

Psycho-social challenges faced by people living with HIV during COVID-19 in Kosovo: a qualitative study

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Abstract

Introduction: The aim of this study was to investigate psycho-social challenges faced by people living with human immunodeficiency virus (HIV) and acquired immunodeficiency syndrome (AIDS) (PLWHA) during COVID-19 in Kosovo. From September 2021 to January 2022, 47 HIV and AIDS patients were enrolled.

Material and methods: Face-to-face interviews were conducted to examine experiences of PLWHA during COVID-19. Thematic analysis was applied as a method for the analysis of interview transcripts using qualitative data analysis software NVivo 12.

Results: Psychological experiences of people living with HIV and AIDS during the COVID-19 pandemic were summarized into four main themes: (1) changes in mental health, (2) accessibility of essential health services during the pandemic, (3) non-disclosure of HIV status, and (4) socio-economic well-being of PLWHA during COVID-19.

Conclusions: Our findings suggest that COVID-19 has further exacerbated mental health issues among people living with HIV and AIDS. There is an urgent need to increase mental health provision for PLWHA. Also, the findings highlight an demanding need for action, particularly in four critical areas, such as to prioritize mental health, improve health and care services for PLWHA, address stigma, and increase socio-economic support.

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Key words: people living with HIV, psycho-social challenges, COVID-19, stigma, socio-economic well-being.

Introduction

Human immunodeficiency virus (HIV) is still an important global challenge. Although today, people living with HIV and acquired immunodeficiency syndrome (AIDS) live longer and healthier lives than fifteen or twenty years ago, they still face problems that make their lives more difficult [1]. Challenges, including stigma, discrimination, sexual relationships, disclosure of HIV status to family, friends, or sexual

partners, mental health issues, socio-economic issues as well as therapy decisions, all make people living with HIV/AIDS (PLWHA) leading hard lives, especially in developing countries, such as Kosovo. The COVID-19 pandemic has led to the interruption of health and other services for people living with HIV, especially women and children, who faced serious difficulties accessing these services. As a result, all this influenced the possibility of isolation, stress, anxiety, depression, and other related mental health issues.

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Review

After the first case of COVID-19 confirmed on March 13, 2020, the Kosovo Government enacted policies to reduce the spread of COVID-19, including closing schools and higher education institutions, limiting traveling, banning social gatherings, and requiring to wear face masks in public spaces. The Kosovo Ministry of Health (MOH) issued a provisional guide application of measures to prevent and combat COVID-19 in public and private institutions [2]. Many other guidelines were issued after the beginning of the pandemic; nonetheless, there was no guidance for facilities providing HIV care ensuring continuation of antiretroviral treatment (ART) while decreasing clinic visits frequency.

Immediately after introduction of the restrictive measures, community-based organizations, which offer care and support for people living with HIV in Kosovo, assisted the Government of Kosovo to ensure the continuation of HIV treatment, i.e., ART. Many challenges and obstacles were reported during this period among PLWHA. A report prepared by the Ombudsperson Institution of Kosovo emphasized violations regarding fulfilling constitutional and legal obligations towards people living with HIV in Kosovo. The report raised serious concerns about the non-functioning of the Centre for HIV Voluntary Counselling and Testing at the Infectious Diseases Clinic since March 2020. This situation caused failure to perform necessary tests and communication of written results for viral load and CD4 tests due to non-contact between the Infectious Diseases Clinic and HIV and AIDS patients during the pandemic [3].

Based on the existing data and the Joint United Nations Programme on HIV/AIDS (UNAIDS) classification system, Kosovo is categorized among low HIV/AIDS prevalence countries, with a prevalence of < 1% in the general population and < 5% in the key population at risk [4]. However, there is a lack of studies regarding psycho-social challenges of people living with HIV in Kosovo, especially during the COVID-19 pandemic. This research aimed to fill this gap by identifying and analyzing the main psycho-social challenges and difficulties of PLWHA in Kosovo during the pandemic.

Material and methods

Study design

This study adopted a qualitative research method that relies on inductive inquiry, starting with a worldview and ending with data analysis [5]. This approach provides the ability to gather in-depth information about the research topic and, at the same time, enables acquiring a full and rounded understanding of the main challenges faced by people living with HIV and AIDS during COVID-19.

