

HIV-Infected Children in Croatia – Medical Care versus Ethical and Social Issues

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ABSTRACT

The era of pediatric HIV-infection in Croatia began in 1987 when the first child from an HIV-infected mother was born. The authors present some medical data of children diagnosed as HIV-infected or observed because of maternal HIV-infection in Croatia until the end of 2005. Although the number of HIV-infected children in Croatia is still relatively small, in the last two decades the Croatian society was confronted with many ethical and social issues regarding HIV-infection and discrimination. There were many obstacles in providing proper care and integrating HIV-infected children in the Croatian society. Stigmatisation, fear and lack of knowledge were major contributors. For the first time, the integration of an HIV-infected child with revealed HIV-status into school was described. Changes in attitudes towards HIV-infected people can only be achieved through planned permanent educational programs.

Key words: HIV/AIDS, children, human rights, discrimination, Croatia

Introduction

The incidence of pediatric HIV-infection, especially in Sub-Saharan Africa is still growing. Worldwide, it is estimated that around 2200 HIV-positive children are born every day¹. Although significant improvement in medical care for HIV-infected people has been achieved, especially in the last decade, 570 000 children died of AIDS in 2005, mainly in underdeveloped countries where health care is less accessible¹. However, the problems of HIV-infected children are not only medical. The care for HIV-infected children includes many ethical and social issues, too. HIV-infected children often have at least one HIV-infected parent and there are also many HIV-infected children who are orphans and who need complex social support and care. Although the number of HIV-infected children in Croatia is still relatively small, it became obvious that socialisation and lack of social care are universal problems and improvements are needed.

The aim of this paper is to present some data on medical care for HIV-infected children and children born to HIV-infected mothers in Croatia and also to describe the obstacles that appeared in social and ethical aspects of caring for HIV-infected children in last few years.

Medical Care and Characteristics of HIV-infected Children and Children Born to HIV-infected Mothers in Croatia

HIV-infected children in Croatia

The era of pediatric HIV-infection in Croatia began in 1987 when the first child from an HIV-infected mother was born. Since then, until the end of 2005, 20 children were observed because of maternal HIV-infection or diagnosed as HIV-infected in Croatia. Ten children were diagnosed as HIV-infected (Table 1), one remained with unknown HIV-status and 9, born from HIV-infected mothers, remained uninfected (Table 2). The first case of pediatric AIDS in Croatia was diagnosed in 1995. The child was a seven-year-old girl with *Pneumocystis jiroveci* pneumonia. Despite all efforts and medical care available at that time that included zidovudine (ZDV, AZT) monotherapy, she died outside Croatia one year after establishing the diagnosis. She was the first, and remained the only Croatian HIV-infected child who died until today.

Due to a centralized system of medical care for HIV-infected patients in Croatia all children with suspected HIV-infection were patients of the University Hospital for Infectious Diseases in Zagreb (UHID). UHID was also responsible for implementation of preventive measures

TABLE 1
CHARACTERISTICS OF HIV-INFECTED CHILDREN IN CROATIA

Child	Sex	Year of birth	Exposure category	Mother's HIV infection diagnosed	Age at				Clinical category: C	CD4 T-lymphocyte at diagnosis				First ARV therapy	Age at starting HAART	CD4 at starting HAART (μ L)
					HIV diagnosis	AIDS diagnosis	First exam at UHID	Death		HIV		AIDS				
										μ L	%	μ L	%			
1	male	1980	blood/blood products	-	6 y	-	16.5 y	-	-	un-known	un-known	-	-	mono ZDV	-	-
3	female	1987	mother to child	unknown	7 y	7y+1m	7y+1m	8y+3m	<i>P. jiroveci</i> pneumonia	534*	25.7	534*	25.7	mono ZDV	-	-
4	female	1993	mother to child	unknown	1.5 y	-	9.5 y	-	-	un-known	un-known	-	-	mono ZDV**	un-known	-
5	female	1994	mother to child	unknown	5 m	-	6.5 y	-	recurrent serious bacterial infections (pneumonia)	un-known	un-known	847	31.3	HAART	6.5 y	507
7	male	1997	mother to child	after delivery	9.5 m	9.5 m	10.5 m	-	recurrent nontyphoid <i>Salmonella</i> septicemia	78	4.4	78	4.4	mono ddi	20 m	27
9	female	1997	mother to child	not diagnosed	2.5 y	-	2.5 y	-	-	893	26.5	-	-	HAART	3.5 y	1072
10	female	1997	mother to child	after delivery	20 m	-	20 m	-	-	2004	23.6	-	-	HAART	21 m	2004
12	female	1998	mother to child	unknown	1.5 m	-	5 m	-	-	3935	48.2	-	-	HAART	5 m	2950
13	female	2000	mother to child	before delivery	2 m	-	10 d	-	-	1360	43.1	-	-	HAART	2.5 m	1360
15	male	2000	mother to child	not diagnosed	2.5 y	-	5 y	-	-	un-known	un-known	-	-	HAART	5y+2m	197

