

## Shame and HIV infection: A narrative review

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### Abstract

**Introduction:** Some diseases such as AIDS more often than not lead to feelings of shame, embarrassment or guilt due to their nature or social burden.

**Purpose:** Investigating the shame experienced by patients suffering from HIV/AIDS infection.

**Methodology:** This narrative review was based on the bibliographic search of reviews and research studies drawn from the international databases. The exclusion criterion of the articles was the language other than English and Greek.

**Results:** People living with HIV report a range of stigmatizing experiences derived from others; including social rejection, exclusion, gossip and poor health care as well as the risk being stigmatized and marginalized. This situation negatively affects people living with HIV, resulting in emotional tensions and outbursts, anger, sadness, a feeling of low self-esteem, fear and shame for their desires and thoughts, shame for themselves.

**Conclusion:** What is needed is the education of society and the adoption of health policies that guarantee that everyone, regardless of the disease they suffer, will have the right to care and health.

**Keywords:** HIV/AIDS infection; Shame; Stigma; Vulnerable social groups

### 1. Introduction

December 1<sup>st</sup> is World AIDS Day, as established in 1988 by a decision of the World Health Organization, which was subsequently approved by the General Assembly of the United Nations (UN) [1].

The exact timing of the appearance of AIDS is not entirely known. There are reports of the appearance of the virus in humans, probably, from the 17th century [2].

Most researchers agree that the virus was transmitted to humans through monkeys – chimpanzees, initially in the regions of Central Africa, which carry the SIV (Simian Immunodeficiency Virus), and which is quite similar to human

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HIV. SIV appears to have been mainly transmitted to humans through the consumption of contaminated meat or the use of contaminated blood in various practices, such as wound healing [3]

The virus passed from Africa to Europe through trade, slave trade, sex trade and immigration, and from there to Asia and the Americas [4, 2]

The transmission of HIV infection seems to have been taking an epidemic form in Europe and America since the 1970s. The first USA announcement was issued by the US government in 1981 about the emergence of a new unknown until then disease, which mainly affected, homosexual men and intravenous drug users [5]

It was initially considered that AIDS concerned only specific groups of people, with specific attitudes, mainly homosexual men, heroin users, Haitian immigrants to the Us and hemophiliac patients; they were dubbed as '4 H's' because of their initials, freeing AIDS from hitherto stereotypical notions [6, 7]

Transmission of the disease was subsequently observed between heterosexual couples, in newborns, in children and in multitransfused patients [8]

Upon diagnosis of the disease, patients are to deal with stigma and usually hostile social reaction, experiencing a lot of discrimination, racism and shame in all aspects of their lives.

**The purpose** of this review study is to investigate the shame experienced by patients suffering from HIV/AIDS infection due to the disease.

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## 2. Methodology

The methodology followed was based on the bibliographic search of review and research studies, which were drawn from the international databases Medline, Pubmed, Cinahl and from the Greek database Iatrotek, with keywords such as, HIV / AIDS infection, shame, stigma, vulnerable social groups. The criterion for excluding the articles was the language other than English and Greek.

### 2.1. Talking about HIV/AIDS

AIDS is defined as "Acquired Immune Deficiency Syndrome". AIDS is caused by disturbances in cellular and humoral immunity caused by the Human Immune Deficiency Virus (HIV) [8]

In 1983 Montagnier and Gallo first isolated and described the virus, naming it, on the side of Montagnier LAV (Lymphadenopathy – associated virus), and on the side of Gallo HTLV – III (Human Tcelllymphotropic virus – III type). It was possible in 1985 to detect the virus through antibodies in the blood; as a result, signaling the start of blood testing before transfusion, and, thus increasing the level of safety in transfused patients. Finally, in 1986 the entire scientific community came up with a common name for the virus that causes AIDS, in Human Immunodeficiency Virus (HIV) [9, 10]

The virus harms the human immune system, attacking T-lymphocytes; thus making the sufferer's body susceptible to numerous infections, with the characteristic symptoms of the disease being Kaposi's sarcoma (KS) and Carinii pneumocyst pneumonia (PCP) [6, 11]

The virus can be transmitted via blood, semen, pre-ejaculatory fluids, rectal mucus, vaginal fluids, and even from mother to newborn, through breast milk. Other ways of transmitting HIV are through syringe sharing, childbirth, transfusions of infected blood, accidental punctures with syringes, but also from unprofessional tattoos, ear piercings, etc. Anyone infected with the virus seems to develop AIDS sooner or later, with the time of the onset of symptoms ranging from two to over ten years [12]

Research conducted on sufferers, claims that 10% of the participants developed AIDS in a short period of time - within two to three years of infection - 5-10% of these people did not show symptoms even after twelve years or more, emphasizing that factors such as genetic individual differences, but also the coexistence of infections by other microbes affect and intensify the rate of progression of the disease [13]

Nowadays it is now widely known how the disease is treated and how the possibility of an HIV infection is prevented. What is needed is the adoption of healthy policies that guarantee that everyone has the right to in be in health. This

includes concerted efforts to address injustices and inequalities that make specific social groups (young women, sex workers, gay men, transgender people, drug users, prisoners, refugees and migrants) more vulnerable and at greater risk of exposure and infection to HIV [14]

