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# “My gut feeling is...”: An Ethnographic Study Exploring Interprofessional Communication About Children and Adolescents With Chronic Musculoskeletal Pain in Paediatric Rheumatology

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**Abstract:** Interprofessional communication about inflammatory and non-inflammatory musculoskeletal conditions is an important component of assessment and management in paediatric rheumatology. Chronic pain is a feature of some of these conditions which likely influences the extent and type of communication about pain. Research investigating interprofessional communication about paediatric pain is limited but has found that communication is inclusive of the biopsychosocial context of children/adolescents as well as their families. The aim of this ethnographic study was to explore interprofessional communication about children and adolescents with chronic musculoskeletal pain in paediatric rheumatology. We observed forty-five healthcare professionals recruited from 3 UK paediatric rheumatology teams during thirty multi-disciplinary team meetings. Contemporaneous field notes created during observations were analysed using grounded theory procedures. Core processes identified in interprofessional communication involved describing, making sense of, and managing children/adolescents with pain and their families. Topic areas discussed within these core processes included healthcare professional perceptions about children's and parents' personality characteristics, as well as healthcare professionals' familiarity with families. Underlying diagnoses and possible attributions of pain aetiology were also discussed. Interprofessional narratives included consideration of the potential anxieties and uncertainties about pain within families. Healthcare professionals communicated about strategies for managing expectations about pain. These findings characterise the nuances in interprofessional communication about pain and can be used to inform future work aimed at understanding and optimising the impact of interprofessional communication on clinical decisions and pain outcomes.

**Perspective:** *This study characterises the processes (series of actions), the function (purpose) and the content (topic areas) of interprofessional communication about paediatric pain in rheumatology settings. These findings should be used to inform interventions targeting both the appropriateness and effectiveness of this communication.*

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**Key words:** *Chronic pain, Paediatric rheumatology, Interprofessional communication, Healthcare professionals, Ethnography*

Children and adolescents with a range of inflammatory and non-inflammatory conditions in which musculoskeletal pain can be a feature are commonly referred to, assessed and managed within paediatric rheumatology.<sup>1–4</sup> Children and adolescents' experiences of chronic musculoskeletal pain can involve several pain locations and result in various physical and psychological impacts.<sup>5–7</sup> Understanding and explaining the causes of pain, the experience of pain and the management of pain is a complex psychosocial process involving the child/adolescent, family and the healthcare professional or team.<sup>8–12</sup> Subsequent interprofessional communication about children and adolescents with chronic musculoskeletal pain following assessment and evaluation is a cornerstone of multi-disciplinary teams (MDTs).<sup>13</sup> MDTs are particularly essential for effective chronic disease and symptom management<sup>14</sup> such as chronic musculoskeletal pain. Internationally, the MDT in paediatric rheumatology often consists of a rheumatologist, nurse, physiotherapist, occupational therapist, and psychologist.<sup>15,16</sup>

In the broader field of research investigating interprofessional communication in MDTs, evidence demonstrates that interprofessional communication can influence the delivery of care and in turn, important patient outcomes in a range of settings such as general medicine, surgery and intensive care.<sup>17–23</sup> The consequences of inappropriate and/or ineffective interprofessional communication in these settings include avoidable harms such as misdiagnosis, delayed or even inappropriate treatment. Research investigating interprofessional communication specifically about pain in the MDT, however, is limited. Anecdotally, interprofessional communication about children and adolescents with chronic musculoskeletal pain is composed of automatic (such as "gut reactions") and purposeful (more contemplative) responses, both of which are shaped by healthcare professionals' implicit beliefs about childhood pain.<sup>24,25</sup> Automatic responses prompt individuals to rapidly and often unconsciously react to situations shaped by emotions experienced in the moment (a phenomenon known as affect heuristics).<sup>26</sup> However, purposeful responses involve conscious consideration to the context and an ability to reflect upon and be aware of cognitions prompted by an individual's interpretation of the context.

In the only study to date of interprofessional communication within the MDT of a US paediatric pain clinic, the content of healthcare professionals' communication

about pain was found to feature biological, psychological and social influences of and explanations for paediatric pain (as well as the potential for interplay between these components) at different times during the conversation.<sup>8</sup> Interprofessional communication was also found to frequently feature discussions about healthcare professionals' perceptions about the role of parents and families in children's pain experiences.

Further exploratory studies investigating the core processes, patterns and mechanisms of interprofessional pain communication in other settings (eg, the UK) and contexts (eg, other specialties such as paediatric rheumatology) is needed in order to better understand the complexities and nuances in pain communication. Interprofessional pain communication in the context of paediatric rheumatology is particularly key to explore considering that chronic pain is a feature of some, but not all of the long-term inflammatory and non-inflammatory musculoskeletal conditions managed in this specialty.<sup>1–4</sup> For example, chronic pain can be a secondary feature to inflammatory diseases such as juvenile idiopathic arthritis (which may be active or in remission), it can be a feature of an underlying non-inflammatory condition such as hypermobility, or it can be a primary idiopathic condition in and of itself. Identifying the core properties and mechanisms in interprofessional communication about pain could be used to ensure that this type of communication is appropriate in patient care. Therefore, the aim of this study was to explore the processes involved in and the content of interprofessional communication about children and adolescents with chronic musculoskeletal pain specifically in UK paediatric rheumatology settings, using an ethnographic study design.

