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Initiating technology dependence to sustain a child's life: a systematic review of reasons

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ABSTRACT

Background Decision-making in initiating life-sustaining health technology is complex and often conducted at time-critical junctures in clinical care. Many of these decisions have profound, often irreversible, consequences for the child and family, as well as potential benefits for functioning, health and quality of life. Yet little is known about what influences these decisions. A systematic review of reasoning identified the range of reasons clinicians give in the literature when initiating technology dependence in a child, and as a result helps determine the range of influences on these decisions.

Methods Medline, EMBASE, CINAHL, PsychINFO, Web of Science, ASSIA and Global Health Library databases were searched to identify all reasons given for the initiation of technology dependence in a child. Each reason was coded as a broad and narrow reason type, and whether it supported or rejected technology dependence.

Results 53 relevant papers were retained from 1604 publications, containing 116 broad reason types and 383 narrow reason types. These were grouped into broad thematic categories: clinical factors, quality of life factors, moral imperatives and duty and personal values; and whether they supported, rejected or described the initiation of technology dependence. The majority were conceptual or discussion papers, less than a third were empirical studies. Most discussed neonates and focused on end-of-life care.

Conclusions There is a lack of empirical studies on this topic, scant knowledge about the experience of older children and their families in particular; and little written on choices made outside 'end-of-life' care. This review provides a sound basis for empirical research into the important influences on a child's potential technology dependence.

INTRODUCTION

The initiation of, or decision not to initiate, technology that will be required long-term to sustain a child's life is extremely complex, often conducted at time-critical junctures in clinical care, such as when a child's existing medical condition deteriorates, or is facing end-of-life care, generally in a paediatric critical care environment, such as paediatric or neonatal intensive care. Such decisions may have profound, and often irreversible, consequences for the child and for the child's family. Factors that influence decisions around initiation may be inclusive of judgements about the best interests of the child and their future quality of life while supported by life-sustaining technology. However, the types of influences that may impact

on decisions made by clinicians at this point-of-care delivery are largely unknown.^{1,2} This review deliberately focuses on clinicians' influences, because of the lack of research into this group at this point-of-care delivery even though they are a key actor in the ultimate decision. This is not to deny the importance of patient and family decision-making, nor the value of shared decision-making. The aim of this review was not to evaluate decision-making frameworks for clinical practice, but to complete an in-depth academic exploration of the reasons and arguments in the literature for initiating or not initiating technology dependence in children made by clinicians. We have defined technology dependence required to sustain a child's life in terms of a wide range of clinical technology to support biological functioning across a dependency continuum, for a range of clinical conditions.³ These are initiated within a complex biopsychosocial context and have wide-ranging sequelae for the child and family and for health and social care delivery. This is the approach to technology dependence taken for the purposes of this review.

To achieve this aim, we conducted a systematic review of reasoning, guided by the methodology outlined by Strech and Sofaer.⁴ This explores how influences on the initiation of technology dependence in acute paediatric healthcare have been, and are currently, conceptualised, in the scientific literature, and increases our understanding of the liminal space between the clinical diagnosis and eventual decision of the (nominally) primary decision-maker in the clinical team.

METHODS

The use of a systematic review of reasoning allows the application of a systematic approach to the argument-based literature of philosophical and empirical bioethics that discusses the issues of initiating life-sustaining technology. The review question is not an ethical question, but the factual question of which reasons have been given to address an ethical question. Thus, a review of reason allows us to identify the ethical questions and decisional elements surrounding technology initiation, from the point of view of clinicians. It achieves this by identifying the individual reasons given in the scientific literature, and assessing them in terms of whether each reason is regarded as 'morally justifiable, impermissible, permissible or obligatory or for the view that a specific intervention should or need not be made'.⁵ Unlike a traditional systematic review, this review does not seek to settle the question of whether technology should or should not

be initiated, nor does it provide guidance for decision-making in this context, as this would be impossible to predict. Instead, it presents an in-depth exploration of the arguments that exist in the literature, the reason being that a full set of reasons for or against the view in question is more useful than an inadequate 'all things considered' conclusion. This highlights the current gaps in these arguments in this fast-changing medical technology environment and can inform future empirical research around the initiation of technology dependence in children. This review of reasoning therefore asks: 'Which reasons have been given for the initiation, or non-initiation, of technology dependence in a critical care environment to sustain a child's life?' A secondary question of the review is: 'how have these reasons been used to argue that initiation of technology dependence in a child should or need not be undertaken?'

Identifying the relevant literature

The search strategy was deliberately wide, and did not search specifically for 'reasons' or 'reasoning' because this would prevent the retrieval of many papers whose main purpose was to discuss reasoning, we were keen to ensure that all papers on the initiation of technology dependence were retrieved, so that we could capture reasoning that may be incidental to the main results of that paper. The search took place between March 2019 and June 2020. A three-strand search of the literature surrounding technology dependence in children was conducted with the aid of a specialist librarian. Seven key databases were identified to ensure a wide coverage of the literature. (EBSCO) Medline (1946–), CINAHL (1981–), PsycINFO (1990–), (Ovid) Embase (1966–), WHOLiS, Web of Science (1864–) and ASSIA (1970–). The databases were first scanned to identify appropriate index terms. A secondary keyword search string was then developed. This was populated using lists of synonyms and with input of keywords suggested by the research team, based on the key concepts of technology dependence; and physical disability, chronic illness and complex care needs. A combination of index terms and keyword search strings were used to create a systematic search. A sampler of the Medline search may be reviewed in the online supplemental material. Additional citation and bibliographic searches were conducted on all included studies to identify additional relevant studies for inclusion. All results were exported into Endnote for deduplication and then into Covidence for screening. Given the fact that this was the first time such a review was conducted on this topic the search had no limits on start and end dates.

Study selection

Publications were included only if they met the inclusion criteria, these are explained in [table 1](#).

We retrieved 1604 papers. After screening of titles and abstracts by two researchers, 1128 papers were discarded. A snowball search⁶ of the references of included papers, notes and

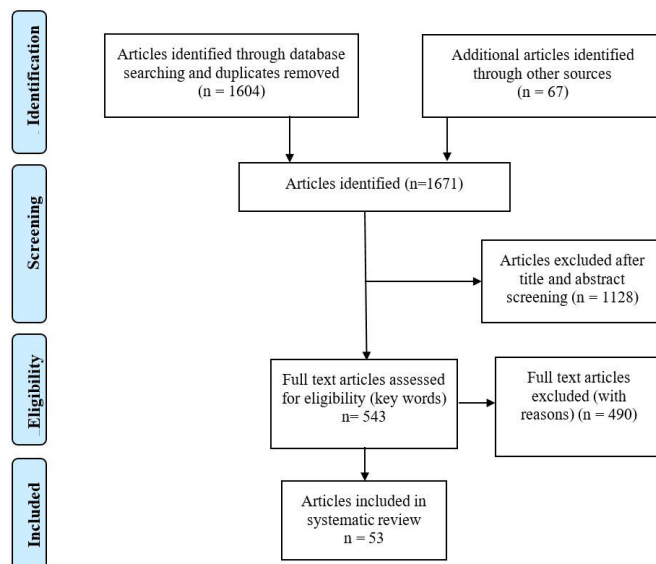


Figure 1 Data search and selection process.

bibliographies identified a further 67 relevant papers. A total of 543 papers were retained for full-text analysis to identify if reasons for initiation or non-initiation of technology dependence were contained in the text. We excluded 490 papers, primarily because they did not address the child population; or they did not discuss life-sustaining technology specifically, but addressed, for example cochlear implants, or wheelchairs which may aid life, but are not essential to sustain it. Papers were also rejected if they were not placed in the critical care environment, many papers focused on the challenges of living with technology-dependence at home, or at school or work. This process left 53 papers included in the review ([figure 1](#)).

Charting the data

Three tasks contributed to the charting of the data to minimise bias and also provide informative results. First, reasons were identified in the text by two researchers (DA and MB). Subsequently, each identified reason was coded by reason type, according to the passage in which the reason appeared; and finally, information about the context of the publication in which it appears (publication identification factors) were recorded.

