

Daniela CALTEA
Department of Sociology, Faculty of Philosophy and Social Political Sciences,
Al. I Cuza University, Iassy

HIV INFECTED CHILDREN'S AND YOUNG RIGHT TO HEALTH IN ROMANIA

Empirical
study

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Risks,
Statistics,
Legislation

Abstract

The study was based on finding the characteristics of the process of acknowledging the right to the best health status of HIV infected children and adolescence in Romania from their perspective.

The aim I was following with this study was the identification and analysis of the risks the HIV infected youth are exposed to when claiming specialised medical treatment. In this respect I focused on the degree of acknowledgement to their right of health received.

I obtained my data after conducting life story interviews with youth from the counties of Iasi and Constanta and the city of Bucharest. In this article I will focus on general aspects concerning HIV infection and AIDS in Romania (statistics), the legislation concerning the right to health of Romanian children and adolescence, the identification and analysis of the barriers met in the acknowledgement to this right and measures to be taken for the eradication of these barriers.

INTRODUCTION

The research was conducted in Romanian counties of Iasi and Constanta and the city of Bucharest. Looking at HIV infected children and youth, the main goal of the project was the analysis of the implementation of their rights to enjoy the highest attainable standard of health.

HIV (human immunodeficiency virus), localizes and multiplies itself within the T4 -CD4 cells, decreasing the body's defense mechanism against infection and disease.

AIDS is the final form of HIV infection, a polymorphic syndrome characterized by repeated and rebel (opportunistic) infections that develop among individuals, leading to a decrease in the effectiveness of their immune system (Ursaci, 2003).

AIDS, and implicitly HIV were initially treated strictly as medical issues, but the psychosocial, educational, economic and cultural consequences that emerged among HIV infected children and their families led to a multidisciplinary approach to this problem. Thus, AIDS has become a concern for various professional categories including social workers, psychologists, and sociologists (Buzducea, 2008).

Their job is to act as a mediator between the medical staff and the community, to educate and involve the members of the society, as AIDS represents an issue affecting the entire community, not only the ones directly harmed by it.

In my research I analysed the implementation of HIV infected children's rights to enjoy the highest attainable standard of health. In my analysis I tried to look at this in the context of negligence, when the youth's requests to specialised medical services (dental, surgical, gynecological etc.) were denied. I need to mention that Romanian institution guarantees by law the right to health of this group of individuals.

In order to provide you with information concerning the numbers in relation to AIDS and HIV infection in Romania I will present you the following statistical data.

In Europe, Romania ranks first in terms of the number of children and young people affected by AIDS, but judging by the total number of cases, it is closer to Western countries than to those from Central and Eastern Europe (tabel no. 1).

According to the same source in our country the counties with the highest percentage of the population infected with HIV/AIDS at 30th June 2012 are: Constanta

(940 cases), Galati (787), Bacau (334) (figure no. 1).

In the area of Moldova on the 30th of June 2012 statistics show that Bacau County had 335 people infected with HIV/AIDS, in Galati County there were registered 300 cases, in Neamt County 257 and Iassy County had a total of 253 individuals affected by AIDS (figure no. 2).

In the Regional Center of HIV / AIDS Iassy the Infectious Diseases Hospital has currently in the dispensary over 1,300 patients. In 2012 scientists found 53 people infected with HIV/AIDS (DSP, 2013). In 2013, specialists diagnosed 70 patients coming from all districts of Moldova. In the records of the Iassy Regional Center of HIV/AIDS there are currently 1400 people registered (table no. 2).

The statistics also reveal that there are 253 individuals suffering from Aids in the County and around 86% of them are young (above 18 years old) and physically able to work. So the risk is represented by the young ones (who are older than 18) who have been infected during 1989-1992 and who are seeking for a job.

However, AIDS/HIV infection is not just a matter of statistics, but a real, worrying phenomenon which requires prompt responses from both individuals and communities. An adequate health policy able to combine prophylactic with therapeutic means in a more efficient manner is also necessary in addressing this issue.

Interacting with the ill made me realize that AIDS is not an outside phenomenon 'from a different world', but a fact whose existence we cannot deny. Therefore, the responsibility of the society is not only to treat it as a statistical figure or an uncommon news topic, but as a real issue experienced by ordinary individuals.

