Research Report

A survey of cognitive–communication difficulties following TBI: are families receiving the training and support they need?

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Abstract

Background: Whilst research into the wide-ranging needs of family members following traumatic brain injury (TBI) is well established, investigation into the specific needs of families in relation to supporting cognitive–communication difficulties, relationships and social participation is limited.

Aims: To identify the family needs for cognitive-communication difficulties following TBI and to explore whether current services are meeting these needs.

Methods & Procedures: Following a successful pilot, family members from the UK and Australia were invited via posters, social media and e-mail to take part in an anonymous, communication needs survey. Data arising from the thirty two closed questions (six eligibility, nine demographic and seventeen needs questions) were analysed using SPSS descriptive statistics. Data arising from one open question were analysed using qualitative content analysis.

Outcomes & Results: A total of 102 family members from the UK (n = 89, 87%) and Australia (n = 13, 13%) completed the survey. The majority of respondents were female (n = 76; 75%), between the ages of 30 and 69 (n = 88; 87%), and either a parent or a partner of the person following TBI (n = 78;76%). Respondents rated information about expected recovery from cognitive-communication difficulties and training in helpful strategies as their most important needs. The majority of respondents (more than 60%) were not satisfied that any of their cognitive–communication needs had been fully met and high levels of unmet need remained evident at three years or more post-injury. Written information, communication partner training and counselling were identified as key supports.

Conclusions & Implications: Families report high levels of unmet need for managing cognitive-communication difficulties following TBI. Access to written information and communication partner training should be available to families at various time points following TBI and not just in the early stages.

Keywords: traumatic brain injury, cognitive–communication difficulties, family needs.

What this paper adds

What is already known on this subject

- Attempting to support a person who has cognitive-communication difficulties following TBI has been found to be highly burdensome for family members. However, few studies have asked how families perceive their needs in relation to cognitive-communication difficulties or measured how well current services are meeting their needs.
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What this paper adds to existing knowledge

- This study demonstrates that current speech and language therapy services are not yet meeting the needs of the relatives of individuals with cognitive-communication difficulties following TBI. Important insights into the information, training and support families’ rate as important are identified in addition to how these needs develop over time.

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

- Speech and language therapy service design requires to reflect the ongoing nature of familial needs for cognitive-communication difficulties following TBI. Families require access to appropriate literature, speech and language therapy support, and communication partner training in the longer term, not just in the acute phase.

Introduction

Worldwide, traumatic brain injury (TBI) causes long-term disability in an estimated 150–200 million people annually (De Silva et al. 2009). Altered communication is common following TBI, with reported incidence rates of more than 75% following moderate to severe injuries (MacDonald 2017). Cognitive–communication difficulties (CCD) resulting from disrupted cognitive processes (e.g., attention, memory, executive function) rather than specific language disorder is the most prevalent communication difficulty following TBI (Coelho 2007). The clinical presentation of a person with a CCD is highly heterogeneous and can include difficulties with information processing (understanding implied, abstract and more complex content), discourse (problems with quantity, quality, relevance and cohesion of conversation) and social communication (difficulty recognizing verbal and non-verbal cues, initiating, maintaining and repairing conversations) (MacDonald 2017). These impairments have been found to have a devastating effect on social participation and interpersonal relationships, resulting in poor psychosocial outcomes for the person following TBI. This includes fewer friendships and social contacts, loss of employment, low mood, loss of identity and family breakdown (Struchen et al. 2011, Douglas 2013, Turkstra 2000).

Attempting to support a person who has CCD following severe TBI has also been found to be highly burdensome for family members (Anderson et al. 2002). The responsibility for providing long-term support frequently lies with informal family caregivers with 40% of individuals following severe TBI continuing to require support at ten years post-injury (Ponsford et al. 2014). Families report feeling poorly prepared for this role (Man 2002), which directly impacts upon their well-being and ability to provide the correct supports for the injured person (Vangel et al. 2011). Depression and anxiety have been reported in as many as 50% of family caregivers (Douglas and Spella 2000), and family distress persists for several years after the injury (Ponsford and Schönberger 2010).

