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THE HIV/AIDS RISK FACTOR IN THE RIGHTS OF THE ILL

Empirical
study

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Abstract

In conducting this study my intention was to provide a general presentation on valuing and respecting the rights of children and youth affected by HIV/AIDS in Romania.

My research goal was to assess the implementation and enhancement of the rights of HIV positive Romanian children and youth.

The themes covered are: conceptual delimitations on the virus infection, the history of HIV/AIDS, statistics including general information on HIV/AIDS in Romania, the legislation regarding the rights of people affected by HIV. I focused on the violation of these rights and on measures taken against discrimination.

INTRODUCTION

In this article I intend to present the preliminary results of a qualitative study on the characteristics of the process of respecting the rights of HIV infected children and youth. The data analysed is from the perspective of the ill and that of the professionals working with this group.

In my study I aimed to identify the risks the category of youth discussed may be exposed, in regard to respecting their rights. Rosa defines 'risk' as 'a situation or event in which a human value (including humans) is exposed (to danger) and which has an uncertain outcome' (Sjöberg, L., Moen, B., E., Rundmo, 2004). The results of my research, which was conducted in the county of Iassy were gathered through individual interviews conducted with two groups of people.

HIV or the human immunodeficiency virus can be found T4-CD4 cells, where it also multiplies itself, decreasing the body's defence mechanism against infection and disease. This causes a severe disease with an extremely long incubation period.

AIDS is the final form of HIV, a polymorphic syndrome characterized by repeated and rebel (opportunistic) infections which develop in individuals whose immune system is severely affected (Ursaci, D., 2003).

In Romania, HIV / AIDS was and it still is a major problem concerning public health. The disease has a big social and economic impact on an individual, local and national level.

In my choice of topic I was motivated by the findings made through my job, specialising in working in with HIV-positive children and young persons who are residents in an orphanage. My dissatisfaction regarding the discrimination they have sometimes been subjected to motivated me further in my work in this field.

I HIV infection /AIDS

1.1. The situation concerning HIV/AIDS in Romania

Romania was the first country in Central and Eastern Europe which got the attention of WHO's AIDS Surveillance Centre in Paris regarding the diagnosis of an AIDS case 1985.

But the communist regime in power at the time did not consider the disease as a threat because it was believed that the country does not host people at high risk of contracting the virus. Because of this assumption the authorities refused to consider the potential risk the entire population was exposed to when facing an epidemic of such great proportion.

Therefore, until the fall of the communist regime no measures were taken to prevent the spread of HIV in Romania.

At that time the health system was facing serious problems and required the medical staff to work without sterilised equipment or sanitary instruments such as surgical gloves, sterile dressings etc. In the meantime, while the health system refuses to accept that HIV represents a danger and it is transmissible in Romania, HIV / AIDS infiltrated and began to spread.

The occurrence of HIV infection in children has been reported from 1989, with notification starting since 1990. 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 pushed the figures making Romania rank the first in terms of the number of children affected by AIDS. Judging by the total number of HIV related cases we are closer to the Western countries than to those located in Eastern and Central Europe. The outbreak of the epidemic among children was so great that at one point we registered over 50 per cent of all HIV-positive children in Europe.

In 2000, HIV / AIDS was declared an issue enjoying national priority and was followed by a national program of 'accelerated ACCESS to treatment and care'.

It can be said that in Romania the HIV/AIDS phenomenon has as distinctive feature the presence of a relatively compact group of affected by nosocomial infection during childhood between 1986 and 1992. The contracting of the virus was facilitated by the use of unsterile equipment and blood products which were not tested for HIV (Buzducea, D., 2008). Over 70 per cent of all children were infected through nosocomial transmission during medical interventions or through blood transfusions (Novonty, T., Haazen, D. and Adey, O., 2003 apud Ursaci, D.2003).

1.2 Statistics

According to UNAIDS Global Report Epidemiology (September 2013).

In 2012 there were nearly 6,300 people newly infected with HIV each day, worldwide.

- over 35 per cent are residents of poor or developing countries;
- approximately 400 are children under 15;
- Almost 5,500 are persons aged between 15-49 - of which 47 per cent female and 39 per cent are aged between 15-24 (Source: Global Report Epidemiology - September 2013).

In Romania from 1985 to 30th of September 30, 2013 were recorded: 19026

cases, out of which 9,937 were children aged less than 14 at the time of diagnosis; 9,087 people aged over 14 years at the time of diagnosis and 6,282 deaths.