Each reason identified was coded with a 'broad' and 'narrow' reason type.³ The codes were inducted from the reason itself and the text passage in which it was identified. A broad reason type gives a general description of the type of reason identified in a paper in one or two words, such as 'responsibility', 'duty' or 'clinical need'. This gave a broad category for scrutiny. Each reason was also coded with a more detailed narrow reason type, which describes the context or intention of the reasoning, allowing greater interpretation of the reasons given. Examples of narrow reason types include 'responsibility to preserve life'; 'expectation of a good quality of life' or 'unable to survive without technology'. Two researchers coded a sample of 10 publications independently. Any discrepancies were identified, discussed and resolved between the two researchers, together with an objective third team member who was not part of this research exercise. This process enhanced the coding validity and reliability for the remaining papers, which were initially coded by one researcher. The codes were subsequently discussed at length by the rest of the research team, where any further discrepancies in interpretation were resolved.

Table 1 Inclusion criteria for the review

1	The paper includes a reason why technology dependence should be initiated or need not be initiated, and
2	The technology dependence is required to sustain a child's life
3	The child referred to is cared for by healthcare professionals in a critical care environment
4	The publication is a peer-reviewed, published academic article or book, national-level report or working paper, PhD thesis, academic commentary or essay or case study and is available in English

In order to record subtle differences of meaning, a distinction was made between a mention of a reason expressed in a specific passage (a reason concept) often using the voice of the author from a direct reasoning from reported empirical evidence (reason mention), where the author reports directly the voice of the practitioner. Each reason was also coded in terms of whether it was in favour of the initiation of technology dependence, rejected technology dependence or whether the paper did not express a preference for or against initiation of technology dependence related to the reason expressed. We also coded, for each reason, whether the paper's overall conclusion supported or rejected the reasoning, or whether the paper drew no strong conclusions about the reasons given.

Data about the publications and papers that contained the reasons were also recorded. We noted whether the paper (or the specific reason) discussed the initiation or non-initiation (including the withholding) of technology dependence; or was in the context of a discussion whether to withdraw technology from a child who was already technology dependent (eg, due to terminal diagnosis). We also noted if the reasoning for initiating or not initiating technology dependence was considered in the context of end-of-life care. We recorded, where possible, the age of the child. We noted the type of paper written (eg, review, empirical research results, discussion or essay) and the voice of the paper (generally a physician, nurse or parent). Finally, we recorded whether the paper was included in a peer-review journal, national report or book chapter as well as the field of study (such as medicine, nursing, law or bioethics), the date of publication, the setting and country of origin of the paper.

Patients were not involved in this research, other than in the identifying of patients' or their advocates' reasons for initiation or non-initiation of technology dependence.

RESULTS

A wide range of papers contributed to the review. The majority of papers focused on the ethical and legal discussions surrounding the use of technology to sustain a child's life, without specifying the type of technology used. A small number specified the type of technology under scrutiny, the most common of which was long-term ventilation.

Publication characteristics

Fifty-three papers were included in the review. In the majority the reasons for or against initiation of technology, or for withdrawal of life-sustaining technology were identified as concepts described in the texts of reviews, or ethical essays ($n=36$). Thus, the reasons given were from the voice of the paper's author, not directly from empirical evidence. Seventeen papers contained empirical data from interviews, surveys or focus groups of physicians. The majority of reasons shown were given by physicians, or reported as physician's reasons for initiating or the non-initiation (or withdrawal) of technology dependence. Four papers also addressed nurses' reasoning, or reasoning from the perspective of nursing; and two papers included reasons given by parents or foster parents of the child. Almost half of the publications discussed life-sustaining technology with regard to the neonatal or infant population ($n=22$). Some papers did not focus on children exclusively, but included all ages, with particular reference or a section on children, and discussions of children of all ages. No papers specifically dealt with children aged 5–9, although one mentioned a 'preadolescent boy' as the subject of a case study,⁷ and another includes a girl in this age range as a case study.⁸ No papers specifically referred to adolescents aged

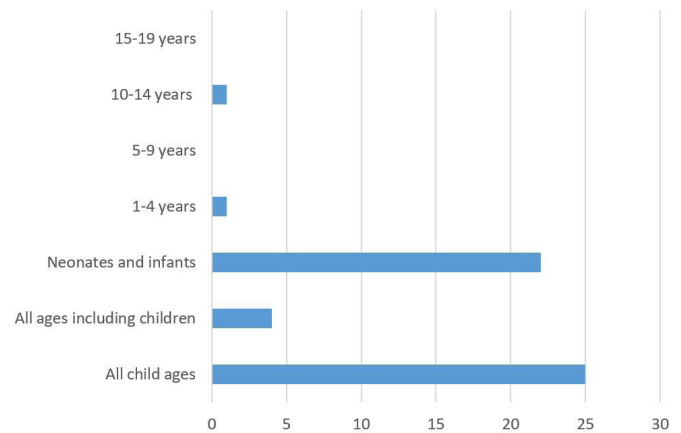


Figure 2 Ages of children who are the subjects of the reasons to initiate or not initiate technology dependence.

15–19. **Figure 2** summarises the patient age distribution of the identified papers.

Eighteen of the 53 papers in the review explored the initiation of technology dependence as part of end-of-life care. Seven papers investigated the initiation of care in the context of continuing this care longitudinally, outside the hospital setting. The remaining papers discussed the initiation and/or withdrawal of life-sustaining technology in a child in various disease, treatment or socioeconomic contexts.

Eleven papers were from sole authors, in the form of a review or providing an expert opinion about the ethical considerations involved. We found no systematic reviews into the issue. Two of the papers were in the form of guidelines or frameworks for practice, one of which was published in a peer-reviewed journal, and two were in the form of education pieces in peer-reviewed journals. Most of the papers were published in medical journals ($n=37$), nursing journals published eight; and another six were published in bioethical or legal journals. One paper was published in a health leadership journal, and two papers were published as book chapters. The publications included ranged in date from 1975 until 2020. The majority of the papers we identified came from developed countries, most commonly from the USA and Canada (see **figure 3**).

Reason types and implications

We classified each identified reason in terms of whether it was in favour of initiating, not initiating technology dependence or reasons that were clearly related to technology dependence, but there could be no conclusion drawn as to whether they supported or rejected technology dependence (eg, a reason given as part of a philosophical discussion).

We identified 116 broad reason types; and 383 narrow reason types. None of the publications mentioned more than 32 broad or 41 narrow types of reason.

Most of the broad and narrow reasons given were not committed to being in favour of initiation nor against initiation of technology, although the reasons were directly related to the issue. For example, discussions around the initiation of ventilation for children at the end-of-life may be accompanied by reasons that do not specify whether an individual child should or should not receive ventilation. The vast majority of the papers supported the reasons given, as part of the wider discussion in the paper.

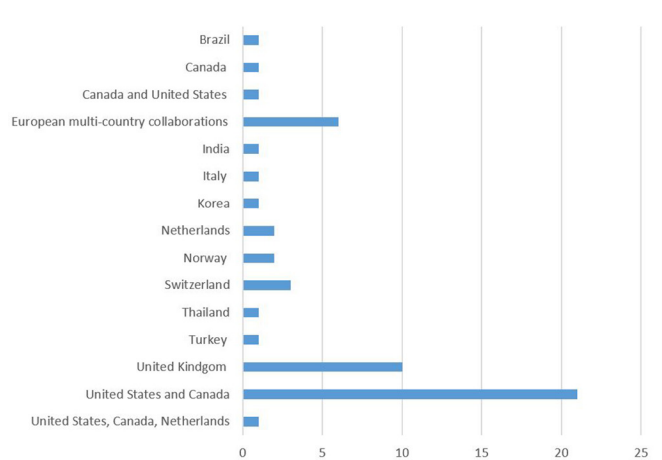


Figure 3 Distribution of reason types by country.

