

## ORIGINAL ARTICLE

# Advocate for children receiving medical care: A study on pediatric care and children's rights

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## ABSTRACT

**Background:** Advocacy for children is an essential part of pediatric medical practice. The rights of children receiving medical care should be protected while accommodating each individual's attributes. The current study aimed to identify the policies and practices on medical care and children's rights based on a survey conducted at 907 hospitals and clinics in 2016 by the Kanto Bar Association.

**Methods:** The survey results were analyzed with the approval of the Kanto Bar Association. This research focused on the rights of children receiving medical care to make their own decisions and psychosocial factors involved in medical practice.

**Results:** Explanation was actively provided to children receiving medical care. Moreover, support was found to be important in providing children with easy-to-understand explanations, assuring that consent was obtained from children, and assessing psychosocial factors affecting decision-making. Improving the physical and human environment can promote and enable the voluntary participation of children. That is, information about the right to voluntary participation among children should be disseminated, medical staffs must be educated, medical fees should be evaluated, and professionals must be trained.

**Conclusions:** This study recommends to protect the personal integrity and dignity of children receiving medical care by respecting them as individuals and ensuring their right to express opinion and self-determination.

**Key Words:** Advocacy, Children's rights, Decision-making, Self-determination

## 1. INTRODUCTION

The rights of children<sup>[1-4]</sup> are most likely insufficiently addressed because children are a minority group and patients receiving medical care.<sup>[1]</sup> For example, children are deprived of the opportunities to play as they wish, have poor access to education (both at a qualitative and quantitative sense), have difficulty pursuing an ordinary social life such as seeing one's family and friends during hospitalization, have few

opportunities to receive an easy-to-understand explanation on one's own illness or medical condition (as children do not have a sense of comprehension or judgment), are left out from the decision-making process regarding one's own medical care, and are subjects of various research studies and awareness-raising activities conducted to ensure their rights to medical care.

A survey conducted using the Medical Care and Chil-

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dren's Rights: Questionnaire on Child Growth and Development and Self-Determination by the Kanto Bar Association in 2016 presented important issues to address pediatric medicine and children's rights in the future.

The current study aimed to investigate the awareness and reality of healthcare professionals regarding the process of explanation and consent for children in healthcare and to make recommendations regarding child advocacy in healthcare.

## 2. METHODS

The rights of children in medical care settings were discussed based on the surveys using a questionnaire on Medical Care and Children's Rights conducted in 2016 by the Kanto Federation of Bar Associations. The questionnaire survey was about the rights and medical treatment of children, and the conducting bodies were the Kanto Federation of Bar Associations and the Symposium Executive Committee. The survey was supervised by the lead author, Tanaka, and was conducted from March 2016 to May 2016. The survey targeted 907 medical institutions within the jurisdiction of the Kanto Federation of Bar Associations, which includes 183 major hospitals with pediatrics departments and 724 clinics where the physicians affiliated with the Japan Pediatricians Association are practicing. Questionnaires were mailed to the institutions. Consent on survey cooperation was assumed if the completed questionnaires were returned. The number of responses was 214, with a response rate of 24%. The report was prepared in 2017.<sup>[5]</sup> The survey covered medical institutions within the jurisdiction of the Kanto Federation of Bar Associations and the Tokyo High Court, which included Ibaraki, Tochigi, Gunma, Chiba, Saitama, Tokyo, Kanagawa, Yamanashi, Niigata, Nagano, and Shizuoka prefectures. There were 907 medical institutions in the same region (183 major hospitals with pediatric departments and 724 clinics with pediatricians affiliated with the Japan Pediatricians Association). The questionnaire was prepared independently by Kanbenren (the Executive Committee of the 2008 Symposium). Based on this survey, a symposium was held by the Kanto Bar Association, and the following recommendations were made:

