

An exploration of families' lived experiences of attention-related communication difficulties following traumatic brain injury

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ABSTRACT

Background. To explore families' experiences of living with someone who has attention and communication difficulties following a traumatic brain injury (TBI). Attention-related communication difficulties are common following TBI, but to date there is limited research into the effects on the family with respect to this cognitive communication difficulty. **Methods.** Recruitment of family members was completed through TBI community rehabilitation services. Inclusion criteria were that the family member needed to be living with an individual who had sustained a moderate to severe TBI at least 6 months prior to the study and that they had self-reported attention and communication difficulties. A semi-structured interview was completed. Qualitative interview data underwent reflexive thematic analysis with an inductive approach. **Results.** Eleven family members (including wives, mothers, a father, and a daughter) were interviewed. Two themes were generated that explored the lived experiences of the family. The first, *adjustment to the new normal*, outlines the changes and adaptations the families made to live with and support their loved one's attention and communication difficulties. The second theme, *the load the family carries*, reviews the two polarities of facilitation and support along with the burden the family endures following the injury. **Conclusion.** The themes outline how attention-related communication difficulties following TBI bring additional burden and challenges for families for years following the injury. Families report adapting their social lives and learning to implement specific strategies to improve their person's ability to interact and participate in conversations. Clinical implications are discussed.

Keywords: adjustment, attention, cognitive communication, family, lived experience, qualitative, TBI.

Introduction

Cognitive, communication, and behavioural difficulties are frequent sequelae following traumatic brain injury (TBI) in adults (Menon et al. 2010). These consequences are prevalent both within the acute phases following the injury as well as years later (Ponsford et al. 2014b). Cognitive communication disorders (CCDs) are a complex set of cognitive and linguistic difficulties that afflict most adults following a TBI (Norman et al. 2021). The specific cognitive areas that affect communication include attention, memory, information processing, and executive functioning (American Speech-language Hearing Association 2007; College of Audiologists and Speech-Language Pathologists of Ontario 2015). More specifically, the nature of attention-related communication can also have an impact on specific areas of social communication, discourse, and linguistic abilities such as word retrieval (Stierwalt and Murray 2002; VanSolkema et al. 2020). Attention is a foundational cognitive skill for effective communication and affects the majority of adults following TBI throughout the recovery and chronic phases (Ponsford et al. 2014a, 2014b; VanSolkema et al. 2020).

Since the initial definition of CCD was introduced in the 1980s (American Speech-language Hearing Association 1983) there has been a continual growth of understanding into how CCDs affect adults following TBI. Recent research has brought to light the subtle yet profound difficulties of CCD and their impacts on family functioning, marital relationships, and families' psychological wellbeing many years after the injury (Bracy and Douglas 2005; Grayson *et al.* 2021). Specifically, the difficulties of the person with TBI are related to social cognition and their lack of insight and awareness of these changes, which affect families' wellbeing (Grayson *et al.* 2021). Extensive research has been completed reviewing families' experiences following a TBI to explore areas such as emotional adjustment (Harris *et al.* 2001; Sander *et al.* 2013; Finn *et al.* 2022), grief related to ambiguous loss and change of the person following the injury (Lond and Williamson 2022), marital adjustment and changes because of the TBI (Blais and Boisvert 2005; Bracy and Douglas 2005), the difficulty and stress families endure even 5 years following the TBI (Ponsford and Schönberger 2010), and how families experience high levels of distress when their loved one has high levels of behavioural, communication, and social problems (Anderson *et al.* 2002). Current literature explores many of these aspects of families' experiences and their coping strategies; however, there is no literature exploring the specific problem of attention-related communication difficulties following TBI. This study aims to understand and explore families' experiences of living with someone who has attention and communication difficulties after sustaining a TBI.

Methods

Study design

This study used a qualitative framework of phenomenological research through the completion of semi-structured interviews. The authors' worldview of critical realism formed part of the study design by assessing the perception of the participants' reality through the authors' cultural lens. For example, the first author, MVS, is a speech-language pathologist (SLP) and researcher within the field of traumatic brain injury. Contextualism is the epistemology most aligned with this project, as it views knowledge as evaluated in terms of utility rather than accuracy (Bal *et al.* 2014; Braun and Clarke 2022).

Data analysis

Reflexive thematic analysis was used to analyse the interview data (Braun and Clarke 2021, 2022). Primarily an inductive approach to coding was completed, where the data content drives the meaning and theme development. Coding focuses on the semantic meaning or surface-level interpretation of the data. The refinement of final themes

was discussed between MVS and CMC to achieve clear definitions for each theme and for purposes of agreement and rigour. The computer software NVivo was used to organise the qualitative data for analysis (QSR International 2020).

