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Ph. D. thesis abstract

Rights and moral dilemmas pertaining to children with medical diagnoses

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Keywords: minor patients, rights: information; listening; self-determination: full autonomy, limited autonomy; confidentiality; freedom of decisions regarding sexual life; health insurance; communication with medical staff – underage patients, needs of underage patients.

The aim and reasons for the study

By analyzing the situation of underage patient care, the author wishes to contribute to growth of social responsibility regarding children's medical care, since the existence of illness at very young ages generates a series of issues to which answers must be found on the level of both health care and family.

Underage patient care must be ensured according to well-established standards. Within this paper, identifying these was done mainly form a legal perspective, and then also from that of underage patient's needs as they are perceived by people involved as research subjects.

Since scholarly literature in Romania makes little mention of this topic, especially regarding the rights of underage patients, this research paper boasts a high degree of originality and topicality. The analyses focused on the assertion of underage patient's rights and the issues discovered during this process.

The structure of the paper

The paper consists of six chapters and is divided into two main parts: the first part contains theoretic research, while the second part, after presenting the empirical research methods, includes the data processed statistically and their interpretation, as well as the conclusions. The contextualization of the research was made based on 133 sources in literature – studies and treatises – as well as three documents of European or worldwide organizations. The publications that refer to other works in the field, by their content, have provided the author with both starting points regarding empirical research as well as a representation of child patients. The data and opinions provided by scholarly literature sometimes converged, other times diverged or even conflicted; in these situations, the results were subjected to meta-analysis and were combined. Thus, starting from the consistencies of one batch of results, more precise and credible results were obtained than in primary studies (Morton, 1997).

From the statistical data gathered by institutions in pediatric health care, information connected with children's health was retained, according to which children's health deserves increased attention.

The **Introduction** (first chapter) encompasses the motivation of the necessity for being preoccupied with the topic studied and the way the research was designed.

The author starts from the idea that the situation of the rights of children with medical diagnoses is a topic of current interest, with significant social impact, and is convinced that legal norms would be able to allow more possibilities than those already utilized in everyday practice. Through the analysis of the situation in which underage patients' health care is in, as well as by identifying the needs of its young beneficiaries, the author of the thesis wishes to advance intervention practices by which the level of health care afforded to children may be improved.

The research primarily intends to analyze the implementation of the rights of underage patients seen as beneficiaries of health care services, as per the design shown on fig. 1.

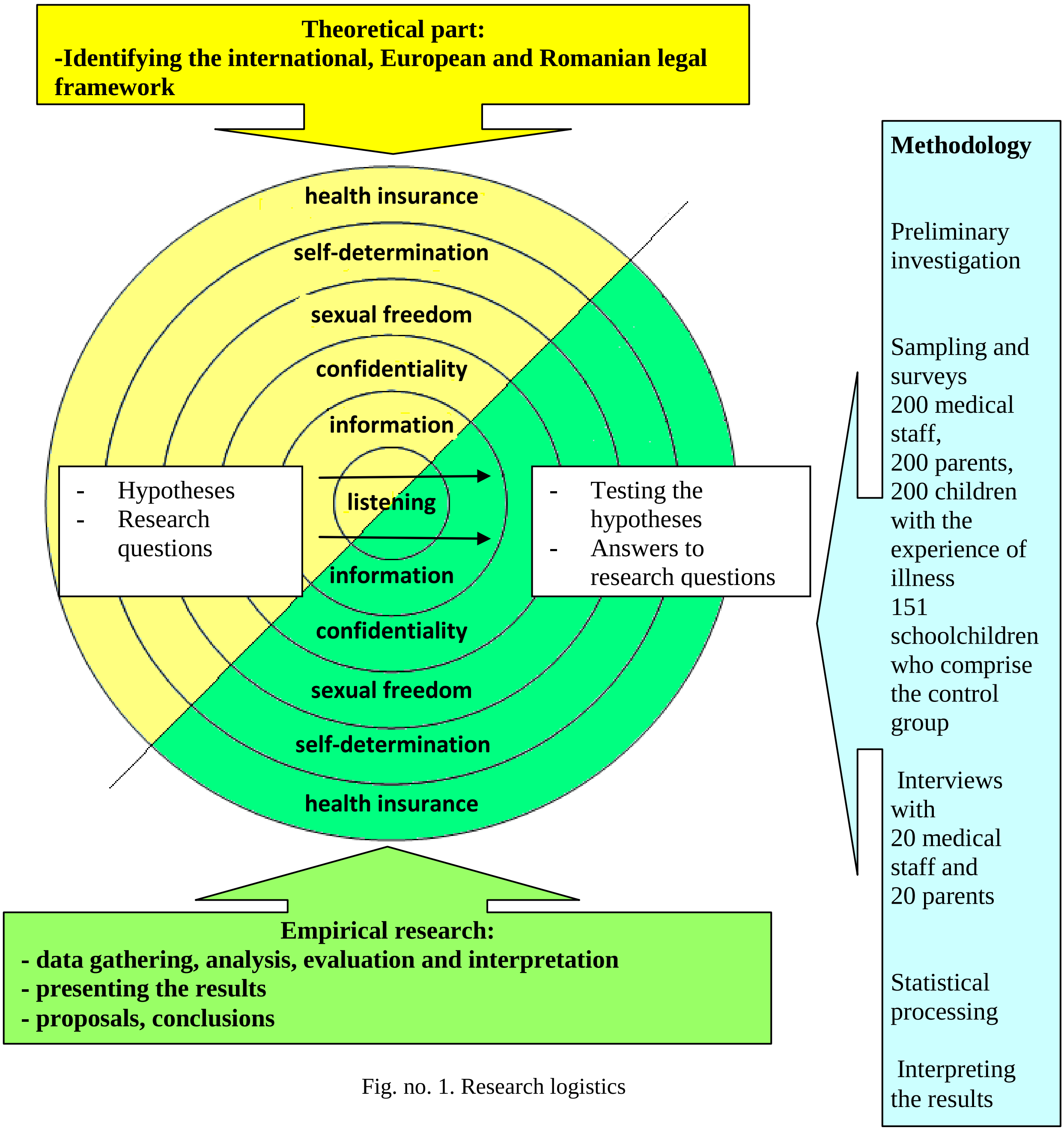

Fig. no. 1. Research logistics

Empirical research is based on the *perceptions* of the persons involved in the triangular relationship between doctor, patient and child. The actual research was preceded by a preliminary investigation consisting of discussions with several specialty medics and parents. The information was, for the most part, obtained via surveys and interviews, conducted ancillary to the study of written documents (for example, reports of national and international organizations).

