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Family-centred care for children with traumatic brain injury and/or spinal cord injury: a qualitative study of service provider perspectives during the COVID-19 pandemic

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ABSTRACT

Objectives COVID-19 has led to rapid changes in rehabilitation service provision for young people living with traumatic brain and/or spinal cord injury. The aim of this project was to understand the experiences of rehabilitation service providers during the acute response stage of the COVID-19 pandemic. Specifically, we aimed to identify innovative approaches to meeting the ongoing needs of young people with traumatic brain and/or spinal cord injury during this time.

Setting This study was conducted at a research institute and involved remote interviews with key informants around Australia and internationally.

Participants Key informants from 11 services supporting children and/or adolescents with traumatic brain injury and/or spinal cord injury were interviewed using a semistructured interview guide. Interviews were transcribed and analysed using inductive thematic analysis.

Results Three key themes emerged: (1) recognising and responding to the experiences of families during the pandemic, (2) the impact of greater use of telehealth on care delivery, and (3) realising opportunities to enhance family-centred care.

Conclusions These themes capture shifting perspectives and process changes relevant to longer term practice. Research findings suggest opportunities for future service development, enabling service delivery that is more family centred, flexible and efficient in meeting the needs of families. Understanding these experiences and the changed nature of service delivery provides important insights with implications for future service improvement.

INTRODUCTION

In 2019, the coronavirus (COVID-19) spread rapidly throughout the world, and was declared a global pandemic by WHO in March 2020.[1] Many governments responded by implementing strategies to alleviate the impact of the pandemic,[2 3] with lockdown approaches commonly used to slow the

STRENGTHS AND LIMITATIONS OF THIS STUDY

⇒ This study included representatives from a broad range of services for children and young people with traumatic brain injury (TBI) and/or spinal cord injury (SCI).
⇒ Qualitative interviews captured the experiences and perspectives of service providers, enabling in-depth understanding of the service changes that occurred as a result of the COVID-19 pandemic.
⇒ The experiences of children and young people with TBI and/or SCI and their families are not captured as part of this study.

spread of the virus.[4 5] Lockdown restrictions, such as school closures, a transition to online learning and limited access to face-to-face healthcare and rehabilitation or carer support, have led to a major shift in the provision of medical and community-based rehabilitation services for children and youth with traumatic brain injury (TBI) and/or spinal cord injury (SCI) and their families.

Due to the multifaceted and complex needs of children with TBI and/or SCI and their families, support from a multidisciplinary rehabilitation team using a family-centred approach is considered best practice.[6] Prior to the COVID-19 pandemic, services supporting children with TBI and/or SCI reported that the main approaches used to delivering family-centred care included hosting regular meetings with families, providing individualised care and care coordination support and engaging families in shared decision-making.[6] Overall, while Australian and international services supporting children following TBI and/or SCI aspired to be family centred, they

identified a number of challenges to delivering family-centred care.[6]

In the initial stages of the pandemic, the delivery of rehabilitation services was adapted or suspended.[7–10] In the Australian context, access to face-to-face assessment and therapy was limited across many healthcare settings, with group sessions, outpatient appointments and community care supports cancelled or severely reduced. Other challenges reported in the delivery of rehabilitation care included the use of telehealth and the inherent constraints to providing physical, neuropsychological and psychosocial assessments and therapies to children remotely.[7 11] To respond to these challenges, services were required to rapidly adapt and consider alternative modes of service delivery.[7 11 12]

There is much community-level evidence about the negative impact on mental health and well-being associated with the COVID-19 pandemic and lockdown restrictions,[13 14] with concern that vulnerable children (including those with TBI and/or SCI) and their families may be at greater risk.[15] Lack of access to rehabilitation was identified as a primary concern of parents,[10] indicating the heightened burden felt by families and caregivers of these young people. Further, a significant increase in caregiver distress and mental health symptoms of caregivers was directly linked to concerns about lack of rehabilitation for their children.[12]

While considerable research has been directed at understanding the experience of children and families during the COVID-19 pandemic,[8 10] understanding the experiences and perspectives of service providers is critical to informing how care can best be provided to meet the ongoing needs of young people with TBI and/or SCI and their families, both as the COVID-19 pandemic continues, and into the future. This study aimed to investigate the experiences and perspectives of paediatric rehabilitation services during the acute response stage of the COVID-19 pandemic (3–6 months after onset). We focused on organisations previously involved in an Australian-based study describing rehabilitation service models and programmes for children and youth who have sustained major TBI and/or SCI.[6] The onset of the COVID-19 pandemic in 2020 provided a unique opportunity to build on this work, re-engage with these organisations and examine their responses during the initial stages of the COVID-19 pandemic. Enablers, barriers and innovative approaches to meeting the ongoing needs of young people with TBI and/or SCI and their families during this time were investigated.

