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Adolescence - A New Multilevel Approach on the HIV/AIDS Patient

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1. Introduction

This paper derives from a series of attempts to study not only the medical characteristics of the HIV infected population in the Moldova area of Romania, but also the psychological aspects that are undeniably linked to them. For the past 22 years (since the fall of the communist regime) the Romanian population has been made aware of the existence of HIV in our country, has been educated in terms of the specific aspects of this infection, and has recently been a target for strong campaigns against discrimination and stigma. All these aspects make up the social background in which HIV infected children, adolescents and adults evolve.

The main population of HIV positives in our country is made up of a specific age group, due to a mass infection in the early 1990's, in children’s hospitals. So now we address mostly adolescents and young people who are known to be infected for 20 or more years.

The authors’ aim in this paper is to describe the unique characteristics that adolescence imposes, as an important age group, in terms of the specific features reflected on the HIV/AIDS patient. This is important because adolescence is defined by a series of processes that finalize in contouring the human mind and defining the personality. Although nothing is fully stable and permanent, and personality can suffer changes in time, adolescence leaves a decisive mark on the way different personality traits and psychological processes manifest themselves.

Also, the specific elements that define the mental and emotional development of the HIV patient determine a certain direction in contouring the adolescent’s personality. That is why we consider that there is need for a certain medical, social and psychological approach to this age group, regarding infected patients. The importance of studying the interaction of these variables is strongly reflected in the improvement of everyday practices in medical and care institutions, as well as in the social perception of HIV infected people (although this is a field in which education is continuous). Informing people about certain issues that have been, until recently, considered "taboo", can be a step in combating discrimination, which would enable the young people in the category we address to effectively insert themselves in society and to have a smooth and complete social, professional, and emotional development.
2. The HIV positive adolescent

In this chapter we will attempt to describe the main characteristics of the HIV/AIDS infection from a medical and social point of view. We will also detail the most important features of the HIV/AIDS infected person aged 16 to 22.

2.1 The HIV infection

The infection with the human immunodeficiency virus (HIV) in its most advanced stage, also known as the acquired immunodeficiency syndrome (AIDS) is characterized clinically by a complex and predominantly cellular immune deficiency, which predisposes to various other infections: bacterial, viral, fungal, protozoal, with invariably fatal developments in months or years. The HIV infection causes a collapse in the CD4 immune defense system, central nervous system infections, opportunistic infections and the emergence of tumors. The causal agent is the HIV retrovirus, which only affects the CD4 receptor-LT4 cells, tissue and neurons, and multiply in the presence of antibodies.

![Fig. 1. The different types of HIV](image)

There are two known strand of HIV. HIV-1 was first described in 1983 by Luc Montagnier, followed in 1984 by Le Gallo. In 1986 HIV-2 was also identified.

The transmission of this retrovirus is done directly - sexually, through blood, intrauterine - or indirectly - through the use of infected syringes by drug abusers, from mother to child during birth, or unsterilized medical instruments. Risk groups most affected are male homosexuals, hemophiliacs, people who have heterosexual relations with multiple partners, blood transfusion recipients, newborns whose mothers are HIV positive.

There are six developmental stages of the virus: incubation, infection, symptomatic infection, generalized lymphadenopathy, ARC (AIDS Related Complex), AIDS.

Incubation (1) extends over a period of 1-3 months, and the asymptomatic or sexual infection (2) 10 to 14 months. Antibodies appear 6-12 weeks after infection. In stage 3 – the symptomatic infection - neurological, liver and skin symptoms are present. Stage 4, the generalized lymphadenopathy is the stage where at least three ganglion groups are
identified, during a period of over three months. They are evidence of the efforts the immune system makes to fight the pathogen that entered the body. Stage 5 - ARC (AIDS Related Complex) is characterized by a remarkable weight loss and the presence of fever for more than a month. In the last stage - AIDS - opportunistic infections and tumors are already present.

According to the AVERT up to date information, there are four known strains of HIV-1. They can be classified into four groups: the "major" group M, the "outlier" group O and two new groups, N and P. These four groups may represent four separate introductions of simian immunodeficiency virus into humans.

Group O appears to be restricted to west-central Africa and group N - a strain discovered in 1998 in Cameroon - is extremely rare. In 2009 a new strain closely relating to gorilla simian immunodeficiency virus was discovered in a Cameroonian woman. It was designated HIV-1 group P. More than 90% of HIV-1 infections belong to HIV-1 group M and, unless specified, the rest of this page will relate to HIV-1 group M only.

Within group M there are known to be at least nine genetically distinct subtypes (or clades) of HIV-1. These are subtypes A, B, C, D, F, G, H, J and K.

