Transitioning between paediatric and adult healthcare services: a qualitative study of the experiences of young people with spinal cord injuries and parents/caregivers

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ABSTRACT

Objectives Healthcare transition (HCT) interventions are pivotal to paediatric rehabilitation. However, there has been limited research focusing on HCT in young people with spinal cord injury (SCI). To date, little has been reported on key factors that may contribute to a positive or negative transition experience and what, if any, are the gaps in the transition process. This study explored the experiences of transition from paediatric to adult healthcare for young people with SCI and parents/caregivers in pursuit of co-designing and developing an intervention to support transition.

Design, setting and participants This qualitative study forms part of the planning phase of a larger participatory action research project. It supports obtaining a rich understanding of the phenomenon and the issues and actions necessary to achieve change. Semi-structured individual interviews were conducted online between April and June 2021 with young people with SCI and parents/caregivers who had transitioned or were preparing for the transition from paediatric to adult healthcare in NSW, Australia. The interviews were analysed using an inductive reflexive thematic analysis approach.

Results The study recruited nine participants, five young people with SCI and four parents/caregivers. The interviews provided invaluable insight into young people with SCI and their parents/caregivers’ experiences of HCT. As HCT experiences were often less than optimal and needs were not adequately met, some recommendations were offered. These included a coordinated and streamlined handover from paediatric to adult healthcare providers, and a ‘one-stop shop’ for young people with SCI and their parents/caregivers to access transition information, such as how it occurs, who to call for ongoing support and advice, and tips on how to transition successfully.

Conclusion Providing a coordinated and streamlined handover process as well as access to more context-related information could improve the transition experiences of young people with SCI and parents/caregivers, resulting in improved health outcomes and greater independence.

STRENGTHS AND LIMITATIONS OF THIS STUDY

⇒ The use of in-depth, qualitative interviews elicited rich data that adds to the limited research on healthcare transition (HCT) for young people with spinal cord injury.
⇒ Using participatory action research methodology gave voice to young people with disabilities and led to the co-design of an HCT intervention.
⇒ Recruitment was impacted by the COVID-19 pandemic.
⇒ The small sample size potentially limits the generalisability of the findings.

INTRODUCTION

Acquiring a spinal cord injury (SCI) as a child or adolescent has a significant impact on the affected individual and their family. The resultant impaired mobility, loss of sensation, dysfunction of the bladder and bowel as well as sexual and autonomic systems dramatically changes the individual’s physical abilities and functioning, and increases the risk of secondary health complications.1,2 These changes can increase the child or adolescent’s reliance on their family and disrupt the achievement of key developmental tasks such as identity formation, the development of intimate relationships and the accomplishment of formal educational and independent living goals.3 Consequently, when compared with their peers, adults with paediatric-onset SCI are less likely to be employed, live independently and be satisfied with their lives.4-7 While many factors influence the success of outcomes in the above areas, medical complications have been found to be predictive of lower success.8 Supporting the transition between paediatric to adult healthcare services, through age-appropriate services...
and routine health screening, may minimise the occurrence of medical complications and facilitate successful outcomes for adults with paediatric-onset SCI.

Healthcare transition (HCT) is a well-researched area of paediatric rehabilitation with the development of several national and international statements and guidelines. Generally, these guidelines suggest that the overarching principles for a successful HCT should include a young adult-centred, strength-based approach; emphasise self-determination, self-management and family/caregiver engagement; be flexible to address the unique needs and circumstances of each individual and their family; start early and be implemented gradually; facilitate autonomy and personal responsibility for health decisions; and stress the importance of communication and coordination of care between paediatric and adult healthcare settings.

Yet, despite these statements guiding policy and programme development in the transition of young people from paediatric to adult healthcare, young people continue to report inconsistencies in care, issues with poor treatment and medication adherence, and poor health and well-being due to a lack of structured HCT interventions. Possible reasons for these self-reported adverse outcomes include disjointed transfers and a lack of communication between paediatric and adult healthcare settings, inadequate preparation and support, and difficulty adjusting to the new environment.

Furthermore, research suggests parents/caregivers also find transition difficult due to a lack of information and preparation, as well as changing roles and responsibilities for both them and their child. Research has explored the overall transition of young people with SCI to adulthood, with some describing the central areas of transition within the framework of emerging adulthood, current rehabilitation models of care and programmes in Australia and globally, and current practice and/or challenges faced in implementing a successful transition model. While Porto and colleagues explored the experience of young people with SCI and parents/caregivers transitioning into adulthood, they did not fully explore the experience of young people with SCI and parents/caregivers transitioning between the paediatric and adult healthcare setting, what factors may contribute to a positive or negative experience and what, if any, are the gaps in the HCT process. This qualitative study is the first that aimed to build on current literature by providing young people and parents/caregivers a platform to voice their needs, advocate for change and collaborate in pursuit of co-designing and developing an intervention to support HCT.

