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Exploring caregiver and participant experiences of the Program for the Education and Enrichment of Relational Skills (PEERS[®]) for youth with acquired brain injury and cerebral palsy

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ABSTRACT

Purpose: This study explored the experience of adolescents with brain injuries and their caregivers who participated in the Program for the Education and Enrichment of Relational Skills (PEERS[®]) in Australia.

Materials and methods: Twenty-seven adolescents and 31 caregivers, who completed the PEERS[®] intervention as part of an RCT, contributed to focus groups following the 14-week program. Semi-structured interviews guided focus groups. An interpretive description methodology was used to understand participants' experiences in the program and suggestions for improvements.

Results: Thematic analysis led to the development of five themes. "Challenging families and meeting expectations" explored the challenge and worth of participating. "Learnt new skills" highlighted skills and strategies gained and methods used to achieve these. "Connecting, belonging and understanding that's our normal" represented the value placed on the group experience. "Confidence in knowing and doing" reflected the changes in everyday social experiences and "Where to from here?" provided many suggestions for adaptation to improve practice.

Conclusion: After taking part in the PEERS[®] social skills group intervention, most adolescents with brain injury and their caregivers perceived improvement in their social participation and had suggestions for improving the group experience. Some adolescents didn't enjoy the program.

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Paediatric rehabilitation; acquired brain injury; cerebral palsy; social functioning; interpretive description



► IMPLICATIONS FOR REHABILITATION

- Offering adolescents with brain injury and their caregivers the opportunity to participate in a group social skills intervention is an important part of paediatric rehabilitation.
- Participants of group social skills interventions are likely to perceive improvements in their everyday social functioning following completion.
- Considering strategies to enhance engagement in the group is expected to be important for outcomes.
- Participants of group social skills programs may need additional support and adjustments to balance the demands of the intervention with other everyday family and school tasks and requirements.


Introduction

Cerebral Palsy (CP) includes a group of disorders of movement and posture as a result of a non-progressive brain injury to the developing foetal or infant brain [1]. Impairments in cognition, communication, sensation, perception, and behaviour also frequently accompany motor difficulties [1]. Acquired brain injury (ABI) describes damage to the brain occurring after birth and leading to difficulties with physical, cognitive, emotional, and behavioural functioning [2]. Youth with brain injury, whether

congenital or acquired, can struggle to make and keep friends [3,4]. Difficulties can be experienced in communication, cognition, and behaviour which impact social abilities, such as being able to initiate and maintain conversation, remembering and learning new skills, and regulating emotions [5,6]. Children with CP are more likely to have had reduced opportunities to interact socially with peers throughout their childhood [4] and youth with ABI may experience an interruption in their social development and peer network with problems reconnecting with friends following an injury or illness [7,8].

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Recently, two qualitative studies conducted following randomised controlled trials (RCTs) of group social skills interventions (GSSIs) [9,10] have revealed additional perceived intervention effects beyond the quantitative results. One of these studies was conducted with youth in Canada who had survived a brain tumour [9] and completed an 8 week Social Skills Intervention Program (SSKIP) and the other was with youth with Autism Spectrum Disorder (ASD) in Australia who had completed the 16-week KONTAKT intervention [10]. Youth discussed increased feelings of self-acceptance and social confidence, positive changes in social communication and interaction skills, reduced sadness, increased empathy, and enjoyment of the group experience. Caregivers noticed their children showed improved understanding of social cues and problem solving, enjoyment of the group experience, increased social confidence, social skills, and empathy, and reduced acting out behaviours. Insights into the degree to which increases in social awareness and social knowledge were transferred into real life situations were also revealed, highlighting the potential importance of qualitative research in understanding treatment outcomes.

The current study was conducted as part of the first RCT utilising the Program for Education and Enrichment of Relational Skills (PEERS[®]) [11] with youth with brain injury (both CP and ABI) in Australia [12]. PEERS[®] is a manualised, 14-week GSSI designed for 11–17-year-olds with ASD, developed in the United States of America (USA) [13]. It teaches social skills using behavioural rehearsal, role play, and group games to practise skills within sessions. A concurrent caregiver group facilitates social coaching skills and homework tasks with the aim of generalising skills to the adolescent's own home and community. With minor adaptation, PEERS[®] has demonstrated efficacy in improving the social competence of youth with ASD in different countries, including Israel, Korea, and Japan [14–16]. A pilot study of PEERS[®] with adolescents with Attention Deficit Hyperactivity Disorder (ADHD) revealed improved social knowledge, an increase in frequency of hosted get-togethers, and new, mutual friendships [17].

