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CHILDREN'S ORTHOPAEDICS

"Waiting for the best day of your life". A qualitative interview study of patients' and clinicians' experiences of Perthes' disease

A. M. Galloway,
S. Pini,
C. Holton,
D. C. Perry,
A. Redmond,
H. J. Siddle,
S. Richards

From University of Leeds, Leeds, UK

Aims

Perthes' disease is an idiopathic avascular necrosis of the developing femoral head, often causing deformity that impairs physical function. Current treatments aim to optimize the joint reaction force across the hip by enhancing congruency between the acetabulum and femoral head. Despite a century of research, there is no consensus regarding the optimal treatment. The aim of this study was to describe the experiences of children, their families, and clinicians when considering the treatment of Perthes' disease.

Methods

A qualitative study gathered information from children and their families affected by Perthes' disease, along with treating clinicians. Interviews followed a coding framework, with the interview schedule informed by behavioural theory and patient and public involvement. Transcripts were analyzed using the framework method.

Results

A total of 24 interviews took place, with 12 child/family dyads and 12 clinicians from UK NHS centres. Interviews identified widespread variation of routine care. Children/their families recounted positive experiences when included in the decision-making process for treatment. There is a strong desire from clinicians and children/families for consistent guidance from everyone involved in care, which should be based on clinical consensus.

Conclusion

This is the first study to describe how children/families and clinicians experienced receiving or providing treatment in Perthes' disease. The results indicate the need for robust evidence to support treatment decisions. Children and families valued feeling involved in the clinical decision-making process. Clinicians acknowledged the central importance of providing patient-centred care, particularly in the absence of robust evidence to guide the optimal treatment decisions. This study will inform a future Delphi project to develop clinical consensus guidelines for the treatment of Perthes' disease.

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Introduction

Perthes' disease causes substantial pain, joint destruction, and limited function as a result of avascular necrosis of the developing femoral head.[1] The aetiology is unknown and incidence rates vary based on geographical location. The incidence in the UK was 5.7 per 100,000 children. Within the UK, there are notable differences between rates in the northwest (9.5 per 100,000) and the south (4.6 per 100,000) of the country. Previous work also identified a link with socioeconomic deprivation.[2]

Current treatments, including surgical and non-surgical interventions, aim to optimize the congruency of the hip joint and the spherical regrowth of the femoral head. Widespread variation of clinical care in the

Correspondence should be sent to Adam Marco Galloway; email: adamgalloway@nhs.net

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UK has been described.[3] The recent British Orthopaedic Surgery Surveillance study provided insight into the management of Perthes' disease in 143 of the 144 NHS hospitals treating children's hip disease in the UK.[4] Definitive non-surgical treatment remains the most common approach for children affected by Perthes' disease, however there is a lack of robust evidence or consensus on the type, timing, or duration of any intervention.[5] The British Society for Children's Orthopaedic Surgery and the James Lind Alliance have identified Perthes' disease as a priority for research to establish optimal treatment pathways.[6,7]

To optimize treatment approaches, it is important to ensure that interventions meet the needs of key stakeholders.[8] To do this, the experiences of children and families receiving clinical care, and of the clinicians treating them, must be explored. This is something that has, until now, not been addressed. The aim of this study was to investigate the experiences of treatment from children affected by Perthes' disease, their families, and the clinicians providing care. While qualitative research is not common in the paediatric-orthopaedic literature, it is widespread in other healthcare disciplines.[9] Recent studies have explored the experience of care using similar interview methods to those outlined here.[10]

Methods

Design. Qualitative interviews were conducted to explore the experiences of key stakeholders comprising two subgroups: 1) children and families; and 2) treating clinicians.

Sample and recruitment. Child and family participants consisted of children with Perthes' disease, who were interviewed alongside a family member (dyad). Child/family participants were recruited from three UK NHS centres (North West England, West Yorkshire, and East Yorkshire/Humber) that commonly treat Perthes' disease. They were recruited after being identified as potential participants during a clinic appointment. Children/family participants were eligible if the child was between five and 16 years old, and had a diagnosis of Perthes' disease initially made between one and five year ago. If eligible, the study was briefly explained and, if happy to proceed, their email address was given to the lead researcher (AMG). An email study invite was then sent, which included instructions for providing informed consent. After this the interviews were booked and completed through a video call. Assent was gained from the child through explanation of the process at the start of the interview.