**METHODS**

This study informs a larger project that aims to co-develop, implement and evaluate an HCT intervention to support young people with SCI during their transition from paediatric to adult healthcare services in New South Wales (NSW), a state within Australia. More details on what this transition process looks like for young people with SCI in NSW can be found in an evidence series published by the Agency for Clinical Innovation. Few studies have outlined the process, barriers and facilitators to co-designing HCT interventions with young people with chronic conditions and disabilities, yet HCT interventions designed with young people are both feasible and acceptable. Gathering information on the experience of HCT for young people with SCI will inform the co-development of future HCT interventions.

**Methodological approach and design**

When planning and conducting research with vulnerable groups, such as children with disabilities, it is vital to give prominence to their voice in the research design and process rather than them being the objects of research. Both the disability and children’s rights movements have emphasised the concept of children and people with disabilities as social actors and experts in their own lives, with their own unique needs, rights and ideas. These movements have driven the view that children and people with disabilities should be active participants in decisions that affect their lives both in policy and practice, a sentiment articulated in Article 7 of the Convention on the Rights of Persons with Disabilities (UNCRPD) and Article 12 of the Convention on the Rights of the Child (UNCRC).

In line with both Article 7 of the UNCRPD and Article 12 of the UNCRC, the larger project in which this study is embedded is informed by participatory action research (PAR) methodology. Involving individuals in the PAR process of collaborative, self-reflective inquiry and action provides opportunities for individuals to express views on matters pertaining to them and to take action to improve the situations in which those involved in the research process find themselves. In the case of public health research, PAR aims to improve health outcomes and reduce health inequalities. As part of the PAR approach, collaboration, participation and reflection occur through iterative cycles of ‘planning, acting and review’. This qualitative study forms part of the planning phase of PAR and supports obtaining a rich understanding of the phenomenon, and the issues and actions necessary to achieve change from an emic perspective. This approach centralises the voices of young people with SCI and parents/caregivers and captures their unique experiences of transition.

**Theoretical approach**

This study is informed in its thematic data analysis by the principles of critical disability theory (CDT). CDT prioritises the voices of people with disabilities and relies on their opinions to challenge ableist assumptions so that people with disabilities are fully integrated into their communities and can be equal participants in society. CDT serves as a lens to examine transition experiences and needs, by respecting their voice and ensuring the rights of children with disabilities are recognised.
Due to variations in reporting methods, data collection systems and injury classification, the exact incidence of paediatric-onset SCI is unknown. However, it has been reported that globally the population of paediatric-onset SCI represents under 4% of the overall incidence of SCI annually, indicating that the incidence of paediatric-onset SCI is rare. In Australia, New and colleagues reported the prevalence of traumatic and non-traumatic SCI for children younger than 15 years. They estimated the prevalence rate of traumatic SCI to be 17–86 per million population in Australia in 2011. Non-traumatic SCI was only estimated for one state of Australia (Victoria) and this indicated a prevalence rate of 6 per million population in 2010. Considering the limited number of paediatric-onset SCI in Australia, participants were recruited from both metropolitan (n=8) and rural (n=1) areas of NSW, Australia.

Despite the low prevalence of paediatric-onset SCI, it is a complex and a life changing condition with wide implications for healthcare. In the USA, a conservative estimated lifetime cost for a 10-year old with an SCI is US $2.5 million to US $6 million depending on the severity of the SCI. Paediatric-onset SCI not only places a strain on society but it also affects the physical, psychological and emotional development of the young person and the daily life of their families.

Recruitment and participants
Non-probability sampling, using a combination of purposive, convenience and snowball techniques, were used to recruit participants (see Bray et al. for full details). The inclusion criteria were that the individual be either a young person aged between 14 and 25 years who had acquired a paediatric-onset SCI (16 years or younger) or parents/caregivers of young people with a paediatric-onset SCI. They also must be preparing for or had made the transition to adult healthcare services. The exclusion criterion was individuals who were receiving rehabilitation in a tertiary children’s hospital for an SCI acquired in the last 12 months and who were not fluent in the English language.

The study recruited nine participants, five young people with SCI and four parents/caregivers. As four of the participants were parent–child pairs, the transition experiences of seven young people were discussed. Four of these young people had already transitioned, one was currently transitioning and two were pre-transition. Please see table 1 for more details on participants, including transition status and parent–child pairs. The young people discussed in the interviews ranged in age from 15 to 21 years and on average had been injured for 7.4 years (±5.8 SD). The majority were woman (57%) and had tetraplegia (71%). All parents/caregivers were mothers. While the sample may not be representative of the entire population of young people with SCI, data saturation was reached at the sixth interview. Three further interviews confirmed no new information or concepts related to the study aims. This conclusion was determined by achievement of theoretical data saturation (interpretative judgement by the researchers) and pragmatic considerations due to the size of the population under investigation.

Data collection
Four interview guides were created for the different participant groups: young people pre-transition and post-transition and parents/caregivers pre-transition.
and post-transition (online supplemental file 1). Prior to the commencement of the semi-structured interviews, a reference group including paediatric SCI healthcare service providers and young people with SCI reviewed and provided feedback on the initial interview guides. The interview guides were then pilot tested with the first two participants; no amendments to the guides were deemed necessary for the remaining interviews. All interviews were included in the final analysis.