METHODS

Research design

Qualitative research methodology was adopted to enable an in-depth understanding of service changes from the perspective of providers.

Patient and public involvement

A steering committee was convened to oversee the project, which included experts from a range of disciplines and organisations including paediatric rehabilitation services and traffic accident insurance commissions, as well as young people and families with experience of traumatic injury (see acknowledgements). This group met throughout the course of the project (May, October 2020 and March 2021) and provided input into the conduct of the study including development of the research questions, the content of the interview guide, as well as feedback and assistance with interpretation of findings and the development of key recommendations.

Research participants/key informants

Key informants from 14 services involved in an earlier environmental scan of family-centred practice models[6] were invited via email to participate in this phase of the research (figure 1). If unable to participate, informants were asked to nominate an alternative representative from their service.

Figure 1 Types of services interviewed. The disability and insurance services were based in Australia. Aus, Australian-based services; Int, international.

Eleven services participated in the study. Three of the original services did not respond to the invitation, and one declined to participate, citing priority work commitments. An additional service was invited following referral from one of the participating services. Interviews were conducted with key informants from each of the services, nine of which were 1:1 and two with multiple participants (two to four participants). In total, 11 interviews were conducted. Key informants were managers or in roles of senior leadership at these organisations, and overall, there were 15 individuals contributing to interview data. The services included five paediatric medical rehabilitation services within Australia, and two international paediatric medical rehabilitation services (New Zealand and the UK), two community-based disability services and two insurance providers based in Australia. At the time of interview, most services were operating with a combination of face-to-face and telehealth service delivery. Purposive sampling of services ensured that the sample represented a range of experiences from the various services that contribute to providing care for children and young people following traumatic injury.

A semistructured interview guide was developed, informed by existing themes explored in the 2019 environmental scan,[6] and in consultation with the project's steering committee. An overview of the questions was provided to participants a week prior to the interview, along with an information sheet outlining the purpose of the study. Questions focused on the impact of COVID-19 on aspects of service delivery such as workforce structure, family-centred care, goal setting, school, child and family mental health and well-being, and transitions. A semistructured interview format provided scope for participants to share information most pertinent to their own experience, and for researchers to probe for further detail when required. Participants were also given the opportunity to provide additional information of clarification to interview related questions via email or telephone within 7 days following the interview; however, no further information was provided.

All interviews were conducted via videoconferencing platform (Zoom) by the study research assistant (AP) and took place from June to September 2020. Although some participants were previously involved in work conducted by the research team, no prior relationship existed between participants and the interviewer. Participants were asked to focus on the acute impacts to service delivery during the initial 3 months of the pandemic; however, given the timing of the interviews (until 7 months after pandemic onset), participants also provided reflections of the ongoing pandemic response to the time of interview. Interviews were approximately 60 min in duration and were audio recorded and transcribed using a professional transcription service. Transcripts were quality checked and corrections were made.

Qualitative data analysis
An inductive approach to thematic analysis was adopted for this project.[16] This enabled us to capture the responses and reflections of participants, ensuring that emerging themes were grounded in the data and experiences of the participants. The process of analysis followed a general qualitative thematic approach,[17] involving stages of coding, reflection and discussion, to identify patterns within and across transcripts. Data from all services were analysed collectively, with any distinction by service type noted in findings where applicable. Initial analysis occurred alongside data collection, with the review of interview recordings, and reading and re-reading of transcripts as they became available. Coding of all transcripts was completed by research assistant AP using NVivo V.12, with secondary coding conducted for four transcripts by a qualitative research expert (KD'C). Relevant codes were collated and organised into themes and subthemes, with saturation evidenced by the repetition of existing codes across new transcripts. Note taking, journal writing and diagramming were completed throughout the interview and analysis process to record reflections and help understand the relationship between themes as they developed. Regular meetings between team members were also used to discuss coding, interpretations and emerging findings. Preliminary data findings were shared and discussed with the project steering committee, with feedback integrated into the development of the final themes and subthemes.

