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RESEARCH ARTICLE



# Caregiver perspectives of scoliosis surgery for children with cerebral palsy: a qualitative study

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## ABSTRACT

**Purpose:** To explore the perspectives of primary caregivers of children with cerebral palsy (CP) who had spinal surgery for scoliosis.

**Materials and Methods:** A qualitative study was conducted using semi-structured interviews and guided by qualitative description methodology. Participants were caregivers of children with CP aged 5–18, who had undergone spinal surgery for scoliosis in Australia. The research team included a parent with lived experience.

**Results:** Fourteen participants (8 biological mothers), aged 40–49 years, completed online semi-structured interviews. Four themes were identified emerged. *Life with a child with CP* underpinned all experiences which were founded on familiarity with their child, medical procedures, and hospitalisation. Three subthemes were *parents are the experts in knowing their child*, *children are vulnerable*, and *impact on caregivers*. Theme 2 involved the significance of *decision making* to proceed with surgery. Theme 3 underscored a need to *be prepared* for the surgical journey and, in Theme 4, participants spoke of needing to *expect the unexpected*.

**Conclusion:** The findings highlight the importance of understanding caregiver experiences and can help inform health professionals and other families in the decision-making process, preparing for and navigating spinal surgery.

## ARTICLE HISTORY

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## KEYWORDS

Cerebral palsy; scoliosis; spinal surgery; caregivers; qualitative research; parents; consumer involvement

## ► IMPLICATIONS FOR REHABILITATION

- Spinal surgery for scoliosis in children with cerebral palsy is a major surgery and poses substantial challenges for the family.
- Understanding the magnitude of the decision for families to proceed with surgery will equip health professionals to adequately support and partner with families.
- Detailed information and extensive preparation are necessary for families to proceed with and navigate surgery, the hospital stay and to return home and to the community.



## Introduction

Cerebral palsy (CP) describes a range of permanent conditions involving disorders of movement, muscle tone, posture, and motor function that are secondary to a lesion in the developing foetal or infant brain [1]. CP is the most common physical disability of childhood, with a prevalence of approximately 1.4 per 1000 live births in Australia [2]. Children living with CP are at risk of comorbidities such as muscle weakness, impaired muscle and trunk control, hip dysplasia, and spinal deformity, which impact their overall health and wellbeing [3]. Children with CP experience significantly higher rates of scoliosis than the general population [4] and the risk of developing scoliosis is higher for children with more significant functional mobility difficulties [3].

Scoliosis in children with CP is a neuromuscular spinal deformity caused by abnormal muscle tone and impaired trunk control [5]. The severity of scoliosis is determined by the degree of curvature

of the spine [6]. Untreated moderate to severe scoliosis can result in motor dysfunction, difficulties moving, positioning issues such as difficulty sitting in a wheelchair, pain, respiratory compromise, reduced quality of life and increased dependency on caregivers and services [7–9]. The primary objective in managing scoliosis in children with CP is to prevent further spinal deformity, alleviate symptoms, and improve quality of life, function, and wellbeing [10–12]. Spinal surgery is a primary intervention for children with CP who have moderate to severe scoliosis. It is a major orthopaedic procedure and has associated risk of complications such as infection, chronic pain, pulmonary and gastrointestinal issues and death, especially in populations like children with CP who present with significant preoperative comorbidities [13,14].

The majority of research investigating caregiver perspectives and experiences of spinal surgery in children with neuromuscular scoliosis, such as CP, is quantitative and evaluates health-related quality of life (HRQoL) [10–12,15–17]. Most research reports some

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improvement in HRQoL following surgery [10–12,15,17]. DiFazio et al. [16], however, reported no improvement at 2 years post-surgery. Caregivers report satisfaction with the outcomes of spinal surgery and would recommend the surgery to others [17].

Qualitative research enables ascertainment of the perspectives of those with lived experience that are usually not achieved by using quantitative means such as HRQoL measures. These perspectives can provide a rich understanding of an issue to guide practice and service delivery. Caregivers are uniquely placed to provide perspectives sought by other families making decisions about spinal surgery and the healthcare professionals supporting them, especially when their children live with significant disability and seeking their views is complex. Qualitative research seeking the perspectives of caregivers about spinal surgery for neuromuscular scoliosis has focused on children with Rett syndrome [18] or children with neuromuscular scoliosis with mixed or unspecified underlying diagnoses [19,20]. The findings counselled caregivers to consider risks, benefits and outcomes of surgery; the recovery process; and warned that this decision-making process was anxiety provoking. The advice was also to avoid prolonged decision making which could delay achieving outcomes for their child [20]. Studies identified that caregivers can experience conflicting emotions such as feelings of relief, anxiety, fear, guilt and even dread about choosing to proceed with surgery [18,20]. The emotional impact and challenges of the decision to proceed with surgery, hospitalization and transition to home and the community during recovery were significant and generally underestimated by providers, family and caregivers [18,19].

Caregiver perspectives of the process of spinal surgery, from making the decision to proceed with surgery, through to resettlement at home and school, specifically for children with CP and in an Australian healthcare context, are not well understood. These perspectives would assist children and families to prepare for, and navigate, the spinal surgery journey, and potentially mitigate some of the emotional impact.