Access to family support following TBI has been found to reduce levels of family stress and increase the caregivers’ ability to cope with the neuro-behavioural effects of brain injury (Winstanley et al. 2006). Families consistently rate health information and a realistic portrayal of the TBI survivor’s difficulties, including expected recovery, as their most important needs (Kreutzer et al. 1994, Serio et al. 1997, Arango-Lasprilla et al. 2010). With increased time post-injury, however, a greater number of needs are rated as unmet by families (Witol et al. 1996) particularly following discharge home (O’Callaghan et al. 2011). The focus of what is important for families also changes with support for relationships, managing behaviour, emotional well-being and finances becoming more important with increased time post-injury (Dillahunt-Aspillaga et al. 2013). Whilst research into the wide-ranging needs of family members following TBI is well established, investigation into the specific needs of families in relation to supporting CCD, relationships and social participation is limited.

One family intervention for CCD following TBI that has been recommended as best practice for speech and language therapists (SALT) is communication partner training (CPT) (Togher et al. 2014). A recent systematic review identified seven studies where joint communication training sessions for the person following TBI and their family member resulted in improved communication outcomes. The authors cautioned, however, that the majority of these studies came from one group of Australian researchers, and further research investigating optimal format and dosage of intervention is required (Wiseman-Hakes et al. 2020). One multi-centre non randomized control trial identified that the everyday conversations of people following
TBI were found to improve most when patients and family members were trained together in a group and that these improvements were maintained at six months post-treatment (Togher et al. 2013). Family members demonstrated an improved ability to facilitate conversations with the person following TBI (Sim et al. 2013, Mann et al. 2015) and reported increased confidence when supporting the person following TBI at social events following this training (Togher et al. 2012).

Similar communication outcomes were obtained when the person following TBI and their family member received CPT as a dyad rather than a group and the use of telehealth to enable participants to access the training remotely did not affect the outcome (Rietdijk et al. 2020).

Family access to information about CCD and CPT training may be limited by poor rates of referral for CCD to SALT services (Lehman et al. 2013). SALTs have also reported reduced confidence in their knowledge of CCD following TBI (Riedeman and Turkstra 2018) and limited time to deliver information specifically tailored to the needs of the family (Short et al. 2014). Time was identified as a barrier to service provision not only in relation to a lack of SALT time but also in terms of service user readiness for receiving information about CCD. Individuals following TBI and their families require time to adjust emotionally and develop an awareness of CCD and this may not occur within the SALT’s episode of care (Short et al. 2014). Further investigation into family perception of current service provision for CCD is therefore merited to explore whether an evidence–practice gap exists, and the implementation of recommendations is not being achieved with current service resources.

CPT programmes across different conditions contain several common core elements, including information about communication changes, positive strategies and negative behaviours to avoid (O’Rourke et al. 2018). However, few studies have directly involved family members in programme design, or sought their opinion about what information and training would best meet their needs. One exception is the family members of people with aphasia (PWA) following stroke. Research has identified sixteen content areas important to family members across five phases of care (Hilton et al. 2014, Rose et al. 2019). Unmet needs particularly in relation to information about how to help the PWA communicate and the long-term effects of aphasia were identified (Rose et al. 2019).

Longitudinal studies investigating the long-term impact of brain injury have found that the functional abilities of individuals following moderate–severe TBI do not remain stable, but can fluctuate and may deteriorate in the longer term (Corrigan and Hammond 2013). Families have also reported that their ability to cope with the effects of TBI varies over time (Townshend and Norman 2018). This lends support to the published proposal that TBI be reconceptualized within a chronic condition framework to acknowledge the need for ongoing input from specialist services (Corrigan and Hammond 2013). Unfortunately, no published studies have plotted the course of CCD following TBI more than three years post-injury (Elbourn et al. 2017). Consequently, we lack insight into any support needs that individuals following TBI and their families may continue to have beyond this timepoint.