FINDINGS
Three main themes were produced from data analysis: (1) 'Recognising and responding to the experience of families during the pandemic', (2) 'Impact of greater use of telehealth on care delivery', and (3) 'Realizing opportunities to enhance family-centred care'. Two of the themes include subthemes (see table 1).

Theme 1: recognising and responding to the experiences of families during the pandemic
Service providers reported that their teams were particularly understanding of the experiences of the children with TBI and/or SCI and their families during the pandemic. Participants recognised this as an immensely challenging and frightening time, explaining '*families felt abandoned and isolated and very scared*' (Participant 7).

In the inpatient hospital context, participants commented on the negative impact of visitor restrictions that meant parents, patients and their siblings were often separated during a time of significant family trauma in the early stages after injury, with limited opportunities to visit in hospital. Participants also reflected on the additional challenges that families were experiencing at home, including reduced routine and structure for children, a subsequent exacerbation of injury-related challenging behaviours in children with TBI and the pressures of remote learning, particularly for children with injury-related cognitive difficulties. As one participant

Table 1 Themes, subthemes and participant quotes

Theme/subtheme	Participant quotes
1. Recognising and responding to the experience of families during the pandemic.	'People felt isolated, and people felt lonely, and disengaged.' (Participant 5) 'For all the patients and families, that was really quite a scary period for them.' (Participant 2) 'I think the families are in a particularly vulnerable state.' (Participant 6) 'I guess the anxiety is one of the things that my staff have seen both from families and for children.' (Participant 9) 'We've also got siblings and other family members that we needed to consider.' (Participant 2) 'They had a greater kind of knowledge and understanding of their child's abilities and limitations, because they were there, they were looking at them all the time, they could sort of see it. And it gave them a greater connection, I think, with their child and their child's difficulties.' (Participant 7) 'My personal concern about COVID-19 pandemics and telehealth, [is] for some of those vulnerable families.' (Participant 8) 'I think overall it demonstrated the resilience of the families we work with.' (Participant 3)
Increased communication and engagement with families.	'We were communicating with a lot more families than we probably usually did.' (Participant 1) 'I think we were very mindful though, just to be checking in.' (Participant 3) 'If we don't get them online, they don't log in, we then phone them and then we do a phone review, so we've actually had much more connection with all of the families who are our routine follow ups as part of COVID.' (Participant 7) 'We've had the psychologists ring as a welfare check and check on people on a regular basis to check whether there's anything that can be provided.' (Participant 9)
Impact to family-centred care and adapting service responses with consideration of family needs.	'There were lots of things we couldn't do that we would normally do to provide family-centred care. It was difficult. It was really difficult.' (Participant 2) 'We had to think about how we really did engage with families a lot more.' (Participant 1) 'Actually learnt, I think, how to be more family centred in this process.' (Participant 1) 'It really was about looking at the family, and where they were at, and what we could do in the midst of all those restrictions and all that stress.' (Participant 2) 'We offered them the choice of telephone, telehealth or even if we hadn't identified that they were a high need to do face-to-face, if they identified that, we provided services for them as a face-to-face service. So we did have that discussion with families that we provided that choice.' (Participant 4)
2. Impact of greater use of telehealth on care delivery.	'Instead of actually being there to show families those things, it's really been about trying to build their capacity over video and by discussion. It has been quite a different mode of service delivery.' (Participant 11) 'OT for example, set up a hand-out that they handed out to patients around manual therapy, how to set yourself up for bimanual. What sort of toys you should have. How would we do the session?' (Participant 1) 'Clinicians spent a lot of time thinking about how they would do therapy via telehealth.' (Participant 1)
The benefits to using telehealth	'A lot of parents have said that they've really enjoyed the video interaction side of being able to perhaps have a call at slightly different hours or sometimes even out of hours.' (Participant 6) 'We got a lot of families that might not necessarily make it to clinic appointments being able to attend.' (Participant 3) 'They have actually preferred the telehealth than face-to-face because it helps them in relation to managing their work and managing the child's therapy.' (Participant 9) 'It meant there was some meetings where we got psychiatry, GP, urologists, all these people together in one spot that we would never have been able to get before.' (Participant 5) 'It actually allows you to look into their home life a lot more than it does when you bring them into the centre. So you see a lot more, you observe a lot more.' (Participant 1)
Limitations to the provision of telehealth	'Not having direct eyes and ears and not being able to correct them if there's something wrong therapy wise, having that completely online has been difficult.' (Participant 9) 'Very, very young children, you're never going to be able to get them to sit on the video for a therapy session and those sorts of things.' (Participant 11) 'Very complex children who, it's too difficult to try and manage and have any kind of conversation over that kind of media.' (Participant 10) 'It's actually incredibly difficult to have an interpreter online with a family online and clinician online to actually then make that work.' (Participant 7) 'Particularly for our families that are very articulate and very health literate, and that are well linked in, [telehealth] worked for in-between appointments, maybe. But it's a very different thing for some of our vulnerable families.' (Participant 2)