While differences in the social functioning of youth with ASD, ADHD and brain injury exist, many of the difficulties experienced by youth with ASD and ADHD can also present for youth with brain injuries. Examples of these include, difficulty understanding sarcasm and implied meanings in language [18], reduced social problem solving [19], and theory of mind skills [20]. A higher risk of co-occurring conditions, such as ASD and ADHD also exists for youth with CP and brain injury [21–23]. The overlap of social functioning difficulties between youth with ASD, ADHD, and brain injury as well as the promising research using PEERS[®] in different cultures and populations, led to the choice of PEERS[®] for our sample of adolescents with brain injury.

High school students aged 11–17 with a brain injury participated in this Australian RCT. Minor adaptation of the program included provision of memory cue cards to support new learning of social skills and small adjustments of language and references to social groups to reflect the Australian context. Quantitative results of the study did not reveal a between group difference in the primary outcome measure of caregiver rated social skills on the Social Skills Improvement System Rating Scale (SSIS-RS) [12]. However, adolescents in the intervention group made significant improvements in their social knowledge, measured on the Test of Adolescent Social Skill Knowledge (TASSK), which were retained at 3 months post-intervention [12]. Caregivers of adolescents in the intervention group also reported significantly improved social participation, measured by the Quality of Socialization Questionnaire,

with an increased number of invited get-togethers with friends three months after completing the program [12].

The current study sought to understand adolescents with brain injury and their caregivers' experience of participating in the PEERS[®] program in this Australian context. It also aimed to explore possible adaptations that might enhance the experience of participating in the intervention and potentially improve outcomes in social functioning for this population of adolescents.

Methods

Research design

This qualitative research study was guided by an interpretive description approach [24]. Interpretive description uses inductive reasoning to identify patterns and relationships, generating a conceptual understanding of an experience [24]. This understanding, combined with knowledge of relevant literature was used to look for ways to improve clinical practice [24]. In this study, the subjective experience of participants of the PEERS[®] intervention was explored with the aim of guiding future delivery of this intervention.

Participants and recruitment

The Friends Project was carried out in Brisbane and Sydney, Australia from August 2017 to December 2019. Participants were identified *via* research databases and paediatric rehabilitation unit databases in Brisbane and Sydney with potential participants contacted to inform them of the study. Interested adolescents and their caregivers, who met the inclusion criteria attended a screening interview. Included adolescents had a diagnosis of ABI (≥ 12 months post-injury) or CP, attended high school, were aged between 11 and 17 years, motivated to develop their social skills, and had a verbal IQ >70 scored on the WASI-II [12]. To be eligible for inclusion in the study, adolescents required parental reports of difficulties with social functioning. Adolescents and caregivers were required to verbally communicate in English and commit to attending the 14-week PEERS[®] intervention, including homework tasks. Thirty-six adolescents (ABI: ≥ 12 months post, $n=19$; CP, $n=17$; 17 females) were enrolled in the RCT, with four of the 36 identified as having the co-occurring condition of ASD, eight with ADHD, and five with epilepsy. See the results paper of the RCT for full details [12]. Of the 36 adolescents enrolled in the RCT, twenty-seven adolescents and their caregivers (25 mothers, six fathers), who completed the intervention either as part of the initial intervention group or waitlist group, participated in focus groups. See Table 1 for adolescent participant demographic information.

Procedure

Adolescent and caregiver focus groups were conducted separately at the conclusion of each 14-week PEERS[®] intervention. Six adolescent focus groups and six caregiver focus groups (each with between 2 and 6 participants) were held face-to-face, led by therapists and researchers not directly involved in delivering the group intervention. The potential sensitivity of the topic was highlighted in the participant information statement and participants could access support if required. Focus group facilitators were clinical/neuropsychologists, speech pathologists, occupational therapists, and social workers experienced in leading discussions concerning sensitive topics and facilitating responses to a guided interview. Participants were assured that the information they shared in focus groups would be de-identified during transcription. Adolescent focus groups

Table 1. Demographic and baseline social competence variables for focus group adolescent participants in PEERS® RCT.

