



THE IMPORTANCE OF FAMILY SUPPORT FOR INDIVIDUALS WITH HIV / AIDS

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Abstract:

Family remains a great support for every individual in the society, but for individuals living with HIV / AIDS this support is a necessity. The aim of this study is to show how important is the family support for a person living with HIV / AIDS. Our study will explore the importance of family support for people living with HIV / AIDS, given that there are few studies conducted in this area. The method used is the qualitative method. There are used semi-structured interviews, where 10 interviews are conducted with people affected by HIV / AIDS, 10 others with families and 10 semi-structured interviews are conducted with key service providers (4 doctors, 3 nurses, 1 social worker, 2 specialists of the National Programs on HIV / AIDS in PHI (Public Health Institution). The study is conducted at the Regional Health Office the VCT-HIV / AIDS, which offers free tests for: HIV / AIDS, hepatitis B / C and Syphilis. The results showed that the support provided by the family is a necessity for a person with HIV / AIDS, because they feel supported from the family and accepted as a member of it, valid and non-discriminated. Without family support, they said that their life would end and there will be no reason and hope to fight HIV / AIDS. From all the interviewed, three of them did not have the support of their families. In conclusion, we can say that the family is the backbone, where these people find warmth and support, and without it, they cannot move forward in life.

Keywords: individuals with HIV / AIDS, family, family support

1. Introduction

Pandemic Human Immunodeficiency Virus / Acquired Immunodeficiency Syndrome (HIV / AIDS) is a very serious health and economic problem that has affected 35.0

million (33.2-37.2) people worldwide by the end of 2014 (WHO 2014), and it is determined by the UNDP (2005), as the disease "*that caused the largest change in human development in the modern history.*"

HIV is an infectious disease with viral etiology recognized as such in 1981 in the US, by some reports with pneumonia from Pneumocistis Carini and Sarcoma Kaposi, diagnosed at several people at a young age, which lived in New York and San Francisco. HIV (Human Immunodeficiency Virus) is a virus that attacks the human immune system. Over time, the majority of HIV-infected people lose the ability to fight secondary infections, or various forms of cancer that can develop. In this way it appears Aids (Acquired Immunodeficiency Syndrome). The epidemic of HIV / AIDS constitutes a global crisis and is one of the most difficult challenges to development and social progress. Throughout the years of war against AIDS, human rights were essential for an effective response to HIV. In countries where no human rights are protected, people suffer more stigma and discrimination, become ill and are unable to support themselves and their families, and if they do not receive treatment, they may die.

Today, most countries (89%) clearly address human rights in their national strategies of HIV / AIDS and 92% of countries report having programs to reduce stigma and discrimination (UNDP, 2005).

On the other hand, studies show that the most common rights related to HIV / AIDS which are violated include: lack of access to health care services; (UNAIDS, 2001), the violation of human dignity -often as a result of family and community actions, violation of rights due to gender- especially regarding the treatment of women by their partners.

Considered a terminal illness, HIV / AIDS has become a chronic disease. Advances in the development of antiretroviral therapy (ART) have raised the level of expectation of life in people living with HIV / AIDS (PJHA). HIV/ AIDS is nowadays one of the biggest concern that face health providers worldwide. Still today, there is not a cure for HIV. This means that if someone is infected, it will always be so. HIV-I is recognized today as a chronic and manageable disease. In comparison with other European countries, as a result of social isolation and the communist system that prevent the free movement of citizens, Albania stood "Immune" to HIV / AIDS until 1990. After the communist system collapsed, the free movement began and Albanians were exposed to sexual behaviors with risk factors of HIV / AIDS. The transformation of society from a traditional and closed society into an open capitalist society, also radical social and economic changes which were a result of this transition, created a new model family, which has nothing in similar with the one of years before. Problems that are facing nowadays the Albanian families are those associated with the economic, political, cultural and social changes in society, with features that defines the nature of the family