Clinician participants were recruited from a range of locations around the UK and consisted of a variety of surgeons, physiotherapists, and nurses. This was in response to an advert shared using social media, and emails to orthopaedic centres and specialist interest professional bodies. Participants were eligible if they had at least two years of experience treating children with Perthes' disease as part of their routine practice. A total of 12 clinicians were recruited to the study. This number provided heterogeneity in the sample (by clinical background), and interviewee recruitment ceased once saturation in the data was reached. Consent for clinicians followed the same process as the child/family participants.

In order to address diversity and representation in the sample, child/family participants were purposively sampled from three NHS sites based on characteristics important to the research questions. Characteristics included age, sex, and whether they had previous surgical intervention.

Data collection. Interviews were conducted via video call due to social restrictions imposed by the COVID-19 pandemic. Prior to the pandemic, video calls were not commonly used for interviewing, although some studies used this method to good effect.[11,12] The video call included a period of time prior to the start of the interview to build rapport with the child. We used photographs, drawings, and similar items that bring the child comfort (e.g. toys/books), suggested through previous research,[12] to open a dialogue and put the child at ease to enhance conversation.

Interviews were conducted between January and June 2022. Interviews followed a topic guide informed by Patient and Public Involvement (PPI) and were underpinned by two behaviour theories relevant to this topic: the Social Determinant Theory and Socio-Ecological Model.[13,14] Both of these theories consider the motivation and factors affecting the behaviours and actions of people, and were well aligned with the aims of this study. The main constructs of both theories informed to the overall framework and content of the topic guide. The questions for both participant groups concerned their experiences of Perthes' disease treatments and their involvement in decision-making. Interviews also included questions concerning the level of agreement and their awareness of the evidence for treatments in Perthes' disease. The topic guide can be viewed in Supplementary File 1. Following the interview, audio files were exported and transcribed verbatim.

This study was awarded a favourable opinion by NHS West of Scotland (REC 1 01/12/2021; IRAS ID 21/WS/0138).

Statistical analysis. Interview transcripts were organized using NVivo (Lumivero, USA) and analyzed using the Framework Method.[15] This method is commonly used to analyze qualitative data, and uses a deductive structured approach by predetermining 'codes' based on underlying evidence or theory. Here, codes were developed using previous literature and PPI input. They related to variation of care, outcomes for patients, and agreement on treatment approaches (Table I).

Table I. Analytic framework developed to support coding.

Coding label	Concepts	Clinician description	Child description	Family description
Variation of care*	Different approaches in different settings/trusts, i.e. clinical uncertainty.	Usual care at current employer Differences in approaches across time, including changes within their own practice Variation of what defines 'conservative' or 'non-surgical' Variation within 'surgical/surgeon' management	Experiences with different doctors or speaking to peers with Perthes' disease who have had different care.	Different approaches that have been used by different specialists previously seen Comments about the management of other children with Perthes' disease
	Needing/wanting guidance regarding decision-making.	Lack of evidence to support the clinical decision-making and decisional uncertainty. Need for consensus.		Family wanting guidance and some reliable information for decisions on treatment.
Assessing patient outcomes*	Patient-reported and clinical outcomes	Debate about what a good outcome is – short-/long-term outcomes Discussing outcomes with patients to inform treatment decision-making.	An understanding of what their outcomes are/might be. Can be long term (good hip shape) or short term (reduced pain/no surgery).	Mentions of short- (pain, function) or long-term (surgery as adult, hip condition by end of disease process) outcomes.
COVID-19†	Theme emerged from interviews	Impact of COVID-19 pandemic on delivery of clinical services Impact of COVID-19 on patients/families with regards to their status (activity/pain levels).	Impact of COVID-19 on child's ability to take part in activities or hobbies Change in Perthes' disease condition during pandemic (pain, stiffness, etc.).	Impact of COVID-19 on care provision for child/family (quality and quantity) Experiences during pandemic that are different to pre-pandemic.

