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Research article

Challenges of Persons Living With HIV/AIDS in Albania Utilizing the Framework of Human Rights

Human Rights and Security

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Abstract

The aim of the paper is to assess the vulnerability of persons living with HIV/AIDS (PLWHA) in Albania and explore to what extent stigma and discrimination prevent people living with HIV (accessing) entitlements and realizing human rights. The questions of individual interviews made with PLHA are divided into several sections, namely in: (i) attitudes, experiences, evocations 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. In total were recruited 36 people, 31 PLWHA accepted to be interviewed and the rest didn't accept. PLWHA find it difficult to talk about their HIV-positive status even though many of them have been living with this disease for several years. Non-disclosure of HIV-status presents as anxiety in PLWHA, and acts as a significant barrier preventing this patient population from attaining different social and health services. Of the PLWHA that were interviewed, 80% were not sufficiently informed about HIV at the time of diagnoses, and 73% did not have information about the rights and protections that exist for PLWHA. Patients interviewed were unaware of existing services and relevant institutions that address their rights when their rights are violated.

Introduction

Since the global epidemic of HIV came to fruition, roughly 78 million people have acquired the virus and half have fallen victim to AIDS-related illnesses (UNAIDS fact sheet 2014). And while AIDS-related deaths have dropped by 35% globally, since the peak in 2005, nearly 35 million people were living with HIV at the end of 2013(UNAIDS fact sheet 2014). With access to and significant reductions in the cost of first-line antiretroviral therapy (ART) medicines low- and middle-income countries have benefited by seeing AIDS-related deaths drop (Global health sector strategy on HIV/AIDS 2011-2015 WHO). The increased financial commitment to combat HIV/AIDS also saw a sharp increase from 2001 to 2009 with 1.6 billion US dollars to 15.9 billion US dollars, respectively (Global health sector strategy on HIV/AIDS 2011-2015 WHO). Yet, challenges still persist as HIV infections are still increasing in some regions of the world ,and the number of individuals living with HIV globally remains high(Global health sector strategy on HIV/AIDS 2011-2015 WHO).

With cases reported around the globe of violation and abuse of persons living with HIV/AIDS (PLWHA) or people who were believed to carry the disease, a challenge associated with the HIV/AIDS epidemic is stigma and discrimination (10, 19). Though the association between stigma and discrimination and the HIV/AIDS epidemic is widely accepted, a deeper understanding of this association may potentially lead to improved outcomes of PLWHA and HIV-related illnesses (The Right to Health). Stigma due to HIV-status has indeed resulted in the lack of adequate care and social support for many PLWHA (11). Consequences of stigma as a result of HIV-status acts as a barrier to PLWHA for various reasons that can impact proper treatment: delays in HIV testing, decreased exposure to prevention programs, and hindering the adoption of preventative behaviors, disclosing status (3). Non-disclosure of HIV-status to family members, friends, and service-providing institutions, thought to derive from stigma, prejudice, and discrimination, stymies adequate health care, social life, family support, and social participation of PLWHA.

Barriers to health care are related to the social stigma that surrounds HIV/AIDS, where lack of information and subsequent consequences are observed among patients and caregivers(16). In a study conduct in Albania the vast majority of patients (97.4%) said that a major barrier they faced in seeking care was that they did not want others to know that they were HIV-positive. Other barriers that were common amongst the patients were that they did not know where they could find medical help for HIV/AIDS (76.6%), did not think that they could get help for HIV/AIDS (71.8%), their medical provider did not know about HIV (70.9%), they did not think they were eligible for HIV medical help (70.9%), and/or they did not think that HIV required medical attention (60.1%) (16) According to a study from 2008, 53% of PLWHA in Albania did not benefit from an income support scheme because they did not want to disclose their HIV-positive status (5)

Until the end of 2013, 699 cumulative cases of persons infected with HIV were –registered which corresponds to 3/100000 of the population (20). Free health care, HIV testing and ARV treatment are accessible and supposed to reduce barriers for those most at risk (20).

Yet, the large majority of people present at a late state of infection and the crude death among the diagnosed population is 17% (20).

Stigma and discrimination associated with HIV/AIDS is perceived to be high and this might lead to an increased likelihood for the rapid spread of HIV/AIDS epidemic, especially among the high-risk groups of the population, including men who have sex with men (MSM), injecting drug users (IDUs), and the Roma (28).

