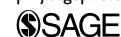


Medical indication regarding life-sustaining treatment for children: Focus groups with clinicians

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Abstract

Background: Decisions about medical indication are a relevant problem in pediatrics. Difficulties arise from the high prognostic uncertainty, the decisional incapacity of many children, the importance of the family, and conflicts with parents. The objectivity of judgments about medical indication has been questioned. Yet, little is known about the factors pediatricians actually include in their decisions.

Aim: Our aims were to investigate which factors pediatricians apply in deciding about medical indication, and how they manage conflicts with parents.

Design: We performed a qualitative focus group study with experienced pediatricians. The transcripts were subjected to qualitative content analysis.

Setting/participants: We conducted three focus groups with pediatricians from different specialties caring for severely ill children/adolescents. They discussed life-sustaining treatment in two case scenarios that varied according to diagnosis, age, and gender.

Results: The decisions about medical indication were based on considerations relating to the individual patient, to the family, and to other patients. Individual patient factors included clinical aspects and benefit–burden considerations. Physicians' individual views and feelings influenced their decision-making. Different factors were applied or weighed differently in the two cases. In case of conflict with parents, physicians preferred solutions aimed at establishing consensus.

Conclusion: The pediatricians defined medical indication on a case-by-case basis and were influenced by emotional reasoning. In contrast to prevailing ethico-legal principles, they included the interests of other persons in their decisions. Decision-making strategies should incorporate explicit discussions of social aspects and physicians' feelings to improve the transparency of the decision-making process and reduce bias.

Keywords

Withholding/withdrawing treatment, terminal care, decision-making, medical futility, life support care, pediatrics

What is already known about the topic?

- Decisions about medical indication in pediatrics are particularly challenging, and different views and values may lead to conflicts with parents.
- Despite legal regulations and guidelines, uncertainties exist about how to define medical indication in individual cases.
- There is little research on how decisions are made in clinical practice and what influences pediatricians in decision-making.

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What this paper adds?

- This study underlines the complexity and the value-laden nature of decisions about medical indication. Pediatricians' personal views and emotions as well as the interests of others play a role in the decision-making process.
- Pediatricians define medical indication differently, depending on the individual case.
- In cases of conflict, pediatricians prefer consensus-oriented strategies or comply with parental decisions.

Implications for practice, theory, or policy

- The results of this study can inform the development of decision-making models and policies.
- Decision-making frameworks should adopt a two-step approach, focusing on the review of the medical indication before entering the dialogue with the patient and parents.
- Decision-making strategies, ethics consultations, and professional education should incorporate discussions of the impact of other people's interests and of pediatricians' attitudes and feelings on decisions about medical indication in order to increase awareness and reduce bias.

Introduction

Decisions on life-sustaining treatment (LST) for children and adolescents raise important medical and ethical questions: What factors determine whether an intervention is considered medically indicated? Who decides what is in the best interests of a child without decision-making capacity? How can conflicts with parents be resolved? Legislation and bioethical guidelines in Germany and Switzerland emphasize the role of the medical indication in treatment decisions.^{1–7} Medical indication is defined as the physician's professional judgment about which treatments are in the best interests of the patient.^{1,8} An intervention is considered medically indicated if (1) there is a realistic chance to achieve the intended treatment goal (treatment effectiveness) and (2) the treatment represents a benefit to the patient that outweighs its burdens (positive benefit–burden ratio).^{1,3,8} The medical indication is legally required for performing any medical procedure, in addition to patient/surrogate consent.¹

The term medical indication is insufficiently precise, like the term futility, raising similar problems with regard to its definition and application.^{8–10} A main concern is that the decisions include not only clinical aspects but also value judgments by the physician.^{8–16} It has therefore been advocated to include the patient's view in the benefit–burden assessment.^{8,9} However, many pediatric patients are too young to form and express their own views. In these children, the caregivers' evaluations necessarily gain weight. Conflicts can arise when physicians and parents disagree about what is in the child's best interests.^{17,18} Moreover, many children who die have complex and rare life-limiting conditions with uncertain prognoses and unfamiliar illness trajectories.^{17–23}

Despite legal regulations and guidelines, uncertainties and different views exist about how to define medical indication and how to manage conflicts with the family.^{8,24} While medical indication is commonplace in clinical practice, little is known about how pediatricians understand and apply it in their current practice.

This study is part of a larger research project on advance care planning and LST decisions in pediatrics. It follows a prior study which revealed uncertainties and discomfort among pediatricians regarding LST decisions.²⁵ In order to better understand and improve the practice of LST decision-making in complex medical situations, we wanted to study how pediatricians comprehend and approach medical indication, which factors they actually include in their decisions, and how they deal with parental dissent.

Methods

This study used a qualitative descriptive approach to explore how decisions about medical indication for LST are made in pediatrics. We collected information by low-structured and case-based focus group discussions. Clinical case vignettes were used to stimulate focused discussions close to real practice, to elicit implicit views and avoid social acceptability bias.²⁶ The research methods and their reporting follow the *consolidated criteria for reporting qualitative research (COREQ)*.²⁷ All raw data related to the study are available from the corresponding author.

