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Original Article

# Perspectives of medical professionals on children's right to participate in medical decision-making

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**Purpose:** Level of maturity, capacity for thought, and age affect the views and choices of children. In addition, different perspectives exist among medical practitioners regarding children's right to participate in the medical decision-making process. Depending on their personal and professional value systems, beliefs, and perceptions, medical professionals may be reluctant to share their healthcare decision-making power with children. The aim of this study is to examine how medical professionals in Taiwan perceive children's participation, freedom of expression, and decision-making in healthcare settings.
**Methods:** We collected the perspectives of 99 medical professionals who work with child or adolescent patients through qualitative interviews.
**Results:** Among the interviewees, 91% agreed that medical decision-making is a rights concept, while 56% agreed that children possess the ability to participate in healthcare decisions. The most common ethical principles were "protection of life" and non-maleficence. Although child patients may state their preferences regarding treatment options, their right to choose is not necessarily respected in the family-oriented and paternalistic culture of Taiwan. Based on these findings, the most common barrier to ensuring children's participation in medical settings is the family, followed by conflicts within medical teams regarding the implementation of clinician's decisions.
**Conclusion:** Paternalistic intervention by adults is more likely to be justified and considered moral when a child's right to participate is in conflict with the clinician's decision (e.g., doing no harm and preserving life).

**Keywords:** children's rights, clinical decision-making, paternalism, professionalism, Taiwan

## 1. Introduction

The 1989 UN Convention on the Rights of the Child (UNCRC) formally brought the rights of children into global focus within the ambit of human rights issues[1]. With the increase in global awareness of children's rights, concepts such as non-discrimination; the best interests of the child; the rights to life, survival, and development; and respect for the views of children have become standard in various settings, including health care[2,3]. Level of maturity, capacity for thought, and age affect children's views and choices. In addition, different perspectives exist among medical practitioners regarding children's right to participate in the medical

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decision-making process[4,5].

The participation of children in healthcare settings is heavily influenced by the overall normative system, such as medical ethics, nursing ethics, or social work code of ethics. Despite widespread discourse on respect for the autonomy and best interests of children, social, cultural, and legal factors have led to imbalances between children's wishes and their best interests, especially in the presence of severe health issues[6]. Although shared decision-making programs have been promoted in healthcare settings in Taiwan since 2016[7], respect for a child's right to participate does not necessarily mean that a child can determine his/her healthcare outcomes. Currently, consideration is given to the balance between respecting the child's freedom of expression relevant to his/her age, maturity level, and decision-making skills and the authority of the child's parents and other responsible adults[8]. Furthermore, researchers have interpreted children's rights, including participation rights, differently based on cultural contexts[9-11]. Healthcare professionals possess different personal and professional value systems, beliefs, and perceptions and may be reluctant to share their healthcare decision-making power with children[12]. The existing literature has primarily addressed vulnerability, age, urgency, and competence as possible restrictive factors for children's participation in medical decision-making[3,13.14].

Since definitions of health and illness are subjective, it is difficult to understand a child's level of discomfort unless expressed or healthcare professionals perceive him/her as a patient. This study's contribution to the literature is two-fold. First, children's participation involves fundamental moral questions, rather than just consideration of age or language ability. Second, children should have the right to participate in the medical decision-making process to strike a balance between their subjective feelings regarding their illness and adults' objective thoughts on what is in their best interests. In other words, children's views and autonomy should be valued. Hence, the aim of this study is to examine how medical professionals perceive children's participation, freedom of expression, and decision-making skills in healthcare settings.

## 2. Materials and Methods

### 2.1. Study population

We qualitatively interviewed 99 medical professionals who work with child or adolescent patients to understand their perspectives on children's participation in healthcare settings. We used snowball sampling to include a diversity of medical professionals of different genders, ages, educational backgrounds, fields of specialization, and years of work experience. Key stakeholders were recruited such as clinicians, nurses, medical/mental health social workers, clinical psychologists, and occupational and speech therapists. In total, 99 transcripts were analyzed. This study was approved by a university hospital's Institutional Review Board (Approval no. CS2-18009) and conformed to the ethical norms and standards set out in the Declaration of Helsinki.

