Provision of Healthcare Services for Children in Iran: Common Ethical Principles and Obstacles to Successful Implementation

Fataneh Sadat Bathaie[1], Bagher Ardeshir Larijani[2], Farshad Farzadfar[3], Saharnaz Nedjat[4], Seyed Hassan Emami-Razavi[5], Maliheh Kadivar[6], Farzaneh Zahedi Anaraki[3], Peyman Zinati[7], Payam Roshanfekr[8], Alireza Olyaeimanesh[9], Davoud Nezamoleslami[1]

[1] Department of Medical Ethics, Tehran University of Medical Sciences, Tehran, Iran

[2] Medical Ethics and History of Medicine Research Center, Endocrinology and Metabolism Institute, Tehran University of Medical Sciences, Tehran, Iran

[3] Endocrinology and Metabolism Research Center, Endocrinology and Metabolism Institute, Tehran University of Medical Sciences, Tehran, Iran

[4] Department of Epidemiology and Biostatistics, School of Public Health, Tehran University of Medical Sciences, Tehran, Iran

[5] Brain and Spinal Cord Injury Research Center, Tehran University of Medical Sciences, Tehran, Iran

[6] Department of Pediatrics Children's Medical Center, Tehran University of Medical Sciences, Tehran, Iran

[7] Department of Social Planning, University of Tehran, Tehran, Iran

[8] Social Determinants of Health Research Center, University of Social Welfare and Rehabilitation, Tehran, Iran

[9] Social Development and Health Promotion Center, Tehran University of Medical Sciences, Tehran, Iran

Abstract- Ethics is an essential element in the provision of healthcare services. Fundamental ethical values determine the manner in which the professional behavior is implemented in the healthcare area. These ethical principles find meaning in time and place and in the social context of ethical values and among children as vulnerable groups. So, this study examined the ethical principles of providing health care services for children and barriers to their application in Iran from key informants' perspective. Therefore, qualitative content analysis method was used by means of semi-structured questionnaire to theoretical saturation scale with the participation of 20 key informants. Each interview underwent the process of implementation, evaluation, coding, and analysis, and then its findings were presented in two dimensions: desirable principles and barriers for its application, including 15 classes. Desirable principles include autonomy, beneficence, non-maleficence, justice, confidentiality, accent, consent, and participation. Obstacles to their compliance also included weakness of the policy landscape, weakness of the judicial system, cultural conservatism, socio-economic inequality, services commodification with unequal distribution, resource mismanagement (limitation), weakness of the professional education system, and the emergence of complex situations. From the key informants' point of view, codes of ethics do not differ significantly from international principles, but their application is faced with difficulties, and they are likely to be improved through evidence-based policies according to the results of scientific studies.

Introduction

Boundaries of health care ethics have been shaped by the emergence of ethical issues in healthcare careers (1). Ethics of care under professional ethics carries critical thinking and value-based rational reasoning in a clinical setting (2-3). In the ethical content of health care, these values have been transformed from its most basic forms, including an individual's oath since 400 BC until today in such a way that it now carries at least four universal virtues of autonomy, beneficence, non-maleficence, and distributive justice (4). These principles are fundamental

Corresponding Author: B. Ardeshir Larijani

Medical Ethics and History of Medicine Research Center, Endocrinology and Metabolism Institute, Tehran University of Medical Sciences, Tehran, Iran

Tel: +98 21 88631296, Fax: +98 2188631296, E-mail address: Larijani@tums.ac.ir

in a two-way relationship between patient and physician to achieve the ethical goals of basic health care. Considering the presence of children in one side of this relationship, the importance of ethics' analysis is doubled because the vulnerability of children affected by their dominant patterns and their lower social power is crucial to adult authority (5-7). Based on this legal and customary adult authority over children, caregivers are given the responsibility for health decision making (7), or in Islam, the guardian is held responsible for materializing this right based on his/her guardianship (8). Also, having doubts about children' informed decision-making power based on the experience weakens both autonomy principle-and other relevant principles such as participation in decision-making (9-11).

