

Croatian Children's Views towards Importance of Health Care Information

Gordana Pelčić^{1,2}, Neda Aberle³, Goran Pelčić⁴, Inge Vlašić-Cicvarić⁵, Darko Kraguljac⁶, Ivica Benčić⁷, Anamarija Gjurjan Coha¹ and Silvana Karačić⁸

¹ University of Rijeka, School of Medicine, Department of Social Sciences and Medical Humanities, Rijeka, Croatia

² Health Care Center of Primorsko-goranska County, Rijeka, Croatia

³ »J. J. Strossmayer« University, School of Medicine, Department of Paediatrics, Osijek, Croatia

⁴ University of Rijeka, School of Medicine, Department of Ophthalmology, Rijeka, Croatia

⁵ University of Rijeka, Rijeka University Hospital Center, Center for Clinical, Medical and Organizational Psychology, Rijeka, Croatia

⁶ University of Rijeka, Rijeka University Hospital Center, Center for Physical and Rehabilitational Medicine, Rijeka, Croatia

⁷ University of Rijeka, Rijeka University Hospital Center, Department of Diagnostic and Rehabilitation of Hearing and Speech, Rijeka, Croatia

⁸ »Sveti Križ« Treatment Center, Trogir, Croatia

ABSTRACT

The aim of research was to investigate: the need for health care information of Croatian adolescents aged from 13 to 18 years; the difference in evaluation of the frequency of receiving information between hospitalized and healthy children; if the hospitalized children expectations about the frequency of receiving health care information differed significantly from information they have actually received; whose information was most comprehensible to the hospitalized children (doctors, parents, other health care givers). The children were either hospitalized in the pediatrics departments or were high schools pupils (healthy children). The hospitalized children »Completely agreed« (92.7%) with the statement »When I am sick, I should receive information about my health« in comparison to the healthy children (85.1%). In comparison to healthy children, the hospitalized children assessed that doctors, other health care givers and parents should give them information more frequently. The experience of hospitalized children indicate that they received less information than they have actually expected. The information received from doctors was mostly in correlation with the understanding of this information. We concluded that the children want to be informed about their health, especially hospitalized children. Health care professionals should offer understandable health care information according to the children's expectation.

Key words: children, Croatia, doctors, health care information, health professionals

Introduction

One of the fundamental duties of health care professionals is communication and provision of health care information¹. The qualitative health care information is an essential part of the informed consent generally. The doctrine of informed consent implies providing the complete and accurate information for the patient in understandable manner and language². The patient should be able to understand the relevant information, to retain this information, to evaluate the information in order to

make a notable choice and at the end to make a voluntary and autonomous decision^{3,4}. In most countries worldwide informed consent is a guaranteed for an adult patient, i.e. older than 18 years. On the contrary, for minors (minors – every human being below the age of eighteen years)⁵ this is not the case. Some countries have a concept of informed assent in children⁶. Informed assent is based on child's receiving information about its health condition adequate in quantity and quality and the ability to un-

derstand this information to make a voluntary choice about proposed procedure^{6,7}. Receiving the qualitative and understandable health care information is a fundamental and primary principle of both concepts, informed consent for the adults and informed assent for the children.

According to the article 13. United Nation (UN) Convention (Croatia ratified it in 1991) the children have right to all kind of information. It means that they have right to receive information about their health in a way and manner that they can understand^{5,6}. On the other side, Croatian Law on Patients' Rights Protection does not give the minors opportunity either to consent or assent in health care decision making⁸. All professionals who work with the children in health care system have duty to respect their rights. As previously mentioned one of those rights is the right for health care information. Giving information to children has a significant influence on the child wellbeing. Previous study shows that children who were better informed about future procedure in health care settings or who had qualitative pre-hospital information were more able to minimize distress, optimize treatment and recovery times⁹⁻¹². Adequate preparatory information helps in building greater trust between the child and health care professionals⁹. Adolescents are a part of the population whose need for the health care information is high. They want to be equal partners in health care system¹³. Today the adolescents' right for health care information is still unacknowledged¹.

