

Parents perspectives on communications with physicians at the point of initiation of invasive long-term ventilation of a child: a scoping review

Jo Greene

Trinity College Dublin

Mary Brigid Quirke

Trinity College Dublin

Denise Alexander

Trinity College Dublin

Carmel Doyle

Trinity College Dublin

Maria Brenner (✉ brennerm@tcd.ie)

Trinity College Dublin

Research Article

Keywords: Children with complex and integrated care needs, Decision-making, Long-term ventilation, Technology-dependent child

Posted Date: May 10th, 2022

DOI: <https://doi.org/10.21203/rs.3.rs-1625035/v1>

License:  This work is licensed under a Creative Commons Attribution 4.0 International License.

[Read Full License](#)

Abstract

Purpose

An increasing number of children with complex and integrated care needs (CICN) are dependent on medical technology such as invasive long-term ventilation (LTV) to sustain their lives. However, the sensitive nature of communications between parents and physicians at the point of initiation of technology dependence is under explored. A systematic scoping review was conducted to map existing research and understand the range of parental perspectives on communications with physicians at this key decision-making milestone.

Methods

Guided by the methodological framework of Arksey and O'Malley, a three-step screening process resulted in ten articles from the 445 initially identified, as meeting the selection criteria for inclusion. Adopting Braun and Clarke's approach, this qualitative evidence was thematically analysed.

Results

Three overarching themes emerged which describe communications at the point of initiation of LTV: the need to ventilate, navigating medical decision-making and perceptions of communications with physicians.

Conclusions

Parents are located at the centre of the decision-making process, but their lack of knowledge of uncommon but critically needed medical interventions places them at a disadvantage. They frequently feel overwhelmed by the need to make quick decisions without complete information, this loss of control can be amplified in the complex environment of the healthcare setting. In communications with physicians, parents value a collaborative and responsive approach to their information needs which facilitates them to make ethical decisions that are appropriate for the long-term care of their child.

What Is Known

What is Known

- Shared decision making is a vital component of PICU care, particularly as medical innovations are increasingly sustaining life, and children with complex care needs are becoming more dependent on these technologies.

- For physicians, initiating invasive procedures such as long-term ventilation (LTV), involves difficult and time-sensitive discussions with parents. For parents, the pressure of making well-informed decisions in the complex environment of health care settings can be overwhelming.

What is New

- When commencing invasive LTV, the decision-making process for parents is highly dependent on guidance from physicians which can infer a loss of control for parents. To alleviate this, parents sought the input and perspectives of the entire healthcare team to enable informed decision-making.
- While parents valued responsive communications with physicians appropriate to their situation, many expressed regret they were not better versed on the long-term experiences of LTV.
- Parental decisions that do not align with medical opinions need a non-judgemental response to find collaborative and ethical solutions.
- The review shows there is a lack of research in this area from a European perspective.

Introduction

With advances in technology, an increasing number of children with complex and integrated care needs (CICN) are dependent on medical technology to sustain their lives [1, 2]. One common technology is long-term ventilation (LTV) [3] however, the process of initiating LTV for a child involves difficult and sensitive discussions with the child's parents. Therefore, the relationships with physicians, and the nature of communications, are crucial for parents for them to make well-informed decisions for their child [4]. Whilst there is a growing shift towards shared decision-making in paediatric healthcare generally [5], there is an absence of literature specifically regarding the parents of children who require invasive ventilation via tracheostomy. At a broader level, there is a body of literature on the lived experience of caring for a child who is dependent on technology [6, 7], parental surveys of treatment decisions [8], the medical perspective of decision-making [9] and analysis of documented family conferences [10]. However, there has been little exploration to date of parental experiences of discussions surrounding key decision-making milestones such as the initiation of LTV for a child. The aim of this review is to understand parental perspectives on communications with physicians at the point of initiation of LTV. This paper systematically maps the literature to establish the range and nature of studies conducted to date, outlining what is known and identifying any possible gaps in the literature.

Methods

Scoping reviews can be described as a method to map the concepts underpinning a research area and identify the main sources and types of evidence available. A study protocol was formulated to guide this review methodology [11, 12, 13]. The authors' review question was: what are parental perspectives on communications with physicians at the point of initiation of invasive LTV for a child?

Search strategy

A three-step search strategy was employed by two reviewers. An initial exploratory search identified potential journal articles and key concepts and phrases. Secondly, key words relating to technology dependence and parental experiences of communications with physicians were identified and this combination of index terms and keyword search strings were used to conduct a full systematic search of the literature. Finally, the reference lists of included studies were hand searched to identify any additional studies for inclusion. Detailed search terms are provided in Appendix 1.

Sources

A structured and robust search of seven bibliographic databases and one search engine for peer-reviewed literature published between 1st January 1970 and 31st March 2022 was conducted. The databases included in the full search were: PubMed, CINAHL Complete, ProQuest, Embase, PsycInfo, Medline, Web of Science and Google Scholar. Qualitative interviews and observational studies formed the main type of research evidence. Quantitative surveys or analysis and reviews were not considered for inclusion in this scoping review. Additionally, the documents for review had to meet the following inclusion criteria: published between January 1970 and March 2022; in a peer-reviewed journal; available in English language.

Study selection

Following the guidelines of Levac [12], a transparent and replicable process to select studies for inclusion was followed. Study screening was carried out in two distinct stages, firstly, titles and abstracts were screened for compliance with the predefined inclusion criteria. This was followed by retrieval of the full text of potential articles which were assessed for inclusion. The search process is reported in a PRISMA flow diagram (Fig. 1).

In total, 445 documents were identified for potential inclusion and were imported to Mendeley reference manager. After removal of duplications, 229 studies were transferred to Covidence screening and data extraction tool. One further study was deemed a duplicate, yielding a total of 228 studies for title and abstract screening. An agreed screening protocol was devised, and MB and JG reviewed the titles and abstracts for compliance with the inclusion criteria. 199 studies were deemed as not meeting the inclusion criteria and were excluded, resulting in 29 studies for full text review. Of the original 29 studies for full text review: five were selected for extraction and further analysis, 24 studies were excluded.