Methods

Secondary data and qualitative method of data collection through semi-structured interviews of PLWHA was used, along with a subset of the interviewed PLWHA keeping a diary about perceived situations of stigma and/or discrimination directed towards them.

Ethics Statement (please include an ethics statement)

Approval for the study was granted from the Biomedical Ethical Committee, which reviewed and approved the assessment protocol. Informed oral and written consent was obtained from each participant prior to enrolling in the study.

Study Setting

The study was conducted at the Ambulatory Care Center in Infectious Disease Center at University Hospital Center of Tirana (UHCT). This clinic offers ARV therapy for PLWHA, which started in 2004 (15). The Center continues to be up-to-date and the only accessible care service site for PLWHA in Albania.

Participants

From February 2012 to July 2012,31 PLWHA were interviewed upon admission to the Ambulatory Care Center in Infectious Disease Center at UHCT. With the help of the Ambulatory Care Center staff, some PLWHA were asked to keep a diary but only four of the 31 patients agreed to keep one. During this period, roughly 140 people came and were treated with ARV therapy at the Center. Intentional sampling was used in this study, which is based on attempts to select the beneficiaries who meet the investigation criteria and cover all the requested variables such as: age, gender, and ethnicity (23). The interviewing process was interrupted when the theoretic saturation was reached, so there was no need for the interviewing process to continue.

Instrument

Interview

The study used a semi structured interview as the main instrument. Patton (1990) suggests some ways of constructing questions that provide access to get information on people's experiences. These ways are:

(1) Experiences-actions, behaviours of a person; (2) opinions-how that person interprets the situation; (3) feelings – as a reaction towards people; (4) beliefs – what the person believes to be a fact; (5) sensitivity – the feelings of a person towards his experience; (6) knowledge.

The semi-structured interview guide for this assessment was constructed based on these orientations. Consultations with service providers of different sectors dealing with PLWHA, including medical doctors, nurses, and psychologists (total number of 8 individuals) helped develop a solid instrument of research. Prior to data collection, the instrument was validated with PLWHA (total number of 3 individuals). These data were not utilized as research findings. The feedback received was reflected used to help finalize the instrument.

The questions of the research guide with PLWHA attempt to collect information on various dimensions. The guide incorporates several sections: (i) attitudes, experiences, evocations of PLWHA; (ii) models and main forms of PLWHA support; (iii) PLWHA perceptions of stigma and discrimination and how these prevents them from realizing their fundamental rights and entitlements.

Patient Diaries were used as an additional instrument to get an individual perspective, some of the participants were asked to keep a diary for two weeks in order to document the following: the evocations and experiences of their everyday life; situations where they believe their rights were violated; and whether they were being stigmatized or discriminated against

Diaries are being used increasingly in medical and social research. In the last decade, they are being applied in the USA in social research to record information related to sexual practices and drug use (9, 18).

Data analysis

After each interview, all of the data recorded on audiotape were transcribed immediately in order to ensure that the information was consistent with the context within which the participants communicated it. One researcher carefully transcribed the data collected. To ensure accuracy, another researcher verified the transcriptions. Transcripts were read several times so that the researchers became familiar with and had a deeper understanding of the collected information. The transcripts were reviewed repeatedly, and prominent observations were organized into categories and coded. Categories and associated codes were then reread for further interpretation and to extract the explanatory themes. The main questions were: Example of codes includes: discrimination, disclosure, rights, etc. Researcher then grouped related codes into themes: support of HIV/AIDS people, stigma and discrimination of PLWHA, rights of PLWHA.

Data was manually coded. The first coding phase included open coding. In this research, the smallest analysis unit was sentence and the coding method used was constant comparison. The phenomena coded under the same category were constantly compared. Selective coding was used afterwards. The most frequently used codes and the most significant ones were highlighted. Selective coding is more abstract because it includes the interpretation of the meaning of open coding categories. This process was an attempt to permit the text to suggest the coding and analysis topics, as well as to restrict the prejudgments of researcher when choosing the topics.