In spite of this particular attention, it is evident that it is possible to observe ethical considerations of the provision of child health services based on the fundamental principles (within the cultural and social context) in concrete conditions and according to circumstances. First, ethical principles, though fundamental in the context of time, place, and various human societies, can be constructed, understood and interpreted (4). These principles should then be explored in concrete conditions based on the reality of the existing status of the health system (internal and external) and barriers to its improvement.

Also, it is difficult if not impossible to observe the ethics of health care in complex situations such as child care (12-13), child abuse during treatment (14), etc. Improving the conditions in which these considerations are observed requires understanding the barriers to the application of these principles. For example, lack of legal support for child abuse intervention or similar unpleasant situations, or cases such as family-doctor conflict caused by the dominant cultural system (15) or the need for rational and optimal choices by saving healthcare resources (Financial, human, physical-therapeutic), are not only the issues related to the death and life of individuals, but also the reflection of ethical, social, and cultural values and at the same time, completely realistic affairs (16). Ultimately, we can say with certainty these ethics are tied to social culture and social structures in the health field (17). Therefore, in order to understand the desirable principles and obstacles to ethical considerations in the provision of children's health services in Iran, we need to investigate them from the perspective of key informants.

Materials and Methods

Qualitative content analysis on the basis of the social construction of reality analyzes the qualitative data (text) and their tabulation in order to reconstruct and re-formulate the explicit and hidden social reality within the text (18-21). The interview requires a semi-structured clear, flexible, but non-deterministic, and non-prejudiced questionnaire to answer the main question in this regard (19).

Participants

Participants in this study include a collection of 20 people, collected by purposive sampling. Individuals from the top policymakers, health department managers, doctors, nurses, psychologists, sociologists, lawyers, and jurists have been interviewed voluntarily. Triangulation of academic specialty, work experience, occupation, and gender diversity is the criterion of choice in this purposive sampling.

Data collection

Texts were compiled of a total of 20 semi-structured interviews in March 2016, with an approximate length of 30 to 60 minutes. At the beginning of each interview, research objectives were described. Participants were assured regarding the confidentiality of their information, the possibility of withdrawal, lack of mentioning any names and any comment. Participants were also encouraged to present their opinions and experience. The number of interviews required to enrich the analyzed text in the qualitative research method was as much as we to reach theoretical saturation. By theoretical saturation, we mean that the process of accumulation of knowledge resulting from new interviews slows down as if reality is revealed to a large extent.

Ethical considerations

The present study was conducted based on code No.1396.3500 issued by the Ethics Committee of Tehran University of Medical Sciences. In order to confirm voluntary participation, confidentiality and non-disclosure in the research, consent letters were prepared. There was also an assurance of withdrawal from the research if desired and participants' consent about the recording of the interview has been obtained.

Data analysis

Interviews were recorded using a tape recorder and evaluated using the standard methods of implementing qualitative interviews. Coding tables, consisting of columns of analysis units, codes, classes, and notes were formed. The texts were later entered in the coding tables

for each question paragraph to paragraph (analysis unit). Based on the common technique in the inductive-deductive encoding of qualitative content analysis, summarization was first carried out after reading the analysis unit, then the hidden or overt message of the semantic unit was categorized and then re-summarized generalized in the initial code. More abstract classes were formed after reconstructing the codes, by screening the duplicates, summarization, merging and aggregating them. The codes and classes were retrieved from the text so that they are reinvestigated and undergo qualitative evaluation by the research team.

Results

The derived codes were categorized into two groups of desired ethical principles and obstacles to their observance. A total of 7 classes of the desirable ethical principles were considered by key informants in the provision of children's health care services. There are, in their view, eight major obstacles to the observance and application of these principles (Table 1).

