Incorporating Parental Values in Complex Paediatric and Perinatal Decisions

Rosa Geurtzen[a], MD, and prof Dominic JC Wilkinson[b,c,d,e,]

Affiliations: [a] Amalia Children's Hospital, Radboud Institute of Healthcare Sciences, Radboud university medical center, Nijmegen, the Netherlands; [b] Oxford Uehiro Centre for Practical Ethics, Faculty of Philosophy, University of Oxford, UK. [c] John Radcliffe Hospital, Oxford, UK, [d] Murdoch Children's Research Institute, Melbourne, Australia, [e] Centre for Biomedical Ethics, National University of Singapore Yong Loo Lin School of Medicine, Singapore.

Address correspondence to:
Prof Dominic JC Wilkinson
Oxford Uehiro Centre for Practical Ethics, Faculty of Philosophy,
University of Oxford,
Littlegate House, 16/17 St Ebbes St, Oxford OX1 1PT,
United Kingdom
Dominic.Wilkinson@philosophy.ox.ac.uk

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Article summary: A review of parental values in complex pediatric decisions, how they are constructed, elicited, and clarified, including practical suggestions.

Contributors Statement

Dr. Geurtzen and Prof. Wilkinson conceptualized and discussed the topic, collected, and reviewed relevant literature and wrote the manuscript. Both authors approved the final manuscript as submitted and agree to be accountable for all aspects of the work.

Abstract

Backgrounds and methods

Incorporating parental values in complex medical decisions for young children is important but challenging. In this paper, we explore what it means to incorporate parental values in complex pediatric and perinatal decisions. We provide a narrative overview incorporating literature from pediatrics, ethics, and medical decision-making, focusing on value-based and ethically complex decisions for children who are clearly too young to be able to express their own preferences. First, key concepts and definitions are explained. Second, pediatric specific features are discussed. Third, we reflect on challenges in getting to know and express values for both parents and health care providers. In the final part, suggestions for clinical practice are included.

Findings and interpretation

Decisional values are informed by global and external values, and may relate to the child, the parents, and the family as a whole. These values should inform preferences and assure value congruent choices. Additionally, parents may hold various meta values on the process of decision making itself.

Complex decisions for young children are emotionally taxing, ethically difficult, and often surrounded by uncertainty. These contextual factors make it more likely that values and preferences are initially absent or unstable and need to be constructed or stabilized. Health care professionals and parents need to work together to construct and clarify values and incorporate them into personalized decisions.

An open communication-style, with unbiased and tailored information in a supportive environment is helpful. Dedicated training in communication and shared decision making may help to improve the incorporation of parental values in complex decisions for young children.

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Key Messages

- Incorporating parental values in complex medical decisions for young children is important but challenging.
- Decisional values are informed by global and external values, and may relate to the child, the parents, and the family as a whole. These values should inform preferences and assure value congruent choices.
- Parents may also hold various meta values on the process of decision making itself.
- Since complex decisions for young children are emotionally taxing, ethically difficult, and often surrounded by uncertainty, values and preferences may be initially absent or unstable and need to be constructed or stabilized.
- Health care professionals and parents need to work together to construct and clarify values and incorporate them into personalized decisions. An open communication-style, with unbiased and tailored information in a supportive environment is helpful.

Introduction

Making complex medical decisions for fetuses, neonates, and infants is ethically and practically challenging. It is vital in both adult and pediatric medicine to incorporate patient (or parent) values[1-10] as part of shared decision making and personalized healthcare[2,5,11-13]. However, in practice, values are not always well elicited or incorporated into decisions[3,14-21].

Decision-making in pediatrics is different from adult medicine[3,4,22,23]. While adults can decide for themselves, fetuses, neonates, and infants cannot; thus, parents or guardians are surrogate decision-makers. (For readability, we use parents in this the paper, we mean to refer to those who have responsibility for a child, like parents or guardians). It is usually beneficial for parents to be part of decisions. For example, Emanuel and Emanuel have argued that a deliberative physician-patient relationship would best promote autonomy and well-being of patients[24]. There is some empirical support for this contention. One study described parents who shared in neonatal end-of-life decisions experiencing less grief in the long-term then those who did not[25]. Other parents expressed that while it was emotional and burdensome to participate in decisions, this enabled them to prepare for or prevent a feared situation, and to feel more empowered[26,27].

