Received: 3 May 2022 | Accepted: 8 December 2022

DOI: 10.1111/1460-6984.12839

International Journal of Language & Communication Disorders

RESEARCH REPORT

Stakeholder views on cognitive communication assessment and intervention for a person living independently in the community with severe traumatic brain injury

Susan Howell PhD[1] | **Joanna Hoskin PhD**[2] | **Debbie Eaton Dip.COT**[3] | **Mark Holloway DSW**[4] | **Rosemary Varley PhD**[1]

[1]Division of Psychology and Language Sciences, University College London, London, UK

[2]Division of Language and Communication Science, City, University of London, London, UK

[3]Debbie Eaton Case Management, High Wycombe, UK

[4]Head First, Assessment and Case Management, Hawkhurst, UK

Correspondence
Susan Howell, Department of Language and Cognition, University College London, Chandler House, 2 Wakefield Street, London WC1N 1PF, UK.
Email: s.howell.12@ucl.ac.uk

Abstract

Background: Cognitive communication disorder (CCD) following traumatic brain injury (TBI) is well documented and these communication problems impede successful re-integration into community living. While there is growing evidence for intervention to both detect and treat the impact of these deficits across the rehabilitation continuum, there are barriers to accessing services. Cognitive communication impairments may be missed because the person can talk, and this may mask the subtle but debilitating impact of a CCD. Referral to a speech and language therapist (SLT) may be overlooked or not timely, which prevents the individual accessing evidence-based interventions. Inadequate treatment provision and an under- or overestimation of communication capability can potentially undermine the effectiveness of wider team assessment and intervention.

Aims: To report stakeholder views on specialist SLT input for CCD within a multidisciplinary team intervention for a community-dwelling individual with severe TBI. The investigation explored perspectives on understanding of CCD, on practice and on outcomes, in order to inform professional groups on perceived impacts of the evidence-to-practice gap.

Methods and Procedures: A semi-structured interview methodology was employed with 11 stakeholder participants involved in a single case. Data were evaluated using a thematic framework method. Themes were inductively derived from the stakeholder narratives.

Outcomes: Stakeholders reported the following outcomes from specialist SLT input for CCD within a collaborative team approach: improved engagement with rehabilitation and support teams, improved health-related quality of life and well-being, and increased client participation in community activities of personal

relevance. Stakeholders also reported inequities in wider service provision where limitations in professional understanding of CCD and knowledge of best practice recommendations preclude access to specialist SLT services.

Conclusions: CCDs are under-recognised and this can have a devastating effect on people with CCD and on those around them. Stakeholder reports provide evidence for the effectiveness of SLT practice recommendations for the treatment of CCD following TBI. They also provide additional evidence of persisting barriers to accessing treatment. Future research to explore ways to close this evidence-to-practice gap is required.

KEYWORDS

cognitive communication, community, multidisciplinary team, speech and language therapy, stakeholder views, traumatic brain injury (TBI)

What This Paper Adds

What is already known on this subject

Cognitive communication difficulties are a well-documented consequence of TBI. There is evidence for the effectiveness of person-centred interventions for CCD across the recovery continuum. International evidence-based practice recommendations are in place for CCD assessment and management. Barriers to accessing SLT expertise for CCD have previously been reported.

What this paper adds to existing knowledge

This investigation explores the views of a diverse group of stakeholders involved in a single case of a community-dwelling individual with severe TBI. Stakeholders report positive real-world outcomes from SLT interventions for CCD within a coordinated multidisciplinary rehabilitation team. Stakeholder reports also indicate inequities in wider service provision and CCD knowledge gaps amongst professional groups providing rehabilitation services for people with TBI.

What are the potential or actual clinical implications of this work?

CCDs are under-recognised, with devastating effect for people with CCD and those around them. These findings underscore the importance of raising professional awareness of CCD and best practice recommendations, in order to improve access to SLT expertise for people with CCD following TBI.

BACKGROUND

Traumatic brain injury (TBI) is one of the major causes of life-long disability. Worldwide, new cases of TBI are estimated to exceed 50 million annually (Maas et al., 2017). In the United Kingdom, it is estimated that 1.3 million people are living with a long-term disability as a result of a TBI (Parsonage, 2016). Following a TBI most people will experience some form of communication impairment (Sarno, 1980). The diffuse neurological damage typically sustained in a TBI means that cognitive communication deficits are frequently reported (Coelho, 2007). Incidence rates of cognitive communication disorder (CCD) have been estimated to exceed 75% in moderate–severe TBI (MacDonald, 2017). These deficits can be subtle, wide-ranging and are more difficult to define than disorders resulting from more focal injuries (Norman et al., 2013). However, their effects on communication competence (spoken, written and non-verbal) can be profound as a result of widespread disruption to cognitive processes, such as attention, recall, organisation, processing, problem solving and executive function, undermining the person's ability to independently manage the communication and social interaction demands of everyday life. The consequences of CCD

following TBI often preclude a successful return to previous life roles and activities (Martelli et al., 2012), erode social relationships (Sander et al., 2010), and result in altered economic status following loss of employment (Norman et al., 2021) and increased social isolation over time (Hoofien et al., 2001). Increased dependence on caregivers for communication support and social contact has been identified as a source of caregiver burden and distress (Knight et al., 1998; Marsh et al., 2002) and families report unmet support and training needs for managing cognitive communication difficulties several years post injury (Grayson et al., 2020).

Given the impact of CCDs on long-term TBI outcomes, the implementation of best practice recommendations for assessment and management is a priority. International evidence-based guidelines recommend that individuals with communication disorders following TBI be offered assessment and treatment by a specialist SLT (Togher et al., 2014). However, there are barriers to accessing SLT expertise, indicating that there is a gap between best evidence and clinical practice. MacDonald (2021) provides a comprehensive account of reported barriers. Broadly, these include gaps in awareness, understanding and recognition of cognitive communication impairment following TBI and a consequent under-appreciation of the adverse impact of the disorder on routine communication encounters in everyday life. CCD may not be identified in rehabilitation settings where more obvious physical needs may be prioritised in order to facilitate discharge. The more subtle effects of a CCD may be overlooked because the person can talk, and the debilitating impact of CCD may be less evident in rehabilitation settings where opportunities to practise skills independently in an empowering social role are not routinely provided (Howell et al., 2020).