| Variable | |
|---|--------------|
| Mean age, year (<i>SD</i>) | 14.0 (1.7) |
| School year, year (<i>SD</i>) | 8.7 (1.7) |
| Diagnosis, ABI, <i>n</i> (%) | 12 (44.4) |
| Diagnosis, CP, <i>n</i> (%) | 15 (55.6) |
| Male, <i>n</i> (%) | 14 (51.9) |
| IQ | 91.9 (16.8) |
| Co-occurring conditions, <i>n</i> (%) | |
| Autism spectrum disorder | 4 (5.0) |
| Attention-deficit/hyperactivity disorder | 6 (7.4) |
| Epilepsy | 4 (5.0) |
| Baseline caregiver rated SSIS-RS: social skills subscale standard score* | 87.4 (14.7) |
| Baseline caregiver rated SSIS-RS: problem behaviours subscale standard score* | 117.4 (11.6) |

SD: standard deviation; ABI: acquired brain injury; CP: cerebral palsy; SSIS-RS: Social Skills Improvement System Rating Scales.

*Standard score with mean of 100 and *SD* of 15 and higher scores indicating increasing frequency of behaviour.

ranged in length from 15 to 50 min and caregiver groups ranged from 35 to 55 min. A semi-structured interview schedule (see [Supplementary Material](#)) was developed to gain participant perspectives on their experience of taking part in the PEERS® intervention. Participants were asked about positive and negative experiences, their expectations, whether they noticed differences in their friendship skills after participating in the program, challenges in participating, and about potential changes that could be made to the PEERS® intervention. Similar interview questions were piloted in a previous study [25] with only slight adaptations made for the present study. Focus groups were audio-recorded and transcribed verbatim by the study co-ordinator.

Ethical approval was provided by the Medical Research Ethics Committee of The University of Queensland (2017000864), the Children's Health Queensland Hospital and Health Service Human Research Ethics Committee (HREC/17/QRCH/87), and the Cerebral Palsy Alliance Ethics Committee (20170802/HREC:EC00402). Written consent was obtained from caregivers and verbal assent was given by all adolescent participants. The trial was registered with the Australian New Zealand Clinical Trial Registry (ACTRN12617000723381). The authors report there are no competing interests to declare.

Data analysis

Focus group data were transcribed by one author (S.G.). Initially, the first author read all transcripts twice, listened to audio recordings, and consulted additional notes from focus group leaders to ensure immersion in the data. The second author read all transcripts. Thirty percent of the interview transcripts were independently coded, followed by a meeting to discuss developing themes. Analysis commenced with patterns and connections in the data being noted and discrepancies discussed. The first author then used NVivo 12 software to upload all transcripts and data was coded using constant comparative analysis [26] to develop themes. Initial coding was informed by knowledge of the literature [26] regarding families engaging with social skills programs. The initial coding was applied to segments of the text which were then assembled together, allowing connections to be made, and then progressing to interpretation [26]. Continued refining of themes occurred as the meaning of patterns and connections were interpreted, in consultation with the second author; guiding the final thematic template. Similarities and differences across and within participant experiences were considered during interpretation. Member checking was conducted, with a narrative summary of themes developed and sent to participants for feedback. The summary was designed to be engaging for youth and their caregivers and written in plain language. A young adult with lived

experience of cerebral palsy, who participated in the adolescent group as a social coach, reviewed it prior to it being sent out and had the opportunity to make suggestions. Caregivers were asked to share the summary with their adolescent and invited to provide feedback from themselves and their adolescent. Three caregivers responded (10%), confirming the summary as an accurate reflection of their recollection of focus group discussions.

In line with the interpretive description approach [24], the lead author used journaling to engage in regular, critical reflection throughout the process of delivering the intervention, analysing and interpreting focus group findings to ensure understanding of how their practice experience and knowledge may have influenced data analysis and interpretation. The first author has 13 years' experience in clinical occupational therapy practice with the target population, and has seven, first author peer-reviewed papers. She is a white, Anglo-Celtic Australian, and this research forms part of her doctoral studies. She grew up with a sister with a neurodevelopmental disability and this was not revealed to the participants of the study. The first author delivered the four caregiver groups which took place in Brisbane. The first author consciously sought to avoid bias when reviewing and interpreting focus group data based on her lived experience of growing up with a sister with a neurodevelopmental disability. This process was discussed with the second author to ensure the trustworthiness of the findings.

Results

Thematic analysis of data led to the construction of five central themes that represent an overall understanding of the experiences of adolescent and caregiver participants in PEERS®: (1) Challenging families and meeting expectations, (2) Learnt new skills, (3) Connecting, belonging and understanding "that's our normal," (4) Confidence in knowing and doing, and (5) Where to from here? Pseudonyms have been used for all participants in the study. See [Supplementary Table 1](#) for an example of thematic analysis. To protect the anonymity of participants, quotations were not included where there was any risk of identification due to a small number of participants with a particular characteristic or a combination of characteristics.