The five included studies were searched for additional sources and 36 further studies were deemed to meet the inclusion criteria. Of these, five were selected for extraction and further analysis. This dual approach yielded a total of 34 studies for full text review, of which, ten met the inclusion criteria. While reasons for exclusions were varied, they include but are not limited to: not specifically relating to LTV, perspectives of medical professionals only, analysis of hospital records or studies on the lived experience of caring for a child on LTV.

Data extraction

The ten selected studies were examined for compliance with the aim of the scoping review. To chart the data and record characteristics and key information, a systematic record of the following was compiled into a data extraction table; author(s), year, place, title, publication, aims, population, methods and summary of findings. This charting form extracts relevant data to characterise the literature and build up a picture of the landscape of research to date. The extraction table is presented in Table 1.

Table 1
Data extraction table: Parents perspectives scoping review

Author(s), Year, Place	Title, Publication	Aim, methodology	Population, methods	Summary of findings
Bogetz J., et al. 2021 USA [14]	Strengthening the Therapeutic Alliance Between Parents of Children with Severe Neurologic Impairment and Healthcare Providers During Critical Decision-Making. <i>Journal of Pain and Symptom Management</i>	To describe the experiences of parents of children with severe neurologic impairment (SNI) during decision-making. Descriptive qualitative study	25 parents facing a decision for a child with SNI admitted to acute or intensive care units at a single tertiary paediatric centre. Parents completed 1:1 semi-structured interviews and brief surveys. Demographic information was extracted from the child's electronic health record. A team of palliative and complex care researchers with expertise in qualitative methods used thematic content analysis to formulate results. Data gathered: August 2019 to February 2020	Responses from parents included 3 major themes: 1) our roles and actions; 2) our stresses and challenges; and 3) our meaning and purpose. Responses highlighted the pervasiveness of parental decision-making efforts and parents advocacy and vigilance regarding their child's needs. Despite this, parents often felt unheard and undervalued in the hospital.
Author(s), Year, Place	Title, Publication	Aim, methodology	Population, methods	Summary of findings

Author(s), Year, Place	Title, Publication	Aim, methodology	Population, methods	Summary of findings
Boss R., et al., 2021 USA [15]	Family Experiences Deciding For and Against Pediatric Home Ventilation. <i>The Journal of Pediatrics</i>	To understand what drives family decisions for, and against, paediatric home ventilation. Qualitative Interviews	38 families (42 parents) of children who faced a decision about home ventilation in the previous 5 years at 3 geographically dispersed institutions. Semi-structured qualitative interviews with parents and data analysed thematically and consolidated into overarching themes that summarise and represent the data. Data gathered: December 2018 to October 2019	Parent perspectives about home ventilation generally reflected whether the child was early, or later, in their disease trajectory. Early on, parents often interpreted prognostic uncertainty as hope and saw home ventilation as a tool permitting time for improvement. For families of children later in their disease course, often already with home technology and home nursing, home ventilation held less possibility for meaningful improvement. Nearly all families experienced the decision as very emotionally distressing. Reflecting back, most families described feeling satisfied with decision they made.
Author(s), Year, Place	Title, Publication	Aim, methodology	Population, methods	Summary of findings

Author(s), Year, Place	Title, Publication	Aim, methodology	Population, methods	Summary of findings
Edwards J., et al. 2020 USA [16]	Decisions for Long-Term Ventilation for Children Perspectives of Family Members <i>Annals of the American Thoracic Society</i>	To assess what families with children with chronic respiratory failure and life-limiting conditions need and want for informed decision- making. Semi- structured interviews	44 parents and 2 patients from 43 families Semi- structured interviews in person or by phone using an open-ended interview guide to assess parents decisional needs and experiences. Qualitative data analysis using a thematic approach based on framework analysis with thematic saturation as a goal. Data gathered: December 2015 to December 2017	Four domains were identified: parents emotional and psychological experiences with decision-making, parents informational needs, parents communication and decision support needs, and parents views on the option not to initiate long-term ventilation. For most parents, making a decision regarding long-term ventilation was stressful, even though they articulated goals and values that could/did guide their decision-making. In general, parents wanted comprehensive information, including what life would be like at home for the child and the family. They wanted their medical providers to be honest, tactful, patient, and supportive. Parents reported that they felt being presented with the option not to initiate was acceptable.
Author(s), Year, Place	Title, Publication	Aim, methodology	Population, methods	Summary of findings

Author(s), Year, Place	Title, Publication	Aim, methodology	Population, methods	Summary of findings
Erby LH., et al. 2006 USA [17]	My Son Is Still Walking: Stages of Receptivity to Discussions of Advance Care Planning Among Parents of Sons With Duchenne Muscular Dystrophy <i>Seminars in Pediatric Neurology</i>	To explore the attitudes, experiences and nature of discussions of advanced care planning for parents of children with Duchenne muscular dystrophy. Semi-structured qualitative interviews	17 parents of sons with Duchenne muscular dystrophy Recruitment survey collected basic demographic information followed by semi-structured qualitative interviews. Data was analysed thematically. Data gathered: 2006	Parents showed a lack of familiarity with and experience communicating about advance care planning. They also discussed opportunities for communication that centered on transitional life events. Parents appeared to vacillate between hope for future treatments, avoidance of emotionally difficult aspects of the disease, and presence with the fullness of life's experiences. These data suggest a model for future research in which windows of opportunity for discussion may exist as sons are approaching significant transitional milestones and parents are able to see the world through a lens of presence.
Author(s), Year, Place	Title, Publication	Aim, methodology	Population, methods	Summary of findings