## 2.2. Talking about the Feeling of Shame

Shame concerns violations of social and moral norms that refer to specific conducts whereas it is associated with blaming oneself for something bad (immoral or disgusting) [15]. However, it can also concern situations for which the person himself is not responsible, such as a defect from birth, the rape of a woman or an illness [16]

Regardless of the cause, therefore, people with increased levels of shame may feel bad by charging themselves with their HIV infection. [17]

Shame is an unpleasant feeling usually associated with defeatism and feelings of sadness and helplessness. Shame is a subtle, basic emotion, described as a moral or social feeling that prompts people to hide or deny their unacceptable deeds. Shame can also be defined as an unpleasant self-conscious feeling that involves the negative evaluation of oneself [18]

In general, feelings of shame involve an awareness of one's 'faulty' personality and involve a reaction that often seems disproportionate to the actual severity of the event [19]. Shame as a feeling includes catholically, the whole, person, including his soul and body. If a person does not manifest shame or feel ashamed, even in childhood, then he is considered to lack some ability, such as not having any cognitive ability [20].

It is a painful feeling that is often associated with the perception that someone has individual characteristics (e.g. body shape), personality elements (e.g. he is boring) or is accustomed to inappropriate behaviors (e.g. lying) that others will find unattractive and that will lead to his rejection or some kind of relegation [16]

Shame might also stem from constant reminders or maybe a mistake for which the person is ashamed, or from the actions of others that make the person feel ashamed. The shame also associated with sex becomes more complex through the stigma of illness and more expressed through worries not to be called a sinner or/and an irresponsible individual [19]

There is also an important relationship between the feeling of shame and the stigma. The term stigma, which has prevailed internationally through scientific literature, comes from the ancient Greek language, and specifically from the verb stigmatize, which literally means "to engrave by nail, to cause a mark with an incandescent seal so as to indicate shame or punishment, and engrave the skin as a sign of dishonor" [21]

Many physical diseases are accompanied by stigma. Certain diseases and disorders, such as AIDS, due to their nature or social burden, most often lead to feelings of shame, embarrassment, rejection or guilt. The stigma and shame they cause also affects those individuals associated with the stigmatized person [22]

## 2.3. Talking about Shame in Patients with HIV/Aids Infection

The stigma associated with HIV is due to a number of factors, such as the fear of infection due to the infectious nature of HIV, concerns about productivity in the workplace where these HIV carriers may be considered unsuitable for employment, or have difficulty in forming friendships. Moreover, the enforcement of social norms could be hard, because HIV risk is associated with socially stigmatized behaviors, and, therefore, the carriers of the virus are viewed with skepticism because of their association with those behaviors [23]

People living with HIV report a range of stigmatizing experiences from others, including social rejection, exclusion, gossip, and poor health care, and risk being stigmatized and marginalized [24]

The factors that facilitate stigma on AIDS carriers and patients are also influenced by laws criminalizing the transmission of HIV or certain occupations (e.g., prostitution) or behaviors (e.g., same-sex sexual relations, injecting drug use), and the lack of universal protection supplies in healthcare facilities [25]

All these humiliating behaviors create feelings of shame in people living with HIV. In general, people are reluctant to speak directly about feeling ashamed, as acknowledging shame means for them that they admit that there is something to be ashamed of. Defensive behavior, or excessive and highly sensitive pride, are indicative of such reactions as are the non-verbal information derived from the posture, the direction of the gaze and the reddening of the person's face [26]

Also, seeking care can be embarrassing for AIDS sufferers. More generally, seeking help when a person is not considered worthy of it can be embarrassing [17] Shame, in addition to preventing us from asking for help, also negatively affects our compliance with treatment [19]

These behaviors make the individual more exposed to the "gaze of the other", something that is directly related to social criticism and rejection and to the feeling of shame [27]

This situation has a negative effect on people living with HIV, resulting in emotional tensions and outbursts, anger, sadness, a feeling of low self-esteem, fear and shame for their desires and thoughts, shame for themselves. After all, one's inability to withstand the enormous blow that shame inflicts on oneself can lead one to harmful behaviors in an attempt to "relieve oneself." An example of such a behavior is the substance abuse, trying to stifle all those feelings of shame with the consumption of drugs or alcohol [28, 29]

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### 3. Conclusion

The shame and stigma experienced by people living with HIV have a detrimental effect on their psycho-emotional ability. It could well be described as the most harmful form of social racism because it poses, in some cases, insurmountable obstacles even to their treatment and health care. As a result, these people enjoy poorer quality of care and life. Furthermore, they have increased mortality and there is an increased risk of spreading the disease. Thus, it is vital strategies be designed and determined so as to compensate for shame, stigma and prejudice by educating society and citizens, as well as health professionals in cooperation with patients and other actors, in order to support AIDS carriers and patients.

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### Compliance with ethical standards

#### *Disclosure of conflict of interest*

There are no conflicts of interest.

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