Challenging families and meeting expectations

Some adolescents and caregivers found the experience of participating in PEERS® challenging, however most but not all reflected on how it met their expectations by helping them develop (or support the development of) friendship skills.

While sometimes unsure, caregivers generally expected “something positive” (Mark, caregiver of 12-year-old female with ABI) to come from the program. Deborah (caregiver of 12-year-old male with ABI) explained, “I think it really met my expectations – yeah, a part about this group that was really attractive was that they were actually going to be role playing within a group. That was the part that was really attractive for us and that there was homework that we had to go off and do so that completely met my expectations.”

Not all caregivers, however, had anticipated how involved they would need to be and how hard some aspects of the program might be, for example, Rebecca (caregiver of 16-year-old female with CP) remarked, “I also wasn’t expecting to have my own sort of personal development as well and develop better skills in trying to listen to her or listen beyond the words if that makes sense. Try and hear what was not being said.”

Some adolescents loved the program. Phillip (15 years; CP), said, “I thought it was awesome ‘cause it helped us improved our social skills and it made me have a lot, a lot more friends as well.” William (12 years; CP), reflected, “I thought the PEERS® group was really good. It has really helped through some tough times and um, it is really helped me learn how to like keep a friendship because before I came into this I didn’t know how to keep a friendship but now I do.”

A small group of adolescents didn’t enjoy the program (five of 27), with another six finding some aspects challenging. “Well personally I really didn’t like it, like it at all and stuff... the program in general, just listening to them, just talk for like an hour and half and stuff... I’ve been trying to quit but my parents didn’t let me.” (Ben, 16 years; CP)

Fitting PEERS® into their daily life routines (school exams, homework, extracurricular activities, juggling other appointments) was challenging. Jessica (caregiver of 12-year-old male with CP) commented, “it’s been fine. It’s yeah, um, I mean life gets in the way, it has been difficult to get here sometimes as well as the distance and traffic involved in travelling to the venue.” Daniel (14 years; ABI) commented, “I was really hesitant to come during exam block but my mum made me do it anyway.” Another adolescent, Jonathan (16 years; CP), summed up the situation, “A good example - tomorrow I have a half yearly for geography and I still need to study except I would be doing it tonight but I can’t because I’m here. I’ve got to study on the way home.” With many, varied family schedules, the afternoon timing didn’t suit everyone, and a few caregivers and teens mentioned fatigue being an issue at that time of day. Leonie (caregiver of 17-year-old female with ABI) said, “Yeah, it was tough, the afternoons as well, because especially Caroline gets very tired in the afternoons, but she did alright, but you can’t do it any other time can you?”

Some caregivers were initially overwhelmed and described going through a realisation about how difficult it was for their adolescent to make friends and handle social challenges. “Probably the gaining of a better understanding of just where he is socially. I’ve been able to just sort of ignore it and just cruise along ‘til now but when you set the various task you shared the high of having the successful calls in the group, out of the group, come to get-togethers but then you also saw him hit the point where he was getting knockbacks and he came to a bit of a realisation of hey, maybe it isn’t cruisy.” (Matthew, caregiver of 15-year-old male with CP). Beth and Adam described how confronted their 16-year-old daughter, with CP, was and their plan to support her, “It was actually increased her level of stress because as she learnt more, then she realised that what she wasn’t doing.” (Adam) “It’s gonna be a

situation that we’ve gotta manage I think to a certain extent going forward and give her the right amount of support.” (Beth)

Learnt new skills

This theme discusses the skills participants learnt over the course of PEERS® and the methods used to learn and retain these skills.

Dealing with conflict, trading information, and recognising what a friend is were identified by caregivers as important skills for their teens to learn about and develop. Adolescents appreciated topics about conversations, bullying, handling teasing, and rumours. Xavier (12 years; ABI) commented, “learning new skills about how to manage bullying—I wouldn’t have learnt that if it weren’t for this program.” Adolescents didn’t like how the “changing your reputation” topic suggested they change themselves for others. Caroline (17 years; ABI) stated, “I didn’t really like how they were teaching you to change yourself – yeah. Didn’t really like that at all... ‘cause I felt like you shouldn’t really be teaching people to change yourselves for other people.”

