Decision-making experiences of health professionals in withdrawing treatment for children and young people: A qualitative study

Abstract

Objective: To explore factors that influence professionals in deciding whether to withdraw treatment from a child and how decision-making is managed amongst professionals as an individual and as a team.

Study Design: Semi-structured interviews were conducted with a purposive sample of health professionals working at a UK Children's Hospital, with children with life-limiting illnesses whose treatment has been withdrawn. Data was transcribed verbatim, anonymised, and analysed using a thematic framework method.

Results: A total of fifteen participants were interviewed. Five interrelated themes with associated subthemes were generated to help understand the experiences of health professionals in decision-making on withdrawing a child's treatment: 1) Understanding the Child's Best Interests (2) Multidisciplinary Approach (3) External Factors (4) Psychological Wellbeing (5) Recommendations to Support Shared Decision-making.

Conclusion: A shared decision-making approach should be adopted to support professionals, children, and their families to make decisions collectively.

Introduction

The decision to withdraw or withhold treatment from children with life-limiting illnesses is complex and emotional for all involved (Meskens, 2013). Literature identifies two main challenges related to this process. The first is parental involvement in paediatric treatment decision-making (Corlett & Twycross, 2006; Dodd, Saggers, & Wildy, 2009; Shah, Rosenberg, & Diekema, 2017); the second is how treatment decisions are made between multi-disciplinary professionals. High profile cases, such as that of Charlie Guard, have highlighted the issue of how parents and professionals work together to make decisions regarding treatment for children with life-limiting conditions. This includes making decisions with the participation of the child (where possible) and their parents on the basis of shared knowledge (Stiggelbout et al., 2012). Shared decision-making is an evidenced-based approach that promotes partnership between health professionals, patients, and parents (Legare et al., 2010). The aim is to maintain a sense of mutual trust and respect between the child, caregiver, and health professional so that they may work together for the benefit of the child (Stiggelbout et al., 2012). By exchanging medical evidence (options, risks, and benefits) and the family's preferences and values, health professionals, patients, and parents can deliberate to determine the best treatment plan (Legare et al., 2010; Stiggelbout et al., 2012).

Yet shared decision-making has been shown to be limited by time and opportunities for dialogue between parents, the child and health professionals (Drotar, Crawford, & Bonner, 2010; Stiggelbout et al., 2012). A study by Boland, McIsaac & Lawson (2016), examined the barriers to implement shared decision making in paediatric settings and reported that the main barrier was gaps in knowledge of shared decision making such as which clinic situations are suitable.

Factors that influence parental treatment decision-making include the child's health status and medical complexity, parents' own emotions, faith, and other community members (Lipstein, Brinkman & Britto, 2012). Studies exploring parental decision making in paediatric cancer treatment found that parents were satisfied with the amount of information provided to them (McKenna,

Collier, Hewitt & Blake, 2010). Sharing reliable information has been found to enable parents' informed decision-making (Valdez-Martinez, Noyes, & Bedolla, 2014). However, it is also recognised that parental decision-making is motivated by love and compassion which can conflict with more objective assessments of the best medical interests of the child (Cave & Nottingham, 2018). Cultural and societal factors, such as ignoring religious viewpoints on death, are further influencers within the decision-making process which can negatively impact the relationship between child, parent, and professionals (O'Connor, Brenner, & Coyne., 2019).

Dynamics between professionals can also impact the decision-making process (De Leeuw et al., 2000; Gallagher et al., 2015). For example, nurses may be more prone than doctors to withhold resuscitation of pre-term babies in the delivery room and are more likely to ask parental opinion regarding subsequent treatment choices (De Leeuw et al., 2000). Further research around the area of decision making needs to explore viewpoints from MDT meetings and professionals. This has been highlighted in long-term conditions such as paediatric epilepsy (Heath et al., 2016) and paediatric cancer (Hamilton et al., 2016). A multidisciplinary and holistic approach is crucial to the decision-making process as different viewpoints are required to reach a unanimous decision (Heath et al, 2016).

Despite emphasis on shared decision-making and multi-disciplinary team processes in paediatric treatment decision-making, medical decisions can still come into conflict with parent and family wishes, leading to both ethical and legal implications. The case of Tafida Raqeeb (Cave et al., 2020) is a clear example of highlighting potential conflict and the role of ethics within the decision-making process. While an NHS hospital trust decided that it was not in the child's best interests to continue life support and treatment should be withdrawn, a court ruled that as Tafida could not feel pain and therefore was not suffering, her parents were permitted to fulfil their wishes of taking their daughter to Italy for further treatment (Dyer, 2019). Tafida proceeded to make incredible progress and has since been moved out of intensive care (Cave et al., 2020). Given the current media

exposure on best interests of children and the current development of Charlie's Law which aims to prevent conflicts between parents, families, and health professionals (HCPs) in health care decision-making; this study was conducted to increase our understanding of the decision-making process from the perspective of multi-disciplinary health professionals.