Occasionally, two viruses of different subtypes can meet in the cell of an infected person and mix together their genetic material to create a new hybrid virus (a process similar to sexual reproduction, and sometimes called "viral sex"). Many of these new strains do not survive for long, but those that infect more than one person are known as "circulating recombinant forms" or CRFs. For example, the CRF A/B is a mixture of subtypes A and B.

One of the CRFs is called A/E because it is thought to have resulted from hybridization between subtype A and some other "parent" subtype E. However, no one has ever found a pure form of subtype E. Confusingly, many people still refer to the CRF A/E as "subtype E" (in fact it is most correctly called CRF01_AE).

A virus isolated in Cyprus was originally placed in a new subtype I, before being reclassified as a recombinant form A/G/I. It is now thought that this virus represents an even more complex CRF comprised of subtypes A, G, H, K and unclassified regions. The designation "I" is no longer used.

The HIV-1 subtypes and CRFs are typically associated with certain geographical regions, with the most widespread being subtypes A and C. As studies have shown, individuals are increasingly presenting with sub-types not native to the country of diagnosis. For example, a rise of non-B sub-types among men who have sex with men (MSM) in the UK has been identified.

Subtype A and CRF A/G predominate in West and Central Africa, with subtype A possibly also causing much of the Russian epidemic. Historically, subtype B has been the most common subtype/CRF in Europe, the Americas, Japan and Australia and is the predominant sub-type found among MSM infected in Europe. Although this remains the case, other subtypes are becoming more frequent and now account for at least 25% of new HIV infections in Europe.

Subtype C is predominant in Southern and East Africa, India and Nepal. It has caused the world's worst HIV epidemics and is responsible for around half of all infections.

Subtype D is generally limited to East and Central Africa. A subtype E has not been isolated. However, CRF A/E is prevalent in South-East Asia, but originated in Central Africa.

Subtype F has been found in Central Africa, South America and Eastern Europe.
Subtype G and CRF A/G have been observed in West and East Africa and Central Europe. Subtype H has only been found in Central Africa; J only in Central America; and K only in the Democratic Republic of Congo and Cameroon.

Fig. 2. HIV Subtypes around the world

A study presented in 2006 found that Ugandans infected with subtype D or recombinant strains incorporating subtype D developed AIDS sooner than those infected with subtype A, and also died sooner, if they did not receive antiretroviral treatment. The study’s authors suggested that subtype D is more virulent because it is more effective at binding to immune cells. This result was supported by another study presented in 2007, which found that Kenyan women infected with subtype D had more than twice the risk of death over six years compared with those infected with subtype A. An earlier study of sex workers in Senegal, published in 1999, found that women infected with subtype C, D or G were more likely to develop AIDS within five years of infection than those infected with subtype A. Several studies conducted in Thailand suggest that people infected with CRF A/E progress faster to AIDS and death than those infected with subtype B, if they do not receive antiretroviral treatment.

The main subtype found in Romania is F, with a very long life span, of over 20 years with proper antiretroviral treatment.

Detection of specific anti-HIV antibodies is done by two methods: ELISA and Western Blot test. Negative results from these tests indicate the absence of infection, while positive results mark the presence of HIV in the blood. These tests can sometimes be negative in infected people, due to the presence of an immunological window of 6-12 weeks (corresponding to the incubation period).
Every person that has clinical manifestations associated with HIV
- Persons with lymphadenopathy of unknown etiology, fever and loss of weight

Persons with sexually transmitted diseases
- People with a high HIV/AIDS infection risk:
  - Homosexuals
  - Bisexuals
  - Drug users
  - Sexual partners of people with a high risk
  - Sexual partners of HIV infected people
  - Prostitutes
  - Heterosexual people with more than one sexual partner in the last 12 months and not using a condom in the last 6 months
  - People who received blood donations

People that consider themselves being at risk, or that ask to be tested
- Pregnant women
- People with active tuberculosis
- People at risk from professional exposure
- Medical staff
- Blood, semen and organ donors

Pre-test counseling
HIV test (ELISA + Western Blot)
Post-test counseling
Confirming the HIV infection diagnosis

Fig. 3. The algorithm for HIV testing

Pre- and post-test counseling is first of all based on the principle of confidentiality, which establishes a trusting connection between the counselor and the patient. There are two main goals in counseling, and these are: 1. preventing the transmission of the HIV infection; 2. socially and psychologically supporting people who have been infected. The most important aspects covered by counseling in the case of HIV/AIDS are:

- supplying information about the HIV infection:
  - what the HIV infection is and how it evolves
  - ways of transmission and ways of prevention
  - diagnosis: the meaning of a negative, undetermined or positive test
- determining the risk factor of a person’s behavior
- helping the person understand and admit the risks certain behaviors pose
- defining the degree of specificity that a certain behavior has for the person’s lifestyle
- helping the person find resources to eliminate a risky behavior
- supporting the person in any positive change

Once the infection is detected, the patient is advised and informed about the importance of adherence to therapy. Medication prevents the spread of HIV in the blood, helps support the immune system, and thus prolongs the patient’s life considerably.