Participants were provided with the main interview questions a week prior to their interview to prepare them for the discussion. The first author (EAB) and another member of the research team (LR) then conducted in-depth, individual, semi-structured interviews at a time convenient to each participant. Two young people with SCI had a disability support worker present during the interview and one of these participants also had a parent nearby. The participants were encouraged to describe how they were preparing for or how they transitioned using specific examples. The questions focused on factors that influence the transition and recommendations they may have to enhance the transition experience.

The interviews took place between April and June 2021, lasted between 40 and 60 min and were conducted via video-conferencing software (Zoom). All interviews were audio-recorded and transcribed verbatim through Zoom and checked for accuracy by EAB and a research assistant.

**Data analysis**

In line with CDT, an inductive reflexive thematic analysis approach, as described by Braun and Clarke,46 was employed to generate major themes and subthemes. ‘Inductive analysis is a process of coding the data without trying to fit it into a pre-existing coding frame or the researcher’s analytic preconceptions. In this sense, this form of thematic analysis is data-driven’.47 This style of analysis involves a six-step process:

*Familiarisation:* EAB and LR independently immersed themselves in the data and engaged in listening to the audio-recordings, reading the transcripts multiple times and making notes.

*Code generation:* EAB and LR identified initial inductive codes starting the analytic process from the data, identifying patterns and organising the data into meaningful sets.

*Constructing themes:* Researcher and participant collaboration in an online co-design workshop, approximately 2–5 months after their interview, confirmed, refined codes and constructed preliminary themes and subthemes that told a rich story and provided a nuanced understanding of the central concepts. Details on this process can be found in a previously published article.48

*Reviewing themes:* The entire research team came together to review themes and subthemes to ensure they captured the essence of the data and related to the research aims.

*Defining and naming themes:* Theme and subtheme names were further refined until consensus was reached among the research team.

*Reporting:* This article reports on the alignment between the data and the research aim.

**Ethics**

Participation in the study was voluntary. Both written and verbal consent was obtained from all participants. Transcripts were de-identified and participants were assigned a pseudonym to maintain confidentiality. A distress management plan was in place and support services were identified in the participant information sheet, which was highlighted to participants at the beginning of the interview. Participants received a gift voucher (AUD $20) as a token of appreciation for their time and insights.

**Rigour and reflexivity**

Trustworthiness of the data was enhanced through paraphrasing and iterative questioning during the interviews. Participants confirmed the authenticity of the generated codes and themes in the online co-design workshop (credibility and reflexivity).49 This co-design workshop occurred at a later date and is not part of the research reported in this article. Participants were also emailed a summary and an unabridged version of the results, with opportunity to correct any misinterpretation (none did so) (credibility).50 The multiple coders for identifying themes/subthemes improved the rigour of the analysis for this study (credibility).50 Verbatim quotes from the data support the contextualisation of interpretations.

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**Table 1** Study participants

<table>
<thead>
<tr>
<th>Young person ID</th>
<th>Parent/ caregiver ID</th>
<th>ID for young person discussed but who did not participate</th>
<th>Age of YP (years)</th>
<th>Time since injury (years)</th>
<th>Paraplegia or quadriplegia</th>
<th>Transition status</th>
</tr>
</thead>
<tbody>
<tr>
<td>YP 1</td>
<td>–</td>
<td>YP 2</td>
<td>20</td>
<td>13</td>
<td>Quadriplegia</td>
<td>Post-transition</td>
</tr>
<tr>
<td>YP 2</td>
<td>–</td>
<td>YP 3</td>
<td>17</td>
<td>6</td>
<td>Paraplegia</td>
<td>Pre-transition</td>
</tr>
<tr>
<td>YP 3</td>
<td>P/C 3</td>
<td>YP 4</td>
<td>19</td>
<td>5</td>
<td>Quadriplegia</td>
<td>Post-transition</td>
</tr>
<tr>
<td>YP 4</td>
<td>P/C 2</td>
<td>YP 5</td>
<td>21</td>
<td>18</td>
<td>Quadriplegia</td>
<td>Post-transition</td>
</tr>
<tr>
<td>YP 5</td>
<td>–</td>
<td>YP 6</td>
<td>20</td>
<td>4</td>
<td>Quadriplegia</td>
<td>Post-transition</td>
</tr>
<tr>
<td>P/C 1</td>
<td>YP 6</td>
<td>YP 7</td>
<td>18</td>
<td>2</td>
<td>Quadriplegia</td>
<td>Transitioning</td>
</tr>
<tr>
<td>P/C 4</td>
<td>YP 7</td>
<td></td>
<td>15</td>
<td>4</td>
<td>Paraplegia</td>
<td>Pre-transition</td>
</tr>
</tbody>
</table>
An audit trail was maintained that traced the thinking processes and decisions made during the conduct of the study (dependability and confirmability). Furthermore, as an individual with an SCI the first author engaged in a process of personal reflexivity reflecting on how her position and perspective may have impacted the study. The researcher reflected on how shared experiences as a member of the SCI community allowed for the development of a rapport with young people and parents/caregivers and created a safe space for young people to express their needs.