Although research has explored parental views of decision-making in terms of withdrawing treatment from a child with a life-limiting illness (Hinds et al., 2000; Hinds et al., 2009; Gagnon et al., 2003; Meyer, 2002; Tilden, 1995), a paucity of literature has investigated the views of health care professionals. This study aimed to explore factors that health professionals consider in deciding to withdraw treatment from a child with a life-limiting illness. Better understanding this decision-making process will identify support needs of professionals and other stakeholders.

Method

Design

Reflecting the importance of taking a multidisciplinary approach to inform treatment decision-making (Hunink et al., 2014), this study aimed to capture the views of health professionals using a qualitative design. A favourable review was obtained from an NHS Research Ethics Committee, the Health Research Authority (HRA) and the Research and Development team of the NHS hospital site in question (19/HRA/0572).

Sample and recruitment

Participants were identified via purposive sampling. Eligible participants included health professionals working at a UK specialist children's hospital who were involved in treatment decision-making. Recruitment posters were advertised on staff notice boards across various wards: Paediatric Intensive Care Unit (PICU), Respiratory, Oncology and Paediatric Surgery. Interested participants contacted the lead author via email who then assessed them according to the eligibility criteria before providing study information and a consent form electronically. Eligible participants included

health professionals working within the hospital and involved in withdrawing a child's treatment. Once participation and consent was confirmed, the researcher established the participant's preference for conducting the interview face-to-face, via Skype or telephone and agreed a suitable date, time, and venue for the interview. Participation was entirely voluntary, and professionals gained a full understanding of the study before consent was obtained. All participants consented to their interview being audio recorded and anonymous quotations being used within study reports.

Data collection

Interview data were collected through use of a semi-structured interview schedule. The interview schedule was informed by a literature review of existing research exploring evidence of roles of paediatric health professionals in decision-making related to treatment withdrawal, ensuring that the aims of the study were met. Topics included how decisions regarding withdrawing treatment were made, challenges faced by HCPs, the professional's role within the process, involvement of the child's family in the process, conflicts between professionals and families. The researcher used open-ended questions which allowed participants to reveal thoughts and feelings on the subject matter. Data collection ceased when appropriate depth and richness of data had been generated (Morse, 2000). All data was anonymised, transcribed, and stored on a secure server to allow remote access.

Data analysis

Data were transcribed verbatim, anonymised, and analysed using a thematic framework method (Ritchie & Lewis, 2003). This method was selected for identifying, analysing, and reporting patterns or themes within data (Braun & Clarke, 2006). Data analysis were carried out in accordance with the five stages of the Framework Method: familiarisation, identifying a thematic framework, indexing, charting, mapping, and interpretation (Gale et al., 2013). Analysis involved the systematic search for patterns to generate descriptions capable of shedding light on the phenomenon under investigation (Srivastava & Thomson, 2009). Data were coded both across and within participant accounts, as well as both deductively (using concepts identified from the literature) and inductively (new themes

generated from the data). Data storage, coding, and retrieval was supported by use of NVivo 12 software. To enhance the validity of the findings, it was ensured that the analysis of the data was as transparent a process as possible. This was achieved by giving full explanations with examples to demonstrate conceptual interpretations of the data as well as discussing emerging findings with members of the research team, to ensure the researcher was exploring perspectives other than their own and reflecting on decisions made (Smith, 2015).

Results

Sample characteristics

A total of fifteen participants were interviewed: clinical professionals (n=9) and non-clinical professionals (n=6). Three participants were male with the remaining participants (n=12) female. Clinical professionals included Consultants (n=2) and Nurses (n=9). Non-clinical professionals included those with roles designed to support families with decision-making processes (e.g., chaplaincy, family liaison, bereavement support). To ensure participant anonymity, the number of each non-clinical professional is not reported. The majority of interviews (n=11) were conducted face-to-face with four conducted via telephone.

Themes

Analysis generated five interrelated themes: (1) Understanding the Child's Best Interests (2) Multidisciplinary Approach (3) Effective Communication (4) External Factors (5) Psychological Wellbeing (6) Recommendations to Support Shared Decision-making. Illustrative quotations for each theme are provided in Table 1.

-suggest insert Table 1 here -

Understanding the Child's Best Interests

Professionals identified that all decisions regarding treatment were based on the best interests of the child. Factors taken into consideration to understand this included competency of the child,

severity of the child's condition and the true realisation of the child's illness. Conversations centred on the child's prognosis and medical complexity. While it was highlighted that deciding to withdraw a child's treatment takes a significant amount of time, professionals stressed that all treatment options were fully explored before the withdrawing of treatment was raised for discussion.

All professionals suggested that including children and young people within discussions who had the capacity to understand, supported the child to feel some control of their treatment. Involving parents and families was also a particularly important part of establishing what was in the best interests of the child. The importance of palliative care was understood to be a vital component of discussions, emphasising the need to work with palliative care colleagues early in the process, as a form of parallel planning, and to ensure advance care plans were developed that could support the decision-making process; using the best plan that fits the child at the time. Parallel planning refers to planning for end of life care while taking account of the unpredictable moments of life-limiting conditions (NICE, 2016; Villanueva et al., 2016).

However, there was also a sense of uneasiness from professionals when parents were perceived to be in denial about the child's condition and actively did not seek further support in terms of understanding their child's illness.