## Study Design

This was an ethnographic study of a series of multi-disciplinary team meetings (MDTMs) in paediatric rheumatology departments in the UK. A common component of MDTs is a recurring MDTM in which healthcare professionals from varying disciplines meet to discuss the care of patients.<sup>27</sup> Other aspects of these meetings can also include healthcare professional education, peer-review, reflective learning and peer-support. Ethnography is a methodology rooted in sociology and anthropology. It involves the researchers immersing themselves in a population of interest to conduct in-depth observations of participants.<sup>28,29</sup> These observations allow for the study of real-world social interactions and dynamics of individuals

who are a part of a specified context over a period of time.<sup>30</sup> The ethnographic data collection procedures followed in this study aligned with standard ethnography practice.<sup>31,32</sup>

Our epistemology is critical realism, which posits that individuals experience different aspects of reality which influences the meaning they assign to experiences. This study was a non-participant ethnography. A non-participant ethnography refers to the position of the observer who was not a member of the healthcare professional teams observed or the clinical care/practices observed. On the converse, a participant ethnography would entail that a healthcare professional who was working within the MDT acted as the observer.

### **Study Population**

Healthcare professionals ( $n = 45$ ) (including consultant paediatric and adolescent rheumatologists, paediatricians, paediatric trainee doctors, nurses, physiotherapists, occupational therapists, psychologists, and pharmacists) participating in paediatric rheumatology MDTMs were recruited from 3 paediatric rheumatology departments in the UK (the hospitals will not be named specifically in order to protect the anonymity of the healthcare professionals recruited to the study). All of the paediatric rheumatology departments were based within large UK paediatric tertiary specialist care hospitals. The teams managed a broad range of inflammatory and non-inflammatory rheumatic conditions including primary pain conditions and secondary pain to underlying conditions (eg, juvenile idiopathic arthritis). Unless explicitly mentioned by healthcare professionals during the MDTMs, diagnostic information about the children/adolescents was not captured due to data protection and information governance legislation and restrictions. The challenges of capturing informed consent from the children/adolescents discussed during MDTMs have been published elsewhere.<sup>33</sup>

### **Procedure**

Ethical approval was provided by the East Midlands Nottingham Research Ethics Committee in the UK (20/EM/0195). All healthcare professionals within the paediatric rheumatology teams at the sites were sent a participant information sheet by the lead researcher (R.R.L) who provided further information to interested healthcare professionals. If healthcare professionals wished to take part in the study, they were asked to provide online electronic informed consent. Healthcare professionals who did not provide informed consent were still able to attend the MDTMs as normal, but no observations/field notes were recorded about them by the researcher. Thus, the lead researcher was unable to monitor all dyadic components of interprofessional communication during the MDTMs.

### **Ethnographic Data Collection**

Ethnographic observations were performed by the lead researcher (R.R.L), a post-doctoral researcher who was known to the paediatric rheumatology teams

through earlier research studies. Data were collected between April 2021 and March 2022. As social distancing guidance due to COVID-19 pandemic evolved during this period and varied due to location, observations were either conducted virtually (where MDTMs were hosted by the paediatric rheumatology teams online) or face-to-face in hospital meeting rooms. Where MDTMs took place online, the researcher turned the computer camera off. Where MDTMs took place face-to-face, the researcher sat separately from the team at the back of the room. MDTMs were scheduled to last for 1–1.5 hours, which was routine clinical practice for each paediatric rheumatology team recruited and not altered by the research. Informal interviews with key informants who were healthcare professional participants within MDTMs were also conducted parallel to observations of MDTMs. Key informant interviews comprised a range of pre-identified questions (eg, sense-checking specific observations and interpretations from the research team) as well as unstructured general conversation about key informant thoughts, opinions and experiences of the observations and interpretations of data. The purpose of these key informant interviews was to explore the accuracy and resonance of emerging issues and themes from the data. Key informants are considered to be experts who can provide deeper insights by virtue of being part of the observed context.<sup>34</sup> These interviews do not alter the position of the observer as a non-participant, as the observer still does not become an active member of the MDT practices in this process. Key informant interviews give broader context and enrich observations.

Field notes were created during each of the MDTMs observed. A structured field note observation checklist was created prior to observation using key texts on ethnography.<sup>35,36</sup> These key texts were used to inform the structured field note observation checklist as the authors of these texts were particularly focused on creating high-quality field notes in observations of healthcare settings. The checklist included categories focused on the structure/organisational features of the meeting, the process of MDTM activities, interactions between healthcare professionals (including specific terminology/dialogue used) and the goals/outcomes of activities and communication. Additional notes and interpretations of field note data were added following a discussion with other members of the research group.

