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Barriers and facilitators to paediatric palliative pain management: a qualitative study --Manuscript Draft--

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Corresponding Author:	Christina Liossi University of Southampton Southampton, UNITED KINGDOM
First Author:	Katie Greenfield
Order of Authors:	Katie Greenfield Bernie Carter, Bsc, PhD Emily Harrop, DCH, MRCPCH, PhD, Dip Pal Med Satbir Jassal, BMedSci, BM, BS, FRCGP, FRCPCH(Hon) Julie Bayliss, RGN RSCN BSc MSc NMP Kate Renton, MSc, BMedSci, MBChB, MRCPCH Simone Holley, PhD Richard Howard, MB, ChB, FRCA, FFPMRCA Margaret Johnson, BSc Christina Liossi, BA, DPsych
Abstract:	<p>Contexts: Inadequate pain management in community paediatric palliative care is common. Evidence to inform improved pain management in this population is limited.</p> <p>Objectives: To explore the barriers and facilitators to paediatric community-based pain management for infants, children and young people at end-of-life as perceived by healthcare professionals.</p> <p>Methods: A qualitative interview study was conducted. Semi-structured interviews were undertaken with 29 healthcare professionals; 12 nurses, five GPs, five consultants and registrar doctors, two pharmacists and five support therapists working in primary, secondary or tertiary care in the United Kingdom and involved in community end-of life care of 0-18-year-olds.</p> <p>Results: The data corpus was analysed using an inductive thematic analysis and seven themes emerged: parents' abilities, beliefs and wellbeing; working relationships between families and healthcare professionals, and between healthcare teams; healthcare professionals' knowledge, education and experience; health services delivery; nature of pain treatment; and paediatric-specific factors. Across themes, the concepts of partnership working between families and healthcare professionals, and within healthcare teams, and sharing expertise were prevalent.</p> <p>Conclusion: Partnership working and trust between healthcare professionals and parents, and within healthcare teams, is needed for effective at-home paediatric palliative pain management. Community healthcare professionals require more education from experienced multidisciplinary teams to effectively manage paediatric pain at end-of-life and prevent emergency hospice or hospital admissions, particularly during the COVID-19 pandemic.</p>

Dear Editors,

We wish to submit an original research article entitled 'Healthcare professionals' experiences of the barriers and facilitators to paediatric pain management in the community at end-of-life: A qualitative interview study' for consideration by the Journal of Pain and Symptom Management.

We believe that this manuscript is of interest to clinicians, researchers and policy-makers working in child health since pain management in paediatric palliative care has been highlighted as a research priority by The UK National Institute for Health and Clinical Evidence (NICE). A recent systematic review of barriers and facilitators to paediatric palliative symptom management (1) also reported a lack of recent, high quality research in this area.

The current study involved thematic analysis of in-depth qualitative interviews with 29 healthcare professionals working in paediatric palliative care. Results highlighted the need for partnership working within healthcare teams, and between healthcare professionals and families, and more education for community healthcare professionals to manage paediatric pain at end-of-life.

We have no conflicts of interest to disclose.

Thank you for your consideration of this manuscript.

Sincerely,

A handwritten signature in dark ink, appearing to read 'Liossi', with a stylized, flowing script.

Professor Christina Liossi

Chair & Honorary Consultant in Paediatric Psychology

University of Southampton & Great Ormond Street Hospital for Children NHS Trust

1. Greenfield K, Holley S, Schoth DE, et al. A mixed-methods systematic review and meta-analysis of barriers and facilitators to paediatric symptom management at end of life. Palliative medicine 2020;34:689-707.

Dear Professor Casarertt,

Thank you for reviewing our manuscript titled "Healthcare professionals' experiences of the barriers and facilitators to paediatric pain management in the community at end-of-life: A qualitative interview study" (JPSM-D-21-00308) to the Journal of Pain and Symptom Management. We are grateful to the reviewers for their constructive comments. We have revised the manuscript highlighting edits as tracked changes and/or in blue, and responded to reviewers' comments below.

Reviewer #1: Thank you for your work on such an important topic, I enjoyed reading the paper. Please consider my comments. In this manuscript, "Healthcare professionals' experiences of the barriers and facilitators to paediatric pain management in the community at end-of-life: A qualitative interview study," the authors use the PARAMOUNT study to evaluate barriers and facilitators to pediatric pain management in the community at end of life. Overall, the manuscript is relevant to the clinical practice of pediatric palliative care and was preceded by a mixed methods systematic review and meta-analysis on the same topic published by Greenfield et al. in 2020. I believe that this manuscript is a valuable addition to the literature. However, I have several questions regarding the methodology of the paper, as well as several comments about content. Additionally, the manuscript is moderately well written, but it would benefit from editorial revisions to improve language, syntax, and narrative flow. Please see my feedback below.

Thank you, we are pleased you consider our manuscript as a valuable addition to the literature.

Abstract:

1. The 'conclusions' section does not clearly communicate the potential impact of the study succinctly and does not clearly tie in the impact on community pain management. The 'key message' was more impactful and written in a more clear manner. I suggest that there is some comment on how findings adverse research, next steps, or implications on clinical practice.

Thank you for your suggestion. We have amended the abstract conclusions section so that it more clearly communicates the impact of the study.

Introduction:

The introduction does help bring context to the problem but does not describe the specific challenges of pain management in pediatric patients, the challenges of caring for a child at EOL at home, a summary of what knowledge exists and what specific gap is missing (see examples below). It also does not describe why this study will help address the knowledge gap, why it is important and how it will help. I think that this introduction needs to be re-written to satisfy these questions. In addition, the urgency of addressing this problem is not clearly described.

We have made changes to the introduction as detailed below. However, Reviewers 2-4 gave very positive feedback about the introduction, describing it as very solid with a literature review that has sufficient breadth, while being concise at the same time. As such, we have not re-written the whole introduction section. In paragraphs 1-3, we described the challenges of caring for a child at EOL at home (pain is a common symptom; homecare relies on non-experts to manage pain; parents may underdose medication due to fears and misconceptions; medical regimes change as conditions progress and children's management differs depending on their condition, needs and ages) and gave a summary of what knowledge exists (the systematic review of barriers and facilitators to symptom management in paediatric palliative care) and what is missing (a lack of current, in-depth research). We have now added more detail to describe why this study will help address the knowledge gap, why it is important and how it will help (paragraph 4).

2. In the first paragraph, the authors state, "In 2017-2018, an estimated 81-87,000 0-19-year-olds were living with a life-limiting or life-threatening condition in the UK (1). This is over double the estimated number in 2001/2002 and a continuing rise in prevalence is predicted (1). Pain is one of the most common symptoms in these conditions (2) and is often managed inadequately (3, 4). Could you please explain the following: a. What accounts for this doubling of children living with life limiting or life-threatening condition in the UK over this time period? b. Why is there rise in this number? c. Pain is the most common symptom of WHICH condition? Why is it managed inadequately? Has this been explored?

- a) The doubling of children living with life-limiting or life-threatening conditions has not been clearly established but the authors suggest it could be driven by an increase in recording of these conditions and an increase in survival. The former may reflect a change in coding practice rather than a true increase in incidence.
- b) The authors projected a continuing rise in numbers based on previous trends and predicted future trends in health improvements. We have now commented on both these points (a and b) in the manuscript (Introduction paragraph 1).
- c) Pain is the most common symptom across life-limiting or life-threatening conditions collectively. These definitions describe the population of children who may benefit from paediatric palliative care services.
- d) We highlight several possible reasons from the literature regarding why pain is managed inadequately, which we covered in the introduction:
 - 'Parents may underdose analgesics due to fears and misconceptions around addiction, sedation and the possibility of hastening death, or, conversely, a belief that they are unnecessary'
 - 'Diverse conditions and differing developmental needs at different ages provide further challenges'
 - 'Clinicians worldwide reported a lack of experience, education, and confidence [in managing pain] as well as revealing issues relating to how different health services worked together'

3. In the second paragraph, the authors state *"Many parents want their child to be cared for and die at home (5) this being associated with higher patient satisfaction and parent quality of life (6). However, homecare relies on families (predominantly parents) and community healthcare professionals being increasingly responsible for pain management, which can be challenging. Parents may underdose analgesics due to fears and misconceptions around addiction, sedation and the possibility of hastening death, or, conversely, a belief that they are unnecessary (6). Inadequate pain management has a detrimental effect on a child's quality of life and relationships with their family (7)."* In the sentence *"Many parents want their child to be cared for and die at home (5) this being associated with higher patient satisfaction and parent quality of life"* - What is 'this'? Please clarify sentence. Do children want to be at home, parents, both?

In the above sentence, 'this' refers to being cared for and dying at home. Children tend to report higher patient satisfaction at home while parents' rate their quality of life as higher when their child is at home rather than an in-patient.

In addition, it makes intuitive sense for community healthcare workers to be responsible for pain management. Furthermore, even in inpatient settings parents are relied upon to note changes in their child's behavior or to help understand the child's communication of symptoms. Is the comparison to an inpatient setting and specifically to EOL care? Perhaps this could be rephrased to talk about how caring for a child of EOL without the structured presence of a nursing team, shifts the burden of pain assessment and relief to the shoulders of the parent. This shift, in the setting of EOL,

can both be a blessing and a burden given the high stress circumstances of the situation and then describe some contributing factors that have been previously reported in the literature.

Yes, the comparison is to inpatient settings where hospital healthcare workers (as opposed to community HCPs and parents) would be responsible for pain management. Although parents would note changes in ICYP's symptoms while they are in hospital, they would not be responsible for administering medication or making decisions about treatment (how much to give and when). Due to wordcount limitations, we have not elaborated on the high stress circumstances of homecare for parents, but we have clarified the shift in responsibility of pain management at home compared to in hospital or hospices.

4. The authors state that the objectives of the study aim to better understand pain management in the community at EOL in pediatric patients. In my experience, life limiting illness and end of life care are different. A child with cancer may have life limiting illness but is not imminently dying. I think the third paragraph needs to be reconstructed to address this specific area, which may include general lack of knowledge of pain management in pediatric patients and palliative care which then also includes specific EOL context.

We agree that there is a general lack of knowledge of pain management in paediatrics as a whole and in paediatric life-limiting conditions – we have now clarified this (Introduction paragraph 3).

Furthermore, the sentence 'Yet, most of the included studies were of low- medium quality and there remains a dearth of current, in-depth research' - is this referring to pediatric pain management in general, pediatric pain management at EOL, etc?

This is referring to paediatric symptom management at end-of-life in the community as the aim of the study was to review 'the barriers and facilitators to effective symptom management in paediatric palliative care' (Introduction paragraph 3).

Methods:

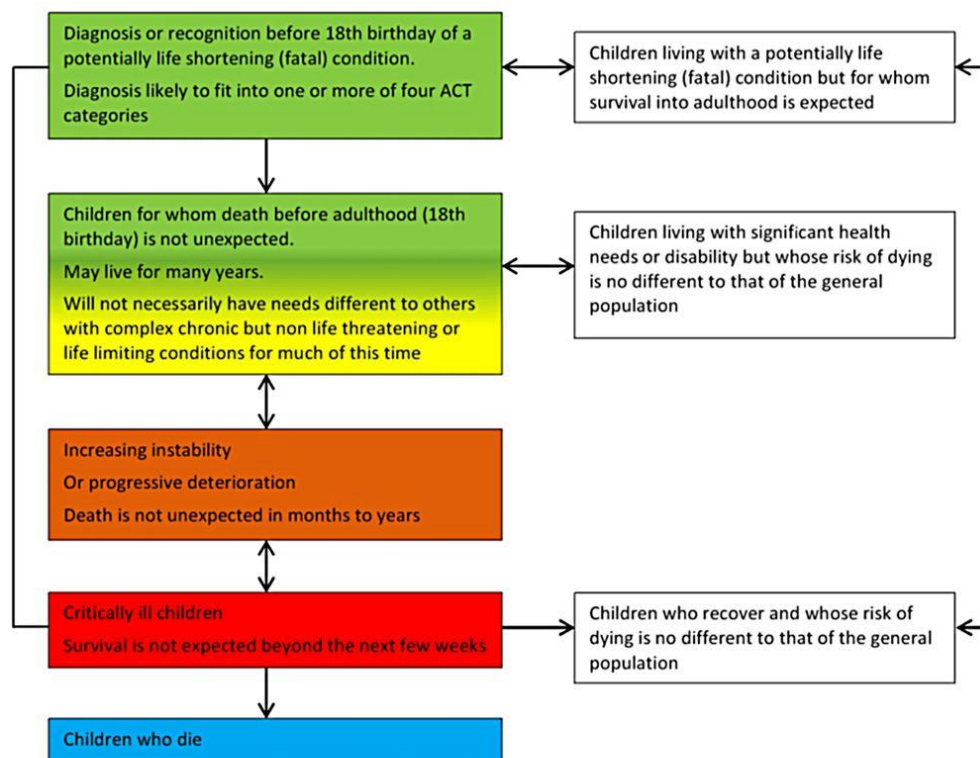
1. The healthcare professional in the abstract is defined to include nurses, general practitioners, consultants/registrar doctors, pharmacists and support therapists. I believe this could be better defined in the methods section. Are all healthcare providers eligible or do they have to be trained in palliative care and hospice medicine for example? What role do these different providers play in pain management?