ARV – antiretroviral, HAART – highly active antiretroviral therapy, ZDV – zidovudine, 3TC – lamivudine, ddi – didanosine, NFV – nelfinavir, RTV – ritonavir, EFV – efavirenz

* CD4 determined 1 month after starting ZDV

** ARV started in USA

in reducing the mother to child transmission of HIV-infection (MTCT) which remains the main mode of transmission of HIV-infection in childhood. Out of 10 HIV-infected children treated in Croatia, 9 were infected by MTCT. Only one child with HIV-infection was infected by transfusion of blood products because of haemophilia in the early 80's.

Out of all HIV-infected Croatian children, 7 were diagnosed as HIV-infected in UHID and the remaining two were diagnosed in other countries where they lived before. There were several reasons for first visit to UHID: two children presented with an opportunistic disease, four came after one/both parents died or recent detection of mother's HIV-infection, two children with known HIV-infection came for further monitoring and treatment, one child came because of an acute illness and finally one child was born from an HIV-infected mother who received perinatal prophylaxis and after follow up the child was diagnosed as infected. Altogether, three children were diagnosed with one of the AIDS-defining illnesses (according to the CDC classification system²): *Pneumocystis jiroveci* pneumonia, recurrent serious bacterial infections (three episodes of bacterial pneumonia) and recurrent nontyphoid *Salmonella* septicemia. HIV-infected children were treated according to the current guidelines for ART and accessibility of antiretroviral drugs at the time.

HIV-infection in pregnancy in Croatia

MTCT occurs in 13 to 40% of all HIV-positive pregnancies without antiretroviral prophylaxis³. Among children

who were not breastfed, about 2/3 of vertical transmission cases occur during labour because of fetal exposure to mother's body fluids, and the rest during intrauterine life, mostly in the last two months of gestation. Most important factors for increased risk of MTCT are mother's higher viral load⁴, lower maternal CD4+ T-lymphocyte count⁵ and mode of delivery⁶. For more efficacious MTCT, medical care for HIV-infected mothers has to start in the early antenatal period. Universal prenatal HIV-1 counseling and HIV-1 testing with consent for all pregnant women is still not established in Croatia and among 89 women of childbearing age diagnosed as HIV-positive until the end of 2005⁷ only 4 were diagnosed during pregnancy. Antiretroviral drugs for HIV-1 infected women during pregnancy have two roles: (1) antiretroviral treatment (ART) of maternal HIV-1 infection (if required) and (2) antiretroviral chemoprophylaxis to reduce the risk for MTCT. In the early 90's it has been shown that chemoprophylaxis with ZDV can reduce the risk for vertical HIV-1 transmission by 66%^{8,9}. The three-part regimen includes oral ZDV for HIV-infected mother initiated at 14–34 weeks' gestation and continued throughout pregnancy, followed by intravenous ZDV during labour and oral administration of ZDV to the infant for six weeks after delivery. Several more studies have shown efficiency of different antiretroviral drugs in reducing perinatal HIV transmission^{10–14}. According to current CDC recommendations ZDV prophylaxis in the era of modern ART is reserved for those rare HIV-infected women with normal CD4+ count and low viral load that otherwise would not require therapy¹⁵. Today, all pregnant HIV-infected women should be offered highly active antiret-

