

Children's rights in pediatrics

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Abstract The United Nations Convention of Children's Rights (UNCRC) introduced in 1989 has generated a global movement for the protection of children's rights and has brought about a paradigm change in how children are perceived. Pediatric healthcare professionals are interacting with children and therefore with children's rights on a daily basis. However, although at least 18 of the 54 articles are relevant for pediatric practice, there is limited systematic training on how pediatricians can support children's rights in the clinical setting. This article discusses the principles and aims of the UNCRC and proposes a comprehensive checklist of rights vis-à-vis issues that arise in clinical practice.

Keywords Children's rights · Shared decision making · Pediatric bioethics · Informed assent · Evolving capacities · Best interest standard · Parental consent

Introduction

Imagine two scenarios: In the first, a physician ignores the opposition of a 13-year-old girl during an osteopathic manipulation [34]. In the second, parents and physician decided to enhance the home care of a 6-year-old severely

handicapped girl by attenuating growth and removing her uterus, ovaries, and breast pads [35]. Between these two very different situations, there are countless examples concerning the rights of children¹ in the daily work of healthcare professionals. But while we advocate, deal, and interfere with children's rights, they seldom are part of our reflection in concrete form and there have been only few publications and limited training on the practical implication of children's rights for pediatrics in western medicine. While a worldwide movement for assuring the basic needs of children living in extreme poverty or war, the United Nations Convention of children's rights (UNCRC) exerts also an increasing influence on the current and future jurisdiction of signatory states as well on the everyday interaction with children and their parents [7, 30]. The UNCRC is a remarkably useful tool for pediatrics in several ways. First, by laying out fundamental principles, it provides the frame and justification for developing policies including health policies that can improve all children's well being. Second, several of its articles (at least 19 of its 54) are relevant for pediatric healthcare professionals, shown in Table 1 [2, 7, 33, 40, 41]. A recent statement by the American Academy of Pediatrics is the latest call for full integration of the UNCRC in health policy as a means to eliminate health disparities and ensure better health for all children in both at the policy level as well as in daily practice [11]. Our paper focuses on the relevance of the UNCRC in pediatrics with specific emphasis on clinical practice. It presents an overview of the relevant content of the UNCRC for pediatric healthcare professionals and

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¹ The UNCRC defines a child as any person younger than age 18 years, unless an earlier age of majority is recognized by a country's law.

Table 1 Relevant articles for healthcare providers

Articles and their purpose

Article 2: Right to protection against discrimination or punishment on the basis of the status, activities, expressed opinions, or beliefs of the child's parents, legal guardians, or family members
Article 3: Best interests of the child shall be a primary consideration; care or protection of children shall conform to the standards established by competent authorities
Article 5: One shall respect parent's rights and duties to provide guidance in the exercise by children's rights in a manner consistent with the evolving capacities of the child
Article 6: One shall ensure right to life and, to the maximum extent possible, the survival and development of the child
Article 9: A child shall not be separated from his or her parents against their will and maintain personal relations and direct contact with both parents on a regular basis except if it is contrary to the child's best interests
Article 12: Right to the child who is capable of forming his or her own views to express those views freely in all matters affecting the child, the views of the child being given due weight in accordance with the age and maturity of the child
Article 13: Right to freedom of expression; this right shall include freedom to seek, receive and impart information and ideas
Article 16: Right to protection of privacy
Article 17: Right to access to material from mass media as well as protection of the child from information and material injurious to his or her well being
Article 18: Both parents have common primary responsibility for the upbringing and development of the child. The best interests of the child will be their basic concern. State parties shall render appropriate assistance to parents and legal guardians in the performance of their child-rearing responsibilities
Article 19: Right to protection from all physical or mental violence, injury or abuse, neglect or negligent treatment
Article 20: Right to protection for children deprived of their families
Article 22: Right to protection if seeking refugee status
Article 23: Right to enjoy a full and decent life, in conditions which ensure dignity, promote self-reliance, and facilitate the child's active participation in the community
Article 24: Right to the enjoyment of the highest attainable standard of health and to facilities for the treatment of illness and rehabilitation of health
Article 27: Standard of living shall be adequate for the child's physical, mental, spiritual, moral and social development
Article 28: Right to education
Article 30: Right to its own culture, own religion, and own language
Article 31: Right to rest and leisure, to engage in play and recreational activities

illustrates its direct impact on clinical practice through a checklist of rights vis-à-vis questions in practice.

