

A qualitative study of parents' and their child's experience of a medial epicondyle fracture and what they think about the treatment options

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Abstract

Aims

To explore parents and young people's experience of having a medial epicondyle fracture, and their thoughts about the uncertainty regarding the optimal treatment.

Patients and Methods

Families were identified after being invited to participate in a randomised controlled trial of surgery or no surgery for displaced medial epicondyle fractures of the humerus in children. A purposeful sample of 25 parents (22 females) and five young people (three females, mean age 11 years (seven-14 years old)) from 15 UK hospitals were interviewed, a mean of 39 days (14-78 days) from injury. Qualitative interviews were informed by phenomenology and themes identified to convey participants' experience.

Results

The results identify parents' desire to do the best for their child expressed through two themes; firstly, 'uncertainty', being uncertain about the best treatment option, and secondly 'facilitating recovery', sharing the experience. Parents and young people were shocked when confronted with uncertainty about treatment, as they felt responsible for the decision. They searched for further information, drew on their own experience and struggled to weigh up risks of the treatments. Discussion with surgeons provided crucial support for decision making and young people were involved to a varying degree. In facilitating recovery, parents balanced increasing activity with protecting their child, but lacked knowledge about pain management, and how to improve strength and function of the arm. They hoped for a return to normal, including competitive sports.

Conclusion

Surgeons are aware of the impact of injury on children and their parents, however they may be less aware of the turmoil created by treatment uncertainty. Confident surgeons, who appreciate and contextualise the importance of pre-existing experience and beliefs, are best placed to help the family develop confidence to embrace uncertainty, particularly regarding participation in clinical trials.

There is widespread uncertainty about the best way to treat a fracture of the medial epicondyle of the elbow in children and adolescents.^{1,2} This uncertainty has prompted the British Society for Children's Orthopaedic Surgery (BSCOS) to make this their number one trauma research priority.³ To address this uncertainty, there is an ongoing UK-wide multi-centre prospective randomised

superiority trial of operative fixation versus non-operative treatment for medial epicondyle fractures of the humerus in children – the SCIENCE study.⁴

The medical uncertainty, embodied by randomised trials, is challenging for patients and their families, as they need to make sense of their participation, randomisation and equipoise. Patients tend to weigh up benefits for themselves alongside feelings of altruism, treatment preference and the impact of allocation to their non-preferred treatment. Distrust may arise where patients are not fully convinced that both treatments are effective, or if they believe that their surgeon is not genuinely uncertain.⁵ In trials of treatment for traumatic orthopaedic injuries in adults, where treatments were simpler (wound dressings) or similar in style (two types of implants) decisions were easier to make than when treatment pathways were different for example, surgery versus no surgery.⁶⁻⁸ Data regarding parents and young people's experience of trauma and their experience of treatment uncertainty is limited.

This study reports the experience of parents and children faced with uncertainty after the child sustained a medial epicondyle fracture. Data was collected as part of a qualitative study embedded in the SCIENCE (www.SCIENCEstudy.org) randomised clinical trial.

Patients and Methods

A purposive sample was obtained comprising 25 parents (female, n=22) and five young people (female, n=3) from 15 NHS hospitals across the UK, who were invited to take part in the SCIENCE study, between June 2019 to March 2020. Most young people were accompanied by their mothers and interviews with young people were exploratory. Further research with fathers and young people is required. Injuries had been sustained through sporting activities at home or at school, such as trampolining, gymnastics and rugby. The mean age of the young people was 11 years old, (range 7-14) and mean number of days since injury at the time of interview was 39 days (14-78 days). Five children had sustained an associated elbow dislocation. The mean duration of an interview was 36 minutes (15 - 65 minutes). Sixteen participants had been randomised in the SCIENCE study, six non-surgical in a cast, ten surgery (two allocated to surgery chose non-surgical treatment after randomisation) and nine interviewed had declined to participate in the trial, eight of whom had a preference for a cast. All sites had training about the study, had access to an informative website, an anonymised instant messaging service, and communication with the Chief Investigator. Parents were informed about the study initially by clinical staff followed by discussions with the research associate and consultant surgeon.