According to those findings and lack of Croatian Law on Patients Rights Protection regarding the children rights in health care system we investigated needs for adequate health care information of Croatian adolescent age from 13 to 18 years, evaluated the difference of expected and actually received information and understanding of this information.

Materials and Methods

Participants and settings

The study was conducted in the pediatrics departments in hospitals in Osijek, Zagreb, Rijeka, Knin and Crikvenica (hospitalized children) and in the high schools in Osijek, Zagreb, Rijeka, Knin and Pula (healthy children) from January to December 2009.

The participants of this study were children aged 13 to 18 years. We thought that children of this age should be included in health care decision making. Two groups of children were investigated. A random sample of 220 hospitalized children was recruited from six hospitals in Croatia – different hospital departments (oncology, cardiology, pulmonology, gastroenterology, nephrology, neurology, surgery, infectology, endocrinology, orthopedic, psychiatry, ophthalmology and physical therapy). The hospitals involved in this investigation were clinics (Rijeka, Zagreb and Osijek University Hospital Center), General hospital Knin and Thalassotherapy Crikvenica. The sec-

ond group of participants was a control group (healthy children) i.e. high school pupils of the same age in the cities of Pula, Rijeka, Zagreb, Osijek and Knin. We assumed that the children questioned in high schools would be mostly healthy children without experience of severe illness and hospitalization. The study was conducted in gymnasiums and in vocational high schools (three and/or four years high school program) in Croatia. We wanted to include participants of different socioeconomic status, from small and large communities. Therefore we conducted a study in various Croatian cities, in small and in large hospitals and in various types of high schools programs. The final sample included 1032 children, out of which 220 (21.3%) were hospitalized and 812 (78.7%) were high school pupils.

The mean age of children was 16.18 years. There were 704 females and 328 males. The percentage of non-respondents was less than 3%.

Ethical approval was obtained from the local ethic committee. Informed parental consent and children's approval was obtained verbally prior to the study participation. All surveys were anonymous.

We analyzed 4 responses:

1. »When I am sick, I should receive information about my health«. The possible answers were 1. Strongly disagree; 2. Disagree; 3. Neither agree nor disagree; 4. Agree; 5. Strongly agree.
2. »According to your opinion from whom you should receive the information about your health?« The possible answers were doctors, parents and other health care givers. Each of them could give information: 1. Never; 2. Rarely; 3. Sometimes; 4. Often; 5. Always.
3. »Who have you received the information about your health from so far?« The possible answers were doctors, parents and other health care givers. Each of them could give information: 1. Never; 2. Rarely; 3. Sometimes; 4. Often; 5. Always.
4. »To which extent did you understand the information about your health?« The possible answers were scaled from 1 (Not at all) to 5 (Completely).

Statistics

We analyzed responses to questions related to the importance of information in health care system. We used test χ^2 -test, t-tests and regression analysis.

Results

Findings from the whole sample

The children were asked to circle the most appropriate answer to the statement »When I am sick, I should receive information about my health«. Considering the small number of answers 2 (only one hospitalized child gave answer 2), we added the frequency for answers 2 and 3 in the same category (Table 1).

The hospitalized children in greater extent completely agreed with the statement (92.7%) in regard to the

TABLE 1
 χ^2 CONTINGENCY TABLE NUMBER OF HOSPITALIZED AND HEALTHY CHILDREN

Answer		Strongly disagree – neither agree nor disagree	Agree	Strongly agree	Total
Hospitalized	No	23 (2.8%)	97 (12%)	688 (85.1%)	808
	Yes	1 (0.5%)	15 (6.8%)	203 (92.7%)	219
Total		24 (2.3%)	112 (10.9%)	891 (86.8%)	1027

healthy children who completely agreed in 85.1% ($\chi^2=9.54$, $p<0.01$, $df=2$).