Historical background

After many years of preliminary work, the United Nations Convention on the Rights of the Child (UNCRC) was adopted on 20th November 1989 by the General Assembly of the United Nations. As it took cultural and ideological differences of countries into account, it was therefore ratified by all but two states (Somalia and USA) [36]. It has since gained wider acceptance than any other previous human rights document and is the most far-reaching and comprehensive commitment to children's rights [13]. Although the thesis that the concept of childhood itself is an achievement attained through cultural advancement is increasingly disputed, many historical sources point to the fact that, for hundreds of years, children in western culture were viewed mainly as property without effective

protection or laws. There is much evidence that, prior to the 17th century, children from 8 years of age were seen as little adults and therefore fully integrated in daily work life. In the 19th century, influenced by a romanticization of childhood as well by the industrial revolution recognizing the future manpower, the vulnerability and the immaturity of children were taken as a reason to create a series of laws protecting children from harm. However, the most radical change in the conception of childhood and its normative significance did not occur until the 20th century (accompanied by the increasing importance of patient autonomy and the ideas of equal rights for races and gender) [18, 27]. Maybe for the first time ever, children came to be viewed primarily as subjects rather than objects. Motivated by the new value of pluralism, society started to systematically ask about problems, responsibilities, and violations that specifically affected children [21]. This cause was taken up by the UNCRC, which is both a product and a tool of such societal and cultural changes.

Paradigm change

Heralded by the UNCRC, a paradigm change of the legal status of the child occurred: legally, children are no longer primarily seen as a member of a family but rather as self-contained individuals with their own rights—the children’s rights [29]. This brings a change in perspective, as childhood is no longer seen as a biologically determined state but more as an actual, variable, and socioculturally influenceable status. Childhood is therefore an important period in life, in which the individual flourishes. It is a stage with its own qualities and goals, rather than merely a transitional phase [39]. This is why children cannot simply be viewed as future or small adults. According to the UNCRC, they must be respected and taken seriously as individuals in their own right with their own needs [18].

Aims and principles

The shared aim of the articles of the UNCRC is to view children as human beings in their own right and to ensure that special needs for their protection and development are sufficiently met.

Based on four basic rights or so-called general principles (Table 2), the main concerns of the UNCRC can be summarized with the three P’s: protection, provision, and participation [16, 38]. The central idea of the UNCRC is the protection of the dignity of the child. What does this exactly mean for healthcare professionals?

Dignity of the child

Appeals to human dignity populate the landscape of medical ethics with vague and slogan-like statements [26]. Although dignity is not specifically defined, it is used in legislation in many countries as well as in international conventions. However, even if we cannot define precisely what dignity is, most of us can sense when dignity is endangered or neglected [7, 10, 25, 37]. The concept of human dignity is a central part of the UNCRC with specific reference to the dignity of the child. This means that every child owns human dignity unconditionally as a universal human right due to his or her very existence and, therefore,

dignity cannot be lost but neglected or harmed. This forbids treating children solely as a mean, an object, or an inadequate version of a later adult. Although the concept of dignity is questioned and criticized, it might well serve as a last, important chance of an emergency stop in critical situations, which forces us to declare our value system and to specify why a certain intervention into the child’s integrity is necessary.

Concerning the initially mentioned treatment of the 6-year-old girl, one could argue that, by respecting her individual needs and improving her quality of life, dignity is taken into account very well. In contrast, the girl’s dignity would be harmed by those interventions if the reason of the intervention had as primary beneficiaries her family [23]. The same would apply if such interventions were done on a macro level in order to keep the costs for social services as low as possible. Therefore, if those invasive interventions on this 6-year-old child were carried out without having as first priority the improvement of the girl’s life quality, her dignity would be at stake.

In that sense, dignity can be seen as an individual threshold value, which forces the involved parties (parents, healthcare professionals, state, society) to disclose and moot their interests, values, and aims. However, while dignity can well serve as the theoretical background in a decision making process, it usually does not solve the specific problem. For the specific problems that arise in everyday practice, the more tangible concept of the best interest standard can prove more useful.