Participants

Participants were family members (spouses/partners, parents, children) of individuals with a TBI in New Zealand. Family members were invited to participate in the study if they lived with or cared for a family member that experienced attention and communication difficulties following their TBI. To be eligible for inclusion in the study, the person with a TBI must have been at least 6 months after their injury, have had a self-reported moderate to severe TBI, and be 18 years or older. Family members were recruited via advertisements placed at an outpatient TBI clinic, emailed to community allied health professionals, and displayed on the brain injury rehabilitation centre's social media pages. Additionally, a random letter drop to previous clients at the rehabilitation centre was also completed to recruit participants.

Procedure

The ethics committee at the University of Auckland approved the study (reference number 021378). Each family member made contact with the research team following the invitation to participate. Written consent was gained from each family member to participate in the interviews. The interviews were conducted by two SLP master's degree students (LD and JH). The interviews took place either online using video call or at a location convenient for the participant (rehabilitation clinic or home). The interviews lasted between 30 and 60 min. Three interviews were conducted face-to-face, and eight were completed via video call. The interviews recorded only the audio information, which was then transcribed verbatim by JH and LD. The content of the interview followed a semi-structured script with targeted questions and open-ended questions (e.g. Box 1). It included an education session related to explaining the types of attention and providing examples of communication difficulties related to these. Family members were encouraged to provide their accounts and stories of their experiences with their person with a TBI having attention-related communication difficulties.

Results

Participant data

The interviewed participants included 11 family members of 12 individuals with TBI (11 males and 1 female). This included a parent who had two sons that sustained separate TBIs and one person who had sustained two TBIs 17 years

Box 1. Semi-structured interview questions and script**Interview questions/script**

Communication is delivering and understanding information and ideas. Attention plays an important part in this. There are four different types of attention (use diagram to support understanding).

The first type is called **sustained attention**. Sustained attention is being able to focus on one task for a long period of time, for example, playing a board game.

Can you describe your family member/partner's ability to...?

- Express their thoughts in words
- Follow a topic
- Shift topics
- Attend to social cues
- Respond accurately during a conversation

The second type is called **selective attention**. Selective attention is being able to focus on one activity without getting distracted by other activities, for example, listening to a friend at a party.

Can you describe your family member/partner's ability to...?

- Filter out external distractions (noise)
- Filter out internal distractions (their own thoughts)
- Pay attention to a conversation while doing something else
- Respond quickly

The third type is called **alternating attention**. Altering attention is being able to go back and forth between tasks, for example, when someone is working on a computer and answers their phone, and then returns to working on their computer.

Can you describe your family member/partner's ability to...?

- Keep up with a conversation with more than one speaker talking
- Follow 'workplace communication' (when there is a lot of information going on at one time)

The fourth and final type of attention is called **divided attention**. Divided attention is being able to multi-task (pay attention to more than one thing at a time), for example, surfing the web while talking on the phone.

Can you describe your family member/partner's ability to...?

- Follow along with two different sources of information
- Listen to two conversations at once
- Keep on topic
- Say the 'right' thing

Have you noticed any other communication difficulties your family member/partner has?

apart (e.g. Table 1). The relationship of the family members to the people with a TBI included six wives (55%), three mothers (27%), one father (9%), and one daughter (9%). For ease of reading, the participants are referred to as the 'family member' or 'family' and the individuals who sustained the TBI will be referred to as their 'loved one'. The average time following the brain injury was 6.3 years, ranging from 1 to 36 years.

Qualitative data

Two qualitative themes were generated during the analysis, each with supporting subthemes that bring focus to the lived experiences of families when considering attention-related difficulties of their loved one. The two themes are *adjustment to the new normal* and *the load the family carries*.

The first theme outlines the *adjustment to the new normal*, where the family member described the aspects of their lives that had changed. This theme tells the story of what it is like living and moving through the journey of recovery and adjustment following a TBI. Families talked about the polarities of living with someone with TBI and attention-related communication difficulties. They discussed the positive and rewarding aspects of their loved one improving or finding success in both large and small aspects of their lives and, in addition, learning about TBI.

The second theme, *the load the family carries*, explores the way families hold both extremes of facilitation and burden. This lived experience includes the gruelling nature of constantly struggling or not knowing what to expect from moment to moment. The burden of this load is carried across

all relationships and roles inside and outside of a family unit (e.g. Fig. 1).

Adjustment to the new normal

Families reported that they changed and adjusted their lives so their loved one could achieve success. Family members spoke about attention-related communication difficulties having changed their loved one and what they do on a

Table 1. Interview participant details outlining the relationship to the person with TBI; years following the TBI; and the mechanism of the TBI.

