Withdrawing treatment for Children and Young People: Decision-making experiences of health professionals

Shanara Abdin

A thesis submitted in fulfilment of the requirements of the University of the West of England, Bristol for the award of Professional Doctorate in Health Psychology

This research programme was carried out in collaboration with the Birmingham Women's and Children's NHS Foundation Trust

Faculty of Health and Applied Sciences, University of the West of England, Bristol

November 2020

Contents

Acknowledgments

Firstly, I would like to thank my UWE supervisors Dr James Byron-Daniel and Dr Nic Hooper for their advice, encouragement, and support throughout this thesis. In particular I would like to thank Dr James Byron-Daniel whose insight and support throughout my health psychology journey has been invaluable. With all the hurdles life has thrown me, your motivation, guidance, and support in keeping me engaged and meeting the required competencies to become a competent Health Psychologist has been nothing short of encouraging.

The work presented in this thesis is a result of a collaboration between Birmingham Women's and Children's NHS Foundation Trust where I was an honorary researcher and the University of the West of England. This collaboration offered a unique framework for the research described within this thesis allowing me to apply health psychology in an applied setting. My sincere thanks go to Dr Gemma Heath who not only made this research happen but has been a pillar of support throughout my journey. I would further like to extend my gratitude to Dr Susan Neilson who offered extensive support and guidance throughout. I extend a special thanks to all the health professionals who agreed to take part in this research as without their input this research would not have been possible.

I would like to thank Dr Julian Bath and Dr Vicky Senior who examined this thesis and made my viva such a relaxing and enjoyable experience.

I would also like to express a huge thanks to Richard Welch who has enabled me to bring together my desire for public health and health psychology by working towards becoming a Health Psychologist in an applied setting. Your continued encouragement, reassurance and positivity has been inspiring and I would not have been able to complete my journey as a Health Psychologist without you.

Lastly, I would like to thank my friends who have believed in me and have always encouraged me to preserve throughout this journey.

This health psychology journey has been incredibly challenging yet rewarding. I could not have got this far without the support of those mentioned above. It is true that the success to a doctorate course is to have supportive individuals rooting for you each step of the way, to which I have been immensely fortunate to have received.

Preface

My journey towards becoming a Health Psychologist

This thesis demonstrates my motivation to become a Health Psychologist. In order to understand the reasons behind my chosen topic it is vital to obtain an understanding of this journey. My interest within health psychology truly began when I undertook an MSc in Health Psychology. As part of my MSc qualification I undertook empirical research with a local NHS hospital where I investigated the decision-making processes of parents when putting their child forward for epilepsy surgery. Undertaking this research made me realise the diversity of a Health Psychologist's role and how we can use and apply our expertise around behaviour change across settings. I jointly worked with my colleagues at Aston University and a UK NHS hospital where I co-authored a paper published in Epilepsy and Behaviour Journal.

Shortly after I completed my Stage 1 training, I secured a job as a Public Health and Wellbeing Research Assistant at Wolverhampton Public Health Department. With no prior experience in Public Health, I was able to use my Health Psychology knowledge within my role and it made me realise how connected and interlinked public health and health psychology are with one another. I was keen to expand my knowledge and skills around health psychology further and remember the day I was offered a place at the University of the West of England (UWE) where I ended up crying upon being accepted on the Doctorate course. I wanted to fulfil my ambition of becoming a Health Psychologist and over the last three years I have faced several battles to achieve this. As a result, my drive to become a Health Psychologist grew further and I worked endlessly to ensure I met the required competencies to become a competent Health Psychologist.

I believe the last three years have allowed me to develop my reflective practice skills. There is a quote that I came across during my first professional skills lecture which has stuck with me throughout my journey – *'We do not learn from experience, we learn from reflecting on experience* (Dewey, 1933 in Rogers, 2002). I have used this quote to enable me to reflect and critically evaluate each experience I have encountered. I feel through reflecting on my day-to-day practice I have come to realise that training to become a Health Psychologist has been difficult and it has tested my resilience, my work-life balance, and my passion for health psychology.

A major hurdle I have experienced throughout my journey is defining my professional identity as a Health Psychologist. When I joined a public health team as a research assistant, behaviour change, and health psychology were not as prevalent as you would expect. I was originally surprised to witness that public health services, interventions and priorities do not reference behaviour change theories or models. Looking back, I can see that within my roles in different public health settings I have managed to offer my skills around health psychology and behaviour change, but it has not been easy. I feel we still have a long way to go as Health Psychologist's working in applied settings such as public health. As a trainee, I have worked to embed health psychology in all my roles whether it is a Research Assistant, Wellbeing Officer, Staff Wellbeing Facilitator, Public Health Commissioning Officer and currently as a Health Improvement Officer.

Working as an autonomous and accountable practitioner has been the backbone of my journey. Continuous professional development (CPD) has been embraced over the last three years and it has supported me to identify myself as a professional and on a personal level too. Throughout the professional doctorate I have presented oral and poster presentations at conferences such as Midlands Health Psychology Conference, Behavioural Science in Public Health Network, Division of Health Psychology BPS conference, PsyPAG conference and British Psychology Society East Midlands Conference. Work presented includes the systematic review on workplace health interventions, the consultancy systematic review on breast cancer and physical activity and the short communication of the population level intervention undertook in Wolverhampton. As part of my CPD, I recently wrote a blog for 'what works wellbeing' organisation relating to the findings on my systematic review which focused on workplace health and wellbeing. Although the journal article was published a year before this blog, I received several correspondences from interested researchers who wanted advice on workplace interventions and how they can use the findings in their workplace.

At the time of writing, I have published 4 journal articles during my Professional Doctorate in Health Psychology and two are currently under peer review. One of these publications includes my systematic review, which is a strand of the BPS research competency. Although it is advised that the systematic review should connect with the research question of the thesis, mine does not. The systematic review investigated the effectiveness of physical activity interventions in improving wellbeing across office-based workplace settings (Appendix 8) and was published within Public Health journal (Abdin et al., 2018). With a passion for workplace health I originally wanted to conduct empirical research within this topic area. However, this was not possible within the timescale available, given the organisation that I wanted to conduct research with was going through a restructure. As a result, my thesis focuses on the decision-making experiences of health professionals in withdrawing a child's treatment. Given current media interest of health professionals withdrawing a child's treatment, and my previous experience in decision-making it was agreed that my thesis explored decision-making within health professionals. Upon writing this thesis, a brief report was sent as a manuscript to the Journal of Paediatrics as part of good practice before the original research is published. I feel my research skills and applying research to real life settings has improved dramatically. I have shown my passion for publishing articles throughout this doctorate. Further to this, as a regular reviewer for peer review journals, I have increased my understanding of the process of peer review, which has helped me when I have sent my manuscripts for publication. Throughout this process, I feel my ability to provide constructive criticism has improved considerably which I have been able to use throughout my practice. The topic of my thesis is emotional and challenging yet incredibly interesting. I believe this work addresses a gap in the current literature and believe this has enabled me to apply health psychology within an applied setting.

My experience to date has allowed me to grow as a reflective practitioner and I have been fortunate with the number of opportunities and experiences obtained integrating psychological theory into practice. My journey towards becoming a Health Psychologist has not been easy but I feel I have grown as a person. My passion for health psychology has only grown stronger over the years and I feel this is the start of my passion and my ambition especially as I work towards my goal of becoming a Chartered Psychologist.

Abstract

Background: The decision to withdraw or withhold treatment from children can be a complex and emotional decision-making process for everyone who is involved. With the complexity of decision-making in paediatric medicine ever increasing due to an increased number of cases, there is a growing need to understand how treatment decisions are made, the impact this has on those making the decisions and how professionals can be supported throughout the decision-making process.

Objectives: The aim of this qualitative study was to explore the decision-making experiences of professionals working in healthcare during withdrawing treatment from children. The study examined factors that influence professionals in deciding whether to withdraw a child from treatment and how decision-making is managed amongst professionals as an individual and as a team.

Method: A purposive sample of health professionals (HCPs) working at a Children's Hospital in the UK, with children with life-limiting illnesses where treatment has been withdrawn, were invited to participate. All participants were given the option to partake in the research in several ways to maximise their potential to participate. This included digitally-recorded face-to-face semi-structured interviews, skype or telephone interviews. Data was transcribed verbatim, anonymised, and analysed using a thematic framework method.

Results: A total of fifteen participants were interviewed. The interview transcripts produced rich data which highlighted how HCPs decide on withdrawing treatment for a child. The thematic analysis process that was applied to the transcripts elicited key concepts. 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) Best Interests of the Child (2) Multidisciplinary Approach (3) External Factors (4) Psychological Wellbeing (5) Recommendations to support decision-making. Although those five themes emerged, the most prominent one was that all decisions were based on the best interests of a child. This led to professionals considering several factors such as exploring all treatment options, the severity of the condition and the competency of the child to decide. Further to this, professionals felt that the child's family played a huge role amongst the decision-making process with communication and cultural factors such as health professionals 'playing god' being reported as key influencers.

Conclusion: The decision-making process was identified as being predominately medically led with medical professionals making the decision. A shared decision-making approach could support professionals, children, and their families if decisions are made collectively. Future research should investigate the views from parents and families on withdrawing treatment and how this influences the decision-making process. To strengthen further studies within this area, a greater number of male health professionals should be included to offer further robust views from the perspectives of diverse health professionals.

Introduction

Background

In the paediatric healthcare context, health professionals are deemed ‘experts in the field’ whereby-parents and families value the opinion of their decision (Frenk et al., 2010). The decision to withdraw or withhold treatment from children can be a complex and emotional decision-making process for everyone involved (Meskens, 2013). Due to the nature of the healthcare environment, all ethical and legal rationale behind every treatment decision should be in the best interests of the child (Kirsch et al., 2018). With the complexity of decision-making in paediatric medicine ever increasing due to ethical theory and law (Katz, Webb & Committee on Bioethics, 2016) there is a growing need to understand how treatment decisions are made, the impact this has on those making the decisions and how parents can be supported throughout the decision-making process.

There has been wide recognition of family centred care within healthcare settings whereby health professionals work in partnership with families to deliver care to a child (Arabiat et al., 2018). Previous literature (Corlett & Twycross, 2006; Dodd, Saggers, & Wildy, 2009) has identified numerous challenges with parental involvement in paediatric healthcare especially amongst decision-making. Particularly, there has been recognition that cultural and society factors are not considered during child healthcare, such as ignoring religious viewpoints on death, and as a result impacts on the relationship between the child, parent and professionals (O’Connor, Brenner & Coyne, 2019). Evidence has highlighted the difficulty of family centred care due to the tension prevalent amongst professionals and families within child healthcare (Heath et al., 2016).

Further to this, literature has highlighted the importance of ‘Knowing the patient’ whereby health professionals are able to recognise changes within a patient (Heath et al., 2016). A resource named ‘Listening to you’ was developed by a UK NHS trust to support communication between parents and health professionals as part of family centred care (Heath et al., 2016). The resource supported parents to ask questions relating to the healthcare of their child and as a result facilitated the approach of family-centred care. Although this resource supported conversations, there was recognition that further collaboration amongst families and health professionals is required. In particular, robust, and thorough evaluations of such resources are recommended to explore the effect on preventing critical deterioration, parent and staff confidence to raise and escalate concerns.

Definition of decision-making

According to Matterson and Hawkins (1990; Muir, 2004), the word ‘decision’ relates to the conclusion or resolution reached after careful consideration. Decision-making tends to end doubt or debate and is based on indications or certain evidence with the inclusion of two or more options. A good decision is made thoughtfully, considers all relevant factors, is consistent with the individual’s philosophy and values and can be explained clearly to significant others (Muir, 2004). Withdrawing treatment from an individual with the deliberate intention to cause death is often referred as passive euthanasia (Keown, 2004). According to the General Medical Council (2013) medical treatment can legally be withdrawn if it is deemed ineffective by professionals.

Medical ethics around decision-making

In medicine, there are four moral principles that are used to analyse medical ethics. These include autonomy, beneficence, non-maleficence and distributive justice (Picard & Lee, 2013). The first rule, autonomy, implies that individuals have a right to control what happens to them and as such these decisions are to be respected by all involved individuals. Beneficence states that all healthcare providers must act to benefit the patient. Following on from this, non-maleficence states that health professionals should at all times avoid causing harm to their patients. Finally, justice implies that health professionals should be fair when treatments are offered and should be able to justify their action (Winter & Cohen, 1999). Individuals have argued that if a form of treatment does not offer any benefit to a patient and it becomes pointless or futile; then treatment may be withdrawn (Beauchamp & Childress, 2001). Furthermore, ethical predicaments tend to occur during end of life discussions, for example preventing further harm and respecting the preferences of patients and families are considered (Schaffer, 2007). Although these moral principles are universal for all health professionals, they do not state how professionals should handle a certain situation.

Best interests of the child

In 2017 a best interest's case of an English boy, attracted worldwide attention (Shah, Rosenberg, & Diekema, 2017). The case of Charlie Gard who had a rare mitochondrial disease was very high profile due to conflict between health professionals and the parents. The parents wanted Charlie to undergo experimental therapy in America, however there was disagreement between Charlie's parents and the medical team about the best course of action. The case was referred to The High Court of Justice, and it was agreed that the new therapy was not in the best interests of the patient and life support for Charlie should be withdrawn (Shah et al., 2017). As a result of this case, publications primarily focused on the ethical and legal issues that arose in complex decision-making cases such as Charlie Gard

(Waldman & Fradder, 2018; Lagercrantz, 2018). A study reported that although parents may know their child best, their decision will be motivated by love and compassion and may conflict with the best interests of the child (Cave & Nottingham, 2018). Literature has also highlighted that parents have sought further treatment to keep their child alive, whilst professionals have sought to consider the physical and psychological impact of decisions and how these affect the child (Ambler, 2014).

Studies have expressed the importance of parental rights, which parents argue as being greater than the welfare of the child (Aucklan & Goold, 2019; Turnbull, 2019). According to the Children Act 1989, parental rights and responsibilities includes all rights, duties, powers and authorities which a parent has in relation to their child (Aucklan & Goold, 2019). Having said this, all treatment options have to be in the best interests of the child and parents cannot demand treatment if it is not in the child's best interests (Aucklan & Goold, 2019).

There appears to be conflict when health professionals express the importance of the best interest of the child and parent's feel their parental rights should have significance when withdrawing a child's treatment (Birchley, 2018). This seems especially important given that the competence of parents to make medical judgements has been brought into question (Birchley, 2018).

Charlie's Law

Charlie's Law was introduced in February 2020, whereby Charlie's parents developed a legislation with medical professionals and ethical and legal experts that will aim to prevent conflicts between parents, families, and health professionals (Sargent, 2019). The law particularly focuses on three areas that existing legislation does not adhere to. The law aims to prevent cases reaching court by offering mediation amongst differences of opinion and allowing access to NHS ethics committee. Charlie's law recognises the importance of providing advice and support for families through ethics, independent second opinions and legal aid (Benbow, 2019). Furthermore, the law aims to protect parental rights by avoiding court involvement within cases where there is a significant harm to a child. At the time of writing this thesis, Charlie's law is waiting to pass with discussions in Parliament due in Summer 2020.

Decision-making with parents

According to literature, decisions relating to a child should be made with the participation of the child and their parents on the basis of shared knowledge (Stiggelbout et al, 2012). This maintains the mutual trust and respect between the child, caregiver and health professional (Stiggelbout et al., 2012). Shared decision-making is an evidenced-based health decision-making approach that promotes partnership between health professionals, patients, and parents (Legare et al., 2010). By exchanging information about the 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 absence of time and opportunities for dialogues between parents, the child and health professionals (Drotar, Crawford, & Bonner, 2010; Stiggelbout et al., 2012).

A significant amount of research has been conducted exploring and examining parental views of decision-making around their child's treatment (Heath et al., 2016; Hinds et al., 2000; Hinds et al., 2009; Gagnon et al., 2003; Meyer, 2002; Tilden, 1995). A narrative review (Lipstein, Brinkman, & Britto, 2012) highlighted that there are a range of influences on parent decision-making on paediatric treatment including preferences of treatments, changes in their child's health status and opinions from other community members. However, more needs to be understood about the relationship between parents and health professionals, specifically what facilitates and debilitates communication and shared decision-making. A qualitative study by October et al (2014) identified a range of factors important for parents to 'be a good parent' to their child when critical decisions are taking place. For example, fathers ranking informed medical decision as important and mothers ranked putting their child's needs first. The study emphasised the need for further research to explore health professional's knowledge around decision-making in paediatric treatment. Parents have reported that they prefer maintaining control of decision-making regarding their child, especially when there appeared to be a perception of high risk in the decision and also when the parent in question felt that a normal part of being a parent involves making decisions about the welfare of their child (Weiss et al., 2018).