There are also gaps in professional awareness of the SLT scope of practice (MacDonald, 2021). Referrals may be routinely made for SLT assessment of dysarthria, voice, aphasia or swallowing disorders, but less frequently for cognitive communication disorders (MacDonald, 2017). Lehman Blake et al. (2013) identified a higher frequency of referrals for cognitive evaluation (memory and problem solving) compared to communication, despite the co-occurrence of such deficits. As a result, with CCD left unidentified, multidisciplinary team intervention and treatments become less accessible for the person as they are verbally mediated. Best practice recommendations are for referral to a specialist SLT working collaboratively within a multidisciplinary team of experts (Togher et al., 2014). However, there may be gaps in SLT knowledge and skills, undermining the value of the role in clinical practice. SLTs are trained to manage the interplay between cognition and communication, but in a survey of SLT knowledge, confidence and practice patterns, Riedeman and Turkstra (2018) identified a lack of knowledge and confidence in the assessment and management of CCD in TBI, and variable use of best evidence in clinical practice.

There is evidence to support the effectiveness of person-centred intervention for cognitive communication impairment across the recovery continuum. Dahlberg et al. (2007), Finch et al. (2017) and McDonald et al. (2008) demonstrated positive gains from interventions for CCD several years post injury. Powell et al. (2002) reported evidence of gain from multidisciplinary community rehabilitation. The cognitive complexity of the disorder means that skill transfer from decontextualised training settings to real-world environments cannot be assumed. Therefore, interventions for CCD need to be tailored to and embedded within the person's everyday routines in order to equip them with the skills to participate and contribute to family, community and a wider social life (Ylvisaker et al., 2003). For community-dwelling individuals, interventions may be targeted at the ability to make decisions and to speak on their own behalf in interactions with healthcare services, legal and finance teams, support teams, employers, providers of community services and in leisure activities as well as with friends and family. Best practice recommendations support training for all involved stakeholders (Togher et al., 2014), acknowledging that communication activities, purposes and priorities will differ for each stakeholder (Larkins et al., 2004). These recommendations draw on evidence to show that training of frequent communication partners (including providers of services) can have a significant and positive influence on interaction outcomes (Behn et al., 2012; Goldblum & Alant, 2009; Togher et al., 2004; Togher et al., 2013; Wiseman-Hakes et al., 2020). Evaluation of outcomes from real-world communication activity is also recommended (Togher et al., 2014).

This investigation explored a range of stakeholder views on CCD assessment and intervention post TBI. The stakeholders were each involved in a single case, supporting a 56-year-old male (known as BB) following a severe TBI sustained in a road traffic accident. BB's Glasgow Coma Scale score was 3 at the scene. Prior to the accident he worked as a chef in a local restaurant. BB received 10 months of acute and post-acute rehabilitation. An SLT assessment identified a mild-to-moderate communication disorder, but no further input was provided as BB did not identify any communication goals and was judged able to clearly communicate his needs, wishes and concerns. Neuropsychology assessment identified impaired verbal memory skills, difficulties with flexible thinking, tangential speech and problems with writing and spelling. Reports from the wider inpatient therapy team documented examples of behavioural outbursts as a result of misinterpreting events in the rehabilitation unit and on community visits, requiring third-party assistance to resolve.

BB was discharged to a flat in a supported housing complex in the community, with one-to-one carer support provided by a specialist brain injury care agency, 10 hours a day, 7 days a week. Inpatient rehabilitation services provided 1 week of home-based support and training for BB and his new carer before handing over to the community brain injury team. He received outpatient appointments with a neuropsychologist and occupational therapist, who identified difficulties communicating in stressful and unfamiliar settings, and difficulties 'reading a situation'. BB was provided with written advice and was subsequently discharged from the service as he was not working on active rehabilitation goals and he had not responded to contact from the team. No further referrals or recommendations for follow-up were made.

Persisting cognitive difficulties and aggressive behaviours posed risks that left BB vulnerable in both his home and community settings and threatened potential loss of his tenancy. He was reviewed by a care expert who identified a significant overestimation of BB's cognitive communication capabilities, and the absence of a support plan to address the pervasive and deleterious impact of this impairment on everyday functioning, on his relationships with his family, his carer, his neighbours and contacts in the community. Twenty months post injury, and further to recommendation by the care expert, a new multidisciplinary team was appointed.

A specialist SLT was instructed to assess BB's cognitive communication capability. During the assessment sessions BB made the following comments:

- "I am not on the same page as other people".
- "People don't get me".
- "I have to work hard to make sure that the face, the words and the body language match".

A range of person-centred interventions and strategies were put in place to support BB's understanding and expressive needs in routine interactions. Specifically, this entailed getting to know BB, in order to understand his values and priorities and listening to the views of his family. It entailed working collaboratively with BB to identify what had changed (assessment), spending time with him in different settings to understand the challenges both for BB and those around him, and presenting and discussing findings with BB in the context of what mattered to him. Intervention included devising, testing and refining task-specific guidelines, making use of his language and vocabulary to encourage ownership of new strategies, building on the use of this shared language with the team to plan for new interventions and for information-sharing, and to trouble shoot and repair in the event of communication breakdown. Guidelines were regularly reviewed to proactively anticipate BB's communication needs, identify training needs and provide support in the event of guidelines not being followed. Training was provided to make everyday spoken and written information more accessible and to promote inclusive decision-making. Bespoke communication partner training was provided for ALL stakeholder groups in contact with BB.

Understanding the perspectives of this diverse group of stakeholders on CCD and its management, the impact of their knowledge on their practice and on the outcome of this case informs future work on strategies to close the evidence-to-practice gap. To the best of our knowledge, this is the first study to explore a broad range of stakeholder opinion on the management of CCD in a single shared case.

AIMS

To explore a range of stakeholder perspectives on the impact of specialist SLT involvement for their understanding of CCD, on their practice and on outcomes for a community-dwelling individual following severe TBI. Findings will inform other professional groups who co-work with SLTs and student SLTs on practice standards and associated benefits of specialist assessment and intervention for CCDs.