Relationship to person with TBI	Person with TBI	Years post injury	Mechanism of injury
Wife	Husband	5	Fall
Mother	Son	2	Bicycle accident
Wife	Husband	3	Bicycle accident
Wife	Husband	4	Assault
Mother	Son	2	Sport accident
Wife	Husband	36–1st TBI	1st motorbike accident
		19–2nd TBI	2nd motorbike accident
Wife	Husband	1	Fall
Wife	Husband	4	Motor vehicle accident
Mother	Son	2	Bicycle accident
Daughter	Mother	4	Pedestrian versus car
Father	Two sons	9	Motor vehicle accident
		4	Motor vehicle accident

daily basis. One way they described their loved one adjusting included completing only one task or conversation at a time. If they did complete more than one task, or had to be part of a group conversation, the family described how difficult this was for their loved one.

Yeah I mean he can't like if he's making dinner he can't have another conversation he can't remember it like you know not and function well, and you can physically see his almost like his body doing this because he's trying to trying desperately trying to do it but it doesn't it doesn't work well for him. Um he cannot listen to two conversations at once that's virtually impossible in fact he literally has to go 'Stop, one of you talk at a time I can't'. (Wife)

Changing conversations and tasks to support the attention of their loved one allowed for successful interactions and completion of tasks. Conversations included more complex thought formulation when having a one-on-one conversation. Some family members reported that returning to employment was largely successful because of the singularity of the tasks involved, whereas another family's loved one did not return to work because of the distractions and busyness of the work environment.

Other tasks that involved more than one person were not successful; this was specifically related to group conversations. This resulted in the family withdrawing from previously meaningful tasks because they were too difficult for everyone. They put it simply: 'We don't do that anymore'. This represented a complete shift of their social activities. The difficulties of social activities included the loved one with TBI withdrawing from the conversation or paradoxically becoming frustrated and agitated. Social activities that were not successful or were avoided by the

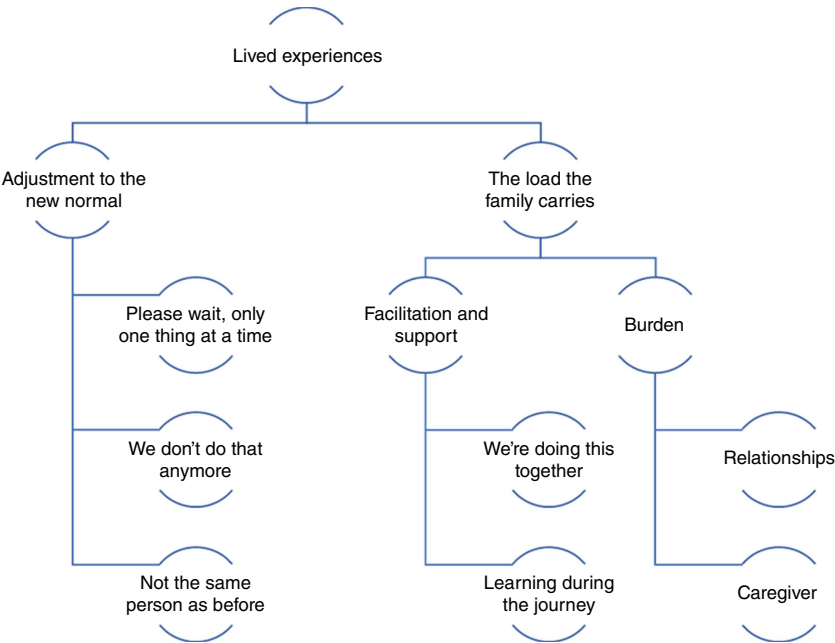


Fig. 1. Thematic map of qualitative themes describing the lived experience of families when considering attention-related communication difficulties.

families included most social gatherings, barbecues, going out for dinner, listening to music, watching TV, watching movies, and reading. The shift in or withdrawal from social activities resulted in the person with TBI losing friendships.

We don't well we don't go, we don't have a lot of dinner parties or multiple event you know where there's multiple people because it's so difficult for him um it's part of it is of course the language that when you know if you have a group of people around a table interrupting each other and being you know speaking, you know making jokes and speaking colloquially he'd have a hard time keeping up anyway. (Wife)

The shift in social activities was also framed within the context of the family member describing their loved one as being a different person from who they were before the injury. This aspect of adjustment and change to core personality was something that the families reported as being a challenging process. They were constantly trying to find new things to do together and explained that the 'old' person would love to do any activity, but the 'new' person could not, or was 'not the man I fell in love with'.