Study setting

The study was conducted in Prishtina, the capital city of Kosovo. Access to people living with HIV and AIDS was obtained through the Kosovo Association for People Living

with HIV and AIDS (KAPHA), a specialized NGO operating in Kosovo that provides care and support for people living with HIV and AIDS, including children and adults.

Study participants and sampling

In this study, a total of 47 ($N = 47$) participants were interviewed. Among them, 42 ($n = 42$) were taking ART for more than 12 months, whereas 5 ($n = 5$) were on ART for less than 12 months. The study included 42 ($n = 42$) male participants and 5 ($n = 5$) females. The Table 1 presents the socio-demographic characteristics of participants in this research, including age, gender, sexual orientation, living area, marital status, education level, employment status, and duration of treatment.

Table 1. Socio-demographic characteristics of participants ($N = 47$)

Variables	<i>n</i>
Age	
18-29	9
30-39	21
≥ 40	17
Gender	
Male	42
Female	5
Sexual orientation	
Heterosexual	32
Lesbian/gay	8
Bisexual	7
Living area	
Urban	28
Rural	19
Marital status	
Unmarried	12
Married	31
Divorced	2
Widowed	2
Education level	
No formal schooling	1
Lower education	22
Higher education	24
Employment status	
Employed	27
Unemployed	20
Duration of treatment	
Taking ART > 12 month	42
Taking ART < 12 month	5

Study procedures

Between September 2021 and January 2022, face-to-face semi-structured interviews were conducted among 47 PLWHA in Kosovo. The interview lasted for 50-60 minutes per participant. Inclusion criteria were age between 18 and 65 years, diagnosed with HIV or AIDS for three months, and on life-long ART. The interview protocol was developed based on literature review findings for psycho-social challenges among people living with HIV. The participants were asked about four general topics: (1) mental health, (2) accessibility of essential health services during the COVID-19 pandemic, (3) non-disclosure of HIV status and stigma, and (4) socio-economic well-being of PLWHA during COVID-19. Each topic contained approximately 5-8 questions, followed by other sub-questions generated from interviews. The interview protocol was revised in an interactive process in response to early interviews. Although it remained substantially unchanged, the order of questions was revised and additional questions were added.

Data analysis

Thematic analysis was used as a method for analyzing interview transcripts, and documentation of PLWHA was examined as well. The analysis was focused on the development of codes that were based on the main objectives of this study. Moreover, these codes were developed from the overall data of qualitative analysis, which was derived from experiences of PLWHA. To understand if the themes were appropriate for the obtained data, the final stage was reviewed with processing codes and detailed analysis. Then, codes and

themes were organized in NVivo 12 software, and the results are represented in Table 2.

Ethical consideration

Informed permission for conducting each interview was obtained. All PLWHA included in the study were informed about its purpose before enrollment. Furthermore, individuals participated voluntarily and anonymously in the study. Confidentiality was guaranteed through data storage, and ensuring that all data would be used for this study only.

Results

Some of the main psychological experiences of PLWHA during COVID-19 were identified throughout the interviews. All these experiences were summarized into four main themes. First, the changes in mental health were mentioned by 43 participants. Second, the accessibility of essential health services during the pandemic was reported by 40 participants. Third, the non-disclosure of HIV status because of stigma was revealed by 38 participants. And fourth, the socio-economic well-being during COVID-19 was mentioned by 42 participants. Participants with a higher level of education declared the topic of mental health more often. In comparison, participants with a lower level of education mentioned the topic of non-disclosure of HIV status because of stigma.