Sampling

Three focus groups were conducted with experienced pediatricians from various subspecialties in order to involve a variety of perspectives. Participants were selected by purposeful sampling, based on the following prerequisites: (1) caring for severely ill children/adolescents; (2) leading position (chief resident, attending physician, head of department); and (3) interest in the research question.

Recruitment

Eligible persons were identified through gatekeepers and personal knowledge according to the above-mentioned

criteria. We chose two study sites (Munich/Germany and Lausanne/Switzerland) because they both have strong pediatric intensive care and palliative care teams with significant experience in making LST decisions for children. The legal and ethical frameworks for medical decision-making in pediatrics are comparable at both sites. One focus group was held with participants of an advanced pediatric palliative medicine course in order to include pediatricians with special interest in palliative care. None of the participants were provided any incentive for taking part in the study.

Data collection

The focus group discussions took place between May and July 2014. Participants received an information letter on the study background, methods, and data protection, and gave written consent to their participation. Two focus groups were chaired by the author M.F., an experienced pediatric oncologist and professor for pediatric palliative care. Focus group 3 was chaired by the author G.D.B., an experienced neurologist and palliative care physician, and director of a palliative care service. Authors J.D.L. and C.M. took field notes. The discussions followed a semi-structured interview guide, developed according to Helfferich,²⁸ and discussed in various research groups with methodological, clinical, and bioethical expertise. The focus groups were audiotaped and transcribed verbatim. Words or phrases stressed by the interviewees were transcribed in capital letters. The study protocol and materials were reviewed and approved by the institutional review board of the Munich University Hospital (No: 049-12). Lausanne waived the necessity of a second approval.

Participants were asked to discuss the medical indication of LST for two case scenarios based on real cases (Boxes 1 and 2). The cases presented complex and in one case rare medical situations, which are often the setting for controversial discussions on LST in pediatric practice. No definition of “medical indication” was given because the term is commonplace in Germany and Switzerland, and we did not want to unduly bias the participants’ own ways to use it in clinical practice. The case scenarios were highly different in order to identify a variety of factors and explore whether and how decision-making differs depending on the case. The vignettes provided necessary information about the patient’s medical condition and prognosis, but left space for participants to fill in details and bring up additional hypothetical factors.^{29,30}

After reading the vignette together with the participants, they were asked, “How do you judge the medical indication for the treatment in question?” Each participant was asked to give a short statement, followed by an open discussion. Vignette 2 was divided into two parts with two subsequent treatment questions, read out and discussed after each other. Finally, the participants were asked—independently of the cases—how they would deal with parental dissent. A short self-administered questionnaire was distributed to collect personal information on participants’ age, sex, years of professional experience, specialization, additional qualifications, and experience with the diseases. The discussions took about 60 min per case.

Data analysis

The transcripts of focus groups 1 and 2 were analyzed by the authors J.D.L. and C.M. Focus group 3 (Swiss) was analyzed and interpreted in French by the bilingual authors

Box 1. Case vignette 1.

Patient features	
Age	An 8-week-old boy
Diagnosis	Spinal muscular atrophy-type I (SMA-I), genetically assured
Prognosis	Rapid deterioration of muscular function, death likely in first year of life due to respiratory insufficiency
Medical history	Little movements in last weeks of pregnancy, considerable deterioration of motor function at 6 weeks after birth
Current status	Beginning dysphagia and nutritional disturbance, progressive respiratory insufficiency Patient seems attentive and communicates non-verbally with parents
Family	One elder sister (3 years) Parents emotionally distressed, think about the impact on their child’s and their own life
Discussed treatment options and outcomes	
Invasive and non-invasive ventilation	Significant prolongation of survival, at best into second decade of life (for invasive ventilation) Loss of motor functions, pulmonary infections, severe osteoporosis, scoliosis, impaired language production, normal cognitive development
Palliative care	Alleviation of respiratory distress by palliative interventions, opioids, and benzodiazepines
Question asked	<i>How do you judge the medical indication for mechanical ventilation?</i>

Box 2. Case vignette 2.

Part 1	
Age	A 15-year-old girl
Diagnosis	Dyskeratosis congenita, diagnostically assured, caused by TERC-mutation that impairs telomere function
Prognosis	Progressive loss of the self-renewal capacity of all stem cells, particularly of the hematopoietic system, skin, mucous membranes, and liver Risk of severe pulmonary disease, particularly in patients with previous blood stem cell transplantation
Medical history	Diagnosis established at the age of 11 years Three blood stem cell transplantations for the treatment of bone marrow failure, graft-versus-host reaction Hospital admission 8 weeks ago, able to walk and express herself clearly at admission
Current status	Chronic liver failure, beginning renal and respiratory insufficiency, transfer to intensive care unit Severe pain caused by osteoporosis and multiple fractures, hypercalcemia Increased ammonia level, somnolence shortly after hospital admission, episodes of delirium
Question asked	<i>How do you judge the medical indication for the liver transplantation?</i>
Part 2	
Further disease course after liver transplantation	Values of ammonia and parameters of liver and kidney function rapidly normalize after liver transplantation No improvement of clinical condition, persisting somnolence, skeletal pain Patient refuses to eat Acute heart failure with severe arrhythmia, caused by myocardial fibrosis
Prognosis	Possible damage to liver graft by heart failure, low chance of medical recompensation of cardiac function
Question asked	<i>How do you judge the medical indication for the heart transplantation?</i>

TERC: telomerase RNA component.