Although communication, social participation and relationships have been identified as key areas of families’ needs following a TBI, no study has addressed family opinion regarding communication focused training and support needs. CPT is one intervention that has demonstrated good efficacy for the TBI survivor, but its impact on the ability of families to manage CCD requires further investigation. Family adjustment and readiness for input needs to be considered as well as documenting family needs in the longer term not just in the early stages post-injury.

Aim

This study sought to identify what family members perceive their needs to be in relation to supporting communication, participation and relationships following a TBI. The project will inform SALT practice and service design by examining the communication training needs of family members.

Study questions

• What do family members perceive as their most important information, training and support needs in relation to CCD?
• Do family members feel their information, training and support needs for CCD have been met by services?
• Does information, training and support need for CCD change over time?
• What services would be beneficial to help meet family information, training and support needs for CCD?

Method

Design

We employed a correlational research survey design as it enabled us to gather and synthesize self-reported data from several participants. This project was approved by Glasgow Caledonian University School of
Life Sciences Ethics Committee (reference number HLS/NCH/17/042).

Participants

Individuals eligible for inclusion were the self-identified family members (aged over 18 years) of people experiencing CCD (defined as difficulty paying attention to conversations, staying on topic, remembering information, responding accurately, understanding jokes and/or following directions) as a result of sustaining a TBI (defined as a brain injury caused by a road traffic accident, fall or assault). Family members of individuals who were less than 3 months after TBI or still in post-traumatic amnesia PTA (defined as the period of disorientation after coma) were excluded. Data on age, gender, relationship and time since TBI were also collated for the family member and person with TBI.

A convenience sample of participants from the UK and Australia were recruited to complete either an open online or paper survey between October and December 2018. The decision to include Australia was made to explore whether Australia’s more established CPT research and therapy programmes would have an impact on participant perceptions of services.

Instrument

Participating family members completed a short, anonymous survey that contained questions about their perceived information, training and support needs (see appendix 1 in the supplemental data online). A pilot survey was drafted based on information gained from an extensive literature review of existing needs questionnaires and in consultation with specialist SALT, patients and family members currently involved with NHS Lanarkshire Community Brain Injury Team. A number of existing surveys informed the development for this survey, for example, The Family Needs Questionnaire (FNQ) (Kreutzer and Marwitz 1989) and The Brain Injury Association of Florida Caregiver Needs Assessment Survey (Dillahunt-Aspillaga et al. 2013). Permission to use the scales and scoring criteria from the FNQ was obtained for this study as this format has been found to be psychometrically robust (Kreutzer et al. 1994).

The survey design was informed by guidelines for transparent reporting (Eysenbach 2004) and best evidence for format, data collection, response methodology (see Material 1 in the supplemental data online). It contained thirty two closed questions distributed across three pages in the paper copy (seven screens in the online version). Six questions related to the participants’ eligibility for the study, nine to the participants’ demographic characteristics, sixteen to the participants’ needs and one related to each participant selecting his/her preferred support options. Respondents were asked to rate each need along two dimensions; level of importance (not important, somewhat important, important and very important) and the extent to which each need has been met (met, unmet or partly met). The survey contained one open question for participants to record any preferred service options not included within the survey. All items included within the survey was examined in order to verify their purpose, necessity, accuracy and to eliminate redundancy. The online and paper formats of the survey were piloted with five allied healthcare professionals working with brain injury survivors and five family members of individuals who had sustained a TBI. A researcher (L.G.) was present on all piloting occasions and modified the questions to reflect feedback. These modifications related to simplifying the wording and shortening the length of question descriptors.

Procedure

Participants were recruited to the project using posters placed in brain injury rehabilitation establishments and carer centres throughout the UK. The online link to the survey was advertised on social media via Facebook and Twitter, carer groups, brain injury charities and centres. SALTs working in brain injury services throughout the UK and Australia were contacted via e-mail and permission was sought for the study to be advertised to the family members of individuals following TBI on their caseload. A total of 300 paper questionnaires were requested and distributed. Weekly reminder e-mails were sent to participating SALTs and the project was advertised weekly on social media.