At 30th of September 2013 there were 12,119 people living with HIV / AIDS (Source: Department of Monitoring and Evaluation of HIV / AIDS, IBI, Matei Bals, Bucharest.).

1.3 Means of transmission

a) Sexual transmission

On an international scale, sexual transmission is the most common way of spreading the virus. The risk of transmission is different depending on the sexual practices used, the variety of partners, and sex and gender of the person. In this sense the transmission from male to female is approximately 20 per cent and from female to male is about 10 per cent. Transmission from men to women has a higher incidence because during vaginal contact a larger area of the female genitalia is exposed to the partner's secretions than in the case of men. In addition to this, the concentration of HIV is generally higher in semen than in vaginal secretions.

In general, young women are more exposed to risk than adult females. The vagina and cervix are not yet mature, so they are less resistant to HIV and other STDs.

During puberty changes in the reproductive system make the tissues in these areas more susceptible to HIV infection. In addition to this, changes associated with the menstrual cycle are often associated with a thinning of the lining that covers the cervix, thinning which may facilitate the easier access of the virus in the body.

USAID estimated that between 5 and 10 per cent of all HIV transmissions are from male to male, but this does not mean that there is no risk of HIV contraction from women who are sexually engaged with other women. CDC Atlanta advises females to protect themselves using plastic gloves or female condoms to reduce contact with the partner's bodily fluids. Due to the fact that HIV can be found in vaginal secretions, menstrual blood and breast milk, exposure to these fluids during sexual relations between women can facilitate the virus contraction.

b) Parental transmission

Virus transmission through blood can be done by:

1. Transfusion of blood or blood derivatives (untested infected blood and infected blood collected from a person before it may have

developed antibodies detectable in normal tests);

2. The use of unsterile syringes or medical instruments, especially by addicts who use injectable drugs;

3. The open wound injury, the penetration of the mucous membranes or skin with unsterile equipment (e.g. needles used for ear piercing or tattoo making, manicure and pedicure scissors, razors or any exposure of injured skin -lacerations to infected blood).

c) Vertical transmission

The rate of HIV transmission from mother to foetus varies in different regions of the world and the causes of these differences are complex and only partially understood.

In developed countries maternal – foetal transmission is very low (below 2 per cent), 98 per cent of children born to HIV – positive mothers being unaffected by the virus if the mother complies with the recommended therapeutic behaviour (treatment during pregnancy, caesarean delivery, **new-born gavage – prin tub –sau ce voiai sa spui prin alimentatie artificiala?**). The chance of contracting HIV drops considerably (below 0.2 per cent) if they receive treatment during pregnancy and after birth (Buzducea, D., 2010).

Mother to child transmission can occur through three different ways:

a) Direct infection in the womb: ante-partum transmission occurring in 49 per cent of the cases

b) Transmission during labour and when giving birth: intra-partum transmission occurring in 50 per cent of the cases.

c) After birth through breast feeding: post-partum transmission (less than 0.1 per cent of all cases).

II. The human rights concerning HIV infected people

The rights represent the one's faculty to claim various services etc. By law this faculty belongs only to human beings and it applies to each one of us individually and, by a legal fiction and under certain conditions it can be implemented to a group of people too. The first condition to hold rights is to be recognized as a 'human being'. HIV infected people's rights are documented in both national or international – specific normative acts.

These laws are in respect to HIV / AIDS infected persons' rights to:

- The right to life
- The right to health
- The right to education
- The right to non-discrimination

- Equality before the law
- Freedom of movement
- The right to work
- The right to a private life
- Freedom of expression and opinion and the right to receive and disseminate information
- The right to marry and to found a family
- The right to participate in social and cultural life
- The right to privacy.

In order to clarify the background of my doctoral thesis titled 'The right of HIV infected children and youth to enjoy the highest attainable standard of health in Romania', in the continuation of this paper I will analyse the legislative framework concerning the right to health of HIV positive individuals.

The right to your health includes a wide variety of factors which help us lead a healthy lifestyle. It refers to a health care system that promotes equality in of individuals' opportunities to prevention, treatment and control of diseases, the access to essential drugs, to children's health, reproductive health, equal and prompt access to basic health services, access to information and education on health (care), the opportunity to reach highest possible level of health and last, but not least, the participation of the community in taking decisions regarding health at a local and national level.

A) International law

1. In Art. 24 the UN Convention on the protection of children's rights enshrines the right of children to enjoy the highest attainable standard of health and the health and rehabilitation services available. According to this no child should be deprived of the right to access to these services. The same law states in Art. 25 that the States Parties recognize the right of the children who has been recommended by a competent authority figure for the purpose of physical or mental care, protection or treatment. In this case the children are entitled to a periodic review of the treatment provided and any other issues regarding their health conditions.

