

***PARTICULARITIES OF COMMUNICATION WITH JUVENILE PATIENTS - AN ETHICAL PERSPECTIVE***

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*Abstract: Background - Knowing the requirements for health professionals to engage in communication with patients - children and their parents in terms of providing the information and knowledge of their legal rights and consent to the necessary medical procedures represents a priority objective of the work of health professionals in any children's hospital. Communication is an important factor in the presentation the rights of patients, both in adults and in children's services ensuring a deep understanding of the special needs of this particular group (children and parents) and contributing to successfully solves these cases.*

*Main aim - The present study explores the extent in which the communication's quality between health professionals and legal representatives of children - patients affect the ability of caregivers to decide ethically correct for their minor children.*

*Method - A quantitative study was conducted by using a questionnaire as a research instrument. The instrument was applied at the time of discharge of patients from Children's Hospital of Brasov. The study sample includes a number of 100 persons with children who were hospitalized. In the application of the research methods were ensured the necessary conditions to submit the international ethical protocols. The instrument aimed at obtaining demographic data about participants (age, education, environment - rural or urban, etc.) as well as data concerning the quality of communication between health professionals and patients/ legal representative of those.*

*Main findings - The approach in which the communication between the health professionals and the legal representatives of children patients was achieved, determined 25% of the interviewed subjects to consider that they were not informed about the proposed medical intervention, by not receiving the information in a sufficiently clear manner.*

*Likewise, from the total of participants, 80% stated that they were trained on the orally administration of the drugs. Also, 82% of parents said they were always given explanations on the administration of drugs by injection and 76% from the group of parents argue that they were always asked for informed consent before administering any drug. The study shows that the majority of respondents mentioned that they were informed about the medical treatment (risks), representing an 85% of the total respondents.*

*Conclusions - This study provides an overall perspective on the patients' experiences and their legal representatives regarding the communication of juvenile patients' rights. The results obtained revealed a relevant percentage (20 – 25% of the investigated sample) of parents who, although have been informed; claim that they did not understand the full information provided by health professionals. Therefore, we can conclude that the explanations offered by health professionals are poorly translated into accessible and clear language and that it is necessary to implement a training program for medical personnel in the field of specific medical communication.*

***Keywords: medical communication, informed consent, parents, juvenile patients' rights.***

### **The theoretical background**

Communication of information and its influence on the quality of the doctor - patient, is an important aspect of the constant concerns of health professional (Stewart, M. A., 1984; Ong, L. M., De Haes, J. C., Hoos, A. M., & Lammes, F. B., 1995; Ong, L. L., Visser, M. R., Kruyver, I. P. M., Bensing, J. M., Van den Brink-Muinen, A., Stouthard, J. M. L., Lammes, F.

B. & De Haes, J. C. J. M., 1998; Breen, G. M., Wan, T. T., Zhang, N. J., Marathe, S. S., Seblega, B. K., & Paek, S. C.; 2009).

The patients outcomes are defined in health care studies as „an observable consequence of prior activity occurring after an encounter, or some portion of the encounter, is completed” (Beckman, H., Kaplan, S. H., Frankel, R., 1989). These outcomes are operationalized through indicators as: patient satisfaction, treatment acceptance; reducing anxiety, quality of life or health status and level of recovery.

In reviewing doctor-patient communication, Ong, L. M., De Haes, J. C., Hoos, A. M., & Lammes, F. B. were interested in these topics: the purposes of medical communication; analysis of doctor-patient communication; the specific communicative behaviors; the influence of communicative behaviors on patient outcomes; and concluding remarks. Ong, L. M. and his colleagues, in this review of the literature about doctor-patient communication, found three different purposes of communication: “(a) creating a good inter-personal relationship; (b) exchanging information; and (c) making treatment-related decisions” (Ong, L. M., De Haes, J. C., Hoos, A. M., & Lammes, F. B., 1995).

Studies results are consistent regarding the importance to take into account the cognitive aspect of communication, by providing complete information in an accessible language to patients and the socio-emotional behavior of the medical personnel by expressing empathy and respect for the patient (Ong, L. M., Visser, M. R., Lammes, F. B., & De Haes, J. C., 2000).

