

Effects of stigma and discrimination upon people living with HIV/AIDS

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Abstract

This article explores the phenomenon of stigma and discrimination and their impact among people living with HIV/AIDS (hereafter, PLWHA). Furthermore, this article describes the stigma and discrimination experiences in workplaces, family, community, healthcare environments and the impact of media. Secondary data analysis, semi-structured interviews and content analyses of individual/personal diaries of PLWHA are used as research methods to explore the research questions. Participants of the study (PLWHA and service providers) have been identified at the Ambulatory Care Center in Infectious Disease Service at University Hospital Center of Tirana (UHCT), Albania.

Data analysis shows high levels of stigma experienced by PLWHA. Stigma related to HIV brings different obstacles and difficulties to PLWHA, which makes them giving up on services for PLHA. There were no cases reported on direct stigma in the workplace, but PLWHA are more than convinced that they would be stigmatised and discharged from their work, if people will come to know that they are infected. Stigma and discrimination expressed by healthcare personnel is more evident in healthcare centers of different cities of Albania where information about PLWHA is missing.

Keywords: discrimination, HIV, AIDS, PLWHA, stigma.

Introduction

Worldwide, stigma related to HIV/AIDS has impacted negatively upon the access to adequate healthcare and social support to PLWHA; as a result, they experience low levels of emotional welfare compared to population in general (1). Stigma and discrimination related to HIV/AIDS is widely known as an obstacle in having access to appropriate healthcare services, to have the right social and psychological support and appropriate medical treatment (2). Evidence suggests that rights limitations can increase the spread of the epidemic and aggravate the impact of HIV on individuals and communities around the world (3). Though the number of HIV/AIDS cases in Albania is reportedly low, the prevalence of HIV/AIDS shows a ten-fold increase from 1996 to 2002 with 87% of the cases derived from heterosexual contact (4).

Stigma impacts upon the life of individuals infected with HIV and their partners, families and children. Often, stigma related to HIV has a bigger impact on PLWHA than the infection itself. Stigma and discrimination lead to identity crisis, isolation, solitude, low self-esteem and lack of interest in treating AIDS (5). At a community level, fear from stigma and discrimination might lead pregnant women to avoid counselling and testing for HIV which, when conducted in the first phases, helps reducing the opportunity of transmitting HIV virus from the mother to her child (6). Even family members, who are identified as supporters to infected family members, suffer from stigma and discrimination (7). Families are considered as the initial context of care, as the social group most affected by illness, as determinants of health and illness and as allies in the treatment process (8).

Methods

Methods used in this study include secondary data analysis and use of qualitative methods of data collection, including semi-structured interviews with PLWHA, and diaries kept by PLWHA. Qualitative research tends to explore and explain the world

through the experiences of social actors (9) and to give light to some data which are not easy accessible by quantitative research.

Subjects included in this study were PLWHA and key people who offer services for these people. People Living with HIV/AIDS were recruited from the Ambulatory Center, close to the Hospital for Infectious Diseases in Tirana. This study included a sample of 31 PLWHA, with whom there were conducted semi structured interviews. Furthermore, 20 semi-structured interviews were conducted with people offering services for PLWHA and 4 additional PLWHA accepted to keep a diary. The questions were constructed based on these orientations. The questions were further developed in consultation with professionals and the interview guide was then built. The questions of individual interviews made with PLHA were divided into several sections, namely into: (i) attitudes, experiences of PLHA; (ii) models and main forms of PLHA support; (iii) PLHA perceptions of stigma and discrimination and their effect on these people's rights.

Results

Stigma and discrimination of PLWHA

Men and women who live with HIV/AIDS often experience high levels of stigma and prejudice as a result of their status of having HIV. Stigma related to HIV/AIDS is very complex, dynamic and deeply rooted in the society. It is related to inequalities that exist in the Albanian society and more often in those societies holding a negative point of view regarding expression of sexual orientation. Stigma related to HIV creates obstacles and difficulties for PLWHA, which makes them give up on services designed for them and reduce their contacts with the surrounding world. Stigma related to HIV is not only related to physical fear, but also with moral and social fear.