Changes in mental health

Changes in mental health were a common theme identified throughout the qualitative analysis of PLWHA. Many

Table 2. Codes and themes derived from interviews with people living with HIV

Codes	Issues discussed	Themes
Anxiety	Sharing experiences about mental health during COVID-19	Changes in mental health
Stress		
Depression		
Obsessive thoughts		
Therapy	Sharing experiences about essential health services during COVID-19 ART therapy provision	Accessibility of essential health services during the pandemic
Non-adherence		
Lack of information		
Isolation	Sharing experiences about decisions to non-disclose HIV or AIDS status	Non-disclosure of HIV status because of stigma
Social judgment		
Sexual partner/ family member	Sharing experiences about stigma regarding HIV or AIDS status	HIV-related stigma
Shame		
Blame		
Calling names		
Poverty	Sharing experiences about challenges with socio-economic issues	Socio-economic well-being of PLWH during COVID-19
Unemployment		
Low education		
Poor nutrition		

answers indicated concerns about increased stress, anxiety, depression, lack of sleep, obsessive thoughts, etc. The following quotes illustrate these above: “I got very anxious from the beginning of pandemic” (HIV-positive 45 years old woman); “I overprotected myself and feared getting COVID-19 on top of HIV” (HIV-positive 38 years old man).

Parents with HIV-infected children were extremely concerned about their children. They reported that children exhibited more aggressive behaviors, especially during the period of isolation: “I was concerned for my children, they both live with HIV and due to isolation, they showed aggressive behaviors. COVID-19 had an extremely bad effect on our mental health” (HIV-positive 40 years old women).

Accessibility of essential health services during the COVID-19 pandemic

Providing antiretroviral therapy for PLWHA was one of the main challenges they often faced in Kosovo. Many participants were worried about running out of HIV medicines during the pandemic. Some of them reported that there had not been sufficient support available for PLWHA during COVID-19. There stated difficulties while trying to access treatment, and responsible health institutions (Infection Disease Clinic is the only institution that deals with HIV patients in Kosovo) were focused on COVID-19 services. PLWHA mainly were supported by the Kosovo Association for People Living with HIV, the only NGO that works with people living with HIV in Kosovo. From the beginning of the pandemic, it delivered medications and provided care and support.

Some of the participants were unable to provide sufficient and accurate information on how to protect themselves from being infected by COVID-19 due to the lack of access to necessary technology and not knowing how to use the Internet services: “I don’t know how to use technology... I had very limited information during the pandemic and I was concerned about my physical and mental health” (HIV-positive 60 years old women).

Another obstacle identified was the lack of communication during the pandemic and accurate information about ART. Moreover, lack of adherence to highly active antiretroviral therapy remains a crucial challenge in successful management of people living with HIV and AIDS. Some of the participants emphasized that during the lockdown, there was poor quality of information provided to all patients. The following quotes illustrate the above: “Because of changes in doctors’ routine work due to the pandemic, distribution of information to patients has not been so good. Nobody from healthcare institutions discussed with me or provided information on ART for more than six months” (HIV-positive 55 years old man).

Non-disclosure of HIV status because of stigma

Disclosure of HIV diagnosis is undoubtedly one of the main challenges faced by PLWHA in Kosovo. HIV partici-

pants declared that decision to disclose their HIV status changes over time, encompassing a process starting with non-disclosure and sometimes even ending in forced disclosure. Some HIV participants declared that they did not want to disclose their HIV status due to fear of stigma and discrimination. Because of the traumatic nature of such experiences, some patients have ended up not adhering to their medications: “It was tough for me to disclose my HIV status, but I was forced to disclose my HIV status” (HIV-positive 22 years old gay man). Another participant declared: “I don’t want to disclose my HIV status to anyone and just want it to be my secret” (HIV-positive 26 years old gay man).

Several HIV participants during the interviews mentioned self-disclosure as a critical issue: “I have disclosed my HIV status to my wife and children. This happened during the lockdown. Luckily, they were very supportive to me” (HIV-positive 46 years old man). On the other hand, sharing information with wife, husband, or sexual partner is very important for health protection and HIV prevention. Some participants declared that usually, sexual partners are the first people they inform about their HIV status: “It has been my wife, who first got to know about my HIV status” (HIV-positive 55 years old man).

Several participants experienced difficulties explaining their illnesses properly to their doctors because of a lack of confidentiality: “Very often, we were accommodated in the same room with other persons. Most of the time there were two patients in the same room. It was complicated to explain properly about the illness, especially when there was a stranger. This worsened especially during the COVID-19 pandemic” (HIV-positive 33 years old man).

