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More than an X-ray: experiences and perspectives of parents of children with cerebral palsy when engaging in hip surveillance

Manuscript Type: Original Article

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ABSTRACT**AIM**

We explored the experiences of parents of children with cerebral palsy (CP) when engaging in hip surveillance for their child and aimed to identify the barriers and facilitators they encounter.

METHODS

We conducted a pragmatic qualitative study through five focus groups conducted with 23 parents and primary caregivers of young people with CP. A semi-structured topic guide was used to facilitate discussion. Recordings were transcribed verbatim and transcripts analysed using content analysis.

RESULTS

Six major categories emerged: 1) Hip surveillance is a shared responsibility, 2) Knowledge is empowering, 3) Hip surveillance should be proactive rather than reactive, 4) Consistency and support from health professionals is valuable, 5) Good communication is crucial, and 6) Challenges associated with having an X-ray are often not appreciated. Participants made recommendations related to: service model enhancements, information provision, and improving both communication and the experience of having an X-ray.

CONCLUSION

Despite having a good understanding of the need and importance of hip surveillance for their child, several barriers to parent engagement exist. Findings will inform the implementation of a family-

centred model for hip surveillance and may be relevant to those undertaking or planning the implementation of hip surveillance in other areas.

KEY WORDS: cerebral palsy, hip surveillance, hip displacement

WHAT IS ALREADY KNOWN ON THIS TOPIC:

- Hip surveillance is effective in reducing the prevalence of hip dislocation in children with CP by facilitating early detection and intervention
- Several barriers to health professionals' implementation of hip surveillance have been identified and reported
- There have been no previous reports of the perspectives of parents and caregivers, and the barriers they encounter

WHAT THIS PAPER ADDS:

- Barriers to parent engagement in hip surveillance include gaps in knowledge and poor communication and coordination.
- There are challenges associated with having an X-ray that clinicians may not be aware of.
- Factors that facilitate hip surveillance for parents align with principles of family-centred care and can be built into implementation models for hip surveillance.

Hip displacement is a common musculoskeletal problem for children with cerebral palsy (CP), with up to 30% developing progressive displacement requiring surgical intervention.^{1,2,3} Hip dislocation in children with CP can cause pain, reduced function and diminished quality of life.^{4,5} Detection of hip displacement through routine 'hip surveillance' is effective when it leads to earlier orthopaedic referral and earlier intervention.⁶ When surgical intervention is offered at the right time invasive salvage procedures for hip dislocation can be avoided.^{6,7}

Clinical guidelines for hip surveillance have been developed in Australia^{8,9} and many other countries.¹⁰⁻¹⁴ Guidelines have been implemented through population-based hip surveillance programs in some areas, significantly reducing the incidence of hip dislocation in those populations of children.^{15,16} Although clinical guidelines encourage evidence-based practice, the presence of a guideline is not sufficient to improve outcomes.¹⁷ Strategies are required to translate guidelines into practice. Consideration of the local context is essential, including identifying barriers that health professionals encounter when undertaking hip surveillance.^{17,18} While exploring the perspective of health professionals has been important,¹⁹ understanding challenges that families may experience is

also crucial as they play a vital role in their child's healthcare,²⁰ with optimal management relying on their engagement.²¹ Parent involvement is pivotal for key steps in the hip surveillance process, including undertaking X-rays, developing plans for monitoring, and agreement with orthopaedic referral when required.

Previous reports of parent perspectives of engaging with health services for children with CP have helped develop the concept of family-centred care, which is now considered best-practice.^{20,22} Understanding parents' experiences of engaging in hip surveillance may enable an improved, family-centred approach to implementation. This has not been studied or reported to date. To address this knowledge gap, and with the aim of informing improvements to a local model for hip surveillance, we explored parent experiences of engaging in hip surveillance, and identified barriers and facilitators they encounter.

