# A BETTER COMMUNCATION WITH THE PATIENTS IMPROVES THE MANAGEMENT OF HIV DISEASE: A NONSYSTEMATIC REVIEW

### VALENTINA TZANEVA¹, TEODORA IACOB²

<sup>1</sup>University Hospital Stara Zagora, Bulgaria <sup>2</sup>Hospital for Infectious Diseases, Iuliu Hatieganu University of Medicine and Pharmacy, Cluj-Napoca, Romania

### **Abstract**

The human immunodeficiency virus (HIV) is a blood-borne, sexually transmissible virus which belongs to a subset of viruses called retroviruses. Patients with HIV disease face problems like stigma, discrimination, poverty and marginalization. These problems also affect the physician-patient communication in HIV disease.

Learning to conduct a consultation is a complex skill which is gradually learned and perfected during training and career. Good physician-patient communication in HIV disease demands medical professional competence, good communication skills, ethical behaviour, respect of patient's dignity, good teamwork skills and maintaining confidentiality.

The most important aspect of patient care is education, which should include empowering patients with basic knowledge about HIV infection, methods of transmission, progression, prognosis, and prevention. A multidisciplinary approach that uses the special skills of nurses, pharmacists, nutritionists, social workers, and case managers is desirable. Effective methods for clinicians to support such development are needed.

**Keywords:** HIV disease, patient-physician communication, treatment adherence, prophylaxis counseling.

## Magnitude of the problem

The human immunodeficiency virus (HIV) is a blood-borne, sexually transmissible virus which belongs to a subset of viruses called retroviruses. The virus is typically transmitted via sexual intercourse, shared intravenous drug paraphernalia, or through contact with unsterilized medical instruments and equipment, HIV virus-infected blood transfusions and mother-to-child transmission, which can occur during the birth process or during breastfeeding.

The most common route of infection varies from country to country and even among cities, reflecting the population in which HIV was introduced initially and local practices.

Two distinct species of HIV (HIV-1 and HIV-2) have been identified, and each is composed of multiple subtypes, or clades. All clades of HIV-1 tend to cause similar disease, but the global distribution of the clades differs [1].

HIV infection manifests in 3 main ways: (1) an

Manuscript received: 02.09.2013 Accepted: 16.09.2013

Address for correspondence: vtzaneva@gmail.com

acute viral illness seen in the initial weeks of infection - the window period that reflects the window of time between infection and the time that antibodies develop, (2) immunologically mediated processes related to host responses to chronic viral infection, and (3) opportunistic diseases. The difference between HIV and AIDS is that AIDS is the final infection resulting from the progressive disease that starts with the HIV virus entering the bloodstream. Once the HIV virus enters the bloodstream, this retrovirus slowly begins to attack the immune system. A person is said to have AIDS when the CD4 count drops below 200. The patient also would be said to have one or more opportunistic infections

There are around 34 million people in the world living with HIV/AIDS and two-thirds of all people infected with HIV live in sub-Saharan Africa, although this region contains little more than 12 percent of the world's population [2].

Data for HIV in Bulgaria: The overall number of officially registered patients living with HIV in the country is 1647. In 2012 346 424 people were tested and 157 of

them were seropositive - 122 males and 33 females; 42% from the newly registered cases are under 29 years old. There are two major vulnerable groups: MSM -35.6 %, i.v. drug users - 25.4%, but the tendency is decline in the group of i.v. drug users and increase in the homo and bisexual community. Among the newly registered cases 9% are Bulgarian citizens who had been abroad for a long time and contracted the disease there and in 2012 returned to Bulgaria.

Until 31 December 2012 818 HIV positive persons were followed up in the 5 centers in the country which provide care and medication; 539 of them receive antiretroviral therapy. There is a network of 19 laboratories and consultation centers and over 50 organizations which provide prevention for the vulnerable groups and support for the patients in Bulgaria [3].

# Challenges in physician-patient communication in HIV disease

The first challenge in the physician-patient communication is when the information for the HIV positive result has to be delivered to the patient. Bad news communication requires special skills. Knowing that this news will change the life of the patient and will have a negative impact, a special attention should be paid to individuals who are vulnerable and worried, who have psychiatric diseases and who are under 16 years of age.