This qualitative research aimed to address this gap in the literature and explored the decision-making process, lived experiences, and perspectives of primary caregivers of children with CP who had undergone spinal surgery for scoliosis in Australia. We aimed to shape and inform future practice.

## Method

The study was guided by qualitative description methodology. Qualitative description fits within an interpretive paradigm and provides a rich description of participant experiences rather than building theory [21–23]. Qualitative description is differentiated from other qualitative approaches as it is not aligned with a particular theoretical orientation like phenomenology or grounded theory [21–23]. Qualitative description involves using participants' own language in coding narrative data and theme development in a recursive and iterative manner [21]. Consequently, researchers remain close to the data and everyday language throughout collection and analysis, facilitating translation and implementation of the findings in clinical or research practice [22,23].

### Consumer involvement

The research team included a consumer investigator [JK] who was a parent of a child with CP who had undergone spinal surgery for scoliosis. JK's involvement is reported using the Short Form of Guidance for Reporting Involvement of Patients and the Public 2 (GRIPP2-SF) [24] in Table 1. Staniszewska et al. [24] developed these guidelines to enhance the quality, transparency and consistency of reporting consumer involvement in research.

### Participant sampling and recruitment

Eligible participants were primary caregivers of children with CP aged 5–18 years at the time of spinal surgery for scoliosis, with surgery occurring between 2017 and 2020 in Australia. This time frame was selected to reduce variability of experiences due to changing surgical practices. Convenience sampling was used to recruit participants in two phases. In the first phase invitations were emailed to eligible caregivers whose child had spinal surgery at the Sydney Children's Hospital or the Children's Hospital at Westmead. The invitation included the opportunity to opt out of further contact. Those not opting out were contacted by telephone two weeks after invitations were dispatched. In the second phase, advertisements were distributed by affiliated CP networks in Australia inviting potentially eligible participants to use an online link to seek further information. A female undergraduate occupational therapy research student, GP, contacted those seeking more information. She explained her role in the study, and the context of completing the research. All participants read a participant information sheet and signed written informed consent. The process of informing about the study and seeking consent was intentionally viewed as an opportunity to develop rapport prior to interviews and was therefore completed by GP following education and practice with the research team.

### Sample size

A sample size of 15 participants was planned, based on estimates of the numbers of children having spinal surgery and the timeframes of the study. This number was also deemed suitable for obtaining a rich description of the experiences and perspectives of participants.

### Data collection

Prior to the interview, caregivers provided demographic information about themselves and the child who had surgery. Semi-structured individual interviews were completed with student researcher, GP, to collect in-depth descriptions of the caregivers' perceptions and experiences of their child's spinal surgery journey from decision-making, through to post-operative care and resettlement following discharge. The interview schedule consisted of core questions with suggestions for prompts and was iteratively amended over the course of the interviews following research team reflection on responses given by participants. Table 2 contains the interview schedule. The schedule was developed drawing on previous literature of caregiver experiences with their child's spinal surgery and the expertise of the team (parent, clinicians working in scoliosis surgery and rehabilitation, researchers). The interview schedule enquired about caregivers' thoughts, feelings and reflections on the decision-making process, communication with healthcare professionals, pre-surgical journey, experiences of surgery, recovery post-operatively, and resettlement into daily life including returning home and to school. GP practiced interviews with JK and KS. JK provided feedback on questions and interview implementation, and participated in team supervision, practice, feedback and debrief. GP maintained a journal, reflected on interviews, kept a clear audit trail of methodological decisions made by the research team and raised key points for discussion, reflection and analysis with the research team. These are strategies recommended to enhance the trustworthiness of the results [25]. Interviews were completed using Zoom video technology to enable caregivers who did not live near the research team to

**Table 1.** Reporting consumer involvement in this study using the GRIPP2-SF [24]—content co-written with consumer investigator JK.

