Assessment of medical, socioeconomic and psychosocial needs of HIV positive children in Albania

Marjeta Dervishi[1], Silva Bino[1], Roland Bani[1], Shpëtim Qyrra[1], Redona Dudushi[1], Florinda Balla[1]

[1] Institute of Public Health, Tirana, Albania.

Corresponding author: Marjeta Dervishi, MD
Address: Institute of Public Health, Rr. "Aleksander Moisiu", No. 88, Tirana, Albania;
Telephone: +35542 364034; E-mail: marjeta_dervishi@yahoo.com

Abstract

Aim: The aim of this study was to evaluate the medical, social and psychological treatment of children living with HIV/AIDS and identify the rate of discrimination they are facing, as well as the role and problems of the Convention on Children Rights and Albanian legislation in this regard in order to shed light into the situation of children living with HIV and their families in Albania.
Methods: We used a semi-structured questionnaire, which included open-ended questions as well, to assess the needs of 19 children living with HIV. Also, focus groups with family members, community, local authorities and health services' members were organized. The information obtained was analized in a qualitative manner.
Results: 26% of the children included in this study were stigmatized and discriminated because of their disease, whereas the rest had not made public their HIV status in order to avoid potential stigma and discrimination. 16% and 32% of HIV children had lost their mother or father, respectively, making them more vulnerable and seriously aggravating their socio-economic status. Late diagnosis has not only affected children's health, but it has also had a high financial cost for families seeking medical help for many years.
Conclusions: Children affected by HIV and their families face medical treatment related problems, lack of other supporting services and a number of barriers to ensure normal living conditions on a daily basis. There is a serious call for urgent actions in order to address the specific needs of this vulnerable subgroup in Albania.

Keywords: Albania, children, HIV, psychosocial.

Introduction

HIV/AIDS represents a major health problem with AIDS-related diseases being amongst the top causes of death in the world. It is estimated that HIV/ AIDS will continue to be one of the main causes of premature death even in the next ten years (1). UNAIDS estimated that 33.3 million people were living with HIV in 2009 and, among them, 2.5 million (1.6 million-4.3 million) were children under 15 years old. Also, around 2.6 million (2.3 million - 2.8 million) new HIV cases were recorded in 2009 (1). Meanwhile, as a result of an increased access to mother-to-child prevention services, a decrease in the total number of children born with HIV has been observed. About 370,000 new cases were diagnosed in 2009 marking a 24% decrease compared to five years ago. The number of deaths related to AIDS has decreased from 2.1 million (1.9 -2.3 million) in 2004 to 1.8 million (1.6 - 2.1 million) thus reflecting the positive effects of treatment and support services. However, unfortunately, death rates continue to rise in Eastern Europe (1).

Deaths among children under 15 years of age are also decreasing. Estimates show that 260,000 (150,000-360,000) individuals have died from AIDS-related diseases in 2009, a figure which is 19% less compared to 2004 expectations. Once again, this trend reflects the extent of services to prevent transmission of HIV. Around 16.6 million children under 18 years of age have lost one or both parents due to AIDS. Most of the children living with HIV/ AIDS and those affected by this disease live in Sub-Saharan Africa (90%) (1).

In Albania, the first diagnosed child with HIV/ AIDS was reported in 1997. Up to December 2012, there were 28 children infected with HIV/ AIDS, of whom 20 were infected vertically (mother-to-child). Most children cases were in the phase of HIV infection at the time of diagnosis but in 2010 a child was diagnosed in late phases of AIDS. He died several weeks later. Apart from the mother-to-child transmission, after 2003, there started to appear also cases which had been infected through blood transfusion, especially among children suffering from diseases requiring frequent supply of blood (2).

Seroprevalence studies on pregnant women do not provide valuable data on countries with low HIV prevalence, such as the case of Albania. According to two seroprevalence studies conducted in 1999 and 2003, among 500 pregnant women who were randomly selected across the country, the prevalence was zero at a time when the prevalence of hepatitis B remained high at about 8% in this population group. Despite the evident improvement of data and assessment studies, we do not have yet accurate estimates of the number of children infected with HIV, beyond the number of recorded cases or those who already live with AIDS.