In this paper, we explore what it means to incorporate parental values in complex pediatric and perinatal decisions. We provide a narrative overview incorporating literature from pediatrics, ethics, and medical decision-making. Our focus is on (1) value-based decisions in which no single best option exists (2) for children who are clearly too young to be able to express their own preferences on (3) ethically complex issues. Such decisions are also sometimes referred to as falling in the grey zone, the zone of parental discretion, or as so-called preference-sensitive decisions; by definition they are ones that parents are permitted to make[1,2,6,9,28-32]. They may feature prognostic uncertainty, insufficient evidence on harms and benefits, or a very personal benefit-harm ratio[2,12,32]. Examples can be end-of-life decisions or advanced care planning in life-limiting diseases[6,33,34]. (It can be challenging to identify whether decisions fall within the grey zone of parental discretion, for this manuscript focus on cases that do clearly fit in this category[6,7,23,35-38]).

A single pediatric definition of shared decision making is lacking, and some prefer alternative terminology[3,5,6,12,21,27,39]. However, common ground is the importance of clarifying parental values and incorporating these into, ultimately, 'value congruent decisions': choices that align with the values of the people most affected by the decision[6,13,40].

Search strategy and selection criteria

A semi-structured search was performed using PubMed. We aimed to find papers on (1) definitions and explanation of the term value, the (2) concept of value clarification including its justification and challenges and (3) guidance for practice. No limitation on dates were used. Search terms were shared or complex decision-making, pediatrics, value-eliciting, and value-clarification. Through 'citations' and 'similar articles' the search was extended. After the first screening (May 2022, n=90 relevant full-text papers), relevant sections were extracted and summarized thematically. Specific literature was searched to complement and strengthen each part of our manuscript, and a search update was performed in Jan 2023 (June 2022 through Jan 2023, n=44 additional relevant full-text papers). Of this total of 134 relevant papers, 94 were ultimately included and cited in this definitive version of our manuscript. Finally, based on reviewers' suggestions' 4 relevant additional manuscripts were added.

Part 1: Key concepts

What is a Value?

'Values' in general refer to what is good and worthy. The word is frequently used in medical decision-making, but often undefined. In psychology, 'personal values' are: "broad desirable goals that motivate and serve as guiding principles. They affect people's preferences and behaviour over time and across situations" [41]. In research on patient decision-aids, definitions can be similarly wide-ranging, e.g.: "An umbrella term referring to what matters to an individual relevant to a health decision" [40]. However, the concept of values, is layered. Key components are[42,43]:

1. Global or basic values: i.e., underlying values, ethical beliefs, or life goals. These exist beyond specific decisions, but influence decision-specific values.

Terms and definitions

Value[40]

An umbrella term referring to what matters to an individual relevant to a health decision.

- Values may be directly relevant to decisions (e.g., ‘‘beliefs, feelings, or perceptions regarding attributes of a treatment option’’) or indirectly relevant (e.g., goals; worldviews; family, religious, or cultural values).
- Values may be represented qualitatively or, in some cases, quantitatively. This definition is deliberately broad

Value clarification[40]

The process of sorting out what matters to an individual relevant to a given health decision.

- This definition emphasizes that what matters to an individual may be broader than attribute-specific values.
- What matters may also include preferences, concerns (e.g., concerns about changes in health status), and issues to do with the context of a person’s life within which they would need to implement a decision (e.g., fitting a treatment plan into one’s work schedule)

Value clarification methods[40]

Strategies that are intended to help patients evaluate the desirability of options or attributes of options within a specific decision context, in order to identify which option [they] prefer.

- Implicit: Strategies for facilitating values clarification that do not require people to interact with anything or anyone—for example, describing ‘‘options in enough detail that clients can imagine what it is like to experience the physical, emotional, and social effects,’’ or simply encouraging people to think about what matters to them
- Explicit: Strategies for facilitating values clarification that require people to interact with something or someone (e.g., filling out a worksheet, using an interactive website, having a semi structured conversation with another person with the explicit purpose of clarifying values, or engaging in another structured exercise).

Preference[40]

The extent to which a decision option or health state is desirable or acceptable, either in the abstract or in comparison to other options or health states.

- Preferences may be represented qualitatively or, more commonly, quantitatively.

Choice[44]

~~The selected option, either intended or actual, for screening~~ The selected option, either intended or actual, for screening or treatment decisions[44]

Value congruency[44,47]

A calculation of the match between the chosen option or “choice” (dependent variable) and the patient’s “values” (independent variable), or in other words, meaning the decision aligns with what matters to the people most affected by the decision.

