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ORIGINAL ARTICLE

Decision-making capacity of children and adolescents—suggestions for advancing the concept's implementation in pediatric healthcare

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Abstract Within the frameworks of shared decision-making and participation in healthcare, children's ability to understand and appreciate information pertaining to illness and treatment is important. Physicians are mainly responsible for assessing decision-making capacity (DMC) but may encounter difficulties arising from the limited basis of evidence with regard to this concept in pediatrics. Three issues contributing to this paucity of knowledge on DMC of children can be identified: (1) conceptual blurriness and absence of clear terminology, (2) lack of validated tools to reliably assess DMC in the pediatric population, and (3) a need to include a developmental framework to understand DMC in children and adolescents. The aim of this paper is to examine these three issues and provide practical recommendations to advance the concept and its assessment in pediatrics as a step to ensuring children's developmentally appropriate participation in healthcare. Finally, the paper highlights the ethical dimension of assessing DMC emphasizing the importance of physicians' attitudes for the assessment process.

Conclusion: A detailed understanding of DMC is necessary to inform developmentally appropriate participation. In order to achieve this, pediatric practice needs to address challenges that are specific to providing healthcare for children, including conceptual issues, assessment, and aspects of child development.

Keywords Decision-making capacity · Children · Pediatrics

Abbreviations

DMC	Decision-making capacity
UK	United Kingdom
US	United States

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Several pediatric associations (e.g., American Academy of Pediatrics, British Medical Association, SIOP Working Committee on Psychosocial Issues in Pediatric Oncology) emphasize the value of children's[1] participation in healthcare at a level that is developmentally appropriate [6, 14, 61]. Participation has been demonstrated to benefit children and reduce stress associated with treatment and procedures [19]. Within the framework of shared decision-making, physician and patient collaborate to make decisions while the extent of the contribution of both parties can vary [38]. In the pediatric setting, shared decision-making is essentially triadic and includes also parents, whose permission for medical treatment is usually required because of children's status as legal minors [28, 35]. Among others, considerations regarding children's developmental achievements influence their level of participation [48]. Patients' ability to understand and appreciate information relevant to treatment, that is, their decision-making capacity[2] (DMC) is an important aspect of decision-making

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[1] The terms child, adolescent, and minor patients are used interchangeably to denominate patients who have not yet attained the legal age of majority.

[2] In this article, we adopt the term *capacity* to denominate clinical decision-making ability (as opposed to usage of the word *competence*).

processes [25, 41]. Additionally, DMC is one of three central elements necessary for informed consent (see Fig. 1) [31, 63]. It is through consent that patients permit physicians to administer a treatment [22]. Another central element is the provision of adequate information in a manner that facilitates understanding [31], which influences patients' comprehension and information-processing skills and thereby the decision-making ability [34]. Informing patients appropriately about treatment or procedures is independent of the presence of DMC [14]. Voluntariness is the third critical feature and represents the absence of undue influence on the decision-making process including fear, pain, false beliefs, or incorrect information [14]. Any consent given under pressure is invalid [22]. However, the questions where boundaries of coercion begin [31] and if persons of any age can fulfil this requirement in light of social expectations and norms has received little attention [54]. In the medical, legal, and ethical literature children's DMC and their ability to satisfy these criteria for consent has been' widely debated with regard to cognitive and behavioral characteristics of children [33, 53], principles of child development [39], ethical considerations (e.g., autonomy vs. best interest approach) [50], parenting practices [55], professional attitudes [47], and legal issues [56].