European multi-country collaborations are: Luxembourg, Netherlands, Sweden, France, Germany, UK, Italy, Spain¹³; Italy, Spain, France, Germany, Netherlands, UK and Sweden¹⁴; Ireland / UK¹⁵; Germany / Switzerland¹⁶; Austria, Switzerland and Germany¹⁷; UK / Belgium¹⁸

Thematic breakdown of the reasons

Broad reason types

The reasons support, reject or describe the initiation of technology dependence. They were categorised into groups that emerged from the application of broad reason types in each

individual paper, taking into account the context in which the reason was given. The groups identified were: ‘clinical factors’, ‘quality of life factors’, ‘moral imperatives and duty’ and ‘personal values’. Moral imperatives, for this purpose, are distinguished from personal factors and virtues because they are constructed by external norms of behaviour and codes of conduct.⁹ Each category contains a mixture of reasons describing internal factors, such as personal values, judgements and hopes; and reasons driven by external factors, such legal obligations, fear of repercussions or being guided by the wishes of parents or professionals, as expressed in the literature from which they were identified. Table 2 shows the broad reason types by category.

Reasons in the group describing clinical factors reflected a need to be impartial when making decisions—whether they supported or rejected technology initiation. Some reasons were more subjective, particularly in describing the potential benefits of treatment when supporting initiation of technology dependence, or describing the uncertainty of outcome after making a decision.

The theme that described quality of life factors included reasons that encompass a wider scope than the immediate medical needs of the patient, such as previous and future life, family well-being and mental as well as physical health. The reasons given for initiation of technology dependence in this category were primarily focused on the future, whether they concerned the initiation, rejection or description of initiating technology dependence.

The third group encompassed moral imperatives and a sense of duty informing the reasons given. This was the largest theme

Table 2 Broad reason types identified in the review

	Clinical factors	Quality of life factors	Moral imperatives and duty	Personal factors and values
Supporting technology initiation	Benefit of treatment ¹⁹ ; Best interest (of the child) ¹⁷ ; Clinical need ^{11 17 20–28} ; Requirement to make a decision ¹⁴ ; Prognosis ¹⁶ ; Treatment ^{8 28–34} ; Treatment decision ²⁹ ; Uncertainty ³⁵	Awareness of future consequences ²⁰ ; Future health ^{36 37} ; Hope ³⁸ ; Hope for future technological improvement ²⁰ ; Possibilities of the technology ³⁵ ; Improve life expectancy ³⁹ ; Survivorship ⁴⁰ ; Well-being ²⁸	Altruism ³⁸ ; Coercion of physicians ⁴¹ ; Communication ^{21 42} ; Decision-making ²⁹ ; Ethical conflicts ¹⁷ ; Fear ^{13 19} ; Human rights ^{23 24} ; Information ³¹ ; Requirement to share information ²⁸ ; Legal obligation ⁴³ ; Obligation ^{13 19 21 38} ; Treatment resources ³³ ; Pressure ¹¹ ; Short-term outcome ²⁶	Anxiety ⁴⁴ ; Attitude towards value of life ³⁵ ; Being positive ³⁵ ; Experience maturity ³⁵ ; Hope for the future ³⁷ ; Purpose of role as physician ¹⁹ ; Responsibility ^{23 26 35 45} ; Values ¹⁷ ; Wishes of parents or staff ⁴⁶
Rejecting technology initiation	Clinical decision ¹¹ ; Clinical need ^{8 11 13 21 28 45} ; Clinical judgement ^{12 47} ; End-of-life care ⁴⁸ ; Following guidelines ⁴⁹ ; Guidelines ¹⁷ ; Intensive treatment ⁴⁸ ; Judgement of futility ¹⁴ ; Prognosis ^{16 21 24 42} ; Prognostication ²² ; Requirement to make a decision ¹⁴ ; Treatment ^{8 27 29 34} ; Treatment decision ²⁶	Quality of life ⁵⁰ ; Unconsciousness of patient ⁴³ ; Well-being ²⁸	Communication ^{15 24 42 51} ; Corporate policy ⁴⁹ ; Decision-making ³⁰ ; Disputes and obstacles to good care ⁴⁴ ; Duty ^{12 52} ; Ethics ^{12 29} ; Fear ⁴³ ; Interpretation of policy ⁴⁹ ; Information provision ^{26 39} ; Legal influence ⁴⁷ ; Medical principle ²⁴ ; Moral dilemmas ²¹ ; Obligation to relieve suffering ¹⁹ ; Obligation ⁵³ ; Purpose of role ¹⁹ ; Responsibility ^{23 24 28 35 47 52} ; Widespread belief ²²	Being familiar with patient or ward ¹³ ; Compassion ¹⁹ ; Cultural influences ¹⁹ ; Distress ⁴⁴ ; Emotions ³⁵ ; Experience maturity ^{15 35} ; Professional experience ¹³ ; Professional objectivity ³⁵ ; Religion ¹³ ; Values ^{16 52}
Unclear whether supporting or rejecting technology initiation	Advocating for child ²³ ; Best interests of child ¹⁵ ; Care burden ⁵⁴ ; Care pathway ⁵⁰ ; Clinical need ^{11 39} ; Decision-making ^{8 14 31 34} ; Difficulty of prognosis ⁵⁵ ; End-of-life care ^{30 48} ; Evaluation ^{16 56} ; Evidence for prognosis ¹⁸ ; Flexibility ²⁴ ; Guidelines ¹⁷ ; Intensive treatment ⁴⁸ ; Judgement ²⁴ ; Prognosis ^{23 45 46 56} ; Prognostication ²² ; Time pressure to act ¹⁵ ; Treatment ^{8 28 29 32–34 48} ; Treatment decision ^{8 26 32} ; Uncertainty ³⁵	Longitudinal responsibility ²⁶ ; Outcomes ^{30 31 42 45} ; Social value ⁷ ; Socioeconomic differences ⁴⁸ ; Survival ⁵⁴ ; Well-being ²⁸	Beneficence ⁵⁵ ; Capacity and resources ^{18 50} ; Communication ^{24 34 35 37 43 51 55 57} ; Compromise ⁵⁶ ; Conflict ¹⁵ ; Contextual reasons ¹⁶ ; Decision-making ^{8 29 30 32 57 58} ; Dilemma ¹⁶ ; Duty to act ⁵⁹ ; Duty to save life ¹⁵ ; Ethical and philosophical meaning ⁷ ; Ethical questions ²⁶ ; Family burden ¹⁶ ; Fear ^{11 19 35 59} ; Human rights ²³ ; Information ^{18 29–32 37 39 54 58} ; Justice ⁵⁵ ; Legal obligation ⁵³ ; Obligation ^{13 19 21 53} ; Opportunity for discussion ¹³ ; Overriding wishes of others ⁵¹ ; Parental decision-making ^{8 32} ; Pressure ²⁵ ; Resource allocation ¹⁶ ; Respect ²⁴ ; Role of physician ²¹ ; Shared decision-making ¹⁷ ; Sharing responsibility ¹⁹ ; Sharing the decision ²⁷	Apprehension ¹⁹ ; Assumptions ⁴⁰ ; Attitudes to decisions ⁸ ; Compassion ⁵⁹ ; Conviction as in belief ⁷ ; Experience ^{28 35 45 56} ; Feelings ^{35 39} ; Grief ³² ; Impartiality ¹⁵ ; Information ⁶⁰ ; Information provision ²⁶ ; Openness ¹⁴ ; Parental satisfaction ³⁷ ; Personal feelings ³⁵ ; Professional objectivity ³⁵ ; Responsibility ^{23 24 26 28 45 46 53 56 57 60 61} ; Risk/danger ^{18 37} ; Survivorship ¹⁹ ; Values ¹⁶

identified. Many of the moral or dutiful reasons for initiation were in fact negative in tone, for example describing the decision to initiate technology dependence because of fear of legal consequences or pressure from another party. The reasons given that had no clear direction for or against initiation of technology were primarily conceptual, describing ethical concepts of beneficence or duty to relieve family burdens. Reasons classified as personal factors encompassed elements of personal values, such as feelings of responsibility, positivity and attitudes; and also personal feelings such as anxiety, compassion or distress.

Some of the same reasons were used to argue for or against, or expressing no particular preference for the initiation of technology dependence. These included the best interests or future well-being of the child and also the need, or even the pressure, to follow guidelines or established procedures. Closely related to this are the reasons that describe the need for information provision and communication.