Healthcare professionals were eligible if they were 'working in primary, secondary, or tertiary care in the UK and involved in community end-of-life care of 0-18-year-olds'. They did not need to have had palliative care or hospice medicine training – they only needed to have experience in caring for an ICYP at end-of-life in the community. The roles that the providers played could be diverse e.g. prescribing medication, dispensing prescriptions, giving non-pharmacological therapy, administering medication etc. We specifically did not exclude healthcare professionals without palliative care or hospice medicine training as we know from previous research (1) that healthcare professionals without such training are required to manage pain in children at end-of-life in the community.

2. I am surprised by the definition of 'end of life' as described in the text and disagree with the definition. As defined by the NCI, end of life describes "care given to people who are near the end of life and have stopped treatment to cure or control their disease." Defining this differently in the text is misleading and confusing. The authors defined end of life as "any patient in whom it would not be unexpected if death occurred within the next 5 years." This does not fit the definition of palliative care either.

This definition was taken from the Spectrum of Palliative Care Needs tool (2) and included ICYP for whom death is not unexpected in the next five years (the red and orange boxes in the figure below). This included children with life-limiting and life-threatening conditions, which are definitions that

have been used to describe the population of children who may benefit from input from paediatric palliative care services (3). NICE states that 'end of life care can mean caring for your child from the time you find out they have a condition that may shorten their life (called a 'life-limiting' condition).' Moreover, Reviewer 3 described the 5-year time frame as 'a nice compromise in the context of uncertainty of illness trajectory and prognosis for paediatric palliative care' between the definition of a life limiting condition of childhood as a condition for which the child would die before 18 years, and the definition couched in terms of the question "Would you be surprised if the child died in the next 12 months". We discussed and decided on the definition as a research group, which included our PPI representative and clinicians from the participating sites. As such, we feel this timeframe is appropriate and useful for the purposes of this study. We have now specified the rationale for this definition in the manuscript (Methods; participants section).



The revised definitions

Diagnosis or recognition before the child's 18th birthday of a potentially life shortening (fatal) condition

- "Would you be surprised if this child died as a result of this condition or problem?"
- It is anticipated that diagnosis or recognition will facilitate identification of one or more relevant ACT groups

Death before adulthood is not unexpected

- "Would you be surprised if this child died before adulthood (18th birthday)?"

Children with Increasingly instability

- "Would you be surprised if this child died in the next few months to years?" Or
- "Would you be surprised if this child died in the next five years?"

Children experiencing Critical illness or end of life care

- "Would you be surprised if this child was alive in a few weeks time?"

3. The authors use the terminology, "diversity from a range of professionals." I was curious as to what the range of professionals included, as to whether they were a range of healthcare professionals caring for pediatric patients versus those who were trained in palliative/hospice medicine? Please clarify the recruitment goal for the study.

Healthcare professionals were eligible if they were 'working in primary, secondary, or tertiary care in the UK and involved in community end-of-life care of 0-18-year-olds'. They did not need to have had palliative care or hospice medicine training – they only needed to have some experience in caring for an ICYP at end-of-life in the community. The roles that the providers played could be diverse e.g. prescribing medication, dispensing prescriptions, giving non-pharmacological therapy, administering medication etc. We specifically did not exclude healthcare professionals without palliative care or hospice medicine training as we know from previous research (1) that healthcare professionals without such training are still required to manage pain in children at end-of-life in the community.

4. Minor detail, but was the interview guide developed de novo or based on any previously studied work?

The interview guide was developed de novo with discussion with the co-investigators, PPI lead and all members of the research team and informed by our systematic review of barriers and facilitators to paediatric symptom management at end of life (1).

5. Another minor detail, why was the references for table listed separately from the references of the text?

We were asked to submit the table separately from the main manuscript hence the references were also separate. These can be combined for the final manuscript.

Results:

The results are organized based on the 7 themes generated during data analysis which I believe to be a great strategy. There is a lot of information presented, and overall, I think that the writing and presentation of content within theme could be improved. It would be helpful for the results section to be re-written, using the subcategories to separate themes, but listing only summaries of data without interpretation or references. This would improve the strength of the data presented, the flow of the section. Currently, the results are disjointed and difficult to read. Not all quotes need to be used and can be summarized. Alternatively, a figure can be created to highlight important quotations. Some examples are shared below:

Thank you, we are pleased you believe the organisation of our results to be a great strategy. There are many different ways of organising qualitative results and it is inevitable that different researchers many choose different ways to present their findings. We have not cut out any of the quotes or re-written the whole results section since Reviewer 2 commended us on working the quotes into the main text and on the transparent description of the data analysis. We hope you appreciate this as one possible, valid strategy for organising the results.

1. In the section on "Parents' beliefs, abilities, and wellbeing," it reads as if the parents themselves were interviewed rather than these are the healthcare professionals' perspectives on parent caregivers and their beliefs, abilities and wellbeing. I think this is misleading and should be re-written.

Thank you for pointing this out. We have now clarified that these are the healthcare professionals' perspectives on the parents' beliefs, abilities, and wellbeing (paragraph 1 and 3 in the Parents' beliefs, abilities, and wellbeing subsection of the results).

2. In the results section, the authors report both objective data and subjective interpretation. This may not be the case but is not clear and I recommend that the section is re-written without

interpretation of the results which can then be addressed later in the discussion. At times, the interpretation does not coincide with what is reported in the data. For example, "Parents may be in denial about their child's symptoms, diagnosis or prognosis and therefore may avoid discussing pain management; 'a family who found it difficult to talk about diagnosis...are likely to have found it difficult to talk about pain.' (T5-Hc)." Denial about symptoms, diagnosis or prognosis is different than having difficulty discussing these topics.

Thank you for pointing out that it may appear that we are reporting both objective data and subjective interpretation. In fact, we only report the data in the results section. To avoid repetition, and to keep to the wordcount, we did not preface every finding to state that this was from the point of view of the participants (rather than the authors). We have now include a sentence at the start of the results section to make it clear that the findings represent the views of the participants rather than objective reality. We have also rephrased the sentence mentioned above to ensure that the quote illustrates the point correctly.

Another example: "Reassurance and professional psychological support for parents can help. Pain assessment could be facilitated by using existing, standardised assessment tools. Apps that allow parents to score pain quickly and share this information with their care team can also help." Is this being offered by the authors as a potential solution or were these solutions offered by the study participants, it is hard to tell.

We have now amended this paragraph (and the rest of the results section) to make it clear that these solutions are offered by the participants rather than the authors.

Discussion:

- The first paragraph repeats the themes identified in the results section unnecessarily and takes up a lot of room. I would encourage not repeating this information in the discussion.

We have now reduced the summary of findings in the discussion.

- The section would be better suited in the intro: "The UK National Institute of Health Research (NICE) highlights paediatric palliative pain management as a research priority (14) and WHO recommends the use of qualitative studies to understand which interventions are most effective (13). There is a lack of recent, high quality research in this area (8, 13)."

Thank you for your recommendation - we have now moved this section to the introduction.

- The data regarding caregivers' reports of pain - again, is from the perspective of healthcare providers and not of the caregivers themselves. Please comment on the potential bias of healthcare providers.

We have now emphasised that this is from the perspective of healthcare professionals only (Discussion paragraphs 2, 4 and 5) and have mentioned this as a potential limitation of the study in the Limitations section.

- How do the results of all the themes come together? This has not been made clear in the discussion. The text of the discussion primarily restates the results with some conclusions made. We discuss how the seven themes come together into three overarching concepts of Partnership working (teamwork between healthcare professionals and families; and teamwork between healthcare professionals) and Education and shared expertise. These concepts are displayed in Figure 1. We also discuss these themes and concepts in relation to the current literature.

More emphases needs to be placed on the interpretation of these findings. How will these findings be used? How does it contribute to research or influence clinical practice? What are the next steps? Why does this matter?

Table 3 (Clinical recommendations for the improvement of community paediatric pain management at end-of-life) lists recommendations for clinical care derived from the study findings. Additionally, we mention in the Discussion that ‘these findings are part of a larger study (The PARAMOUNT study), which draws on the views of family caregivers, children, and professionals to co-produce an educational intervention to help caregivers manage paediatric pain at home. This study highlights the need for such a resource and will help to guide its development’. We have now also added that further research is needed to specifically explore the views of family caregivers and children on the barriers and facilitators to pain management.

Furthermore, there is no discussion of limitations of the study.

Thank you for pointing this out. We have now added a section on the limitations of the study.

The figures are not discussed in the text. How does figure 1 help in thinking of potential interventions to improve care?

There is only one figure, which is referenced in the Results section, paragraph 2. We have now also referenced it in the Discussion (paragraph 1) before going on to describe the overarching concepts shown in the figure. We then go on to suggest ways to improve care based on these concepts in the Discussion and in Table 3 Clinical recommendations for the improvement of community paediatric pain management at end-of-life.

Reviewer #2: An extremely interesting and important piece of work that notably reflects some themes identified in pain recognition, assessment and management in older adults with conditions that impair or reduce their ability to express pain (e.g. dementia). The paper does well to distil the critical issues into concise, well-written segments that cover many perspectives, including those of parents and children, and makes important recommendations not only for future research but also clinical practice. It is very refreshing to see concerted effort to translate research findings back into clinical practice and/or guidelines for practice. The paper raises some critical points around barriers presented by circumstances beyond health professionals' control (i.e. organisational and institutional) and highlights the potential deficit in confidence of primary care practitioners to engage in paediatric palliative care. I would have liked to have seen some more participant quotes; I have not seen them worked into the main text like this before but I do understand the eternal difficulty of trying to get the participants' perspective across using their own words whilst also explaining the theme and staying within the word limit. I commend the authors for their transparent description of the data analysis and the excellent presentation of the key findings in Figure 1. Thank you, we are pleased that you consider this an extremely interesting and important piece of work. Due to the word limit, we were not able to add any more quotes to the manuscript.

Reviewer #3: Overall a well written article, using qualitative research methodology to better understand facilitators and barriers to pain management within the community.

Thank you.

Introduction: The introduction identifies key references, and the gap in knowledge and research, that has led to the study. The literature review had sufficient breadth, while being concise at the same time.

Thank you for your positive comments on the introduction.

Methodology:

This is concisely presented, with data analysis presented as a separate table. This consisted of undertaking qualitative interviews with 29 Healthcare Professionals (HCP). Was there a suggested structure or perform for the interviews?

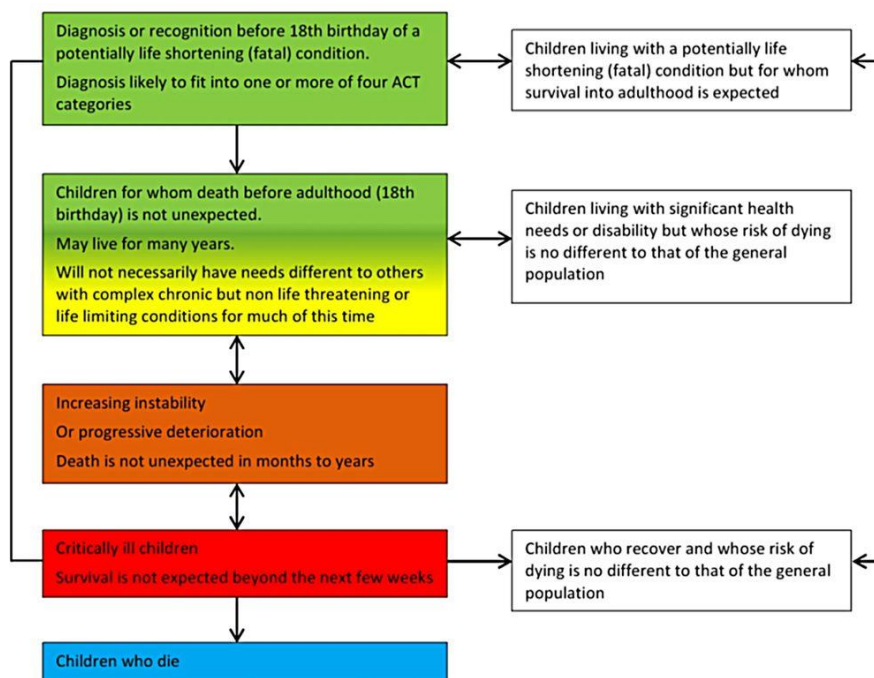
The interviews were semi-structured. They followed an interview guide (Supplementary File 1) and open questions were used, including questions not included in the interview guide, depending on the points that the participants raised.

Did HCPs give informed consent to participate in this study?

Yes, this is noted on page 3 (Recruitment): 'All participants provided written and verbal consent.'

The authors stated that "End of Life" was defined as any patient in whom it would not be unexpected if death occurred in the next 5 years. Could the authors please give rationale or references for this time frame. A life limiting condition of childhood is traditionally defined as a condition for which the child would die before 18 years, as the authors would well know. The surprise question is often couched "Would you be surprised if the child died in the next 12 months". The 5 year time frame seems like a nice compromise between these two other time frames, in the context of uncertainty of illness trajectory and prognosis for paediatric palliative care.