Since children's abilities evolve with maturation and experience [48], their involvement in treatment should likewise increase as they develop [65]. This requires that physicians, who are generally responsible for assessing DMC [12], distinguish those children who have capacity to make or contribute to a certain decision from those who have lesser abilities [33]. Considering this, clinicians should have a clear understanding of children's decision-making ability [67], and any assessment of DMC must be done with utmost care [35, 39]. A faulty judgement can result in either denying choice or participation when this is not appropriate or overwhelming children with decisions that are too difficult for them [18]. In light of the importance of this topic, a strong empirical basis regarding children's decision-making abilities is required to facilitate assessment practices [50]. In a seminal study, Weithorn and Campell studied healthy children and adolescent's capacity to make treatment decisions [64]. They concluded that from age 14 years onward, adolescents appear equally capable of decision-making as adults. Younger children (9 years) showed lesser abilities but were still capable of making a reasonable choice. It should be noted that a judgement of a participant's capacity in this study included "reasonableness of choice" (i.e., choice that is hypothetically wise, which a mature person might make). Although it is acknowledged that a patient's disagreement with professional recommendations will often lead to questioning the patient's capacity, the content of the decision is not a criterion in Appelbaum's well-established definition [7]. The presence of DMC is determined if an individual fulfils the following criteria (see Fig. 1 and Table 2): (a) understanding of necessary information, (b) appreciation of the situation and likely consequences, (c) reasoning about treatment options, and (d) communication of a choice. Hence, patients must demonstrate that they understand the nature of their illness as well as the information provided on proposed treatment option(s) and risk and benefits associated with these options (criterion a). They must further accept that they are ill and grasp the effects that treatment(s) will have (e.g., what treatment can do for them, what will happen if the condition remains untreated) (criterion b). Patients also must be able to compare treatment options and provide reasons for their choice (criterion c). Finally, they must clearly indicate one choice (criterion d), which excludes patients who may frequently change their mind [7].

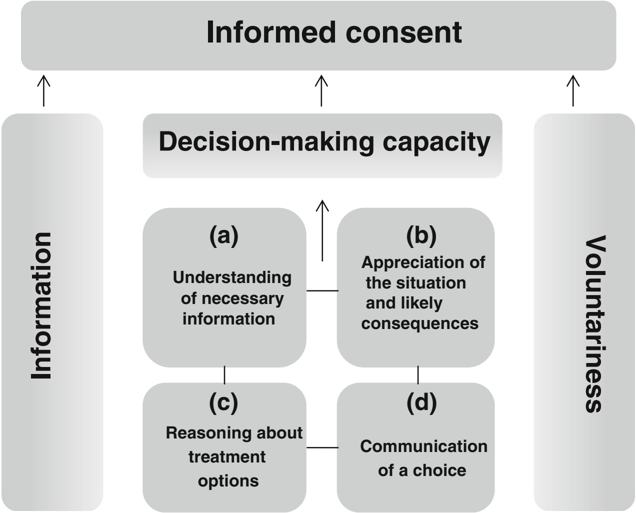

Fig. 1 The concept of DMC in relationship to informed consent (based on [7, 31, 63])

As such, capacity is to be judged with regard to a specific decision and can vary within one individual; that is, persons can have capacity to make small choices (e.g., choosing syrup or pill) but not important decisions (e.g., which treatment to follow) [11, 25]. Although DMC has received much attention in research on adult patients (e.g., [7, 23, 25, 26, 30, 31]), the concept is considerably less understood in children and has not been examined in a consistent manner [20, 50]. In a narrative review, Miller, Drotar, and Kodish criticize the use of inconsistent definitions and incoherent operationalization of DMC across pediatric studies [50]. That is, while DMC is defined as a multidimensional construct, studies in children usually do not examine all relevant domains, making it difficult to compare findings from different studies. Most research (except for the study by Weithorn and Campbell described above) investigates children's ability to understand while neglecting other areas (e.g., reasoning skills). Hence, studies fail to provide a unifying framework for interpreting their results [50]. These shortcomings lead to the question of why a longstanding tradition to debate DMC in minor patients has not resulted in the application of a consensus definition and the development of validated measures, which would allow for a more coherent and reliable assessment.

The aims of the paper are to first examine three concerns that can be identified from the literature surrounding DMC of children: (1) conceptual blurriness and inconsistent terminology, (2) difficulties in operationalization and measurement of DMC, and (3) a need to include a developmental framework to understand DMC in children and adolescents. In doing so, we unify several aspects and present a more complete picture of these problems associated with DMC in pediatrics which in turn impede children's adaquate participation in treatment decisions. Second, based on this analysis, we discuss recommendations to advance the implementation of the concept of DMC in pediatric healthcare, thereby representing a first step in ensuring children's participation in treatment decisions that is consistent with developmental achievements of the child.

Terminology and jurisdiction

DMC is a necessary requirement for legal competence [13]. While DMC is defined as a person's cognitive ability to manipulate information in order to reach a decision [31], competence refers to the authority of a person to transform such choices into legally binding decisions within the limitations of the law [59]. As such, competence is usually used as a legal concept (except for legislation in the UK, as discussed below), while DMC is a clinical construct and a criterion for legal competence. Whereas adult persons are presumed to have legal competence unless the presence of DMC is rebutted [46, 62], children as minors lack competence [58]. Therefore, they cannot provide legally valid consent to medical treatment. Generally, in order to treat a minor patient, physicians need permission from a parent or a guardian [58]. However, some legislatures (for examples see Table 1) acknowledge that the ability to make healthcare decisions may be present in older children and thus give limited decision-making rights to those who fulfil standards of DMC [4].

