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To cite this article: Hajar Almoajil, Tim Theologis, Helen Dawes, Jo Pierce, Andrew Meaney, Aziz Baklouti, Lara Poverini, Sally Hopewell & Francine Toye (2022): Exploring the factors that influence stakeholders' expectations and subsequent perception of lower limb orthopaedic surgical outcomes for ambulant children with cerebral palsy – a qualitative study, *Disability and Rehabilitation*, DOI: [10.1080/09638288.2021.2025272](https://doi.org/10.1080/09638288.2021.2025272)

To link to this article: <https://doi.org/10.1080/09638288.2021.2025272>



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Published online: 12 Jan 2022.



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## Exploring the factors that influence stakeholders' expectations and subsequent perception of lower limb orthopaedic surgical outcomes for ambulant children with cerebral palsy – a qualitative study

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### ABSTRACT

**Purpose:** To explore the perspectives of children with CP, their parents or carers, and health professionals on factors affecting expectations and perceptions of surgical outcomes for lower limb orthopaedic surgery.

**Materials and methods:** Semi-structured interviews were conducted with 10 healthcare professionals, 10 children and young people with CP, and 8 parents. Interview data were analysed by content analysis supported by the Framework Approach using the International Classification of Functioning, Disability, and Health (ICF-CY).

**Results:** A comprehensive list of 10 factors including facilitators, barriers, motivational and demotivational factors were identified and categorized into two overarching themes (Environmental and Personal factors): interdisciplinary collaboration, communication and information resources, holistic care, and shared goal setting are reported as environment facilitators of outcomes expectations. In contrast, reported barriers include lack of time and resources and divergent expectations. Personal motivators include family encouragement, patient's self-determination, and previous experiences, whereas personal demotivators include fear of a new environment.

**Conclusion:** The recognition of potential factors influencing expectations and perceptions of surgical outcomes could assist clinical reasoning when planning surgical interventions for ambulant children with CP. If these factors are integrated into the healthcare practice, it will most likely enhance the positive stakeholders' experiences postoperatively.

### ARTICLE HISTORY

Received 5 April 2021  
Revised 21 December 2021  
Accepted 29 December 2021

### KEYWORDS

Cerebral palsy; surgery; children; interview; factors

### ► IMPLICATION FOR REHABILITATION

- Understanding relevant stakeholders' experiences offer a positive contribution to holistic and person-centred approaches in healthcare.
- People with cerebral palsy and their caregivers require adequate information on surgery and post-surgical rehabilitation regime in order to reach informed decisions.
- Previous experiences can influence surgical expectations and subsequent perceptions of the outcome.

## Introduction

Cerebral palsy (CP), a permanent disorder of the development of movement and posture causing limitations in activity, is often accompanied by disturbances of sensation, perception, cognition, communication, behaviour, and musculoskeletal problems. CP is the most common cause of childhood physical disability, affecting 2–3 individuals per 1000 live births globally [1,2]. Musculoskeletal deformities and resulting gait abnormalities are common and progressive during childhood and lead to pathological and compensatory gait patterns [3]. Many children with CP undergo lower

limb orthopaedic surgery to address these musculoskeletal deformities with the aim of improving or maintaining mobility [4].

Lower limb surgeries for CP include release and lengthening of musculotendinous units, tendon transfers, osteotomies, and arthrodesis. Correction of musculoskeletal deformities with single-event multilevel surgery (SEMLS) has been the standard of care [5]. The surgery is complex and resource-intensive and requires extensive rehabilitation, representing a significant investment for the child, family, and healthcare system [4]. It is therefore important that the outcomes of surgical interventions encompass

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constructs that are meaningful and relevant to a range of stakeholders, including patients and their representatives, clinicians, and researchers.

Development of Core Outcome Sets (COSs) has been proposed to identify a minimum set of important outcomes to be assessed and measured in all clinical trials for particular health conditions [6,7]. Kirwan et al. defined the relevant domains to inform COSs, and noted the importance of identifying contextual factors that might “influence the interpretation of outcomes in the setting in which they are applied.” [8]. It was evident that contextual factors have the potential to support and hinder the outcomes of interest, improve the measurement of outcomes, and therefore improve the quality of care [9,10]. As such, in order to present a complete picture of the relevant outcomes, consideration must also be given to contextual factors that may influence a stakeholders’ expectations of lower limb orthopaedic surgery.