Nowadays the aspects regarding information and the knowledge of the legal rights of patients - children and their parents and the act of giving the consent to the required medical procedures is an interdisciplinary area studied carefully by experts. A controversial issue is the modalities to communicate the information between health professionals and patients and caregivers, tutors or parents. Communication is an important factor in the presentation of patient rights, both in adults and in the children cases, providing a deep understanding of the special needs of this particular group (children and parents) and also contributing to the successful resolution of cases. “Parents’ perception of the credibility of the diagnosis and treatment recommendations is influenced both by their expectations and the effectiveness of clinician communication” (Cabral, C., Ingram, J., Hay, A. D., & Horwood, J., 2014).

It is well known that hospitalization has a negative impact on the individual, be it a woman or a man, a child, an adult or an elderly person. However, the stress that hospitalization cause it, the rupture of the loved ones are factors that influence more potent the children and can cause behavioral changes, even trauma. The increasing concern for quality of medical services provided by hospitals bring into discussion the humanizing of the conditions from children's hospitals, children's preparation for the meeting with the hospital without turning the hospital or medical staff in a sentence. Although it is difficult to identify how vulnerable are children to hospitalization is normal to try to protect them, to support them in their efforts to cope with such a situation.

Although in Romania there have been made few studies on how children and parents cope with hospitalization to know what are the objectives of which should stop the medical team, the specialized foreign literature is consistent with these kinds of studies. In the phase of the theoretical documentation on this research we search for relevant scientific studies

using the following keywords: *pediatric clinician-patient communication*. Using the databases Plos and ScienceDirect we discovered a number of 349 articles in which are analyzed specific aspects of the communication between doctor and patient. In the second phase, in which we studied the abstracts of these articles, it remained eligible only 27 studies dating from 1984 - 2014. The search was restricted to articles written in French and English.

### **The research purpose**

The present study explores the manner in which the quality of communication between health professionals and parents or legal representatives of patients - children affect the ability of parents to take a correct decision from an ethical standpoint for their minor childrens.

### **Objectives**

- Estimating the degree of satisfaction of the investigated population towards health services
- Assessment of knowledge and attitudes of parents regarding the rights and obligations of patients and mandatory health insurance system.

### **Hypotheses**

1. The quality of communication between health professionals and the parents of the patient children, operationalized by the availability of information provided to them, influences the level of patient' parents satisfaction.

The quality of communication between health professionals and the parents of the patient children, operationalized by the degree of empathy and respect provided, influences the level of patient' parents satisfaction

### **Research method**

A quantitative study was conducted by using the survey method and the questionnaire as a research tool. The instruments were applied at the time of discharge of the patients from Children's Hospital of Brasov. The study population comprises of 100 persons (caregivers, tutors or parents) whose children were hospitalized. In the implementation of the research methods, there were respected the necessary conditions to meet the international ethical regulations. The questionnaire's items aimed to obtain the demographic data about participants (age, education, environment - rural or urban, etc.) and the data regarding the quality of communication between the medical personnel and patients.

As shown in Table no. 1 Description of the population by demographic variables, the group contains 73 male individuals, representing 73% of the investigated population and 27 females, representing 27% of the lot. 43% of parents from the study have children aged between one and 10 years, and 57% have children aged between 10 and 16 years. 60% from total number of subjects come from an urban environment and 40% of subjects come from a rural environment.

DEMOGRAPHIC VARIABLES		Frequency	Percent
Sex	Male	73	73,0
	Female	27	26,0
	Total	100	100,0
Total		100	100,0
		Frequency	Percent
Childs age	1-10 years	43	43,0
	10-16 years	57	57,0
	Total	100	100,0
		Frequency	Percent
Area of residence	Urban	60	60,0
	Rural	40	40,0
	Total	100	100,0

*Table no. 1 Description of the population by demographic variables*

To verify the level of fidelity which the constructed questionnaire has, we applied Cronbach Alpha method using SPSS 20.00 for Windows, obtaining a coefficient of 0.677, a result which allowed us to continue the investigations. The questionnaire proved to have reliability, to be valid and effective.

Within the research it have been analyzed several situations, but for the purpose of this study, we will refer only to those situation concerning the quality of communication between health professionals and legal representatives of patients - children. Communication quality was operationalized on two dimensions: the first captures the accessibility, the clarity, the sufficiency of information provided by health professionals to parents of pediatric patients, and that the second is referring to the degree of empathy and respect offered by health professionals to patients and caregivers, used to create a climate of trust and cooperation. Both dimensions have been investigated through 6 questions each.

