**Title:** Parents’ perspectives on conflict in paediatric healthcare: a scoping review.

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**Word count:** 2676

**ABSTRACT**

**Background**

Conflict in paediatric healthcare is becoming increasingly prevalent, in particular relation to paediatric end of life. This is damaging to patients, families, professionals and healthcare resources. Current research has begun to explore perspectives of healthcare professionals (HCP), but the parental views on conflict is lacking.

**Objectives**

This scoping review explores parental views on conflict during a child’s end of life. In addition, parental views are mapped onto HCP’s views.

**Methods**

A search was completed of the databases CINAHL, PubMed, Web of Science, Embase and Medline between 1997 and 2019, focussed on parents of children with involvement with palliative or end of life care referring to conflict or disagreements.

**Results**

The review found ten papers that included parental views on conflict. Data on conflict was categorised into the following seven themes: communication breakdown, trust, suffering, different understanding of ‘Best Interest’, disagreements over treatment, spirituality and types of decision making. In particular, parental expertise, perspectives on suffering and ways of making decisions were significant themes. A subset of themes mirror those of HCPs. However, parents identified views of conflict unique to their perspective.

**Conclusions**

Parents identified important themes, in particular their perspective of what constitutes suffering and ‘best interest’. In addition, parents highlight the importance of being recognised as an expert.

**What is already known about this topic:**

* Conflict in paediatric healthcare is severely damaging to patients, families, professionals and resources
* Health care professionals report causes of conflict to be most commonly communication breakdown, disagreements over treatment and unrealistic expectations

**What this study adds:**

* Parents highlighted the following as influencing conflict: parents not being recognised as experts, parents perceptions of child suffering, and varying approaches to decision making
* Parents showed consideration of circumstantial factors that make conflict more likely, such as feelings of exhaustion and different ways of processing information
* This study shows some similarities between parent and health professionals views on conflict, however parents also have unique views that can contribute to the dynamics of conflict

**INTRODUCTION**

Advances in healthcare technology mean that children are living longer, with increasingly complex co-morbidities and dependence on healthcare.[1–3] Clinicians are faced with prognostic uncertainty and ethical considerations of treatment burden versus benefit.[4] Similarly, there has been a move towards shared decision making in healthcare, as endorsed by leading critical care organisations.[5] However, the application of shared decision making varies in practice.[6] Conflict is defined as a construct involving a process in which two or more people perceive opposition of another.[7] Often conflict arises in paediatric healthcare surrounding the decision to withdraw or withhold life sustaining treatment, and around the benefits and burdens of invasive treatment.[8–10] For example in the UK, the cases of Charlie Gard, Alfie Evans and Ashya King made international news and literature.[11,12] The risk of conflict is high when parents feel they have received mixed messages, or incorrect information previously.[13–15] This often occurs when prognosis is uncertain, or a specific treatment brings high risk.[16] Evidence emphasises the importance for health care professionals (HCP) to allow parental role and input to be maintained.[8–10,17]

Work is emerging in understanding conflict in paediatric healthcare but evidence is scarce. Forbat[16] reported causes of conflict from the HCPs’ perspectives. They found the three main causes as: communication breakdown, disagreements over treatment, and unrealistic expectations.[16] However, the parent voice is often lacking in current research: there is no review focussing on parent’s perspectives on conflict and disagreements in paediatric palliative and end of life care.

This scoping review aims to explore parents’ views on conflict. This review will also map parents’ perspectives against those of HCPs, as described by Forbat.[16] The objectives of this paper are:

1. To explore parental views on conflict within in paediatric end of life care
2. Map these findings onto healthcare professional causes for conflict (as outlined by Forbat[16]) and identify similarities and differences

**METHODS**

A scoping literature review was completed based on the framework set out by Arksey and O’Malley.[18] The search was completed using the databases CINAHL, PubMed, Web of Science, Embase and Medline, using combinations of the following search terms: parent, perspective, view, perception, conflict, dispute, disagreement, paediatric healthcare, end of life, paediatric palliative care, withdrawing withholding life sustaining treatment. A full search strategy used for PubMed is as follows:

((((((((parent\* perspective) OR parent\* view) OR parent\* perception) AND conflict) OR dispute) OR disagreement) AND paediatric healthcare) AND "end of life") OR "paediatric palliative care")

Papers were included when discussing perspectives of parents/carers of children with involvement of palliative care or end of life, if they made reference to any form of conflict or disagreement between parents and professionals. All healthcare settings were included. Papers were excluded if not published in English and those published before 1997. This date was chosen as the time that Together for Short Lives charity published the first Guide to Children’s Palliative Care, which has led research and practice in this area.[19] These criteria were used during title searches, followed by abstract searches. As conflict is not the sole focus of the papers found, a full manuscript review was required to satisfy inclusion and exclusion criteria. Reference lists of the final articles were hand searched for additional papers, however this did not identify any additional papers for inclusion.

**Data Analysis**

Eligible articles were analysed by the author and data was extracted, including information relating to conflict and disagreement. Each of the papers were critically appraised using Joanna Briggs Institute (JBI) critical appraisal tools where available.[20] No tools were available for narrative reviews, therefore guidance published in Ferrari was used as a guide for best practice.[21] A condensed summary table demonstrating characteristics of the final articles is included in Table 1.

Analysis identified data relating to conflict and disagreement and these results were synthesised into themes, broadly following qualitative thematic analysis.[22] These were then mapped onto the causes defined by HCPs: communication breakdown (defined as ‘struggles in composing and decoding conversations about treatment choices which result in a lack of collaborative and joint understanding’); disagreements over treatment; unrealistic expectations.[16]

**FINDINGS**

512 papers were found in initial search, 10 papers were included for review (Figure 1). Of these 10, 6 were qualitative research,[17,23–27] 2 narrative reviews,[28,29] 1 integrative review,[30] and 1 empirical ethics study.[31] 4 studies were undertaken in United States of America,[23,26,29,30] 2 in the Netherlands,[17,25] 1 in Australia,[28] 1 Italy,[24] and 2 from the United Kingdom.[27,31] Characteristics of these papers are included in the summary table below (Table 1). Parents included in the collective studies were mainly mothers, a small proportion of fathers. These were parents of children aged birth to 19 years, some of whom had pre-existing life limiting conditions, and others had acute illnesses (including neurological conditions, metabolic conditions, malignancies, respiratory distress and extreme prematurity). In terms of nationality of participants, studies included parents from the Netherlands, Morocco, Italy, Australia and the UK. In terms of ethnicity, studies predominantly included parents described as Caucasian, as well as African American, Hispanic, and Native American. Parents were recruited after being approached through local health services (Paediatric Intensive Care) or through disease specific clinics. Themes determined from these papers are shown in Figure 2 are further explained below (Table 2).