At each individual interview, fear from stigma and discrimination shows high levels. In most cases, people try to avoid stigma by hiding their positive HIV status from people they think will stigmatise them.

"I need to speak. My relatives come, but I can't tell because they don't get close. I want them to leave as soon as possible. I feel like from time to time they will learn about my disease. When other relatives call and say they will come and visit, I ask them not to come because I am fine. I don't want anyone to come here. If something is serious people will spread the information and then everyone will know. Stress is bad. Here we don't have the right mentality. You don't have with whom to talk. They will leave. I have seen it on television. They didn't accept children at school." (Tirana, 11, man, 26 years old).

"I don't feel judged upon, because I haven't told anyone about the kind of disease I have, because if I do so they will leave. The only thing that scares me to death is the disease I have." (Tirana, 22, woman, 20 years old).

Fear from stigma is huge. There are persons who, when entering the Ambulatory Center, attempt to change their outside appearance completely by holding dark glasses. They fear a lot that others will understand why they frequent this center, because they know that this center is only for people living with HIV/AIDS. Some of them even control the street in front of hospital entrance because they fear that they will come across someone they know and if this is the case, they want to be able to change direction at the right moment. Fear from stigma sometimes makes them lie about their illness, when their relatives or friends suspect and ask about their health conditions.

"I fear coming here to take medicines because others might see me. People can understand for what you come here, because this place is only for ill people like us. I don't want my bride to fetch the medicines for me, despite she tells me that she can do that for me; but I fear people will see her." Before he leaves the room, he wants the doctor to check if there are people outside and he then leaves running. The nurse who brings the medicine,

opened the door of the room we were holding the interview, and he hides because he fears of other people who might be with her. He says that he never has stayed for so long. He arrives and leaves quickly (spending just five minutes to take the medicine). (Tirana, 16, man, 35 years old).

"Today, I was at the hospital for a visit. It has been a while since I don't go so frequently. I got upset because there were people and I had to wait for too long. I feared someone would pass there and they would see me. Every time I go to the hospital my feet shake, I feel emotions, I remember every single situation in the beginning of my illness. Hospital staff looked at us like we were an UFO." (Tirana, Diary 1, female, 34 years old).

The fear that even the family can be stigmatised because of their HIV/AIDS status is high. Isolation and withdrawal happens to protect the family from stigma and discrimination that relatives, society and the community might express.

"Mentality. Little information, they won't understand me. I don't want to create problems for my family; I don't want to psychologically weigh on relatives, because I bear the burden and I will suffer it. Stigma and the abandonment of others would be a problem for the family, because the repression in society is hard and difficult to go through. If my nephews would learn it from others, they wouldn't come anymore to visit me, because they are little and wouldn't understand the situation." (Tirana, 25, man, 47 years old).

PLWHA express that they would refuse even the healthcare services and other services because of fear of stigma and discrimination. This is one way that PLWHA choose to face it at the first moments of diagnosis, and express difficulties in looking/asking for help, because they are not yet used with the idea of being infected. The progression of the

infection and various other concerns that might show up later makes them gradually start taking concrete steps to seek help, especially in health institutions.

“Removal, seclusion is terrible. I wouldn’t come to take medicines, I would have had mental disorders.” (Librazhd, 2, man, 47 years old).

Stigmatisation in the workplace

Stigmatisation and discrimination in the workplace is one of the greatest violations of human rights, because of individuals being deprived from the opportunity to secure incomes for a safe living and to cover social needs, which increase even as a result of their infection.

There are no cases reported as directly related to stigmatisation in the workplace, because of the fact that employed PLWHA have chosen not to reveal their positive HIV/AIDS status; but, they feel sure that they would be stigmatised and get fired from their employer.