Author(s), Year, Place	Title, Publication	Aim, methodology	Population, methods	Summary of findings
<p>Gower W., et al. 2020 USA [5]</p>	<p>Decision-Making About Tracheostomy for Children With Medical Complexity: Caregiver and Health Care Provider Perspectives. <i>Academic Pediatrics</i></p>	<p>To identify facilitators and barriers to tracheostomy decision-making (TDM) process for children with medical complexity (CMC). Descriptive qualitative study</p>	<p>56 caregivers of 41 CMC who received tracheostomies and 5 focus groups with 33 health care providers. Semi structured qualitative interviews with caregivers of children with medical complexity. Focus groups with health care providers. Qualitative data analysed consistent with thematic content analysis. Data gathered: December 2013 to October 2015</p>	<p>Five themes were identified.</p> <ol style="list-style-type: none"> 1) Caregivers perceived decision about tracheostomy for their children was theirs to make. 2) Strategies that increased caregivers active participation in the TDM process facilitated the TDM process. 3) Caregiver emotional stress and lack of understanding about tracheostomy were barriers. 4) Good HCP communication during the TDM process was valued; poor communication was a barrier. 5) Collaboration among HCP-facilitated TDM, especially when nurses were involved, whereas fragmentation in care was a barrier.
Author(s), Year, Place	Title, Publication	Aim, methodology	Population, methods	Summary of findings

Author(s), Year, Place	Title, Publication	Aim, methodology	Population, methods	Summary of findings
Lin J., et al. 2020 USA [18]	Parent Perspectives in Shared Decision-Making for Children With Medical Complexity <i>Academic Pediatrics</i>	To describe parent perspectives of shared decision-making (SDM) for children with medical complexity and identify opportunities to improve elements of SDM specific to this vulnerable population. Qualitative interviews	32 parents of children with medical complexity Semi-structured interviews using modified grounded theory to develop initial interview questions which probed topics until thematic saturation was achieved. Transcripts were coded and distilled into themes. Data gathered: October 2016 to September 2017	Three categories of themes emerged: participant, knowledge, and context. Key opportunities to improve SDM included: providing a shared decision timeline, purposefully integrating patient preferences and values, and addressing uncertainty in decisions
Author(s), Year, Place	Title, Publication	Aim, methodology	Population, methods	Summary of findings
Murrell D., et al. 2017 USA [19]	The Experience of Families With Children With Spinal Muscular Atrophy Type I Across Health Care Systems <i>Journal of Child Neurology</i>	To understand from the parents perspective, experiences of the family and child in the emergency centre, hospital, and clinical care settings to identify gaps in care. Descriptive qualitative study	19 families (29 biological parents) of 22 children with spinal muscular atrophy I. Focus group interviews with 1 to 4 participants. Interview guide contained open-ended semi-structured questions. Data was analysed thematically. Data gathered: 2014	Three overarching themes emerged from parent interviews describing a range of experiences surrounding diagnosis, informed medical decision-making and acute care practice. Identified quality improvements include development of a diagnostic screening tool, a medical decision tool, and emergency centre informational template individualized to the child and providing an overview of spinal muscular atrophy I.

Author(s), Year, Place	Title, Publication	Aim, methodology	Population, methods	Summary of findings
Nageswaran S., et al. 2018 USA [20]	Caregiver Perceptions about their Decision to Pursue Tracheostomy for Children with Medical Complexity <i>The Journal of Pediatrics</i>	To describe the perceptions of caregivers of children with medical complexity (CMC) about their decision to pursue tracheostomy for their children, in particular the satisfaction with their decision. Qualitative study	56 caregivers of 41 CMC who had received tracheostomies in the past five years. In-depth semi-structured interviews with an interview guide developed by the study team and revised to capture emerging concepts. Data was analysed using thematic content analysis. Data gathered: December 2013 to November 2014	Study found that caregivers often chose tracheostomy because extending the lives of their children and being able to care for them at home were important. Caregivers reported the benefits and negative effects of tracheostomy. Providing medical care for CMC with tracheostomy at home was difficult but improved over time. Caregivers were generally satisfied with their decision to pursue tracheostomy for their CMC.
Author(s), Year, Place	Title, Publication	Aim, methodology	Population, methods	Summary of findings

Author(s), Year, Place	Title, Publication	Aim, methodology	Population, methods	Summary of findings
Okido A., et al. 2015 Brazil [21]	Care for technology dependent children and their relationship with the health care systems <i>Revista Latino-Americana de Enfermagem</i>	To understand the experience of care delivery to technology dependent children based on the mothers experience. Exploratory qualitative study	12 mothers of technology dependent children Open interviews in the home environment. Narratives analysed based on interpretive analysis and grouped into thematic categories. Data gathered: October 2010 to December 2010	The narratives were organized into three thematic categories: the family system, identifying the care forms, the association between popular and scientific knowledge and the participation of the social network; the professional system, which discusses the relations between professionals and family, the hegemony of the biomedical model and the role of nursing; and the popular system, presenting popular care practices like spirituality and religiosity.
Author(s), Year, Place	Title, Publication	Aim, methodology	Population, methods	Summary of findings

Author(s), Year, Place	Title, Publication	Aim, methodology	Population, methods	Summary of findings
Qian Y., et al. 2015 USA [22]	Understanding the experiences and needs of individuals with Spinal Muscular Atrophy and their parents: a qualitative study <i>BMC Neurology</i>	To address the gap on how individuals with Spinal Muscular Atrophy (SMA) and their parents experience this condition. Descriptive qualitative study	96 participants including: 21 with individuals with SMA; 64 parents of individuals affected by SMA; and 11 clinicians who specialize in the care of SMA patients 16 focus group sessions and 37 semi-structured telephone interviews using grounded theory to uncover core concepts and identify unifying themes until data saturation was achieved. Data gathered: June to October 2014	The Diagnostic Journey: Families reported substantial diagnostic delays owing to: 1) lack of awareness and knowledge about SMA; 2) the difficulty of distinguishing normal from abnormal development; and 3) the challenge of differential diagnosis. Lack of sensitivity in how clinicians communicated this potentially devastating diagnosis compounded parents negative impressions.

Study and Population Characteristics

The data in the studies was collected between 2006 and 2020, nine of the studies were conducted in North America and one study was based in Brazil. The population under study were parents of children who faced a decision about the commencement of LTV for their child. The included studies had a spectrum of research questions relating to caring for a child who is technology dependent and all specifically addressed the decision-making process around initiation of LTV and parental perspectives of communications with physicians at this point.