**Patient and public involvement**

Young people with SCI and parents/caregivers were not involved in setting the research question or design of the study. However, as this study was informed by PAR, participants were provided with a platform to voice their needs, advocate for change, identify practical solutions within the HCT process and supported the data analysis. A reference group, consisting of paediatric SCI healthcare service providers and young people, were also consulted to provide advice on recruitment and provided feedback on the interview guides. Further details on this process can be found in an earlier article by Bray et al.

**RESULTS**

Three major themes were co-constructed, informed by the participants’ experiences with, and recommendations for, transition from paediatric to adult healthcare services. The themes reflect both the emotional highs and lows and often tumultuous journey for young people with SCI and parents/caregivers in navigating complex healthcare systems, while advocating for change. The themes are discussed in more detail below with additional illustrative quotes in online supplemental file 2.

**Theme 1: Transition expectations—‘I’m not going to be in the little kids’ section [anymore]’**

The transition to adult healthcare services was met with a level of uncertainty, most participants reported not knowing what to expect for the transition. However, generally young people looked forward to the prospect of growing up and having greater independence and choice, yet parents/caregivers were more apprehensive about the logistics of the move.

**Subtheme 1: The unknown—‘I didn’t really know what to expect’**

Participants reported that in the lead up to the transition they did not know what to expect and that they were uncertain what the transition process entailed.

“I wasn’t sure what the next steps were.” (YP 1, post-transition)

Participants often used language such as ‘frightened’, ‘overwhelmed’ and ‘daunting’ to describe their feelings about transition. Young people were scared and overwhelmed about the prospect of entering new and unfamiliar environments.

“It was pretty scary for me because I’m not used to transferring and I’m not used to a new lifestyle, and I stayed in [name of paediatric hospital] from when I was 4 years old until 18.” (YP 4, post-transition)

This fear became particularly poignant when the young people spoke about the trusted and supportive relationships they had with their paediatric healthcare providers and the daunting task of having to ‘start from scratch’ to establish new relationships.

“I had known those doctors, since I started going to the hospital when I was younger so going to all the new doctors made it very scary. I didn’t know them at all. And I had to start from scratch with those relationships with doctors.” (YP 1, post-transition)

Similarly, parents/caregivers described the strong relationships and the significant emotional attachment they had to their child’s providers saying, ‘we are treated like royalty here (paediatric service)’ and while they expressed similar concerns about building new relationships, parents/caregivers also worried about their child taking on more responsibility and having to become more independent.

“Scared, I guess. Scared of [YP 7] having to do things on their own … at the moment, I’ve been with them every step of the way.” (P/C 4, pre-transition)

**Subtheme 2: Growing up—‘they won’t treat you like you’re a little kid’**

While both young people and parents/caregivers expressed concerns and worries, young people also reported positive hopes for what the transition process signalled as a part of growing up. Young people voiced that they looked forward to increased independence and choice, more opportunities and greater autonomy and control over their own healthcare decisions.

“Kind of excited just growing up … knowing that I’m not going to be in the little kids’ section, and I get to make choices.” (YP 2, pre-transition)

Parents/caregivers acknowledged that the transition to adult healthcare services was a normal developmental milestone and that the adult healthcare services would be able to provide the necessary age-appropriate care.

“[Speaking of the paediatric hospital] [YP 3] got to the point of just going this isn’t looking at what I’m wanting.” (P/C 3, post-transition)

**Theme 2: The transition experience—‘I felt a bit like they kicked me out the minute I turned 18’**

Participants described that there was limited, and in some cases absent, information available on the transition from paediatric to adult healthcare services before it took

place. As a result, for those that had a transition, the transition appeared to happen quite suddenly. Participants then found the transition process difficult to navigate due to a lack of communication between the paediatric and adult healthcare settings. The change from a family-oriented model of care to a person-centred approach was a significant adjustment for both young people and parents/caregivers.

Subtheme 1: Transition—‘it happened, very quickly’
Some participants explained that they had been informed verbally about the upcoming transition around the age of 18 years. Others realised themselves that this would be the case but acknowledged that they had not been consulted in the planning process.

“We knew that … there was a shift, that when [YP 6] turned 18 they change system, so we were aware of that, so it wasn’t a shock or surprise, but … you don’t have any choice or say in it.” (P/C 1, transitioning)

When probed for further details on how the paediatric healthcare service providers prepared them for the transition process, participants’ responses appeared to lack detail.

“I’ve never really talked to them about what happens when [YP 7] turns 18. I just know that they will stop, but I don’t know if there is, like, another maybe it’s an adult outreach service or something … I don’t know.” (P/C 4, pre-transition)

The information that was provided seemed to leave participants with many unanswered questions about the transition process and a limited understanding of the workings of the adult healthcare system.

“What would make the move easier is … some correspondence that says … here are all of the specialists that you need to keep seeing … as [YP 6] transitions over and what they need to see them for so that they understand that, and then how often they need to see them, is that once a year, twice a year?” (P/C 1, transitioning)

The lack of clarity surrounding the transition process meant that for most participants the transition to adult healthcare services seemingly occurred overnight without a formal handover.

