#### **ABSTRACT**

of the doctoral dissertation for the degree of Doctor of Philosophy (PhD) in the specialty 6D 110200 - "Public Health" Iskakova Balnur "Measuring HIV-related stigma in healthcare settings"

## Relevance of the study

Stigma and discrimination are one of the biggest ongoing challenges faced by people living with HIV (PLHIV) worldwide. Irrational fears of HIV infection and negative attitudes towards PLHIV remain to be the constant obstacle in fighting the epidemic in spite of the scientific advances and attempts made over the prevention and treatment of HIV worldwide [1,2]. Stigma and discrimination not only contribute to the spread of the epidemic, but also negatively affect the lives of PLHIV, leading to social exclusion, stress and emotional strain, and denial of the right to social and economic resources [3].

Stigma and discrimination on the part of healthcare workers in medical organizations have a particularly negative impact on the health of PLHIV, their quality of life and their ability to conduct productive activities. HIV prevention, testing and treatment services put people's lives at risk. Discriminatory attitudes, non-consensual HIV testing, denial of care and treatment, and breaches of confidentiality have been reported among large numbers of health workers, with a detrimental impact on the lives of PLHIV [4-7]. Negative and judgmental attitudes demonstrated by the healthcare staff create barriers in HIV diagnostics and treatment. Those who experience HIV-related stigma in healthcare are less likely to go through diagnostic measures of HIV, to uptake treatment and comply with other preventative measures such as condom use, medication adherence and retention in care [6]. These measures are the essential steps of the HIV care continuum.

In order to contribute to the HIV response in any country, one of the most important actions is to conduct regular participatory training for all medical personnel aimed at increasing knowledge about HIV, standard precautions, as well as awareness of stigma and discrimination and their harmful consequences, as well as addressing wrong perceptions and underlying fears among health workers about HIV transmission. Efforts to reduce stigma in some countries have led to significant changes in the attitudes and practices of health care staff, as well as improvements in the quality of care for PLHIV and other key populations such as men who have sex with men (MSM), people drug users, transgender people and sex workers [8]. The WHO also testifies that "the most effective responses to the HIV epidemic are those that aim to prevent HIV-related stigma and discrimination and protect the human rights of people living with HIV and people at risk [5]. However, it has been shown that health care workers who received limited training on HIV-related stigma were more likely to exhibit stigmatizing behavior towards patients [8].

A stigma-free health care facility is a facility that treats PLHIV and other key populations with respect and compassion and provides high quality care. In stigma-free settings, employees can also protect themselves from workplace transmission of HIV by using the Standard Precautions, which WHO defines as a baseline of

infection control precautions for all patients. In a stigma-free facility, staff are also confident that they themselves can live with HIV and continue to work.

Patients' perspectives on the issue of HIV-related stigma have been well addressed in several studies, yet, evidence from the perspective of healthcare providers is limited. This problem is specific to Kazakhstan since limited numbers of reports and scientific literature are available on the topic and the available ones are based on quantitative measurements of HIV-related stigma among HIV positive patients. The earlier surveys conducted among people living with HIV (PLHIV) in Kazakhstan suggest that (Stigma Index-2015,2021) healthcare facilities are the most commonly reported settings of experienced stigma and discrimination and especially in healthcare centers that provide care to non-HIV related health conditions [9,10]. There is a need for obtaining more detailed data on this issue due to the fact that stigma itself is a complex phenomenon and addition of qualitative data about the opinions and behaviors of healthcare workers around PLHIV would be more valued for understating the sources of stigma. There is also a scarcity of the standardized and validated assessment tools of HIV-related stigma that are available in Kazakh and Russian languages. Therefore, we attempted to address these gaps of HIVrelated stigma research in the country by collecting quantitative and qualitative data from healthcare workers of all levels in Almaty.

It is also crucial to have standardized and validated HIV-related stigma assessment tools in Kazakh and Russian in order to obtain reliable data on the issue. Considering the above, in our work we have tried to fill the gaps in research on HIV-related stigma in the country by collecting quantitative and qualitative data from employees of medical organizations at the level of primary healthcare centers and the Center for AIDS Prevention and Control in Almaty.

#### Aim:

To assess the level of HIV-associated stigma and factors leading to stigma among medical workers of PHC organizations in Almaty based on mixed method research data using an adapted tool to the specific context of the HIV epidemic in the Republic of Kazakhstan.

