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STIGMATIZATION AND DISCRIMINATION OF PEOPLE LIVING WITH HIV IN THE CZECH REPUBLIC: A PILOT STUDY

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SUMMARY

Objectives: HIV positivity diagnosis is often accompanied by stigmatization and discrimination, even in developed societies. The aim of the study was to obtain current information on the quality of life of people living with HIV in the Czech Republic, to assess the level and perception of stigmatization and discrimination, and to identify existing problems of people living with HIV concerning health services, family and the public.

Methods: Data for the pilot study were collected by convenience sampling between 2021 and 2022. Respondents were recruited from residents of Czech nationality and foreigners living with HIV in the Czech Republic who participated in an ECDC online questionnaire study or attended a convalescent stay for people living with HIV. Likert scales were used to capture key opinions, attitudes and beliefs of respondents. Data were processed using descriptive analysis.

Results: The study involved 42 people living with HIV. A total of 77% of the respondents reported that they had learned to live with their HIV-positive status, but 21% admitted to having low self-esteem due to their status. A total of 81% of the respondents had disclosed their HIV-positive status to someone outside of the healthcare setting, however, 40% of the respondents found it difficult to do so. Assault or threats from a sexual partner were reported by 17% of the respondents. A total of 27% of the respondents admitted having been denied or suspended health care, 44% reported inappropriate comments from healthcare workers, and 32% of the respondents avoided visiting the healthcare facility. Alarmingly, 41% of the respondents had been refused dental care at some point in the past because of their HIV-positive status.

Conclusions: Although the study presents only limited findings due to the small number of respondents, it is clear that stigmatization and discrimination of people living with HIV exists in the Czech society. It brings the risk of loss of motivation and involvement of people living with HIV in working together with healthcare providers on their treatment. There is a clear need for a larger study to identify the causes of stigmatization and to find ways to prevent it.

Key words: stigmatization, discrimination, people living with HIV, quality of life, health care, ECDC questionnaire

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INTRODUCTION

The Human Immunodeficiency Virus (HIV), discovered in 1983, causes damage to the human immune system called the Acquired Immune Deficiency Syndrome (AIDS), which was first clinically diagnosed in 1981. The WHO estimates that by 2021, a total of 84.2 million (64.0–113.0) people worldwide were infected with HIV and 40.1 million (33.6–48.6) people died as result of this infection. In 2021, 38.4 million people were living with HIV infection, 1.5 million were newly infected, and 650,000 HIV/AIDS-related deaths occurred that year (1).

In the Czech Republic, HIV/AIDS prevalence has been monitored since 1985. The National Reference Laboratory for HIV/AIDS of the National Institute of Public Health recorded a total of 4,366 HIV infected persons as of 31 December 2022, of whom 824 had progressed to the AIDS stage. Of the HIV infected persons, 567 have died, 372 of them in the AIDS stage (2).

The number of newly diagnosed cases in the country has been increasing steadily since 2003 from a level of about 50 cases per year to a peak of 286 cases in 2016. After a decline in 2017–2018, the trend has stabilized. In 2020, however, with the COVID-19 pandemic there was an increase in the number of cases to 251 and then to 292 in 2022 due to migration caused by the war in Ukraine. In addition, in 2022, 586 HIV-positive refugees from Ukraine were newly registered in the Czech healthcare system, of whom 90.5% already knew they were HIV-positive and the vast majority were receiving antiretroviral treatment, and 9.5% were newly diagnosed as HIV-positive (2). The Czech Republic remains a country with a relatively low level of HIV infection within Europe and the world.

The diagnosis of HIV positivity is associated with a high psychological burden, both in the form of an acute stress response following the disclosure of HIV-positive status and during the later life of an HIV-infected person. The highly successful development of antiretroviral therapy has resulted in increased effectiveness, simplification of treatment regimens and a significant reduction in side effects. This has fundamentally changed in quality of life and increased life expectancy. Yet HIV infection brings constant fear and anxiety to the people living with HIV and their loved ones about how the body will respond to treatment, whether the clinical condition will deteriorate during the treatment and, although advanced society does not want to admit it, stigma and discrimination against these people. Moreover, HIV/AIDS infection remains incurable.