“One day, I was there, the next day it was completely different … I wasn’t expecting it to all happen so quickly as soon as I turned 18. And I felt a bit like they kicked me out the minute I turned 18.” (YP 1, post-transition)

Out of the four post-transition experiences discussed there was only one that reported receiving a formal handover. Both the young person and parent/caregiver in this dyad explained this handover as being instrumental to feeling more comfortable and prepared for the transition.

“At our last meeting, everyone was there … the new rehabilitation specialists and CNC [clinical nurse consultant] … and that made us [feel] at ease … that was for us a beautiful transition because we knew that if [something happens] these doctors will still assist and they will exchange information themselves.” (P/C 2, post-transition)

Subtheme 2: Navigating the transition—‘going back and forth’
As they navigated the transition, only one young person out of four who had already transitioned reported that a transition support service included them in the planning, made a list of all their new doctors and assisted them to organise the initial appointments. The young person explained that this support made them feel valued and heard, making the transition process easier.

“[The transition support service] organised the initial appointments with the new doctors. And they made sure that I was involved. So that made me feel more comfortable, knowing that I had a say in all those things … They made a list of all my new doctors, which made it easier for me because I have so many. So, I was able to remember everyone’s names and they also offered to go to the initial appointments, but I didn’t need that.” (YP 1, post-transition)

For the remaining post-transition participants as well as the transitioning participant, the transition process was generally described as disjointed and messy. These participants reported a lack of communication between the paediatric and adult healthcare services, resulting in delays at the point of transition, necessitating repeat medical tests and time reiterating historical and current medical information.

“We already had an X-ray of [YP 6]’s scan and things of their neck, but they couldn’t get the files to [adult hospital], so he had to go and have another X-ray so that it was in the correct format … to feed into their system, which was infuriating because it was a waste of time, it was a waste of health’s money.” (P/C 1, transitioning)

Subtheme 3: Changing roles and responsibilities—‘we wanted him to have a voice in what was going on for him’
Not only was the actual transition process confronting for young people and parents/caregivers, but the change in communication style and expectations for the young person within the adult healthcare system was an additional burden at an already stressful time. In the paediatric setting, young people reported that most communication was directed toward their parent/caregiver. For instance, YP 3 recollected family meetings where: they made it like a circle and it was all talking about me, so I didn’t like it like that, instead of talking to me’ and YP 1 mentioned ‘they would talk to me, but they would talk to my mum more.
The abrupt change from a family-centred to a person-centred style of communication seemed to overwhelm the young people.

“It was a bit overwhelming because all these support teams are coming towards you, they’re all asking you [questions and] providing support. I wasn’t expecting it, because … when I was in children’s, they just went to my parents, so they went to me this time and it was a surprise.” (YP 3, post-transition)

This sense of being overwhelmed was further exacerbated as young people reported difficulties talking to doctors independently. Young people described that they were not prepared to speak with doctors independently, struggled to articulate their needs, and felt confronted by the perceived power imbalance.

“In the meetings, I felt like they were very confronting. I felt like … you just sat there and listened, and you didn’t really know what to say or what to do.” (YP 5, post-transition)

Consequently, young people reported an unwelcoming atmosphere within the adult healthcare services.

“You don’t feel as welcome because the adult’s hospital is very dull, the atmosphere. You feel intimidated. They don’t treat you as well as they did at the kid’s hospital. Because they just assume that you can do it all now because you’re an adult, it’s not as gentle an approach as the children’s.” (YP 1, post-transition)

Despite wanting more autonomy and independence in their healthcare and parents/caregivers wanting the same, we wanted [YP 3] to have a voice in what was going on for them (P/C 3), young people continued to rely on their parents/caregivers to support them with their healthcare needs.

“Sometimes they [adult healthcare services] don’t have the patience to take the time to try and understand what I’m saying, because my voice is soft … so sometimes I don’t feel comfortable going to the appointments without my mum. So, she comes to most appointments now because I want her to.” (YP 1, post-transition)

Parents/caregivers also found it difficult to relinquish control of their child’s healthcare resulting in a sense of interdependence between the young person and their parent/caregiver.

“I think [YP 4] is still very much dependent … they were always overprotected probably by us and … when someone is not directly dealing with something it’s easy to just … not worry because they have never administered any medication to themself and then they didn’t bother remembering everything.” (P/C 2, post-transition)

Theme 3: Needs and recommendations—“Do you know how stressful it is for me to … tell the story again and again from scratch?”

Participants had clear ideas about the best ways to manage the move from the paediatric to adult healthcare setting, including that this should begin at least 1 year in advance.

Subtheme 1: Knowledge is powerful—‘explain what services were going to be handed over, when and to whom’

The participants expressed a desire for more information about the transition to adult healthcare services. They wanted information not only on how the transition would take place but also on services that could help, what each of their doctors do (both old and new), how the adult healthcare services operate, what medical tests they need and how often, troubleshooting information and tips on what questions to ask.

