RISK FACTORS OF THE MEDICAL SYSTEM FROM THE PERSPECTIVE OF UNDERAGE PATIENTS

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Abstract: The study proposed for presentation is based on research carried out within doctorate studies in an interdisciplinary field: psychosociology – law – medicine, focusing on the situation of children in need of medical care. The timeliness and importance of the topic derives from the fact that identifying the needs of underage patients and analyzing the achievement of children's right may contribute to an increase in social responsibility towards their medical care.

The research took place in the 2011-2012 time period, encompassed several counties in Romania and used surveys, document studies and interviews. The sample comprised 200 persons in health care, 200 parents and 200 children who had experienced medical examinations and illness.

The author's analyses are based on the assumption that: although the judicial norms that make up the legal framework regarding underage patients are comprehensive and in keeping with modern practices, there are nonetheless difficulties in application. The conditions for examinations and hospitalization display an image that is less than pleasant, although the majority of children have not been seriously affected by this. The greatest issue is that medical staff have not realized the importance of establishing a therapeutic relationship with the children. This relationship might be built on positive communication, by explaining to children about their situation in terms they comprehend, and respectively, by encouraging a relationship of cooperation with the ailing children and their parents.

Keywords: heath care, children, medical rights, risks, underage patients

Introduction and developing the topic

The present study is based on research carried out within doctorate studies in an interdisciplinary field: psychosociology – law – medicine, focusing on the situation of children in need of medical care. Conveying the results regarding the situation underage patient care is in, identifying the needs of underage patients and analyzing the achievement of children's rights may contribute to an increase in social responsibility towards their medical care.

From a psychological and legal standpoint, the situation of minors is a peculiar one, since they need special attention and support from society owing to their vulnerability. The underage patient of *the child with medical issues* must be listened to while respecting confidentiality, and then informed about their options and the possibilities for their treatment. If they have grasped their own situation and the possible consequences, their consent must be obtained, and only then can the treatment be performed; in other words, the right to self-determination must be respected.

The phrase *child with medical issues* denotes any child that is to be examined or subjected to medical treatment. They most benefit from all services provided for within health insurance. From the moment they encounter their physician, the child has patient status, and the term 'patient' denotes any healthy or ailing person resorting to health care services with the right to the highest quality of medical services society can offer, in compliance with human,

financial and material resources. Efficient treatment for children assumes that medical decisions are taken, as a matter of principle, by joint consent among parents and children, under the guidance of the physician.

In order to visualize the framework of problems and deficiencies in underage health care services, including the stances of the persons involved, I have analyzed the perceptions of three factors – parents, medical staff and children – about the general circumstances offered by medical services.

In this study, we shall present the perceptions of children about how they are treated and cared for during medical consultations and hospitalization. Our analyses start from the assumption that: although the judicial norms that make up the legal framework regarding underage patients are comprehensive and in keeping with modern practices, there are nonetheless difficulties in application.

Research methodology

Information gathering took place between November 2011 and March 2012, a period in which a total number of 600 surveys were completed: 200 each for medical staff, parents and their children. The snowball non-probability sampling technique was used, since there were no data concerning the whole of the population studied, starting with investigating known individuals from Cluj, Mureş, Harghita, Bistriţa and Covasna counties. The data were processed using the SPSS software suite with simple descriptive and other statistical analysis methods. The sample of 200 medical staff contains the answers of 57 physicians, 111 nurses and 32 auxiliary personnel (laboratory technicians, anesthesiologists, residents). The age of a total number of 200 children was ranged between 7 and 17 years, with an average of 11.25 years, out of which 47% were male and 53% female.

Perceptions of children about their medical care

In describing underage patient assistance by medical staff, we will first concentrate on *how the children's examination took place*, and then we shall analyze *the conditions of hospitalization*.

The encounter between physician and patient has special significance on the therapeutic relationship, since the ailing base their perceptions on the general impression that the physician makes and tend to generalize it (Kattel, 2010). The time spent at the physician's office has a role in creating this impression. According to the author quoted, if we ask patients about the duration of the actual meeting with the physician, they will estimate it to have been shorter or longer than its actual span based on the degree of satisfaction derived from the consultation. This observation was done with adult patients. The objective or real time and the subjective time subsequently estimated by the patient is even harder to differentiate in the case of children. The subjective time is influenced by how waiting took place. "Eventful" physician-patient meetings result in a shorter subjective time. To obtain information about this, we have asked the children questions referring to how they perceive waiting times.