This definition was taken from the Spectrum of Palliative Care Needs tool (2) and included 0-18-year-olds for whom death is not unexpected in the next 5 years (the red and orange boxes in the figure below). We have now specified the rationale for this definition in the manuscript (Methods; participants section).



The revised definitions

Diagnosis or recognition before the child's 18th birthday of a potentially life shortening (fatal) condition

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- "Would you be surprised if this child died in the next five years?"

Children experiencing Critical illness or end of life care

- "Would you be surprised if this child was alive in a few weeks time?"

Results: Helpful and informative overall. These were developed from the qualitative interviews with the health care professionals. The demographics of the HCP were presented in Table 2. Themes discussed included

1. Parent's beliefs, abilities and wellbeing
2. Working relationships between families and HCP
3. Working relationships between HCP
4. HCPs knowledge, education and experience
5. Health services delivery
6. Nature of pain treatment
7. Paediatric-specific factors

I am wondering whether some of the themes could be grouped together

Partnership

- Working relationships between families and HCP
- Working relationships between HCP

The research team developed the themes after reading and re-reading the data and developing codes. The themes were refined after several discussions to ensure that the data fitted the themes, and that the themes were separate and distinct entities. 'Working relationships between families and HCPs' and 'Working relationships between healthcare teams' were kept separate as the nature of these working relationships and the barriers and facilitators within them are distinct. We believe that the results are clearer and more coherent if these themes are kept separate.

The authors discuss the parent's reluctance to perhaps acknowledge poor prognosis, and the child's pain and to treat this pain. Did any interviewer report reluctance of HCP to treat pain in children, especially non-verbal children. Were their concerns by HCP in relation to not knowing the cause of the pain, or perhaps there being multiple causes, and that the parents were perceiving distress as pain, when it could be attributed to other factors?

Participants described how GPs with little/no experience of pain management in paediatric palliative care feared prescribing pain medication for children; *'they're scared of using a drug that they don't understand, at a dose that looks really high, and they are frightened of giving, using a medication that they don't fully appreciate'* (GP1-Hc). We have now added this to the manuscript (Results: 4. HCPs' knowledge, education and experience – paragraph 1). Concerns from HCPs regarding not knowing the cause of pain were not specifically mentioned but, as noted in the manuscript, 'participants mentioned that some parents may lack the necessary objectivity to assess pain, judging that *'any distress must be pain'* (GP4-Hc).'

In relation to point 3, working relationships between healthcare professionals. Was there any mention of the role for multi-disciplinary, inter-agency and family meetings to facilitate communication between teams and with the family?

One participant noted that *'within an MDT environment, these complex children we'll discuss on a weekly basis in our MDT, and so actually everyone will contribute to the decision-making'* (N4-HI), which was seen as a facilitator. We have now added this to the manuscript (Results: 3. Working relationships between HCPs

In relation to point 4, It was helpful for the authors to describe daily reviews, as opposed to weekly reviews, in terms of assessment at end of life. Linkage between the community nurse doing assessments and the prescriber is also important in this context.

Thank you.

Could the authors more generically describe what a "clinical commissioning group (CCG) is? I am not sure if readers in North America's or Australasia would be aware of this term, although similar groups or committees may exist in these context.

Thank you for your suggestion. We have now described what a CCG is in the manuscript (Health Services Delivery, paragraph 3).

In relation to point 6, the authors describe the benefit of syringe drivers to manage continuous pain. They also briefly mention PCAs (presumably this may also include parent-controlled analgesia?). Perhaps the authors could also mention the importance of managing breakthrough pain - and the role of PCA or pre-made syringes, which the authors do mention later.

Although we agree that managing breakthrough pain is very important, we have not mentioned this in the results section since participants did not directly discuss breakthrough pain.

Re: Point 7

Did the interviewees describe the process or complexity of measuring pain in non-verbal children? Relying on behavioural cues and also parent proxy report.

As noted in the manuscript, participants described how pain indicators may be subtle '*especially if their child is non-verbal or pre-verbal*' (N6-HI)' and that '*getting to know the child and how they react to pain*' (N1-C) facilitated accurate pain assessment.

What role does the psychologist have in managing pain in a child who is pre-verbal, non-verbal or cognitively impaired?

The psychologist worked with verbal children experiencing pain and with families (parents and siblings) of verbal and non-verbal children.

Discussion: There was helpful further discussion and synthesis of the 7 themes presented in the results. I couldn't see where Figure 1 was referenced in the manuscript of the article. Please excuse me if I missed this. I am also interested in whether the journal will be able to accommodate the colour coding in the final published manuscript.

Figure 1 is mentioned in the Results section, paragraph 2. We have now also referenced it in the Discussion, paragraph 1. We have changed the figure so that it is now greyscale instead of black and white.

There was helpful discussion of the importance of providing care 24 hours a day, and 7 days a week. Suggest "As found in previous studies (20,21), teamwork can breakdown during evenings and weekends when on-call staff may lack knowledge of a patient's specific pain signs and management plan".

Thank you for your suggestion, we have now added 'and management plan' to the sentence above.

It was very helpful for the author's to mention the importance of telephone and virtual check-in's to enhance home care, particularly during the time of Covid-19. E.g. A Virtual Children's Hospice in response to Covid-19 - The Scottish experience. J Pain Symptom Manage 2020; 60(2):e40-43.

Thank you for your suggestion, we have now added this to the manuscript (Discussion – Conclusion section).

References to multi-disciplinary meetings, and family meetings, to improve cohesion of the various partnerships could be helpful. E.g. see Walter JK. Teamwork when conducting family meetings: concepts, terminology and the importance of team-team practices. Journal of Pain and Symptom Management 2019 doi:10.1016/j.painsymman.2019.04.030

Thank you for your suggestion, we have added this to the manuscript in the Discussion paragraph 3.

Re: Point 5 in the results, and further developing this them in the discussion.

An interesting finding was the perception that symptom management can be better in hospital or hospice. Although there are other benefits of being at home. One helpful reference in this context, although related to adult care is ... Eagar K eat al. Palliative care is effective: but hospital symptom management superior. BMJ Supportive and Palliative Care , do1: 10.1136/bmjspcare-2018-001534. [Due to the differences in adult and paediatric palliative care, we have not referenced this article.](#)

RE: Education and shared expertise

Is the time required to develop rapport, and understand the child and family, and then provide education also a barrier for HCP? Particularly when perhaps the primary general paediatrician may know the child very well, but not have that time to spend discussing pain management strategies with the child and family in the home, and to a degree may need to outsource this to community or home care teams and paediatric palliative care services.

[Although a lack of time for HCPs to get to know a child and family was not a code in our thematic analysis, participants did acknowledge that it takes time to build up a good relationship with a family and that education and trust cannot occur in just one conversation, as mentioned in the Results section 2. Working relationships between families and HCPs and 7. Paediatric-specific factors.](#)

It was helpful the authors discussed the challenge of obtaining scripts, and also then finding pharmacists to provide these medications (including after hours).

[Thank you.](#)

Would a "just in case" box help with managing pain after hours?

[Thank you for your suggestion. We have now added this to Table 3 Clinical recommendations for the improvement of community paediatric pain management at end-of-life.](#)

The authors describe the need to reference prescriptions (e.g. medication, why it is being used, dose). Would it be possible for pharmacies to be provided with a formulary (e.g. APPM formulary) such that individual referencing for medicines was not required, but only when the medicine was not covered by the formulary.

[Typically, pharmacists working in units where there are paediatric palliative care teams will already use the APPM formulary and may also refer to the \(adult\) Palliative Care Formulary or other hospital guidelines.](#)

Conclusion: Table 3 was a nice summary of results.

[Thank you.](#)

Both ICYP and CYP are used, perhaps stick with ICYP.

[We have now added the definition of CYP in the Figure 1 legend for clarity.](#)

There was also no reference or discussion of Figure 1 in the manuscript.

[Figure 1 is mentioned in the Results section, paragraph 2. We have now also referenced it in the Discussion, paragraph 1.](#)

Reviewer #4: Overview:

In this manuscript "Healthcare professionals' experiences of the barriers and facilitators to paediatric pain management in the community at end-of-life: A qualitative interview study," the authors aim to provide a qualitative assessment of clinician views on pediatric pain management in the community. Overall, I think this is a valuable piece and contribution to the literature in understanding what clinician perceive as impediments and support for adequate pain management in the community.

However, I do have a few concerns about the manuscript that require further elucidation and revision.

Thank you, we are pleased you consider this a valuable piece and contribution to the literature.

Introduction:

1. Minor thing but please be sure to spell out any abbreviations. For example, in paragraph 1 of the introduction in line two it is the UK.

We have now spelt out United Kingdom.

2. Very solid introduction that highlights the importance of home-based care for children with life-threatening illness and the challenge in ensuring they have adequate symptom management.

Thank you.

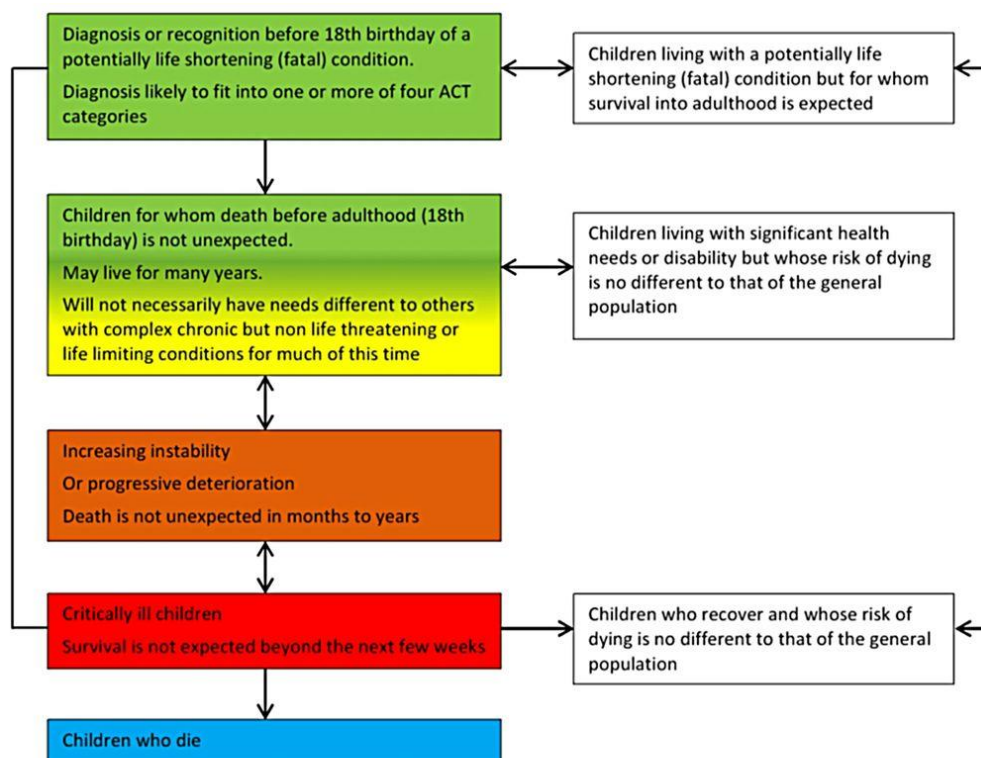
Methods:

1. In the section on Design it describes that this research is a part of a larger multi-centre study the "PARAMOUNT" study. However, there is very little on this study. Have there been other manuscripts published from this study or is this the first one? What are other elements that are being studied in this larger study? It would be helpful to elaborate a little bit more on how this particular manuscript fits within the larger whole

In the Introduction (paragraph 4), PARAMOUNT is described as 'a larger multi-centre study aiming to improve paediatric palliative care pain management in the community through the development of an educational intervention for caregivers.' The conclusion section of the discussion also mentions that the study 'draws on the views of family caregivers, children, and professionals to co-produce an educational intervention to help caregivers manage paediatric pain at home.' Due to wordcount restrictions we were unable to elaborate on PARAMOUNT any further, but we have now added references to published work conducted as part of the study in the Introduction, paragraph 4.

4. In the section on Participants it describes the definition of "End-of-life" as within the time frame of 5 years. I struggle with this methodology as 5 years seems to be a VERY long time. Is there somewhere in the literature in which it is defined as 5 years. Certainly, the definition of end-of-life is not firmly established in the literature but for acceptance to Hospice in the United States, the life expectancy is 6 months or less. Obviously, there are critical differences in the healthcare systems between the United States and the United Kingdom but for many readers that 6-month time frame will be a more common timeframe of reference. If there is evidence or previous literature that defines the period of end-of-life within 5 years, then it will be important to reference.

This definition was taken from the Spectrum of Palliative Care Needs tool (2) and included ICYP for whom death is not unexpected in the next five years (the red and orange boxes in the figure below). This included children with life-limiting and life-threatening conditions, which are definitions that have been used to describe the population of children who may benefit from input from paediatric palliative care services (3). We have now specified the rationale for this definition in the manuscript (Methods; participants section).