GRIPP2-SF section Item	Response to GRIPP2-SF Item
1. Aim Report the aim of consumer involvement in the study	Our aim was to embed the lived experiences of a family member, whose child had spinal surgery for scoliosis, in all stages of the research from development of the research question through to dissemination of research findings. We aimed specifically to: (i) ensure the research design, methods and implementation were optimised to achieve the most meaningful outcomes and (ii) to assure a respectful and safe participant experience.
2. Methods Provide a clear description of the methods used for consumer involvement in the study	JK was invited from KS's networks and joined the research team at the outset. She was an experienced consumer partner, having collaborated on previous research projects. JK attended team meetings and contributed to all aspects of study design, developing research questions, the ethics application, participant-facing documentation, recruitment, informed consent conversations, the interview schedule, interpreting data, naming and defining themes, and editing and approving the publication. She also completed practice interviews with the interviewer and provided detailed feedback. JK was not paid for her time.
3. Study results Outcomes—Report the results of consumer involvement in the study, including both positive and negative outcomes	JK was instrumental in the following: <ul style="list-style-type: none"> <li>• Respectfully worded recruited emails to capture attention.</li> <li>• Recruitment processes to optimise communication and information, and minimise burden.</li> <li>• Wording of demographic questions more sensitively</li> <li>• Interview schedule questions, content, wording, flow, and interview termination were all improved and reflected greater knowledge of the surgical process as well as child and caregiver experiences.</li> <li>• Practice interview and feedback and facilitated student researcher's (GP) reflective practices on the interview approach which assisted in more empathetic and informed implementation. JK provided ongoing education and support for the student researcher about effective use of silence and responding during interviews with empathy.</li> <li>• Data analysis—understanding the perspectives of the participants, and deeper knowledge of their family and surgical contexts brought invaluable insights to the analysis and interpretation. JK challenged the team to interrogate their own biases and experiences, and their impact on the study design, implementation and interpretation of findings.</li> </ul>
4. Discussion and conclusions Outcomes—Comment on the extent to which consumer involvement influenced the study overall. Describe positive and negative effects	JK's involvement at each stage of the project added a richness brought about by lived experience and deep understanding of living with CP and of having experienced caring for a child who completed the spinal surgical journey. The lived experience contributed to the ways the team considered each aspect of the study and particularly the data analysis and interpretation. The influence on the participant experience is perceived as profound, with all participant-facing processes (e.g., recruitment, interviews, member checking) and documentation (recruitment material, participant information letters and consent forms) being influenced by JK's expertise.
5. Reflections/critical perspective Comment critically on the study, reflecting on the things that went well and those that did not, so others can learn from this experience	JK was involved in all aspects of the project therefore contributing a lived experience perspective in addition to experience brought from other aspects of her life to the entire project. The lived experience perspectives were invaluable for their practical impact on the study and provided the opportunity for clinicians and researchers to reflect on their practices and develop a deeper understanding of the lives of the children and families with whom they interact. The opportunity to have JK's input to all aspects of the research was a substantial benefit. JK's guidance optimised participants' experiences, which is an important outcome. A positive experience is also likely to increase the numbers of participants recruited and their engagement in the interviews. JK supported considerate and efficient participant correspondence and engagement throughout all stages of the research. JK reflected that attending meetings around busy family and work life was a challenge, and that there was little flexibility in the meeting times and the project timeframes. JK disclosed that her involvement with the research caused feelings and emotions related to her child's surgery to re-surface. A strong recommendation from these disclosures is to regularly and carefully review individuals' involvement to check that it was meeting their goals for involvement, was structured and organised in a way that facilitated involvement, that supports were in place if needed, and that the involvement was a positive experience. JK was not paid for her contribution as there was no funding. JK's view was that she volunteered to "give back". Others in the team felt uncomfortable about not paying JK as it was contrary to values related to respecting and recompensing consumers for their time and expertise. Funding should be sought to cover payment, however, the preferences of consumers need to be considered. Other forms of acknowledgement could also be provided if possible.

participate, and to accommodate the prevailing COVID-19 restrictions. Interviews were recorded and transcribed verbatim.

### Data analysis

Thematic analysis was used to identify and define the key themes of the participants' experiences according to Braun and Clark's guidelines [26] and guided by qualitative description [22,23]. Data collection and analysis occurred concurrently, enabling the iterative analysis to inform subsequent interviews. Transcripts were carefully read by all the research team to develop a strong understanding of the narratives. Iterative in-vivo coding (NVivo) [27] used participants' own language to label units of meaning. GP generated initial themes from codes with shared meaning. Themes were refined following full research team reflections, discussions and checking back with the full datasets. Themes were named and descriptive meaning statements generated [25,28]. Consistent with qualitative description, the research team adopted an inductive or data driven approach in their thematic analysis to remain close to the data and accurately portray the rich description of participant experiences [29]. Therefore, the planned outcome was to

derive an analysis of the narrative data which was relevant and translatable to knowledge users for implementation in decision making and practice [22]. A summary of themes in the early stages of analysis and suggestions that participants made to healthcare professionals and future families were sent to participants as a means of member checking. Participants were asked to provide feedback on how the themes represented their experiences, views on the names of themes and subthemes, and to offer any additional observations or comments. No feedback was received.

### Ethics

Prior to commencing the study, ethical clearance was sought from the Sydney Children's Hospitals Network (#2020/ETH02487) and registered with Australian Catholic University (External Ethics Register Number: 2021-10R).

### Results

Fourteen participants completed interviews—one mother and sibling chose to complete the interview together. See Figure 1

**Table 2.** Summary of the content of the semi-structure interview schedule.

Broad areas	Main questions and prompts
The lead up to spinal surgery	Can you tell me about how you arrived at the decision to go ahead with the surgery? <i>Prompts related to:</i> initial referral, professionals involved, decision making processes and roles, expectations of and feelings about surgery.
Preparation	What did you and your family do to prepare in the lead up to the surgery? <i>Prompts related to:</i> family preparation for surgery, differences in preparing for this versus other surgeries
Hospital stay	What are the things that stand out most in your mind about the time in hospital? <i>Prompts related to:</i> Positive and negative experiences for the family and the child, time course, information needed, comparisons with expectations.
Return home and back to school	Tell me about the first few weeks you returned home from the hospital. <i>Prompts related to:</i> Preparation for discharge and being home, support services. What did returning to school look like for your family? <i>Prompts related to:</i> preparation, decision to return, services used. Apart from home and school, what were other places or parts of life that your family and [child] needed to settle back into?
Outcomes	How did the surgery make a difference for [child]? <i>Prompts related to:</i> expected and unexpected outcomes for child and family.
Overall experience and advice	If you could make suggestions to hospital staff to make a difference to children and families, what would they be? <i>Prompts related to:</i> helpful information, important considerations, advice for families.
Conclusion	Is there is anything about [child's] spinal surgery journey that I have not asked about, or that is important for us to know?

for the recruitment process and outcome, which was undertaken in two phases. Interviews ranged in length from 25 to 120 min (average 45 min).