We compared the opinion of the hospitalized and healthy children when we asked them »According to your opinion from whom you should receive the information about your health?« The sources of information were doctors, parents and other health care givers. We calculated three t -tests for testing the difference in the evaluation of the frequency of receiving information between hospitalized and healthy children. There was a statistically significant difference in evaluating the frequency of obtained information between the hospitalized and healthy children (Figure 1). The hospitalized children evaluated that doctors should give them information more frequently in comparison to healthy children ($t=2.54$, $df=1010$, $p<0.01$). The hospitalized children evaluated that parents should give them information more frequently in comparison to healthy children ($t=2.79$, $df=883$, $p<0.01$). And finally, the hospitalized children evaluated that other health care givers should give them information more frequently in comparison to the healthy children ($t=2.07$, $df=638$, $p<0.05$).

Findings from the group of the hospitalized children

The number of hospitalized children was 220 ($N=220$), the mean age was 15.72 years, female ($N=147$) and male ($N=71$).

We wanted to investigate if the hospitalized children expectations about the frequency of receiving health care information differed from what they have actually received. There was a statistically significant difference between the frequency of expected and received informa-

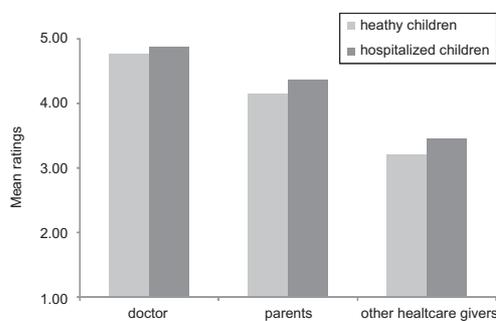


Fig. 1. Mean ratings in evaluation the frequency of receiving information between hospitalized and healthy children.

tion (Figure 2). The hospitalized children expected to receive more frequently the information than they have actually received from doctors ($t=9.22$, $df=210$, $p<0.01$). The hospitalized children expected to receive more frequently the information than they have actually received from other health care givers ($t=4.58$, $df=118$, $p<0.01$). There was no statistically significant difference between the frequency of expected and actually received information from their parents. The hospitalized children expected to receive more frequently the information from doctors and other health care givers than they have actually received.

We were interested in question about whose information (doctor's, parent's or other health care giver's) was most comprehensible to the hospitalized children. We analyzed the responses to this question using regression analysis. Predictors were the amount of information which hospitalized children received from each source and the criterion was the assessment of understanding information. The descriptive data are shown in the Table 2. The variables in this analysis were in a relatively weak correlation as shown in the Table 3.

The information received from doctors was mostly in correlation with the understanding of this information. The information received from other health care givers is in lower correlations. When we analyzed the whole model (with 3 predictors) we could see that 16% of information understanding variance could be attributed to those three predictors. If we pay attention to the predictor level, only the information received from medical doctors was a statistically significant predictor (Table 4).

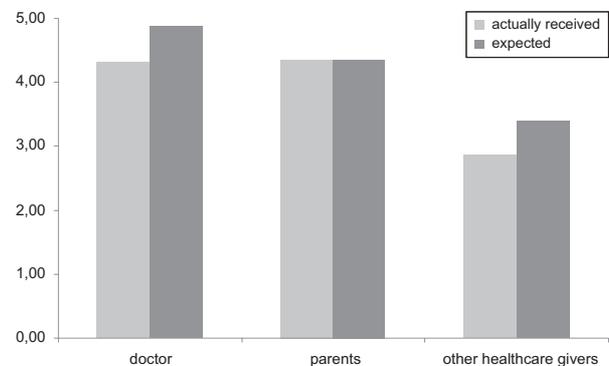


Fig. 2. Mean ratings of hospitalized children expectations about the frequency of expected and actually received health care information.