I chose this research topic because I was motivated by my previous experience at workplace. Specialising in HIV infected (orphan) children, my job offered me the opportunity to face the discriminatory practices the youth often encounter when requesting specialised medical services. In addition to this, another decisive factor for me was the insufficient, limited previous research conducted on the topic of AIDS in Romania, especially research focused on the elimination of existing barriers in the field concerning the right to the highest attainable standard of health for HIV infected children and youth (Buzducea, 2011).

To sustain my argument I claim that every person should be treated equally by law, as the national and international constitution

requires. Individuals suffering from AIDS are included in this category and should enjoy all human rights without being subject to discrimination.

I. HIV infection

I.1. Groups at risk of HIV infection

In the case of HIV/AIDS infection, just as it is with any other disease, it is easier to prevent than to treat, so I will list the ways in which infection is possible (table no. 3).

The most important risk groups are: drug users, poly-transfusants, people who have casual or unprotected sexual intercourse, people who practice commercial sex, homosexuals, immigrants returning in their own country after a long period of time, emigrants, people suffering from TB, inmates, people who already suffer from other sexually transmitted diseases, people who do not have access to education in general (Buzducea, 2007, 2010).

I.2. AIDS and HIV infection in Romania

The first confirmed case of HIV infection in Romania was registered in 1985, but the communist regime did not consider the disease as a threat because it was believed that the country's citizens were not at high risk of contracting the virus. Due to this faulty belief the authorities failed to consider the risk the population was exposed to and therefore, it was not until the fall of the communist regime that measures were taken to prevent the spread of the virus (Iftimoaei, 2004).

Back then, the health system was on the verge of bankruptcy and the medical staff was forced to work without sterilized equipment, sanitary surgical gloves and sterile dressings. As a consequence of this, while the heads of the health system refused to accept that HIV represented a threat in Romania, the virus continued to infiltrate and begun to spread.

The phenomenon of HIV/AIDS in Romania has as a distinctive element in the relatively compact group of young children infected during 1986 and 1992. The nosocomial (hospital-acquired) infection was due to the use of unsterile equipment and blood products untested for HIV (Buzducea, 2008).

In Romania in 1990 over a thousand people were diagnosed with AIDS, most of which were children (Department of Monitoring and Evaluation of HIV/AIDS Matei Bals, Romania). This fact led to ranking Romania as the country with most children affected by AIDS, closer to the Western countries than to the ones located in Central and Eastern Europe. The rise of the epidemic among children was so great that at one point

we had recorded over 50% than the total cases of HIV infected adolescence in Europe. In Western Europe the number of cases gradually increased over the years, while in Romania the situation became critical in 1990.

The main features of HIV infection in Romania:

- Prevalence of infection among children, mostly represented by children born between 1988-1990;
- Over 70% of children were infected through nosocomial transmission during medical interventions or through blood transfusions (Novonty, T., Haazen, D. and Adey, O., 2003 cited in Ursaci, D.2003);
- An increase in the number of newly diagnosed cases among adults and especially among young people;
- The perspective of an increase in the number of cases of vertical transmission (from mother to child);
- A growing number of HIV infections transmitted through unsterilized needles in the case of drug users (the situation worsened with the increase of injectable drug users and patients diagnosed with AIDS);
- An increase in the number of HIV-positive people who need medical care and treatment, according to the Ministry of Health and the National Commission Fighting against AIDS.

II . Legislation concerning HIV/AIDS

A) International Law

1. The UN (United Nation) convention regarding child protection enshrines in **Art. 24** children's right to enjoy the highest attainable standard of health and the right to equality regarding the access to recovery treatment and health services. As part of the same act, **Art. 25** specifies that States Parties recognize the right of children by competent authorities for the purposes of care, protection or treatment for physical or mental health issues and sanctions the right to a periodic review of the treatment provided and any other aspects of their placement.

2. In Art. 25 the Declaration of Human Rights states that every individual has the right to a standard of living which can guarantee their own, as well as their family's health.

3. The International Covenant on Civil and Political Rights in Art. 12 states that the States Parties recognize every person's right to the enjoy the greatest physical and mental health state that can be achieved.

B) National legislation

a) general

1. The Romanian Constitution specifies in **Art. 34** that the right to health care is guaranteed and that the state is responsible to

take measures to ensure public health and hygiene.