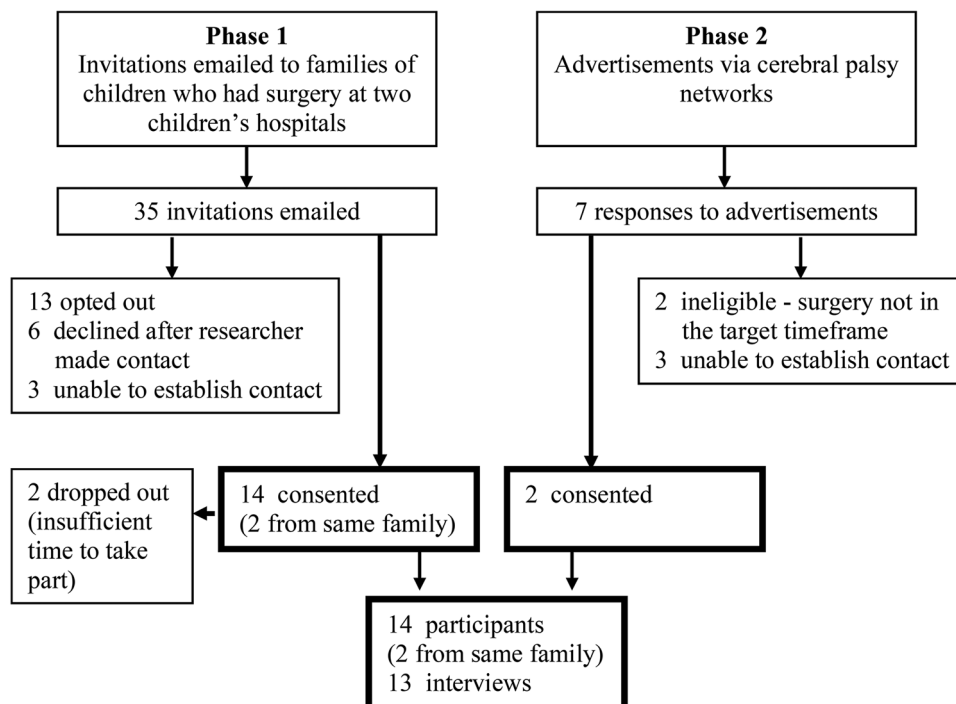
Most participants were mothers ( $n=8$ ), aged 40 to 49 years ( $n=6$ ), tertiary educated ( $n=10$ ), living in metropolitan areas ( $n=8$ ), with one child (the child with CP;  $n=7$ ), Table 3. Six of the 13 children who had surgery were female, with a median age of 14 years at the time of surgery. Most children had significant physical disability, needing full support for seating and full assistance for mobilising in a wheelchair (Gross Motor Function Classification System (GMFCS) Levels IV and V) [30,31]. Most children were non-speaking with complex communication needs (see Table 4), for instance 10 of 13 children had no understandable speech (Viking Speech Scale Level IV) and 10 of 13 children were unable to consistently communicate with familiar people (Communication Function Classification System Levels IV and V) using any means.

Four themes were identified from the interviews that described caregivers' experiences and perspectives of the spinal surgery journey: *life with a child with cerebral palsy; decision-making; be prepared; and expect the unexpected.*

#### *Theme 1: Life with a child with cerebral palsy*

*Life with a child with cerebral palsy* was identified as the underlying context within which the spinal surgery occurred. Participants described being familiar with the health care system, with substantial time spent with their child in previous hospitalisations, and in medical and therapy appointments. Major procedures, such as spinal surgery, were identified as an inherent part of *life with a child with CP*. Participants often related the spinal surgery to other surgical experiences such as hip surgeries, baclofen pump surgeries, and spinal surgery adjustments and revisions.

[P8] "the surgery wasn't anything, going into hospital and having this procedure, isn't anything new".

**Figure 1.** Participant recruitment process.

This familiarity with the health care system enabled some participants to better advocate for their child. Participants considered that surgery undertaken whilst their child was still in the paediatric hospital system was a considerable advantage, partly due to long standing relationships with the healthcare professionals.

[p14] *"I'm not going to have that contact with people that specialize, not only in children, but in disabilities. It's going to be very different when we go to the adult settings".*

Participants expressed resignation with the number of appointments their child required and the difficulties in managing these with family and school commitments. They also portrayed an acceptance of the processes of the health care system including long wait lists, juggling multiple appointments, and positive and negative experiences with health care staff.

This theme incorporated three subthemes: caregivers are the experts in knowing their children; children are vulnerable; and impact on caregiver.

Parents and caregivers consider themselves to be *the experts in knowing their children* and their needs, particularly for children

like this population who have significant and complex communication needs. They have implicit understanding of their child that is built up over the course of their *life with a child with CP*. Caregivers know when their speaking or non-speaking child is in pain and what makes them happy, sad or fearful. Participants clearly indicated a desire for health professionals to trust this knowledge throughout health-related interactions.

