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## Original research article

# The stigmatization of people living with HIV/AIDS in the Czech Republic (from their own perspective)

Q1 **Monika Bjelončíková\***, Alice Gojová

University of Ostrava, Faculty of Social Studies, Ostrava, Czech Republic

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## ABSTRACT

The issue of HIV/AIDS is on the front burner in the Czech Republic because the number of newly diagnosed cases has been rising dramatically. One of the essential problems is late diagnosis of the disease. Another typical trend is longer life expectancy for those with HIV, including people with HIV who live to retirement age or start a family. HIV/AIDS is considered to be a so-called stigmatizing disease. In this context, there is no scientific evidence of the social impacts of the disease that could serve as a basis for social assistance provided to this target group. This article offers partial results of a qualitative research conducted in 2016. It deals with the phenomenon of stigmatization from the perspective of people living with HIV/AIDS in the Czech Republic, and considers it to be a social consequence of HIV-positivity. Data collection was based on the techniques of an in-depth semi-structured interview, observation, and two focus groups with people living with HIV/AIDS. Data analysis made use of the method of social constructionist embedded theory (described by K. Charmaz) and altogether it comprised 11 testimonies of people living with HIV/AIDS and 2 other relevant persons. The research results (which are framed by Goffman's theory of stigma) proved that stigmatization is a key issue for the respondents and that in their opinion, stigma related to HIV/AIDS significantly affects the lives of HIV-positive people.

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## Introduction

An important part of the strategy against HIV/AIDS is to monitor the prevalence of HIV in the population. In the conditions of the Czech Republic, the situation is monitored by the National Reference Laboratory for HIV/AIDS, The National Institute of Public Health in the Czech Republic (hereinafter NRL). In 2015, the NRL announced the indisputably highest

annual incidence of HIV infection in the Czech Republic—266 [1]. It also pointed out that this growing tendency has been observed over the last 13 years. In 2014, HIV was newly diagnosed in 232 cases, in 2013 in 235 cases, in 2012 in 212 cases, and in 2011 in 153 cases [2]. From the beginning of 2016 up to November 30th, there were 275 new cases of HIV/AIDS registered by the NRL. This implies that the number of new cases diagnosed by the end of November 2016 exceeded the total number in 2015 [3].

\* Corresponding author at: University of Ostrava, Faculty of Social Studies, Fr. Šrámka 3, 709 00 Ostrava, Czech Republic.

E-mail address: [monika.bjeloncikova@osu.cz](mailto:monika.bjeloncikova@osu.cz) (M. Bjelončíková).

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In addition to the considerable increase in new cases of the infection, a high number of late diagnoses of HIV have been observed. "In 2014, 19 cases (8.2%) were detected in the AIDS stage and 13 cases (5.6%) in the symptomatic non-AIDS stage. These two groups (stages C and B according to CDC classification) account for a total of 13.8% and represent those HIV cases which are diagnosed definitely late" [4, p. 298]. In 2016, 34 new cases of AIDS were diagnosed, of which up to two thirds – 23 cases – were diagnosed as HIV positive in the given year. According to NRL, what is alarming is the increasing coinfection of HIV and other sexually transmitted diseases such as syphilis (154 new cases in 2015) or venereal lymph node (28 new cases in 2015); it was a matter of re-infection in dozens of the cases [5].

When the whole complexity of the issue is taken into consideration, domestic social science literature does not treat the issue of HIV/AIDS adequately and the explicit focus on helping professions is completely absent [6–8]. The research activity is oriented mainly in the medical direction [9–11] and from a medical point of view HIV is one of the most explored biological entities in nature [12]. Foreign literature treats the social aspects of this disease much better and many social science publications on social assistance and work with stigma can be found there [13–18]. One of the highly respected researchers and authors of numerous expert texts and studies on the above mentioned issue is the anthropologist Richard Parker [19–22] who started his ongoing research into social and political aspects of HIV/AIDS in Brazil in the early 1980s. In addition to medical and social science publications, there are numerous declarations, political statements, international conventions, and other documents treating the international and national HIV/AIDS strategies that are regularly adopted and adapted [23–35].