2. The Act 272 from 2004 states in **Art. 43** that children too have the right to enjoy the greatest health state they can achieve and to benefit from medical and rehabilitative services necessary to ensure this.

As part of the same Act, in **Art. 46** it is emphasized that a disabled child is entitled to special care tailored to their own ability and needs of education, rehabilitation, compensation and integration, in the purpose of personal development. The special care provided must ensure physical, mental, spiritual, moral and social development.

b) specific

1. The mandatory minimum standards for residential services for disabled children were published in Monitorul Oficial (The Official Gazette) on 8th of June 2004 and entered into force on 1st of January 2005.

Standard 12 makes reference to children's health state and illness prevention. It also specifies that that residential childcare service should provide conditions and appropriate measures for identification and continuous assessment of both physical and emotional and health state of every child. These needs should be met in order to respect the standards imposed for the residential childcare services. Children should receive medical, dental and other support health services, they should maintain a good general condition and be educated in the spirit of a healthy lifestyle.

2. In Art. 10 of the Act 448 from 2006, republished on the 3rd of January 2008, regarding the protection of disabled persons it specifies that they are entitled to free medical care, including medicines, both during hospitalization and for patient use at home. This entitlement is in agreement with the health insurance system, and the conditions established in the contract.

3. In Art. 9 of the Act 584 from the 29th of October 2002 regarding AIDS' prevention from spread and the protection of HIV infected people, there is stated that health facilities and physicians, regardless of specialty field are obliged to hospitalise and provide medical care in accordance with the patient's pathological needs.

The same law, in **Chapter IV, Art. 8**, paragraph (1) and (2) emphasises that confidentiality of data on HIV and AIDS is mandatory for the employees of the health network, as well as their employers and the civil servants who are granted access to such data.

4. Act 324 from 2006 amending and supplementing Government Ordinance 137

(2000) sanctioning all forms of discrimination states that HIV infected people or those living with AIDS have the right to non-discrimination. All citizens including those with HIV/AIDS should enjoy equality, therefore all human rights without discrimination.

III. Research questions

Q1: To what extent does AIDS/HIV infection feed the risk of violation of (HIV positive) children's rights?

Q2: What are the main barriers standing in the way of respecting the rights of HIV infected people?

Q3: What measures can one take in order to eradicate the barriers standing in the way of respecting the rights of HIV infected persons?

Q4: What are the means of support that HIV positive children (and youth) could benefit from in the sense of respecting their non-discriminatory rights?

IV. Research objectives

1. General objective

- Evaluation of the implementation of HIV positive children's right to health in Romania.

2. Specific objectives

- Identifying and analysing the legislative framework in which the right to health of HIV infected children and youth is recorded;
- Identifying and analysing situations and manners in which the right to health of HIV infected children and adolescents is respected and valued in Romania;
- Identifying the various barriers encountered in respecting the right to health of HIV infected children and youth, as perceived by themselves or by professionals working with this group;
- Identifying efficient measures necessary for the removal of barriers standing in the way of respecting the right to health of HIV infected young people.

V. Research Method

1. Research Strategy

In the research conducted I used qualitative methods, descriptive and comprehensive.

2. Research Sample

In my research I used a sample of HIV infected children and young people aged between 10 and 29, and specialists working with this group in social and medical institutions, both governmental and non-governmental.

3. Sampling methods

For the selection of respondents I used non-probability sampling, like sampling method based on a pre-defined goal and the snowball method. The snowball technique

helped me find more participants, being introduced to them by some of the individuals I had already interviewed.

4. Techniques used

For in-depth research I used:

- Research;
- Participant observation;
- The life- story interview;
- Focus- group (group interview), which was conducted with individuals who are part of the target group and specialists working with HIV infected persons (social workers, psychologists, doctors and nurses).

VI. Ethical implications of the research

HIV infected people or individuals suffering from AIDS belong to a vulnerable social category, due to the meaning attached to the disease and the general attitude of the public towards it.

In my project the most important ethical issues were communicating the aim of the research to the participants, obtaining their legal guardians' (when under-aged) consent for taking part in the interviews; the issue of confidentiality concerning data that might reveal their identity, the diagnosis and social and sexual practices. Another ethical concern was the recognition of the potential effects the interviews might have on the subjects, both on short and long term.