[p12] *"about this particular person, who knows better is the parents. Ask them, listen".*

Participants believed they have an important role in advocating for their child whilst in hospital but also acknowledged that making decisions on behalf of a non-verbal child can be problematic as the child's views are not able to be communicated.

[p6] *"because ... he's non-verbal, and he was unable to communicate. I was always sort of thinking, if he had a choice, how would he feel about it? So, we sort of made the choice for him, thinking [it] is the best thing for him. But I was quite worried about him not actually being able to voice how he felt".*

The second subtheme was *children are vulnerable*. Participants reported feeling unprepared for how *vulnerable* their child was during and after surgery. Spinal surgery was considered a major surgery. Their children, who were usually quite dependent, required even more care and were potentially unable to communicate their own needs during hospitalisation. This dependency contributed to caregivers' sense of their child's vulnerability.

[p14] *"And when you have a child that's nonverbal, and can't, you know, get anybody's attention. She doesn't even cry loudly, you know".*

This vulnerability also contributed to many participants' unexpected and comforting observation that children recovered surprisingly quickly.

[p1] *"So going off to ICU for 24 hours, ... but the next day, he was quite good, was back sitting in a wheelchair almost immediately, very comfortable. We had little to no issues, essentially."*

**Impact on caregiver.** The hospital was reported to be physically and emotionally draining for caregivers. Caregivers reported feeling lonely, isolated and unable to leave the child's bedside while in hospital for fear that their non-speaking child's care-needs would not be identified and met. Caregivers also found it confronting to see their child in such a vulnerable state, often experiencing pain and discomfort following surgery.

**Table 3.** Participant characteristics – caregivers.

Characteristic	Categories	
Sex (n)	Male	2
	Female	12
Age (years)	20–29	1
	30–39	3
	40–49	6
	50–59	2
	60–69	1
	70–79	1
Caregiver role (n)	Mother	8
	Father	2
	Sister	2
	Foster mother	2
Level of education completed (n)	Secondary	4
	Tertiary	10
Number of children (n)	1	7
	2	3
	3	1
	4	0
	5	0
	6	1
	Missing data	2
Residential location (n)	Metropolitan	8
	Regional	4
	Rural	2
State in which surgery occurred (n)	New South Wales	11
	Victoria	2

**Table 4.** Child characteristics.

Participant number of parent / caregiver	Sex of child	Age at time of surgery (years)	Length of hospital admission (days)	GMFCS	MACS	Viking Speech Scale	CFCs
P01	Male	12	7	V	V	IV	IV
P02	Female	15	7	V	III	III	I
P04	Male	16	14	V	V	IV	V
P05a/P05b	Female	14	6	IV	V	IV	V
P06	Male	15	9	V	V	IV	V
P07	Male	12	14	III	III	II	II
P08	Male	14	21	IV	V	III	III
P09	Female	7	7	V	V	IV	V
P10	Male	6	20	V	V	IV	V
P11	Female	15	40	V	II	IV	IV
P12	Male	15	8	V	V	IV	V
P14	Female	16	7	V	V	IV	V
P15	Female	13	7	V	IV	IV	IV

Notes: All classification systems rate I as higher functional ability and IV or V as lower functional ability. GMFCS: Gross Motor Functional Classification System expanded and revised [30,31]. MACS: Manual Ability Classification System [32]. CFCs: Communication Function Classification System [33]. Viking Speech Scale [34].

[p2] *"it's hard to leave.... cannot be left unattended. So, it's hard sometimes to, yeah, even go and have a shower, because you just can't leave them."*

Additional stressors included being discharged from hospital before feeling ready and post-surgical complications during recovery.

Mitigating factors were familiarity with healthcare processes gained as part of *life with a child with CP*, children's recovery, and good communication by the health care team. Preparation for the hospitalisation, practically and mentally, also helped.

[p1] *"I think that knowing it was coming it was easy to prepare beforehand. And sort of preparing for [the] worst case scenario, helped quite a bit, because after it went so well I didn't have to worry as much, and I probably [was] mentally able to deal with 99% of it myself."*

### **Theme 2: Decision making**

The process of making the decision for a child to have spinal surgery was the second theme. Participants reflected on the significance and magnitude of the decision and the concerns that prevailed, even while considering that the surgery was necessary for the wellbeing of the child. Experiences related to making the decision to progress with surgery were different across families. Some families had been having long term conversations about spinal surgery with their rehabilitation and surgical teams.

[p1] *"we had the conversation quite early on and I did quite a lot of research and things to prepare myself."*

Other families hadn't realised that surgery may be imminent.

[p5] *"I was a bit hesitant because I thought well, I didn't even have surgery in my mind."*

Some participants accepted the surgical recommendation while others took some time to agree to surgery. Decisions took into account medical recommendations but were made after seeking information from other sources including caregivers whose children had experienced surgery, their extended family, and other care teams.