J.D.L. and G.D.B. A qualitative content analysis was performed,³¹ using the software MAXQDA-10. We extracted all information consecutively from the three focus groups that referred to factors considered for medical indication. Categories and subcategories were inductively developed, checking back with the original data. Category contents, coding rules, and prototype examples were defined to increase transparency and reliability. The category system was cross-validated, reviewed by the research team, and discussed in a multidisciplinary research meeting, resulting in no major revisions. The (sub)categories were compared between the two case scenarios. Differences between focus groups were not systematically analyzed because this was not our research focus.

Results

In all, 17 participants were recruited according to the selection criteria. All participants had experience with at least one of the diseases presented. Table 1 lists the participants' demographics.

Factors considered for medical indication

Participants based their assessment of the medical indication on their professional experience, case examples, and

empirical data. They asked for more information, including scientific evidence, expert input, and interdisciplinary discussions. In case 2, they advocated further diagnostic measures to reduce prognostic uncertainty.

Table 2 summarizes all factors participants considered when discussing the medical indication for LST in the two cases. The factors were categorized in those relating to treatment and prognosis, to the physician, patient or family, as well as to ethical, legal, and economic aspects.

Participants considered the medical prognosis and treatment effectiveness in achieving goals such as life prolongation or symptom control. They also evaluated the anticipated benefits and burdens associated with the specific intervention. They discussed the patient's presumed wishes and views, and took into account the parents' perception of their child. The consequences for the family, other patients, and society (e.g. economically) were also considered. Additionally, emotional reasoning and difficulties with LST limitation played a role in the decision-making. In the following, the factors considered will be described in more detail for each of the two cases.

Case 1: spinal muscular atrophy-type I

In this case about an infant with spinal muscular atrophy-type I (SMA-1), treatment-related and prognostic factors,

Table 1. Sample characteristics ($n=17$).

Focus group	Represented pediatric disciplines	Place of work	Gender	Age (years)	Professional experience (years)
Focus group 1	Pediatric cardiology, pediatric neurology, pediatric hematology and oncology, pediatric critical care, pediatric palliative care, pediatric primary care	Munich, Germany	Male=5 Female=1	$M=47$ $SD=6.9$	$M=18$ $SD=5.5$
Focus group 2	Pediatric cardiology, pediatric neurology, pediatric hematology and oncology, neonatology, pediatric critical care, pediatric palliative care, pediatric primary care, clinical ethics counseling	Würzburg/Kiel/ Heidelberg/ Munich, Germany Innsbruck, Austria	Male=3 Female=3	$M=41$ $SD=5.9$	$M=11$ $SD=6.5$
Focus group 3	Pediatric cardiology, pediatric hematology and oncology, pediatric critical care, pediatric palliative care, pediatric primary care, neuro-rehabilitation, clinical pharmacology	Lausanne, Switzerland	Male=4 Female=1	$M=43$ $SD=9.4$	$M=18$ $SD=7.7$
Total			Male=12 Female=5	$M=44$ $SD=7.5$	$M=16$ $SD=7.1$

M: mean, SD: standard deviation.

Table 2. Factors considered in decisions about medical indication.

Thematic category	Factors considered ^a
Treatment-related and prognostic factors	Treatment goal, available treatment options Treatment invasiveness and treatment-related impairment, risk of complications and non-survival, necessary follow-up treatments, lacking prospect of better treatments in the future Reversibility of damages, chance for symptom improvement Expected disease course, life expectancy Expected level of motor and cognitive functioning, expected communication abilities and capacity to consent Anticipated quality of life: autonomy, participation in life, psychological suffering
Patient-related factors	Patient age, decision-making capacity Underlying disease and causes of symptoms, comorbidities Stability of current health status, symptom severity, cognitive situation Previous symptoms and suffering, previous treatments and treatment outcomes Patient's (presumed) wishes, patient's (presumed) subjective experience of the disease and psychological distress, treatment compliance
Family-related factors	Family context: siblings, cultural background Family/parent wishes and attitudes Burden on the family and coping resources
Physician-related factors	Difficulties withholding and withdrawing life-sustaining treatment, fear of over-treatment Optimism, hope for medical progress or a miracle Personal involvement in patient's care, own emotional response, "gut feeling" Professional specialization, own experience with similar patients, usual practice
Ethical and legal factors	Right for life, protection of life Child's best interests, harm avoidance Distributive justice, respect to organ donor Legislation allowing for treatment limitations
Economic factors	Financial costs for society associated with provision of treatment/care resources

^aListed order of reasons does not reflect priority.

physician factors, family, and patient factors were particularly important. Ethical and legal factors were also considered, but to a lesser extent.