METHOD AND PROCEDURES

We employed a semi-structured interview methodology grounded in a thematic framework to gather the data (Ritchie & Spencer, 1994). The Consolidated Criteria for Reporting Qualitative Research (COREQ) (Tong et al., 2007) were used to report these findings. University College London (UCL) REC approval LCD-2-21-14 was granted for this study in March 2022.

Participant recruitment

At the time of this study, the person with CCD was judged able to give informed consent to the research. An accessible study information sheet was prepared and discussed with him using communication supports to enhance understanding and retention of the information. Written consent for the research was obtained.

Eleven stakeholder participants involved in this case were initially invited by phone or email using purposive sampling procedures. One potential participant declined to participate as they were on long-term sick leave. Ten

TABLE 1 Participant characteristics

Participant characteristics	*N*
Age (years)	
20–29	1
30–49	4
50–60+	5
Experience with traumatic brain injury (years)	
0–10	3
10–20	3
20+	4
Roles	
Healthcare professionals	6
Legal	3
Family	1

participants were therefore sent an invitation letter and a participant information sheet by email. A sample size of between 5 and 25 participants has been cited as adequate for semi-structured interviews (Saunders, 2012). The sample included six healthcare professionals (one representative each from the following professions: case manager, care expert, physiotherapist, occupational therapist, neuropsychologist, support worker), one relative and three legal professionals. Participant characteristics are reported in Table 1. Stakeholder participants gave written consent to a semi-structured interview with a member of the research team via Microsoft Teams, as a secure platform for conducting confidential interviews. The interviewer (an SLT and postdoctoral researcher) was a skilled online interviewer with experience of the framework analysis methodology, without knowledge of the case and not known to the interviewees.

Interview procedure

Interview topics were informed by evaluation of the literature on best practice recommendations for the management of CCDs following TBI (Togher et al., 2014) and barriers to the implementation of best practice (MacDonald, 2017, 2021). From this evaluation, the following interview topics were derived.

Interview topics:

1. The benefits (if any) of having a specialist SLT involved in this case
2. Changes in participant understanding of the person with CCD as a result of SLT involvement
3. Changes in practice as a result of SLT involvement
4. The impact of SLT involvement on the outcome of this case
5. The impact on communication with other cases as a result of working with this team
6. Perspectives on CCDs more generally
7. Other comments

Online interview duration was between 7 and 40 min and took place between March and April 2022. Each stakeholder was interviewed individually. The interviews were video recorded and transcribed within Microsoft Teams. All participant names were anonymised during the interviews. Final transcripts were not shared with participants.

Data analysis

A member of the research team manually cross-checked the verbatim transcripts against the video recordings for accuracy. Final transcripts were evaluated using the Framework Method for thematic analysis (Ritchie & Lewis, 2003). This method has previously been used to evaluate qualitative data in health research (e.g., Parkinson et al., 2016; Smith & Firth, 2011). It provides a structure for the systematic analysis of complex data sets that incorporates a range of perspectives, including data derived from in-depth interviews (Goldsmith, 2021). Procedures for analysis followed the sequence described by Gale et al. (2013). Two members of the research team (both experienced SLTs and clinical researchers) familiarised themselves with the transcribed data and independently identified and extracted the SLT and CCD-related themes and ideas of interest from the same two transcripts. Coders conferred and drew on interviewer field notes and the interview topics to produce a jointly derived framework of SLT and CCD-related categories, codes and definitions. This framework was tested on three further independently coded transcripts. Additional codes were added and definitions refined. Code and category saturation (the point at which no further codes or categories were generated) was reached at five interviews. This framework was employed to code the remaining five transcripts.

The interview transcripts and coding framework were uploaded into QDA Miner Lite (http://www.provalisresearch.com). This software enables coders to mark codes digitally, review code use across the complete data set and allows the automated retrieval of text for each code across interviews. Themes were inductively derived from these data using the QDA Miner Lite visual mapping feature and through discussion between the researchers. A matrix was then created for each category to summarise the data by case and code. Figure 1 shows the coding tree derived from these data. Four themes are illustrated horizontally with their associated codes listed below.