This implies that the fourth decade of the HIV/AIDS epidemic in the Czech Republic is characterized by inadequate social science research, an increasing number of HIV-positive people, a non-decreasing number of late diagnoses, and coinfection of the infection and other sexually transmitted diseases. It is also characterized by the fact that medicine availability increases the number of people living significantly longer with HIV, as well as of those who live to retirement age or start a family.

Society is not prepared for this phenomenon in terms of individual tools (prevention, social and health services, social work, etc.) [36–39]. Social services implementing tertiary prevention programmes (i.e. needle and syringe exchange programmes) and that are bearing fruit in the form of a permanently low annual number of pinpointed HIV transmissions through needle and syringe sharing [1–4,40,41] are exceptional. Many helping professionals whose clients are not primarily injecting drug users or street sex workers do not have up-to-date and scientific information on complex HIV/AIDS issue at their disposal. Information on the stigma and discrimination faced by people living with HIV/AIDS in the Czech Republic is absent.

The aim of this article is to understand stigmatization as a perceived social impact of life with HIV/AIDS from the perspective of people living with HIV/AIDS, and to briefly present and describe its causes and consequences as perceived by the communication partners (hereinafter CP).

## Foundations of the issue of stigmatization of people living with HIV/AIDS

Every disease has its biomedical and experiential dimension. The social constructionist approach to diseases considers HIV/AIDS to be a disease that stigmatizes its carriers with attributed social and cultural meanings. These meanings influence social impacts on a patient and health care, and on other helping professions [42]. The social constructionist and cultural meanings of diseases with stigmatizing potential represent one of the crucial lines of sociological research [43–47].

The most famous work is Goffman's [48], which defines stigmatization as a dynamic degradation process that discredits an individual in other people's eyes. In his publication, Goffman deals with the issue of "mixed contacts" – interpersonal interactions where the stigmatized and "the others" (members of the non-stigmatized population) find themselves in the same "social situation" defined as a mutual immediate physical presence, e.g. conversation or only co-existence in a non-specified environment. In situations where the stigmatized and "the others" attempt to talk together "both sides will necessarily be confronted with the causes and consequences of stigma" [48, p. 22–3].

According to Goffman, HIV/AIDS related stigma is a type of stigma that refers to "character defects perceived as weak will, dominant and unnatural passions, false and uncompromising beliefs and dishonesty" [48, p. 12]. These conclusions are derived from the list of high-risk population groups, i.e. people at highest risk of HIV transmission. These are mainly street sex workers and their customers, injecting drug users, and men having sex with men [30]. This implies that within individual cultures there are certain characteristics of individuals perceived and defined as inappropriate or disreputable.

HIV/AIDS related stigmatization is a process that ascribes negative characteristics to the virus carriers and to those population groups that are identified as the most vulnerable in terms of transmission. Stigmatization tends to develop and strengthen negative connotations by associating the infection with behaviour that is condemned by society. For the stigmatized, the result is a growing fear. Another typical feature of the stigmatization process is blaming a particular individual or a group who are different in order to distract attention from recognizing one's own risk or from facing the problem [21,49].

According to Goffman, stigma is always created and supported via language. "In common speech, we use specific stigmatizing terms like cripple, bastard, and imbecile as metaphors and symbols, usually without considering their original meanings" [48, p. 13]. In the case of HIV/AIDS, there are too many linguistic metaphors for death, guilt and punishment, war, crime, and difference, which create and promote stigmatization of people living with HIV/AIDS [49].

Such a narrative style of the epidemic ascribes certain characteristics to certain groups of people, which can result in discrimination. Perhaps the greatest tragedy is that the energy needed to create such a stigmatizing environment could be better used for the prevention of the virus infection. HIV/AIDS cannot only remain a problem of certain social groups that are formed around the disease. It requires more effective prevention, which, logically, requires a full understanding of

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