Seven categories of rights comprising the basis of the specific regulatory framework, i.e. the right to be heard, to information, confidentiality, self-determination, freedom of sexual life as well as the access to health care services. The author of the thesis believes that the final goal of the entire legislative framework that includes specific health care rights of child patients should be the insurance of children’s wellbeing.

Aside from aspects pertaining to legislation – and in order to have a complete picture of the situation of underage patient’s health care –, risk factors present at the level of children with previous experience of illness were highlighted, and investigation was undertaken concerning the needs of children requiring medical care.

Laying the basis of research begins with analyzing the social responsibility of the medical act towards children. The data gathered form specialty articles and the documents studied have helped the author to reconstitute on a theoretical level the social realities existing between the three categories of persons targeted by the research: medical staff, parents and the child.

Chapter 2 (which includes six subchapters) presents the contextual research with relevant data and information from scholarly literature. The methods used were inspired by the theoretical research that has specialty articles, legal norms and periodic reports made by various institutions in the field as its *sources.* The author resorted to *document analysis, meta-analysis* and *comparison* in this first stage of theoretical research.

In order to broach the topic researched, ascertaining the acceptation of terms such as child, patient, illness and health was considered to be a priority.

As a point of departure in contextualizing the topic, the author insists on the existence and importance of the connection of health and health care rights with human rights and children’s rights, respectively: “health issues in the 20th century were almost exclusively confined to diagnosis, treatment and prevention of illness (...), and practitioners fail to recognize the relationship between health and human rights and, as a consequence, consistently marginalize their role in promoting health in society” (Iacopino, 2002, p. 3).

Health depends on respecting several complex rights with regard to living conditions. “Conceptualizing human rights as essential conditions for health was first mentioned in the mid-1990s. Since then, health care professionals increasingly recognize the importance of human rights in the protection and promotion of individual and global health. The importance of human rights in medical and health care practices has also been recognized in several declarations and by publications from professional health care organizations” (Cotter et al. 2009, np.).

Then, the topic referring to children’s health needs and the quality of being an object of rights is developed. It is shown that the approach based on rights has at its core universally accepted normative standards. The regulatory framework is ensured by the human rights stipulated internationally, and children are considered human beings with specific needs, which has a positive influence on implementing medical assistance for children, helping shape social policies of health care. A fundamental trait of the approach based on rights consists of considering the child as a subject with rights. This new point of view appears as a stark contrast to the traditional model, where the child was perceived as a discretionary object of intervention, treated in accordance with the will of adults (Tobin, 2006).

Furthermore, there is talk of social responsibility towards children, since minors are not capable to fully represent their own interests because of their tender age and limited life experience. The social policies of child protection are presented, at it is shown that changes in the field of child protection “aims for a more sensitive rapport from local communities, politicians and the government in favor of children and their families, but also an increased professionalization of social services” (Roth-Szamosközi, 2005, p. 34).

The social responsibility of the medical act towards children is reflected in the legal framework of the rights of underage patients that support health care services, but at the same time raise further moral dilemmas. These dilemmas are grouped around children’s autonomy and the sphere of executive power in health care issues. Thus, one must take into account “the multiple repercussions that illness exerts on the patient’s family and social environment” and must prevent the “destabilizing effects that dysfunctional processing of the illness by the family or the community may exert on the patient. To that end, it is also important that medics evaluate the way they best provide health care to the patient not only from a strictly medical point of view, but also from that of the principle of solidarity, necessary for maintaining and developing the life of the community in its complexity (Miu, 2004, p. 13).

From a legal point of view, the situation of minors is idiosyncratic, since they need special attention and support from society because of their vulnerability.

In this chapter, several more studies are presented in light of scholarly literature; these are related to health care policies as well as strategies for implementing children's rights. The studies cited emphasize the timeliness of the topic, indicating a multitude of issues concerning the system of children's health care. Such an issue would be the situation of decisions pertaining to children's health. The author of the thesis is of the opinion that the minor must be taught from the earliest age how to make a responsible decision, and to that end, must be involved in the decision-making process without powers of decision: one must "assure to the child who is capable of forming his or her own views the right to express those views freely in all matters affecting the child, the views of the child being given due weight in accordance with the age and maturity of the child" (UNO 1989, art. 12.).

The same chapter contains the legal status of underage patients, which comprises two things: on the one hand, it contains children's rights regarding health safety and access to medical services, and on the other hand it contains the special rights of hospitalized adults. In reference to the legal status of underage patients, it can be noted that minors enjoy special protection, with rights that differ from those of adult persons.

In the following, we present the main categories of rights that underage patients enjoy. The author of the thesis insists upon the fact that respecting the rights of underage patients would have positive consequences on the whole of society, as Mârza-Dănilă asserts (2009, p. 51): „progressively switching over from focusing on treating illness to increasingly taking into account the dimensions of the patient, i.e. focusing on a unique and complex subject, would allow the improvement of the population's health as a whole." This complex also includes implementing the rights of underage patients; these can be grouped into 6 categories of rights, as shown in Fig. no. 2.

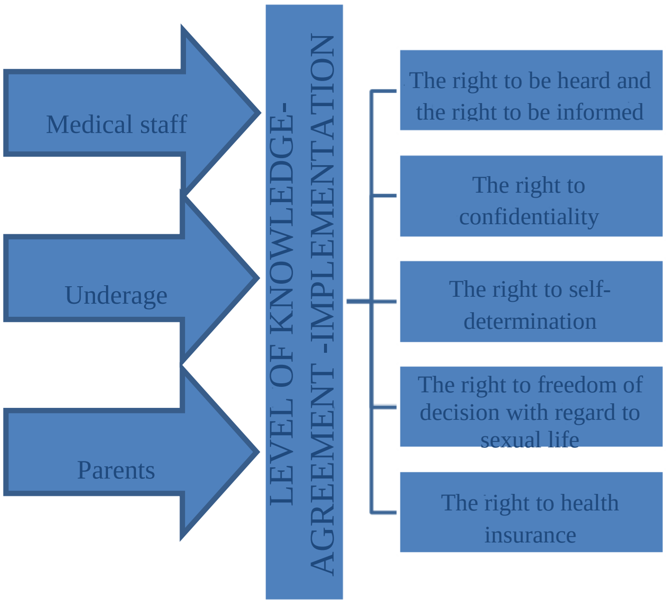

Fig. no 2. The structure of the analysis of rights categories with respect to child patients

These categories of rights have been analyzed both from the perspective of medical staff as well as that of parents, and respectively, children.