Decision-making amongst health professionals

Studies have highlighted that power dynamics between professionals can impact the decision-making process (De Leeuw et al., 2000; Gallagher et al., 2015). For example, nurses are more prone than doctors to withhold resuscitation in the delivery room and are more likely to ask parental opinion regarding subsequent treatment choices (De Leeuw et al., 2000). Moreover, a quantitative study (Heyland et al., 2003) found that professionals working in intensive care units wanted to share their decision-making responsibility amongst the team. This study stressed that professionals sought support and adequate communication to reach a joint decision with colleagues.

With many decision-making processes not taking a multidisciplinary team (MDT) approach (Smalley et al., 2014), further research around this area needs to include viewpoints from

MDT meetings and professionals. This has been highlighted in numerous long-term conditions such as paediatric epilepsy (Heath et al., 2016) and paediatric cancer (Hamilton et al., 2016). Heath et al. (2016) investigated the decision-making process of health professionals when parents put their child forward for epilepsy surgery. The study used a qualitative approach and discovered that a multidisciplinary approach was crucial to the decision-making process as different viewpoints were required to reach a unanimous decision. Also, advocating for the family was perceived to be the responsibility of non-medical professionals.

Research has suggested that decision-making tends to comply with policies and guidelines concerning the diagnosis or treatment such as the department of health policy and NICE guidelines (Atwal & Caldwell, 2006; Lanceley et al., 2008). For example, Atwal and Caldwell (2006) expressed the importance of team working as part of the decision-making process ensuring that healthcare policies are adhered to. Further to this, decision-making conversations can also be influenced by whether the patient is known by any members of the multidisciplinary team (Atwal & Caldwell, 2006). Research has identified the attitudes, characteristics, and preferences of patients such as their confidence in treatment options influences the decision-making process (Visintini, Ubbiali, Donati, Chiorri, & Maffei, 2007). The confidence of health professionals and their perceived abilities and their relationships with other professionals, the child and parents has also been evidenced as further influences of decision-making (Stavrou, Cape & Barker, 2009).

Furthermore, evidence has reported that clinical decision-making requires health professionals interacting with children and their families to consider their religious and spiritual values. A qualitative study by Superdock and colleagues (2018) emphasised that parents consider religious and spiritual values an importance aspect of decision-making. There was recognition that uncertainty regarding a child's condition influenced decisions regarding treatment initiation, procedures', and options, especially amongst families whereby religious and spiritual values were important. In particular, professionals reported that many parents with strong religious and spiritual views felt God was in control and everything should be decided by God, especially when professionals felt that nature should take its course. Professionals demonstrated frustration amongst families who have strong religious and spiritual beliefs when professionals felt it was not in the best of the child to continue treatment. However, allied health professionals such as chaplaincy and the pastoral care team were highly rated in terms of offering support to families during such situations (Superdock et al., 2018).

Following the beneficial impact of allied health professionals amongst decision-making, there have been recommendations that conversations around decision-making should involve a range of professionals (Devitt, Philip & McLachlan, 2010). The presence of allied health professionals such as psychologists, chaplains and nurses have been identified as advantageous in facilitating family decision-making conversations (Hogden et al., 2012). This was especially beneficial for health professionals to understand parental wishes and would enable allied professionals to support parents and family should they need to.

Parents have highlighted the importance of straightforward, open, and honest information from professionals (Madrigal et al., 2018). There was a realisation that parents felt they were overwhelmed with the sheer volume of information provided (Lantos, 2018; Meyer et al., 2006). As well as considering parental views, professionals have identified the importance of supporting the child's voice in decision-making. Previous literature has reported that supporting children and including them in decisions regarding their own health can create a complex and challenging situation especially when there are conflicting discussions between the child and family (Boland et al., 2019; Coyne et al., 2014). Although professionals reported that including children and young people who may be too ill to participate in discussions is a challenge, they maintained that including children and young people in decision-making is beneficial. This was especially reported as they can discuss with the child the amount of information they want and how they want to be involved (Day et al., 2016; Jordan et al., 2018). However, although children and young people may want to participate in conversations discussing their treatment and the possibility of withdrawing, parents felt it was important to hide distressing information from them (Brand et al., 2017; Jordan et al., 2018). Parents acknowledged the importance of listening to distressing information regarding their child without their child present (Brand et al., 2017). This enables the parent to fully understand the situation before tackling the emotions involved with including the child (Jordan et al., 2018).

Theoretical framework and models around decision-making

The complexity involved within clinical decision-making is reflected in a number of theories and models. Previous literature has identified the importance of common psychological theories in decision-making in health care. These theories include the theory of reasoned action, transtheoretical model and fuzzy trace theory (Reyna & Brainerd, 1995). In particular there has been recognition that these models and theories support the notion of explaining risky decision-making, behavioural change, health promotion and medical decision-making by professionals. Models such as the theory of reasoned action aims to explain how a behaviour intention transforms into a behaviour (Montano & Kasprzyk, 2015). Fishbein and

Ajzen (2011) maintained that an individual’s intention to behave and make a certain decision results from considering all available alternatives. This model was further improved with the theory of planned behaviour, which integrates factors such as social norms, attitudes, beliefs and self-efficacy (Ajzen, 2011). There is realisation that informed decision-making is based upon a thorough description and understanding of all possible options. Similarly, the transtheoretical model identifies individuals in the precontemplation stage of decision-making as understanding the pros and cons of an option (Prochaska, 2008). Although the transtheoretical model explains decision-making, it is individualised, and assumes that individuals make logical plans during their decision-making process which may not always be true especially within a healthcare setting (Segall, 2017). Further to this, the Fuzzy-trace theory suggests that decision-making is based on simple and mental representations of memory choices and ignores detail. This theory explains why detailed information such as risks are often not effective in supporting medical decision-making (Reyna, 2008).

The constructs of theoretical models can help identify and explain a health professional’s behaviour regarding decision-making in healthcare. Theoretical models aid understanding of professional’s decision-making regarding medical treatments. One advance that has been informed by theoretical models is the Adaptive Decision Maker which helps individuals identify important factors when decision-making (Beresford and Sloper, 2008). As part of the adaptive decision-maker framework, the influence of the physician’s own demographic characteristics has been found to influence clinical decision-making such as own religious beliefs (Berger, 2008). Further to this, there has been recognition that this model suggests that personality traits and emotional influence decision-making amongst health professionals (Beresford & Sloper, 2008).

Moreover, it has been argued that negative emotion interferes with decision-making (Hancock & Warm, 1989). Particularly, Folkman and Lazarus (1988) argue that individuals adapt to negative emotion by coping in two ways: problem solving coping or emotion focused coping. Problem solving individuals aim to solve problems rationally whilst emotion focused individuals avoid the situation. This suggests that professionals may take different strategies to cope with the emotion that is attached to decision-making. Although such models explain individual cognition and do not directly explain group decision-making, these models can be applied to clinical practice by applying individual thought processes.

The common-sense model of self-regulation (CS-SRM; Cameron & Leventhal, 2003; Leventhal, Leventhal & Contrada, 1998) emphasises that individuals have illness representations which is based on existing knowledge. This is most relevant amongst parental decision-making whereby the motivation to change behaviour is driven by social and cognitive beliefs of the illness and patients' and their carers' aim to avoid harmful outcomes. The model describes five components of illness representations: identity, cause, timeline, consequences, and curability, which may influence decision-making. This model, along with the theory of reasoned action, highlight the importance of cognitive determinants in influencing behaviour and as a result decision-making. The models aim to demonstrate the thought processes of patients, which supports health professionals in understanding the decision-making process. However, one may argue that health professionals in clinical practice are not aware of such decision-making models and knowledge within this area needs to be strengthened (Legare et al., 2008).

Further to this, understanding parental decision-making aids health professionals' thoughts on decision-making (Legare et al., 2018). Influences on parental decision-making are outlined in the necessity-concerns framework (NCF; Horne et al., 2013), a multidimensional theory exists that suggests a relationship between necessity beliefs and concerns and outcomes. It recommends that individuals weigh-up treatment pros and cons, considering the risks and associated side effects. Moreover, the prospect theory (Kahnemann & Tversky, 1979) emphasises that individuals are risk seeking and risk opposed and will not seek the option where risks are perceived low. Therefore, individuals consider the necessity of a treatment with the risks and uncertainty of outcomes. Research has supported the NCF in many chronic illnesses including, cystic fibrosis, asthma, and cancer (Bucks et al., 2009; Horne & Weinman, 1999; Horne & Weinman, 2002) and found this model to be effective in explaining adherence to treatment. Given the importance of team decision-making within healthcare and especially during withdrawing treatment, the models do not support the notion of individual decision-making within a multi-disciplinary environment such as healthcare. As a result, medical decision-making consists of consensus amongst professionals and individual viewpoints are not solely taken into consideration.

Rationale for the current study: A summary

There has been limited literature around the decision-making process used by health professionals in withdrawing a child’s treatment (Michelson et al., 2009). Therefore, the current study aims to enhance our understanding by obtaining the views of health professionals in this difficult yet interesting area. With qualitative research having a long history in being an essential part of health research (Holloway & Galvin, 2016); the current study adopted a qualitative methodology. Previous literature has primarily focused on the ethics and legality of withdrawing a child’s treatment and none have examined the viewpoints of health professionals during this difficult time. To the author’s knowledge, this is the first qualitative study investigating the viewpoints of health professionals withdrawing a child's treatment. There is limited literature and knowledge around the decision-making processes used by health professionals and their experiences of decision-making within a multi-disciplinary team, using qualitative investigative methods. There is also no existing research around the general experiences of health professionals when making complex decisions, as many studies have focused solely on parental views (Michelson et al., 2009).

Aims

The aim of this study was to explore the decision-making experiences of health professionals in withdrawing treatment from children.

Objectives

Particularly, the study examined professionals' understanding of their role in withdrawing treatment for a child; factors that influence professionals in deciding whether to withdraw a child from treatment and how decision-making is managed amongst staff as an individual and as a team.

Method

Design

Given the nature of working in a healthcare environment, previous literature has identified qualitative methodology as appropriatewithin such settings due to their flexibility offered (Russell & Gregory, 2003). With the huge importance of a multidisciplinary approach to inform decision-making (Hunink et al., 2014), this study aimed to capture views of the various health professionals who are involved in the process by conducting interviews. The use of semi-structured open-ended questions can generate rich and detailed data about individual experiences and perspectives and offer the researcher the flexibility to probe topics of interest and ask unplanned questions in response to what professionals disclose (Braun & Clarke, 2013). Interviews allow the researcher to gather in-depth information for one participant over an extended period of time (Opdenakker, 2006). Qualitative interviews focus on drawing out individual experiences and allow the researcher to explore specific concerns or issues and be flexible about the wording of questions and even add questions about relevant topics that arise (Green & Thorogood, 2018). A favourable review was obtained from the Health Research Authority (HRA) and Health and Care Research Wales and the Research and Development team of the NHS hospital site in question.

Semi-structured interviews generate rich and detailed data with a view to giving voice to the health professional’s experiences and perspectives, as in line with Braun & Clarke (2013). The use of semi-structured open-ended questions can generate rich and detailed data about individual experiences and perspectives and offer the researcher the flexibility to probe topics of interest and ask unplanned questions in response to what professionals disclose (Braun and Clarke, 2013). Interviews allow the researcher to gather in-depth information for one participant over an extended period of time (Opdenakker, 2006). Qualitative interviews focus on drawing out individual experiences and allow the research to explore specific concerns or issues and be flexible about the wording of questions and even add questions about relevant topics that arise (Green & Thorogood, 2018).

Setting

The study was undertaken at a UK specialist children’s hospital.

Theoretical framework

An over-arching interpretative approach with thematic analysis methods was employed in the current study (Jackson, Drummon, & Camara, 2007). The ontological and epistemological assumptions underlying the interpretive tradition reject the existence of an objective knowable reality beyond the human mind (Vasilachis, 2009). Rather, they stipulate that knowledge is constituted through our lived experience of reality and thus, knowledge must be considered within the cultural, linguistic, and historical context in which it is situated (Slevitch, 2011).

The study adopted an interpretive theoretical standpoint. Interpretivism assumes the understanding of the world is gained through social constructions such as shared meanings, languages and consciousness and not objectively determined (Lin, 1998). An interpretive approach generates knowledge based on meanings and interpretations, to provide an understanding using personal and flexible research methods (Black, 2006). The researcher remains open to new knowledge with prior contextual insight. This informs interpretivist beliefs, as it allows researchers to understand subjective experiences that are time and context bound (Hudson & Ozanne, 1988). Subsequently, the study aimed to understand professional's experiences of decision-making in withdrawing treatment. The foundations of interpretivism enabled the researcher to adopt a qualitative methodology which led to interviews enabling data collection. The reality captured through this method was socially constructed, multiple and contextual (Black, 2006). This provided an opportunity to explore factors that influence decision-making in withdrawing treatment (Hudson & Ozanne, 1988).

Participants and Recruitment

A purposive sample of health professionals working at a UK children's hospital, who have worked with children with life limiting illnesses and where treatment has been withdrawn, were invited to participate.

Participants were identified by a local collaborator on the study who works at the hospital, and permission posters were advertised on staff notice boards across various wards: Paediatric Intensive Care Unit (PICU), Respiratory, Oncology and Paediatric Surgery. Interested professionals were asked to contact the interviewee via email. This approach also led to a snowballing effect as some professionals were aware of the study from other participants. Participation in the study was entirely voluntary, and professionals gained a full understanding of the study before consent was provided through participant information sheets, consent forms and the opportunity to ask any further questions. Professionals were allowed 2 weeks to consider and if they were interested in taking part, were asked to contact the researcher to arrange a date, time, and venue for interviews. All participants were given the option to participate in the research in several ways to maximise their potential to participate. This included face-to-face semi-structured interviews, skype or telephone interviews.

All participants contacted the lead researcher initially via email who then assessed interested participants according to the eligibility criteria. Eligible participants included health professionals working within the hospital and involved in withdrawing a child’s treatment. Participants were initially thanked for their interest in the study and were provided with the information sheet and consent form electronically. The initial email also provided participants with an option to either complete the interview face-to-face, or by telephone or skype. If participants did not respond after 2 weeks, a reminder email was sent to them asking if they were still interested in the research. If they agreed to take part, the researcher confirmed their preference for conducting the interview face-to-face or telephone and a suitable date, time and venue for the interview was agreed.

Research Poster

The research poster (Appendix 1) was designed to recruit participants electronically and face-to-face. As part of the recruitment process, the research posters were circulated amongst the hospital and colleagues were asked to disseminate the poster. Printed copies of the research poster were situated on staff rooms where permission to do so was granted. The poster in appendix 1 provided information such as the aims of the research, how data would be collected including the average length of interview and method. Contact details of the researcher were provided and interested participants were asked to contact if they were interested in taking part or required more information.

Participant Information Sheets

The participant information sheets were designed as per the guidelines from Health Research Authority (HRA), which is based on original guidance developed by the Central Office for Research Ethics Committees (COREC). The information sheet covered the purpose of the study, procedure for taking part, benefits of taking part, disclosure of data protection and how these are in line with UWE protection notice and how the results of participation will be used (Appendix 2). The information sheet also disclosed the names and contact details of all study investigators and the procedure of making a complaint or withdrawing if they choose to do so. The information sheet was circulated via email as part of the recruitment process with the research poster. When participants contacted the research team to take part, the information sheet was circulated again along with the consent form. Upon the interview, participants were offered the chance to ask further questions relating to the study and were provided with a verbal response on the aims of the research.

Consent form

The consent forms were designed as per guidelines from HRA. Consent forms were circulated via email to participants demonstrating interest in taking part in the study. All consent forms were completed and returned prior to commencing interviews via email. For face-to-face interviews, the researcher and the participant signed and dated two consent forms each. For telephone and skype interviews, participants were emailed a consent form prior to the interview taking place and were asked to return via email 24 hours before the interview commenced. Participants were asked to keep one copy for themselves and the researcher maintained a copy also. The consent form consisted of six statements asking the participant to agree on confirming they have read and understood the participant information sheet, that participation is voluntary, consent to the interview being audio recorded, understanding that if participants disclose something that causes harm to themselves or others then the research team would breach confidentiality (Appendix 3). Participants were asked to initial each box linked to each corresponding statement and were asked to disclose their name, provide their job title, their signature and date the form. For interviews that were conducted electronically such as telephone or skype, consent forms were completed prior to commencing the interview and a signed version with the researcher’s signature was sent back. All consent forms were collected and were stored separately from raw data in a locked environment to maintain anonymity and confidentiality.

Interview Schedule

One semi-structured interview schedule was used for all interviews (Appendix 5). The interview schedule was designed by the lead researcher informed by a literature review of existing research ensuring that the aims of the study were met. The interview schedule was reviewed thoroughly by local collaborators from the hospital and the opinion from a neutral board of examiners from UWE was obtained to ensure the questions were suitable. Feedback consisted of starting the interview with a softer approach which was taken into consideration and the schedule was amended.

The interview schedule consisted of nine questions, with several sub questions under each question. The interview schedule focused on topics suitable to meet the aim of the study to ensure data was comprehensive. 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, any conflicts between professionals and families. The researcher used open-ended questions which allowed participants to reveal thoughts and feelings on the subject matter.