Unlike the field of psychology, in which four higher order values are quite well defined (conservation, self-enhancement, openness to change and self-transcendence), in medicine and particularly paediatrics, values are not well characterised[41]. In a report from a children’s hospital ethical committee, the three most important factors influencing parental decisions were the child’s quality of life, the chance of getting better and degree of discomfort[48,49]. A paper on advanced care planning (ACP) in children with rare diseases reported five domains expressed by parents: getting out and moving freely, feeling included and engaged, managing symptoms and disease burden, optimizing coordinated care among many team members, and planning for the future[50]. Some papers identify the influential values of ‘being a good parent’ and ‘protect[ing] your child against harm’[5,22,27,51-53].

Part 2: Paediatric specific features

Parents or guardians are default surrogate decision-makers for young children[3,4,12,22,53]. In most countries, they also have legal decision-making responsibilities that differ from surrogates in adult decision making[5,19,22]. Paediatric decision-making is more complicated, in part because there is usually more than one parent with decision-making responsibilities[23]. Each parent may vary in their views, values, and ability to process information and participate in the decision-making process[10]. Choosing for self-versus-others influences treatment preferences[3]. For very young children, ‘substituted decision-making’ (knowing what a person would want in these circumstances) is not applicable[5,22]. While parents are used to making decisions for their children, shared medical decision making can cause stress, anxiety, and an emotional burden for surrogates[19,54].

Some unique features of decisions for young infants include potential perceived social pressures e.g., a view that ‘children should not die’[5,22]. Decisions potentially carry a heavy ethical weight because of the potential for long-term risks and benefits, combined with a relatively high level of uncertainty about prognosis[8,19,32,55,56]. In the perinatal period the patient may not yet even be born, parents may not yet feel like parents. Decisions need to be made in a sensitive period of parent-child bonding when a firm place for the child within the family or social structure may be lacking[57]. Lastly, parental autonomy is more restricted than adults’ autonomy to make decisions for themselves, since decisions that would cross the harm-threshold and risk significant harm for their child are not (or should not be) permitted[58]. (Although extremely important, such potentially harmful fall outside the scope of this manuscript).

Part 3: Challenges in getting to know and express values for parents and health care professionals.

An overview of challenges (and potential strategies) in knowing and clarifying values can be found in Table 2.

Global values develop throughout childhood and adolescence, remain relatively consistent during adulthood, and reflect *“a lens through which all decisions are viewed”* [41,42]. They may be influenced by (e.g.) personality, or religion[42]. Parents’ global values may be relevant in part because of the potential similarity of values between

parents and children, through direct transmission as well as indirectly through shared environment, culture, and socio-economic status[41]. However, existing (limited) evidence suggests that health professionals often concentrate more on biomedical decisional values and preferences, than on global psychological, spiritual, and social values[20,26,59].

Depending on the context, parents' values may also be influenced by family, school staff, other parents, community members[3,42]. It can be challenging to distinguish between unwanted external pressure, and situations where parents choose to involve important others in medical decision-making "on the basis of ongoing relationships, reciprocal concerns, respect of others' advice and mutual interests without implying coercion or undue influence" [42].

Value Construction and context

Parents may have pre-existing decisional values and preferences (for example where they have faced similar decisions before). But, for complex medical decisions, it is likely that values need to be uncovered or even constructed at the time that a decision arises[37]. This raises a further problem: it is not easy to know one's own values and preferences in ethical decisions affected by high stake consequences, conflicting priorities, high levels of uncertainty and emotion, low levels of familiarity with the decision, and sometimes time-pressure[23,60-62].

There are a range of contextual factors that influence the expression of values and preferences including the adequacy of information, credibility of information source, clarity of communication, affective caregivers responses, choice architecture, emotions, perceived social norms, and (dis)comfort with the medical environment[1,3,23,27,37,54,56,60,61,63,64].