The research part concludes with a study comparing international and European legislation with Romanian legislation. Following the comparative analysis, the conclusion emerges that *Romanian legislation concerning child protection and patient's rights is in accordance with international as well as European legislation.*

Chapter three, entitled: *Social perception with regards to the rights of child patients. The methodology of quantitative research.* – it presents the methods by which the degree of practical implementation of rights as well as the state of underage patients' health care. The *sources of information* of the empirical research stage are the opinions expressed by specialists in charge of underage health care, parents, and children.

The author relied on *quantitative* as well as *qualitative* data in order to get as realistic a picture as possible of the situation concerning child patients' rights as they appear in the **perception of the persons** targeted by the research.

Quantitative information was obtained via **surveys:** three survey models had been developed, taking into account the specifics of each category of persons targeted by the research: medical staff, parents and children. The surveys were inspired by scholarly work from authors involved in the protection of child patients (Aldersen, 2001 and 2009; Brabin et al., 2007; Jenkins, 2010; Lansdown, 2000; Parekh, 2007; Perera, 2008; Tobin, 2006).

The sample comprised, at the beginning, a total of 600 cases made up of 200 persons from the field of medicine, 200 parents and 200 children that had had the experience of medical examination and illness.

Subsequently, the sample involving children was extended with 151 more cases – the control group – made up of pupils aged 7-17, representing the population of children from public schools. Thus, the author was able to perform comparative statistical calculations.

The *qualitative* data resulted from **interviews** that have been used both in the preliminary investigation with the aim of setting the boundaries of the research field as well as after the surveys had been done, in order to clarify certain aspects. Within the interviews with the topic of difficulties in implementing children's rights, the author sought to evaluate the relevance of the issues identified and the possibilities to amend these. The interview was based on a guide concerning the way children's health care system works. Thus, the author set out to verify the credibility of *quantitative* data, as well as their completeness. A total of 40 interviews were conducted, of which 20 with pediatricians and 20 with parents. The interviews helped the author in working out models of explanation and a descriptive assessment of the state underage patients' rights are in.

The non-probability or non-random, "snowball" method was chosen as the sampling method. The majority of those included in the research were from an urban environment: the towns of Cluj-Napoca, Tg. Mureş, Gheorgheni, Odorheiu Secuiesc, Zalău, Sf. Gheorghe, Reghin, Sovata, Huedin and Braşov, as well as adjacent rural settlements.

The data were processed with the SPSS statistical software package using descriptive methods such as frequency calculation, crosstabs (cross-tabulations), calculating averages, and analytic methods such as bivariate correlation, paired sample T-test and independent sample T-test (simple ANOVA). To identify issues on the level of children's health care system, I have developed a social diagnosis with the help of the PRECEDE model, as well as an evaluation of the situation in implementing underage patients' rights via SWOT analysis.

According to the conclusions of theoretical research and the preliminary analysis, the judicial norms that make up the legal framework related to underage patients, though extensive and conceived in a modern spirit, have some deficiencies in their application. In order to ascertain this general statement, a series of *research questions* were formulated that address the perceptions of the subjects taking part in the research concerning the situation of the rights of underage patients:

1. What are the general conditions offered by medical services, and which are its main deficiencies?
2. Which category of adults included in the research: medical staff – especially doctors – or parents, are the ones that are most familiar with the rights of child patients?
3. How does the child's right to be heard appear in medical practice?
4. Is the child's right to medical information respected in medical practice?
5. What is the practice with regards to respecting confidentiality in the case of children?
6. Is the child's right to self-determination respected or not?
7. Who is the person making the final decision in matters of health when there is no consensus between doctor, parent or child?
8. What is the situation of the child's right to freedom of decision regarding their sexual life, viewed as a health right?
9. What is the main reason for the inefficiency of the health insurance system?

The author of the studies set out to verify four hypotheses.

The second part of the thesis, after presenting the methodology specific to this section and the demographic data, contains a complex statistical analysis with all three categories of persons targeted by the research (medical staff, parents and children), including the conditions of hospitalization.

Chapter 3, entitled *Results and discussion*, features an analytic description, a diagnosis of the situation of underage patient care, with the aim of formulating alternatives that target finding solutions for the issues connected to assisting ailing children. The PRECED-PROCEED model was utilized (Green et al., 1980), which is an integrative analysis and projection model. *The social and educational diagnosis* was set in several phases:

In *Phase 1.* – it could be ascertained that: the judicial norms that make up the legal framework related to underage patients, though extensive and conceived in a modern spirit, have some difficulties in their application.

In *Phase 2.* – of the analysis, the needs of underage patients highlighted in the course of the thesis were presented synthetically. Based on these, an epidemiological diagnosis began to take shape, i.e. the issues that have the greatest impact on the functioning of the underage patient care system were identified.

- *Issues highlighted by medical staff*: the lack of funds for instruments, modern diagnostic and treatment facilities; expensive medication and their unavailability on inventory; unfriendly physical environment (obsolete furniture); unfavorable, hostile entourage and climate (lack of decorations and toys); staff with no specialized training; the lack of techniques for communicating with children; too many patients per specialized staff; lack of psychologists; lack of education about health for children.