Data Analysis

Following Braun and Clarke's [23] guide to thematic analysis, data synthesis and analysis was conducted by JG to identify, analyse and report patterns within the data and was extensively discussed and refined by the research team at all stages. Using this approach, themes were conceptualised based on the data which represent the meanings and perceptions the research population hold, as interpreted by the

researchers. This was achieved by reading the articles and noting features in a systematic way. Twenty codes emerged which were grouped into concepts, and following refinement and review, three coherent themes emerged which captured the coded data. The codebook with associated examples from the literature is presented in Appendix 2.

Results

The literature clearly locates parents at the centre of the decision-making process, although many parents have little knowledge of uncommon but critically needed medical interventions. Parents regularly feel stressed and out of their depth by the need to make quick decisions without complete information to support their choices. These critical decisions can be made in stressful and unfamiliar environs and parents are highly dependent on physicians to support and guide them through the decision-making process. The literature indicates three overarching themes that describe communications at the point of initiation of LTV: the need to ventilate, navigating medical decision-making and perceptions of communications with physicians.

The need to ventilate

When facing decisions about initiating LTV, the literature suggests most parents feel they are the ultimate decision-makers [5, 14, 18], but the process is often intensely lonely and emotionally distressing [15, 16, 19]. Some parents described feeling frustrated and felt their opinions were undervalued [14] in the context of the healthcare setting. Decisions regarding treatments were often time-sensitive and frequently occurred in the intensive care unit (ICU) or during a prolonged hospital stay after a long journey to diagnosis [15, 19, 22]. For many parents, the weight of responsibility of making urgent and serious decisions for their child meant they relied on their physician, particularly if they felt they had incomplete information to guide them [5, 19]. In such situations, parents deferred to their physician [18] and for some, their perceived lack of medical expertise implied a sense of loss of control [17, 18]. The review shows that LTV was often presented to the parents as the logical next step and as a procedure that had to be done [15, 18], but was often the only treatment option offered [5, 20]. The option to not pursue LTV was rarely described in the literature as a consideration [16], this may be because there was no other option to preserve life [5] or because LTV was viewed as inappropriate for the child [16]. Differences of opinion on treatments could emerge in many circumstances, such as when parents were uncertain about how the condition would progress; when they were reluctant to consent to their child having an invasive procedure or were unsure of the impact of technology dependence [18]. When parents deviated from their physicians' recommendations, they felt they were an annoyance [18] or that the healthcare team viewed them as uncaring [16]. Physicians were found to be key in driving critical decision-making [18] but often had limited understanding of how to guide ethical decision-making alongside the parents [19], a central facet of deciding to ventilate.

Navigating medical decision-making

Although the guidance of physicians and an ongoing positive parent-expert partnership was crucial [17, 19], the review shows that positive communications with parents were also facilitated by good collaboration across the healthcare team [5, 17, 19] and physicians actively involving nurses in conversations was viewed as a positive step [5]. Parents valued the input of the entire healthcare team and frequently sought perspectives from outside the core team [15] to support their discussions with physicians. Nurses and respiratory therapists were seen as playing valuable roles as they could further address concerns and questions. The review shows that the input of other professionals such as palliative care and social workers was also valued, as parents sometimes felt more comfortable and trusting of them [5, 15]. When faced with difficult treatment choices, parents felt they needed to fully understand all the options available [16, 19] rather than to simply accept the initial physician advice. There was a need to educate themselves about rare medical conditions and procedures as they had little relevant life experience to rely on [15, 17] to make a well-informed decision for their child [16]. Sometimes, spiritual or non-conventional approaches were drawn upon as a coping strategy or to generate feelings of hope [5, 16, 18, 21] and increasingly, social media sources were found to be influential [15, 18]. There was a sense of taking one day at a time and to cross the decision-making bridge as it arrived [17]. For many, the journey of the decision-making process evoked an emotional response that evolved over time. The initial devastation of the diagnosis [16] and feelings of loss of hope and grief [15] often transitioned to an adjustment of life expectations and the necessity to adapt as a person in response to their child's life-limiting illness and changing needs [14]. Parents navigating the medical decision-making process required responsive and timely interventions by physicians, often with supports from the healthcare team, to enable well-informed decision-making.

Perceptions of communications

Parents had different communication needs with physicians, some valued early and frequent information [15, 17], while others felt overloaded with information [5, 15]. Good communications with physicians were essential for parents who found qualities such as honesty, tactfulness, patience and accuracy important during the decision-making process [5, 16]. Sharing stories about other children with similar conditions was helpful [5]. Empathetic communications directly relevant to their own child's condition [16, 19] were valued as some parents found the information presented to them about LTV was overwhelming [15] and admitted that they may not have understood all the information that was shared with them at the time [5]. There was a reluctance to hear 'bad news' with some parents reporting they preferred to receive only positive information [16].

Barriers to decision-making occurred when information was delivered insensitively, this was particularly pertinent when parents were given unexpected bad news with weighty implications for their child's life and their family [22]. Unhelpful conversations were characterised by insufficient information, pressured decision-making, changing staff and depersonalisation of the child [5, 15, 16]. Parents regularly felt the need to advocate for their child [14, 19] and their best interests, particularly when a child was unable to vocalise their pain or preferences [18, 19]. Concerns about uncertain health trajectories were to the fore [18] with many parents finding that physicians did not fully inform them about the long-term

consequences of LTV [15, 20] and how the decision impacts the whole family [14]. Many expressed the wish to have been better versed on the experiences of home nursing [16] and felt there was too much focus on clinical outcomes [18]. Some parents found that a hierarchal relationship with their physician implied that parental knowledge and experience was often overlooked [21]. Reflecting on the initiation of LTV, most parents were satisfied with their decision [15] but some wished they had access to other families' experiences to aid their own decision-making process [15].

Discussion

There is limited research surrounding the critical decision-making processes that parents encounter when their child requires life-sustaining technology such as invasive LTV. This review highlights parents are central decision-makers, however, without in-depth medical knowledge they often find making key decisions about invasive procedures for their child overwhelming. This perceived loss of control can make the experience of decision-making a daunting and isolating experience for many, which is frequently amplified in the complex environment of the healthcare setting. To combat this, parents value a collaborative approach and wider research indicates they value good communications with their physician and being treated as allies in a trusting relationship [24]. This review collates parental perspectives and four key areas are identified as aiding the decision-making process for parents, enabling them to make more informed decisions for their child at the point of commencement of invasive LTV.