Factors considered by families in making the decision to proceed with surgery were to mitigate existing medical issues such as pain, seating discomfort and compromised respiration; minimising future risk and complications; and the implications of worsening scoliosis. Another consideration was the family's needs and lifestyle, acknowledging the impact on the whole family of the health, well-being, care needs and medical dependency of the child with CP.

Participants reported varying emotions about making the decision to proceed with surgery. These stemmed from previous negative experiences with hospitalisation, and their child's responses to surgery and other medical procedures. Participants expressed concern about how their child would cope with issues such as the anaesthetic, post-operative pain and altered body positioning. Family and caregivers understood and were fearful about the magnitude and invasiveness of the surgery and the resultant recovery from this major surgery.

[p2] *"really upset by it and... it felt like a hugely invasive surgery, with any of these sort of surgeries lots of different things can go wrong."*

Some participants reported positive emotions or feeling relieved about their decision to proceed. Although acknowledging these significant concerns, participants believed that spinal surgery was the best option and was necessary for their child. The decision was largely made by weighing up the

implications of not proceeding with surgery with the potential benefits.

[p4] *"I came to that decision that it was in her best interest to have the surgery, because if we didn't do anything, it was either just going to get worse and her posture and positioning would get worse."*

### **Theme 3: Be prepared**

The third theme involved the need to *be prepared*, practically, emotionally and with information, to manage and adapt to each stage of the surgical and recovery processes. Participants felt more prepared when there was a plan, and they knew what to expect.

[p15] *"If you know what's going to happen, and you're prepared for that, and it doesn't happen, then your journey is much easier."*

Participants described needing to consider multiple facets of life when preparing for the period of hospitalisation, and return to home and school. Preparation for hospitalisation itself, involved multiple logistical considerations, but was just one of the considerations. Participants drew on their experiences of *life with a child with cerebral palsy*, in their preparations, which included preparing the family unit for the surgical journey, conversations with siblings and the extended family, organising time off work, and working around the family schedule.

[p14] *"We kind of had all of [the child's] needs covered. It was more what we had to do at home, managing conflicting schedules and considering the needs of other family members during this time"*

Participants reported less emphasis on preparing the child for what lay ahead. Participants were uncertain as to how to prepare their child. One caregiver chose not to tell their child until the morning of the surgery, as they were uncertain as to whether the child would retain the information they provided and how the child might react to the knowledge of the surgery. Others reflected on the difficulty of preparing their non-speaking child. [P14] *"we do tell her but what she would remember or what she would contain is, is hard to really know"* and [P14] *"obviously, it was a big thing for her to go through. And her comprehension would be limited, you know, like, so I was knowing she was trusting us"*. Substantial preparation for discharge and recovery at home was frequently undertaken by participants. Changes in the child's function immediately after surgery resulted in a higher level of dependence on caregivers, and additional manual handling for transfers and self-care tasks, for which preparation was needed. Following surgery, children commonly required new equipment such as hoists, or modifications to existing equipment such as their wheelchairs. Support for home-based post-surgical management of wounds and pain was also necessary. Despite these needs, caregivers reported they preferred to be at home for this recovery period.

Being prepared involved considerable work liaising with others to understand and manage practicalities of the hospital admission, altered support needs of the child post-surgery, and returning to home and school. Contact with hospital and community health care teams, community services, support workers, immediate and extended family, and schools was integral to preparation. Participants referred to the support, guidance and reassurance provided by healthcare professionals about returning home after surgery. They found that being able to anticipate personal care needs post-surgery and any potential short-term limitations, such as increased support for transfers, was beneficial. Some participants had been able to anticipate the needs of their child based

on healthcare recommendations, and coordinated additional support services such as caregivers, home doctor services, equipment, and community nursing and allied health professionals. Other participants didn't have all these supports and identified they would have been helpful.

Return to school was complex and often required considerable preparation. The length of time away from school was unpredictable and varied for many reasons, including surgical complications, restrictions related to COVID-19, and ongoing health care and support requirements. Decisions around when the child returned to school were based on medical recommendations, pain, sitting tolerance and the availability of equipment to support the child at school. Many participants reported sitting tolerance as a key indicator of readiness to return to school.

[p6] *"being in your chair 6 hours...that's when we decided he could go back to school".*

Families reported positive and negative experiences regarding their child's return to school. Managing differing expectations and clear communication with school about time away from school, equipment requirements and availability; and knowing when and how to grade return to school, were identified as important considerations in preparing to return to school. Some schools, with prior experience of children undergoing major surgeries, were reported as being supportive and accommodating, whilst other schools required more support and reassurance that the child was ready to return and the school was capable of supporting the child.

#### **Theme 4: Expect the unexpected**

Although participants counselled that *being prepared* was key to approaching spinal surgery, some, but not all, also reported the need to *expect the unexpected* and remain flexible. Some participants experienced unexpected challenges, others unexpected positive experiences.

Many participants had not expected the day of surgery to be so long and difficult. Most anticipated a stay in the intensive care unit following surgery, but some found their overall hospital stay was much longer than expected due to blood loss, low blood pressure, feeding and continence issues. Participants also didn't expect that some children required spinal revisions involving further surgery and longer hospitalisations. Other participants expressed their surprise at the speed of recovery post-surgery.

Most outcomes from spinal surgery were expected and involved structural changes, reduced pain, and improved sitting, respiratory function, and comfort.