- *Issues highlighted by parents:* difficulty in procuring medication and finding the appropriate certified specialist; difficulties in establishing the diagnosis; excessive waiting times or scheduling periods; inappropriate attitude from the medical staff (e.g. impatience, haste, lack of attention, manifestations of superiority, accepting gifts and money from parents, etc.); great distance from specialized units; lack of attention towards children, lack of communication with them concerning their state of being; overcrowding in hospitals; lack of hygiene, inadequate ventilation in the hospital; parents' accommodation near hospitals; office visit fee.
- *Issues highlighted by the underage patients themselves:* difficulties in procuring medication; lack of toys, boredom; lack of hygiene and unpleasant odors; excessive waiting times; impatience, harshness from the medical staff; great distance from specialized units; lack of attention towards them, lack of communication concerning their state; overcrowding in hospitals; lack of companionship; not ensuring the process of teaching-studying.
- *From the perspective of implementing the rights of ailing children,* a few observations had begun to take shape:

  A. *Concerning the right to be heard and to be informed:*

- medical practice does not place sufficient emphasis on communication with the child;
- oftentimes, parents speak for the child, which may distort essential information;
- the number of cases where mainly parents are consulted, and not the child, comes to 42.6%, which is noted as a negative aspect;
- the legal definitions regarding the right to be informed are not adapted to children;
- persons who work in health care are ignorant of certain fundamental rights, the medical educational system presents some deficiencies;
- sometimes, the medical staff does not make sufficient effort to communicate with the parents of the child in question;
- the main cause for which children are not fully informed resides in the fact that they are considered incapable, there isn't sufficient time, and involving them in medical issues is considered to be useless;

- a larger emphasis must be placed on informing parents, since they hold an active role in conveying medical information to the children.

B. Concerning the right to confidentiality:

- only a quarter of the children trust the medical staff; the children do not wish to conceal the medical issues that they have from their parents, but do need confidentiality;
- doctors as well as parents are willing to respect the child's wish to enter consultations alone, but parents will not give up information regarding the state of their child;
- parents as well as children believe that the right to the confidentiality of communication between doctor and patient are generally respected.

C. Concerning the right to freedom of decision regarding sexual life and reproduction:

- the decision of parents on abortion deeply affects the self-determination of young adolescent girls;
- doctor's advice matters in most of the cases, but when decisions are made on abortion, parents disagree with the decision being made by the underage girl.

D. Concerning the right to self-determination:

- medical staff is not entirely familiar with the content of the right to self-determination;
- when there is no consensus regarding the medical issue between parents, child and doctor, the parents are the ones who make the final decision;
- many children are not asked at all regarding a medical consultation;
- a limited autonomy is recognized for minors who are sufficiently informed and responsible, but it is rarely respected.

E. The analysis of the right to health insurance:

- parents must often buy medication for children out of their own resources;
- parents are dissatisfied with the availability of subsidized pharmaceuticals;
- doctors generally have a better opinion of the health care system than parents.

Within the epidemiological diagnosis, a *comparison* was drawn *between certain traits of children who have experienced illness (the vulnerable group) and those of the control group.*

Each child from the vulnerable group *had been to the doctor* at least three times a year. This situation in the case of children from the control group presents itself thusly: 17.6% say that they have not visited the doctor in the previous year; 38.5% have been seen by the doctor at most three times a year; 29.1% have been to medical consultations from 3 to 5 times a year; 10.1% have been to the doctor from 5 to 10 times; and 4.7% state that they had had to meet with the doctor more than 10 times a year.

Chronic illness in the vulnerable group is present in 11.4% of the children, while the control group presents a percentage of 8.8%. From the group with the experience of illness, 69.3% have been *admitted into hospitals*, while the control group has a 4.1% proportion of admission.

The distribution of the frequencies of admission in the children from the two categories was also analyzed. The percentage of children from the vulnerable group that have had no admissions is 30.7%; 42.7% have had less than 3 hospitalizations; 17.3% were in the hospital from 3 to 5 times; 8% have stayed in the hospital between 5-10 times; 1.3% have undergone more than 10 hospitalizations.

The following is characteristic to those from the control group: 55.5% have had no admissions; 19.5% have had less than 3 admissions; 9.6% have been admitted from 3 to 5 times; 2.7% have been admitted between 5 and 10 times; and also 2.7% have had more than 10 hospital admissions.

In *Phase 3.* – Behavioral and environmental diagnosis: the behaviors as well as environmental factors that must be modified in order to correct the issues identified in phases 1 and 2 were identified. To this end, Schaalma and Kok's (2006) model was utilized, which helped to analyze doctors' behavior and bring to light the elements of the doctor-patient relationship that ensure optimal resonance among those taking part in this relationship. It was ascertained that: for this, it is necessary that the doctor take part in the medical act with an attitude conscious of all elements making up the exchange of information; a mutual accommodation between the sender and the one decoding the message should be accomplished; the decoded message activates a series of factors at the level of the patient, as it can be traced on Fig. no. 3. Thus, the conclusion was reached that aside from the medical issue, a multitude of other factors come into play in the relationship with the patient that have to do with the personality of the doctor, and these determine the way the message doctors send is received. Decoding the content of the message depends not only on cognitive processes, but primarily on emotional, motivational as well as volitive properties of the participants to the medical act. In order to obtain a certain expected behavior from children, it is necessary that medical staff have a clear intention of positively influencing the behavior of underage patients and not to limit themselves to the treatment of symptoms. For this, they should have the appropriate attitudes, consciously assumed, and a motivation to create a framework in which the children feel safe and are capable of accepting the treatment proposed for them. The values and convictions of the medical staff, the strength of the self, their motivation, as well as the power of influence they enter into the doctor-patient relationship all have great relevance.