For the first dimension that refers to the accessibility, clarity, sufficiency of information provided by health professionals to parents and legal tutors of pediatric patients, the questions focused on obtaining answers on the following: informing on proposed medical interventions (risk, alternative, etc.); training on the administration of oral medications; explanation of the administration of drugs by injection; giving consent before administering a drug; information on medication administered (risks, alternatives, etc.) and the satisfaction degree with the information received.

For the second dimension, concerning the investigation of the degree of empathy and respect provided by health professionals to patients and tutors, the items included the following issues: the way in which health professionals treated them as a human or as a case that they are obliged to treat; main motivations for having resorted to the hospital where they were admitted (high degree of accessibility, being close to home, the endowment with modern equipment, professionalism of the medical personnel, how the patient has been treated in the

past); what they've liked about the doctor (willingness to give information, thorough check up, transposition of medical information in common language, the degree of reduction of anxiety); the efficiency's assessment for the hospital medical care; the doctor's behavior and attitudes and the behavior and attitude of nurses.

The way the communication between medical staff and legal representatives of pediatric patients was carried out, has led to 25% of the interviewed subjects to express their believe that they were not informed about the proposed medical intervention, not receiving information in a sufficiently clear manner. Analyzing the responses clustered by the area of residence, we observed that the subjects who come from rural areas tend to appreciate the information provided by a low level.

Only 79% of respondents considered that they were always trained on the administration of oral medication, 20% said that they were only sometimes trained, and 1% said that they were never trained on the administration of oral medication. In terms of providing an explanation of how the administration of drugs by injection, 74% of respondents said that they have always received explanations, 20% sometimes, and 6% never. Informed consent before administering a drug has been recognized by 88% of subjects, 12% claiming that they were not asked. Out of the total number of subjects, 83% said they were informed about the medication administered (risks, alternatives, etc.), while 17% said they were not notified.

Not always the health professionals considered necessary to obtain their informed consent - bearing in mind that they have the truth and apply the paternalistic model of the relationship with patients. The difference of only 6% between those who believe they have received sufficient information about the injection or oral administration of treatment based on the attitude of parents to protect children from the pain induced by injection, and the very small percentage of those who consider that they have sufficient information is correlated with the tendency of parents to find out more details about the treatment of their children.

The level of satisfaction regarding the information's received reported by respondents is in a proportion of 81% high (high level of satisfaction), 11% of respondents declare themselves moderate satisfied, only 6% are dissatisfied with the information received, and 2% are very dissatisfied with this aspect.

We used SPSS 20.0 program to perform the statistical analysis by correlating scores on satisfaction questionnaire items declared by subjects in both dimensions. Results were considered statistically significant if the significance threshold is  $p < 0.005$ .

As shown in Table no. 2 Pearson Correlations on Information and Tutors' satisfaction scale, our observation according to which a low level of education leads to a misunderstanding of the way of expressing of health professionals. Thus, it can be seen that the area of residence negatively correlated with the level of information and the stated satisfaction level, namely subjects in rural areas tend not to understand the information received as against subjects from urban areas. Although the Pearson correlation coefficient values are small, they are statistically significant.

## Correlations

	Area of residence	Grad_sat_info	F1	F5	F6
Pearson Correlation (r)	1	-0,226*	-0,215*	-0,264**	-0,264**
Sig. (2-tailed) (p)		0,024	0,031	0,008	0,008
N	100	100	100	100	100

\*. Correlation is significant at the 0.05 level (2-tailed). \*\*. Correlation is significant at the 0.01 level (2-tailed).

Table no. 2 Pearson Correlations on Information and Tutors' satisfaction scale

The same situation is found for the dimension that investigated the socio-emotional factors involved in doctor - patients' communication. As shown in Table no. 3. Pearson correlations Socio-emotional dimension and Parent's satisfaction, it can be noticed the existence of a statistically significant negative correlation between area of residence and items investigating socio-emotional relationship between health personnel and parents.

