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## RESEARCH ARTICLE

WILEY

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

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## 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professionals working at a UK Children's Hospital, with children with life-limiting illnesses whose treatment has been withdrawn.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 were transcribed verbatim, anonymized and analysed using a thematic framework method.

**Results:** A total of 15 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 well-being and (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.

## KEYWORDS

decision making, healthcare, professionals, treatment

## 1 | INTRODUCTION

The decision to withdraw or withhold treatment from children with life-limiting illnesses is complex and emotional for all involved (Meskens & Guinet, 2013). Literature identifies two main challenges related to this process. The first is parental involvement in paediatric treatment decision making (Corlett & Twycross, 2006; Dodd et al., 2009; Shah et al., 2017); the second is how treatment decisions are made between multidisciplinary 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 (Légaré et al., 2014). 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,

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risks and benefits) and the family's preferences and values, health professionals, patients and parents can deliberate to determine the best treatment plan (Légaré et al., 2014; 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 et al., 2010; Stiggelbout et al., 2012). A study by Boland et al. (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 et al., 2012). Studies exploring parental decision making in paediatric cancer treatment found that parents were satisfied with the amount of information provided to them (McKenna et al., 2010). Sharing reliable information has been found to enable parents' informed decision making (Valdez-Martinez et al., 2014). However, it is also recognized that parental decision making is motivated by love and compassion that 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 that can negatively impact the relationship between child, parent and professionals (O'Connor et al., 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 preterm 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 multidisciplinary team (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 MDT 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. Although 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 that aims to prevent conflicts between parents, families and healthcare professionals (HCPs) in healthcare decision making, this study was

### 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 healthcare 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.

conducted to increase our understanding of the decision-making process from the perspective of multidisciplinary health professionals.

Although research has explored parental views of decision making in terms of withdrawing treatment from a child with a life-limiting illness (Gagnon & Recklitis, 2003; Hinds et al., 2000, 2009; Meyer et al., 2002; Tilden et al., 1995), a paucity of literature has investigated the views of HCPs. 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.

## 2 | METHOD

### 2.1 | 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).

### 2.2 | 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.

### 2.3 | 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 and conflicts between professionals and families. The researcher used open-ended questions that 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 were anonymized, transcribed and stored on a secure server to allow remote access.

### 2.4 | Data analysis

Data were transcribed verbatim, anonymized 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 was carried out in accordance with the five stages of the framework method: familiarization, 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 were 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).

## 3 | RESULTS

### 3.1 | Sample characteristics

A total of 15 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 and 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.

### 3.2 | Themes

Analysis generated five interrelated themes: (1) understanding the child's best interests, (2) multidisciplinary approach, (3) effective communication, (4) external factors, (5) psychological well-being and (6) recommendations to support shared decision making. Illustrative quotations for each theme are provided in Table 1.

### 3.3 | 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 realization of the child's illness. Conversations centred on the child's prognosis and medical complexity. Although 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, emphasizing 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

**TABLE 1** Emergent themes and illustrative quotes for each theme

## Theme 1: Understanding the child's best interests

Although in the field I work in. It's very it's very rare for the child to be considered old enough. Usually parents do not want to fully inform them. And even if they are teenagers. (Clinical professional 1, female)

No one is giving them permission to name the literal element because everybody is trying to protect them and wider families and there is a general feeling that many of these children do understand what is happening but do not feel at liberty to say it to not upset their family. (Clinical professional 2, female)

I think its children being empowered making decision for themselves. (Non-clinical professional 1, female)

If the patient has been with us for quite a long time the child may the patient may be very old enough and conscious enough to be you know engaging with us. (Non-clinical professional 2, male)

It's not about only doing what the families want. But, you know, you can only make a collective decision for that family. And that child exists within that family. They do not exist in isolation. And actually, if we do what we believe is right for the child, but it is wholly wrong for the family. That's not right for the child, because that child's going to sit in that environment and the family are going to be incredibly upset. (Clinical professional 3, female)

I want to reassure that child, even though that whatever level of knowledge of the child has about that, that, you know, that that symptoms can be controlled, that that he's going to be respected. (Clinical professional 4, female)

Most of our withdrawal of treatments are not just like the next day after you know a child's been brought into us you know there's lots of procedures and tests and investigations and operations that they will obviously try and do and do everything they can before they get to that situation. (Non-clinical professional 2, male)

Once they have got a life limiting condition and moving to palliative care and that might be the direction of how fragile their child is and plans can then be made. (Non-clinical professional 3, male)

I mean honestly I just do not understand why palliative care is not involved from the start day one really palliative care needs to be involved sooner way before any decisions are made or even discussed. (Non-clinical professional 4, female)

Well I think they need to be fully informed completely about their child but also their condition you know sometimes parents struggle to understand and then they compare their child to other children, and they talk to other families which in my opinion does not always help. (Non-clinical professional 5, female)

We had parents that were scared but this goes back to sometimes they do not understand how ill their child is. (Non-clinical professional 6, female)

We've currently got family who do not 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, female)