Interview process

All face-to-face interviews were conducted in a private, closed room within the hospital. The rooms were allocated and booked by the participants. Telephone interviews were all conducted in a closed room within the researcher's home ensuring that privacy was maintained throughout the interview. The researcher ensured that participants on telephone interviews were conducting interviews in a private room. Participants were asked if they had any questions and if happy to continue the recording commenced. All participants were informed that the researcher would be taking notes during the interview to support constructing further questions. Before the interview began, the researcher informed participants that they have the option to stop the recording at any time and they do not have to answer any questions that were asked of them. Following on from this, the interview commenced when the participant was happy to do so. Upon the researcher introducing themselves to the participant, a brief introduction regarding the study was provided. For individuals during the face-to-face interviews consent forms were provided at this point. Telephone and skype interview participants were thanked for returning consent forms back electronically. Participants were informed that recording the interview was to ensure the data was a true representation of participant's thoughts and feelings. Participants were provided with the option to still take part in the study if they did not agree to their interview being recorded. During the interview, there was minimal response from the researcher with occasional affirmations. After the interview was completed, participants were provided an opportunity to ask questions, were thanked for their time, and participation in the research and were debriefed.

Data collection

Interview data was collected and recorded in an anonymised manner. Participants were given the opportunity to choose a pseudonym, if they so wished, or had one allocated to them. An encrypted audio recorder with password protection was used. Given the issue of data protection in using a Dictaphone, the research team followed the University of the West of England's Data Protection Policy reference in line with GDPR throughout the research. The extracts chosen for the final report were checked for any identifying information and anonymised or changed if necessary, to preserve anonymity of professionals. Data collection ceased when appropriate depth and richness of data has been generated (Morse, 2000).

Interview Distress Protocol

The interview distress protocol was developed to ensure the researcher was able to identify distress should participants experience any form of distress during the interview. Given the nature of the topic, it was anticipated that some professionals may get emotional and support would be required. The distress protocol consisted of five steps: distress, stage 1 response, review, stage 2 response and follow up (Appendix 6). The distress stage indicated that the researcher recognised that the participant was feeling uncomfortable, experiencing emotional distress or high level of stress. This then led to a stage 1 response where the participant was asked if they wanted the interview and the audio recording stopped. The researcher would offer immediate support such as comforting the participant during this stage and would assess the participant's level of distress including their thoughts, feelings, and ability to continue with the interview if safe to do so. The review stage consisted of reviewing the next steps, which included reviewing whether the participants felt able to continue with the interview. If during this stage the participant was unable to continue stage 2 was initiated. During stage 2 the researcher would discontinue the interview completely and continue to support the participant. Further to this, the researcher at this stage would encourage the participant to contact relevant support organisations available such as the Employee Assistance Programme available at the hospital. If this was not suitable for the participant, then an option for a member of the research team to contact relevant support such as Mind was suggested with consent from the participant. Following this, the final stage consisted of a follow-up telephone call a week after to the participant if consent was obtained.

Debrief form

The debrief form was designed to provide participants with further information regarding the study, how their results would be used and procedure on withdrawing following data collection (Appendix 4). The debrief form thanked participants for partaking, provided them with a reminder of the aims of the study. Participants were reminded that they had 2 weeks from the date of their interview to withdraw from the study and the procedure for how to do so was outlined in the form. The debrief form was circulated to all participants either face-to-face or electronically. Participants whose interviews were conducted face-to-face received the debrief form instantly after the interview ended. Participants who were interviewed via telephone, received the debrief form via email as soon as the interview was completed.

Ethical Considerations

The study adhered to the British Psychological Society's (2009) Code of Ethics and Conduct. Following the guidance provided at http://www.hra.nhs.uk/documents/2013/09/defining-research.pdf. The present study did not require NHS ethical approval as the study was asking for experiences of health professionals working in healthcare. Although NHS ethics was not required, as NHS staff were to be interviewed an Integrated Research Application System (IRAS) form was completed to obtain Research and Development approval. In addition to this, the study received ethical approval from the University of the West of England.

Recruitment: Participants were provided with detailed information and sufficient time on which to base an informed decision regarding participation. Potential participants were contacted by email and sent an information sheet and asked to respond if they were interested in participating. Should there not be any interest from invited employees, there was a potential to follow this up. The research team followed up any interested participants by sending a courtesy email asking interested professionals if they still wish to take part. Participants were able to discuss participation with a member of the research team, who was able to answer any questions or queries. Information was provided about the nature of the research, the members of the research team, how data was collected and used. The forms also stated how data was discarded after the research comes to an end. Moreover, participants were given the opportunity to gain feedback or receive the study findings should they wish to do so.

Consent: Written informed consent was obtained from all participants prior to data collection. Before the interviews began, participants had the opportunity to ask any questions about the study.

Withdrawing from the study: Participants were informed that they could withdraw from the study during any time of the interview and within 2 weeks after their interview was conducted. After this time, they were informed that their data would be part of the analysis. To withdraw, they were told to email the lead researcher and they were informed that in the case of withdrawal that their data would be deleted.

Confidentiality: Audio recorded data was transferred from an encrypted voice recorder to a secure server as soon as possible and deleted from the portable device. Data was then transcribed and anonymised. Following transcription and checking, digital audio files was destroyed. Anonymised transcripts were stored on a secure server, which was accessed remotely in accordance with the University of West of England's governance and data protection requirements.

Psychological risks: Discussion of withdrawing treatment may evoke distressing memories. Participants were informed that the study would include some questions that may bring back memories. As a result, a distress protocol was produced as part of the study. This involved stopping the interview, offering support, or encouraging the professional to seek emotional support from a senior colleague. This protocol was adhered to and was applied to telephone and skype interviews and face-to-face interviews. Professionals were offered and signposted to the hospital's Employee Assistance programme where Chaplaincy or counselling services was available for professionals should they require support.

Worthiness of research: Lincoln and Guba (Amankwaa, 2016) discuss the importance of evaluating the worth of a research study. Their criteria for trustworthiness involved establishing credibility, transferability, dependability, and confirmability. The present study ensured that the criteria was adhered to by ensuring there was credibility and truth within the findings and the findings were shaped by the respondents themselves.

Data Analysis

Data was transcribed verbatim, anonymised and analysed using a thematic framework method (Ritchie & Lewis, 2003). This was the most appropriate method of analysis for this study as it is a method for identifying, analysing and reporting patterns or themes within data (Braun & Clarke, 2006). It is a widely used qualitative method within psychology (Roulston, 2001) and moreover, it is suitable for experiential questions and can provide a complex, rich and detailed understanding (Braun & Clarke, 2006).

The duration of interviews lasted between twenty to sixty-five minutes and participants were asked questions using the interview schedule. All participants consented to their interview being audio recorded and were reminded that consent for this was sought on the consent form. All data was fully anonymised and transcribed and was stored on a secure server to allow remote access. The files were password protected with the password only known to the researcher undertaking the study. The participant's number and pseudonym acted as the identifier on the data file rather than their own name. Any printed copies of the data were stored in a locked filing cabinet.

This approach was appropriate for multi-disciplinary health research and supports projects where there is a need to explore specific issues, while also leaving space to discover other new and unexpected aspects of the participants' experience or the way they assign meaning to phenomena (Gale et al., 2013). Thematic Framework Analysis involves the systematic search for patterns to generate descriptions capable of shedding light on the phenomenon under investigation (Srivastava & Thomson, 2009). It enables coding of data to be carried out 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 analysis was carried out in accordance with the five stages of the Framework Method: familiarisation, identifying a thematic framework, indexing, charting, mapping and interpretation. Data storage, coding, and retrieval was supported by the use of NVivo software. All transcripts were uploaded onto Nvivo 12 software. The lead researcher analysed all transcripts using the software created thematic codes.

To enhance the validity of the findings from this research, 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 any conceptual interpretations of the data, reflect on any decisions made, and to ask the opinion of other members of the team to ensure the researcher was exploring perspectives other than their own (Smith, 2015).

Trustworthiness was maintained using several strategies: keeping a clear and transparent audit trail, maintaining a reflexive diary stipulating how the interviewee may have influenced the research findings, discussing emerging understandings within a research team, and demonstrating a clear logic of enquiry. In addition, a subset of transcripts was independently coded by two members of the research team to ensure reliability and consensus on coding schemes. Any differences in interpretation were resolved through discussion, and with involvement from a third researcher if necessary.

Reflexive Practice

As the interviewer for all health professionals I ensured that the questions asked were open and flexible and the data was interpreted accordingly. As a South Asian female with no children I had no direct emotional contact with the topic of discussion. I ensured all interviews were conducted and transcribed by myself to obtain a thorough picture of the data. Given the nature of the topic a reflexive diary was maintained where my thoughts and feelings were disclosed. There was one interview in particular where I reflected significantly, and it made me realise the difficulty health professionals face whilst working in an environment such as a paediatric hospital. A health professional in particular showed signs of emotion during the interview as she reflected on a previous encounter whereby a child passed away. I instantly followed the distress protocol and offered support and at this moment I realised the difficulty of this topic and emotional strength required by a professional. I realised the pendulum upon which professionals sit with parents regarding deciding to withdraw a child’s treatment. With previous experience of interviewing parents on deciding to put their child forward for epilepsy research, I felt I could use my previous experience to manage my own emotions during the interview. On a personal level, from a very young age I have always been able to manage my emotions really well and I believe my own resilience has allowed me to endure and listen to the interviews without showing my own emotions. The topic is incredibly difficult, and I cannot truly imagine what health professionals and parents go through during this difficult time. However, through using my reflective listening skills I believe I have been able to capture and interpret the findings as true to the professionals involved.

Results

Sample characteristics

A total of fifteen participants were interviewed all of whom were health professionals involved in discussions around withdrawing a child's treatment at the children's hospital. Majority of the interviews (n=11) were face-to-face whilst the remaining four were conducted over the telephone. Three of the participants were males with the remaining participants (n=12) were female. The professionals were spilt into medical professionals such as consultants and nurses (n=9) and allied health professionals (n=6). The majority of medical health professionals consisted of nurses (n=7) and the remaining two medical professionals were male consultants. A total of 6 allied health professionals were interviewed which consisted of chaplaincy, family liaison coordinator, and bereavement coordinator. Due to maintaining confidentiality at the request of some professionals, the number of each allied health professional is not reported.

Analysis results

Analysis generated five interrelated themes with associated subthemes to further understand the experiences of health professionals when deciding to withdraw a child's treatment: (1) Best Interests of the Child (2) Multidisciplinary Approach (3) External Factors (4) Psychological Wellbeing (5) Recommendations to Support decision-making.

Theme 1: Best Interests of the Child

As part of the decision-making process, professionals identified that all decisions were based on the best interests of the child. In particular, different professionals had different ideas on what the best interest of the child meant. Professionals reported that their judgement and decision was based on taking into account all relevant factors to do with the child. Several factors were considered by professionals when taking into account the best interests of the child. These included the competency of the child, discussions around the severity of the child's condition and true realisation of the child's illness.

Competency of the Child

Professionals demonstrated the importance of ascertaining the child's perspective and their viewpoint whilst deciding on the best interests of the child. Professionals felt that end of life discussions were vital with young people who especially had the capacity to understand. Both medical professionals and allied health professionals suggested that including children and young people within discussions allowed the child to feel empowered and somewhat in control of their treatment. As well as including parents and families, the competency of the child and their ability to contribute to decision-making was deemed appropriate, especially if the child had been a patient within the hospital for a significant time.

> *'although in the field I work in. It's very it's very rare for the child to be considered old enough. Usually parents don't want to fully inform them. And even if they're teenagers.' (Nurse, 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 don't feel at liberty to say it to not upset their family' (Nurse, Female)*

> *'I think its children being empowered making decision for themselves' (Allied Health Professional, 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' (Allied Health Professional, Male)*

Allied Health Professionals reported that the age of the child significantly mattered especially with professionals suggesting that '*older children do realise how ill they are'*. Professionals felt that not including children within discussions restricted them from having a voice. It was reported that professionals recognised that parents were protecting their child and recognised that some children do have the understanding on what is happening but felt the child was not able to speak out on the basis that it would upset their family. Part of the decision-making process included focusing on the child and taking a collective decision approach with the family and child present. In particular there was recognition that including parents as agents within a multi-disciplinary approach was important. As a result, professionals reported that when a child was able to speak this created a difficult environment between the child, professionals, and the family.

> *"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 don't 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" (Medical Professional, 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." (Medical Professional, Female)*

Discussions around severity of child’s condition

Health professionals maintained that decision-making and withdrawing a child’s treatment was based on discussion about the severity and the condition of the child. It was reported by professionals that conversations around the matter and all discussions were based on the condition of the child. Many professionals maintained that withdrawing a child’s treatment generally takes a significant amount of time to reach a decision. After a child has been admitted, professionals tend to discuss and explore procedures and tests to establish the severity of the child’s condition. It was emphasised that all options regarding treatment are fully explored before professionals discuss withdrawing of treatment.

> *“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” (Allied Health Professional, Male)*
>
> *“ok umm so it would really depend of on the condition of the child” (Allied Health Professional, Male)*

There was a wide emphasis of including palliative care within discussions with this providing an indication on how ill the child is especially when life limiting conditions were diagnosed. Professionals emphasised the importance of working with palliative care colleagues earlier as a form of anticipatory planning within the treatment to ensure advanced care plans were developed that could support decision-making conversations with the child and their family. Also, there was an importance of including palliative care within initial discussions around treatment especially before any discussions were had with the child or family.

> *‘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’ Allied Health Professional, Male.*

> *'I mean honestly I just don't understand why palliative care isn't involved from the start day one really palliative care needs to be involved sooner way before any decisions are made or even discussed' Allied Health Professional, Female*

As part of the discussions around severity of the child's condition, professionals emphasised the importance of honesty and transparency with the child and their families. There was a clear recognition around ensuring families were debriefed on the condition of their child. Professionals discussed the importance of all information being cascaded to the child and their family. This was further stressed especially if the child was developmentally able to engage within discussions. Further to this, the families' perception of how ill their child is was influenced by comparing to other children on the wards. Sometimes parents felt their child was not as ill as professionals informed them as they would compare their child to another child on the ward who may look more ill. Professionals maintained that the conversation between families and professionals were difficult especially when families did not realise the true condition of their child which in turn made the decision-making process difficult.

> *'Tell them honestly the situations and the case of the child we offer too much emotional support and give them too much power when they don't know the full background' (Allied Health Professional, Female)*
>
> *"Families compare themselves well their child to other families so like they will look at the bed next to them and see the other child looks a lot more ill than their child and they would talk to the other family and say to us well the other child looks more ill than mine and that makes things worse" (Allied Health Professional, Male).*

Professionals maintained that explaining the severity of the child's condition to parents was a difficult conversation to have especially when they did not agree with the professional's diagnosis or viewpoint. When HCPs discussed the condition with the child and their family and the matter of withdrawing treatment, many professionals reported that they could witness the difficulty of parents understanding and accepting the situation.

> *"Everything takes time to sink in. And it's a very, very deep conversation to have." (Allied Health Professional, Male)*

> *"You know like I see parents who just don't understand where the professional is coming from and that's a struggle" (Allied Health Professional, Female)*

True Realisation of Child's Illness

Professionals identified the importance of realising the true extent of a child's illness with many explaining that after exhausting all treatment options, withdrawing treatment is in the best interest of the child. Allied health professionals particularly reported that they sensed a fear from parents especially when they do not realise how ill their child is. Professionals maintained that parents struggled to understand the situation and accept the decisions made regarding their child.

> *"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 doesn't always help" (Allied Health Professional, Female)*

> *"We had parents that were scared but this goes back to sometimes they don't understand how ill their child is" (Allied Health Professional, Female)*

Furthermore, there was a sense of uneasiness from professionals when parents appeared to be in denial and actively did not seek further support from professionals in terms of understanding their child's illness. This was made clear by professionals who identified that denial was common amongst these discussions especially when parents thought they had the best interests of the child by not giving up on treatment. This was further aggravated by parents who sought advice on treatment options from other sources such as other families instead of professional advice from the HCPs involved in their child's healthcare. In particular, professionals reported that parents felt the importance of gaining confirmatory evidence to support the belief that their child is not as sick as the medical professionals' stated. Further to this, HCPs identified the importance of parents and families understanding the rationale behind HCPs withdrawing treatment, but a clear sense of denial and lack of acceptance was evident amongst families.

> *"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." (Medical Professional, Female)*
>
> *"It helps if parents have knowledge of their child's condition you know if there were more informed, but they don't realise or understand shall I say the condition and it's difficult because that's what doesn't help" (Allied Health Professional, Female)*

Theme 2: Multidisciplinary Approach

All professionals identified the importance of adhering to the medical model as using medical evidence as part of the decision-making process. Having said this, it was widely accepted by professionals that decision-making conversations consisted of a multidisciplinary approach incorporating expertise from a range of professionals.