There are currently more than 20 approved antiretroviral drugs in the US and Europe (including combined formulations) and many more in the expanded access programs and trials. Like most medicines, antiretroviral drugs can cause side effects. These unwanted effects are often mild, but sometimes they are more serious and can have a major impact on health or quality of life. On rare occasions, side effects can be life threatening.

Once started, antiretroviral treatment must be taken every day for life. Every missed dose increases the risk that the drugs will stop working. It is therefore vital that people receiving antiretroviral treatment get all the help they need to minimize the impact of side effects. Often there are several ways to lessen the harm, either by treating the side effects or by switching to alternative antiretroviral drugs.

<table>
<thead>
<tr>
<th>Symptom</th>
<th>Drug used</th>
<th>Advice on how to reduce the symptom</th>
</tr>
</thead>
<tbody>
<tr>
<td>Diarrhea</td>
<td>Especially protease inhibitors</td>
<td>- Eat less insoluble fiber (raw vegetables, fruit skins, wholegrain bread or cereal, seeds and nuts) and replace with soluble fiber (white rice, pasta)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>- Cut down on caffeine, alcohol and the sweetener sorbitol</td>
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<tr>
<td></td>
<td></td>
<td>- Avoid greasy, fatty, spicy and sugary foods</td>
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<tr>
<td></td>
<td></td>
<td>- Reduce dairy products in case of lactose intolerance</td>
</tr>
<tr>
<td></td>
<td></td>
<td>- Consult a dietician</td>
</tr>
<tr>
<td>Nausea and vomiting</td>
<td>Almost all antiretroviral drugs</td>
<td>- Eat several small meals instead of a few large meals</td>
</tr>
<tr>
<td></td>
<td></td>
<td>- Avoid spicy, greasy and rich foods; choose bland foods</td>
</tr>
<tr>
<td></td>
<td></td>
<td>- Eat cold rather than hot meals</td>
</tr>
<tr>
<td></td>
<td></td>
<td>- Don’t drink with a meal or soon after</td>
</tr>
<tr>
<td></td>
<td></td>
<td>- Avoid alcohol, aspirin and smoking</td>
</tr>
<tr>
<td></td>
<td></td>
<td>- Avoid cooking smells</td>
</tr>
<tr>
<td>Rash</td>
<td>Nevirapine, abacavir</td>
<td>- Avoiding hot showers or baths</td>
</tr>
<tr>
<td></td>
<td></td>
<td>- Using milder toiletries and laundry detergents</td>
</tr>
<tr>
<td></td>
<td></td>
<td>- Wearing cool fibers such as cotton, and avoiding wool</td>
</tr>
<tr>
<td></td>
<td></td>
<td>- Humidifying the air</td>
</tr>
<tr>
<td></td>
<td></td>
<td>- Trying moisturizers/emollients or calamine lotion</td>
</tr>
</tbody>
</table>
Switching antiretroviral treatment should stop the symptoms getting worse, but is unlikely to lead to much improvement once the condition has advanced.

Switching antiretroviral treatment should stop the symptoms getting worse, but is unlikely to lead to much improvement once the condition has advanced.

<table>
<thead>
<tr>
<th>Lipodystrophy</th>
<th>Combinations of drugs from the NRTI and protease inhibitor classes</th>
<th>Switching antiretroviral treatment should stop the symptoms getting worse, but is unlikely to lead to much improvement once the condition has advanced.</th>
</tr>
</thead>
</table>
| Lipid abnormalities that cause heart conditions | Combinations of drugs from the NRTI and protease inhibitor classes | - Give up smoking  
- Take more exercise  
- Cut calories and eat less fat  
- Consume more fibers and omega-3 fatty acids |

Table 1. Main types of side effects

Side effects vary from person to person and it is impossible to predict exactly how each individual will be affected. Some people take antiretroviral treatment for years with few problems, while others find the same drugs intolerable. Nevertheless some characteristics and pre-existing conditions (such as high blood pressure or hepatitis infection) are known to increase the risk from certain side effects. Doctors should assess these factors before advising patients on which drugs to choose.