The World Health Organisation International Classification of Functioning, Disability, and Health – Children and Youth (ICF-CY) categorises the factors that influence health and health-related status [11]. It defines functioning and disability as a multi-dimensional concept relating to the body function and structure, activity and participation, and environmental factors. It also recognises that personal factors for children and their parents, such as motivation, influence an individual’s perception of clinical outcomes. In the context of CP, Bjornson et al. [12] suggested that intervention strategies could be mediated by certain environmental and personal factors in a child’s daily life: for example, availability of equipment (environment) and child’s desire to be active (personal). Therefore, investigation of the factors motivating stakeholders’ decision to undergo lower limb orthopaedic surgery is likely to form an important component of the COS development in this field.

A previous systematic review of qualitative research has identified factors that shape the experience of children and families toward lower limb orthopaedic surgery [13]. For example, the review identified the importance of support from healthcare providers and the value of a positive patient-health provider relationship: it also indicates that social attitudes toward CP can influence outcomes. The review identified two key knowledge gaps: First, few studies ( $n=4$ ) addressed the impact of the contextual factors on surgical outcomes, and second, there has been no qualitative exploration of potential contextual factors that might have an impact on healthcare professionals’ experiences. It is important to address the knowledge gap and identify factors that might contribute to the expectation of surgical outcomes in order to inform a future core outcome set in this field [14].

This qualitative study aimed to explore the contextual factors that influence stakeholders’ expectations and subsequent perceptions of health outcomes through a series of interviews with key stakeholders, including health professionals, children, and young adults with CP and caregiver’s representatives. It was conducted and reported using COnsolidated criteria for REported Qualitative research (COREQ) [15].

## Materials and methods

### Study design

A qualitative methodology using semi-structured, topic-guided interviews with relevant stakeholders. This study was approved by the Research Ethics Committee (19/SC/0357) and received R&D approval from the relevant Hospital.

### Study sample and sample size

A purposive approach to sampling was used to represent the diversity and balance of stakeholders’ demographic characteristics such as patient’s age, Gross Motor Function Classification System (GMFCS) level [16], the surgery type and time of surgery, health professionals, background, and years of experiences. This process was facilitated by a sampling matrix. Participants’ characteristics were recorded against the matrix, and subsequent attempts were made to identify participants with characteristics not yet identified in the sample, to fill the gaps.

The sample included (1) health professionals specialising in CP lower limb orthopaedic interventions or health researchers with an interest in CP or other childhood disability, (2) children with CP, aged between 8 and 18 years old, ambulant or within level I, II, III of the GMFCS who had experienced or were considered for lower limb orthopaedic surgery (3) parents/carers of children with CP meeting the above criteria. The sample was drawn from a leading hospital in the UK specialising in lower limb orthopaedic surgery for children with CP.

There are no agreed criteria for determining sample size in qualitative research [17]. Participants were recruited until data saturation was achieved. Data saturation was defined as the point at which three consecutive interviews generated no additional coded data [18,19].

### Recruitment

Potential participants who attended the paediatric orthopaedic service at the hospital between October 2019 and June 2020 and fulfilled the criteria were invited to participate by the direct care team, who asked to confirm that the potential participants were sufficiently interested and happy to discuss the research in detail with the main interviewer (HA). An invitation was sent by email to potential health professionals, asking them to take part in the study. The invitation included an information sheet making it clear that participants could withdraw from the study at any time. Written consent was obtained from participants before the interview. Participants’ demographic information was collected during the interview to ensure that the sample included a range of experiences.

### Interviews

A semi-structured interview guide was developed following a qualitative evidence synthesis [13], with the support of a range of stakeholders, including a specialist in CP orthopaedic surgery, a social scientist, researchers, a young adult with CP, and a parent of a child with CP. One researcher (HA) collaborated with a play specialist to review and validate the topic guide for children with CP. All of the team members checked the accuracy and suitability of the language, the clarity, and relevance of the questions to answer the research question. The interview guide included a series of open-ended questions to ensure that key areas were covered and to facilitate discussion, rather than a closed question and answer format [20].

All participants were interviewed by the same researcher (HA). Most interviews were undertaken in the hospital or participants’ homes. However, due to the restrictions imposed by the Coronavirus pandemic (COVID-19), five interviews with children and parents were conducted online through Microsoft Teams, which was approved by the relevant research ethics committee.