Table 1. Categories of findings extracted from participants responses

Desirable ethical principles	Obstacles to application of desirable principles
Autonomy	The weakness of the policy-making area
Beneficence	The weakness of the judicial system
Non-maleficence	Cultural conservatism and extreme traditionalism
Assent and consent	Service commodification and limited and unequal distribution
Confidentiality and privacy	Restrictions and mismanagement of resources
Justice and equality	The occurrence of complex situations
Participation of child	The weakness of the professional education system

Desirable ethical principles in the provision of child health care services

Seven ethical principles identified by key informants included the following: beneficence, non-maleficence, autonomy, consent and assent, confidentiality, justice, and the participation of children.

Autonomy

Belief in the child's autonomy and individuality is fundamental and determines other principles. Perhaps the most controversial principle is the differentiation of children and adults. However, some argue that children at an early age do not have the ability to make informed choices and decisions. Hence, the guardian has the autonomy of declaring consent and agreeing to receive health care. On the other hand, some emphasize the importance of a sort of age classification based on the competence and intellectual development of children of different ages.

Beneficence

The main guideline in the ethical judgment of various choices, especially in the event of conflict and confusion is the referral to the principle of child beneficence. The beneficence principle involves a kind of rational cost-benefit about the results of action and intervention for a child. Believing in this principle, the behavior of the party involved with the child changes in a positive way.

{Specialist in Medical Ethics No. 13}: *"In case of*

conflict between the interests of the child and parental consent. If beneficence and benefits of the child involve actions that are agreed upon by parents, then the doctor is responsible ..."

Non-maleficence

In the eyes of key informants, the basic element of this principle was minimizing harm, suffering, and pain to the child, meaning avoiding non-beneficial intervention and any act that may result in irreparable harm (like death) to the child. Non-maleficence and beneficence are two sides of a coin, and by having these two together, certain conflicts among doctors and patients' families are unavoidable.

Assent and consent

Getting the child's assent or consent depends on the level of autonomy in the caregiver's care. Based on the recognition of the intellectual developmental level of a child of different ages, it has been suggested that the child's tacit consent should be obtained through notification at the age of 5. Talking with the child is based on appropriate behaviors or encouragement of a suitable strategy. At the age of 12 and, of course, by judging the level of intellectual development of a teenager, it can be inferred that it is necessary to obtain informed consent from him/her.

{Pediatric Nurse Practitioner No.7}: *"Assent should be obtained in case of a child over five years or twelve*

years older, and sometimes even a consent should be taken, because the child will get a good understanding of what is going to happen to him/her. "

Confidentiality and privacy

In the current context, child health information is shared with parents or even relatives. There is a weak belief in a level of confidentiality in the intersection with principles such as beneficence. In some cases, such as mental health counseling and counseling in the treatment process, it is necessary to ensure the mental comfort of the child. It is more common and prevalent that some of the staff check the baby naked in the busy atmosphere and they are not aware of the ethical dimensions, while the child will more likely feel resentment.

Justice and equality

This principle is to provide fair and equitable treatment of children's health on the basis of need and not economic power in an equal and non-discriminatory manner. It is fundamental to consider non-discrimination in service delivery based on race, gender, and other socioeconomic levels. According to key informants, child's health is not replaceable with money, and in any case, his/her health as a human being is a priority.

{Doctor of medical Ethics No. 10}: *"Every child, regardless of whether he is poor or rich, lives in Tehran or the farthest place of the country, regardless of race, religion or color and nationality, needs to receive health care."*

This ethical principle also implies the necessity of fair balancing and distributing (and redistributing) of resources and services from a geographic, class, gender, racial perspective. Justice and equality can not be achieved without access to resources. Access which, from the perspective of key informants, is possible with free de-commodification.