Some side effects appear shortly after starting an antiretroviral drug and disappear within a few weeks as the body gets used to the new chemicals. This is often the case with nausea, diarrhea and headache, for example. Unfortunately other side effects – such as peripheral neuropathy (nerve damage) and lipodystrophy (fat redistribution) – tend to worsen over time and may never go away. Also some problems may not emerge until months or even years after treatment is started.

The main feature of patients living with HIV in Romania is that they are part of a large cohort representing almost 90% of children born during 1988-1989. These patients were diagnosed with HIV infection at the age of 3-6 years and have lived with HIV entire period of childhood and adolescence, being supervised and monitored by both families and medical staff of the infectious diseases clinics. Therefore they have grown along side the development of therapeutic lines, while passing from mono- and bi-therapy to HAART therapy. Many of them have over 10 experimental regimens, including the use of the latest generation of protease inhibitors and coformulations of nucleoside inhibitors. Another specific feature for these patients is the coinflection with hepatitis B and C in over 12% of all cases. The delta strand of the hepatitis virus is also present, 1% of all HIV/AIDS adolescents suffering from a hepatitis B + D + C coinfection.

2.2 Social aspects of HIV/AIDS

Jonathan Mann, former Director of the Global HIV/AIDS of World Health Organization, made reference, in 1987, to three major HIV-related global epidemics. The first concerns the epidemic of the HIV infection, which enters silently and unnoticed in the community as the infected person may not be aware of it throughout the incubation period and even in the asymptomatic infection.

The second is the AIDS epidemic, which occurs when the HIV infection causes serious disease – when a pathogen enters the body and the immune system can not cope, resulting in severe immunological collapse and all the symptoms previously described.

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The third component is the social, cultural, economic and political, response given to the first two types of epidemics. "The sociological and epidemiological research on the AIDS phenomenon focuses on the dimensions and implications of socio-cultural, demographic, economic and political aspects of this complex phenomenon, which began as a medical problem, and became in time a real and disturbing social problem." (Buzducea, 1997) It is linked to discrimination, stigma, blaming, collective rejecting, which prevents an effective fight against the first two types of epidemics.

In her paper published in 2003, Doina Usaci made a survey of public attitudes towards the threat of AIDS. She stresses out that behavioral and attitude responses reflect a gap between the four plans addressing the phenomenon: cognitive, affective, behavioral and attitudinal. Each of these plans is marked, in turn, by the internal contradictions and ambivalent tendencies, which confirm an inadequacy of psychological responses in relation to the magnitude of the epidemic.

The cognitive plan is ahead of the other plans in terms of its development, as proven by a good level of knowledge regarding ways of transmission of the virus and ways of protection. But it is burdened by conflicting issues and ambivalent trends, rendering it inoperable in terms of the person’s inner state.

The affective plan prevails over the cognitive in terms of maintaining inner balance. Fear is the dominant emotion, distorting perception and risk assessment, in the sense of over-evaluating it – up to reactions of phobic avoidance of sexual relations - or undermining its importance, as a result of the maladaptive action of defense mechanisms such as denial or rationalization, designed to reduce anxiety.

From a behavioral point of view, the author identifies ambivalent trends regarding the option for certain protective strategies, and an obvious gap between intention and act in terms of their implementation.

![Fig. 4. The interaction between the three types of epidemics](www.intechopen.com)

The attitude plan is itself encumbered by striking internal contradictions, with mostly social effects. Attitudes towards infected people are ambivalent, oscillating between solidarity and distance, even rejection and guilt.
The author concludes that HIV/AIDS infection-related issues define an "irrational" conduct in relation to the magnitude of the epidemic and the dangers of social division which it hides.

"Stigma, silence, discrimination and rejection, as well as breaches in confidentiality, damage all efforts of prevention, care, treatment, and increase the impact of the AIDS epidemic on individuals, families, communities and nations." United Nations Declaration of Commitment on HIV/AIDS

2.3 Growing up with HIV/AIDS – the main characteristics of the Infected child and adolescent

Kristin Close (2007) presented data that highlighted the prevalence of HIV in the population under 15 years. Thus, in 2007, approximately 2.1 million children under 15 were living with HIV, and the same year 290,000 children died due to infection.

In Romania, more than two thirds of the infected population consists of adolescents. Most were infected in the first years of life through unscreened blood transfusions. They are innocent victims of the pandemic. An impressive number of them have been abandoned in orphanages because of parental ignorance, poor living conditions or other disabilities associated with the disease. The rest remained in the family, where they had essentially two distinct types of attitudes: acceptence and support, or blame and stigma – according to their parents' education level and understanding of the disease (Buzducea, 1997).