Medical Model

Medical professionals, especially consultants, stressed the importance of the medical model within the decision-making process. The medical model is practised by doctors and healthcare professionals and focuses on diagnosis, cure and the treatment of illness. It focuses on physiological and biological factors of illness (Engel, 1977). In the present study a consultant stressed the difficulty of engaging with families and parents especially when they did not understand the rationale behind professionals withdrawing treatment. This was demonstrated via a professional mentioning that '*you know it can be difficult with family and parents there because they don't see or sometimes understand the medical model*'. This was echoed amongst medical professionals with families not '*understanding our way of thinking the medical model and that makes it difficult when talking about treatment'.* Parents and families not understanding the medical model was also stressed by allied health professionals who reported that *'it's for the parents to understand the professionals you know medics won't stop treatment without knowing for sure and the families that I see sometimes they struggle to understand this'*. In particular, professionals reported that decision-making was a form of evidence-based healthcare and in particular medical professionals took a biomedical conception of illness whereby the body was viewed as a machine. Professionals maintained that there was also admission from a consultant that emphasising the medical model allowed the conversation to be '*less emotional when we have more professionals'.* It was recognised that conversations relating to medicine and treatment were based on fact and allowed professionals to be clear and direct with families. Furthermore, there was a sense of professionals protecting themselves emotionally and dealing with concrete facts and evidence was essential during a very emotional and difficult time. It was clear that withdrawing a child's treatment had a huge impact on health professionals.

There was recognition from both medical and allied health professionals that the roles of medical staff involve treating the child and to '*make sure we have done everything we can*'. It was stressed that professionals exhaust all options before withdrawing a child's treatment and moving to palliative care, but health professionals perceived that parents and families did not acknowledge this. In particular, a consultant demonstrated a clear example that their role was rooted in the medical model with the need for decision-making conversations to be '*less emotional'* with medical staff accepting that they *'can't always help and can't always cure'* and the need for them to *'do our jobs'*. Professionals maintained that death was inevitable given the nature of their job and as medical professionals they *'need to be strong and be less emotional'*. This was echoed by an allied health professional who suggested that '*just occasionally we are not allowing doctors to be just doctors and make the decision that a doctor needs to do'*. Further to this, when professionals were discussing historical cases such as the Charlie Gard case, an allied health professional mentioned that medical staff are '*used to fixing people'* and it was recognised that's where disagreements occur between health professionals and families. There was recognition that medical professionals such as doctors needed to make the decision based on medical information and facts as part of their profession as reflected by a professional *'because that would be on a medical basis on whether that decision is being made'.*

> *"Clinical staff are used to fixing people that that's where battles like Charlie's case happen" (Allied Health Professional, Female)*

Having said this, there was recognition that some clinicians felt a sense of failure when treatment was withdrawn. There was an indication that clinical roles were to cure patients and some professionals deemed the death of a patient as a failure on their part. This was acknowledged by an allied health professional who mentioned that *'it gets difficult'* when some professionals mostly professionals in clinical roles feel they have failed in their job when they withdraw treatment.

It was particularly demonstrated by a medical nurse that consultants predominately led on the care of a child due to their extensive medical knowledge. Although both allied health professionals and medical staff such as nurses work closely with the lead consultant, it was recognised that nursing staff did not feel included within these conversations. This was suggested by an Allied Health Professional who mentioned

> *“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 don't because they're often not present in those situations” (Allied Health Professional, Female)*

Professionals also mentioned that historically decision-making consisted of solely clinical staff such as consultants. Particularly, one allied health professional mentioned that previously, clinicians did not disclose patient information to other colleagues, which led to poor communication and poor outcomes.

> *“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” (Allied Health Professional, 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're not. We know we're not in possession of all the medical facts and biology to be able to contribute to that”. (Medical Professional, Female)*

Further to this, professionals emphasised that the medical model was a major part of the decision-making process. Biological factors of the child’s illness were taken into consideration during the process. It was established that a medical perspective was vital and aided conversations around withdrawing treatment as medical information was factual and something professionals had to adhere to.

> *“The decision-making is it is is actually in part based on what we know about the historical and the biological factors associated with the disease. And the decisions that we made so make subsequent to that are based based on that. So, although there is multidisciplinary discussion, it's very much the foundation is in what we know about the disease process” (Medical Professional, Female)*

Joint decision-making

The views of professionals and families are respected and taken into consideration as part of the decision-making process. There was acceptance that all individuals involved within the decision-making process including professionals and family members were equal and ‘*no one is in the wrong’.* It was expressed by an allied health professional that *‘you have to include professionals and you have to include the family’* suggesting that decision-making process was jointly undertaken. As part of the conversations, it was clear that professionals recognised the wishes of parents, with an allied health professional reporting that they ‘*never go against the wishes of a parent’*. Although there was a clear sense of frustration from professionals on this, it was demonstrated that involving parents and wider family were vital. Professionals identified that all conversations were initially discussed during MDT meetings where each individual case was raised, and all options were discussed. A medical professional mentioned that discussions were raised through *‘MDT meeting around the case we have various people involved from consultants to the family members’*. There was huge emphasis that the decision was very much centred on the child and all views of health professionals and family members were acknowledged.

Upon raising the discussion of withdrawing a child’s treatment, it was recognised that all conversations were ‘*elicited by the clinician with the family’*. This was particularly reported as being raised by the ‘*lead PICU consultant for that child and then any other specialist consultant for that child’.* These conversations were acknowledged as being ‘*very very good umm participative conversations going on with all parties’.* Further to this, there was a sense of respecting all views as part of the decision-making process where a medical professional stated that ‘*everyone contributes’* and *‘everyone stays professional and it’s all around the* *child'*. Having said this, there was realisation that the roles of professionals involved within the conversation around withdrawing treatment were determined by each individual case. It was stressed that some initial MDT meeting did not consist of the correct professionals who would be able to discuss the case and the decision. As a result, some conversations regarding the decision took longer and this was particularly frustrating within cases where the child was 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' (Allied Health Professional, Female)*

Although each professional within the MDT meetings are not asked individually regarding their opinion, medical professionals emphasised that *'MDT discussion necessarily means everybody within that MDT will get asked for an opinion'*. There was a realisation that joint decision-making included working in partnership with parents and other professionals. There was acknowledgement that all decisions were made within an MDT approach where a sole individual was not in a position to make a decision on their own.

> *'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, it's there's a kind of cross checking process. It's not a there's not really a scenario where it's one person' (Medical Professional, Female)*

While it was claimed that decision-making was undertaken through a multidisciplinary approach, a medical professional in particular identified that from their experience they have witnessed nursing staff who felt they were not part of the discussions regarding withdrawing treatment. This was expressed through a professional stating that

> *"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 don't because they're often not present in those situations" (Allied Health Professional, Female)*

This was further expressed by an allied health professional who admitted that historically they were not part of MDT discussions. The allied health professional stated that:

> *"we are rarely involved. It's so frustrating because we are always the last ones to find out information on a case, but we are the ones that actually see the child a number of times a day. I mean only recently like the last 3 weeks we are part of discussion where we meet with other health professionals and discuss a case or cases individually" (Allied Health Professional, Female)*

It was acknowledged that upon attending MDT meetings, professionals felt that they received vital information regarding a case that they would not have obtained. There was clear dialogue between professionals, but some allied health professionals reported that they felt these conversations were not discussed within MDT meetings.

> *'We find out information that we didn't know on a case if we didn't 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 don't think it's very discussed in those meetings' Allied Health Professional, Female.*

Support from Allied Health Professionals

Although decision-making conversations were initially raised by medical professionals, all professionals recognised the importance of allied health professionals within the conversations. There was an appreciation that involving Allied Health Professionals during conversations around withdrawing treatment was vital for both professionals and parents especially to *'help everybody understand different perspectives'.* There was realisation that supporting the conversation required encouragement from allied health professionals for both other professionals and families. In particular, medical professionals reported that Family Liaison, Chaplaincy and professionals act as advocates for children and their families during this difficult time. This was reflected by professionals who stated that additional support was provided from '*the family liaison team or chaplaincy*'. There was recognition that sometimes medical professionals require additional assistance from allied health professionals to support conversations with parents and families. This was evidenced through a professional stating that '*sometimes they will just bring in like somebody like chaplaincy*'. A number of allied health professionals acknowledged that their role consisted of supporting the family and they were not necessarily apart of decision-making conversations. It was acknowledged that these roles were to support families to make a decision regarding withdrawing treatment. Professionals suggested that the majority of decisions were made by medical professionals and allied health professionals were more to advocate. This was reflected by several Allied Health Professionals:

> *'I have a big role in supporting the families you know that's my role I'm not a medical profession' (Allied Health Professional, Female)*
>
> *'well I don't do anything sorry I meant I'm not a part of the decision-making because I'm not clinical' (Allied Health Professional, Female)*
>
> *'I don't really help with making any decision you know I don't have the power to do that' (Allied Health Professional, Female)*
>
> *'sure well chaplaincy will be involved by virtue of being support with the family and that could be long term short term invariably it is at least medium term because you know most of our withdrawal of treatments are not just like the next day after you know a child's been bought 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 and so we will then be we will offer to support the family' (Allied Health Professional, Male)*

Furthermore, some professionals identified that parents and families sometimes requested support from Allied health professionals which was demonstrated by a professional stating that

> *"They would ask for some support staff to come in and 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" (Medical Professional, Female)*

There was recognition that Allied Health Professionals advocated for families especially when parents felt guilty when treatment was withdrawn. It was recognised that allied health professionals were involved throughout the decision-making process and they supported the family *'when a decision has been reached but even when decisions haven't'*. A chaplain reported that

> *"One of my observations is maybe suspicions is that we have swung so far the other way that we try and involve people in making these decisions and I wonder whether that is fair if that we participate we we help families make the decision so much that they are then often in situations whereby they are blaming themselves for agreeing for their child's treatment to be turned off and I just wonder whether just occasionally we are not allowing doctors to be just doctors and make the decision that a doctor needs to do but I understand the motives" (Chaplaincy, Male)*

There was admission from Allied Health Professionals that as expected withdrawing treatment was a difficult decision for families to make and felt that medical staff should take the decision out of families' hands. Furthermore, as part of supporting parents and families, there was recognition that Allied Professionals supported families with explaining medical jargon and ensured parents understood the rationale for withdrawing treatment. A family bereavement professional mentioned that

> *"I have interesting discussions with colleagues and consultants which I think can help them like I know of one case where I spoke to the family and they didn't really understand what the doctor was saying you know all that medical jargon so I acted as an advocate for the family to speak to professionals and you know I think that helped" (Allied Health Professional, Female)*

The support offered by Allied Health Professionals was recognised as helpful for both families and medical professionals. This was particularly expressed by an Allied Health Professional who mentioned that their discussions with medical staff consisted of supporting the family. This was evidence through '*I can't speak to consultants about the ins and outs of treatment, but I feel I am able to talk to them about supporting the family I think medical staff have a lot more control to make those decisions'*.

Although support from Allied Health Professionals was greatly appreciated, some medical professionals reported that sometimes Allied Health Professionals hindered the decision-making process especially when it was assumed that they were supporting the family and influencing their decision. It was recognised that professionals supporting parents and families were to be neutral and impartial in order to act as an advocate. This was demonstrated through

> *"That has been very odd occasion where I felt that a chaplain was hindering rather than helping, but I suppose that was partly because she was totally siding with a family's view of continuing treatment at all costs. And we could see the child getting sicker and sicker" (Medical Professional, Female)*

Even though professionals recognised that supporting parents and families appeared predominantly from allied health professionals, medical professionals especially nurses highlighted that their role consisted of supporting families too with them having familiarity with the child and family. There was recognition that familiarity with families supported the decision-making process especially when determining how families would take the news of professionals withdrawing treatment. This was reflected through a medical professional who stated that *'I've got some families that I quite honestly couldn't give you any clue where their head would be at But I've got others that I could really second guess what they are going to say'.* Understanding the relationship of the patient and their family and receiving support from allied health professionals acted as a support mechanism during the decision-making process. Although it was clear that allied health professionals are not necessarily involved in the decision-making process, their roles were involved in supporting family.

Competency of Professional

Professionals identified the remit of their roles and how they influenced decision-making process. There was a clear difference between allied health professionals and medical professionals in terms of how they viewed their role within the decision-making process. It was clear within allied health professionals that making the decision regarding withdrawing treatment was 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'*. There was recognition that during the decision-making process many parents and families changed their minds several times on the treatment for their child and professionals had to be confident enough to deal with this. It was demonstrated by a professional that '*we are equipped to deal with them changing their minds and not being critical with them and then supporting them in making that decision'.* Further to this, a medical nurse identified their role as families reaching out to them for information by stating that '*they look to us for that information'*. This was especially identified when parents and families struggled to understand the viewpoint of medical professionals and the rationale behind their decisions.

Professionals understood their roles and their capability regarding their input within the decision-making process. There was emphasis that allied health professionals focus on the ‘bigger picture’ and don’t focus solely on the medical aspect of the child. There was recognition that this viewpoint allowed professionals to work with parents and families on focusing on the situation of the child and constructing a plan for end of life.

> *“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’” (Allied Health Professional, Female)*

Theme 3: Effective Communication

Professionals identified the importance of communicating with the child, family and between professionals regarding the withdrawal of treatment from a child. There was a consensus amongst health professionals regarding how overwhelming families with information influenced the decision-making process significantly.

Within Families

Professionals identified that parents and families received a significant amount of information regarding their child that appeared to be overwhelming. There was a sense of including parents within decision-making and providing them with enough significant information to make a decision, which HCPs recognised was in fact a difficult decision to make. Further to this, there was realisation amongst professionals that the overload of information was acting as too much pressure for the family, which in turn made it difficult for them to take in. Professionals reported that a major challenge as part of the decision-making process was that sometimes parents and families received too much information.

> *"I like I say, I just question whether we just sometimes put too much on the family" (Medical Professional, 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" (Allied Health Professional, Male)*

Professionals reported that time was important for the child, parents and family especially when they were provided with a significant amount of information. There was realisation that when families are provided with information, they are not provided with enough time to evaluate the information to make an informed decision. An Allied Health Professional reported for example, that:

> *"well we sometimes don't allow enough time for parents to voice their opinions you know we can't just say this is the decision and then get them to decide within a day it doesn't work like that we need to allow parents and family to think and for it all to sink in" (Allied Health Professional, Female)*

There was a clear realisation that the nature of the conversation was difficult and sometimes professionals did not give parents the time and distance to make an informed yet timely decision.

This was further stressed by professionals who recognised that disagreements were encountered even more so when discussions included family members outside of the immediate family. One medical professional relayed this by stating '*sometimes they bring other family members who create issues*'. This emphasised that the decision-making process regarding withdrawing treatment was not only professionals, child and immediate family. It was emphasised that wider family members such as uncles, aunties and grandparents were often included by families within the decision-making process. Professionals stated that sometimes opposing views from family members made it difficult for parents and professionals to reach a unanimous decision. This was further enhanced by professionals who stressed the difficulty of parents and families not realising the individuality of all cases. One allied health professional mentioned that '*they don't realise that all cases are different, and they only look at what's in front of them which isn't right.'* There was a realisation that disagreements between families and professionals was not a sense of blaming each other but it allowed both parties to discuss the issues in depth and *'help everybody understand different perspectives'.* Furthermore, there was awareness that although encountering disagreements between families and health professionals was inevitable, it was not a case of health professionals against families and parents. To reflect this, one medical professional emphasised that '*I don't see that it's an us and them'.* There was realisation that part of managing disagreements was for HCPs working collectively with the child and family in order to move forward.

Part of encountering disagreements meant that children who were developmentally aware of their condition remained silent on the situation due to the fear of upsetting their loved ones. One allied health professional revealed that *'there is a general feeling that many of these children do understand what is happening but don't feel at liberty to say it to not upset their family'.* There was acknowledgement by professionals that disagreements arose from lack of communication with parents with a medical professional reporting that *'sometimes they don't listen to us professionals' and 'it gets difficult when parents don't agree with us'.*

There was emphasis from allied health professionals that their roles predominately consisted of supporting parents, families and medical professionals in managing conflict. An allied health professional particularly reported that their role was to *'help everybody understand different perspectives'*. It was suggested that disagreements were often between parents, families and medical professionals and that allied health professionals acted as an advocate to mediate and manage the situation. When professionals were asked about how conflict and disagreements were managed in these situations, allied health professionals expressed the difficulty in managing conflict. However, a medical consultant admitted that there were no challenges as part of the decision-making process by stating that *'I don't think there are any challenges you know everyone stays professional and it's all around the child'.* It was clear from this professional that managing conflict was not as relevant within the decision-making process as they stated '*well I think sometimes we forget where families are coming from you know like it's their child and sometimes they don't listen to us professionals you know we know more we know what is best because of our qualification'*. Although the professional realised that medical professionals sometimes do not take parents and families views into consideration, they admitted that their views were not taken seriously given their medical qualification and expertise by parents.