Treatment-related and prognostic factors. These factors were highly relevant in this case. Discussed treatment

goals included life prolongation, improvement of current symptoms (respiratory insufficiency), and quality of life. The participants focused particularly on the evaluation of the benefits and burdens of mechanical ventilation for the child. They discussed the treatment invasiveness and related burden, the prolonged life expectancy, the loss of

motor function, the normal cognitive development, as well as the anticipated level of autonomy and participation in life. However, participants differed in their evaluations of the consequences for the patient's future quality of life:

Then, this brings up the question about the quality of life associated with this [life] prolongation. What we see in children with similar pathologies is that the restriction of autonomy and communication is so extreme that, in my opinion, there is indeed no medical indication for initiating [mechanical] ventilation in any case. (Pediatrician in neuro-rehabilitation and pediatric palliative care)

They can have in fact a VERY satisfying life, also later. This has shaped me, and for this reason, I would in ANY case allow enough time in all of these children, and I would provide as much information as possible that mechanical ventilation, of whatever kind, is entirely feasible nowadays, also at home and on the road, in the airplane or wherever. (Pediatric critical care physician)

Patient factors. The participants took into account the patient's incurable disease, normal cognitive function, current medical condition, and age at death. It was considered easier to limit LST in an infant than in older children. However, there were also suggestions to initiate treatment and wait until the patient could be involved in the decision about his treatment. Participants discussed how the patient might view his situation at a more advanced age, after having been treated with mechanical ventilation.

Family factors. Major consideration was given to the parents' views and preferences and their ability to cope with the situation ("what they can bear"). Some participants wished to discuss treatment options with the parents before deciding about the medical indication:

Well, I would literally RELY on parents' assessment of their child's existence on non-invasive or invasive ventilation with a tracheostoma in the critical care unit, so I could, perhaps, develop a recommendation based on the parents' view. (Neonatologist experienced in pediatric oncology)

Physician factors. Participants' individual attitudes, emotional responses, and personal experience were also important. Participants' own discomfort regarding LST limitations was particularly important. They hesitated to withhold LST, pointing to the possibility of withdrawing it later. However, withdrawing LST once started was perceived as very difficult, too. This ambiguity is well illustrated by two quotes from the same physician:

Of course, it is a difficult decision NOT to use an available therapy. [...] It requires to show a lot more backbone [Note: German colloquial for courage] NOT to start. (Pediatric cardiologist)

What I consider difficult is: Once you go down the road of [mechanical] ventilation, you cannot really relinquish it. So this has to be really thought through before you can start on this journey. (Same pediatric cardiologist)

Ethical and legal factors. Participants relied on the legal right to limit LST, but morally questioned this right in the case of a child with normal intelligence and a potential life expectancy of over 20 years under LST. The child's best interests were balanced against the family's interests:

[I] think that as a physician, who actually advocates for the child, you have to be very careful not to do things for the parents that, at the same time, rather prolong the child's suffering. [...] and to be very clear: where do we relieve something for the child and where do we prolong suffering? (Pediatric neurologist)

Economic factors. Participants also referred to the resources necessary for the child's care (e.g. care homes) and the associated costs for society.

Case 2: *dyskeratosis congenita*

In this case of a congenital disease with a high prognostic uncertainty, participants found it difficult to assess the medical indication for the liver transplantation, but agreed that there was no indication for the subsequent heart transplantation. Similar factors were used in both treatment decisions, but some were evaluated differently. The participants focused on the patient's medical condition and prognosis. Ethical factors differed from those in case 1. Physician factors were similar to those in case 1, but less important. Family factors were hardly addressed.

Treatment-related and prognostic factors. As in case 1, these factors were highly important in case 2. Discussed treatment goals included cure of the underlying disease and improvement of current symptoms (e.g. liver failure, neurological symptoms). Factors relating to the medical prognosis and treatment effectiveness were particularly important, including the anticipated disease course, the chance for cure, the reversibility of current symptoms—particularly the neurological symptoms—and the risk for treatment complications. Symptom reversibility was strongly doubted after the failure of the liver transplantation.

Patient factors. The participants focused on the patient's diagnosis (disease involving multiple organs), her neurological impairment, and medical history. No medical indication was established for the heart transplantation because of further deterioration of the patient's condition and lacking neurological improvement after the

Table 3. Options for dealing with parental dissent regarding life-sustaining treatment.

Favored option for dealing with parental dissent	Justifications ^a
Override parental decisions	<p><i>Justification for overriding parental decisions when parents refuse indicated LST:</i> Physicians' medical expertise, duty to deliver care according to best evidence Protection of the child's best interests</p> <p><i>Justification for overriding parental decisions when parents request non-indicated LST:</i> Avoidance of harm to the child Other patients' interests in case of limited resources Clear and reassuring legislation, refusal to act against own conscience</p>
Comply with parental decisions	<p><i>Justification for complying with parental decisions when parents refuse indicated LST:</i> Parents' decision-making power, necessity of parental consent Uncertain clinical judgments, recommendations that may be rejected Parents' better ability to assess the child's presumed wishes</p> <p><i>Justification for complying with parental decisions when parents request non-indicated LST:</i> Avoidance of doctor shopping and associated harm for the child Parents' well-being Close relationship with parents, difficulties withstanding parents' firm demands Subjectivity of medical decisions Court rulings expected to be in favor of parents, fear of legal consequences</p>
Search consensus: give parents time, continue negotiations, and shared decision-making	<p><i>Justification for searching consensus with parents when parents refuse indicated LST:</i> More time for parental coping</p> <p><i>Justification for searching consensus with parents when parents request non-indicated LST:</i> More time for parental coping Importance for parents to see the disease progressing</p>
Suggest change of physician	<p><i>Justification for change of physician when parents request non-indicated LST:</i> Duty to offer all possibilities, broken trust Chance that a second physician confirms the decision</p>

LST: life-sustaining treatment.