In her paper Kristin Close (2007) describes the three main stages from childhood to adult stage. Pre-adolescence is described as a period of change in preferences, in terms of re-orientating attachment from parents and care-givers to fellow peers. Adolescence itself is predominantly marked by building self-image and abstract thinking. Late adolescence is the period of equilibrium, in which young people begin to feel comfortable with that identity and develop a social framework.

HIV infected people face a number of obstacles in addition to completing these steps. One major consequence of ineffective treatment or late identification of the disease is poor physical development, along with impaired neurological and psychological development. Even if the proper treatment is established, taking it may have serious end often visible side effects, as listed above.

Dislipidemy, for example, is a metabolic anomaly of plasmatic lipids and lipoproteins with a high risk of coronary disease, and it is very important in the development of HIV patients. Affecting the distribution of fat throughout the person’s body is one of the most obvious and easily noticeable symptoms of this condition. In the case of a child or a teenager, this may affect their body image, as well as the way they are perceived by others.

Any physical condition is sure to mark the adolescence period and may cause difficulty in identifying with persons of the same age. This in turn affects the person’s chances to interact with peers and get close to someone, thus forming meaningful relationships. Since personal identity emerges by comparing with others, young people aware of their HIV positive status may have a more negative self-image, may feel inferior, especially in the presence of social stigma.

Adolescence is also a period of exploration of oneself and the social environment. The stress of living with a chronic illness, such as AIDS, can prevent young people in taking any exploratory steps, or any initiatives that they should normally have. Living with AIDS...
implies facing a number of challenges that shape identity, leading to a particular perspective on the world.

3. Realities faced by HIV-positives

In this third part of our paper we will present two relevant studies that underline the feelings HIV/AIDS patients have towards discrimination and the attitudes they come across every day. We will also describe a particular group of HIV infected adolescents, the residents of the “Gulliver” Hospice Placement Center.

3.1 Discrimination

A very important problem in the complex area of social interactions derives from every individual’s unique way of being. Each person is different from every one else of its kind, even though we are all similar in a fundamental manner. It is this uniqueness that makes interactions dynamic and challenging, but it is also the basis of a rejection process, that targets everything that is too uncommon. Two words come to mind when dealing with this phenomenon – discrimination and stigmatization.

According to the Romanian Dictionary, “discrimination” is defined as a politic in which a certain country or group of citizens are deprived of certain rights, on an unfounded basis, and “stigmatization” is the casting on someone of public disgust, the feverishly condemnation of someone to dishonor.

Seen as a problem of interest for society as a whole, psychologists have tried to find the roots of the discrimination phenomena. The most pertinent conclusion is that discrimination comes from childhood, from our education, and it is founded on many generations of prejudice. It is hard for us to think flexibly because we are educated in a manner that encourages classifications. Everything has to be “put into boxes” and “stored on shelves”, which makes us have a good perspective on things, but not on people. One tends to judge appearances more than essence, and so each individual is depersonalized, classified according to one feature or aspect that is relevant to the classifier. So one often ignores what people really are, overseeing real value. In order to rid ourselves of this highly indoctrinating way of thinking, we are in desperate need to open ourselves to the new.

The Romanian law system forbids discrimination in terms of race, nationality, ethnic or social background, sex or sexual orientation, or any other criteria that may restrain or stop the use of equality, human rights, or fundamental freedoms, politically, economically, socially, culturally or in any other public area. But discrimination exists! A survey made by Metro Media Transylvania - Barometrul de opinie privind discriminarea în România - 2004 shows that our country has high levels of discrimination against women, elderly people, poor people, national minorities, sexual minorities and HIV/AIDS infected people.

National minorities, sexual minorities, people with a low social status, have all been discriminated against for a long time, and the discrimination has been fought rigorously. As for HIV/AIDS patients, the disease and all the phenomena it causes are relatively new.

An online survey by the „Deschideți inima” (“Open Your Heart”) organization posed this question: “How frequent do you think discrimination against HIV/AIDS infected people in Romania is?” The results were that the majority of people who answered believe that discrimination is “Very Frequent” (53.55%) or “Frequent” (34.04%). This proves that people are well aware of discriminating attitudes towards themselves or other people.
For the HIV infected person, discrimination manifests itself every day, through the interactions with different people – a neighbor, a friend, or former friend, even a relative. Coming across phrases like: “I can’t shake hands with you.”; “You’re not my son anymore.”; “Leave my street!” becomes a daily routine. Finding rejection where there was once trust and understanding is one of the main aspects people fear when they find that their HIV result came out positive. All the attitudes of people around a patient have a huge impact on his mental state, affecting self-esteem, as well as compliance to therapy, performances in life, and the ability to interact with others.