The revised definitions

Diagnosis or recognition before the child's 18th birthday of a potentially life shortening (fatal) condition

- "Would you be surprised if this child died as a result of this condition or problem?"
- It is anticipated that diagnosis or recognition will facilitate identification of one or more relevant ACT groups

Death before adulthood is not unexpected

- "Would you be surprised if this child died before adulthood (18th birthday)?"

Children with Increasingly instability

- "Would you be surprised if this child died in the next few months to years?" Or
- "Would you be surprised if this child died in the next five years?"

Children experiencing Critical illness or end of life care

- "Would you be surprised if this child was alive in a few weeks time?"

5. While you do reference the supplemental file 1 which contains the interview, it may be helpful to have a sentence or two which describes the overarching themes of the questions to anchor the reader.

Thank you for your suggestion. We have now added a sentence describing the overarching themes of the interview questions.

6. It is very difficult to follow Table 1. For example, step 2 describes the inductive thematic analysis but it seems like steps 3 and beyond are how they implemented the analysis. Additionally, for step 7, what was done if consensus wasn't achieve and was there any adjudication that needed to happen with the larger group of authors/investigators. I see the value in having a table/figure to demonstrate the data analysis but in its current iteration it is difficult to follow. Potentially a flow chart or other means of guiding the reader along.

We have now amended Table 1 so that the methods used to analyse the data are clearer. We have also explained the process had consensus not been achieved.

Results:

7. Figure 1 is VERY busy and is difficult to follow. This is all extremely valuable information and having it all in one figure makes it crowded and a challenge to highlight the important pieces. Would consider breaking the figure up or highlight a few of the key points. Additionally, while the manuscript describes the key themes they are not easily visible or identified in the key concepts. Thank you for appreciating the value of the information in Figure 1. We acknowledge that there is a lot of information, but we feel it is important that all the themes and concepts are included in the same figure to show how they relate to each other. The most important parts of Figure 1 are the key themes and the key overarching concepts (white boxes). The additional boxes are included to provide examples of the types of barriers and facilitators within each concept. We have now added this as a note to the figure (Note 2). The key themes are listed in the top box of Figure 1 and the manuscript (Discussion section) describes how the key concepts are overarching across the themes. We have not amended the Figure since the other reviewers have not recommended changing this and Reviewer 2 commended us on the excellent presentation of the key findings in Figure 1.

8. The themes are well described but I am left with a few questions. How frequently were these different themes brought up between the different providers? Were there themes that were more common depending on healthcare responsibility? Once again, how did these themes play within the 3 identified concepts in Figure 1?

The Figure 1 legend summarises the key findings from the subgroup analysis. Due to word count limitations, this was included here instead of the main body of the manuscript. Subgroup analysis revealed the following: a) HCPs working in different settings gave broadly similar responses, b) Consultants, registrars and nurses mentioned all the main themes, c) GPs discussed their own limited knowledge, problems recognising pain, issues around balancing pain relief and quality of life, and fears about paediatric palliative medications. They mentioned few barriers related directly to ICYP, d) Support therapists described barriers including parents' beliefs and emotions, and CYP's problems communicating pain. Facilitators included adopting a biopsychosocial approach to pain management, good communication, clear pain management instructions, and ongoing support for families, e) Pharmacists described barriers related to medicine management including dosing errors, parents' literacy and numeracy skills, logistical and financial issues to accessing treatments, a dearth of available treatment and a lack of scientific literature to support prescribing. They identified HCPs' expertise and pre-drawn up medications as facilitators.

Since this was a qualitative study (rather than quantitative) we have not listed the frequency of each theme as mentioned by different providers as our analysis was guided by the quality and depth of the data rather than the quantity (4).

Discussion:

9. One of the most important elements about this study is that this is the perception from the healthcare perspective. This is incredibly valuable and important and is not well highlighted in the discussion. What is about this manuscript that sets it apart from the other articles referenced in the discussion? How does this manuscript add to the literature?

We have now added a *Strengths* section to the discussion to highlight the value of this study.

I loved the piece about the contradictions between participants saying parents are either better evaluators of pain in their children or worse. This is something that left me wanting more. Were there differences in which providers felt that way?

There was not a clear difference between providers. A combination of primary, community, and tertiary care staff expressed these contrasting views.

10. Additionally, there is no discussion on limitations and bias. This is a qualitative research project which we need more of in the literature, but we have to identify the strengths and limitations of this approach. The fact that this is from the healthcare professional viewpoint only is a major limitation and must be addressed. Additionally, the methodology of semi-structured interviews has many strengths but also limitations and must be elucidated. Finally, there must be discussion about the limitations and coder biases that may be influencing the findings.

The aim of this study was to explore the views of healthcare professionals, therefore we do not see this as a limitation of the study as it was part of the design. We acknowledge that they are not the only demographic involved in paediatric palliative care, but they are a very important one. We have now discussed the limitations of qualitative research in the discussion (Limitations section).

Conclusion: 11. The recommendations should come in the discussion and not in the conclusion and there should be further elaboration on these recommendations and how the data supports these recommendations.

Recommendations are interwoven throughout the Discussion. We have now moved the reference to Table 3 (Recommendations for clinical care) to earlier in the Discussion (paragraph 8).

Additionally, there was no discussion of the impact of COVID-19 earlier in the manuscript that I can recall until the very end. This should not come in at the conclusion. If it impacted the study and resulted in alterations and adjustments this should be described in the methods and results. Certainly, highlighting that we can still perform these interventions despite a pandemic is critical, but this once again should be supported by the evidence from the data.

We mention in the Methods that three interviews were conducted via phone due to the pandemic. No other alterations were needed. The telephone interviews were conducted in the very early stages of the pandemic (before the first lockdown in March 2020) and all other interviews were conducted before the pandemic. Thus, there was no discussion of the pandemic in the interviews and therefore no evidence from the data that interventions can be performed despite it. Instead, we have referenced a recent study (5) indicating that telephone and/or video calls with healthcare professionals can help caregivers at home.

Thank you for your consideration of this manuscript.

Yours sincerely,



Professor Christina Liossi
Chair & Honorary Consultant in Paediatric Psychology
University of Southampton & Great Ormond Street Hospital for Children NHS Trust

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Healthcare professionals’ experiences of the barriers and facilitators to paediatric pain management in the community at end-of-life: A qualitative interview study

Dr Katie Greenfield BSc, MSc, PhD¹
Professor Bernie Carter BSc, PhD²
Dr Emily Harrop DCH, MRCPCH, PhD, Dip Pal Med^{3,4}
Dr Sabtir Jassal BMedSci, BM, BS, FRCGP, FRCPCH(Hon)⁵
Ms Julie Bayliss⁵
Dr Kate Renton MSc, BMedSci, MBChB, MRCPCH^{7,8}
Dr Simone Holley PhD¹
Dr Richard F. Howard MB, ChB, FRCA, FFPMRCA⁹
Ms Margaret Johnson BSc¹⁰
*Professor Christina Liossi BA, DPsych^{1, 6}

¹ School of Psychology, University of Southampton, Highfield, SO17 1BJ, UK
² Faculty of Health, Social Care and Medicine, Edge Hill University, St Helens Road, Ormskirk, Lancashire, L39 4QP, UK
³ Helen & Douglas House Hospices, 14A Magdalen Road, Oxford, Oxfordshire, OX4 1RW, UK
⁴ Oxford University Hospitals NHS Trust, John Radcliffe Hospital, Headley Way, Headington, Oxford, OX3 9DU, UK
⁵ Rainbows Hospice, Lark Rise, Loughborough LE11 2HS, UK
⁶ Great Ormond Street Hospital for Children NHS Foundation Trust, The Louis Dundas Centre, Great Ormond Street, London WC1N 3JH, UK
⁷ University Hospital Southampton NHS Trust, Southampton General Hospital, Tremona Road, Southampton, Hampshire, SO16 6YD, UK
⁸ Naomi House & Jacksplace, Stockbridge Road, Sutton Scotney, Winchester, Hampshire SO21 3JE, UK
⁹ Great Ormond Street Hospital for Children NHS Foundation Trust, Department of Anaesthesia and Pain Medicine Level 4, Old Building, London, WC1N 3JH, UK
¹⁰ Patient & Public Representative, UK

* Corresponding author:
Email: cliossi@soton.ac.uk
0044 (0)238059 4645
School of Psychology, University of Southampton, Highfield, SO17 1BJ, UK

Running title: At-home paediatric palliative pain management

Number of tables: 3
Number of figures: 1
Number of references: 29 (+ 5 in Table 1)
Word count: ~~3488~~3496

Abstract

Contexts: Inadequate pain management in community paediatric palliative care is common. Evidence to inform improved pain management in this population is limited.

Objectives: To explore the barriers and facilitators to paediatric community-based pain management for infants, children and young people at end-of-life as perceived by healthcare professionals.

Methods: A qualitative interview study was conducted. Semi-structured interviews were undertaken with 29 healthcare professionals; 12 nurses, five GPs, five consultants and registrar doctors, two pharmacists and five support therapists working in primary, secondary or tertiary care in the [United Kingdom](#) and involved in community end-of life care of 0-18-year-olds.

Results: The data corpus was analysed using an inductive thematic analysis and seven themes emerged: parents' abilities, beliefs and wellbeing; working relationships between families and healthcare professionals, and between healthcare teams; healthcare professionals' knowledge, education and experience; health services delivery; nature of pain treatment; and paediatric-specific factors. Across themes, the concepts of partnership working between families and healthcare professionals, and within healthcare teams, and sharing expertise were prevalent.

Conclusion: [Partnership working and trust between healthcare professionals and parents, and within healthcare teams, is needed for effective at-home paediatric palliative pain management](#)~~work together, and that mutual trust is built up through two-way conversations.~~

Community healthcare professionals ~~would benefit from~~[require more](#) education from experienced multidisciplinary teams to effectively manage paediatric pain at end-of-life and prevent emergency hospice or hospital admissions, particularly during the COVID-19 pandemic.

Key message: This article describes a qualitative interview study exploring healthcare professionals' perceptions of barriers and facilitators to at-home paediatric palliative pain management. Results highlighted the need for partnership working within healthcare teams, and between healthcare professionals and families, and more education for community healthcare professionals to manage paediatric pain at end-of-life.

Keywords: Caregivers, paediatrics, pain management, palliative care, parents, qualitative research

Introduction

In 2017-2018, an estimated 81-87,000 0-19-year-olds were living with a life-limiting or life-threatening condition in the UK (1). This is over double the estimated number in 2001/2002 and a continuing rise in prevalence is predicted, [which may be driven by an increase in recording these conditions and in survival due to health improvements](#) (1). Pain is one of the most common symptoms in ~~the~~[these](#) conditions (2) and is often managed inadequately (3, 4).

Many parents want their child to be cared for and die at home (5), this being associated with higher patient satisfaction and parent quality of life (6). However, [while experienced staff manage pain during a paediatric hospital or hospice admission, at home this is increasingly the responsibility of homecare](#)~~relies on~~ families (predominantly parents) and community healthcare professionals (HCPs) [being increasingly responsible for pain management,](#)~~—~~ which can be challenging. Parents may

underdose analgesics due to fears and misconceptions around addiction, sedation and ~~the possibility of~~ hastening death, or, conversely, a belief that they are unnecessary (6). Inadequate pain management has a detrimental effect on a child's quality of life and relationships with their family (7).

Children ~~with life-limiting conditions~~ receiving palliative care often require complex medical regimens that change as their condition progresses. Diverse conditions and differing developmental needs at different ages provide further challenges. A systematic review published in 2020 on the barriers and facilitators to effective symptom management (including pain) in paediatric palliative care (PPC) found that clinicians worldwide reported a lack of experience, education, and confidence, as well as revealing issues relating to how different health services worked together (8, 9). Yet, most of the included studies were of low-medium quality and there remains a dearth of current, in-depth research. There is a lack of knowledge regarding paediatric pain management in general (10), and the aim of this study was to identify and explore the barriers and facilitators, as perceived by healthcare professionals, to community-based paediatric pain management at end of life. The UK National Institute of Health Research (NICE) highlighted paediatric palliative pain management specifically as a research priority (11).

The current study is part of a large multi-centre study aiming to improve PPC pain management in the community through the development of an educational intervention for caregivers (PARAMOUNT study (8, 9, 12, 13)). The World Health Organisation and WHO recommends the use of qualitative studies to understand which interventions are most effective (14) and the Medical Research Council (15) recommend conducting qualitative studies to understand the problem to be targeted and the necessary components of an effective intervention. As such, the aim of this study was to identify and explore the barriers and facilitators, as perceived by HCPs, to community-based PPC pain management.

There is a lack of recent, high quality research in this area (8, 14). The current study included the experiences of 29 professionals in a variety of settings and roles across the UK, providing much needed in-depth data regarding how pain management can be improved.

The aim of this study was to identify and explore the barriers and facilitators, as perceived by healthcare professionals, to community-based paediatric pain management at end of life.

Methods

National and local ethical approvals were obtained [London – Bloomsbury Research Ethics Committee (IRAS reference: 262102)] on 2nd August 2019.

Design

~~This~~ This was a qualitative interview-based study, which formed part of ~~forms part of~~ a large multi-centre study aiming to improve at-home paediatric palliative care PPC pain management in the community through the development of an educational intervention for carers (PARAMOUNT study).