### 2.2. Data collection and analysis

Since the authors work in a medical university, they approached potential participants from among alumni currently employed as medical or mental health social workers. The snowball sampling method was adopted so that those who had been recruited could invite other potential participants. The following research questions were addressed:

Question 1: Do you agree that children's participation in medical decision-making is a rights concept?

Question 2: Do you agree that children should participate in medical decision-making?

Question 3: With respect to ethical principles, what is your priority regarding children's participation in medical decision-making?

Question 4: What barriers have you encountered to enabling children's participation in medical decision-making?

To understand the interviewees' interpretations of children's participation in the medical decision-making process, the authors reviewed the transcripts several times. In the initial coding process, the transcripts were analyzed line by line, with coding of specific terms and reduction of data to core concepts. Then, SPSS 19 was used to generate descriptive statistics.

## 3. Results

Table 1 summarizes the demographic characteristics

of participants. Among the participants, 19% identified as male, 80% as female, and 1% as gender non-conforming.

Among the interviewees, 91% agreed that children's participation in medical decision-making is a rights concept, whereas 9% disagreed or were unsure (Table 2). Responses to question 1 are presented in relation to occupation in Table 3. When asked whether children should participate in medical decision-making, 56% agreed, 3% disagreed, and

**Table 1. Demographics of the sample (N=99)**

| | Characteristic | Number | % |
|---|---|---|---|
| Gender | Male | 19 | 19.2 |
| | Female | 79 | 79.8 |
| | Other (e.g., gender variant/non-conforming) | 1 | 1.0 |
| Age | ≤29 years | 19 | 19.2 |
| | 30–39 years | 38 | 38.4 |
| | 40–49 years | 32 | 32.3 |
| | 50–59 years | 9 | 9.1 |
| | ≥60 years | 1 | 1.0 |
| Educational background | Junior college/vocational | 5 | 5.1 |
| | Bachelor's degree | 55 | 55.6 |
| | Master's degree | 33 | 33.3 |
| | PhD | 5 | 5.1 |
| | Other | 1 | 1.0 |
| Marital status | Single | 46 | 46.5 |
| | Married | 52 | 52.5 |
| | Single parent | 1 | 1.0 |
| Occupation | Physician | 19 | 19.2 |
| | Nurse | 36 | 36.4 |
| | Social worker | 28 | 28.3 |
| | Psychologist | 6 | 6.1 |
| | Occupational therapist | 9 | 9.1 |
| | Speech therapist | 1 | 1.0 |
| Years of experience | <5 years | 11 | 11.1 |
| | 5–9 years | 29 | 29.3 |
| | 10–14 years | 21 | 21.2 |
| | 15–19 years | 16 | 16.2 |
| | 20–24 years | 12 | 12.1 |
| | ≥25 years | 10 | 10.1 |

41% agreed but with some reservations, answering "not sure", "it depends on the depth of participation", or "under some conditions" (Table 2). Respondents' answers to question 2 in relation to occupation are presented in Table 4.

Furthermore, 17 interviewees identified age as a determining factor in children's ability to participate in medical decision-making, which points to a perceived difference in competency between adolescents and young children. A psychiatrist pointed out that although children are capable of participating in the decision-making process, they cannot take complete control over their lives, necessitating a balance between parental supervision and children's

**Table 2. Distribution of responses to questions 1 and 2.**

| Item | Agree | | Disagree and unsure | |
|---|---|---|---|---|
| | Number | % | Number | % |
| Children's participation in medical decision-making is a rights concept | 90 | 91 | 9 | 9 |
| Children should participate in medical decision-making | 55 | 56 | 44 | 44 |