It helps if parents have knowledge of their child's condition you know if there were more informed, but they do not realize or understand shall I say the condition and it's difficult because that's what does not help. (Clinical professional 6, male)

## Theme 2: Multidisciplinary approach

Clinical staff are used to fixing people that that's where battles like Charlie's case happen. (Non-clinical professional 6, female)

We have very close working relationships with the medical staff. We work literally side by side. And I do wonder whether or not sometimes the ward nursing staff may feel that they have not so much input into those discussions. Well, they do not because they are often not present in those situations. (Non-clinical professional 1, female)

**TABLE 1** (Continued)

I remember around 18 months ago there was a case whereby decisions regarding treatment for a child in this ward was possibly discussed within clinical staff but not us and I had to treat this child, but he ended up passing away because of lack of communication he was only little. (Non-clinical professional 5, female)

I think because the doctors possibly quite rightly feel that we were not there, that the consultants are the one leading the care and they are not. We know we are not in possession of all the medical facts and biology to be able to contribute to that. (Clinical professional 7, female)

Professionals need to be involved quicker like sometimes some cases where the first initial decision meeting does not 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 is not on our hands. (Non-clinical professional 1, female)

You know, even if one individual member of the team is making a decision about that, it will be brought back to an MDT to be signed off anyway. So, there's a kind of cross checking process. It's not a there's not really a scenario where it's one person. (Clinical professional 8, female)

We find out information that we did not know on a case if we did not attend I mean it's only recent so there is still lots to do long term ... so we have dialogue with all staff doctors nurses consultants and we tell them what we think but I do not think it's very discussed in those meetings. (Non-clinical professional 6, female)

I have a big role in supporting the families you know that's my role I'm not a medical profession. (Non-clinical professional 4, female)

So I work with children and young people with life limiting illnesses I act as the advocate for the child and I focus on the bigger picture not just looking at the medical side I am an advocate and my role is all about supporting the family by focusing on the here and now planning with them. (Non-clinical professional 1, female)

### Theme 3: Effective communication

I like I say, I just question whether we just sometimes put too much on the family. (Clinical professional 1, female)

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. (Non-clinical professional 2, male)

We've had families who have been at opposite poles about treatment decisions. And actually, at the end of the day that if they both have parental responsibility, one of them ends up making a decision. And and, you know, you hope that they will go with the decision process that we believe is the most appropriate. (Clinical professional 9, female)

I understand the desires but I just think it's an interesting observation that seems to be the swinging of the pendulum from being maternal paternal with these families to going what would you like to do when actually their choices are actually very very limited because they they their child is critical ill. (Non-clinical professional 3, male)

We make lots and lots of life and death and treatment decisions all the time. (Clinical professional 4, female)

I think sometimes we forget where families are coming from you know like it's their child and sometimes, they do not listen to us professionals. (Clinical professional 6, male)

Parents think there is hope and when they have that hope it is difficult to change their minds. (Non-clinical professional 2, male)

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 do not know the full background (Non-clinical professional 6, female)

(Continues)

TABLE 1 (Continued)

We wonder with older children why do not 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 is 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, female)

"It's very it's very rare for the child to be considered old enough. Usually parents do not want to fully inform them. And even if they are teenagers. (Clinical professional 7, female)

#### Theme 4: External factors in decision making

I think sometimes we forgot how big of a picture this you is know it's not just us professional and the family its beliefs and culture. (Non-clinical professional 4, female)

Honestly, the media and tv programmes make such a difference you know like I remember I had family members ask me what I think because of how it was portrayed in the news it was horrible and its incorrect it's not fact and that's the issue with tv programmes. (Non-clinical professional 6, female)

I think sometimes they will just bring in like somebody like chaplaincy we do use some external advocacy services when necessary umm we have a clinical ethics advisory groups in which clinicians can bring the case just to ensure that they are acting that they acting in an ethical way and I think that provides a lot. (Non-clinical professional 5, female)

Sometimes we do have to go to court and I just see that as sometimes as reflecting the struggles of a family of us ultimately making a decision of withdrawing and for them its killing their child and whether sometimes it even needs to be taken out from the hands of a clinician where sometimes a third arbitrary person so say I've examined all the evidence and it's the best interests of the child to withdraw treatment and so I do not always see it as failure for the courts to come in just occasionally it can become a bit of circus but it's not a failure in relationship or a family wanting to wanting to make the most of the media and I think it's sometimes too difficult for a family to be involved in that process. (Non-clinical professional 2, male)

I mentioned religion earlier well we have families who are religious, and they think withdrawing treatment is us as professionals playing god there is no chance a religious family will make a quick decision like that. (Non-clinical professional 6, female)

Like the other week we had a Muslim family and they went off to get advice from their local mosque on what to do. (Non-clinical professional 5, female)

#### Theme 5: Psychological well-being

So, I get my clinical supervision from a psychologist so actually, I get psychology advice that so I know that if I needed there are multiple other avenues that I could get support. (Clinical professional 1, female)

I think support wise I'm ok I do not think I need anything else it's just looking after your own health and well-being is not it and I think I do that well. (Non-clinical professional 5, female)