HIV-affected children face particular challenges during their everyday activities. They might face discrimination, stigma and peer pressure. Very little information is available about these important aspects and issues in Albania. In this context, the aim of this study was to evaluate the medical, social and psychological treatment of children living with HIV in Albania and identify the rate of discrimination they are facing, as well as the role and problems of the Convention on Children Rights and Albanian legislation in this regard in order to give a contribution towards building of a positive local environment for children living with HIV and their families.

Methods

In this study, parents or relatives of HIV positive children were interviewed with the support of the Institute of Public Health (IPH) in collaboration with the People Living with HIV/ AIDS Organization. The conditions in which these children lived were specifically assessed. The instrument used in this study consisted of a questionnaire including semi-structured and open questions that allowed respondents to freely express their opinions regarding the more subtle and complex issues of HIV/AIDS.

Besides providing general information for the child and his/her family (age, education, employment), the questionnaire also included open questions about the experiences of these persons, the effects of the disease on their daily life, attitudes of the community towards it, their experiences in health, social and psychological services, what they would like to change and what their plans for the future were. These questions aimed to shed light into the situation of Albanian children infected with HIV and affected by HIV/ AIDS. Also, the purpose of this study was to document data on the situation, protection and

support services offered to children living with HIV/ AIDS in transitional Albania.

This exploration was further deepened during the second phase of the study, through focus groups organized with families of children living with HIV, Tirana University Hospital Center "Mother Teresa" (TUHC) medical staff who deal directly with the treatment of these children, as well as round tables in the districts with representatives of local authorities. The third phase consisted of a substantial discussion of results at central level with various actors, analysis of the data (qualitative analysis) and the inclusion in the joint report of all findings and recommendations arising from the activities of the first two phases.

Results and Discussion

This survey included 19 children living with HIV/ AIDS and their family members. Most of them were living in rural areas.

Stigma had affected the family, sisters or brothers of children infected with HIV/ AIDS despite the fact that they had not been infected with this virus. The economic situation of families of these children is very difficult but sometimes we found that despite these precarious conditions they did not receive any social support (for example KEMP revenue) due to stigma and discrimination, that they might be facing when others would come know about their disease. The right to education is a basic right for every child. Nevertheless, the majority of HIV positive children were facing violations of this right, which often revealed in the form of an expulsion behavior from parents whose children are not affected by the virus.

Medical care and treatment for children with HIV/ AIDS are offered only at the pediatric service while children older than 14 years of age are treated at the infectious disease service for adults in TUHC. When talking about vertical transmission, it often happened that the child's health problems led to his/ her diagnosis of HIV and subsequently the mother was diagnosed (or sometimes both parents). But the situation is different when parents are diagnosed earlier and then the child/ children are found to be HIV positive as well. In some cases the disease was diagnosed in late stages of AIDS condition which poses an urgent task for our healthcare system, such as the establishment of a National Program for Prevention of Transmission from mother-to-child. Diagnosis timeline ranges from 1-13 years (Table 1). Late diagnosis has had not only serious consequences

Table 1. General information about HIV diagnosis among children in Albania

HIV cases	Year of diagnosis	Possible year of infection	Diagnosis period
1	1997	1996	1 year
2	2003	2002	1 year
3	2003	2001	2 years
4	2003	1995	8 years
5	2003	2001	2 years
6	2004	1996	8 years
7	2006	2002	4 years
8	2006	2004	2 years
9	2006	1998	8 years
10	2007	2006	1 year
11	2006	1998	8 years
12	2007	2005	2 years
13	2007	2006	1 year
14	2007	2007	Within the year
15	2008	1999	9 years
16	2009	2008	1 year
17	2009	2009	Within the year
18	2010	1997	13 years

on children's health, but it also has had a high financial cost for families going from one hospital to another one for many years. Two cases were diagnosed abroad (in Austria and Italy, respectively).

