

THE RIGHT TO MEDICAL INFORMATION OF PEDIATRIC PATIENTS

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ABSTRACT: *The study examines the extent of children's rights to medical information, considered a condition of self-determination. The author would like to study the implementation-level of this right as applied by children, to research attitudes of parents and medical personnel and finally to verify if there are any shortcomings of legal background. Quantitative methods were used and the results were evaluated with comprehensive descriptive statistics. A number of 600 questionnaires were applied on three different target categories: health professionals, parents and children. Accessing medical information is essential for health-related decisions taken by the autonomous child. This fundamental right derives from human rights and allows for each person to gain access to his own medical data, diagnosis and different treatment-options. In absence of necessary medical information nobody could be able to take responsible health-decisions. Medical information coming from physicians should be correct and integral. This information must reach the child no matter if directly or through his parents. We can only speak about the effectiveness of this right when the transmitted information is understood by the child. There are still problems with incomplete or inappropriate legal definitions, medical staff is not properly educated and sometimes loses his interests. The author has identified the major causes of defective information. As a conclusion, parents have a great responsibility and active role in transmitting medical information to the child.*

KEYWORDS: *children, confidentiality, medical information, self-determination*

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1. INTRODUCTION

The situation of medically diagnosed children's rights has an important social impact because illness has an influence on the patient's family and social environment. Consequently the effects of illness, which make the patient's family or community unstable, have to be prevented. Physicians have to evaluate the ways how they can provide the best assistance to a patient (Miu 2004). However, communication with

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patients is equally important. The patients' cooperation can only be obtained if they are offered not only pharmaceutical treatment but appropriate information, too.

The study presents a selection of the partial findings of the author's PhD research. The author would like to know about the attitudes of parents and medical personnel in this matter. The main question is whether the implementation of these rights to medical information is on an acceptable level in case of children. The hypothesis is, based on literature, that the right to be informed has shortcomings of legal background and it isn't applied in practice as it is supposed to be. The collected data offer an answer to the research question whether pediatric patients have access to medical information.

Article 12 of the United Nations Convention on the Rights of the Child provides that children shall be assured the necessary information in order to fully participate in the process of decision. Since Romania adopted this international convention, minor patients have to be given support to obtain all the medical information which adults have access to, without any kind of discrimination. The right to medical information, both in the case of persons above and under the age of majority, refers to knowing all the aspects of the patient's own health status. The subject matter can be found in Art. 4-12 of Law on the Rights of Patients No. 46/2003. According to the law, the patient has the right to information of different categories, such as those related to health services and those concerning his/her personal health status (diagnosis, prognosis, risks etc.)

The right to medical information is of a major practical use, being connected with other rights. There are certain situations in which the minor's consent is solicited for certain treatments or decisions regarding his/her health. Before accepting any kind of consent, the physician has to assure that both child and parents have understood the consequences of the treatment and the adopted decision is a joint one (Shield and Baum 1994). The informed consent permits the child to exercise his/her right to self-determination or autonomy. There are three elements necessary for an informed consent: it has to be informed, it has to be competent and voluntary (Friedman 1997, Brabin et al 2007). The child's agreement to his/her medical treatment is his/her right, and he/she can refuse or stop the intervention (Freeman 2000). The minor's autonomy is associated with the right to private life and confidentiality, acting according to his/her own will, to his/her own moral responsibility and to the acceptance of responsibility for the choices made (Brabin et al 2007).

Therefore we can state that it is essential to inform children in order to implement their rights related to the autonomy of a human being's personality.

2.METHODS

The design of this research starts from identifying the social problems related to patients' information, followed by the analysis of the legal framework of this subject. In the end there is a verification of the formulated rights of minor patients and a testing of hypotheses. The methods used are quantitative and the data were collected between November 2011 and March 2012, using a total number of 600 questionnaires out of which 200 were completed by medical personnel, 200 by parents and 200 by their children at random, mainly in Cluj, Mures and Harghita County. The data were processed with the SPSS software with simple descriptive methods and other methods of statistical analysis. The sample of 200 medical staff consists of the answers of 57 physicians, 111 assistants

and 32 auxiliary personnel (laboratory assistants, anesthesiologists, resident physicians). The children were 7-17 years old, with an average age of 11.25, out of which 47 boys/male and 53 girls/female. In order to avoid data distortion, the selection rule applied was to ask one parent and one child from the same family.

3.RESULTS

Studying the legal background of this subject we can conclude that the legal status of pediatric patients includes a series of rights and obligations originating both from the child status and from the patient status. Consequently, the provisions of Law No. 272/2004 on protection and promotion of children's rights corroborated by Law nr. 46/2003 on patients' rights, are incidental.