### **Data Analysis**

Data collection and analysis occurred concurrently so that topics highlighted in earlier phases of the fieldwork could be used to subsequently shape the focus of further data collected. To demonstrate one particular example of this iterative process in action, the lead researcher (R.R.L) focused on how healthcare professional conversations about children/adolescents started. Initial observations identified that healthcare professionals often discussed the presenting characteristics of the child/adolescents. This analysis prompted the researcher to hone in on the specific types of personality traits that were described by

healthcare professionals, alongside identifying supporting quotations.

Procedures from first-generation grounded theory (eg, coding, memoing, and constant comparison) were used to guide the analysis of field notes.<sup>37</sup> Initially, independent coding of the field notes was performed and analytical memos were created by the lead researcher (R.R.L) between each of the observed MDTMs. This involved the lead researcher coding field notes line-by-line with their interpretation and writing further field notes about their reflections whilst line-by-line coding. Independent coding of the field notes was also performed and analytical memos were created by another member of the research team (A.F) after the first 10 MDTMs were observed. Independent codes and analytical memos were then cross-checked and discussed between R.R.L and A.F. Once codes and memos began to reflect patterns and group into broader themes within the data, preliminary themes were discussed in individual as well as team data sessions with all study authors. During these meetings, interpretations of key issues emerging from the data were shared and exchanged. Following these discussions, the lead researcher attended further MDTMs and added broader team interpretations to field notes, memos and emerging themes. The themes were further refined by subsequent team discussions and then presented to key informants toward the end of data collection (after 8 MDTMs had been observed with each respective paediatric rheumatology team). Key informants were asked to comment on the themes identified during these discussions in the final analytical and interpretation stages in a process referred to as member validation. This is a standard ethnographic practice<sup>31,32,38</sup> which ensures that the themes identified resonate with the experience of participants. Subsequently, the lead researcher added key informant interpretations to field notes, memos and emerging themes. The themes were then further refined following these key informant interpretations. The final refined themes from all authors and key informant discussions and interpretations are presented. In presenting the results of the study, the authors have drawn on anonymized quotes (signified in the narrative by “”) directly from healthcare professionals during MDTMs, alongside a narrative of data interpretations from the research team and key informants.

## Results

### *Participant Characteristics*

Each paediatric rheumatology team consisted of between 18 and 26 healthcare professionals. The number of each profession per team included: 4 to 7 consultant paediatric and/or adolescent rheumatologists, 3 to 4 paediatric trainee doctors, 5 to 6 nurses, 2 to 4 physiotherapists, 1 to 3 occupational therapists, 1 to 2 psychologists, 0 to 1 pharmacists, 0 to 3 research coordinators. The team compositions changed between meetings for a variety of reasons (eg, annual leave or sickness absences). Of the 67 healthcare professionals who

were members of the three paediatric rheumatology centres MDTMs, 45 consented to take part in the study. This included consultant paediatric and/or adolescent rheumatologists (n = 14), nurses (n = 9), physiotherapists (n = 7), psychologists (n = 6), paediatric trainee doctors (n = 4), occupational therapists (n = 4) and pharmacists (n = 1). Ten meetings from each team (n = 30) were observed, totalling an approximate observation time of 40 hours. Informal interviews (over a total of 7.5 hours) were conducted with 6 key informants which included discussions with consultant paediatric and adolescent rheumatologists (n = 2), a nurse (n = 1), a physiotherapist (n = 1), an occupational therapist (n = 1) and a psychologist (n = 1) from the teams involved in the study.

Three meetings from one of the paediatric rheumatology teams were hosted face-to-face and the remainder were observed virtually (n = 27). The number of child/adolescent cases discussed in MDTMs (lasting 1–1.5 hours long) ranged from 0 to 26 (Median = 8.5, IQR = 5.75–14.5) with a total number of 297 (new and follow-up) patient cases discussed across all MDTMs observed. Some MDTMs had few healthcare professionals present (due to annual leave or sickness absences). In these instances, 0 patients were discussed. Some teams had a stimulus to facilitate discussions (eg, a list of the children/adolescents who the team planned to discuss) and other teams did not.

### *Core Processes of Interprofessional Communication About Pain*

Three core processes were identified in interprofessional communication about children and adolescents with chronic musculoskeletal pain within paediatric rheumatology MDTMs (See Fig 1).

#### **Process 1: Describing the Child/Adolescent With Pain**

Interprofessional communication began with a description of the child/adolescent's clinical presentation. Descriptions included providing an overview or an update about a child/adolescent (and/or their families) presenting characteristics, their treatment and/or their care. This process enabled healthcare professionals to inform one another and distribute knowledge about the child/adolescent's background and experiences from the outset of interprofessional communication. These discussions would also prepare other healthcare professionals about what they might expect if they were to later see a child/adolescent in consultations, which may also include their family.