Narrow reason types

Three hundred and ninety reason types were identified in this review. The detail given by the narrow reasons, each of which accompanies a broad reason, gives further detail about the context and issues that inform the broad reason given. We identified different thematic headings depending on whether the reasons were given in support of, against or describing the initiation of technology dependence. The narrow reasons are shown in the online supplemental material.

Themes that emerge in the reasons supporting the initiation of technology dependence include actively positive reasons, aimed at improving the condition for the child, or preserving hope for the future. However, a theme of having to make a choice despite none being entirely satisfactory is also present, including buying time when a prognosis is not clear, obligation to initiate technology and the need to make the decision in the consideration

of a wider context—such as future health, and family health and well-being. Figure 4 shows the themes identified.

Some of the reasons given not to initiate technology dependence also describe a number of different influences, including avoiding prolonging suffering for the child. Many reasons describe the experience and confidence of the decision-making physician—being able to make difficult decision, or to act in what is believed to be the child’s best interests despite the wishes of the child’s family. This encompasses themes of knowledge and professional judgement, and avoiding or effectively resolving disputes.

Reasons given without clear indication whether they supported or rejected technology dependence describe the issues that are perceived as important when technology dependence is a potential outcome. These reflect altruism and the need for effective communication in order for the involved parties to work effectively together. Reasons reflect the need for health professionals to take an impartial and wide-focused view on the situation, particularly when avoiding or resolving disputes. The need to take into account or recognise the influence of emotions, values and feelings also emerges from these reason types.

DISCUSSION

The aim of this review was to identify the reasons that have been given for the initiation or non-initiation of technology dependence in children. This allows an academic exploration to begin to understand this dynamic and ethically complex situation.

However, this exercise is of little value without a more in-depth examination of the implications of the reasons, and the pressure this puts on the complex ethical arguments that currently exist. Many of the reasons were used more than once, to justify more than one decision outcome, which demonstrates the complexity of the issue in respect of how the concerns and

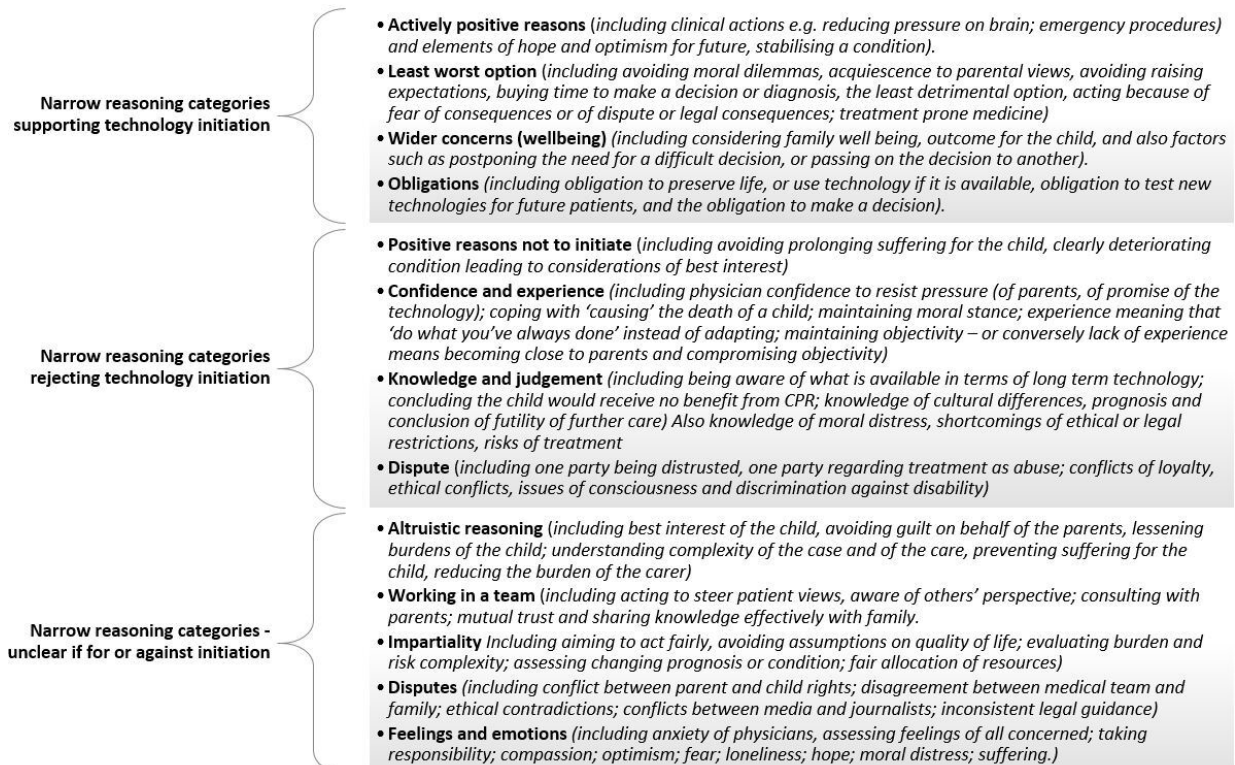


Figure 4 Themes identified in the narrow reason types.

uniqueness of each situation are interpreted to make a decision. There are no 'right answers' to be found in life or in the literature with regard to initiating technology dependence in a child. Therefore, we identified reasons given for and against initiation of technology dependence and also reasons with no clear direction of intent given in the paper. By identifying the reasons that have been reported in the literature, this systematic review of reasoning allows a greater understanding of the implicit and explicit reasoning processes that influence the initiation of technology dependence.

Range of publications

The papers identified in the review came from a range of sources: medical journals, nursing journals, law journals and publications from health management and bioethics. Most of the research or journal papers originated from developed countries, which was not unexpected given the subject matter of extremely sophisticated, and expensive, medical technology use. In addition, any cultural differences between technology dependence initiation in different countries would be an important avenue of research to explore, including the influence of the strength of religious beliefs in different country or cultural settings.

Age of the children

In terms of the literature, it seems that most of the reasons given surrounding the initiation of technology dependence in children were relevant to neonates and younger children. There is scant literature specifically about the initiation of technology for older children, although there is increasing literature about children growing and living with technology dependence. We found no papers that discussed the initiation of technology for children aged 5–9 years, or for teenagers aged over 15 years. In addition, the focus on neonates as subjects of the initiation of technology dependence incorporates a number of ethical discussions about proxy decision-making, and about the concepts of quality of life for an infant; as well as navigating the potential dissonance in values and expectations of each of the decision-makers. Although these issues are present in all cases of children's technology dependence (and arguably for adults too), neonates have no life experience to inform what their wishes should be. The grey areas of discussion and uncertainty are challenging in different ways for neonates than for other ages.

Reasons for, against or about the initiation of technology dependence

Some of the reasons given reflect the physician's attempts to retain an impartial role, by focusing on clinical factors, or using personal and professional experience to avoid making decisions informed by value-based or unfounded assumptions. However, many of the reasons identified suggest that value-based factors are important features of the process of initiating or rejecting technology dependence. Altruistic reasons such as alleviating guilt, doing the best for the child and taking responsibility feature in reasoning both for and against initiating dependence. The need for consideration of a child's family and imparting information to the family to facilitate decision-making is important. But reasons surrounding this also suggest a degree of manipulation, such as imparting incomplete information—ostensibly for altruistic purposes, such as shouldering a burden of guilt and taking responsibility for decisions. This could be regarded as a form of paternalism, even if it is generally understood as an act of beneficence.

Some reasons were based on feelings such as anxiety and fear as influences on clinical judgement, as were emotions such as

empathy, hope and compassion surrounding the child, family and other health professionals. Other aspects of non-clinical reasoning include obligation to act in certain ways, such as fear of prosecution despite feeling that not initiating or withdrawing technology dependence would be best for a terminally ill child. Resource issues were also given as reasons in some cases. Reasons may also be made that are aimed at preventing dispute, rather than being focused solely on the needs of the child. These may involve external influences, such as the threat of legal prosecution, or adverse personal consequences of a 'trial by media' or being in opposition to popular opinion.