TABLE 2
CHARACTERISTICS OF HIV-NEGATIVE CHILDREN BORN TO HIV-INFECTED MOTHERS IN CROATIA

Child	Sex	Year of birth	Weeks of gestation	Mode of delivery	Chemoprophylaxis		Mother's data		
					During pregnancy	To child	Diagnosed HIV-infection	Before labour	
								Viral load*	CD4 cell/ μ L
2	female	1987	unknown	vaginal	–	–	after delivery	unknown	unknown
6	female	1994	unknown	vaginal	–	ZDV (6 wks)	during pregnancy (unknown week of gestation)	unknown	unknown
8	female	1997	42	vaginal	ZDV	ZDV (6 wks)	during pregnancy (14 th week)	2820	905
11	male	2000	38	vaginal	ZDV	ZDV (6 wks)	during pregnancy (18 th week)	0	506
16	female	2001	39	vaginal	HAART	ZDV (6 wks)	during pregnancy (18 th week)	0	173
17	female	2002	40	vaginal	ZDV	ZDV (6 wks)	before pregnancy	0	574
18	female	2002	31	SC**	–	–	after delivery	unknown	unknown
19	female	2004	unknown	vaginal	ZDV	ZDV (6 wks)	before pregnancy	0	573
20	female	2005	38	elective SC	HAART	ZDV (6 wks)	before pregnancy	0	815

ZDV-zidovudine, HAART- highly active antiretroviral therapy, SC-cesarean section

*standard method (HIV-1 RNA copies/mL), **cesarean section because of intrauterine fetal hypoxia

roviral therapy (HAART) to maximally suppress viral replication (to undetectable levels) thus reducing the risk of vertical transmission and minimising the risk of development of resistant virus¹⁵. When choosing a combination of drugs one should keep in mind the safety and toxicity of drugs during pregnancy¹⁶.

The use of ZDV prophylaxis in Croatia started in 1994 and until the end of 2005, 7 mother-child pairs received ZDV prophylaxis (Table 2). Out of 11 children who were born in Croatia from HIV-infected mothers and followed up after delivery, in four cases a three-part regimen of ZDV prophylaxis was administered (with modification of regular recommendation: not a single woman was given intravenous ZDV during labour because of technical reasons, only oral ZDV in doubled dose). In four cases HAART was given to mother during pregnancy + ZDV during labour and to child, one child received ZDV but the mother received no therapy during pregnancy (in 1994), and finally, in two cases no prophylaxis was given because mother's HIV-infection was diagnosed after delivery (Table 2). In two cases in whom prophylaxis of MTCT was given (in both cases: HAART to mother), the outcome was unfavourable. A male child born by cesarean section in the 35th week of gestation because of intrauterine asphyxia and intrauterine growth retardation died few days after delivery because of fetal hydrops (not shown in table). His mother had undetectable viral load done just before labour with CD4+ cell count of 495/ μ L. Unfortunately, HIV-status of the child, as well as possible reasons for fetal hydrops remained unknown. Another poor outcome was caused by a mother's inadequate and inconsistent taking of antiretrovirals (HAART combination) during pregnancy. The child born to this mother (shown in Table 1), received ZDV for 6 weeks but despite that HIV-infection was confirmed by HIV-1 RNA PCR at the age of 7 weeks. She was born at the 34th gestational week, by vaginal delivery despite mother's high viral load before labour (64400 copies/mL) and low CD4+ T-lymphocyte count (171/ μ L).

According to current recommendations for prevention of MTCT, HIV-1 RNA levels in HIV-infected pregnant women should be evaluated at 34–36 weeks of gestation in order to decide on the mode of delivery. Although it has been shown that higher maternal viral load represents a higher risk for vertical HIV transmission⁴, there are also studies when predictive value of RNA copy number for transmission has been relatively poor^{17,18}. An HIV-1 RNA threshold below which there is no risk for transmission has not yet been identified. ZDV is effective in reducing transmission regardless of maternal HIV-1 RNA copy number⁹. Perinatal HIV guidelines recommend using elective cesarean section (SC) as an intervention to reduce perinatal transmission¹⁵. Scheduled SC should be considered for pregnant women with HIV-1 RNA levels >1000 copies/mL near the time of delivery¹⁹. If a decision is made to perform a scheduled cesarean delivery to prevent HIV-1 transmission, it should be done at 38 weeks' gestation, determined by the best clinical estimate and avoiding amniocentesis¹⁹. Despite all our efforts, only in

one Croatian HIV-infected pregnant woman scheduled cesarean delivery was performed (end of 2005).