Participants

Eligible participants were ~~healthcare professionals~~HCPs working in primary, secondary, or tertiary care in the UK and involved in community end-of-life care of 0-18-year-olds. ~~The definition of 'End-of-life' was based on the Spectrum of Palliative Care Needs tool (16) and was~~ defined as any patient in whom it would not be unexpected if death occurred within the next 5 years.

Recruitment

Participants were recruited from UK hospitals, hospices and GP practices between September 2019 and March 2020. The study was advertised via posters, press releases, professional organisations, and social media. All participants provided written and verbal consent. A purposive sampling procedure was used to ensure diversity from a range of professionals. Recruitment stopped when data saturation was reached (17).

Interviews

In-depth, semi-structured interviews lasting 30-60 minutes were conducted face-to-face in hospitals, hospices, and community centres, or by telephone due to the COVID-19 pandemic (n=3) using an interview guide (see Supplemental File 1), ~~which included questions about experience in, and barriers and facilitators to, pain management.~~ Interviews were conducted by KG, SH; both experienced interviewers, and a Masters student (n=2; after observation and supervision).

Data analysis

See Table 1 for data analysis.

Results

Twenty-nine ~~healthcare professionals~~HCPs participated (see Table 2). The analysis generated seven key themes related to barriers and facilitators to pain management, listed below.

Across themes, three concepts were prevalent: 1) families and ~~healthcare professionals~~HCPs working in partnership; 2) ~~healthcare professionals~~HCPs working in partnership; and 3) expert ~~healthcare professionals~~HCPs sharing expertise. See Figure 1 for themes, prevalent concepts, and subgroup analysis. ~~We acknowledge that the findings below represent the views of the participants rather than objective reality.~~

1. Parents' beliefs, abilities, and wellbeing

~~HCPs described how parents' beliefs, abilities and wellbeing effected pain management. They felt that P~~parents may ~~be in denial about their~~find it difficult to discuss their -child's symptoms, diagnosis ~~or prognosis and or therefore may avoid discussing~~ pain management; 'a family who found it difficult to talk about diagnosis...are likely to have found it difficult to talk about pain.' (T5-Hc). Preparing families to anticipate disease progression and 'parents being in the right place to be receptive to guidance' (T1-HI) can facilitate pain management.

Comprehensive, tailored, "very clear" symptom management plans written so 'parents understood them' (N2-C) and 'based on what we think may happen' ~~are were seen as~~ facilitative but ~~participants~~ acknowledged the need to 'expect the unexpected' (N5-C). Delays in instigating or explaining plans and lack of regular reviews were ~~pain management~~ barriers ~~to good pain management~~.

~~HCPs felt that P~~ain indicators may be subtle '*especially if their child is non-verbal or pre-verbal*' (N6-HI), which can lead to disagreements between professionals and parents. Participants recognised that a large element of their role involved '*adequately assessing and judging what is pain*' (D5-C) and encouraging parents to use pain assessment tools. Parents may feel overburdened by assessments; '*they don't want to answer questions, they want a solution*' (N5-C) or ~~may believe that~~ they can recognise pain without formal assessments, resulting in reduced symptom reporting and potential under-dosing.

~~Participants mentioned that S~~ome parents may lack the necessary objectivity to assess pain, judging that '*any distress must be pain*' (GP4-Hc) because they are '*too tired, too emotional, too sleep-deprived*' (D1-Hc). Reassurance and professional psychological support for parents ~~are helpful-can help-~~ Pain assessment could be facilitated by Uusing existing, standardised assessments ~~tools and-~~ Aapps that allow parents to score pain quickly and share this information with their care team ~~are helpful-can also help-~~.

~~Participants felt that p~~arents may resist palliative pain relief due to fears of reducing quality of life, accidental overdose, addiction, sedation, or perceptions of '*an increase in pain medication as an increase of disease progression*' (N11-C) that signals death. ~~HCPs mentioned Resistance may also arise from~~ parents' negative perceptions of '*opioids being linked to corruption, crime, social depravity*' (P1-HI), ~~which may be~~ fuelled by the media, social networks or other professionals. ~~A GP described how, W~~hen families research or use therapies not advised by their healthcare team, this can create conflict regarding '*the rights and wrongs of it*' (GP4-Hc). Facilitators include exploring families' preconceptions, providing education and ~~managing expectations by~~ explaining '*that there isn't a one drug that is a magic bullet, that...sometimes you have to use a combination of different approaches*' (N6-HI). This can be challenging when working with families who speak little English as reliance on interpreters means information must be condensed into a 1-2-hour session.

Uncertainty and fear ~~were cited as may be~~ barriers for parents tasked with administering pain relief, particularly when this involves controlled drugs, intravenous or subcutaneous administration. Poor literacy and numeracy skills further compound this issue; ~~since medications look similar and regimes may be complex. Dosing errors are more common when parents feel panicked as their~~ '*ability to cope and calculate and be analytical just drops off*' (P1-HI). Training parents to administer medication and giving them practical solutions (e.g. colour coding medication) can facilitate pain management.

2. Working relationships between families and ~~healthcare professionals~~HCPs

~~HCPs described how families may~~ Families coping methods may include avoiding in-depth conversations with their care team. It is important that professionals build '*trust*' and '*confidence*' (GP5-Hc) and manage pain as '*a partnership*' (N2-C). ~~Healthcare professionals~~ HCPs should not expect to '*come to a resolution just after one chat to the parents*' (GP5-Hc). ~~This takes time and P~~ parents should feel understood and respected during regular conversations; '*it's the communication that's the key part, listening more, reflecting back, myth-busting...and being honest*' (GP4-Hc). A telephone/virtual check-in service could pre-empt and avoid crises. Barriers to effective pain management occur when parents report different symptoms to different people, '*[parents] have an idea in their head that 'oh this person would help us with this bit of it-and this person would'-...and then things get divided up a bit unhelpfully*' (T2-HI).

3. Working relationships between ~~healthcare professionals~~HCPs

HCPs described barriers when a barrier to pain management can arise if a child's care teams does not work cohesively as staff may 'struggle...trying to work out who's actually going to come and look after this patient' (D4-HI). This can result in siloed care. For example, eCommunity nurses may carry out routine checks while palliative care nurses focus on pain history. Nurses who visit regularly rarely have the prescribing powers to alter treatment; they must relay information to a prescriber (e.g. a GP) who may not prioritise action. Good relationships and trust between specialists and the community nursing teams were facilitators; 'the nurse prescriber from the specialist hospital ... was more than happy to increase medications and take advice from the community nursing team over the phone in between her weekly reviews, so actually pain was managed on a daily basis rather than weekly' (N1-C).

Clear, regular, communication between care teams was described as a key facilitator. It is important that everyone is 'kind of thinking the same' (N1-C), is aware of what each team is willing to do and can contribute to decision making. Shared understanding across teams is crucial; 'we'd all understand what the plan is, we'd have a plan written in the notes...so it's a good team' (N4-HI). This may be achieved via multidisciplinary team (MDT) meetings; 'these complex children we'll discuss on a weekly basis in our MDT, and so actually everyone will contribute to the decision-making' (N4-HI).

4. Healthcare professionals' knowledge, education and experience

HCPs noted there is a lack of GPs with expertise in paediatric palliative care PPC. This could be because of the small number of paediatric palliative care PPC patients a GP will see in their career, and/or that they perceive it to be difficult or intimidating and 'so they shy away from it' (N7-HI). In hospital settings, high staff turn-over makes sustaining education challenging. Confidence can be increased via information, mentoring and support from experienced multi-professional teams, and education around the biopsychosocial model of pain and multimodal pain management. GPs may fear prescribing pain medication for children; 'they're scared of using a drug that they don't understand, at a dose that looks really high, and they are frightened of giving, using a medication that they don't fully appreciate' (GP1-Hc). Lack of experience can also result in misinterpreting or not recognising symptoms or using inappropriate assessments (e.g., one that does not account for neurodevelopmental problems). Regular, detailed assessments can facilitate pain management while 'daily reviews at home.... reporting back... rapidly changing things... [can] prevent... admissions' (D3-HI). Assessments should be based on 'listening to [the patient]...their own reports of pain and how they feel' (N2-C), and 'getting to know the child and how they react to pain' (N1-C).

5. Health services delivery

HCPs described a shortage of clinicians available to give medication and support parents, a barrier to community-based care, especially for families those in rural locations, is the shortage of clinicians available to give medication and support parents, who may have to 'make a choice about better pain management in hospital or, not sub-optimal, but...it's sort of less targeted pain management at home' (N6-HI). Delays in effective pain management may occur as finite resources mean that community healthcare professionals HCPs are 'putting out the fires rather than being preventative' (D3-HI).

Some community-based teams only operate between 9am to 5pm Monday to Friday on weekdays. As such, parents are 'on their own then for 48 hours at the weekend and...I think that can be quite, quite challenging' (N9-Hc). Out-of-hours issues included poor handovers, difficulties accessing drugs, and on-call teams lacking expertise and knowledge of the child.

Participants talked about disjointed working between primary care, secondary care, pharmacies, and clinical commissioning groups (CCGs; organisations that decide which health services are needed for the local area). ~~can result~~ing in barriers to requesting prescriptions. A pharmacist noted that *'part of my role ends up being, talking to the local GPs, trying to smooth out CCG issues with trying to get medication'* (P1-HI). Regional funding variations and the expense of some ~~end-of-life~~ medications, which require authorisation from NHS trusts, NHS England and/or CCGs, ~~are create~~ additional barriers. These can be addressed if hospital pharmacies help to put paediatric medications onto hospital formularies.

Pharmacists described how ~~R~~resources to guide ~~pharmacists to~~ dispensing ~~of~~ prescriptions are often not readily available for ~~paediatric palliative care~~ PPC medications. ~~Therefore, t~~They have difficulty saying *"this is safe" if I can't back it up with anything robust* (P2-HI) unless prescriptions ~~are detailed and~~ include references. Poor availability of paediatric pain medications is a further barrier since they are often controlled, drugs and can also be affected by manufacturing and supply chain issues. Families can find it challenging to maintain medication stock levels at home. Facilitators include help with stock checks, anticipatory prescribing, and requesting medication well in advance.

Participants mentioned that GPs who do not prescribe palliative pain medication on a routine basis may *'lack confidence in using medications that have an association with death, but also unintentional death'* (N5-C) especially if they ~~are rarely prescribed, medications and dosages are rarely prescribed,~~ seem high, may be unlicensed for children, and are not in standard resources. Other barriers include the lack of clarity in guidelines around dose escalations and ~~changing delivery modes from one mode of delivery to another~~. This can be compounded by ~~healthcare professionals~~ HCPs' fears and concerns about potential litigation or medication abuse by others in the home. These barriers can be overcome if GP prescribers can access expert advice and reassurance.

6. Nature of pain treatment

A GP described a key pain management challenge ~~concerning~~relates to medication side-effects such as drowsiness and the balance between *'getting the pain controlled and leaving the child conscious enough to have a quality of life'* (GP1-Hc). ~~HCPs noted that P~~poor management may arise from under/over-medication due to administration or prescription errors; or when medications used to treat other symptoms, such as agitation, mask pain. Facilitators ~~described~~ included plans to use simple analgesics before/as well as opiates; and rotating, adjusting, or trying different combinations of drugs. Taking children's interests into account is important so that, where possible, they can still enjoy activities.

The lack of suitable ~~paediatric palliative~~ PPC pain treatment ~~was mentioned as is~~ a barrier. Wastage can occur due to short shelf-lives and a lack of medications available in small doses. Additionally, children may have issues swallowing, absorbing, and tolerating medications. Treatment administration may be too complex for parents; *'I cannot ask most family members to break open a glass vial of concentrated, very potent controlled drug, draw up an appropriate amount and administer it to their child, it's just not safe, really'* (D1-Hc). Syringe drivers ~~were mentioned as can~~ facilitate good pain management, yet staff are required to undertake the daily (or weekly) change of syringe and provide 24/7 cover if there are any driver issues. ~~A participant explained that P~~problems associated with calculation or drawing up errors can be avoided with preloaded syringes while patient-controlled analgesia pumps (PCAs) can facilitate the management of rapidly escalating pain but these require training.

7. Paediatric-specific factors

Participants described how ~~C~~ children may resist taking pain medication due to ~~unwanted~~ side effects such as ‘the feeling of being out of control’ (N6-HI), wanting ‘less medicine because that medicine is making them feel sick or constipated’ (D2-HI) or a belief that the medication will not work. Patients may also think ‘I’m having periods of being ok, I don’t kind of need anything and it’s about explaining to them that they need a constant level of medication to keep their pain, pain-free’ (N9-Hc). Aspects related to administration (e.g., needles, nasogastric tubes, or unpleasant tasting ~~oral~~ medications) can ~~be a source of cause~~ anxiety. Exploring children’s perceptions, offering a choice of medication; changing the look of ~~the~~ drugs; or involving them in developing symptom management plans ~~can help~~ ~~are~~ facilitators, as is ~~—~~ Pain management can be facilitated by ‘~~doing~~ ~~doing~~ a lot of planning talk[ing] them through it....so they’re prepared’ (N8-Hc).