Results

The majority of people interviewed had never heard about the rights of people living with HIV/AIDS and do not know any institutions that deals with these rights, or which can offer assistance on this matter. They state that if their rights were violated, they would not ask for help as they assume nobody would offer any help to them. PLWHA seem to lack both knowledge and trust on these institutions: *"I do not know any institution dealing with our rights and I am not interested in knowing them"* **(Librazhd, 2, man, 47 years old)**

Since stigma and discrimination level perceived by PLWHA is very high, the level of status disclosure is very low and there are a limited number of people they choose to share this information with. *"I haven't told my parents because they are advanced in years and would not understand me. It is better if they don't know anything at all. It would give them a great deal of trouble."***(Durres, 13, female, 41 years old)**

All interviewees confirmed to be afraid of being stigmatized and discriminated. Most of them admitted to have made efforts to avoid stigma by hiding their HIV-positive status from the people they think will stigmatize them. *"I don't feel prejudiced, because I haven't told anyone what I suffer from. If I tell them, I know they will stay away from me. The only thing that scares the life out of me is my disease"*. **(Tirana, 22, female, 20 years old)** *Today I went to the hospital for a medical examination. Last time I was there was long ago. I avoid going to that place. I got bored because there were too many people and I waited for a long time. I was afraid that somebody might pass by and see me there. Every time I go to the hospital, my legs shake, I feel anxious and I recall all the situations since the beginning of the disease. The hospital director stared at us as if we were extra-terrestrials."* **(Tirana, female, 34 years old)**

PLWHA declare that they would refuse health services and other services from fear of being stigmatized or discriminated against. *"Alienation, segregation is horrible. If I didn't take the medicine, I would have mental disorders."***(Librazhd, 2, male, 47 years old)**

Fear of being stigmatized by family members is also a difficult experience for the participants. Family is often perceived as the only environment that could offer support and safety for the progress of the treatment. However, this is proving to be a worrisome experience since the fear to face family members' reactions rules out their potential as a source of support to treat the after-effects of living with HIV/AIDS and to take care of physical and mental health of PLWHA. *"My father doesn't know about the disease because I don't speak with him. He only knows that I'm taking medicines and he doesn't ask further questions. My brother is disapproving because of ignorance. He is withdrawn from me and doesn't even speak to me. I stay alone in my own room and food is brought here for me. My family doesn't approve my disease. They don't accept my disease, my opinion."* **(Vlore, 6, male, 35 years old)**

The participants report that they have felt stigmatized even in their relationships as a couple. *"…tranquillity, marital life. We don't have that impetus. Even though I have a wife, we keep distance. We don't go out at all. It seems to me that everyone will find out and they will understand that I am sick."***(Tirana, 16, male, 35 years old)**

Society and community stigmatization is also perceived to be hard. PLHA relate this to the attitude that the society holds towards "other's behaviour", which the society considers it to be deviated and unacceptable. All the interviewed people are highly convinced that they would be stigmatized and discriminated by the community, if they got information on their disease. *"My friends don't know. If they knew, I wouldn't be able to get out in their company. In the area where I live, my neighbours respect me and if they hear from others about my disease, they would not believe it. But they would exclude me anyhow. It would be terrible if they found out what I suffer from."***(Tirana, 16, male, 35 years old)**

Fear of being refused by their family is immense and unbearable. PLWHA often choose not to reveal the truth about the disease, so that they can still be close, supported and accepted by their families.*"My family…I don't have courage to tell them about my disease."***(Librazhd, 2, male, 47 years old)**

The support that family offers is so important to PLWHA that they choose not to disclose the information, from fear of losing this support, or even harsher, from fear of causing pain and unpleasant consequences to their family members. *"My mother has heart problems. She has suffered so much in her life and I don't want to make her suffer even more. What should I tell her? How would she help me?"* **(Librazhd, 23, male, 25 years old)**

Health services are perceived by PLWHA to be very important and vital for their disease and the difficulties they face in other environments. Caregivers are perceived as the most important, and the relationship they build with these people is of great significance for their health, life quality and well-being. Caregivers are not considered only as service providers, but they are also thought of as an important source of social support.
"I feel so good when I come here to get health services. The doctors pay attention to us and they care about our health." **(Tirana, 4, male, 63 years old)**

Many PLWHA state that they would not go to their community health centers or hospitals in their cities to get the recommended services. They are very much afraid of being stigmatized or discriminated against, or even having their privacy violated. The only place they feel secure when they get health services is the Infectious Disease Service at UHCT and Ambulatory Care Center in this hospital. *"The services are good. I don't want to get health services from my community health centers or health centers in my city because I am afraid that the information will come out."* **(Durres, 8, male, 41 years old)**