According to the CDC recommendation that infected women should not breastfeed to avoid postnatal transmission of HIV-1 to their infants through breast milk²⁰, neither one of our HIV-infected women has breastfed.

Monitoring and treatment of HIV-infection

In last two decades significant improvements have been made in monitoring and treatment of HIV-infection in Croatia. For adequate monitoring of disease progression as well as efficacy of ART two laboratory markers: (1) CD4+ T-cells count and (2) viral load (number of HIV-1 RNA copies per mL of plasma) are of crucial importance. Before 1997, determination of CD4+ T-cells count at UHID was performed by using direct immunofluorescence method. Since 1998, quantification of CD4+ T-cells in HIV-infected patients (expressed as the number of cells per microliter of the peripheral blood) has been performed by flow cytometry, according to the CDC recommendations². HIV-1 DNA qualitative test was available at UHID in 1994²². Viral load is determined by commercially-available quantitative polymerase chain reaction assays which were implemented at UHID in 1996²². Plasma viremia (number of HIV-1 RNA copies per mL of plasma) is important for the assessment of disease stage, determination of risk for progression of disease and analysis of treatment efficacy. Since 1996, viral load was determined by using a commercially-available assay with the level of detection between 400–750 000 copies of HIV RNA/mL (standard method). Since 1999 new ultrasensitive method with the level of detection between 50–75 000 copies/mL has been used. Determination of antiretroviral drug resistance by HIV-1 RNA sequencing was available since 2002²⁴.

Nowadays the diagnosis of HIV-infection in infants in Croatia is based on virologic diagnostic test (PCR RNA assays) confirmed by repeat testing on the second blood specimen. According to current recommendations²⁵, PCR RNA is performed within the first 48 hours of life, at age 1–2 months and at age 3–6 months. Additional testing at age 14 days is sometimes done. HIV-infection is diagnosed by two positive HIV virologic tests performed on separate blood samples, regardless of age. HIV-infection was excluded with two or more negative virologic tests performed at age >1 month, with one of those being performed at age >4 months.

The era of ART in Croatia started with ZDV monotherapy. ZDV as the only antiretroviral agent has been available in Croatia since 1987 and, thanks to a donation, didanosine (ddI) has been available since 1995. Protease inhibitors (PI) became reimbursed by the Croatian Institute for Health Insurance in April 1998 and since then they became a part of HAART according to current guidelines for ART^{25,26}. Details on ART of children in Croatia are shown in Table 3.

TABLE 3
ANTIRETROVIRAL THERAPY ADMINISTERED TO THE
CHILDREN IN CROATIA (ARV STARTED AT UHID)

Child	Birth (month/year)	Starting ARV	Drug or Combination
1	4/1980	4/1997 ^a	ZDV
3	11/1987	1/1995 ^b	ZDV
5	6/1994	12/2000 5/2001 1/2003	ZDV+3TC+NFV d4T+3TC+NFV d4T+3TC+LPV/RTV+EFV ^c
7	2/1997	1/1998 10/1998 10/2004	ddI ZDV+3TC+RTV ZDV+3TC+NVP
9	6/1997	3/2001	ZDV+3TC+NFV
10	11/1997	8/1999	ZDV+3TC+RTV
12	6/1998	11/1998	ZDV+3TC+RTV
13	10/2000	12/2000 12/2001	ZDV+3TC+RTV ZDV+3TC+NVP
15	8/2000	10/2005	ZDV+3TC+EFV

ARV – antiretrovirals, UHID – University Hospital for Infectious Diseases, ZDV – zidovudine, 3TC – lamivudine, NFV – nelfinavir, d4T – stavudine, LPV/RTV – lopinavir/ritonavir, EFV – efavirenz, ddI – didanosine, RTV – ritonavir, NVP – nevirapine

^a zidovudine monotherapy until 4/1999, no ARV after that

^b until death, ^c resistance to zidovudine and nelfinavir confirmed

Ethical and Social Issues

In the last almost twenty years the Croatian society was confronted with many ethical and moral dilemmas regarding HIV-infection. In contrary to ingrained opinion that HIV-infection is reserved for marginal population, it is obvious that children are not guilty for their HIV-status. Despite those facts, there were many obstacles for caring and integration of HIV-infected children in the Croatian society. Stigmatisation, fear and lack of knowledge were major contributors. Unfortunately, it took many years to make some improvements in public opinion and to change attitudes towards HIV-infected people. Some issues which appeared with HIV-infected children will be presented regarding the society's and government's unpreparedness to face the problems that forced some political and public changes.