Table 1 Different legislations with regard to children's decision-making rights in healthcare

United States (US) "Mature minor doctrine"	Adolescents of the age of 14 years and above can consent if they understand the nature and consequences of a proposed treatment, the procedure does not entail greater than minimal risk and is standard medical practice. For major procedures or refusal of life-sustaining treatment, either parental or judicial consent/permission is required [35].
United Kingdom (UK) "Gillick competence"	Adolescents from 16 years of age or children considered "Gillick competent" (no age limit), that is, those who demonstrate "sufficient understanding and intelligence … to fully understand what is proposed" and have "sufficient discretion to … make a wise choice …" can provide consent to treatment [5], p 2273). However, a refusal can be overruled if treatment is considered to be in the child's best interest [27, 41].
Switzerland	No distinction between adult and minor patients but between patients with (*urteilsfähig*) and without capacity. If a patient, regardless of age, is considered to have capacity he or she can provide legally valid consent [49]. Patients between 12 and 18 years of age can be expected to have capacity but have to be judged on an individual basis [52].
Germany	From age 14 years, particularly from age 16 years, adolescents who understand nature, consequences, and risks associated with a procedure and do not decide hastily or irrationally can be considered to have DMC (*einwilligungsfähig*) [21]. However, it is disputed whether capacitated minors alone can provide consent or whether parental permission is required [21, 51, 66].
The Netherlands	Under 12 years of age, children cannot give consent (no assessment necessary). For children between 12 and 15 years, if DMC is established, their consent is required along with parents' consent. Above 16 years, adolescents are presumed adult-competent and can give consent alone [34].

While legal competence and DMC are two distinct concepts, an inconsistent use of terminology as well as unclear conceptualizations can be found in the literature and in practice [7, 13]. This may partly stem from the close relationship between the two [13] and from differences in the use of these terms across countries (legal competence and clinical decision-making capacity are used in the US, legal capacity and decision-making competence in the UK [12, 13], occasionally, also the term competency can be found [15, 60, 64]). Appelbaum argues that a distinction between competence as a legal construct decided in court and DMC as a clinical concept judged by healthcare professionals does not reflect current medical or legal practice in adult care [7]. A judgement of clinical incapacity may actually have the same practical consequences as that of incompetence, that is, a patient is not entitled to make a decision [31]. In pediatrics, however, it seems important to keep these two terms clearly apart because, although children do not generally have the right to make legally binding decisions, they may consent to treatment if they demonstrate DMC [52]. DMC and competence are close concepts, but they are not interchangeable, and possessing DMC does not automatically lead to having competence in minors. This becomes evident when turning to jurisdiction in the UK where minor patients from 16 years of age or judged to be *Gillick competent* are commonly granted the right to consent to treatment [3, 14, 41, 57] but not to refuse it [13, 27].

The examples in Table 1 highlight the discrepancies that exist between countries. Legislatures that do not specify age limits or circumstances under which children cannot consent (e.g., risky procedures) may promote children's participation more, as they do not exclude certain situations at the outset. However, this places greater demands on physicians' abilities to make judgments about DMC for each individual patient. On the one hand, legislations which provide clear guidance as to which patient can be expected to have DMC decrease this burden on physicians, as some children do not have to be assessed such as children under 12 years in The Netherlands. On the other hand, they are also less sensitive towards pediatric patients who possess abilities outside of these age boundaries. For example, Alderson showed that patients younger than 12 years with diabetes can make informed decisions in their disease management [5]. Furthermore, discrepancies exist between legal scholars regarding the interpretation of the law. In Germany, for example, consent to treatment for children is often handled as a matter of parental rights, but there have been exceptions when minor patients were judged to have DMC, and parental consent was not needed [51, 66]. Additionally, perceptions diverge as to whether there exists a qualitative difference between acceptance and refusal of treatment and whether different levels of DMC are required [57]. Although a thorough analysis of legal issues is beyond the scope of this paper, these examples show that divergent legal notions and termsmay have contributed to the blurriness surrounding DMC in pediatrics. Greater clarity with regard to conceptualization and awareness of differing terminology is needed to ease communication and implementation of research related to pediatric DMC across countries and across clinical and legal specialties. As physicians' insight into how legislation affects their practice is important, exchange across disciplines should be stimulated. This step is necessary to create legal security for physicians' practices as well as steady and unequivocal interpretations of capacity in order to foster children's participation in healthcare decision-making. Considering the legal consequences of an assessment of DMC in many countries, it seems important to provide pediatricians with adequate means to make such judgements. In the following, we will consider several aspects that are especially important for DMC assessment.