At the symposium, in addition to the questionnaire survey discussed in this paper, we reported the results of a fact-finding survey on children's medical care environment, including an inspection of hospitals that are making advanced efforts to improve children's medical care environment, hearings from patient groups, hearings from the board of education with jurisdiction over children undergoing medical treatment including their education, and an inspection of in-hospital classrooms. The survey results on the children's medical

treatment environment were discussed. In response to these findings, a panel of medical and legal practitioners discussed measures to improve the children's medical care environment. Thus, the declaration was adopted at the 2016 Kanto Federation of Bar Associations Regular Convention held on the same day as the symposium. The declaration is also available on the website of the Kanto Federation of Bar Associations (<http://www.kanto-ba.org/declaration/detail/h28a03.html>). The summary is as follows:

- (1) The national and local governments are responsible for providing a good medical environment for children receiving medical treatment, including play participation, interaction with family members, and the assignment of nursery schoolteachers and psychosocial support specialists. Further, they should take necessary legal and financial measures to ensure that children receiving medical treatment will grow healthy in accordance with their condition.
- (2) To guarantee the right to education for children receiving medical treatment, the national and local governments should provide consistent and continuous education in connection with the local community and human and material support for school enrollment and commuting, develop schools and classes attached to hospitals, and eliminate the discontinuity of educational opportunities by not requiring the transfer of school registers when children are hospitalized.
- (3) The national and local governments should establish and implement a system to provide childcare services in hospitals to ensure that hospitalized children have opportunities to receive childcare.
- (4) To protect the personality and dignity of children undergoing medical treatment, respect them as individuals, and guarantee their right to express their opinions and self-determination, children undergoing medical treatment should be provided with sufficiently clear and well-designed arrangements for the medical treatment they receive according to their circumstances. Thus, they can freely express their opinions based on their own will, and the results of such opinions should be given due consideration. To guarantee the right of the child to receive medical care, the state and local governments should ensure that the medical care delivery system provides measures to guarantee the child's independent participation in medical care. In addition, the government of Japan should consider and implement measures to ensure the right of self-determination of children who can consent to medical treatment.

This study aimed to discuss how child advocacy in health-

care can be implemented in the field based on the results of a survey conducted by the Bar Association. In addition, it provided recommendations for healthcare professionals.

### 3. RESULTS

#### 3.1 Current situation regarding informed consent for children

The average age at which explanations can be provided to children was 5.8 years. Hence, preschool children received explanations. By contrast, the average age at which consent was obtained was older than the age at which assent was obtained (7.6 vs. 5.7 years). A huge gap exists between the age of children who provided consent and the age of children who was granted refusal to treatment (see Table 1).

**Table 1.** Ages for explanation, obtaining consent, obtaining assent, and complying with refusal

Responses from health care providers (ages [years])		
Age at which explanation should be provided	Mean	5.82
	SD	3.10
Age at which consent should be obtained	Mean	7.69
	SD	2.33
Age at which assent should be obtained	Mean	5.77
	SD	3.55
Age at which refusal can be accepted	Mean	9.98
	SD	3.25

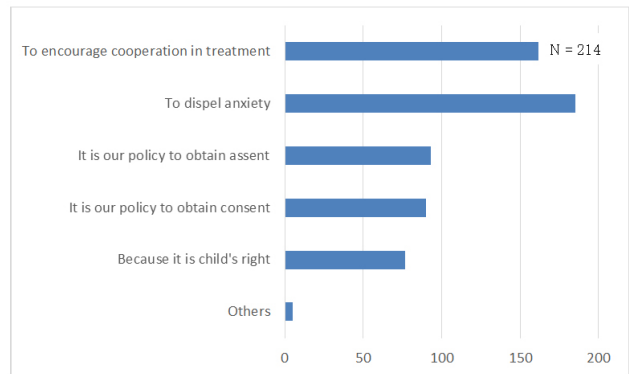
#### 3.2 Factors that should be considered when providing explanations to children

Explanations were commonly given to children to eliminate anxiety and encourage cooperation (see Figure 1). Child’s comprehension and age were factors that should be considered in providing explanations to children (see Figure 2). Up to 88% of the participants believed that opposition from parents was an obstacle in providing explanation to children. Furthermore, manpower constraint and the unavailability of medical fees make it difficult to provide effective explanations to children (see Figure 3).