2. In Art. 25 of the Declaration of Human Rights is stated that everyone has the right to a standard of living adequate for their own or their family's health.

3. Art. 12 from the International Covenant for Economic, Social and Cultural Rights states that:

3.1. The States Parties at present Covenant recognize the right of every individual to enjoy the highest attainable level of physical and mental health.

3.2. The measures taken by the States Parties in to fulfil this are:

a) The prevention against the birth of stillborn children, infantile mortality and the healthy development of children.

b) The improvement of all aspects of hygiene in the environmental and industrial field.

c) The prevention, treatment and control of epidemic and endemic diseases, as well as the one which have the potential to be contacted at workplace.

d) Creating conditions that ensure the provision of adequate services and medical attention in case of illness.

4. Art. 5 (e)(IV) of The International Convention on the Elimination of All Forms of Racial Discrimination (1965) .

5. Art. 11 (1) (f), 12 and 14 (2) (b) of the Convention on the Elimination of All Forms of Discrimination Against Women (1979).

6. Art. 28, 43 (e) and 45 (c) of the International Convention on the Protection of the Rights of All Migrant Workers and Members of Their Families (1990).

7. Art. 25 of the Convention on the Rights of Persons with Disabilities (2006).

8. Alma- Ata Declaration (1978) focuses on the importance of basic (primary) health care which addresses the main health issues in the community, bringing into question the significance of services dealing with promotion, rehabilitation and treatment. It stresses on the fact that access to basic health care allows people to lead an economic and socially productive life and to achieve the highest possible standard of health.

The right to health is also recognized by several regional bodies, such as the African Charter on Human and Peoples Rights (1981), the European Social Charter (1961, revised in 1996) and the additional Protocol to the American Convention on Human Rights in the area of Economic, Social and Cultural Rights, also known as the Protocol of San Salvador (1988). The American Convention on Human Rights (1969) and the European Convention on the Promotion of Human Rights and Fundamental Freedoms (1950) contain provisions on health, such as the right to life, the prohibition of torture and other inhuman and degrading forms of treatment and the right to a family and privacy.

B) National legislation

a) General

1. In Art. 34 the Romanian Constitution states the fact that the right to health is guaranteed and that the state is obliged to take measures to ensure hygiene and public health.

2. In Art. 43 of Law 272 from 2004 it is stated that children have the right to enjoy the highest

attainable standard of health and to benefit of the medical and rehabilitation services necessary to ensure the fully realization of this right.

In Art. 46 of the same act it is emphasized that a disabled child is entitled to special care tailored to their needs regarding education, rehabilitation, compensation and integration. The care provided should be adapted to one's own capacity and aimed at one's personal development. It must ensure the physical, mental, spiritual, moral or social development of disabled children.

b) Specific

1. The mandatory minimum standards for residential services for disabled children, published in the Official Gazette on the 8th of 2004, entered into force on the 1st of January 2005.

Standard 12 relates to the health and the prevention of illness among children. In addition to this it states that residential child protection services provide the necessary conditions for identification and continuous assessment of the physical, emotional and health needs of every child and that appropriate measures are taken in order to meet personal hygiene needs and the standards for supervision and maintenance of health. Children should receive medical and dental care or other support services, as well as education on the promotion of health, should have a good health status and should be educated in the spirit of a healthy lifestyle.

2. Law 448/2006 revised and republished on the 3rd of January 2008, on the protection of persons with disabilities specifies in Art. 10 that disabled individuals are entitled to free medical care, including free medicines, both for patient treatment and during hospitalization, following the conditions established in the scheme contract, as part of the health insurance system.

3. Law 584 from the 29th Of October 2002 focuses on prevention and spread of AIDS in Romania and protection of people living with HIV / AIDS. In Art. 9 of the Law stated above it is emphasized that both health facilities and doctors, regardless their field of specialty, are obliged to hospitalize and provide the medical care they are specialized in, according to the patient's pathology.

In Chapter IV, Art. 8, para. (1) and para. (2) of the same law states that the confidentiality of data on HIV and AIDS health network is mandatory for the employees of the health system in Romania, as well as the employers of the ill and the civil servants who have access to data on those affected by the virus.