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 have not had one for a while but that helps me talk and things and understand it a bit better. (Non-clinical professional 6, female)

I'm just interested in the long term cycle psychological well-being 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 1, female)

**TABLE 1** (Continued)

We use to have a psychologist for families before but she left and I do not think they have or will replace her she was needed I think as professionals we can do more to support the well-being of parents you know it's not easy it must be so upsetting for them to see their child like this and I know as [job role] we do want we need to do and then when the child passes away there is no support I mean maybe there is but I'm not aware of any so we need psychology we need to use therapy and offer it to families too. (Non-clinical professional 4, female)

It was an element of psychological support for parents and families to cope with. (Non-clinical professional 5, female)

I think that urgent access to very skilled psychologist. (Non-clinical professional 1, female)

#### Theme 6: Recommendations to support decision making

I think staff need more training actually a lot of training around death and dying maybe in the induction day we could put something together because the professionals do not really understand death. (Non-clinical professional 4, female)

If I was being ultra-critical of what we could improve I would probably say include helping families with spiritual and religious needs and factors in that process because there is a huge dilemma particularly in religions such as Islam where they understand that only Allah has the right to take life and those breakdown in communication are because they have cultural and religious beliefs of what withdrawal of treatment means to them and I think we would do well with training more of our chaplains in helping them understanding in withdrawing treatment. (Non-clinical professional 1, female)

I think training around cultural and religious needs and I think the other aspect that we do have a protocol and discussion around organ donations and the take up in paediatrics is very low and with the low changing in opting in and opting out I'm just interested to see of what implications this will have on which way round and that conversations still needs to happen because I think its children being empowered making decision for themselves and vice versa and I think that's particularly a difficult situation and I think conversations earlier could be bought earlier in advanced care plans and staff being training as a part of breaking bad news. (Non-clinical professional 4, female)

I think we are training staff much more competency in advanced communication in breaking bad news and not avoiding those difficult conversations and I think something that needs to be rolled out universally in that staff are trained in that breaking bad news. (Non-clinical professional 2, male)

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 have 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, female)

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.



### 3.4 | Multidisciplinary approach

Professionals described how all conversations regarding patient treatment were initially discussed within weekly 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 emphasized 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 recognized the remit of their roles and how they influenced the decision-making process. For example, non-clinical professionals recognized 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.

### 3.5 | Effective communication

The importance of effective communication between the child, family and professionals as well as between professionals themselves was recognized, 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 recognized 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."

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 recognized 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 realized 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.

### 3.6 | 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 recognized 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 recognized 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.

### 3.7 | Psychological well-being

Professionals recognized 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 well-being 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 recognized 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 well-being 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 well-being 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)

### 3.8 | 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 realization 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)

## 4 | 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 humanized 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 recognized 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 et al., 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 et al., 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 (Weiss et al., 2016) and health professionals should support this.

The importance of parents seeking shared knowledge from other parents in a similar situation is recognized (Youngblut et al., 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 (Légaré et al., 2014).

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 et al., 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 et al., 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).

#### 4.1 | 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 that may not always be truly represented (Ottman et al., 1990). However, retrospective interviews gather perceptions of professionals' decision making that 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 were 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.

#### 4.2 | 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 summarizes practical suggestions for supporting health professionals in this aspect of their work.

**TABLE 2** Implications

##### Taking a multidisciplinary approach

Shared decision making has been recognized as an interpersonal process whereby health professionals and patients and families work together to support the child's healthcare.

This could include the following:

- Implementing shared decision-making policies, practices and ensuring they are clear on how clinicians should involve parents within such discussions (Birchley, 2014; Richards et al., 2018).
- Involvement of a range of health professionals amongst multidisciplinary team meetings (de Vos et al., 2015; Légaré et al., 2008).

##### Upskilling workforce through behaviour change

Decision making can be explained through behaviour change theories or techniques, which may support health professionals during withdrawing a child's treatment. The importance of behaviour change within decision making has been recognized amongst existing literature (Reyna & Farley, 2006).

This could include the following:

- Training healthcare professionals in motivational interviewing (Rollnick et al., 2008).
- Exploring coping mechanisms and increasing self-efficacy (Nørgaard et al., 2012).
- Preparing health professionals for end-of-life discussions through training; including focused training on cultural and spiritual factors in death and dying (Johnson & Panagioti, 2018; Pekmezaris et al., 2011).

##### Psychological support and well-being

Given the difficulty and the emotional strain on health professionals during decision making and end-of-life situations, psychological support for health professionals is required.

This could include the following:

- Mindfulness sessions for healthcare professionals that have been shown to reduce burnout (Goodman & Schorling, 2012).

## 5 | 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 well-being 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, that is, emotional support from parents that may further help reduce gaps in the literature regarding this underresearched area.

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The authors declared no potential conflicts of interest in respect to the research, authorship and/or publication of this article.

### ETHICS STATEMENT

The study was approved by the ethics board of the Health Research Authority (HRA) and Health and Care Research Wales and the Research and Development team of the NHS hospital site in question (19/HRA/0572).

### DATA AVAILABILITY STATEMENT

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

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