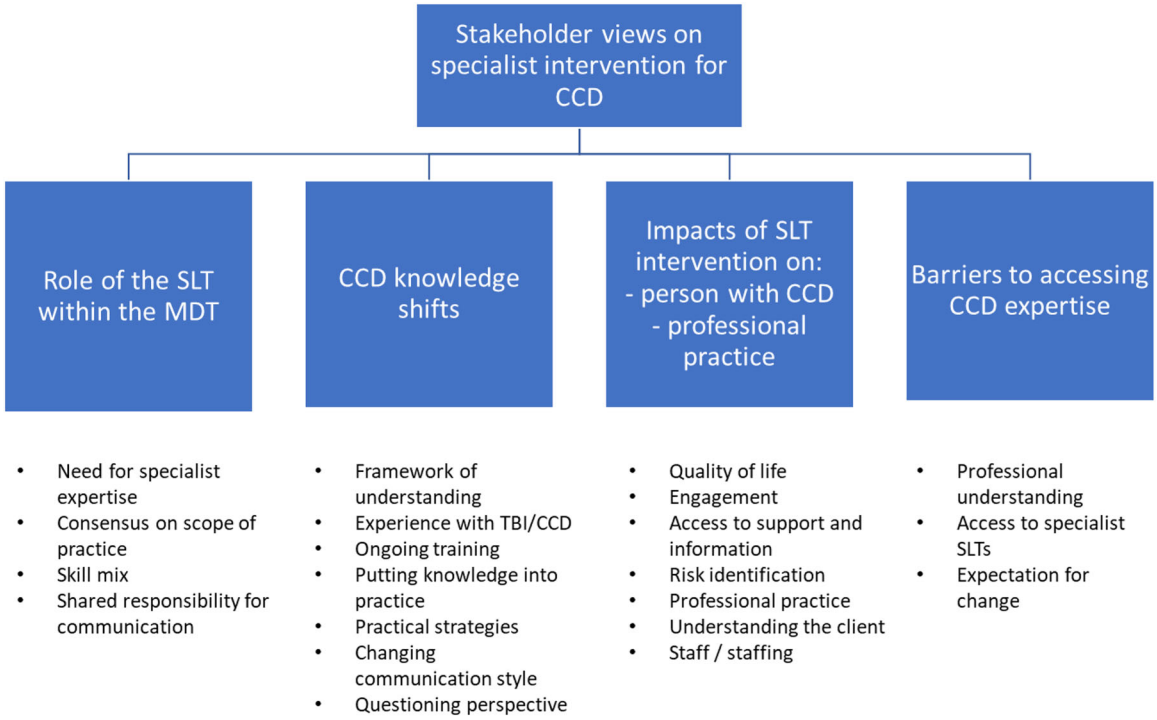

FIGURE 1 Coding tree for stakeholder views on specialist intervention for CCD
Abbreviations: CCD, cognitive communication disorder; MDT, multidisciplinary team; SLT, speech and language therapist; TBI, traumatic brain injury
[Colour figure can be viewed at wileyonlinelibrary.com]

OUTCOMES AND RESULTS

Four themes were derived from the analysis: the role of the SLT within the multidisciplinary team; CCD knowledge shifts; the impact of SLT intervention on the person with CCD and on professional practice; and barriers to accessing CCD expertise.

The role of the SLT within the multidisciplinary team

Interviewees acknowledged that supporting a person with cognitive communication impairment presents specific challenges, making it essential for specialist expertise within the team. All participants commented on the challenge of recognising the complexity of the impairment.

> "I probably thought 'hmm ok…there's lots of interesting confabulations and all sorts going on here but I wouldn't have picked up on just how profound his lack of ability to interpret nuance was". (Health Professional #1)

> "When you look at him and everyone that's met him thinks that he thinks completely like us. I mean normally, I mean like he did before… understands everything quickly, talks, chats back and everything. But really inside, I think he's not understanding, he's not on the same wavelength at all. And then suddenly you realise that he doesn't understand the conversation, and he gets into a loop of talking and can't get out of it". (Relative)

> "The team think they have communicated with him in the best way, but he's either not understood it or not understood it fully. So, he takes away part of a conversation and builds his own story around that which is often incorrect". (Health Professional #4)

There were some differences in stakeholder experience of who routinely provides the CCD expertise, with a few identifying the role as traditionally within the remit of neuropsychology, but others seeing the role as within the SLT scope of practice. However, all stakeholders acknowledged that the right skill mix within the team is essential in order to facilitate change for people with CCD. Healthcare and legal professionals identified a role for the SLT within this skill mix to ensure that the challenges experienced by the individual are understood by the whole team

and that workable strategies are devised and shared with all stakeholders.

> "I have this visual image. I imagine her like a tent peg in the ground of the circle and she kind of goes round and impacts all the other therapists who sit round the edge of it and the support workers, and she kind of knocks into all of us because she has to. It's her input that underpins what we do. If her input wasn't there, the others can't operate. It's that fundamental because his cognitive communication difficulties are so significant". (Health Professional #1)

Most participants described the management of CCD as a shared responsibility, acknowledging that, as communication partners within the interaction, everyone has a role in facilitating participation.

> "I think this case just highlights how we all have to have a consistent way of communicating, and it's a really important thing". (Health Professional #3)

The role of the SLT was also seen as integral as the case moved forward. Both health and legal professionals identified the need for ongoing input to map out procedures to share new information, to plan ways forward following communication breakdown, to design new strategies where communication challenges persist and to train new team members.

CCD knowledge shifts

All stakeholders reported new or enhanced knowledge as a result of involvement in this case. They all reported previous experience working with TBI (some reporting more than 20 years of experience). A few had previously worked with SLTs in the management of CCD. For some stakeholders, new to the concept of CCD but not to brain injury, their experience of TBI provided a helpful foundation for CCD understanding. All stakeholders reported that involvement of a specialist SLT was beneficial for the team's understanding of BB's profile of cognitive communication needs, giving a better appreciation the challenges that he faces in everyday life and that it reinforced the complexity of the disorder.

> "The assessment was really pivotal in helping the team understand cognitive communication". (Health Professional #5)

> "It has made me more focused on trying to understand what it is that he might be saying and not just taking everything on face value". (Legal Professional #3)

> "It's opened my eyes to the pre-judgement, just because you can hold a conversation with somebody and they use the right words. But the way he communicates with the world and we communicate with him is the absolute fundamental key for everything else". (Legal Professional #1)

> "It definitely made me realise that he's not coping inside". (Relative)

Stakeholder participants reported that both initial and ongoing advice and training changed the way they communicate with BB and had an impact on the quality of their interactions with him. For healthcare professionals, experienced in regular interactions with individuals with cognitive disorders, there was acknowledgement of a need for a change in the practicalities of the way they communicated with BB. Some reported that knowing the 'how and why' of the recommended communication approach is different from actually doing it.

> "I think I've got quite a good understanding.… But you just can't in this case take it for granted, at all. And having the SLT there, almost that voice on my shoulder when I'm talking to him and thinking 'ok, you have to get it right, otherwise things can go horribly wrong'". (Health Professional #4)

Legal professionals reported value from initial training sessions but also benefitted from a practical demonstration in order to more effectively change their communication style.

> "I then actually went out to visit him with the SLT and I remember leaving and thinking it was fascinating because on the face of it, you think he can absorb information and communicate in one way. But the information I already had from the SLT meant that I was reading into things differently and very much changing the way that I communicated with him, which you just wouldn't realise unless you had that involvement from the SLT". (Legal Professional #3)

> "Whilst you can teach someone, you need to actually be there with them, because you can read things and understand 'oh this is how I'm supposed to phrase things' and whatever. But you need to get into the swing of everything and to actually be talked and walked through it, because it's so easy - I mean, I find this – to go off script when you shouldn't do". (Legal Professional #1)

For all participants, the use of practical strategies was beneficial in facilitating a change in terms of how people communicated with BB. Examples cited included how to structure a conversation, strategies to get the conversation back on track, the use of key phrases, the use of scripts, formulating text messages and other written documentation to make it both accessible and a usable resource.