The physicians need to be aware that when facing the fact that they are HIV positive, the patients experience catastrophic stress and transition into 3 sensitive periods: First, when the diagnosis is established, which is a big psychological trauma with suicidal risk.

The patients worry if their secret will be kept, feel guilty for the possibility to infect someone else, feel remorse about their behavior, uncertainty of the future life and sometimes may be aggressive to the eventual source of the infection. The second period when patients' psychological vulnerability is elevated and they need support is when they start to experience the clinical signs of the disease with development of opportunistic infections and deterioration of their physical condition. The third critical period is when the disease has come to its terminal phase. They experience the 5 stages of dying: denial, anger, bargaining, depression and acceptance.

It is a big challenge for a physician to deal with all these situations and to be adequately prepared to provide the necessary care.

Patients with HIV disease face problems like stigma, discrimination, poverty and marginalization. These problems also affect physician-patient communication in HIV disease. The stigma has been attached to HIV infection, mostly because of the virus's association with sexual acquisition and the inference of sexual promiscuity. Consequences of this stigma have included discrimination, violence and personal rejection of people with AIDS and

reluctance to be tested for HIV infection. The stigma of HIV infection is also associated with a fear of acquiring a fatal infection - most human beings are afraid of acquiring a serious illness. Patients are scared to tell their relatives and friends the diagnosis, because of the existing stigma. The stigma cuts across most of the other challenges – the fact of massive social condemnation and marginalization after disclosure of the status [4,5].

The lack of social support to help these patients cope with their everyday life is a problem. They have problems in the hospitals, in case they need some healthcare. HIV positive individuals meet difficulties to receive treatment as the other patients especially when they have dental, surgical or gynecological problems, despite the fact that the degree of risk of transmission in HIV infection is smaller compared to the much more easily transmitted Hepatitis B for example. Their families and friends often change totally their attitude when they learn the diagnosis. Even if they continue to support them – the care of a person with AIDS is an emotional strain for the household members and also a strain on the household resources. Loss of income, additional care-related expenses, reduced ability of caregivers to work may push affected households deeper into poverty. For HIV-positive individuals living in socially vulnerable circumstances, the complexities of accessing and navigating healthcare system can be overwhelming [6]. The greater needs of patients presenting with HIV and the limited time and resources in the healthcare to address these needs may partially contribute to physician's negative attitudes regarding their patients.

The impact of the disease on the nervous system provides additional challenges in physician-patient communication. Human immunodeficiency virus (HIV) enters the central nervous system (CNS) early in the course of the infection and causes several important CNS conditions over the course of the disease, such as HIV encephalopathy and AIDS dementia complex [7]. HIV-associated progressive encephalopathy (HPE) is a syndrome complex with cognitive, motor, and behavioral features [8]. The overall psychosocial and emotional burden on the family and friends of patients with HIV dementia is tremendous, far beyond that of a cognitively intact patient with AIDS. Patients with cognitive difficulties have problems with compliance and adherence to their medication regimen. Because of their neuropsychiatric problems, these patients are likely to be less inhibited and are more prone to HIV-related risk behavior, and they therefore pose a greater risk of transmission of the virus.

An important aspect of managing health care for the patient with HIV is to discuss the issue of cognitive decline. In cases where HIV-associated dementia is established, addressing issues of competence to make medical decisions is also important. Patients may at times reject treatment offered by a physician, even at the risk of remaining ill. A person's right to autonomy cannot be challenged, provided that he or she has the competence to understand the risks and benefits of the treatment offered. The only exception to this situation would be a medical emergency in which the hospital or physician may obtain consent from a surrogate, a close family member, or a spouse [9]. Studies have found that physician-patient relationships and communication quality are related to medication adherence and outcomes in HIV care.

# The role of physician-patient communication in HIV disease in educating the patients

Since the onset of HIV, tremendous progress has been achieved in HIV prevention.

The physician – patient communication is extremely important for the patients' education.

In the medical consultation patients with HIV infection should be counseled about the risks of infecting their sexual partners with HIV. This includes encouraging compliance to safer sex practices and treatment of concurrent sexually transmitted diseases, both in the patient and in sexual partners which considerably reduces the risk of transmission. Patients with HIV infection should be encouraged to inform their sexual partners of their status. They should be educated that blood donation is forbidden, that they have to tell their dentist that they are HIV positive. They need to be informed that treatment is available and it should start as early as possible and the need for good control of the viral load should be explained [10].