So we've had to rejig our lives and he's had to adjust quite significantly at work and home is um where he feels safe so he tends not to be as structured yeah I know it's um the I think the main part was that to go from somebody who is so significantly different to the person that he is now and having to kind of relearn who that person is. (Wife)

This shift in personality and personal values related to a perceived change of self-confidence, not being motivated by the same things, being more passive, and some behaviours being more exaggerated, such as being impatient with the kids, having rigid beliefs, and being more aggressive. Families also reported the change of employment and interests to be positive, with new opportunities being present because they were not able to return to work, therefore, they had more time for other ventures. Furthermore, because of the personality shift, changes to employment, and reduced social connections, this also made space for improved relationships with other members of the family.

The load the family carries

This theme focused on how the families hold two spaces related to facilitating and supporting their loved one with attention and communication difficulties, alongside the burden and hardship.

Facilitation and support

Families spoke of what it looks like for them when they are helping their loved one. Multiple participants spoke of

togetherness and working through difficult situations that involve guilt (as expressed by their loved one) related to them not contributing, or the change of roles and responsibilities since the brain injury, 'and he gets guilts saying 'I've done nothing for you' and I'm like 'yes you have you've survived you're kicking it' like 'you're still here that's all I want' I'm like 'I've got this, we've got this''. (Wife)

Parents also spoke about helping their child with the brain injury and needing to support them in everything they do such as going out into the community or financial support. One parent spoke of letting the larger community around their loved one know how to help as an efficient and long-lasting strategy. Other parents stated that having a larger support network or familiar people around their son allowed him to be successful in returning to work and living as independently as he could.

Family members discussed the intricacies of how they support their loved one's language and communication. They talked about knowing and anticipating what their loved one is trying to say alongside allowing them time to formulate their responses and guide their focus within a conversation. They would give them key words and clarifications to facilitate their participation in social conversations. Families also understood and could interpret their loved one's difficulties or the subtle cues when they were distracted and struggling.

Cause he sits there and you can see him listening, but he then, he won't possibly become involved in the conversation. Because I think the hardest thing is that because I'm not inside his head, like he said to me the other night, he said mum I wish that you could be inside my head and see my thoughts. You know and I said, you know I would love that too so much so I could help him, you know? And, but I can't, so yeah, so he looks like he's listening, but I can't actually tell you what he's taking in, or how much he's understanding. (Mother)

Another aspect of facilitation and support that was held by the families was learning about their loved one's brain injury and communication difficulties. Parents talked about being empowered and supported by clinicians and funders when knowledge was imparted to them. This also involved observing therapy sessions so they could better understand their loved one's attention and communication deficits.

Sometimes you see the rewards you see the rewards but the way that you keep positive is understanding the injury and that's where ACC [Accident Compensation Corporation] have supported me in giving in going to seminars and learning about um [my son's] injuries. (Father)

Burden

The two aspects of burden reported by the families were on *relationships* and being a *caregiver*. These two have

different attributes but together provide the landscape of the emotional cost of caring for someone who has had changes to their attention and communication abilities because of the TBI. The toll on each relationship with their loved one resulted in these connections being severed and requiring active intervention and support.

All sorts of things from left field and you do feel your life's a guessing game living with a person with a brain injury I think most people don't survive the relationship because it's so difficult. (Wife)

Wives discussed being separated from their husbands with TBI in order to get help for themselves through gaining perspective and receiving both individual and marriage counselling. Wives also described their relationship with their husband as being a 'marriage from hell' and dealing with the emotional insults related to their husband speaking in hurtful tones and not seeing how this affected his wife or children.

Um yeah I think a thing I've noticed one of the things I've learnt not to do learnt to do is I shut down after a while because I felt like every time we spoke about anything that you know his behaviours were it got into an argument so then I stopped talking and that's partly while when I went to the to the split because I just gave up and that's not you know that's not me in general but because it became so hard I moved away from kind of confronting anything with him so we'd one of the things I say I can say has been really helpful is always understanding that if I don't say anything then it won't help him um and that's been a key thing from the split is that I realise that if I want to be with him forever which I do because I love him and we love each other then I have to be strong as well like I have to be the stronger person yeah and I have to kind of make sure and that's what I mean its helped us deal with this me dealing with him I have to be the one who does the hard stuff because he actually doesn't see that he doesn't see it at all so it you know it nearly destroyed us but it's definitely been good learning yeah there is none there's no self-awareness for him. (Wife)

One family also discussed the role of their loved one as a father. This role and the relationship the father with his children were also taxed. Wives discussed not wanting their children to observe their husband (person with TBI) treating them poorly. They also discussed the fathers with TBI being more frustrated and less patient around their children because of the internal emotional processing they were experiencing.