Three important factors are knowledge, bias, and emotions, especially in the health care professional-parent relationship [1,56,61,64-66]. It is important to provide all relevant information about the condition and options and it is also important for parents to understand this[23,37,56] Low health literacy or low numeracy (lack of familiarity with graphs and probabilities) can be a barrier for expressing preferences[2,4,23,63,67]. However, health care professionals do not always assess parents' level of understanding[63]. Information irrelevant to the consideration of options can be included, or selective neglect of either current or future factors may occur[1,37,61,66]. Health care professionals may introduce bias, consciously or unconsciously, and bring their own values into the conversations. Influences of choice architecture include framing (positive – such as survival rates, or negative – such as mortality rates) or the order of options (e.g., presenting a default). Lastly, emotions can make it harder to understand and interpret information and may alter perceptions[1,56,61]. Parents may have feelings of guilt or failure[3]. When parents feel anxious, overwhelmed, in denial or defensive, this may hinder the expression of values and preferences[23].

Conflicting Values and Preferences

Values can conflict, for example, prolonging life versus maximising comfort. This can be within one parent, but also between persons. Translating these into specific preferences can be very difficult[27,37,42,67]. Furthermore, specific preferences can conflict with underlying values, for example when they relate to a preferred intervention not compatible with the valued outcome or are open to interpretation (e.g., "I want everything done") [63,68]. In the paediatric situation, there are potential conflicts between values relating to the wider family versus the child[53,69]. Moreover, parental values are inextricably linked or entangled with those of the child[32,69]. Finally, conflicting values may occur between the community/society and the individual values of the family[7,38].

Meta Values

Most parents prefer to have a role in decision-making, but, depending on personality and/or context, may vary in how great a role[3,4,12,19,33,56,70-79]. In adults, a mismatch between actual and preferred roles in decision-making is associated with greater anxiety and less satisfaction[56]. In general, parents prefer more responsibility for decisions that are high risk, when they have experience with the decision, when the decision is thought to be part of the normal parental role, when big picture goals are involved (such as palliative care), and for decisions with the potential to harm the child[3,6,33,55,79]. Having other children was found in one study to be associated with parents' preference for making the final decision, another study found previous paediatric intensive care admissions and private insurance associated with a preference for more medical influence[33,79]. Finally, another study found no predicting parental characteristics[78]. On the other hand, parents have expressed a desire for more health care professional centred responsibility in decisions that are highly urgent, require high medical (technical) expertise, and decisions with potential to benefit an infant[33,55,79]. Finally, the preference for the decision-making responsibility is also culturally influenced; for example, some cultures do not encourage shared decision making[19,80]. It is important to realize that health care professionals are often unable to predict the role preference

of patients in the decision-making, and false assumptions are common[3,27,66,72,78,81,82]. While variation in role preferences regarding parents' final decision-making responsibility exists, and some may not (yet) be ready for a value conversation, it is unlikely that parents want their values to be ignored.

Parents also differ in *how* they wish to make complex decisions. Some prefer a more rational or deliberative process: effortful, conscious, and analytical[62,64]. Others prefer a less rational, intuitive process: less effortful and less conscious[62,64]. Explicit deliberation helps to verbalize and articulate preferences and reasons, to make congruent decisions, to feel better about how the decision was made and it allows for explicit consideration of likelihood of outcomes and values of these. However, negative emotions may be intensified, parents may generate reasons for preferences that are inaccurate and may limit focus to a few decision attributes that are easiest to verbalize while overlooking others[1,62,64,68]. A more intuitive process might help in implicit integration of large amounts of information; intuitive feelings can be surprisingly accurate. The risks are the influence of bias (although this may also apply to rational processes), the lack of logical sounding reasons that help to convince others and self that the decision is good, and in early stages of decision-making (e.g. information gathering) it may lead to uninformed decisions[62].

Interaction between Parents and health care professionals

Value clarification is often suboptimal in practice for both adults and children[43,59,83]. Three studies using actual audiotaped conversations with surrogates on adult, paediatric and neonatal intensive care units showed that a shared approach and value discussions were rare (although more common on neonatal and paediatric then adult intensive care units) and that family responses were mostly passive[16,19,21].

Several problems have been identified for value clarification. Patients, including parents, rarely discuss their values directly[26,84]. Barriers are numerous: the lack of perceived parental readiness, health care professionals' assumptions to know values and preferences, (perceived) lack of time in clinical encounters, lack of skills including education of these skills, the lack of a good relationship between health care professional and parents, the lack of a constant contact person, bad communication, too strong emotions (on both sides), health care professional holding a negative bias towards value clarification, the lack of a good way for a health care professional to evaluate value congruency and the lack of a supportive system in terms of supportive guidelines, supportive tools and a supportive organisation[6,8,23,26,34,54,66,67,82,84,85].