> *"We've currently got family who don't want to have the support at all and actually are very much doing their own thing and everybody is very uncomfortable about it."* [Clinical professional 5]

Professionals reported that parental *'denial'* was commonly witnessed in discussions where parents equated upholding the best interests of their child with not giving up on treatment. This 'denial' was further aggravated by parents who sought advice on treatment options from other sources (e.g. other families) instead of seeking professional advice. In particular, professionals perceived parents to seek confirmatory evidence to support the idea that their child was not as sick as the medics advised. Reaching consensus on what constituted the child's best interest was therefore perceived

as a complex process, requiring understanding and gentle negotiation between medical and familial assessments.

Multidisciplinary Approach

Professionals described how all conversations regarding patient treatment were initially discussed within weekly multidisciplinary team (MDT) meetings. Emphasis was placed on the decision being centred on the child, meaning that the views of all health professionals (including non-clinical professionals) and family members including those outside of the immediate family were acknowledged.

Having said that, non-clinical professionals reported incidences where some initial MDT meetings did not consist of the appropriate professionals, noting implications for how long it takes to make complex treatment decisions for and with a child and their family. This was particularly frustrating within cases where the child was clinically deteriorating.

> *"Professionals need to be involved quicker like sometimes some cases where the first initial decision meeting doesn't involve the correct people of the correct professionals which makes it difficult, and the decision turns out to be longer or take longer to reach and sometimes time isn't on our hands"* [Non-clinical professional, 4]

Clinical professionals, especially consultants, stressed the importance of medical processes and outcomes within the decision-making process, focusing on physiological and biological factors of illness including diagnosis, cure, and treatment. Such emphasis on biomedical understandings was considered to enable the conversation to be '*less emotional*' (clinical professional). Remaining 'factual' thus facilitated professionals to be clear and direct with families, which also helped professionals to protect themselves throughout emotional and difficult conversations. There was also an indication that the role of the medical professions was to cure patients, meaning that some professionals perceived the death of a patient as a failure on their part.

Involving non-clinical professionals in conversations was seen as vital for both professionals and parents, helping *'everybody understand different perspectives'*. Nevertheless, sometimes clinical professionals required additional assistance from non-clinical professionals to support conversations with parents and families. This was emphasised by a medical professional who stated, *"They [parents] would ask for some support staff to come in and so sometimes chaplaincy would come in and be invited by the family and also maybe suggested by the clinician to the family that they might want somebody else like chaplaincy in with them".* In particular, clinical professionals reported that Family Liaison, Chaplaincy, and other non-clinical professionals act as advocates for children and their families during this difficult time.

Professionals recognised the remit of their roles and how they influenced the decision-making process. For example, non-clinical professionals recognised decision-making as not part of their job role. This was demonstrated during an interview with a chaplain who mentioned that *'with regards to the decision-making process I would say that's not within our working remit'*. Non-clinical professionals saw their focus being on the *'bigger picture'* and not solely on the medical aspect of the child allowing professionals to work with parents and families constructing a plan for end of life. Therefore, demonstrating that non-clinical professionals supported the decision-making process rather than influencing the decision.

Effective Communication

The importance of effective communication between the child, family, and professionals as well as between professionals themselves was recognised, with agreement amongst health professionals that overwhelming families with information negatively influenced the decision-making process.

The importance of providing families with significant information to make a decision was recognised as a difficult decision to make. This was reflected by a non-clinical professional *"we are trying so hard to involve the family that we are trying to involve them in a decision-making way that is impossible for the family to make".*

9

Professionals stated that opposing views made it difficult to reach a unanimous decision, especially when conflicts with members of the family arose. Part of encountering disagreements meant that children who were aware of their situation remained silent on the situation due to the fear of upsetting their loved ones.

It was suggested that when disagreements arose between families and clinical professionals, non-clinical professionals acted as an advocate to mediate and manage the situation, *'sometimes they bring other family members who create issues'*.

When parents and professionals were not able to reach consensus, and parents did not wish to attend court, in many cases treatment was continued until the child passed away. Thus, suggesting that although decision-making was incredibly difficult for all parties involved, treatment was recognised as being non-curative or palliative.

There were concerns from a non-clinical professional that allowing parents *'too much power'* during the process appeared to cause more issues to decision-making between parents and professionals.

> *"I think we give them too much power sometimes you know to decide we should just be blunt … we offer too much emotional support and give them too much power when they don't know the full background" [Non-clinical professional, 6]*

Reaching consensus was difficult when parents and families were unaware of the treatment options or the reasons behind withdrawing treatment.

The 'power' professionals assumed parents and families had in deciding was contrasted against the hope parents had for their child's recovery. Professionals reported that empathy and compassion were therefore fundamental components of conversations about treatment withdrawal. Nevertheless, the combination of optimism and power for parents caused some friction between professionals and parents especially when changing the minds of parents.