The processed research data shows that half of the sample examined is of the opinion that they didn't have to wait much for the consultation. The other half estimates that waiting times were longer for them. We have found out from parents that "long waiting times" are around or exceeding one hour.

Considering the issue of waiting times thusly – more palpably –, i.e., whether the child had had anything to busy themselves with while waiting, the answers are closer to reality. In their opinion, 43.6% of children were not bored, and more than half of the sample (56.4%) were. Thus, children have a tendency (to a higher degree than adults) to appreciate the passage of time in a subjective way; they measure time by activities performed and conditions they experience. This fact draws our attention on the necessity of creating conditions in which underage patients do not suffer more because of boredom and monotony. Their basic need of being engaged must be respected. Depriving them of external stimuli and allowing them to be bored worsens their general disposition.

Another inconvenience regarding underage patient care is the difficulty of reaching specialized medical units. The preliminary investigation supplied us with the information that parents complain of problems caused by long travel times involved in reaching specialist physicians. We wanted to know what children thought of this. To the question *Did you have to travel far to be examined by the physician*, 67.7% of respondents answered no, and 20.7% feel that, although they have traveled much, it did not represent a problem. 11.6% report that they have traveled much, and this was a problem for their family.

We were curious how medical examinations take place as seen by children; how children appreciate the actual medical consultations: whether they feel they are given proper attention and whether they feel the interest of medical staff not only for their symptoms, but towards their person as well. This aspect was brought to light by the question, *Who did the physician talk to? Who was at the center of attention during the consult, the child or the parents?* The majority of children are satisfied in this respect, since 12% of them report that they themselves were at the center of attention, and 45.4% opine that the physician addressed both them and their parents. But quite a significant number of children (42.6%) were under the impression that the physician paid more attention to their parents. Even if the child is of a younger age, medical staff should attach more importance to establishing a therapeutic relationship with children, since only when they feel they are more involved in this relationship will the child be able to muster their own forces towards healing, and only then will they assume responsibility for positive behavior in relation to their health. Table no. 1. demonstrated the above.

Table no. 1. Who did the physician talk to?

	children's answer	Frequency	Percentage	Valid percentage
Valid	mostly with me	22	11.0	12.0
	mostly with my parents	78	39.0	42.6
	both with me and my parents	83	41.5	45.4
	Total	183	91.5	100.0
Invalid		17	8.5	
Total		200	100.0	

Attention towards the young patients can also be shown by respecting their personal autonomy. Medical staff should ask the children's consent to be examined. When asked appropriately, most children readily collaborate.

Table no. 2. The opinion of children regarding the request posed to them to be examined

	The consent of children to b examined and to be treated	Frequenc	Percentag	Valid percentage
Valid	yes, I agreed	89	44.5	45.9
	yes, but I didn't agree and was examined anyway	17	8.5	8.8
	I was not asked	88	44.0	45.4
	Total	194	97.0	100.0
Invalid		6	3.0	
Total		200	100.0	

The proportion of those reporting that they were asked permission to be examined (45.9%) is equal to those that were not asked for consent for medical consultations (45.4%). Those who refused, but were examined without consent represent a percentage of 8.8%. We believe that these children should have been asked about their apprehensions and they should have been given the possibility to express their fear or anxiety. It can be seen that the medical staff is not aware to an adequate degree of the importance of respecting the will of underage patients with regard to being heard and listened to. It is our conviction that if discussion takes place in a way children can relate to, they will collaborate with medical staff in the majority of cases.

Another question that was meant to reveal the attitude of the medical staff towards underage patients relates to informing them about their illness and healing.

We wished to find out from the children if the cause of their illness is explained to them, and we have found that a proportion of 43.8% were given explanations by physicians as well as parents, 19.1% apprised by physicians, and 37.1% have understood the cause and nature of the illness thanks to information received from their parents.