HCPs explained that ~~C~~ children may underreport their pain, leading to pain escalations. They may be ‘tired of constantly being asked about pain’ (N5-C), feel that ‘just simply discussing pain makes their pain experience worse’ (N6-C), worry that reporting increasing pain will result in hospitalisation or may want to avoid upsetting their parents. Others may associate pain with disease progression and therefore ‘pretend you’re not in pain...you don’t have to think about dying’ (D4-HI). ~~Q~~ Overcoming this may require ‘assessing the child separately from the parent’ (N8-Hc), ~~unpicking misconceptions~~, and exploring fears. Some may be shy, uncommunicative or find it hard to describe their pain. ~~T~~ This can be managed by ‘giving them time, giving them reassurance, giving them different ways to express themselves’ (T4-Hc). Additionally, ‘there’s often overlap between pain and anxiety or pain and low mood’ (T2-HI) and ‘if you were really anxious and concerned, your pain is much worse’ (GP5-Hc). Psychological support and creating opportunities for patients to get their ‘headspace back’ (D1-Hc) ~~can be~~ ~~was seen as~~ facilitative; “if every child in pain could have access to a pain psychologist and a team of therapists to work on non-pharmacological therapy that would be amazing” yet “there can be long waiting lists” for this type of support (D1-Hc). It ~~can is~~ still ~~be~~ beneficial if ~~care team members~~ HCPs can discuss patients with therapists even if the therapist cannot see the patient directly, to “kind of send a bit of psychological thinking” to the team (T2- HI). Non-pharmacological strategies (e.g., complementary therapies, distraction techniques, play therapy, massage, ~~hot baths~~, weighted blankets, and hydrotherapy) and support from physiotherapists and occupational health ~~were also seen as~~ ~~are also~~ helpful.

Discussion

This study explored ~~healthcare professionals~~ HCPs’ views on ~~the~~ barriers and facilitators to at-home paediatric palliative ~~PPC~~ pain management. ~~Thematic analysis of interviews identified themes relating to families’ beliefs, abilities, and wellbeing; working relationships between families and professionals and within healthcare teams; healthcare professionals’ knowledge, education, and experience; health services delivery; pain treatment and paediatric specific factors. Thematic analysis of the data revealed~~ Barriers ~~barriers~~ concerning treatment side-effects, lack of ~~training and~~ education for ~~healthcare professionals~~ HCPs and problems with health service delivery; and facilitators related to specialist support, ~~which~~ were found in a recent systematic review ~~of research on this topic~~ (8). In the current study, the concepts of partnership working and sharing expertise and knowledge were prevalent across themes, ~~as shown in Figure 1.~~

~~The UK National Institute of Health Research (NIHR) highlights paediatric palliative pain management as a research priority (11) and WHO recommends the use of qualitative studies to understand which interventions are most effective (14). There is a lack of recent, high quality research in this area (8, 14). The current study included the experiences of 29 professionals in a variety of settings and roles~~

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~~across the UK, providing much-needed in-depth data regarding how pain management can be improved.~~

~~Our data regarding caregivers' reports of pain were somewhat contradictory. Some participants emphasised that parents were experts in knowing their own child's pain while others suggested that parents' pain reports were more subjective than professionals'. These varying views likely reflect the challenges of identifying pain and the lack of suitable pain assessment tools (13). The development of pain assessment tools for this population could aid pain management.~~

Partnership working. Studies have revealed conflict and disagreement between professionals and parents as a barrier to symptom management (18-20). Our findings support this in relation to pain management specifically from the view of HCPs and highlight the importance of building trust, ~~though this takes time.~~

As in other research (21), disjointed working between different teams and providers is a barrier to requesting prescriptions and dispensing medications. This is compounded by a lack of dispensing resources, poor medication availability, and a lack of licensed paediatric treatment. NICE states that specialist ~~paediatric palliative care~~ PPC teams should always include a pharmacist with expertise in this area (11). Issues with medication dispensing could be avoided if other team members could easily contact the expert pharmacist. As found in previous studies (22, 23), teamwork can breakdown ~~out-of-hours during evenings and weekends~~ when on-call staff may lack knowledge of a patient's ~~specific~~ pain signs and management plan. Siloed care between hospital and community staff can be avoided if care team members ~~are in regular~~ communicate regularly, have a clear sense of who has overall responsibility ~~for each child~~ and a good understanding of ~~the~~ symptom management plans. Regular MDT meetings to discuss pain management can facilitate good communication and partnership working (24).

Education and shared expertise. Parents report a lack of information and support around symptom management (25-27). ~~As such, they may choose to move their child away from their preferred place of care (28). HCPs highlighted the importance of~~ checking parents' understanding of symptom management plans and not overestimating their ability to administer medication ~~is important~~. As in other studies (21, 29, 30), participants felt that parents (and some professionals) were reluctant to use palliative symptom management medication. Pain management can be improved when care teams spend time educating parents ~~and~~ discussing ~~parents' and children's~~ their fears. ~~Similarly, care teams can facilitate pain management by listening to children's concerns~~ and, where possible, finding alternative treatments.

Our findings emphasise the ~~importance of~~ need to use standardised pain assessment ~~tools~~, recognising ~~inge~~ idiosyncratic pain signs, and listening ing to patient's pain accounts. ~~Building up a trusting relationship with children may help them to provide more accurate reports. HCPs believed that~~ parents can feel overburdened by regular assessments and care teams should help to find a suitable tool. Parents' emotional health can impact on their ability to objectively assess pain. Future research could explore whether ~~Psychological support and reassurance may~~ would help.

Healthcare teams can feel they lack ~~the~~ education and support ~~required~~ to manage paediatric palliative symptoms (8). A lack of opportunities, time, and the cost of training are barriers to developing expertise (29). Participants in the current study suggested that GPs may ~~choose to~~ avoid ~~paediatric palliative care~~ PPC training ~~if they~~ perceiving it as difficult or intimidating. Our findings and previous research ~~When healthcare professionals and families can contact and work with specialist support, this can facilitate pain management, supporting previous research (31, 32) indicate the importance of community HCPs and families working with specialist teams.~~

Limitations: The development of pain assessment tools for this population could aid pain management. The qualitative nature of this study means that the findings reflect participants' views

rather than objective reality and data the findings lack generalisability. Our data regarding caregivers' reports of pain were somewhat contradictory. Some participants felt that parents were experts in knowing their child's pain while others suggested that parents' pain reports were more subjective than professionals'. These varying views likely reflect the challenges of identifying pain and the lack of suitable pain assessment tools (13).

Strengths: This is the first in-depth qualitative study exploring HCPs' views on barriers and facilitators to at-home paediatric pain management at end-of-life (8), which was emphasised as a research priority by NICE (11). Using the study findings, we have developed recommendations for clinical care (derived from participants' discourse are listed in Table 3). These findings are part of a larger study (The PARAMOUNT study), which draws on the views of family caregivers, children, and professionals to co-produce an educational intervention to help caregivers manage paediatric pain at home. This study highlights the need for such a resource and will help to guide its development.

Conclusion

Recommendations for clinical care derived from participants' discourse are listed in Table 3. Sharing expertise and cohesive, partnership working between professionals and parents, and between healthcare teams, is critical for optimal community paediatric palliative PPC pain management. The COVID-19 pandemic has demonstrated that this can be maintained via telephone and/or video calls (33). These findings are part of a larger study (The PARAMOUNT study), which draws on the views of family caregivers, children, and professionals to co-produce an educational intervention to help caregivers manage paediatric pain at home. This study highlights the need for such a resource and will help to guide its development.

Disclosures

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Healthcare professionals' experiences of the barriers and facilitators to paediatric pain management in the community at end-of-life: A qualitative interview study

Dr Katie Greenfield BSc, MSc, PhD¹

Professor Bernie Carter BSc, PhD²

Dr Emily Harrop DCH, MRCPCH, PhD, Dip Pal Med^{3,4}

Dr Sabtir Jassal BMedSci, BM, BS, FRCGP, FRCPC(Hon)⁵

Ms Julie Bayliss⁶

Dr Kate Renton MSc, BMedSci, MBChB, MRCPCH^{7,8}

Dr Simone Holley PhD¹

Dr Richard F. Howard MB, ChB, FRCA, FFPMRCA⁹

Ms Margaret Johnson BSc¹⁰

*Professor Christina Liossi BA, DPsych^{1, 6}

¹ School of Psychology, University of Southampton, Highfield, SO17 1BJ, UK

² Faculty of Health, Social Care and Medicine, Edge Hill University, St Helens Road, Ormskirk, Lancashire, L39 4QP, UK

³ Helen & Douglas House Hospices, 14A Magdalen Road, Oxford, Oxfordshire, OX4 1RW, UK

⁴ Oxford University Hospitals NHS Trust, John Radcliffe Hospital, Headley Way, Headington, Oxford, OX3 9DU, UK

⁵ Rainbows Hospice, Lark Rise, Loughborough LE11 2HS, UK

⁶ Great Ormond Street Hospital for Children NHS Foundation Trust, The Louis Dundas Centre, Great Ormond Street, London WC1N 3JH, UK

⁷ University Hospital Southampton NHS Trust, Southampton General Hospital, Tremona Road, Southampton, Hampshire, SO16 6YD, UK

⁸ Naomi House & Jacksplace, Stockbridge Road, Sutton Scotney, Winchester, Hampshire SO21 3JE, UK

⁹ Great Ormond Street Hospital for Children NHS Foundation Trust, Department of Anaesthesia and Pain Medicine Level 4, Old Building, London, WC1N 3JH, UK

¹⁰ Patient & Public Representative, UK

* Corresponding author:

Email: cliossi@soton.ac.uk

0044 (0)238059 4645

School of Psychology, University of Southampton, Highfield, SO17 1BJ, UK

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Abstract

Contexts: Inadequate pain management in community paediatric palliative care is common. Evidence to inform improved pain management in this population is limited.

Objectives: To explore the barriers and facilitators to paediatric community-based pain management for infants, children and young people at end-of-life as perceived by healthcare professionals.

Methods: A qualitative interview study was conducted. Semi-structured interviews were undertaken with 29 healthcare professionals; 12 nurses, five GPs, five consultants and registrar doctors, two pharmacists and five support therapists working in primary, secondary or tertiary care in the United Kingdom and involved in community end-of life care of 0-18-year-olds.

Results: The data corpus was analysed using an inductive thematic analysis and seven themes emerged: parents' abilities, beliefs and wellbeing; working relationships between families and healthcare professionals, and between healthcare teams; healthcare professionals' knowledge, education and experience; health services delivery; nature of pain treatment; and paediatric-specific factors. Across themes, the concepts of partnership working between families and healthcare professionals, and within healthcare teams, and sharing expertise were prevalent.

Conclusion: Partnership working and trust between healthcare professionals and parents, and within healthcare teams, is needed for effective at-home paediatric palliative pain management. Community healthcare professionals require more education from experienced multidisciplinary teams to effectively manage paediatric pain at end-of-life and prevent emergency hospice or hospital admissions, particularly during the COVID-19 pandemic.

Key message: This article describes a qualitative interview study exploring healthcare professionals' perceptions of barriers and facilitators to at-home paediatric palliative pain management. Results highlighted the need for partnership working within healthcare teams, and between healthcare professionals and families, and more education for community healthcare professionals to manage paediatric pain at end-of-life.

Keywords: Caregivers, paediatrics, pain management, palliative care, parents, qualitative research

Introduction

In 2017-2018, an estimated 81-87,000 0-19-year-olds were living with a life-limiting or life-threatening condition in the UK (1). This is over double the estimated number in 2001/2002 and a continuing rise in prevalence is predicted, which may be driven by an increase in recording these conditions and in survival due to health improvements (1). Pain is one of the most common symptoms in these conditions (2) and is often managed inadequately (3, 4).

Many parents want their child to be cared for and die at home (5), this being associated with higher patient satisfaction and parent quality of life (6). However, while experienced staff manage pain during a paediatric hospital or hospice admission, at home this is increasingly the responsibility of families (predominantly parents) and community healthcare professionals (HCPs), which can be challenging. Parents may underdose analgesics due to fears and misconceptions around addiction, sedation and hastening death, or, conversely, a belief that they are unnecessary (6). Inadequate pain

management has a detrimental effect on a child's quality of life and relationships with their family (7).

Children receiving palliative care often require complex medical regimens that change as their condition progresses. Diverse conditions and differing developmental needs at different ages provide further challenges. A systematic review published in 2020 on the barriers and facilitators to effective symptom management (including pain) in paediatric palliative care (PPC) found that clinicians worldwide reported a lack of experience, education, and confidence, as well as revealing issues relating to how different health services worked together (8, 9). Yet, most of the included studies were of low-medium quality and there remains a dearth of current, in-depth research. There is a lack of knowledge regarding paediatric pain management in general (10), and the UK National Institute of Health Research (NICE) highlighted paediatric palliative pain management specifically as a research priority (11).

The current study is part of a large multi-centre study aiming to improve PPC pain management in the community through the development of an educational intervention for caregivers (PARAMOUNT study (8, 9, 12, 13)). The World Health Organisation (14) and the Medical Research Council (15) recommend conducting qualitative studies to understand the problem to be targeted and the necessary components of an effective intervention. As such, the aim of this study was to identify and explore the barriers and facilitators, as perceived by HCPs, to community-based PPC pain management.

