**Parents’ experience of advance care planning for children and young people with a life-limiting condition: a scoping review.**

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**ABSTRACT**

Background: Advance care planning is considered best practice for children and young people with life-limiting conditions but there is limited evidence how parents’ perceive, understand, and engage with the process.

Aim: To understand parents’ experience of advance care planning for a child or young person with a life-limiting condition.

Design: Scoping review, theoretically informed by Family Sense of Coherence. Parents’ experience was conceptualised in terms of meaningfulness, comprehensibility, and manageability.

Data sources: Electronic databases Medline, Cinahl and PyschINFO were searched for studies published between 1990 and 2021, using MESH and broad base terms.

Results: 150 citations were identified and screened; 15 studies were included qualitative (n=10), survey (n=3), and participatory research (n=2). Parents’ experience of advance care planning was contextualised by their family values and beliefs, needs and goals, and the day-to-day impact of caring for their child and family. They valued conversations, which helped them to maximise their child’s quality of life and minimise their suffering. They preferred flexible, rather than definitive decisions about end-of-life care and treatment.

Conclusions: Advance care planning which solely focuses on treatment decisions is at odds with parents’ concerns about the current and future impact of illness on their child and family. Parents want advance care planning for their child to reflect what matters to them as a family. Future longitudinal and comparative studies are needed to understand the influence of advance care planning on parental decision-making over time and how social, cultural, and contextual nuances influence parental experience.

**KEY MESSAGES**

**What was already known?**

* Advance care planning underpins quality end-of-life care
* Implementation of advance care planning is patchy

**What are the new findings?**

* Parents want to participate in advance care planning for their child
* Parents engage with advance care planning when it takes account of the context of their day-to-day-life, their hopes, fears, preferences, and goals

**What is their significance?**

1. **Clinical**
* Parents value advance care planning which takes account of their family values, hopes, fears and goals, and respects their capacity to engage in end-of-life decisions
* Parents value clinical discussion which explores the meaning of potential interventions and helps them weigh up the implications for their child
1. **Research**
* Further research is needed to understand the influence of advance care planning on parental decision-making over time and how social, cultural, and contextual nuances influence parental experience.

**INTRODUCTION**

Advance care planning is an important part of palliative care for children and young people with a life-limiting condition, considered in policy as indicative of gold standard practice integral to the process of clinical decision-making.[1,2] Conversations will involve those with parental responsibility to help guide best decisions with clinicians. Whereas historically such decisions would predominately focus on Do Not Resuscitate Orders (DNR), contemporary advance care planning focuses on preferences and goals of current and future care and treatment[1]

Whilst health care professionals perceive advance care planning as helpful,[3] implementation is patchy and inconsistent[4,5,6] and content and quality of advance care plans varies.[6,7] Effective implementation is influenced by several factors, including health care professionals’ discomfort in facilitating discussions, tensions between professionals about roles and responsibilities in decision-making and the best course of action, and difficulty anticipating likely consequence of deterioration.[3,8,9,10]

Barriers to advance care planning are indicative of the growing intricacy of end-of-life care for children with life-limiting conditions. Innovations in care and treatment have extended life expectancy and resulted in increasing clinical complexity, as well as ambiguity and uncertainty about outcome.[5] Moreover, these complexities make it difficult for parents to decide what is best for their child and their family, and how to influence communication with clinicians.[11] Consequently, parental decisions often fall into what Norman[12] describes as a ‘grey zone’, where options are neither right or wrong, but characterised by trying to achieve the best balance between the relative harm and benefits of different options. For example, rather than making withdrawal of treatment and do-not-resuscitate decisions, parents tend to make decisions to modify treatments and the extent of resusciation[5] with the result that increasing numbers of children and young people receive long term ventilation, or intensive care, to manage acute deterioration and distressing symptoms, as part of their palliative care.[5]

A substantial body of research has focused on enhancing the implementation of advance care plans and developing tools and interventions for use with children with long term conditions.[13,14,15] Debate addresses issues like when to initiate advance care planning[4] and the frequency of such discussions[3] and most of this body of work is characterised by professional experience of advance care planning,[16,17] predominately generated through surveys[10,16-19] and audits.[6,7,20-22] In contrast, there is a paucity of research investigating parental experiences of advance care planning for children with life-threatening or life-limiting conditions. Little is known about how parents perceive, understand, and engage with advance care planning for their child, yet these perspectives are important to inform health care professionals’ approaches to these conversations and ensure care is supportive and congruent with parents’ needs and values.

**AIM**

Our aim was to review parents’ experience of advance care planning for their child, to inform implementation, best practice, and future research.

**METHOD**

Given the paucity of research about parents’ experience of advance care planning for children, a scoping review method was used. Scoping reviews enable a wide range of literature to be examined[23] and inclusion of diverse sources of evidence and research methodologies.[24] Specifically, we followed the scoping review methodology for the process and reporting of the review, described by Arksey and O’Malley[25] and the subsequent PRISMA extension for scoping reviews (PRISMA-ScR).[26] This process consisted of identifying a research question; identifying relevant studies; selecting studies; collating and charting the data; and summarising and reporting results.[25]

**Guiding theoretical framework and research questions**

The scoping review was theoretically guided by Family Sense of Coherence theory.[27] This ensured parents’ experience of advance care planning was contextualised in relation to their family experience of living with a child with a life-limiting condition. Moreover, the theory provided clearly defined concepts through which to analyse and synthesise parental experience, important to an inclusive and thorough review[28] and had the advantage of minimising bias brought to the analysis from our professional experiences.