# **Objectives:**

- 1. To re-validate an HIV-related stigma assessment tool in Kazakh and Russian languages based on focus group discussions and factor analysis
- 2. To investigate the level of stigma against people living with HIV (PLHIV) in primary healthcare centers (PHC) in Almaty.
- 3. To study the factors leading to stigmatization of PLHIV among PHC workers.
- 4. To study the opinions and beliefs of PHC workers about HIV, PLHIV and key populations.
- 5. To provide recommendations on how to reduce HIV-related stigma in healthcare settings.

#### Methods.

Sequential mixed method design was used to collect quantitative and qualitative data on HIV-related stigma and on its attributes. Before conducting surveys on the

main sample, the brief HIV-related assessment tool was validated in two study languages (Kazakh, Russian) and demonstrated good psychometric properties. For the main quantitative surveys healthcare workers of 8 polyclinics in Almaty were randomly chosen including clinical and non-clinical staff. Assessment of stigma was based on a 9-item questionnaire measuring negative opinions (NOs) towards PLHIV and the HIV key populations. Overall percentage of people holding NOs towards PLHIV was treated as an outcome variable and included in logistic regression models. Bivariate analysis was conducted on NOs towards PLHIV and years of work, fear of getting infected with HIV, receiving training on HIV-stigma and basic knowledge on HIV transmission. Statistically significant associations were then adjusted to social demographic data on multiple regression models. In-depth, semi-structured interviews included questions regarding opinions about PLHIV, HIV and its key populations. Content analysis method was used to explore the qualitative data.

**Study Object:** Healthcare workers (clinical and non-clinical staff) of primary healthcare settings in Almaty city.

**Study Subject:** Stigma related to HIV, as well as stigma and discrimination against People Living with HIV (PLWH) in medical organizations

#### **Provisions for defense**

- 1. A tool for assessing HIV-related stigma in medical organizations with good psychometric properties and evidence-based validity in Kazakh and Russian languages.
- 2. Results of assessing the level of HIV-associated stigma against people living with HIV (PLHIV) in PHC organizations in Almaty.
- 3. Results of the study of factors leading to the stigmatization of PLHIV among PHC workers.
- 4. Findings on studying the opinions and beliefs of PHC workers about HIV, PLHIV and key populations.
- 5. Recommendations for reducing HIV-related stigma in healthcare settings.

# Main study results

- **I.** Re-validation and adaptation of the HIV-related stigma tool to the Kazakhstani context. The instrument showed good psychometric properties (GFI -0.97, TLI 0.97, RMSEA-0.07, Cronbach's alphas factor 1:  $\alpha = 0.66$  Cronbach's alphas factor 2:  $\alpha = 0.85$ ) and is available in Kazakh and Russian for further assessment of HIV-associated stigma in healthcare facilities.
- II. The level of negative attitudes towards PLHIV studied among 448 employees of PHC organizations was high: 87 % (n=387) of the respondents agreed with at least one of the stigmatizing statements on the HIV-stigma scale; around 85% (n=286 out of 335 involved in medical procedures) of the respondents reported some level of fear of contracting HIV during work and almost half of the respondents reported using extra precautions while working with HIV positive patients (wearing

double gloves - 54.3% and avoidance of physical contact - 48.18%). Numbers of respondents indicating correctly all the body fluids that can transmit HIV were low (n=129, 30%).

III. Longer years of work in healthcare and experience of working with PLHIV reduced the level of negative attitudes towards PLHIV and key populations. Logistic regression models showed significant associations between: longer work experience and less chance of NOs against PLHIV (AOR = 0.33, 95% CI: 0.12, 0.84, p = 0.02), exposure to an HIV-positive patient during last 12 months and lower levels of Nos (AOR=0.34, 95% CI: 0.18, 0.62, p=0.001), while those who expressed a high fear of contracting HIV reported higher levels NOs about PLHIV (AOR=3.33, 95% CI=1.34;8.2, p=0.01). Knowledge of HIV transmission was associated with older age (Chi2=18.74, p<0.001), longer work experience in health care (Chi2=22.33, p<0.001), observation of an HIV-positive patient during the last year (Chi2=5.84, p=0.01) and with training in infection control and PEP (Chi2=7.90, p=0.004).

IV. A study of opinions about PLHIV and key populations among PHC workers showed their general negative attitude and reluctance to provide care to these patient populations if health workers had a choice. The qualitative data revealed the following: 1. Most respondents emphasized the need for more frequent education on HIV-related issues; 2. Respondents were also more likely to believe that HIV is spread mainly through "out of control sexual behavior" or from sex workers to men. 3. General negative attitudes towards key populations at high risk of HIV infection: describing sex workers as "disgusting" and that they would be "ashamed" of acquaintances who would do this; associated non-traditional sexual orientation with some kind of "disorder" and expressed their unwillingness to contact such individuals. On the other hand, respondents showed empathy for IDUs.