as a social institution. The first case of HIV in Albania was reported in 1993. During the first period of HIV infection in Albania (1993-2000) the average number of cases reported was 6-7 persons per year; in the years 2001- 2003 there was a doubling of the number of cases, on average 20 new cases diagnosed per year; in the period 2004-2010 this number has exceeded 30; after 2010 the number was almost doubled. Based on data collected by PHI, up to November 2015 were registered 870 cases of reported HIV / AIDS in Albania. Existing data show that Albania has no generalized epidemics or concentrated HIV infection. Based on current data, it remains a country with low prevalence of HIV infection. Results indicate the prevalence of HIV in our country is 0.03% and 0.003% incidence, November 2014 (population according to INSTAT 2014). Although the prevalence of HIV infection is low, there is a growing trend in the number of new cases in recent years. The number of people who have HIV positive result for 2015 (November 2015) is 87 persons, among them is reported a child. The total number of children infected is 40. It is worth mentioning that, unlike the previous year, this year are recorded fewer victims. So, if in 2014 died 11 people affected by HIV / AIDS, in 2015 the number of victims was 9.

In total affected by HIV / AIDS in the city of Elbasan are 51 cases, 36 of them men , 15 women , 24 cases are diagnosed in the later stages of AIDS, 14 cases have died from AIDS, and 10 cases are residing in the village. According to the World Health Organization (WHO), Albania is still considered with a low prevalence of HIV infection, 0.1% (1 in 1,000).

2. Statement of the problem

Learning HIV status through laboratory diagnosis is a traumatic experience that will change life (Leserman, 2008). Difficulties are related to discrimination and the need for support, which complicates coping processes that address the psychological, spiritual and physical dimensions for people living with HIV (Barroso & Powell-Cope, 2000). These experiences contribute to stress and difficulties in adaptation. (Clark, Lindner et al., 2003; Heckman, Anderson et al., 2004; Lee, Kochman et al., 2002). Studies show that people who lack family support experience high levels of stress and are more likely not to comply with the treatment regime with HIV medicines (Rintamäki, Davis et al., 2006). In addition, research has shown that the rapid progress of the disease is associated with low social support (Leserman, Petitto et al., 2000). Stigma may make PJHA (Persons Living with HIV / AIDS) to waive their right to health services, can reduce the desire to go to be tested for HIV, affecting so the efforts for prevention and early treatment (Berger, Ferrans et al., 2001). Barriers to care are associated with social stigma surrounding HIV / AIDS in Albania or lack of information as for patients and

service providers (Morrison, Banushi et al., 2011) although AIDS is now considered a chronic and manageable disease for many people (McReynolds, 1998). Physical symptoms that experience PJHA significantly affect careers, everyday roles and quality of life (Anthony, 2002). Antiretroviral are defined as the main treatment (WHO, 2007). The data also show that antiretroviral therapy significantly improves the quality of life of people living with HIV, if they start early the treatment (Wang, Vlahov et al., 2004). Studies in many countries and in particular in developed countries, underline that the basic needs for palliative care are the relief of pain and symptom management, psychosocial support, spiritual support, and family support with food and financial needs (Coughlan, 2004; Harding & Higginson, 2004; Lasechinger, Van Manet et al., 2005). PJHA social support is directly related to the quality of life and health (Nunes, Raymond et al., 1995). Removal, rejection and isolation can threaten hope and prosperity of PJHA (Miller, 1989).

Supportive social environments, especially family and friends, directly influences on improving the quality of life PJHA (Friedland, Renëick et al., 1996; Ichikaëa & Natpratan, 2006). Russel and Schneider (2000) define formal support as the support provided by governmental institutions, private clinics, NGOs and voluntary organizations. Informal support is the support offered by family, friends and the community in general.

Garbarino (1983) points out that many people seek the support of friends, family members and relatives before they seek professional support from doctors or counselors. Stigma plays an important role in people's decision to reveal their HIV status to family, friends, and often has a negative effect on the quality of their relationships. Stigma and discrimination leads to a crisis of identity, isolation, loneliness, low self-esteem and lack of interest to treat the disease of AIDS (Valdiserri, 2000). Some studies have reported cases PJHA who are abandoned by their families, are separated from their partners (especially women) are killed, isolated, expelled from their communities at the moment they discovered their positive HIV status (Kegeles, Coates et al., 1989; Bujura, 2000; Moore & Williamson, 2003; Campbell, Foulis et al., 2005).

