBI who have lived with their injuries for many years.

## Methods

### Participants

Six female relatives of individuals with TBI and longstanding challenging behaviours, including four mothers, one sister and one spouse, participated in the study. While this is a relatively small sample, in qualitative research, basic meta-themes have been found to emerge from as few as six interviews [19]. Individuals with TBI were screened by a neuropsychologist according to the following inclusion criteria: (1) sustained a severe TBI, where severity of the brain injury was indicated by a score on the Care and Support Needs Scale [20] of three or above, indicating that they could be left alone for a few days a week, while needing contact for occupational activities, interpersonal relationships, living skills or emotional support a few days a week; (2) 18 years and above; (3) greater than 2 years post-injury; (4) living with or regularly spending time in the family home of the relative participating; and (5) the presence of at least one type of challenging behaviour as determined by the treating neuropsychologist. Individuals with TBI were excluded if they had a degenerative neurological condition or resided in a setting without open access to the local community. All individuals had sustained very severe TBIs, with PTA duration exceeding 1 month in all cases. While five participants were from metropolitan Melbourne, one lived in a regional area. Family member participants' ages ranged from 41–71 years ( $M = 54.17$ ,  $SD = 11.03$ ). Frequency of family contact ranged from daily to fortnightly. Demographics of individuals with TBI are displayed in Table I.

Time post-injury for the individuals with TBI ranged from 9–23 years ( $M = 17$ ,  $SD = 6.36$ ). Eighty-three per cent were high school graduates and 17% had a TAFE certificate/Diploma. Scores of individuals with TBI on the Community Integration Questionnaire (CIQ) ranged from 6–14 out of 29 [21] and indicated overall low levels of participation in home, social and productive activities.

### Design and procedure

A qualitative study design was employed in order to understand the breadth of issues experienced by family caregivers in response to challenging behaviours after severe TBI [19]. Three open-ended research questions were developed by the researchers to elicit responses consistent with the overall aims of the study, whilst aiming not to constrain the participant responses: (1) What behaviours does he/she do that you, your family or others find challenging?; (2) How do

Table I. Demographic information of individuals with severe TBI.

| Sex    | Age (years) | Cause of injury        | Time since injury (years) | Interviewee |
|--------|-------------|------------------------|---------------------------|-------------|
| Male   | 30          | Motor Vehicle Accident | 23                        | Mother      |
| Female | 41          | Motor Vehicle Accident | 22                        | Mother      |
| Male   | 29          | Motor Vehicle Accident | 9                         | Mother      |
| Male   | 28          | Fall                   | 19                        | Mother      |
| Male   | 43          | Motor Vehicle Accident | 9                         | Spouse      |
| Male   | 39          | Motor Vehicle Accident | 20                        | Sister      |

the behavioural issues impact on his/her ability to participate in everyday activities?; and (3) What would you like to tell me about your experience of caring for an individual with challenging behaviours? Prompts were used to encourage participants to elaborate on responses.

Ethics approval for the study was received from the Monash University Human Research Ethics Committee. Participants were recruited from Osborn, Sloan & Associates (OSA) (Melbourne, Australia). Eligible potential participants were contacted and informed of the study by the neuropsychologists at OSA. This was followed by an email inviting people interested in the study to contact the researcher to arrange a time to conduct the interviews and questionnaires in their homes. Informed consent was obtained from the family member participating in the study and the individuals with TBI. Prior to interview, participants answered demographic questions and completed the CIQ in regards to their family member with the TBI. Face-to-face interviews were conducted at a time and place of convenience to participants and ranged in duration from 28–77 minutes ( $M = 53.75$ ). All interviews were digitally recorded and later transcribed verbatim.