Art. 23 of Law No. 272/2004 contains only the general terms of children's right to access "information from a variety of sources", which has in view children's interests. Parents or the legal representatives of the child have the legal obligation to "provide them with information, explanations and advice according to their age and degree of understanding". These texts are to be completed with the special provisions of Law No. 46/2003 on patients' rights. Although the latter regulatory act does not contain any concrete reference to the situation of minors, its provisions are completely applicable to pediatric patients. It is not specified but it is implied that patients' rights can be exercised by children depending on their age and their degree of understanding. As we can see it in the specialty literature potential problems arise when the child is not mature enough to make a health related decision, because there are no criteria available for physicians to test the level of understanding and degree of maturity in case of children (Perera 2008).

In accordance with Law No. 46/2003 the right to information has some other characteristics, too. The patient has this right at his disposal, and he/she can renounce of information that could cause him suffering.

The major patient has the right to specifically request not to be informed or he/she can appoint another person who will be given the medical information. The patient's relatives and friends can only be informed respecting the confidentiality of the evolution of investigations, diagnosis and treatment, and with the prior consent of the patient. Moreover, if the patient does not trust his attending physician, he/she can request and obtain a second medical opinion.

The question arises whether these are applicable in the case of children, too. Normally the beneficiaries of medical information are both child and parents. Based on the text of law could it be possible not to inform the parents at the child's request? If yes, in what kind of situation? And if the parents or guardians cannot be, who is responsible to determine whether the child's wish is in his/her best interest? One can continue endlessly asking questions with no sure answers in this matter. We think that we have detected an incompleteness of the law.

In spite of the fact that the main form of communication between physician and patient is the oral one, the patient has the right to request and to obtain a written summary of investigations, diagnosis, treatment and care provided during hospitalization, but not

before being discharged from hospital¹. In the silence of the law we think that this right can be exercised by parents or legal guardians in the interest of children.

Other legal provision contains indications regarding the way how information shall be communicated to the patient: “in a respectful manner of speaking, clearly, using the least specialty terms possible”.² If the patient does not know Romanian language, this cannot be an impediment of communication. The patient has the right to obtain medical information in his/her mother tongue or in a language he/she understands. There even can be used other forms of communication, such as gestures, body language, signs or drawings. Although it makes no mention of children, this formulation is favorable for them, too, due to its provisions regarding communication on each child’s level of maturity and understanding.

The hypothesis that there is an incompleteness of the law regarding the right to information proves to be confirmed, as we demonstrated that certain texts of the law are ambiguous and not adjusted to children. And what is more, there is absolutely no concrete criterion to determine the degree of maturity and wisdom of children.

After analyzing the legal aspects of the right to medical information, we verified the level of implementation of this right, which first of all implies knowledge and application. The knowledge of these rights is of major importance according to the Constitution of the World Health Organization, which makes this statement in the sense that well informed opinions and active cooperation of the public are the most important in improving people’s health status.³

In spite of this fact, the specialty literature foresees some problems. In Great Britain there was a study in which a group of young physicians were tested from the point of view of their knowledge in the field of applying children’s rights. The results were not satisfactory because the physicians were found to have insufficient knowledge, most of them with no thorough grounding in legal proceedings (Ashtekar et al 2007).

The problem arisen is how to identify the conditions of exercising the right to medical information. The starting-point is provided by the regulatory acts permitting children to exercise this right according to their age and their degree of understanding. There are neither sure criteria of determination nor any age limitations.

Some authors (Lansdown 2000, Alderson 2001) think that even very small children wish to be informed clearly, tactfully and in an appropriate rhythm, because they are capable of absorbing complex and painful information. Small children are capable of understanding difficult or painful information which were often hidden or negated by adults. There are frequent cases when adults retain information from children aiming to protect them. However, children do not like when certain information is hidden from them or when their access to information is hindered. It is claimed that children’s exclusion creates even more confusion and concerns.

¹ Art. 12 of Law Nr. 46/2003

² Art. 8 of Law Nr. 46/2003

³ Constitution of the World Health Organization http://www.who.int/governance/eb/who_constitution_en.pdf, accessed at 04.09.2011

The child is a legal subject, not only the beneficiary of adults' good will, and as such, he/she shall be included into the process of decision as a participant (Lansdown 2000).

Given the fact that all minors have legally appointed guardians (parents), in order to be able to exercise their social role, the information about pediatric patients have to reach their guardians as well. Therefore the recipient of the right to medical information is the child and the legal guardian (parents, tutor or curator).

The sources of medical information are physicians and medical assistants, but there are situations when the information about the child's illness or treatment is forwarded through the mediation of the parents and not directly through the medical personnel (Aldiss 2009).

As it results from the discussions with the medical personnel during our research, the information of a child can take a long time, and it is more energy consuming for the staff than in the case of adult persons. Thus, parents are often asked to mediate the received information towards their children.

From the above presented facts we conclude that the right to information works effectively in the case of minors if the information gets from the physician to the child and the other way round, even if through the mediation of parents.

4.DISCUSSION

The medical personnel including physicians, assistants and auxiliary personnel as well as the parents were asked if they knew about the child's right to medical information.