Family Sense of Coherence proposes family resilience is influenced by how family members collectively perceive, experience and organise their world - ‘how they do things as a family’ in response to crisis.[27] The theory comprises three constructs, comprehensibility, manageability, and meaningfulness. Each of these constructs contribute to family wellness and influence how parents face the uncertainties associated with their child’s limited life, their treatment and care, and adjustments they make as their child’s condition deteriorates. Meaningfulness, the motivational dimension of the theory, describes the desire to resolve difficulties and invest energy to get through a stressful situation (‘it’s worth it’). Comprehensibility, the cognitive dimension of the theory, describes the ability to organise and sort information to understand stressful situations (‘it makes sense to us’). Manageability, the instrumental or behavioural dimension of the theory, describes how resources to meet family challenges are secured and harnessed (‘we can do it’). Thus, our working definition of parental experience was inclusive of whether parents considered advance care planning worthwhile and how they engaged with and incorporated this process into their life-world.

Consequently, we posed three research questions:

* Do parents consider advance care planning worthwhile? (meaningfulness)
* What sense do parents make of advance care planning? (comprehensibility)
* How do parents engage in advance care planning? (manageability)

**Operational definition of advance care planning for children and young people with life-limiting conditions**

Whilst there is no universally accepted definition of advance care planning for children, published definitions share common principles, The following was adapted from the Association of Paediatric Palliative Medicine to guide the scoping review as indicative of these principles.

*Advance care planning for children and young people with life-limiting and life-threatening conditions will help them plan for and receive care at the end of their life that is in line with their wishes. Talking with the child or young person, and their parents or carers, at appropriate stages gives them the opportunity to influence the care that they receive and improves their experience of care. Advance care plans should be appropriate to the circumstances and continuously updated throughout the delivery of care and support. Alongside family wishes and preferences, the information within the plans will include individualised treatment plans for a range of medical scenarios, as well as specific information about cardiopulmonary resuscitation.*

Life-limiting conditions were defined as conditions for which there is no cure and death is inevitable, either in childhood or early adulthood.[2] Early adulthood was defined as up to the age of 25 years.[29]

**Identification of relevant studies**

Databases: A structured search of the electronic databases Medline, CINAHL, and PyscINFO, was used to identify relevant papers. In addition, reference lists were examined in papers retrieved for any sources not catalogued in search databases.

Search terms: The search terms were identified using the framework Population, Concept and Context (PCC) (Table 1).[26] The search terms were kept purposively broad to ensure relevant sources were considered. Thus, the search combined the MeSH and broad base terms of *advance care planning*, and *child, parents and palliative and end of life care*.

**Table 1**  **PCC framework to identify search terms**

|  |  |  |  |
| --- | --- | --- | --- |
| **PCC** | **Term/concept** | **Key search words** Combined with OR | **MeSH/Broad base term** |
| **Population**  | Children, or parents  | Child/childrenParents | ChildParents |
| **Concept**  | Advance care planning | Advance care planningAdvance directivesAdvance Medical planning | Advance care planning |
| **Context**  | Palliative care and end of life | Palliative careTerminal careEnd of life care | Palliative care |

The search was limited to papers published in English between 1990, the date advance care planning was first recommended in UK policy, to October 2021. (An Example of the search strategy for Medline is provided in Table 2).

**Table 2. Search Strategy for Medline**

|  |  |
| --- | --- |
| **Search number** | **Mesh term, text word and combination** |
| 1 | Advance care planning (Mesh term) |
| 2 | Advance directive\*  |
| 3 | Advance decision\* |
| 4 | Advance Medical planning |
| 5 | Palliative care (Mesh term) |
| 6 | End of Life |
| 7 | Hospice |
| 8 | Child\* (Mesh term) |
| 9 | Children |
| 10 | Young people |
| 11 | Parents (Mesh term) |
| 12 | 1 or 2 or 3 or 4  |
| 13 | 5 or 6 or 7 |
| 14 | 8 or 9 or 10 or 11 |
| 15 | 12 and 13 and 14 |
| 16 | Limit 15 to year 1990- October 2021 |
| 17 | Limit 15 to English Language |

**Inclusion and exclusion criteria**

Identified papers were independently assessed for relevance and eligibility against inclusion and exclusion criteria (HEB, SD) (Table 3). Papers were included if they focused on the palliative care of children with life-limiting conditions, defined as above. Papers were therefore excluded if they addressed end-of-life decisions in children dying because of trauma, mental health, HIV. Papers were excluded if they solely focused on do-not-resuscitate (DNR) orders and were not inclusive of the principles of advance care planning expressed in the operational definition above. Conversely, papers were included if they contributed debate about parents’ experiences of engaging with advance care planning inclusive of the principles expressed in the operational definition. Papers were included if they discussed parents’ experiences of being involved in advance care planning for children and young people. Scoping reviews vary in their use of methodological critique as part of the inclusion and exclusion criteria; unlike systematic reviews, this is not an essential process.[24] Because we anticipated finding a small body of published research, we chose not to include this process, in order to include the breadth and quality of published debate and provide a comprehensive map of knowledge in this field. Nevertheless, we included a descriptive analysis of the methodology adopted by each included study.