The consent of children for treatment can only be obtained if they understand their condition and their role in the healing process. For this purpose, they should understand the reasons for being subjected to pain, i.e., to be informed about the treatment. Children might actively participate in being cured if they are aware of the process they undergo and are motivated by adults. We have attempted to find out from whom – physicians or parents – the children receive the information necessary to understand what they must do in order to be cured. Table no. 3. shows how children have experienced this issue.

Table no. 3. The experience of children with regard to understanding medical information

	children's answer	Frequency	Percentage	Valid percentage
Valid	The physician informed me and I understood	78	39.0	43.8
	The physician tried to inform me, but I didn't understand	48	24.0	27.0
	I didn't understand the information given by the physician, my parents explained it to me afterwards	52	26.0	29.2
	Total	178	89.0	100.0
Invalid		22	11.0	
Total		200	100.0	

The answers given to the question, '*Who explained the cause of your disease and the treatment needed?'* shows that physicians have given explanations children could grasp in a proportion of 43.8%. In 27% of the cases, physicians have not succeeded in conveying information in a way that could be understood by the child. 29.2% of children have subsequently received the explanations needed from parents, and only thus were they able to understand their state of health.

In light of this situation, it is no wonder that the trust children have towards physicians does not attain the expected level. To the question '*If something ails you, who do you turn to?*', 70.1% among underage patients say they turn to their parents, only 5.7% name their physicians, while 24.2% say that they make use of both kinds of assistance.

Children's trust in physicians was also tested by the question '*Are there certain things that you would only tell your physician?*' 19.6% of our sample would want that certain things regarding their state of health be communicated only to physicians, without their parents knowing about these. 80.4% do not have this need. Taking into consideration the age of these patients, we find that those who want to discuss certain things only with their physician are between 12 and 14 years of age.

The accounts of children reveal that the majority (83.9%) have not had the experience of information shared with physicians being divulged to parents. Nevertheless, a percentage of 16.1% had their right to confidentiality breached, since their secrets had been told to parents.

We wanted to know about the option children have regarding the presence of parents during medical examinations, since the discussions preceding the study revealed that both children as well as most parents prefer to stay together during hospitalizations, seeing as how this has a positive effect on the child being cured – a fact also supported by scholarly literature (Anastasia et al., 2004; Simons et al., 2001). When asked, 82.2% of children (n=191) said that their parents were present at the examination and that they weren't bothered by their presence. 13.1% entered the physician's office alone, and 4.7% felt bothered by the presence of the

parent. We have carried out the *t test* in order to ascertain whether there are significant differences based on the children's gender (90 boys and 101 girls), but the differences did not prove to be statistically significant (t=-0.860, p=0.391). Nor did we find any significant differences based on whether a chronic illness was present (t=0.43, p=0.966); we note that 11.4% of children have reported that they have chronic illnesses.

As shown before, the process of understanding–accepting by children has a decisive role in being cured. All procedures and interventions meant to rehabilitate children's health must be proffered in a way that underage patients can accept them.

To establish how this takes place in medical practice, we have asked children about the situations when they did not consent with medical measures or treatment undertaken.

Table no. 4. Consent of children regarding treatment

	Children's answer	Frequency	Percentage	Valid percentag
Valid	I consent to all that I am told	97	48.5	50.0
	I did not consent, but it was done anyway	61	30.5	31.4
	I did not consent, and my decision was respected	6	3.0	3.1
	I was never asked	30	15.0	15.5
	Total	194	97.0	100.0
Invalid		6	3.0	
Total		200	100.0	

Table no. 4 is very telling in this respect: half of the sample taking the survey says that they consented to everything they were asked to in order for them to be cured – it is probable that with these children, the path to collaboration had been found; 3.1% had refused the intervention and their will was respected; 15.5% relate that they were never asked; and 31.4% were asked but their will was not respected. These data show that not everything is being done to gain the cooperation of children for their healing. Scholarly literature (Füzesi and Lampek, 2012) holds, and rightly so, that without patients mustering their inner forces for healing, expensive treatments will not have the expected result. The work and effort put into obtaining the consent of children for interventions needed have clearly superior efficiency over cases where treatment is forcibly undertaken on ailing children.