## Analysis

Analysis of the interview transcripts followed the six-phase thematic analysis approach outlined by Braun and Clarke [22, 23]. The initial phase involved familiarization with the data through the process of transcribing and repeated reading of the transcripts. The first author documented initial patterns and codes (basic meaningful elements of raw data), which were cross-checked and refined by the other three authors. Subsequently, these codes were gathered and categorized to produce an overarching hierarchy of themes, each with several sub-themes. Resultant themes were then reviewed to ensure that they reflected the coded texts and were representative of the broader data set. The final two stages involved naming and defining each theme. Strategies used to ensure the rigour of the analysis included triangulation between the four authors via team discussion and cross-checking of the transcripts, codes and revision of themes.

## Results

### Families' reflections on the changes they find challenging

Family caregivers identified a broad array of behavioural changes following their relative's TBI. Examples and meanings attributed to the term 'challenging behaviours' differed considerably.

#### *She'll get so angry*

Despite the differences in the presentation of challenging behaviours, individuals were frequently reported as expressing anger and frustration both verbally and physically. Family caregivers commonly described verbal outbursts, involving personal insults and shouting directed towards family members and others in the community:

[she] loses her temper... she'll get so angry that she's just so nasty to the visitors... and very personal, hurtful,

terrible things that she says [to me], she wishes I wasn't her mum, that I was dead. (Mother)

#### *His social behaviours*

Socially inappropriate behaviours created a sense of embarrassment for the family caregivers in public:

Because of his social behaviours... he can be a bit embarrassing because he tries to overcompensate. So he tries to be funny, he tries to be silly... sometimes it's funny, sometimes he's an idiot. (Spouse)

Family caregivers found some antisocial behaviour childish:

It's like a childish 2 or 3 year old that will have a tantrum on the floor and that's what's hurtful because you've got a 30-year-old man acting like a 2 or 3 year old. (Mother)

#### *Repetitive behaviours*

Family caregivers highlighted that individuals with TBI could perseverate on behaviours, such as illustrated in the utterances and actions below:

He'll always be like 'I'm hungry' or 'I'm tired'... and it can go on for hours and hours and grinding of the teeth... he can get stuck in that mode of saying the same thing. (Sister)

#### *Dangerous behaviours*

Absconding was a behaviour reported by several family caregivers that resulted in a high level of risk for their relative, sometimes life threatening, as described by a mother:

[He] has been a chronic absconder... when he was upset [he would] just take off... He was crossing... the highway without the lights. Holding his hands up to the trucks. It became life threatening and we were at our wits' end... it's the times that I've driven in the streets crying in the dark looking for [him]. (Mother)

#### *It's not just the behaviours*

All family caregivers attributed behavioural changes to the TBI and identified key injury-related cognitive problems when asked about 'behaviour' changes. As illustrated in Table II, families identified connections between cognitive difficulties and behaviours such as agitation, verbal outbursts, physical aggression, interrupting, impatience and a lack of initiative.

#### *What makes it worse? What makes it better?*

The presentation of behaviours varied according to different contexts. For example, when individuals were in an unfamiliar environment, behaviours were reportedly more frequent:

If you take her out of her comfort zone [neighbourhood]... she loses everything. She loses balance quickly,

Table II. Descriptions of the cognitive underpinnings of challenging behaviours.

| Cognitive impairments         | Descriptions by family caregiver   |
|-------------------------------|--|
| Memory problems               | Sometimes he might feel upset about something and he's guessing what he's upset about. He's got the feeling but he doesn't remember exactly what triggered it. (Mother)  |
| Lack of foresight             | He doesn't have the foresight to see things. Like he can come in there [kitchen] and see the fire going but doesn't see that there needs wood for the fire... It's just things that he misses. (Spouse)  |
| Impulsivity                   | If there was one of those fridges in the supermarket... he would go and grab an extra drink and... I have a confrontation with him over it. So in the end, I had to just not go to that place for months. (Mother)   |
| Egocentricity                 | When there's people around us. I think it's jealousy over [my husband] and I, and then she'll behave inappropriately towards the people. Even talking to them on the phone, she doesn't like you talking on the phone to them. (Mother)  |
| Slowed information processing | Not understanding what the conversation's about... he might interrupt not knowing the flow of the conversation and then gets flustered and that's sort of what stops him socially interacting because he sometimes struggles with keeping up with conversations... he misinterprets things or body language... and then that can make him really agitated very quickly. (Spouse) |
| Inability to express emotions | [He] jumps and becomes agitated rather than expressing his feelings. (Mother)  |
| Rigid thinking                | He's inflexible. He's got his things that he wants to do. He doesn't want to try new things, doesn't want to go out. (Mother)  |

nothing sticks in the head at all... Nothing's certain... there's a lot of behavioural outbursts as well. (Mother)