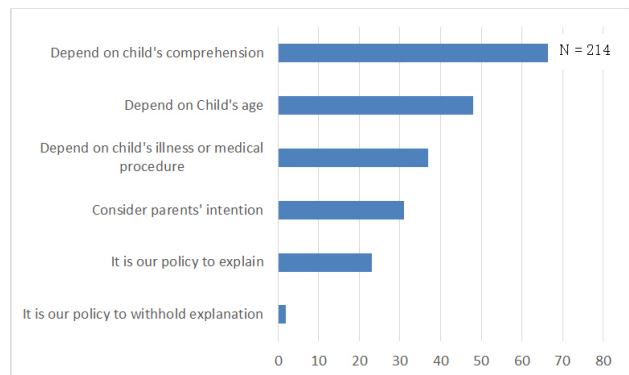
#### 3.3 Addressing disagreements between children and parents

As for the response “Explain in principle” for the question “If parents or other caregivers ask you not to explain to their children,” 35% answered “decide not to explain according to the caregivers’ intention.” Meanwhile, 60% answered “may decide to explain according to each case” (see Figure 4). Further, 65% responded yes to the question “Do you perform the necessary medical practice without consent from the child if the parents or other caregivers have given approval?” (see Figure 5) Approximately 66% of participants responded no to

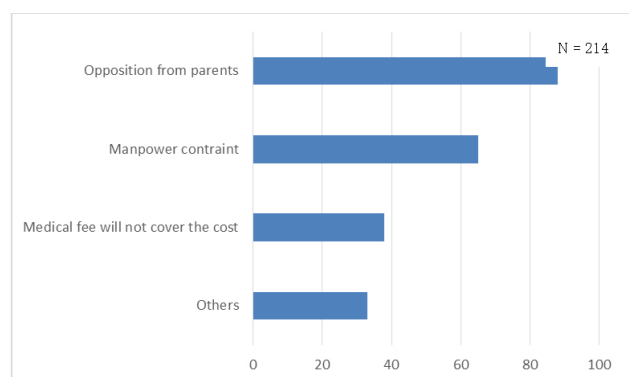
the question “Do you perform the necessary medical practice with consent from a child even if the parents or caregivers disapprove?” (see Figure 6) The method of answering the questions shown in Figures 4 through 6 is to select the one most appropriate answer.



**Figure 1.** What is the purpose of providing explanations to a child? Please select all that apply



**Figure 2.** What do you commonly consider when deciding whether or not to provide explanations to a child? Please select one that applies the most



**Figure 3.** Are there any obstacles in providing explanations to children? Please select all that apply

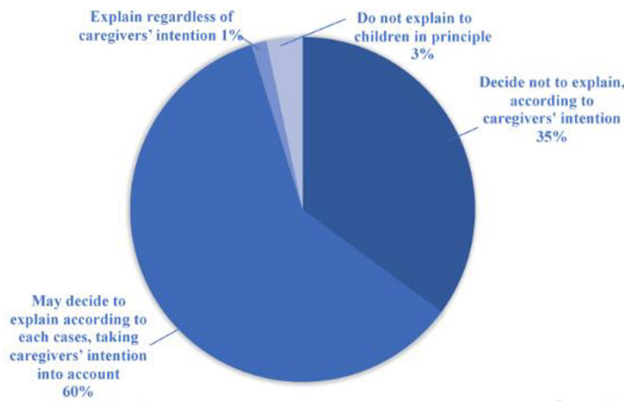


Figure 4. How do you address the issue when the caregivers ask you not to provide explanations to the child?

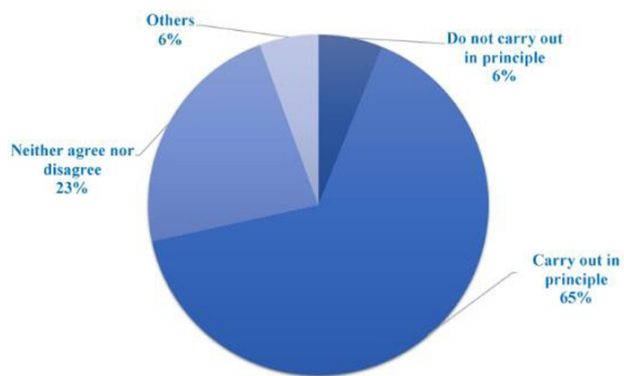


Figure 5. If the caregivers have approved, do you carry out the medical practice needed without the child's consent?