*Note that codes 1 and 2 broadly followed the theoretical framework for this study.
†Code 3 (COVID-19) was inductive and emerged from the dataset.

Framework analysis also allows for an element of induction, as new codes/themes can emerge during data collection.[16] The Framework methodology is rigorous but can be time-consuming, and therefore relies on having experienced members of a team to assist with this (SR, SP). The first three interviews of each participant group were coded by AMG, with clinician interviews moderated by SR and child/family interviews moderated by SP. The moderators have over ten years' experience in this methodology. Review from second and third authors was completed to ensure that the codes were grounded in the data. More detail of the process for design and implementation of this theoretical framework can be seen in Figure 1.

Results

Participant characteristics are presented in Table II. Of 21 child/family dyads identified as eligible for this study, 12 were interviewed. Dyads varied in terms of age (mean age of child 10.8 years (6 to 16)). Three of the 12 participants were female, which was consistent with the known sex distribution of Perthes' disease. There was an even divide in the number of children who had undergone previous surgery and those who had not. Clinician participants included children's orthopaedic physiotherapists, consultant surgeons, and a clinical nurse specialist. As intended with the purposive sampling, there was similar representation from surgeons and physiotherapists. There was a larger proportion of female consultant clinicians in this dataset (9/12 participants), and the mean duration of interviews was 23 minutes (12 to 44).

The results are presented within three main themes and illustrated with a sample of quotes. A quote table, including the fuller dataset, is presented in Supplementary File 2. Thematic tables displaying the frequency of each theme mentioned by the participants are presented in Supplementary File 3. The final list of codes/subthemes included can be viewed in Supplementary File 4. The main themes are: 1) variation of care; 2) assessing patient outcomes; and 3) COVID-19.

Theme 1 – Variation of care. Throughout the course of the interviews, participants demonstrated the variation of care they had experienced both as part of a clinical team, and as the child/family receiving the care. Variation also presented itself when discussing the evidence to support decision-making, which prompted a lot of discussion about the disagreement and uncertainty among clinicians.

The variation of approaches clinicians had made along the course of their career was evident:

> "In the early years in my practice, I probably operated on more than I would now. And I have a suspicion that they're the ones that had the good outcomes, so they're probably the ones that if I left alone would probably have done quite well as well."
>
> Surgeon 1

> "When I first started work all the information (regarding activities) was 'no impact.'"
>
> Physiotherapist 4

Participants also described the current usual care they provided, and their focus being around maintaining function and activity for children with Perthes' disease.