Incurable diseases have been always associated with stigma. Before the HIV epidemic, the social consequences of chronic infections affected, for example, those with tuberculosis, leprosy, plague, and syphilis. These diseases had long been untreatable and incurable and often resulting in the death of the sufferer relatively soon after diagnosis. The issue of stigma was addressed as early as in the 1960s by E. Goffman, who included homosexuals among the members of marginal groups on the fringes of society, i.e., alongside prostitutes, drug addicts and alcoholics (3). Goffman defined stigma as a strongly discrediting status that can take the form of physical ugliness, character defects, and stigmas of race, nation, and religion. Stigma in the context of chronic illness has its own specificities and conceptualization, according to the eminent British psychiatrist G. Thornicroft (4), who has worked on the issue of stigma and discrimination against people with mental health disorders, and includes three basic elements, namely ignorance (a problem of knowledge), prejudice (a problem of attitudes) and discrimination (a problem of action).

Link and Phelan (5) conceptualized the phenomenon of stigma as a social process involving four interrelated components: the identification of differences, attribution of negative attributes, distancing that results in loss of status, and the discrimination that can be seen as the end point of the stigmatization process.

In the case of sexually transmitted diseases, there is an additional negative aspect, namely the way in which individuals become infected. HIV/AIDS is classified as a stigmatizing disease both because of its incurability and because of the way in which it is transmitted, often through homosexual contact. Moreover, sexual intercourse with a person of the same sex is still difficult for a part of the public, lay people and medical professionals alike to accept, and individuals who practice these activities are stigmatized and often discriminated against, even in developed societies. A typical feature of the stigmatization process is the attribution of blame to a specific individual or group that is different, in order to distract from acknowledging one's own risk or confronting the problem (6).

The examples of uninformed stereotypes, myths and misconceptions associated with people living with HIV/AIDS include attitudes and beliefs that these individuals are responsible for their illness through their sexual behaviour and are therefore fully responsible for their HIV-positive status. Negative attitudes towards a stigmatized individual or group are related to emotions and attitudes that most often include rejection, disgust, hostility or anger, and are manifested in the relationship of the majority to the negatively labelled minority. It is this behaviour, based on ignorance and primarily negative attitudes, that usually leads to stigmatization and discrimination. There are also differences in the level of stigma by diagnosis, with HIV positivity and AIDS currently being among the most stigmatized of all chronic infectious diseases.

People with HIV are exposed to several forms of stigma, which are closely related. These include enacted, vicarious, perceived normative and internalized stigma (7). According to Chambers et al. (8), HIV-related stigma is a widespread phenomenon that manifests itself in many social settings including healthcare settings. Significant associations have been found between enacted stigma and perceived normative stigma, which affect health care utilization, treatment adherence, and the overall health and well-being of people living with HIV.

A number of meta-analyses have shown significant associations between HIV stigma and depression, adherence to antiretroviral therapy, and access to and use of health and social services (9). However, in order to combat stigma and discrimination, we need a better understanding of how prevalent they are and how they operate in the context of HIV (10).

While in the early 1990s the Czech Republic was one of the most tolerant countries towards non-heterosexuals (11), a sober look at the available data shows that currently the level of local stigmatization or discrimination against non-heterosexuality in the Czech Republic, compared to other European countries, is rather in the middle between progressive and liberal countries, such as the Scandinavian countries, and countries relatively "hostile to non-heterosexuals", such as Russia or Ukraine (12). More than a quarter (26%) of Czech respondents to the European Men Who Have Sex With Men Internet Survey (EMIS) in 2017 said they had been intimidated in the past year because of their sexuality, and almost a third reported experiencing verbal abuse (13).