Others showed a tendency to engage in challenging or inappropriate behaviours at times of high anxiety, fatigue or when lacking confidence in a situation:

[His] cognitive and behavioural impairments are also exacerbated during times of high emotional stress and anxiety. (Mother)

#### *It is ongoing*

Some family caregivers described the challenging behaviours as ongoing and constant, and highlighted how they had been working on the same issues over many years:

It's ongoing and... you're always striving to... sort out the issues. [It's been] many years and we're still working on the same thing [behaviours]. (Mother)

However, other family caregivers recognized significant improvements in challenging behaviours with time, use of medication, strategies and therapeutic assistance:

We used to have so many [behaviour problems but] because we've worked on them... He's developed a lot of mechanisms to put it back into place. (Spouse)

### **Impact of challenging behaviours on participation**

#### *Seeing friends and family*

Family caregivers described major changes in friendships and this was seen as one of the key distressing impacts of challenging behaviours. Friendships were often lost and individuals faced social isolation due to their challenging behaviours:

[His] friends, every single one of them has gone and not one has contacted him since the accident. (Mother)

It was also difficult for the individuals with TBI to form new friendships:

The biggest problem I think after brain injury is forming friendships. This has been the biggest challenge because he wants it, but doesn't know how to go about it and becomes absolutely silly with people. (Mother)

Family caregivers identified low self-esteem and a fear of stigmatization in their family members as contributing to their social isolation:

He used to be very socially outgoing... [But now] he fears that people will make fun of him but sometimes he does silly stuff... he might be a little bit scared that he might blow out there so he really limits his time out there [in the community]. (Spouse)

The lack of understanding of the challenging behaviours could be a reason for the loss of relationships:

Unfortunately, he does have another brother but he hasn't seen him for over a year or so now. And I think it's part of the other brother not understanding [his] behaviours and his issues. (Sister)

#### *Help in the home*

It was evident that the challenging behaviours, such as a lack of initiation, underpinned challenges in participation within the home settings:

At home, he'd do nothing if you didn't encourage him... You need to prompt him to have a shower, getting dressed. (Mother)

Another factor reportedly influencing participation in the home environment was the aggression.

[He] didn't do any disciplining [of the children]... because we didn't know when [he] would know when to stop... He would smash chairs, he would grab knives... He was

exceptionally explosive. You were always walking around on egg shells. (Spouse)

### *Work, study and leisure*

Productive activities refer to work, study and leisure. Due to their level of disability, no individuals were currently involved in paid employment.

The challenge is going out into the community groups and doing activities. He's not one for that; he'd just shut down or... lash out. (Sister)

As a result of the challenging behaviours, participation in school was difficult.

We had terrible behaviour. We had phone calls all the time from school. Come and pick him up... [He] got expelled in the end because he hit the aide. (Mother)

### **Family experience**

Family outcomes varied considerably. Many changes to the family system as a whole, as well as effects on the individual family caregiver, were reported in response to challenging behaviours.

