WHO EMRO | Problems of providing services to people affected by HIV/AIDS: service providers and reci

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مشاكل تقديم الخدمات للأشخاص المصابين بفيروس العَوَز المناعي البشري / الإيدز : من وجهة نظر مقدمي الخدمات والمستفدين

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رحماني، حسين ملك أفضلي أردكاني

: هدفت هذه الدراسة إلى التعرُّف على مشاكل الرعاية الصحية المقدَّمة للأشخاصالخلاصة
المصابين بفيروس العَوَز المناعي البشري في مدينتين كبيرتين : طهران وكرمنشاه .
فباستخدام طرق كيفية، شاركت مجموعتان رئيسيتان من مجموعات الأطراف المعنية - هما
مقدِّمو الخدمات (واضعو سياسات ومديرون وأطباء ومستشارون) ومتلقو الخدمات (الأشخاص
المصابون بفيروس العَوَز المناعي البشري وأقاربهم) - شاركوا في مناقشات جماعية مركّزة
ومقابلات متعمِّقة . وقد حدّد الباحثون 24 موضوعاً تغطي المشاكل الصحية الرئيسية
للأشخاص المصابين بفيروس العَوَز المناعي البشري؛ بما في ذلك : نقص تغطية خدمات
الرعاية الصحية وعدم ملاءمتها، وتعاطي المرضى للمخدرات، وخوف المرضى من الوصمة،
والإرهاق المهني لمقدِّمي الخدمات، وعدم رضا المرضى عن بعض الخدمات المقدَّمة من
قِبَل مراكز / عيادات الإرشاد، وعدم مراعاة الطاقم الطبي للسرّية، وعدم حصول المرضَى
على الخدمات التخصصية المطلوبة . وخلص الباحثون إلى أن المشاكل والاحتياجات التي تم
التعرُّف عليها يمكن أن تثري تصميم وتنفيذ البرامج الصحية في هذا البلد وفي أماكن أخرى
من إقليم شرق المتوسط .

ABSTRACT This qualitative study aimed to identify the health-care problems of people living with HIV (PLHIV) in 2 large cities: Tehran and Kermanshah. Two main groups of stakeholders — service providers (policy-makers, managers, physicians and counsellors) and service recipients (PLHIV and their relatives) — participated in focus group discussions and in-depth interviews. We identified 24 themes covering the major health problems of PLHIV, including: incomplete and inadequate coverage of health-care services; patients' substance abuse; patients' fear of stigma; occupational burnout of certain service providers; patients' dissatisfaction with some of the services provided by counselling centres/clinics; medical staff's failure to observe confidentiality; and patients' lack of access to required specialized services. The problems and needs identified can inform the design and implementation of health

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programmes in our country and elsewhere in the Eastern Mediterranean Region.

Difficultés dans l'offre de services aux personnes touchées par le VIH/sida : point de vue des prestataires et des bénéficiaires de services

RÉSUMÉ La présente étude qualitative visait à identifier les problèmes de soins de santé pour les personnes vivant avec le VIH dans deux grandes villes : Téhéran et Kermanshah. Deux grands groupes de parties intéressées — des prestataires de services (responsables politiques, administrateurs, médecins et conseillers) et des bénéficiaires de services (les personnes vivant avec le VIH et leur famille) — ont participé à des groupes de discussions thématiques et à des entretiens approfondis. Nous avons identifié 24 thèmes couvrant les principaux problèmes de santé des personnes vivant avec le VIH et notamment la couverture incomplète et insuffisante des services de soins de santé, l'abus de substances psychoactives des patients, la crainte de la stigmatisation ressentie par les patients, l'épuisement professionnel chez certains prestataires de services, l'insatisfaction des patients au sujet de certains services proposés par des centres de conseil/des dispensaires, l'échec du personnel médical à respecter la confidentialité, et le manque d'accès des patients aux services spécialisés nécessaires. Les difficultés et les besoins identifiés peuvent servir de base à l'élaboration et la mise en œuvre de programmes de santé dans notre pays et ailleurs dans la Région de la Méditerranée orientale.

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Introduction

Although the overall prevalence of HIV in the World Health Organization (WHO) Eastern Mediterranean Region (EMR) is still low, the Region is at high risk regarding the spread of HIV/AIDS (1,2). In the Islamic Republic of Iran, one of the most populous countries in the EMR, government data recorded 27 041 HIV-positive individuals to the end of September 2012 (1), while the United Nations estimated as many as 71 000 (53 000–100 000) individuals were living with HIV in 2012 (2). The country's HIV epidemic is concentrated among injecting drug users (IDUs); 68.1% of cases are due to needle-sharing versus 12.7% to sexual transmission, 0.9% to infected blood and blood products and 1.2% to mother-to-child transmission (3).