Caregivers and some teens found that videos, role play, and games were enjoyable ways to learn and reinforce new strategies. “I liked how whenever we learnt something new at the end of the day, we would always do it in a role play and they would go step by step through it with us... It helped me feel more confident, a lot more confident.” (William, 12 years; CP). Alison (caregiver of 13-year-old female with ABI) discussed how these methods of delivery promoted learning for adolescents with a brain injury. “It was very interactive, um, some kids learn differently obviously, especially with the brain injury so that I found was really good because, um, she picked up on a lot more because of the, um, the memory of the role play or the memory of watching the videos which were quite entertaining themselves.”

Caregivers reflected on the idea of this program going through the basics step by step but how this is important, albeit difficult for their teen. “It did break all the steps down... into a set of rules that could be followed because he thrives under highly structured environments and he’s never understood, and it basically gave him a way to understand social setting that he’s never had before.” (Olivia, caregiver of 14-year-old male with ABI). Caregivers liked sharing the same language as their adolescents. Belinda (caregiver of 12-year-old female with ABI) commented, “we’ve got the common language when we try and talk to her about social situations” and Justin (caregiver of 12-year-old male with CP) liked the way the terms were repeated, such as “trading information, common ground, cover story.” Handouts were seen as a useful summary and resource. Caregivers thought the topics were useful and the length of the program necessary to allow for skill development. “There’s no shortcut. You need to give the children time to develop the skills. You just, you can’t rush them. Especially because at first they get really nervous, anxious so yeah, you couldn’t condense it and you have to have the commitment to do it.” (Isabelle, caregiver of 15-year-old female with CP).

Undertaking homework tasks had a mixed response but overall, most caregivers and adolescents thought the program “could have simplified it and dialled it down a bit.” (Daniel, 14 years; ABI) “I think for me, it’s the stress of organising, every week... because one week is not enough to do the organising and um, plus the kids are not always available so maybe fortnightly would work ‘cause it becomes stressful, once, you don’t enjoy it anymore because you become stressed of coming here and not being able to do the homework.” (Isabelle, caregiver of 15-year-old female with CP). Some caregivers thought the amount of homework was necessary to help generalise the in-group learning. Janet (caregiver of 17-

year-old male with CP) explained, *"I would have liked less homework, but I don't think it would have worked if you did not do the homework."* Homework was challenging, requiring the development of new skills to enable tasks to be completed. Dana (13 years; ABI) stated, *"I didn't know how to ask for somebody's number since I've never done that, so it took a long time to do that and to actually succeed with getting that homework done."* William (12 years; CP) reflected, *"The one that helped me the most was the phone calls, because I knew nothing about making a phone call,"* whereas Evelyn (12 years; CP) explained, *"I learnt that it's painfully awkward to be forced to call someone."* Caregivers thought learning how to make phone calls was a good skill, not just for talking to friends but for the workplace later.

Connecting, belonging, and understanding "that's our normal"

Most adolescents and caregivers recognised the similar experiences of others, feeling a sense of belonging within the group.

Caregivers valued the acceptance and connection with other caregivers. Alexandra (caregiver of 13-year-old female with ABI) described the recognition of others facing similar struggles as *"that's our normal."* Adolescents and caregivers valued meeting people with shared experiences. *"He was absolutely over the moon, he loved the fact that there were other kids like him and he walked away from the first few sessions going, Mum, they're like me! They've got the same issues and the same things that I deal with."* (Anne, caregiver of 14-year-old male with CP).

Both caregivers and adolescents found the rule of no socialising with other group members until after the group was completed, restrictive. *"It was a huge barrier for him... so that information was something that put him on the outer and that made him quite reserved in his interactions and ways... I think I struggled with it a bit too 'cause I thought ok, I can't be all in- I need to be just a bit because we're not allowed to bond."* (Bella, caregiver of 12-year-old male with ABI). Caregivers of adolescents who hadn't been able to successfully organise homework get-togethers in the timeframe commented that *"it would be a possibility if we did an in-group get-together."* (Natalie, caregiver of 12-year-old male with CP). Some caregivers reflected on the missed opportunity to connect with other caregivers during the group program. *"I think it would have been a great idea to have catch ups and I think it would have been nice for the parents too to have a bit more emotional support in the background, so that the kids could have gone and had an activity outside and we could have had a cup of coffee, and you know it's ok and support each other too."* (Dana, caregiver of 13-year-old female with ABI).

Confidence in knowing and doing

Adolescents and caregivers reflected on a developing confidence in knowing what to do and how to behave in social situations.