#### **Process 2: Making Sense of the Child/Adolescent With Pain**

Next, the MDT worked together to make sense of a particular child/adolescent's clinical presentation. The team would explore specific elements of the child/adolescent's presentation, obtaining further information and clarifying issues to better understand the child/adolescent and/or family's experience. This process

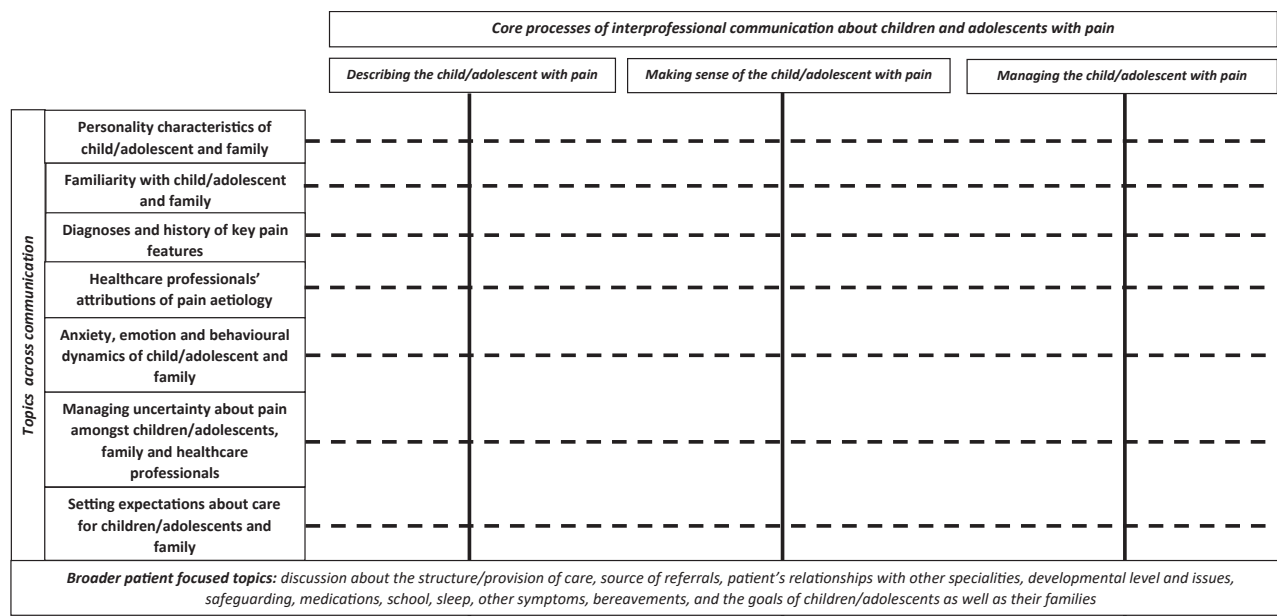


Figure 1. Core processes and inter-related topics of interprofessional communication about children and adolescents with pain.

enabled healthcare professionals to gain support from other healthcare professionals about their ideas and hypotheses and facilitated formulating new ideas and hypotheses together as an MDT.

### Process 3: Managing the Child/Adolescent With Pain

The team then would focus on developing a management plan for the child/adolescent and/or the family as an MDT. The MDT would explore whether specific approaches (including evidence-based techniques and strategies) and plans were appropriate, at times offering reassurance to one another about potential management plans and at other times suggesting alternative strategies. When no management plan could be made, the MDT functioned as a debriefing point for healthcare professionals where they could offload their experiences and perspectives of children/adolescents and/or their families.

### Content of Interprofessional Communication About Pain

The content of interprofessional communication about children and adolescents with chronic musculoskeletal pain in paediatric rheumatology included seven topics of communication that intersected across the three core processes of communication, including:

1. Personality characteristics of child/adolescent and family
2. Familiarity with child/adolescent and family
3. Diagnoses and history of key pain features
4. Healthcare professionals' attributions of pain aetiology
5. Anxiety, emotion and behavioural dynamics of child/adolescent and family

6. Managing uncertainty about pain amongst children/adolescents, families and healthcare professionals
7. Setting expectations about care for children/adolescents and family

These seven topics did not feature evenly across all of the three core processes; communication was a dynamic interplay between processes and content rather than being systematic or linear. For example, discussion about personality characteristics of the child/adolescent and family featured more heavily in healthcare professionals' descriptions about children/adolescents with chronic musculoskeletal pain, but the presence of this content was not exclusive to this part of the communication process. During key informant interviews in particular, healthcare professionals commented upon how they did not realise there were specific processes and content in the ways they were communicating about pain. They reported that they were unaware of these nuances in their communication prior to the lead researcher highlighting them.