Table 1 Continued

Theme/subtheme	Participant quotes
3. Realising opportunities to enhance family-centred care.	'I think what it has done is allow us as a modern-day health service across Australia, to actually review what we do.' (Participant 1) 'I think our sense is it's brought about a real opportunity to think much more widely as an organization around trauma.' (Participant 6) 'I would like to see this as an opportunity to really maybe have a bit of a look at some key processes and see if we can make some teams stronger and more resilient as a result of this.' (Participant 2) 'It's also given us more confidence to go for some regional and remote opportunities. So…we're going to have another look at some regional and remote areas because we've developed great confidence in online therapy that we didn't have before.' (Participant 5) 'We've got no idea really what world we're coming into out of this. In terms of what has started as a health crisis, is now an economic crisis. And is potentially a social justice crisis, because the impact of this is going to be disproportionately on people who have less resources …. So, I think it's going to be hugely challenging.' (Participant 9)

explained, '*I just think that probably a lot of families are just so overwhelmed with just living day-to-day and just getting through the day with their children with very high needs at home, so they're really in survival mode*' (Participant 11).

Participants recognised that some families appreciated the additional time they could spend with their children. Online learning was considered beneficial for some children, and participants reported some families responded very positively to additional time at home, including gaining a greater understanding of their child's abilities. Participants also acknowledged families' resilience, suggesting the pandemic experience highlighted families' flexibility and strengths.

Subtheme 1: increased communication and engagement with families

Participants described communicating and 'checking-in' more frequently with families in response to the pandemic, allowing them to gain an improved sense of connection and understanding of family experiences. Both community-based and medical rehabilitation services described clinicians having increased and more flexible contacts with patients and their families via phone, text messages and FaceTime connection, when contact had previously been predominantly through in-person appointments and occasional phone contact when required. For some of the services, this increased contact was a way of providing emotional support to patients and their families. '*We tried to get re-engaged with our patients…and keep them engaged in the service and knowing that we were here to help*' (Participant 1).

Subtheme 2: impact to family-centred care and adapting service response in consideration of family needs

Services affirmed their commitment to providing family-centred care; however, usual delivery methods were impacted by the pandemic context. Participants explained that, in inpatient settings, standard processes around family-centred care were restricted, including limited visitor access, more complex discharge arrangements and physical distancing requirements for staff, all of which made it more difficult to support families and

provide care for patients. Participants explicitly described that '*there were lots of things we couldn't do that we would normally do to provide family-centred care. It was difficult. It was really difficult*' (Participant 2).

By contrast, there were mostly positive reflections on the level of engagement required from both staff and families while using telehealth, and the impact of this on provision of family-centred care. One participant explained that, in using telehealth, '*we had to think about how we really did engage with families a lot more*' and as a result, clinicians '*actually learnt, I think, how to be more family-centred in this process*' (Participant 1). The use of telehealth necessitated more considered engagement with families, as well as greater understanding of family experiences and needs, and this reinforced the family-centred focus of the interactions.

Services described telehealth as a practical means of maintaining connection with families, particularly during times of strict 'lock down' restrictions. The shared experience of learning and engaging virtually was considered helpful for building rapport between providers and families, potentially lessening the perceived power differential. Participants also commented that telehealth provided a useful insight into family's living circumstances, contributing to a greater sense of engagement, and drawing focus to their everyday lives and experiences. '*I think we do learn a bit more about their family functioning… just them being in their homes*' (Participant 2).

There were also examples of adjustments made to service delivery, within the scope of restrictions, aimed to support the changing needs of families. This included providing choice to families where possible about their preferred mode of service delivery (in person or via telehealth), identifying and proactively engaging with families who may be in a position of increased vulnerability, and reports of increasing well-being support, from staff who recognised the lack of peer-to-peer support available for families. Participants reported an increase in social worker and psychological referrals (in some cases extending these services to allow access by additional family members, such as siblings), to assist the whole family during this time.