{Doctor of medical ethics, No. 10}: *"No child due to his family's social and economic status should be deprived of basic health services. Iranian children, not even immigrant children, and even those who are illegal immigrants should be provided with human rights services in the country."*

Participation of the child

Participation is more than just saying yes or no rather it is a tendency to actively engage the child in the process of self-treatment and to intervene. Child-friendly hospitals should be designed in accordance with the interests of children. Children also have the potential for voluntarily or motivational participation in the process of participation in the treatment of peer group.

{Pediatric nurse practitioner No. 7}: *"We can get help from children either to help themselves or others. I tried this. We had a kid who wouldn't allow us to walk him. He would not let us take IV. I chose one of the children and said, your friend is like that. Come on. Help him. It was interesting that he came to the kid and said, "My friend, we are here to get better. The words of this kid had a positive effect on that kid and changed him to the extent that he himself said he wanted to undergo venipuncture ..."*

Obstacles ahead of observance of desirable ethical considerations

The ethical principles of care are practical. The question of various causes and factors that could allow us to apply ethical considerations has led to the formation of eight classes of barriers which include the weakness of policy arena, weakness of judicial system, cultural conservatism, socio-economic inequality, commodification of services with uneven distribution of resources, resource constraints and mismanagement, weakness of professional education system, and emergence of complex situations.

The weakness of the policy-making area

In spite of the tendency to observe ethical principles, from a structural point of view, a non-progressive attitude to the concept of childhood has limited the possibility of leading policies (such as ethical protocol on the observance of ethical considerations of the child). In case of a desire for intervention, there is no comprehensive and dynamic information system on the health status of children. In the absence of necessary resources, policies do not have the necessary diversity and focus according to the types of needs (physically and mentally handicapped children). Furthermore, these policies are not well-designed, do not reflect the current culture in Iran, there is no uniformity in implementation, and there is no integrated evaluation system after their implementation.

{Doctor of medical ethics No. 13}: *"There was a center where mentally retarded children who did not have a guardian are taken care of. It was a catastrophic situation. That means the kid was kept in the worst position. Older children with a little retardation were sedated instead of being rehabilitated; only hormonal drugs were given to them in order to change them in terms of sexual desire they all had inhuman life. It seemed to me that they were just lucky enough to be given some food in an institute ..."*

The weakness of the judicial system

The judicial system does not safeguard the ethical principles required in this regard. Considering the legal gap, the absence of protocols for the observance of ethical considerations and deficiencies in existing laws in areas such as child abuse as well as the weakness of judicial support for personnel who report cases of non-compliance with the law, we should not expect much from the current situation. Many personnel prefers not to comply with existing laws because they do not think that the system of rewards and punishment has been properly designed. Also, changing these rules in accordance with the current culture requires an explanation of the jurisprudence.

Cultural conservatism and extreme traditionalism

According to the key informants, current culture in Iranian society is sometimes at fault because, according to the customary logic of guardianship, children are considered as the property of their parents, so they are treated like objects without autonomy or authority. The existence of a culture of false fostering, such as physical punishment or tabooing sexual education is a form in such matters. Also, belief in superstitions and misunderstandings about the therapeutic procedures or belief in traditional medicine is in conflict with modern medicine.

{Pediatric Nurse Practitioner Number 7}: *"Children were neglected in most places. Parent's presence was dominant, and children felt that they are like some damaged device, such as a watch or a cellphone that were brought to the repairman. Children feel that humanity and the fact that I am not an object, I am not the property of these parents, but I am an independent person and have the right to choose, and have the right to express myself. "*

Socio-economic and gender inequality

Fair access to health care services based on the children's need in the realm of life is highly influenced by socio-economic determinants of health. Children of lower socio-economic groups are more likely to be at risk for a variety of injuries, diseases, and inconvenient events; hence, they may more feel the need for services. On the one hand, their access to such services is much lower than others. This inequality limits geographical, gender and ethnicity dimensions and makes access nearly impossible for the most vulnerable groups (children without birth certificates, Afghan immigrant, working and street children).