We have also analyzed cases when the necessary consensus between children and parents did not materialize regarding the treatments needed. To the question, '*if you do not agree with your parents concerning the treatment, who has the last word?*', the underage patients answered: 3.1% say that they have the last word, with 62.2%, parents give the verdict, and in 34.7% of the cases, the physician is the one who decides the treatment to be used. It is a matter of course for physicians to be primarily responsible for the treatment used, but they should make it so that parents as well as children understand and accept the acts involved in the process of rehabilitation. Physicians need a partnership with parents and children, because otherwise, the most important factors of healing are lost.

Another very important issue in assisting underage patients is represented by the situation of *hospitalization cases*. It is known (Füzesi and Lampek, 2012) that if the psychological comfort of children is ensured, they heal faster, and for this reason it is important to analyze the perception of children in connection with their experiences in the case of hospitalizations.

Out of the 200 children who have experienced illness, 69.3% have had hospitalizations. With reference to the frequency of hospitalizations, we have found that: 30.7% from the vulnerable group had not been hospitalized at all; 42.7% had been hospitalized less than three times, 17.3% had between 3 and 5 hospitalizations; 8% had stayed in hospitals from 5 to 10 times; and 1.3% had been hospitalized more than 10 times.

We have also gathered data about the duration of time spent in the hospital, and thus, we have found that: 30% had not been at hospitals at all; 55.4% had been in the hospital for a week at most; 6% had been hospitalized for two weeks at most; and finally, 8.6% had spent more than two weeks in hospital.

In perceiving the time spent in hospitals, the fact whether parents were allowed to stay with children has a determining role. According to their reports, most children (62.9%) were not inconvenienced by their parents not being there with them during hospitalization, since parents were allowed to stay with them. 37.1% among those queried said that parents were not allowed to be permanently by their children's side. Taking into consideration the age of the children questioned, we have realized that those who said they had been hospitalized without their parents had been aged over 14.

Analyzing the issue in terms of other questions with respect to the presence of parents in the hospital, we have ascertained that with more than half of the sample (64.2%) of children queried, parents stayed as long as they wished at the hospital. 26.7% state that their parents were not allowed in, and 8.5% say that their parents were asked to leave while the child was hospitalized. The difference from the preceding question is that in this case, we have also taken into account the situations when parents spent only some of the hospitalization period with their children. Table no. 5. displays these findings.

Table no. 5. At the hospital, were your parents ever asked to leave, or were they forbidden from seeing you?

	Children's answer	Frequencies	Percentage	Valid percentage
Valid	my parents were not allowed in	47	23.5	26.7
	my parents were asked to leave	15	7.5	8.5
	my parents stayed as long as they wished	113	56.5	64.2
	I don't remember	1	.5	.6
	Total	175	89.0	100.0
Invalid		25	11.0	
Total		200	100.0	

The answers to open questions have shown that it is the way to spend time, the possibility for engagement or lack thereof that is most defining about the experience of children with regard to hospitals.

The underage patients included in the research were asked about what they were allowed to do and what pastimes they could have during hospitalization. Fig. no. 11. shows their responses.

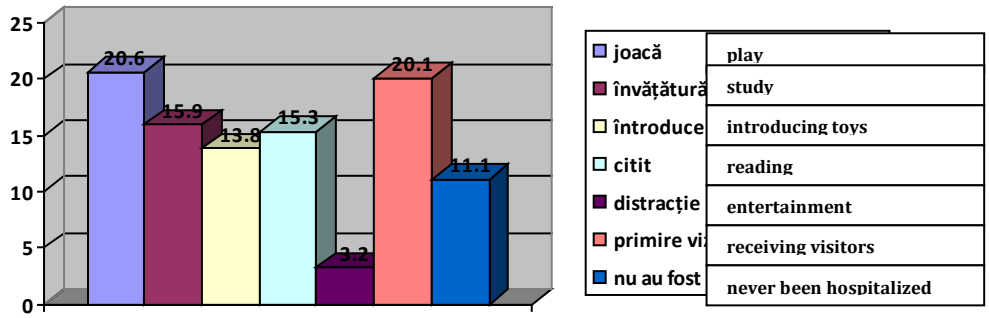

Fig. no. 1. Pastimes of children during hospitalization

We can see that most children name playing and receiving visitors as preferred activities during hospitalization. To prevent *hospitalism syndrome*, the usual activities children engage in should be respected. Even in the circumstance of being hospitalized, they must have the possibility for companions, play and learning.