MATERIALS AND METHODS

Study design

With no previous reports of parent's experiences of hip surveillance, a qualitative phenomenological approach was deemed appropriate for this study.²³ Study methodology was designed according to the Consolidated Criteria for Reporting Qualitative Studies (COREQ).²⁴ The Royal Children's Hospital Human Research Ethics Committee granted ethical approval (HREC #35138D).

Participants

Participants were invited via the Victorian Cerebral Palsy Register.²⁵ Invitations were sent to 200 parents of children across a range in age, Gross Motor Function Classification System (GMFCS) level, and geographical location, with reminders sent two and three weeks later. The study was also advertised through e-newsletters of a CP research centre²⁶ and parent support network.²⁷ Forty-nine parents indicated interest: 18 could not be contacted, 2 were ineligible (child's age >21 years), and 6 expressed interest but did not attend a focus group.

Data collection

Focus groups were utilised to capture participants' experiences in a non-threatening environment.³⁰ Open ended questions were developed based on academic literature and clinician experience (Table I) and were piloted with a parent advisor and experienced researchers and clinicians in the field.

Focus groups were held at metropolitan community centres or by teleconference to facilitate involvement of participants across the state. They were conducted by two authors (RT, KW), both physiotherapists with postgraduate research degrees and prior experience conducting qualitative research. All groups were facilitated by a primary moderator (RT), with a second moderator (KW) seeking clarification from participants and making field notes. Discussion was digitally recorded and transcribed verbatim.

Analysis

Transcripts were analysed using content analysis.³¹ Data were initially coded deductively by two authors (RT, KW) according to the topic guide (Table I), then inductively through a process of open coding and categorisation.²⁷ This iterative process involved several stages of independent review followed by discussion that continued until consensus regarding codes and categories was achieved. Data were managed using NVivo software (Version 11, QSR international, <http://www.qsrinternational.com>). Credibility of analysis was sought through member-checking,²³ with a results summary sent to participants for review and feedback regarding the extent to which the analysis reflected their experiences.³²

RESULTS

Twenty-three caregivers participated. Their children represented a range in age (2-19 years) and GMFCS level (Table I). The majority resided in areas classified as a Major City of Australia,²⁸ with relative socio-economic status classified average or advantaged²⁹ (Table II).

Five focus groups, two face-to-face and three by teleconference, were conducted (mean length 84 minutes; range 74-108). Six major categories emerged about parent experiences of hip surveillance with no changes suggested by the single respondent to the member-checking process.

Representative quotes are presented for each category, with pseudonyms used to maintain privacy.

1. Hip surveillance is a shared responsibility

Participants described that several health professionals can be involved in their child's hip surveillance, including paediatricians, physiotherapists and rehabilitation teams. This can be a hindrance, as it is unclear who holds responsibility:

"I don't actually know who is supposed to be [responsible]. I think it should be rehab ... [they know how] his legs are going more than the paediatrician... but she's the one they've said needs to be in charge of it. So I don't really know" (Mary; son, 8 years, GMFCS II)

As discussion evolved, parents identified themselves as being positioned to take some responsibility for their child's hip surveillance:

"I sort of see myself as in some ways responsible for making sure that we're having regular surveillance" (Donna; son, 8 years, GMFCS IV)

"I agree with Donna that ultimately as the parent I feel that I have some responsibility in making sure this happens" (Annette; son, 12 years, GMFCS III)

Ultimately, there was consensus among parents that hip surveillance works well when responsibility is shared:

"It's like a three way thing between ourselves as parents, our physiotherapist and our orthopaedic specialist and all of us having input" (Anna; son, 12 years, GMFCS V)

"It really needs to be a parent in partnership with whatever department, team, hospital is closest or most directly related to managing the hip" (Donna; son, 8 years, GMFCS IV)

2. Hip surveillance should be proactive rather than reactive

Parents identified that 'reactive' hip surveillance, when remembered and organised during a consultation, can lead to longer intervals between hip surveillance episodes and create anxiety for parents while they await results:

"I don't even think I've had the results...I'm sitting here freaking out cause I don't know where he's at" (Prue; son, 3 years, GMFCS II)

There was general agreement that parents prefer hip surveillance to be organised proactively by having an X-ray booked immediately prior to a medical appointment, facilitating immediate discussion about the findings and future planning:

"We'd get the X-ray and an hour later we'd see the X-ray with first the registrar and physios...and then the surgeon will come in and give his run down...then I'd get a letter"

explaining what the view is...so that kind of ticked all the boxes” (Michelle; 10 year old son, GMFCS V).

Parents highlighted that coordination of services is necessary for hip surveillance to be organised proactively, such as having a physician review, an X-ray and an appointment with an orthopaedic surgeon on the same day:

“I know the hospital does try to facilitate that when they can...it’s really very beneficial if we can manage to only take one day out of school or work to do two or three appointments” (Dianne; son, 13 years, GMFCS II)

3. Consistency and support from health professionals is valuable

Through the discussions, continuity in care emerged as a facilitator of hip surveillance. Parents valued having consistent and supportive health professionals to guide them through the process, identifying that hip surveillance can be difficult when they see multiple services, or have frequent changes in clinicians.

“Continuity of care has made a big difference so in situations where we’ve been able to have the same health professional looking after us over an extended time period I think that’s made an enormous positive difference...In some health services we see different people frequently and that has a negative impact” (Anna; son, 12 years, GMFCS V)

When discussing supportive health professionals, parents frequently identified physiotherapists as key facilitators of hip surveillance and as trusted and accessible sources of information and advice:

“We were just lucky that we had a good physio who put me onto this one who put me onto that one and the next thing you know suddenly you’re doing [hip surveillance] and you didn’t even plan it” (Alison; daughter, 12 years, GMFCS IV)

“She [the physiotherapist] is sort of my go to girl because she’s at the ground level with [my son] and obviously professionally she picks up a lot of things that I don’t notice” (Kelly; son, 11 years, GMFCS V)

4. Knowledge is empowering

Parents discussed the importance of having knowledge about hip surveillance in enabling them to feel empowered to play a key role:

“Knowledge is power... once you know what it’s about the anxiety levels drop” (Prue; son, 3 years, GMFCS II)

“[providing information] gives [parents] a sense of control in an area that is really uncontrollable” (Donna; son, 8 years, GMFCS IV)

Parents generally had a good understanding of the cause of hip displacement. Hip surveillance was understood to be more than simply taking an X-ray, but a long-term monitoring process to identify hip displacement and facilitate orthopaedic assessment, with the aim of providing surgical intervention when needed to prevent future negative consequences of dislocation:

“Our understanding is around...lack of consistent weight bearing to help the joint develop correctly and the abnormal forces that kids put on it...for us it wasn’t just about having a look at how enlocated [the hips] were...it was also having to pick the right time for any surgeries he might need to have.” (Donna; son, 8 years, GMFCS IV)

However, some parents felt less informed about certain aspects of hip surveillance including how the frequency of surveillance is determined, the effectiveness of interventions for hip displacement, and potential risks of radiation exposure during X-rays. Overall, lack of knowledge was identified as a barrier to engaging in surveillance:

“They’ve just said he needs hip x-rays...there’s no ‘what you need to do to help try and stop [hip displacement]’...so for us there’s quite a big gap” (Mary; 8 year old son, GMFCS II)

Feeling uninformed was often related to receiving inconsistent messages from different health professionals, or a lack of time available to discuss hip surveillance during appointments:

“Sometimes I have felt that I’ve been rushed out the door...without being given adequate time to ask the questions that I needed” (Kelly; son, 3 years, GMFCS IV)

5. Good communication is crucial

Parents reported that their knowledge and role in hip surveillance is enhanced when they are included in communication:

“Communicating together...that’s very helpful...when everybody’s [copied in] that’s very helpful because then everybody’s receiving the same information and so they’re all up to date...”