Since there is very little current research on this topic in the Czech Republic it is necessary to know the views of people living with HIV on their discrimination in the current developed Czech society. The aim of the study was to obtain current information on the quality of life of people living with HIV in the Czech Republic, to assess the level and perception of stigmatization and discrimination and to identify existing problems of HIV-positive people with health services, family and the public.

MATERIALS AND METHODS

Between 2021 and 2022, the European Centre for Disease Prevention and Control (ECDC), in collaboration with partner organisations in each country, conducted an online survey to understand the stigma faced by people living with HIV in the European Union. In addition to assessing the quality of life of people living with HIV, the aim of the study was to gain more information about the existence and extent of stigma within the community of people living with HIV/AIDS, their position in society and, in particular, their potential problems when in contact with health services (14). The survey was developed in collaboration with three community-based organisations, namely the European AIDS Treatment Group (EATG), AIDS Action Europe and the UK National AIDS Trust. The ECDC survey was promoted online and through the websites and networks of the community partner organisations. A total of 3,272 respondents from 54 countries took part in the survey.

Convenience sampling was used to select the participants for the current study, as this is a closed, hard-to-reach social group. The ECDC survey provided 15 respondents from the Czech Republic. The survey questionnaire was then distributed by experts from the National Institute of Public Health in collaboration with the NGO Red Ribbon during a recovery stay for people living with HIV in 2022. On site, they collected another 27 completed questionnaires from participants of the stay who had been diagnosed HIV positive between 1990 and 2017. A total of 42 questionnaires formed the basis of a small-scale preliminary pilot study to assess levels of stigma and to validate research procedures to be used in the conducting of a larger study in accordance with the requirements of the National HIV/AIDS Programme for the period 2023–2027 (15).

Satisfaction was assessed using Life Satisfaction Scores (LSS) on a scale of 0–10, where 0 is "completely dissatisfied" and 10 is "completely satisfied". For the analysis purposes, a score between 0 and 3 is interpreted as "dissatisfied", a score between 4 and 6 as "moderately satisfied" and a score between 7 and 10 indicate "satisfied". Current health was rated on a five-point Likert scale from "very poor" to "very good". Feelings were rated on a five-point Likert scale from "strongly agree" to "strongly disagree". Questions about experiences of stigma were rated on a five-point Likert scale of "yes, within the last year", "yes, 2–3 years ago", "yes, 3–10 years ago", "yes, more than 10 years ago" and "no", with additional options of "don't know" and "no response".

The data were processed using Microsoft Excel 2016 and SPSS, version 24 (IBM Corp., Armonk, U.S.A.). The obtained data are presented as numbers and percentages; the differences between groups were tested with Fisher's exact test. Statistical tests were performed at the 0.05 level of significance.

RESULTS

Characteristics of Participants

A total of 42 questionnaires from respondents of Czech nationality or permanent residents of the Czech Republic were processed and analysed. In terms of age distribution, the age group of 41–50 years was the most represented in our sample of respondents. In terms of gender, the sample consisted of 40 males, 1 person did not indicate gender and 1 person indicated the category "female including trans women". In terms of sexual orientation, 37 respondents categorized themselves as gay/lesbian/homosexual (Table 1).

Table 1. *Distribution of participants by socio-demographic characteristics (N=42)*

	n (%)
Age (years)	
31–40	8 (19.0)
41–50	17 (40.5)
51–60	11 (26.2)
61–70	4 (9.5)
71–80	2 (4.8)
Gender	
Male (including trans men)	40 (95.2)
Female (including trans women)	1 (2.4)
Not specified	1 (2.4)
Sexual orientation	
Gay/lesbian/homosexual	37 (88.1)
Heterosexual	3 (7.1)
Bisexual	1 (2.4)
Men who have sex with men	1 (2.4)

Life Satisfaction Score and Current Health Status

When asked how satisfied they were with their lives according to the LSS, 71% of the participants were "satisfied". A total of 76% of the respondents rated their current health status as "very good" or "good" (Table 2). At the same time, the respondents were asked about the relationship between life satisfaction and their current health status, again using the LSS rating scale as a criterion. A high proportion (84%) of the respondents chose the rating "satisfied", but this is not consistent with the fact that 56% (23 people living with HIV) reported little interest or pleasure in what they had done in the last 2 weeks, and that 46% of all respondents (18 people) reported feelings of despondency, helplessness or even signs of depression in the last 2 weeks.