We have prepared a cross table to be able to track children's pastimes in the hospital according to their age. If we follow the frequency with which they engage in certain activities, we are able to recognize the preferences of hospitalized children vis-a-vis the types of activities that offer the most satisfaction. Thus, for children aged 9-13, it is very important that they have the possibility to play; around ages 8-10, children prefer to bring their own toys to the hospital; between 11-13 years of age, the possibility to have intellectual pastimes (study, reading) comes to the forefront; entertainment is preferred mostly between 9 and 12 years of age; and receiving visitors is prevalent among those aged 11 to 14. These data are useful to ensure conditions necessary for children so that they can be cured as quickly as possible.

Ensuring physical, psychological and social circumstances are, however, not sufficient for the rehabilitation of underage patients. These factors only make up the framework for rehabilitation, while ensuring the appropriate medication still comes first. We have asked the children interviewed whether they had ever been in a situation in which they needed medicine their parents could obtain. It is of note that around 10% (usually, 4.1%, and often, 6.7%) of ailing children do not receive necessary medication. Equally dire is the fact that in 42.1%, this happens, rarely. Only in 47.2% out of underage patients can continuous treatment prescribed by physicians be ensured.

The situation presented above shows the fact that many children are exposed to various risk factors when they come into contact with the medical system. Because of this, after a clear picture had materialized (after having processed the data),, we have conducted talks in the form of interviews with physicians and parents about the relevance and possibilities of improving risk factors regarding underage patient care. For this purpose, we have prepared Table no. 6,

which contains the relevance of risk factors pointed out by the children. The most severe among these have been marked with three + *signs*. And the extent to which these might be improved upon have also been marked with + *signs*, in which case the issues marked with three signs are the most susceptible to change. Risk factors that, during the evaluation by physicians and parents, had received only one sign, are less prone to be influenced by rethinking and attitude change on the part of parents. In these cases, it is a matter of more complex socioeconomic conditioning.

Table no. 6. The relevance and changeability of the issues highlighted

Variables analyzed	**Relevance**	**Changeability**
securing medication	+++	+
lack of toys, preventing boredom	++	++
lack of hygiene, unpleasant smells	++	++
overlong waiting or scheduling times	+++	+
attitude of medical staff, impatience, harshness	++ +	++
long distance to specialized units	++	-
disregard toward children, lack of communication with them about their condition	+ + +	+++
overcrowding in hospitals	+ +	-
lack of company for the child	+ +	+ +
physical circumstances (beds, sheets, furniture)	+	-
ensuring the process of teaching-learning	+	+

By improved measures for better issue management and by respecting basic needs as well as the age characteristics of the children, several of these issues seem to be solvable. Improving the conditions for underage care must be based on respecting the needs of ailing children. In the following, based on the research data, we have attempted to create an adaptation of the Bartholomew et al. model (2006, p. 219) in describing the needs of underage patients.

The model synthesizes the various categories of issues affecting health recovery in children, and plays a part in ascertaining the level at which underage patient care is ensured. These factors determine their quality of life.

Based on this model, we are able to recognize the risk factors that hamper the fulfillment of basic needs that underage patients have. The levels at which intervention is necessary in order to develop the health care system are emphasized. Thus, it concerns developing an adequate behavior at the level of the human factor, interventions meant to develop pro-health behavior, to ensure quality with regard to improving conditions in the environment and promoting the legislative framework that can ensure certain solutions that are in the interest of child patients.