There is a weak, negative correlation, statistically significant between residence environment and treatment as a human being, not as a case to be treated ( $r = -0.202$ ,  $p = 0.044$ ), so we can state that persons from rural areas tend to evaluate the behavior of health professionals as one lacking compassion.

The negative statistically significant correlation between the area of residence and the main reasons for which the parents chose the hospital in which they were admitted ( $r = -0.229$ ,  $p = 0.022$ ), shows that for the persons from rural areas dominate those related to accessibility, neighborhood housing, and less with the medical professionalism and the way they have been treated in the past.

The negative statistically significant correlation between area of residence and appreciation of the doctor's behavior ( $r = -0.228$ ,  $p = 0.022$ ), shows that subjects from rural area of residence do not consider that the doctor provides them the needed psychological comfort. Regarding the nurses' behavior, the situation is similar ( $r = -0.235$ ,  $p = 0.019$ ).

## Correlations

	Area of residence	SE1	SE2	SE3	SE5
Pearson Correlation (r)	1	-0,202*	-0,229*	-0,228*	-0,235*
Sig. (2-tailed) (p)		0,044	0,022	0,022	0,019
N	100	100	100	100	100

\*. Correlation is significant at the 0.05 level (2-tailed).

\*\*. Correlation is significant at the 0.01 level (2-tailed).

Table no. 3 Pearson Correlations on Socio-emotional dimension and Parent's satisfaction

## Conclusions

This study provides an overview of the patients' experiences and their legal representatives of patients' rights from the perspective of communication the minor patients' rights. The results show a fairly significant percentage (20-25% of the total investigated population) of parents who, although being informed, prove that they did not understand fully the information provided by health professionals. Therefore, it can be concluded that the explanations offered by health professionals are poorly translated in a clear and accessible language. There is a necessity to implement a training program for medical personnel in this specific medical communication. The research results are consistent with previous studies (Ong, L.M.L. et al, 2000), identifying the importance of the affective tone used by medical personnel in communication and the socio-emotional behaviour of the doctor in relation to patient satisfaction.

One of the limitations of this study is the small number of subjects who participate in this research, which does not allow us to generalize the findings to the whole population. It would be useful to validate these results in all Romanian population.

Also it can be note that one of the directions in which the work of health professionals must focus is to increase the degree of empathy of the medical personnel shown to patients in these sectors, but also the degree of trust in their ability to make decisions in accordance with individual rights, as they emerge from all national and international regulations. The important aspect that this research is focused on is the development of a pilot study regarding the communication with caregivers of children patient from an ethical standpoint and its aims to improve the quality of psychosocial health services offered.

## References

- Beckman H, Kaplan SH, Frankel R. (1989). Outcome-based research on doctor–patient communication: A review. In: Stewart, M. A., Roter DL, editors, *Communicating with medical patients*, Newbury Park CA: Sage Publications.
- Breen, G. M., Wan, T. T., Zhang, N. J., Marathe, S. S., Seblega, B. K., & Paek, S. C. (2009). Improving doctor–patient communication: Examining innovative modalities vis-à-vis effective patient-centric care management technology. *Journal of medical systems*, 33(2), 155-162.
- Cabral, C., Ingram, J., Hay, A. D., & Horwood, J. (2014). “They just say everything's a virus”—Parent's judgment of the credibility of clinician communication in primary care consultations for respiratory tract infections in children: A quatitative study. *Patient education and counseling*, 95(2), 248-253.
- Ong, L. L., Visser, M. R., Kruijver, I. P. M., Bensing, J. M., Van den Brink-Muinen, A., Stouthard, J. M. L., Lammes, F. B. & De Haes, J. C. J. M. (1998). The Roter Interaction Analysis System (RIAS) in oncological consultations: psychometric properties. *Psycho Oncology*, 7(5), 387-401.
- Ong, L. M., De Haes, J. C., Hoos, A. M., & Lammes, F. B. (1995). Doctor-patient communication: a review of the literature. *Social science & medicine*, 40(7), 903-918.

Ong, L. M., Visser, M. R., Lammes, F. B., & De Haes, J. C. (2000). Doctor–patient communication and cancer patients’ quality of life and satisfaction. *Patient education and counseling*, 41(2), 145-156.

Stewart, M. A. (1984). What is a successful doctor-patient interview? A study of interactions and outcomes. *Social science & medicine*, 19(2), 167-175.