“Like, on the website if you had … maybe like a bunch of questions that said … stuff that you could ask and what your transition is about … I felt like that could have probably been a big help.” (YP 5, post-transition)

“A simple letter to explain what services were going to be handed over, when and to whom and also what services are not going to be handed over and why. This info [information] is important to know why the handover is needed for some issues but not others.” (P/C 1, transitioning)

Suggested formats for delivery of this information included brochures, websites, podcasts and videos. However, what was most important was to have this information available for them to access in their own time and at their own pace.

In addition to the general information on transition, participants also wanted more written information about their medical history that they could provide to new doctors and suggested a personalised booklet would be useful. Re-telling the story of their or their child’s injury repeatedly to new doctors was emotionally stressful and traumatic.

“Do you know how stressful it is for me to go every time and tell the story again and again from scratch. It is psychologically draining to the nth degree … maybe if your patients want to have a little booklet about maybe medication and … history of the events that led to injury on paper, rather than telling them the story over and over.” (P/C 2, post-transition)

Subtheme 2: Transition-specific meetings—‘I felt like they both could have come together in a meeting and just explained … what is really involved’

Participants reported that a pre-transition meeting with the adult and paediatric healthcare providers would be helpful for both young people and parents/caregivers. The participants suggested that the adult provider should ideally participate in the last visit at the paediatric healthcare service. They could use this time to provide a
Participants also wanted the transition to be staggered and suggested that there should be an overlap in care with transition support spanning a longer period of the young person’s adolescence, from approximately 16 to 24 years. In this way, services can assist with additional life transitions occurring simultaneously to the move between healthcare services such as the move to tertiary education or work and the move to living out of home. The service would also be able to address common adolescent concerns surrounding sexual health and sexuality, independently accessing the community, driving and mental health.

“It would be helpful if there was like some sort of transition program with it. From like 16 to 24 because I just was thrown into the deep end when I turned 18. There were no stepping-stones to it. I felt upset because it was kind of like ‘bye your 18, we’re not going to see you anymore’, so it would have been nice if there was some sort of program over a couple years to help with that transition.” (YP 1, post-transition)

“Instead of having the two, the adult and the child, I think it will be good to have … the support of a service going through from 16. They can discuss sexuality and those kinds of things that’s not necessarily the parent’s conversation but it’s moving into an adult kind of structure.” (P/C 3, post-transition)

By having one service or health professional they could call on, or one point of contact, this would assist with maintaining continuity of care across the transition process.

“To know that [YP 6] has got an experienced healthcare professional that they can contact for those … medical questions around … bowels or catheter issues or … skin problems … to have that check in I think will help keep them safe.” (P/C 1, transitioning)

Subtheme 3: Building skills and confidence—‘I also want to do that by myself’

Parents/caregivers identified the challenges involved with young people taking over responsibility for their own care when perhaps they did not have the skills to be able to do so.

“From a child’s point of view I think it’s very important to be able to help with that transition.” (YP 1, post-transition)

“Instead of having the two, the adult and the child, I think it will be good to have … the support of a service going through from 16. They can discuss sexuality and those kinds of things that’s not necessarily the parent’s conversation but it’s moving into an adult kind of structure.” (P/C 3, post-transition)

Parents/caregivers recommended the development of a ‘life guide’, the opportunity for young people to learn about their healthcare and support services, and the space to gain self-management skills. Young people confirmed this need to enhance self-efficacy and to capacity build their skills and confidence.

“There is a need for a ‘life guide’ to help kids transition to adults … to manage their medical and care needs independent of family members. So, they know they have choice and what they need to do to make their choice happen and to know what supports are available to help them transition to their next stage of life.” (P/C 1, transitioning)

“It felt like they should have spoke[n] to both of us and … let us both learn at the same time.” (YP 5, post-transition)

Subtheme 4: Support from someone like me—‘to talk to somebody that had been through it’

For some young people, peer support was seen to be invaluable; the opportunity to share experiences with someone who understood their situation. Parents/caregivers also acknowledged the vital role peer support played in their child’s recovery.

“It was a big thing to have someone who was in the same predicament to come see you and then … you could ask him questions and tips and trick” (YP 5, post-transition)

Participants who did not report receiving any peer support expressed that it would have been beneficial to talk to and connect socially with people with a similar injury, as they would understand what they were going through and could offer ongoing support. Peer support was seen as empowering as they would then know that they were ‘not alone with the whole process’.

“It would be helpful to talk to somebody that had been through it and get their thoughts and perspective on the process and mentor you through it.” (YP 1, post-transition)

Discussion

Health literature that explores the experiences of young people with chronic conditions demonstrates unique challenges to how they each experience and navigate the changes associated with transition.\textsuperscript{53–57} This qualitative study aimed to understand the experience of transition for young people with SCI from the perspective of both young people and parents/caregivers to develop recommendations for an HCT intervention. In line with CDT, the study has prioritised the lived experience by listening to participants’ voices and their needs as they advocate...
for change. Overall, the findings indicated that although young people with SCI and parents/caregivers valued the care they received from paediatric healthcare providers they were not satisfied with the transition from paediatric to adult healthcare services and advocated for additional information, support, and services.