(Dianne; son, 13 years, GMFCS II)

No single format of communication may suit all parents:

"I need to have that verbal discussion...If I was to pick one [format]...it would be the verbal [discussion]" (Helen; daughter, 8 years, GMFCS IV)

"I like the written...even though I don't understand a lot of the jargon, sometimes it prompts me to think of other questions that I hadn't at the time of the consultation." (Dianne; son, 13 years, GMFCS II)

It also became apparent that written communication can include terminology that is difficult for parents to understand. They described potential for a greater understanding and ability to play an active role in hip surveillance if reports were written in plain language:

"I don't feel like the language in those letters are written aimed at myself...it's definitely for other health care professionals...it makes me think, should we be the audience?" (Helen; daughter, 8 years, GMFCS IV)

6. Challenges associated with having an X-ray may not be appreciated

The challenge of having an X-ray was an unanticipated but common point of discussion. Parents identified transferring and positioning their non-ambulant child as particularly difficult:

"It's the practical issue of getting (your) child onto the table and holding them...I have to get my husband to take the morning off work to come and help me" (Anna; son, 12 years GMFCS V)

Several described their child's anxiety during the procedure:

"She'd always freak out about it...especially as she got older she became very anxious about it even though it's completely painless" (Amy; 16 year old daughter, GMFCS III)

The importance of maintaining their child's dignity during the radiograph was also highlighted:

"they're expected to strip off...it'd just be nice if there's a level of modesty...even just a sheet that they could pop over them" (Cheryl; son, 19 years, GMFCS IV)

Parents suggested that health professionals may not be aware of these challenges:

"It just seems like it's a simple thing to just go on and get an X-ray but for us it's something that we dread having to do" (Helen; daughter, 8 years, GMFCS IV)

DISCUSSION

All children with CP should have hip surveillance, making it an experience relevant to all families. Health professionals' experiences of implementing hip surveillance have recently been reported,¹⁹

however this is the first known study to report the perspective of parent and caregivers. Whilst experiences are individual to each caregiver, our qualitative approach allowed common categories to emerge and, importantly, has given a voice to families. The range in their children's age and GMFCS classification enabled a broad range of parent experiences of hip surveillance to be captured - from children for who surveillance has just begun, through to those who have been under long-term surveillance, and capturing the experiences of parents of both ambulant and non-ambulant children.

The findings have implications for efforts to improve hip surveillance processes. Pragmatically, they will enhance family-centred implementation so that hip surveillance may be more accessible and better accepted by parents. Building partnerships, a proactive approach to coordination, and clear reporting and communication are important considerations for the future. Providing necessary information in radiology referrals, such as requiring a hoist for transfers for a non-ambulant child, may improve the X-ray experience for many children and parents. Addressing barriers encountered by both families and clinicians may facilitate engagement in surveillance from both perspectives.¹⁷ A survey of health professionals identified that clinicians perceive lack of adherence to their recommendations to be associated with limitations in parent understanding of the importance of surveillance.¹⁹ Parents reported feeling more empowered to play an active role in their child's hip surveillance when they are informed and educated about its value. Provision of information to parents through multiple formats will be central to enhancing their engagement.

Interestingly, the study categories align with knowledge regarding family-centred care for children with CP. The main factors that render care 'family-centred' include communication, partnership, availability and accessibility, advocacy and coordination, information and education, and counselling.²⁰ Each of these factors align with the categories that emerged in this study. These principles of family-centred care have also been reported in other qualitative studies exploring the experiences of parents of children with CP, including engaging in therapy³³ and transitioning to adult services.^{34,35} This consistency supports the use of the study findings as guiding principles in developing family-centred hip surveillance services. While consideration of the local context remains important for knowledge translation, this study's findings may be useful to services seeking to establish or improve models for hip surveillance. For example, the challenges associated with having X-rays may influence family engagement and highlight a need to consider this component from a

family perspective. Clinicians may also seek to enhance their communication with parents and the other health care providers supporting their child.