Part 4: Towards clinical practice

There is not a single correct way to incorporate parental values into paediatric decision-making. It will vary depending on the type of choice to be made, on what information parents want to have, on which role parents wish to play in the choice and on how rational parents can or want to be in the decision-making.

Information exchange

Parents should be encouraged to become informed[62,63,67]. They must understand the diagnosis, prognosis, and likely trajectory, although this requires sensitivity to their needs[67,86]. Uncertainty should be addressed[13,87]. Parents, in turn, should provide information on their personal situation. Outcome parameters known to be relevant for both health care professionals and parents must be incorporated in the conversation[88,89]. If available, a list with topics known to be important may be useful as starting point for the provision of information, as parents do not always know where to start, are naïve, and simply want to gain understanding but don't know what information they may ask for[90].

Starting points for Value Clarification

The approach to value clarification depends on context and preferences of those involved. If a well-defined decision has to be made, health care professional and parents may work either from choice to value or the other way around. In medical high-risk situations with no specific choice yet to be made, health care professionals generally start with a more general discussion of values.
Starting from a specific decision means acknowledging the decision at stake, including the options and its pros and cons. Ideally parents and health care professional work together from uninformed to informed preferences for this specific decision, reflecting a deeper understanding[67]. Health care professionals should allow both intuitive and rational deliberation, explore specific health beliefs and help to optimize mental representations[37,63]. Iteration is needed for this dynamic, non-linear process with values and preferences unfolding, influenced by emotions[37,63]. Parental understanding about both the medical facts and the understanding of their own values should be checked. For all, but especially for the most intuitive decisions, it may be important to allow for some

time and suspend the selection of the initial option[63]. An advantage of this approach is that parents are more likely to appreciate that there is a decision to be made and that their input is of importance[2,71]. It also allows for paediatricians deciding beforehand on whether or not the decision is preference-sensitive, and to let parents only participate when there is an actual decision to be made, avoiding the problem of "speaking of decisions if there is nothing to decide yet or nothing to decide anymore" [6,12,91]. Lastly, parental autonomy in making decisions is more easily preserved when starting with a specific decision.

On the other hand, starting with an exploration of values is common in paediatric ACP or paediatric palliative care in order to better tailor care to each individual family and be better prepared when decisions arise[34]. An advantage is that choices are sometimes defined (or not) by specific values, especially when these values are less uncommon. These alternative choices may have been overlooked if conversations had started from predefined decisions[6,38,42]. Even with a well-defined decision at stake, working from value to choice is readily applicable. Parents must think about their own values, given some understanding of the medical condition of their chid, and subsequently health care professionals can help translate these, if needed, into a specific preference[67]. This recognizes the importance of both the parental and health care professionals input, that patients can meaningfully engage without requiring a 100% understanding of the (complex) situation and that parental autonomy is preserved in deciding "how life preferably should unfold" [67]. Furthermore, starting with parental values may be more appropriate for the parents who prefer not to feel responsible for the final decision-making, and for parents with incomplete preferences[34,64,92].

COMMUNICATION ABOUT VALUES

It is potentially helpful to first check if it is a good time for a conversation, to address parental meta-values on decision making and to empower them to participate (see communication strategies, Table 3) [1,8,54,55,63,68,82].

Table 3 Communication skills: phrases that are potentially useful for health care professionals (modified experts' suggestions and authors' experiences).