I clearly specified to all of my participants (children, young people and professionals) that they are free at any point to avoid answering questions that put them in a state of discomfort.

In this sense I can argue that the results of the research will have a positive impact not only on the youth suffering from AIDS, but also on the society as a whole.

VII. Findings

In the study presented, through qualitative research I tried to analyse the implementation of HIV infected youth's rights. The analysis was done from the perspectives of both professionals dealing with this group and individuals suffering from AIDS. From the data collected on HIV positive persons' right to health, I was particularly interested in the identification and analysis of the existing legislation regarding this particular group, the circumstances and manner of compliance/non-compliance to the law, and the identification and analysis of barriers standing in the way of respecting HIV infected youth's right to health.

Health and disease cannot be studied separate from a social, economic and cultural context. The environment has a major impact on health as the employment situation, cultural

beliefs, social support and economic background all contribute and interfere in a person's wellbeing.

AIDS should not only be seen as a set of numbers, a matter of statistics. It represents a real problem which requires a clear response from individuals and communities, a coherent health policy able to combine both prophylactic and therapeutic means in a more efficient manner.

People affected by the disease are forced to cope with unbearable situations of high emotional stress, which cause negative feelings and have a devastating effect on mental health.

Some of the most serious problems faced by the ill are discrimination and social stigmatization (e.g. marginalization, educational and employment exclusion, refusal of certain medical services such as dental and microsurgery etc.).

The Romanian Constitution stipulates the rights of people directly affected by AIDS, but the implementation of these laws is deficient. The disease is being associated with poverty and therefore, in most cases children affected by it cannot be raised by their biological parents and are subject to alternative measures of care and protection.

Usually the HIV positive persons are referred by others as 'different' (which holds both a positive connotation – the care that is implied in relation to the ill, and especially a negative meaning – the labeling given through stigmatisation).

The main findings in my study were:

- AIDS/HIV infection associated with poverty has determined the fate of most children infected with the virus. Due to the lack of material resources parents are forced to allow someone else to raise their babies, who usually benefit from alternative measures of protection. There have been numerous cases where parents abandoned their HIV positive children in hospitals or orphanages as an attempt to protect other family members from contracting the virus.

- Fuelled by fear and prejudice the image of a HIV infected child is altered. The belief that they cannot function as a healthy person leads to the 'need' for special treatment. Directed to receiving special education, not being allowed to play or interfere with the healthy children (in case of an accident that may lead to bleeding, therefore transmission of the virus), they are denied their right to an opinion and education.

- Sometimes HIV positive people face situations when their right to health is being violated by the denial or postponement of

specialised healthcare because of their diagnosis. Healthcare discrimination is most often met in dentistry, surgery and gynecology. The forms of discrimination encountered are both direct (refusal, isolation of and from the patient) and indirect (delays in providing the services required, exaggerated and unjustified protective measures). In reality access to specialised treatment is possible, but lately monitoring healthcare has proven to be problematic.

- HIV positive youth often have employment issues, their right to work being, once again, violated. A particular case is the HIV test required by some institutions before employment. This does not portray a violation of privacy, but also a form of discrimination against individuals who are HIV positive. It is believed that the disease should not constitute a barrier to socio-professional integration and that in fact one's abilities, skills and training are more relevant.

- Disclosure of diagnosis in the case of HIV infected children and youth has been proven to be an impediment in developing friendship and intimate relationships. This makes it harder for this group to exercise their right to start a family and to live a normal social life. Being accepted in a group of friends as a HIV positive individual constitutes a challenge. Even if AIDS should not form an obstacle, prejudice, lack of information or misinformation and fear represent the root causes for marginalisation. Being friends with the ones suffering from AIDS we can encourage them and give them more hope in life. Offering love to a HIV positive person means you will receive back love, but it does not mean that you will get infected yourself. The lack of information in the community often leads to actions which serve as a violation of rights among HIV infected individuals.

VIII. Recommendations

- Educational programs disseminated in schools aimed for the prevention and eradication of discrimination towards HIV positive individuals;
- Adequate infrastructure for healthcare;
- Coherent health and social policies that combine both prophylactic and therapeutic means;
- National programs facilitating the access of HIV positive children to mainstream schools;
- Adequate schooling and training for employees working with HIV infected individuals;

- Greater involvement of governmental and non-governmental organizations in promoting the rights of HIV infected people.