Some of the reasoning given in the literature is actively positive, such as to relieve clinical symptoms, preventing adverse consequences of a disease or condition and achieving medical stability. However, the complexity of balancing risk and benefits for a child who may need technology to sustain life is challenging, and as a result, uncertainty is a common theme. Technology dependence may be initiated to gain more time to establish a diagnosis, prognosis or simply to postpone a difficult decision. Some decisions reflect legal or institutional pressure to treat a child, despite no clear outcome data to guide decisions. Some of the reasons given for initiating technology dependence were negative and reflected feelings of being coerced by the strong moral standpoints of other decision-makers, ethical conflicts and fear in the form of repercussions including legal consequences if technology is not used. Thus, the initiation of technology dependence is not always regarded as beneficial by the decision-maker but may be a source of moral distress if individuals feel that the child is subject to intrusive and painful treatment, or will never achieve subsequent good quality of life.¹⁰

In terms of the reasons given against the initiation of technology dependence, some of the reasons identified show how the 'negative' outcome of non-initiation is influenced by positive reasons. For example, when not initiating technology dependence is considered to be in the best interests of a severely ill child if death is inevitable and intervention would merely prolong discomfort or pain. In some of the narrow reason types, we see the effect of physician's experience or confidence, such as the moral duty to relieve suffering, experience of outcomes and confidence to resist parental pressure, and the belief in a moral requirement to not provide futile care. Clinical factors, such as poor prognosis or terminal illness inform much of the reasoning not to initiate technology dependence. However, these are not incontrovertible as reflected in reason types such as coercion, obligation, ethical conflicts and fear, where in the papers the context shows that fear of legal repercussions or pressure from parents may also influence decisions. Some of the reasons given suggest the avoidance of dispute, or the input of an external factor instead of personal decisions, such as judgement of futility, following guidelines, apprehension and duty to act. Fear is an important stimulus for action, and appears in all three categories of reasoning, and in both broad and large reason types. Differences of opinion may lead to moral distress among healthcare professionals, as well as among parents, depending on the resulting decision.

Most of the reasons identified did not have a direct relationship with initiating or not initiating technology dependence, but were expressed to describe or discuss the surrounding issues. Most of the papers were essays or opinion pieces, where reasons were given as part of the author's arguments. As a result, most of the reasoning is endorsed by the author. This may be because of a lack of empirical research, but also it is indicative of the challenging nature of the decisions. Some of the most contentious cases result in the need for external legal intervention to

determine the best course of action,^{11 12} but even in these cases, decisions made depend on the circumstances that surround the clinical situation. This raises the question about the lack of recognition of all the voices of decision-making, including the voices of the physicians.

Limitations

The majority of the reasons we identified were not found in papers that were specifically addressing the point of initiation of technology dependence in a child, but were identified in papers addressing issues related to this issue, such as the care of children with complex care needs, life-limiting conditions or papers addressing the ethics of life-sustaining technology. Therefore the reasons identified were not often discussed in terms of theoretical concepts that describe the arguments in which they were based.

Only English language papers were included. This may have excluded relevant papers that originate from non-English-speaking regions, such as in Africa, Asia, Europe or the Middle East. These countries may also provide different cultural perspectives to technology initiation, which could be identified in the reasons. In addition, the vast majority of the papers we identified were from North America, which suggests that there is a need to understand the voice of other parts of the world. We found that personal morals and values produce many reasons for decisions, and these are likely to be influenced by national cultures. Research data from all parts of the world, including Africa, the Americas, Asia, Australasia, Europe and the Middle East are likely to provide interesting data about influences and obligations concerning technology dependence in children.

The relevance of the systematic nature of the review is that a greater variety of reasons is likely to be identified through the systematic and extensive search process. However, it is potentially misleading to draw conclusions from the number of times a reason is mentioned in the literature. The review of reasoning is unable to critically analyse or weight the reasons given, principally because circumstances are different depending on the unique situation in which the reasoning is conducted. Also it is possible that there are more published literature that includes less contentious reasons, rather than those relating to controversial topics for example the influence of financial constraints. As a result, we did not count the number of times each reason appeared in the literature, because this is unlikely to represent the importance, or value, of any one reason and its influence on a decision.

Many of the papers retrieved in the literature search did not address the moment of technology initiation; this led to a considerable number of papers rejected for inclusion in the study at the stage of full-text reading. An increasing amount of literature describes children and families living with technology dependence rather than debating the point of its initiation. It is possible that this literature suggests a shift in focus from whether to initiate or not, towards the growing importance of future health and well-being.

Most of the reasons we identified were reason concepts rather than reason mentions. Any review depends on the quality of the studies on which it is based, and it is possible that the large number of papers that are discussion essays or expert opinion may constitute a bias in the results. A review of reasoning, however, does not attempt to critically appraise the reasons, but illustrates what reasons appear in the literature as influences on the initiation or non-initiation of technology dependence in children.

Most papers we identified discussed technology initiation in the context of end-of-life care. In these cases, technology may sustain life in a terminally ill individual. It is possible that there is a gap in our knowledge about initiation of technology dependence for children who are expected to live with technology dependence on a more long-term basis, because life-sustaining technology is only relatively recently, but increasingly, being used to this aim.

CONCLUSIONS

This paper has explored *how* the influences on the initiation of technology dependence in acute paediatric healthcare have been conceptualised in the scientific literature. This was to identify which reasons have been given for the initiation or non-initiation of technology dependence in a critical care environment to sustain a child's life and to examine how have these reasons been used to argue that initiation of technology dependence should, or need not, be undertaken. The wide variety of reasons we identified in the scientific literature extended beyond clinical factors, and involved moral, value-driven and personal influences on the child's condition and future condition and potential treatment.

Relatively few papers focused specifically on the rationale for reasons given for action or non-action regarding technology dependence. This suggests that although this is an important point-of-care delivery, there has been scant specific exploration of the influences on decisions. The next phase of our research will begin to build on the findings from this review of reasoning, to focus on the influences on decisions in the liminal space between a child presenting with a life-limiting condition and the decision to initiate technology dependence. This is important in order to understand the interplay of conscious and unconscious influences, and the strength of these influences. Furthermore, research involving differing ages of the child is important to investigate if this alters the importance of influencing factors. Similarly, specific research in varying scenarios of technology dependence initiation, for example comparing influences on technology dependence in life-limiting situations, or as potential long-term support over many years is important to understand the range and importance of influencing factors. Increasing transparency at this point-of-care delivery allows the recognition and minimisation of bias and increases confidence in the process of accessing such care for patients, families and clinicians, potentially reducing disputes and reducing moral distress.

This research has provided a sound basis for greater understanding about access to care and the human relationship with technology. The number of children with complex needs who are subject to these debates and decisions is increasing. As a society, we struggle to articulate what is acceptable legally, ethically and medically, and importantly what constitutes a positive outcome in such complex cases. Transparency in the factors that influence care decisions will increase rigour, and make explicit influences, which are at present, largely unspoken.

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SUPPLEMENTARY MATERIAL

Medline Search Sample:

Concept 1: technology dependence

Keywords: “technology depend*” OR “technology-depend*” OR “technological depend*” OR “technological-depend*” OR “screen depend*” OR “mobile depend*” OR “device depend*” OR “screen-depend*” OR “mobile-depend*” OR “device-depend*” OR “medical technol*” OR “dependen* on medical technol*” “technology relian*” OR “technolog*-relian*” OR “technological relian*” OR “screen relian*” OR “mobile relian*” OR “device relian*” OR “screen-relian*” OR “mobile-relian*” OR “device-relian*” OR “medical relian*” OR “relian* on medical technol*” OR “over*reliance in technolog*” OR “over*dependence on technolog*”

Concept 2: Physical disability OR chronic illness OR complex care OR complex medical care OR complex needs

Medline: (MH “Complex Care”) OR (MH “Chronic Disease”) OR (MH "Critical Illness") OR (MH "Disabled Persons+")