Perceptions of HIV Status

Respondents were also asked how being HIV positive had affected their lives. Only 12% of respondents strongly disagreed that they had learned to live with their HIV status. Low self-esteem due to their status as a person living with HIV was admitted by 21% of respondents and 17.5% felt ashamed of their status. However, the proportion of respondents who found it difficult or definitely difficult to tell others about their HIV positivity was higher at 40%, while 30% had no problem doing so. Nevertheless, 34 respondents in the sample (81%) had disclosed their HIV-positive status to someone outside the healthcare setting. Respondents were more likely to share their health status with friends (21 respondents, 62%), family (18 respondents, 53%), a partner (17 individuals, 50%) and the lowest number of respondents (8 individuals) disclosed their status to colleagues at work (24%). The remaining 8 individuals (19%) said they had not disclosed their HIV-positive status to anyone in their community (Fig. 1).

Experiences of Stigma from Family and Friends

When asked if they had ever been blackmailed by people in their neighbourhood, 80% of the respondents said they had never

Table 2. *Impact of COVID-19 on doctors working in COVID-19 units*

	n (%)
Life satisfaction	
Dissatisfied	4 (9.5)
Moderately satisfied	7 (16.7)
Satisfied	30 (71.4)
Current health status	
Very bad	1 (2.4)
Bad	7 (16.7)
Acceptable	2 (4.8)
Good	15 (35.7)
Very good	17 (40.5)
Little interest or pleasure in doing things*	
Yes	23 (56.1)
No	18 (43.9)
Feeling down, depressed or hopeless*	
Yes	18 (46.2)
No	21 (53.8)

*Missing data are not shown.