Caregivers noticed their adolescents grew in confidence in making phone calls, handling teasing, understanding what makes a good friend, having conversations, and organising and hosting get-togethers with friends. Olivia (caregiver of 14-year-old male with ABI) remarked, *"Now I can honestly say he has his tribe at school, he has his group of friends, they are stable, solid, they have common interests. He's having, you know, outings and the conversations and chats, catch-ups with them. It's been transformative."* Janet (caregiver of 17-year-old male with CP) reported, *"My mother-in-law said that she noticed a big change when, because David used to just go yeah, no, you know, walk away on the phone. Where he now actually holds a conversation then uses a cover story*

to leave." Caregivers found strategies to coach their adolescent in preparation for social situations useful for both their adolescent as well as siblings.

Some adolescents found the lessons helped them understand what to do in social situations. *"My friends are treating me different because before I was, I was just like I don't know what to do, so I'd just stand back and I'd let all my friends do all the talking and I would just listen, but now that I know how to exit and enter a conversation like, like um yeah, stuff like that. It's a lot easier."* (William, 12 years; CP). Heath (15 years; CP) also described changes in friendships. *"I feel like this is like benefit, benefitted me more than anything but um because um I feel like I'm more open, like to talk to people I don't know like, for example some of my friends that I don't normally talk to, I feel like I'm more open to talk to them."* Cathy (15 years; CP) discussed her increasing confidence in organising social get-togethers with friends, *"I think once I started this group, um, then I got more confident in organising get-togethers than before I didn't, like before this group even started."*

While some adolescents noticed these changes, others thought not much had changed for them. *"I'm still having difficulty implementing the early things we've learnt. But that's me personally because I'm an introverted child. I just, I find it difficult to step outside that zone... I really like, I have the skills, I know how to do it, but it doesn't feel good to do it, it makes me feel anxious and I just don't want to do it."* (Lucinda, 15 years; CP)

Where to from here?

This theme encompasses the many suggestions adolescents and caregivers had for the future use of PEERS®.

Caregivers, generally, talked about PEERS® being a positive experience with Natalie (caregiver of Xavier, aged 12; ABI) commenting, *"I never had any trouble getting Xavier here, like it was obviously very enjoyable what they're doing in there, 'cause he never complained about coming."* Caregivers and adolescents shared numerous ideas for developing the content of the program further. Updating the material on technology to include communicating through text messages and managing online friendships and bullying were suggested. A few caregivers suggested adding a session on romantic relationships and offering booster sessions after the group had finished. *"This is where you finish and you go off into the world, but I think if you just had a couple of sessions where you could come back and say, hey this is really working for us, this much further down the line, rather than just we're finished the group and now it's gone."* (Sally, caregiver of 12-year-old male with CP).

Some adolescents appreciated the length of the program. Dana (13 years; ABI) stated, *"I reckon it wasn't too long or too short, 'cause I can actually remember all the stuff, like at school they just went another topic, and it's really confusing. But here I can remember all the topics."* Zane (12 years; ABI), on the other hand, thought that the program was *"too long... I reckon it should be done in about nine weeks."*

Caregivers suggested increasing the variety in actors in the video role plays, changing American terminology to Australian references in the handouts and giving individual feedback on adolescent's progress with skills. Natalie (caregiver of 12-year-old male with CP) wanted *"open, honest feedback that you know that they're really lacking in this skill."* She also wanted to know *"how far they've (group leaders) seen them come from the beginning to the end."* Caregivers suggested having an overview of all the program content and homework at the start of the group to help

plan their time. They also wanted sheets and information provided electronically if a session was missed.

A booklet for adolescents to keep track of PEERS[®] homework was suggested. Caregivers and adolescents wanted to have get-togethers within the group and make friends during the program, especially those just starting high school and struggling to get contact details from others at school. *“The one thing I did find frustrating was having to try to find a play date from school, because a lot of them had just started high school, year 7, um, it would have been good if we could somehow, I think, if we had of been able to do playdates within the group.”* (Natalie, caregiver of 12-year-old male with CP). If within group get-togethers were allowed, Jasmine (13 years; CP) had an idea for how a group leader might address any fallouts and problem solve difficulties between friends in the group, *“What I suggest is that people could bring up their, um, concerns, obviously not in front of everyone, tell the facilitator beforehand and then the facilitator could just privately touch and how to deal with that issue.”*

Discussion

This study reveals important insights about the experience of participating in PEERS[®] for adolescents with brain injury and their caregivers in Australia. The information provided goes beyond the quantitative outcomes of the RCT, identifying a number of areas to consider adapting for future research and clinical practice to increase the acceptability and feasibility of the intervention. Adolescent and caregiver participants valued the need for the intervention to allow personal connection and support as well as increase social functioning. While the majority of adolescents enjoyed the program and valued the experience, the mixed experience of the program is acknowledged and highlights the importance of the intervention being meaningful and enjoyable within itself to promote engagement throughout the intervention. Varied experiences in the translation of learned skills into an adolescent's own community also raise questions about how best to support the transfer of knowledge and skills related to participation.

