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REPORT

IRANIAN PERSONS LIVING WITH HIV/AIDS UNVEIL THE EPIDEMIC OF STIGMA (AN OVERVIEW OF PATIENTS' ATTITUDES TOWARDS THE DISEASE AND COMMUNITY IN FIRST GIPA GATHERING IN TEHRAN)

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The first Iranian AIDS patients' assembly took place on 21st November 2002 in the Research Center for Gastroenterology and Liver Disease (RCGLD), an affiliate of Shaheed Beheshti University of Medical Sciences, Tehran. This was a meeting for persons living with HIV/AIDS (PLWHAs). The goals of this session were to scrutinize the problems of HIV/AIDS-afflicted individuals, including stigma, and to examine ways to initiate inter-group activities in the form of support groups and societies for patients (an analogue of the "Greater Involvement of People Living with AIDS" [GIPA] program launched in many regions of the world[1]). We present an overview of the problems that patients are facing, focusing on the psychosocial dilemma in which they are trapped.

About HIV stigma

Throughout history, many diseases have carried considerable stigma, and HIV/AIDS being the latest of such diseases.[2] AIDS-related stigma refers to prejudice, discrediting, and discrimination directed at PLWHAs as well as the individuals and groups with which they are associated as secondary targets.[3] This imposes on patients the experiences of guilt, anger, grief, and fear of abandonment due to others' fear of the infection and associated stigma.[4] This additional suffering has often interfered with and hampered treatment, care and social benefits. It stops patients developing healthy habits and preventing the disease by seeking decent medical care and discontinuing behaviors that transmit HIV. Some patients even behave in a way that jeopardizes healthy individuals in revenge and anger at communities that discount sick people.[3, 5, 6] Researchers have revealed that when fewer PLWHAs are confronted with discrimination and stigma, there is increased social support and PLWHAs use active coping strategies to achieve higher levels of general life satisfaction.[7] Descriptive studies are necessary to develop an understanding of the ways in which stigma is manifested in society's institutions. To date, most of the research on AIDS stigma has focused on perpetrators rather than targets, but the complexity of the network of factors and reactions related to this issue makes it essential to study the problem from the patients' perspective.

Iranian PLWHAs

In Iran, 4,229 people were known to have been infected with HIV by December 2002, with a considerable rise in the transmission of virus through drug injection since the onset of the HIV epidemic in Iran, now comprising 66% of infected individuals.[8, 9] The drug abusers group mostly consists of those who reside and were infected in prisons and rehabilitation centers.[10] Sexual transmission, the second most common route of transmission in Iran, contributes to 8.1% of cases, followed by 4.5% from blood transfusion.[9] AIDS

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patients in Iran face a thick mist of stigma hindering their appearance in the community, seeking their rights for care and support, or even communicating with families and friends in a trustful manner. Unfortunately, secondary-target stigma is also visible in the resistance and opposition to initial measures taken to support and help PLWHAs in many countries; Iran is no exception.

First GIPA gathering

In the first GIPA gathering in Tehran, the aims and scope of this type of activity in other regions of the world were described by a member of the RCGLD. The attendees then discussed their experiences and ideas on the issue. In spite of the fact that there were too few attendees to represent all Iranian patients, the meeting was considered a great step towards building commitment to be informed by PLWHAs. In order to gain insight into the attitudes of PLWHAs towards their condition and their experiences within the community, we designed an open questionnaire to be filled out anonymously by attendees.

Only 17 PLWHAs (of 45 invited individuals) attended the meeting. Their physical well-being and morale were sufficient to encourage them to attend the meeting, so their anonymous answers should be regarded as the most optimistic viewpoints and narrations among PLWHAs.

Targets of HIV stigma unmask discrimination towards them

The results for three major lines of questions were as follows:

1. ***Existence of a party supporting PLWHAs***: the attendees knew that no organization is supporting PLWHAs. Provision of current services is limited to a few known centers where medical treatment is available. Nevertheless, most patients were grateful for this scanty service, which meant they were not aware of their right to other forms of support than providing pharmaceuticals and medical tests. Among expectations cited from such an association, helping patients to overcome isolation, to obtain their rights, to build appropriate coping strategies, and to find proper treatment and consultation were most commonly expressed. Only three responders stated that they wanted an association that would inform people about prevention and financial help, and collaborate in policymaking for the AIDS problem. Forty-five percent of the attendees gave no answer to this question, which may reflect their doubt about the necessity for, or skepticism about the effectiveness of, such a foundation. Half of the attendees thought that the activity of such a society should be hidden, totally or at least initially, about 40% were proponents of visible activities, while others either stated they had no idea or provided no answer.

2. ***Social attitude towards PLWHAs***: 90% of responders thought that the social attitude towards PLWHAs was bad and ignorant, including a mixture of wrong beliefs and discrimination. The responders were in less agreement regarding governmental bodies' attitudes. Few stated that they had never had contact with governmental bodies; a minority thought that the government was helpful in forming public centers, about 60% expressed their very bad experiences in this section. Nearly half of the attendees believed that medical staff had a fairly good to very good attitude, although some responded with uncertainty. Some were grateful to their physician, but one-fifth stated that the attitudes of medical staff were bad.

3. ***Personal state of mind and ideals***: regarding their own experiences, the responses were more diverse, irrelevant or absent. They covered a range of emotional problems (frequently expressed); isolation; problems of receiving care, information, and pharmaceuticals; negligence of policymakers; and financial problems. This shows the vast range of problems that PLWHAs may face, urging research on this agenda. Most thought that the community's awareness and acceptance of PLWHAs would lead to a helpful society that facilitated coping with HIV. Others emphasized that founding a society from patients, occupational facilities and workplace support was essential. Forty-five percent of respondents said that their major challenge was coping with the disease; a minority of them said that their morale was poor, and condemnation among family and friends was perceived by few of the PLWHAs. Negative psychological states were also evident; one respondent even declared his/her

willingness to contaminate a crowd with an infected needle! In response to a question requesting them to express their utmost desire, 70% of individuals wanted the discovery of a treatment for AIDS and 30% wanted all diseased people to be cured, especially those afflicted with AIDS, and wished that no one would ever contract HIV.