Each interview was audio-recorded and transcribed verbatim. To maintain anonymity, participants were identified by a

participant ID code. Critical and reflexive dialogue with the research team, including an experienced qualitative researcher (FT) encouraged the development of ideas grounded in the data during the interview and analysis process.

### Data analysis

Data were analysed by content analysis supported by the Framework Approach [21]. This is an approach that uses an *a priori deductive* framework to code data. The ICF-CY framework was employed as a guide in this research to ensure that major factors of interest with regard to CP and surgical outcomes were not omitted.

The individual interviews transcripts were read to get an overview of the data and to identify concepts. Each line of text obtained by transcripts was linked to the most precise ICF-CY code and category according to the ICF framework linking rules [22]. If the code was not contained in the ICF and was clearly a personal factor, it is assigned "personal factor." If the content of a code was not explicitly named in the ICF-CY categories, the "not defined" and "not covered" categories of the ICF-CY were applied.

As recommended, the linking was carried out by at least two researchers trained in the procedures of coding the transcripts and in using the ICF-CY classification system, to check for consistency of the analysis. HA, AB and LP coded health professionals' interviews, and HA and JP coded children and parents' interviews. Two researchers (HA, FT) categorised all identified codes into categories and overarching themes. Differences arising in interpretation between the researchers were resolved through discussion.

## Results

A total of 20 interviews were conducted (10 health professionals, 8 children, and parent dyads, 2 young adults individually). Participants' demographic data are shown in Table 1. Interviews lasted from 25 to 53 min.

Findings highlight 10 environmental and personal factors that could influence stakeholders' outcome expectations. The *environmental factors* referred to the environment in which the child and their family lives, and the health and care service environment. It consists of facilitators and barriers that could facilitate or inhibit optimal outcomes. The *personal factors* referred to characteristics of the child or parent such as motivation or demotivation that are likely to influence the outcome.

### Theme one: environmental factors

#### Facilitating factors

The participants talked about five environmental factors that facilitated the best outcome and these were primarily related to healthcare services: Interdisciplinary collaboration, communication and information resources, holistic care, shared goal-setting, and accessibility to equipment.

**Interdisciplinary collaboration:** A Multi-Disciplinary Team (MDT) approach was considered an important element in healthcare delivery. However, the approach was not always seen as holistic, and a parent of an 11-year-old child described the MDT as ineffective postoperatively.

Table 1. Characteristics of the sample.

Stakeholder group 1: Health professionals (HP) (n = 10)			n
Role			
• Paediatric surgeon			3
• Allied health or nurses			4
• Researchers			3
Gender			
• Male			3
• Female			7
Years of experiences			
• ≤20 years			6
• >20 years			4
Stakeholder group 2: Children with CP/parents (n = 18)	Children with CP (CH)	Parents (P)	
Role			
• People living with CP	10		
• Representatives (parents/carers)			8
Gender			
• Male	6		2
• Female	4		6
Age			
• <16 years	6		5
• 16–18 years	4		3
GMFCS levels			
• GMFCS I	1		1
• GMFCS II	6		4
• GMFCS III	3		3
Time from operation			
• Pre-surgery	4		4
• <3 years	2		–
• 3–5 years	3		3
• 6–10 years	1		1
Operation			
• Single event multi-level surgery	9		7
• Hamstrings, gastrocnemius lengthening	1		1

HP: Health Professional; CH: Children; P: Parent.

If I talk to the physio, the physio will only talk to me about his physical issues. If I talk to, for example, a medic to do with his mental capacity, then he'll only talk to me about his mental capacity, and the two seem never to talk to each other (P08, 11 y, GMFCS II)

the surgery shouldn't just be a single intervention and then is about their life rather than just their one surgery. So much more of MDT holistic (HP02, Allied Health and Nurse)

Participants highlighted the importance of physiotherapy input as part of the MDT postoperatively:

physiotherapists are better in looking at the child and multitude of motor-function tasks rather than just level of walking like most surgeons would focus on (HP10, Surgeon)

The physios and doctors would come every day, do stretches every morning, stretch on that machine which stretches my knee, my leg for about, do my exercise for about 45 minutes every morning. And that was the big, important thing in the strategy. So that's how I think it's successful (CH09, 16 y, GMFCS II)

**Communication and information resources.** Participants valued interaction and communication between health professionals, children and parents, and felt that this could have a positive impact on the child's experience and expectations.

supporting the child's choices and listening to the child and the parents of what is important. They know their child and they know what the greatest impact is (P03, 17 y, GMFCS I)

Trust is a key, to make sure that they trust us and that we listen to them. We can't block their opinion, but we have to be careful, and especially if the kid is a bit voiceless, so the parents are overpowering. We have to make sure that we hear the kid as well (HP09, Researcher)

Health professionals also described the importance of providing information about what to expect over the course of surgery and recovery. However, they emphasised that the provision of information should be based on the individual child and family's needs as there was no "one-size-fits-all" approach.

