

## **Stigma of people living with HIV/AIDS**

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### **ABSTRACT**

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A specific character of HIV/AIDS has caused numerous complications either medical, legal or social. HIV infection exposes its carriers to frequent acts of intolerance or stigma by the healthy part of the population. Negative social consequences found after detection and disclosure of HIV perfectly match the theory of stigma by Goffman. This theory elucidates mechanisms of stigma or self – stigma affecting these members of the society that via their behavior or life style break the basic social, moral and religious norms. Despite numerous achievements, this disease cannot be overcome completely. People living with HIV/AIDS are still stigmatized and discriminated in

the society. They suffer being rejected and isolated by a family, partners and friends. The results demonstrated in the present review, obtained from the examinations conducted among people with HIV/AIDS, in Poland and abroad, attesting stigma, discrimination, low evaluation of the quality of life are the basis for further in-depth studies concerning this issue. This must reinforce educational efforts which will constrain inequality of people with HIV/AIDS, in Poland and abroad.

The aim of this study is to inform and sensitize a recipient about stigma among people with HIV/AIDS.

**Key words:** HIV/AIDS, stigma

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## INTRODUCTION

In the literature on the subject, the term stigma – stigmatizing is widely used not only in social sciences but in common parlance as well, where it is not precisely defined. In the theory of labeling, stigma is an identification of a personal or social feature branding [ref.1]. In the Polish literature, the term ‘a mark of discredit’ is frequently used as a synonym of ‘a stigma’ [1]. Goffman [1], a creator of a stigma - theory distinguishes its three types: stigma of character traits, physical stigma, and stigma of group identity and emphasizes that stigma can be reduced or increased with time. The author believes that *stigma is the creation of a given social audience, representing a specific culture, not a specific person's characteristics*. In his opinion, it can play a central (e.g., disability, obesity, chronic disease, ethnicity) or peripheral (e.g., different sexual orientation, poverty) role [1].

The present study is a review based on the reports of the National Institute of Public Health – National Institute of Hygiene in Poland, Polish and foreign literature and studies /publications from the data base of PubMed from the years: 2001-2012.

It is emphasized that HIV infection or developing AIDS is very frequently associated with behavior of marginalized groups, so all people living with HIV/AIDS are perceived as belonging to these marginalized groups, and some of these people can be stigmatized in the way they have not experienced so far [2]. Therefore, a specific vicious circle develops, because HIV/AIDS escalates stigmatizing people and groups that are already marginalized, simultaneously increasing their susceptibility to HIV/AIDS, contributing to their further stigmatization and marginalization [3].

Negative social consequences after HIV detection and disclosure correspond perfectly with Goffman's theory of stigma [4]. This theory explains mechanisms of negative stigma and self-stigma of these members of the society who break fundamental social, moral and religious standards through their behavior or lifestyle [4].

Aggleton [5] believes that stigma may be treated as one of the most potent social means used to marginalize, exclude or demonstrate power towards people who have undesirable traits as a society's response to the fear they experience, especially, when it cannot be avoided or removed. According to Alonzo and Reynolds [6], stigma is a very poignant social etiquette which radically changes the way people perceive themselves and are perceived by others. In 2001 year, the phenomenon of stigma was described by Link and Phelan [7]. In their work entitled „Conceptualizing stigma”, they emphasized that stigma could be talked about when the following correlated elements existed: labeling, stereotypization,

separation of ‘us’ from ‘them’, based on the stereotypes created and the loss of social status and discrimination.

The sensed stigma or anticipated discrimination has a great influence on people with HIV/AIDS [8]. Disclosure of one's seropositivity causes more anxiety than only fear and uncertainty of other people's reaction [9].

The concept of quality and satisfaction with life are very useful for processes of strengthening health and treatment, holistic care and the rehabilitation process [10]. Researchers studying the quality and satisfaction with life underline the necessity of their assessment with regard to the patient's somatic condition, his/her well-being, social relations and physical fitness [11]. A health condition is one of the most fundamental factors of good quality and satisfaction of life [12], while the level of acceptance of illness significantly affects the adaptation to the limitations imposed by the disease [13].

The studies of HIV/AIDS stigma prove that people with HIV/AIDS are stigmatized because HIV/AIDS are associated with the behavior that has already been condemned or regarded as deviant, especially, homosexuality and intravenous application of narcotics; people with HIV/AIDS are considered to be responsible for contracting HIV/AIDS; HIV/AIDS is a life threatening disease ; people are afraid of HIV infection; religious or moral beliefs make people conclude that HIV/AIDS infection was caused by moral guilt. Thus, foreboding or anticipating discrimination causes more concern and worries than only fear and uncertainty of people's reactions. This also results in low evaluation of quality of life.

According to Al Robaee [13], the level of acceptance of illness influences the adaptation to the limitations imposed by the disease, dependence on others and self-esteem. The foregoing factors affect the subjective feeling of the quality and satisfaction with life and determine the level of the patient's own activity [13]. Each disease evokes negative emotions and difficulties, imposing limitations or changes in social functions [14].

In the scientific literature, it is emphasized that the higher the level of illness acceptance, the better the adaptation and the lower the accumulation of negative emotions in patients [15].

The world has been facing HIV epidemic for 25 years. In Poland, the first cases were diagnosed in 1985-1986 years [1].

The data of the National Institute of Hygiene indicate that in Poland, from the implementation of studies in 1985 year to 30 September 2014 year, HIV infection was established in 18,323 people, 3,172 cases of AIDS were reported and 1,283 patients died [16].