[p4] *"she is straight and there's no pressure on any organs and um she can obviously breathe really well and stuff like that."*

Many participants reported unexpected structural improvements in their child's head control and function of the child's arms, with associated changes in oro-motor control. One impact of this was an 'unmasking' of the child's character. Participants considered that the altered head control enabled children to view the world and other people.

[p5] *"She became a lot more emotive. I guess that's the word—using a lot of facial expressions. Particularly her eyebrows. She's very expressive through her eyebrows. Yeah. Yeah, voice is there, but eyebrows is a big thing. She developed like a whole other new personality after the surgery. She was a lot more carefree."*

Less positive and unexpected issues were some children's short-term urinary incontinence, extended or repeated periods in

intensive care, need for spinal surgery revisions, infections, and surprise at the size of the incision scar and numbers of stitches. The positioning of the spine unmasked an unexpected malalignment of one child's hips post-surgery.

Participants also reported less-expected positive changes in quality of life, health and wellbeing of the child, impacting children and caregivers alike. Participants did not expect the extent of impact that improvements in areas such as sitting posture, length of time children could remain seated, and comfort, would have on the child and family. Participants experienced enhanced ability to be out and involved in the community, and increased ease of care in daily care, including showering and dressing. They reported that children's increased function and comfort, and greater ability to engage with the community relieved their own stress and concerns. On balance, participants found that the end justified the means, particularly in terms of the quality of life outcomes for their child.

[p2] *"Certainly not an easy process post-surgery and, you know it's, it's a fairly lengthy recovery time and so forth. But I definitely think it was worth it and, you know, would definitely go through that process again if [child's name] required it to get the results that she now has."*

The interview transcripts were examined for advice and recommendations for future families approaching spinal surgery for their child with CP, and health professionals. These recommendations are organised according to the themes derived from analyses (see [Table 5](#)).

## **Discussion**

This research explored the lived experience and perspectives of primary caregivers of children with CP who had spinal surgery for scoliosis in Australia. Our aim was to inform practice. The presence of moderate to severe scoliosis is common in children with CP, particularly those functioning at GMFCS Levels IV and V [6], and spinal surgery is often the recommended intervention. This study addressed a gap in knowledge about caregivers' perspectives and their lived experience about spinal surgery in this vulnerable population.

The experiences of caregivers in this study reflected many of those expressed by caregivers in studies of children with other diagnoses who experience spinal surgery [18–20]. Caregivers drew upon a lifetime of knowing their child when approaching and managing the surgical journey, based on their *life with a child with CP*. This knowledge, which included substantial experience of navigating the health system and previous hospitalisations, underpinned their decision-making processes, and preparations for the hospitalisation, recovery and return to everyday life.

Similar to the findings of other studies, caregivers accepted medical recommendations for surgery and the decision to proceed was a difficult one often associated with significant anxiety [18–20], along with conflicting emotions of worry, anxiety, guilt and relief [18,20]. Caregivers felt they didn't have a choice, that spinal surgery was necessary to mitigate their child's ongoing health concerns. Despite the significance of the decision to proceed with surgery, caregivers reported satisfaction with health and quality of life outcomes. This is consistent with findings from Jain et al. [10] that also reported families rank spinal surgery as one of the more beneficial interventions in the lives of children with CP. Like other studies, caregivers also would recommend children and families in similar situations progress with the surgery [16].

Caregivers are the experts in knowing their children, and, similar to the findings of Garrity et al. [20] and Marr et al. [18],



**Table 5.** Caregiver feedback and advice for other families and professionals.

Theme	Advice for future parents and caregivers	Feedback for healthcare professionals
Life with a child with cerebral palsy	<ul style="list-style-type: none"> <li>Trust your familiarity with the health care system and your relationships with the healthcare team, this can help you better advocate for your child.</li> <li>You are the expert in knowing your child.</li> </ul>	<ul style="list-style-type: none"> <li>Continue to tailor information delivery and service provision to the unique needs of the family.</li> <li>Acknowledge and trust that families are the experts in their child.</li> <li>Do not underestimate the challenges that spinal surgery will pose for families during decision making, hospitalization and caring for their child during recovery at home.</li> </ul>
Decision making	<ul style="list-style-type: none"> <li>Ask questions and seek additional information from multiple trusted and informed sources at all stages of the process.</li> <li>Making the decision to have spinal surgery is difficult and fraught with conflicting emotions. Proceeding with scoliosis surgery is worth the outcome.</li> </ul>	<ul style="list-style-type: none"> <li>Start the conversation about possible surgery as early as possible.</li> <li>Acknowledge that surgery is a major decision for families, and it may take families time to make and then adjust to the decision.</li> <li>Continue to provide opportunities for questions and encourage information-seeking.</li> <li>Offer opportunities for caregivers to speak with others who have been through the process.</li> </ul>
Be prepared	<ul style="list-style-type: none"> <li>Be as prepared as you can, for your child, yourself, and family—both practically and mentally—for hospitalization and return to home, school and community.</li> <li>Preparation may require liaising with multiple health care professionals and community agencies.</li> <li>Ask questions and seek information if you don't understand or feel uncomfortable.</li> <li>Prepare for return to school regarding expectations, equipment and timing.</li> </ul>	<ul style="list-style-type: none"> <li>Provide information about what will be required to prepare for hospital and the return to home and community. Inform families that the return home is part of the process and needs good preparation.</li> <li>Advise about the variety of potential impacts of surgery, especially potential complications, and what may be needed to accommodate these.</li> <li>Provide information about community supports following discharge such as community nurses, additional carers, after-hours and weekend contacts for emergencies.</li> </ul>
Expect the unexpected	<ul style="list-style-type: none"> <li>You can't anticipate everything, expect some aspects will not go to plan, e.g., a longer or shorter than anticipated hospital stay, time in ICU, need for surgical revisions, lengthy or speedy recovery.</li> </ul>	<ul style="list-style-type: none"> <li>Families value healthcare professionals checking in with them after surgery and throughout recovery.</li> </ul>