Operationalization and measurement

The need for a reliable assessment of DMC in pediatrics has been widely acknowledged [24, 34, 66], but important challenges can be identified [47, 50]. To begin with, DMC has to be judged with regard to a specific decision while considering the gravity of the decision's outcome [41]. It has not been clearly established exactly how high the required level of capacity for a certain type of decision should be [23]. As such, any tool or test that is used to measure DMC should be versatile to fit a particular question at hand [8]. Yet, research in children has mostly treated DMC as a general trait rather than a decision-specific ability. This is problematic because it leaves aside potentially important influencing factors such as difficulty of a decision [50]. Also, capacity should be operationalized by closely examining those functional areas that are related to its criteria rather than assessing overall cognitive abilities [8, 32]. Age can only provide a rough estimation to the presence or absence of DMC [63]. However, a literature review by Martenson and Fägerskiöld reveals that children were often assessed to have capacity in consideration of their age or by measuring their reading skills or ability to remember a text [47]. Additionally, Miller and colleagues point out that most pediatric studies usually limit themselves to only examining some of the domains related to capacity [50]. These inadequate assessment practices can be explained by the fact that, until today, there is no validated and reliable tool to assess DMC in children [34]. On the contrary, for adults, there are a number of tests available among which the MacArthur Competence Assessment Tool for Clinical Research (MacCAT-CR) and the MacArthur Competence Assessment Tool for Treatment (MacCAT-T) have gathered the most empirical support [23]. Both versions of the MacCAT provide insight into all four criteria of DMC [7].

In order to address the lack of adequate measurement in pediatrics, a research group in The Netherlands aims at validating a modified version of the MacCAT-CR in a population of 6- to 18-year-old patients during the consent process for a clinical study [34]. They published the methods for their prospective study planning to compare outcomes from the MacCAT-CR of 160 participants against judgements of investigators as well as those of a panel of experts (consisting of medical ethicists, child psychiatrists, and psychologists). The study also seeks to examine the correlation with factors such as age, IQ, or parental judgment. Finally, the reliability, validity, and reproducibility of the tool will be investigated [34]. Efforts to introduce the use of this test into pediatrics would close a gap in the operationalization of DMC in pediatrics. However, the assessment would remain a challenging task for pediatricians. A tool validated for research purposes may not prove useful for DMC assessment in pediatric practice that is multifaceted and can be influenced by time and staff constraints. Even more important, the MacCAT tools were designed as decision aids and do not provide cut-off scores [23]. Hence, while using a standardized test brings more objectivity to the assessment of DMC and provides information on all domains of capacity, the final judgement of whether a patient should or should not be entitled to make a decision still lies with the physician [7]. Additionally, as the criteria for DMC evaluate the patient's cognitive functioning when making a decision, pediatricians need to engage with children in the very process of decision-making to gain an understanding of their ability to manipulate information and consider relevant aspects [25, 37]. In case of a minor patient, discussing important issues surrounding a treatment may easily lead the child to believe that he or she will be allowed to choose for him- or herself. Joffe and colleagues provide a helpful distinction between "soliciting a child's view" against "inviting a child's decision" ([36], p 865). Hence, when involving minor patients in decision-making, they should be informed that others may have the final say [37]. The same is true for any assessment of DMC because the extent to which a child will be allowed to decide is not clear beforehand. In summary, while a standardized operationalization of DMC in pediatrics may overcome problems of assessment, a responsible use of such a tool requires considerable research regarding validity and practicality in the pediatric population.