4. Law. 324/2006 amending and supplementing the Government Ordinance no.137 / 2000 on sanctioning of all forms of discrimination states that people directly affected by HIV or AIDS have the right to non-discriminatory treatment. By 'discriminatory' is meant any form of distinction, exclusion, restriction or preference based on race, nationality, ethnicity, language, religion, social category, beliefs, sex, sexual orientation, age, disability, non-contagious disease, HIV infection, the belonging to a disadvantaged category, as well as any other criterion which has as outcome or purpose the restriction, prevention of recognition, of use or exercise of equality in the enjoyment of fundamental freedoms and human rights recognised by law if the field of political, economic, social, cultural or other areas of public life.

Equality in recognition of rights must be respected for all categories of persons; under both national and international law all citizens including those living with HIV / AIDS should enjoy all human rights without discrimination.

III. Research methodology

The research I conducted represents a qualitative study made by comparison between the two target categories of populations. The first group is represented by the HIV infected children and youth and second category is depicted by the specialists who work with persons from the first population group. I opted for a qualitative approach because of my desire to explore in depth the implementation of the right to the highest attainable standard of health for HIV positive children and youth in Romania. Due to the relatively low scope of the study I did not intend the generalization of results for the entire population, but their validity in the research zone.

3.1 Objectives and aims of the research are:

a). General objective:

- The assessment of the implementation of the right to health of HIV infected children in Romania.

b). Specific objectives:

- Identifying and analyzing the legislative elements in which are recorded the rights of children and youth affected by HIV / AIDS;
- Identification and analysis of different situations and manners in which the rights of HIV infected children and youth are respected in Romania;
- Identifying the various obstacles encountered in respecting and valuing the rights of this group, as perceived by both HIV positive youth and professionals working with these cases;

- Identifying effective measures necessary to the removal of barriers in the area of respecting the rights of children and youth who are directly affected by HIV / AIDS in Romania.

3.2 Research sample

The research sample was constituted by HIV infected children and young persons and experts who work or have previously worked with this group. Until the moment of writing I have conducted five interviews with HIV positive individuals and I interviewed five specialists in the field, all who had contact with the ill, as part of their work- related experience.

3.3. Respondents' selection criteria

1. For children and young people affected by HIV / AIDS:

- 'HIV positive' status
- aged between 10 and 29.

2. For experts:

- work experience in dealing with HIV positive children and youth.

3.4. Sampling methods

For the selection of respondents I used the nonprobability sampling technique like sampling based on a predefined purpose and snowball sampling (Babbie, 2010).

I decided to use the snowball sampling method when I the specialists interviewed offered me information regarding the locations where I could find HIV infected persons.

3.5 Research methods

The study conducted is represented by qualitative research, by identifying and analyzing the existent legislation concerning HIV infected individuals, by documentation, participant observation, by conducting a focus-group interview with the experts and individual interviews with children and youth affected by HIV / AIDS.

IV. Ethical implications of the research

By its nature the present study is characterized by a series of ethical challenges deriving from the high risk of producing emotional harm when approaching the theme studied, especially in the case of the vulnerable category of the ill and when discussing a delicate matter such as children's rights (Frankel, Siang, 1999, cited in Babbie, 2010) state that the existing legal and ethical structure regarding the protection of human beings, subjects in a research study, is based on the principle of autonomy, justice and compassion. The autonomous principle claims that all subjects should be treated with respect, as autonomous agents and that those with diminished autonomy must benefit from special protection. In my study this principle

took the form of informed consent. By signing to it the specialists have been disclosed both the risks and the benefits arising from the research. The principle of compassion involves maximizing benefits and the well- being of the subjects, as well as minimising the possible risks and damage that may result from the conduction of the research.

This principle has guided the scientific approach that I have taken so far in my study in the sense that in relation to my findings I am looking to gather information regarding a social phenomenon that has been insufficiently researched in the past. By actively using the results obtained we are offered the potential to contribute to finding solutions to the problems HIV infected children and youth may encounter on a daily basis. The principle of justice seeks a fair distribution of duties and benefits associated with the research in order that certain individuals or groups must not support more risks, while others enjoy most of the benefits. According to this principle I can argue that in the present study I attempted to minimize the risks involved, the results being presented in such a manner that none of my interviewees could be identified. In addition to this I aimed that the presentation of the findings of the study would provide a realistic picture, as drawn from the research conducted.