**Table 3. Distribution of responses to question 1 in terms of occupation**

| Position/Item | Is children's participation in medical decision-making a rights concept? | | |
|---|---|---|---|
| | Yes | No/ Not sure | Total |
| Physician | 17 | 2 | 19 |
| Nurse | 31 | 5 | 36 |
| Social Worker | 28 | 0 | 28 |
| Psychologist | 6 | 0 | 6 |
| Occupational therapist | 7 | 2 | 9 |
| Speech therapist | 1 | 0 | 1 |
| Total | 90 | 9 | 99 |

**Table 4. Distribution of responses to question 2 in terms of occupation**

| Position/Item | Should children participate in medical decision-making? | | | |
|---|---|---|---|---|
| | Yes | No | Not sure | Total |
| Physician | 9 | 0 | 10 | 19 |
| Nurse | 19 | 1 | 16 | 36 |
| Social Worker | 21 | 0 | 7 | 28 |
| Psychologist | 1 | 1 | 4 | 6 |
| Occupational therapist | 5 | 1 | 3 | 9 |
| Speech therapist | 0 | 0 | 1 | 1 |
| Total | 55 | 3 | 41 | 99 |

wishes. Briefly, interviewees who perceived children as entitled to participate did not necessarily support the idea of children being the key decision-makers.

The most common ethical principle was "protection of life", which was mentioned in 55% of the transcripts. Those who voiced support for this principle believe that protection of life supersedes all other ethical principles. The professional obligation to preserve life is found in due-care standards and is a core principle of professional ethics, such as the Hippocratic Oath and the ethical principles for social workers developed by Dolgoff, Loeweber, and Harrington[15]. Furthermore, a participant who works with children and adolescents with suicidal tendencies expressed that protecting life is the priority.

The second most indicated ethical principle was non-maleficence, "do no harm/do least harm", which was mentioned in 39% of the transcripts. Moreover,

**Table 5. Characteristics and statements regarding children's participation in medical decision-making**

**Children's age**
- *Adolescents can participate in medical decision-making, while preschool- or elementary school-aged children are unlikely to be able to do so---Pediatric Nurse*
- *Adolescents have some autonomy, as such their viewpoints can be taken into consideration. For those who are too young … parents or surrogates should be the decision-makers---Pediatrician*
- *Minors who are over 15 years old can participate in the discussion regarding treatment options---Pediatric Nurse*

**Shared decision-making**
- *Parents are more likely to make the final decision, especially when they are the legal agents of children. So, I think children can be involved in the decision-making process, but it is not necessarily the children themselves who make the final decision---Mental Health Social Worker*
- *I think children can participate to some degree. However, it is the parents who should participate in the discussion of treatment options and decide the best option for their child. Of course, parents should discuss it with the child and take the child's opinion into consideration…Psychiatrist*

**Table 6. Ethical principle priorities in terms of implementation of children's right to participate in medical decision-making.**

| Ethical principle | Number | % |
|---|---|---|
| Protection of life | 54 | 55 |
| Do no harm/do least harm | 39 | 39 |

**Table 7. Statements regarding ethical principles of children's participation in medical decision making**

**Protection of life**
- *If no longer alive, there is no need to talk about the rest---Child Protection Case Manager*
- *For a physician, preserving the life of his or her patient is of the highest priority---Pediatrician*
- *There are too many teenagers in the psychiatric department whose suicidal urges are quite strong… In the field I work in, protecting life is the most important aim. Only by first stabilizing one's life can one look for other possibilities…Mental Health Social Worker*

**Do no harm/do least harm**
- *A sixth-grade child was pregnant beyond the gestational stage that she could choose to have an abortion. Her mother wanted to force her to undergo an abortion. Here, I focused on protecting the life of and doing least harm to the girl…Medical Social Worker*
- *We wanted to make this decision to achieve the least harm to the sick child and his family. We had to not only relieve his clinical symptoms but also comfort his parents… Pediatric Nurse*

11 interviewees expressed that "protection of life" and "do no harm" cannot be separated. One interviewee shared a case of an underage unplanned pregnancy. Although this pregnancy affected the child and her family, the interviewee prioritized the prevention of harmful side-effects and risks of late abortion. Another interviewee had cared for an adolescent patient who was terminally ill and in great pain. The only possible way to control the pain was to administer morphine. However, this led to urinary retention. The main caregiver's (mother's) preference was to control the pain through morphine, whereas the patient preferred to endure the pain to avoid this side effect.