### Topic 1: Personality Characteristics of Child/Adolescent and Family

Healthcare professionals generally began their descriptions about children and adolescents with a statement about their perceptions of the child/adolescent's presenting personality characteristics (eg, "he/she is chatty/shy/mature/academic/articulate/bright/high-achieving/sensitive/bubbly/lovely"). These statements provided a brief overview and quick contextual about the child/adolescent to other healthcare professionals. In some instances, a child/adolescent was introduced to the team as "complex" or a "complicated one" at the beginning of a description, as though pain was a defining feature of that child/adolescent (eg, "she is a

chronic pain", "she is a bit painy"). Healthcare professionals would also regularly introduce their perceptions about the parents' personality and/or families' presenting characteristics alongside these initial descriptions (eg, "mum is a strong personality", "this family is tricky as they are very protective").

## Topic 2: Familiarity With Child/Adolescent and Family

Healthcare professionals also shaped their descriptions of children and adolescents with information about whether they and/or their families were known to a particular healthcare professional or the MDT more broadly (eg, "I know him well", "I've seen her for many years", "she knows loads of people"). Healthcare professionals regularly communicated about the necessity of knowing the child/adolescent and their background before they could understand the pain and make decisions about how to manage it (eg, "there's a lot in the background I don't know about this child"; "I don't know what's going on at home", "I haven't got a measure on the family yet"). Healthcare professionals communicated about a range of approaches they had used to build familiarity with children/adolescents and their families. These strategies included conducting assessments ("I did an initial assessment to try to get to know her and get a sense of her") as well as spending more time with the child/adolescent which led to a natural progression in familiarity over time (eg, "over time she got used to me and the team"). Healthcare professionals would often encourage one another to identify additional information about children and adolescents with pain in order to build familiarity about the context of the child/adolescent (eg, "we need to do some digging to find out what else is going on"). Familiarity with children and adolescents appeared to be valuable for conveying the chronicity of the condition to the team and for relaying that different management approaches to pain had been tried in the past. Disclosing this familiarity enabled healthcare professionals to compare back with how things had been before (eg, "she is doing much better in my point of view", "clinically, she was very well last time I saw her", "it's not as bad as it's been before").

## Topic 3: Diagnoses and History of Key Pain Features

Underlying diagnoses (if present) would often be introduced to the MDT ("this patient has arthritis", "this patient has CRMO [chronic recurrent multifocal osteomyelitis]", "I want to talk about a patient that has Raynaud's"). When a diagnosis did not exist for the child/adolescent, sometimes absence of a diagnosis would be discussed ("we don't have a diagnosis that we see her for"). The pain histories and pain characteristics of children and adolescents introduced to the MDT were also communicated about in detail by healthcare professionals. Key pain features discussed included:

Interprofessional paediatric pain communication

- Pain sensations/qualities (eg, "she had burning sensation in her legs", "he had stabbing/shooting pain")
- Pain location (eg, "she had pain down her arm", "he had pain in his right ankle", "she is in pain everywhere")
- Pain timing (eg, "her pain is intermittent")
- Pain emotion (eg, "she has a lot of sadness around pain")
- Whether pain was provoked/unprovoked (eg, "this patient has been in pain at rest, but not lying or on movement")
- Scores from questionnaire measures (often disease specific such as the CHAQ- Childhood Health Assessment Questionnaire<sup>39</sup> which is regularly used in paediatric rheumatology [eg, "her CHAQ score was very high, with high pain"])

## Topic 4: Healthcare Professionals' Attributions of Pain Aetiology

The results of medical investigations were communicated about in combination with healthcare professionals' observations of the child/adolescent's physical functioning, to inform their discussions about what they believed the underlying pain aetiology of the child/adolescent could be attributed to. Results from medical investigations (such as x-rays, blood tests, ECGs, PET scans, CT scans, MRI scans, ultrasound scans, and nerve conduction tests) and discrepancies between the results of these tests and children/adolescents' reports of pain were a focus for healthcare professional communication (eg, "the MRI didn't show any evidence of inflammation to explain her low back pain"; "there is a mismatch between symptoms and their ultrasound findings", "she is focused on pain but I can't find anything").

Healthcare professionals' observations of a child/adolescent's level of physical functioning and potential discrepancies with the child/adolescent's pain reports were also commonly mentioned (eg, "have we witnessed that dislocation happening?"; "when she's in clinic, she is dancing, not in pain"; "when she has a bad spell, she is completely not functional"). Sometimes such discrepancies could also be informed by the healthcare professionals' physical examination of the child/adolescent (eg, in healthcare professional's reference to 3 different patients, quotations included "she had miserable, horrible joints"; "her joints felt absolutely fine"; "there was no joint swelling"). Discrepancies could also be related to the healthcare professionals' perception of the child/adolescent's underlying diagnosis (eg, "her condition does not account for the whole body pain that she has"). Healthcare professionals also communicated about using the results of investigations to "re-assure" and "please" the family (eg, "I'll see what the investigations say, mum will be happy with that, lots of reassurance").