^aListed order of reasons does not reflect priority.

liver transplantation and because of the diagnostic uncertainties:

Well, I think, now [Note: after liver transplantation] at the latest, I would like to have an answer to the question: How can the neurological situation be explained? [...] The child has been transplanted because she deteriorated neurologically, and it has not gotten better. And now the next organ fails and we have NO idea what is the cause. For me that would be a clear contra-indication to a heart transplantation. (Neonatologist and pediatric critical care physician)

It was considered particularly difficult to limit LST in an adolescent patient compared to infants or elderly people. The patient's wishes were viewed as important. The participants asked about previously stated preferences or hoped to stabilize the patient in order to clarify her wishes.

Ethical and legal factors. Ethical considerations focused on distributive justice and the interest of other patients in cases of limited resources:

The waste of the organ transplant, this is a rather strong argument, [...] we have the possibility to refuse. Maybe this is the only exception where you can do it because we have

the argument of the benefit to someone else. (Pediatric primary care physician)

Dealing with parental dissent

Participants discussed several options for resolving conflicts with parents, listed in Table 3. They tended to comply with parental decisions. The main reasons for accepting parents' refusal of indicated LST were discussed: the necessity of parental consent and parents' right to reject clinical recommendations. The main reasons for complying with parents' requests of non-indicated LST included parents' suffering, physicians' fear of legal consequences, and avoidance of doctor shopping. However, the participants most frequently favored consensus solutions that evolve from continued discussions with parents. Physicians were also willing to provide medically non-indicated LST for a certain period of time to open doors for shared decision-making:

To be faced with a different opinion by the parents who wish to initiate treatment while we think it is not worth it—this simply means that the process of acceptance is not easy, so we have to give time, we can always negotiate about temporary measures. (Pediatric cardiologist)

In cases of unsolvable conflicts with parents, it was suggested to change the physician in charge because of broken trust or in the hope to reach an agreement with the confirmation by a second opinion.

Discussion

This study examined the factors pediatricians include in their decision-making on medical indication regarding LST. The results show that pediatricians base their decisions on multiple factors and do not completely adhere to the narrow legal definition of “medical indication.” The data also demonstrate that decisions about medical indication are more than a purely clinical judgment of the treatment effectiveness and benefit–burden ratio. In fact, these decisions are intermingled with value judgments. This matches with predominant normative conceptions.^{1,3,8} The benefit–burden judgment has been described in the literature as *physicians’ indication* (in contrast to *medical indication*) and is comparable with Schneiderman’s notion of qualitative futility.^{8,32,33} This component is the major cause for criticism of the indication concept, because it depends on the physician’s individual values.^{8,11,16,34} It has been shown that physicians differ in their attitudes and practices regarding LST.^{35–41} Moreover, they rate the quality of life of severely impaired children lower than the children themselves or their parents.^{42–44} Our results demonstrate that benefit–burden judgments are subjective and are sometimes more influenced by physicians’ individual experience with single patients than by medical evidence.

Furthermore, our participants were influenced by their own emotional responses. This may be even more important in the setting of a real case when personal involvement is higher. Individual views and feelings should be made explicit in the decision-making process, for example, through ethics consultations, in order to increase pediatricians’ awareness, and to reduce emotional interference and subjectivity of decisions.

Our participants also included the interests of the family in their decision-making, as has been shown in previous studies.^{45,46} They considered aspects of social justice such as harms for other patients in cases of limited resources. However, these are considerations from the point of view of social ethics, while the medical indication refers to the individual patient.⁸

In case of parental dissent, the participants tended to comply with parents’ decisions, although performing non-indicated treatment on parents’ request does not conform to the principle of best interests of the child as defined by German and Swiss law.^{1,4,5} However, this has been considered as ethically justified in cases of extreme psychological suffering of the family, as long as it does not cause harm for the child.⁴⁷

One of the reasons mentioned by our participants for complying with parents’ decisions was the uncertainty and subjectivity of the medical indication. In cases such as

ours, when the child cannot express its own view, the burden of surrogate decision-making is perceived as extremely challenging by physicians. Thus, some of our participants tended to pursue LST—even in situations like SMA-1—until the child might reach decision-making capacity.