**Table 3 Inclusion and exclusion criteria**

|  |  |  |
| --- | --- | --- |
|  | Inclusion | Exclusion |
| Publication source | Papers published in peer reviewed journals | Papers in non-peer reviewed journals and unpublished papers |
| Publication type | Research studies addressing advance care planning from across disciplines and fields of practice | Editorials or letters |
| Language | Papers reported in English | Papers reported in language other than English |
| Publication date | Papers published between 1990 to October 2021 | Papers published before 1990 and after October 2021 |
| Population | Parents of children and young people (up to age of 25 years) with life-limiting conditions  | Parents of young adults over 25 years |
| Concept | Papers addressing advance care planning (see operational definition) | Papers which excluded a focus on advance care planning |
| Context | Papers concerned with palliative and end of life care | Papers concerned with acute and sudden death  |

**Charting and collating: Data extraction, analysis, and synthesis**

Included papers were read independently by two authors (HEB, SD). Standard information was extracted (aims, design and methodology, population and sample, findings, and key discussion points) and charted independently. We then collectively constructed a tabulated summary of included papers.

In the next stage, we extended the summary to include data about the premise, rationale and results from each paper, and the potential of the study to inform health care practice (example provided in supplementary material 1) We subsequently undertook a deductive, thematic analysis of the results, guided by Family Sense of Coherence Theory.[27] (SD, HEB).

Finally, the outcomes from the thematic analysis were tabulated against the research questions (Supplementary material 2) and collated to generate discussion points, referring back to each paper to ensure accurate representation. The narrative approach enabled the identified themes to be portrayed in relation to the context and meaning depicted by the reviewed studies, the contradictions as well as commonalities.[30]

**RESULTS**

**Selection of sources of evidence**

One hundred and thirty-nine papers were identified from the selected databases and a further 11 papers from reference lists, hand-search, and cross referencing (n=150). Following the removal of duplicates (n=46) the title and abstract of 104 papers were screened; 69 papers were assessed as potentially relevant. Of these 69 papers, 54 were excluded after full-text review because they did not address the research questions. Thus, a total of 15 papers were included in the review (Figure 1).

**Characteristics of sources of evidence**

The reviewed papers were published between 1996 and 2020 and conducted in North America (n=9),[18,31,-38] and Europe (n=6).[5,39-43]. The studies comprise qualitative designs (n= 10),[5,32-34,36-38,40,42,43] survey (n=3),[18,31,35] and participatory research (n=2).[39,41] Four studies explicitly reported parent’s participation as members of the study team in accordance with patient and public involvement in research (PPI).[5,31,35,39] No longitudinal or comparative studies were identified. When mapped against Family Sense of Coherence, all of the studies portrayed how parents managed their engagement in advance care planning (manageability n=15); all but two studies described parents’ understanding of advance care planning (comprehensibility, n=13) and two-thirds of the studies described parents’ evaluations of the value of advance care planning (meaningfulness, n=10) (Table 4).

**Descriptive analysis of included studies**

The included studies represent the experiences of 695 parents, most of which were mothers (mothers n=549, fathers, n=93, role not identified n=53). None of the studies aimed to understand how parents might differ in their views according to the parental roles they adopted. Most parents were currently caring for a child with a life-limiting condition when they participated in the included research (n=491), others participated after their child had died (n=171), not stated (n=33). Participants were parents of children and young people with a range of life-limiting conditions, for example complex neurological conditions (n=9 studies), Duchene’s Muscular Dystrophy (n=1 study), chronic illness and special needs (n=5 studies). One of the studies included parents from differing ethnic communities,[18] but none investigated cultural, socioeconomic or ethnicity differences in parents’ experiences of advance care planning.

There was consistency across the studies in how advance care planning was operationalised, as future care and treatment planning, decision-making and goals of care[5,18,33,34,37,38,40-43]. Definitions of advance care planning were not confined to completion of a written plan but included parents’ opinions and experiences of engaging in anticipatory care and treatment planning. Thus, n=119 parents across the studies had recorded their care and treatment decisions for end-of-life care and an additional n=28 parents had engaged in advance care planning conversations. Data from a further n=407 parents was reported from parents who had not recorded their decisions in an advance care plan (data not provided for the remaining n=143 participants).

All studies used convenience or purposeful sampling. Participants were recruited from discrete populations such as conference attendees[31], members of a condition specific association,[32] current or past user of a care service[5,18,32,34-38,40-43) or residents in a specific geographical location.[39] (table 4). Participants were recruited from hospital medical records or bereavement records and parent networks.