The first child born from an HIV-infected mother nineteen years ago was vaginally delivered without episiotomy and without surgical care after rupture of perineum. This happened not because of lack of knowledge among medical personnel in maternity wards about the ways of HIV-transmission but purely because of fear from HIV-infection. Fortunately, significant improvements have been made in attitudes of medical personnel toward HIV-infected people and children in the last years and those initial obstacles based principally on private animosity were replaced with a more professional approach.

The occurrence of the first HIV-infected orphan in Croatia raised some issues that put to test entire legislation system, social care system and even Croatian Government. The problem arised at the beginning of 2000, after the death of the child's parents. Soon after the child was also diagnosed as HIV-infected, she was immediately hospitalised at the UHID. National newspapers revealed the child's identity by publishing a sensational story with the child's full identity, HIV diagnosis and a photo from the family album. No child welfare institutions were prepared to take care of the child because of her HIV-infection. An 8-month long hospitalisation followed because of inability of institutions to find an adequate home for this child. In an attempt to try and solve this problem the Ministry of Health and Social Welfare decided to contact the media (newspapers and radio). Finally, a foster family came forward, willing to take care of the child. Their photos were also published in the newspapers several times and they also appeared on the TV. By mid-2001, another HIV-infected child without a family was admitted to the UHID and soon after she was also placed into care with the same foster family.

The problem of HIV-infected orphans was not only in seeking a foster family. After their full identity was revealed to the public they had to face social rejection. Namely, nurseries refused to admit HIV-infected children. In an attempt to help the foster family with two HIV-infected children, the mayoress of Zagreb (the capital city of Croatia) has decided to allocate an apartment for this family but once again, the newspapers revealed this new address and immediately kindergarten and schools, opposed accepting these children once again. Potential new neighbours strongly rejected the idea of foster family moving into their neighbourhood, publicly disapproved the idea and even threatened the family. Finally, the foster family decided not to accept the new apartment.

Integration into school of HIV-infected child with known HIV-status

In autumn 2002 one of the two orphans with HIV-infection had to enroll into school. In a small town where the family lived at that time, the identity of the first-grade HIV-infected child was known to public and the local authorities decided to ask parents of other first graders to voluntarily allow their children to attend the same class as HIV-infected child. Only one parent gave permission that his child attends the same class as the HIV-infected child. After that, lessons for HIV-infected child were organised in the school library. Finally, the foster family had to move to a different town because of people's prejudices.

In preparing the child's transition to school in another town, the starting point was education of teachers in school she was about to attend, in order to gain their cooperation and support. Taught by the previous experience with the media, the whole project was kept in discrete. Systematic and serious education of teachers and school staff was started. From initially evident resistance

and fear of infection, the teachers finally accepted and understood the complex situation they were in. But, the fear for their jobs and existence if all the students withdrew from school still remained. In order to calm down the situation, the Ministry of Education obliged to give salaries to all the teachers regardless of the number of students in their classes, believing that the parents will accept the newly risen situation, too. Unfortunately the educational process of the parents did not go smoothly. At the very first meeting they showed great resistance and lack of comprehension. Loud leaders, partly motivated by the local relationships and stories, overpowered the opinion of a few who sought explanations about the disease and tried to understand. It became more and more clear that the widest range of people had to be educated. A couple of public tribunes held by our most eminent doctors were of supreme importance. Great help and support to the whole project came from the young, secondary school students and university students in this town who organised themselves and signed petition as well as encouraged people in their community to humaneness and understanding. Therefore, the young in Croatia, besides having some basic knowledge on HIV-transmission²⁷, proved to be more mature and compassionate than many adults.

Finally, in autumn 2003 the older child enrolled into second grade. Once again, the whole situation was covered by media. Despite efforts made by the Ministry of Health's expert team to change attitudes towards HIV-infected people through meetings held with parents whose children would be possible schoolmates of HIV-infected child and after providing appropriate and detailed information on HIV-infection for several days, the result was: HIV-infected child shared class with only two other children. The parallel class attended eleven children and all other children moved to other schools according to their parents' decision.