The majority of the cases discussed by professionals were children of a young age. However, professionals realised that young people who were aware of their condition required extensive support from professionals to be involved in the decision-making process. Professionals particularly identified that young people from the age of 13 onwards required emotional support:

> "*We wonder with older children why don't families want the conversation and we are sure they are just wanting to become a wonderful parent by protecting them but not having the conversation disempowers that child to have end of life discussions and we have a hypothesis that those conversation will have distress of the child and the parent and I just wonder whether we could do more to help those families and figure it why not and how could we help with their child who is perhaps 13 14 15 16". [Non-clinical professional, 1]*

During conversations regarding withdrawing treatment, it was thought that the child, their parents, and families needed to be made aware that professionals have explored all treatment options for their child including research trials, but to no avail. These difficult decisions were therefore thought to require honesty and compassion, ensuring that families understood that a decision regarding withdrawing treatment was only made after all treatment options were exhausted. Providing accurate and honest information was considered vital to support the decision-making process.

External factors in decision-making

Professionals suggested that various factors could influence decision-making, including for example, culture, religion, and other more neutral, external bodies, such as advocacy. With professionals supporting a diverse population, there was recognition that conversations around withdrawing treatment were difficult to understand outside of the family's lifeworld context, especially in families where English was not the first language. Due to language barriers, professionals identified that they experienced difficult relationships. Language barriers influenced conversations as professionals maintained that there could be misunderstanding between parents and professionals when an interpreter was not supporting the conversation:

> *"Language barrier is key cause I've noticed especially where cases where the family doesn't speak English well or understand it then other family members get involved to interpret and that is difficult but what can we do"* [non-clinical professional 6]

Professionals described how families with strong religious and spiritual views often sought guidance and support from their community and cultural leaders. Professionals identified that amongst families with a religious faith, many parents assumed that they were '*playing god'* and the decision of ending a life should not be in the hands of professionals. Upon raising the discussion of withdrawing treatment with these families, many individuals would relay the information back to their religious community to discuss withdrawing treatment, which sometimes would then cause disagreements between HCPs and families.

Professionals recognised that many parents and families may use or have previously used the media to strengthen their case and support their decision and not permit withdrawal of treatment. Here, professionals maintained that media action instigated conversations, and this was echoed during the example of Charlie Gard.

Where professionals and families could not reach a unanimous decision, cases were referred to a third party to intervene. All professionals recognised that using impartial mediation during the decision-making process was a vital aspect in maintaining communication:

> *"We bring in external people who are neutral who don't know the professionals or the family I'm not clinical, so my role is more supporting, and the conflict is difficult to resolve unless it goes to court or if the parents and family come to the same conclusion as the professionals"* [non-clinical professional 6]

Professionals maintained that transferring the case to courts was predominantly advocated by parents and families, especially when they did not agree with the rationale for withdrawing treatment.

Psychological Wellbeing

Professionals recognised that withdrawing a child's treatment was a difficult decision to be involved in. In particular, there was acknowledgement from all professionals that clinical supervision played an important role in supporting them psychologically. Support from their peers was also considered effective, with resources such as *'team huddles'* and *'clinical supervision'* supporting professionals to discuss emotional matters. There was acknowledgement from some professionals that the current support received was sufficient for them with a non-clinical professional particularly implying that *'it's just looking after own health and wellbeing isn't it'.* Seeking support from a Psychologist as part of supervision was further appreciated by professionals and it was evident that understanding emotions and actions was vital for their day job.

> *"Well honestly speaking I have a supportive team and we have team huddles and of course clinical supervision which happens mostly monthly but due to annual leave I haven't had one for a while but that helps me talk and things and understand it a bit better" (non-clinical professional, 6)*

Confidence in using their own coping mechanisms (e.g. physical activity, such as walking and running) was demonstrated by professionals as a major support during difficult work situations. Professionals recognised the importance of managing their work-life balance to ensure their professional life did not interfere with their personal life and the benefit of psychological support.

Professionals reported that withdrawing a child's treatment had a significant effect on the psychological wellbeing of parents. It was suggested that hope played an important part and psychological support for parents such as counselling was advised to be available and reported as beneficial. Stigma surrounding mental health and acknowledging that support is required was perceived as a barrier for parents asking for psychological support, as professionals reported that some parents felt that they needed to be mentally ill to seek help.

"I'm just interested in the long-term cycle psychological wellbeing with the occasional family member who feels it's been them that has then killed their child because they have agreed for their child's treatment to be withdrawn" (Non-clinical professional, 5)

Recommendations to support shared decision-making

There was acknowledgement that professionals required support to understand end of life, to allow them to cope with their role. There was wide recognition that professionals required further training in withdrawing treatment and that palliative and end of life care should be more prominent within professional training. In particular, further training regarding communication, breaking difficult news and cultural and spiritual influences was required.

There was realisation that as part of the decision-making process, issues around afterlife should be discussed such as organ donation. It was especially stressed that young people who are competent should have the opportunity to contribute to decisions about afterlife themselves. Organ donation was an aspect of decision-making that professionals felt was necessary for children to be a part of and should be included within advanced care planning for children with life-limiting conditions.