**Table 4: Summary of reviewed papers**

| **Authors** | **Design and aims** | **Design** | **Sampling and sample** | **Dimensions of parental experience addressed (Constructs of FSC)** |
| --- | --- | --- | --- | --- |
| **Wharton et al 1996****USA** | To explore parental attitudes, understanding and how they wanted to participate in ACP. | Questionnaire survey  | Convenience sampling n=76 Completed ACP n=4; no ACP n=72 | MeaningfulnessManageability |
| **Hammes et al 2005****USA** | To understand the process and population involved in paediatric ACP. | Retrospective evaluationvia interviews and content analysis | Purposive sampling n=13 from 12 families Bereaved parents included but proportion not statedExperience of ACP not specified | MeaningfulnessComprehensibilityManageability |
| **Erby et al 2006****USA** | To explore parents’, childrens’ and adolescents’ attitudes and experience of ACP, and how this process can be improved. | Exploratory qualitative study using interviews and thematic analysis  | Purposive sampling n=17 No ACP n=17 | ComprehensibilityManageability |
| **Noyes et al 2013****UK** | To develop, pilot & evaluate implementation of a tool designed to facilitate future care planning. | Participatory study via semi-structured interviews, pre and post study questionnaire, web-based consultation. | Convenience sampling n=15 (bereaved n=3)Completed ACP not specified | MeaningfulnessManageability |
| **Liberman et al 2014****USA** | To explore parents/carers experience, knowledge, and preferences of ACP. | Prospective cross-sectional questionnaire survey  | Convenience sampling n=307 Experience of ACP n=27 | MeaningfulnessComprehensibilityManageability |
| **Beecham et al 2017****UK** | To investigate how parents’ approach and experience ACP. | Qualitative (semi-structured) interview study analysed using grounded theory principles | Purposive sampling n=18 (bereaved n=9)Completed ACP not specified | MeaningfulnessComprehensibilityManageability |
| **Lotz et al 2017****Germany** | To investigate parents’ experiences and views to identify their needs and barriers to ACP. | Qualitative (semi-structured) interview study, analysed using descriptive and evaluative coding | Purposive sampling n=11 bereaved parentsCompleted ACP n=2; no ACP n=3; unknown n=4 | MeaningfulnessComprehensibilityManageability |
| **DeCourcey et al 2019****USA** | To describe ACP communication priorities of bereaved parents and whether ACP influenced parental preparedness for their child’s death. | Cross-sectional survey, using self-administered semi-structured questionnaire  | Purposive sampling n=114 bereaved parentsCompleted ACP n=70; No ACP n=37; unknown n=7 | MeaningfulnessComprehensibilityManageability |
| **Mitchell et al 2019****UK** | To provide in-depth insight into experiences & perceptions of bereaved parents who had experienced EOL decision making in PICU.  | Qualitative (semi-structured) interview study, thematically analysed | Purposive sampling n=17 bereaved parentsExperience of ACP not specified | MeaningfulnessComprehensibilityManageability |
| **Hein et al 2020****Germany** | To identify key components of paediatric ACP  | Participatory study using discursive data collection methods, content analysis  | Purposive sampling n= 9 bereaved parentsExperience of ACP not specified | ComprehensibilityManageability |
| **Orkin et al 2020****USA** | To develop an in depth understanding of ACP experience from the perspective of parents and HCP’s. | Qualitative (semi-structured) interview study analysed using content analysis | Purposive sampling n= 14 Experience of ACP conversation n=14 | MeaningfulnessComprehensibilityManageability |
| **Lord et al 2020****Canada** | To explore the experiences of bereaved families with ACP for children with medical complexity | Qualitative (semi-structured) interview study analysed using content analysis | Purposive sampling n= 13 bereaved parentsEngaged in ACP conversation n=13 | ComprehensibilityManageability |
| **Fahner et al 2020****Holland** | To elucidate how parents contemplate the future and what influences how they share their perspectives with healthcare professionals  | Qualitative study using interviews and focus groups and analysed thematically | Purposive stratified sampling n= 20 Experience of ACP not specified | MeaningfulnessComprehensibilityManageability |
| **DeCourcey et al****2020****USA** | To conceptualise develop and refine, a multicomponent structured ACP intervention  | Qualitative participatory research study using focus groups and interviews, adapted framework analysis  | Purposive sampling n=9Experience of ACP not specified  | ComprehensibilityManageability |
| **Verberne et al****2020****Holland** | To explore how parents and HCP’s anticipate the future of the child and family. | Qualitative interview study using thematic analysis | Purposive sampling n= 42 (bereaved n= 6)Experience of ACP not specified  | ComprehensibilityManageability |

**Results of individual sources of evidence**

The thematic analysis of parents’ experiences of advance care planning is provided in table 5, mapped against the constructs of Family Sense of Coherence. The synthesis of these themes and map of the narrative portrayal of the themes, is provided in supplementary material 2. The following section draws on this map to address the research questions.