TABLE 2
DESCRIPTIVE INDICATION OF MEANS AND STANDARD DEVIATION OF THE AMOUNT OF INFORMATION THAT HOSPITALIZED CHILDREN RECEIVED FROM CERTAIN SOURCES AND UNDERSTANDING THIS INFORMATION

	N	\bar{X}	SD
Understanding of their own situation	179	4.11	1.15
Information provided by doctor	214	4.31	0.84
Information provided by parents	197	4.38	0.81
Information provided by other health care givers	140	2.89	1.16
The total number (with data in all variables)	106		

TABLE 3
CORRELATION MATRIX OF EVALUATION AND OF UNDERSTANDING THE SOURCE OF HEALTH CARE INFORMATION (DOCTORS, PARENTS AND OTHER HEALTH CARE GIVERS)

	2.	3.	4.
1. Understanding of their own situation	0.32**	0.12	0.26**
2. Information provided by doctor		0.03	0.21*
3. Information provided by parents			0.31**
4. Information provided by other health care givers			

** $p < 0.01$

TABLE 4
REGRESSION ANALYSIS'S RESULT

	B	R ²	F _(3, 103)
1. Information provided by doctor	0.34**		
2. Information provided by parents	0.05		
3. Information provided by other health care givers	0.15	0.16	6.47**

** $p < 0.01$

Discussion and Conclusion

Many authors suggest the relationship between the ability to consent of children and adults with the qualitative and extensive information that they have received¹⁴. According to the fundamental ethical principle the pediatrician should do everything in the best interest of the child¹⁵⁻¹⁷. Therefore they should secure the right for the information that is available in a language, culture¹⁸ and at a developmental level that children will understand¹⁹. Every child should receive the complete information about medical procedures and interventions appropriate to their maturity, given in the way that he or she can understand. The language and the communication should be adjusted to the ability of the individual child⁶. The consultation with children and their parents should include those components²⁰.

There have been various researches that prove the minors' wish for receiving the information about their health and involving them in the decision making^{1,13,21-23}. On the other side, in practice, children often do not receive the information that they are asking for²⁴. That could be very stressful, especially in the case of hospitalization, which is a stressful event by itself. Adequate previous information helps patient to cope with the forth-

coming event, minimize stress, optimize outcome and generally have better outcome⁹.

Our data suggest that Croatian adolescents want to be informed about their health. Both healthy and hospitalized children statistically significantly agree that they should receive the information about their health. The hospitalized children in greater extent agree (92.7%) with the statement in comparison with healthy children. The experience of the sickness and hospitalization has probably influenced sick children to seek more information. These data coincide with other authors who also emphasize previous experience as one of important components which has a positive impact on children's ability to consent¹⁴ and understand. Understanding their health condition and being involved in decision making help children better control their disease and, as Gordon said, optimize the diseases outcome⁹. For example, Alderson and colleagues show how adequate information is essential in chronic condition such as diabetes type 1. In their research very young children are able to understand the control of diabetes and make wise decision after they have received appropriate information²⁵.

One of the fundamental factors which obstruct children's involvement in decision making is health profes-

sional communication styles²⁴. The sources of health information may be the parents, doctors, other health care givers, friends, internet, medical data basis.

According to the study of Gordon et al., children received information from their parents in 46.7%, from doctors in 41.3% and in 12% of cases they received information from both doctors and parents. About 63% of children were satisfied with the received information⁹.

Our study suggests that hospitalized children expected to receive information about their health from doctors, other health care givers and parents more frequently than healthy children. On the other hand hospitalized children expected to receive more frequently the information than they have really received from doctors and other health care givers. The hospitalized children valued the health care information. Qualitative information helps them to cope with their illness. Therefore their expectation was greater in comparison with the reality. The parents fulfilled the expectation of children in our study. The parents play an important role in informing their children. As it was mentioned earlier, in Gordon's study children received 46.7% of information from their parents, but he questioned the parent's capacity and certainty to give those information⁹.

Health care providers endue patients with a large amount of different kind and ways of information. The health literacy is one of the important factors to understand the information and to give valid informed consent²⁶. In our study the most comprehensible information was given by doctors. This was not the case with other health care givers. Therefore they have to adjust their communication according to the health care literacy and education of pediatric patients. Pediatricians have to think about the language and style of giving information because the purpose of information is that patient can understand. As Morgan's and Monaghan's study shows, the children who did not understand explanation about dental care were more likely to have caries²⁷.