Most of our participants clearly favored strategies that focus on negotiation and consensus with parents, as advocated by medical societies and shown in previous studies (shared decision-making).^{5,45,48} In order to facilitate such discussions, pediatricians’ communication skills need to be improved by communication trainings and guides.¹⁷ Adult approaches to communication in conflictual meetings with relatives could be adapted.⁴⁹ Moreover, advance care planning may provide a means for mitigating conflicts because it focuses on a guided process of information transfer, exploration of wishes and values, and negotiation of goals, aiming at shared decision-making and good quality of communication.^{50,51} However, in case of unsolvable conflicts, it is the obligation of the physician to appeal to the court when he fears serious harm to the child.^{7,12,52}

Our data show that pediatricians do not apply a universal definition of medical indication, but define it on a case-by-case basis. This suggests that universal definitions of medical indication may be difficult to apply in concrete cases.^{11,12,53} Instead, procedural approaches which focus on determining the medical indication and resolving conflicts in individual cases may be more useful.^{9,11,12,53,54} Various interventions are helpful to provide normative guidance and improve the decision-making practice: institutional policies, tools for ethical decision-making, ethics consultation, legal and ethical education, and supervision for physicians.^{8,55–58} They should incorporate explicit discussions of factors that may unduly bias the decisions (e.g. personal feelings, interests of others). Decision-making frameworks should adopt a two-step approach, focusing on the review of the medical indication in relation to the individual patient, before entering the dialogue with the parents. In addition, utilization of clinical practice guidelines and decision support tools needs to be fostered through education and integration into organizational structures.^{59,60} Previous data show that guidelines are insufficiently known and underutilized.^{24,60–62} This was also the case in our study.

Our study has several limitations. First, the focus groups differed in several aspects. This was intended to broaden the spectrum of different practices and attitudes, and was compensated by performing data analysis across groups. The gender imbalance in our study reflects the actual gender distribution among pediatricians in senior positions in Central Europe. Second, performing the study in two countries with different languages might constitute a limitation. However, the ethico-legal context for LST decisions in children is similar in both countries. Correspondingly, data analysis did not indicate significant differences between the German and Swiss discussions, which argues in favor of the validity of the results. Third, case vignettes were used to

explore pediatricians' decision-making, which may reduce generalizability to real-life situations. However, available evidence shows a high level of concordance between physicians' responses to vignettes and real-life situations.^{63–65} Moreover, vignettes are useful to reduce social desirability bias and elicit implicit views, and less hypothetical than abstract questions on attitudes and practices.^{26,29,30,65–67} Fourth, the case vignettes present rather rare and complex clinical situations, and the information provided for the discussion was necessarily limited. However, this reflects real situations pediatricians face in many severely ill children, where decisions on the medical indication are often based on limited medical evidence.

Conclusion

The results of this qualitative study help us to better comprehend how pediatricians define medical indication in the context of LST. Our results can increase the awareness of how various factors influence pediatricians' decisions. They may inform the practice of clinical ethics consultation and assist in the development of tools to guide ethical decision-making for LST in pediatrics. Procedural approaches to medical indication might provide better guidance in concrete cases than universal definitions. The applicability of developed instruments needs to be verified and ensured. It is particularly important to openly address physicians' personal views and feelings in order to prevent undue bias in decision-making.

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References

1. Wiesing U, Jox RJ, Hessler HJ, et al. A new law on advance directives in Germany. *J Med Ethics* 2010; 36: 779–783.
2. Deutsche Gesellschaft für Medizinrecht (DGMR). *Medizinrechtliche Aspekte 6. Einbecker Workshop der Deutschen Gesellschaft für Medizinrecht in Zusammenarbeit mit der Deutschen Gesellschaft für Kinderheilkunde 24.–26. März 1995*. Berlin, Heidelberg: Springer, 1995.
3. Jacobs P, Jox RJ, Weber J, et al. Leitlinie zur Frage der Therapieziel-änderung bei schwerstkranken Patienten und zum Umgang mit Patientenverfügungen, 2013, https://www.klinikum.uni-muenchen.de/download/de/Fachbereiche/Palliativmedizin/Leitlinie_PV_Langfassung.pdf
4. Schweizerische Akademie der Medizinischen Wissenschaften (SAMW), Schweizer Ärztinnen und Ärzte FMH. *Rechtliche Grundlagen im medizinischen Alltag. Ein Leitfaden für die Praxis*, 2013, http://www.fmh.ch/files/pdf12/Rechtliche_Grundlagen_2013_D.pdf
5. Schweizerische Akademie der Medizinischen Wissenschaften (SAMW). *Intensivmedizinische Maßnahmen. Medizinethische Richtlinien und Empfehlungen* [Intensive-care interventions. Medical-ethical guidelines and recommendations]. Basel: Gremper AG, 2013. file:///C:/Users/Julia/Downloads/e_RL_Intensiv_Juli13_Web.pdf
6. § 1901b. Abs. 1 Satz 1 Bürgerliches Gesetzbuch (BGB), http://www.gesetze-im-internet.de/bgb/_1901b.html
7. Bundesärztekammer. Grundsätze der Bundesärztekammer zur ärztlichen Sterbebegleitung. *Dtsch Arztebl Int* 2011; 108(7): A346–A348.
8. Jox RJ, Schaidler A, Marckmann G, et al. Medical futility at the end of life: the perspectives of intensive care and palliative care clinicians. *J Med Ethics* 2012; 38: 540–545.
9. Wilkinson DJ and Savulescu J. Knowing when to stop: futility in the ICU. *Curr Opin Anaesthesiol* 2011; 24: 160–165.
10. Truog RD, Brett AS and Frader J. The problem with futility. *N Engl J Med* 1992; 326: 1560–1564.
11. Moratti S. The development of "medical futility": towards a procedural approach based on the role of the medical profession. *J Med Ethics* 2009; 35: 369–372.
12. Burns JP and Truog RD. Futility: a concept in evolution. *Chest* 2007; 132: 1987–1993.
13. Helft PR, Siegler M and Lantos J. The rise and fall of the futility movement. *N Engl J Med* 2000; 343: 293–296.
14. Brody BA and Halevy A. Is futility a futile concept? *J Med Philos* 1995; 20: 123–144.
15. Council on Ethical and Judicial Affairs, American Medical Association. Medical futility in end-of-life care: report of the Council on Ethical and Judicial Affairs. *JAMA* 1999; 281: 937–941.
16. Jox RJ. *Sterben lassen. Über Entscheidungen am Ende des Lebens*. Hamburg: Edition Körber-Stiftung, 2011.
17. Forbes T, Goeman E, Stark Z, et al. Discussing withdrawing and withholding of life-sustaining medical treatment in a tertiary paediatric hospital: a survey of clinician attitudes and practices. *J Paediatr Child Health* 2008; 44: 392–398.
18. Durall A, Zurakowski D and Wolfe J. Barriers to conducting advance care discussions for children with life-threatening conditions. *Pediatrics* 2012; 129: e975–e982.
19. Davies B, Sehring SA, Partridge JC, et al. Barriers to palliative care for children: perceptions of pediatric health care providers. *Pediatrics* 2008; 121: 282–288.
20. Graham RJ and Robinson WM. Integrating palliative care into chronic care for children with severe neurodevelopmental disabilities. *J Dev Behav Pediatr* 2005; 26: 361–365.
21. Brook L and Hain R. Predicting death in children. *Arch Dis Child* 2008; 93: 1067–1070.
22. Yoshida S, Shimizu K, Kobayashi M, et al. Barriers of healthcare providers against end-of-life discussions with