Professionals have witnessed conflicting viewpoints amongst immediate parents within the decision-making process. This has been managed by health professionals to ensure both parents are content with the decision made. Given the difficult nature of the conversation concerning decision-making, professionals have reported conflict and disagreements between parents deciding on whether to withdraw a child's treatment. This was reflected through an allied health professional when they mentioned managing conflict was difficult *'even conflict between parents so one parent may say something and it's difficult because* *how do you manage that.'*

Many professionals identified the struggles witnessed amongst some families with professionals referring to this experience as quite '*fragmented*'. It was clear that family dynamics and the roles of family members influenced the decision-making process. There was a sense of defining authority within family members and it was assumed that the decision of withdrawing treatment would lie within a specific family member. This was particularly evidenced through an allied health professional who mentioned that

> *"I have seen perhaps psychological gain happened with families and family members struggling with regards to permissions of parental responsibilities with some families that become quite fragmented of where there is authority within families and that may well not be within that family unit with the parent or parents and if it's with the parents there may be some intimidation within parents who don't have the final authority for consent and I think there's some issues when that doesn't like we get there but because of family's systems and family dynamics" (Allied Health Professional, Female)*

This was further stressed with immediate parents where a mother and father would have conflicting views on withdrawing treatment which would in turn make it difficult to decide. Professionals recalled that this situation was difficult to manage with an allied health professional suggesting *that 'sometimes there is conflict between parents so a dad could say something, and the mum wouldn't agree so that doesn't help'*. Further to this, a medical professional reported that parents who have separated demonstrated different views and as a result the conversation became challenging – *'You know, sometimes parents even fail together in a relationship. We'll have different views'.*

Furthermore, there was also realisation that during situations where both parents have responsibility, one parent would make the final decision regarding withdrawing treatment. This has been managed by health professionals to ensure both parents are content with the decision made. Given the difficult nature of the conversation concerning decision-making, professionals have reported conflict and disagreements between parents deciding on whether to withdraw a child's treatment. This was reflected through an allied health professional when they mentioned managing conflict was difficult 'even conflict between parents so one parent may say something and it's difficult because how do you manage that'. Professionals clearly stressed that when parents were contemplating on deciding, they hoped that the decision made by parents was the most appropriate. With professionals explaining that this is particularly relevant amongst families who had conflicting views regarding treatment. A medical professional identified that

> *"We've had families who've 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" (Medical Professional, Female)*

Although decision-making was influenced by several individuals, an allied health professional voiced their opinion regarding parents deciding with stating that *'The choice is theirs. And they have to go away, and they have to make a decision on it'.* It was clear that professionals felt that parents would be required to live with the decision made and if they decided upon withdrawing treatment, they would need to ensure a decision was made comprehensively.

Within Professionals

There was a clear indication that the majority of Allied health professional's role involves a significant amount of supporting the family. This was clear when HCPs were asked of their own role amongst the decision-making process and how they viewed the importance of their role. Only several medical professionals, predominately nurses, identified their role as supporting with an importance of a family focused approach and person-centred approach. It was mentioned that empathy played a significant part in the decision-making process especially when they could witness the difficulty parents and family endure during such a difficult time. Many professionals demonstrated the impression that families were backed into a corner with deciding to withdraw treatment and the emotional support from HCPs was greatly welcomed.

> *"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" (Allied Health Professional, Male)*

There also appeared to be some recognition from Allied Health professionals in ensuring other staff amongst other departments across the hospital were more *'Pastorally minded for the family'*. This in turn demonstrated that Allied Health professionals recognised the importance of ensuring families and parents are included within all discussions with professionals reporting that they '*never go against the wishes of a parent'.* Further to this, medical professionals recognised that sometimes they overlook the viewpoint of families especially as the patient is their child. It was emphasised by professionals that as HCPs making decisions was a standard practice as it is their job to discuss and negotiate with treatment options.

> *'we make lots and lots of life and death and treatment decisions all the time.' (Medical Professional, Female)*
>
> *'I think sometimes we forget where families are coming from you know like it's their child and sometimes, they don't listen to us professionals' (Medical Professional, Male)*

However, having said this, some professionals demonstrated that although empathy supports the conversation, this can end up making it difficult in supporting parents with decision-making. A consultant reported that professionals should not be ‘too emotional’ with parents and family and should be clear and direct within their approach around withdrawing treatment. Similarly, there were concerns that allowing parents with *‘too much power’* during the process appeared to cause more issues within the decision-making process. This meant thatprofessionals reported that parents were involved too much within the decision-making process which often caused conflict. This was further strengthened amongst professionals who recognised that this was largely difficult when parents and families were not aware of the complete treatment option or the reason behind withdrawing treatment. Although professionals recognised that the patient is their child there was a sense that allocating a significant amount of power within the decision-making process was not beneficial. The power employed by parents and families was complemented by the hope parents had for their child’s recovery. Professionals reported that although empathy and compassion were fundamental components of conversations about treatment withdrawal; it was difficult when parents and families had hope in the recovery of the child. The combination of optimism and power for parents caused some friction between professionals and parents especially when changing the minds of parents.

> *“Parents think there is hope and when they have that hope it is difficult to change their minds” (Allied Health Professional, 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 don’t know the full background” (Allied Health Professional, Female)*

As a part of providing empathy to parents and families to aid decision-making, there was a clear recognition that it was important to not hurry conversations with families. This was especially identified as an issue when the child was deteriorating quickly, and decisions had to be made instantly or fairly quickly. Professionals emphasised the importance of relationships with the child, parents and family which influenced the conversations held to discuss withdrawing treatment.

> *"Trying not to rush families. But that's not always a luxury we have. Particularly the child's deteriorating fast. And we feel we feel it's. It's it's not in their best interests." (Allied Health Professional, Female)*

> *"I think that we have very long and often very long-standing relationships with families" (Medical Professional, Female)*

> *"when it comes to if it comes to a removal of the life support machine, there is already established a therapeutic relationship, which then helps that family to begin to hear what I might be saying" (Allied Health Professional, Female)*

As part of informing parents and families, professionals identified that there appeared to be conflicting information from professionals, which made it difficult for parents and families to make a decision regarding their child. This conflicting information was recognised as being confusing for parents. One consultant in particular identified that it is common for professionals to state different viewpoints regarding treatment options which makes it difficult for the family. '*one consultant is saying one thing another is saying something else I think it gets confusing when there is so many different teams involved you know oncology palliative care it can get confusing and I think parents struggle with this'*. This was further acknowledged by an Allied Health Professional who reported that '*when one doctor is saying one thing, and another is saying a conflicting view point the families get confused you know they don't know who to listen to or what to do'*. There was a sense of feeling 'stuck in the middle' for parents with professionals stressing that parents did not know who to listen to when there was conflicting information amongst professionals. This was identified as a challenge for many professionals with the difficulty of supporting parents and families when conflicting information was reported by professionals. Another Allied Health Professional reported that

> *“what I’ve always noticed is that sometimes different people I mean different colleagues say different things and that’s confusing for parents they have told me before they don’t know what to believe and who to believe but because we aren’t clinical we can’t really help as it’s all stuck in the middle” (Allied Health Professional, Female)*

Although the majority of professionals reported managing conflict between professionals and families, some professionals made reference to experiencing conflict within professionals. Some allied health professionals reported although their roles were to support families during this difficult time, it was particularly challenging for some allied health professionals as they expressed that many parents felt professionals were naturally supporting clinical staff. One professional made reference to their experience with *‘my experiences have shown me that there's sometimes a lot of rejection of having the chaplain there because they see this chaplain as being on their side, on the clinicians side’.* Additionally, managing conflict was difficult when there were disagreements within professionals, which proved to be a challenge in managing and mitigating the situation. This was reflected by an Allied health professional who mentioned that disagreements and conflicting information between professionals was common during the decision-making process ‘*well the most common one is that not everybody agrees there is sometimes not agreement in the same specialities which makes things difficult’.*

Between Professionals and Families

Professionals recognised the importance of supporting the child, parents and wider family members during the decision-making process. Further to this, professionals maintained that parents required a significant amount of emotional support given the nature of withdrawing their child's treatment. When professionals were asked on how parents are supported during the decision-making process, many individuals suggested that they are supported throughout. A consultant maintained that parents receive significant support from staff by mentioning that *'well they get a lot of support from staff you know they have multi chats with consultants it's not just one conversation you know.'* It was clear that supporting parents during this difficult time allowed professionals to work with families and if possible, reach a collective decision. Further to this, there was acknowledgement from Allied Health Professionals that supporting families was a major aspect of their role: *'I'm not a medical profession so I can't speak to consultants about the ins and outs of treatment but I feel I am able to talk to them about supporting the family'.* Professionals maintained that supporting parents was achieved by ensuring they were informed throughout the decision-making process: '*we tend to ensure that the parents are informed really thoroughly but it isn't always a simple as that*'. It was identified that a means of supporting parents and families involved extensive communication. This was particularly demonstrated by an Allied Health Professional who stated that *'what we do is keep in touch and in contact with them ensure the parents know what is happening but it's not just parents you've got siblings too they have to understand what is happening cause you know one day they will wake up and their brother or sister isn't there'*. There was acknowledgement that the support offered to parents, siblings and external family members did not differ. Professionals worked closely with parents to inform siblings on the news of their brother or sister. This was echoed amongst all professionals where supporting individuals consisted of allowing family members to come to terms with withdrawing treatment. There was realisation that there were situations where parents were unsure on the decision to make and agreed with whatever professionals said. Professionals emphasised that ‘*parents have given up, so they just go with whatever the professionals say’*. It was clear from this that this supported parents during the decision-making process as the onus fell on the professional rather than the parent and family. Although decision-making was a collective decision, many parents felt they had reached an impasse and therefore agreed with the decision made by professionals.

The majority of the cases discussed by professionals were of children of a young age. However, professionals realised that young people who were aware of their condition required extensive support from professionals. Professionals particularly identified that young people from the age of 13 onwards required emotional support from professionals. Professionals reported that most parents did not want decision-making conversations to be held with children especially with older children who were coherent and developmentally able to understand. This was reported via an allied health professional who mentioned:

> *“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 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” (Allied Health Professional, Female)*

Further to this, professionals demonstrated that parents wished to protect their child hence keeping information away from the child. This was highlighted by an allied health professional who reported that

> *“Many of suspect that older children do realise how ill they are but 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 don't feel at liberty to say it to not upset their family" (Allied Health Professional, Female)*

During situations where parents and professionals were not able to reach a consensus, and parents did not wish to attend court, professionals reported that in many cases treatment was continued until the child passed away themselves. Thus, suggesting that, although decision-making was incredibly difficult for all parties involved, professionals felt sometimes the child would give up themselves by passing away. This was particular discussed amongst professionals who felt children who were aware of the situation realised the pain they were in and as a result *'gave up'* to avoid any further disagreements with family.

> *"We've come we've carried on until the child's declared themselves by passing away." (Allied Health Professional, Female)*
>
> *"It's very it's very rare for the child to be considered old enough. Usually parents don't want to fully inform them. And even if they're teenagers" (Medical Professional, Female)*

Supporting families was highlighted as being personalised where professionals *'look at individual family cases like everyone is different offer different support some parents get the decision of professionals and some don't'*. There was realisation that the personalities of families and how they accepted the news of professionals withdrawing treatment influenced how families were supported. Additionally, when professionals were asked regarding the Charlie Gard case, there was acknowledgement that supporting parents and families required gaining trust and offering a helping hand during this difficult situation. This was mostly identified by allied health professionals with one professional mentioning that *'I think sometimes all they want is for someone to listen to them and just hear them out really I don't know what else'.* Professionals also maintained that trust enabled parents and families to engage with them and discuss their child. There was the realisation that confidentiality played a huge role within supporting parents, families and the child. Particularly Allied health professionals demonstrated that parents especially felt confident in discussing the decision-making process away from external family members after trust was obtained with the professional. There was recognition that sometimes these conversations would be held with one parent especially when there were conflicting views between parents. Supporting families and gaining trust with them influenced the decision-making process as it enabled professionals to work with family members and understand the rationale between medical professionals withdrawing treatment. This was especially prevalent amongst cases where professionals maintained that eventually families have decided with the professional with one medical professional suggesting that *'To this day, even though some of them have been intense struggles, I have not had a case where it has worked, where the family haven't decided in the end that it is the right thing to do'*. Further to this, all professionals maintained that it was not very prevalent for cases to be sent to court. The majority of the cases reached a collective decision amongst professionals and parents with professionals suggesting that '*Normally the family have come around and accepted* it'. Thus, highlighting that parents and families eventually understood the rationale behind professionals withdrawing treatment and after receiving support were able to reach a collective yet informed decision.

> *'And when they understand about the confidential, confidential, confidential nature of our of our our intervention, our interaction, that's when they start to begin to trust us more. They're able to speak about things that they can't always speak about with others or even speak speak to us when families, other members of the family are not around so could be mom on her own, it could be dad on his own or it could be mom and dad without in-laws and parents, grandparents or without their children around, or their siblings, uncles and aunts so they begin to understand' (Allied Health Professional, Female)*

There was sense of frustration amongst both allied and medical health professionals when support to parents and families was not greatly appreciated. It was clearly demonstrated that although families receive ‘*incredible amount of support’* from health professionals, this was not welcomed by some families who chose to ignore any advice offered. Parents would opt to discard advice and continue on their own accord, which many professionals felt uneasy about. Some parents would seek support and further advice from other means such as the internet, which professionals identified as being unreliable and therefore made them uncomfortable.

> *“Our families an incredible amount of support. 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” (Medical Professional, Female)*

Professionals admitted that amongst families where support was not actively welcomed, a collective decision in those cases was not achieved. As a result, majority of these situations required professionals and families attending court as both parties had reached an impasse. Many families did not understand the decision made by professionals and therefore refused support offered by health professionals. A major aspect of communication was reported by professionals as ensuring information provided to parents, families and the child was transparent and honest. There was a sense of ensuring that decision-making conversations occurred as early as possible with parents. Professionals recognised that being honest with parents and family supported the decision-making process. One Allied Health Professional made reference to the importance of transparency and honesty when making reference to the Charlie Gard case: *‘I think I would have been open and honest to the family we need transparency and the only way we can do that is if we are honest’*. This was further acknowledged by an Allied Health Professional who reported that '*clinical staff are used to fixing people that that's where battles like Charlie's case happen'*. This evidenced that staff challenges were evident with allied health professionals reporting that clinical staff tend to refer to the medical model more.

As part of honesty there was the realisation that conversations regarding withdrawing treatment were difficult and parents and families needed to realise that professionals have sought all treatment options for the child including research trials but to no avail. This led to difficult decisions which required honesty ensuring that families understood that a decision regarding withdrawing treatment was exhausted after all treatment options were implemented and tested. Professionals identified that providing accurate and honest information was vital to support the decision-making process. A medical professional reported that communicating through transparency and honesty allowed the professional to feel at ease especially when they felt this approach had '*less emotion'.* This was further enhanced and stressed by professionals when they felt being honest supported their relationship with the parent. Professionals maintained that a key aspect for the decision-making process was to ensure parents and families trusted professionals and this was aided through honest and transparent communication.

> *'we have tried everything including research trials then there is nothing else we can do sometimes we can't always help we can't cure and that's why we have to make difficult decisions' (Allied Health Professional, Female)*
>
> *'there is less emotion and more of the accurate information which helps I offer my thoughts and opinions and it works well' (Medical Professional, Male)*
>
> *"we need the parents to trust us and we need to trust them and the only way we can do that is if we are open and honest to them in the first place" (Allied Health Professional, Male)*

Professionals felt that a key element of communication was ensuring family members were briefed on the child's progress. There was clear indication that HCPs recognised the importance of informing relatives to ensure they were provided with full details of the child's progress. Professionals discussed that although it was important to brief relatives, it was also imperative that they clearly understood what was going on. HCPs emphasised that they were able to recognise and mitigate poor communication by working closely with the family. This was particularly relevant to allied health professionals, who felt from previous experience that it was important to work closely with family members regarding the child's progress.

> *"ensure the parents know what is happening" (Allied Health Professional, Male)*
> *"In terms of just making sure that the families understood everything" (Allied Health Professional, Female)*

There was also a sense of trial and error amongst treatment options where HCPs recognised that they tended to be direct with parents especially when a treatment intervention was the final viable option. One Allied health professional reported that '*the last family we were supporting every intervention that has been tried the family have been told that if this doesn't go well then there is not much more we can do'.* Further to this, professionals maintained that parents in their experience felt guilty if they did not exhaust all possible treatment options. However, professionals reported as part of their role it was imperative that they exhausted all options before withdrawing treatment; but this was not recognised amongst families. This was further expressed amongst families who felt guilty when they eventually decided to agree for their child's treatment to be withdrawn. There was also a sense of miscommunication with families especially with the thought that professionals would withdraw treatment without consent from families. As a result of this, HCPs highlighted the importance of fully debriefing parents and relatives to avoid confusion.