**Table 5 Thematic analysis**

|  |  |  |
| --- | --- | --- |
|  | **Theme** | **Sub themes** |
| **Meaningfulness** | Worthwhile albeit difficult and challenging | ValuableClinical information importantConveyed hopes and fearsEnsured quality of life and minimised sufferingReduced confusion and conflict with cliniciansPeace of mindReduced decisional regretSustained hopeFacilitated adjustment |
|  | Unacceptable | Giving up hopeGiving up on childNegative experience  |
|  | Ambivalence | Dependent on resources for care preferences |
| **Comprehensibility** | Live in the present, plan for future | Focus on presentAnticipate future to provide good careIterative decision making throughout a child’s life |
|  | Plan with the bigger picture in mind  | More than treatment and care decisionsMore than limitations of treatmentAbout family context and impact on family lifeAbout quality of child’s life - goals and values, hopes and fears |
|  | Decision making central to parental role  | Shared decision makingRole devalued if decisions not documentedRole devalued if decisions contradictedLacking knowledge and voiceOutnumbered |
|  | Keep options open | Flexibility to change mindDifficulty visualising future scenariosHard to work with hypothetical situationsUnaware potential treatment options |
|  | The ‘right’ decision | To do the best for your childBalance quality of life with potential sufferingBalance quality and quantity of lifeBalance risk and benefitNothing to lose |
| **Manageability** | Dissonance and conflict | Vacillation between present and futureVacillation between hope for survival and realisation impending deathPresent about taking one day at a timeFuture about unbearable knowledge their child will dieNo right time to think about child’s deathOverwhelmed and exhausted |
|  | Turning points influencing engagement in ACP | Change in child’s conditionSafeguarding careSocial cues from medical staff[ |
|  | Parent resources for ACP decision-making | Knowledge of their childPrevious experiences medical crisisOngoing conversations with clinical staffDiscussion with familyTime and space |
|  | Clinical practice influencing parents’ engagement in ACP | Clinicians who knew their childClinicians who tried to understand impact on familyTrusting and compassionate relationshipsSensitive and timely conversationsDecisions not judged[Decisions respected |
|  | Clinical practice influencing parents’ ACP decision-making | Clearly presented informationInformation focused on what was possibleExplanation of the meaning of information presentedContinued communication at times of uncertainty |
|  | Infrastructure factors influencing parents’ ACP conversations | Lack of staffLack of staff timeLack of interprofessional communicationLack of social, community and tertiary resources |
|  | ACP documents | Conversations more helpful |

**SYNTHESIS OF RESULTS: Thematic analysis mapped against research questions**

**Meaningfulness: Do parents consider advance care planning worthwhile?**

Most parents were unaware of advance care plans or lacked understanding of their purpose, prior to their involvement in research or clinical advance care planning conversations.[18,33,37,40] Following involvement, most parents were positive about their value[5,18,35,37,38,40] although some parents were ambivalent, pointing out resources may not be available to achieve their care and treatment preferences.[39] However, some parents found advance care planning a negative experience, because they equated it with preparing for the worst[37] or considered advance care planning for their child unacceptable, because thinking about their child’s impending death and future care needs was akin to giving up hope or tantamount to giving up on their child.[5]

For those parents involved in making advance plans for their child, such conversations were experienced as important opportunities to ensure clinicians were on the *‘same page*’ as them[5,36] to reduce confrontation, conflict, and confusion.[5,18,31,32] Thus, parents considered advance care planning a process by which their needs could be understood, which in turn provided confidence their child’s needs would be understood.[31]

Parents described benefits of completing an advance care plan such as peace of mind, direction, and a sense of control[32] and helped them adjust to their child’s condition and forthcoming death.[34] Compared to parents who had not completed an advance care plan, they were more likely to feel their choices and preferences had been respected,[32,41] to consider their child had received good quality end-of-life care,[35] and were less likely to have experienced decisional regret.[35]

**Comprehensibility: What sense do parents make of advance care planning?**

Advance care planning made sense to parents when it was undertaken in the context of their family and as an iterative communication-based decision-making process.[36] Thus, parents understood advance care planning, not just in terms of treatment decisions,[40,42] but in terms of anticipating their child’s care needs, education, living arrangements and financial plans.[33,42] Therefore, most parents preferred advance care planning conversations to occur throughout their child’s illness, from early in the course of illness.[34,35,38] as a process of successive ongoing conversations. This provided time and space to discuss possible options, the significance of these options, and to make decisions without pressure.[41]

Parents wanted advance care planning conversations to include the day-to-day care needed by their child and impact of this on the family,[34] and the individual needs and preferences of each family member.[5]

They also wanted advance care planning to be inclusive of their values, hopes, fears and goals,[37,42] as well as consideration of how to preserve their child’s quality of life and prevent unnecessary suffering,[18,32] treatment and care options.[42,43]

In other words, it was important to parents that advance care planning took account of ‘*the bigger picture*’,[40p682] rather than be solely focused on medical treatment. However, whilst most parents who had completed an advance care plan for their child had an opportunity to discuss their goals and worries with clinicians, most reported not having the opportunity to discuss their values and family needs.[35,37,42]