Like I remember him being really he so he did experience depression for a while there and I remember him being really down about like you know 'it's not even just work

I'm not even a decent dad anymore and I'm just you know I'm just angry and grumpy all the time!' And he was really grumpy generally like with me but it wasn't you know it wasn't in an awful way and it was never in an awful way to the girls either it was just frustrated towards them and that meant that he just couldn't be around them or with them as much as he wanted to so... (Wife)

The role of the caregiver brought extensive amounts of burden that was expressed by all family members interviewed. Caregiving brought with it the feeling of always being on watch and needing to respond, through being an advocate and the family member having to explain or defend their loved one's actions and behaviours.

It's very frustrating living with someone like that because you want to help them... but he just can't help himself and I'm coming to this realisation now that ... his intention is that he wants to but he just can't do it so I have to be with him to... help him follow through and ... that's very draining for me you know? it's f*cking awful I hate it. (Father)

In addition, the role of being a caregiver was held by all members interviewed. This role was something that they reported doing, but they also reported struggling with grieving and losing their previous roles and identity. This also touched on the concept of comparative suffering as the family members did not sustain the brain injury themselves so they should not complain.

Like sometimes it does my head in but I just go with it and sometimes I feeling I'm losing my identity a bit if you know what I mean but the way I see it or remind myself is [husband] done it harder [husband] has survived [husband] lives this but then I'm living it too yeah I'm a partner first I don't want to be a mother and that's the hardest. (Wife)

The brain injury was quite significant, so she [therapist] was like absolutely floored and said, you know he's a bit of a miracle in what he can do considering his injury. And so I feel a bit guilty that I have a son who's a miracle. (Mother)

Another aspect the family members reported was the support they were yearning for related to the invisible cognitive and behavioural difficulties they endured daily. They commented that no one understood because their loved one looked fine.

I've always felt like in my relationship with him that I'm keeping my head just about water it's been quite a hard life because people don't understand they say well look he looks fine it must be fine and so when he does his you

know when he acts or says things he does people don't understand um. (Wife)

They commented on the mental turmoil and not having the pillars of wellbeing intact, as a reference to the Māori model of health and wellbeing, Te Whare Tapa Whā, which represent taha wairua (spiritual wellbeing), taha hinengaro (mental and emotional wellbeing), taha tinana (physical wellbeing) and taha whānau (family and social wellbeing) (Durie 1984). Families discussed that their loved one receives psychological support from professionals, but nothing is provided to the family.

If I wasn't there caring for him it would be costing the state a lot of money and he wouldn't really be getting any care he would just be babysat you know? There's no mental you know? If they are going to care for him they would have to care for the family as well four pillars you know I can't even tell you what they are but they are his physical, mental, spiritual and family! And none of those are being met you know? I can't meet them because I'm struggling to keep my head above water just with all the bullsh*t that I have to deal with the brain injury... *sighs*. (Wife)

Discussion

This study explored the lived experiences of family members following TBI when considering attention-related communication difficulties. By focusing on this presentation of TBI the findings validate and provide insight into something that is largely invisible but felt intensely by individuals living with attention-related communication difficulties. The themes generated from the families' stories are discussed below.

Adjustment to the new normal

This theme outlines the process related to adjustment that occurs following TBI. The family members discussed in detail how they had to change the way they interacted with their loved one, but also how the change of interaction reduced and shifted the family's way of interacting socially with others. Furthermore, the withdrawal from all social interactions was not only felt by the person with TBI, but the entire family unit. These findings are supported by another study which explored the lived experience of families related to CCDs. They found that the family members interviewed also reported that social cognition and overall social communication difficulties affected relationship and everyday interactions for the individuals with TBI (Grayson *et al.* 2021). The withdrawal from meaningful social interactions and activities was reported by this study as being a result of their loved one not being able to keep up in conversations or struggling with group conversations. Families found success in reducing the demand on their

loved one's attention-related communication, such as having one-on-one conversations, shifting to more solitary social events, and completing singular tasks in order to still participate in meaningful activities. Additionally, the families reported a process of adjustment, especially related to the change of personality of the person with TBI. This was alongside the change of previous life roles of the family members, where partners shifted to caregivers. Whiffin *et al.* (2021) found similar themes when exploring the families' complex, ever-changing and evolving processes of adjustment to their *new* loved one. In an earlier study, by the same author, they connected these challenges to the family struggling with identity change of the person with TBI. They reported the challenge on the family when adjusting to a loved one that is not the same person as before the injury (Whiffin *et al.* 2019).