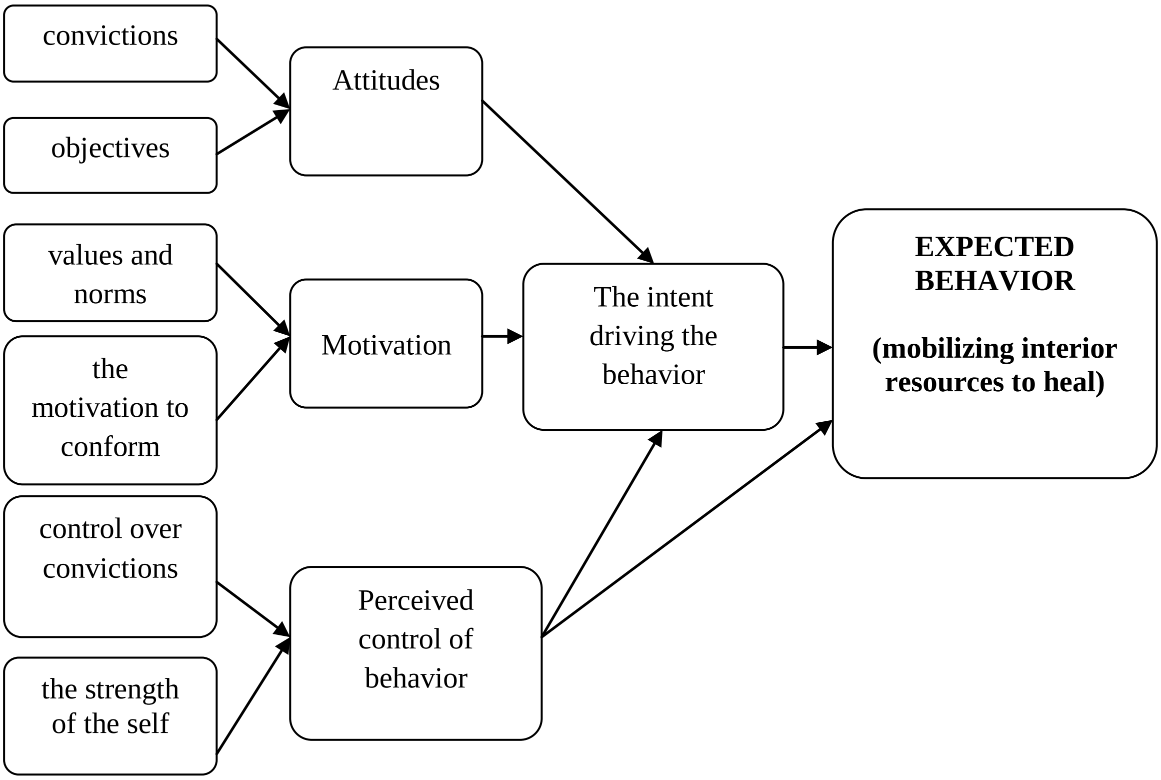

Fig. no 3. The “Theory of planned behavior” model. Source: Montagno, Kasprzyk, Taplin, 1997 – cited by Schaalma, Kok, 2006, p. 514) – adapted to the communication of medical staff with underage patients

In *Phase 4.* – Educational and organizational diagnosis: risk factors as well as protection (consolidation and support) factors that act on the level of the system studied by the author’s thesis were identified. To this end, interviews were conducted with pediatricians. Yet on this occasion, the medical staff was very reserved, and did not supply concrete data concerning practical issues they are confronted with day by day. Both in a group situation and individually, while on hospital premises, they have not reported cases in which the rights of underage patients had supposedly been infringed upon, or cases that have suffered because of deficiencies in the health insurance system. The information that the author of the thesis had received referred to issues they had already known beforehand, i.e. motivating hardships by the lack of material resources. The fear of pediatricians to make public the woes the medical system is confronted with is to be noted.

To have an image about the situation in which the minors' health care system is in – based on the synthesis of data gleamed from the subjects of the research –, the author offers a model (Green et al. 1999) to evaluate the factors that influence the quality of life among underage patients. It is a model structured on several levels (four stages presented horizontally), which also reveal latent (indirect) determiners in the degree of satisfaction among underage patients. It can be seen (fig. 5.) that the satisfaction of children and the quality of their lives is influenced by a series of subjective factors, such as the motivation of the medical staff in regards to their work, the way they relate to the beneficiaries, their openness to change, their view about the state of illness and the illness itself, the degree of information about new regulations in the health care system.

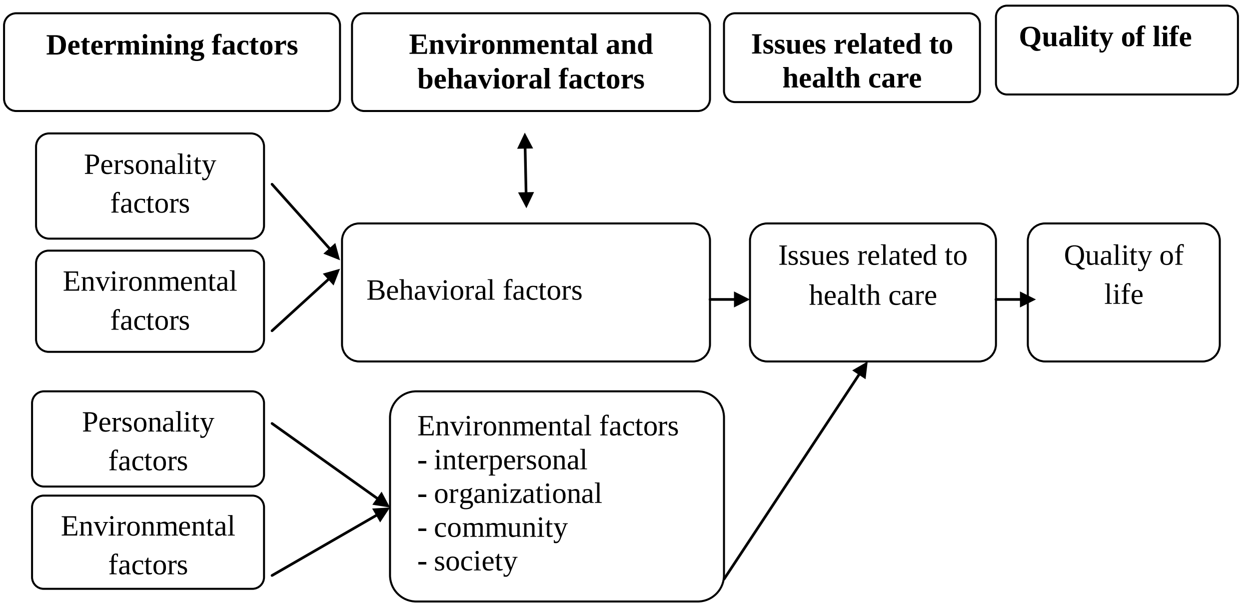

Fig. no 4. The model for evaluating risk factors that obstruct the satisfaction of underage patients' needs (Logic model for needs assessment), source: Bartholomew et al., 2006, p. 209)

beneficiaries, leads to an increase in the quality of life among underage patients. Reading the model (as instructed by Green et al. 1999) is done from the right to the left, i.e. the expected result is known, and the risk factors that hamper the attainment of the goal must be identified.