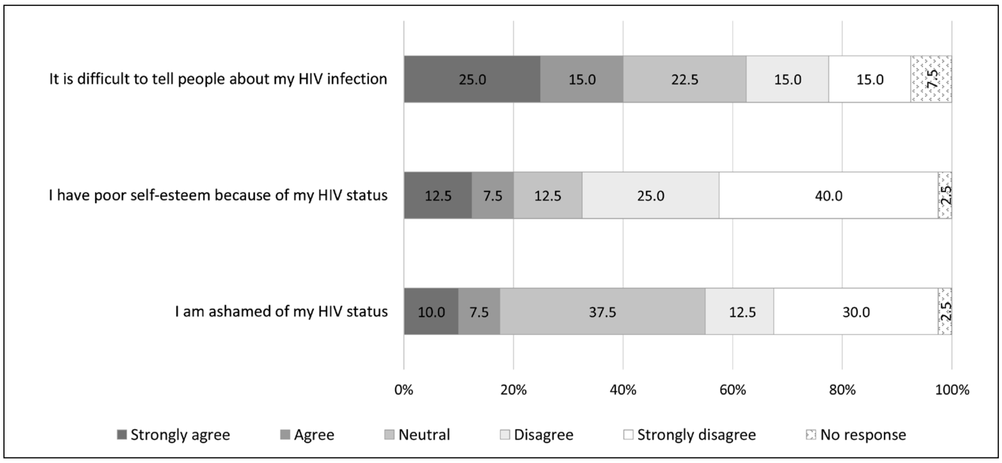

Fig. 1. *Feelings of respondents with HIV-positive status in percent.*

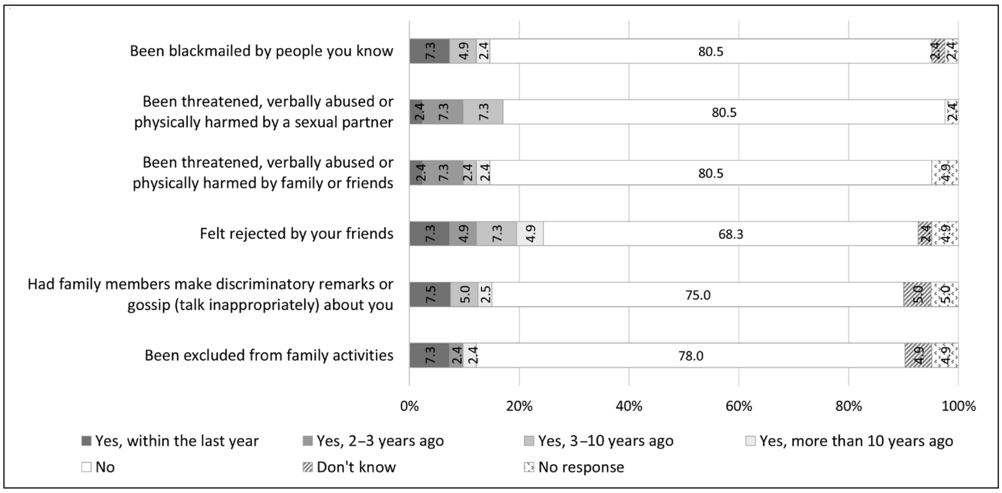

Fig. 2. *Experiences of stigma from family and friends in percent.*

been blackmailed, but 15% admitted to having been discriminated against in the past. Physical assault, verbal attacks or threats by a sexual partner were reported by 17% of the respondents. In response to questions mapping reactions and behaviour of family members or close friends, 15% of the respondents reported physical harm in the past, the same proportion reported inappropriate, discriminatory remarks about themselves, 12% were excluded from family activities, and rejection by friends was admitted by 24% of the respondents (Fig. 2). Those who reported having poor or very poor health were more likely to have been rejected by friends in the past than those who rated their health as neutral or positive (62.5% vs. 16.7%, $p = 0.019$). They were also more likely to be excluded from family activities (37.5% vs. 6.9%, $p = 0.057$), although the difference was not statistically significant.

Experiences of Stigma in Healthcare Setting

The study also mapped stigmatization of people living with HIV by health professionals. The fact that they had been tested in the past without consent was admitted by 5% of the respondents. Denial or delay in treatment due to HIV positivity at some point in the past was reported by 27% of the respondents, and a quarter of the respondents admitted subjective feeling that they had not been treated well, while 44% of the respondents said that they had overheard inappropriate comments made by healthcare workers about them. A relatively high number of the participants, namely 46%, said they were concerned about being treated differently from other patients by healthcare staff, and 32% avoided visiting a healthcare facility for this reason. A total of 41% of the respondents had experienced a concern of visiting a health facility in the past (Fig. 3).

Experiences of Stigma in Dental Care

Respondents were also asked about dental care in more detail. Fear of going to a dentist at some time in the past was admitted by more than half of all respondents, namely 54%. It is striking that almost a quarter of the respondents, 24%, had experienced such anxiety in recent past, within the last 3 years. A negative subjective feeling of being treated differently from other patients by a dentist was reported by 44% of the respondents, and 30% admitted the fact that fear of being treated differently from other patients was the reason for deliberately avoiding dental care. Crucially, 41% of the respondents had been refused dental care at some point in the past because of their HIV-positive status (Fig. 4). One respondent reported that "he had concealed his diagnosis from the dentist, thus eliminating the fear of being refused care".