The above statements demonstrate that medical decision-making by children is not simply an individual issue but, rather, a relationship issue. Although pediatric patients may state their treatment preferences, their right to choose is not necessarily respected in Taiwan, due to the family-oriented and paternalistic culture. We asked the interviewees for their perspectives on the barriers to implementing children's participation in medical settings. The most common barrier was the family, as observed in 75% of the transcripts.

One interviewee shared her experience of an adolescent patient suffering from leukemia. Her parents attempted to change her mind about wanting to die, but ultimately respected her choice. This account reflects the dilemma of healthcare professionals regarding respect for an adolescent's choice and the priority of saving lives. In some cases, there is no reconciliation between the child's choice and paternalistic intervention. Parents are the

**Table 8. Barriers to children's participation in medical decision-making**

| | Number | % |
|---|---|---|
| Family | 74 | 75 |
| Medical team | 13 | 13 |

**Table 9. Statements regarding barriers to children's right to participate in medical decision-making**

**Family**

- *A teenage girl with leukemia underwent chemotherapy for two years, after which she signed a DNR order. We had multiple meetings about this because her parents refused to let her go. During one meeting, her parents tried to persuade her by saying, "Don't sign it. It doesn't matter. We have money. Doctors still have medical measures." But she felt that her life quality had been greatly impacted by this disease. We respected her wishes in the end and let her die, without resuscitation… Nurse*
- *I cared for a child patient with short bowel syndrome, with constant diarrhea a complication after surgery. The child expressed his wish to return home but his parents found it troublesome to take care of him by themselves due to the complexity of his condition and felt that it was better for him to stay in the hospital...Nurse*
- *I had a few cases where children were very willing to come back and talk again. But parents felt that the information I released to them was not detailed enough. So, they decided not to let the child continue therapy… If parents are unwilling, children cannot receive treatment…Clinical Psychologist*

**Medical team**

- *From the healthcare perspective, shared decision-making requires completing many documents and more time spent by doctors. Why is it necessary to make this extra effort? I guess this is the biggest obstacle to children's participation… Pediatrician*
- *In fact, the attending physician has the final say in medical settings. When there are differing opinions among specialists on the team, we voice our concerns and try to communicate with the attending physician, but it is impossible to communicate with some of them…Mental Health Social Worker*
- *Children may need a treatment, but family members refuse the treatment. Some doctors try to persuade these families or even insist on the treatment...Pediatric Intensive Care Unit Nurse*

main decision-makers, even if the child expresses his/her wishes.

Decisional conflict within a medical team or adherence to clinician's decision was the second most important barrier, mentioned in 13% of the transcripts. Stakeholder attitudes, particularly those of medical team members, that endorse child patient and family involvement in the decision-making process serve to facilitate children's right to participate in decision-making in medical settings. In many cases, decision-making does not even involve the patient's parents. A pediatrician pointed out that people commonly perceive children as lacking the ability to make autonomous decisions, so they do not listen to their viewpoints. It is the adults (parents and medical professionals) who make decisions together.

These cases show how physicians can dominate the decision-making process. Even decisions regarding the best medical treatment or advice might be problematic and vary depending on the professionals who are involved. Do the perspectives of clinicians differ from those of other healthcare professionals? It can be argued that saving lives is what clinicians are trained to do and believe in. Hence, we specifically analyzed how clinicians answered this question. Fourteen of 19 (74%) clinicians identified family/parents as the main barrier to children's participation in decision-making in medical settings; three identified children's characteristics (e.g., being young or immature), and two identified financial situation or systemic factors (e.g., educational system). When children were considered incapable of making autonomous decisions regarding their treatment, the decision-making responsibility was assumed by adults, such as the parents. If prolonging life is considered of the highest moral significance in medical settings, clinicians should exhaust all possible options to reduce the suffering of and risk to pediatric patients. Hence, decisional conflicts exist not only between children and parents, but also between parents and medical professionals, particularly clinicians.