caregivers in this study recognised that advocating for their child and themselves was essential to manage the surgical journey. Advocacy is especially important because the children in this study, and most children with CP having spinal surgery for scoliosis, were non-speaking. Staff in busy hospitals may not have time, skills or confidence to adequately communicate with these children or to read their cues. Iversen et al. [35] also found that caregivers of children with CP can feel vulnerable in scenarios when their children are unable to express their needs, and this experience contributes to their stress.

Being prepared was integral to coping. Like the decision to have surgery, caregivers identified that the surgical journey had an impact on them, that they experienced a range of emotions related to their child's pain and vulnerability, stress of hospitalisation and recovery, expenditure of time and energy in planning and navigating the surgical process. Participants in Garrity et al. [20] study specifically identified a wish to be prepared that they may experience strong emotions to accompany the experience of surgery and to anticipate that a child might experience significant pain as part of recovery. Unexpected complications, events and outcomes were rarely expected although are reported clearly in the literature [11,16]

### Trustworthiness of findings

The findings of this study were strengthened by involvement of a parent with lived experience of spinal surgery with her daughter with CP. This involvement informed all phases of the research process, and grounded our data gathering, analysis and interpretation in that lived experience. In addition, our team includes clinicians experienced in supporting young people with CP through the rehabilitation required before and after surgery. Thus, we benefited from the insider knowledge brought by our team members. Team discussions were structured to allow us to challenge our individual interpretations of the interview text, resulting in in-depth discussions and collective agreement on the findings. The study would have been strengthened by the inclusion of the voices of those with CP, and this is a recommendation for future research.

### Implications for practice

Barnard et al. [19] proposed that the risks to the child and the challenges of the surgical journey may diminish the benefits of the spinal surgery. On balance, participants in our study identified that they made the right decision to proceed with spinal surgery. Alongside Barnard et al.'s and other studies [18,20], information from caregivers about spinal surgery will contribute valuable knowledge to support future families with decision making, preparing for surgery and recovery, and coping with the journey. Caregivers advised future families to be prepared for the practicalities of each stage of the process, and described the multiple considerations involved in navigating the surgical journey. These included having early conversations about spinal surgery where possible, doing research to seek information and understand the process of surgery from hospital through to return to the community, and managing expectations. Both caregivers and health professionals can advise future families about the substantial amount of practical preparation that is needed, encompassing mobilising additional supports and equipment, and liaison with multiple stakeholders such as hospital, community services, support workers and schools. The needs and support of the family unit also require consideration when planning for surgery and the return home. The preparation for families approaching spinal surgery in the future could be enhanced with information about *expecting the unexpected* as the unexpected may not be avoidable, and that being prepared is crucial and includes marshalling additional supports. Knowing that the unexpected could be positive outcomes and experiences, as well as negative, is also important. Detailed information is necessary to proceed with and manage surgery, and to be prepared for the experience.

### Future directions

This study provides information about the perspectives of caregivers to inform families of children with CP and scoliosis preparing for surgery as well as the health care providers supporting

them. Targeted knowledge translation strategies are now needed to ensure these stakeholders receive information to inform their decisions in ways that will impact practice and family experiences. Understanding the perspectives of young people themselves would provide additional depth to practices around spinal surgery. Most children of caregivers interviewed for this study had significant physical disability and complex communication needs. People with complex communication needs are infrequently included as research participants and their perspectives are therefore missing from the knowledge base. Dedicated resources and expertise are necessary to ensure that their perspectives are obtained and included in evidence-based practices [36]. New work is providing guidance on how to involve people with communication difficulties in research [37]. Similar research could be conducted with caregivers of children with CP, and the children themselves, for other major surgeries such as hip reconstruction and baclofen pump implants, to determine the similarities and differences in caregiver and child experiences, and provide opportunity to adapt service provision and/or adopt universal recommendations.

## Conclusions

This research on Australian caregivers' lived experiences and perspectives about spinal surgery for scoliosis in children with CP contributes evidence to the developing body of knowledge of caregiver perspectives and experiences in the healthcare literature. Knowledge gained from this study of lived experiences are invaluable in informing a comprehensive understanding of spinal surgery to support health professionals and families to optimise the experience and outcomes of surgery. Participants of this study experienced scoliosis surgery within the context of their life with a child with CP, describing the magnitude of making a decision to have the surgery, the need for substantial preparation, and how important—and difficult—it was to expect the unexpected.

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