Service commodification and limited and unequal distribution

Inequalities in the present social and economic system seem to be very complicated when health services are purchasable goods, and the extent to which they are benefited depends on the wealth and income of the household. With this in mind, it is like a dream to administrate justice in the health field. In this case, the neediest will have the least benefit, and the least needy will have the most access to services, while the limited distribution of services, such as child psychological counseling, will target higher social and economic groups, and hence individuals do not enjoy equal access to services.

Restrictions and mismanagement of resources

Current capacities in a health system that is incapable of admitting a large number of clients lead to resource mismanagement in addition to resource constraints. The shortage of manpower in deprived areas and lack of hospital beds for children challenge the ideas of justice and social equity for the benefit of children.

{Policymaker # 9}: *"Money is not in the pocket of the health system [otherwise]. It would spend more ... "*

The occurrence of complex situations

In the interaction between the cultural context and the judicial system, family-doctor conflict, inter-parental conflict, parent-child conflicts are everyday issues, even to the point where the relatives interfere. These conflicts in situations of acute cases, such as child death, painful treatment, incurable disease or other emergency situations lead to a set of complex situations where it is more difficult to practice ethical conduct than ever.

{Pediatrician No. 3}: *"I had a patient, a kid with respiratory distress. During shift, I went to visit her and did some basic procedures --- but her uncle came during the meeting hours and said that this kid was here for a week and nothing was done to her, he removed her angiocath and went to the door while taking the kid under his arm. "*

The weakness of the professional education system

There are shortcomings in the training of professional ethics for service personnel. Many of them are not familiar with the importance of ethical codes; so they are less sensitive to the ethical dimensions of the profession.

{Doctor No. 11}: *"I was teaching my students when I heard the sound of a crying child. The mother was so tired that she was beating her baby, and it was interesting it was not important to any of my colleagues to interfere and calm the mother down. "*

Discussion

Ethical principles of professional child health care provision constitute a system of concepts consisting of four principles of autonomy, beneficence, non-maleficence, and justice. Three ethical principles of confidentiality, assent (or consent), and participation are based on a rational combination of those four principles. These universal principles are internationally endorsed from the middle of the twentieth century (22). In a study on professional ethics on working with children in the area of responsibility towards authorities, Kelly *et al.*, investigated six principles of equality, respect, confidentiality, autonomy, beneficence, and non-maleficence, which is consistent with the results of this study (40). Those four basic principles are basis to which the behavior is referred; however, is the observance of these principles in relation to children (and mentally retarded individuals) true everywhere? (23).

It is essential to study the meanings and patterns of ethical behavior in the social and cultural context (23-24). With regard to the autonomy, some are inclined to fully delegate child's autonomy to the family or indeed to the guardian by referring to the custom and law; others believe in recognizing and leveling child's autonomy based on intellectual growth, health status, family circumstances, and socio-economic background. Then infer the necessity of getting consent or assent based on child's age and solve the conflicts of interest in this way. Among other principles, justice has gone beyond the same treatment of service providers with patients (child and family) without racial, ethnic, religious, class or gender discrimination. The issue is just about the possibility to receive the service by the child because many children are deprived of receiving care services for some reason, such as expensive health care and social services and facing with social issues such as lack of birth certificate. Therefore, the beneficence and non-maleficence are guaranteed based on the administration of justice in the title of the distribution (and redistribution) system (25). The issue that is against the autonomy principle in children determines the child's confidentiality and privacy practices. However, confidentiality is not only a desirable ethical principle but also a necessary element in the process of providing mental health services to a child (26). Judgment is based on the principles of beneficence and non-maleficence and in accordance with existing laws. Milanifar *et al.*, (27) have considered the rules for reporting children's health status in Iran. Although the results of Keshvari-Afshar *et al.*,'s study on the priorities of nursing ethics indicate a

desire for confidentiality among Iranian nurses (28), child privacy is not a priority.