A key finding in our study was the sense of connection adolescent and caregiver participants felt with others group members. For many, it was their first opportunity to meet other adolescents with brain injury and they reflected on their desire to develop friendships and support with others facing similar challenges. They discussed the potential for friendships to extend beyond the timeframe of the group. The PEERS[®] intervention emphasises that friendships between group members should wait until group completion due to the risk of friendships affecting group functioning. Our findings offer a different lens for viewing this issue, with some participants discussing how this “rule” of the group held them back from connecting with others. The intent of this rule in the PEERS program is that skills are generalised outside the group setting, however, the importance of connecting with others and belonging with a group is documented in other qualitative research exploring the experience of youth participating in group social skill interventions [9,10]. Adolescence is recognised as a period of increased growth and learning, with intense change in social situations and social responsibilities, and adolescents' particularly sensitive to belonging and feeling valued [27]. Therapists delivering future PEERS[®] groups for youth with brain injury might consider and plan how much they emphasise this rule and if a change in the program was considered, a planned approach to managing conflicts would need to be developed.

While the majority of adolescents enjoyed and valued the program, the mixed experience is acknowledged and perhaps is explained by a mismatch between expectations and what it was like to participate in the program. Group interventions present challenges in engaging and maintaining motivation in a diverse group of adolescents, with different preferences and personalities. For those adolescents who reflected negatively on the experience, the importance of the intervention being meaningful and enjoyable is highlighted to promote engagement throughout the intervention.

Many opportunities exist for facilitators to support individual adolescent engagement and motivation while delivering PEERS[®] to youth with brain injury. Of the adolescents who found aspects of the program challenging, the explicit teaching component of the program, including homework was often discussed, and yet explicit teaching has been identified as an important element in achieving improvements in social functioning [28]. While most adolescents and caregivers expressed enjoyment of the intervention with many adolescents looking forward to attending the group each week, adolescents who didn't enjoy the program expected the program to be more fun and have less repetition. Caregivers reflected on how challenging their adolescent found the homework practice. Similar views were expressed by participants with ASD in the KONTAKT study [29]. These voices speak to the challenge for facilitators to ensure adolescent motivation before the commencement of the intervention and support engagement throughout. In the current study, a mismatch between some adolescents' expectations and their experience was evident, despite an initial interview explaining the nature of the group and confirming each adolescent's willingness to attend. It is understandable that individual motivation may wane when confronted by difficulties in mastering homework tasks, facing challenges fitting the intervention into daily life, or discovering that the program had fewer games than expected.

Paediatric rehabilitation research and best-practice emphasises the importance of understanding how to support engagement in therapy [30]. Specific ideas voiced by adolescents from the focus groups included more chances to move, more games, and less repetition. Participants, caregivers, and trainers in the KONTAKT study suggested individualising homework and goals, increasing choice, and introducing more games Australian adolescents would typically play [29]. The KONTAKT group also has an informal snack time in the middle of the group. A combination of techniques to enhance individual choice, ensure the intervention is a high priority for adolescents, increase movement opportunities, fun and flexibility while maintaining enough structure to allow for explicit teaching of social rules may support an adolescent's motivation and engagement in the group. Individual goal setting has been used in clinical trials focused on increasing participation with youth with CP [31] and ABI [32] to establish and prioritise goals, enhance motivation for goal achievement, and measure change. PEERS[®] allows for individual check-ins between sessions, which can be used to problem solve with adolescents and their caregivers regarding individual social concerns and potential solutions. This capacity for individualisation of the group intervention, along with the addition of individual goal setting may be useful strategies to ensure the intervention is in line with individual goals and supports engagement in the intervention.