The method drew on phenomenology and the work of Heidegger.⁹ An approach used to explore the lived experience. In healthcare it is used to collate individual experience into a collective summary that might be used to guide practice.⁶ The researcher acts as a conduit gathering participant's experience, using the individual elements to create an overview of the experience of the group. As little is known about this area it was important to allow parents and young people to identify what was important to them. Parents and young people therefore took part in lightly structured interviews which focused on the experience of injury and recovery, and what it was like for them to be faced with uncertainty regarding the best treatment option. Open questions enabled parents and young people to share their experience of what was important to them as used in other studies of injury.¹⁰ For example in response to what has it been like for you? Participants identified their feelings of shock and concern about treatment uncertainty. They were prompted with: tell me more about that, what were you thinking at that point, how did you feel about that? As themes and categories developed they were corroborated with participants.

Ethical approval was granted by Greater Manchester Central Research Ethics Committee (reference 19/NW/0158, 25March2019). Participants had an information sheet and at least 24 hours before

providing verbal consent for a telephone interview. Interviews were digitally recorded and transcribed verbatim. Interviews were undertaken by female researchers with no prior contact with participants, an experienced health care researcher ET (n=11) and a psychology graduate KP (n=14). Both researchers analysed the data by reading the transcripts and drawing together sentences with similar meanings into codes, categories and themes, whilst being aware of similarity and difference across data. For example codes such as 'not knowing', 'being overwhelmed', 'not wanting to blame yourself' were drawn together into the category 'feeling responsible, feeling shocked' and then the theme 'uncertainty, being uncertain about the best treatment option'. The analysis was led by parents' data, with young people's experience incorporated within the themes. A software package NVIVO 11 (QRS international Warrington, United Kingdom) was used to help organise the data. Rigour was conveyed through reading transcripts, researchers' awareness of their own cultural perspectives, reflection on interpretation of the data and provision of an audit trail.¹¹ Saturation of themes, where no new categories emerge, was achieved after 20 interviews, five more were undertaken to ensure this was correct. Resonance with the findings was identified through discussion with the young people's PPI group Generation R Liverpool and five parents. A copy of the transcript was offered to participants but they declined. The results are presented as a description of each theme with a quotation to provide an illustration of the data. Where there was evidence that the parents and young people shared the experience the term participant is used.

Results

The results of this study identified the overall concept of 'doing the best for my child' which conveys what parents do in response to their child's medial epicondyle fracture, to process their strong emotions and seek solutions for treatment, participation and recovery. The themes and categories are presented in figure 1. Doing the best for my child was expressed through two themes: 1) uncertainty, being uncertain about the best treatment option, with categories of, a) feeling responsible, feeling shocked, b) seeking knowledge, needing to know, c) making the decision, d) developing trusting relationships, and; 2) facilitating recovery, sharing the experience with categories of, a) being with my child in pain, b) helping and protecting my child, c) working towards the best outcome.

Theme one 'uncertainty, being uncertain about the best treatment option', was the response when surgeons were unable to provide advice on the best treatment for a young person, but invited the participants to take part in a trial to address this uncertainty.

Being responsible, feeling shocked demonstrated the emotional and physical impact of injury combined with treatment uncertainty. Often it was the family's first experience of a fracture and participants preferred the surgeon, as the expert, to make the treatment decision. As a consequence participants felt responsible for the choice of treatment but lacked the appropriate knowledge base.

"I appreciate that's the reason behind it but it was just totally alien to me to be given that decision because usually the doctors know best and so it just felt crazy to be honest." Parent 4

To parents it felt like an enormous decision to take on behalf of their child. Parents and young people worried that if something went wrong they would blame themselves.

"So in the end we decided to go with the research, just in case we made a decision that would affect him and feel awful for it." Parent 17

Seeking knowledge, needing to know identified how lack of confidence in knowing what was best led participants to seek further knowledge from the SCIENCE study website, the internet, research papers, family and friends.

"I did a load of work looking on the internet, trying to understand all of the medical studies, to try and get some sort of layman's hand on whether or not this would be a good idea, with this injury. Everything seemed very inconclusive, which is why I know you're doing the research and I was slightly resentful that I was having to do all of that research while I also had all this stuff with my daughter on my plate." Parent 5

Once obtained, making sense of information and weighing up which treatment was best for their child was a struggle. Parents questioned all aspects of the trial. Internet information, research papers, whilst useful, were often hard to contextualise or provided inconclusive evidence. Extended family were often involved and different views could require a degree of negotiation.

"I rang my husband and talked to him and he just flatly refused [for our child] to go into a medical study ... said that was ridiculous, that a doctor shouldn't be asking a 13 year old what they want to do and so it's actually caused a bit of an argument." Parent 1

Young people were involved to a varying degree, depending on their degree of distress, maturity and parenting styles. They could have strong opinions and some influenced their parent's final decision.