I think pre-op education, that involves everything. A complete package of what to expect (HP02, Allied Health and Nurse)

I think the balance to be had with those discussions but be led by the patient and what they want to know if it was about information (HP03, Allied Health and Nurse)

Although some parents and children reported that they were well-informed about the surgery, others said that they did not receive much information about the surgery or its consequences. A mother of a 15-year-old explained the consequences of poor information postoperatively:

One thing that I found I would have liked to have been warned about is basically after the operation he had really painful muscle spasms and I found that really scary and I didn't know why they were happening, and I started thinking maybe this is something he has developed as part of the operation and it's not going to go away. And he was in extreme pain and I didn't know why. Whereas if, maybe they don't want to put you off the operation but maybe even just after the operation they could tell you this is a really common thing that muscles are going to spasm and it'll be painful and it's just muscles readjusting to the new position, I think I would've felt better (P06, 15 y, GMFCS II)

Participants described two strategies in relation to the information provided to improve children and families' understanding of realistic surgical outcomes. First, providing comprehensive pre-operative information on what to expect from the surgery and allowing sufficient time for decision-making and questions.

I think that rush to decisions is not a good idea. I have had quite regularly families that have come to me and they have read about it, they heard information about the surgery, they are really prepared and

focused for it. My effort is to reign the enthusiasm in and give them more time for discussions to consider everything, to learn more about this from us (HP10, Surgeon)

Second, prepare the children and families by showing them a range of videos of postoperative changes. All participants emphasised the need to clearly present best- and worst-case scenarios to facilitate decision-making.

I want to know the best-case scenario, the worst-case scenario, and what is the most likely scenario. I think, if I had surgery now, I'd have a much better ability to understand and manage my expectations accordingly. So, that's important (CH07, 17 y, GMFCS III)

we try to show them not only videos of children who have had successful surgery, but also videos of children who were not the top of our results. If you only show them good results, they will assume that only good results come out of the surgery. They have to be aware that's not the case (HP10, Surgeon)

Normally if they tell [child's name] how to go about things, and they maybe then watch a video about it all, like the operation if there was an operation that they could see, so then he could understand it better. Whereas, if you talk to him about it, it does go in, but then he's like, 'Mum, I wasn't sure about that. What do they mean by that?' Whereas if he saw the video, or sort of diagrams or wherever, it gets into his head a bit better (P04, 16 y, GMFCS III)

**Holistic care.** Participants described the current focus of surgical assessment on the child's body structure and function. However, they noted the importance of a shift toward broadening the assessment beyond the child's body to include their activities and participation level. A holistic postoperative approach was described as important to help the child to have the best possible health outcomes.

we're a bit focused on structural outcomes, body structure rather than the participation and activity (HP05, Surgeon)

there was quite a bit of emphasis on I guess straight leg, having my legs straight and keeping them open. Because I had to wear gaiters for a long time to try and keep my legs straighter (CH06, 15 y, GMFCS II)

Trying to look as holistically as possible so that we've got everything covered (HP06, Allied Health and Nurse)

Participants also discussed the essential role of a shift towards patient-relevant outcomes. They were aware of the importance of seeing the child as a person in unique circumstances.

It's their lives. It's their bodies. It's what do they want? It's not what we can do, it's what do they want (HP02, Allied Health and Nurse)

it shouldn't just be, "This is the five main things that we do for post-surgery CP," because it will depend on each child (HP03, Allied Health and Nurse)

A 17-year-old young person shared her experiences on this shift:

before, I was scared that I was going to be examined, and they were going to tell me, "Well, this seems good. We need to fix this", and they're looking at something else now. So, it's going in the right direction. Most of the conversations we've had have been concerning my psychological wellbeing rather than my physical wellbeing (CH07, 17 y, GMFCS III)

**Shared goal setting.** Health professionals described the importance of shared goal setting with children and their parents. They described the importance of learning about goals from the child's perspective. Some described patients' reported outcomes as integral to clinical practice. There was also a positive attitude towards caregivers' goals and felt that it was important to include their point of view with their children's goals.



interestingly, my last couple of visits have been mostly about, 'How are you feeling about this?' Before, when I was younger, it was questions were directed to my mom and my dad. And so, it's better now. They want to know my opinion (CH07, 17 y, GMFCS III)

I think the only way to improve our treatment and get a higher percentage of children and families being happy after the operation is by understanding what makes the outcome from their perspective more positive (HP10, Surgeon)

Participants felt that the relative involvement of children and parents in goal setting is based on the age of the child. They described unrealistic goals from younger children and also recognised that a child's goals might change as they grew older.