Suitable participants were identified via six eligibility questions at the start of the survey. This enabled the survey to be open access to any potential participant willing to take part. It also eliminated the need for SALTs to take time to identify suitable participants. Responses to the survey were accepted over a period of ten weeks.

Participants accessed the online survey (hosted by survey monkey) by scanning a QR code on the poster, clicking on the online link from an e-mail/social media post or completing a paper copy and returning via stamped addressed envelope. All invitations included a participant information sheet with details about the study and return of the questionnaire was taken as voluntary consent to participate. Only one online entry per device was possible and IP address collection was disabled to ensure anonymity.

Data collection and analysis

Data arising from the closed-ended questions were entered into a spreadsheet and analysed using the
Statistical Package for the Social Sciences, v.24 (SPSS) descriptive statistics (i.e., frequency and percentage distributions, measures of central tendency and cross-tabulations). Participant responses to the open-ended question were transcribed and analysed using a thorough six-step, qualitative content analysis approach (Creswell and Creswell 2018). This involved reading the responses to get an overall sense of the data before coding the main ideas and sorting them into potential themes. The research team then refined the themes and identified suitable extracts for each theme.

**Results**

We received 131 surveys, of which 102 questionnaires were eligible for inclusion in the study. Figure 1 displays a flow chart of survey response rates and participant eligibility.
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Table 1. Participant demographics

| Gender (m = 2) | N (%) | TBI survivor characteristics |
|----------------|-------|-----------------------------|
|                |       | Gender | N (%) |
| Female         | 76 (75%) | Female | 23 (23%) |
| Male           | 24 (25%) | Male   | 79 (77%) |
| Age (years) (m = 1) |       | Age |       |
| 18–29          | 4 (4%) | 16–29 | 15 (15%) |
| 30–49          | 32 (32%) | 30–49 | 40 (39%) |
| 50–69          | 56 (55%) | 50–69 | 40 (39%) |
| ≥ 70           | 9 (9%) | ≥ 70  | 7 (7%) |

| Relationship to TBI survivor | N (%) | Place of residence | N (%) |
|------------------------------|-------|--------------------|-------|
| Parent                       | 32 (31%) | Place of residence | 15 (15%) |
| Partner or Spouse            | 46 (45%) | UK                 | 89 (87%) |
| Son or daughter              | 11 (11%) |                    | 13 (13%) |
| Other Relative               | 13 (13%) | Australia           | 13 (13%) |

| Notes: |       |       |
|--------|-------|-------|
| a      | m = missing data. |
| b      | Scotland 41 (40%), England 34 (33%), Northern Ireland 8 (8%) and Wales 6 (6%). |

Table 2. Family communication needs with the highest to lowest reported importance ratings

| Need (subscale) | n = 93 |
|----------------|-------|
| What do family members perceive as their most important information, training and support needs in relation to CCD? |

Any missing data was documented within the results. Table 1 displays the demographic information for family members and the brain injury survivor they support.

All the needs in this survey were rated as important (defined as a rating of ‘important’ or ‘very important’) by more than 70% of respondents and the top eight needs were rated as important by at least 90% of respondents. Family members rated their need for training as equally important to their need for information (89%) whereas support needs were rated as slightly less important (81%). Table 2 shows the communication needs rated as most to least important by family members.

Information about the long-term impact of CCD was rated as the most important need by the family members taking part in this study. Three of the six most important needs related to families receiving training in helpful CCD strategies. Only one support need (community support services) was rated within the top six needs.
Do family members feel their information, training and support needs for CCD have been met by services?

Family members taking part in the study then rated whether each need had been met, partly met or was unmet. Training needs were least likely to have been met (67% unmet), followed by support needs (63% unmet) and information needs (41% unmet). Table 3 depicts the needs most to least frequently rated as met.