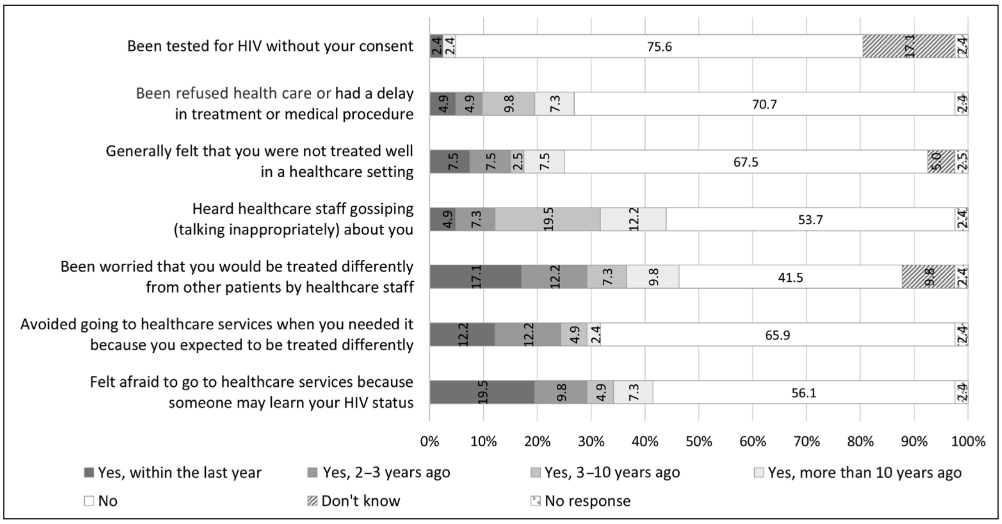

Fig. 3. *Experiences of stigma in the healthcare settings in percent.*

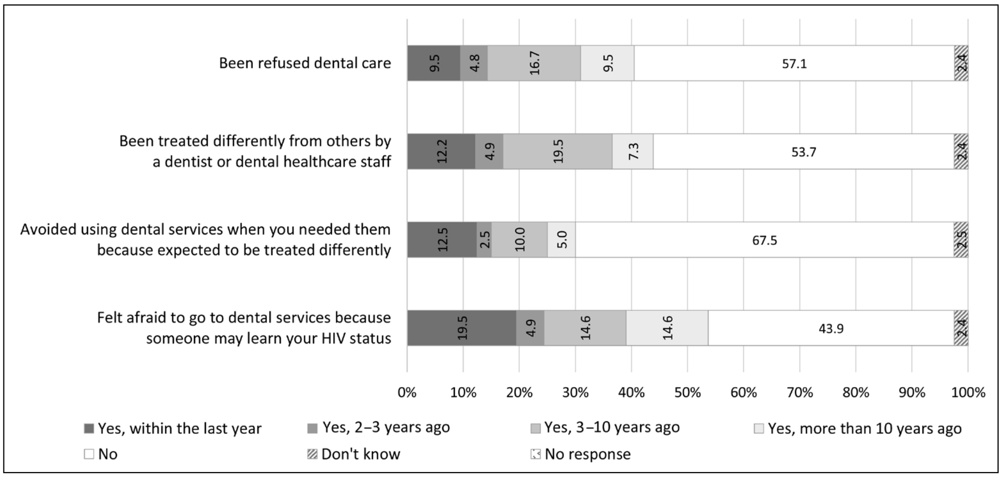

Fig. 4. *Experiences of stigma in the dental care in percent.*

Stigma at Work and in Public

Responses to questions about the area of legal norms relating to the status of people living with HIV also revealed important findings. Again, almost a quarter of the respondents, 24%, reported that in the past they had been concerned that they might be detained, accused or even charged with endangering their sexual partner, and 10% of the respondents had been blackmailed by a stranger at some point in the past because of their HIV-positive status. Furthermore, 5% of our respondents admitted to having been detained, and 5% had been arrested or taken to court in relation to their HIV-positive status (Fig. 5).

DISCUSSION

According to the UNAIDS, the essence of stigma is the tendency to associate the infection with types of behaviour that are condemned by society, resulting in the reinforcement of fear of those stigmatized (16). Noori et al. (14) report that in an ECDC study, people living with HIV who rated their health as “poor” or “very poor” were more than twice as likely to have been threatened or verbally or physically abused by their family or friends or excluded from family activities. Our results showed similar trends, but the differences were not statistically significant due to the small number of respondents.