V. Our recommendations for reducing stigma in PHC are to apply internationally accepted interventions in different formats and on a regular basis. The scientific literature offers interventions to address HIV-related stigma and discrimination, as well as disseminating knowledge about HIV in a variety of formats such as group discussions, games, role-plays, and interactive modular training on stigma, infection control, and medical ethics. An integration of HIV care services (selective PHC) with primary health care organizations to provide comprehensive care in line with the WHO recommendation of "transitioning from disease-focused health systems and institutions to health systems designed for and with people is also promising, yet more research is needed to explore the impact of such integration on stigmatization of PLHIV.

### Scientific novelty

For the first time:

1. an assessment of HIV-related stigma among medical workers of PHC organizations in Almaty was carried out using a mixed method of research, including the analysis of quantitative and qualitative data.

- 2. a re-validated and well-structured tool for assessing stigma against PLHIV among healthcare workers, adapted to the specific context of the HIV epidemic in the Republic of Kazakhstan, is obtained.
- 3. the validity of the Kazakh and Russian versions of the HIV-related stigma assessment tool was proved based on the implementation of several validation and adaptation stages, including a pilot study, focus group discussions and the application of factor analysis.
- 4. a high level of negative attitudes towards PLHIV (83%), the fear of contracting HIV during medical procedures (85%), and the use of additional precautions when working with PLHIV (wearing double gloves 54.3% and avoidance of physical contact 48.18%) among medical workers of PHC organizations were detected.
- 5. it has been shown that longer years of work in healthcare and an experience of working with HIV positive patients reduces the level of negative attitudes towards PLHIV and key populations. Similar positive relationships were detected between training on infection control and on post exposure prophylaxis and better knowledge on HIV.
- 6. qualitative research was conducted among a group of healthcare workers in PHC organizations to study the more detailed opinions and beliefs about PLHIV and key populations, which showed their general negative attitude and unwillingness to provide care to key populations if a healthcare worker had a choice. This dictates the need to develop targeted multilateral interventions to address the stigmatization of PLHIV and the increasing prevalence of HIV infection in the Republic of Kazakhstan.

## The practical significance of the work

Adapted and validated tool for assessing the level of HIV-associated stigma among healthcare workers is reliable and can be recommended for use in other medical organizations and regions of the Republic of Kazakhstan to obtain data at the country level.

Conducted studies using quantitative and qualitative methods revealed a high level of HIV-associated stigma among health workers of PHC organizations, which can be an obstacle to accessing and receiving outpatient medical care for people living with HIV, thereby contributing to the spread of HIV infection.

The lower level of stigma among health care workers with more experience and better knowledge about HIV among those who had training on the aspects of HIV indicates the need for further comprehensive training on HIV, including topics such as modes of transmission, standard precautions, emergency first aid and HIV post-exposure prophylaxis, stigma and discrimination.

## **Implementation of research results**

1. Obtained a Certificate of state registration of rights to an object protected by copyright. "Certificate of inclusion in the state register of rights to objects protected by copyright." No. 35871, dated May 18, 2023.

- 2. The results of the study were introduced into the work of the City Polyclinic N8 in Astana. The Act of implementation of the results of the research work "Tool for assessing HIV-associated stigma" dated 19.05.2023 was issued.
- 3. A webinar on the topic: "Educational webinar for employees of the AIDS Centers of the Republic of Kazakhstan on vaccination against coronavirus infection and stigma associated with HIV / AIDS" at the Scientific Center for Dermatology and Infectious Diseases at the RSE on REM". 06/9/2023.

#### Personal contribution of the author.

All research and the results of the dissertation work were obtained by the doctoral student independently, which indicates her personal contribution to science in the field of Public Health. The reliability of the results formulated in the dissertation, the main provisions to be defended, the results and conclusions are fully confirmed by the results of the scientific literature review, surveys conducted among 448 employees of PHC organizations, in-depth interviews, and statistical analysis of data and their interpretations.

The study is an initiative of the New York State International HIV Education and Research Program, State University of New York, # D43TW010046

### Conclusion.

Overall, results of our study support other research that suggests high levels of negative opinions towards PLHIV among medical workers, particularly mid-level medical staff. Associations found between lower levels of negative opinions towards PLHIV and seeing an HIV positive patient may suggest the positive impact of potential integration of AIDS care into primary healthcare settings by increasing the contact between healthcare workers and PLHIV. Low levels of HIV knowledge among the mid-level medical staff should also be a priority for any interventions addressing HIV-related stigma and discrimination. We also acknowledge that there could have been changes over the past few years since the frequency of training has increased since 2019. In such a scenario, we recommend replication studies in primary healthcare centers to enable the comparison of changes over the years. Regarding HIV-related stigma and negative opinions, misconceptions and judgmental opinions found in this study, we think that the quality of the intervention including the type of intervention should be paid more attention to than the quantity of training conducted among medical staff.