> "The most amazing thing she did was she wrote a list of phrases he uses and what they actually mean. And one of them was 'oh well, if you like', and that was 'I really don't want to do this'". (Health Professional #2)

> "It's been pivotal in helping us understand what we communicate, the language we use, the amount of language we use at any one time, and how and when we do that". (Health Professional #5)

> "How to approach things… to break it down, or make it very simple and straightforward for him to get the message." (Health Professional #6)

Some participants commented that this new or enhanced knowledge resulted in a more questioning perspective. At the level of everyday interactions in this case, knowledge of how BB might be perceiving events equipped both relatives and team members with the tools to anticipate points of potential communication breakdown and navigate around them. For other stakeholders, this questioning perspective had a wider impact on their understanding of CCD from their involvement with the person in this case and on their practice more generally.

The impact of SLT intervention on the person with CCD and on professional practice

- For the person with CCD

Stakeholders identified an overall improvement in BB's quality of life as an outcome of intervention for CCD within the overall team approach.

> "Changing how you communicate is also part of the environment we are providing. And if we get that right, we are literally enabling him to function in the community. But worse, if we get that wrong, we are causing… we are exposing the disability. And he's the one who loses out". (Healthcare Professional #1)

> "I didn't realise that a brain injury could change someone so much, yet be able to live in the community which is really good. I was shocked actually". (Relative)

Improved engagement with support and with members of the team was also cited as a positive outcome from intervention for CCD. For support staff, jobs became easier when they understood their client.

> "It's not an easy job but it's made it easier as I can understand now how he sees things". "It helps him and us be on the same level". (Healthcare Professional #6)

Most participants identified that the person-centred interventions and strategies put in place to promote effective communication facilitated improved client access to support and information, better relationships as a result of improved understanding, more agency in decision-making and an overall sense of control.

> "My involvement is very financial and he wouldn't be able to understand the extent of what's going on, how the money is to be used and the process for communicating with us to be able to get the outcome that he wants if those things weren't in place". (Legal Professional #2)

> "It also enabled and helped his family understand why he was the way he was. So that was really important because it reduced the tension within the surrounding wider family". (Legal Professional #1)

> "So, I think what he has now is a greater sense of control. And I think he actually has some control. So, it's not just a sense, a sense is really

important, but actually he has some control". (Health Professional #2)

Stakeholders also talked about outcomes in terms of the risks to BB if his cognitive communication impairment had not been identified in this case.

> "Without SLT involvement for CCD I don't think we'd be in there. He would not have the quality of life he has, and it's very unlikely that he'd have still been in his placement because it was at risk". (Healthcare Professional #1)

> "He was at real risk of losing his community placement. He was at real risk of driving support away. He was at real risk that every single thing that happened to him was confronting". (Healthcare Professional #2)

Both legal and healthcare professionals identified the risk of misunderstanding the complexity of CCD and misattributing the presentation to challenging and aggressive behaviour.

> "Because actually I think what was happening, and I think what often happens is he was being blamed if you like for his behaviour, whereas actually it was his communication, and we are responsible for making sure we get that right. It was a treatable thing". (Healthcare Professional #1)

> "He was discharged on the NHS and he was discharged under this placement where he'd been for six months. They were going to chuck him out because he was getting aggressive with other clients that were there, and it was all down to the fact that they had misdiagnosed or failed to diagnose his communication issues, so they weren't communicating with him properly. So, what I find upsetting is how many people are misdiagnosed or go completely undiagnosed". (Legal Professional #1)

- On professional practice

Some stakeholders reported that involvement in this case changed their perspective on cognitive communication disorders more generally.

> "And it did make me realise that there are probably so many other people with brain injuries who are exactly the same as that and you just don't realise the extent of their needs". (Legal Professional #3)

> "It now means whenever I go anywhere, [I think] is what I am witnessing someone's fractured thinking or is this actually a CCD as well? Or instead?" (Healthcare Professional #2)

> "I'm not just accepting of 'oh, there's no issue'. I want to get it confirmed by an appropriate specialist". (Legal Professional #1)

For others it altered their expectation of what can be changed for a person with CCD following severe TBI.

> "So, I think where it's changed my practice is saying 'this is something you can change'. If you change the way you communicate with this client, maybe that problem will no longer be a problem". (Healthcare Professional #1)

Some stakeholders reported adopting some of the transferrable techniques and strategies learned in this case with other clients with CCD in TBI, specifically citing the presentation of written information and accessible documentation.

Barriers to accessing CCD expertise

Most stakeholders identified the level of professional understanding and awareness of CCD practice standards as the greatest barrier to accessing expertise for the person with CCD.

> "There hasn't been great understanding from certain medics I think, in term of what is necessary. And maybe the perception of what SLT is about, what SLT does, I think. So we need to fly that flag a bit more, really". (Health Professional #5)

> "Quite a few times I have said to case managers, 'you know I really think we need to think about an SLT', and then have had to

> spend often months explaining and gathering evidence of 'this is another example of why this is a cognitive communication problem', and it's not so recognised sometimes". (Health Professional #4)

Stakeholders also identified practice knowledge within the SLT profession as a barrier to accessing specialist expertise.

> "I didn't have an appreciation for the difference in the understanding or maybe the training of speech and language therapists. I just assumed it was a niche area and they all did the same thing. Because I accepted [it] when I was told by two SLTs that he didn't have any issues". (Legal Professional #1)

Low expectation for change post injury was also cited as a potential barrier to accessing specialist expertise, which implicitly places the person with CCD in a powerless position.

> "Changing him is actually really, really hard. The easiest thing is changing things around him. And if you don't do that, you're condemning people to live their impairment as their best option". (Healthcare Professional #2)

> "It's certainly changed how I've approached probably my expectations of what can be changed. The SLT has shown that with really keeping at all of us and saying 'look, you've got to do this right, you've got to keep doing this right'". (Healthcare Professional #1)

DISCUSSION

Despite the availability of international practice-based recommendations for the assessment and management of CCD and a growing evidence base for the effectiveness of person-centred intervention, CCDs continue to go undetected, undermining rehabilitation outcomes and with devasting effect for people with CCD and their families as they negotiate their way through the communication demands of everyday life. In order to close this evidence-to-practice gap, understanding the knowledge and support needs of the multiple stakeholders who interact with the person with CCD and their families is essential. This investigation explored the perspectives of a range of stakeholders involved in a single shared case of a person with CCD following TBI. Specifically, we aimed to explore perspectives on the benefits of specialist SLT input for CCD and its impact on stakeholder understanding of CCD, on practice and on outcomes.