Kalichman et al. (17) report that people living with HIV find it difficult to disclose their HIV-positive status to others, including potential sexual partners. However, this step is essential to eliminate the risk of further spread of HIV infection. Contrary to what these authors claimed in 2005, 81% of respondents in our sample disclosed their HIV-positive status to someone close to them, although 40% of the respondents admitted that they found it difficult to disclose their HIV status to others.

According to Nanni et al. (18), whether or not respondents disclosed their HIV-positive status to a loved one strongly influences their psychological state. Depression has long been considered a predictor of negative clinical outcomes in HIV-infected patients, such as decreased adherence to medication, decreased quality of life, worsened disease progression, and increased mortality. This assertion is consistent with our findings, as a total of 56% of the respondents in our cohort admitted to having little interest or pleasure in what they had done in the past 2 weeks, and a feeling of despondency, helplessness, or even signs of depression in the past 2 weeks were reported by 46% of all the respondents. The highest prevalence of feeling

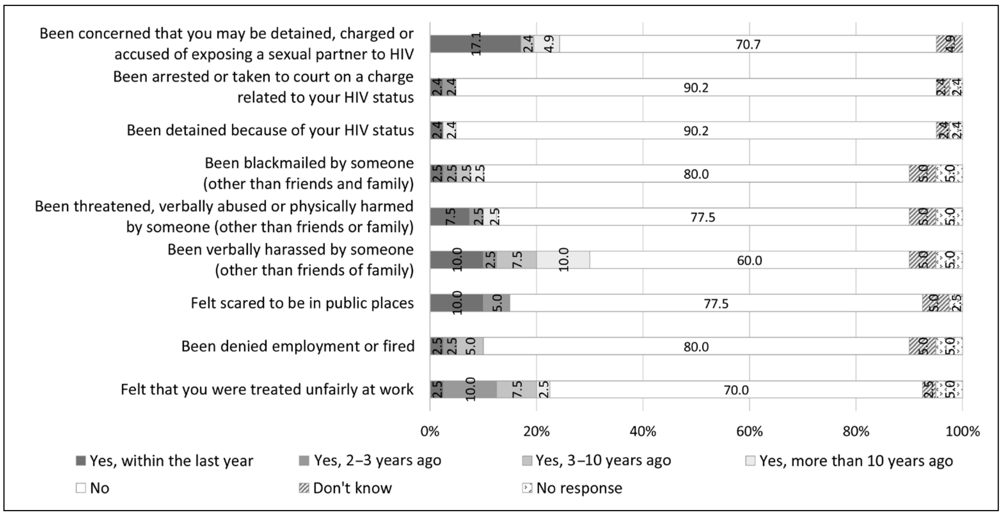

Fig. 5. *Experiences of stigma in the workplace, in public and in the justice system in percent.*

helpless, downhearted and depressed was reported by individuals who did not confide in anyone close to them about their condition.

Parker and Aggleton (6) noted that people facing overly stigmatizing environments seek to make themselves invisible to society, and identified key contexts in which HIV/AIDS-related stigma and discrimination are salient. These include the family and community, educational institutions, employers and workplaces, the healthcare system, travel and migration, and HIV/AIDS prevention and control programmes themselves. Contrary to the findings of Nanni et al. (18), Vanable et al. (19) report that stigma is more likely to be experienced by people who disclose their HIV status to a wide range of social contacts. A total of 15% of the respondents in our cohort reported physical assault by family members or close friends, and the same number reported inappropriate, discriminatory comments about themselves by these individuals. Because of their HIV-positive status, 12% of the respondents had been at some point excluded from family activities, although according to Shivairová et al. (20), social support, especially from family members, is a strong predictor of improved quality of life for people living with HIV. As early as in the 1990s, Chesney and Smith (21) published that individuals who suspected that they may have been infected with HIV delayed taking an HIV test because of fear of the consequences of such a finding.