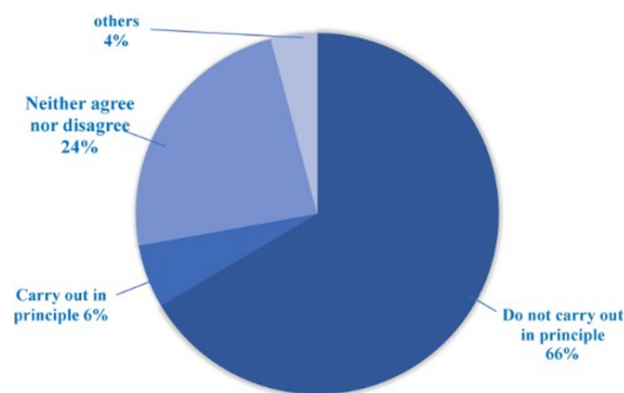


Figure 6. Do you carry out the medical care needed with consent from the child even when caregivers disapprove?

### 4. DISCUSSION

#### 4.1 Change in awareness regarding “explanations for children”

Physicians and other health care providers have endeavored to provide patients with secure and the finest medical care. Meanwhile, as the overall quality of medical practice improves, the importance of valuing the quality of life has been

recognized among those engaged in pediatric medical care. Based on the 2005 Tochigi Bar Association survey on medical care and children’s human rights, approximately 40% of participants positively considered the implementation of providing “explanation for children regarding medical practices.” In addition, according to the 2012 survey conducted by the author at the Institute of Scientific Research, Ministry of Health, Labor and Welfare, approximately 80% of participants had already implemented the practice positively.<sup>[6]</sup> Furthermore, in this survey, over 90% of participants responded that they could provide explanation to children.<sup>[7]</sup> Awareness regarding the importance of providing explanations to children is increasing in the pediatric field.

#### 4.2 Assuring the effectiveness of “explaining to children”

In this survey, the most common purposes for providing explanations to children were to dispel anxiety and encourage treatment cooperation. The act of explaining to children is recognized as a process of preventing trauma and stabilizing the emotional state of children. However, the factors that hinder explanations to children include opposition from parents, manpower constraint, and absence of additional medical fees.

Anyone has the right to consent, decide, or refuse medical practice that he or she receives according to his or her free will after understanding and receiving sufficient information and easy-to-understand explanations. If the patient is a minor, the caregivers (mostly parents) commonly receive explanation, provide consent, and choose or refuse medical practice. This survey revealed the fact that even with the assent from a child, in reality, the decision is made according to the intention of parents. Based on the perspective of the Convention on the Rights of the Child, which acknowledges the rights of children and respects their individuality, just because a child is minor is not an adequate reason for parents to be in authority to decide the medical practice for their child. The Convention on the Rights of the Child guarantees the right of children to express one’s opinion by stating that “Parties shall assure to the child who is capable of forming his or her own views the right 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 the maturity of the child” (Article 12-1 of the Convention).<sup>[1,4]</sup> The right has been pointed out to consider the child as the “independent subject” of the right, which seeks appropriate procedures that widely reflect the will of the child on deciding any issue pertaining to the child. Moreover, children have the right to demand that their own will be respected (encouragement of self-determination) in determining their own living conditions (including their own place to grow and develop) and

social conditions. For children to be able to express such views, they should be given sufficient information regarding the determination of living and social conditions, with well-thought-out explanations that are easy for them to understand. Medical practices are exceptionally invasive and, thus, are directly related to life and body. Thus, medical treatment is a subject of right to express opinions, and children must receive explanations about the details of their medical treatment. To substantially assure such rights, physicians must have a thorough knowledge of the child's development in accordance with the nature of the illness or medical practice. Moreover, easy-to-understand and well-thought-out explanations should be provided.