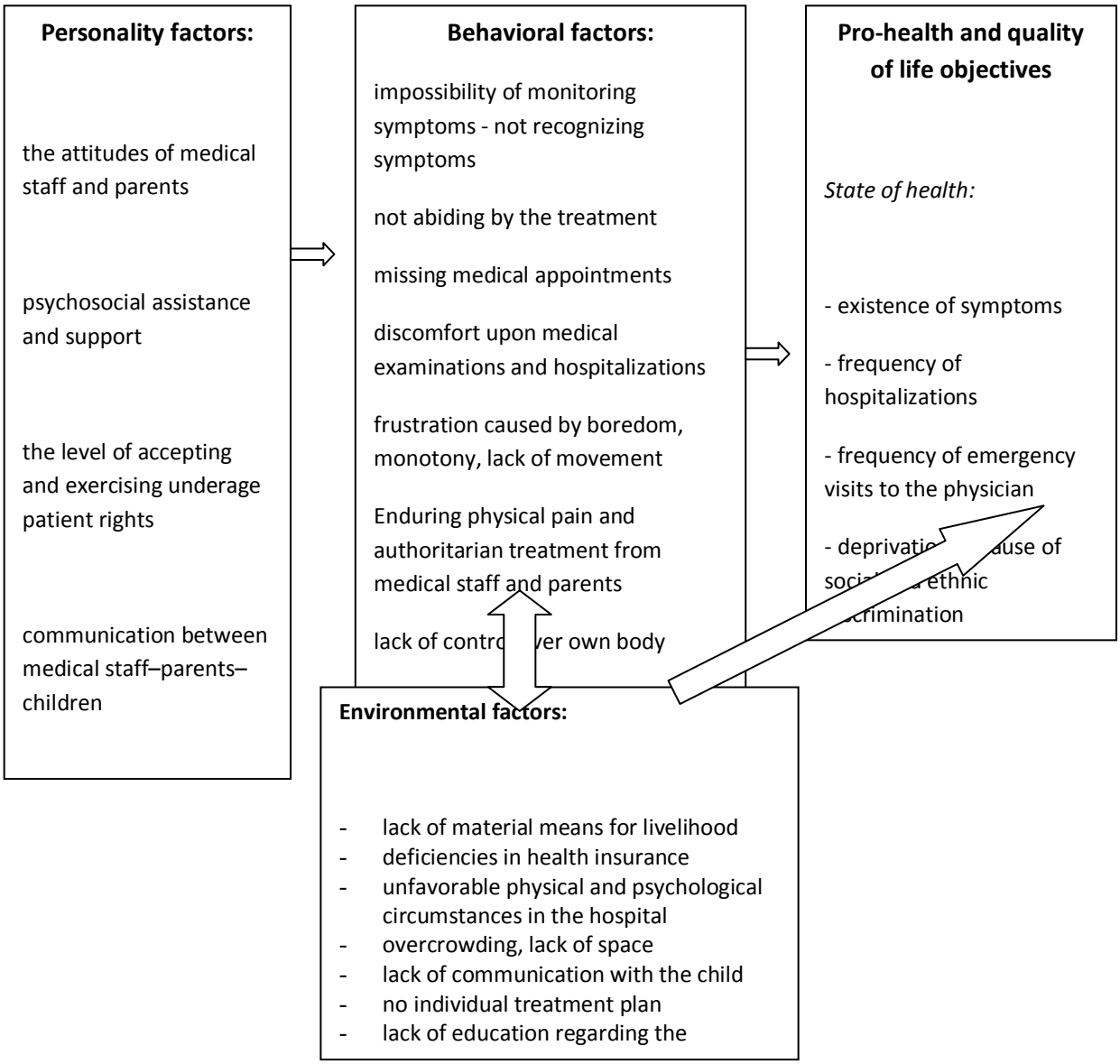

Fig. 2. Adapting the Bartholomew et al. model (2006, p. 219) to the description of determining factors in underage patient care.

Conclusions and discussion

The conditions for examinations and hospitalization display an image that is less than pleasant, although the majority of children have not been seriously affected by this. The greatest issue is that medical staff have not realized the importance of establishing a therapeutic relationship with the children. This might be built on positive communication, by explaining children their condition in terms they comprehend, by encouraging a relationship of cooperation with the ailing children and their parents.

Another risk factor regarding underage patient care is the lack of funds and the lack of subsidized drugs, but medical staff try to cope with these obstacles and has a generally positive attitude towards children and day-to-day issues.

The order in which the issues were pointed out is the following:

- physicians complain of insufficient financial resources (both in material and personnel);
- parents are dissatisfied with the price of drugs and with the accessibility of treatments;
- children complain of unpleasant smells, boredom, poor food and pain they must endure;
- there are signs of discrimination in the health care system.

By these analyses, we are able to maintain our assumption, which posits that: although the judicial norms that make up the legal framework regarding underage patients are comprehensive and in keeping with modern practices, there are nonetheless difficulties in application.

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