#### *My family's changed*

Changes in relationships were a common outcome for families. Most family caregivers indicated that there was a breakdown of relationships within the family structure that were often related to challenging behaviours:

I've lost the relationship between my eldest daughter and me because if you're on the phone and she's within earshot, you're uptight. You're thinking oh she's going to go off in a minute, so you cut the phone call short and I think over time, that's had an impact on the relationship between our eldest daughter and us [husband and I]. (Mother)

#### *My role in the family has changed*

When family members had taken on carer duties, this role change impacted on their previous roles within the family. Family interactions change in order to manage the impact of the challenging behaviours in the family. A sister explained that she had to monitor the relationship dynamics between her brother with TBI and their mother:

Mum was very involved in his programme as a worker... we had to get mum in that mindset that she's the mum and not the worker... So that she could continue to have that relationship with him, mother and son, that's very important. (Sister)

Family caregivers also performed the role of facilitating participation of the individuals with TBI within social settings:

It's me that always feels oh he's being left out... so I try to bring him in but it's hard work. (Mother)

Family caregivers described that, when they took on additional roles, it could be challenging for the TBI individual if they are aware of it. To avoid triggering a behavioural or emotional response, families described working behind the scenes, making this role change covert to them:

She went to woodwork; we had the woodwork guy paid... She never knew that he was paid, and that worked out well and she loved it. (Mother)

#### *It's quite draining on me*

It was evident that family caregivers were still traumatized by behaviours that occurred in the earlier days of the TBI. Although individuals no longer displayed some behaviours, family caregivers often talked about these critical incidents. A spouse described the events that occurred following the initial discharge from the hospital:

He was holding my head down here [table] with a knife, chasing me out there [backyard]. I got [our son] in the car. My brother was luckily living down here as well, that was years ago and he'd rung the police and we had six undercover cops. (Spouse)

Family caregivers described the experience of assisting their family members as challenging and described feelings of hopelessness and loss of hope:

It's just, you feel like there's no end. That's how it feels like a tunnel, you can't see the light... [It] disappoints us if we've had a period of him being balanced for a while. When we always think oh maybe he's getting better, the hope. And then it [the behaviours] comes back at you and we get so disappointed. (Mother)

A mother further elaborated that the challenges were created not only by the behaviours, but also her sense of responsibility for her son:

This sounds really awful. Sometimes I wish he had died [because] it would have been easier for me. Because I had to stop working. I don't feel I have a life anymore. And it's not because of his behaviours, because of my responsibility toward giving my son the best life he can have. (Mother)

The ongoing grief and loss families experienced was seen as impacting on subsequent life stages of the family:

We're not going to have grandchildren, which is a really sad thing... I feel left out because most of [my friends] talk about their grandchildren all the time. (Mother)

The impact on the mental health of family caregivers can be significant:

I developed post-traumatic stress, anxiety, depression all of that happened to me and that's why I'm on a disability pension. (Mother)

## Family strategies

Despite ongoing issues, family caregivers recognized that the challenging behaviours had in some ways improved over time. Family caregivers described numerous other strategies for the management of challenging behaviours, as illustrated below.

### *Modifying living environments and demands*

Living environments or family living arrangements were restructured in some cases to manage challenging behaviours:

He never used to live here [house]. We had this rule where we had a caravan and it'd be at a friend's house . . . He would come and stay here maybe two, three times a week and live in that caravan every other time and if he got angry, he would go to that caravan. That was our safe spot and his safe spot because he was very volatile back then. (Spouse)

The use of reminders, routines, notes and prompting was a strategy used to assist with the lack of initiation, as well as memory and planning problems. A spouse commented on the benefits of lists in minimizing the frustration he experienced and subsequently the challenging behaviours:

I had to leave him a detailed list trying to get wood in, try and bring the washing, hang it in, and feed the kids . . . The lists are very important because they stop him from getting frustrated. (Spouse)

Additionally, taking pro-active measures could help prevent some challenging behaviours escalating:

We're very conscious of making sure we nip things in the bud and address issues as they come up. (Sister)

### *Modifying interactions and responses*

Changing the way one interacts with the individual with TBI was a key method utilized by family caregivers:

'I can scream at you all the time. But you don't understand it so when you're in that angry state, I'm wasting my breath because you can't get it' . . .Afterwards when he's calmed down . . . then we can talk. (Spouse)

Having firm limits and providing feedback following inappropriate behaviours were described as essential:

Sometimes you know he may lash out but we make him apologise and to say sorry . . . So it's being firm and disciplined with him. (Sister)

Prompting time-out was used to de-escalate behaviours:

When he behaves appropriately, we have him around us. When he doesn't, we say he has to be in that space [his lounge room]. (Mother)

Giving the individual with TBI more control over their lives had proven to be an effective strategy for some:

[We] try to make him feel like he has a bigger control on everyday life. We've introduced him to go do shopping

with us and the carer . . . Go into the chemist to pick up his medication. (Sister)

### *Looking at things differently*

An important strategy involved acceptance and increasing the understanding of behaviours after TBI:

[Family therapy] really helped me put the brain injury and understanding in my head . . . It's the brain, it's not him and that's how I think I cope with it . . . So it was like you had the brain injury and you had him and when he did something wrong or naughty or unacceptable, it was the brain injury so that I was then able to separate it and not personalize it on him. (Spouse)

To assist in coping, family caregivers commonly tried to understand the triggers to the behaviour and the link with the brain injury:

At the end of the day, we all have bad days and we [family] think it's his way of lashing out a bit . . . His way of communicating is through his banging and you know trying to grab. (Sister)

A common strategy used by family caregivers was reframing their perspective by focussing on the positives, rather than just the negatives:

[We] live in a beautiful environment. We've got trees, we're lucky we own our place; we're relatively healthy . . . I think [that's] how I survive it. I try to be philosophical and just you know, enjoy life; you're a long time dead. (Spouse)

Family caregivers acknowledged the importance of breaks and holidays for families. Being able to have some time for oneself was also important:

I find the best thing for me is the painting. When I go in my space, I feel I'm achieving something and also feel like I'm doing something, I'm something other than a carer. (Mother)

Following a TBI, seeking support through spirituality was also identified as a strategy adopted by family caregivers:

I believe in Buddhism and Hinduism so I believe in karma . . . to me the glass is always full, not empty, so I think having that perspective makes it not as bad, not as traumatic. (Spouse)

### *Support networks*

Family caregivers described how having social and professional supports helped them cope with the behaviours:

You need time out. When he's really angry and I say to [my husband], just go for a walk. You know, we take over. We swap . . . One of you is not handling it, the other one can come in. (Mother)

Friendships for the family caregivers were also important:

I've got a couple of long-term girlfriends that understand him and...they've been very tolerant and they're supportive. I'll ring them, go over there and have a wine or have a chat and they help you talk through things. (Spouse)

The availability of professional support was also seen as critical for families, although at times was inadequate. The need for respite was identified by family caregivers:

More help with out of home respite, definitely, which we don't get. That would help a hundred times. (Mother)

Family caregivers believed that attendant carers had not received enough training in caring for the individuals with TBI:

The [attendant] carers aren't trained well enough, to understand that...he's got something in mind but he can't express it. (Mother)

On the other hand, a sister indicated the family's satisfaction with a programme and attendant carers, which has helped minimize his challenging behaviours:

The [attendant] carers are regularly trained by the therapists every 6 weeks. So it's constant reviewing, there's routine, a care plan that everyone needs to follow and that certainly has helped minimize the agitation. (Sister)

Having professionals in the background is helpful, particularly in emergency situations:

It's always knowing that if something does come up, you know, we've got the people that we can call or email. (Sister)

## Discussion

The current qualitative study was conducted to explore the experience of family caregivers for individuals with challenging behaviours following severe TBI. Its unique contribution was its qualitative methodology, which allowed for in-depth exploration of the nature and effects of challenging behaviours from the perspective of family caregivers living with individuals with TBI for over an average of 17 years after injury. Family caregivers highlighted the chronicity of the behaviours, although many indicated that improvement or adaptations had lessened their impact over time. Themes reflected the significant impact of behaviours on community participation of the injured individual, on the family caregiver and on family relationships, as well as strategies used by families to manage the behaviours.