Since the introduction of Highly Antiretroviral Therapy (HAART) the quality of life and prognosis has improved dramatically and, changed the way the diagnosis was accepted in the beginning. However, a large proportion of patients have poor adherence to HAART and this is the main reason for treatment failures and the development of viral resistance. Several factors are related to non-adherence, especially patient-related factors such as depression, abuse, weak social support, regimen complexity, adverse effects of the drugs but communication difficulties and poor patientphysician relations are considered as a main barrier in patients' adherence to HIV medication and lack of trust in the treatment. Barriers in physicians' communication with patients are lack of time and resources, lack of training and shyness when taking history about the intimate life. Experienced physicians achieve trusting patient-physician communication and manage to convince the patient about the benefits of the treatment which is associated with better adherence to HAART.

The reduction in mother-to-child transmission of human immunodeficiency virus (HIV) is regarded as one of the most effective public health initiatives. In the absence of treatment, the risk of vertical transmission of HIV is as high as 25-30%. Transmission may occur during intrauterine life, delivery, or breastfeeding. With the implementation of HIV testing, counseling, antiretroviral

medication, delivery by cesarean section prior to onset of labor, and discouraging breastfeeding, the mother-to-infant transmission has decreased to less than 2% in the United States. Pregnant women should be tested for HIV during pregnancy. The Centers for Disease Control and Prevention (CDC) recommends routine third-trimester screening in women with high-risk behaviors or who exhibit signs or symptoms of the disease [11].

Clinicians who care for women with HIV need to provide family planning services and counseling regarding optimizing health status. Stressing the importance of taking their medication regularly to decrease the possibility of the development of antiretroviral drug resistance may encourage women to comply with therapy. Women should be extensively counseled regarding the ability to decrease the risk of perinatal transmission with highly active antiretroviral therapy (HAART) prophylaxis or treatment. Women must be counseled on methods to avoid transmission to others, including safe sex practice and avoiding donation of blood or organs. Regular use of latex condoms and avoidance of unprotected intercourse is important. Treatment of genital tract infections and inflammation in both partners is important to avoid mucosal breaks. Women should not share toothbrushes or razors, as small amounts of blood may be present.

Because morbidity is increased in women infected with HIV who undergo cesarean delivery, discussion of the option of scheduled cesarean delivery should begin as early as possible in pregnancy with every pregnant woman infected with HIV, to give her an adequate opportunity to consider the choice and plan for the procedure. The risks, which appear to be greater for the mother, must be balanced with the benefits expected for the neonate [12]. The patient's autonomy must be respected when making the decision to perform a cesarean delivery, because the potential for maternal morbidity is significant.

In educating the public the mass media are an important vehicle for health promotion. Media campaigns, distribution of patient information leaflets and websites successfully promote favorable norms and safer sexual behavior. The role of mass media in health message communication combined with school education can result in decreased risk of HIV infection. Exposure to celebrities through the media can also have an important influence on the public's health-related attitudes, beliefs, and behavior. The force of a famous personality could be a major catalyst for AIDS awareness, education and prevention efforts. The announcement by Los Angeles Lakers' basketball star Magic Johnson that he tested positive for HIV infection was intended to promote HIV/AIDS prevention, to increase the level of accurate knowledge in persons and the desire to obtain more information about HIV and AIDS. In his appeal for prevention he said that he wanted young people: "to understand how to protect themselves, and that it can happen to anybody, even me, Magic Johnson".

### What should be done

Learning to conduct a consultation is a complex skill which is gradually learned and perfected during training and career.

Good physician-patient communication in HIV disease demands medical professional competence, good communication skills, ethical behaviour, respect of the patient's dignity, good teamwork skills and maintaining confidentiality. Physician's communication with patients may be awkward and superficial, even when physicians try to create a friendly atmosphere. To "de-shame" patients is important for facilitating communication. Patients need to feel assured that their personal information is being handled appropriately. They need to be put at ease to be made free to ask and to be asked open ended, nonjudgmental questions. The physician should not make assumptions about the patient's sexual orientation and practices. The physician's interpretation of the believability of patient's statements on adherence to therapy is a major factor in the communication process. When an appointment for a follow-up visit is scheduled patients feel more engaged to comply with treatment.