Stigma in other regions of the world

AIDS is a global pandemic, and its associated stigma is present everywhere. However, the stigma takes different forms and degrees as a result of local epidemiology of HIV and its changes, as well as shared values and beliefs at a cultural and individual level.[3, 11 – 13] At the cultural level, it is manifested in laws, policies, and popular discourse. At the individual level, it takes the form of behaviors, thoughts, and feelings that express prejudices against persons infected with HIV. From the very early days of the epidemic, PLWHAs have been fired from their jobs, evicted from their homes, and denied services.[3] Even laws mandating HIV testing without consent or protection of confidentiality contribute to stigma.[3] PLWHAs face not only the disease itself, but also the loneliness, emotional isolation, and social isolation revealed in the narratives of AIDS patients and the research into them.[14 – 16]

Experience in other countries shows that the measures taken against some acts considered immoral, which are known as risky behaviors for HIV (like prostitution or drug abuse), have led to the concealment of these phenomena and the obstruction of anti-AIDS measures, as well as the spread of HIV/AIDS infections.[17] However, stigma is likely to be a central factor in the community's readiness to acknowledge its own risk for HIV in a realistic manner.[3]

In a review of 21 interventions to explicitly decrease AIDS stigma around the world, these means were listed: general information-based programs, contact with affected groups, coping skills acquisition, and counseling approaches. This reflects an understanding that stigma must be dealt with at both a collective and individual level.[2] Above all, in this review only two examples of national level effects were found. Although this review shows that stigma can be reduced at least in the short term and on a small scale, we need programs to scale up efforts to combat stigma. One should note that sometimes well-intentioned research or interventions might lead to reinforcement of AIDS stigma in a variety of ways. For instance, when the epidemiological construct of "risk groups" was adopted, it reinforced perceptions of PLWHA as an "out group", aliens, "them" rather than "us"; this obviously places obstacles to the reduction of AIDS-related stigma and its consequences.[3] Various attempts have been made in many regions of the world, even using e-mail discussion forums or open discussions with participation of PLWHAs,[1, 5] which were found to be quite useful to elicit different aspects of the problem. Direct interpersonal contact with PLWHAs is often associated with lower levels of stigma, which suggests that fostering of such contact experiences may reduce stigma among some uninfected individuals.[1, 3]

There are some key points related to stigma that include: 1) Law, which in some circumstances promotes stigma, for example, in firing PLWHAs and forbidding discourse on social phenomena such as prostitution and homosexuality, but inhibits stigma by the right of confidentiality for everyone;[3] 2) Mass media, which plays an ambivalent role in engendering or combating stigma by disseminating the ways of contracting HIV;[3] 3) Religion, whose response to the epidemic is conflicting and ambivalent where it condemns discounting sick people, compared to condemnation of groups at risk;[3] 4) The workplace, which has proved to be a key place to face and fight stigma in some countries,[1] but the usual manifestation of stigma is firing of the person from work; 5) Healthcare staff, who are sources of stigma by expressing negative attitudes and their preference not to treat a PLWHA, or whose sensitivity to afflicted people's problems, assuring the confidentiality of sick people, and their informative and educational role may contribute to fighting the stigma;[3, 18 – 20] 6) Structured activities, such as GIPA, an assembly of people to support and care for PLWHAs; 7) Inter-group relations, which include the attitudes of different social groups towards groups at risk; and 8) Families and friends, who can support or abandon the patient.

Suggestions

HIV/AIDS-related information, education and communication (IEC) is of significant importance in preventing and combating the epidemic. It should be based on accurate information and case studies.[17] In studies of means of knowledge acquisition, most responders announced that television, press, and radio were their main sources

of information.[17, 20] Thus, the mass media is a very good choice for delivering the message, but this propaganda should be based on careful studies and measures to avoid opposite results. Intra- and inter-sectoral collaboration in fighting the stigma are important, as are means of voluntary testing and also care and acceptance of affected individuals into their family/communities.[5] Empirical research on AIDS stigma will fill important gaps in current knowledge and provide critical information for the design of strategies to overcome the effects of stigma.[3] For example, direct contact with PLWHAs with socially acceptable lifestyles (who were infected in involuntary and unavoidable circumstances) positively changes lay people's perceptions of PLWHAs in some countries,[1] but the usefulness of this method is of doubt in Iran. In respect of such difficulties, most of the attendees were reluctant to initially open GIPA activities to the public.

This report can be the basis for future activities; preparing an operational research agenda for HIV/AIDS-related stigma and identifying potential technical and financial partners to conduct research and utilize the findings. Although the findings of this evaluation are consistent with those in many countries, especially in general terms of stigmatization and personal reaction and feeling of PLWHAs, the exact coping or response mechanisms to such imposed adversity would be different from other parts of the world, reflecting the cultural norms and characteristics of Iranian society. Thus, special programs should be tailored to fit our clients' needs. We believe that some organizations whose employees are at higher risk of contact with the virus (such as the navy, transportation companies, prisons and medical centers) should consider additional education and empowerment for self-protection and willingness to take tests. We urge everyone engaged in policymaking and giving care to sick people, in addition to political leaders, to make a strong commitment immediately to work to stop the epidemic of stigma if we are ever to confront AIDS seriously.

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