A pediatrician has to keep in mind that children may seek for the information out of health care setting and

their homes. One of the emerging possibilities is the Internet with the great benefits but with many traps also^{28,29}. Electronic records and medical data basis may become children's tools in the future³⁰. Therefore, Clinical practice in a 21st century needs to substantiate with more studies of children's views and experience of being informed²⁵ and incorporate it in everyday practice. Therefore some authors suggest that healthcare professionals should remain the main source of information²⁸.

In conclusion, the results of this study suggest that children want to be informed about their health. This wish is greater in the case of hospitalized children who expected to receive more information than they actually have. Health care professionals in general, not only doctors, should offer understandable health care information to the children, according to their age and capacity.

Limitations

In our study there were several limitations; i.e. a disparity between the number of hospitalized children and healthy children; disparity between the number of female and male participants (704 females, 328 males); we did not include the diagnosis of hospitalized children in the study.

Acknowledgements

We would like to thank to the principles, professors and students of Trade and textile school in Rijeka, First Croatian Sušak's Gymnasium, Medical school in Pula, Gymnasium Pula, High school »Lovre Monti« Knin, Hospitality and tourist school Zagreb, Upper town gymnasium Zagreb, Gymnasium in Osijek, Economy highs school in Osijek. Also our great gratitude is due to patients, nurses and doctors of following pediatric departments in Croatia: Zagreb, Rijeka and Osijek University Hospital Centers, Infectology Clinic »Dr. Fran Mihaljević« Zagreb, General hospital Knin, Thalassotherapy Crikvenica.

REFERENCES

- BERESFORD BA, SLOPER P, *J Adolesc Health*, 33 (2003) 172. DOI: 10.1016/S1054-139X(03)00047-8. — 2. ANONYMUS, Committee on Bioethics, *American Academy of Pediatrics, Pediatrics*, 95 (1995) 314. — 3. ALDERSON P, *Soc Sci Med*, 65 (2007) 2272. DOI: 10.1016/j.socscimed.2007.08.005. — 4. CARMI A, *Informed consent (Israel National Commission for UNESCO, Haifa, 2009)*. — 5. UNICEF, *Convention on the Rights of the Child*, accessed 08.02.2011. Available from: URL: <http://www2.ohchr.org/english/law/crc.htm>. — 6. DE LOURDES LEVY M, LARCHER V, KURZ R, *Eur J Pediatr*, 162 (2003) 629. DOI: 10.1007/s00431-003-1193-z. — 7. UNUGURU Y, COPPERS MJ, KAMANI N, *Pediatr Clin N Am*, 55 (2008) 211. DOI: 10.1016/j.pcl.2007.10.016. — 8. *Narodne novine*, 169/04, 37/08. — 9. GORDON BK, JAANISTE T, BARTLETT K, PERRIN M, JACKSON A, SANDSTROM A, CHARLESTON R, SHEEHAN S, *Child Care Health Dev*, 37 (2011) 727. DOI: 10.1111/j.1365-2214.2010.01190.x. — 10. JOHNSON JE, *Res Nurs Health*, 22 (1999) 435. DOI: 10.1002/(SICI)1098-240X(199912)22:6<435::AID-NUR2>3.0.CO;2-Q. — 11. CLAR RL, WALKER LS, BARNARD JA, *J Pediatr Gastroenterol Nutr*, 34 (2002) 68. DOI: 10.1097/00005176-200201000-00016. — 12. JAANISTE T, HAYES B, VON BAEYER CL, *Clin Psychol*, 14 (2007) 124. DOI: 10.1111/j.1468-2850.2007.00072.x. — 13. VAN STAA A, JEDELOO S, VAN DER STEGE S, *Patient Prefer Adherence*, 5 (2011) 291. — 14. ADEWUMI A, HECTRO MP, KING JM, *Br Dent J*, 191 (2001) 256. DOI: 10.1038/sj.bdj.4801157. — 15. KURZ R, GILL D, M JONES S, *Eur J Pediatr*, 165 (2006) 83. DOI: 10.1007/s00431-005-0002-2. — 16. LARCHER V, *Clin Ethics*, 2 (2007) 208. DOI: 10.1258/147775007783560175. — 17. WELLESLEY H, JENKINS I, *Anaesth Intensive*, 10 (2009) 196. DOI: 10.1016/j.mpaic.2009.01.006. — 18. SWOTA AH, HESTER M, *Pediatr Rev*, 32 (2011) 39. DOI: 10.1542/pir.32-3-e39. — 19. ANONYMUS, *American Academy of Pediatrics, Council on community pediatrics and committee on native American child health. Policy Statement – Health Equity and Children's Rights*, *Pediatr* 125(2010) 838. DOI: 10.1542/peds.2010-0235. — 20. CROSSLLEY J, DAVIES H, *Med Educ*, 39 (2005) 807. DOI: 10.1111/j.1365-2929.2005.02231.x. — 21. COYNE I, *J Clin Nurs*, 15 (2006) 61. DOI: 10.1111/j.1365-2702.2005.01247.x. — 22. LEWETOWN M, *Pediatrics*, 121 (2008) e1441. — 23. MOULES T, *J Child Health Care*, 13 (2009) 322. DOI: 10.1177/1367493509344824. — 24. COYNE I, *Int J Nurs Stud*, 45 (2008) 1682. DOI: 10.1016/j.ijnurstu.2008.05.002. — 25. ALDERSON P, SUTCLIFFE K, CURTIS K, *Arch Dis Child*, 91 (2006) 300. DOI: 10.1136/adc.2005.