Acknowledging developmental aspects of DMC in pediatrics

As a threshold concept, DMC separates those children who are entitled to make a decision from those who are not [24]. However, insufficient DMC should not lead to completely excluding children from decision-making [47]. The United Nations Convention on the Rights of the Child emphasizes the importance of children's participation in matters that concern them [29]. With regard to medical decision-making, Alderson specifies four levels of participation: (1) being informed, (2) expressing a view, (3) influencing a decision, and (4) being the main decision-maker ([3], p 36). In turn, children's level of participation should be informed by both their abilities and preferences [43, 48]. A distinction between consent and assent is discussed in the literature as a means to account for the developmental nature of decision-making abilities in children [40, 45]. Whereas consent presumes DMC and thus the right to make a final choice, assent acknowledges children's active involvement in healthcare and recognizes that their decision-making abilities are developing [42]. Leikin suggests that those children who do not have DMC can participate through assent [43]. A distinction between DMC and *capacity to assent* may provide helpful guidance in identifying those children who can participate in Alderson's first three levels of decision-making from those who have full abilities and can be the main decision-maker. Similar to the criteria for DMC, Leikin delineates requirements for capacity to provide assent essentially as comprising the abilities to understand, make a choice, and recognize that others will be in charge of the final decision (see Table 2) [44]. Hence, capacity to assent represents a lower level of DMC given that appreciation and reasoning criteria are not applicable. If a child is considered capable of assent, his or her assent should be sought in addition to parental permission [43].

The concept of assent has received criticism. A strong opinion is put forth by Baines [9] who argues for its abolishment. He points out that, although assent is widely acknowledged to be desirable, its understanding remains blurry. If wrongly applied, it represents a threat to the decision-making rights of those children who have DMC because physicians may content themselves with seeking assent while parents' give consent. Furthermore, it fails to provide guidance in situations where children and parents disagree. In order to proceed, one party will be over-ruled. If parents' consent takes precedence over the child's assent, he claims that assent becomes meaningless. In a different vein, Bartholome [10] emphasizes that an understanding of assent does not necessarily have to be linked to the questions of who makes the final decision. To him, assent represents a means of ensuring that children who are capable of grasping some aspects of the decision at hand are not overlooked and included in the process to an appropriate extent. Bartholome cautions that not soliciting assent even in situations where treatment is considered imperative overlooks the importance of taking into account the child's view. Furthermore, in case the child disagrees, such conflict should be addressed, and attempts should be made to resolve it together with the patient.

Hence, conceptualizing assent as inferior to consent is not useful for a developmental conceptualization of decision-making capacities. Instead, the capacity to assent needs to be perceived as a stepping stone in capacity development carrying value in informing appropriate participation. As there are several levels for possible participation, it becomes evident that an accurate assessment of patients' abilities is important not only with regard to a threshold (i.e., who makes the final decision) but also to adequately determine the extent of children's involvement. Conceptualizing children's DMC as developing and not static emphasizes the importance of recurrent evaluations in order to harmonize participation with emerging abilities [67]. This makes assessment in pediatrics considerably more demanding than in adult care, where the question is mainly about a patient's lack of capacity to make a decision [7].

Discussion: advancing DMC in pediatrics

While participation in healthcare and shared decision-making are important values, children can only be optimally included if those caring for them recognize how to involve patients in a developmentally appropriate fashion. A first step towards ensuring children's participation can be accomplished by gaining knowledge on a particular child's abilities to understand and appraise information on

Table 2 Criteria for DMC and capacity to assent

Criteria for DMC	Criteria for capacity to assent
(a) Understanding of necessary information	(a) Awareness that permission for the proposed action will be sought independently
(b) Appreciation of the situation and likely consequences	(b) An understanding of what is being proposed
(c) Reasoning about treatment options	(c) Ability to make an independent choice free from outside influences
(d) Communication of a choice	