## Topic 5: Anxiety, Emotion and Behavioural Dynamics of Child/Adolescent and Family

Healthcare professionals frequently communicated about their perceptions of anxiety in children/adolescents and their parents/family (eg, "I think she is an



anxious tendency child", "mum's anxiety is on the ceiling", "dad is worried", "I think the family are anxious and panic a lot"). Healthcare professionals frequently reflected upon contrasts between parent and child/adolescent reports in their communication to other healthcare professionals. In some instances, anxiety in children/adolescents and the parents/families were believed to be influencing each other (eg, "mum and [child/adolescent] bounce off each other's anxieties"). Other emotions discussed included healthcare professionals' beliefs about the frustration of children/adolescents (eg, "she has a lot of frustration from being in pain") and anger/demand from parents (eg, "mum is very angry", "mum got cross with me").

A child/adolescent with pain could be described as "complaining" or as being "behavioural," the implication being that the child/adolescent might have an underlying motive for displaying or reporting pain (eg, "I think it is more his mood," "he just doesn't want to do it but he can", "he can clearly do it when he has to"). The behavioural responses of parents were also communicated about in conversations about children/adolescents with pain (eg, "mum is over-focusing", "mum is over-medicalising", "dad is disengaged", "they are hyper-vigilant"). In many healthcare professional interpretations, parents' actions could be seen as "helpful" or "demanding" in terms of their involvement with pain in children/adolescents (eg, "dad wasn't very helpful", "mum demanded pain relief"). In some instances, family could be seen as a "deep-rooted" cause of pain (eg, "they have a pain family focus", "there are dynamics in that family").

### Topic 6: Managing Uncertainty About Pain Amongst Children/Adolescents, Family and Healthcare Professionals

Managing the uncertainty of the pain presentation, diagnosis and management was a key feature of inter-professional communication. Healthcare professionals regularly discussed "gut feelings" or "vibes something else was going on," which seemed to be discussed when reliable and/or accurate information about pain was lacking (eg, "There's something more going on that we don't know about"). In some cases, the healthcare professional would infer that there were specific triggers (eg, setting or emotion) important to the child's pain experience (eg, "I get the feeling something else is going on at school").

Another key component that shaped uncertainty was seeing what "time" and different contexts may bring (eg, "let's see how we go from there", "let's see what life brings us", "let's wait, there is more exploring to be done that can be done", "we need to see what happens when she gets home"). Healthcare professionals would also talk about feeling "stuck" with a patient and not knowing what else to do when uncertainty persisted (eg, "It's a bit of a mess, I don't know what else we can possibly do"). This led to discussions about what could potentially be anticipated next in the course of the child/adolescent's condition (eg, "That's not something we would anticipate being necessary for a patient with

arthritis"). Reactions to such uncertainty often included healthcare professionals voicing their own feelings and concerns about children and adolescents with pain to their healthcare professional peers during communication (eg, "I needed to cry with all the problems this [child/adolescent] is facing").

### Topic 7: Setting Expectations About Care for Children/Adolescents and Family

Another key component of interprofessional communication about children and adolescents with chronic musculoskeletal pain was a discussion about setting expectations for treatment and care for them and their families (eg, "we need to let her know we can't give her medication to improve her pain"). Healthcare professionals would often discuss whether children/adolescents and their families accepted the expectations set around treatment and care, which particularly related to the child's diagnosis or the treatment strategies suggested by healthcare professionals (eg, "they are always on board with doing therapy and physio"). Part of managing these expectations also included managing the "hopes" of children/adolescents and their families for particular treatment and questioning family's perception of advice they had been given (eg, "mum has said this will resolve the pain, but is that what she has been told or is that what she heard?").

When healthcare professionals felt that diagnoses and/or treatment had not been accepted (eg, "she wasn't buying into that explanation"), communication focused on how patients needed to learn to accept their pain (eg, "he needs to get used to it", "he needs to get back to life"). A key feature of setting expectations and acceptance of pain appeared to be related to discussions about whether the child/adolescent and/or family were able to learn about pain and retain the information given to them about their pain (eg, "I don't think she retains much", "I don't think the dad is retaining anything").

Communication about setting expectations also included communication between healthcare professionals about the need to set specific boundaries for contact with the team from children/adolescents and their families (eg, "I had to set expectations for the mum because it was getting a bit too much", "mum is harassing", "we need to re-assure but not always be available so we don't reinforce the behaviour, we need to set boundaries").