It depends on the age of the child. Obviously. I think when they start getting pubertal, early teens, then that may change and is more of a shared decision-making process. But earlier on, I think they're just going to go with what their parents say to a certain extent (HP07, Surgeon)

However, health professionals expressed concerns that although patient and family's goals are important, this should always still combine clinical outcomes from the clinician's point of view.

the clinical outcomes are important, and they help us guide the surgeries. And how do we do research if we don't have the clinical outcome? But actually, there should be a bigger focus on what it meant for the patient and to be able to pass that on to other patients (HP02, Allied Health and Nurse)

### *Inhibiting factors (barriers)*

The participants talked about two inhibiting factors or barriers that prevent them from improving patient experiences and expectations of surgical outcomes: Mismatch and divergence of expectations and Lack of time and resources.

***Mismatch and divergence of expectations.*** Although some participants felt that their outcome expectations of child, caregiver, and professional matched, others felt that there were discrepancies and that this could have a negative impact.

much you explain that to parents, there's still this element of hope that their child will exceed the expectations that the surgeon has. I think that's human nature (HP05, Surgeon)

The levels of expectation may differ but that's because I suppose the levels of reality are different between adult and a child. We understand a bit more than a child as to what you can realistically expect to achieve against what you [child] would ideally like. And they're never going to be the same (P01, 14 y, GMFCS II)

there is differences but other than between the health professional with the children, but it's more about between their children (HP02, Allied Health and Nurse)

However, health professionals had concerns about the sensitivity of negotiating realistic expectations and the impact that this might have. For example, they felt that children and carers might expect full recovery more quickly after surgery, whereas this could take an extended amount of time. Some felt that it could be particularly difficult for children to conceptualize time in terms of surgery recovery.

some patients expectations are, I'm going to be able to walk, I'm going to be able to run. It's going to be fantastic. And that's true, but their time frames are messed up because they're children, and of course as an adult a year is a year and as a child a year is forever. Like it's the longest time in the world (HP06, Allied Health and Nurse)

immediately post-surgery, she didn't feel the goal had been met. She'd obviously thought this would happen very quickly after surgery despite us trying to meet those expectations (HP03, Allied Health and Nurse)

Health professionals described experiences of unrealistic expectations from children and caregivers of returning to a healthy "normal life" without limitation. Parents described "return to normality" as a benchmark of surgical success.

I think expectation around goals can be a little bit more around to really normalizing their child (HP03, Allied Health and Nurse)

She wants to feel more normal within an age-appropriate range (P03, 17 y, GMFCS I)

I want to get to live my life more like if you will, a normal person (CH06, 15 y, GMFCS II)

In contrast, health professionals described the importance of explaining to the child and caregiver that surgery could not return the child to "normal."

I would not promise normality to anyone really because orthopaedic surgery improves the mechanics of the lower limbs and helps to extend with walking and motor functions if it works well, but it doesn't restore normality. What I would normally tell children and families is that the problem arises from the brain and the operation is done on the legs. It's like we are not treating the problem where it is, but we're treating some of its mechanical expressions (HP10, Surgeon)

***Lack of time and resources.*** Health professionals highlighted the impact of time constraints in the clinic that prevented them from being able to measure desired outcomes.

If you want to measure a lot of these things, it will take time. And also, it is depending on how you measure them can take even longer (HP07, Surgeon)

Participants also described uncertainty about the amount of healthcare service input the child received compared to the optimal practice. Parents commented on the lack of continuous health services as a barrier to improving surgical outcomes.

they've had to reduce down the number of times that you can see a child. And we know that the rehab of post this type of surgery is so crucial to the outcome (HP03, Allied Health and Nurse)

Occupational therapy seems to be overburdened and I haven't been very impressed with the local OT. We've not had much help there. And I need to chase it up somehow. Yeah, that's the major thing that I would like with OT, because sometimes you don't know how to teach them things like putting his socks on or things like that because there are different ways of doing it that you wouldn't see (P06, 15 y, GMFCS II)

Parents also described the importance and impact of rapid access to equipment for better surgical outcomes.