Support for fathers was also thought to be needed as the majority of support was offered to mothers who were assumed to be the primary caregivers. Several non-clinical professionals specifically mentioned that fathers required support during the decision-making process. After witnessing a gap in support for fathers, professionals introduced a support group for fathers. Professionals identified the group as beneficial especially as fathers would not always openly discuss their emotions:

"We always assume and go straight to the mothers and mum but that's not right I think we need to support dads you know only recently we have set up a dad's group and its helped we've had dad's talk to other dads, and you know males keep their emotions to themselves, but these groups help them speak out and tackle whatever is going through their mind"

[non-clinical professional, 5]

Discussion

This study aimed to explore health professionals' views about the decision to withdraw treatment from children with life-limiting illnesses, and how decision-making is managed amongst staff as individuals and as a team.

Professionals reported that decisions they were involved in regarding withdrawal of a child's treatment were made in the best interests of the child. This involved consideration of a number of factors including exploration of all treatment options, severity and complexity of the child's condition and competency of the child to decide. Consistent with previous literature (Birchley, 2016) professionals identified that reaching consensus on the child's best interest supported the clinical decision-making process. Birchley (2016) identified that cases such as Charlie Gard were a clear example of where there was conflict between health professionals and parents. There was reference from HCPs that although cases reaching court were rare, it helped decision-making conversations between health professionals and parents when the decision was taken out of the hands of both parties. This was particularly prevalent when the relationship had irretrievably broken down. Nevertheless, cases such as those of Charlie Gard and Tafida Raqeeb highlight the importance of understanding how and when to implement strategies that support a humanised healthcare for all involved.

Although conflicting viewpoints could cause frustration for professionals and in particular for the family, there was understanding that involving individuals from clinical professionals to non-clinical professionals and parents and wider family members was vital. Further to this, health professionals recognised that fathers required support within the decision-making process especially as the majority of support was offered to mothers who tended to be the primary caregiver. This was in line with previous literature whereby a father's involvement in a child's healthcare is perceived as limited and more research needs to focus on the viewpoints of fathers within the decision-making process (Zvara, Schoppe-Sullivan, Dush, 2013).

In particular, non-clinical professionals felt that the child's family played a huge role in the decision-making process with communication and cultural factors being reported as important influencers. However, prominence of the biomedical approach was questioned by non-clinical professionals, particularly when parents and families received conflicting information from different medical professionals. There was recognition that health professional's role is to provide treatment and that parents would somehow see the death of their child as a failure if they did not exhaust all possible options. Health professionals maintained that parents felt professionals gave up on their child when discussions to withdraw were initiated. Health professionals identified that parents sought open and honest conversations to support a trusting relationship during the decision-making process supporting previous research (Ekberg, Bradford, Herbert, Danby, & Yates, 2018). Parents maintain that making decisions such as withdrawing a child's treatment is a normal part of parenting in terms of making decisions for their child (Wiess et al., 2018) and health professionals should support this. The importance of parents seeking shared knowledge from other parents in a similar situation is recognised (Youngblut, Brennan, & Swegart, 1994) however findings from this study demonstrate that, from the perspective of professionals, this can cause difficulty within the decision-making process. Further to this, shared decision-making is an evidenced-based health decision-making approach that promotes partnership between health professionals, patients, and parents (Legare et al., 2010).

Non-clinical professionals demonstrated the importance of shared decision-making with other professionals and the child and families. However, this was not echoed by clinical professionals such as consultants who tend to be key decision makers in clinical practice. Professionals should adopt a flexible approach during the decision-making process especially when decisions from parents can change. As nurses have more contact with children and their families, they play a central role in the decision-making process, acting as the bridge between clinical professionals and families. Although shared decision-making plays a role within paediatric decision-making, future policies should include guidance on involving children in the decision-making process (Butler, Copnell, & Willetts 2014).

Health professionals reported on the importance of taking into consideration the religious and spiritual needs of the child and family. Consistent with existing literature, parents consider religious and spiritual influence fundamental to paediatric decision-making (Superdock, Barfield, Brandon, & Docherty, 2018). Training health professionals in end of life should be a key aspect of all HCPs training. It has been recommended that improving communication regarding end of life is required for health professionals (Hales & Hawryluck, 2008). Training around self-efficacy has been found to be beneficial amongst health professionals, especially as lack of confidence may influence any decision-making conversations (Chung et al., 2016).

Strengths and limitations

This study is, to the best of the authors' knowledge, the first to explore health professionals' views and experiences of deciding to withdraw treatment from a child with a life-limiting illness, and how decision-making is managed amongst staff as an individual and as a team. Despite the importance of these findings, limitations have been identified which suggest directions and challenges for future research. First, interviews provided retrospective perceptions of professionals' experiences in decision-making. This retrospective nature is reliant on recalling past experiences which may not always be truly represented (Ottman, Hauser, & Stallone, 1990). However, retrospective interviews gather perceptions of professionals' decision-making which may be difficult to obtain using other methods. A longitudinal study that interviews health professionals throughout decision-making may capture a more detailed and representative experience.

It is acknowledged that only health professionals were interviewed and therefore parents of children's whose treatment has been withdrawn were not reflected within the study. It is important to obtain the views of both professionals and parents to understand the decision-making process from both perspectives. Further to this, the study reflects the experiences of health professionals from only one UK paediatric hospital. The sample included a predominance of white female health professionals and there was a limited number of clinical staff such as consultants who have been

shown to make these medical decisions (Heath et al., 2016). Therefore, the findings of the study may not be representative of all health professionals involved in withdrawing a child's treatment.