Responsive

The review findings suggest that during decision-making at critical moments such as the initiation of LTV, physicians can aid parents by being responsive to their informational needs depending on the parents' experience of the healthcare environment. These findings build upon the emerging evidence demonstrating that the type and amount of information required by parents is wide ranging and can relate to their child's immediate condition and also expectations for their ongoing care [25, 26]. Parental needs can reflect where a child is on their disease trajectory - at early stages, parents can feel overwhelmed in the medical environment, while at later stages, parents feel more in control and seek to clarify or request additional information to aid decision-making.

Facilitate

Emphatic communications with parents help them make the best decision for their child. This echoes the literature showing that healthcare providers can focus on relaying medical information sometimes to the neglect of providing information in a sensitive and understandable manner [10, 27]. Incorporating the support of the wider healthcare team with perhaps different perspectives, can enable parents to feel more empowered in the decision-making process. Time pressures and stressful environments were found to be barriers to the decision-making process so creating space for parents to engage positively with the healthcare team and build a trusted relationship is essential [28]. Parents have access to a wide variety of informational sources [29] but connecting with other families who have similar experiences helped parents to overcome feelings of isolation and aided their informational needs [25]. Informal supports in a

formalised manner such as support groups could be a useful strategy to help active participation in decision-making [15, 16].

Ethical

Relevant and timely information is crucial for assisting parents in the decision-making process enabling them to make informed ethical decisions for their child. Difficult discussions and dilemmas such as deciding not to initiate LTV, need to be made in a sensitive manner where parents have access to all the information they need from physicians to guide decision-making in the best interest of their child [30]. Previous studies have shown parents of technology dependent children can be critical of decisions prioritising survival rates rather than quality of life [31]. Parental decisions that deviate from medical opinion need to be respected and dealt with in a non-judgemental way to find collaborative ways to address difficult decisions and alternatives [32]. Recognition should be given to the differing cultural and social contexts of the decision-making process as many influences can shape parents collective value system and need to be incorporated into discussions [26, 33]. Physicians that are open to alternative approaches and points of view are likely to build more trusting and collaborative relationships.

Long-term

This review highlighted that sharing stories of similar cases helped parental decision-making, this was particularly relevant in the context of long-term care for a child. Timely sharing of information about the long-term outcomes of LTV was valued by parents as this enabled them to make appropriate decisions for their child and wider family and to manage expectations about expected outcomes for their child. This reflects the wider literature on caring for a child with a critical illness and their informational needs on long-term care post discharge [25, 34, 35].

Conclusion

This review provides an initial assessment of the scope of qualitative research literature on parental perspectives of communications with their physicians at the point of initiation of invasive LTV of a child. It highlights that a timely, responsive approach to conversations with parents is essential to enable informed and active parental decision-making. Parents are centrally positioned to make decisions in the best interests of their child but need to be facilitated to do this. It was found that understandings of parental perspectives at the commencement of LTV is limited by a lack of in-depth qualitative research and this review offers an insight into this under researched area. While there has been some research conducted, this is mainly situated in North America, with the perspectives of other global regions not adequately explored to date. Parents are not a homogenous group and variations in the geographical and cultural contexts of decision-making needs investigation. The authors found a distinct lack of acknowledgement of different family types with studies to date focused on traditional family types. A further aspect to examine is the impact of gender and how this affects decision-making. With increasing reliance on technology to sustain a child's life [1, 3], a study of parental experiences of communications with physicians at the commencement of invasive procedures such as LTV, would be a valuable

contribution to the existing literature and provide an understanding of the decision-making processes undertaken at critical junctions.

Abbreviations

CICN Complex and integrated care needs

ICU Intensive care unit

LTV Long-term ventilation

PICU Pediatric intensive care unit

Declarations

Funding

This project has received funding from the European Research Council (ERC) under the European Union's Horizon 2020 research and innovation programme (grant agreement No 803051).

Competing Interests

The authors have no financial or non-financial interests to disclose.

Contributions

All authors contributed to the study conception and design. Material preparation, data collection and analysis was performed by Jo Greene. The first draft of the manuscript was written by Jo Greene and all authors commented on previous versions of the manuscript. All authors read and approved the final manuscript.

Ethics Approval

Ethical approval was not required for this scoping review as it is a review of previously published literature.

References

1. Brenner M, Greene J, Doyle C, Koletzko B, del Torso S, Bambir, I, De Guchteneere, A, Polychronakis, T, Reali, L, Hadjipanayis, A (2021) Increasing the focus on Children's Complex and Integrated Care Needs: a position paper of the European Academy of Pediatrics. *Front Pediatr* 9:758415. <https://doi.org/10.3389/fped.2021.758415>
2. Nicholl H, Doyle C, Moran S, Guilfoyle M (2013) Identifying the types of technology that are used by children with intellectual disabilities and associated complex needs living at home in Ireland. *British*