Based on the patriarchal care (28) or the role models (instructor) determine the dominant atmosphere (29). Nevertheless, a participant in the present study considers the issue of child participation in changing the care environment as well as accompanying the treatment of her peers. This issue has not been internalized in the scientific literature of the country; other scholars have talked about promoting a collaborative model emphasizing the family (30). Also, the policies of child-friendly hospitals also do not involve the participation of children in determining the caring atmosphere or therapeutic procedures (31).

It is not enough to talk about desirable ethical principles, implementing such a goal requires serious discussions. According to Burhani *et al.*, moderate ethical sensitivity has been observed among health care providers (nursing students) in Iran, but there are ambiguity and conflict due to some obstacles (32). Borhani *et al.*, have not addressed barriers to the application of professional ethics, but we have identified, in the present study, barriers such as the weakness of the policy area, weakness of the judicial system, cultural conservatism, socio-economic inequality, and services commodification with unequal and limited distribution, limitation and mismanagement of sources, weaknesses in the general and professional education system.

From a policy-making perspective, it is still no necessary transition from the patriarchal and object-oriented approach to children's citizenship. Therefore, children policies are not centralized. There is a vital gap between health policy-making and the judiciary and, despite the necessity, there is no ethical protocol for child health care. Sanjari *et al.*, considered the Nursing Ethics Protocol to be based on native culture and Islamic beliefs (33). Kadivar *et al.*, also showed that, in the absence of clear written rules, care provider personnel might face confusion about existing processes and ethical behaviors (34). This situation is exacerbated by the weakness of the professional education system and the lack of sufficient training materials in the field of professional ethics. Many service personnel is not aware of the ethical dimensions of their responsibility. This lack of knowledge of professional ethics codes has also been confirmed by previous studies in Iran (34-35). When the minimum regulations are in place, insufficient legal protection of the treatment staff leads to their ignoring of serious ethical issues such as child abuse.

Conservative culture and extremist traditionalism or social issues (poverty, etc.) put children in inhumane

situations such as physical punishment, sexual harassment, gender discrimination, etc. Occasionally, care personnel experience conflicts with their families. On the other hand, other studies have pointed out that the culture of surrender before doctors is prevalent in Iran (36). Kadivar *et al.* stated that the most frequent ethical dilemmas involved uncertain or impaired decision-making capacity, limitation of treatment at the end of life and disagreements among family members. (37).

In addition to the difficulties in individual judgment and interpersonal relationships, material situations are also very influential. In line with the findings of this study, Dehghani also perceived environmental barriers, lack of resources and income constraints as factors preventing professional ethical standards in the clinical care (38). Meanwhile, it should be added to Dehghan's statement that services such as mental health, sometimes are not available in some areas, depending on the degree of their deprivation. In addition to lack of resources and its uneven and limited distribution, the monetary value of health services in Iran has made it a luxurious commodity for underprivileged groups. Children of lower socio-economic groups are more likely to be exposed to the greater impact of social and economic factors due to variety of health problems, and their lower access to the health system has led to inhumane conditions. Many studies have examined the situation of children's health inequality in Iran, Panahi and Al-Imran have estimated the long-term relationship between the mortality of children less than one year and poverty in Iran (39). In response, there has been a reform policy that has aimed to reduce out of pocket payment of patients.

Based on the findings of this study, key informants on children's health care in Iran have largely similar perspectives on common ethical principles, including health policy-makers, doctors, nurses and psychologists, but the internal meaning of these concepts is different depending on native Iranian-Islamic backgrounds. However, there is some obstacle to the implementation of these principles. Organizational and implementation policy-making and shortcomings of a supportive judicial system along with the everyday Iranian culture and its unequal economic and social status all shape the dimensions of the current state of observance of ethical considerations in the provision of health services. The main purpose of the authors was to improve the current status by using the results of these studies.

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