Concrete facts of such a nature that would worsen the situation in which the child patients have been gleamed mostly form the accounts of parents. These are:

- the quality of life in ailing children may be compromised by the following facts:
    - the child was dissatisfied because they could not study in the hospital,
    - the child was deprived of a stimulating environment, was bored,
    - children were kept in unfavorable physical conditions and were not treated adequately.

- issues related to health care:
        - the special diet could not be maintained,
        - hasn't received the necessary medication because more expensive drugs were replaced with other, cheaper ones,
        - almost half of the children from the sample studied had had issues because the treatment had to be interrupted or modified because certain medication were not to be found or could not be purchased,
        - certain biological tests could not be performed, these being expensive and/or lacking the necessary facilities,
        - infections caused by lack of hygiene (skin rashes).
- environmental and behavioral factors:
    - behavioral factors
        - harshness and impatience towards the children,
        - the lack of adapting the way of communication to the child's level of maturity,
        - the child was not asked, informed, was treated like "an object",
        - the emotional state of the child was not taken into consideration (they were scared).
    - environmental factors
        - lack of hygiene in the ward,
        - overcrowding,
        - the child's mother had to sleep on the same bad as the child without receiving bed linen,
        - the ward was cold and there weren't enough blankets,
        - sinister physical environment in the wards and restrooms.
- determining factors
    - behavioral factors
        - lack of interest towards the children,
        - disinterest in their work, especially nurses and auxiliary staff,
        - rigidity in the doctors' behavior.[1] (I have been doing it this way for 30 years, I will keep on doing it this way),

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[1] A concrete case: Parents' 45-day medical leave (10 days from the family medic + 35 from the specialist) – medics do not know this regulation

    - disinterest towards new legislation,
    - the auxiliary staff makes noise and disturbance in the morning (suddenly waking the children),
  - environmental factors
    - the lack of financial resources,
    - regulations putting both medical staff and patients at a disadvantage,
    - a narrow list of subsidized pharmaceuticals.

The model presented has the advantage of differentiating between the levels of origin of the risk factors. To ensure a positive quality of life for underage patients – remarks the author of the thesis – we must begin from reshaping the determining factors, since these, by the behavior displayed on the part of the medical staff and the conditions created can affect the state of health, and through this, the quality of life of ailing children.

The next chart – conceived by the author of the thesis – took shape with the intention of formulating positive alternatives regarding the improvement of the medical act destined for children.