The load the family carries

Facilitation and burden were the polarities of this theme reported by the families. The families discussed the positive aspects they have found in order to cope with the significant disruption in their lives. These included a sense of connection and togetherness with their loved one, and a sense of community when the layer of support and facilitation went beyond the family unit. Families also reported feeling empowered and grateful when they were able to learn and understand about their loved ones' difficulties. This act of learning and supporting the family is echoed in other qualitative studies, where ongoing education and training of CCD, behaviour, and general coping strategies allow the family to function and thrive following the TBI (Holloway *et al.* 2019; Grayson *et al.* 2020; Dawes *et al.* 2022). Despite the actions of resilience felt by the family members, they also acknowledged the extreme burden and relentless nature of caring for someone following a TBI. Family members reported the feeling of isolation and lack of understanding by others, because of the invisible nature of attention-related communication difficulties. They reported constantly needing to be present to facilitate effective communication because the person with TBI could not do this on their own. This was especially the case with unfamiliar communication partners, as they were unable to cope with the person with TBI's rapid topic changes, abrupt comments, or complete withdrawal from conversations. Holloway *et al.* (2019) (in the United Kingdom) reviewed the support and challenges of family members following TBI, with similar findings related to the impairments being 'invisible' therefore being discounted. Burden was reported as a feature in all relationships (e.g. parental, marital, friendships, and vocational) and within the role of being a caregiver. The wives from the current sample reported participating in both marriage and individual counselling in order to cope. Equally, family members reported not receiving support for themselves, and the focus being solely on the person with

TBI. This sentiment was also reported by Whiffin *et al.* (2021), where the need for the family to maintain their own sense of wellbeing is encouraged, but neurorehabilitation service models lack clear momentum related to treating the family, and instead only focus on the person with TBI.

Limitations

There are a number of potential limitations to this study. This study had a small sample size within a specific geographical location and represents their perspectives and opinions. Findings should be interpreted with caution when considering other contexts. The addition of video recording of each interview may have provided more observational data related to the participants' narratives, but this was not done in the current study (because we did not have ethics approval to use this information). It is also acknowledged that the difficulties and concepts discussed by the family members represent the complexities of cognitive and behavioural difficulties that are present among attention and communication difficulties following TBI. The perspectives discussed here were pre-empted by attention-related communication difficulties and the perspectives encompass the depth of the lived experience. It is recommended that future studies of this nature could pair the family perspectives with data related to individuals with TBI, through both neuropsychological and communication assessments, and their lived experiences. This would further capture the nature of attention-related communication difficulties.

Clinical implications

The clinical implications include the need for support and information related to this invisible symptom from the beginning. This involves targeted education and multiple opportunities for the family to learn about cognitive communication disorders and attention-related communication difficulties (Grayson *et al.* 2020; VanSolkema *et al.* 2022b), and how to be a supportive communication partner through communication partner training (Togher *et al.* 2016; Behn *et al.* 2021). Integration of specific attention strategies into communication partner training such as focusing on one conversation at a time, prioritising tasks/conversations during the day, and reintegration of social activities that accommodate the attention deficits should be considered. Also, it is important to ensure models of resilience and family adjustment are considered and discussed with the family during all points of the recovery, especially in the beginning (Spina *et al.* 2005; Kreutzer *et al.* 2010; Sander *et al.* 2013). This incorporates the family as part of the treatment rather than only focusing on the person with a TBI. Walking families through their own education sessions,

including the use of problem solving strategies to manage the cognitive and behaviour changes of their loved one, is another aspect of supporting the entire family unit (Simpson *et al.* 2021). This includes assessment of family systems functioning to ensure families have a good understanding of their loved one's cognitive, emotional, and behavioural changes, in addition to the family's ability to cope and adjust to these significant changes (Sander *et al.* 2013). Family members will take the role of carer because they want the best for their loved one, even at the expense of their own self-identity and quality of life (Bodley-Scott and Riley 2015).

Conclusions

The granularity of loving, adjusting, and suffering through hardships is common ground for each family member interviewed. Families take on the load and the roles of active adjustment when the person with a TBI cannot or requires support to do so. This involves the family having awareness of the cognitive changes experienced by their loved one; regulation and learning how to function in a new way; taking on new roles of responsibility; being the stronger one; always being on guard or patrol; and absorbing their loved one's previous roles. Despite that load they reported wanting to care for them because they knew their loved one could not do it alone. This is the evolution of family responsibility that comes with adjusting to living with someone with attention-related communication difficulties. The impact that attention-related difficulties has on the family continues years after the injury, with the average length following the injury within the current sample being 6 years. Family members require specific and targeted support and treatment alongside their loved one following the TBI throughout the entire recovery. Providers of rehabilitation are encouraged to include family interventions as part of their program (Kreutzer *et al.* 2010). Future research is recommended to evaluate programs that include family-centred treatments related to cognitive communication and the impact these have over time (O'Shannessy *et al.* 2022). Attention-related communication difficulties are far reaching and can touch all aspects of the life of people with TBI (VanSolkema *et al.* 2022a); the family unit is no exception. Understanding the impact of cognitive skills, including attention-related communication in isolation, provides additional granularity to the existing literature regarding the lived experience of TBI.