Patients usually appreciate physicians who know and care about their medical condition, who are clear and direct about instructions, and who are accessible. Some of the HIV positive patients had struggled to overcome addiction and emotional turmoil before gaining control over their lives and becoming adherent to medications. Their adherence to therapy is a function of autonomous motivation. Successful coping with HIV with its prevalent behavioral co-morbidities, stigma, and other challenges requires a transformation of identity and internalization of motivation to maintain health.

Caring for patients with HIV is challenging and a physician needs to be mindful of special issues that encompass this population, like medical, psychological, and social challenges involved, along with the stigma associated with the disease. There are also many difficulties for a physician dealing with HIV among undereducated or underfunded populations. In resource-poor country HIV and AIDS is causing an increased demand on health care workers with poor pay of physician and nurses and migration to richer countries and is adding additional pressure on the health sector.

Currently, when vaccine is not available for HIV, prevention is crucial to decreasing the risk of transmission. The most important aspect of patient care is education, which should include empowering patients with basic knowledge about HIV infection, methods of transmission, progression, prognosis, and prevention. A multidisciplinary approach that uses the special skills of nurses, pharmacists, nutritionists, social workers, and case managers is desirable [13]. Effective methods for clinicians to support such development are needed.

### Conclusions

The comprehensive, holistic management of HIV patients should include very good communication with the patients and the people around them. It is a need to increase awareness of healthcare providers to offer more support to these special patients.

### Acknowledgement

This paper is based on a lecture presented at the Workshop on Medical Communication, Cluj, 27-29 March 2013; part of this has been published in the proceedings of this meeting. The work was produced in the frame of the CEEPUS project CIII-RO-0016-08-1213.

### References

- 1. WHO, UNICEF, UNAIDS Progress report 2011: Global HIV/AIDS response.
- 2. World Health Organization. AIDS Epidemic, 2009. Available from: http://data.unaids.org/pub/Report/2009/JC1700.
- 3. Ministry of Health HIV/AIDS Prevention program.
- 4. Idemudia ES, Matamela NA. The role of stigmas in mental health: A comparative study. Curationis, 2012; 35(1), Art. #30, 8 pages. http://dx.doi.org/10.4102/curationis.v35i1.30
- 5. Madiba S. The impact of fear, secrecy and stigma on parental disclosure of HIV status to children. Glob J Health Sci, 2012; 5(2):49-61.
- 6. Center for Disease Control and Prevention. Available from: www.cdc.gov
- 7. Goodkin K, Aronow A, Baldwin G, Molina R, Zheng, W, et al. HIV-1 associated neurocognitive disorders in the HAART era. The Spectrum of Neuro-AIDS Disorders. Washington DC, ASM Press; 2008.
- 8. Bradley WG, Daroff RB, Fenichel GM. Neurologic manifestations of human immunodeficiency virus infection in children. In: Neurology in Clinical Practice, 2004; 2:1603-1611.
- 9. McArthur JC. HIV dementia: an evolving disease. J Neuroimmunol, 2004; 157(1-2):3-10.
- 10. U.S. Preventive Services Task Force. Screening for HIV. Available from: http://www.uspreventiveservicestaskforce.org/uspstf/uspshivi.htm.
- 11. Connor EM, Sperling RS, Gelber R, et al. Reduction of maternal-infant transmission of human immunodeficiency virus type 1 with zidovudine treatment. Pediatric AIDS Clinical Trials Group Protocol 076 Study Group. N Engl J Med, 1994; 331(18):1173-1180.
- 12. The mode of delivery and the risk of vertical transmission of human immunodeficiency virus type 1--a meta-analysis of 15 prospective cohort studies. The International Perinatal HIV Group. N Engl J Med, 1999; 340(13):977-987.
- 13. Adapted from Guide for HIV/AIDS Clinical Care. U.S. Department of Health and Human Services Health Resources and Services Administration HIV/AIDS Bureau: Published January 2011.