- Journal of Learning Disabilities 41:229-236. <https://doi.org/10.1111/bld.12045>
3. Amin R, Sayal P, Syed F, Chaves A, Moraes TJ, MacLusky I (2014) Pediatric long-term home mechanical ventilation: twenty years of follow-up from one Canadian center. *Pediatr Pulmonol* 49(8):816–824. <https://doi.org/10.1002/ppul.22868>
 4. Alexander D, Quirke MB, Doyle C, Hill K, Masterson K, Brenner M (2022) The meaning given to bioethics as a source of support by physicians who care for children who require long-term ventilation. *Qual Health Res*. <https://doi.org/10.1177/10497323221083744>
 5. Gower WA, Golden SL, King N, Nageswaran S (2020) Decision-Making About Tracheostomy for Children With Medical Complexity: Caregiver and Health Care Provider Perspectives. *Acad Pediatr* 20(8):1094-1100. <https://doi.org/10.1016/j.acap.2020.06.004>
 6. Hebert LM, Watson AC, Madrigal V, October, TW (2017) Discussing Benefits and Risks of Tracheostomy: What Physicians Actually Say. *Pediatr Crit Care Med* 18(12):e592–e597. <https://doi.org/10.1097/PCC.0000000000001341>
 7. Toly VB, Musil CM, Carl JC (2012) A longitudinal study of families with technology dependent children. *Res Nurs Health* 35(1):40-54. <https://doi.org/10.1002/nur.21454>
 8. Lindahl B, Lindblad B (2011) Family members' experiences of everyday life when a child is dependent on a ventilator: A metasynthesis study. *J Fam Nurs* 17(2):241-269. <https://doi.org/10.1177/1074840711405392>
 9. Lövgren M, Sejersen T, Kreicbergs U (2016) Information and treatment decisions in severe spinal muscular atrophy: A parental follow-up. *Eur J Paediatr Neurol* 20(6),830–838. <https://doi.org/10.1016/j.ejpn.2016.08.008>
 10. Michelson K, Clayman ML, Ryan C, Emanuel L, Frader J (2017) Communication During Pediatric Intensive Care Unit Family Conferences: A Pilot Study of Content, Communication, and Parent Perceptions. *Health Commun* 32(10):1225-1232. <https://doi.org/10.1080/10410236.2016.1217450>
 11. Arksey H, O'Malley L (2005) Scoping studies: towards a methodological framework. *Int J Soc Res Methodol* 8(1):19–32. <https://doi.org/10.1080/1364557032000119616>
 12. Levac D, Colquhoun H, O'Brien KK (2010) Scoping studies: advancing the methodology. *Implement Sci* 5:69. <https://doi.org/10.1186/1748-5908-5-69>
 13. Peters MDJ, Godfrey CM, Mclnerney P, Baldini Soares C, Khalil H, Parker D (2015) Methodology for JBI scoping reviews. In: *The Joanna Briggs Institute reviewers' manual 2015*. Australia: The Joanna Briggs Institute.
 14. Bogetz JF, Lewis H, Shipman KJ, Jonas D, Trowbridge AC, Rosenberg AR (2021) Strengthening the Therapeutic Alliance Between Parents of Children with Severe Neurologic Impairment and Healthcare Providers During Critical Decision-Making. *J Pain Symptom Manage* 61(3):646. <https://doi.org/10.1016/j.jpainsymman.2021.01.023>
 15. Boss RD, Henderson CM, Raisanen JC, Jabre NA, Shipman K, Wilfond BS (2021) Family Experiences Deciding For and Against Pediatric Home Ventilation. *J Pediatr* 229:223-231. <https://doi.org/10.1016/j.jpeds.2020.10.014>

16. Edwards JD, Panitch HB, Nelson JE, Miller RL, Morris MC (2020) Decisions for long-term ventilation for children perspectives of family members. *Ann Am Thorac Soc* 17(1):72-80. <https://doi.org/10.1513/AnnalsATS.201903-271OC>
17. Erby LH, Rushton C, Geller G (2006) "My Son Is Still Walking": Stages of Receptivity to Discussions of Advance Care Planning Among Parents of Sons With Duchenne Muscular Dystrophy. *Semin Pediatr Neurol* 13(2):132-140. <https://doi.org/10.1016/j.spen.2006.06.009>
18. Lin JL, Clark CL, Halpern-Felsher B, Bennett P, Assis-Hassid S, Amir O, Casteneda Nunez Y, Miley Cleary N, Gehrmann S, Grosz B, Sanders LM (2020) Parent Perspectives in Shared Decision-Making for Children With Medical Complexity. *Acad Pediatr* 20(8):1101-1108. <https://doi.org/10.1016/J.ACAP.2020.06.008>
19. Murrell DV, Lotze TE, Farber HJ, Crawford CA, Wiemann CM (2017) The Experience of Families with Children with Spinal Muscular Atrophy Type i Across Health Care Systems. *J Child Neurol* 32(11):917-923. <https://doi.org/10.1177/0883073817716853>
20. Nageswaran S, Golden SL, Gower WA, King NMP (2018) Caregiver Perceptions about their Decision to Pursue Tracheostomy for Children with Medical Complexity. *J Pediatr* 203:354-360. <https://doi.org/10.1016/J.JPEDI.2018.07.045>
21. Okido ACC, Zago MMF, de Lima RAG (2015) Care for technology dependent children and their relationship with the health care systems. *Rev Lat Am Enfermagem* 23(2):291-298. <https://doi.org/10.1590/0104-1169.0258.2554>
22. Qian Y, McGraw S, Henne J, Jarecki J, Hobby K, Yeh WS (2015) Understanding the experiences and needs of individuals with Spinal Muscular Atrophy and their parents: a qualitative study. *BMC Neurol* 15:217. <https://doi.org/10.1186/s12883-015-0473-3>
23. Braun V, Clarke V (2006) Using thematic analysis in psychology. *Qualitative Research in Psychology* 3(2):77–101. <https://doi.org/10.1191/1478088706qp063oa>
24. Bennett RA, LeBaron VT (2019) Parental Perspectives on Roles in End-of-Life Decision Making in the Pediatric Intensive Care Unit: An Integrative Review. *J Pediatr Nurs* 46:18–25. <https://doi.org/10.1016/j.pedn.2019.02.029>
25. Laudato N, Yagiela L, Eggly S, Meert, KL (2020) Understanding parents' informational needs in the pediatric intensive care unit: A qualitative study. *Prog Pediatr Cardiol* 57:101172. <https://doi.org/10.1016/j.ppedcard.2019.101172>
26. Zaal-Schuller IH, Willems DL, Ewals FVPM, van Goudoever JB, de Vos MA (2016) How parents and physicians experience end-of-life decision-making for children with profound intellectual and multiple disabilities. *Res Dev Disabil* 59:283–93. <https://doi.org/10.1016/j.ridd.2016.09.012>
27. Gillick MR (2015) Re-engineering shared decision-making. *J Med Ethics* 41(9):785–788. <https://doi.org/10.1136/medethics-2014-102618>
28. Mitchell S, Spry JL, Hill E, Coad J, Dale J, Plunkett A (2019) Parental experiences of end of life care decision-making for children with life-limiting conditions in the paediatric intensive care unit: a