Theme 2: impact of greater use of telehealth on care delivery

All participants commented on a reduction in face-to-face visits and the necessity to provide services for patients and families by phone or in a virtual capacity. Although the extent to which services adopted telehealth practices varied, it was uniformly recognised as one of the major changes to service provision that occurred because of the pandemic.

The ways in which staff adjusted to telehealth differed between disciplines and services. For example, while some services described '*more success online with our psychosocial cohorts*' (Participant 5), others explained that the '*clin-psych and social work and counselling adjustment is a real challenge*' (Participant 7). Likewise, the difficulty of providing physiotherapy remotely was highlighted by several services, with again a divergence of opinions on its feasibility and efficacy. While some found the practical nature of physical therapies difficult when not face to face, another explained that their staff felt that providing physiotherapy online was '*just the same and there's no problem*' (Participant 7). The impact of telehealth on multidisciplinary team functioning was also noted.

> We're a very multi-disciplinary team. When [the family] come in … they get the context of there's a physio, there's an OT, there's speech, there's dietician, there's social work, there's a doctor… When you're all online, I think that sense of team cohesion is a little bit different. (Participant 8)

Subtheme 1: the benefits to using telehealth

A primary advantage of telehealth was the increased convenience and ease for families to attend appointments remotely compared with being present in person. As one participant explained:

> I've even had families who live in…our suburb, saying how much easier it is for them to do a telehealth. It takes them two hours to get here by the time they've got the kids in the wheelchairs, and driven here, and parked, and got them out. (Participant 8)

In some cases, participants connected this increased convenience with improved attendance in therapy and a greater engagement from families. A virtual connection was also used to provide greater flexibility for different family members to participate in therapy sessions. As one participant described: '*I think it also then provided us a link with some of those families that don't always come to the appointments, because it's too hard to get them here*' (Participant 2).

Participants from the community-based services highlighted that it was easier to convene multiple health professionals in the one meeting using telehealth. They reported, '*It meant there was some meetings where we got psychiatry, GP, urologists, all these people together in one spot that we would never have been able to get before*' (Participant 5).

Subtheme 2: limitations to the provision of telehealth

Participants recognised there were also challenges associated with telehealth, for both families and staff. Unexpected technical difficulties, a lack of access to reliable internet and appropriate devices were factors described by participants as compromising the quality of their service provision and engagement with families. There was also consensus among participants that telehealth is not equally appropriate for all patient groups. Participants reported the successful use of telehealth was dependent on several variables, including the age of the child, the nature and complexity of their injury, their family situation and the type of appointment. For example, participants reported difficulty working with young children under the age of 12, who are less likely to engage over a virtual platform, providing physical therapy remotely and using interpreters online with families and clinicians.

Concern was also raised about the use of telehealth for families from vulnerable or disadvantaged backgrounds, regarding issues of equipment and internet access as well as the more distant nature of virtual communication. The complexities of assessing and responding to child and family safety were particularly concerning. As one participant commented:

> My personal concern about COVID-19 pandemics and telehealth, for some of those vulnerable families, I'm worried about domestic violence or abuse. I think you can hide behind telehealth. I have concerns about some of those families that are more vulnerable, if we don't have face-to-face you might not see some things that you probably do want to see. (Participant 8)

Participants spoke about the loss of in-person connection with patients and their families, and how communicating and building rapport virtually limited the dynamic of these interactions and relationships, particularly for new families without an existing connection to the service.

Theme 3: realising opportunities to enhance family-centred care

There was a shared recognition among participants of the sense of opportunity brought about by forced change to service provision. Many of the participants noted that the pandemic experience provided a unique opportunity to review and improve family-centred service provision for children with TBI and/or SCI and their families. This included the opportunity to adopt potential hybrid models of care and to expand the use of telehealth where appropriate.

Such sudden and universal change experienced by services provided an opportunity to review, reflect and learn. As one participant explained: '*I think what it has done is allow us as a modern-day health service across Australia, to actually review what we do*' (Participant 1). There was specific acknowledgement of broader opportunities for service improvement, particularly in the way mental health and well-being support is provided in the context

of family trauma. As one provider explained: '*It's brought about a real opportunity to think much more widely as an organization around trauma*' (Participant 6). There was also concern for the ongoing impact of the 'long tail' of the pandemic on vulnerable families.