Stigma accompanied by discrimination is still prevalent in Kosovo, and is considered a serious concern of people living with HIV. All HIV participants declared that stigma towards them was one of the biggest issues they experience daily. A 60 years old widow said, “The problem that I’m facing as a person living with HIV is a huge stigma. If you say, ‘I am HIV-positive and widow’, people are going to blame you”. Another participant shared his experience: “To me, stigma still exists a lot and it will never go away” (HIV-positive 43 years old man). Stigma among HIV-infected gay men is still high in Kosovo population, and was also apparent among HIV participants in this study: “Because of my sexuality and my HIV status, I’m more stigmatized by society” (HIV-positive 22 years old gay man). In addition, people tended to distance themselves from the disease, did not want to talk openly about HIV in the community, which fostered a stigma: “I don’t want that my community (a gay community) to understand that I have HIV” (HIV-positive 24 years old gay man).

Some HIV participants indicated that they have reduced their contact with family members and friends, and avoided social contact to talk about their HIV status. Also, HIV participants mentioned that they avoid social contact or events because they do not want to be confronted with stigmatizing reactions by other people: “I avoid contact with other people, sometimes even with my family members. I don’t want to talk about my HIV status” (HIV-positive 22 years old man).

Furthermore, gender plays a substantial role in experiencing stigma, which was evident among participants in the study. Female participants declared that HIV status had been an obstacle even in other activities due to stigma from others: “HIV status had affected many aspects of my life” (HIV-positive 37 years old woman); “Because I’m a woman and a widow, I was more prejudiced by family and society” (HIV-positive 50 years old woman).

Socio-economic well-being of people living with HIV during COVID-19

Socio-economic circumstances are undoubtedly one of the main challenges faced by PLWHA in Kosovo. Unemployment rate, which is one of the highest in Europe [6], creates difficulties even for people who are not infected. As expected, problems and challenges of people living with HIV can be numerous. PLWHA considered their HIV and AIDS status as secondary to daily life stressors, including poverty, unemployment, and problems with constant provision of antiretroviral therapy (ART). The following quotes illustrate the above: “HIV is secondary to me... the core of my problem starts at a socio-economic level” (HIV-positive 50 years old women). Another HIV-positive person shared his experience: “Socio-economic factors make more difficult my life with HIV” (HIV-positive 33 years old man).

COVID-19 has further exacerbated the socio-economic circumstances of PLWHA in Kosovo: “I was worried about money since the start of the pandemic” (HIV-positive 55 years old man). Another participant shared her experience: “Since I’m a widow, I need to take care of my family. COVID-19 has made mine and daughters’ lives more difficult” (HIV-positive 50 years old woman).

Discussion

This study identified important gaps between the needs of PLWHA and the available services during the COVID-19 pandemic in Kosovo. PLWHA reported several psychosocial challenges and difficulties, especially during the lockdown. Mental health issues are present among PLWHA, and they are reported to worsen because of COVID-19. Almost all participants in the current study mentioned the growing need to support their mental health during the COVID-19 pandemic, because they struggled with increased fear of infecting COVID-19, stress, anxiety, depression, lack of sleep, and obsessive thoughts. The findings of our study are supported by Pantelic *et al.* (2021), who reported that most PLWHA declared having difficulty with mental health during the COVID-19 pandemic. In addition, several other studies showed a high level of anxiety among people living with HIV during COVID-19. A study conducted in Turkey revealed that one-fourth of people living with HIV experienced anxiety during the COVID-19 pandemic. According to the same study, having a pre-existing psychiatric disorder, perceiving that they were practicing insufficient preventive

measures, not being sure about the presence of any individuals with COVID-19 in their environment, and living with a household member with a chronic disease, were all found by PLWHA to be the risk factors for experiencing anxiety during the pandemic [7].