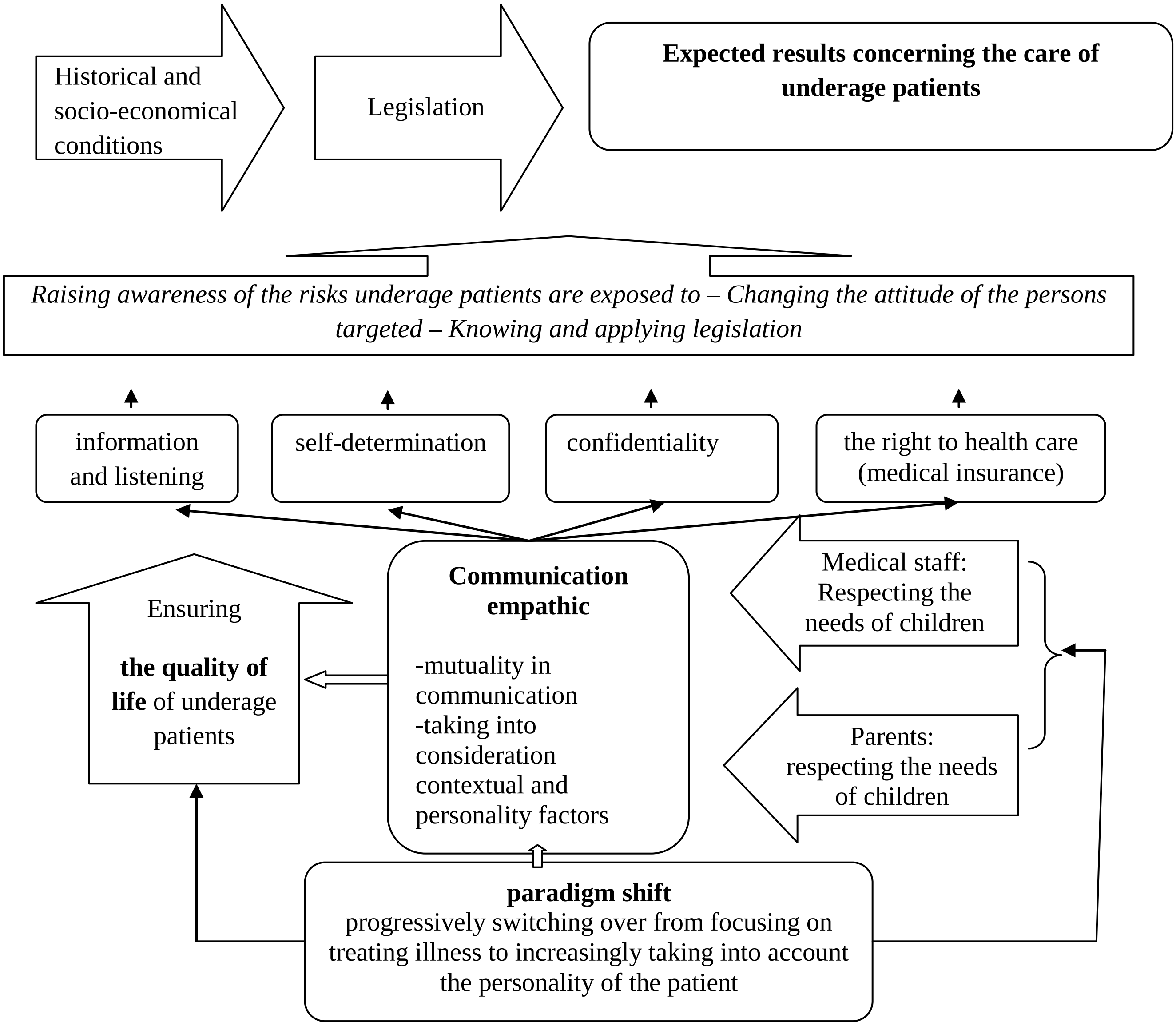

Fig. no 5. Orientation and action plan for those performing the medical act

The author of the thesis is of the opinion that for good underage patient care, one must take into account that the medical act is done in a certain historical phase, in the given social and economic circumstances. These indisputably influence the level of care, but not all hardships can be ascribed to these objective circumstances. For now, the dominant tendency on the part of the medical staff is to invoke lack of funds as the source of all issues. 80.4% blame financial problems as risk factors in the system. In the author's opinion, a paradigm shift, focusing on the needs of the patients as well as respecting their rights would represent a possible improvement of the quality of life in ailing children, and especially of those with chronic illness, since they are in permanent contact with the health care system.

In *Phase 5.* – Administrative and policy diagnosis: the internal and external (policy) issues that could stand in the way of improving the situation had to be identified. Yet identifying administrative issues has been precluded by the medical staff – although permission had been obtained from the Mureș Public District Health Authority – to conduct interviews on this issue with pediatricians.

To draw conclusions, a *SWOT analysis* was performed on the underage patient care system, with the goal of highlighting points of strengths, internal weaknesses, and the opportunities of the system as well as threats that have an impact on the quality of life in ailing children. From the SWOT analysis of the underage patients' health care system, the following could be concluded:

- the necessity for awareness concerning the importance of doctors communicating with their patients;
- the importance of studying patients' needs, especially of those in vulnerable categories;
- doctors should acquire communication skills during their training;
- respecting certain important aspects of communication, such as actively listening to the patient, expressing empathy, making certain that explanations have been understood, the harmonics of time and rhythm in everyday medical practice.

In the same chapter, we move on to present the moral dilemmas from the perspective of the categories of rights. The author has succeeded in detecting the following problems that have gathered around the *right to be heard:* the legal definitions regarding the right to be informed are not adapted to children; persons working in the field of health care are ignorant of certain fundamental rights; sometimes, the medical staff does not make sufficient effort to communicate with the parents of the child in question.

The right to the confidentiality of medical information does not present any special problems in practice, although there is an information leak in all directions: from children to parents, from parents to doctors, and respectively from doctors to parents and children.

In connection with the decisions made about sexual life, both the majority of the medical staff as well as that of the parents have expressed their disapproval, despite the fact that legally, this right is recognized for children above 15 years of age.

In the same way, the children's *right to autonomy* is recognized mostly in theory. In the opinion of the adults queried, this right can be respected only if children have a certain degree of maturity and if they are considered to be sufficiently informed. This opinion is justified, but in practice, parents often neglect to inform children and ask them about their medical issues.

The health insurance system might work better if parents were more informed about available facilities; doctors generally have a better opinion of the health care system than parents.

Chapter 4 presents the testing of the hypotheses. **The first hypothesis** *stating that there is an interdependence between different categories of rights*, as suggested by the literature (Tobin, 2006) was confirmed via several correlations between rights at a significance threshold below $r=0.05$.

Concerning the **second hypothesis**, it has been demonstrated that *among all the rights of child patients, self-determination achieved to the least degree (positive correlation with an r coefficient of 0.034).* At the same time, it came to light that achieving self-determination depends on achieving other rights such as being informed and heard, confidentiality, and the right to the freedom of sexual life with an r coefficient of under 0.05.

The **third hypothesis** expressed as to whether *the health insurance system enjoys more confidence in the perception of medical staff than in that of the parents* is confirmed by the following: 73.5% of the parents' answers showed that the health insurance system does not meet the needs of underage patients, because they are forced to buy medication for the child out of their own money. This fact is also confirmed by the children, 52.8% out of the sample of 200 underage patients noted that their treatment was difficult because of lack of medication.

The author has reached the conclusion that the appreciation of the health insurance system by the medical staff differs from the opinion of the parents, and that there is a significantly differing mathematical mean ($t=5.080, p=0.001$) than in the case of parents.

The fourth hypothesis was formulated as follows: *children who have experienced illness (those who have suffered several medical interventions, consultations and treatments) are exposed to more risk factors and are in an exceptional situation as compared to children who have not experienced illness. This exceptional situation that exhibits increased responsiveness to medical issues, i.e. minors with the experience of illness perceive their own situation better than the children in the control group, who have fewer medical problems.*

The risk caused by chronic illness, the frequency of admissions as well as surgical interventions were chosen as markers of the exceptional situation in which underage patients are. From this point of view, they can be considered a vulnerable group.

In order to obtain a statistically valid result, an “initial group” was needed (children with the experience of illness) and a “control group” (healthy children). Yet the author has not succeeded in detecting significant differences *($t=0.533$, $p=0.595$)*, and thus the fourth hypothesis has not been confirmed.

Chapter five – *Results and conclusions* – establishes that the topic of child patient rights is intensely debated in foreign scholarly literature, yet there are few studies on a national level. In connection with the situation of underage patients, it is thought, alongside Lansdown (2000), that patients should enjoy increased attention with regard to their informed, non-discriminative and equitable access to health care services. Investments in children’s health are probably the most efficient strategies for ensuring a stable, humane and democratic society in the future. The challenge falls on specialists who are committed to respect children’s rights and have the information and the power to make a difference in the way services are delivered. Respecting children’s rights cannot be perceived as an option, as a question of favor or kindness towards children or as the expression of charitable acts, but as social obligations and responsibilities that must be honored. Children rarely have the opportunity to contribute their experience and points of view to the development and quality of medical services rendered; these tasks are the duty of adult.

Enabling children to take part in making decisions in matters of health improves the quality of services, develops general decision-making abilities and strengthens self-esteem, thus promoting the protection of children. There is also evidence that children’s participation in decision-making may have positive effects on the healing process. By ensuring participation in decision-making, adaptation skills, competence and the understanding of the illness are improved (Kilkelly and Donnelly, 2011).