Respondents rated training for supporting relationships (n = 69, 74% unmet) and social participation (n = 67, 72% unmet) as the needs least likely to have been met. Five of the six most frequently met needs related to information, although information about expected recovery was least likely to have been met (n = 41, 44% unmet). No training needs and only one support need (community support services) were in the top six most frequently met needs.

There was a trend for participants in the UK to rate their training needs for helpful and unhelpful strategies as unmet (n = 59, 67%, and n = 57, 65% unmet) more frequently than their Australian counterparts (n = 2, 18%, and n = 4, 27% unmet). This trend was not observed in ratings for supporting relationships or social participation, with more than 70% of participants from all countries rating these areas as unmet.

Does information, training and support need for CCD change over time?

Participant ratings for importance and the percentage of unmet needs were then cross tabulated with length of time since the TBI event. Information and training for CCD remained important areas of need regardless of time since injury. Both areas were rated as important by at least 87% of participants at 0–12, 18–36 and ≥ 36 months post-injury. Support needs for CCD became more important for participants with time and increased from 64% at 0–12 months to over 80% important/very important at the later time points. Information about the long-term impact of CCD was consistently rated in the top three most important needs at all time points post-injury. Table 4 displays the percentage of unmet needs in relation to time since injury with needs rated as unmet by more than 50% of respondents highlighted in bold.

What support would be beneficial to help meet information, training and support needs for CCD?

The number of respondents who indicated that they did not require any input from SALT increased with time, although 73% (n = 33) of respondents who were more than 3 years post-injury continued to report needing support. Table 5 displays the supports deemed useful by participants in relation to time since the TBI event.

Written information was the most frequently selected useful support regardless of time since injury. Family members who were less than a year post-injury also indicated the need for a family support group without the presence of the TBI survivor as a key support (n = 15, 75%). This was selected as useful much more frequently than a group with the TBI survivor (n = 7, 35%). This trend was not observed with increased time post-injury with 38% (n = 17) of respondents 3 years plus post-injury rating both types of groups as equally useful. Respondents who were more than 3 years post-injury also indicated a joint TBI survivor and family

### Table 3. Family communication needs most to least frequently rated as met

| Need (subscale^) | % Met | % Partly met | % Unmet |
|------------------|-------|------------|--------|
| How speech and language therapy can help me and my family member (I) | 33 (35%) | 26 (28%) | 34 (37%) |
| How the brain injury has affected my family member’s ability in social activities (I) | 27 (29%) | 40 (43%) | 26 (28%) |
| How the brain injury has affected my family member’s ability to take part in conversations (I) | 25 (27%) | 40 (43%) | 28 (30%) |
| How the TBI might affect my family member’s relationship with me (I) | 19 (20%) | 27 (29%) | 47 (51%) |
| How the TBI might affect my family member’s relationships with others (I) | 18 (19%) | 34 (37%) | 41 (44%) |
| Talking to someone about how the brain injury has affected my relationships (S) | 14 (15%) | 21 (23%) | 58 (62%) |
| Talking to someone about what brain injury support services are available in the community (S) | 14 (15%) | 29 (31%) | 50 (54%) |
| Talking to someone about how to access emotional support (S) | 13 (14%) | 17 (18%) | 63 (68%) |
| Talking to someone about how the brain injury has affected me emotionally (S) | 13 (14%) | 22 (24%) | 58 (62%) |
| Expected level of recovery in relation to conversations, relationships and activities (I) | 11 (12%) | 41 (44%) | 41 (44%) |
| Talking to someone about how the brain injury has affected my social life (S) | 11 (12%) | 19 (20%) | 63 (68%) |
| How conversations, activities and relationships might be affected over the next two years (I) | 10 (11%) | 36 (39%) | 47 (50%) |
| Training in what to do to help my family member take part in conversations (T) | 10 (11%) | 26 (28%) | 51 (58%) |
| Training in what is unhelpful for my family member when taking part in conversations (T) | 9 (10%) | 27 (29%) | 51 (61%) |
| Training in how to support my family member with relationships (T) | 8 (9%) | 16 (17%) | 69 (74%) |
| Training in how to support my family member with social events and activities (T) | 7 (8%) | 19 (20%) | 67 (72%) |

Notes: ^I, information; T, training; and S, support.