Fig. 5. The distribution of answers to the online survey made by „Deschideți inima” (“Open Your Heart”)

In 2008 the Regional Center for HIV/AIDS Iași conducted a study aimed to evaluate the degree of discrimination felt by the HIV infected patient in every-day social interactions. 100 patients assisted by the regional HIV/AIDS centre were tested using the clinical interview. Of these, 58 were male and 42 female, 32% from the rural area and 68% form the urban area. The average age was 20.9 years. The subjects had an average of 6 grades, with extremes from 4 grades to upper education. While 70% came from normal families, 20% had dysfunctional families and 10 % came from foster care. Of these, only 12% had a stable job, 88% being unemployed.

Patients were encouraged to speak freely about the way in which informing others about their HIV status caused a change in attitude. Psychologists used a series of questions meant to pinpoint discrimination at the work place, in families, in groups of friends, as well as in other social contexts. One particular question – “Do you believe that the people around you who don’t know you are infected would see you differently if they found out?” – was meant to reveal the patients expectations on other people’s reactions, based on their experience. The clinical interview revealed that 75% of all patients felt discriminated against, due to being infected with HIV.
3.2 An adolescent’s view on social stigma
As stated earlier, growing up with a life long chronic condition such as AIDS has a strong impact in the physical, mental, emotional, as well as social development of an adolescent. The specific features of the post-communist society in Romania gives this struggle a whole new dimension, due to people’s fear, lack of information and A similar study was conducted in 2009, also in the HIV/AIDS Regional Center in Iaşi. It targeted the particular way in which HIV infected adolescents assisted by the Center perceived discrimination and/or the support of their social environment. The study included 200 HIV/AIDS infected patients, who were asked to answer a series of questions devised by the team of psychologist from the Iaşi Regional Center. They also took part in a clinical interview and focus groups. The majority of patients were male (59%), with an average age of 21.1 years. 66% came from an urban environment. As for schooling, the average level was 6 grades, with extremes between 2 classes and higher education. 14% of patients had a stable work place at that time. 38% came form broken up families or foster care. The clinical interview, as well as the questionnaires, revealed that 83% of patients feel marginalized in society, due to being infected, and most of them (92%) try to hide their status in social interactions. For us this study was important because it made clear the fact that the altered perception of HIV-positives in social relations and work, the low school level, as well as their background, coming from dysfunctional families, makes these particular adolescents a vulnerable population that requires an ethical approach from a series of angles and disciplines.

3.3 Orphans living with HIV/AIDS – case study on the young people in the “Gulliver” hospice placement center
The “Gulliver” placement center is a hospice-type care institution. It provides shelter for approximately 40 HIV positive young people, which have been abandoned at birth. The institution was established in the early 1990s, a time when Romania faced an outbreak of HIV. Fear and lack of knowledge led families D. Bowlby called the personality type of a baby abandoned at birth "character without emotion." The most important traits of this specific type are: intellectual retardation, failure to establish deep relationships with others, low emotional reactions, aggression, low self-confidence, heightened by antisocial trends that are closely linked to emotional problems - even smiling and crying are affected and less representative for genuine emotions. Records also report tantrums, hyperactivity, and passiveness, extreme levels of apathy and in some cases going as far as autism. Even the relatively well-integrated and apparently balanced children encounter difficulties in developing authentic feelings and in establishing social contacts. Family abandonment is the main act that marks the abandoned personality. The effects of early psycho-trauma are undeniable and they mark the whole socio-psycho-emotional development of children.
Institutionalization is considered by the state to be a temporary solution, especially for what experts call either family failure or its vulnerability or inability to provide care and education. However, the social and economic situation in Romania determines a large number of families to consider placing their children in an orphanage. Care institutions accommodate children to continuous exposure, excessive control, and poor relationships with significant adults, away from natural backgrounds such as family and
wider social community. Constant exposure limits the child and future adolescent’s possibility to relax and engage in activities to release tension. A recent study conducted in November 2002 showed that 50% of Romanian people believe that young people leaving placement centers do not have a real chance of integration into society when they come of age. Young people, in their desire to integrate into the system, must cope and deal with a number of instances of socialization and control. Marginalization of youth stems from a limitation of their orientation to social work. Their situation is thus characterized by the absence of mechanisms that allow them to govern their own existence. Most often, marginalization leads to antisocial behavior, accompanied by school neglect, indifference to social norms, alcohol and drugs, physical and verbal aggression.