"I was worried if it was the operation because I didn't really want the operation but I knew that it would probably be the better option for me because I do a lot of physical activities that would help." Young person 23

Making the decision was stressful as parents wished to do the best for their child and protect them from harm. Knowledge about their child, their likely future, health beliefs, fear of surgery and past personal and family experience of fractures were incorporated alongside trial information. Parents felt that surgery was only for patients with severe injury and many felt it should be avoided unless essential. Despite wanting to help, protecting their child was fundamental, therefore leaving it to the process of randomisation was often unacceptable.

"I felt it was my job to protect her from what could be quite intrusive surgery, to actually just have a cast and hopefully the same recovery, that's where I came from and that's how I felt. I felt that I have to protect. We don't need to do this to get the outcome that we want and that's how I felt." Parent 16

"You want to help with medical research but you don't want an unnecessary operation inflicted on your own child do you. Morally and ethically as a parent it is very difficult." Parent 5

Factors that influenced a preference for a cast were: strong health beliefs about natural healing, greater familiarity with casts, high levels of distress, pain or disruption to their care, and prior negative experience of surgery. For some parents 'natural' bone healing was considered to be stronger with less risk of infection. For other parents metal work was considered to be stronger, provided a better 'guarantee' of union and quicker return to sport. Parents and young people could also gain relief from taking part in the trial or being randomised to their preferred treatment. During recovery most seemed content with their treatment, even if it was not their preferred choice.

Developing trusting relationships with surgeons aided participants' decision making, regardless of whether they went into the trial or not. Helpful elements were: the provision of consistent information, seeing X-rays, answering questions, openness to repeated visits, reassurance, feelings of being personally cared for, and focusing on their child.

"We all came away feeling that we'd had every scrap of information that we could possibly have been given and the decision was based on everything she could tell us but it was just unfortunate that she couldn't really make a recommendation as to which treatment would be best for the long term outcome." Parent 11

Medical uncertainty did not detract from trust in the surgeon's expertise, however surgeons were often 'tested' by asking if they would put their own child into the study. Overall parents felt their child was safe, care was of a high standard and interactions with staff were positive.

Theme two facilitating recovery, sharing the experience conveyed the emotional and practical work that parents undertook to promote recovery. Activities were driven by daily family life, a concern for their child and a desire to maximise recovery. Participants worked out how best to undertake activities day by day, negotiating each challenge but lacked knowledge about pain management and the degree and frequency of exercise required.

Being with my child who is in pain identified the impact of pain on families. The worst pain was often following the initial injury, but movement of the arm for radiographs and the reduction of dislocations were also identified. Pain during recovery could affect sleep and school attendance. Parents could be shocked by the degree and duration of pain. They found it hard to be present when their child was in pain, for example during reduction of dislocations. Parents felt powerless when they were unable to alleviate their child's pain.

"It was really hard to be there when we first went there and there was a temporary cast that day that was really difficult because he was just in so much pain. We had the two nights of wearing a temporary cast. He and I were just up all night, downstairs on the couch so that was particularly horrible." Parent 2

"I was screaming and crying in pain and it was really hard for Mum because she can't do anything about this. She just has to see her child screaming in agony." Young person 2

When promoting recovery parents could worry about the degree of exercise required and were anxious about constant pain.

"That constant pain gets very wearing for the child. I mean you can see them just being very stressed by it. It's that constant stress that's making her feel fed up and sort of irritable and avoiding the exercises if she can, saying "it's too painful" to have them done. She doesn't want it, yes it's not very easy." Parent 5

Helping and protecting my child was a crucial activity for parents. Parents and young people slowly discovered what was required to manage everyday life. Parental concern was focussed on balancing dependence and independence, encouraging activity whilst protecting their child from further harm.

"Yes, he went back this weekend [contact sport] but I'm not entirely sure whether he should be, but he's been so fed up. He said "Mum I just want to keep playing" and so he's gone! So hopefully he'll be okay." Parent 15

Help was needed with activities of daily living particularly the little things that were often taken for granted. Support for writing, showering, bathing, dressing, tying hair, buttons and cutting up food.

"It's like her going back to being a baby really, where I've had to help her in the bath and stuff like that, but apart from that it's been fine." Parent 4

Working towards the best outcome and returning to normal was the ideal. However whilst uneventful for some, recovery was a cause of anxiety, particularly returning to competitive sport. Participants hoped for a quick recovery and return to their normal level of activity, arm extension, strength and motion. Many struggled with the 'frail' look of the arm and parents felt they were naïve in thinking it would be a trouble-free recovery.