In general, there were problems with the treatment of HIV positive children and the treatment scheme had not been always applied. HIV-infected women affected with opportunistic pathogens might be more likely than women without HIV infection to transmit these infections to their infants (3). The major problem for these children is the provision of drugs used for treatment of Opportunistic Infections (OI), which have to be provisioned by their own families. Particular attention is required for children with thalassemia. Lack of blood is identified as a serious problem especially in the hot summer season. For example, the affected individuals had to go twice a month at the blood bank in the district of Lushnja to obtain blood and once a month they had to come to Tirana, thus overburdening further their economic situation.

These children and their parents need specific psychosocial support. To ensure that, in the pediatrics and infectious disease service at TUHC there is a number of psychologists who deal directly with counseling and psychosocial support for children living with HIV and their families (4,5).

We observed that a large proportion of parents of HIV positive children, were unemployed, which makes even more difficult facing the economic, psychosocial and emotional problems accompanying HIV/ AIDS. In none of the cases were the mothers or the fathers employed in the public sector and unemployment prevailed. This probably relates to the fact that the majority of these children (63%) were living in rural areas where access to employment is minimal. There is little doubt that stigma and discrimination against HIV/ AIDS are still barriers that prevent parents of HIV children to find a job.

Housing was another major problem worsening their living conditions. Often parents of HIV children were forced to be isolated in one of the house's rooms. *"We were living together with my husband's family, but when the latter became aware for the three of us, they isolated us in a room. This room should serve as a living room, kitchen and bedroom for us and our little child"*, stated one respondent.

Living in rural areas adds up to the already difficult situation of children living with HIV and their families. In these conditions, any social benefit would serve to improve their conditions. However, only 12 or 63% of them received this kind of assistance. Four or 21% of them did not receive it as a result of stigma and discrimination and in one case the child was orphan and his relatives neglected him by jeopardizing his life. However, the KEMP assistance is too little to cover the numerous needs these children have, such as medicines for treatment of IO, or the transportation costs for the next visits.

Regarding the transportation costs, 21% of these children currently resided more than 200 km away from Tirana, 11% of them 125 km away from Tirana, 16% of them 80 km away, 11% around 40 km from Tirana and the others were living in Tirana. The transportation cost is not negligible. Since services to HIV positive children are offered only at the pediatric section of the UHC in Tirana, these children had to come at least once a month to be visited by the doctor. None of these children and their companions had received reimbursement for transportation costs despite the fact that this is a right based on the Albanian Law No. 9952 (6).

Losing parents at a young age is a tragedy, because the loss is associated with the lack of attention, care and love of other people, relatives or society. It affects psychologically, socially and economically the child. But losing parents from HIV/ AIDS comprises a greater trauma. Apart from losing their beloved parents they also face the abandonment from the society. Loss of parents exposes these children to many threats and challenges, risks that are increasing with the rising incidence of AIDS. For this reason, the decision-making structures should plan intervention that is directly linked with HIV positive orphans, as well as their families and communities (7).

Out of 19 HIV positive children included in our study, five children had lost one parent due to AIDS while further two children had lost both parents and currently live with their relatives.

It should be emphasized that these children need a special treatment that according to pediatric medical staff should be offered by a specialized center (8), which actually is lacking.

There are two documents defining the rights of children infected with HIV.

1. Convention on Children Right (9);
2. The law on HIV/ AIDS approved since 2000, reviewed and adopted in 2008.

There is a need for this Law to be introduced and recognized from all institutions that are dealing with the people living with HIV/ AIDS. Based on our findings, there is an urgent need to establish mechanisms and guidelines for its implementation as well as to evaluate its related economic costs.

Conclusions

This study clearly illustrates that there are still numerous problems waiting to be resolved for HIV positive children. Integrating HIV testing and counseling for pregnant women in the basic package of antenatal care services will reduce mother-to-child HIV transmission (10). It is of crucial importance to offer psychosocial and financial support for children with HIV/ AIDS and their families. Prior to a blood transfusion to a child, parents should be explained the window period and should explain the risk that this transfusion may cause. Factors such as development level, health condition, and home situation all impact the optimal disclosure process for the child, which may involve a long period of partial disclosure - where the child is given health and preventive information, but is not told that he or she has HIV - leading to full disclosure, when the child is mature enough to understand the information. Given the central role of the parent/ caregiver in deciding what information will be shared with the child and when, several promising approaches build parent/ caregiver capacities to understand disclosure-related issues and how to communicate with their child (10).