Keywords: “Physically Handicapped” OR “physical handicap*” OR “Physically Disab*” OR “Physical disability*” OR “Physically Challenged” OR “chronically ill” OR “chronic illness*” OR “chronic disease*” OR end-of-life OR “end of life” OR “life-limiting condition*” OR “life limiting condition*” OR life-threatening OR “life threatening“ OR “terminal illness*” OR “life-limited” OR “life limited” OR life-sustaining OR “life sustaining” OR “sustaining life” OR “Life Limiting Illness*” OR “Life-Limiting Illness*” OR “Genetic Disease*” OR “Genetic Disorder*” OR “Genetic condition” OR “Inborn Genetic Disease*” OR “Single-Gene Defect*” OR “Single Gene Defect*” OR “Critical Illness*” OR “critically ill” OR “Catastrophic Illness*” OR “Multiple Chronic Conditions” OR “Multiple Chronic illnesses” OR “complex care” OR “complex caring” OR “complex nursing” OR “complex need*” OR “multifaceted need*” OR “multifaceted care” OR “complex medical need*” OR “complex medical care” OR “multiple needs” OR “multiple care” OR “medically fragile” OR “medically frail*” OR blind* OR “visual impair*” OR deaf* OR “hearing impair*” OR “mobility impair*” OR “physical deficiency” OR “physical incapacity” OR “physically limited”

Technology	Medline
Technology	6,061
Phys Disab /Complex/Chronic	865,087
Combined	498
Peer Review	n/a
Total	498

#	Query	Limiters/Expanders	Last Run Via	Results
S6	S4 AND S5	Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - MEDLINE	498
S5	AB ("technology depend*" OR "technology-depend*" OR "technological depend*" OR "technological-depend*" OR "screen depend*" OR "mobile depend*" OR "device depend*" OR "screen-depend*" OR "mobile-depend*" OR "device-depend*" OR "medical technol*" OR "dependen* on medical technol*" "technology relian*" OR "technolog*-relian*" OR "technological relian*" OR "*" OR "screen relian*" OR "mobile relian*" OR "device relian*" OR "screen-relian*" OR "mobile-relian*" OR "device-relian*" OR "medical relian*" OR "relian* on medical technol*" OR "over*reliance in technolog*" OR "over*dependence on technolog*") OR TI ("technology depend*" OR "technology-depend*" OR "technological depend*" OR "technological-depend*" OR "screen depend*" OR "mobile depend*" OR "device depend*" OR "screen-depend*" OR "mobile-depend*" OR "device-depend*" OR "medical technol*" OR "dependen* on medical technol*" "technology relian*" OR "technolog*-relian*" OR "technological relian*" OR "*" OR "screen relian*" OR "mobile relian*" OR "device relian*" OR "screen-relian*" OR "mobile-relian*" OR "device-relian*" OR "medical relian*" OR "relian* on medical technol*" OR	Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - MEDLINE	6,061

	"over*reliance in technolog*" OR "over*dependence on technolog*")			
S 4	S1 OR S2 OR S3	Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - MEDLINE	865,08 7
S 3	AB ("Physically Handicapped" OR "physical handicap*" OR "Physically Disab*" OR "Physical disability*" OR "Physically Challenged" OR "chronically ill" OR "chronic illness*" OR "chronic disease*" OR end-of-life OR "end of life" OR "life-limiting condition*" OR "life limiting condition*" OR life-threatening OR "life threatening" OR "terminal illness*" OR "life-limited" OR "life limited" OR life-sustaining OR "life sustaining" OR "sustaining life" OR "Life Limiting Illness*" OR "Life-Limiting Illness*" OR "Genetic Disease*" OR "Genetic Disorder*" OR "Genetic condition" OR "Inborn Genetic Disease*" OR "Single-Gene Defect*" OR "Single Gene Defect*" OR "Critical Illness*" OR "critically ill" OR "Catastrophic Illness*" OR "Multiple Chronic Conditions" OR "Multiple Chronic illnesses" OR "complex care" OR "complex caring" OR "complex nursing" OR "complex need*" OR "multifaceted need*" OR "multifaceted care" OR "complex medical need*" OR "complex medical care" OR "multiple needs" OR "multiple care" OR "medically fragile" OR "medically frail*" OR blind* OR "visual impair*" OR deaf* OR "hearing impair*" OR "mobility impair*" OR "physical deficiency" OR "physical incapacity" OR "physically limited") OR TI ("Physically Handicapped" OR "physical	Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - MEDLINE	579,51 4

	handicap*" OR "Physically Disab*" OR "Physical disability*" OR "Physically Challenged" OR "chronically ill" OR "chronic illness*" OR "chronic disease*" OR end-of-life OR "end of life" OR "life-limiting condition*" OR "life limiting condition*" OR life-threatening OR "life threatening" OR "terminal illness*" OR "life-limited" OR "life limited" OR life-sustaining OR "life sustaining" OR "sustaining life" OR "Life Limiting Illness*" OR "Life-Limiting Illness*" OR "Genetic Disease*" OR "Genetic Disorder*" OR "Genetic condition" OR "Inborn Genetic Disease*" OR "Single-Gene Defect*" OR "Single Gene Defect*" OR "Critical Illness*" OR "critically ill" OR "Catastrophic Illness*" OR "Multiple Chronic Conditions" OR "Multiple Chronic illnesses" OR "complex care" OR "complex caring" OR "complex nursing" OR "complex need*" OR "multifaceted need*" OR "multifaceted care" OR "complex medical need*" OR "complex medical care" OR "multiple needs" OR "multiple care" OR "medically fragile" OR "medically frail*" OR blind* OR "visual impair*" OR deaf* OR "hearing impair*" OR "mobility impair*" OR "physical deficiency" OR "physical incapacity" OR "physically limited")			
S 2	(MH "Complex Care") OR (MH "Chronic Disease") OR (MH "Critical Illness")	Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - MEDLINE	279,255
S 1	(MH "Disabled Persons+")	Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases	61,659

			Search Screen - Advanced Search Database - MEDLINE	
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Narrow reason types identified by the review

Narrow reasoning categories for initiation	Narrow reasoning categories against initiation	Narrow reasoning categories - unclear if for or against initiation
<p><i>Actively positive reasons</i></p> <p>Action to reduce pressure on the brain[28]</p> <p>Acute situations[25]</p> <p>Acute treatment to avoid death[32]</p> <p>Benefit to patient[38]</p> <p>Child unable to meet nutritional needs orally[28]</p> <p>Doctor-centred[27]</p> <p>Emergency situation [26, 28]</p> <p>Established diagnosis and treatment[17]</p> <p>Feeding tube for survival[23]</p> <p>Hope for a miraculous or unexpected good outcome[16]</p> <p>Hope/ expectation of good quality of life[33]</p> <p>Improve or ensure respiration[28]</p> <p>Improved child health[29]</p> <p>Life prolonging attitude[21]</p> <p>Long term outcome[27]</p> <p>Medical stability of the child[18]</p> <p>Need for respiratory support[23]</p> <p>Perceived as safe and expected treatment[37]</p> <p>Preserving hope[21]</p> <p>Recovery or bridge to transplantation[34]</p>	<p><i>Positive reasons not to initiate</i></p> <p>Alleviate moral dilemmas[22]</p> <p>Avoiding distress for the child[11]</p> <p>Avoiding prolongation of suffering[13]</p> <p>Acute deterioration of respiratory condition[15]</p> <p>Best interest and open discussion[25]</p> <p>Best interests of the child[29]</p> <p>Best interests, avoiding intensive futile care[47]</p> <p>Caring responsibility[27]</p> <p>Cultural factors supporting child death at home[34]</p> <p>Due consideration to value of continuing life sustaining support[24]</p> <p>Family, caring responsibility[29]</p> <p>Future quality of life, life expectancy[30]</p> <p>Improve quality of life, preserving remaining life[15]</p> <p>Parental insight into child's prognosis[34]</p> <p>Poor quality of life on technology[38]</p> <p>Providing supportive comfort care[8]</p> <p>Quality of life would be compromised by treatment[8]</p> <p>Respect patient or parent's wishes[51]</p> <p>Responsibility to prevent needless pain[25]</p>	<p><i>Altruistic reasoning</i></p> <p>Accurate information and wellbeing[29]</p> <p>Alleviate burden of guilt[25, 29, 61]</p> <p>Alleviate burden on parents[34]</p> <p>Authority to make decisions[56]</p> <p>Best interest of the child[11, 27, 29, 42]</p> <p>Burdens on family, family context[33]</p> <p>Burden on parents[55]</p> <p>Burden of treatment at home[37]</p> <p>Capacity of services and resources[19]</p> <p>Carer well-being[29]</p> <p>Child well being[29]</p> <p>Child and family under stress[39]</p> <p>Control family's uncertainty through selective communication[14]</p> <p>Decisions based on rang of conditions, experience and prognosis[19]</p> <p>Doubt about parent understanding of consequences[21]</p> <p>Empathy[27]</p> <p>Empathy from professionals[27]</p> <p>Evaluating patient future quality of life[33]</p>