In order to integrate the younger HIV-infected child into first grade more easily, a local team of professionals was made with an epidemiologist leading the group. They worked as a team, in coordinated manner, without media. They organized meetings with groups of parents of kindergarten children but also held individual sessions/courses. The results of this four month program of intense education of parents were satisfactory: HIV-infected child was integrated in the first grade with eight other children, 19 children attended parallel class, and only 5 parents withdrew their children from the school. All parents had to make a choice between class with HIV-infected child and parallel class. These results show great improvement in attitudes of parents of future first grade children compared to the situation the previous year. Changes in attitude towards HIV-infected children were the result of a planned educational program. Direct and permanent contact with parents (by phone, individual courses) in an atmosphere of mutual confidence between the expert team and the parents was established, where the parents' will and freedom of choice were respected²⁸.

During the last several years, both HIV-infected children participated in extracurricular activities (scouts, artistic group) where they were accepted among many other children as their equal.

This year, the older HIV-infected child attends the fifth grade. After being in class with only two children (second grade), then three children in the next two years, today she has 21 schoolmate. Throughout these years, the education of people in the local community continued on the individual basis, without the presence of media.

Pupils and teachers' attitudes towards HIV-infected children – present situation in Croatia

At the end, the question that arose is: »Has anything changed in comprehension and understanding of HIV-infected children's problems from the time of presented case till today?« Trying to answer the question we performed a small investigation among five graders (peers of the older HIV-infected girl) and among their teachers.

The number of respondents was 97 pupils and 31 teacher (N=128). The questionnaire was anonymous and the students were made aware of the fact that their participation was voluntary, they were only asked to answer the questions sincerely. Altogether 92 pupils filled out questionnaires while 5 pupils handed in empty ones.

We wanted to find out if the pupils knew what HIV/AIDS/SIDA was. Seventy seven pupils (83.6%) knew about the terms. But 15 pupils (16.3%) reported that they were not acquainted with the terms.

The pupils reported that they were informed about the terms HIV/AIDS/SIDA mostly by TV (62 of them, 67.3%), then by their parents (42 of them, 45.6%) and the lowest percentage of them heard about the terms in school (15 pupils, 16.3%). They also added that they got information about the terms from magazines, books and posters in hospitals. Low percentage of pupils who were informed about such an important issue in school can be partly explained by the fact that this issue is probably spoken about in biology classes in higher grades.

Altogether 31 pupil (33.6%) reported that they would play with HIV-infected children, while 40 pupils (43.4%) reported that they wouldn't play with HIV-infected children and 6 pupils (6.5%) were indecisive. Pupils who claimed that they would play with HIV-infected children gave surprisingly mature opinions in their comments and instructions in humaneness. We will cite only some of them:

- »I think that children with AIDS should not be separated because they are in no other way different from us. If we didn't play with them they would feel even worse.«
- »They are people like us. They only have an incurable disease. But that doesn't mean we can't be their friends.«
- »I think that those children are a little bit different. But they are only children. Only they need more love and care.«

Pupils who claimed that they would play with HIV-infected children were aware of the way this disease is transmitted, which means that their YES was not random. In their comments they point out:

- »It is transmitted through blood, so it is almost harmless to play with somebody infected.«
- »Yes, I would play but not sexually.«
- »HIV is not transmitted through play, glasses or toilet bowls. The whole world should know that by now.«

Pupils who claimed that they wouldn't play with infected children explain in their comments that they are primarily afraid of the infection. Both they and the group of indecisive pupils explain their fear of not knowing about the facts of infection possibilities and they point out:

- »I would like you to come to all schools in Zagreb and to inform us about those diseases.«
- »I would like to know more about it. For example what are the consequences, is there a cure, how does one get it?«

Most of the pupils, regardless of their responses, point out the need and curiosity to learn more about this dangerous disease.

The poll included 31 teacher. Out of them, 28 teachers (90.3%) would accept an HIV-infected child in their class while 3 teachers (9.6%) wouldn't.