To all the psychological and social difficulties that young people growing up in orphanages face, the HIV / AIDS status adds an even greater burden, that of being labeled and rejected. Adolescents deal with their peers’ fear of the disease, which translates into a fear of the person carrying the disease.

Marginalization of the HIV-positive young people, more so those coming from placement centers, feeds their the inability to achieve long term objectives, like adherence to the ARV treatment, finding a job, supporting themselves, developing meaningful relationships with the opposite sex.

4. The management of the HIV-infected adolescent

The HIV/AIDS patient has a number of features that need to be addressed in a specific manner. It is important to focus on three major targets – biological, social and psychological – when dealing with this particular type of patient. The biological target is usually set by the infectious diseases doctor and it involves mainly the personal effort of the patient. The social and psychological targets, however, are set by the patient and the psychologist and social worker who assist him in finding his balance and evolving in society. These two targets are destined not only for the patient, but also for the community in which he lives, that needs to undergo changes in order to accommodate him.

4.1 The biological target in addressing the HIV/AIDS adolescent

The first target is the biological aspect of a patient’s treatment. The objectives in this case can be discussed from a clinical, virusological and immunological point of view. The main clinical objective is to prologue the patient’s life span and to improve his quality of life. The virusological objective is to reduce the viral load as much as possible, preferably under 20 copies/ml and for a long period of time. This is a key factor in stopping or slowing down the progression of the disease, and also in preventing or delaying the appearance of resistant strands. Immunologically, the goal is to reconstruct the immune barrier by increasing the number of CD4 blood cells as much as possible, and by supporting them in their effectiveness. These objectives can be fulfilled by using a series of well set criteria in administrating antiretroviral drugs, in order to achieve the biological target and also to determine as few as possible adverse reactions as well as a good adherence to treatment. Equally important is the social and psychological support derived from close collaboration within the team of infectious diseases doctors and psychologists assisting the infected
patient. It helps develop a multidisciplinary approach, sustained also by cardiologists, nutritionists, obstetricians and any other specialist that any come in contact with the HIV / AIDS patient in his lifetime.

4.2 The social target in addressing the HIV/AIDS adolescent

The social target has two key factors. One is collaboration with the authorities responsible for education, in order to prevent school dropout, a common phenomenon not only among infected patients, but also among all young people in rural areas or with poor material conditions.

The other is the need to raise patients’ employability, because in the case of this particular population finding a job is difficult, if not impossible, due to the conditions we have explained earlier in this paper.

In addressing this specific target, the Regional Center in Iaşi works closely with non-government organizations such as the ADV Foundation (Fundatia „Alături de voi”). It was founded in March 2002 by Holt International Children’s Services with USAID funding, and has taken in all the HIV programs conducted in Romania by Holt since 1992. In 2008, ADV began a program designed to offer HIV positive young people a work place and a steady income.

4.3 The psychological target in addressing the HIV/AIDS adolescent

Regarding the psychological target, we consider two main directions: first of all, information and acceptance, and then cognitive restructuring.

When the patient performs a test to determine the HIV status, even before receiving the results, he is counseled by a psychologist. He is informed about the characteristics of infection, as well as its possible consequences on his life.

Everyone’s experience will be different but being diagnosed with HIV can create a raft of emotions including anger, denial, depression, anxiety, shock, and fear of death. Further emotional stress could stem from thoughts about who people should tell, how lifestyle will change and if it will be possible to have children. Some may also experience guilt, viewing their infection as a punishment for their sexual orientation or consumption drugs, or for the worry they may cause to other people and for possibly infecting others. Just as reactions differ, so too will the ways in which people deal with them. There is no standard method of dealing with something as profound as a positive HIV diagnosis and it is the counselor’s responsibility to find the proper way to approach each patient.

Counseling can be helpful in order to come to terms with the diagnosis and resulting feelings, and as a precursor to dealing with the virus itself. Discussing the patient’s immediate emotional concerns is recommended by the World Health Organization (WHO) as part of post-test counseling. Such steps could enable the patient to more effectively absorb information regarding the consequences of their diagnosis, and they might make better-considered decisions about their next steps including preventing risky behavior and beginning treatment.