Alderson (2007) presented four levels in the decision-making process, which are as follows: 1) receiving information, 2) expressing opinions, 3) influencing decision-making, and 4) becoming a major decision maker.<sup>[8]</sup> The first step toward ensuring children's participation is achieved through their understanding of the information on their own illness and treatment and by obtaining information on decision-making abilities. To that end, support is essential to promote developmentally aligned participation. In addition, a child's decision could be influenced by others such as parents, family, and friends. Heim et al. have stated the importance of cautiously implementing a shared decision-making model appropriate for pediatric care. Furthermore, they suggest that studies on the mechanisms (e.g., experience of illness, family structure, and social background) may contribute to understanding the development of decision-making abilities and require clinicians to grow such perspectives.

#### 4.3 Is "consent" by a child guaranteed?

In this survey, 35% of the participants responded that if parents did not wish their child to receive an explanation, they would not explain it to the child. In addition, 66% of the respondents answered they will not perform the medical practice if the parents or caregivers refused, even if the child had provided consent (see Figures 4-6). However, in the pediatric field, when a child who can give consent could not provide one, it is quite common that medical practice will be performed if the parent approves. On the contrary, the current study shows that even with consent from a child, the medical practice is often not performed if the parent or caregiver refuses. Whether or not the child is acknowledged as capable of giving consent, the intention of the parent or caregiver is more valuable. In reality, parents and caregivers decide for their children. Such disagreement between parents and children is a phenomenon that requires cautious discussion to secure the best interests of children. If parental custody is often perceived as critical, there is no legal mechanism to

ensure that children's competence to consent is recognized. Hence, concerns regarding the legality of the medical practice, which relies solely on the consent of the child. When the child possesses some competence to comprehend the explanation and make good judgment, informed consent should be provided to the child, thereby acknowledging his/her competence. The existence of a child's competence to consent by age could not be unequivocally defined. However, age is an important indicator. Hence, the assessment of children's competence to consent will be an important issue in the future. Hein et al.<sup>[9,10]</sup> have shown that the following four cognitive functions comprise consent capability: general knowledge of the disease, cognitive ability (self-recognition of one's disease), logical thinking, and ability to express own decision. Furthermore, Grootens-Wiegers et al.<sup>[11]</sup> have reported about the children's decision-making ability from a neurophysiological perspective, specifying the following points:

- Self-control skills develop from 12 to 18 years old
- Around the same period, the reward system acts excessively, causing the dopamine response to be elevated
- Adolescents develop a trait that favors risky behavior<sup>[11]</sup>

Children's competence to consent could be more developed than expected. As competence to consent develops during the unique period of adolescent mentality, some cases may require psychological care. In addition, when the child does not possess sufficient competence to comprehend explanations or judgment ability, the child cannot be acknowledged legally to have the competence to consent.<sup>[12]</sup> Nevertheless, even in such cases, a procedure (informed assent) that requires an easy-to-understand explanation to the extent that the child can understand and provide consent should be carried out.

#### 4.4 Children whose competence to consent is still developing should also be supported to participate in their own decision-making

To substantially ensure a child's right to self-determination or the right to express their opinion and the right as a premise to receive explanation, children must be provided support to enable them to understand and help them participate in their own decision-making. Decision-making support is provided when a person is considered "incapable of making a decision." Before making the judgment, the child should not be incompetent to provide consent. Even if the consent ability is in the developmental stage, a person close to the child or family should stay aside and provide the necessary information in accordance with the child's attribute to enable the child to make decision. Various considerations must be

allowed for the child to make decisions. By creating opportunities for thought-out explanation or experience, the child could foresee the results of decision-making. In this regard, a medical explanation mainly by a physician and, in some cases, a procedure to support the child to make decisions may be necessary. Further, if the patient participating in decision-making is a minor, the child should be informed that others may have the final decision.<sup>[13]</sup>

A method called “preparation” is used by child life specialists in Western countries and by childcare support specialists in Japan. The method provides explanations appropriate to the child’s cognitive developmental stage and is intended to provide an environment and opportunities that bring out the coping ability of children.<sup>[14,15]</sup> Hence, it is attracting attention as one of the practical methods of decision-making support for children. Moreover, if the child or parent has a traumatic reaction, a psychologist or child psychiatrist should be consulted for such cases.<sup>[16-19]</sup> As for family integration or social resources, support from social workers is required, including interprofessional collaboration. Similar to physicians, pediatricians also need training in explaining a child’s medical condition in a way that is easy for children to comprehend. Moreover, it will be essential for pediatricians to develop an attitude of multidisciplinary collaboration.