> "Early physiotherapy I feel is really important."
>
> Surgeon 3

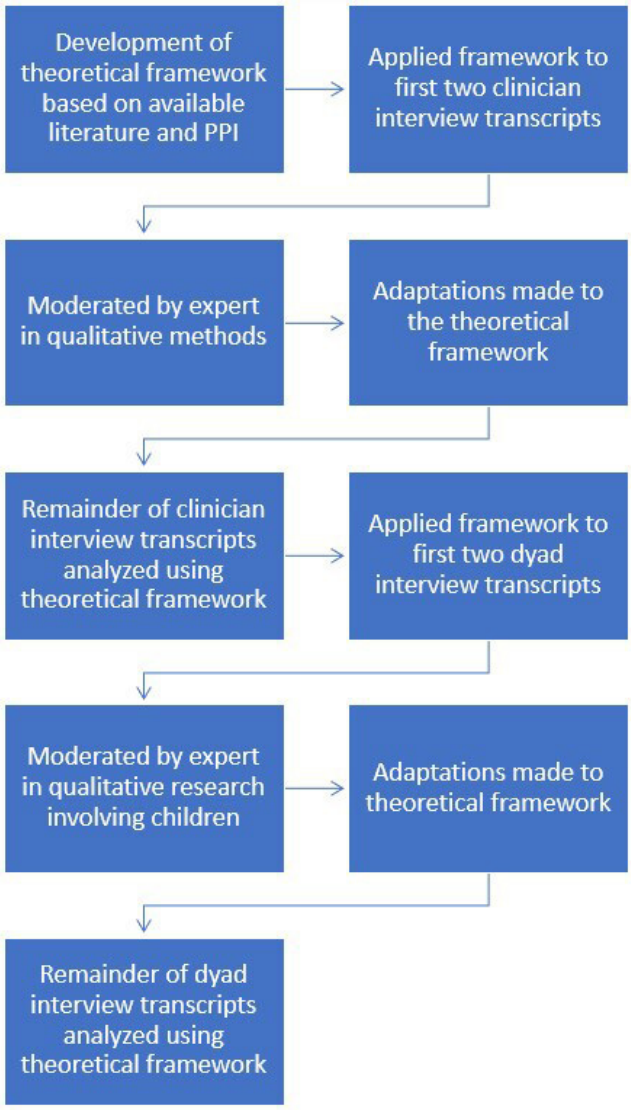

Fig. 1

Process of theoretical framework design and application. PPI, Patient and Public Involvement.

Activity modification is common in Perthes' disease, and while no robust evidence guides the degree of modification in clinical care, many report some modification while attempting to maintain a level of 'normality'.

> "Our approach is to avoid bouncy castles and trampolines, but otherwise let them have a normal life."
>
> Surgeon 5

Child/family participants were aware that variation in care existed, and that there was disagreement among clinicians regarding the optimal treatment.

Table II. Characteristics of study participants.

Characteristic	Child	Family	Clinician
Participants, n	12	12	12
Female, n (%)	3 (25)	11* (92)	9 (75)
Mean age, yrs (range)	10.8 (6 to 16)	N/A	N/A
Previous surgery, n (%)	6 (50)	N/A	N/A
Physiotherapist, n (%)	N/A	N/A	6 (50)
Surgeon, n (%)	N/A	N/A	5 (42)
Clinical nurse specialist, n (%)	N/A	N/A	1 (8)

*Ten mothers and one grandmother (one father also included).
N/A, not applicable.

> "That's what [my consultant] said. He was like, I'm so sorry, if you go and see any consultant, we'll all say something different."
>
> Mother of ten-year-old male
>
> "There are so many different treatments, nobody agrees."
>
> Surgeon 1

Though accounts of the variability of care arose in most interviews, it is important to note that the inclusion of children/families in the decision-making was well received and valued. Recommendations were made for clinical interventions, but it was clear that children/family members were involved in those decisions and it was a collaborative approach to doing what is best for the child.

> "At every point along the way we've had a choice, haven't we? So with the osteotomy, even though that was what was recommended...there was still a choice."
>
> Mother of 16-year-old female

Theme 2 – Assessing the outcomes. Understanding the outcomes is of central importance to children with Perthes' disease, their families, and the clinicians treating them. In this theme, quotes illustrate the concern from clinicians and families about the uncertainty around things such as how long Perthes' disease will last, and the rationale for treatment approaches.

This quote is one of many that highlighted the lack of ability to measure the effect of the interventions currently available to clinicians. This uncertainty around the best outcome for the child leads to clinical staff having substantial uncertainty when treating these children.

> "You see a child with Perthes' and you genuinely don't really know in your heart of hearts the best treatment for them."
>
> Surgeon 4

The uncertainty was not only with clinical staff: children shared their insight and feelings towards the long-term outcomes of Perthes' disease, such as whether they may need a total hip arthroplasty. For instance, the following

quote highlighted the impact that Perthes' disease has had on this child, irrespective of clinical outcomes.

> "I'm just...I don't know, I'm just waiting for it to go, if you know when it's going to go, you're waiting for the best day of your life basically."
>
> Ten-year-old male

Participants explained what a good outcome would be for them. The grandmother of a seven-year-old recounted her grandson saying, "*if it means getting rid of the pain, I'll have the operation*". Similarly, clinicians talked of quality of life and function:

> "I'm thinking about the child, I don't want them to be in pain, I don't want them to be limping, I don't want them to be off school for six months so that they get mental health issues."
>
> Surgeon 3

Insight from children, families, and clinicians highlighted that the real focus of any treatment approach is to reduce pain, and improve function.