> *“We are not just going to turn off machines without the consent of the families” (Allied Health Professional, Male)*
>
> *“Often in situations whereby they are blaming themselves for agreeing for their child's treatment to be turned off” (Allied Health Professional, Female)*
>
> *‘if the family were unsure that everything had been done and had been tried, we may very well be able to kind of help where poor communication has happened’ (Allied Health Professional, Female)*

However, a medical professional reported that disagreements and conflicting conversations arose due to ‘*families get involved too much and that can make it difficult*’. This was stressed as sometimes families not understanding the situation fully which caused conflict and disagreements between both parties. There was realisation that the decision-making conversations and discussions were difficult especially ‘*when parents don’t agree with us*’. Although encountering disagreements was a common theme reported by professionals, there was realisation from professionals that disagreements and conflicts did not occur as often. This was emphasised by an allied health professional who reported the importance of mitigating disagreements through communication ‘*I wouldn’t say happens often but when it does happen we need to talk to the parents you know’.* Professionals emphasised that generally disagreements were encountered due to parents and families not understanding the reasons behind professionals withdrawing a child’s treatment. An allied health professional reported that *‘it’s for the parents to understand the professionals you know medics won’t stop treatment without knowing for sure and the families that I see sometimes they struggle to understand this’*. There was realisation that disagreements were due to lack of understanding from both professionals and parents, which created difficult situations. It was clear that situations similar to Charlie Gard case did not occur often. Health professionals identified that scenarios of actively researching further treatment options were prevalent within their experience. There was persistence from parents and families with pursing other treatment options after professionals raised the discussion of withdrawing treatment. This was clear amongst medical staff who reported '*there may also be a scenario where if, you know, families are going to continue to pursue something and it is something that essentially is deliverable here and you want to prevent them to run you run off to Timbuktu for it, that actually there may be discussions around the appropriateness of that'.*

Moreover, there was acknowledgement that managing conflict involved extensive communication between professionals and families. It was clear from a medical nurse that conflict was generally managed by '*we you know, we come to a collective decision. And actually, there is always the possibility of discussing those things. I think at the end of the day, it's about working with what is most comfortable with that family. So, we will always put the ideal scenario from a medical perspective.*' It was clear from both medical and allied health professionals that managing conflict was vital especially with supporting the child, parents and families in the heart of their decisions.

Further to this, there was acknowledgement that professionals use pathways to support them managing conflict between parents and medical professionals. An Allied Health Professional reported that '*well it depends I mean we have a pathway when parents and medical staff don't agree to follow, and it works but obviously a pathway doesn't always work'.* It was clear that managing conflicts was not easy and sometimes external factors were considered within the decision-making process.

Theme 3: External factors in decision-making

Professionals suggested that various factors could influence the decision-making process such as culture, religion, and other neutral external bodies such as advocacy.

Cultural Considerations

There was significant recognition from professionals, particularly allied health professionals, that it was important to consider the cultural factors of the child and family within the decision-making process. This was reflected when a professional mentioned that '*it's a cultural issue with regards to how authority decision-making is made within that family and culture it might very well mums name down with decision-making but outside the clinician that decision-making may well be going on elsewhere*'. It was clear from professionals that decision-making conversations were not solely between HCPs and families. Decision-making consisted of wider factors with beliefs and culture taking an importance on conversations around withdrawing treatment.

> *'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' (Allied Health Professional, Female)*

Professionals identified that it was necessary to recognise that discussing withdrawing treatment was influenced by factors such as language barriers. With professionals supporting a diverse population, there was recognition that conversations around withdrawing treatment were difficult to understand especially within families where English was not their first language. An allied health professional identified that '*these things can be misunderstood of why people are not agreeing and if I was being really idealistic I think some of our departments would perhaps not have enough staff around to be more pastorally minded for the family to be there that the family's voice is being heard*'. Language barriers influenced conversations as professionals maintained that there was misunderstanding between parents and professionals when an interpreter was not supporting the conversation. An allied health professional mentioned that *'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'*. This was echoed amongst a number of professionals especially allied health professionals *'like cultural differences and languages you know not everyone we see speaks English so it can be difficult to get the messages across'*.

Due to language barriers, professionals identified that they experienced broken relationships with parents and families especially regarding withdrawing treatment. There was acknowledgement that professionals sometimes struggled to take into consideration a patient's cultural differences, which in turn led to disagreements or broken-down conversations.

Further to this, professionals reported that the media played an influence on parental decision-making, which in turn influenced conversations that were raised by professionals. This was particularly raised during discussions around the Charlie Gard whereby professionals reported that parents were influenced by media during discussions around withdrawing treatment. There was a sense of admittance from professionals that many parents and families used media to strengthen their case and support their conversations against withdrawing treatment. Professionals maintained that the media acted as an instigator amongst conversations and this was echoed during the example of the Charlie Gard case. There was the realisation that information portrayed on the media was incorrect and this caused friction between professionals and families especially when families were adamant the information received via the media was correct.

> *“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” (Allied Health Professional, Female)*

> *“As professionals we would do anything different I mean everything was portrayed by the media and the media played a huge role in creating problems they don’t know the full story I mean I didn’t know the full story but the media created this battle between the hospital and the family” (Allied Health Professional, Female)*

> *“The media really don't help because they know that they don't know what they're talking about all the time. They're coming out with incorrect facts” (Medical Professional, Female)*

Impartial Body

Professionals identified that in situations where professionals and families could not reach a unanimous decision, cases were referred to a third party to intervene. All professionals recognised that using a neutral and impartial body during the decision-making process was vital for maintaining communication. This was particularly mentioned by allied health professionals who stated *that ‘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’*. There were discussions that attending court to manage conflict was not very common but when it occurred it was not viewed as failure.

There was the realisation that during these difficult conversations, seeking support from additional sources such as impartial bodies, mediation and courts allowed professionals and families to obtain a second opinion. Allied Health Professionals reported the importance of obtaining a second opinion by '*get a second opinion or a couple of opinions someone who is neutral and outside the hospital'*. Seeking impartial advice enabled professionals and parents to receive an objective decision regarding the child by individuals who were not known by the child, professional or family. Professionals maintained that transferring the case to courts was predominately advocated by parents and families, especially when they did not agree with the reasons behind professionals withdrawing treatment. It was clear that HCPs identified the difficulty of parents and professionals reaching a unanimous decision and felt attending court enabled both parties to reflect and allow the decision to be made by an unbiased body.

> *"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" (Allied Health Professional, 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 don't 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" (Allied Health Professional, Male)*

There was acknowledgment that reaching for an impartial body took the pressure away from professionals and parents in terms of making the decision. It was also recognised that an external body was more impartial and neutral and therefore would not be influenced by external factors such as any cultural or religious views or any personal relationships within the family. It was widely acknowledged that professionals and parents were influenced by external factors such as culture and religion, which did not influence impartial bodies. Professionals emphasised that court appearances during the decision-making process were on the increase, especially since the Charlie Gard case. It was recognised since the high-profile case of Charlie Gard; professionals reported that parents had more confidence to take their child's case to court since witnessing Charlie Gard's case.

Religious and Spiritual Considerations

Further to cultural considerations, professionals identified the importance of religion and spiritual influences. Many professionals reported the difficulty of engaging with parents and families when they held strong religious viewpoints regarding end of life.

There was recognition from professionals that chaplaincy predominately acted as an advocate for families in supporting with spiritual and pastoral care. An Allied Health Professional expressed the importance of their role as a Chaplain through stating '*chaplaincy staff are trained in offering the spiritual and pastoral care we are able to offer and engage with every family'.* 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. An allied health professional reported that '*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'*. There was a huge emphasis from professionals that families with religious views stated that '*God will cure him on any treatment'* and therefore would not take withdrawing treatment as an option.

It was clear that families with strong religious and spiritual views influenced the decision-making process. It was stressed that many medical professionals did not take such views into consideration. Upon raising the discussion of withdrawing treatment with families, many individuals would relay the information back to their religious community to discuss withdrawing treatment. Parents and families would seek advice from their local community, which sometimes would cause disagreements between HCPs and families. Some families preferred involving religious leaders within decision-making conversations to guide them and offer support especially as they believed withdrawing treatment as a '*murderous act'.* Professionals recognised that communication between professionals and parents was influenced by religious perspectives. This was further expressed by an Allied Health Professional who mentioned that sometimes parents felt that professionals did not understand their religious backgrounds and viewpoints.

> *"I have tried in my capacity to help the family to understand this, because it's not easy, is it? You know, even jargon isn't easy to understand for anybody. And if you're not in the medical profession, it's it's not easy. So, when when the clinicians are trying their best to help the families understand that they're trying to to use lay language as well, to help them to understand. But even when they've understood that lay language, they are often feeling that this clinician doesn't understand my religious perspective of it." (Allied Health Professional, Female)*
>
> *"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" (Allied Health Professional, 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" (Allied Health Professional, Female)*

Theme 4: Psychological Wellbeing

Given the nature of the topic and the requirements of their roles, all professionals identified the importance of psychological wellbeing amongst themselves and families.

Psychological Wellbeing of Health professionals

Professionals recognised that withdrawing a child's treatment was a difficult decision to make or be involved in whether they are a medical professional or an allied health professional. There was acknowledgement from all professionals that supervision played an important role in supporting them psychologically. Professionals admitted that support from their peers was greatly appreciated with resources such as '*team huddles'* and *'clinical supervision'* supporting professionals to off load and discuss any pressing and emotional matters. There was acknowledgement from some professionals that the current support received was sufficient for them with one allied health professional particularly implying that '*it just looking after own health and wellbeing isn't it*'. There was acknowledgement that professionals felt they were in control of their emotions and felt they were looking after their own mental health and wellbeing. Peer support from other colleagues was especially welcomed by professionals, as professionals highlighted that discussing their day or difficult situation with colleagues was beneficial as they understood the working day. There was acknowledgement that receiving support from other colleagues facilitated improving psychological wellbeing. A medical professional reported that *'I work with a group of colleagues. We all support one another. We talk and yeah, having a difficult day or with one another to get support from colleagues'*. There was also recognition that professionals seeking support from a psychologist was greatly appreciated. This was evidenced amongst professionals where they felt understanding their emotions and actions was vital for their day job.

> *‘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’ Medical Professional, Female*
>
> *‘I think support wise I’m ok I don’t think I need anything else it’s just looking after your own health and wellbeing isn’t it and I think I do that well’ Allied Health Professional, 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 haven’t had one for a while but that helps me talk and things and understand it a bit better’ Allied Health Professional, Female*

In particular, one professional demonstrated the difficulty of the topic and withdrawing a child’s treatment when they began to get emotional during the interview. A professional explained that due to lack of communication within a previous case, a child lost their life with the professional showing clear signs of emotion. This was reflected during

> *‘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 Allied Health Professional, Female*

The professional admitted that as a result of that situation, their resilience had increased and therefore felt better within themselves ‘*I’m a lot better now it happened years ago, and it’s made me a better person and it’s built my resilience I’m ok I just felt it was my fault we lost the child’*. Upon discussing support during this difficult time, the professional mentioned that peer support was welcomed with communication being recognised as imperative. This was reflected through *‘my seniors were very supportive, and I learnt that communication is* *key there needs to be a consistent pattern around communication especially around treatment everyone needs to be involved and informed'.*

Further to this, professionals reported taking part in physical activity, such as walking and running, helped improve their psychological wellbeing. There was acknowledgement from professionals that they were confident with their coping mechanisms to support them during difficult work situations. An Allied Health Professional emphasised this by '*I have coping mechanisms which work well so after work I go for long walks just aimlessly in the park just to clear my head before I walk into the doors at home'.* There was recognition from professionals that although some days were difficult given their job role, they felt it was important to ensure they had a coping mechanism. This was particularly demonstrated by professionals as managing their work-life balance to ensure their professional life does not interfere with their personal life.

Psychological Wellbeing of Parents

Professionals reported that withdrawing a child's treatment had a significant effect on the psychological wellbeing of parents. There was wide acknowledgement that parents struggled with deciding to withdraw their child's treatment. This was reflected amongst parents deciding on whether to withdraw treatment and also during the decision-making process when a decision had been made.

> *'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' Allied Health Professional, Female*

Professionals emphasised that hope played an important part in the psychological wellbeing of parents. This was reflected by an Allied Health Professional who reported that *'parents think there is hope and when they have that hope it is difficult to change their minds'*. There was also realisation that supporting parents influenced parental wellbeing with professionals identifying that they needed to be flexible with parents. This was particularly demonstrated by an allied health professional, who admitted that their child passed away at this hospital and therefore they were able to understand the difficulty faced by parents. *'We need to be flexible with parents and be supportive as professionals we can only imagine what parents are going through, but I know it's difficult my child died at this hospital a few years ago'.* Although it was not clear whether their child passed away as a result of withdrawing treatment, the professional was able to explain the difficulty from a professional and a parent who has lived the experience.

Further to this, professionals identified that psychological support for parents was available but limited due to long waiting lists. Support such as counselling was reported as advantageous for parents and professionals identified that the further counselling sessions were beneficial. This was reflected by an allied health professional who stated that '*we have very long waits for referring on for stuff like psychology and counselling and that there is availability'*. There was also realisation that professionals witnessed parents requiring psychological support, but they were hesitant to discuss due to the long waits. This was especially emphasised for parents and families where withdrawing treatment had already been decided or the child passed away as a result of it. Although some professionals acknowledged that psychological support is available, there was realisation that support for parents required a psychological perspective. This was particularly emphasised by an allied health professional who mentioned *that 'I mean it's not easy for parents I really believe all* *this needs a psychological perspective we need some psychology support or therapy for parents'*. There was realisation that professionals understood the support required for parents was necessary especially when a decision was made. An Allied health professional demonstrated that

> *"we use to have a psychologist for families before but she left and I don't think they have or will replace her she was needed I think as professionals we can do more to support the wellbeing 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" (Allied Health Professional, Female)*

During situations where psychological support was recommended to parents, many professionals identified that parents reported facing stigma upon seeking psychological support. There was a clear sense of realisation that professionals felt they were not able to support parents and families to a high extent due to the close relationship they have. Stigma was perceived as a barrier for parents asking for psychological support, as there was an assumption by parents that individuals needed to be mentally ill to seek help. Professionals identified that parents required mental health support during and after the decision-making process. This was particularly emphasised by a professional who stated that '*parents need psychological support and I know there is stigma attached with psychology because parents think they may be going mad or crazy but they need low level support they need someone to help them we can't do that we are too close to the situation so I think that is what is needed'.*

> *'I've certainly had a child recently died and she hadn't as yet got her psychology appointment' (Allied Health Professional, Female)*

> *'It was an element of psychological support for parents and families to cope with' (Allied Health Professional, Female)*
>
> *'So, I think that urgent access to very skilled psychologist' (Allied Health Professional, Female)*

Theme 5: Recommendations to support decision-making

As part of the decision-making process, professionals felt further availability to training courses and resources to support decision-making were vital. There was acknowledgement that professionals required support around understanding death to allow them to cope with their role. Professionals acknowledged that future support was required for parents and families to enable them to make an informed decision and support their wellbeing.

Supporting professionals with decision-making

Although professionals identified that support such as clinical supervision and team huddles was beneficial there was wide acknowledgement that professionals required further assistant to cope with the struggles of their role when withdrawing a child's treatment. In particular, there was wide recognition that professionals required further training. This was especially stressed as training around withdrawing treatment and death should be more prominent within their training years.

> *'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 don't really understand death'* (Allied Health Psychology, Female)

As well as standard training around death and dying, professionals reported that, training regarding communication was needed for health professionals. There was recognition that communicating with families in '*breaking bad news'* was required to support the decision-making process.

Professionals reported that understanding a families' cultural and spiritual influences was vital to support the decision-making process. Professionals especially allied health professionals identified that further support regarding cultural and spiritual factors was required. This was correlated with professionals acknowledging that communication regarding breaking difficult news was required.

> '*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*' (Allied Health Professional, Female)

Further to this, there was acknowledgement how withdrawing treatment ties with organ donation and should include cultural and spiritual factors considerably during the process. There was realisation that as part of the decision-making process, issues around afterlife should be discussed. It was especially stressed that children who were of a certain development stage should have the opportunity to decide for themselves. Organ donation was an aspect of decision-making that health professionals felt was necessary for children to be a part of. It was suggested that decisions such as these should be included within care plans.

> ‘*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’* (Allied Health Professional, Female)

Given the difficulty of the topic, professionals demonstrated that enhancing communication to discuss bad news was necessary for all staff whether they were medical or not.

> *‘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’ (Allied Health Professional)*

This was echoed by another allied health professional, who discussed that enhancing communication required working with ‘*advance care plans’* and there was acknowledgement that these communications needed to *‘ensure that people understand any culture or religious factors involved’.*

Supporting parents with decision-making

As professionals have identified previously, supporting parents was a huge aspect of their role and throughout the decision-making process. Professionals identified that currently the hospital have a facility for palliative care, bereavement care and support. It was demonstrated that this calm and peaceful environment facilitated professionals to meet children, young people and their families to have discussions regarding palliative and end of life care decisions. There were discussions that this facility allowed children and families to access therapies such as massage, play and counselling.