Methods

National and local ethical approvals were obtained [London – Bloomsbury Research Ethics Committee (IRAS reference: 262102)] on 2nd August 2019.

Design

This was a qualitative interview-based study, which formed part of a large multi-centre study aiming to improve at-home PPC pain management (PARAMOUNT study).

Participants

Eligible participants were HCPs working in primary, secondary, or tertiary care in the UK and involved in community end-of-life care of 0-18-year-olds. The definition of 'end-of-life' was based on the Spectrum of Palliative Care Needs tool (16) and was defined as any patient in whom it would not be unexpected if death occurred within the next 5 years.

Recruitment

Participants were recruited from UK hospitals, hospices and GP practices between September 2019 and March 2020. The study was advertised via posters, press releases, professional organisations, and social media. All participants provided written and verbal consent. A purposive sampling procedure was used to ensure diversity from a range of professionals. Recruitment stopped when data saturation was reached (17).

Interviews

In-depth, semi-structured interviews lasting 30-60 minutes were conducted face-to-face in hospitals, hospices, and community centres, or by telephone due to the COVID-19 pandemic (n=3) using an

interview guide (see Supplemental File 1), which included questions about experience in, and barriers and facilitators to, pain management. Interviews were conducted by KG, SH; both experienced interviewers, and a Masters student (n=2; after observation and supervision).

Data analysis

See Table 1 for data analysis.

Results

Twenty-nine HCPs participated (see Table 2). The analysis generated seven key themes related to barriers and facilitators to pain management, listed below.

Across themes, three concepts were prevalent: 1) families and HCPs working in partnership; 2) HCPs working in partnership; and 3) expert HCPs sharing expertise. See Figure 1 for themes, prevalent concepts, and subgroup analysis. We acknowledge that the findings below represent the views of the participants rather than objective reality.

1. Parents' beliefs, abilities, and wellbeing

HCPs described how parents' beliefs, abilities and wellbeing effected pain management. They felt that parents may find it difficult to discuss their child's symptoms, diagnosis or pain management; *'a family who found it difficult to talk about diagnosis...are likely to have found it difficult to talk about pain.'* (T5-Hc). Preparing families to anticipate disease progression and *'parents being in the right place to be receptive to guidance'* (T1-HI) can facilitate pain management.

Comprehensive, tailored, *"very clear"* symptom management plans written so *'parents understood them'* (N2-C) and *'based on what we think may happen'* were seen as facilitative but acknowledged the need to *'expect the unexpected'* (N5-C). Delays in instigating or explaining plans and lack of regular reviews were pain management barriers.

HCPs felt that pain indicators may be subtle *'especially if their child is non-verbal or pre-verbal'* (N6-HI), which can lead to disagreements between professionals and parents. Participants recognised that a large element of their role involved *'adequately assessing and judging what is pain'* (D5-C) and encouraging parents to use pain assessment tools. Parents may feel overburdened by assessments; *'they don't want to answer questions, they want a solution'* (N5-C) or believe they can recognise pain without formal assessments, resulting in reduced symptom reporting and potential under-dosing.

Participants mentioned that some parents may lack the necessary objectivity to assess pain, judging that *'any distress must be pain'* (GP4-Hc) because they are *'too tired, too emotional, too sleep-deprived'* (D1-Hc). Reassurance and professional psychological support for parents are helpful. Using standardised assessments and apps that allow parents to score pain quickly and share this information with their care team are helpful.

Participants felt that parents may resist palliative pain relief due to fears of reducing quality of life, accidental overdose, addiction, sedation, or perceptions of *'an increase in pain medication as an increase of disease progression'* (N11-C) that signals death. HCPs mentioned parents' negative perceptions of *'opioids being linked to corruption, crime, social depravity'* (P1-HI), fuelled by the media, social networks or other professionals. A GP described how, when families research or use therapies not advised by their healthcare team, this can create conflict regarding *'the rights and*

wrongs of it' (GP4-Hc). Facilitators include exploring families' preconceptions, providing education and explaining *'that there isn't a one drug that is a magic bullet...sometimes you have to use a combination of different approaches'* (N6-HI). This can be challenging when working with families who speak little English as reliance on interpreters means information must be condensed into a 1-2-hour session.

Uncertainty and fear were cited as barriers for parents tasked with administering pain relief, particularly when this involves controlled drugs, intravenous or subcutaneous administration. Poor literacy and numeracy skills further compound this issue since medications look similar and regimes may be complex. Dosing errors are more common when parents feel panicked as their *'ability to cope and calculate and be analytical just drops off'* (P1-HI). Training parents to administer medication and giving them practical solutions (e.g. colour coding medication) can facilitate pain management.

2. Working relationships between families and HCPs

HCPs described how families may avoid in-depth conversations with their care team. It is important that professionals build *'trust'* and *'confidence'* (GP5-Hc) and manage pain as *'a partnership'* (N2-C). HCPs should not expect to *'come to a resolution just after one chat to the parents'* (GP5-Hc). Parents should feel understood and respected during regular conversations; *'it's the communication that's the key part, listening more, reflecting back, myth-busting...and being honest'* (GP4-Hc). A telephone/virtual check-in service could pre-empt and avoid crises. Barriers to effective pain management occur when parents report different symptoms to different people, *'[parents] have an idea in their head that 'oh this person would help us with this bit of it...and then things get divided up a bit unhelpfully'* (T2-HI).

3. Working relationships between HCPs

HCPs described barriers when care teams do not work cohesively as staff may *'struggle...trying to work out who's actually going to come and look after this patient'* (D4-HI), resulting in siloed care. Community nurses may carry out routine checks while palliative care nurses focus on pain history. Nurses who visit regularly rarely have prescribing powers to alter treatment; they must relay information to a prescriber (e.g. a GP) who may not prioritise action). Good relationships and trust between specialists and community nursing teams are facilitators; *'the nurse prescriber from the specialist hospital ... was more than happy to increase medications and take advice from the community nursing team over the phone in between her weekly reviews, so actually pain was managed on a daily basis'* (N1-C).

Clear, regular, communication between care teams was described as a key facilitator. It is important that everyone is aware of what each team is willing to do and can contribute to decision making. Shared understanding across teams is crucial; *'we'd all understand what the plan is, we'd have a plan written in the notes...so it's a good team'* (N4-HI). This may be achieved via multidisciplinary team (MDT) meetings; *'these complex children we'll discuss on a weekly basis in our MDT, and so actually everyone will contribute to the decision-making'* (N4-HI).

4. HCPs' knowledge, education and experience

HCPs noted a lack of GPs with expertise in PPC. This could be because of the small number of PPC patients a GP will see in their career, and/or that they perceive it to be difficult or intimidating and *'so they shy away from it'* (N7-HI). In hospital settings, high staff turn-over makes sustaining education challenging. Confidence can be increased via information, mentoring and support from

experienced multi-professional teams, and education around the biopsychosocial model of pain and management. GPs may fear prescribing pain medication for children; *'they're scared of using a drug that they don't understand, at a dose that looks really high, and they are frightened of giving, using a medication that they don't fully appreciate'* (GP1-Hc). Lack of experience can also result in misinterpreting or not recognising symptoms or using inappropriate assessments. Regular assessments can facilitate pain management while *'daily reviews at home.... reporting back... rapidly changing things... [can] prevent... admissions'* (D3-HI). Assessments should be based on *'listening to [the patient]...their own reports of pain'* (N2-C), and *'getting to know the child and how they react to pain'* (N1-C).

5. Health services delivery

HCPs described a shortage of clinicians available to give medication and support parents,, especially those in rural locations,, who may have to *'make a choice about better pain management in hospital or, not sub-optimal, but...it's sort of less targeted pain management at home'* (N6-HI). Delays in effective pain management may occur as finite resources mean that community HCPs are *'putting out the fires rather than being preventative'* (D3-HI).

Some community-based teams only operate between 9am to 5pm on weekdays. As such, parents are *'on their own then for 48 hours at the weekend and...that can be quite, quite challenging'* (N9-Hc). Out-of-hours issues included poor handovers, difficulties accessing drugs, and on-call teams lacking expertise and knowledge of the child.

Participants talked about disjointed working between primary care, secondary care, pharmacies, and clinical commissioning groups (CCGs; organisations that decide which health services are needed for the local area) resulting in barriers to requesting prescriptions. A pharmacist noted that *'part of my role ends up being, talking to the local GPs, trying to smooth out CCG issues with trying to get medication'* (P1-HI). Regional funding variations and the expense of some medications, which require authorisation from NHS trusts, NHS England and/or CCGs, are additional barriers. These can be addressed if hospital pharmacies help to put paediatric medications onto hospital formularies.

Pharmacists described how resources to guide dispensing of prescriptions are often not readily available for PPC medications. They have difficulty saying *"this is safe" if I can't back it up with anything robust'* (P2-HI) unless prescriptions include references. Poor availability of paediatric pain medications is a further barrier since they are often controlled, drugs and can also be affected by manufacturing and supply chain issues. Families can find it challenging to maintain medication stock levels at home. Facilitators include help with stock checks, anticipatory prescribing, and requesting medication well in advance.

Participants mentioned that GPs who do not prescribe palliative pain medication on a routine basis may *'lack confidence in using medications that have an association with death, but also unintentional death'* (N5-C) especially if they are rarely prescribed, dosages seem high, may be unlicensed for children, and are not in standard resources. Other barriers include the lack of clarity in guidelines around dose escalations and changing delivery modes. This can be compounded by HCPs' concerns about potential litigation or medication abuse by others in the home. These barriers can be overcome if GP prescribers can access expert advice and reassurance.

6. Nature of pain treatment

A GP described a key pain management challenge concerning medication side-effects such as drowsiness and the balance between *'getting the pain controlled and leaving the child conscious enough to have a quality of life'* (GP1-Hc). HCPs noted that poor management may arise from

under/over-medication due to administration or prescription errors; or when medications used to treat other symptoms, such as agitation, mask pain. Facilitators described included plans to use simple analgesics before/as well as opiates; and rotating, adjusting, or trying different combinations of drugs. Taking children's interests into account is important so that, where possible, they can still enjoy activities.

The lack of suitable PPC pain treatment was mentioned as a barrier. Wastage can occur due to short shelf-lives and a lack of medications available in small doses. Additionally, children may have issues swallowing, absorbing, and tolerating medications. Treatment administration may be too complex for parents; *'I cannot ask most family members to break open a glass vial of concentrated, very potent controlled drug, draw up an appropriate amount and administer it to their child, it's just not safe, really'* (D1-Hc). Syringe drivers were mentioned as facilitating good pain management, yet staff are required to undertake the daily (or weekly) change of syringe and provide 24/7 cover if there are any driver issues. A participant explained that problems associated with calculation or drawing up errors can be avoided with preloaded syringes while patient-controlled analgesia pumps (PCAs) can facilitate the management of rapidly escalating pain but these require training.

7. Paediatric-specific factors

Participants described how children may resist taking pain medication due to side effects such as *'the feeling of being out of control'* (N6-HI), wanting *'less medicine because that medicine is making them feel sick or constipated'* (D2-HI) or a belief that the medication will not work. Patients may also think *'I'm having periods of being ok, I don't kind of need anything and it's about explaining to them that they need a constant level of medication to keep their pain, pain-free'* (N9-Hc). Aspects related to administration (e.g., needles, nasogastric tubes, or unpleasant tasting medications) can cause anxiety. Exploring children's perceptions, offering a choice of medication; changing the look of drugs; or involving them in developing symptom management plans are facilitators, as is *'doing a lot of planning talk[ing] them through it....so they're prepared'* (N8-Hc).

HCPs explained that children may underreport their pain, leading to pain escalations. They may be *'tired of constantly being asked about pain'* (N5-C), feel that *'just simply discussing pain makes their pain experience worse'* (N6-C), worry that reporting increasing pain will result in hospitalisation or may want to avoid upsetting their parents. Others may associate pain with disease progression and therefore *'pretend you're not in pain...you don't have to think about dying'* (D4-HI). Overcoming this may require *'assessing the child separately from the parent'* (N8-Hc) and exploring fears. Some may be shy, uncommunicative or find it hard to describe their pain. This can be managed by *'giving them time, giving them reassurance, giving them different ways to express themselves'* (T4-Hc). Additionally, *'there's often overlap between pain and anxiety or pain and low mood'* (T2-HI) and *'if you were really anxious and concerned, your pain is much worse'* (GP5-Hc). Psychological support and creating opportunities for patients to get their *'headspace back'* (D1-Hc) was seen as facilitative; *"if every child in pain could have access to a pain psychologist and a team of therapists to work on non-pharmacological therapy that would be amazing"* yet *"there can be long waiting lists"* for this type of support (D1-Hc). It is still beneficial if HCPs can discuss patients with therapists even if the therapist cannot see the patient directly, to *"kind of send a bit of psychological thinking"* to the team (T2- HI). Non-pharmacological strategies (e.g., complementary therapies, distraction techniques, play therapy, massage, weighted blankets, and hydrotherapy) and support from physiotherapists and occupational health were also seen as helpful.