“I am not employed, but I am sure that if I would have a job and others would know about me, it is clear enough that they would expulse me because of my disease. Even the economic help I get, KEMP, only I know how hard it is; only because of my bad situation I go there.” (Elbasan, 1, man, 39 years old).

“I don’t fear, because I haven’t told anyone. The day before yesterday I cried at work, because I still felt bad about what happened to me. Friends saw me and held me close. They don’t know what I have, but they think that I cry for my ill mother (she is paralyzed).” (Tirana, 30, man, 45 years old).

Stigmatisation from healthcare personnel

Stigmatisation and discrimination expressed by healthcare personnel is more evident in medical centers of different cities in Albania, where the information and ability levels of working with PLWHA are limited.

The majority of PLWHA interviewed express that

they would not prefer taking healthcare services at the local level because they fear stigmatisation and confidentiality breaching. Even if they were to benefit from services at the local level, they state that they would hide their sero-positive status because of stigmatisation, prejudice and refusal of services.

“I have health problems in the womb and I went to Elbasan. My dad said that we had to tell the doctor of my problems so he could take protective measures. I was scared but he was insisting. As soon as my dad talked to the doctor, he went out and said in front of the nurses: ‘I won’t treat her because she is infected with AIDS’. I started to insult him and in that moment I was ready to go and put my hands in his throat, but my dad didn’t allow me. I started to shake and then we left. After that, the doctor met my father and told him that I should come back two weeks later, but I didn’t want to go to the same doctor.” (Elbasan, 24, woman, 40 years old).

Stigmatisation in the family context

Stigma related to AIDS is present even in the family environment. For the interviewed individuals this was very hard and is something that is continuous and creates tensions and problems in family relationships. Some of these stigmatisation experiences make them feel excluded from others, or make them start imposing self-isolation to avoid tensioned situations. The history of living with AIDS often turns into a family secret, where everyone knows but refuses to discuss it.

Fear of stigmatisation from family members is a hard experience for individuals, because they are perceived as the possible environment/setting to offer support and safety. This is a disturbing situation, given that it eliminates the opportunity of family members being a potential source of support to treat the consequences of living with HIV/AIDS and to take care of the physical and mental health of PLWHA.

“My dad doesn’t know that I have AIDS,

because I don't speak with him. He only knows that I'm taking some medicines and doesn't ask too much. My brother is very objective because of his ignorance. He stays away from me and doesn't talk either. I stay alone at my room, and they even bring me the food there. My family doesn't accept my infection. They don't accept my infection, my opinion." (Vlorë, 6, man, 35 years old).

"Our relatives ask when our son will end up his cure, since he is taking medicines frequently. And we tell them that he is taking medicines to treat spleen enlargement. Think about what if they would know that we are taking medicines too, terrible. My son now is 5 years old, and he says: 'The doctor has said don't take anymore medicines', because he doesn't want to take them anymore. One day he took mine and his own medicine and threw them into water". (Rubik, 9, man, 32 years old).

Despite the fact that family members have accepted their sero-positive status, they still show signs of disapproval, acting in stigmatised manners which are hard to be accepted by PLWHA.

"My uncles know it, but I think even the neighbours know. My uncle doesn't come to our house; even when he comes he doesn't accept to take coffee. Sometimes my mother gets mad and tells about HIV in front of him. This is the hardest thing. I feel horrible and ashamed. It would have been better if she didn't know." (Kavajë, 17, man, 41 years old).

Stigma in couple relations

Subjects of the study have reported that they are feeling stigmatised even in couple relationships. In all reported cases below, males have felt rejected, as they are the only ones infected, while their partners are sero-negative. Despite their efforts to save their marriage, the fact that they are not

infected makes them be more distant and protective about their health and protective towards other family members. In some cases the partners tend to be careful, because they would feel guilty if their partner will get infected after they have discovered their status.

"My wife gets upset when she is reminded of my infection. Sometimes I get upset and even cry, on the other hand it's a shame. She often says to me 'shove off!'. She takes care of me, but sometimes complains that I had to be her burden. In the beginning she went away with our children, and after 2-3 months they came back again." (Tirana, 18, man, 48 years old).