079442. — 26. LORENZEN B, MELBY CE, EARLS B, AORN J, 88 (2008) 23. DOI: 10.1016/j.aorn.2008.03.001. — 27. MORGAN MZ, MONAGHAN N, Community Dent Health, 27 (2010) 200. — 28. SCULLARD P, PEACOCK C, DAVIES P, Arch Dis Child, 95 (2010) 580. DOI: 10.1136/adc.

2009.168856. — 29. WACOGNE I, SCOTT -JUPP R, Arch Dis Child, 95 (2010) 576. DOI: 10.1136/adc.2009.176917. — 30. SPENCER A, LOW D, Arch Dis Child, 96 Suppl 12 (2011) 1167. DOI:10.1136/adc.2009.178129.

G. Pelčić

University of Rijeka, School of Medicine, Department of Social Sciences and Medical Humanities, Braće Branchetta 20,
51000 Rijeka, Croatia
e-mail: pelcicgo@medri.hr

STAVOVI HRVATSKE DJECE O VAŽNOSTI INFORMIRANOSTI O ZDRAVLJU

SAŽETAK

Cilj istraživanja je bio istražiti potrebu hrvatskih adolescenata, u dobi od 13. do 18. godina, za zdravstvenom informacijom; razliku u evaluaciji učestalosti primanja informacije između hospitalizirane i zdrave djece; jesu li očekivanja hospitalizirane djece s obzirom na učestalost primanja zdravstvenih informacija znatno drukčija od onoga što su zapravo primila; čije su informacije bile najrazumljivije hospitaliziranoj djeci (liječnici, roditelji, drugi zdravstveni djelatnici). Djeca su bila ili hospitalizirana na pedijatrijskim odjelima ili su bili učenici srednjih škola (zdrava djeca). Hospitalizirana djeca su se »Potpuno složila« (92,7%) s izjavom »Kad sam bolestan, ja bih trebao/la primiti informaciju o mom zdravlju« u odnosu na zdravu djecu koja se u potpunosti slažu u (85,1%). Hospitalizirana djeca u usporedbi sa zdravom djecom smatraju da bi im liječnici, drugi zdravstveni djelatnici i roditelji trebali davati informaciju češće. Iskustva hospitalizirana djeca pokazala kako su primili manje informacija nego su zapravo očekivali. Informacija koju su primili od liječnika je bila u najvećoj korelaciji sa razumijevanjem te informacije. Zaključujemo da djeca žele biti informirana o svom zdravlju, posebno hospitalizirana djeca. Zdravstveni djelatnici trebaju djeci dati razumljive informacije u skladu s očekivanjem djece.