illness and treatment. However, we have only limited knowledge concerning children's DMC which is in part due to the three conceptual and practical limitations of the concept, as discussed above. Thus, professionals are left with very little guidance as to how children can be adequately engaged [19]. Before the concept of DMC can unfold its potential for pediatric healthcare, more research is needed that addresses the three concerns elaborated in this paper by (1) establishing clarity with regard to conceptual issues, (2) investigating reliable tools to operationalize DMC, and (3) studying DMC as a continuous concept (i.e., how it evolves over time, which factors contribute to the acquisition of skills, how can specific skills be translated into participation). A first step towards an implementation of DMC in pediatrics that is both in line with legislation and in agreement with ethical values should be the adoption of institutional guidelines. Pediatric healthcare institutions could ease DMC assessment procedures by giving practical recommendations designed in collaboration with legal and ethical consultants. This will allow creating awareness for conceptual issues as well as providing guidance in situations that may be especially challenging. Professionals involved in the care of pediatric patients should be invited to contribute to these guidelines which in turn will facilitate adherence. Several recommendations already exist from different pediatric associations (see, e.g., [6, 14]). However, providing guidance at institutional level would allow for more specific advice while accounting for distinct features of a setting (e.g., a country's legal provision, day clinic vs intensive care). Apart from such recommendations, research on children's abilities manifested in various contexts within healthcare is needed as it would allow estimating what can be expected from pediatric patients with regard to their abilities in decision-making. Greater knowledge would also provide a framework for interpreting results of DMC assessment. Additionally, the effects of decision-making responsibility on the child and others (e.g., parents) need to be examined to ensure that no undue burden is placed on the patient or relatives. Research on mechanisms that influence DMC (e.g., illness experience, familiarity with the setting, family structure, and culture) would provide a better understanding of the development of capacity and thus allow clinicians to foster these abilities in children. Furthermore, interventions for promoting participation that is in line with developmental achievements are needed, and these interventions should also investigate how possible conflicts between children with DMC, their parents, and clinicians could be solved. From our analysis, we conclude that greater focus on these research areas would result in a comprehensive knowledge base of DMC in pediatrics, which, in turn, could enable professionals to foster the concept's implementation in practice and inform developmentally appropriate participation.

Despite our call for advancing research concerning children's DMC, we also caution against two pitfalls. First, although there is a clear need for validated assessment, using standardized tools should not mean subjecting children to a sort of sanitized "testing" of their abilities. Children are sensitive to context, and their abilities may vary greatly as a function of different factors including physician's attitudes, parenting practices, provision of information, as well as the content of the information and the time frame set for a decision [3, 17, 34, 47, 48]. In order to account for these influences, any assessment of DMC in pediatrics should be completed with additional information about the patient's abilities from other available sources (e.g., parents, nurses, therapists) and preferably across the course of treatment [15, 31, 67]. This will strengthen the reliability of the assessment and reduce the potential for individual bias. Second, the presence of DMC in a minor patient does not imply that other actors such as parents and family are no longer included in the decision or that the interests they bear suddenly become superfluous. There is research showing that children very carefully take into account other people's opinions [2, 36], and even capacitated minors may prefer to share or delegate decisions to their parents and/or physician [18]. In case of disagreement, only very few pediatric patients may disregard the wishes of others [2]. A judgement of DMC should not be seen as a power-play tool. It should rather be incorporated in a shared decision-making model that is suitable for pediatric care and where the level of DMC could inform the role the child patient occupies (for such a model see Whittney et al. [65]).

Conclusion

Despite a longstanding tradition of debating children's capacity to make decisions in healthcare, knowledge on the concept in pediatric care is limited due to lack of clarity and evidence. There is a need to promote research aiming at providing conceptual clarity, assessment tools, and profound knowledge of DMC within a developmental framework. By doing so, DMC may become informative and fruitful in providing pediatric patients with adequate and achievable possibilities to participate in or make healthcare decisions. Finally, when discussing DMC, it should not be forgotten that it has an ethical dimension. Any judgement of DMC remains a normative decision rather than an empirical finding [11]. The MacCAT does not provide a cut-off score freeing clinicians from the responsibility of making a judgement on whether a patient has enough capacity for a particular decision or not [7]. In assessing children's abilities, physicians and other healthcare professionals should identify those patients whose DMC allows them to make their own choices while protecting those who cannot. As such, physicians' role is to balance the ethical concept of respect for a person's self-determination against best interest [11]. This notion is important because, despite the desirability of reliable measurement tools, a DMC assessment is never totally objective. Personal attitudes and values form part of the judgement and reflect expectations with regard to decision-making. Consequently, those assessing DMC should not only be trained to adequately implement a tool, but also invited to reflect upon their own position on children's participation and self-determination in healthcare. Furthermore, they should be informed about how to adequately address conflict that can emerge from differing perceptions with regard to children's participation. DMC is not just an isolated ability of one person, but also largely depends on social context [1]. The way childhood and children's position in society are conceptualized influences how they are perceived and shapes the broader framework in which assessments of DMC take place [16]. Bioethics' approach to capacity in pediatrics has long been influenced by theoretical assumptions with regard to child development that clearly underestimated children's abilities [1]. In order to acknowledge them as partners in their medical care and comply with the value of participation expressed in pediatric guidelines, the questions of "if" and "when" children can contribute needs to be overcome in favour of the question "how" they can participate.

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