> *‘I think that parents are supported in the process so I wouldn’t say anything needs to change or be done better I mean the setting and environment is ideal especially with us being so lucky with magnolia house’ (Allied Health Professional, Female)*

> *‘we have had magnolia house since 2017 and it’s a place where families and child can find peace honestly speaking it actually where discussions around life threatening illness and decisions are made its open and peaceful and you know parents and sit down and just get their head around things especially if they need a minute to digest what the staff have said and we are so so lucky I mean I know not many hospital have this facility’ (Allied Health Professional, Female)*

Professionals also reported that supporting fathers was necessary as the majority of support was offered to mothers who professionals assumed were primary caregivers. Several allied health professionals specifically mentioned that father’s required support during the decision-making process. After witnessing a gap for support for fathers, professionals introduced a support group for fathers. Professionals identified the group as beneficial especially as fathers would not openly discuss their emotions. This was reflected by

> *‘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’ (Allied Health Professional, Female)*

Interestingly, a medical professional emphasised that media plays an important role within supporting parents with decision-making, which in fact causes problems between health professionals and families. There was acknowledgement that stories within the media influence parental decision-making as parents would use those case studies to compare their child's situation. . A professional recognised that parents seeking support from like-minded individuals on an online forum proved to be advantageous. This was reflected by an allied health professional who stated that '*Usually after talking on some kind of forum with other parents rather than rather than sort of typing something into Google or so it's usually quite it's quite usually quite informed information'.* There was recognition that this avenue assisted professionals with supporting parents.

Discussion

The present study aimed to explore health professionals' experiences of decision-making with regards to withdrawing a child's treatment. The study aimed to understand health professionals' role within the decision to withdraw treatment and how decision-making is managed amongst staff as individuals and as a team. This is the first study to the author's knowledge that has explored the views of health professionals in withdrawing a child's treatment. The findings of this study enhance previous literature and aim to address a gap. The results of the study identified five master themes: (1) Best Interests of the Child (2) Multidisciplinary Approach (3) External Factors (4) Psychological Wellbeing (5) Recommendations to support decision-making. Professionals identified that all decisions were made in the best interests of the child. This involved consideration of a number of factors such as exploring all treatment options, the severity of the condition and the competency of the child to decide. In particular, allied health professionals felt that the child's family played a huge role amongst the decision-making process with communication and cultural factors being reported as influencers. However, clinical professionals felt that families were an inconvenience to the decision-making process. The decision-making process was identified as predominantly being made through a clinical approach, whereby medical professionals offered suggestions on withdrawing treatment and it was up to the family to decide.   There was a realisation that incorporating the views of the child, parents and other professionals influenced the decision-making process. Albeit professionals reported that conflicting viewpoints caused frustration, there was realisation that involving all individuals was vital. Further to this, health professionals recognised that fathers require more 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 limited and more research needs to focus on the viewpoints of fathers within the decision-making process (Zvara, Schoppe-Sullivan, Dush, 2013).

Although majority of literature has demonstrated the importance of the views of parents withdrawing a child's treatment (Heath et al, 2016; Hinds et al, 2000; Hinds et al, 2009; Gagnon et al, 2003 & Meyer, 2002) further research would need to focus on the differences between mothers and fathers during the decision-making process. Interestingly, parents maintain that making decisions such as withdrawing a child's treatment is a normal part of parenting in terms of making decision for their child (Wiess et al., 2018) and health professionals should support this. Contrary to this, health professionals maintained that parents hold too much power when they are not trained medical professionals during the decision-making process and professionals provided them with too much control. This was particularly emphasised by medical professionals who reported that families did not always understand the complexities of the rationale behind HCPs decision-making. Furthermore, it would be interesting to understand the experiences of parents and families upon hearing that some HCPs believe too much support is offered. With a huge emphasis on family centred care within healthcare (Kuo et al., 2012), further research would need to explore the experiences of families during this difficult time.

In particular, a consultant demonstrated an air of confidence that their role was rooted in the medical model and they were just undertaking their roles as medical professionals. There was recognition that medical professionals required to not show emotion and that adhering to facts as per the medical model were vital. However, the authentication of such model and approach can be questioned as allied health professionals mentioned that parents and families tend to receive conflicting information from different consultants and as a result if the medical model were infallible all medical professional would be stating the same. In particular, a case of Tafida Raqeeb is a clear example of where medical professionals made the wrong decision and their decision-making can be questioned. The case of Tafida who was on life support since February 2019 was taken to the high court. The NHS hospital trust reported that it was not in the child's best interests to continue life support and treatment should be withdrawn. It was ruled that as Tafida could not feel pain and therefore not suffering, it was the correct decision for her parents to take her to Italy for further treatment (Dyer, 2019).At the time of writing this thesis, Tafida has since made incredible progress and has been moved out of intensive care unit in Italy (Cave et al, 2020). Therefore, demonstrating a clear example of when the medical model may be problematic and parents have the right to question such decisions.

Furthermore, professionals emphasised that the decision-making process consisted of a multi-disciplinary approach with medical professionals particularly making reference to the medical model. It was clear that majority of allied health professionals were not part of the decision-making process and felt it was very medical focussed. This echoed previous literature whereby power dynamics between health professionals were prevalent especially during the decision-making process (De Leeuw et al., 2000; Gallagher et al., 2015). Further to this, the results of this study were separated amongst medical professionals, which included consultants and nurses and allied health professionals, consisting of chaplaincy and family support workers. It was clear that supporting parents during this difficult time was offered by health professionals, especially nurses, and a number of allied health professionals. Similar to existing literature, nurses were more likely to ask the opinion of parents regarding treatment options (De Leeuw et al., 2000).

Furthermore, in line with research, allied health professionals reported that decision-making should be a collective approach ensuring the views of all professionals medical or otherwise should be considered (Heyland et al., 2003). Although it is inevitable for conflict to occur between health professionals and families, especially when HCPs report parental involvement within such decisions acts as a barrier (Kirk, 2001), literature has identified the importance of a partnership approach amongst professionals and families (Kirk, 2001). Health professionals in the current study reported the difficulty when parents and families sought further information from other parents to support them with the discussions. Although professionals identified that this caused difficulty within the decision-making process, existing literature identified the importance of parents seeking shared knowledge from other parents in a similar situation (Youngblut, Brennan, & Swegart, 1994). A systematic review explored the facilitators of decision-making of parents during child health decisions (Jackson et al., 2008). The review identified that parents reported information on the child's health was vital to inform decision-making and feeling a sense of control over the decision-making process influenced parental decisions. Further to this, parents have reported that being a good parent is a critical aspect of making decisions regarding their child (October et al., 2014). In particular, fathers ranked making informed medical decisions as most important within their child’s healthcare, whereas mothers focused on putting their child’s need over their own. This corresponds with the present study as health professionals reported differences amongst fathers and mothers during the clinical decision-making process.

Consistent with previous literature, professionals identified that the best interest of the child supported clinical decision-making process (Birchley, 2016). The results of this study 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 not evident amongst the Charlie Gard case where the courts were advocating for mediation when communication broke down between families and professionals.

In accordance with the common-sense model of self-regulation (CS-SRM; Cameron & Leventhal, 2003; Leventhal, Leventhal & Contrade, 1998) health professionals emphasised that withdrawing a child’s treatment was based on medical knowledge. Further to this, in accordance with the identity components of the model many professionals felt withdrawing treatment was a last resort and professionals had no choice. Medical professionals maintained that decision-making was based on facts and medical evidence. Moreover, professionals maintained that a parent’s perception of how ill their child is was influenced by comparing to other children. Professionals reported that sometimes parents felt their child was not as ill as professionals expressed as outlined within existing literature (Diaz-

Caneja et al., 2005). It was recognised that this was due to lack of understanding of the health and illness of their child.

Although a specific condition was not reported by professionals, professionals identified that in cases where withdrawing treatment was in the best interests of a child, it was important to understand the rationale behind the decision. Furthermore, as suggested by Folkman and Lazarus (1985), professionals identified using coping strategies to support them with the emotional distress related to withdrawing a child's treatment. Many professionals demonstrated an emotional focused solving strategy by distracting themselves by engaging in physical activity, such as going for a run after work to ensure their professional life does not interfere with their personal life. However, contrary to this, professionals also maintained that a problem-solving coping mechanism was explored by seeking help from clinical supervision, peers and employee assistance programmes. Furthermore, health professionals emphasised the necessity of withdrawing a child's treatment as per the necessity and concerns framework (NCF; Horne et al, 2013).

Although the model originally focuses on patient's beliefs and concerns (Phillips et al, 2014), it could explain that health professionals implicitly weigh up the costs of withdrawing a child's treatment against the benefits. Medical professionals in particular demonstrated that decisions were based on the need of the child to which allied health professional echoed although those decisions were actively made by them. Additionally, the necessity and concerns framework take into consideration professionals beliefs and concerns as part of the decision-making process. This in particular relates to the factors that influence a professional's decision such as communication, conflict, cultural, religious and spiritual considerations of families.

Professionals identified that their experiences considering decision-making and withdrawing a child's treatment consisted of encountering disagreements between professionals and families. There was a realisation that managing conflict was important to avoid situations where cases appeared in court. Power dynamics between professionals amongst decision-making was demonstrated amongst the present study.

Moreover, health professionals maintained that the decision-making process consisted of other family members not just parents. In particular, there was recognition that if the child had siblings or grandparents then their viewpoints would be involved within the process and sometimes cause conflict. A study investigated the relationship between parents and health professionals during the care and treatment of children with life-limiting illnesses (Bluebond-Langner et al., 2017). There was recognition that health professional's role is to provide treatment and parents felt the death of their child would show failure if they did not exhaust all possible options. Health professionals in the current study maintained that parents felt professionals gave up on their child when discussions to withdraw were discussed. Furthermore, similar to the current study health professionals identified that parents sought open and honest conversations to support a trusting relationship during the decision-making process (Ekberg, Bradford, Herbert, Danby, & Yates, 2018).

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). Additionally, health professionals have maintained that recognising the influence of religion and spiritual in a family's decision-making process supports health professionals to provide the best possible care to the child

(Superdock et al., 2018). Moreover, frustration amongst health professionals has identified that parents and families with strong religious views have held onto hope through a miracle to prevent withdrawing a child's treatment which in turn has caused conflicts within the process (Brierley, Linthicum, & Petros, 2013). In addition, all health professionals within the current study expressed the importance of the best interests of the child during the decision-making process. This was particularly identified as the competency of the child influenced the decision-making process, especially when the child was of a certain development age and was able to understand what was happening to them. A study explored health professionals views on the involvement of teenagers with leukaemia and found this to be advantageous for the patient (Day et al., 2017). Moreover, the World Health Organisation, (2017) demonstrates seven standards according to the rights of children in hospital. One of such standards includes the participation of children within healthcare decisions. As a result, a literature review identified the need of including children and adolescent's within decision-making in line with their human rights (Cilar, Stricevic, & Halozan, 2019). Further to this, although shared decision-making plays a role within paediatric decision-making, there is a need for future policies to focus on the standards and participation of children amongst decision-making (Butler, Copnell, & Willetts 2014).

Further to religious and cultural views, health professionals maintained that issues regarding afterlife and organ donation should be discussed prior to treatment being withdrawn and within care plans. In the UK, from spring 2020 organ donation will be an opt out decision whereby individuals over the age of 18 will be considered as a potential organ donor when they die (Hussain & Soni, 2020). Health professionals-maintained afterlife was vital and if children were of a certain development age should be involved within afterlife discussions. Although the law has not changed for under 18s, involving children and young people within such discussions would support the decision-making process and respect the wishes of the child. Having said this, literature exploring the views of organ donation within Islam found that organ donation was a matter that was decided by the parents of the child (Aktas et al., 2019). Furthermore, families believe organ donation following the death of a child should be viewed as a positive experience as it would support them during the grief process (Jackson & Vasudevan, 2020).

Limitations

This study is, to the best of the author's knowledge, the first in this area where health professionals discussed their views and experiences of deciding to withdraw a child from treatment and how decision-making is managed amongst staff as an individual and as a team. Although the findings of the present study are informative, limitations have been identified which suggest directions and challenges for future research. 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 obtain 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 present study reflects the experiences of health professionals from only one UK paediatric hospital. Furthermore, the sample included a predominance of white female health professionals and there was a limited number of clinical staff such as consultant who tend to make medical decisions. Therefore, the findings of the study may not be entirely representative of all health professionals in withdrawing a child's treatment.

Implications for health psychology and wider practice

The findings of the present study have important practical implications. Allied health professionals demonstrated the importance of shared decision-making with other professionals and the child and families. However, this was not echoed by medical professionals such as consultants who tend to be key decision makers in clinical practice. Professionals require adopting a flexible approach during the decision-making process especially when decisions from parents can change. With nurses having most contact with children and their families, they play a central role in the decision-making process with acting as the bridge between medical professionals and families. Previous literature has demonstrated that health professionals who are involved in end of life treatment decisions are influenced by cultural, legal, financial, and religious characteristics (Ntantana et al., 2017). Training health professionals in end of life should be a key aspect of all medical 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).

Taking a multi-disciplinary approach

Shared decision-making has been recognised as an interpersonal process whereby health professionals and patients and families work together to support the child's healthcare. This is particularly important during decisions where cultural factors are important during interactions. Health professionals identified that involving all professionals including allied health professionals early within the decision-making process is vital to ensure a shared decision-making approach is present. Implementing shared decision-making polices, practices and involvement of a range of health professionals amongst multidisciplinary team meetings should be adopted.

Making use of behaviour change theory and techniques

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 recognised amongst existing literature. Health professionals could use the theory of planned behaviour (Ajzen,2011) to support them during the decision-making process and would explain how multi-disciplinary decisions are made. The model aims to explain behavioural intent stating that behaviour is influenced by the attitude of a behaviour with evaluation of the risks and benefits taken into consideration (Cote et al., 2012). Health professionals take an evaluation of withdrawing a child's treatment and this behaviour is influenced by motivational and social norms of the individual. It is acknowledged that informed decision-making is based upon a through description and understanding of all possible options for the decision to be made (Thompson-Leduc et al., 2015). It is recommended that understanding decision-making is vital for health professionals and training for such should be welcomed in clinical practice.

Further to this, given the emotional difficulty of the topic for health professionals, coping mechanisms should be explored and identified within professionals. Research has identified that individuals adapt to negative emotion by coping in two ways: problem solving coping or emotion focused coping (Folkman & Lazarus, 1988). Therefore, professionals may take different strategies to cope with the emotion attached to decision-making and withdrawing a child’s treatment.

Upskilling the workforce

Professionals require training and support to feel confident within the decision-making process and regarding end of life. There is recognition of health professionals feeling confident within end of life discussions ensuring that the child and their families are included within these discussions. Existing literature has identified that health professionals fail to raise such discussions and improving end of life communication skills is vital amongst health professionals. Health professionals, such as consultants and nurses, have been identified as completing their training unprepared for end of life discussions (Johnson & Panagioti, 2018; Pekmezaris et al., 2011). Educational interventions focusing on end of life should be implemented early on within professional training to ensure they are confident in during end of life discussions should such situations arise. Motivational interviewing (MI) would be appropriate to support the decision-making as MI provides a practical approach to support a family centred care (Elywyn et al., 2014). In particular, MI would support the decision-making process, as it would aim to include health professionals, the patient, and their families.

Psychological support and wellbeing

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. Health professionals require additional and consistent support during their day job to ensure their own wellbeing is supported. Caring for individuals who are terminal or towards end of life has been considered to be a stressful aspect of their profession (Hopkinson et al., 2003). Supporting the mental health and wellbeing of health professionals is advantageous especially when poor wellbeing can be linked to burnout and poor decision-making (Hall et al., 2016).

Further to the psychological wellbeing of health professionals, the psychological wellbeing of parents and families should be addressed. The wellbeing of parents and families is essential during the decision-making process and after a child's treatment has been withdrawn (Koch & Jones, 2018). With health professionals identifying the difficulty of parents living with the decision of withdrawing a child's treatment, further support should focus on the wellbeing of families. Existing literature has identified that children pass away within minutes of withdrawing treatment and therefore support for parents and families is required as soon as this occurs (Zawistowski & DeVita, 2004). The needs of the parent should be identified during the process and after and support should be obtained through avenues such as counsellors and mental health professionals.