## Discussion

This is the first ethnographic study to observe inter-professional communication about children and adolescents with chronic musculoskeletal pain in UK paediatric rheumatology settings. Findings identified three core processes involved in interprofessional communication about children and adolescents with chronic pain, which included describing, making sense of and managing pain. Inter-related topics of communication featured in these core processes focused on healthcare professional perceptions

about personality, familiarity, diagnoses, pain aetiology, anxiety, uncertainties and expectations about pain in children/adolescents and their families. Findings highlight the complexities of interprofessional communication about pain specifically in children and adolescents who have long-term inflammatory and/or non-inflammatory musculoskeletal conditions in which pain can be a primary feature, a secondary feature to an underlying disease or not a feature of the conditions at all.<sup>1-4</sup>

These findings are important because children and adolescents report common occurrences of perceived pain dismissal in paediatric rheumatology settings, regardless of the underlying condition.<sup>40</sup> Children/adolescents particularly perceive pain dismissal to occur by healthcare professionals when pain is not severe or when medical investigations show no underlying cause which explains pain. In these instances, children/adolescents report that healthcare professionals do not listen to their reports of pain, may change the topic of conversation and close down communication related to pain. Pain dismissal by healthcare professionals appeared to transpire through the themes identified in this study (eg, interprofessional discussion about patients needing to get used to experiencing pain). Our findings and past research highlight the importance of addressing pain dismissal particularly in future interventions targeting healthcare professional approaches to pain communication. Principles of shared decision-making (the process by which children/young people, parents and healthcare professionals discuss and jointly decide on treatment options<sup>41</sup>) could potentially be effective in addressing perceived pain dismissal, ensuring that key concerns about pain from children/adolescents and parents are acknowledged by healthcare professionals. A challenge shared amongst all healthcare professional specialties in paediatric rheumatology is that they do not have the time, resources or training to communicate about pain directly with children/adolescents and/or their families during consultations.<sup>42,43</sup> However, results presented here reveal that healthcare professionals do have opportunities to communicate to other healthcare professionals about children and adolescents with pain and their families during MDTs. In line with past research investigating interprofessional communication about children and adolescents with chronic pain in a US pain clinic, the content of communication in the current study was inclusive of biological, psychological and social factors involved in pain, which took priority in communication at different times.<sup>8</sup> These domains and explanations for pain provided useful interpretative frameworks from which healthcare professionals drew, often with emphasis upon reaching new conclusions over time. Importantly, at times healthcare professionals drew upon these different (biopsychosocial) components of pain to distance themselves or absolve themselves of responsibility in addressing pain (eg, if that particular component was perceived to be outside of the healthcare professional's control).

Interprofessional communication included discussion of children/adolescents and families within the broader

biopsychosocial context, confirming that there are parallels between interprofessional communication about children and adolescents with chronic pain in both the US and the UK. In terms of family factors in particular, healthcare professionals appeared to discuss negative family pain 'models' in their communication to one another. In other literature, these negative family pain models have been described as over-protective and distressed parents who may have a history of chronic pain themselves.<sup>44</sup> Family dynamics were repeatedly and critically evaluated amongst healthcare professionals in the present study, with healthcare professionals often discussing how these dynamics could partially explain the pain experiences of children and adolescents.

Particularly towards the beginning of describing a child/adolescent with pain, healthcare professionals discussed their perceptions of the child/adolescent and their family's personality characteristics, perceptions which predominantly appeared to be positive (eg, "They are chatty/academic/articulate/high-achieving/bubbly/lovely"). It was not clear as to why these particular kinds of characteristics were mentioned within interprofessional communication and key informant interviews did not shed further light on the significance of academic level, chattiness or other specific personality factors. Future research which explores the types of implicit biases exchanged in interprofessional communication and the function of these biases is important for ensuring communication is appropriate. Sharing similar types of phenotypical narratives about individuals with pain has been referred to in past literature as 'personhood diagnostics'.<sup>45</sup> In other ethnographic observations of US paediatric pain clinics, similar descriptive terminology as found in the present study was used to describe patients (eg, "smart", "academic", "high-achieving"). These narratives, therefore, do not appear to be UK-specific and may be present in interprofessional communication regardless of whether a child/adolescent has primary pain or secondary pain to underlying rheumatic disease. Healthcare professional narratives about psychological phenotypes in children and adolescents with pain have also been found to reflect upon the 'cognitive rigidity' of children/adolescents and their families.<sup>46</sup> Cognitive rigidity in the context of chronic pain is used to refer to children/adolescents who are 'stuck' focusing on their pain.