Furthermore, for most parents, anticipating the future was an inevitable part of ensuring good care for their child[36,43] and doing the best for their child.[5] They therefore understood advance care planning in terms of their involvement.[37] They wanted to be involved in decision-making about future care and treatment plans for their child[32] and for this role to be taken seriously.[34]

However, parents experienced varying degree of involvement in decisions. Whilst they were sometimes happy to go along with the decision made by clinicians, they did not feel they always had a voice,[40] and some reported previously agreed plans being discarded in an emergency situation.[34] They also described feeling outnumbered and overwhelmed by the number of clinicians in advance care planning meetings.[5]

In addition, parents made sense of advance care planning in terms of making the ‘*right*’ decision.[41] Overall, parents were reluctant to commit to a specific decision but preferred to make decisions, which kept their options open for as long as possible[40] and gave them flexibility to change their mind[5,40,42] For some parents this negated the point of making decisions in advance *‘I didn’t really get the point because you [parent] can override it*’,[40p680] but for others it helped them to balance the desire to do everything they could to extend their child’s life, to limit their suffering and balance the risks and benefits of potential treatments.[40]

**Manageability: How do parents engage in advance care planning?**

Parents’ capacity to engage in advance care planning for their child was influenced by the day-to-day impact of caring for their child and family and the unbearable knowledge that their child would die.[33] They coped by taking one day at a time, using a mixture of hope, avoidance, and being in the present, sometimes vacillating between these strategies or using them simultaneously.[33,34] Hence, engaging in advance care planning evoked conflicting emotions, from hope for survival to the realisation of impending death, and consequently parents experienced stress, anxiety, inner conflict and cognitive dissonance during this process.[5]

Consequently, some parents did not want to engage in advance care planning conversations until there was a reason to think about advance care and treatment decisions, ‘*if I don’t have to deal with it, why deal with it*’,[33p135] preferring to *‘cross that bridge when [they] come to it*’.[33p135] However, parents also felt it inappropriate to make decisions when they were facing a crisis in their child’s health and under significant pressure.[35,38,41]

Parents considered there was no ‘*right*’ time for advance care planning conversations,[41] and instead considered advance care planning appropriate at specific moments in their child’s illness[41] and inappropriate at times of crisis.[35] Parents described reaching a turning point between not wanting to talk about future plans and being able to do so.[41] Circumstances influencing this turning point included a change in their child’s condition or care needs or their child’s condition becoming unstable.[33,39,40,42]

Parents also described social and environmental cues, which influenced their understanding of the situation and engagement in advance care planning conversations. For example, moments by which parent’s recognised progression of their child’s illness,[36] and understanding their child was very sick and likely to die by clinical indicators such as monitor reading, or the actions of clinicians.[5] Thus, parents often recognised their child was deteriorating and dying before health care professionals openly discussed this with them. They described knowing ‘*in their heart*’, or feeling that ‘*something was not quite right*’.[5p5]

Parents drew on their knowledge of their child and previous medical situations as a resource when making advance care decision.[5,38] Rather than making decisions based solely on their child’s medical condition, parents tended to ‘*take every episode on its own merits*’[40p679] and make advance care planning decisions according to the type of decision needed, the course of illness, their child’s condition, and response to previous treatments.[40]

Parents’ ability to engage in advance care planning was positively influenced by trusting and compassionate relationships with clinicians.[5,38,40] Parents valued clinicians who knew their child, took account of their family values, hopes and fears, tried to understand the challenges they faced, recognised them as experts in their child’s care, did not judge their perspectives and took account of hopes and fears.[42]

In addition, parents wanted and valued the opportunity to talk to family and friends[31,39,41] and other parents[5] to gather information before making a decision. Sometimes they made a decision as a family without consulting clinicians and in some circumstances did not want clinicians to be involved in their decisions.[40]

Conversely, parents’ ability to engage in advance care planning was negatively influenced by insensitive or untimely communication,[41] for example, if they felt clinicians were not listening to them or discussing treatment options with them, if they needed to repeat themselves over and over again,[5] or their decisions were questioned.[41,42] In addition, they were concerned their decisions would not be enacted[18] or conversely, held to their decisions[18] without an opportunity to change their mind.[42]

The way in which clinicians approached advance care planning conversations influenced parents’ engagement in decision-making. Whilst parents found advance care planning for their child difficult and challenging[34] they preferred clinicians to share information with them, no matter how bad or potentially distressing the information might be.[31] They wanted information presented clearly, even if ‘*brutally honest*’[5p6] and emphasised fear of the emotional impact of such conversations, should not stop clinicians discussing future plans with them.[42] Furthermore, whilst parents experienced clinical uncertainty as confusing and difficult,[5] they preferred clinicians to use uncertainty as a trigger for advance care planning rather than a reason to avoid such conversations.[34,36,43] As one parent explained, ‘*waiting and not knowing is much worse than the facts*’.[34p767]

Parents’ experience of advance care planning for their child was also influenced by the language used by clinicians. For example, parents reported the phrase ‘*to stop treatment*’ preferable ‘*to letting their child die*’.[5] Similarly, they preferred clinicians to focus on how they could support their child to achieve what they were able to do, rather than focusing on what was wrong with their child.[37]