As recommended by Vetenskapsrådet (cited in Skånfors , 2009) to protect the child a number of ethical issues should be considered. In this sense I obtained the legal consent of the contractual representative of the under-aged youth interviewed. In addition to this, every respondent's right to privacy was respected by giving made up initials to the ones who took part in my research. According to Taylor (cited in Balen, 2006) the consent of the under-aged individual is extremely important even if the parent has given their consent for the child to be involved in the research. This can help avoiding situations where parents give their approval, despite children's unwillingness to participate in the research. The youth and the children interviewed were informed about the possibility of refusal in the case of addressing certain issues they do not want to talk about and of their entitlement to require at any time the finalisation of the interview. As known from the literature in the field of research, I attempted throughout the interview meetings to identify issues that could indicate the respondents' desire to withdraw from the interview situation, even if this was not expressed verbally (Alderson, 2004 in Skånfors, 2009).

The focus- group realised with the experts in the fields was preceded by obtaining the informed consent for participation in the research and providing information about the purpose and risks of the involvement in the study.

Findings

The study conducted represents a qualitative analysis on the implementation of the rights HIV infected children and youth in Romania. The issue is investigated from a double perspective, on one hand of the young individuals affected by HIV / AIDS and on the other hand, the one of specialists working with this group. From the data collected on the aspects of respecting the rights of HIV infected people I was particularly interested in identifying and analyzing the existent legislation on the rights of this social category, the circumstances and manner of respecting/non-respecting their rights and finally, the identification and examination of the barriers met in the area of respecting the rights of people living with HIV / AIDS.

Health and disease cannot be studied outside of a social, economic and cultural context. The environment has a major impact on health, which is manipulated by the economic conditions, work situations, cultural beliefs and social support.

AIDS is not just a matter of statistics. It is a real and drastic phenomenon infiltrated in neighbouring distance from our home, work place and favourite social areas. It demands adequate answers from individuals and communities, as well as a coherent health policy which combines prophylactic with therapeutic means in an efficient manner. In relation to this the ill interviewed admitted to be forced to face unbearable situations of high emotional stress, to blame for the devastating escalation of negative feelings and the destructive effects it has on mental health.

The most serious problems faced by the ones affected by HIV / AIDS relate to discrimination and social stigmatization, such as marginalization in schools, refusal of employment and of certain medical services such as dentistry and microsurgery.

The Romanian constitution includes laws which stipulate the rights of HIV positive individuals, but methodology of implementation is inadequate. According to the opinion of those who took part in my research, in a community, the image of the HIV infected children is altered. The general public considers that the ill are not able to perform certain tasks in a manner that a healthy person would, hence the need for special treatment. In

this sense the HIV positive child is oriented towards special needs education. This represents a violation of the right to education and opinion. In addition to this, during school breaks, they are not allowed to play with other children teachers fearing they might injure themselves (or each other) and bleed.

People living with AIDS face situations where sometimes the right to health is violated by the denial of specialised healthcare or by being offered late interventions in case of a health emergency because of their diagnosis. Discrimination in the health system is most pregnant in dental services, surgery and gynaecology. Forms of discrimination are encountered both direct (denial or isolation) and indirect manners, such as delays in the provision of services and exaggerated or unjustified protective measures. For the ill researched, access to specialised treatment is possible, but in the last years the audit on treatment has been proven deficient.

The young individuals living with HIV/ AIDS consider finding employment and the labour market very challenging. This represents a violation of the right to work of this category of persons. Usually, the issues occur at a pre-employment situation. A special case is the HIV test requested by the some employers or institutions. This does not only represent the violation of privacy of every person who is requested to take this test, but a discriminatory practice against people living with HIV/ AIDS. It is believed that the HIV status should not constitute a barrier to socio-professional integration and that one's abilities, skills, talents and training should provide real opportunities in the chance for a satisfying professional and social life.

For the young individual, disclosure of HIV diagnosis represents an impediment to creating a friendship bond or an intimate relationship. Because of this it very difficult for the individuals who suffer from AIDS to fulfil their right to found a family and to lead a desired social life. For HIV infected people it is a lot harder to be accepted in group of friends. HIV / AIDS should not represent a barrier to friendship, but prejudices, lack of information and the fear of contacting the virus determines the marginalization of this group. Being friends with the ones living with HIV / AIDS we encourage them to have hope and make them feel that their rights are respected. Offering love to a HIV infected person means that we can receive love in return, but it does not mean that we will contract the virus they are carrying. The general view of the society and the lack of information can sometimes lead

to negative actions influencing the violation of rights of people living with HIV/ AIDS.

Expected outcomes:

- Easier and wider access to medical services for HIV infected individuals;
- Maintaining the health status of people affected by HIV / AIDS;
- Extending the life expectancy of people living with HIV / AIDS;
- Improving the quality of life for HIV positive persons.

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