> We've got no idea really what world we're coming into out of this. In terms of what has started as a health crisis, is now an economic crisis. And is potentially a social justice crisis, because the impact of this is going to be disproportionately on people who have less resources …. So, I think it's going to be hugely challenging. (Participant 10)

Realisation of these challenges and potential opportunities corresponded to a sense of action and direction for the future. There was an understanding from participants about the need to both respond to the learnings from this time and capture the momentum for change, with the hope that it could be used productively to enhance family-centred care into the future.

> COVID has really pushed people to… think differently and to be flexible and to be more understanding of the changing needs [of children and their families] that … potentially is going to make for a better service delivery, different, very different service delivery, but hopefully a better one. (Participant 7)

DISCUSSION

The three themes identified in this qualitative research project capture insights into the experience of paediatric rehabilitation services providing care to children and adolescents with TBI and/or SCI during the early stage of the COVID-19 pandemic. The themes also include recognition of and response to families' experiences, the impacts of the increased use of telehealth on family-centred care and a realisation of opportunities to enhance family-centred care for the future. Understanding the reflections of service providers during this time provides important insights into the changed nature of clinical practice, and the shifting perspectives in providing family-centred care in the longer term for children with TBI and/or SCI and their families.

There was a strong understanding and recognition from the rehabilitation service providers' perspectives about the increased challenges experienced by families caring for children with TBI and/or SCI during the pandemic. While not specific to TBI and/or SCI, reports from both Australia and internationally have captured the feelings of fear and increased vulnerability of children and young people with disability and their families more broadly throughout the pandemic.[8 18] Reduced access to community support services has been reported as a consequence of lockdowns, with one in three families experiencing cancellation of support workers (either by self or service) and other services during the initial months of the pandemic.[8] Participants in our study reported

a need to respond to reduced services and increased distress, emphasising efforts taken to invest more time and attention to 'checking in' with families and accordingly developed an increased understanding of the family's experiences and needs. Telehealth processes in part enabled more immediate and responsive interaction with families, and engagement was supported through increased and more flexible communication methods such as text messages, calls and FaceTime connections.

This increased communication and engagement with families was described by the key informants as facilitating a better understanding of family needs, potentially allowing services to be more family centred in their approach to service delivery. Other research has pointed to the emerging opportunities to enhance and refocus a family-centred approach as a result of the pandemic, and specifically the increased use of telehealth throughout the COVID-19 pandemic as a potential enabler to improve family-centred care.[11 19] While the challenges to achieving truly family-centred care remained constant to service experiences, the pandemic has shown: (1) the importance of communicating with families through regular, informal 'check-ins', allowing service providers to better understand family needs, and (2) the opportunity to offer families greater choice in the service delivery mode. Recognised as central components to providing a family-centred approach, finding ways in which these potential enhancements to family-centred care in the context of paediatric TBI and SCI rehabilitation can be maintained in the long term will be important.

The shift to the use of telehealth service delivery was a key theme of this study. Telehealth or the use of videoconferencing platforms or phone calls was implemented for processes such as intake referrals, assessments, interventions and child/family education. Recognition of the benefits and limitations across both traditional face-to-face and novel telehealth service models has been reported in a range of contexts since the onset of the pandemic.[19 20] While there were logistical challenges in implementing telehealth at such a rapid pace, service providers are now better prepared to adopt these processes more routinely, enabling greater choice and flexibility in the delivery of rehabilitation services in the future. The varied and complex nature of the healthcare needs of children and adolescents with TBI and/or SCI necessitates a diverse rehabilitation team, incorporating several disciplines, which span the continuum of care from hospital to community-based rehabilitation programmes. Strong interpersonal communication between health professionals, families and others is key to providing effective family-centred interdisciplinary rehabilitation. Due to their complex care needs, the capacity for greater use of telehealth to enhance rehabilitation for young people with TBI and/or SCI through better communication and teamwork is considerable.

Our findings also demonstrate that the use of telehealth has shifted the dynamic of interactions between patients, families and clinicians. For services traditionally

providing clinic-based appointments, telehealth offered a valuable insight into the everyday lives and experiences of patients and their families. Referencing the Australasian Faculty of Rehabilitation Medicine definition, we define paediatric rehabilitation as the diagnosis, assessment and management of young people living with a disability, and their families, to maximise their quality of life and participation. In considering the goals of rehabilitation as functional and real world based, the use of telehealth and shift towards understanding family experiences more broadly potentially allows for more authentic and realistic engagement than could be achieved in a clinic setting. A reflection on how rehabilitation services can achieve more person-centred and individualised care, through service delivered in manner that more closely reflects the real-world context, was noted to be a positive effect of the shift in service provision during the pandemic.