Implications

The results of this study suggest a number of challenges experienced by HCPs in withdrawing treatment, involving non-clinical professionals at the start of decision-making conversations, and managing conflict between parents and professionals. Making use of existing policies and frameworks, table 2 summarises practical suggestions for supporting health professionals in this aspect of their work.

- *Suggest Insert table 2 here -*

Conclusion

This qualitative study has provided a powerful insight into the complex and emotional situation of deciding to withdraw a child's treatment from the perspective of health professionals. Identified factors and challenges that add to the literature include recognition that families require further support during the difficult time of withdrawing a child's treatment. Further to this, psychological wellbeing for professionals is needed in order for them to support families. Prospective qualitative studies are required to understand the influences of factors involved throughout professional decision-making and the conflicts that may arise i.e. emotional support from parents which may further help reduce gaps in the literature regarding this under-researched area.

Key Messages:

- The decision to withdraw or withhold treatment from children with life-limiting illnesses is complex and emotional for all involved.

- A significant amount of research has explored parental views of decision-making in terms of withdrawing treatment from a child with a life-limiting illness. However, a paucity of literature has investigated the views of health care professionals.

- This qualitative study aimed to explore factors that health professionals consider in deciding to withdraw treatment from a child with a life-limiting illness.

- It has provided a powerful insight into the complex and emotional situation of deciding to withdraw a child's treatment from the perspective of health professionals.

- It has identified factors and challenges that add to the literature, including recognition that families require further support during the difficult time of withdrawing a child's treatment.

Data Availability statement

The data that supports the findings of this study are available within the supporting documents of this manuscript.

References

Birchley, G. (2016). Harm is all you need? Best interests and disputes about parental decision-making. *Journal of Medical Ethics, 42(2),* 111-115.

Birchley, G. (2014). Deciding together? Best interests and shared decision-making in paediatric intensive care. *Health care analysis*, *22*(3), 203-222. https://doi.10.1007/s10728-013-0267-y

Boland, L., McIsaac, D. I., & Lawson, M. L. (2016). Barriers to and facilitators of implementing shared decision making and decision support in a paediatric hospital: a descriptive study. *Paediatrics & child health,* 21(3), e17-e21. https://doi.org/10.1093/pch/21.3.e17

Butler, A., Copnell, B., & Willetts, G. (2014). Family-centred care in the paediatric intensive care unit: an integrative review of the literature. *Journal of clinical nursing*, 23(15-16), 2086- 2100. https://doi.org/10.1111/jocn.12498

Braun, V. and Clarke, V. (2006) Using thematic analysis in psychology. *Qualitative Research in Psychology [online].* 3 (2), pp.77-101 https://doi.org/10.1191/1478088706qp063oa

Cave, E., Brierley, J., & Archard, D. (2020). Making Decisions for Children—Accommodating Parental Choice in Best Interests Determinations: Barts Health NHS Trust v Raqeeb [2019] EWHC 2530 (Fam); Raqeeb and Barts Health NHS Trust [2019] EWHC 2531 (Admin). *Medical Law Review, 28(1*), 183-196. https://doi.org/10.1093/medlaw/fwz038

Cave, E., & Nottingham, E. (2018). Who knows best (interests)? The Case of Charlie Gard. Medical *Law Review, 26(3).* https://doi.org/10.1093/medlaw/fwx060

Chung, H. O., Oczkowski, S. J., Hanvey, L., Mbuagbaw, L., & You, J. J. (2016). Educational interventions to train health professionals in end-of-life communication: a systematic review and meta-analysis. *BMC medical education, 16(1),* 131. https://doi.org/10.1186/s12909-016-0653-x

Corlett, J., & Twycross, A. (2006). Negotiation of parental roles within family-centred care: a review of the research. *Journal of clinical nursing, 15(10*), 1308-1316. https://doi.org/10.1111/j.1365-2702.2006.01407.x

De Leeuw, R., Cuttini, M., Nadai, M., Berbik, I., Hansen, G., Kucinskas, A., ... & Reid, M. (2000). Treatment choices for extremely preterm infants: an international perspective. *The Journal of pediatrics, 137*(5), 608-616. https://doi.org/10.1067/mpd.2000.109144

de Vos, M. A., Bos, A. P., Plötz, F. B., van Heerde, M., de Graaff, B. M., Tates, K., ... & Willems, D. L. (2015). Talking with parents about end-of-life decisions for their children. *Pediatrics*, *135*(2), e465-e476. https://doi.org/10.1542/peds.2014-1903

Dodd, J., Saggers, S., & Wildy, H. (2009). Constructing the 'ideal'family for family-centred practice: challenges for delivery. *Disability & Society,* 24(2), 173-186. https://doi.org/10.1080/09687590802652447

Drotar, D., Crawford, P., & Bonner, M. (2010). Collaborative decision-making and promoting treatment adherence in pediatric chronic illness. *Patient Intelligence*, (1), 1-7. https://doi.org/10.2147/PI.S8820

Dyer, C. (2019). *Hospital trust asks High Court to rule whether it can withdraw girl's life support.*