Physicians (n=57) 77.2%, medical assistants (n=111) 64% and auxiliary personnel (n=32) 56.3% gave a positive answer, which means that the more advanced the professional education, the more they know about patients' rights. However, if we centralize the answers to the level of medical personnel (n=200) 33.5, they admit that they are not completely familiar with children's rights to medical information. This way we can infer that if 1/3 of health care professionals do not know certain fundamental rights, the medical educational system has some shortcomings. Similar problems have been reported in other countries, too, as we mentioned before about the research which found physicians with insufficient knowledge about the legal aspects of their profession (Ashtekar et al 2007).

In the case of parents (n=198) data are not significantly different from the results obtained in the case of medical personnel: 66.7% know they right to medical information and 33.3% do not know about this right.

From the answer given to the question whether the medical personnel (n=198) agrees with this right it can be seen that 73.7% of them think that the minor has to be informed only if he/she is mature enough. In the case of parents (n=198) this percentage is 65.7. Only 19.7% of the medical staff and 24.7% of the parents think that the minor should have the right to information in every case. The proportion of those who think that it is sufficient if only the parents have the medical information is 6.6% in the case of medical personnel and 9.5% in the case of parents. These results confirm the idea of children's rights being limited (Friedman 1997), according to which children's rights cannot be put on the same level with adults' rights in all domains of life.

The persons responsible for the child's information are both parents and physicians, as it results from 80.4% of the medical personnel's answers (n=199) and from 74% of parents' answers (n=200). The specialty literature (Aldiss 2009) makes mention of situations when the information about a child's illness or treatment is forwarded through the mediation of the parents and not only directly through the medical personnel. The numbers indicate that parents feel more responsible for informing their child.

According to 80.4% of medical staff's answers (n=199) and 60% of parents' answers, the persons to whom medical information is offered are mainly the parents (n=200). Only 13.6% of the medical personnel and 36.5% of the parents think that information gets both to parents and children.

We asked the medical personnel what their opinion was about the age when children become able to understand the diagnosis. The results indicate that more than 50% of the personnel (n=198) attribute this capacity to children under the age of 10. Only 7.1% of them think that a child between the age of 3 and 5 could be able to understand the diagnosis. The number of those who think that minors under the age of 3 acquire the above-mentioned ability is insignificant, only 1%. These results do not support the idea of certain authors (Lansdown 2000, Alderson 2001) according to whom very small children are able to understand their illness.

Our research tried to identify the reasons why children do not get complete information. Medical staff (n=198) and parents (n=198) were asked as well. The most popular variants of answer were as follows: children are considered to be unable to understand medical information (47.5% of medical personnel, 46.5% of parents), there is not enough time to communicate with children (21.7% of medical personnel, 32.8% of parents), involving the child is considered to be useless (16.2% of medical personnel, 13.1% of parents).

We also studied the attitude of medical staff regarding their efforts made to communicate with children. 87.7% of the questioned physicians usually, often or even always make an effort in this sense, but this rate lowers with the level of education of health care providers. In the case of medical assistants this rate is of 72.7% and in the case of auxiliary personnel it is of 73.4%.

A series of questions were addressed exclusively to parents aiming to find out their opinion about the medical staff's performances. Parents' image of the medical staff is not quite positive. 50.5% of the parents state that physicians rarely or even never try hard enough to make the child understand the information about their illness and treatment.

In the parents' opinion (n=196) in most of the cases physicians are not impatient with children. 14.3% of the parents declared that the physician had often been impatient, 45.9% ticked the 'rarely' variant, and 39.8% declared that the physician had never been impatient with them.

In the parents' opinion (n=196) physicians generally fully inform children about their illness. Only 9.7% of the parents declared that the physician had often neglected his/her obligation to inform the child. 50.5% of the parents report that it often happened to them that they were not completely informed, and 39.8% declared that the physician had never omitted his obligation to inform them.

In order to obtain as more truthful results as possible, we also collected data from children. They were asked if the physician had tried to explain about their illness or treatment. 43.8% of the children gave a positive answer adding that they had understood

the explanations. 27% of them were given explanations but they did not understand anything, and 29.2% of them were given explanations by their parents subsequently.

37.1% of the children (n=194) think that they are mainly informed by their parents, and only 19.1% of them think that the main source of information is the physician. However, a majority of 43.8% of the children declare that they obtain information both from physicians and parents equally. Out of all these data we can conclude that parents play the most active role in transmitting information to their children.

5. CONCLUSIONS

The essence of this right is correct and complete information provided by the medical staff. The information has to get to the child through physicians and parents. The information can only be considered effective when the child has understood his/her illness and the rest of his/her medical problems.

We succeeded to detect certain problems regarding the right to information. The legal definitions concerning the right to information are not adapted to children. Health care professionals do not know certain fundamental rights, and the medical educational system has some shortcomings. Sometimes the medical staff does not make enough effort to communicate with parents and children. The main cause of children not being completely informed is that they are considered to be unable to understand, there is not enough time for that, and involving them into the medical problems is considered to be useless. It has to be laid emphasis on parents' information because they play an active role in transmitting medical information to their children.

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