These stakeholder reports have illustrated the potentially detrimental consequences for a person with significant cognitive communication impairment following severe TBI being discharged into the community without assessment or treatment for CCD. For the person in this investigation, his CCD was not identified until 20 months post injury. This finding reflects the barriers reported by MacDonald (2021), that CCDs are under-recognised or there is an under-appreciation of the impact of the disorder on everyday life. This finding also reflects barriers identified by MacDonald (2017): BB's CCD was not identified during the inpatient rehabilitation phase, resulting in premature discharge without assessment or onward referral for SLT evaluation in the community. Once in the community, BB's maladaptive communication coping strategies were attributed to persisting behavioural difficulties, rendering him vulnerable and putting his independent living placement at risk.

This case also demonstrates that person-centred intervention delivered by an expert team can benefit people with long-term conditions at any stage along the rehabilitation continuum and in any setting (Wade, 2020). Best practice recommendations were followed for the assessment and treatment of BB: referral to a specialist SLT, the provision of tailored interventions and strategies to promote participation in real-world activity and communication partner training to maximise capability in everyday communication contexts (Togher et al., 2014). A range of positive, real-world outcomes were reported by stakeholders: improved engagement with support, better access to information, improved relationships with family, increased control in everyday decision-making and an overall improvement in quality of life.

However, and notwithstanding the available evidence to support best practice recommendations, the health professionals involved in this case identified professional awareness as an ongoing barrier to accessing appropriate expertise. Their reports suggest that, despite detecting CCD and gathering evidence to advocate for specialist SLT involvement, lack of understanding by decision-makers can either prevent or delay access to services. Reports from the legal professionals demonstrate the benefits of the interventions that enabled this person with significant CCD to independently engage with their services, but they also demonstrate the dependence of these service providers on clinical expertise for diagnosis and referral in the first place. Stakeholder reports illustrate the impact of lost time in this case on BB's quality of life and

relationships. Although not explicitly stated in these interviews, there are implied economic consequences to this lost time if the multidisciplinary interventions (that are typically verbally mediated) are not fully accessible for the person with an undiagnosed CCD, resulting in suboptimal therapeutic outcomes. More research is required to guide decision-makers from a health economics perspective.

This case report has illustrated the gaps in awareness of best practice in the management of CCD not only amongst commissioning healthcare professionals but also within the SLT profession itself. The inpatient SLT evaluation of BB did not identify the CCD. Riedeman and Turkstra (2018) concluded that knowledge and confidence in this field of practice is a wider problem within the profession. The findings in this report lend weight to the argument for postgraduate training for SLTs in the management of CCD in TBI. Findings can be utilised by professional bodies to shape the knowledge and skills that underpin current practice-based recommendations, such as signposting SLTs to information on continuing professional development opportunities; raising awareness of the availability of current published research, CCD courses and conferences; and encouraging linkage with colleagues through clinical excellence networks and peer support groups to contribute to the body of practice-based evidence (e.g., reporting case studies and developing treatment frameworks).

In contrast with previous studies investigating the effectiveness of established communication partner training programmes with stakeholder groups (e.g., family members and/or carers), the training delivered in this case was tailored to the specific interaction needs and priorities of the different stakeholders involved with one person. This approach is in line with practice recommendations to address the interaction needs and priorities of stakeholders individually (Togher et al., 2014). The stakeholders involved in this case reported the communication partner training to be essential, with the legal professionals identifying particular benefits from intermittent but ongoing SLT involvement for bespoke training needs (such as the implementation of new procedures or planning for difficult conversations). In common with communication partner reports from other training programmes, stakeholder reports in this investigation highlighted the benefits of practical demonstration rather than just being told what to do (Togher et al., 2012). All stakeholders reported positive change in their communication and in the outcome of an information exchange with BB as a result of these bespoke interventions, whilst acknowledging that their application to real life events requires a view of SLT provision within a broad rehabilitation plan over the long term. This has resource implications for service provision. Findings from this research can be utilised by stakeholder groups including commissioning healthcare professionals to raise awareness of CCD, its impact and the role of SLT within the multidisciplinary team.

LIMITATIONS AND FUTURE DIRECTIONS

Findings from this investigation were drawn from single interviews conducted with 10 stakeholders with reference to a single case. Although a diverse range of participants were recruited to maximise variation (and theme saturation was reached at five interviews), additional stakeholders from a broader range of professionals and service providers may have introduced new perspectives. A further limitation is that this investigation into SLT provision for CCD following TBI was conducted by a predominantly SLT research team. Although we controlled for possible bias by selecting a researcher who was unfamiliar with BB and unknown to interviewees to conduct the interviews, she was an SLT by profession and this may have influenced the views that the stakeholder interviewees chose to share.

With regard to future research, comparison of the perspectives of stakeholder groups involved with other single cases across residential and community settings will strengthen these findings. The voices of legal and finance professionals in this report have proved insightful. More in-depth consideration of non-healthcare perspectives is essential in order to understand stakeholder needs for the long-term management of people with CCD following TBI.

CONCLUSION

This investigation illustrates the potentially devastating consequences for people with CCD and their families when CCDs following TBI are not recognised, and where the adverse impact of the disorder on everyday life and relationships is underestimated. Stakeholder groups in this investigation report positive real-world outcomes from specialist SLT provision for a man with significant CCD post TBI within an expert rehabilitation team, but perceived inequities in wider service provision have also been identified. Barriers to accessing services include poor knowledge and understanding of CCD and poor awareness of current best evidence and practice standards amongst the professional groups providing rehabilitation services for people with TBI. Stakeholder views in this report illustrate the negative consequences of this knowledge to practice gap on quality of life for the person with CCD. Stakeholder reports also illustrate the positive impact of an expert team working collaboratively to change the communication environment at a late stage in TBI recovery, changing expectations of what can be achieved. This

finding from a single case emphasises the importance of raising professional awareness to improve access to specialist SLT provision for CCD post TBI.