Moreover, parents wanted clinicians to explain the meaning and implications of the information provided for their child’s care.[31,36,40] Parents found it difficult to imagine hypothetical situations[5] and were often unaware of the potential treatment options necessary to make a decision, but valued discussion and explanation of possible scenarios, before making advance care decisions.[32,40]

Some parents described major infrastructure problems which inhibited advance care planning conversations, for example, lack of staff, lack of staff time, or lack of communication between professionals.[34,37] Their decisions were also tempered by available social and community resources, which might make their preferred care options unachievable.[38,39]

Parents had mixed views about the use of written resources to guide and record decisions. Some parents used written resources to think through different options[39] and guidelines to ensure their decisions were in their child’s best interests.[31] Parents who coped by not thinking about the future death of their child, preferred not to use written tools or resources.[39] Some parents reported advance care planning conversations more helpful than a written record of decisions.[34,39,41] Other parents felt if their decision preferences were not recorded their involvement was devalued.[41] Conversely, some parents were concerned a written record committed them to a decision.[39]

**DISCUSSION**

**Summary of evidence**

The 15 studies that constituted this review provided sufficient evidence to address the scoping review research questions. To summarise, most parents value advance care planning as an opportunity to discuss their family values, challenges, hopes, and fears so clinicians can develop a holistic understanding of their needs and goals. However, in two studies it was noted advance care planning was unacceptable for some parents because it equated to planning for the worst or giving up on their child or had negative experiences of advance care planning. The proportion of parents holding this view was not stated (meaningfulness). Most parents described triggers, such as changes in their child’s condition, which prompted the need to think about future care and treatment. Although many parents did not know the term advance care planning, they had a clear understanding of the concept of future and anticipatory planning, framed by their family context and previous experiences and shaped by balancing life-sustaining possibilities with their child’s quality of life (comprehensibility). Moreover, health care professional’s facilitation skills and discussion within the family were important resources which supported parents’ engagement in advance care planning (manageability).

The evidence presented in this review, is largely supportive of the implementation of advance care planning in practice for children with life-limiting illness. Although some studies report hesitancy by health care professionals to discuss advance care planning, for fear of causing parental distress,[4,9] parents saw their role as central to advance care planning and wanted to be involved,[34] however potentially difficult.[40] Rather than clinical uncertainty or ambiguity often precluding advance care planning conversations, parents wanted clinicians to use this as a cue to raise discussion.[38]

Interestingly, in contrast to the emphasis on advance care planning tools in implementation studies of advance care planning, we found limited and conflicting evidence about the value of such tools to parents. Tools were unacceptable to parents who did not want to think about the possibility their child would die.[39] and on the whole parents valued conversations with clinicians more than written information. They were ambivalent about the value of a written record, wanting their decisions to be respected but not wanting the written record to mean they were held to that decision.

Furthermore, we noted some important differences between parental and clinician conceptions of advance care planning. These need to be reconciled in practice to ensure advance care planning takes account of what is important to parents and their families.

Firstly, whilst the clinical purpose of advance care planning is to enhance the quality of dying through definitive care and treatment decisions,[6,7,19,20] parents’ purpose focused on enhancing the quality of living for their child and family. This did not reflect hesitancy to make decisions but the need to make the ‘*right*’ decision[41] which maximised their child’s quality of life and minimised their suffering.[40] They therefore made flexible, rather than definitive, decisions which kept their options open so they could be responsive to expected and unexpected changes to their child’s condition.

Thus, parents valued conversations which explored their hopes and fears, values and goals of care[36] and discussed how they could best care for their child[34,43]and objected to conversations in which clinicians used negative language, such as expressions such as ‘*letting their child die’*.[5] It is not unusual for end-of-life care decisions to be framed by negative language,[44] for example, advance care planning tends to be discriminated from usual medical consultations by discussion about withholding, withdrawing, or limiting treatments.[4,42] However, expressing end-of-life care in this way, undermines the care being provided[44] as well as personal and family values.[45] Therefore, language used to discuss advance care planning needs be congruent with family values, otherwise it can ‘*unintentionally depersonalize those for whom care is provided*’.[45p70] For example, the passivity in the phrase ‘to let die’, could convey to parents they no longer have influence over their child’s care and comfort.

Secondly, rather than being confined to medical decisions about treatment and care at the end-of-life that reflects the initial purpose of advance care planning, parents considered advance care planning inclusive of the day-to-day demands of caring for their child and their future social, educational, financial and care needs.[34,40] Thus, whilst clinicians tend to use medical markers, such as the stage of illness, as triggers for advance care planning,[4] parents described a variety of health and social cues which triggered vacillation between managing the here and now and awareness of their child’s deteriorating condition and need to think about future plans.[5,33,42] Therefore, for parents, advance care planning was part of an ongoing process of supporting their child, [38,41] where the focus on the everyday gradually became more subsumed by anticipating end-of-life care decisions.

