Bone & Joint Open

Supplementary Material

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NON-STOP: NON-Surgical Treatment Of Perthes' Disease

TOPIC GUIDE FOR CHILD/FAMILY

AIM OF THIS GUIDE

This guide is for the interviewer to use in order to guide the interview process with the intended participant in this instance, the child/family dyad (pair).

It includes some questions and prompts that can be used during the interview as well as reminders for the interviewer as to the format of the interview.

IMPORTANT STEPS PRIOR TO STARTING INTERVIEW

Ensure participants have had time to read and understand the participant information pack and any further check for any further questions they may have.

Ensure participants understand that they do not have to take part in the interview and that they can stop the interview at any time.

At the beginning of the interview, make it clear that the interview will be recorded but that everything said will remain confidential and any information used will be anonymised. Their clinical care team will not be informed about any of the answers that they give in the interview. Be sure to inform the participant that recording has started and stopped.

QUESTIONS/PROMPTS TO BE USED DURING INTERVIEW

Child:

- What do you know about your hip problem (Perthes' Disease)?
- What treatment do you do for your hip? If physio, what physio?
- What do you like/not like about the treatment of your hip problem? Why?
    - Do you use any apps on your phone/tablet at the moment? If not, how would you use an app?
    - How do you feel about using an app to help you with Perthes' Disease?

Parent/legal guardian:

- What are your experiences of treatment of Perthes' Disease?
- What are your thoughts on non-surgical treatment of Perthes' Disease?
- What works well/not so well in terms of treatment of Perthes' Disease?
- Can you tell me about a time you were given a choice about your child's treatment for Perthes' Disease?
- What are your thoughts on using an app to help with your child's management of Perthes' Disease?
    - What sort of things would an app like this include?
- Ask child/family if they have any questions or if there is something else that they would like to add.

FINAL ACTIONS

Reiterate the plan following interview i.e. interviews with other participants, data analysis and the dissemination plan.

"How have you found the interview" – as a transition 'out' of the interview.

NON-STOP: NON-Surgical Treatment Of Perthes' Disease

TOPIC GUIDE FOR CLINICIANS

AIM OF THIS GUIDE

This guide is for the interviewer to use in order to guide the interview process with the intended participant in this instance, the clinician.

It includes some questions and prompts that can be used during the interview as well as reminders for the interviewer as to the format of the interview.

IMPORTANT STEPS PRIOR TO STARTING INTERVIEW

Ensure that participants understand that they do not have to take part in the interview.

Ensure that participants understand that they can stop the interview at any time.

At the beginning of the interview, make it clear that the interview will be recorded but that everything said will remain confidential and any information used will be anonymised. Be sure to inform the participant that recording has started and stopped.

Their clinical team will not be informed of any answers given during this interview.

QUESTIONS/PROMPTS TO BE USED DURING INTERVIEW

- What is your experience of treatment of Perthes' Disease?
    - If particularly successful/unsuccessful, why do you think this is?
- What is your experience of non-surgical treatment of Perthes' Disease?
    - If particularly successful/unsuccessful, why do you think this is?
- What are the factors when considering non-surgical treatment of Perthes' Disease?
    - Any barriers or enablers to making this decision?
    - What are the key influences?
- What is important to you in terms of treatment of Perthes' Disease?
    - What works well/not so well?
- What are your thoughts on using an app to help with management of Perthes' Disease?
    - How might families react to the app?
    - How much would an app like this get used?
    - What content might the app include?
- Ask the clinician if they have any questions or if there are any points that they would like to raise/discuss before the end of the interview.

FINAL ACTIONS

Reiterate the plan following interview i.e. interviews with other participants, data analysis and the dissemination plan.

"How have you found the interview" – as a transition 'out' of the interview.

This table shows direct quotes from participants within the study. Interviewer questions are reproduced in square brackets. For example: "[What do you like about the treatment you do for your hip?]".