In 2016, Bjelončíková and Gojová (22) published the results of 11 testimonies of people living with HIV/AIDS in the Czech Republic, which showed that the stigma associated with HIV/AIDS significantly affected their lives. The participants interpreted the consequences of stigma as secondary stigma affecting their family members and life partners which further resulted in the loss or difficulty in establishing social contacts, difficulty in accessing treatment and care, and in discrimination, self-stigmatization and (self-)isolation. The individual experience of living with HIV/AIDS is characterised by psychological and emotional suffering. Consistent with these findings, a total of 77% of the respondents in our cohort reported that they "strongly disagree" (54%) or "disagree" (23%) with the statement that they would learn to live with their HIV-positive status.

People living with HIV continue to experience stigma in the healthcare system because of their HIV status. Nöstlinger et al. (23) have published the results of an international study conducted in 14 European countries including the Czech Republic, showing that discrimination related to HIV-positive status by healthcare providers persists across Europe. Countries with the highest levels of discrimination against people with HIV in health care included Austria, Poland and Greece, and the most frequently reported discriminatory healthcare providers were internists (46%), dentists (39%), general practitioners (22%), gynaecologists (16%), and HIV specialists (10%).

This statement is entirely consistent with our results, as 27% of our respondents reported that they had been denied or delayed care because of their HIV-positive status at some point in the past, and 44% of the respondents reported overhearing inappropriate comments about them from healthcare workers. A significant proportion of the respondents, 46%, were concerned about being treated differently from other patients by healthcare staff, and 32% avoided visiting a healthcare facility for this reason. The fear of going to a health facility in the past was admitted by 41% of the respondents. Alarmingly, we found that 41% of the respondents had been refused dental care at some point in the past because of their HIV-positive status, and one respondent reported that he had resolved his fear of rejection by concealing his diagnosis from the dentist. According to Noori et al. (14), training and education of medical staff must be a priority, not only to raise awareness of stigmatization and discrimination against people living with HIV in healthcare settings, but also to combat the attitudes and prejudices that lead to stigma.

The International Labour Organization reports that in 50 countries only 50.5% of respondents said that people living with HIV should be able to work in direct contact with other people, and no difference was found between the views of men and women (24). In our cohort, 30% of respondents reported feeling unfairly treated at work at some time in the past. This can lead to social isolation, a deterioration in the patient's quality of life, as well as inducing feelings of guilt in the patient and those close to them. It can lead to impaired cooperation with doctors and other professionals and loss of self-involvement in the outcome of treatment (6).

Despite the limitations resulting from the small number of participants and the two different data collection procedures, the underlying tendencies of stigma and discrimination are clearly evident and the results provide a good basis for targeting further research on this issue. The most problematic area appears to be health care, where healthcare workers' attitudes and approaches to people living with HIV do not match current scientific knowledge about the limited ways of transmission and spread of the disease, and where unnecessary concerns about health care for people living with HIV persist (10), particularly in dental care in our cohort.

Ending the HIV/AIDS epidemic by 2030 will require addressing stigma more systematically than is currently the case, as existing global evidence shows that stigma is a barrier to achieving each of the 90-90-90 targets (25). Efforts should be made through inter-sectoral collaboration to ensure that all existing UNAIDS recommendations to combat stigma against people living with HIV in the country are adopted and implemented (26).

CONCLUSION

Although the pilot study provides limited findings due to the small number of respondents, it is clear that stigma against people living with HIV is present in the Czech society and should be given much more attention in the future than it has been so far. The stigma is based not only on the attitudes of the general public, but sometimes also on the attitudes of the professional community. The stigma of a chronic disease leads to discrimination in the form of limitations in employment.

In the future, the authors of the pilot study will try to work with all HIV centres in the Czech Republic to recruit as many respondents as possible for a study, the results of which will clearly prove or disprove stigmatization of people living with HIV/AIDS in contemporary Czech society, and will help in the search for ways to prevent stigmatization.

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Conflicts of Interest

None declared

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