References

- American Speech-language Hearing Association (1983) Committee on language: Definition of language. *Asha* 24, 44.
- American Speech-language Hearing Association (2007) Scope of practice in speech-language pathology. Available at www.asha.org/policy
- Anderson MI, Parmenter TR, Mok M (2002) The relationship between neurobehavioural problems of severe traumatic brain injury (TBI), family functioning and the psychological well-being of the

- spouse/caregiver: Path model analysis. *Brain Injury* 16(9), 743–757. doi:10.1080/02699050210128906
- Bal M, Müller N, Nelson R (2014) 'Handbook of qualitative research in communication disorders.' (Psychology Press)
- Behn N, Francis J, Togher L, Hatch E, Moss B, Hilari K (2021) Description and effectiveness of communication partner training in TBI: A systematic review. *Journal of Head Trauma Rehabilitation* 36(1), 56–71. doi:10.1097/HTR.0000000000000580
- Blais MC, Boisvert JM (2005) Psychological and marital adjustment in couples following a traumatic brain injury (TBI): A critical review. *Brain Injury* 19(14), 1223–1235. doi:10.1080/02699050500309387
- Bodley-Scott SEM, Riley GA (2015) How partners experience personality change after traumatic brain injury – Its impact on their emotions and their relationship. *Brain Impairment* 16(3), 205–220. doi:10.1017/BrImp.2015.22
- Bracy CA, Douglas JM (2005) Marital dyad perceptions of injured partners' communication following severe traumatic brain injury. *Brain Impairment* 6(1), 1–12. doi:10.1375/brim.6.1.1.65476
- Braun V, Clarke V (2021) One size fits all? What counts as quality practice in (reflexive) thematic analysis? *Qualitative Research in Psychology* 18(3), 328–352. doi:10.1080/14780887.2020.1769238
- Braun V, Clarke V (2022) 'Thematic Analysis A Practical Guide.' (Sage Publications Ltd.)
- College of Audiologists and Speech-Language Pathologists of Ontario (2015) 'Practice Standards and Guidelines for Acquired Cognitive Communication Disorders.' Available at www.caslpo.com
- Dawes K, Carlino A, van den Berg M, Killington M (2022) Life altering effects on children when a family member has an acquired brain injury; a qualitative exploration of child and family perceptions. *Disability and Rehabilitation* 44(2), 282–290. doi:10.1080/09638288.2020.1766582
- Durie M (1984) "Te taha hinengaro": An integrated approach to mental health. *Community Mental Health in New Zealand* 1(1), 4–11.
- Finn JA, Klocksieben FA, Smith AN, Bernstein J, O'Neil-Pirozzi TM, Kreutzer JS, Sander AM, Dreer LE, Niemeier JP, Cotner BA, Nakase-Richardson R (2022) Family needs after traumatic brain injury: A VA TBI model systems study. *Journal of Head Trauma Rehabilitation* 37(6), 327–337. doi:10.1097/htr.0000000000000799
- Grayson L, Brady MC, Togher L, Ali M (2020) A survey of cognitive-communication difficulties following TBI: Are families receiving the training and support they need? *International Journal of Language & Communication Disorders* 55(5), 712–723. doi:10.1111/1460-6984.12555
- Grayson L, Brady MC, Togher L, Ali M (2021) The impact of cognitive-communication difficulties following traumatic brain injury on the family; a qualitative, focus group study. *Brain Injury* 35(1), 15–25. doi:10.1080/02699052.2020.1849800
- Harris JKJ, Godfrey HPD, Partridge FM, Knight RG (2001) Caregiver depression following traumatic brain injury (TBI): A consequence of adverse effects on family members? *Brain Injury* 15(3), 223–238. doi:10.1080/02699050010004040
- Holloway M, Orr D, Clark-Wilson J (2019) Experiences of challenges and support among family members of people with acquired brain injury: a qualitative study in the UK. *Brain Injury* 33(4), 401–411. doi:10.1080/02699052.2019.1566967
- Kreutzer JS, Marwitz JH, Godwin EE, Arango-Lasprilla JC (2010) Practical approaches to effective family intervention after brain injury. *Journal of Head Trauma Rehabilitation* 25(2), 113–120. doi:10.1097/HTR.0b013e3181cf0712
- Lond BJ, Williamson IR (2022) Acceptance, grief and adaptation amongst caregivers of partners with acquired brain injury: an interpretative phenomenological enquiry. *Disability and Rehabilitation* 44(11), 2285–2294. doi:10.1080/09638288.2020.1829104