Best interest standard

In early childhood, autonomy is diminished due to the limited capacity of the child for self-determination [16, 27]. During this early phase, the principles of beneficence and do-not-harm take priority over the principle of autonomy. The UNCRC respects those special features of children’s entitlements by holding the ‘best interest standard’ as a primary consideration in all actions concerning children. However, it does not define what exactly is to be understood as ‘best interests of a child’ [15]. The lack of clarity in determining the best interests can be seen either as a strength or as a weakness. Determining a child’s best interests is certainly highly individualized, remains dependent on socio-cultural context and underlying values, and is directly or indirectly affected by the child’s family. It therefore requires communication and close cooperation of all interested parties, namely, family, healthcare professionals, and if ever possible the child itself [8, 24].

As the UNCRC forces us to find arguments on a case-by-case basis, the best interests of the 6-year-old, severely

Table 2 Basic rights and general principles of the UNCRC

1. Non-discrimination
2. Best interests of the child
3. The right to live, to survive, and to develop
4. Respect for the views of the child

handicapped girl has to be determined by a close cooperation between parents, healthcare professionals, and the child.

In the case of the 13-year-old girl, who certainly as an adolescent had an increased capacity for self-determination, neither her wish as a patient was heard nor good cooperation between the remaining interested parties (parents, healthcare professionals) was achieved.

Non-discrimination

According to the UNCRC, all rights apply to all children without exception. It is the State's obligation to protect children from any form of discrimination and to take positive action to promote their rights [5]. However, inequality and discrimination still is daily reality and has many faces [9]. While discrimination based on race, religion, and gender may be more easily detectable, other forms of it can be more subtle but equally harmful. For example, some exponents of the disability rights movement raised a concern that the decision to treat the above-mentioned disabled girl was influenced by discrimination towards her condition [12, 14]. Medical decision making that is influenced by any sort of discrimination towards the child or his/her parents do not serve the child's best interests. The fundamental question is: What is the justification of treating someone differently? The fair answer should be based on the best interest standard and the concept of human dignity. Therefore, open communication with the parents and the child itself (to extent possible) plays a key role in ensuring that the principle of non-discrimination is respected.

Participation

A cornerstone of the UNCRC is the claim for the children's participation in the decisions and actions that impact on their lives. Often mentioned as the most revolutionary part of the convention, article 12 grants to each child who is capable of forming its own views the right to express those views freely in all matters affecting the child. The views of the child must be respected and given due weight in accordance with its age and maturity. The direct implication of article 12 to pediatric care is that healthcare professionals need to discuss the child's care with the child as well as with the parents. Although article 12 does not spell out a right of self-determination, the child's position is significantly strengthened [8, 20, 39]. The UNCRC neither defines the age at which a child is competent to have its own view nor does it connect the right to express an opinion with the right to decide about

its own healthcare. Therefore, the competence for decision making claimed by article 12 of the UNCRC as a precondition for participation should not be seen as a limitation of the child's right to be heard and respected. It is rather a request that concerns healthcare professionals and parents who have to support and assist the child's competence to develop opinions depending on the particular situation and developmental stage. In practice, the UNCRC leaves room for individual and situational differences [32]. In the case of the 13-year-old girl, the violation of the child's right to be heard is obvious. However, the UNCRC does not contain explicit instructions about the further handling. It obliges the health professionals to determine the child's capacity to consent or assent for a certain situation and to do each intervention in the best interests of the child. If a child opposes to a recommended therapy, the child can still be treated under certain conditions. However, if a younger child can demonstrate capacity to express an informed view on her or his treatment, this view is given due weight [8]. Obviously, this is not always possible without reservations and conflicts, which will be discussed in the next section.

Conflicts and implications

The open form of the UNCRC itself offers space for contradictory interpretations if applied in everyday life. In particular, the rights to protection in certain circumstances can be considered at conflict with the participation rights [25]. Healthcare providers and parents can be torn between the intention not to overprotect a child and the fear not to excessively burden the child by allowing his or her active participation in the decision making process. On one side, we are often guided by an assumption that a child has insufficient capacity for decision making, on the other side there is a claim to respect the evolving capacities of the child. These conflicts can be mitigated if adults are willing to support the child in critical situations and to share the burden of responsibility according to her or his developmental stage [26]. Moreover, several studies and firsthand reports suggest in regard to co-deciding and information processing that children are generally more capable than we feel [1, 4, 20, 22]. On the other hand, it is doubtful if a fully informed consent/assent is possible at all, regardless if adult or child. Therefore, the individually adequate quantity and quality of information is even more important. Participation does not speak out against a frame, which sets clear boundaries. Should the child's view be at conflict with his or her best interests, it poses less of a problem than a duty: the duty to determine the child's best interests truly, conscientiously, and far from convenient or habitual preliminary decisions. Therefore, the UNCRC reminds us