Only some PLWHA get Disability Support Pension due to the disease they carry and these people live mainly in Tirana. PLWHA who live in other cities in Albania say that they would not accept Disability Support Pension because they would prefer to not disclose their HIV-positive status in the cities where they live. This refusal is caused by a fear of stigmatization and being excluded from their community due to HIV-status.
"I don't receive Disability Support Pension. Even if I were starving to death, I wouldn't get it." **(Durres, 13, female, 41 years old)**

Discussion

The results do confirm that HIV still remains an epidemic of ignorance, fear, and negation in Albania. Analysis of the information from all patients included in the study confirmed that the fear of being stigmatized and discriminated against prevents PLWHA from getting the proper health and social protection services, services that should be given to them as a basic entitlement

Status disclosure is difficult but it is made as PLWHA are in great need for support: financial, material, moral and emotional, and treatment. The results of the study confirmed that 64%of PLWHA say they also make it to preserve family ties: they want to protect the rest of the family from HIV, but they fear that that their new behaviours or any health change will be noticed by the family. These reasons are in accordance with previous studies conducted on the motivation of status disclosure (4).

Status disclosure with other people besides family not only remains difficult, but it also prevents PWLHA to get the services and the entitlements, which should be a fundamental right. Stigmatization may cause PLWHA to give up their right to health and to show less desire to undergo HIV testing, by affecting the attempts on prevention and early treatment (1). Indeed, the study confirmed that the fear of being stigmatized has made most of the participants disclose their status at a later stage; thus losing their chance to get support as early as possible and get the appropriate interventions to treat the disease.

Fear of discrimination also makes PLWHA withdraw their economic rights. Although most of the patients included in the study are unemployed and live in very difficult circumstances, they refuse to apply for financial support; an entitlement provided by the Albanian law, as they fear lack of confidentiality from the authorities and therefore fears of being discriminated in the community. While global evidence (13) confirm the positive outcome of employment in the life of a person affected with HIV, none of the interviewed patients have thought or made an effort to ask for a job. .

The results of the study show that PLWHA do not prefer to be a part of self-help groups. PLWHA are greatly afraid of stigmatization, discrimination and violation of privacy, therefore they do not desire to be in touch with other people who carry the same disease. The findings of other studies emphasize that PLWHA prefer to be a part of self-help groups because they offer more information about the disease and they are qualified to manage the disease better. Foucault (1980) emphasizes that with more knowledge, the individuals will feel empowered o handle the situations and their problems. Being involved in self-help groups helps them to understand that they are not the only ones living with HIV/AIDS. Referring to Castells theory (1997), self-support groups create a collective strength for all PLWHA and this collective strength helps them to satisfy their needs.

On the other hand, being alone does not help. The mechanisms that PLWHA develop in order to face the disease change gradually and are developed according to the individual skills and external support, if any. Findings show that the majority of PLWHA have built a strategy to confront emotions focusing mainly on reducing anxiety and cannot build concrete skills to handle the new situation. Most studies on the subject argue that endurance strategies focused on the problem, such as safety, taking an attitude and combative spirit, and planning a series of actions, bring more effective results and adaptation than emotion endurance strategies that aim at reducing anxiety (26).

Conclusions

It is a right and an immediate need to ensure support for PLWHA, building and/or utilizing formal and informal approaches. Assistance should be provided starting from the moment of HIV status disclosure, at post counselling session after HIV testing. The support provided should aim to empower and develop skills amongst PLWHA in handling challenging daily situations. Interventions planned and implemented should facilitate better access of quality health services, social services, and economic services. There is room for PWLHA to become more active in advocacy initiatives for policy improvements, and mobilize resources to ensure and promote the fulfilment of their health, social and economic rights and needs. PLWHA should be able to make choices for their lives in a way that confirms their participation in social, cultural and economic processes. PLWHA involvement in decision-making processes should be a key approach to empower them, and to guarantee that rights and needs are fulfilled. It is of paramount importance to break the cycle of stigma and discrimination deriving from social norms, as a prerequisite for PLWHA to ask for their entitlements and protections of their basic rights.

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