### Nature of challenging behaviours

The chronicity of challenging behaviours after TBI highlighted in this study is concerning; however, the findings also show that, by living with these behaviours over many years, families had come to manage them better. Years of experience

with challenging behaviours had helped family caregivers to develop a good understanding of factors that made them worse or better. Family caregivers identified several environmental factors that influenced the expression of challenging behaviours, including the degree of familiarity or complexity of environments and the extent to which family members and others were tolerant, accepting and flexible. Family caregivers identified characteristics of the individual with TBI that influenced their behaviours. Some of these were enduring injury consequences, such as physical or cognitive impairments. Other factors such as fatigue, anxiety and self-confidence varied according to the context and could to some extent be controlled.

These findings provide clues as to avenues of intervention, either by addressing problems with memory, fatigue, anxiety or self-confidence, reducing the complexity or demands of tasks in the environment or increasing understanding and tolerance of other people with whom the person with TBI is interacting. Whilst such so-called antecedent interventions have previously been recommended by various authors [24–26], there has been limited controlled evaluation of their effectiveness. The fact that family caregivers reported implementing some of these strategies with success provides support for their use by rehabilitation practitioners. In the only controlled group trial of behavioural interventions to date, Carnevale et al. [27] found no significant difference at the end of the treatment phase, between natural setting behaviour management, involving education and provision of an individualized behaviour modification programme delivered over 8 weeks, and education alone or no treatment. However, there was greater reduction in disruptive or aggressive behaviours in the individualized treatment group 3 months post-treatment. Therefore, it may be that families are able to use such strategies with benefit over extended periods.

### Impact on community integration

In line with prior quantitative [9, 28] and qualitative research [11], challenging behaviours were strongly associated with difficulties with many aspects of community integration. The effect of challenging behaviours on social relationships was a key concern for family caregivers, contributing to loss of friendships and marked social isolation in most cases. Inappropriate social behaviours, reduced self-esteem and fatigue were reported to contribute to a loss or decrease in the quality of relationships with friends and family. The family caregivers also described how challenging behaviours such as poor initiation and aggression impacted on the person's ability to engage in activities in the home and in the community. Given that challenging behaviours made integrating into the community difficult, the person with TBI usually spent most of their time in the home environment, which increased the caring responsibility of the family member. These findings support past quantitative evidence of reduced community participation in the face of challenging behaviours [9, 28]. Recent research suggests that the relationship between challenging behaviours and community participation may be bi-directional [28]; that is, reduced participation also leads to increases in challenging behaviours. It is important that

people with TBI and their families are actively supported to gain and maintain access to community and social activities and that challenging behaviours are effectively managed in these settings.

### Family experience

The accounts of the family caregivers confirmed the broad-ranging and at times devastating impact that challenging behaviours can have on the family after TBI. In addition to necessitating lifestyle changes such as moving accommodation and changing employment, family caregivers recognized changes in their interactions with their family members with TBI, as well as other people in their lives. A decline in relationships with other family members was reportedly associated with intrusive behaviours or aggression. As described in previous research, family members had experienced changes and increases in responsibilities and roles following severe TBI. Besides increased domestic responsibilities, they often provide emotional and practical support, supervise social activities and monitor triggers to circumvent behavioural problems [12, 14].

Family caregivers described their own emotional reactions, including a sense of hopelessness, ongoing grief and loss, as well as mental health issues such as post-traumatic stress and depression, consistent with previous studies [17, 29]. However, despite all these long-term challenges, family caregivers showed enormous forbearance towards the individuals with TBI and their challenging behaviours. Family caregivers expressed a sense of adjustment to and acceptance of the behaviours of the individuals and attempted to understand the role of the TBI in causing them. Additionally, they indicated a determination to focus on the positive aspects of their situation. This exemplifies the reframing of a difficult situation and use of positive appraisal towards a traumatic event discussed by McCubbin and McCubbin [30]. Through such reframing and adjusting, the family caregivers had been able to remain supportive of their injured relative over many years.