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| Table 1: Summary table of papers included in final review | | | | |
| **Author/Location** | **Study Aim** | **Sample Size/Population** | **Methodology** | **Critical Appraisal (using Joanna Briggs Institute appraisal tools)** |
| Bennet and Le Baron (2019)[30]  USA | To understand and summarise parents preferences regarding their roles and health care professional roles during end of life decision making in PICU | Papers included from USA between 2008 – 2018. Included papers regarding PICU, excluded papers from hospices, oncology, and Neonatal Intensive Care Units. | Integrative literature review | Critical appraisal of systematic review: Score 6/10  No tool was found for integrative review, and no clear definition of an integrative review was found.  Therefore there were some elements that were not clear in the paper, such as the search strategy. However, it is clear from elements such as the PRISMA flow diagram that a clear search has occurred here, and publishing more explicit elements of this may make this review more robust. These aspects were considered acceptable due to the nature of the review |
| Birchley et al. (2017)[31]  United Kingdom | To report how ‘best interest’ standard is applied in practice, in relation to ‘non treatment’ | 14 parents, 10 doctors, 8 nurses, 7 member of ethics committees from 3 PICUs. | Empirical ethics study. Interviews with participants thematically analysed. | Critical appraisal for qualitative research: score 8/10.  This article could benefit from considering the influence of the researchers on the interviews and findings. |
| Darbyshire et al. (2015)[24]  Italy | To investigate experience of parents in South Tyrol regarding caring for a child with a life threatening or life limiting illness  To ascertain how well palliative and therapeutic needs of parents of children with life limiting conditions are met  To discover barriers or facilitating factors to paediatric palliative care and to contribute to developing this service | Interviews with families of 9 children with life limiting or life threatened conditions, 5 of whom were deceased. 7 additional parents completed online surveys. | Qualitative research, interviews with families found by purposeful sampling in addition to online survey. | Critical appraisal for qualitative research: score 10/10  It discusses the authors and researchers culturally and considers the impact this would have on interviews and findings.  By using multiple authors of differing cultural bases, Darbyshire et al. have aimed to reduce cultural/language impacts. |
| De Vos et al. (2015)[17]  Netherlands | To describe a case study where parents want to withdraw care and health care professionals disagree | 1 child case study and their parents | Qualitative research, using chart review, audio discussions of team discussions and meetings with parents and medical teams. Interviews completed with parents and key professionals within 6 months of patients death. | Critical appraisal for qualitative research: score 8/10.  More information on the researchers and how they came to choose this family would be useful, to assess any researcher bias. |
| Duc et al. (2017)[28]  Australia | To describe complex care of children with life limiting conditions and intellectual disabilities (ID) and commentary with ‘best practice’ guide. | Papers identified by systematic literature search and additional seminal papers identified by ‘expert consensus group’. Included papers relation to children with ID (either acquired or congenital) | Narrative review using expert consensus group to reference seminal papers | Critical appraisal of narrative review:  Narrative review is suitable this topic and aim, and allows a clinical concept to be structured around emerging themes.  There is no clear mention of a search strategy or inclusion/exclusion criteria. This would be useful) to acknowledge the risk of subjectivity in study selection. However, this review is part of a wider research study, where a systematic review will be published, presumably making this search strategy clear |
| Forbat et al. (2015)[27]  UK | To explore clinician and family experiences of conflict, to map trajectory of conflict escalation | 20 doctors, 10 nurses, 8 parents, 3 chaplains, 2 lawyers, 2 managers of Patient Advice Liaison Service, 1 hospice head of care.  Participants from district general hospital, 2 teaching hospitals, 2 children’s hospices | Qualitative research, semi-structured interviews | Critical appraisal for qualitative research: this paper score 9/10. Methodology is congruous with the aims. It represents the views of all participants clearly. Would be beneficial to note any influence the researchers may have had on the results to assess any bias. |
| Rosenberg and Wolfe (2017)[29] | To review literature related to paediatric palliative care in oncology and highlight important opportunities for future research. | Papers related to Paediatric palliative care and oncology between 1974 and 2017 | Narrative review and searches of authors own files, reference lists of key papers and opinions from members of Pediatric Palliative Care Research Network. | Critical appraisal for narrative review:  Narrative review is suited to the research aim, as it allows for tracking of the change and development of paediatric palliative care over time. The search strategy is published which is not necessary for a narrative review, but does add robustness to their findings |
| Sharman et al. (2005)[23]  USA | What influences parents decisions to forgo life support for their children | 14 parents of 10 children | Qualitative prospective study, semi-structured interviews. | Critical appraisal for qualitative research: this paper score 10/10. Methodology is congruous with the aims. It represents the views of all participants clearly |
| Superdock et al. (2018)[26]  USA | To demonstrate how religion and spirituality impacts on parents decision making and explore how providers interact with parents to whom religion and spirituality is important. | 16 cases were used, including 28 parents and 108 health care professionals. 27 parents identified as Christian. | Qualitative research. Longitudinal series of one on one narrative-style interviews, field notes, questionnaires, medical chart review. | Critical appraisal of qualitative research: score 9/10.  Clear methodology, authors have worked hard to remove as much bias as possible by using standardised tools and numerous researchers |
| Zaal Schuller et al. (2016)[25]  Netherlands | To compare parents and physicians experiences in end of life decision making process | 14 parents of children with profound and multiple disabilities and life limiting conditions | Qualitative, retrospective study using semi-structured interviews | Critical appraisal for qualitative research: score 9/10  Unclear as to what influence the researcher could have had on results and vice versa. However, this it is clear that a number of authors were involved in writing the questions and coding/theming, which would minimise any individual bias. |