Being able to provide a rationale and apply clinical reasoning for an intervention is based on many factors, some of which are based on robust evidence (information) and consensus (agreement among clinicians). In the first theme, the lack of agreement can be seen. When referring to the long-term outcomes, participants described the need for information, summarized effectively here:

> "You can't manage anything unless you have information."
>
> Physiotherapist 3

Once again, the level of involvement that children with Perthes' disease have or want in their own care was ever-present. It was clear not only in the interviews with the children themselves and their families, but in the interviews with clinical staff, who shared their experiences of patients at the centre of their own care.

> "No matter how young the kids are, they want to be involved in their own care on the whole."
>
> Physiotherapist 4

This is something that was echoed by child/family participants. For example, the next quote demonstrates the impact that information sharing and inclusion has had on this child, but could also have on other children with Perthes' disease:

> "He can't go and join a football team, he's not allowed to go on a bouncy castle, if he could have a bit more understanding of why he can't do those things, that's the one thing that he really, really, struggles with."
>
> Mother of six-year-old male

Theme 3 – COVID-19. The final theme was not part of the original coding framework, but emerged as participants spoke about how the COVID-19 pandemic restrictions had greatly impacted on their experiences of delivering and receiving care. The pandemic disrupted routine, non-urgent care: many clinic appointments were delayed or cancelled for an extended period, and meant that children with long-term conditions were not reviewed as per usual practice.

> "We've had COVID for two years so we, kind of, haven't been seen. We've just been shoved on a shelf."
>
> Mother of nine-year-old female

Access to local services and infrastructure, which many relied on as part of their routine/usual care, were also impacted by the pandemic. For example, hydrotherapy is commonly used as part of the treatment for Perthes' disease, however the pandemic caused closure of many local pools.

> "We used to use hydrotherapy but we unfortunately don't have a pool anymore, it was closed during COVID and it's not looking like it's going to open."
>
> Physiotherapist 2

Discussion

This study was the first to explore the experiences of children with Perthes' disease, their families, and the clinicians who provide treatment. Participants described a variation in the care they deliver and receive. Clinicians particularly described a lack of clinical consensus, with no robust evidence to support their treatment choices. They demonstrated the desire for more information and evidence to support treatment for Perthes' disease so that outcomes for children can be optimized. The disruptions caused by the COVID-19 pandemic highlighted the ongoing importance of regular appointments and clear clinical communication with children and families. All of the themes highlighted the value added by including children with Perthes' disease and their families in the decision-making process when considering treatments.

Variation within centres treating children with Perthes' disease in the UK has been demonstrated previously,[3] but the factors driving this variation were yet to be explored. Throughout the interviews, participants told us how the variation was driven, in part, by training and evolving experience at managing the condition (e.g. some surgeons opting for a more conservative approach as they have gained more experience). This is something that the previous research was unable to capture. Similarly, the lack of agreement on what constitutes best practice was commonly expressed, and a main driver for new research directed towards finding the most effective treatments.[17] This study highlighted that this uncertainty also drives variations in care, and both clinicians as well as child/family participants wanted better evidence to support their decision-making.

Understanding the decision-making processes among clinicians, and the input that children and families have in this process, has not previously been

explored. The insight that this study brings, from a sample across the breadth of the UK and in a range of clinical settings, is a strength of this work. Online interviews enabled geographical boundaries to be overcome and were important to the success of this work, especially given the logistical impracticalities of face-to-face interviews in the context of the COVID-19 pandemic. PPI was strong throughout the development and delivery of this study, with an engaged project advisory group and regular review of study materials. PPI allowed the study to better explore the elements of treatment decisions that were most important to families.