Consequently, as emphasised elsewhere, parents did not consider advance care planning a discreet event, associated with a particular point in their child’s illness[4] but as a series of opportunities during clinical consultations to discuss family values, parents’ fears and goals, the impact of caring for their child on their family and the consequent needs of the family. Moreover, it was considered an opportunity for ‘*guidance on the job*’,[43] where clinicians explained the importance of aspects of care in terms of future needs and coached the delivery of both current and future care.

**Research limitations of reviewed evidence**

The reviewed research represents a growing body of research focused on parents’ experiences of engaging in advance care planning for their children. Although, the number of studies identified was small, despite the breadth of the search adopted, the included studies provide rich data about parents’ experiences of advance care planning. Nevertheless, there are several limitations in this body of work.

Firstly, proportionately fewer fathers participated in the reviewed studies than mothers. This observation mirrors paediatric research more generally, where mothers are more likely to be invited to participate in studies.[46] This might be explained by our observation that the samples in some studies were identified from hospital case notes or via an approach by a clinician, which tends to result in an invitation bias towards those undertaking the major care role, usually mothers.[46] However, no such bias was found in a recruitment analysis[47] for the study reported by Beecham et al.[40] Three other studies reported invitations extended to both parents where both parents participated.[5,34,40,36] Consequently, we consider the scoping review to be inclusive of mothers’ and fathers’ experiences of advance care planning, but the review cannot discern how parental roles influence experiences of advance care planning. Secondly, and noted above, the scoping review is limited to North American and European contexts and none of the studies investigated cultural, socioeconomic or ethnicity differences in parents’ experiences of advance care planning. We therefore do not know whether or how these factors influence parents’ experience of advance care planning, yet the prevalence of life-limiting conditions in children is significantly higher in deprived and non-white communities.[48] Studies in adult populations suggest advance care planning is less likely to be acceptable in these communities and family decision-making more strongly emphasised.[49]

Thirdly, the lack of comparative and longitudinal studies limits our knowledge about what works best for parents and how they want to be involved in the process of advance care planning at different moments in their child’s illness or whether advance care planning influences outcomes like parental bereavement and family wellbeing. Neither can we comment on whether parents’ experience of advance care planning is influenced by their approach to coping with changes in their child’s condition and how clinicians might tailor their support to prepare parents to participate in end-of-life decisions.

**STRENGTHS AND LIMITATIONS OF THE SCOPING REVIEW**

This scoping review followed the process described by Arksey and O’Malley[25] and the subsequent PRISMA extension for conducting and reporting scoping reviews (PRISMA-ScR).[26] This process was strengthened by the use Family Sense of Coherence theory [27] which provided a theoretical framework of experience through which to analyse and synthesise data[28] and address the research questions. Nevertheless, the review was not without its challenges, particularly during the process of discriminating research pertaining to our intended focus and research, which focused more generally on the process of decision-making at the end-of-life. Adopting an iterative process of refining the selection of papers as data extraction and analysis progressed, helped us identify the appropriate studies where there was an anticipatory or future focus to end-of-life care decisions and planning.

**IMPLICATIONS**

**Implications for clinical practice**

Implications for practice, drawn from the review are organised in figure 2 according to Family Sense of Coherence Theory.

In summary, parents value advance care planning for their child when it:

* augments usual practice rather than undertaken as a distinct activity[36]
* incorporates and takes account of family values, hopes, fears, preferences, and goals[18,31,36-38,42,43]
* is respectful of parents’ role in decision-making, their knowledge of their child, and capacity to engage in decisions[5,31,34,37-39,42]
* supports parents to focus on their child’s quality of life and to minimise their suffering[32,34,37,40,43]
* is situated in the context of family life, (integration of present and future challenges; acknowledging the impact of caring for a child with life-limiting condition, the needs of other family members; education and financial plans)[34,37,40,42,43]
* is respectful of family resources (discussion and support from other family members; community agencies; previous experiences)[31,40,41]
* helps parents to understand the meaning and consequences of potential treatment and care options – to navigate the complexity of end-of-life care[5,32,33,36,40,41]
* respects the aim to keep options open[40]

**Implications for research:**

* Further research is needed to investigate whether parents’ experiences of advance care planning are influenced by their parental role and by socioeconomic and cultural factors.
* Longitudinal and comparative studies are needed to understand what works best for parents, how their experience with advance care planning changes over time and whether and how advance care planning influences outcomes such as parental bereavement and family resilience.
* Family centred research is needed to understand how parents involve their child or young person with a life-limiting condition in the advance care planning process and how to support a family-centred approach to this process.

**CONCLUSION**

Advance care planning for a child or young person with a life-limiting condition can be clinically complex and is often focused on supporting parents to make treatment decisions and options for care. In contrast, the scoping review demonstrates that parent’s value advance care planning when it also takes account of what is important to them as a family, respects their role in decision-making for their child and enables flexibility in the decisions made. Future research is needed to understand how parent’s experience of advance care planning for their child changes over time, and how socio-economic, cultural, and contextual factors influence their experience.

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There are no competing interests to declare.

**CONTRIBUTOSHIP STATEMENT**

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Conceived and designed the paper and analysis

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