Goals and potentially useful/example phrases
Address emotions
How are you doing right now? [1]
I am really sorry that you're going through this[1]
Tell me how you are feeling?
We can make this decision together now, but you may want to have a bit more time to think about it, or discuss with others[90]
This must feel like an impossible situation for you[94]
I'd like to suggest that we try to buy a little more time... to keep in touch and to give you some time to process what I've told you[94]
You were upset by what I was telling you, weren't you? Please can you tell me what was distressing you? [16]
Many parents in your situation feel overwhelmed, angry, or sad. These are normal feelings[93]
I realize this must be a very difficult time for you, so we will take it one step at a time[93]
Invite / empower to participate in decision-making and make clear that >1 option is available
Is it okay if we talk about your options together? [68]
Is now a good time to talk? [1,55]
We face some decisions here[1]
For some families… While for other families.... [82,95]
As parents you are experts on how the condition affects your child[8]
Are there other important people that you want to talk to in making this decision? [96]
There are [e.g.] two routes that we can take in this situation, we do not know exactly which suits you the most[90]
There's no question that you know what's best for her[94]
Is this a good time? [93]
Would you want somebody else to be here or for us to call that person? [93]
Thank you for pointing this out, you know [name] so well[93]
Address meta-values in decision-making process
Responding to cues like "this is too hard – I cannot make the decision" or "what would you do, if this was your child?" [55]
Some parents would like recommendations from me while others prefer to make the decision on their own, where do you fall for this decision? [82,90]
Would you like me to share with you what I see as you most reasonable medical options? [68]
You do not have to decide[21]
Open eliciting of values
What are you hoping for your child / family / yourself? [1,55,82]
What is your biggest fear/worry? [1,39,55,67,82]
Do you regret anything that's been done? [1]
What are the main problems for your child, for your family? [1]
What gives your life meaning? [67]
How does your child look to you? [55]
What are your concerns if we go down path A? [82]
What is most important to you [as a family] in what I have just said? [39,68]
What is your first feeling / intuition[62]
Do you have all the information you think you need to weigh up these two options? [96]
If you think about what we have just discussed, what are the most important things for you in this decision? [90]
How do you feel that the benefits of [X] relate to the benefits of [Y]? And what about the disadvantages? [90]
Acknowledge uncertainty
Unfortunately, we cannot be completely certain what will happen to your child[90]
Many parents I speak to find this uncertainty really difficult to deal with[21]
General
Tolerate silence, listen, watch for cues in body language[1,55,63,78,82,93]

Reflecting and checking on values
So, what I'm hearing you say is... [1]
[describe using their descriptions, e.g.] *she seems to be in pain*[1]
It sounds like [..] is important to you, which means.. [67]
What does it mean to you to be a good parent now that we have this information? [82]
It sounds like you are saying [repeat] – do I have this right? [68]

Introducing doubt / gently challenge preferences
For some a [certain percentage] risks seems like a lot, but for others it seems small compared with the benefit[61]
Although you have some negative images of what it would be like to live with [diagnosis], you might be surprised that most patients report a high quality of life" [61]
Is this what you really most want? [68]
We can make this decision together now, but you may want to have a bit more time to think about it, discuss with others[90]
The real life experience of disability can be very different than it sometimes seem to people who are not disabled [27]
If we don't look at the acute problems, but at the long-term problems, your child… [94]

Address conflicts between participants on values and preferences
It seems that each of us is focusing on a particular aspect of this situations[63]
Let's incorporate your standpoint into the discussion that we are having as [child's name] medical team[94]
Of course, I understand that this is against your instincts as a parent […] but we focus on what would be best for [your daughter/son] in the interests of your daughter, not in our own interests[16]
Find common ground
We are both hoping for that goal[1,55]
Well, this means, we would not initiate [resuscitation], we would say that it is fine, we have tried, and we really did everything we

Some parents may directly indicate what role they prefer, but others do not or may do so indirectly e.g., 'Doctor what would you do?' [12,27,55,68]. Providing guidance upon request is not paternalistic, but if sensitive to role preferences, can be culturally sensitive and helpful for parents who feel burdened by the decision[68,75,80,92]. Meta values may also be conflicting, e.g., when the wish for autonomy in decision-making seems to result in a non-value congruent decision[85]. Furthermore, parents may differ in how 'rational' versus 'intuitive' they want the decision-making process to be. Therefore, health care professionals should aim for acceptable (instead of perfectly rational) decisions[64].

To prevent strong emotions from impeding a conversation about values it is often advised to address and share emotions first, or to build in a delay or distraction prior to deliberation[1,62,63,68]. Screening tools and psychological support may be helpful[56]. It is important to actively listen, watch for cues in body language, face or voice and remain silent at appropriate times[1,55,63,78,82].

Health care professionals must actively work not only to elicit parents' values, but also to help parents construct them. Open-ended questions should reflect on what parents are hoping for, what they fear and on what makes life meaningful to them. Health care professionals can ask for specific concerns and hopes related to each option if applicable, on what parents think is most important to them and what information is missing[1,55,57,67,68,82]. Parents should be encouraged to also share their feelings towards options, even if they may be difficult to explain[62,63]. It may help to ask parents what it would mean to them to be a good parent, as this may help prioritize conflicting values[82].