"... tranquillity, marital life. We are not the same; even when we are together, we are distant to each-other. We don't go out, I feel like everyone will know and understand that I am infected." (Tirana, 16, man, 35 years old).

Stigmatisation in society and community context

Society and community stigmatisation is perceived as very harsh from interviewed individuals, only imagined in most of the cases, who relate it to the attitude that society holds regarding other behaviours who are considered deviant, not acceptable. It is a high belief in every individual interviewed that they would be stigmatised and discriminated in their community, if the community members would learn about their infection. This leads to withdrawal and isolation from society, and lack of capability to face the situations that can help in showing up their status.

"Friends and companions don't know. If they would know, I wouldn't go out of home. In the place where I live, neighbours have respect and if others would say that I have this infection, they wouldn't believe it. It would be terrible if they learn about my infection." (Tirana, 16, man, 35 years old).

“One of my friends meets me every day and we take a cup of coffee together. She said to me that she has a gypsy neighbour who was ill and said: ‘oh God...I think she is suspected to have AIDS’, and continued to say: ‘and she is near me and I don’t want this.’ ‘No,’ I told to her, ‘it’s okay. Even she might be infected, she can’t transmit it to you.’ She replayed ‘Noooo, I can’t live near her’, because their houses were close. Imagine if she knows about us. She comes every day to me. My friend, neighbour, wouldn’t come anymore... There is no way that we can tell to anyone what we have. This is how it is going to be. Only our children know and...” (Durrës, 26, woman, 42 years old).

Stigmatisation and discrimination in the media context

Most of the individuals interviewed feel stigmatised and feel uncomfortable with the messages transmitted by the media regarding HIV/AIDS. They believe the way media give information increases the levels of fear amongst people who are not infected, and at the same time makes PLWHA feel more isolated and self controlled when living their lives.

“Awareness-raising campaigns have their positive and negative aspects. Here they portray it as terrible, while it is not so. People are scared, because it is represented as a scary infection.” (Tirana, 12, man, 54 years old).

“Media informs more than it should and it is thereby minimizing our opportunity to hide our infection” (Durrës, 13, woman, 41 years old).

“I don’t like the information media transmits. It is not correct; it is not the right one. It creates doubts and fears to others who don’t have this infection.” (Elbasan, 20, man, 61 years old).

Conflicts of interest: None declared.

Conclusions

This study shows that fear from stigma and discrimination is huge and that, consequently, PLWHA often don’t benefit from social and economic support and other services at local level.

The evidence from the USA has shown that PLWHA taking anti-retroviral treatment had lower levels of HIV in their blood if they felt they had strong social support (10). PLWHA in Albania have high levels of current medical and social needs, so interventions at this level may minimize the level of stigma and discrimination (11). Intolerance and unacceptability of some specific behavioural models and individual choices often shift towards the stigmatisation of different groups, which then are forced to share models of vulnerability and social refusal. Even service providers consider stigma as one of the biggest problems which impedes the prevention and treatment of HIV/AIDS. These findings are also compatible with studies which show that stigmatisation can make people living with HIV/AIDS give up their right to healthcare services and can make others less willing to seek care and testing for discovering their HIV status and thereby affecting many people’s attempts of early prevention and treatment (12). Evidence shows that approximately one-third of HIV-positive adults in Los Angeles reported experiencing high levels of internalized stigma and those respondents were four times more likely than others to report poor access to health care (13).

Self-perceived stigma includes feelings such as blame, shame, anxiety and insecurity. Some individuals develop feelings of self-exclusion from activities and social life raising feelings of blame on their self with the belief that they deserve this given punishment. In conclusion, stigmatization and discrimination deny the fundamental rights of PLWHA including right to health, social care, privacy, freedom from inhuman and degrading treatment, or punishment, employment, and education (14).

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