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| Table 2: Findings from scoping review: themes of causes of conflict defined by parents | | |
| Theme | Sub Theme | Explanation |
| Communication Breakdown | Poor communication style | Communication perceived as “Abrasive, untimely or incomplete” lead to disagreements[27,30] |
| Parental expertise | The wish to be treated as an expert or translator for their child[24,28,30] |
| Feeling unheard | Staff not listening to parental concerns regarding their child, leading to a loss of control[28] |
| Perceived lack of knowledge of child's condition | Parents reporting lack of understanding surrounding children with intellectual disabilities[25,28] and long term conditions[24] |
| Trust | Lack of continuity of care | Difficulty trusting new clinicians[27,28] |
| Mistrust from previous experiences | Previous errors in healthcare impacting on parents’ ability to trust HCPs[25,27,30] |
| Need to advocate for child's value | Parents reporting children with intellectual disabilities are valued less than a typically developed child[24,25] |
| Suffering | Assessment of suffering | Difficulty for parents assessing suffering due to high doses of analgesic or sedatives, and reduction in cues of suffering[17] |
| Degree of suffering that is acceptable to parents | Parents and HCPs differ in their interpretation and acceptance of suffering[23,26,29–31] |
| Connection of suffering to religion and spirituality | Suffering as part of God’s plan that should not be intervened with[26] |
| Perceptions of Best Interest | Personal interpretations of ‘best interest’ | Parents reporting ‘best interest’ involving purely the child’s needs, but HCPs consider parent and family[17,31] |
| Disagreements About Treatment | Observation of child | Parents are more strongly influenced by their observations of their child than clinical observations[17,23,29,30] |
| HCP’s protecting parents | Parents report feeling that HCPs are not focused on their child when they are protecting parents[31] |
| Practicalities of care | Barriers to care at home (practicalities and lack of services)[24] |
| Spirituality | Spiritual needs of their family | Parents report HCPs neglect to recognise their spiritual needs[29,30] |
| Spirituality impacts on parents approach to decision making | Need for HCPs to frame medical issues in light of spirituality [26] |
| Perceptions of Decision Making | Information processing affects decision making[17,23,26,29–31] | Parents report being either rational or intuitive decision makers[23] |
| Perceptions of shared decision making | Shared decision making perceived by parents as HCPs persuading them[31] |
| Time pressure[25,28] | Discussion of end of life preferences happens at times of acute deterioration (high pressure and stress) rather than earlier[25] |
| Positive Influence of Disagreements | Disagreements leading to positive outcomes | Disagreements can lead to discussion of all options (giving confidence in decision making)[25] |

**Circumstantial Factors**

Parents identified a number of causes of conflict. In addition to these, they referenced factors that did not directly cause conflict, but that were circumstances leaving them more vulnerable for conflict to arise or escalate. Specifically, parents report exhaustion intensifies grief, confusion and anger which leads to a vulnerability for communication breakdown.[17] Similarly, parents also find it difficult to retain complex medical facts and report finding it easier to recall observational information.[23] Therefore, this suggests that the way the HCP share information with parents may determine whether parents agree with professionals. Acknowledgement of these factors can guide HCPs in their approach to difficult conversations and decisions.

**Communication Breakdown**

Expertise of parents was mentioned by 3 papers.[24,28,30] When parents are feeling their expertise is being challenged, they believe conflict is more likely.

**Trust**

Trust was referred to in numerous studies.[25–28,30,31] Parents recognise that conflict arises during times of uncertainty in prognosis:[17,25] trust of their HCPs is vital for parents to feel confidence in the information and guidance provided.

When there is a lack of continuity of care, resulting in parents having to deal with different clinicians on multiple occasions, this can lead to parents finding it difficult to trust new clinicians with the care of their child.[27,28]

Parents of children with intellectual disabilities or life limiting conditions report they are always needing to ‘fight’ for small things, which can accumulate feelings of frustration, adding to high pressure circumstances.[24,25] Therefore, they do not trust that the professionals will be able to provide what their child needs without them having to ‘fight’.