ACKNOWLEDGMENT

The authors received no financial support for this research.

CONFLICT OF INTEREST

The authors report no conflicts of interest.

DATA AVAILABILITY STATEMENT

Due to the nature of this research, participants in this study did not agree for their data to be shared publicly, so supporting data are not available.

ORCID

Susan Howell PhD https://orcid.org/0000-0002-8329-7529
Joanna Hoskin PhD https://orcid.org/0000-0002-7442-619X
Debbie Eaton Dip.COT https://orcid.org/0000-0002-3249-9884
Mark Holloway DSW https://orcid.org/0000-0003-3491-8242
Rosemary Varley PhD https://orcid.org/0000-0002-1278-0601

REFERENCES

Behn, N., Togher, L., Power, E. & Heard, R. (2012) Evaluating communication training for paid carers of people with traumatic brain injury. *Brain Injury*, 26(13–14), 1702–1715. https://doi.org/10.3109/02699052.2012.722258 PMID: 23163251

Coelho C. (2007) Management of discourse deficits following traumatic brain injury: progress, caveats, and needs. *Seminars in Speech and Language*, 28(2), 122–135. https://doi.org/10.1055/s-2007-970570 PMID: 17427051

Dahlberg, C.A., Cusick, C.P., Hawley, L.A., Newman, J.K., Morey, C.E., Harrison-Felix, C.L., et al. (2007) Treatment efficacy of social communication skills training after traumatic brain injury: a randomized treatment and deferred treatment controlled trial. *Archives of Physical Medicine and Rehabilitation*, 88(12), 1561–1573. https://doi.org/10.1016/j.apmr.2007.07.033 PMID: 18047870

Finch, E., Cornwell, P., Copley, A., Doig, E. & Fleming, J. (2017) Remediation of social communication impairments following traumatic brain injury using metacognitive strategy intervention: a pilot study. *Brain Injury*, 31(13–14), 1830–1839. https://doi.org/10.1080/02699052.2017.1346284 PMID: 28750171

Gale N.K., Heath G., Cameron E., Rashid S. & Redwood S. (2013) Using the framework method for the analysis of qualitative data in multi-disciplinary health research. *BMC Medical Research Methodology*, 13, 117. https://doi.org/10.1186/1471-2288-13-117 PMID: 24047204

Goldblum, G. & Alant, E. (2009) Sales assistants serving customers with traumatic brain injury. *Aphasiology*, 23(1), 87–109. https://doi.org/10.1080/02687030802024094

Goldsmith L. (2021) Using framework analysis in applied qualitative research. *The Qualitative Report*, 26(6), 2061–2076. https://doi.org/10.46743/2160-3715/2021.5011

Grayson L., Brady M.C., 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 and Communication Disorders*, 55(5), 712–723. https://doi.org/10.1111/1460-6984.12555 PMID: 32618085

Hoofien, D., Gilboa, A., Vakils, E. & Donovick, P.J. (2001) Traumatic brain injury (TBI) 10-20 years later: a comprehensive outcome study of psychiatric symptomatology, cognitive abilities and psychosocial functioning. *Brain Injury*, 15(3), 189–209. https://doi.org/10.1080/026990501300005659 PMID: 11260769

Howell S., Beeke S., Pring T. & Varley R. (2020) Measuring outcomes of a peer-led social communication skills intervention for adults with acquired brain injury: a pilot investigation. *Neuropsychological Rehabilitation*,31, 1069–1090. https://doi.org/10.1080/09602011.2020.1760892

Knight, R.G., Devereux, R. & Godfrey, H.P.D. (1998) Caring for a family member with a traumatic brain injury. *Brain Injury*, 12(6), 467–481. https://doi.org/10.1080/026990598122430

Larkins B.M., Worrall L.E. & Hickson L.M. (2004) Stakeholder opinion of functional communication activities following traumatic brain injury. *Brain Injury*, 18(7), 691–706. https://doi.org/10.1080/02699050310001617389 PMID: 15204330

Lehman Blake, M., Frymark, T. & Venedictov, R. (2013) An evidence-based systematic review on communication treatments for individuals with right hemisphere brain damage. *American Journal of Speech–Language Pathology, Journal Article*, 22(1), 146. https://doi.org/10.1044/1058-0360(2012/12-0021)

Maas A.I.R., Menon D.K., Adelson P.D., Andelic N., Bell M.J., Belli A. et al. (2017) Traumatic brain injury: integrated approaches to improve prevention, clinical care, and research. *Lancet Neurology*, 16, 987–1048. https://doi.org/10.1016/S1474-4422(17)30371-X PMID: 29122524

Macdonald S. (2017) Introducing the model of cognitive-communication competence: a model to guide evidence-based communication interventions after brain injury. *Brain Injury*, 31(13–14), 1760–1780. https://doi.org/10.1080/02699052.2017.1379613 PMID: 29064304

Macdonald S. (2021) The cognitive-communication checklist for acquired brain injury: a means of identifying, recording, and tracking communication impairments. *American Journal of Speech-Language Pathology*, 30(3), 1074–1089. https://doi.org/10.1044/2021_AJSLP-20-00155 PMID: 33871283

Marsh, N.V., Kersel, D.A., Havill, J.H. & Sleigh, J.W. (2002) Caregiver burden during the year following severe traumatic brain injury. *Journal of Clinical and Experimental Neuropsychology*, 24(4), 434–447. https://doi.org/10.1076/jcen.24.4.434.1030 PMID: 12187457

Martelli M.F., Zasler N.D. & Tiernan P. (2012) Community based rehabilitation: special issues. *Neurorehabilitation*, 31(1), 3–18. https://doi.org/10.3233/NRE-2012-0770 PMID: 22523014