that the best interests of a child (based on feelings, evolving capacities, values, relationships, etc.) may differ significantly from the values and ideologies of a biomedical approach (e.g., a benefit of parental bonding at home may outweigh the benefits of prolonged hospitalization). However, the participation of children in decision making is still limited and far from being standard [33, 34]. This has been attributed to the fact that child participation requires advanced communication skills on the healthcare professional's part. But healthcare professionals are inadequately trained on this area [6, 17, 31]. Professionals with the necessary communications training and a good understanding of the relevance of the UNCRC to the pediatric practice can be instrumental in realizing children's rights [28].

To gain wider acceptance of giving children a stronger voice in medical decision making about their healthcare, more evidence about the outcome of shared decision making and certainly more familiarity with the UNCRC is needed [3, 19]. To support the latter, we present a practical checklist, which shows the relevance of the UNCRC to the daily pediatric practice in the form of practical questions vis-à-vis the articles of the UNCRC (Table 3). The checklist serves as a bidirectional tool: showing how clinical practice questions we ask ourselves frequently are tightly linked to the UNCRC and showing how 17 articles of the UNCRC are relevant to our work in the clinics.

Conclusion

The understanding of what a child is has radically changed during the last century. We showed in this article that the UNCRC is not only the product of this development but also a way to help dealing with it. Although many real-life cases cannot be solved solely by a children's rights approach, the UNCRC nevertheless is a powerful and instructive instrument. Like most laws, however, the UNCRC merely contains general, abstract rules and regulations, and it does not specifically spell out what a world appropriate for children should look like. What these children's rights mean for a particular case must be detected individually, according to developmental stage, values, and situation. As shown in Table 3, the UNCRC obligates us to learn how we can realize its articles in our daily work; thereby helping to ensure children's rights is not only accepted but also exercised. This demands from healthcare providers a strengthened attendance in an interdisciplinary search for solutions and an intensified training of communication skills for applying them more effectively.

At the same time, the UNCRC moves healthcare providers away from an all-or-nothing decision between perfection of the biomedical approach on one side and the child's independent choice of its ideal therapy on the other. It does so by suggesting a way to embrace the child's own qualities and goals while always ensuring that we act on the child's best interests.

Table 3 Practical implications of the UNCRC

Deduced questions (related article)

Do I try my best to arrange all conversations with children and parents undisturbed in a likable atmosphere with sufficient time? (Art. 3, 9, 16, 23, 31)

Do I rather talk with the child than only about the child as soon as possible? (Art. 12, 13, 16)

Do I explain the whole purpose of a treatment or an intervention to the child in an age-appropriate manner? [duration, speed, pauses, word choice, demonstration with drawings, toys, videos or computer] (Art. 12, 13, 30, 31)

Do I indicate to the child that he or she can know everything, even if it could be difficult to understand everything? (Art. 13)

Does the child have enough time and support for a proper decision making process? Are there repeated opportunities to raise questions? (Art. 5, 13, 31)

Do I let the child feel that it would not be alone with his or her problems? (Art. 9, 19, 24)

Am I of sufficient openness and impartiality for a proper dialog? (Art. 2, 12, 13)

Does the child with linguistic and/or symbolic communication make a contribution to the decision making process? (Art. 3, 12)

Do I try to understand arguments and decisions even if they seem wrong to me? Do I appreciate the cultural background as a part of the child's interests? (Art. 12, 24, 27, 22, 30)

Do we determine the child's best interests interdisciplinarily by a broader consultation including children and parents or merely from the biomedical perspective? (Art. 3, 5, 9, 18, 24, 31)

Do I allow the child to acquire experience with the decision making process in well-considered and appropriate situations, and in such cases do I even allow the child to make the wrong decisions? (Art. 6, 12, 13, 30)

Do I provide and plan with the same professionalism curative as well as supportive, palliative, and comfort therapy? (Art. 3, 19, 23)

Do I take into consideration the basic needs of the child and his or her family? (Art. 6, 18, 19, 22, 27)

Do I advance my communication skills through appropriate training? (Art. 2, 3, 6, 12, 13, 24)

Conflicts of interest None.

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