You need to assess the situation they're in. Do you have the facilities at home to aid with the recovery? Will you need to move a bed downstairs, a commode, to make sure you've got everything you need? (P01, 14 y, GMFCS II)

Equipment-wise at home, we've gone from having paediatric up, down chairs that could be moved around to a stair lift to a bath hoist, and all that is gone. It's a normal house now (P02, 14 y, GMFCS III)

## ***Theme two: personal factors***

### ***Motivational factors***

The interviews identified personal motivators that might influence the outcome: family encouragement, patients' self-determination, and previous experiences.

***Family encouragement.*** Although participants described the parent's overwhelming responsibility, and the physical load involved in caring for a child with CP, they highlighted good

support and interaction between parent and child might be encouraging and motivating.

I just want to go back to work, I do. But I can't at the moment. So, I'm on my own looking after [child's name] (P03, 17 y, GMFCS I)

I don't think you can put in the amount of work that's needed after the surgery to get the best benefit. Because it was like 24-hour care really (P06, 15 y, GMFCS II)

I think the parents take a lot of responsibility to engage their child to encourage (HP02, Allied Health and Nurse)

I want my family to support me, and challenge me a bit more, like walk, walk up step (CH02, 14 y, GMFCS III)

**Patients' self-determination.** Health professionals and children described personal characteristics, such as self-determination, the drive to be the same as everyone else and to be independent, and aesthetic motivations.

the child motivation always seems to be, they just want to keep up with what's happening around them and they don't want to be left behind. And I think that's a great motivation (HP02, Allied Health and Nurse)

I think sometimes motivations are not spoken, and that can be, often, along the aesthetic line (HP05, Surgeon)

Considering how big a deal the operation was, I didn't want to waste it or anything, I didn't really want to end up [other people] helping me in the end (CH06, 15 y, GMFCS II)

**Previous experiences.** A positive previous experience in the hospital was also felt to be helpful to facilitate the child to keep up with the surgery regime and stay motivated.

I've had the surgery, it was very successful. It helped me in many ways. It had a big impact in my life in a good way. I can do a lot of many good things in my life now that I wasn't able to do before and it was just a big success, so I would recommend it to them (CH09, 16 y, GMFCS II)

a lot of their experience in hospital can be based on their previous experiences. Some of the things we do where we've done the right side and then they've come back in to have the left done, you get a lot of anecdotal about how it's made— so, for example, some of the foot surgeries that we do, how it's made life so much easier. Their shoes are fitting better, their AFOs are easier to fit. And so, they're then excited about the prospect of having the opposite side done (HP02, Allied Health and Nurse)

### **Demotivational factors**

The interviews identified fear of a new environment as a personal demotivator that might influence a child's motivation postoperative.

**Fear of new environment.** Participants described fear, anxiety, and stress of the unknown or feeling frustrated in a new environment might demotivate the child and family pre- and post-surgery.

a lack of experience means that it is a huge amount of fear of the unknown (HP06, Allied Health and Nurse)

They might have no experience of hospitals and as such there's the chance that just walking in the hospital doors is terrifying. Whereas, you know, for us walking in the doors, this is every day. I suspect that quite a lot of it is anxiety led (HP06, Allied Health and Nurse)

To reduce the level of fear and uncertainty, participants felt that meeting other families may help to motivate the child toward the surgery and manage expectations.

I think meeting with other families who have been through the surgery can be helpful (HP05, Surgeon)

a support network for parents, again, would have been really useful, really useful. I think it would've helped us and it would've helped [child's name], ultimately (P07, 17 y, GMFCS III)

Health professionals described how demotivation could have an impact on the child's positive outcome of surgery.

I have certainly seen poor results in children or families who wasn't enough motivated after the surgery to achieve a good result (HP10, Surgeon)

## **Discussion**

This study reports a list of 10 factors that could influence stakeholders' expectations and subsequent perceptions of surgical outcomes, which were organised under four sub-themes: facilitating factors, inhibiting factors (barriers), motivational and demotivational factors. These findings add insights to support healthcare system changes to provide optimal care to ambulant children with CP.