Accessing essential health services and information on how to care for themselves during the COVID-19 period as well as providing antiretroviral treatment, are the main challenges PLWHA face very often in Kosovo. Many participants worried about running out of antiretroviral treatment during the pandemic. Some of them reported insufficient support available for PLWHA during COVID-19. As a result, there was a failure to perform tests and communication of written results for viral load (VL) and CD4 tests [3], which linked to non-contact between the Infectious Diseases Clinic and HIV and AIDS patients during the pandemic. Participants also reported difficulties accessing treatment in other healthcare institutions around Kosovo. The same challenges have been reported in most countries of the world. COVID-19 has been claimed to cause up to 75% of HIV services to be disrupted in several countries [8, 9]. Treatment adherence depends on a good understanding of the illness, developing proper relationships with services provided, and maintaining a network of social support [10].

Another challenge that participants highlighted was non-disclosure of HIV status because of stigma and discrimination. Usually, they felt unable to face the distress of social judgment by others. Thus, they often refuse to disclose their HIV status, even to their sexual partners or family members. Because of the traumatic nature of such experiences, some patients have not been adhering to ART. Our findings are supported by Kumarasamy *et al.* (2005), who showed that most patients declared that they did not disclose their HIV status due to fear of being victimized, rejected, or accused of infidelity [11]. The same results are reported by Thi *et al.* (2008), who showed that PLWHA avoid social contact with family, friends, healthcare system, and public services due to fear of stigmatization and discrimination. These lead directly to low self-esteem and self-isolation [12].

Stigma among HIV-infected gay men is still high in Kosovo society [13], an obvious fact disclosed by HIV participants in this study. The same results are reported by Smit, Brady, Carter, Fernandes, Lamore, Meulbroek, and Thompson (2012), where gay men may confront multiple layers of stigmatization and discrimination based on their sexuality, behavior, and their HIV status from other HIV-negative and HIV-positive gay men. The consequences of HIV-related stigma can be personal and community-wide, including impacts on mood and emotional well-being, prevention, testing behavior, and mental and general health [14].

Another challenge that participants highlighted was socio-economic status. The high unemployment rate can cause living difficulties even for people who are not infected. Understandably, difficulties and challenges for HIV-infected individuals can be numerous. In the current study, PLWHA considered their HIV or AIDS status as secondary to daily life stressors, such as poverty, unemployment, and problems

with constant provision of antiretroviral therapy (ART). The findings of our study are supported by Pantelic *et al.* (2021), who showed that most PLWHA declared they were worried about economic instability, which can cause problems in meeting their needs concerning HIV diagnosis [15]. In addition, a comparative study conducted in 5 countries (France, Mexico, Brazil, Taiwan, and Russia) showed that people living with HIV faced financial difficulties during COVID-19. As a result, the ability to perform daily tasks and obligations became very difficult, making their lives much more complicated [16].

Conclusions

The present study briefly describes the psycho-social challenges faced by PLWHA during COVID-19 in Kosovo. Our findings pointed out that COVID-19 has further exacerbated mental health issues among people living with HIV and AIDS. There is an urgent need to increase mental health provisions for PLWHA. Psycho-social counselling will help to overcome problems they encounter, and important challenges will also be resolved. In addition, it is crucial to improve government policies to provide better care and support for people living with HIV and AIDS in Kosovo. The current study highlights the ongoing role of HIV and AIDS-related stigma in HIV community, and the impact of the stigma on decisions to disclose HIV status. These findings confirm the need for disclosure issues to be an essential component of a risk reduction intervention for PLWHA in Kosovo. In addition, the social context of factors, such as poverty, contributes to infection and re-infection among PLWHA and their partners. On the other hand, socio-economic circumstances seem to be one of the biggest challenges for people living with HIV in Kosovo. Since many PLWHA live with their families, there should be adequate programs to support them and their families in economic and social aspects.

Limitations

These findings are the first to be reported among PLWHA in Kosovo during the COVID-19 pandemic. However, the study has some limitations, which are suggested to be avoided by researchers in the future. First, the sample of study was not very large. Second, only people who received health and psycho-social services at the Kosovo Association for People Living with HIV and AIDS were included in the study. There are other people living with HIV in Kosovo to whom we did not have the access. Future studies should increase the sample size in order to achieve a clearer picture of the challenges and psychological problems faced by PLWHA in Kosovo.

Disclosure

The author declares no conflict of interest.

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