- Menon DK, Schwab K, Wright DW, Maas AI (2010) Position statement: Definition of traumatic brain injury. *Archives of Physical Medicine and Rehabilitation* 91(11), 1637–1640. doi:10.1016/j.apmr.2010.05.017
- Norman RS, Swan AA, Jenkins A, Ballard M, Amuan M, Pugh MJ (2021) Updating and refining prevalence rates of traumatic brain injury-related communication disorders among post-9/11 veterans: A chronic effects of neurotrauma consortium study. *Perspectives of the ASHA Special Interest Groups* 6, 1060–1072. doi:10.1044/2020_PERSP-20-00011
- O'Shannessy E, Reeder S, Vishwanath S, Hill S, Perta A, Jolliffe L, Morarty J, Hunter P, Lannin NA (2022) Mixed methods study to understand the experiences of adults with acquired brain injury and their family members who receive specialised rehabilitation. *Brain Impairment* 24, 39–53. doi:10.1017/BrImp.2022.3
- Ponsford J, Schönberger M (2010) Family functioning and emotional state two and five years after traumatic brain injury. *Journal of the International Neuropsychological Society* 16(2), 306–317. doi:10.1017/S1355617709991342
- Ponsford J, Bayley M, Wiseman-Hakes C, Togher L, Velikonja D, McIntyre A, Janzen S, Tate R (2014a) INCOG recommendations for management of cognition following traumatic brain injury, Part II: Attention and information processing speed. *Journal of Head Trauma Rehabilitation* 29(4), 321–337. doi:10.1097/HTR.0000000000000072
- Ponsford J, Downing M, Olver J, Ponsford M, Acher R, Carty M, Spitz G (2014b) Longitudinal follow-up of patients with traumatic brain injury: Outcome at two, five, and ten years post-injury. *Journal of Neurotrauma* 31(1), 64–77. doi:10.1089/neu.2013.2997
- QSR International (2020) NVivo 12. Available at <https://www.qsrinternational.com/nvivo-qualitative-data-analysis-software/home>
- Sander AM, Maestas KL, Clark AN, Havins WN (2013) Predictors of emotional distress in family caregivers of persons with traumatic brain injury: A systematic review. *Brain Impairment* 14(1), 113–129. doi:10.1017/BrImp.2013.12
- Simpson GK, Anderson MI, Daher M, Jones KF, Morey P (2021) Testing a model of resilience in family members of relatives with traumatic brain injury vs spinal cord injury: Multigroup analysis. *Archives of Physical Medicine and Rehabilitation* 102(12), 2325–2334. doi:10.1016/j.apmr.2021.06.016
- Spina S, Ziviani J, Nixon J (2005) Children, brain injury and the resiliency model of family adaptation. *Brain Impairment* 6(1), 33–44. doi:10.1375/brim.6.1.33.65478
- Stierwalt JAG, Murray LL (2002) Attentional impairment following traumatic brain injury. *Seminars in Speech and Language* 23(2), 129–138. doi:10.1055/s-2002-24989
- Togher L, McDonald S, Tate R, Rietdijk R, Power E (2016) The effectiveness of social communication partner training for adults with severe chronic TBI and their families using a measure of perceived communication ability. *Neurorehabilitation* 38(3), 243–255. doi:10.3233/NRE-151316
- VanSolkema M, McCann C, Barker-Collo S, Foster A (2020) Attention and communication following TBI: Making the connection through a meta-narrative systematic review. *Neuropsychology Review* 30(3), 345–361. doi:10.1007/s11065-020-09445-5
- VanSolkema M, McCann C, Barker-Collo S, Foster A (2022a) Outcomes of attention-related communication deficits following traumatic brain injury: Perspectives of international health professionals. *Brain Injury* 36(3), 406–414. doi:10.1080/02699052.2022.2034189
- VanSolkema M, McCann C, Barker-Collo S, Foster A (2022b) The treatment journey of attention-related communication difficulties following traumatic brain injury: Perspectives of international health professionals. *Neuropsychological Rehabilitation* doi:10.1080/09602011.2022.2147552
- Whiffin CJ, Ellis-Hill C, Bailey C, Jarrett N, Hutchinson PJ (2019) We are not the same people we used to be: An exploration of family biographical narratives and identity change following traumatic brain injury. *Neuropsychological Rehabilitation* 29(8), 1256–1272. doi:10.1080/09602011.2017.1387577
- Whiffin CJ, Gracey F, Ellis-Hill C (2021) The experience of families following traumatic brain injury in adult populations: A meta-synthesis of narrative structures. *International Journal of Nursing Studies* 123, 104043. doi:10.1016/j.ijnurstu.2021.104043

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