A participation focus is recommended in paediatric rehabilitation with coaching of caregivers, practise of desired behaviours, and use of multiple strategies to achieve change in natural learning environments considered important [33,34]. Translating skills into the community environment to increase social participation

is a key aim of PEERS® [35]. Behavioural rehearsal and role play within sessions provides a safe space to learn and practise social skills. Homework tasks support transference of skills to community environments with group discussion time at the start of each session designated to problem solving issues encountered during community practice. Concurrent caregiver sessions are used to facilitate caregiver social coaching skills and ability to provide opportunities for social participation, for example, discussing the caregiver role in supporting get-togethers with peers with similar interests. Providing caregivers with support is aimed at embedding the learning in a more naturalist context. Caregivers can use strategies to assist their adolescent to practise skills within their family, in preparation for gatherings with friends, and as a problem-solving partner for social experiences at school. The addition of establishing individual, ecologically based goals in the lives of young people prior to the group could also help an adolescent and caregiver break down barriers to participation in the community. Supplementing the group program with the addition of an individual problem-solving session with a therapist could further support the transitioning of skills. Caregivers in this study also suggested providing “booster sessions” to continue problem solving following group completion and providing feedback to caregivers about their individual adolescent’s progress during the group to allow them to target their social coaching. A booklet for adolescents to record homework in was suggested. The purpose of the booklet was to support memory, enabling group discussion at the following session and supporting participation.

The explicit learning approaches used in PEERS® and other GSSIs are grounded in cognitive behavioural therapy and evidence based for youth with ASD [11,36,37] with emerging evidence for youth with brain injury [38]. Within these programs, fun practising of skills in games or at informal snack times are included, which offer implicit learning opportunities. PEERS® and other similar programs are designed for adolescents who are motivated to attend the program. Motivation ebbs and flows throughout a group, as different challenges are faced. Caregivers in this study valued the use of the explicit learning approaches for their adolescents with brain injury. They voiced support for the step-by-step teaching of skills and practise through role play and behavioural rehearsal. Many adolescents expressed opinions related to increasing the fun and connection with others. Exploring options in future research to increase the implicit learning opportunities that are paired with explicit behavioural approaches may enhance adolescent engagement, acting as a buffer through changes in motivation levels during the group [10].

Strengths and limitations

The data from this study is gathered from a group of adolescents with acquired or congenital brain injuries located in urban only settings in Brisbane and Sydney, Australia. Adaptation of the program is likely to be required for adolescents in more remote parts of Australia, where distance influences how adolescents socialise. If Aboriginal and Torres Strait Island people were interested in participating in a PEERS® group, researchers or clinicians would need to review content with families to check its’ cultural suitability and safety, as well as identify adjustments that need to be made. A decision was made to gather data through focus groups rather than an individual interview format. The hope was that participants would feel comfortable sharing their experiences, given their familiarity with each other after participating in the 14-week intervention. There is potential that some caregiver and

adolescent participants in this study may have felt more comfortable sharing their experiences in an individual interview instead. Some adolescents with challenges with language may have also had difficulty expressing their thoughts and ideas about their experience. Additionally, the language used in the focus group interview guide could explore other elements of social abilities alongside discussion of friendships.

To maximise the trustworthiness of the data, the first author reflected on her position in the research and how this could affect interpretation. Particular attention was given to acknowledging the first author’s experience of delivering the caregiver group in the program and inherent wish for the group to be a positive experience with desired increases in social participation for adolescents and their caregivers. The first and second author aimed for a position of “empathetic neutrality” [39], understanding and accepting that this can never be fully achieved. In this context, themes were critically analysed, ensuring appropriate weight was given to preliminary themes. The analysis was discussed with the second author and followed a member checking process of result summaries with participants. Ten percent of caregivers responded to the narrative summary provided, which although not uncommon [40], may be considered as a limitation.

Conclusion

Understanding participants’ experiences in GSSIs is an essential step in determining how these interventions may be generalised beyond autistic youth to enhance social functioning and social participation of youth with brain injury. Participants in this study valued a sense of personal connection with other group participants with similar experiences. The importance of the intervention being meaningful and enjoyable was highlighted with a need to appeal to a group of adolescents, who had some similar life experiences, yet were also exploring their identity, with different preferences and opinions. This was highlighted by the small group of participants who didn’t enjoy being involved in the intervention.

Many ideas for improving the program were raised by participants, including updating the technology section of the intervention, increasing the variety of role play videos, providing individual feedback to caregivers regarding their adolescent’s progress, giving a written overview of the intervention and homework tasks at the start of the group and a booklet for adolescents to record homework. Both caregivers and adolescents also discussed the possibility of within group get-togethers, acknowledging planning for difficulties would need to be considered. Suggestions for strategies to maximise engagement when transferring skills from knowledge and practice in the group intervention to the community setting were explored in recognition of how crucial this process is to achieve individual everyday social functioning and social participation goals.

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