^n = 93; missing data = 9.
Table 4. Percentage unmet needs over time with more than 50% unmet highlighted in bold

| Need (subscale) | 0–12 months ($n = 22$) (% unmet) | 12–36 months ($n = 26$) (% unmet) | ≥ 36 months ($n = 45$) (% unmet) |
|----------------|----------------------------------|----------------------------------|---------------------------------|
| How the TBI has affected my family members ability to take part in conversations (I) | 6 (27%) | 7 (27%) | 15 (33%) |
| How the TBI has affected my family members ability in social activities (I) | 6 (27%) | 7 (27%) | 13 (29%) |
| How the TBI might affect my family member’s relationship with me (I) | 11 (50%) | 14 (54%) | 22 (49%) |
| How the TBI might affect my family member’s relationships with others (I) | 12 (55%) | 12 (46%) | 18 (40%) |
| How SALT can help me and my family member (I) | 5 (23%) | 13 (50%) | 16 (36%) |
| How conversations, activities and relationships might be affected over the next two years (I) | 14 (64%) | 13 (50%) | 20 (44%) |
| Expected level of recovery in relation to conversations, relationships and activities (I) | 13 (59%) | 10 (38%) | 18 (40%) |
| Training in what to do to help my family member take part in conversations (T) | 13 (59%) | 16 (62%) | 28 (62%) |
| Training in what is unhelpful for my family member when taking part in conversations (T) | 14 (63%) | 17 (65%) | 25 (56%) |
| Training in how to support my family member with relationships (T) | 17 (77%) | 20 (77%) | 30 (67%) |
| Training in how to support my family member with social events and activities (T) | 17 (77%) | 20 (77%) | 30 (67%) |
| Talking to someone about how the TBI has affected my relationships (S) | 13 (59%) | 15 (58%) | 28 (62%) |
| Talking to someone about how the TBI has affected my social life (S) | 14 (64%) | 18 (69%) | 30 (67%) |
| Talking to someone about how the TBI has affected me emotionally (S) | 13 (59%) | 17 (65%) | 28 (62%) |
| Talking to someone about how to access emotional support (S) | 13 (59%) | 19 (73%) | 30 (67%) |
| Talking to someone about what TBI support services are available in the community (S) | 12 (55%) | 12 (46%) | 25 (56%) |

Notes: *I, information; T, training; and S, support.*

Table 5. Useful speech and language therapy (SALT) support in relation to time since the TBI event

| Type of speech and language therapy support (SALT) | Overall ($n = 93$) | 0–12 months ($n = 20$) | 12–36 months ($n = 28$) | ≥ 36 months ($n = 45$) |
|-------------------------------------------------|-------------------|---------------------|---------------------|---------------------|
| No support                                      | 18 (19%)          | 0 (0%)              | 6 (21%)             | 12 (27%)            |
| Written information communication               | 50 (54%)          | 15 (75%)            | 12 (43%)            | 23 (51%)            |
| Written information community supports          | 59 (63%)          | 16 (80%)            | 16 (57%)            | 27 (60%)            |
| SALT appointment (family member only)           | 27 (29%)          | 9 (45%)             | 3 (11%)             | 15 (33%)            |
| SALT appointment (family member and TBI survivor) | 39 (42%)          | 11 (55%)            | 10 (36%)            | 18 (40%)            |
| Group for family members only                   | 39 (42%)          | 15 (75%)            | 7 (25%)             | 17 (38%)            |
| Group for family members and TBI survivors together | 33 (36%)          | 7 (35%)             | 9 (32%)             | 17 (38%)            |

Note: *Participants could select more than one option (mean = 3; range = 1–6).*

Response to the open question

One-quarter of respondents ($n = 26, 25\%) completed the open question about support. The majority of these responses ($n = 20, 76\%) were from family members who’s loved one was more than two years after TBI. Key themes that emerged from this group was a continued need for, but an absence of, services with specific knowledge of brain injury. This included counselling (both relationship and whole family), conversation partner training and groups with other family members who have loved ones at the same level and severity:
2.5 years on I think a SALT appt would be useful but perhaps also with neuropsychology and a specialist counsellor to help with these ongoing problems.