Code	Theme	Participant quoting
1	**VARIATION OF CARE**	
1.1	**Current usual care**	
	My mainstay of treatment is to maintain their range of motion, make sure that their pain is controlled, and to let them have as normal life as possible.	Surgeon 1
	If they've got a good range of abduction, I don't routinely refer them to physio. If they've got a decreased range of abduction, then I refer them to physio and ask the physio to assess them for hydro if they have that available to them.	Surgeon 4
	[What do you like about the treatment you do for your hip?] I get to swim more.	9-yr-old female
	Early physiotherapy I feel is really important.	Surgeon 3
	Our approach is to avoid bouncy castles and trampolines, but otherwise let them have a normal, a normal life.	Surgeon 5
	Do whatever you want but restricting bouncy castles and trampolines. There's no evidence for it but it, kind of, seems, kind of, sensible and they're easy to avoid.	Surgeon 5
	Aqua works well, because it's easy for them, it's lovely, you can have fun.	Physio 6
1.2	**Different approaches**	
	In the early years in my practice, when I was quite keen, 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
	As orthopaedic surgeons our whole career we've been told, no, no, no, you can't do an early hip replacement, you have to wait until they can't walk anymore and in terrible pain. But actually younger people do very well and it gives them a new lease of life, so it's not the worst outcome in the world if that's what they end up having.	Surgeon 2
	Practice is changing. It used to be, we talked about slings and springs years and years ago, trying to keep range of motion going and then, I don't think slings and springs was probably taught in physiotherapy colleges for some years. And then, lo and behold, my consultant were saying, oh, any chance of doing something with slings and springs? So like it's gone a full circle.	Physio 1
	We stopped doing the broomstick casting, so that was really helpful.	Physio 2
	When I first started work all the information was no impact.	Physio 4
	We tried doing a class at one point. We did a Perthes' class. We had about 20 kids at one point, it was ridiculous.	Physio 5
1.3	**Evidence to support decision-making**	
	I think ruining some poor child's childhood with lots of big femoral osteotomy when we don't necessarily know that they really make a difference to their function or the age that they're	Surgeon 1

	going to have a hip replacement, it doesn't seem like a very good thing to be doing to them.	
	You can't manage anything unless you have information.	Physio 3
	You see a child with Perthes' and you genuinely don't really know in your heart of hearts the best treatment algorithm for them.	Surgeon 4
	I'd like to know whether surgery made a difference or not.	Surgeon 5
	Even if it didn't make a difference to the hip, so, to the shape of the hip which is what surgeons care about, I'd be interested to see whether surgery made the difference to patient outcomes. To, kind of, pain and stuff. Because I don't know that.	Surgeon 5
	If you know how long you're going to have it for you will be like me, I'm just…I don't know, I'm just waiting for it to go, if you know when it's going to go probably, you're waiting for your best day of your life basically.	10-yr-old male
1.4	**Agreement among clinicians**	
	It would be really nice if we could move towards some consistency or consensus of how the patient should be managed so that we're all giving the same kind of information.	Surgeon 1
	I'd like to see is some consistency so that a) we've got some guidance as to, look, this is what you should be doing, and then have a large proportion of people doing it for all patients.	Surgeon 2
	I certainly didn't agree with the [other treating centre's] ethos of let's put them in a wheelchair for a year, because I don't think that made any difference to the outcome.	Surgeon 2
	There are so many different treatments, nobody agrees.	Surgeon 1
	I think BSCOS obviously should and will want to be involved in this. They'll probably just set up another Delphi consensus group, to be perfectly honest, which will take three years to sort out. Because especially with Perthes, because it's probably one of the most varied treatment managements that we see.	Surgeon 3
	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 10-yr-old male
2	**OUTCOMES**	
2.1	**Defining outcomes**	
	It tends to be the active, happy children whose parents are engaging and want their child to be better, in my experience, that have the best outcome.	Surgeon 3
	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, which we're seeing a lot of right now.	Surgeon 3
	I genuinely don't know what's successful and what's not successful.	Surgeon 5
	Improvement in function which translates into better quality of life for them to play in the playground with their friends, to take part in sports, to be pain free, to have a good night's sleep. I also hope that I'm improving their hip enough to salvage it for further on in their growth and into adulthood.	Physio 4
	He did say if it means getting rid of the pain, I'll have the operation and I'll have a new hip.	Grandmother of 7-yr-old male