While the findings have implications for practice, some limitations are acknowledged. The majority of participants resided in areas classified as a Major City of Australia,²⁸ either a suburban area of the state capital or a major regional city, and tended to live in areas with greater socioeconomic advantage. Therefore, findings may not represent experiences of families living in rural and remote areas, or of those from areas with relative socioeconomic disadvantage. Further consultation may be necessary prior to implementation in these areas. In a broader context, application of the findings may also be limited within health services in developing countries or in locations without universal health care.

Together with information gained through a survey of health professionals,¹⁹ our findings will inform improvements in the implementation of a state-wide hip surveillance model for hip surveillance. Awareness of family experiences and the barriers encountered when engaging in hip surveillance may guide clinicians or health services in other areas to establish family-centred hip surveillance services that are well accepted by both families and health professionals.

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Table I Topic guide and exploratory questions

Primary question	Potential secondary questions
<ul style="list-style-type: none"> Can anyone share what they understand hip surveillance is? 	<ul style="list-style-type: none"> What is hip displacement? Why do children with CP develop hip displacement? Why does your child require regular X-rays of their hips? What does hip surveillance mean for your child? What do you understand about how frequently children need to have hip X-rays? Are there any aspects of hip surveillance or hip displacement in children with CP that you would like to know more about?
<ul style="list-style-type: none"> Who takes responsibility for monitoring your child's hips? 	<ul style="list-style-type: none"> Is it always the same person? Who does it make sense to be the main person to take responsibility for monitoring your child's hips? When and where do you get the X-rays done? Who remembers when the X-ray needs to be done?
<ul style="list-style-type: none"> Can you tell us about your experiences of finding out the results of X-rays? 	<ul style="list-style-type: none"> What happens after the X-ray is done? Does someone share the results with you? If so, how?
<ul style="list-style-type: none"> Are there things that make it easier for your child to get regular X-rays of their hips? 	<ul style="list-style-type: none"> Has anyone ever done anything that has made it easier for your child to get a hip x-ray?
<ul style="list-style-type: none"> Are there any aspects of your child requiring regular hip X-rays that are challenging? 	<ul style="list-style-type: none"> If you could change anything about current hip surveillance process, what would it be?
<ul style="list-style-type: none"> Do you have any suggestions or ideas that might make hip surveillance easier for you and your child? 	<ul style="list-style-type: none"> In an ideal world, how would hip surveillance work for you and your child?

Table II Characteristics of caregiver participants and their children

Characteristics of Caregivers (n=23)	n (%)
Caregivers	
Mother	21 (92)
Father	1 (4)
Grandmother	1 (4)
Child's GMFCS level (n=24)	
I	1 (4)
II	6 (25)
III	4 (17)
IV	5 (21)
V	8 (33)
Geographic location (ABS RA)	
Major City of Australia	21 (91)
Inner Regional Australia	2 (9)

Outer Regional Australia	0 (0)
Remote Australia	0 (0)
Very Remote Australia	n/a†
Socio-economic status (ABS IRSAD)	
Very disadvantaged (1 st -2 nd Decile)	2 (8)
Disadvantaged (3 rd -4 th Decile)	3 (13)
Average (5 th -6 th Decile)	5 (22)
Advantaged (7 th -8 th Decile)	5 (22)
Very Advantaged (9 th -10 th Decile)	8 (35)

†No area of Victoria is classified as 'Very Remote Australia'; ABS RA, Australian Bureau of Statistics 'Remoteness Area' classification; ABS IRSAD, Australian Bureau of Statistics Index of Relative Socioeconomic Advantage and Disadvantage; GMFCS, Gross Motor Function Classification System.



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