However, issues of access, familiarity with technology for patients and families, while previously appreciated, have been further highlighted as a result of the accelerated and widespread implementation. Particularly notable, from both our findings and other commentary, is a concern regarding the possibility for telehealth to introduce additional healthcare disparities among disadvantaged populations.[20] Consideration must also be given to the potential isolation associated with remote communication. While telehealth can be responsive to the needs of families around time and accessibility, we recognise there is a risk of isolating families from other families and their peer community, and, in turn, the incidental support that can occur across family groups. The benefits and limitations identified also point to the understanding from participants that more consideration of how telehealth can be used to its fullest capacity is needed, to maximise the benefits for patients and families.

Findings in relation to telehealth also highlight the need for a considered and personalised approach in adopting hybrid and alternative models of service delivery now and in the future. As Camden and Silva[19] outline, there is a range of factors, including logistical considerations, family and child attributes and service capabilities, to consider in determining the appropriateness of telehealth. It is important to individualise and tailor this decision to specific child and family needs so that the perspective of both the family and the providers can be considered when choosing the mode of service delivery. Ensuring families are provided a degree of choice as to how they will receive care is important. Given the complexities and range of considerations required for the rehabilitation of children with TBI and/or SCI, developing robust decision-making tools and processes to support implementation of hybrid models of care that best meet the needs of families is necessary. These considerations will be particularly important in the context of large interdisciplinary/multidisciplinary rehabilitation services.

Finally, the necessity to do things differently provided an opportunity for services to reflect on the potential for service improvement to better meet the needs of children with TBI/SCI and their families. Similar findings have been reported by Rosenbaum *et al*[21] who discussed the importance of seizing the opportunity for change, and not to go 'back to normal' in service delivery more generally for children with disabilities, but rather look at ways to be more efficient and effective in meeting the needs of families. The increased use and acceptance of telehealth and virtual communications, for example, could be used to improve linkage with external providers as a way to improve experiences for families at key transition times, such as throughout the discharge planning process, school transitions and transition to adulthood. Implementing changes in response to COVID-19 harnessed an energy to embrace opportunities for change in services for children and adolescents with TBI and/or SCI, potentially addressing existing barriers to family-centred practice.

Limitations and future research

There are limitations that should be considered in interpreting these findings. While participants nominated by each service were considered capable of providing a complete view of their service's model of care, there is potential bias in interviewing participants from managerial and leadership positions who may not be in a direct patient care role and may be reluctant to share negative experiences about their service response to the pandemic. Interviewing patients with TBI and/or SCI and their families was beyond the scope of this project; however, further research incorporating the perspectives of families is important in considering the acceptability and impact of such service changes more broadly.

It is also important to acknowledge the time and context in which interviews were conducted. While two international services were involved in this study, most participants represented services located in Australia. Given the ranging international response to the pandemic, and the relatively lower rate of infection experienced in Australia, we are mindful about generalising results to an international context. These findings are primarily reflective of services responding to lockdown circumstances rather than communities responding to widespread disease experiences.

It is also recognised that this work was conducted from June to September 2020, and as such captures a specific time frame in the pandemic response. In its conception and design, the study focuses on immediate and short-term service changes, rather than aiming to assess the impact of the COVID-19 pandemic over the longer term. We recognise that future considerations and some of the potential medium-term and longer term impacts of changes to service provision may be under-represented in our findings, potentially due to the point in time in which interviews were conducted. It is worth noting participant perspectives and reflections may also change over time. This potential limitation could be addressed with further research, re-engaging with services to consider the service

responses during subsequent phases of the pandemic response (eg, 12 months after vaccination).

CONCLUSION

Engaging with a range of service providers of rehabilitation programmes for young people with TBI and/or SCI, this project sought to examine the experiences of service providers during the early stages of the COVID-19 pandemic. Research findings highlighted that the need to do things differently provided key learnings that allowed services to adopt a more family-centred approach now and into the future. Potential improvements included better understanding of family needs and experiences, a focus on family well-being, more frequent 'check-ins' and providing greater family choice in mode of service delivery. Developing robust processes and protocols will be necessary to ensure the lessons of the crisis are recognised and adopted to improve care for children with TBI and/or SCI and their families into the future.