Engel, G. L. (1977). The need for a new medical model: a challenge for biomedicine. *Science,* 196(4286), 129-136. 10.1126/science.847460

Gallagher, A., Bousso, R. S., McCarthy, J., Kohlen, H., Andrews, T., Paganini, M. C., ... & Abu'El-Noor, M. K. (2015). Negotiated reorienting: a grounded theory of nurses' end-of-life decision-making in the intensive care unit. *International journal of nursing studies,* 52(4), 794-803. https://doi.org/10.1016/j.ijnurstu.2014.12.003

Gale, N. K., Heath, G., Cameron, E., Rashid, S., & Redwood, S. (2013). Using the framework method for the analysis of qualitative data in multi-disciplinary health research. *BMC medical research methodology*, *13*(1), 1-8. https://doi.org/10.1186/1471-2288-13-117

Gagnon, E. M., & Recklitis, C. J. (2003). Parents' decision-making preferences in pediatric oncology: The relationship to health care involvement and complementary therapy use. *Psycho-Oncology*, 12(5), 442-452. https://doi.org/10.1002/pon.655

Goodman, M. J., & Schorling, J. B. (2012). A mindfulness course decreases burnout and improves well-being among healthcare providers. *The International Journal of Psychiatry in Medicine*, *43*(2), 119-128. https://doi.org/10.2190%2FPM.43.2.b

Hales, B. M., & Hawryluck, L. (2008). An interactive educational workshop to improve end of life communication skills. *Journal of Continuing Education in the Health Professions*, 28(4), 241-255. https://doi.org/10.1002/chp.191

Hamilton, D. W., Heaven, B., Thomson, R. G., Wilson, J. A., & Exley, C. (2016). Multidisciplinary team decision-making in cancer and the absent patient: a qualitative study. *BMJ open*, 6(7), e012559. http://dx.doi.org/10.1136/bmjopen-2016-012559

Heath, G., Abdin, S., Begum, R., & Kearney, S. (2016). Putting children forward for epilepsy surgery: a qualitative study of UK parents' and health professionals' decision-making experiences. *Epilepsy and Behavior,* 61, 185-191 https://doi.org/10.1016/j.yebeh.2016.05.037

Hinds, P. S., Oakes, L., Quargnenti, A., Furman, W., Bowman, L., Gilger, E., ... & Drew, D. (2000). An international feasibility study of parental decision making in pediatric oncology. *Oncology nursing forum* 27,8, 1233-1243.

Hinds, P. S., Oakes, L. L., Hicks, J., Powell, B., Srivastava, D. K., Spunt, S. L., ... & Furman, W. L. (2009). "Trying to be a good parent" as defined by interviews with parents who made phase I, terminal care, and resuscitation decisions for their children. J*ournal of Clinical Oncology*, 27(35), 5979 https://dx.doi.org/10.1200%2FJCO.2008.20.0204

Hunink, M. M., Weinstein, M. C., Wittenberg, E., Drummond, M. F., Pliskin, J. S., Wong, J. B., & Glasziou, P. P. (2014*). Decision-making in health and medicine: integrating evidence and values.* Cambridge University Press.

Johnson, J., & Panagioti, M. (2018). Interventions to improve the breaking of bad or difficult news by physicians, medical students, and interns/residents: a systematic review and meta-analysis. *Academic Medicine*, *93*(9), 1400-1412. https://doi:10.1097/ACM.0000000000002308

Légaré, F., Ratté, S., Gravel, K., & Graham, I. D. (2008). Barriers and facilitators to implementing shared decision-making in clinical practice: update of a systematic review of health professionals' perceptions. *Patient education and counseling*, *73*(3), 526-535. https://doi.org/10.1016/j.pec.2008.07.018

Légaré, F., Ratté, S., Stacey, D., Kryworuchko, J., Gravel, K., Graham, I. D., & Turcotte, S. (2010). Interventions for improving the adoption of shared decision-making by health professionals. *Cochrane Database Syst Rev,* 5(5). https://doi.org/10.1002/14651858.CD006732.pub3

Lipstein, E. A., Brinkman, W. B., & Britto, M. T. (2012). What is known about parents' treatment decisions? A narrative review of pediatric decision-making. *Medical Decision making*, 32(2), 246-25. https://doi.org/10.1177%2F0272989X11421528

McKenna, K., Collier, J., Hewitt, M., & Blake, H. (2010). Parental involvement in paediatric cancer treatment decisions. *European journal of cancer care*, *19*(5), 621-630. https://doi.org/10.1111/j.1365-2354.2009.01116.x

Meskens, N., & Guinet, A. (2013). Decision-making in healthcare. https://dx.doi.org/10.1016/j.dss.2012.10.014

Meyer, E. C., Burns, J. P., Griffith, J. L., & Truog, R. D. (2002). Parental perspectives on endof-life care in the pediatric intensive care unit. *Critical care medicine,* 30(1), 226-231.

Morse, J. M. (2000). Determining Sample Size. *Qualitative Health Research*, 10(1), pp. 3-5.