- qualitative interview study. *BMJ Open* 9;9(5):e028548. <https://doi.org/10.1136/bmjopen-2018-028548>
29. Anesa P, Fage-Butler A (2015) Popularizing biomedical information on an online health forum. *Ibérica* 29:105-128.
 30. Weise KL, Okun AL, Carter BS, Christian, CW (2017) Guidance on Forgoing Life-Sustaining Medical Treatment. *Pediatrics* 140(3):e20171905. <https://doi.org/10.1542/peds.2017-1905>
 31. Rapoport A, Harrison C, Carnevale FA (2018) Section 3: Ethics of initiation of long-term ventilation in children at home. *Canadian Journal of Respiratory, Critical Care, and Sleep Medicine* 2:sup1:16-22 <https://doi.org/10.1080/24745332.2018.1494491>
 32. Elwyn G, Lloyd A, May C, van der Weijden T, Stiggelbout A, Edwards A, Frosch DL, Rapley T, Barr P, Walsh T, Grande SW, Montori V, Epstein R (2014) Collaborative deliberation: a model for patient care. *Patient Educ Couns* 97(2):158–164. <https://doi.org/10.1016/j.pec.2014.07.027>
 33. Larcher V, Craig F, Bhogal K, Wilkinson D, Brierley J (2015) Making decisions to limit treatment in life-limiting and life-threatening conditions in children: a framework for practice. *Arch Dis Child* 100:s1-s23. <https://doi.org/10.1136/archdischild-2014-306666>
 34. Bowles JD, Jnah AJ, Newberry DM, Hubbard CA, Roberston T (2016) Infants With Technology Dependence: Facilitating the Road to Home. *Adv Neonatal Care* 16(6):424–429. <https://doi.org/10.1097/ANC.0000000000000310>
 35. De Jesus-Rojas W, Mosquera RA, Samuels C, Eapen J, Gonzales T, Harris T, McKay S, Boricha F, Pedroza C, Aneji C, Khan A, Jon C, McBeth K, Stark J, Yadav A, Tyson JE (2018) The Effect of Comprehensive Medical Care on the Long-Term Outcomes of Children Discharged from the NICU with Tracheostomy. *Open Respir Med J* 12:39–49. <https://doi.org/10.2174/1874306401812010039>

Appendix

Appendix 1: Detailed search terms

("parent" OR "parent*" OR "mother" OR "father" OR "guardian" OR "family") AND ("child" OR "children") AND ("physicians" OR "healthcare professional" OR "doctor" OR "medical practitioner" OR "consultant" OR "clinician" OR "clinical" OR "pediatric" OR "paediatric") AND ("technology depend*" OR "technology-depend*" OR "invasive ventilation" OR "long term ventilation" OR "long-term ventilation" OR "artificial respiration" OR "mechanical ventilation" OR "tracheostomy") AND ("communication" OR "conversation" OR "decision-making" OR "decision making" OR "articulation" OR "disclosing" OR "advocacy" OR "shared" OR "engagement" OR "attitude")

Appendix 2: Codebook with associated examples from the literature

Core theme	Sub-themes	Example in literature
<i>The need to ventilate</i>	Who decides?	Parents have ultimate decision despite incomplete information [14]
		Parents felt they should be in control of decision, the ultimate decision maker [18]
		Caregiver perceived decision about LTV was theirs to make, sometimes an urgent decision [5]
		Providers often have limited understanding of how to guide ethical decision-making [19]
	Emotional experience	Emotionally distressing [15]
		Social isolation, lonely experience [14]
		Pressure to make a quick decision, leading to stress [19]
		Frustration at not being listened to [14]
		Some parents felt unheard and opinion undervalued [14]
		Weight of responsibility of decision-making [14]
		Intensity of parenting [14]
		Conflict between parents [15]
	Context of decision-making	Decision to initiate usually taken during a prolonged hospital stay [15]
Discussion of home ventilation initially in ICU [15]		
Factors affecting how families arrive at a diagnosis, sometimes a long journey [10]		
Unexpected diagnosis or difficult treatment choices [22]		
HCP View	Doctors present LTV as logical next step [15]	
	HCP said procedure 'had' to be done [18]	
	No other option given [5]	
	Trach was often the only option presented [20]	
Other options	Not take LTV option, rarely offered, a choice in tough situations [16]	
	LTV not always obligatory [16]	
Differing opinions	Parent who did not pursue LTV option felt medical team viewed her as uncaring [16]	
	Parents felt they were an annoyance when they had differing	

opinions [18]

Reluctance to commit to LTV when uncertain about life-course trajectory, its impact and technology dependence [18]

***Navigating
medical
decision-making***

The healthcare team

Parents guided by medical team (experts) [17]

Physicians involving nurses was positive [5]

Nurses and respiratory therapists play a major role, more comfortable and trusting [5]

Good collaboration between medical team was valued [5]

Need for a 'go to' person, to coordinate the different parts of medical system [19]

Health system constraints impaired decision-making (shorten decision-making window) such as availability of key professionals/ medical equipment / therapies / rooms [18]

Information

Parents need to fully understand options available to make informed decision [19]

Educate myself to be his primary care physician [17]

Other sources

LTV is an uncommon procedure, little relevant life experience to draw upon [15]

Parents sought perspectives from outside core team [15]

Parents valued non-professional/other sources as more influential [18]

Parents use social media sources [15]

Spirituality

Faith in a higher power [16]

Spirituality [5]

Complementary and alternative therapies, non-conventional approaches [21]

Religion: prayers, helps coping, generates feelings of hope [21]

Emotional needs

Take one day at a time, cross bridge (decision-making) when come to it [17]

Adjust life expectations and financial expectations [14]

Signal loss of hope, grief [15]