It is often considered ineffective to discuss possible clinical procedures with the patient soon after their diagnosis, and that this should generally be postponed until a later time. So, upon receiving a positive result, the patient is first and foremost encouraged to consciously realize that he is infected. He is offered support to gradually accept the situation, and to comply in taking the treatment prescribed to lead a normal life.
In terms of cognitive restructuring, this is achieved by eliminating the so-called "dysfunctional thoughts." Most HIV/AIDS patients suffer from inferiority complexes due to physical appearance. In discussions with them, we often encounter lines like: "I am very weak; people will know that I have AIDS" (the "AIDS-like" syndrome). The impact of physical changes experienced by patients is significant, in emotional terms, generating anxiety, depression and stress. An effective way to eliminate dysfunctional thoughts is by replacing them with compensatory positive thoughts. It is the psychologist’s duty to give out the proper information, so that the patient realizes his situation, as well as the importance of his treatment, which will reduce or eliminate any sign of the disease of taken properly.

Disability, weakness, and rejection from people around him can cause low self-esteem in the infected patient. To lead a normal life, he must fight these burdens. Although it is not easy, he must understand and truly believe that he can be and act the same as other, healthier people.

In order to achieve these targets, the efforts of the infectious diseases doctor and the psychologist working with the patient are not enough. Research shows that the environment in which HIV positive patients live, work or receive their treatment has a major impact on the evolution of their self-esteem (McGovern, 2002). Stress is another factor that has a major influence, and it has been shown that it may cause a more rapid disease progression (O’Cleirigh, Ironson, 2007).

5. Conclusions

While recent scientific efforts have resulted in a series of discoveries and advances in understanding and controlling the virus that causes AIDS, this progress has had limited impact on the majority of HIV infected people and populations living in developing countries. The social and economic conditions that nurture the spread of the virus have to be confronted as essential elements in local and global efforts to stem its spread and create effective solutions to halt the epidemic. They must also be considered in supporting and improving the quality of life of the infected people.

The fact that stigma remains in developed countries, where treatment has been widely available for over a decade, indicates that the relationship between HIV treatment and stigma is not straightforward. It is not enough to discover new drugs and high-tech treatments that reduce physical and metabolic symptoms. The social symptoms must also be addressed for a proper management any HIV/AIDS infected person.

The specifics of the adolescent HIV infected population in the Moldova area has been widely discussed throughout this paper. Their opinions have been presented, and a clear picture of the current situation has been described. But that is only the first step, because being aware of a situation is far from solving it.

If in the past taking care of the HIV infected person was the duty of the infectious diseases doctor and the patient’s family, today the idea of a whole team of specialists working together is becoming increasingly popular. The psychologist’s role is more clearly defined, as well as the implications of the social worker. And more importantly, a large number of doctors from different fields are becoming more and more involved and open-minded about treating this type of patient.

The mentality of the population in general is also changing. The speed of this change differs from country to country, and in Romania accepting new ideas is not done at a fast pace.
However, people are becoming increasingly more aware of different aspects that involve their everyday safety and this includes correct information about being infected with HIV and developing AIDS.

Even though the F type HIV that is the main cause of infection in our country has, so far, allowed a longer than expected life span, the young infected people have grown up with the knowledge that at any given time they might die. For adolescents, it is difficult to build a life on this kind of foundation that is still unsure and filled with past and current frustrations about discrimination and being different. Growing up with AIDS has not been and is not an easy task. This explains many young people’s desire to live their life on a more accelerated rate than post persons do. One of the main characteristics of HIV infected youth is their tendency to fall in love and want to get married early, their acute desire to have children, and enjoy all the positive aspects of life “as soon as possible”.

However, the availability of support groups, non-governmental organizations and counselors may make things easier. More so than in the past, HIV infected adolescents are encouraged to express their feelings and concerns and a number of programs are developed to help them.

The most important aspect, though, is education, not only of the HIV positives, but also of the general population, that may or may not be at risk of infection. Constant information, constant exposure, are the most effective ways to actively fight discrimination, rejection, and also the spread of the virus. And this in turn might be the best way to support the already infected adolescents and young people in living with AIDS.

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7. References


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Two new factor have been added to the ideological change in the second half of the past century: the "ecological impact" of humankind on the environment due to the population increase; and the "innovative impact of science, first with atomic physics, which introduced the scission of the fundamental unit of matter, the atom, and then with molecular biology, which led to the decoding of genetic information and intervention of biological engineering that annihilate our concepts of individual and species as fundamental units in biology.

This stage of fundamental rethinking is however overshadowed by the threat of ecological disaster and catastrophic population increase, which not only impose limits to development, but undermine the very survival of Humankind. The future survival our species in fact depends on the interaction between its reproductive characteristics and the productivity of the territory, which, even if increased by the intellectual capability of the human brain, has intrinsically limits. The adaptive choices (which are also biotechnological and biomedical) of the interaction between human population and the natural ambience is the conceptual basis of the new discipline "Global Bioethics".

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