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HIV or AIDS, article 9 and chapter IV, article 8.

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- [14] *The Romanian Constitution, 2003, article 34.*
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- [16] *The Declaration of human rights, 1948, art. 25.*
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Appendices

Appendix A

Tabel No. 1

AIDS/HIV infection in Romania from 1985 to 30th of September, 2013

Total of AIDS/HIV infection cases recorded	19026
Children- younger than 14 when diagnosed	9937
Children-older than 14 when diagnosed	9087
Total number of patients alive	12119
Total number of lost records	625
Deaths	6282

Appendix B

Tabel No. 2

Spread of AIDS/HIV infection among the counties of Romania at 30th of June, 2012

Recorded data from the HIV Regional Centre, Iasi – from 1985 to 30th of June, 2012

Total number of registered patients	1358
Number of patients in the active record	253
Number of patients receiving antiretroviral treatment	224

* Source: <http://www.cnlas.ro/date-statistice>, Compartimentul pentru Monitorizare și Evaluare a infecției HIV/SIDA în România (Department for Monitoring and Evaluation of HIV/AIDS in Romania) – IBI „Prof.Dr.M.Bals”

Appendix C

Tabel No. 3

The ways in which HIV-AIDS infection is possible to be transmitted

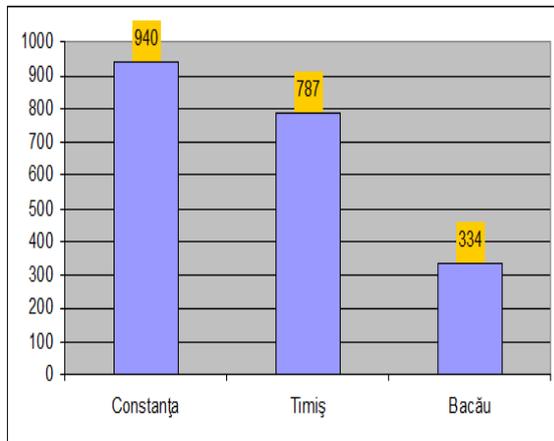
1.	Ways of transmission	Biological products involved in transmission
2.	Sexual	Sperm, vaginal secretions
3.	Parental	Blood or biological products containing blood
4.	Vertical	Maternal milk

Note: (Iftimoaei, 2004)

Appendix D

Figure No. 1

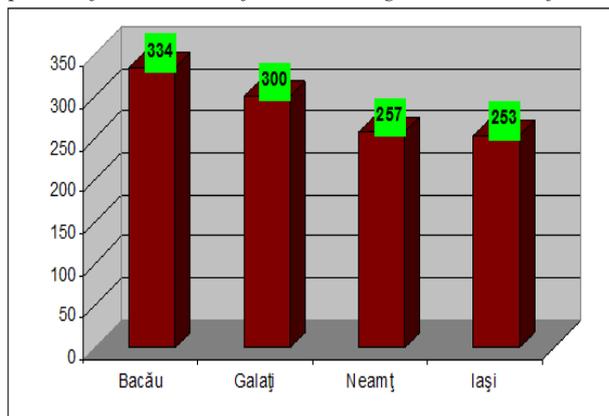
Spread of AIDS/HIV infection among the counties of Romania at 30th of June, 2012



Appendix E

Figure No. 2

Spread of AIDS/HIV infection among the districts of Moldova at 30th of June, 2012



* Source: <http://www.cnlas.ro/date-statistic>, *Compartimentul pentru Monitorizare și Evaluare a infecției HIV/SIDA în România (Department for Monitoring and Evaluation of HIV/AIDS in Romania) – IBI „Prof.Dr.M.Bals”*

Abbreviations

ADV – Fundația *Alături de voi* România [Foundation *Close to You* Romania].

ARAS – Asociația Română Anti-Sida [Romanian Association Against AIDS].

DGASPC – Direcția Generală de Asistență Socială și Protecție a Copilului [General Directorate of Social Assistance and Child Protection].

DSP – Direcția de Sănătate Publică Iași [Department of Public Health Iassy].