Mcdonald S., Tate R., Togher L., Bornhofen C., Long E., Gertler P., et al. (2008) Social skills treatment for people with severe, chronic acquired brain injuries: a multicenter trial. *Archives of Physical Medicine and Rehabilitation*, 89(9), 1648–1659. https://doi.org/10.1016/j.apmr.2008.02.029 PMID: 18760150

Norman, R.S., Jaramillo, C.A., Amuan, M., Wells, M.A., Eapen, B.C. & Pugh, M.J. (2013) Traumatic brain injury in veterans of the wars in Iraq and Afghanistan: communication disorders stratified by severity of brain injury. *Brain injury*, 27(13-14), 1623–1630. https://doi.org/10.3109/02699052.2013.834380 PMID: 24131337

Norman R.ŋO.S., Swan A.A., Jenkins A., Ballard M., Amuan M. & Pugh M.J. (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(5), 1060–1072. https://doi.org/10.1044/2020_PERSP-20-00011

Parkinson, S., Eatough, V., Holmes, J.,Stapley, E. & Midgley, N. (2016) Framework analysis: a worked example of a study exploring young people's experiences of depression. *Qualitative Research in Psychology*, 13(2), 109–129. https://doi.org/10.1080/14780887.2015.1119228

Parsonage, M. (2016) Traumatic brain injury and offending. An economic analysis. https://www.centreformentalhealth.org.uk/publications/traumatic-brain-injury-and-offending [Accessed: 25 March 2022].

Powell J. (2002) Community based rehabilitation after severe traumatic brain injury: a randomised controlled trial. *Journal of neurology, neurosurgery, and psychiatry*, 72(2), 193–202. https://doi.org/10.1136/jnnp.72.2.193 PMID: 11796769

Riedeman S. & Turkstra L., (2018) Knowledge, confidence, and practice patterns of speech – language pathologists working with adults with traumatic brain injury. *American Journal of Speech–Language Pathology*, 27(1), 181–191. https://doi.org/10.1044/2017_ajslp-17-0011

Ritchie, J. & Lewis, J. (2003) *Qualitative research practice—A guide for social science students and researchers*. London, Thousand Oaks, CA: Sage Publications Ltd.

Ritchie, J. & Spencer, L. (1994) *Qualitative data analysis for applied policy research*. In: Bryman, A. & Burgess, R. (Eds.) *Analyzing Qualitative Data*. London: Routledge, pp. 173–194. https://doi.org/10.4324/9780203413081

Sander, A.M., Clark, A. & Pappadis, M.R. (2010) What is community integration anyway? Defining meaning following traumatic brain injury. *The Journal of Head Trauma Rehabilitation*, 25(2), 121–127. https://doi.org/10.1097/HTR.0b013e3181cd1635 PMID: 20134333

Sarno, M.T. (1980) The nature of verbal impairment after closed head injury. *Journal of Nervous and Mental Disease*, 168(11), 685–692. https://doi.org/10.1097/00005053-198011000-00008 PMID: 7441232

Saunders, M. (2012) Choosing research participants. In: Symon, G. & Cassell, C. (Eds.) *Qualitative organizational research*. London: SAGE Publications, Inc, pp. 35–52. https://doi.org/10.4135/9781526435620.n3

Smith, J. & Firth, J. (2011) Qualitative data analysis: the framework approach. *Nurse Researcher*, 18(2), 52–62. https://doi.org/10.7748/nr2011.01.18.2.52.c8284. PMID: 21319484

Togher, L., McDonald, S., Code, C. & Grant, S. (2004) Training communication partners of people with traumatic brain injury: a randomised controlled trial. *Aphasiology*, 18(4), 313–335. https://doi.org/10.1080/02687030344000535

Togher, L., McDonald, S., Tate, R., Power, E. & Rietdijk, R. (2013) Training communication partners of people with severe traumatic brain injury improves everyday conversations: a multicenter single blind clinical trial. *Journal of Rehabilitation Medicine*, 45(7), 637–645. https://doi.org/10.2340/16501977-1173. PMID: 23803687

Togher, L., Power, E., Rietdijk, R., McDonald, S. & Tate, R. (2012) An exploration of participant experience of a communication training program for people with traumatic brain injury and their communication partners. *Disability and Rehabilitation*, 34(18), 1562–1574. https://doi.org/10.3109/09638288.2012.656788 PMID: 22360709

Togher, L., Wiseman-Hakes, C., Douglas, J., Stergiou-Kita, M., Ponsford, J., Teasell, R., et al. (2014) INCOG recommendations for management of cognition following traumatic brain injury. part IV: cognitive communication. *Journal of Head Trauma Rehabilitation*, 29(4), 353–368. https://doi.org/10.1097/HTR.0000000000000071 PMID: 24984097

Tong A., Sainsbury P. & Craig J. (2007) Consolidated Criteria for Reporting Qualitative Research (COREQ): a 32-item checklist for interviews and focus groups. *International Journal for Quality in Health Care*, 19, 349–357. https://doi.org/10.1093/intqhc/mzm042 PMID: 17872937

Wade D.T. (2020) What is rehabilitation? An empirical investigation leading to an evidence-based description. *Clinical Rehabilitation*, 34(5), 571–583.https://doi.org/10.1177/0269215520905112

Wiseman-Hakes C., Ryu H., Lightfoot D., Kukreja G., Colantonio A. & Matheson F.I. (2020) Examining the efficacy of communication partner training for improving communication interactions and outcomes for individuals with traumatic brain injury: a systematic review. *Arch Rehabil Res Clin Transl*, 2(1), 100036. doi:10.1016/j.arrct.2019.100036 PMID: 33543065

Ylvisaker, M., Jacobs, H.E. & Feeney, T. (2003) Positive supports for people who experience behavioral and cognitive disability after brain injury. *Journal of Head Trauma Rehabilitation*, 18(1), 7–32. https://doi.org/10.1097/00001199-200301000-00005 PMID: 12802235

How to cite this article: Howell, S., Hoskin, J., Eaton, D., Holloway, M. & Varley, R. (2023) Stakeholder views on cognitive communication assessment and intervention for a person living independently in the community with severe traumatic brain injury. *International Journal of Language & Communication Disorders*, 1–13. https://doi.org/10.1111/1460-6984.12839