The common characteristic of the epidemic worldwide is that HIV affects mainly young people

– almost 40% of people living with HIV in the world are between 15 and 24 years old [1].

In Poland, the similar tendency can be observed: 7% of all infections were revealed in people younger than 20 years old, whereas 46% of all HIV infections affected people between 20 and 29 years old [16]. In Poland, (84%) people at working age (20-49 years old) predominate among people infected with HIV and afflicted with AIDS. It has been estimated that as many as 70 % of people infected with HIV are not aware of the infection and they are not included in the statistics. At present, very young and young people are infected with HIV, which is very disturbing. Therefore, the activities focused on the high risk population should be elaborated and reinforced. Epidemiological data indicate the relatively stable epidemiological situation of HIV/AIDS in Poland. However, taking into consideration the fast rising number of HIV infections in the countries of Central and Eastern Europe, there is a potential risk of rapid spread of the epidemic in the region, which may also influence directly the situation in Poland [1].

The studies carried out by Theilgaard et al. in Tanga, in Tanzania found that people living with HIV/AIDS experienced stigma and discrimination in the society [17]. In the studies performed in Canada, Mill et al. [18] evaluated stigma practices in the institutions of public health in Ottawa and Edmonton and found out that stigma could be used as a mechanism of social control imposed on patients with HIV/AIDS. Their respondents described both active and passive social control mechanisms: avoidance and ostracism, labeling and marginalizing in the health care practice. According to the authors, these results show the urgent need for the intervention at numerous levels to decrease stigma of people living with HIV/AIDS [18].

The literature on the subject focuses attention on the significance and complexity of physical, psychological, and social factors such as health and life quality and conditionings in people infected with HIV [19]. The available data suggest that physical symptoms, antiretroviral therapy, psychic well-being, social support systems, coping-with- stress strategies, spiritual well-being and coexisting psychiatric diseases are important indicators of life quality in this population [19].

In the study, investigating African American women with HIV who reside in the state of Massachusetts, by means of SWLS, Looby found the direct and indirect relationship of subjective well-being to the adherence to antiretroviral therapy, positive prevention and medical appointments among this population, among others [20].

The studies carried out by Ogbuji et al. in Nigerii among people living with HIV/AIDS

revealed that discrimination towards them by a family, friends and the community affected negatively their quality of life [21].

In the studies performed among patients with HIV/AIDS in North India, Wig et al. found a low esteem of respondents in four domains of life quality: social, psychological, physical and environmental [22].

According to the data from the literature, people accepting the disease are the people understanding and aware of their disease, with an optimistic, hopeful attitude to life, trust in doctors and treatment as well as taking an active part in the therapy [23].

The studies of knowledge and behavior associated with HIV/AIDS, carried out in the different parts of the world, show the same misconception of this subject [24-26]. Karmacharya et al. dealt with the subject of awareness and knowledge about HIV/AIDS [27]. In her study, the author found the significance of diagnosis of the prevalence and risk factors leading to HIV infection and other sexually transmitted diseases among street children and youth of Kathmandu in Nepal [27].

The studies carried out by Yahaya et al. among the youth in Kwara State in Nigeria, examining factors hindering acceptance of HIV/AIDS voluntary counseling and testing(VCT), revealed that stigma and discrimination were the major factors responsible for the low acceptance of patronage of Voluntary Counseling and Testing centers in Kwara State [28].

In the studies carried out by Thomas et al. [29], Zelaya et al. [30], Mahalakshmy et al. [31] and Finn et al. [32], stigma was also found to have a significant negative correlation with QOL.

However, in the study in an urban clinic of adult HIV patients, Relf et al., examining HIV stigma by means of the Berger Scale of Stigma, found that stigma was associated with depressive symptomatology and a lower quality of life [33]. Similar results were obtained in the studies performed by Wingood et al. in the Western Cape in South Africa [34] and by Van Damme-Ostapowicz et al. in the studies carried out in Poland [35].

In the studies, diagnosing the association between stigma, depression and quality of life among people living with HIV/AIDS in South India, Charles et al. found a significant association between severe depression and poor QOL ( $p < .05$ ) as well as the fact that those people who experienced severe “personalized” and “negative” stigma were 3.4 (1.6-6.9) and 2.1 (1.0- 4.1) times respectively more likely to have severe depression ( $p < 0.05$ ) [36].

According to Galwan et al., HIV stigmatization can harm the lives of those living with HIV in many ways [37]. These can include a

loss in self-esteem as well as deteriorated social interactions with others. The way how HIV-positive people manage HIV stigma and the strategies they use can be influenced by the extent of social resources they have available in their lives [37]. Social resources refer to family, friends, and others who can provide emotional support to HIV-positive people, which in turn can increase their self-esteem and self-confidence [37].

According to Galvan et al. [37], these social resources are important because they may affect the extent to which an individual feels impacted by HIV stigma in their own lives.

## CONCLUSIONS

The results of the studies carried out among people with HIV/AIDS, in Poland and abroad, presented in this review, proving stigma, discrimination and low evaluation of the quality of life are the basis of further, in-deep studies and activities aimed at this issue. Informing and sensitizing a recipient about stigma among people with HIV/AIDS will reinforce educational activities that will reduce inequality of people with HIV/AIDS, living in Poland and abroad.

## Conflicts of interest

We declare that we have no conflicts of interest.

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