While the results of this study are consistent with much of the literature on the experience of HCT for young people with chronic conditions and disabilities, this study adds to the limited qualitative literature on SCI and transition to adulthood, providing an Australian perspective where collaboration and voice are central to the interpretation. For the last 30 years, the importance of supporting the successful transition of young people between paediatric and adult healthcare settings has been discussed in great detail with the release of consensus statements and development of policies, guidelines and/or frameworks surrounding HCT and the provision of effective HCT interventions. What is somewhat discouraging is that despite the availability of this information, young people with chronic conditions and disabilities, including those with SCI, and parents/caregivers are still reporting gaps in the transition process and continue to champion for more information, support and services. Thus, in addition to a description of the experience of HCT for young people with SCI and parents/caregivers, this study also provides the initial process of reporting their recommendations for improving this experience, which in turn will inform the co-design and development of future HCT interventions.

In the current study, participants were ambivalent about leaving the paediatric healthcare setting and a family-oriented model of care, where care plans were developed and implemented in collaboration with the family as a unit, considering illness-specific educational needs to a more person-centred model of care in adult healthcare settings. As part of a person-centred model of care, the focus is on the person and their needs, fostering a respectful and trusting relationship with them where their voice is heard. There is an expectation of greater independence and responsibility in decision-making on the individual although involvement of parents/caregivers in care coordination is important. In our study, the challenge for young people and parents/caregivers was moving away from the providers with whom they had established trusted relationships and had come to rely on for support. At the same time, young people also looked forward to increased choice and autonomy, and parents/caregivers viewed the transition as part of a natural progression to adulthood. These findings support the work of other qualitative researchers in that young people and parents/caregivers have both positive and negative expectations of the transition. The commonly reported fear of leaving the family-centred approach to care, standard within the paediatric healthcare setting, and the sense of safety associated with this model highlights the value young people and parents/caregivers place on the patient-healthcare professional relationship.

It further re-affirms the importance of meeting the new adult healthcare team so that relationships are established early. This study builds on understanding the guiding role healthcare professionals can have in the transition process by highlighting where participants experienced gaps in the continuity of care. A key recommendation from the participants to support this process was to offer an overlapping adolescent service, spanning the ages of 16–24, or joint visits with paediatric and adult healthcare providers to facilitate the transition and promote relationship development with new healthcare providers.

While various transition tools exist, Schmidt et al explain that a portable medical summary shared between the young person, parents/caregivers, as well as the healthcare providers has been used to support the transition of young people with chronic conditions. Porto et al similarly proposed ‘the development of readily available, concise, and comprehensive overviews of individuals’ medical history’ as a strategy to improve communication between healthcare settings and transition outcomes for young people with SCI. Our participants emphasised this same need and reported potential benefits in that a portable medical summary could reduce the negative emotional impact of having to re-tell their story time and again. Acquiring an SCI would be a traumatic experience for the individual and their significant others and during interviews some participants spoke about the stress of having to repeat the story of how they or their child acquired their SCI, with some parents/caregivers becoming visibly emotional. Reliving experiences appeared to be re-traumatising for participants, particularly the parents/caregivers. Consequently, participants recommended increased communication between the two healthcare settings and a more streamlined handover of information through joint transition appointments and a portable medical summary.

Participants perceived there to be a lack of preparation for the transition and a scarcity of information regarding the transition process. As such, participants reported that they wanted specific information on the transfer process and how it would be carried out, a ‘to-do’ list to get ready for the move, information on how to find new healthcare providers, and tips on how to communicate with adult healthcare services to elevate their voice. These findings are consistent with previous research exploring the experience of HCT for young people with other paediatric-onset chronic conditions and parents/caregivers. Dwyer-Matzky et al suggest that providing assistance with transition preparation and greater information can reduce anxiety and uncertainty and results in a smoother transition process. Findings from this study highlighted the information healthcare professional should be providing to facilitate an understanding of the changes young people with SCI and parents/caregivers could anticipate during the transition process and in the adult healthcare system.

A transition process that encourages independence and self-management was important for the young people...
who wanted the opportunity to learn and for parents/caregivers to feel confident in relinquishing control. In addition to education that cultivates self-management skills and independence, young people and parents/caregivers indicated that peer support would help with learning how to prepare for and navigate the transition while also providing emotional support and an empathetic understanding of the challenges of daily life with an SCI. The WHO has recommended the use of peer support in the rehabilitation of individuals with SCI. Peer support programmes have the potential to improve outcomes for individuals with SCI and family members as they provide needed social support, knowledge, and hope to individuals.

While several community organisations in Australia have established peer mentor programmes, these tend to focus on the adult SCI population. Despite this, the research for adults with SCI demonstrates that peer mentorship can increase efficacy in self-management abilities and decrease medical complications. Zimmerman et al further proposes that peer support may improve transition to adult healthcare for paediatric patients with chronic diseases. Therefore, offering peer mentorship to young people with SCI during their transition may foster greater transition readiness and success.