It is very important to encourage local governments to implement social policies for employment of people living with HIV/AIDS which will make them less vulnerable.

Despite the evident improvement of data and assessment surveys, we do not have yet accurate estimates of the number of children infected with HIV, beyond the number of assessments recorded or those who are sick with AIDS. Even though this number is considered small, it reflects HIV/ AIDS situation in our country with a low prevalence, but simultaneously through identification of transmission routes it highlights our two main public health problems namely the lack of programs for prevention of transmission from mother to child and the fragile system that provides secure blood.

Stronger linkages between PMTCT services and community-based support, family planning, STI and general health services are needed to ensure that women receive services that cover their wide range of health needs (11). Providing HIV testing and counseling for pregnant women free of charge in public and private institutions, and advice on maternal and child health as part of the National Program for Transmission Prevention from Mother to Child (NPTPMC) will reduce the number of HIV positive newborns resulting from their respective HIV-infected mothers (12,13).

References

1. UNAIDS Report on the Global AIDS. Accessed April 2013. Available at: http:/ / www.unaids.org/ globalreport/ global_report.htm
2. ISHP, Annual Report on HIV/ AIDS, 2012.
3. CDC. Guidelines for the Prevention and Treatment of Opportunistic Infections Among HIV-Exposed and HIV-Infected Children, August 2009. Accessed March 2013. Available at: http:/ / www.cdc.gov/ mmwr/ preview/ mmwrhtml/ rr58e0826a1.htm?s_cid=rr58e0826a1_e
4. USAID. Meeting the psychosocial needs of Children living with HIV in Africa. USAID, June 2011. Accessed March 2013. Available at: http:/ / www.aidstarone.com/ focus_areas/ care_and_support/ resources/technical_briefs/foundation_future
5. WHO. Strategic Approaches to the Prevention of HIV Infections in Infants. WHO, Switzerland, March 2002. Accessed March 2013. Available at: http:/ / www.who.int/ hiv/ pub/ mtct/ en/ StrategicApproachesE.pdf
6. Ligji Nr.9952, datë 14.7.2008 "PËR PARANDALIMIN DHE KONTROLLIN E HIV/ AIDS-IT".
7. IATT. Expanding social protection for vulnerable children and families. Inter-Agency Task Team (IATT) on Children and HIV. Accessed February 2013. Available at: http:/ / www.unicef.org/ aids/ files/ Expanding_Social_Protection.MTemin.May2008.pdf
8. UNICEF. Enhanced Protection for Children Affected by AIDS, March 2007. UNICEF. Accessed March 2013. Available at: http:/ / www.unicef.org/ publications/ files/ Enhanced_Protection_for_Children_Affected_by_AIDS.pdf
9. UNICEF. Implementation handbook for the convention on the rights of child. UNICEF. Accessed March 2013. Available at: http:/ / www.unicef.org/ publications/ files/ Implementation_Handbook_for_the_Convention_on_the_Rights_of_the_Child_Part_1_of_3.pdf

10. WHO. Priority Interventions , HIV/ AIDS prevention, treatment and care in the health sector. WHO. Accessed April 2012. Available at: http:/ / www.who.int/ hiv/ pub/ priority_interventions_web.pdf

11. WHO. Towards Universal. WHO. Accessed 2010. Available at: http:/ / www.who.int/ hiv/ toronto2006/ towardsuniversalaccess.pdf

12. WHO. Policy requirements for HIV testing and counseling of infants and young children in health facilities, 2010. WHO and UNICEF. Accessed June 2010. Available at: http:/ / whqlibdoc.who.int/ publications/ 2010/ 9789241599092_eng.pdf

13. UNAIDS, Voluntary Counselling and Testing. UNAIDS. Accessed March 2012. Available at: http:/ / www.unaids.org/ en/ media/ unaids/ contentassets/ dataimport/ publications/ irc-pub01/ jc379-vct_en.pdf.