In Albania, there are no studies on the importance of the family support for this target group, paying greater attention to the disease prevention and assessment of populations (population groups) with risky behavior. Programs for the prevention and treatment of HIV / AIDS are provided by health institutions (PHI Hospital Infection, These CVCT) and some NGOs which are supported primarily by foreign donors. In the medical care services provided are included antiretroviral therapy, diagnosis and management of infections and other associated diseases and psychosocial support to the affected people and their families. Over two decades of treating HIV is confirmed

that the protection and promotion of human rights constitute an important component in preventing transmission of HIV and reduce the impact of HIV / AIDS. Declaration of Commitment on HIV / AIDS and the 2001 Political Declaration on HIV / AIDS of the year 2006 highlight the importance of human rights and a national response to HIV based on the alignment of rights and fundamental freedoms (UNAIDS, 2007).

Although there is no treaty or international agreement that deals specifically with HIV, there are a number of provisions of international treaties and declarations of human rights that are interpreted to have a number of implications to effectively respond to AIDS. In the Albanian legislation, a special attention was paid to the guaranteeing of human rights and fundamental freedoms as one of the pillars of the modern civilized society. Human rights today recognize a wide dimension and effective universal respect not only by the announcement of their national basic acts but also through their institutionalization at the international level. Legal provisions provided in international laws are applied directly through the application of legal norms laid down in international instruments or through commitments made to adopt these standards as part of the domestic law. Albanian legislation includes a number of laws and regulations, national strategy, accession and ratification of conventions, which regulate the human rights, health, social services, and the fight against the spread of infectious diseases (HIV / AIDS).

3. Methodology

The main purpose of this study is to show how important is the family support for people with HIV / AIDS.

3.1 Objective

1. To identify and analyze the attitudes, experiences of the family when they are informed that a person of their family is affected by HIV / AIDS.
2. To estimate the impact of the family to people living with HIV / AIDS (PJHA) in Elbasan.
2. To identify the main sources and forms of support for persons living HIV / AIDS and appreciate their roles and functions provided as groups formal groups support and informal groups support.

3.2 The method used

The method used is the qualitative method of collecting data through semi-structured interviews with people living with HIV / AIDS, their families and semi-structured interviews with key persons that provide services for people living with HIV / AIDS.

The Qualitative research has its bases in a philosophical position and is largely "a performer" in the sense that it is focused on how it is interpreted, understood, experienced or established social world (Beauchamp & Childress, 1985). In this context, given the objective of the study are used secondary data analysis and qualitative methods of collecting data through semi-structured interviews with people living with HIV / AIDS and stakeholders that provide services for these people.

Since 1980, the qualitative research has deepened our understanding of issues related to the culture and lifestyle of PJHA (Martin, Rissmiller et al., 1995) issues such as HIV status and disclosure of sexual identity (Bernard, 1993). In qualitative research, data is collected using various techniques such as monitoring of the participants, semi-structured interviews, field notes, memos, documents, reports, journals, (Noll- Hoskins & Mariano, 2004). For the purposes of this study, data were collected using semi-structured interviews.

3.3 Sampling and choice of the instruments

Interviews have been a mainstay of the qualitative research for decades, and are essentially "conversations with a purpose" (Burgess, 1984) although their form and structure can vary. Semi-structured interviews were chosen as the best approach to obtain information freely about a number of important issues. Interviews are more flexible in gathering information for a specific event and context, presenting reality, attitudes and experiences expressed by participants. Semi-structured interviews create to the participants the necessary space to speak for themselves, with little interference of the interviewer. The semi-structured interviews allow different levels of prescription and improvisation. In the Semi-structured interviews the questions are specified, the interviewer is free to explore beyond the answers and enter into a dialogue with the interviewees. There are realized (made) a total of 20 semi-structured interviews with people with HIV / AIDS and members of their families as well, and 10 semi-structured interviews with key people (4 doctors, 3 nurses, 1 social worker, 2 specialists of the National Program on HIV / AIDS in SLI, which offer services for these people.