The common topic of public debates is the question of whether it is necessary to know that a HIV-infected child attends a particular school or class and who must have this information. 27 of the respondent teachers (87%) think that the form-master should know (out of them 3 think that this information should be known only to the form-master and nobody else), 24 teachers (77.4%) think it should be the headmaster (1 of them thinks it should be the headmaster and nobody else). 16 teachers (51.6%) think that all the teachers should have this information and 11 teachers (35.4%) think that parents of other pupils should also know that fact. The teachers added that school pedagogues and physical training and sanitary culture teachers should certainly be informed about the problem as well. Most of the teachers think that the information about HIV-infected child shouldn't be a secret but the fact known to the school officials, form-master and teaching staff.

The teachers who responded that they wouldn't accept HIV-infected children in their classes explain their decisions as following:

- »The problem of such children should be solved without endangering other children. Although the disease is not transmitted through usual social contact, the children's spontaneity increases the risk of endangering other children.«

In the statements of teachers who would accept infected children in their classes there is also the wish for help as well as the fear and feeling that they are not suffi-

ciently educated and prepared because »... we should know how to give such a child an adequate help and secure him and his environment.«

What the teachers pointed out in their comments could be a starting point in the work with them:

- it is necessary to break the myth about HIV, and to break the fear and prejudices;
- as they are not sufficiently acquainted with the problems, they pointed out that they needed help in »how to safely deal with such children«;
- they emphasize the need for guidance of medical professionals.

Discussion

The accessibility to health care and especially to ART for HIV-infected children, as well as other HIV-infected people in Croatia is good, principally due to the fact that a majority of their health care needs including ART and immunisations can be fulfilled in a single medical institution – UHID. In the last decade experts from UHID made notable efforts to change the approach to HIV-infected patients among members of other medical specialties.

Among the human rights principles relevant to HIV/AIDS are, apart from the rest, the right to non-discrimination, equal protection and equal accessibility to the legal institutions, the right to the highest attainable standard of physical and mental health, the right to privacy, the right to equal access to education, the right to social security, assistance and welfare²⁹. All HIV-infected children have undoubtedly the right to privacy which includes the obligation to seek informed consent for HIV testing and to respect the confidentiality of all information relating to a person's HIV status²⁹. Privacy of information is necessary because of the stigma and discrimination attached to the loss of privacy and confidentiality if HIV status is disclosed. The state authorities should take all appropriate measures to ensure that the child is protected against all forms of discrimination and ensure the rights of each child³⁰.

Children's right for privacy was violated when the newspapers revealed their full identity. The source of this information was never revealed, but it is an inexcusable and irresponsible act, especially if there was a medical disclosure/breaking of professional secrecy made by medical professionals. Every physician should preserve absolute confidentiality on everything he knows about his patient even after the patient has died^{31,32}. Confidential information can only be disclosed if the patient gives explicit consent or if the law expressly provides for this. Consent may be presumed where disclosure is to other health care providers involved in that patient's treatment³³. Disclosure of children's HIV-status stigmatised them and made their childhood full of rejections. Journalist undoubtedly broke codes of journalistic ethics. Journalists should show compassion for those who may be affected adversely by news coverage. They should be

especially sensitive when dealing with children as well as when seeking or using interviews or photographs of those affected by tragedy or grief³⁴. According to the Croatian Journalists' Association Code of Ethics, a journalist is to protect man's private life from unjustified or sensational exposure to the public. Special care and responsibility is needed in reporting about accidents, family tragedies, diseases, children and the minors, court proceedings, where the journalist must respect presumed innocence, integrity, dignity and feelings of all the persons involved³⁵.

The Croatian society was completely unprepared to take care of HIV-infected orphans. It took months before the foster family was found. Despite willing health care professionals, mental health professionals, social workers and non-governmental organisations, foster care agencies, even religious charitable organisations refused to take care of the children. Unfortunately, the Government still has no policy or mechanism to take care of HIV-infected orphans. Beside one family that took over these two children there is no foster care system developed and no solutions for all other children who might be in the same situation in the future. There are no reasons to restrict foster care or adoptive placement of HIV-infected children in order to protect the health of other family members. Also, there is no need to restrict the placement of these children in child care settings to protect personnel or other children because the risk of transmission of HIV in these settings is negligible³⁶. Theoretically, exudative skin lesions or aggressive biting behaviour are conditions in which an increased risk of exposure occurs in children attending day care centres and schools^{37–39}. All foster parents should receive education about HIV infection. Foster parents providing care to HIV-exposed infants should be educated about all issues in the management of the HIV-exposed infant that usually are discussed with the biological parent⁴⁰.