"If I'm honest I'm hoping it's going to be like she's never had the accident, she's going to be going back to what she was, but it is obviously taking longer. I was quite naïve in thinking 'oh she's had the plaster off and she'd be back to normal very, very quickly.'" Parent 16

Parents worried about the timeline for recovery, wanted more information, sought help from, and waited for physiotherapist advice.

“It’s like trying to wrestle with a frozen chicken, that’s exactly what it’s like, trying to pull the leg down on a frozen chicken. I can understand why I can’t do that with a chicken, but I can’t understand properly why I can’t do that with my daughter’s arm.” Parent 5

Readiness to move forward was largely determined by the young person but both parents and young people wished for greater guidance. Concerns were expressed about lack of progression particularly around extension of the arm and continued pain but also in some cases non-union on radiographs.

Discussion

The study identified two key themes. Firstly, when confronted with medical uncertainty, parents were shocked and struggled to make a decision about the best treatment for their child. Secondly, participants hoped for a return to normal function, learnt through experience but lacked knowledge about how to promote recovery and return to competitive sports. Making the decision about best treatment and facilitating recovery was an experiential process where parents drew on many sources of knowledge. Key elements were: i) strong emotions engendered by a child’s injury and parents’ desire to do the best for their child, ii) strongly held health beliefs such as natural healing, iii) knowing their child’s past and present experience of illness and injury, iv) preference for the degree of involvement of the child in decision making, v) limited knowledge about injury, treatment, normal recovery and difficulty assimilating new knowledge whilst in acute care, vi) surgical uncertainty whilst understood was hard to accept in the context of a child’s injury, and vii) supportive interactions with surgeons where there was trust and concern for the individual child were helpful alongside the provision of empirical knowledge.

Participants needed time to make sense of the uncertainty presented to them as part of the SCIENCE study. A family centred approach that enabled parents and young people to develop the confidence to make a decision within a supportive environment was crucial. Organisational challenges, such as weekends, could disrupt communication about the study but interactions with consultant surgeons were highly valued. A strength of the study was that it included the experience of recovery up to 78 days. Participants tended to focus on their current experience but also reflected on the past and concerns about the future, adding data to both themes. Clinicians and surgeons may make use of this study in three ways. Firstly, educating families about injury, treatments and recovery may increase their confidence and self-efficacy to make decisions. Direction to use the SCIENCE website was helpful for families but future development of a decision aid may also increase knowledge and lead to more accurate perceptions of risk.¹² Future research could focus on rehabilitation and how best to support families to optimise recovery and ameliorate parental concerns. Secondly, supportive styles of communication, including reassurance, but also acknowledging the challenge of medical uncertainty for parents and young people. Recognising the importance of experience, pre-existing preferences, the involvement of the child and the families understanding of research might help decision making and allow clinicians to gently challenge pre-existing views.¹³ Thirdly, developing clinician’s confidence in the trial and clarifying their views of equipoise may foster trust in the trial. In this study, participants trusted clinicians despite their own struggle with uncertainty. Families identified the importance of surgeons presenting uncertainty with confidence. Portraying participation in the study as ‘the optimal treatment strategy’ increased their confidence in trial participation. However they also questioned the trial, sought their own information and tested surgeon equipoise, as in other surgical trials.⁵ Future work will explore equipoise through interviews with staff.

There were some limitations to the study. Only three fathers chose to take part and we have no evidence that the sample was ethnically diverse. Further research with fathers and young people

may identify new aspects of participation. However, the sample was purposive, included parents from across the UK, and saturation of the data from mothers was achieved.

Conclusion

In the context of traumatic orthopaedic injury and two very different treatments, parents and young people found the experience of decision making emotionally and mentally challenging. Time and support was required to develop their confidence to make a decision. Surgeons who appreciate and contextualise the importance of pre-existing experience and beliefs, are best placed to help the family develop confidence to embrace uncertainty, particularly regarding participation in clinical trials.

Key message

- Making decisions about treatment options in the context of traumatic injuries in children, including the decision to take part in a surgical trial, is challenging for families.
- Surgeons who appreciate and contextualise the importance of pre-existing experience and beliefs, are well placed to help families develop the confidence to make a decision.

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Figure 1, Presents the themes and categories for doing the best for my child