	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 and there was still a choice.	Mother of 16-yr-old female
	I did feel like we could have said, no. We did have an option.	Mother of 9-yr-old female
	The other thing I love with apps is that it enables the child to take some ownership and some responsibility and they have therefore some understanding of what they're trying to achieve. No matter how young the kids are, they want to be involved in their own care on the whole, I've found. And I think that's important to acknowledge that and to respect that and to enable that. So yeah, bloody love an app.	Physio 4
	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, I don't know if that would help, but that's probably the one thing that he really, really, struggles with	Mother of 6-yr-old male
2.2	**Rationale for treatment**	
	There's research that says potentially we could offer you…there's some evidence that it might improve things, but in reality… Because that was on the basis of radiologic outcomes, wasn't it, not functional outcomes? So in reality, is that very good evidence for it.	Surgeon 1
	I've got to put my hands up and say I do very little with these kids now because over time you know that these kids, a lot of them will come out the other end no matter what you do with their own outcome.	Physio 5
	These kids are in pain, it's limiting their function, it's impacting their…they're getting pain daily, they're limping, they're having to use a stick at university, they can't participate in sports. And actually you give them a hip replacement and they're cracking on like nothing's ever wrong and they love it. I had one boy emailed me from climbing Machu Pichu in Peru for his follow-up PROMs data and he'd had it for Perthes.	Surgeon 3
	My approach is very much, very much to, kind of, let your kid be normal.	Surgeon 5
	The older presentation ones, the ones that are your eight plus, nine, and I just think sometimes no matter what you do, movement exercises, it doesn't improve things.	Physio 2
	The financial ability of the parent and their time to be able to take the kid swimming, to access swimming, to access cycles – they may not be able to afford a bike.	Physio 4
3	**Any other business (AOB)**	
3.1	**COVID impact**	
	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.	Physio 2
	Silver lining of COVID is everybody's become so much more au fait with technology.	Physio 3
	If I make a decision that I want them to have an arthrogram that's a time dependant decision for me, so I'll list them to be	Surgeon 4

	done within three months, and generally I can. Obviously, there's pressure on services at the moment and waiting lists.	
	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 9-yr-old female
	I do think for us lockdown became quite a positive thing for Perthes' because like I say, he just couldn't…I think that's what the best thing was, was just to rest it.	Mother of 12-yr-old male

These tables show frequency counts for each participant within the interview study, and show the number of responses each participant gave in each theme/sub-theme.

Thematic table for clinician participants

Code	**Participant**											
	Surg1	**Surg2**	**Surg3**	**PT1**	**PT2**	**PT3**	**Surg4**	**Surg5**	**PT4**	**PT5**	**CNS1**	**PT6**
1.1 Usual care currently	*	5	11	2	2	1	3	8	4	1	2	3
1.2 Different approaches used or experienced	6	10	6	3	1	3	*	1	2	5	1	*
1.3 Evidence to support decision making	6	2	3	3	4	1	3	3	4	2	*	1
1.4 Agreement among clinicians	2	4	4	1	1	*	2	*	1	*	*	*
2.1 Defining outcomes	3	4	7	4	*	2	*	2	1	*	*	2
2.2 Rationale for treatment	4	7	4	1	1	2	*	1	2	1	1	2
3.1 COVID-19 impact	1	*	*	1	1	1	1	*	*	*	*	*

*No response related to theme from participant.

CNS, Clinical Nurse Specialist; PT, physiotherapist; Surg, surgeon.

Thematic table for child/family participants

Code	**Participant**											
	Child 1	**Child 2**	**Child 3**	**Child 4**	**Child 5**	**Child 6**	**Child 7**	**Child 8**	**Child 9**	**Child10**	**Child11**	**Child12**
1.1 Usual care currently	*	*	*	*	*	*	1	*	*	*	*	*
1.2 Different approaches used or experienced	1	*	*	2	*	1	2	*	*	*	*	*
1.3 Evidence to support decision making	*	1	*	1	*	1	2	*	2	*	*	1
1.4 Agreement amongst clinicians	2	*	*	*	*	*	1	*	*	1	*	*
2.1 Defining outcomes	1	3	*	2	1	1	2	*	1	*	*	*
2.2 Rationale for treatment	*	*	1	1	*	1	*	*	*	*	*	*
3.1 COVID-19 impact	1	*	*	*	*	*	*	*	*	*	*	2

*No response related to theme from participant.

1 Outcomes

1.1 Discussion around what constitutes a good or bad outcome
1.2 Mention of reason why a treatment option is chosen (good or bad outcome)
1.3 Outcomes at different points in time (skeletal maturity vs early osteoarthritis (OA)).

2 "Who/when/where"

2.1 Discussion around where the app would be used (home/school/other)
2.2 Different users of the app, i.e. clinician, patient or family, or combination
2.3 Technology access issues.

3. COVID-19 impact