Support group that discusses people’s communication and relationships problems. Not catered for in [group name] group we attend.

Other themes that emerged included support for mental health for both the TBI survivor and family member and services to help maintain employment. Headway was viewed as a positive support from UK respondents.

Key themes that emerged from family members in their first two years after TBI was the need for information and training sessions to help support communication, social and psychological changes. Information on what to expect in the future and the education of the individual with TBI’s wider social network (extended family/friends) was viewed as important:

An informational meeting about all the aspects mentioned here like what to expect over the next couple years.

Written information that I could give to our extended family and close friends. In particular those that don’t live in same town so haven’t seen him and think he looks fine so is back to normal.

Discussion

The findings show that the families of individuals following TBI have continued CCD needs throughout the recovery process and beyond three years after injury. Information about expected recovery for CCD was the most important need overall. Support needs for the family were rated as less important with only community support services ranked among the most important needs at all time points following TBI. These results are consistent with the findings of previous studies investigating family needs following TBI (Arango-Lasprilla et al. 2010, Serio et al. 1997, Witol et al. 1996) and emphasize the need for further research into patterns of CCD recovery over time and the impact longer term follow-up would have on the family (Elbourn et al. 2017).

Participants rated their training needs for CCD to be of equal importance to information with three out of four training items featuring in the top six most important needs. This demonstrates that CPT is not only beneficial for TBI survivors but also is a key need identified by families so should be a central part of any TBI rehabilitation programme for CCD (Togher et al. 2014). Although training in how to change unhelpful communication styles was identified as a core element in CPT programmes (O’Rourke et al. 2018), participants in this study rated this area as less important than training for helpful strategies. Involving individuals following TBI and their families in the content and design of future CPT programmes will ensure the needs of all parties are met. This co-design model has proven successful in recent research with people with aphasia (Kulnik et al. 2019).

The majority of respondents (more than 60%) were not satisfied that any of their CCD needs had been fully met. This is a higher level of unmet need than the findings of general family needs surveys following TBI (Witol et al. 1996, Arango-Lasprilla et al. 2010), but is more in line with studies exploring the family experience of PWA following stroke (Rose et al. 2019). This suggests that supporting family communication information and training needs should be considered as a priority area requiring development by SALT services. Time to create family specific information has been identified by SALT’s as a key barrier to service delivery for CCD following TBI and changes to the format and content of this information is required (Short et al. 2014). Recent CPT studies are beginning to address the evidence–practice gap by creating shorter, more accessible versions of established programmes (Rietdijk et al. 2020).

Respondents rated their training needs as least likely to have been met overall with training to help maintain relationships and social participation receiving ratings of less than 10% met by participants from all countries. These results indicate that developing programmes that incorporate training in how to support CCD in relationships and social participation is an area of need for families. As these areas are not just CCD specific but cross several cognitive, behavioural and psychosocial domains, working jointly with clinical psychology, counselling and social work services to incorporate CPT into couples/family counselling sessions would be of benefit.

The need for information and training remained consistently important, for family members in this study, regardless of length of time since the TBI event. The need for support increased with time post-injury and a significant number of participants continued to have unmet needs in relation to CCD at both 18–36 months and more than 36 months post-injury. This echoes the findings of several family needs surveys that have been completed over the last twenty years in a number of countries (Witol et al. 1996, Arango-Lasprilla et al. 2010, O’Callaghan et al. 2011, Dillahunt-Aspillaga et al. 2013), reinforcing the need for services to reconceptualize TBI as a chronic condition (Corrigan and Hammond, 2013).