<p>Role of healing[14]</p> <p>Technology to improve survival[39]</p> <p><i>Least worst option</i></p> <p>Acquiescence to parent views[31]</p> <p>Active euthanasia (attitude negative)[40]</p> <p>Avoid raising expectations that create a moral dilemma[22]</p> <p>Buy time to make a reasonable diagnosis[22]</p> <p>Child well-being[29]</p> <p>Choice of treatment reflects resources[37]</p> <p>Choosing the least detrimental alternative (slight negative tone)[14]</p> <p>Complex decision making[32]</p> <p>Continue short-term invasive therapy[43]</p> <p>Disagreement with relatives (attitude negative)[40]</p> <p>Fear of charges of homicide, abuse or neglect[14]</p> <p>Keeping alive for benefit of others (author against this reason)[24]</p> <p>Legal consequences (attitude negative)[40]</p> <p>Legal consequences influencing action [13]</p> <p>Legal obligation[14, 40, 44]</p> <p>Maximum therapeutic care despite physician opinion[34]</p> <p>Neonatal resuscitation unclear prognosis[17]</p> <p>Not withdrawing care without prognosis[17]</p> <p>Ongoing dependence[41]</p>	<p>Sensitive communication and respect[47]</p> <p>Withdrawal of care as ethical in futile cases[17]</p> <p>Withdrawal of technology dependence[32]</p> <p><i>Confidence and experience</i></p> <p>Acceptability[31]</p> <p>Confidence to resist pressure[21]</p> <p>Causing the death of the child[21]</p> <p>Closeness to patient prevents objectivity[21]</p> <p>Distinction between acts and omissions[51]</p> <p>Duty to preserve life and health[51]</p> <p>Duty to the dying and to the sick is different[12]</p> <p>Easier to limit LST in young children[33]</p> <p>Experience of outcomes[46]</p> <p>Favouring the status quo[51]</p> <p>Length of professional experience[40]</p> <p>Moral duty to uphold ethics despite the consequences[51]</p> <p>Moral obligation to relieve suffering[14]</p> <p>Morbidity, device malfunction and poor quality of life[38]</p> <p>No confidence to withdraw treatment if survival possible[46]</p> <p>No parental support[30]</p> <p>Non-acquiescence to parent views[31]</p> <p>Not required to provide futile care[52]</p>	<p>Evaluating what family can bear[33]</p> <p>Family well-being[29]</p> <p>Fear of frightening the parents[21]</p> <p>Greater prospects of survival but living with substantial disability[37]</p> <p>Lack of home care nurses to provide home support[54]</p> <p>Life-sustaining and prevention of suffering - holistic outcomes[11]</p> <p>Morbidity post-technology dependence[38]</p> <p>Outcome likely to be poor[32]</p> <p>Overriding parental decisions based on child welfare[47]</p> <p>Perceived inability to provide good quality of life[32]</p> <p>Poor outcome[32]</p> <p>Quality of life[34]</p> <p>Responsiveness to patient needs[61]</p> <p>Risk to child and family health[39]</p> <p>Taking burden from parents[31]</p> <p>Tensions between sanctity of life and quality of life[19]</p> <p>Uncertain prognosis and what is best interests of child[42]</p> <p>Uncertainty of future improvement[41]</p> <p>Unclear prognosis[46]</p> <p>Understanding complexity of case[14]</p> <p>Understanding future consequences[29]</p> <p>Values of physician - best interests of the child[33]</p>
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<p>Over optimism and appearing not to give up[19] Parental hope of miracle recovery[34] Treatment[27] Treatment prone medicine[21] Treatment to allow clear assessment[42] Uncertain prognosis[21]</p> <p><i>Wider concerns (wellbeing)</i> Family well being[29] Future quality of life, future consciousness[33] Influence of personal beliefs[17] Minimise risk of long term morbidity[19] Outcome for the child[21] Post investigation[26] Postponing or passing on responsibility[21] Pressurized by parents to initiate[46] Prolonging treatment opposed to active euthanasia[24] Survival but increased morbidity[35] Treatment covered by health insurance[37]</p> <p><i>Obligations</i> Experience of physician to make decisions[8] Obligation to preserve life[14] Obligation to use the technology if it is there[16] Others will benefit from testing the technology in this case[16]</p>	<p>Physicians not to provide services that are futile[49] Poor prognosis and no benefit of treatment[32] Responsibility to minimise harm and maximise benefits in a clinical and wider sense[51] Risks to home caring abilities[29] Taking action (withdrawing care)[21] Taking burden from parents[31] Technology only prolongs death[22] Technology dependence not beneficial[50]</p> <p><i>Knowledge and judgement</i> Awareness of home mechanical ventilation in adults influencing paediatricians[15] Child receive no benefit from CPR[25] Correcting nocturnal or proven (diurnal) ventilatory failure[15] Cultural differences as influences on ethical differences[48] Cultural variation in 'position statements' of viability[48] Disability future quality of life[49] Fatal or terminal illness – prognosis[40] Futile care[49] Futile treatment withdrawn[25] Futility of care[33] Futility of further treatment[12] Future consequences for patient views / views of</p>	<p><i>Working in a team</i> Act to steer patient views[14] Appropriate language used to describe unclear options[56] Aware of parent or patient perspective[53] Burdensome to talk about death[44] Child's ability to communicate views[8] Consensus decision making[58] Consideration of advance directives[60] Consultation with family but clinical team make final decision[25] Counselling families of all possibilities[32] Difference in perception of well being[38] Difficult treatment decisions[32] Effective communication[29] Effective communication[11] Effective communication for the child and parent[57] Empathy and appreciation for parental decision making[59] Ensure full understanding of options[56] Family assessment of child's condition[33] Family caring responsibility[29] Family understanding of clinical need[39] Future family wellbeing[45] Indirect involvement of parents[31]</p>
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<p>Parental desire for treatment[8]</p> <p>Pressure of public expectation of technology's capabilities[11]</p> <p>Sole decision making[21]</p>	<p>patient[42]</p> <p>Individual unit approach to decision making[48]</p> <p>Ineffective treatment[29]</p> <p>Lack of confidence in ethics[21]</p> <p>Lack of community resources leads to intensive treatment at end of life[50]</p> <p>Legal and moral considerations[33]</p> <p>Legal support[47]</p> <p>Miserable and unhappy[21]</p> <p>Moral distress[27]</p> <p>National differences in determining futility[31]</p> <p>Need for agreement[21]</p> <p>Need to relieve life-threatening symptom[29]</p> <p>No chances of survival[30]</p> <p>Non elective ventilation[15]</p> <p>Non-curative treatment[29]</p> <p>Obstacles to transition home[45]</p> <p>Over-pessimistic[23]</p> <p>Poor future quality of life[11]</p> <p>Poor neurological prognosis[11, 22, 25, 40]</p> <p>Providing nutrition and hydration only[24]</p> <p>Regret reported by parents who opted for tracheostomy[36]</p> <p>Severity of prognosis[8]</p> <p>Socio-economic and cultural differences of parents[48]</p> <p>Treatment risks [29]</p>	<p>Information about diagnosis and prognosis[54]</p> <p>Information for parents for options at end of life[34]</p> <p>Lack of evidence as guidance for parents[54]</p> <p>Lessons learned from family[29]</p> <p>Long-term caring requirements for the child[39]</p> <p>Mutual trust and shared knowledge[25]</p> <p>No opportunity for parental involvement[34]</p> <p>Opinions of other professionals[21]</p> <p>Parents as information receivers[34]</p> <p>Parents as significant decision makers[34]</p> <p>Parental decision based on medical advice[47]</p> <p>Parental involvement[31]</p> <p>Parents may prefer a form of paternalism[36]</p> <p>Patient autonomy[29]</p> <p>Patient's future ability to interact with others[7]</p> <p>Presence of hospital ethics committee[40]</p> <p>Physicians as information providers[34]</p> <p>Potential for conflict[32]</p> <p>Psychological support to parents[38]</p> <p>Reassurance from colleagues, experts, ethical committee[57]</p> <p>Receptive to parental / family needs and views[29]</p> <p>Repeated opportunities for imparting information[36]</p> <p>Respect for other members of clinical team[25]</p> <p>Risk of catastrophic event at home[54]</p> <p>Risk of social isolation in the long term[39]</p>