#### **4.5 Assessment of the psychosocial factors inhibiting the process of pursuing a child’s best interest is crucial**

Based on the idea of the best interest of the child (Article 3 of the Convention), cautious analysis is essential both on the disagreement between the child and the parent, and on the psychosocial factors behind the refusal to consent. Childhood illness is a traumatic experience for children and their families.<sup>[16,17]</sup> If the traumatic reaction is intense, it affects the consent competence such as cognition and logical thinking. If traumatic reactions such as avoidance, invasion, cognitive distortion, depression, and dissociation are severe, care for the psychological symptoms should be prioritized. Furthermore, the presence of domestic discord or child abuse affects decision-making capabilities.

Kessler (1997) identified the factors that influence the competence to consent as follows: 1) state of consciousness, 2) mental state (depression, intense anxiety, and traumatic response), 3) cognitive level, 4) values and beliefs, 5) past experience related to decision-making, and 6) complexity of medical practice.<sup>[20]</sup> In children, as mentioned earlier, in some cases, the relationship between parents and children should be evaluated. For example, children with chronic illnesses are more likely to be mentally, physically, economically, and substantially dependent on their parents.

#### **4.6 Proposals for assessing the voluntary participation of and advocacy for children in medical care**

Ensuring the voluntary participation of children under medical care indicates not only to implement the rights acknowledged in the Convention on the Rights of the Child but also to ensure patient rights. Improving the physical and human environment will be key to promoting and enabling the voluntary participation of children, such as the dissemination of the “right of voluntary participation” to children, education to the medical staff, evaluation of medical fees, and training of professionals. To protect the personality and dignity of children under medical care, to respect them as individuals, and to ensure their right to express opinion or self-determination, the following recommendations are proposed:

- (1) Children under medical care can receive explanations about their own medical care in a well-thought-out and easy-to-understand manner in accordance with their age, comprehension level, medical condition, and the content of the medical practice. Children can express their views on the required medical care on their own free will, and their opinion should be valued accordingly.
- (2) As a means to encourage children’s voluntary participation, personnel arrangement and care systems must be established to assess and care for the psychosocial factors that can be a hindrance in the pursuit of the children’s voluntary participation.
- (3) Research is essential for assessing the development of children’s competence to consent and to standardize support based on the assessment.

#### **4.7 Limitations**

The current study had several limitations. The analysis involved descriptive statistical analysis only, and cross tabulation was not performed. For example, there might be differences in the priority given to children’s rights based on the type of hospital (whether it is a hospital specializing in children, university hospital, or general hospital). The survey was conducted on physicians and did not reflect the opinions of other professionals, such as nurses. In addition, differences by medical field (e.g., life-threatening chronic diseases such as childhood cancer,<sup>[21]</sup> and acute diseases such as injuries and accidents) are also issues to be addressed in the future. This study only included partial survey results due to character limitations. That is, all survey results were published in Japanese and were not accessible to the general public.

## 5. CONCLUSIONS

In the field of pediatric medicine, awareness about the human rights of children receiving medical care is increasing. However, the practice of obtaining informed consent from children is not fully established. Further, children must receive explanations on medical care in accordance with their level of competency. Thus, they can make their own decision regarding treatment. This study recommends to protect the personality and dignity of children receiving medical care by respecting them as individuals and ensuring their right to

express opinion self-determination.

## AUTHOR CONTRIBUTIONS

Ayako Itoh and Kou Hirahara contributed to the conception and design of this study. Kyoko Tanaka drafted the manuscript. All authors critically reviewed the manuscript and supervised the whole study process. All authors read and approved the manuscript.

## CONFLICTS OF INTEREST DISCLOSURE

The authors declare no conflicts of interest.

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