Conclusion

The present study explored health professionals experiences of decision-making in withdrawing a child's treatment. Health professionals encounter many issues and difficulties when deciding to withdraw a child's treatment. In particular, there is recognition of further support needed during this difficult time of withdrawing a child's treatment. Further to this, psychological wellbeing for professionals and parents was identified by health professionals as important to support them. Prospective qualitative studies are required to understand the influences of factors involved throughout professional decision-making and may further help reduce gaps in the literature regarding this under-researched area. Further experiential research is required to replicate the findings of the present study across other hospital sites to extend the understanding of health professionals within this difficult yet emotional topic. This study has provided a powerful insight into the world of health professionals during a complex and emotional situation where numerous factors are involved and has added to the literature. A major contribution of this study is that the current study is the first to qualitatively examine the views of health professionals in deciding to withdraw a child's treatment. In fact, given the current media exposure on best interests of child and the current development of Charlie's Law which aims to prevent conflicts between parents, families and health professionals; this study was conducted at a time when understanding the decision-making process was vital.

Word count: 26,619

References

Abdin, S., Welch, R. K., Byron-Daniel, J., & Meyrick, J. (2018). The effectiveness of physical activity interventions in improving well-being across office-based workplace settings: a systematic review. *Public Health*, 160, 70-76.

Aberegg, S. K., & Terry, P. B. (2004). Medical decision-making and healthcare disparities: the physician's role. *Journal of Laboratory and Clinical Medicine*, *144*(1), 11-17.

Auckland, C., & Goold, I. (2019). Parental rights, best interests and significant harms: who should have the final say over a child's medical care?. *The Cambridge Law Journal*, 78(2), 287-323.

Aktas, M. A., Kazmi, R. K., Randhawa, G. R., & Brierley, J. B. (2019). G361 Children, organ donation and islam: a report of a multi-disciplinary day.

Amankwaa, L. (2016). Creating protocols for trustworthiness in qualitative research. *Journal of Cultural Diversity, 23(3).*

Atwal, A., & Caldwell, K. (2006). Nurses' perceptions of multidisciplinary team work in acute health-care. *International journal of nursing practice, 12(6),* 359-365.

Ajzen, I. (2011). *The theory of planned behaviour: reactions and reflections*.

Ambler, J. (2014). When is the right time? Complex issues around withdrawing life-sustaining treatment in children. *South African Medical Journal*, *104*(7), 507-509.

Arabiat, D., Whitehead, L., Foster, M., Shields, L., & Harris, L. (2018). Parents' experiences of Family Centred Care practices. *Journal of pediatric nursing*, *42*, 39-44.

Beauchamp, T. L., & Childress, J. F. (2001). *Principles of biomedical ethics*. Oxford University Press, USA.

Benbow, D. I. (2019). An Analysis of Charlie's Law and Alfie's Law. *Medical law review*.

Bluebond-Langner, M., Hargrave, D., Henderson, E. M., & Langner, R. (2017). 'I have to live with the decisions I make': laying a foundation for decision-making for children with life-limiting conditions and life-threatening illnesses. *Archives of disease in childhood*, 102(5), 468-471.

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. (2018). Charlie Gard and the weight of parental rights to seek experimental treatment. *Journal of medical ethics*, *44*(7), 448-452.

Braun, V. and Clarke, V. (2013) Successful Qualitative Research: A Practical Guide for Beginners [online]. *Sage.*

Braun, V. and Clarke, V. (2006) Using thematic analysis in psychology. *Qualitative Research in Psychology* [online]. 3 (2), pp.77-101.

Boland, L., Graham, I. D., Légaré, F., Lewis, K., Jull, J., Shephard, A., ... & Stacey, D. (2019). Barriers and facilitators of pediatric shared decision-making: a systematic review. *Implementation Science*, *14*(1), 7.

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.

Brand, S. R., Fasciano, K., & Mack, J. W. (2017). Communication preferences of pediatric cancer patients: talking about prognosis and their future life. *Supportive Care in Cancer*, *25*(3), 769-774.

Brierley, J., Linthicum, J., & Petros, A. (2013). Should religious beliefs be allowed to stonewall a secular approach to withdrawing and withholding treatment in children?. *Journal of medical ethics*, *39*(9), 573-577.

Cave, E., & Nottingham, E. (2018). Who knows best (interests)? The Case of Charlie Gard. *Medical Law Review*, 26(3),

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.

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.

CILAR, L., STRIČEVIĆ, J., & HALOŽAN, D. (2019). Children's Rights in Hospital: a Literature Review. *Compendium of Contemporary Legal Issues*, 123.

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.

Côté, F., Gagnon, J., Houme, P. K., Abdeljelil, A. B., & Gagnon, M. P. (2012). Using the theory of planned behaviour to predict nurses' intention to integrate research evidence into clinical decision-making. *Journal of advanced nursing*, *68*(10), 2289-2298.

Coyne, I., Amory, A., Kiernan, G., & Gibson, F. (2014). Children's participation in shared decision-making: Children, adolescents, parents and health professionals' perspectives and experiences. *European Journal of Oncology Nursing*, *18*(3), 273-280.

Day, E., Jones, L., Langner, R., Stirling, L. C., Hough, R., & Bluebond-Langner, M. (2018). "We just follow the patients' lead": Health professional perspectives on the involvement of teenagers with cancer in decision-making. *Pediatric blood & cancer*, *65*(3), e26898.

Day, E., Jones, L., Langner, R., & Bluebond-Langner, M. (2016). Current understanding of decision-making in adolescents with cancer: a narrative systematic review. *Palliative medicine*, *30*(10), 920-934.

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.

Devitt, B., Philip, J., & McLachlan, S. A. (2010). Team dynamics, decision-making, and attitudes toward multidisciplinary cancer meetings: health professionals' perspectives. *Journal of oncology practice*, *6*(6), e17-e20.

Diaz-Caneja, A., Gledhill, J., Weaver, T., Nadel, S., & Garralda, E. (2005). A child's admission to hospital: a qualitative study examining the experiences of parents. *Intensive care medicine*, *31*(9), 1248-1254.

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

Drotar, D., Crawford, P., & Bonner, M. (2010). Collaborative decision-making and promoting treatment adherence in pediatric chronic illness. *Patient Intelligence*, *2010*(1), 1-7.

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

Ekberg, S., Bradford, N. K., Herbert, A., Danby, S., & Yates, P. (2018). Healthcare Users' Experiences of Communicating with Health professionals About Children Who Have Life-

Limiting Conditions: A Qualitative Systematic Review. *Journal of palliative medicine*, *21*(10), 1518-1528.

Elwyn, G., Dehlendorf, C., Epstein, R. M., Marrin, K., White, J., & Frosch, D. L. (2014). Shared decision-making and motivational interviewing: achieving patient-centered care across the spectrum of health care problems. *The Annals of Family Medicine*, *12*(3), 270-275.

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

Fägerskiöld, A. (2006). Support of fathers of infants by the child health nurse. *Scandinavian journal of caring sciences*, *20*(1), 79-85.

Fishbein, M., & Ajzen, I. (2011). *Predicting and changing behavior: The reasoned action approach*. Psychology press.

Frenk, J., Chen, L., Bhutta, Z. A., Cohen, J., Crisp, N., Evans, T., ... & Kistnasamy, B. (2010). Health professionals for a new century: transforming education to strengthen health systems in an interdependent world. *The lancet,* 376(9756), 1923-1958.

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.

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.

General Medical Council (2013) Good medical Practice [Online]. Available: http://www.gmc-uk.org/guidance/ good_medical_practice.asp (last accessed 1 Mar 2020)

Green, J., & Thorogood, N. (2018). *Qualitative methods for health research*. Sage.

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.

Hall, L. H., Johnson, J., Watt, I., Tsipa, A., & O'Connor, D. B. (2016). Healthcare staff wellbeing, burnout, and patient safety: a systematic review. *PloS one*, *11*(7).

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.

Hatala, R., & Case, S. M. (2000). Examining the influence of gender on medical students' decision-making. *Journal of women's health & gender-based medicine*, *9*(6), 617-623.

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

Heath, G., Montgomery, H., Eyre, C., Cummins, C., Pattison, H., & Shaw, R. (2016, March). Developing a tool to support communication of parental concerns when a child is in hospital. *Healthcare* (Vol. 4, No. 1, p. 9). Multidisciplinary Digital Publishing Institute.

Heyland, D. K., Cook, D. J., Rocker, G. M., Dodek, P. M., Kutsogiannis, D. J., Peters, S., ... & O'Callaghan, C. J. (2003). Decision-making in the ICU: perspectives of the substitute decision-maker. *Intensive care medicine*, *29*(1), 75-82.

Hinds, P. S., Oakes, L., Quargnenti, A., Furman, W., Bowman, L., Gilger, E., ... & Drew, D. (2000, September). An international feasibility study of parental decision-making in pediatric oncology. *Oncology nursing forum* (Vol. 27, No. 8, pp. 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. *Journal of Clinical Oncology*, 27(35), 5979.

Hinds, P. S., Oakes, L., Furman, W., Quargnenti, A., Olson, M. S., Foppiano, P., & Srivastava, D. K. (2001). End-of-life decision-making by adolescents, parents, and healthcare providers in pediatric oncology: research to evidence-based practice guidelines. *Cancer Nursing*, *24*(2), 122-134.

Hopkinson, J. B., Hallett, C. E., & Luker, K. A. (2003). Caring for dying people in hospital. *Journal of advanced nursing*, *44*(5), 525-533.

Hogden, A., Greenfield, D., Nugus, P., & Kiernan, M. C. (2012). Engaging in patient decision-making in multidisciplinary care for amyotrophic lateral sclerosis: the views of health professionals. *Patient preference and adherence*, *6*, 691.

Holloway, I., & Galvin, K. (2016). *Qualitative research in nursing and healthcare*. John Wiley & Sons.

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.

Hussain, N., & Soni, D. (2020). Max and Keira's law: an overview on the advantages, disadvantages and alternatives to an opt-out organ donation system in the UK. *The British Student Doctor Journal*, *4*(1).

Jackson, C., & Vasudevan, C. (2020). Palliative care in the neonatal intensive care unit. *Paediatrics and Child Health*.

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.

Jackson, C., Cheater, F. M., & Reid, I. (2008). A systematic review of decision support needs of parents making child health decisions. *Health expectations*, *11*(3), 232-251.

Jordan, A., Wood, F., Edwards, A., Shepherd, V., & Joseph-Williams, N. (2018). What adolescents living with long-term conditions say about being involved in decision-making about their healthcare: a systematic review and narrative synthesis of preferences and experiences. *Patient education and counseling*, *101*(10), 1725-1735.

Katz, A. L., Webb, S. A., & Committee on Bioethics. (2016). Informed consent in decision-making in pediatric practice. *Pediatrics*, e20161485.

Kendall, M., Murray, S. A., Carduff, E., Worth, A., Harris, F., Lloyd, A., ... & Sheikh, A. (2009). Use of multiperspective qualitative interviews to understand patients' and carers' beliefs, experiences, and needs. *BMJ*, *339*, b4122.

Kirk, S. (2001). Negotiating lay and professional roles in the care of children with complex health care needs. *Journal of advanced nursing*, *34*(5), 593-602.

Kirsch, R. E., Balit, C. R., Carnevale, F. A., Latour, J. M., & Larcher, V. (2018). Ethical, Cultural, Social, and Individual Considerations Prior to Transition to Limitation or Withdrawal of Life-Sustaining Therapies. *Pediatric Critical Care Medicine*, 19(8S), S10-S18.

Koch, K. D., & Jones, B. L. (2018). Supporting parent caregivers of children with life-limiting illness. *Children*, *5*(7), 85.

Kothari, C. R. (2004). *Research methodology: Methods and techniques*. New Age International.

Keown J (2004) Euthanasia, ethics, and public policy: an argument against legalisation [Online]. Port Chester: *Cambridge University Press*. Available: http://site.ebrary.com/lib/soton/ docDetail.action?docID=10021934

Kuo, D. Z., Houtrow, A. J., Arango, P., Kuhlthau, K. A., Simmons, J. M., & Neff, J. M. (2012). Family-centered care: current applications and future directions in pediatric health care. *Maternal and child health journal*, *16*(2), 297-305.

Lanceley, A., Savage, J., Menon, U., & Jacobs, I. (2008). Influences on multidisciplinary team decision-making. *International Journal of Gynecological Cancer*, *18*(2), 215-222.

Lantos, J. D. (2018). Ethical problems in decision-making in the neonatal ICU. *New England Journal of Medicine*, *379*(19), 1851-1860.

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).

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), 246-258.

Madrigal, V. N., & Kelly, K. P. (2018). Supporting Family Decision-making for a Child Who Is Seriously Ill: Creating Synchrony and Connection. *Pediatrics*, *142*(Supplement 3), S170-S177.

Marcum, J. A. (2017). Clinical decision-making, gender bias, virtue epistemology, and quality healthcare. *Topoi*, *36*(3), 501-508.

Meskens, N., & Guinet, A. (2013). Decision-making in healthcare.

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

Meyer, E. C., Ritholz, M. D., Burns, J. P., & Truog, R. D. (2006). Improving the quality of end-of-life care in the pediatric intensive care unit: parents' priorities and recommendations. *Pediatrics*, *117*(3), 649-657.

Montano, D. E., & Kasprzyk, D. (2015). Theory of reasoned action, theory of planned behavior, and the integrated behavioral model. *Health behavior: Theory, research and practice*, *70*(4), 231.

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

Muir, N. (2004). Clinical decision-making: theory and practice. *Nursing Standard*, *18*(36), 47-55.

Ntantana, A., Matamis, D., Savvidou, S., Marmanidou, K., Giannakou, M., Gouva, M., ... & Koulouras, V. (2017). The impact of health professionals' personality and religious beliefs on the decisions to forego life sustaining treatments: an observational, multicentre, cross-sectional study in Greek intensive care units. *BMJ open*, *7*(7), e013916.

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.

October, T. W., Fisher, K. R., Feudtner, C., & Hinds, P. S. (2014). The parent perspective:"being a good parent" when making critical decisions in the PICU. *Pediatric critical care medicine: a journal of the Society of Critical Care Medicine and the World Federation of Pediatric Intensive and Critical Care Societies*, *15*(4), 291.

Opdenakker, R. (2006). Advantages and disadvantages of four interview techniques in qualitative research. In *Forum Qualitative Sozialforschung/Forum: Qualitative Social Research* 7, (4).

Payne, J. W., Payne, J. W., Bettman, J. R., & Johnson, E. J. (1993). *The adaptive decision maker*. *Cambridge university press.*

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.

Picard O & Lee G (2013) *Medical School Interviews*. 2nd ed. London: ISC Medical.

Pope, C., & Mays, N. (1995). Qualitative research: reaching the parts other methods cannot reach: an introduction to qualitative methods in health and health services research. *Bmj*, *311*(6996), 42-45.

Prochaska, J. O. (2008). Decision-making in the transtheoretical model of behavior change. *Medical decision-making*, *28*(6), 845-849.

Reyna, V. F. (2008). A theory of medical decision-making and health: fuzzy trace theory. *Medical decision-making*, *28*(6), 850-865.

Rogers, B. (Ed.). (2002). *Teacher leadership and behaviour management*. Sage.

Sargent, S. (2019). Charlie's Law: Clarifying the Legal Standard to be Used in Medical Decision-making for Children.

Segall, P. J. (2017). Readiness for Positive Change: A Conceptual Framework Integrating Positive Psychology and the Transtheoretical Model of Behavior Change.

Schaffer, M. A. (2007). Ethical problems in end-of-life decisions for elderly Norwegians. *Nursing Ethics*, *14*(2), 242-257.

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

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.

Smith, J. A. (Ed.). (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.

Stavrou, S., Cape, J., & Barker, C. (2009). Decisions about referrals for psychological therapies: a matched-patient qualitative study. *Br J Gen Pract*, *59*(566), e289-e298.

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.

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.

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

Thompson-Leduc, P., Clayman, M. L., Turcotte, S., & Légaré, F. (2015). Shared decision-making behaviours in health professionals: a systematic review of studies based on the T heory of P lanned B ehaviour. *Health Expectations*, *18*(5), 754-774.

Turnbull, J. (2019). “Facts” and “Feelings” in the Discursive Construction of the “Best Interests of a Child”: The Charlie Gard Case. *Lingue Culture Mediazioni-Languages Cultures Mediation (LCM Journal)*, *6*(1), 45-64.

Visintini, R., Ubbiali, A., Donati, D., Chiorri, C., & Maffei, C. (2007). Referral to group psychotherapy: A retrospective study on patients' personality features associated with clinicians' judgments. *International Journal of Group Psychotherapy*, *57*(4), 515-524.

Waldman, E., & Frader, J. (2018). Charlie Gard: How Did Things Go Wrong?. *Current Pediatrics Reports,* 6(2), 173-177.

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.

Winter B & Cohen S (1999) ABC of intensive care. Withdrawal of treatment. BMJ 319(7205): 306-308. Yardley, L. (2000). Dilemmas in qualitative health research. *Psychology and health, 15(2),* 215-228.

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

Zawistowski, C. A., & DeVita, M. A. (2004). A descriptive study of children dying in the pediatric intensive care unit after withdrawal of life-sustaining treatment. *Pediatric Critical Care Medicine*, *5*(3), 216-223.