As with all research, this study had limitations. Children/family dyads were sampled from three NHS sites drawn from diverse geographical areas, who were recruited via their existing orthopaedic appointments. Collecting data from three sites runs a risk of not representing the heterogeneity of the patient population more broadly across the UK and beyond. Similarly, we were unable to analyze subgroups of the cohort in terms of clinician experience, sex (of either participant type), or treatment received, which might limit the transferability of the study findings. It is worth noting that the nature of qualitative research is such that 'representativeness' is not the aim, rather transferability of results that may describe a phenomenon. To mitigate this as much as possible, purposive sampling was used, as well as clear discussions and instructions to clinicians at each recruiting site. This was to ensure that participants were recruited to accurately represent the diversity of the patient population, but also the demographic of family members. This worked for children, with a varied cohort of sex, age, and surgical/non-surgical management previously. However, family member homogeneity was more notable: of the 12 family members who participated, there was one grandmother, one father, and the rest were the mothers of the children. This was somewhat bound by the responses and the scope of this project. For instance, five fathers were contacted to take part after expressing interest, but only one responded to the invitation. There is a potential for their viewpoint to be different to that received in this study, and could be considered in future studies.

Implications for practice. Children with Perthes' disease, their families who care for them, and the clinicians who treat them have all demonstrated a desire for more information to guide treatment. They have highlighted the magnitude of the variation of care within this patient population. Most importantly, they have provided an insight into the value of including children with Perthes' disease and their families in decisions made about their care. This is something that should be considered as an implication for clinical practice in order to ensure that children with Perthes' disease and their families are included in the decision-making process when considering treatments.

Take home message

- Widespread variation of routine care exists, both in the lived experience of children and their families, as well as self-reported disagreement among clinicians.
- Children with Perthes' disease and their families recounted positive experiences when included in the decision-making process for treatment.
- There is a strong desire from clinicians and children/families for consistent evidence for everyone involved, and in the absence of firm data this should be based at least on clinical consensus.

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Supplementary material

Interview topic guides for both child/family and clinician participants; a quote table showing all quotes taken from participants during the study; thematic tables that display the frequency at which each participant provided a response to each theme/sub-theme; and a list of the sub-themes that existed within the coding framework.

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Author information:
- A. M. Galloway, MSc, BSc (Hons), MCSP, Specialist Children's Physiotherapist and NIHR/HEE Clinical Doctoral Research Fellow, Leeds Teaching Hospitals NHS Trust and University of Leeds, Leeds, UK.
- S. Pini, PhD, NIHR Senior Research Fellow
- S. Richards, PhD, Professor of Health Services Research & Director of the Leeds Unit for Complex Intervention Development (LUCID)
  Leeds Institute of Health Science, University of Leeds, Leeds, UK.
- C. Holton, MSc (Mech Eng), BSc (Anatomy Hons), MBChB, FRCS (Tr & Orth), Consultant Orthopaedic Surgeon and Clinical Director, Leeds Children's Hospital, Leeds Teaching Hospitals NHS Trust, Leeds, UK.
- D. C. Perry, FRCS, PhD, Professor, Consultant Orthopaedic Surgeon, Alder Hey Children's Hospital, University of Liverpool, Liverpool, UK.
- A. Redmond, PhD, Professor of Clinical Biomechanics and Physical Medicine
- H. J. Siddle, PhD, Consultant Podiatrist and Senior Clinical Lecturer
  Leeds Institute of Rheumatic and Musculoskeletal Medicine, University of Leeds, Leeds, UK.

Author contributions:
- A. M. Galloway: Conceptualization, Data curation, Formal analysis, Funding acquisition, Investigation, Methodology, Project administration, Resources, Writing – original draft, Writing – review & editing.
- S. Pini: Formal analysis, Methodology, Project administration, Writing – review & editing.
- C. Holton: Conceptualization, Resources, Writing – review & editing.
- D.C. Perry: Conceptualization, Methodology, Resources, Writing – review & editing.
- A. Redmond: Conceptualization, Methodology, Writing – review & editing.
- H.J. Siddle: Conceptualization, Methodology, Writing – review & editing.
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