## 4. Discussion

Studies on bioethics and children's rights have indicated that cultural differences affect approaches to promoting children's participation in medical settings[16]. The promulgation of the 2014 Implementation Act of the Convention on the Rights of the Child reinforced the government's determination to legally implement the UNCRC in Taiwan, although Taiwan is not a UN member [17]. However, this 2014 Implementation Act has not resulted in significant reforms. Most interviewees recognized children's participation in medical decision-making as a rights concept. However, adult authorities such as medical professionals and parents do not necessarily encourage it. Most medical professionals consider children's participation in medical decision-making processes to be complex rather than straightforward. Since they believe in the ethical principles of preserving life and doing no harm and consider their professional duty to relieve pain and promote a better quality of life, medical professionals do not prioritize consideration of children as autonomous agents with specific rights.

Discussions on topics related to children's right to participate in medical settings have not been limited to decision-making or autonomy. They have included how children can involve themselves, express their viewpoints, and participate in all aspects that are relevant to them. According to the results of this study, children tend to express their preferences, which often differ from those of adults or go against their own interests. In consideration of disease stability or children's characteristics (e.g., being young or immature), children's preferences are likely to be ignored with treatment counseling sessions attended by adult authorities only.

Alternatively, children's preferences are noted but not considered to be in their best interests or those of their families. In other words, participation by children, parents, and medical professionals in the decision-making process is unequal. Often, straightforward paternalism, parental power, and medical paternalism overshadow children's wishes. Our findings are consistent with those of other studies, in that families play a dominant role in Taiwanese culture and have the right to withdraw mechanical ventilation for dying children[18,19]. Taiwanese culture is often perceived as group-oriented[20] with families the smallest decision-making units. Parents nurture and care for their underage children and the merits

of the group and interdependence are emphasized[21]. Hence, paternalistic interventions by adult authorities are more likely to be justified and considered moral whenever there is a conflict related to rights. This corresponds with the Confucian perspectives of beneficence and non-maleficence, whereby one tries to create the best utility for others[22].

In this study, only the views of medical professionals are presented. However, health and illness should not only focus on physical and physiological aspects, but also on social dimensions, due to the relationships between medical professionals and child patients, parents and child patients, and medical professionals and parents. In other words, social meaning underlies children's rights to participation and autonomous decision-making in medical settings.

This study's main limitation is that there was no collection or analysis of data on risk, illness duration, setting, or disease complexity. These factors might influence the availabilities of treatment options.

## Conclusion

Pain and suffering are subjective. The findings of this study indicated that despite endorsement of children's participation in medical decision-making, perceived as a rights concept, the family and decisional conflicts within medical teams hinder such participation. When medical treatment is sought for or by children, their needs and feelings must be considered. Children are less likely to be aware of their status and negotiating the boundaries of interactions between individuals and complex environments and developing the ability to control one's self-interests in everyday life are considered adult responsibilities.

Further, paternalistic intervention by adults affects children's right to participate in medical decision-making. Adults are obliged to help children become autonomous decision-making individuals. Such autonomy requires practice, as well as time and opportunities. As John Harris indicates, "there is no such thing as complete autonomy" (p. 200) [23]. When children's right to participate in decision-making in medical settings is raised, it should be perceived as a moral argument. For young children with little autonomy, medical decision-making is open to paternalism. However, their feelings or emotions, as expressed through body language, symbols, or gestures, should be taken seriously. Paternalism is considered acceptable when necessary information is disclosed and explained to child patients by adults such as parents and medical professionals. If children are capable of expressing their wishes, adults should encourage them to do so to maximise their autonomy. This may lead to increased respect for and understanding of children's rights to participate in all matters affecting their lives.

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