## Approbation of work.

The main results of the dissertation work were tested by presenting research materials and publishing them in the materials of international scientific and practical conferences:

- 1.18th European AIDS conference. European AIDS Clinical Society. (EACS) October 27-30.2021. London, UK;
- 2. Interact on HIV research and practice (conference). EECA. 13.12 15.12.2022. Riga, Latvia;

- 3. 19th European AIDS Conference (EACS 2023), Warsaw, Poland invited as a panelist for a session on reducing HIV-associated stigma.
- 4. Asfen 1st International Forum. 5-6.06.2023. Almaty, Kazakhstan.

## Information about publications.

The results of the study are published in local and international peer-reviewed journals with an impact factor (Q1):

- 1. Iskakova B, Nugmanova Z, Murat Yucel R, Gamarel KE, King EJ. Revalidation and cultural adaptation of the brief, standardized assessment tool for measuring HIV-related stigma in healthcare settings in Almaty, Kazakhstan. Plos one. 2022 Nov 2;17(11):e0276770
- 2. Iskakova B, King EJ. Measuring HIV-related stigma in healthcare settings. Вестник Казахского Национального медицинского университета. 2019(1):563-5.
- 3. Iskakova B, Nugmanova Zh., King E. "It is usually the prostitutes who spread the disease on purpose so that they are not the only ones infected": attitudes and beliefs about HIV-positive patients in Almaty polyclinics. Mixed method study findings. Abstract booklet- EECAINTERACT,2023.

### The structure of the thesis

The work is presented on 138 pages, consists of an introduction, a review of scientific publications on the problem under study, methods, results, discussion, practical recommendations, a list of references and supplementary documents. The work is illustrated with 5 tables, 9 figures. The list of references contains 168 local and international sources.

### References

- 1. Van Der Kooij YL, Kupková A, Den Daas C, Van Den Berk GE, Kleene MJ, Jansen HS, Elsenburg LJ, Schenk LG, Verboon P, Brinkman K, Bos AE. Role of self-stigma in pathways from HIV-related stigma to quality of life among people living with HIV. AIDS Patient Care and STDs. 2021 Jun 1;35(6):231-8.
- 2. Nachega, J.B.; Morroni, C.; Zuniga, J.M. et al. HIV-related stigma, isolation, discrimination, and serostatus disclosure: A global survey of 2035 HIV-infected adults. J. Int. Assoc. Phys. AIDS Care, 2012, 11, 172–178;
- 3. Turan, J.M.; Nyblade, L. HIV-related stigma as a barrier to achievement of global PMTCT and maternal health goals: A review of the evidence. AIDS Behav., 2013, 17, 2528–2539)
- 4. *HIV basic knowledge and stigma reduction in health care settings* (no date) *World Health Organization*. Available at: http://www.emro.who.int/asd/asd-

- infocus/hiv-basic-knowledge-and-stigma-reduction-in-health-care-settings.html (Accessed: 19 May 2023).
- 5. Schuster, M.A.; Collins, R.; Cunningham, W.E. et al., Perceived discrimination in clinical care in a nationally representative sample of HIV-infected adults receiving health care. J. Gen. Intern. Med. 2005, 20, 807–813;
- 6. Stringer, K.L.; Turan, B.; McCormick, L.; et al., HIV-Related Stigma Among Healthcare Providers in the Deep South. AIDS Behav. 2016, 20, 115–125;
- 7. Alexandra Marshall, S.; Brewington, K.M.; Kathryn Allison, M.; et al., HIV-related stigma among healthcare providers: A systematic review. AIDS Care 2017, 29, 1337–1345)
- 8. Geter, A. R. Herron, and M.Y. Sutton. HIV-Related Stigma by Healthcare Providers in the United States: A Systematic Review. AIDS Patient Care and STDs, 2018, V.32, N10, pp. 418-424
- 9. CAAPL Central Asia Association of PLHIV [Internet]. [cited 2023Apr22]. Available from: https://caapl.org/wp-content/uploads/2020/11/kazakhstah\_stigma\_index\_report\_eng\_17\_05\_20.p df
- 10.STIGMA INDEX OF PEOPLE LIVING WITH HIV, 2.0. CAAPL- Central Asian Association of PLHIV; Available from: https://caapl.org/en/glavnaya-english/