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	<p>Updated guidelines support Withholding or withdrawing care [40]</p> <p><i>Dispute</i></p> <p>Being distrusted, treatment as abuse [13]</p> <p>Courts discussing values of respect for life [49]</p> <p>Discrimination against disability [49]</p> <p>Facilitating parental change of mind once accepting of terminal diagnosis [34]</p> <p>Families reluctant to consent [39]</p> <p>Futility as a means of reclaiming lost decision-making power [12]</p> <p>Loyalty conflicts [46]</p> <p>Parental refusal of consent [11]</p> <p>Parents' wishes are legally classed as euthanasia [44]</p> <p>Persistent vegetative state legal possibility to discontinue treatment [44]</p> <p>Reducing fear of legal consequences [17]</p> <p>Resisting parental request [30]</p> <p>Secrecy of acts/ euthanasia [14]</p>	<p>Risk of unilateral decision making[32]</p> <p>Sharing decisions to empower families[28]</p> <p>Shared discussions leading to decisions[32]</p> <p>Sharing the decision[8]</p> <p>Supportive and empathetic information provision[29]</p> <p>Support to make decisions slowly[39]</p> <p>Time to make best decisions[29]</p> <p>Timely discussion before a child requires technology dependence[32]</p> <p>Timing of information to inform decisions[50]</p> <p>Understanding how to communicate information[59]</p> <p>Willingness to involve parents in decisions[17]</p> <p><i>Impartiality</i></p> <p>Aiming to act fairly[53]</p> <p>Assessment of quality of life[23]</p> <p>Assumptions based on quality of life[41]</p> <p>Availability of resources[33]</p> <p>Avoid value-based or unfounded assumptions on quality of life[42]</p> <p>Avoiding close relationships with parents[46]</p> <p>Certainty of outcome[24]</p> <p>Changing prognosis/child's situation[25]</p> <p>Complex evaluation of burden and risk[42]</p> <p>Confidence in decision[21]</p> <p>Cost and complexity of care[54]</p>
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		<p>Criteria for withholding or withdrawing treatment[34]</p> <p>Culturally appropriate communication[53]</p> <p>Death expected or survival unacceptable quality of life[24]</p> <p>Decision based on diagnosis, prognosis and quality of life [24]</p> <p>Delegating effective care[61]</p> <p>Differences between neonates and older children[8]</p> <p>Economic resource costs[33]</p> <p>Economic and labour costs[45]</p> <p>Estimation of quality of life[23]</p> <p>Excluding information believed to be irrelevant[43]</p> <p>Financial or economic impact[29]</p> <p>Future challenges in diagnosis[28]</p> <p>Future morbidity[28]</p> <p>Future outcomes[57]</p> <p>Future quality of life[57]</p> <p>Global fair allocation of resources[53]</p> <p>Guidelines influence decision making[17]</p> <p>Importance of quality of life on decision making[24]</p> <p>Increased survival but also morbidity[55]</p> <p>Information reflecting linguistic and cultural needs[50]</p> <p>Institutional treatment and caring[29]</p> <p>Judgement of benefit or risk of treatment[25]</p> <p>Legal obligation[14, 29, 40]</p> <p>Longitudinal outcome[27]</p>
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		<p>Non curative treatment[29]</p> <p>No difference in mortality between those who do and don't rely on technology[36]</p> <p>Objectivity hiding parts of the truth[21]</p> <p>Obligation to be responsible for care at home[61]</p> <p>Outcomes[27, 53]</p> <p>Overtreatment[21]</p> <p>Physician responsible for final decision[25]</p> <p>Potential for consciousness[24]</p> <p>Power/trust in technology[29]</p> <p>Prolong life[61]</p> <p>Rationing of resources[58]</p> <p>Realistic assessment of problem[14]</p> <p>Responsibility[27]</p> <p>Responsibility for outcomes[61]</p> <p>Responsibility to avoid bias or judgement about quality of life[42]</p> <p>Responsibility to do the least harm[53]</p> <p>Right to determine how skills are used[57]</p> <p>Role is to preserve life[22]</p> <p>Technology potentially incompatible with child growth and development[38]</p> <p>Treatment associated with benefits and burdens[36]</p> <p>Treatment related factors - invasiveness, complications, reversibility, life expectance, functioning, quality of life, psychology[33]</p> <p>Uncertain or inaccurate prognosis[21, 43]</p>
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		<p>Uncertain outcomes[27]</p> <p>Uncertain prognosis[8]</p> <p>Using facts to determine moral decision[43]</p> <p>Wider concept of best interest of the child[25]</p> <p>Worth the economic costs[27]</p> <p><i>Disputes</i></p> <p>Answers to disputes are empirically based[7]</p> <p>Complex ethical and legal challenges[8]</p> <p>Conflict between child rights and parent rights[46]</p> <p>Conflict between hospital and community care[45]</p> <p>Conflict in decision making[36]</p> <p>Conflict with media/ journalists[46]</p> <p>Conflict with nurses[46]</p> <p>Difficult to communicate because of health care requirement to treat[44]</p> <p>Dull the need to reappraise actions[43]</p> <p>Fear of tracheostomy[39]</p> <p>Inadequacy of outcome measures to inform prognosis[19]</p> <p>Increased conflict in adults[8]</p> <p>Inconsistent legal requirements international[52]</p> <p>Information is understood differently by both parties (parents and clinicians)[55]</p> <p>Intensive treatment at end of life[50]</p> <p>Lack of availability of skilled home nursing care[37]</p>
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		<p>Lack of consensus between physicians[8] Loyalty conflicts[46] Media spotlight[58] Not using information in decision[54] Obstacles to transition home[45] Parents sidelined due to complex clinical situation[35] Paternalism of information provision[24] Physician / family disagreement[29] Physician doubt about parent motivation[21] Potential litigation[11] Potential for racial bias in care provision[50] Pressure from parents[21] Public nature of discussion dictates action[14] Recommending a treatment they would not want for themselves[27] Risk of paternalism[56] Socioeconomic disparity at the end of life[50] Undisclosed fears of prosecution[14]</p> <p><i>Feelings and emotions</i></p> <p>Anxiety influencing clinical judgement[42] Anxiety and fear of the entire process (family)[39] Assessing feelings[61] Assuming responsibility for risk of the decision[57] Attitudes influenced by personal and psychological factors[8]</p>
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		<p>Awareness / consciousness[24]</p> <p>Compassion for life 'slippery concept'[58]</p> <p>Considerations of quality of life and values[8]</p> <p>Decisional regret after tracheostomy[36]</p> <p>Emotions and discomfort[33]</p> <p>Experience, optimism, patient subjective experience[33]</p> <p>Fear and anxiety, loneliness[21]</p> <p>Fear of media criticism[21]</p> <p>Fear of mistakes[21]</p> <p>Fear of prolonging suffering[46]</p> <p>Good and bad[61]</p> <p>Hesitation in withholding and withdrawing[33]</p> <p>Hope[27]</p> <p>Increased emotional input - humour, anger, animation[7]</p> <p>Lack of importance of prognosis to experienced parents[35]</p> <p>Less regret because technology was better than expected[36]</p> <p>Moral distress[27]</p> <p>More experience greater fear of negative media attention[21]</p> <p>Narratives of being 'good parents' with no regrets[19]</p> <p>Need to do something[36]</p> <p>Not allowing anxiety to influence clinical decision[42]</p> <p>Overwhelming power of technology[22]</p>
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		Personal agony[14] Personal convictions and values[8] Personal factors and experiences influencing decisions[8] Presence of hope[29] Relieve suffering (ambivalent)[61] Relieve suffering[58] Regret[36] Stigmatisation[29] Suffering at end of life[35] Transparent and honest[29]
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