According to the Convention on the rights of the child, every child has the right to education on the basis of equal opportunity³⁰. HIV-infected children should be admitted without restriction to child care centres and schools and allowed to participate in all activities to the extent that their health and other recommendations for management of contagious diseases permit⁴¹.

Children and youth with HIV-infection should receive the same education as those with other chronic illnesses. The spread of HIV-infection in the school has not been documented and it is not required that the school be notified of HIV-infection. Disclosure of the child's HIV status should be done only with the consent of the parents or legal guardians and the student if appropriately aged⁴². Some families may not permit disclosure which should not prohibit the student from attending the school. Some HIV-infected children who attend school have not had their conditions diagnosed. So, the generic principles of Standard Precautions in the CDC guidelines generally have to be applicable to children in all health care set-

tings, schools but also at home⁴³. Persons in homes, schools, and child care facilities who may have contact with blood or body fluids containing blood should be educated about Standard Precautions to prevent transmission of HIV and other blood-borne pathogens. HIV-infected children and adults should be educated about appropriate precautions⁴¹. Prejudice and fear toward HIV-infection have to be overcome by appropriate education of all school personnel. Our experience shows what the consequences might be in case of disclosure of identity of HIV-infected children. HIV/AIDS education program for parents of school/kindergarten children was necessary in order to provide accurate information about HIV-infection and its transmission and in order to create positive attitudes and more accepting environment for the HIV-infected children in schools. In society where confidentiality of HIV-infection status is respected and maintained parents of other children wouldn't be able to stigmatise and isolate infected pupils. Unfortunately, knowledge about HIV-transmission does not (although is thought to) correlate with attitudes toward HIV-infected people because of prejudice and fear⁴⁴.

Although the sample of our pilot research in one elementary school is not large, it still represents an average school in Croatia in which some HIV-infected child could appear again. Obtained results are indicative. Compared to the situation when the first HIV-infected girl appeared in Croatia, things are considerably different today. Both children and teachers obviously know more about HIV problem, but there is still a large number of those who, due to fear and ignorance or low-quality knowledge, wouldn't have contact with HIV-infected children. Teachers and students clearly point out the wish and need to be educated about that disease and the ways of protection. As for the students, the attention to this disease shouldn't be drawn just occasionally but also through class meetings and subjects which aim to raise the level of sanitary culture. The problem of HIV and the work with such children should specially be interpolated in the programmes for professional improvement of teachers.

Permanent education of the public is necessary with emphasis on limited modes of HIV transmission in order to decrease discrimination. The improvement in health workers' attitudes and confidence in dealing with patients with HIV diseases can be made^{45,46}. As long as disclosure of HIV-infection can stigmatize children and families, confidentiality is important. Confidentiality of HIV-infection status should be respected and maintained. All medical professionals have to consider confidentiality as one of the patient's rights. After a bitter experience with social integration of HIV-infected children in Croatia⁴⁷ we have to be prepared and willing to take care of HIV-infected children.

Are we willing to admit our mistakes? There is hope that Croatian society has learned that HIV-people are among us and should be accepted in community with dignity and respect.

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**DJECA ZARAŽENA HIV-om U HRVATSKOJ – MEDICINSKA SKRB,
ETIČKI I SOCIJALNI PROBLEMI**

S A Ž E T A K

Razdoblje HIV-infekcije u djece u Hrvatskoj počinje 1987. godine rođenjem prvog djeteta majke zaražene HIV-om. Autori prikazuju neke medicinske podatke djece zaražene HIV-om i djece praćene zbog majčine HIV-infekcije u Hrvatskoj do kraja 2005. godine. Iako je broj djece zaražene HIV-om u Hrvatskoj još uvijek relativno malen, u zadnja dva desetljeća hrvatsko društvo bilo je suočeno s mnogim etičkim i socijalnim problemima vezanim za HIV-infekciju i diskriminaciju. Značajni problemi pojavili su se pri skrbi i integraciji djece zaražene HIV-om u društvo. Stigmatizacija, strah i neznanje glavni su čimbenici. Po prvi put opisuje se integracija u školu zaraženog djeteta s poznatim HIV-statusom. Promjene u stavovima prema osobama zaraženima HIV-om mogu se postići jedino planiranim edukacijskim programima.