Discussion

This study explored HCPs' views on barriers and facilitators to at-home PPC pain management. Thematic analysis of the data revealed barriers concerning treatment side-effects, lack of education for HCPs and problems with health service delivery; and facilitators related to specialist support, which were found in a recent systematic review (8). In the current study, the concepts of partnership working and sharing expertise and knowledge were prevalent across themes, as shown in Figure 1.

Partnership working. Studies have revealed conflict and disagreement between professionals and parents as a barrier to symptom management (18-20). Our findings support this in relation to pain management specifically from the view of HCPs and highlight the importance of building trust.

As in other research (21), disjointed working between different teams and providers is a barrier to requesting prescriptions and dispensing medications. This is compounded by a lack of dispensing resources, poor medication availability, and a lack of licensed paediatric treatment. NICE states that specialist PPC teams should always include a pharmacist with expertise in this area (11). Issues with medication dispensing could be avoided if other team members could easily contact the expert pharmacist. As found in previous studies (22, 23), teamwork can breakdown out-of-hours when on-call staff may lack knowledge of a patient's pain signs and management plan. Siloed care between hospital and community staff can be avoided if care team members communicate regularly, have a clear sense of who has overall responsibility, and a good understanding of symptom management plans. Regular MDT meetings to discuss pain management can facilitate good communication and partnership working (24).

Education and shared expertise. Parents report a lack of information and support around symptom management (25-27). HCPs highlighted the importance of checking parents' understanding of symptom management plans and not overestimating their ability to administer medication. As in other studies (21, 28, 29), participants felt that parents (and some professionals) were reluctant to use palliative symptom management medication. Pain management can be improved when care teams spend time educating parents, discussing parents' and children's fears and, where possible, finding alternative treatments.

Our findings emphasise the importance of standardised pain assessments, recognising idiosyncratic pain signs, and listening to patient's pain accounts. HCPs believed that parents can feel overburdened by regular assessments and care teams should help to find a suitable tool. Parents' emotional health can impact on their ability to objectively assess pain. Future research could explore whether psychological support and reassurance would help.

Healthcare teams can feel they lack education and support to manage paediatric palliative symptoms (8). A lack of opportunities, time, and the cost of training are barriers to developing expertise (28). Participants in the current study suggested that GPs may avoid PPC training, perceiving it as difficult or intimidating. Our findings and previous research (30, 31) indicate the importance of community HCPs and families working with specialist teams.

Limitations: The development of pain assessment tools for this population could aid pain management. The qualitative nature of this study means that the findings reflect participants' views rather than objective reality and data the findings lack generalisability. Our data regarding caregivers' reports of pain were somewhat contradictory. Some participants felt that parents were experts in knowing their child's pain while others suggested that parents' pain reports were more subjective than professionals'. These varying views likely reflect the challenges of identifying pain and the lack of suitable pain assessment tools (13).

Strengths: This is the first in-depth qualitative study exploring HCPs' views on barriers and facilitators to at-home paediatric pain management at end-of-life. Using the study findings, we have developed recommendations for clinical care (Table 3). These findings are part of the PARAMOUNT study,

which draws on the views of family caregivers, children, and professionals to co-produce an educational intervention to help caregivers manage paediatric pain at home. This study highlights the need for such a resource and will help to guide its development.

Conclusion

Sharing expertise and cohesive, partnership working between professionals and parents, and between healthcare teams, is critical for optimal community PPC pain management. The COVID-19 pandemic has demonstrated that this can be maintained via telephone and/or video calls (32).

Disclosures

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Table 1. Data analysis of interviews with healthcare professionals exploring their experiences of the barriers and facilitators to paediatric pain management in the community at end-of-life

1. Interviews were audio-recorded, transcribed verbatim, de-identified, checked for accuracy, and imported into NVivo 12 (1)
2. KG and CL conducted an inductive thematic analysis (2-4) on the data using an iterative coding procedure and constant comparison techniques (5). This method was chosen to identify and sort data into prominent themes related to barriers and facilitators to pain management. The following steps were undertaken: <ul style="list-style-type: none"> • KG read and re-read the interviews and became immersed in the data before generating initial codes • KG and CL discussed the codes with successive independent re-reading of the data • KG developed preliminary themes from the codes and further refined these after discussion with CL • Using an iterative process, KG re-read the transcripts to check the data fitted the themes, further refine the themes, and check for any relevant uncoded data • Consensus between KG and CL was reached on all codes. If there had been any disagreements regarding codes, these would have been discussed and resolved with a third researcher (BCDS)
3. After finalising the themes and codes, subgroup analysis was conducted on participants' data depending on their professional role and work setting
4. Findings were discussed and interpretations agreed between the co-investigators (including the PPI representative)

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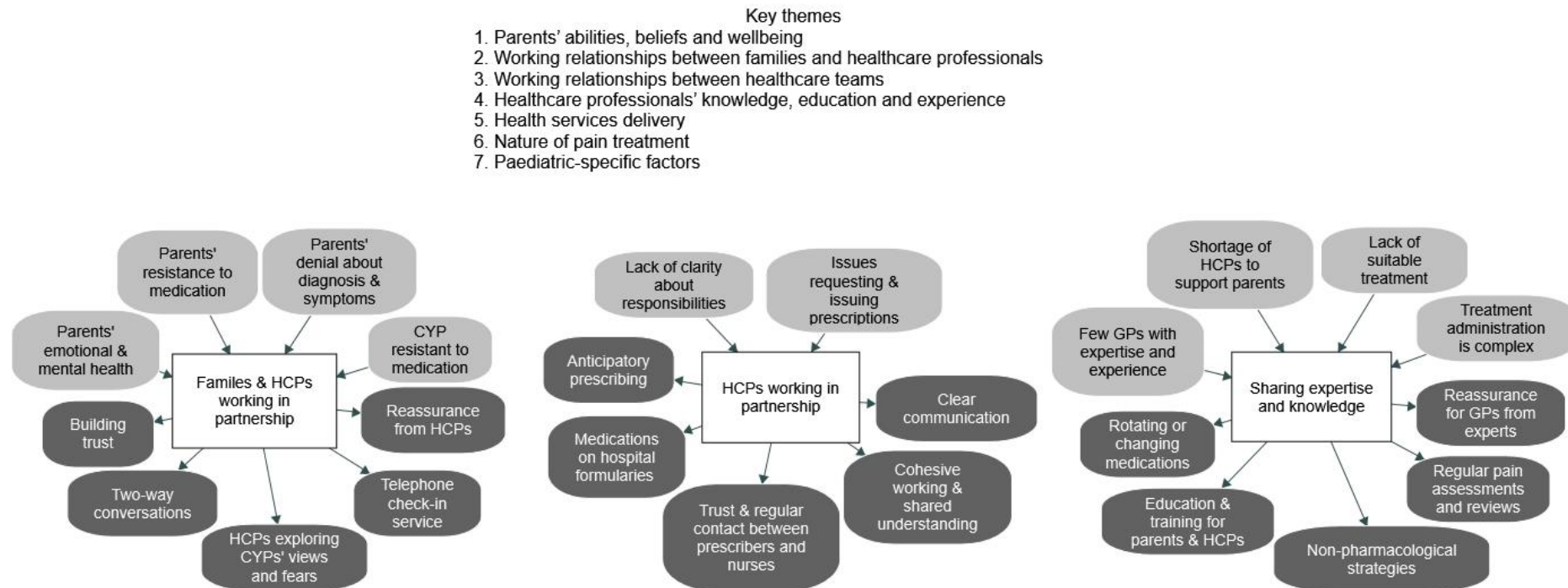
Table 2. Demographics of healthcare professionals who participated in interviews of their experiences of the barriers and facilitators to paediatric pain management in the community at end-of-life (N=29)

Demographics	n (%)
Age (average \pm SD)	44.59 \pm 8.14 years
Age (range)	26-61 years
Female	25 (86.20)
Role	
Nurse	12 (41.38)
GP	5 (17.24)
Consultants and registrar doctors	5 (17.24)
Pharmacist	2 (6.90)
Psychological, social & physical support therapists	5 (17.24)
Work setting	
Community	9 (31.03)
Hospice	10 (34.48)
Hospital	10 (34.48)
Years in paediatric palliative care (average \pm SD)	11.06 \pm 8.14
Years in paediatric palliative care (range)	2 months - 25 years
<i>Note:</i> To protect participants' anonymity, consultants and registrar doctors were grouped into one category and psychologists, counsellors, play therapists, occupational therapists and social workers were grouped into another. Labels for quotations indicate group (D=Doctor, GP=General Practitioner, N=Nurse, P=Pharmacist, T=Therapists), setting (C=community, Hc=Hospice, Hl=Hospital) and number for individual (e.g. N1-C is a quote from Nurse 1 working in the community).	

Table 3. Clinical recommendations for the improvement of community paediatric pain management at end-of-life

Joined up working between primary, secondary, and tertiary care and third parties
Comprehensive handovers and out-of-hours contacts
Regular, two-way conversations between healthcare professionals and parents
Listening and communication between healthcare professionals and patients, where possible
Online or in-person education and mentoring from experienced specialists for community healthcare professionals
Detailed, clear symptom management plans
Shared, standardised pain assessment tools
More direct, simplified pathways for accessing paediatric palliative pain relief
Anticipatory prescribing
Clear, detailed prescriptions with references
Families to have a 'just in case' box at home containing a small supply of medications to be used if there is difficult accessing treatment out-of-hours

Figure 1. Barriers and facilitators to community paediatric pain management at end-of-life as perceived by healthcare professionals in the UK



Note 1: HCP: healthcare professional; ICYP: infant, child or young person; CYP: child or young person

Note 2: White boxes = prevalent concepts across themes; Light grey = selected barriers; Dark grey = selected facilitators;

Note 3: Subgroup analysis revealed the following: a) **HCPs** working in different settings gave broadly similar responses, b) **Consultants, registrars and nurses** mentioned all the main themes, c) **GPs** discussed their own limited knowledge, problems recognising pain, issues around balancing pain relief and quality of life, and fears about paediatric palliative medications. They mentioned few barriers related directly to ICYP, d) **Support therapists** described barriers including parents' beliefs and emotions, and CYP's problems communicating pain. Facilitators included adopting a biopsychosocial approach to pain management, good communication, clear pain management instructions, and ongoing support for families, e) **Pharmacists** described barriers related to medicine management including dosing errors, parents' literacy and numeracy skills, logistical and financial issues to accessing treatments, a dearth of available treatment and a lack of scientific literature to support prescribing. They identified HCPs' expertise and pre-drawn up medications as facilitators.

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Supplementary File 1. Interview guide to explore healthcare professionals' experiences of the barriers and facilitators to pain management in the community in infants, children, and young people at end of life

This qualitative interview-based study forms part of a large multi-centre study aiming to improve paediatric palliative care pain management in the community through the development of an educational intervention for carers (PARAMOUNT study). Only answers and discussions in Part 1 were analysed and reported for this article.

Background: We would like to understand what healthcare professionals perceive to be good pain relief for children with life limiting illnesses when being cared for 'out of hospital'. We will also be interviewing family carers about their experiences of managing pain related to palliative care at home, and we will speak to children and young people to also gain their perspective.

With regards to life-limiting illnesses, our focus is on understanding the experiences of children who are considered orange or red on the Spectrum of Palliative Care Needs Tool [show tool]. If you are not familiar with it, defines children for whom death would not be unexpected in a few weeks to five years.

Part 1

- Could you tell me your age, your professional role, and the number of years you have been working in paediatric palliative care?
- Can you tell me more about how you are involved in pain management for infants, children and young people (ICYP) when they are in the community? How often? Types of diagnoses? Ages? Developmental needs?
- How does this contrast with hospice care? (if applicable)
Have you encountered any barriers or do you think there are any barriers to providing good pain relief for ICYP in the community? Can you think of any examples?
- Are you involved in supporting family carers to manage their child's pain at home? For example, giving information to parents on what and how to administer? If so, could you tell me more about this?
- Do you feel confident supporting family carers and giving information about pain management? Do you encounter any difficulties? Does anything help with this? Do you have any examples where things have gone well?
- What do you think helps family carers to manage their child's pain in the community?
Do CYP get involved in their pain management? How do you involve them? When? Why? Do you face any difficulties with this?
- Do you have further comments about any barriers or facilitators to good pain management in the community for ICYP?

Part 2

We plan to use the information from the interviews to develop a resource (such as an educational booklet) to support and help carers and healthcare professionals when administering pain relief and managing pain out of hospital. We hope this will help parents feel more confident managing their child's pain at home, which will then allow children and young people to spend more time being cared for at home at the end of their lives, if that is the wish of the family and child.

- *What are your initial thoughts on this?*
- *What things do you think should be included in such a tool to make it useful?*
- *What format do you think would be most useful? E.g. paper, app-based*
- *Do you have further comments about this tool?*

Part 3

My last two questions are about breakthrough pain.

- *How do you define breakthrough pain in your everyday clinical practice?*
- *Do you use an assessment tool for BTP?*
- *Do you think a BTP assessment tool for ICYP would be useful? Why?*
- *Is there anything else you want to add before we end the interview?*

Note: Adjustments to the language of the interview were made according to the respondent and probes were used, as needed, to elicit more detailed and elaborate responses to key questions.