**Implications for research and practice**

Despite 30 years of research around HCT, this study indicates that gaps persist in the HCT process for young people with SCI. From this, further research needs to identify and understand why these inequities in care still exist. Implementation science offers a lens through which to study the factors, processes and strategies at multiple levels that influence the uptake, use and sustainability of interventions and policies. Future research on HCT for young people with SCI could explore healthcare professionals’ views on the constraints of the healthcare system when it comes to HCT and adopt an implementation science lens to explore the influence healthcare professionals’ behaviour has in determining uptake and changes to practice, identifying the barriers to change. While findings from this study could be useful for others working in the broader area of research in HCTs.

Many young people with SCI and parents/caregivers have long-standing relationships with their paediatric providers and an in-depth knowledge of the paediatric healthcare setting. However, this knowledge and experience did not prepare them adequately for the HCT transition and unfamiliar adult healthcare services. They would benefit from the provision of more information, preparation and on-going guidance to support them to better understand and navigate the transition from paediatric to adult healthcare services. Many medical organisations and government bodies have published clinical reports, developed frameworks and have provided recommendations and guidelines to help services improve the transition process. Common features include a systematic and formal transition process, early preparation, the identification of a transition coordinator, good communication, individual transition plan, self-management education and follow-up. Providing a structured HCT process, as described, can lead to improvements in population health, quality of life, self-care skills and satisfaction with care. Moving forward, the transition needs of young people with SCI and parents/caregivers should be translated into a structured HCT process with interventions that include more transition-related information, increased communication, a joint handover meeting, self-management education and peer support/mentoring. Further guidance on the development of HCT programmes based on current evidence can be taken from Marani et al’s systematic review of HCT models for young people with paediatric-onset chronic conditions.

**Implications for policy**

In Australia, the Royal Australasian College of Physicians (RACP) and Agency for Clinical Innovation (ACI) provide principles and recommendations for a successful transition to adult health services. These principles include a developmentally appropriate process, tailored to the needs of the young person, active case management and follow-up, close communication between paediatric and adult services, and the development of successful self-management in young people with chronic conditions. This study provides evidence that some of these principles and recommendations are not being addressed for young people with SCI. Furthermore, the Spinal Cord Injury Model of Care Diagnostic Report recommends that the transition to adult SCI services needs to be streamlined. As such, further work is required that focuses on developing a policy for transition for young people with SCI with the aim of ensuring such policy is inclusive of the lived experience.

**Strengths and limitations**

The results from this study complement previous research by Porto et al in the USA which offers insights into young people with SCI and parents/caregivers perspective on the transition to adulthood and highlights the barriers and facilitators to successful transition outcomes. Their research identified healthcare as being one element of the transition to adulthood that acts as both a support and a barrier. This Australian study’s strength is that it explored the HCT experiences for young people with SCI and parents/caregivers and in alignment with CDT principles has elevated the voice and visibility of young people and parents/caregivers as advocates for change within the process of HCT. By centring the HCT experience of young people with SCI, the authors take a unique approach toward intervention development, by using a PAR approach and co-design methods that enhance capacity building and empowerment.

Participant recruitment has been described as one of the most challenging aspects in SCI research and as identified earlier, there was only a small population available from which to recruit participants for this study.
When combined with the impact of the global COVID-19 pandemic, recruitment for this study was difficult. Parents/caregivers were hesitant to commit to participate in the study as they faced employment stressors and were home schooling children while in lockdown. To combat these challenges, the researchers offered to conduct interviews outside of traditional business hours, conducted all interviews online and provided gift vouchers in thanks for time and participation.

In addition to its small size, the sample of participants also lacked cultural, linguistic and gender diversity. Social and cultural disparities exist pertaining to the provision of HCT services. Future research will need to explore the impact of diversity on service delivery and outcomes for young people. Regarding gender diversity, the lack of representation of fathers and other types of caregivers in the study is a limitation.

Geographical disparities also exist as young people with disabilities living in regional and remote areas often experience limited access to tertiary services. As such, the experiences of young people transitioning from paediatric to adult healthcare services in rural areas may vary greatly from young people residing in metropolitan areas. Extending recruitment to participants outside of metropolitan Sydney meant that the perspectives of young people and parents/caregivers in these regions could be included and is a strength of this study.

Parent–child pairs involved in this study provided similar accounts of the transition experience and highlighted similar needs within the transition process, as within the NSW health service there is a standard process for transition. Furthermore, as part of the PAR process that underpinned the larger research project, participants were arbiters of knowledge production and were asked to confirm the findings from the interview analysis in co-design workshops and post write-up. Corroboration between parent–child pairs and confirmation of findings added further strength to the interpretation and respected voice and visibility.

Conclusion

Despite existing guidelines for HCT, young people with SCI and parents/caregivers reported that their transition experience was disjointed and that their needs were not adequately met. This qualitative study confirms the importance of information, preparation and continued support for the transition of both young people with SCI and parents/caregivers. Through the co-design process, inviting the voice of young people with SCI and their parents/caregivers provides insight into their perspectives on transition and recommendations for the development of effective HCT interventions.

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