Participants identified access to written information, about both CCD and community support groups, as the most useful support. This is consistent with
studies exploring the experience of families of PWA (Rose et al. 2019). Family members in the study also viewed participation in group work to address CCD needs positively and this was evident at all time points post-injury. Respondents emphasized the need for ongoing support from services with a specialist knowledge of brain injury. This included not only SALT but also clinical psychology and counselling services.

**Strengths and limitations**

This study is a first step to exploring family perception of communication needs following TBI and provides new knowledge in this area. The international sample and use of the FNQ scoring scale (Kreutzer and Marwitz 1989) strengthen the findings although the results cannot be taken to reflect the experiences of all families following TBI due to the following limitations. In order to ensure participants remained anonymous we relied on SALT’s and brain injury charities for distribution of the surveys. We thus had no facility to send reminders directly to the participants. The short time frame for advertisement and return of the survey may have resulted in a geographical sample bias with good representation from areas closer to the research site e.g., Scotland and England but fewer returns from Australia, Northern Ireland and Wales. The limited number of returns from Australia also prevented any direct comparisons relating to service provision with the UK from being possible. A significantly higher number of participants were more than 36 months post-injury compared with 0–12 or 12–36 months, limiting the ability to make comparisons between the groups. The majority of participants were also family members of TBI survivors who were living in the community therefore comparisons between inpatient and outpatient needs were not possible.

The findings of this study are based upon the experiences of the participants and reflects their perceptions of the services provided. Although this may not fully reflect the reality of the information, training and support received, research has identified that perceived support (an individual’s cognitive appraisal of the support provided) is more closely related to positive health outcomes than actual support (Ergh et al. 2002). Gathering family perception of services therefore has significant value in determining how services can make the biggest difference to ultimate outcome.

**Research implications**

Family needs for managing CCD following TBI is an area requiring further investigation. A longitudinal study design would provide more information about how families develop awareness of CCD over time, highlighting information and training required during different phases of care. More detailed qualitative evaluation of the lived experience of family members in relation to managing CCD following TBI would help to identify which CCD’s have the greatest impact upon family life in addition to family perception of the most useful SALT supports over time. Further studies exploring the impact of intervention for CCD including family training and education programmes longer post-injury are required. More information from UK SALT’s on their current practice patterns for CPT including perceived implementation barriers and facilitators would be beneficial. Once identified, future studies could continue to explore the effectiveness of training approaches that have been adapted to reflect service resources. This may include shortened versions of evidence-based programmes, self-guided modules and the use of telehealth to improve accessibility.

**Clinical implications**

The results of this study indicate that current SALT services are not yet providing the families of individuals with CCD following TBI with adequate information, training and support. Written and verbal information for families should be designed specifically for their needs at unique time points post-injury. This should include information about the long-term impact of CCD on conversations, relationships and social participation, including prognosis for recovery. SALT services should examine current barriers to delivering timely information about CCD and CPT to families and explore how ongoing access to these services can best be facilitated. This may include increased use of online platforms and telehealth to enable families to access information, take part in CPT and ask questions remotely. A more fluid service design which enables families to return for ‘top up’ information and training, as insight, adjustment and personal circumstances develop, may also need to be addressed. This is more in line with service provision for chronic conditions and facilitates supported self-management in the community. SALT’s should continue to promote awareness of CCD to the wider health community to encourage improved and timely referrals to SALT for individuals following TBI and their families. Joint working with psychology, counselling and third sector support services to incorporate SLP specific knowledge of CPT into couples/family counselling sessions would also be beneficial.

**Conclusions**

High levels of unmet need were identified at all time points post-injury. The majority of respondents (more
than 60%) were not satisfied that any of their cognitive–communication needs had been met and training needs were least likely to have been met overall. Participants identified information about expected recovery and training in helpful strategies as their most important needs. Written information was selected as the most useful support for families regardless of time since injury although group work and joint appointments were also identified as useful. Further research into the needs of families for CCD following TBI is required to enable SALTs to meet their needs more effectively.

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Supporting Information

Additional supporting information may be found online in the Supporting Information section at the end of the article.

Supplementary Information

Supplementary Information