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REFERENCES

1 Sohrabi C, Alsafi Z, O'Neill N, *et al*. World health organization declares global emergency: a review of the 2019 novel coronavirus (COVID-19). *Int J Surg* 2020;76:71–6.
2 Remuzzi A. Remuzzi G: COVID-19 and Italy: what next? *The Lancet* 2020;395:1225–8.
3 Parodi SM, Liu VX. From containment to mitigation of COVID-19 in the US. *JAMA* 2020;323:1441–2.
4 Chintalapudi N, Battineni G, Amenta F. COVID-19 virus outbreak forecasting of registered and recovered cases after sixty day lockdown in Italy: a data driven model approach. *J Microbiol Immunol Infect* 2020;53:396–403.
5 Blakely T, Thompson J, Carvalho N, *et al*. The probability of the 6-week lockdown in Victoria (commencing 9 July 2020) achieving elimination of community transmission of SARS-CoV-2. *Med J Aust* 2020;213:349–51.
6 Botchway EN, Knight S, Muscara F, *et al*. Rehabilitation models of care for children and youth living with traumatic brain and/or spinal cord injuries: a focus on family-centred care, psychosocial wellbeing, and transitions. *Neuropsychol Rehabil* 2022;32:537–59.
7 Koterba CH, Baum KT, Hamner T, *et al*. COVID-19 issues related to pediatric neuropsychology and inpatient rehabilitation - challenges to usual care and solutions during the pandemic. *Clin Neuropsychol* 2020;34:1380–94.
8 Dickson H, Yates S. *More than isolated: the experience of children and young people with disability and their families during the COVID-19 pandemic*. Melbourne, 2020.
9 Coetzer R, Coetzer R, Bichard H, *et al*. The challenges and opportunities of delivering clinical neuropsychology services during the covid-19 crisis of 2020. *Panamerican Journal of Neuropsychology* 2020;14:29–34.
10 Cacioppo M, Bouvier S, Bailly R, *et al*. Emerging health challenges for children with physical disabilities and their parents during the COVID-19 pandemic: the echo French survey. *Ann Phys Rehabil Med* 2021;64:101429.
11 Rao PT. A paradigm shift in the delivery of physical therapy services for children with disabilities in the time of the COVID-19 pandemic. *Phys Ther* 2021;101:1–3.
12 Grumi S, Provenzi L, Gardani A, *et al*. Rehabilitation services lockdown during the COVID-19 emergency: the mental health response of caregivers of children with neurodevelopmental disabilities. *Disabil Rehabil* 2021;43:27–32.
13 Rossell SL, Neill E, Phillipou A, *et al*. An overview of current mental health in the general population of Australia during the COVID-19 pandemic: results from the COLLATE project. *Psychiatry Res* 2021;296:113660.
14 Alzueta E, Perrin P, Baker FC, *et al*. How the COVID-19 pandemic has changed our lives: a study of psychological correlates across 59 countries. *J Clin Psychol* 2021;77:556–70.
15 Jones B, Woolfenden S, Pengilly S, *et al*. COVID-19 pandemic: the impact on vulnerable children and young people in Australia. *J Paediatr Child Health* 2020;56:1851–5.
16 Oxford University Press. *Research methods in health : foundations for evidence-based practice (ed)*. Third edition. New York, NY: Oxford, 2017.

17 Braun V, Clarke V. Using thematic analysis in psychology. *Qual Res Psychol* 2006;3:77–101.

18 Provenzi L, Grumi S, Borgatti R. Alone with the kids: tele-medicine for children with special healthcare needs during COVID-19 emergency. *Front Psychol* 2020;11:2193.

19 Camden C, Silva M. *Pediatric Teleheath: opportunities created by the COVID-19 and suggestions to sustain its use to support families of children with disabilities*. 1. Great Britain, Informa Healthcare, 2021: pp 1.

20 Pritchard AE, Sweeney K, Salorio CF, Taylor & Francis. *Pediatric neuropsychological evaluation via telehealth: novel models of care*. 7-8. Netherlands, 2020: 1367.

21 Rosenbaum PL, Silva M, Camden C. Let's not go back to 'normal'! lessons from COVID-19 for professionals working in childhood disability. *Disabil Rehabil* 2021;43:1022–8.