Interprofessional communication about children/adolescents' pain aetiology demonstrates how healthcare professionals may question the legitimacy of pain in the absence of organic explanations or diagnoses but also often question existing biological explanations for pain if there are any diagnoses present. Healthcare professionals managing paediatric pain report challenges with treating and managing pain because of their experiences of diagnostic uncertainty, which can be defined as a healthcare professionals' subjective inability to provide an accurate label, diagnosis or explanation for pain.<sup>47,48</sup> Diagnostic uncertainty plays a key role in the management of paediatric chronic pain by healthcare professionals, who frequently find it

challenging to decide when to cease diagnostic testing to determine an underlying cause for pain. The findings of the current study demonstrate that interprofessional communication about pain in children and adolescents explicitly features diagnostic uncertainty as healthcare professionals often report leaning upon their 'gut reactions', in line with anecdotal evidence.<sup>24,25</sup> An important and unique finding of the present study was that interprofessional communication about 'gut feelings' and thus diagnostic uncertainty appeared to shift the MDT sense-making process deeper into the psychosocial domain. Disclosure of 'gut-feelings' appeared to be an authoritative-based practice to shift the conversation away from biological, organic pain explanations. Our findings highlight that education and training of healthcare professionals in the biopsychosocial nature of all pain, regardless of whether there is or is not an underlying pathology present, should be a future point for intervention. MDTs are now common throughout healthcare specialities but vary in their approaches to interprofessional communication. The creation of a safe environment that provides the opportunity for healthcare professionals to offload about difficult clinical situations has been found to be integral to effective team working, particularly in the context of managing chronic pain.<sup>49,50</sup> To achieve effective and efficient interprofessional communication amongst the MDT of healthcare professionals, using common terminology and language, producing and co-ordinating team action plans, addressing pertinent challenges during meetings, exchanging peer-review feedback and setting priorities has been found to be essential.<sup>51</sup> There are now key standards for interprofessional communication in paediatric and adolescent healthcare in the UK<sup>52</sup> and there are examples of research and clinical attempts to make interprofessional communication about patients systematic (eg, using the SBAR acronym: Situation/Background/Assessment/Recommendation).<sup>53</sup> Despite the development of standards and guidelines for communication, there is no focus specifically on effective communication about paediatric pain between professionals or with children/young people and parents in these examples. Our study findings highlight this is an important gap to address in the future of the field.

The current study uniquely utilised an ethnographic research method in a UK paediatric rheumatology setting. Although it was not possible to identify the resonance of the themes identified in this study with all members of the MDTs observed, participants who did take part in key informant interviews were able to recognise particular processes and content when presented by the researcher. Healthcare professionals commented upon how they did not realise there were specific processes and content in the ways they were communicating about pain until themes were presented to them by the lead researcher. This was a critical finding as it highlighted how these data would not have been obtained via other methods such as interviews and/or focus groups, which require healthcare professionals to be able to notice, acknowledge, understand and directly report upon their communication. However, field notes could only be made about the discussions which

were had between actively consenting healthcare professionals. As such, some relevant discussions had to be ignored during ethnographic data collection, which is a potential limitation of the study.

To our knowledge, there are no interventions focused on ensuring that interprofessional communication about paediatric pain is appropriate and free from negative attitudes towards individuals with pain. Findings from the current study are key for informing the design of future interventions that can ensure that interprofessional paediatric pain communication is both appropriate and effective, particularly with regards to shaping both the structure of and the topic areas comprised in this type of communication. The study figure, which describes the intersections between communication processes and content, provides an overview of key target areas for improving interprofessional communication specifically about paediatric pain in future interventions (eg, discussion about personality characteristics, familiarity, diagnoses/key pain features, etc may be ripe starting points to modify in communication). The purpose of interprofessional communication about pain is to ultimately build collective wisdom about patients and their family amongst the MDT, with communication and exchanges subsequently shaping other healthcare professionals' interpretations from there onwards. The content of communication may shut down certain avenues of potential treatment and care and/or it may open other possibilities. Identifying potential interactions and characterising the dynamic interplay between processes and content in interprofessional communication about paediatric pain requires further research. How these communication processes and mechanisms impact upon pain management specifically requires further investigation, particularly considering past research demonstrating that interprofessional communication impacts upon care and patient outcomes long after the MDTM has taken place.<sup>17-23</sup> Healthcare professionals from different healthcare professional groups (eg, nurses vs physiotherapists vs occupational therapists etc) may share similar outlooks on paediatric pain. On the converse, some content may be unique to specific healthcare professional groups. This also requires further research which will highlight implications for different healthcare professional groups within interventions targeting communication.

In conclusion, this study highlights the complexities of interprofessional communication about children/adolescents with pain and their families who are managed within UK paediatric rheumatology settings. Through an ethnographic study design, our findings highlighted that there are three core processes involved in interprofessional communication about pain, which includes describing, making sense of and managing the child/adolescent with pain as well as their family. The content of this communication was inclusive of the whole biopsychosocial presentation and interpretation of the child/adolescent and their family and included communication about specific topic areas such as personality, familiarity, diagnoses, pain histories, pain aetiology, anxiety, uncertainties and expectations. This study

highlights that further research investigating the impact of interprofessional communication on pain outcomes of children and adolescents with chronic musculoskeletal pain is key, particularly as past research has demonstrated a strong association between interprofessional communication and patient outcomes in other settings and populations.<sup>17–23</sup> We need to ensure that interprofessional communication about paediatric pain positively influences the care of this patient group in clinical practice.

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Interprofessional paediatric pain communication

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