The study described the importance of interdisciplinary support in CP care. The complexity of the condition can make treatment challenging and requires a multidisciplinary approach, particularly with major surgery. Having available teams with special CP competence to assist in challenging situations of the surgery in terms of safety, physiological, psychological, and social impact on the child's pre- and post-surgery care is likely to improve the quality of the CP care. Mineiro et al. [23] emphasised the importance of a multidisciplinary approach when considering surgical correction of spinal deformities in CP and noted that this approach improved not only the outcome of surgery but also the patients' and carers' quality of life and satisfaction.

The study highlights a novel shift toward understanding children and parents' priorities and needs following lower limb surgery by applying a holistic approach to goal setting. Briffa [24] revealed that understanding children and parents' priorities and goals may have implications for improving compliance and perception of surgical outcomes. However, our study highlights potential challenges to a holistic approach due to time constraints, availability of equipment, and limited resources such as availability of rehabilitation services. The study indicates that adequate access to rehabilitation services for those with CP undergoing surgery is integral to the delivery of good outcomes. This resonates with a previous review by Van Bommel et al. [25].

In addition to multidisciplinary and holistic approaches, the findings support the need to build on communication and provide clear information. Although it is unsurprising that children and families undergoing surgery may not understand all the information given to them and may have unrealistic expectations, our findings confirm the importance of providing clear information and ensuring that patients understand this information prior to surgery. Our findings indicate that parents wish to receive as much information as possible in order to make a fully informed decision about surgery and that better-informed children and parents might result in more realistic expectations. These findings are consistent with other studies, demonstrating that the patients highly value complete information [26–28].

Based on the participants' experiences, motivation such as family or carer encouragement and the intrinsic reward of achieving valued outcomes were identified as facilitating positive expectations. This, in turn, encourages children to adhere to the surgical regime and postoperative rehabilitation. Bartlett et al. [29]

highlight the importance of personal factors (e.g., the motivation of a child with CP) and family factors, in facilitating improvement in the motor ability. This resonates with our own findings and indicates that it is important to consider contextual factors as key elements in the clinical reasoning and decision-making strategies when applying the ICF-CY framework for clinical goal-setting [30,31].

Previous experiences and preoperative anxiety and uncertainty of the unknown were considered to have a role in enhancing or hindering child and family motivation and influencing their perception of surgical outcomes. For some, orthopaedic surgery was described as a stressful experience that evoked previous experiences and feelings during different stages of surgical recovery. These phenomena are in accordance with other studies of paediatric surgery [32,33]. Thus, providing educational and realistic information about the potential effects of surgery, and the risks of complications or expected adverse effects, are considered a prerequisite for children and families to be able to make an informed decision about the surgery.

This research forms part of the third component of the core outcome set study, for which the method was established *a priori* in a study protocol that had undergone a robust peer-review process [14]. The coding and analysis were undertaken by a minimum of two experienced researchers. The factors identified by the participants will be used, as part of an ongoing research study, to develop a core outcome set in the field of lower limb orthopaedic surgery for ambulant children with CP.

A potential limitation of this present interview study is that participants are stakeholders of one orthopaedic hospital. However, that hospital covers a wide geographic area of South England. Qualitative research does not report statistical findings and does not aim to represent a particular population: rather, it aims to generate ideas from a purposive sample that will help us to understand a particular experience.

The results of this study highlight factors that influence outcome expectations and perceptions of lower limb surgery in CP. The facilitators and barriers addressed by participants can be supported by person- and family-centred care services, holistic approaches, supporting team-based care provision, and providing adequate information for shared decision making. If these elements are integrated into the healthcare practice, it is likely to enhance the stakeholders' experiences postoperatively.

### Authors' contributions

HD, FT, SH, and TT supervised the field research. HA, FT, HD, and TT contributed to the design of the study. HA, AM, and TT contributed to data collection. HA, FT, JP, AB, and LP contributed to data analysis. HA and FT drafted the manuscript, with significant inputs from all co-authors. All authors reviewed and approved the final version of the manuscript.

### Disclosure statement

The authors have no conflict of interest to declare. The views expressed are those of the authors and not necessarily those of the NHS, the NIHR, or the Department of Health.

### Funding

HA is funded by a postgraduate scholarship from Imam Abdulrahman Bin Faisal University, Saudi Arabia. HD is funded by

Elizabeth Casson Trust and the NIHR Oxford Health Biomedical Research Centre.

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