**Suffering**

The consideration of ‘suffering’ was discussed repeatedly.[25,32,36,38,39] Disagreements were cited in relation to the extent to which a child is suffering, and to what degree suffering is acceptable. This is significant as suffering is a considerable factor when determining what treatment is appropriate for a child.

Some parents from a study discussing religion and spirituality were able to accept a child’s suffering as part of a wider plan from God.[26] In addition, Bennet and Le Baron [30] reported ‘best interest’ of a child to parents was related to ensuring longevity of life, as opposed to limiting suffering.

**Perceptions of Best Interest**

There is a difference in how parents and health professionals interpret ‘best interest’: parents would like only the child’s needs to be considered. However, health professionals take into account parents and child’s needs when making recommendations regarding care.[17,31]

**Disagreements About Treatment**

Parents reported disagreements in both extremes of treatment: when parents wanted all treatment when medical team felt treatment was futile and vice versa.[17,25,30]

Parents report using their own assessment to make decisions around treatment. Parent’s assessments of their child is guided by their own observations of their child, whereas health professionals are more likely to include clinical observations (including test results and scans) in addition to observations of the child.[17,23,29,30]

**DISCUSSION**

This review is the first to collate parental views on conflict in paediatric healthcare, during palliative and end of life care. Parents reported many causes of conflict: importance for parents to have their expertise recognised; interpretation of suffering; views of ‘best interest’; shared decision making.

By mapping these findings onto those from HCPs described by Forbat et al.,[16] it is demonstrated that many of parents views on conflict match with those of HCPs. Specifically, parents’ views on communication breakdown mirror those of professionals, in particular the reference to the negative impact of abrasive or untimely communication. In addition, parents and professionals both recognise that conflict can occur when there is disagreement over whether treatment is futile or not. However, it is clear there are differences between professionals and parents’ factors contributing to conflict. Additionally, parents did not report any unrealistic expectations (as highlighted by HCPs) being a factor leading to conflict. This review offers a broader understanding of parental perspectives and how we can use these to supplement our knowledge of professionals’ views.

Many of these findings can be linked to parental roles: parents feel conflict arises when their role is challenged. Hinds et al. found that parents of seriously ill children believe it is their role to strive to be a ‘good parent’.[32] In particular, parents recognised that respecting their expertise was important to avoid conflict. It is important for all HCPs to respect this expertise at every encounter.[24,33] When parents feel that this has not been respected, and they have had to fight to have their views heard, this builds up an underlying mistrust of HCPs.[34] This is very complex for HCPs to navigate, as parental expertise is a nuanced concept, which will vary between families. In addition, many parents of chronically ill children carry out complex technical care at home and can find it difficult to reconcile with the limitations of care they are allowed to complete in a hospital environment.[35] Parents report feelings of fear, helplessness and stress due to an inability to participate in care in a Paediatric Intensive Care Unit.[36] Therefore it is beneficial to parents for nurses to encourage them to be involved in all aspects of care, as this can help parents feel they are achieving their role of ‘good parent’, respecting their expertise for their child, and also can improve their child’s physical and psychological wellbeing.[32] This is especially important for conflict, as the findings here demonstrate that parents feel stress and helplessness leave them more vulnerable to communication breakdown, and subsequently conflict with professionals.[17]

Suffering was also highlighted as an area of contention between parents and professionals. Suffering is a subjective element of healthcare which is difficult to measure and assess, by parents and professionals alike.[37] When they agree on the degree to which a child is suffering, parents are more likely to be satisfied with the level of care their child received.[38] Furthermore, suffering is a significant determinant of what treatment is offered to a child. This is complicated further by the subjective nature of what level of suffering is acceptable to a family, and how widely this can vary from one family to the next.[23,26,31]