Health care professionals should reflect back and check parental values using parents' own words, confirming understanding[1,13,55,63,67,68,82]. Also, clear differences between stakeholders should be addressed[63]. Furthermore, health care professionals may want to gently challenge the preference, to know if it is stable and informed or not. Ways of doing this include asking whether the preference is really what they want given the values that the health care professional learned about, to encourage the suspension the initial option (postpone judgement to form an overall impression first), to suggest that preferences may change after parents learn more about risks and benefits, introducing doubt and to uncouple short term positive or negative emotions from long term effects that may be the opposite[62,63,68].

Health care professionals and parents should work together to translate values into a value congruent choice. Again, using parents' own words is useful, as well as finding common ground and assuring non-judgemental support[1,55,59,68,70,82]. Finally, the final decision may be made, postponed, or be made provisional on contextual factors. It is not possible to predict how parents will feel subsequently and how context will evolve, so parents and health care professional should communicate about follow-up[63,82].

Environmental and Organisational aspects

Individual health care professionals should prepare themselves, create a safe and quiet place, make sure to (let parents) invite important relatives, show basic politeness (e.g. no pagers, phones, know the name of the child, introduce oneself, sit), and write or formulate a plan and communicate this to others involved[1,49,54,57]. Repeated meetings with a common contact person are often needed, and ideally should start as early as possible with conversations about values. Time invested allows for building relationships and constructing values[12,13,54,56,57,97]. Lastly, involving a multidisciplinary team is useful for ensuring a holistic perspective (e.g., social work, chaplaincy, palliative care, midwives, nurses, or therapists) [12,56,57,80].

More broadly, the health care system should be facilitating and ensuring that clarifying values is supported and economically viable[63]. Guidelines could be adapted to encourage this, by e.g., moving away from one-size-fits-all recommendations to explicitly describing options and trade-offs or to incorporate tools[81,98].

Tools such as digital information, multimedia and patient decision-aids may be helpful in providing information on health care conditions, and on potential options in a relatively unbiased way avoiding choice architecture problems[63]. They should be used in addition to communication (not replace it) and only by those parents who want to use it. One study reported benefits from a campaign to empower patients e.g., by showing three questions ("What are my options?" "What are the benefits and harms?" "And how likely are these?") in waiting rooms[96].

Patient decision-aids are specifically designed to help complex decisions, and include information about the decision, but may also help with value clarification[40,44,47]. Two commonly used value clarification methods in patient decision-aids are to ask people to think about pros and cons, or to rate the importance of option attributes. Although these reduce decisional conflict, they did not increase value congruence when tested in isolation from conversations[47]. Methods that showed most promise were those that explicitly and dynamically showed people how options aligned or failed to align with their values[47]. However, the best approach for a patient decision-aid may be contextual[40]. Value Clarification Methods are most useful in well-defined decisions when information is available on common attributes and how they relate to each other and to each option. However, the lack of flexibility in unique and less well-described decisions can be a disadvantage[40]. Also, attributes can be too widespread, too uncertain, or not even known and thus they may introduce bias[40,64].

Training, education and understanding

Value clarification skills of health care professionals may currently be insufficient but can be taught[63]. In particular, communication training may be useful, as well as education on common factors identified by parents to be central to their decision-making process, peer to peer coaching and mirror interviews with families[19,49,56,59,63,66]. These and other training modalities should be incorporated in medical education programs. Next to these practical training and education goals, a clear normative overview of the landscape of terms used in this field would be helpful.

Conclusions

Incorporating parental values in complex medical decisions for young children is important but challenging. Decisional values are informed by global and external values, and may relate to the child, the parents, and the family as a whole. These values should inform preferences and assure value congruent choices. Furthermore, parents may hold various meta values on the decision making itself which should be acknowledged. Complex decisions for young children are emotionally taxing, ethically difficult, and often surrounded by uncertainty. These contextual factors make it more likely that values and preferences are initially absent or unstable and need to be constructed or stabilized. Health care professionals and parents should work together to construct and clarify values and incorporate them into personalized decisions. An open communication-style, with unbiased and tailored information in a supportive environment is helpful. Dedicated training in communication and shared decision making may help to improve the incorporation of parental values in complex decisions for young children.

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Figure/Table Legends

Figure 1 Overview of concepts and relations in value-based decision making for fetuses, infants, and young children

Table 1 Overview of concepts and definitions

Table 2 Challenges for knowing and clarifying parental values in complex paediatric and perinatal decisions

Table 3 Communication skills: phrases that are potentially useful for health care professionals (based on experts' suggestions and authors' experience).