- pediatric cancer patients. *Jpn J Clin Oncol* 2014; 44: 729–735.
23. Mitchell S and Dale J. Advance care planning in palliative care: a qualitative investigation into the perspective of Paediatric Intensive Care Unit staff. *Palliat Med* 2015; 29: 371–379.
 24. Wandrowski J, Schuster T, Strube W, et al. Medical ethical knowledge and moral attitudes among physicians in Bavaria. *Dtsch Arztebl Int* 2012; 109: 141–147.
 25. Lotz JD, Jox RJ, Borasio GD, et al. Pediatric advance care planning from the perspective of health care professionals: a qualitative interview study. *Palliat Med* 2015; 29: 212–222.
 26. Barter C and Renold E. The use of vignettes in qualitative research. *Soc Res Update* 1999; 25: 1–4. <http://sru.soc.surrey.ac.uk/SRU25.html>
 27. Tong A, Sainsbury P and Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *Int J Qual Health Care* 2007; 19: 349–357.
 28. Helfferich C. *Die Qualität qualitativer Daten: Manual für die Durchführung qualitativer Interviews*, 2nd ed. Wiesbaden: VS Verlag für Sozialwissenschaften, 2005.
 29. Braun V and Clarke V. An introduction to the vignette method, 2013, <http://studysites.uk.sagepub.com/braunandclarke/study/Learning%20Resources/An%20Introduction%20to%20the%20Vignette%20Method.docx>
 30. Kelly E and Lesh R. Understanding and explicating the design experiment methodology. *Build Res Capacit* 2002; 3: 1–3.
 31. Schreier M. *Qualitative content analysis in practice*. Thousand Oaks, CA: SAGE, 2012.
 32. Schneiderman LJ. Defining medical futility and improving medical care. *J Bioeth Inq* 2011; 8: 123–131.
 33. Eickhoff C. *Patientenwille am Lebensende? Ethische Entscheidungskonflikte im klinischen Kontext*. Frankfurt: Campus Verlag GmbH, 2014.
 34. Weijer C and Elliott C. Pulling the plug on futility. *BMJ* 1995; 310: 683–684.
 35. Lago PM, Devictor D, Piva JP, et al. End-of-life care in children: the Brazilian and the international perspectives. *J Pediatr* 2007; 83: S109–S116.
 36. Cuttini M, Nadai M, Kaminski M, et al. End-of-life decisions in neonatal intensive care: physicians' self-reported practices in seven European countries. EURONIC Study Group. *Lancet* 2000; 355: 2112–2118.
 37. Rebagliato M, Cuttini M, Broggin L, et al. Neonatal end-of-life decision making: physicians' attitudes and relationship with self-reported practices in 10 European countries. *JAMA* 2000; 284: 2451–2459.
 38. Sprung CL, Maia P, Bulow HH, et al. The importance of religious affiliation and culture on end-of-life decisions in European intensive care units. *Intensive Care Med* 2007; 33: 1732–1739.
 39. Baggs JG, Norton SA, Schmitt MH, et al. Intensive care unit cultures and end-of-life decision making. *J Crit Care* 2007; 22: 159–168.
 40. Gresniuk CS and Joffe AR. Variability in the pediatric intensivists' threshold for withdrawal/limitation of life support as perceived by bedside nurses: a multicenter survey study. *Ann Intensive Care* 2011; 1: 31.
 41. Hardart MK, Burns JP and Truog RD. Respiratory support in spinal muscular atrophy type I: a survey of physician practices and attitudes. *Pediatrics* 2002; 110: e24.
 42. Saigal S, Stoskopf BL, Feeny D, et al. Differences in preferences for neonatal outcomes among health care professionals, parents, and adolescents. *JAMA* 1999; 281: 1991–1997.
 43. Morrow AM, Hayen A, Quine S, et al. A comparison of doctors', parents' and children's reports of health states and health-related quality of life in children with chronic conditions. *Child Care Health Dev* 2012; 38: 186–195.
 44. Janvier A, Farlow B and Wilfond BS. The experience of families with children with trisomy 13 and 18 in social networks. *Pediatrics* 2012; 130: 293–298.
 45. Carnevale FA, Farrell C, Cremer R, et al. Struggling to do what is right for the child: pediatric life-support decisions among physicians and nurses in France and Quebec. *J Child Health Care* 2012; 16: 109–123.
 46. Fauriel I, Moutel G, Duchange N, et al. Decision making concerning life-sustaining treatment in paediatric nephrology: professionals' experiences and values. *Nephrol Dial Transplant* 2005; 20: 2746–2750.
 47. Truog RD. Is it always wrong to perform futile CPR? *N Engl J Med* 2010; 362: 477–479.
 48. American Academy of Pediatrics Committee on Bioethics: guidelines on foregoing life-sustaining medical treatment. *Pediatrics* 1994; 93: 532–536.
 49. Billings JA. The end-of-life family meeting in intensive care part I: indications, outcomes, and family needs. *J Palliat Med* 2011; 14: 1042–1050.
 50. Detering KM, Hancock AD, Reade MC, et al. The impact of advance care planning on end of life care in elderly patients: randomised controlled trial. *BMJ* 2010; 340: c1345.
 51. Romer AL and Hammes BJ. Communication, trust, and making choices: advance care planning four years on. *J Palliat Med* 2004; 7: 335–340.
 52. Führer M, Jox RJ and Borasio GD. Therapieentscheidungen bei schwerstkranken Kindern und Jugendlichen [Treatment decisions for severely ill children and adolescents]. *MMW Fortschr Med* 2011; 153(37): 35–38.
 53. Rubin E and Courtwright A. Medical futility procedures: what more do we need to know? *Chest* 2013; 144: 1707–1711.
 54. Truog RD. Tackling medical futility in Texas. *N Engl J Med* 2007; 357: 1–3.
 55. Schneiderman LJ, Gilmer T, Teetzel HD, et al. Effect of ethics consultations on nonbeneficial life-sustaining treatments in the intensive care setting: a randomized controlled trial. *JAMA* 2003; 290: 1166–1172.
 56. Johnson LM, Church CL, Metzger M, et al. Ethics consultation in pediatrics: long-term experience from a pediatric oncology center. *Am J Bioeth* 2015; 15: 3–17.
 57. Truog RD and Mitchell C. Futility—from hospital policies to state laws. *Am J Bioeth* 2006; 6: 19–21; discussion W30–W32.
 58. Bosshard G. *Klinische Ethikberatung: Machtfreier Diskurs im Spital?* SGBEBulletinSSEB 2008; 57: 9–11, http://www.pflegeportal.ch/pflegeportal/Klinische_Ethikberatung_Machtfreier_Diskurs_im_Spital.php
 59. Ploeg J, Davies B, Edwards N, et al. Factors influencing best-practice guideline implementation: lessons learned