In light of the above, it is essential that medical staff working with children be instructed how to communicate with minors. A respectful attitude towards children is required from adults, which should culminate in promoting the exercise of children’s rights in health care as well as promoting wellbeing. Medical activity may be best accomplished in a team in which all medical personnel have similar approaches with regard to applying children’s rights (Waterston, 2005).

Legislation: In light of the analysis of the child protection system on an international and European level, it was found that legal norms adopted in Romania respect the minimum requirements that appear in treaties and external conventions. The legislative framework is modern, but less comprehensive in places.

From the synthesis of the main legislative sources for children and underage patients, the following health rights took shape:

- the right to be heard and the right to information;
- the right to the confidentiality of medical information;
- the right to freedom concerning sexual life;
- the right to self-determination;
- the right (access) to health insurance (services)

Despite the existence of modern legislation, the author has encountered certain legislative gaps that converge around self-determination. He has succeeded in identifying only a handful of principles that were of help in establishing the limits of self-determination. Moral dilemmas regarding child patients are born out of their intellectual and emotional capacity that is still in development. Limited life experience is also a main factor, next to intellectual and emotional capacity specific to children.

The conclusion was reached that children’s rights must be interpreted in light of traditions and values currently predominant in society. Any right conferred to minors must be understood, promoted and exercised by taking into account the principle of the child’s interest prevailing in the long term.

The issues and dilemmas related to children’s health cannot be solved by the ad litteram application of rights because of possible idiosyncrasies. Legal sources referring to children offer only starting points (principles), and health care decisions made by the persons involved (doctors, parents and the child) must be in accordance with the values protected by the law. One liability of arresting this evolution is the accessibility and distribution of resources that are limited and differ from one state to the other.

Perceptions of the persons targeted by the research: A significant part of the specialists, but also of parents are not fully familiar with the rights of child patients. The practice – in the view of specialists and parents – is dominated by traditional concepts that are more restrictive as to children’s rights than the facilities offered by the current legislative framework. Despite the fact that rights – among which especially self-determination – are not put into practice barring rights-based interaction models, we have not detected general discontent among children. There were only some isolated cases of dissatisfied children.

Nevertheless, research data reveals that minors prefer adequate communication, as observed by other authors as well (Avery, 2009; Miu, 2004; Kilkelly and Donnelly, 2011; Lansdown, 2000; Alderson, 1993).

It was found that medical practice does not place sufficient emphasis on communication with the child, and often, parents are consulted instead of children. Children are not fully informed because they are considered inept. Parents do not receive all available information, and doctors can be impatient, which represents another impediment to communication, although parents have an active and very important role in conveying medical information to children.

Respecting confidentiality does not present any special problems, although there is an information leak in all directions: from children to parents, from parents to doctors, and respectively from doctors to parents and children. It is notable that minors prefer to communicate honestly with their parents about medical issues.

The concept of limited self-determination is accepted: minors who possess a certain degree of maturity and sufficient information may make certain decisions (especially if it coincides with the will of the parents). Neither parents, nor medical staff is completely familiar with the extent of self-determination, and many children are not even asked about treatment options.

The freedom of decisions made concerning the sexual life of minors is not accepted without reservations by either parents or medical personnel, however it is considered that an acceptable level of knowledge regarding safe sexual practices is accrued starting from ages 14-16. Parents agree that minors choose their own contraceptive methods once they have sufficient knowledge.

Parents are not sufficiently informed about the health insurance system, and subsidized medication does not suffice in all cases. Many times, medication needs to be augmented by the parents’ own resources, outside the health insurance system.

With regard to the circumstances of hospitalization, it was found that because of lack of funds and sustained attention to special care for children, optimal hospitalization conditions cannot be ensured. Hospitals are unevenly equipped at the level of localities. The health insurance system is incapable of ensuring subsidized medication for children in need, thus it does not function efficiently. The human factor (doctors and the rest of the staff) tries to meet expectations, thus compensating for deficiencies, but the classic view in which they focus on the disease without giving attention to the personality factor is predominant.

Proposed solutions: From a health care point of view, the situation of children can be improved, for example by influencing social policies, but the field of health care competes, among others, with that of educations, housing, workplaces, environment and transportation, and thus results are difficult to come by. Procedures might be developed that would request from medical staff a method of interaction based on informing the child according to their age and consulting them, so that the doctor can ensure the cooperation of the child based on their right to self-determination.

If influencing a process of policy is required, a form of power must be attained or a partnership with the means to effect change must be established (Bergman 1994).

According to scholarly literature, minors extend unusual importance to communication with medical staff and prefer that this happened without intermediaries, in a direct way, and using adequate language. The purpose of communication is to involve children in making decisions that concern health. Other identified expectations were empathy and humor from the medical staff (Kilkelly and Donnelly, 2011). These indications were also confirmed by our own research, which identified and contributed – especially during the interviews – to *acknowledging issues* by the specialists in the field. Certain paths through which respecting children’s rights could be ensured on a higher level had begun to take shape. On the one hand, there is a need for a *paradigm shift*, i.e. the progressive switchover from focusing on treating illness to increasingly taking into account the personality of the patient, and on the other hand, there is a need to *change the way of communicating* with underage patients, respecting the idiosyncrasies of their age.

The issues and dilemmas are concentrated around the autonomy of children, since the criteria of determining children’s aptitude or ineptitude with regard to exercising their self-determination are completely absent from legal norms.

There are many issues and dilemmas related to children’s health that cannot be solved by the simple application of norms; in consequence, solving these depends on the human factor and the exercise of social responsibility towards children who find themselves in exceptional situations, situations of illness.

Promoting the participation of children in decision-making should be more insisted upon, since gaining the trust and cooperation of the minor may have a positive influence on healing. Children must be assisted in learning how to make a responsible decision in matter of health. Both doctors and parents should place more emphasis on personality factors that contribute to a great extent to the recovery of the child; focusing only on medical treatment is not enough.

Limits of the research: An important limit to this study is connected to the fact that the doctors' cooperation could not be obtained to shed light on the health care system of minors.

Future tendencies: The rights of child patients in general are not rigid and leave room for interpretation, since they are formulated on the level of principles. Respecting them may constitute a guideline for introducing new interaction procedures in pediatric practice, which, aside from adequate treatment, take into consideration, and moreover, respect the personality of the patient, even if it is still in a stage of development.

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