Similarly, parents also determine making decisions in their child’s best interest as part of their ‘role’. HCPs similarly practice under the best interest approach, and in many jurisdictions are legally obliged to do so.[15] This is a paradigm first established for adult healthcare, therefore there is added complexity when applying this to paediatrics, due to the involvement of parents as proxy decision maker.[39] HCPs often consider the best interests of the family rather than solely of the child.[17,31] Many clinicians wish to protect parents from any guilt associated with decisions surrounding withdrawing care, but parents report wishing to focus entirely on the child.[17,31] In addition, it is a legal obligation to make decisions in the child’s best interest, which may limit parental discretion.[15] This adds further complexity and predisposition to conflict, as parents report they should be able to make independent decisions regarding end of life.[31] Parents who are not part of the decision making during their child’s end of life, retrospectively report wishing for further involvement to protect their child’s wellbeing.[40]

Moreover, as parents consider decision making a significant aspect of their role,[32] professionals could consider how parents approach decision making, on an individual basis. Psychological biases in information processing can mean that different weight is attributed to certain information types.[23] For example, it is easier to recall physical observations as these are vivid and tangible, as opposed to indirect information (such as medical information).[23] Decision making is often characterised in the literature as either rational or intuitive approaches: rational decision makers use objective facts and logic, whereas intuitive decision makers will base it on feelings, values and human concerns.[41] Most parents use a combination of facts and feelings. Professionals would benefit from taking time to ascertain how their parents make decisions. This can help ensure that parents receive the information that is of most concern to them, in a manner that they can access it, and subsequently help to reach a consensus decision.

In addition, shared decision making is considered the most appropriate means of decision making in healthcare. However, parents described shared decision making as being persuaded to a clinicians point of view.[25] Birchley et al. reports that parents were not dissatisfied with this, and appreciated professionals making them feel like they were involved in decision making.[25] However for parents who may already distrust professionals or fear that the physician is not acting in the child’s best interest, if they perceive that they are trying to be persuaded onto a different point of view, it may entrench further conflict and mistrust. Parents wish for a collaborative approach, allowing them to retain some control, and reducing the feeling of needing to ‘fight’ for care.[24] It would be beneficial for clinicians to make it clear they are open to new ideas and divergent points of view during discussions:[25] this may be something professionals feel they do, but this is not how it is perceived. Improved communication skills would allow professionals to establish the information parents find useful to support with decision making.

**Limitations**

Conflict has not been the sole focus of any of the studies included, therefore it is possible that parents would have offered alternative perspectives if considering conflict directly. However, it demonstrates the significance of conflict that it arises in numerous studies without prompting. Similarly, only a small number of papers were identified, from a range of heterogeneous sources which makes generalisations challenging, as is often the limitation of a scoping review. However, collating these views is a valuable starting point for understanding parents’ perspectives on conflict that will benefit from further focussed research.

**CONCLUSION**

This review has demonstrated the breadth and complexity of conflict from the parents’ perspectives. Parents have shown they require a greater understanding of their desire to maintain their role of a ‘good parent’: professionals need to appreciate the strength of parental advocacy and expertise for their child, but also that this means different things to different families. Professionals need to have the skills to learn the parents’ perspectives on suffering, best interest and decision making, taking into account their previous experiences. This can help remind professionals of the shared goals with parents and redirect mediation efforts towards this. Increasing professional confidence in discussing these sensitive topics could start to improve collaboration with parents. Perhaps these conversations should become an integral part of professional training programmes.

As this area is emerging, further conflict-specific research must be completed to fully understand all interactions involved. It would be especially beneficial to involve the child’s voice, as this is very rarely found in current research, particularly those with chronic complex conditions. It is not possible to eradicate conflict entirely, and as parents have indicated here, conflict and disagreement can have benefits to ensure all possible options have been explored. Paediatric healthcare is becoming increasingly complex: it is essential we begin to understand the dynamics of conflict in health at a deeper level.

**Competing Interests**

None to declare

**Funding**

No funding was received for this research

**Data sharing statement**

Data sharing not applicable as no datasets were generated for this study

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**Figure captions**

Figure 1: Flowchart demonstrating scoping review search process

Figure 2: Parent persepctives on factors that contribute to conflict