4. Conclusions

1. "Keeping secret" the status turns to be a big obstacle to the lives of people with HIV / AIDS, because they have to find various excuses for their family members or relatives for their frequent visits to the hospital, medicines they take, etc. The major part of the interviewees did not have information about the disease at the moment that are diagnosed, they had the general information that AIDS is a terrible disease. They fear stigma and discrimination, so PJHA choose carefully

who will be the persons with whom they will talk about their disease. Service providers too, see stigma and discrimination as a barrier for getting various social, economic or medical services. Most of PJHA feel stigmatized and not comfortable with messages that media convey about HIV / AIDS. The way in which the information is provided by the media increase the level of fear in people who are not infected and there is no awareness of the community about AIDS. Service providers also support the same idea that media is not professional but is very superficial in the way it conveys messages of HIV / AIDS. There is no awareness activities on the issue of HIV / AIDS as well as on the various phenomena like: psychosocial, economic, occurring as a result of this disease.

2. We can find stigma in the family environment as well. Stigma within the family is perceived as serious and when is repeated constantly it creates tensions and problems in relationships with family members. This creates another obstacle to the creation of social and emotional support within the family. Family support is considered important for PJHA and service providers too. Service providers often see families as partners for a successful management of the disease. PJHA often choose not to tell to their family because they fear that they will lose them, and for them this is worse than the disease itself. On the other hand, not all the families accept this situation. Service providers receive a number of needs that are important for improving the health of PJHA, such as free health services, economic support when PJHA are unemployed, integration into the labor market for people who have physical skills, social and psychological support in order to strengthen the PJHA group to protect their rights.
3. PJHA's families also need psycho-social support in the first moments when they have just learned about the disease. Service providers point out that the family needs information about the disease because this increases the support and acceptance of people with HIV / AIDS from the family.
4. The informal support offered from family and friends is casual, very individual, and based on the options and characteristics of each family. As we showed above service providers report cases of PJHA who have been abandoned by their families. On the other hand, the formal services are more organized in view (function) of needs and specifications of PJHA. Formal services are not sustainable and not planned because they do not meet many of the needs identified by the PJHA and service providers. Service providers recognize that there is a lack of bylaws, which will make possible the implementation of the Law on HIV / AIDS and meet the needs of PJHA and their families. The

structures created at the local level do not have the capacity and skills for the management of HIV / AIDS and to provide social and psychological support.

5. According to the service providers, there are a variety of programs and services to be developed to enable the implementation of the rights of PJHA and increase the quality of services provided to PJHA and their families.
6. It is worth mentioning that all interviewed said that family support was important for passing along their pain. Without family support, everything was useless and impossible, but not all families were willing to accept a member with HIV / AIDS. This has happened to three people who participated in this study; their partners had refused them after they showed the truth. While 7 others had the support of family and feel safer with them.

5. Recommendations

1. Development of awareness programs on HIV / AIDS to increase the number of voluntary testing and reduce stigma against the disease by the general population.
2. Sensitization of families to accept the diagnosed members with HIV / AIDS, showing how important is their support to them.
3. Strengthening and enhancing cooperation between service providers and the families.
4. Every person with HIV / AIDS should be respected and supported equally with others, because everyone has the right to feel equal by their families and to other institutions.
5. Staff working with this target - group should specialize constantly in order to be able to help these people.
6. HIV-infected persons should be helped and strengthened in the first moments when they get "the response", to cope with negative emotions and experiences, so that do not become an obstacle to further treatment and care.
7. Relatives and family members of persons affected by HIV should be empowered and involved in consulting and educational programs, in order to be aware of the new situation and know how to meet the new needs together in the family.
8. People affected by HIV should be more active in seeking assistance or in search of their rights. Institutions have the first responsibility to provide information about rights and services and people affected by HIV should be active researchers of these rights.

9. People living with HIV / AIDS should be aware, counseled and educated about the treatment, forms, and aspects of a healthy living, which will increase the quality of life and will transform AIDS from a disease, in a situation that accompanies their living.
10. People affected by HIV / AIDS should be supported to understand and maintain the responsibility to their family - husband, wife, children, whether infected or not.
11. To a great importance is to strengthen and increase the capacity of the family (relatives) in order to reduce the level of stigma and discrimination against people living with HIV.
12. Creating groups of psycho-social support for people living with HIV / AIDS and their families will increase the dynamics of services both formal and informal, leading to increasing levels of access to services for people living with HIV / AIDS.

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