In line with previous literature [11], some family caregivers displayed a negative attitude towards service supports, in particular, the lack of respite care and competence of some carers [31]. Others had gained great benefit and reassurance from the assistance received from professionals. This highlights the importance of continuing professional support even after many years post-injury, which may represent a key factor in maintaining the family caregivers' capacity to provide continuing care for a relative with challenging behaviours.

### Family strategies for managing behaviours

Family strategies used to adapt and adjust to the challenging behaviours were regarded as 'part and parcel' of dealing with these changes. In line with Braine's [14] study, there was considerable variability in the strategies used by families. Consistent with the above-mentioned premise that pro-active modification of the environment or tasks may minimize challenging behaviour, family caregivers reported that they had changed their lifestyle and living arrangements, used routine or changed the responsibilities of the individual with TBI to reduce demands or triggers for challenging behaviour.

Families also used a range of strategies to deal with the behaviour once it was expressed, including allowing the individual time to calm down, setting firm limits and providing feedback. Family caregivers identified the importance of developing self-efficacy in the person with TBI and wanted to maximize their sense of independence and control over their lives.

Family caregivers identified a need to manage their own emotional responses to behaviours as a coping strategy. In order to achieve this, families sought to understand and accept the TBI and its effects through self-reflection or spirituality. This has been identified in previous studies [32]. Family caregivers also emphasized the importance of receiving understanding and support from other family members, friends and professionals in managing the challenging behaviours.

### Methodological considerations and directions for future studies

This study has a number of limitations. A larger sample size would have been advantageous since data saturation typically occurs within the first 12 interviews in qualitative research [33]. However, Guest et al. [33] argue that basic meta-themes still appear after as few as six interviews, supporting the value of the data collected through this study. The study interviewed female family caregivers of males with TBI and may be less representative of experiences of the broader family caregiver population such as fathers or male partners. For two of the six participants, the individual sustained their TBI in childhood, which may be associated with different caregiving experiences to when the TBI happens in adulthood. Although the age of TBI onset did not emerge as a key theme in this study, this was not a focus of the research questions and may have emerged if questions were more targeted to this issue. In considering generalization of these findings, it is also important to note that the sample used involved participants who had received long-term rehabilitation support with family caregivers who remained supportive of and continued to provide care to the individual with TBI over many years. Many other individuals with severe TBI and challenging behaviour are not so fortunate.

### Concluding remarks and clinical implications

The findings of the present study have, nevertheless, provided valuable insights into the challenging behaviours exhibited by some individuals over many years following very severe TBI and their impact on their community participation, the family caregiver and family relationships, from the perspectives of their family caregivers. The findings regarding the nature of challenging behaviour and their impact on community participation are largely consistent with previous literature, based on observation or quantitative studies [2, 5, 10], although this and other qualitative research [14] suggest that inclusion of cognitive impairments in the conceptualization of challenging behaviours may be appropriate. A unique contribution of this study was that family caregivers had lived with the challenging behaviours over an average of 17 years after injury. This highlighted the chronicity of challenging behaviours and the importance of families and TBI clients having

life-long access to professional services and supports, which may in turn decrease the likelihood of caregiver burnout. Despite the detrimental impact of challenging behaviours on the family members, these families, who had received rehabilitation support, showed great understanding and capacity for managing the behaviours of concern. Families clearly represent a vital source of support to individuals with TBI, particularly given the loss of other social relationships which families view as one of the most devastating impacts of the challenging behaviours. The qualitative information gleaned from these family caregivers support the premise that understanding the brain injury and developing strategies to minimize the impact of cognitive impairments may lessen challenging behaviours. Minimizing fatigue and anxiety, modifying the environment and interactions of others and providing professional support to the injured individual and family may assist in minimizing challenging behaviours in severely brain-injured individuals. The findings from this and further studies of both a qualitative and quantitative nature will allow a better conceptualization of challenging behaviours from the perspective of family members, which may guide the development of new assessment tools and potentially enhance the quality-of-life of individuals with severe TBI and their families.

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### 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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