		Devastation at child's condition [3]
		Transform as a person in response to child's need [14]
Why LTV?		Parents chose to extend lives of child and care for them at home [20]
		Desire for 'getting home' drove decision-making [15]
Perceptions of communications	HCP Comms: Positive	Sharing stories about children with similar conditions was helpful [5]
		Good communications were valued [5]
		Valued qualities: honesty, allowed time, tactful, supportive [3] honest, patient, hopeful [5]
		Empathic communications with increased information from medical team [19]
		An early and ongoing relationship with doctor was valued [17] (continuity of care)
	HCP Comms: Negative	Inconsistently discussed [15]
		Did not value qualities: insufficient information, not timely, lack of detail, pressure to make decision, changing staff, depersonalisation of child [16]
		Rush or pressure to make a decision was perceived as negative [5]
		Insensitive or unhelpful HCP, very hard especially when unexpected diagnosis or treatment choices are presented [22]
		Focus on clinical outcomes [18]
	Parent as advocate	Being the child's voice [14]
		Patient preferences rarely sought [18]
		Parents advocate for child (when HCP are unfamiliar with their condition), child is unable to vocalise pain [19]
		Important to know everything about condition to enable making a well-informed decision [16]
		Concerned about uncertain health trajectories [18]
	Information	Some parents preferred only positive information. Did not wish to hear negative information and only information directly related to their child's condition [16]

	Information provided by HCP could be overwhelming [5]
	Parents not willing to accept 'bad news' [5]
	Different reactions to discussions with HCP, some valued early and frequent information, others felt overwhelmed, information overload and tried to avoid [15]
Long-term	Too little information on long term experience and outcomes and mostly training for home nursing [15]
	Wished better informed of difficulties of home nursing [16]
	Clinicians did not counsel adequately about long-term negative consequences of trach [20]
Authority	Physicians regarded as professional class with social power and ignore maternal knowledge and experience [21]
	Relations between HCP and parents/patients should be conducted in a non-hierarchical manner [21]
Reflections	Parents pick up pieces healthcare system cannot provide [14]
	Decision for child impacts whole family [14]
	Most satisfied with their decision [15]
	Wished had access to other families experiences [15]
	Tracheostomy decision-making is an iterative process, occurring over time, an ongoing information exchange [5]
	Parents should ask doctors about benefits of trach and only pursue if absolutely needed [20]
	Decision should be based on individual child rather than diagnosis [19]
	Balance quality of life with longevity [19]
Resources developed to aid decision-making process	LTV booklet [16] Family reflections website [15]

Figures

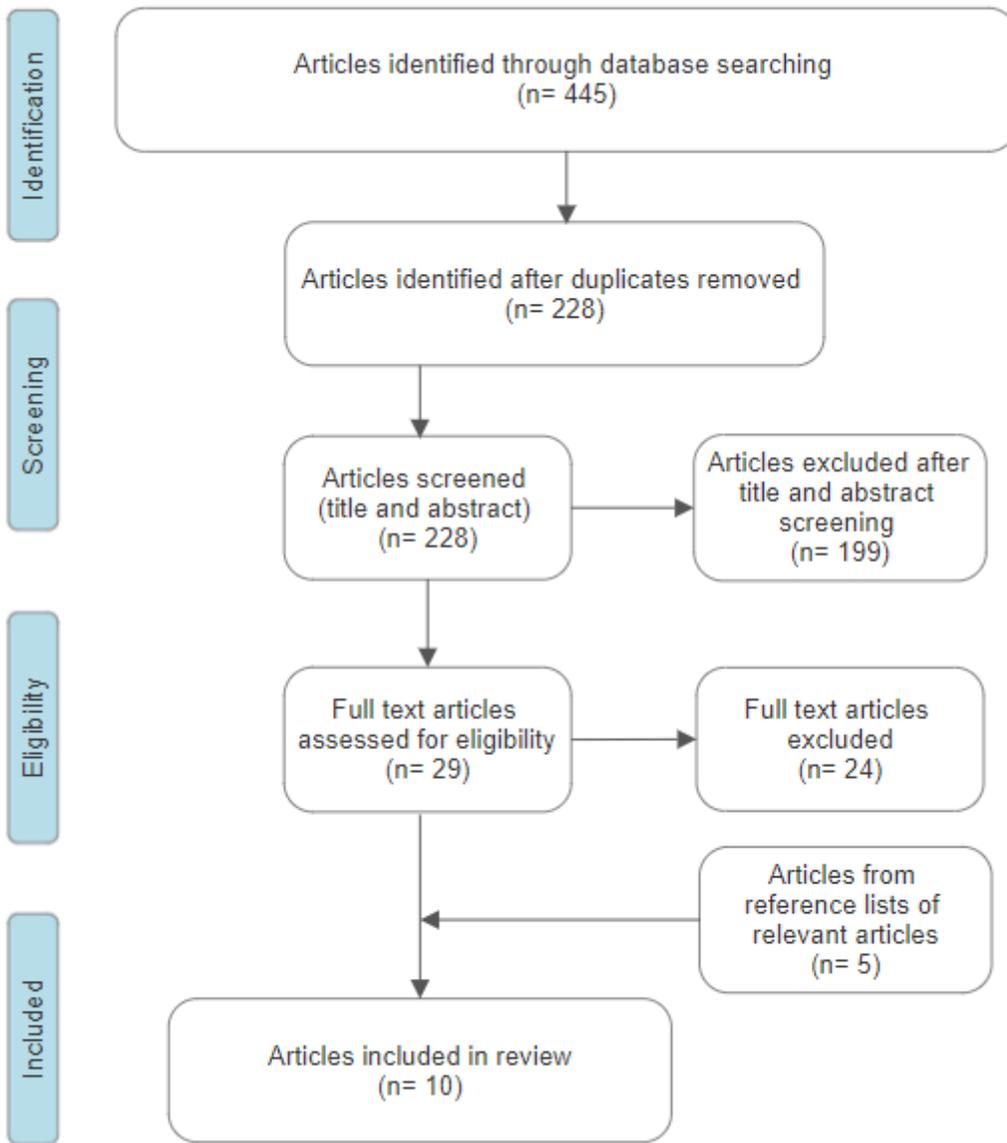


Figure 1

PRISMA flow diagram of study selection process