NICE. (2016). End of life care for infants, children and young people with life-limiting conditions: planning and management. https://www.nice.org.uk/guidance/ng61/chapter/recommendations

Nørgaard, B., Ammentorp, J., Ohm Kyvik, K., & Kofoed, P. E. (2012). Communication skills training increases self-efficacy of health care professionals. *Journal of Continuing Education in the health professions*, *32*(2), 90-97. https://doi.org/10.1002/chp.21131

O'Connor, S., Brenner, M., & Coyne, I. (2019). Family-centred care of children and young people in the acute hospital setting: A concept analysis. *Journal of clinical nursing,* 28(17- 18), 3353-3367. https://doi.org/10.1111/jocn.14913

Ottman, R., Hauser, W. A., & Stallone, L. (1990). Semistructured interview for seizure classification: agreement with physicians' diagnoses. *Epilepsia*, *31*(1), 110-115. https://doi.org/10.1111/j.1528-1157.1990.tb05368.x

Pekmezaris, R., Walia, R., Nouryan, C., Katinas, L., Zeitoun, N., Alano, G., ... & Steinberg, H. (2011). The impact of an end-of-life communication skills intervention on physicians-in-training. *Gerontology & geriatrics education*, *32*(2), 152-163. https://doi.org/10.1080/02701960.2011.572051

Richards, C. A., Starks, H., O'Connor, M. R., Bourget, E., Hays, R. M., & Doorenbos, A. Z. (2018). Physicians perceptions of shared decision-making in neonatal and pediatric critical care. *American Journal of Hospice and Palliative Medicine®*, *35*(4), 669-676. https://doi.org/10.1177%2F1049909117734843

Reyna, V. F., & Farley, F. (2006). Risk and rationality in adolescent decision making: Implications for theory, practice, and public policy. *Psychological science in the public interest*, *7*(1), 1-44. https://doi.org/10.1111%2Fj.1529-1006.2006.00026.x

Rollnick, S., Miller, W. R., & Butler, C. (2008). *Motivational interviewing in health care: helping patients change behavior*. Guilford Press.

Shah, S. K., Rosenberg, A. R., & Diekema, D. S. (2017). Charlie Gard and the limits of best interests. *JAMA pediatrics,* 171(10), 937-938. https://doi.10.1001/jamapediatrics.2017.3076

Smalley, L. P., Kenney, M. K., Denboba, D., & Strickland, B. (2014). Family perceptions of shared decision-making with health care providers: results of the National Survey of Children with Special Health Care Needs, 2009–2010. *Maternal and child health journal,* 18(6), 1316-1327. https://doi.org/10.1007/s10995-013-1365-z

Smith, J., & Firth, J. (2011). Qualitative data analysis: the framework approach. *Nurse researcher*, *18*(2), 52-62. http://dx.doi.org/10.7748/nr2011.01.18.2.52.c8284

Smith, J. A. (2015). *Qualitative psychology: A practical guide to research methods*. Sage.

Srivastava, A., & Thomson, S. B. (2009). Framework analysis: a qualitative methodology for applied policy research.

Stiggelbout, A. M., Van der Weijden, T., De Wit, M. P., Frosch, D., Légaré, F., Montori, V. M., ... & Elwyn, G. (2012). Shared decision-making: really putting patients at the centre of healthcare. *Bmj,* 344, e256. https://doi.org/10.1136/bmj.e256

Superdock, A. K., Barfield, R. C., Brandon, D. H., & Docherty, S. L. (2018). Exploring the vagueness of Religion & Spirituality in complex pediatric decision-making: a qualitative study. *BMC palliative care*, 17(1), 1-14. https://doi.org/10.1186/s12904-018-0360-y

Tilden, V. P., Toile, S. W., Garland, M. J., & Nelson, C. A. (1995). Decisions about lifesustaining treatment: Impact of physicians' behaviors on the family. *Archives of Internal Medicine,* 155(6), 633-638. https://doi.10.1001/archinte.1995.00430060097012

Valdez-Martinez, E., Noyes, J., & Bedolla, M. (2014). When to stop? Decision-making when children's cancer treatment is no longer curative: a mixed-method systematic review. *BMC pediatrics*, *14*(1), 1-25. https://doi.org/10.1186/1471-2431-14-124

Villanueva, G., Murphy, M. S., Vickers, D., Harrop, E., & Dworzynski, K. (2016). End of life care for infants, children and young people with life limiting conditions: summary of NICE guidance. *Bmj*, *355*. https://doi.org/10.1136/bmj.i6385

Youngblut, J. M., Brennan, P. F., & Swegart, L. A. (1994). Families with medically fragile children: an exploratory study. *Pediatric Nursing,* 20(5), 463-468

Weiss, E. M., Barg, F. K., Cook, N., Black, E., & Joffe, S. (2016). Parental decision-making preferences in neonatal intensive care. *The Journal of pediatrics,* 179, 36-41. https://doi.org/10.1016/j.jpeds.2016.08.030

Zvara, B. J., Schoppe-Sullivan, S. J., & Dush, C. K. (2013). Fathers' involvement in child health care: associations with prenatal involvement, parents' beliefs, and maternal gatekeeping. *Family relations*, *62*(4), 649-661. https://doi.org/10.1111/fare.12023