- from administrators, nursing staff, and project leaders. *Worldviews Evid Based Nurs* 2007; 4: 210–219.
60. Keiffer MR. Utilization of clinical practice guidelines: barriers and facilitators. *Nurs Clin North Am* 2015; 50: 327–345.
 61. Jox RJ, Winkler EC and Borasio GD. Changing the treatment goal at the end of life: effects of a guideline at a hospital. *Dtsch Med Wochenschr* 2012; 137: 829–833.
 62. Solomon MZ, Sellers DE, Heller KS, et al. New and lingering controversies in pediatric end-of-life care. *Pediatrics* 2005; 116: 872–883.
 63. Peabody JW, Luck J, Glassman P, et al. Measuring the quality of physician practice by using clinical vignettes: a prospective validation study. *Ann Intern Med* 2004; 141: 771–780.
 64. Langley GR, Tritchler DL, Llewellyn-Thomas HA, et al. Use of written cases to study factors associated with regional variations in referral rates. *J Clin Epidemiol* 1991; 44: 391–402.
 65. Evans SC, Roberts MC, Keeley JW, et al. Vignette methodologies for studying clinicians' decision-making: validity, utility, and application in ICD-11 field studies. *Int J Clin Health Psychol* 2015; 15: 160–170.
 66. Schoenberg NE and Ravdal H. Using vignettes in awareness and attitudinal research. *Int J Soc Res Methodol* 2000; 3: 63–74.
 67. Alexander CS and Becker HJ. The use of vignettes in survey research. *Public Opin Q* 1978; 42: 93–104.