Many diagnostic, treatment and counselling services for people living with HIV/AIDS (PLHIV) are provided free of charge in the Islamic Republic of Iran. These include counselling services, harm reduction, CD4 count tests, antiretroviral therapy, regular visits by general physicians, infectious disease specialists and psychiatrists, family planning services, and treatment of tuberculosis. The majority of these services are offered in special centres known as counselling centres for behavioural diseases. There is one centre in cities with a population of less than 1 million, while in other cities with over 1 million residents, there are up to 4 centres depending on the population (4). In addition, in all provinces "triangular clinics" provide specialized services for high-risk individuals and PLHIV, which include counselling for behavioural disorders, centres for vulnerable women, clubs for HIV-positive people, voluntary counselling and testing centres, shelters for homeless drug users, and clinics in prisons (5,6).

Although interventions such as antiretroviral therapy have increased patients' lifespan, PLHIV still face many social and psychological problems and difficulties in accessing health services. Compared with uninfected individuals, PLHIV suffer from stigma, anxiety, depression, job loss, poorer access to health-care services and lower quality of life. Several studies have shown that the nature of the epidemic and the culture and environment of a particular country or city are the most important factors which affect the services received by patients (7–9). In a study in Western Cape, South Africa, HIV-positive women perceived stigma from health providers which negatively affected their access to services, their visits to health service centres and their engagement in social interactions (10).

Despite the many services available and attempts to provided care and treatment of PLHIV in Islamic Republic of Iran, there are still many challenges for diagnosed individuals. To the best of our knowledge, there has been no published qualitative study in this or other countries of the EMR to investigate the problems of providing rehabilitation and supportive services for PLHIV. The available quantitative studies do not provide a deep understanding of the existing problems (11), whereas qualitative studies are more able to shed light on deeper layers of care- and

treatment-related problems of PLHIV (12). Determining the problems in offering services can be an appropriate guide for future planning of health and treatment services. A study was therefore conducted in 2012 to investigate the health-care problems of PLHIV in the Islamic Republic of Iran from the perspective of 2 main groups of stakeholders: service providers (i.e. policy-makers, managers, experts, physicians and counsellors) and service recipients (i.e. PLHIV and their relatives).

Methods

In this qualitative research, participants' views about the problems of PLHIV with regard to health-care services and supportive measures were collected using a number of FGDs and in-depth interviews.

Sampling

We selected participants from 2 cities: Tehran, the capital city, and Kermanshah, another major city where many people with HIV/AIDS are living. We used purposive sampling to select the most informed and knowledgeable participants (13). Different criteria were used for selecting the participants depending on the stakeholder group. PLHIV were those who had been HIV-positive for more than 2 years; had a minimum experience of 6 months in visiting one of the centres providing services for PLHIV; and were aged over 18 years and literate. The relatives of these PLHIV were those who had a continuous life with the PLHIV as his/her spouse, parent, sibling, child or caretaker; and were aged over 18 years and literate. Physicians and counsellors were selected from among those who had at least 1 year of experience working in one of the centres providing services for PLHIV. A total of 40 PLHIVs, 20 PLHIV relatives, 10 physicians and 10 counsellors were invited for FGDs; 70 people accepted the invitation and participated in the discussions. We also selected 6 key persons among policy-makers and managers who had considerable experience of providing health services for PLHIV. All 6 invited to the FGDs accepted and participated in the discussions. In addition, 6 individual interviews were conducted with the managers and policy-makers.

Data collection

A total of 4 FGDs were conducted with the HIV-positive people, 2 FGDs with the relatives and 2 FGDs with physicians/counsellors, with a minimum of 6 people per focus group. It was hoped that participants would be more comfortable sharing ideas in an homogenous group. Two researchers participated in each FGD; one of them managed the FGD and the other recorded the nonverbal interactions of participants. Following the participants' agreement, some of these sessions were recorded and transcribed. To conduct the FGDs the facilitators, who were trained in qualitative methods, started by presenting the aim of the FGD and then proceeded with a set of questions and follow-up probe questions to investigate the problems of providing health-care services for PLHIV (for example, barriers to accessing services, family problems and problems related to health-care delivery systems). Every FGD took between 1.5 to 2 hours.

To conduct the in-depth interviews with managers a similar question guide was used, with probe questions to gain a deeper understanding of the responses.

The FGDs were conducted in a silent room and the individual interviews took place in the managers' offices.

Ethical considerations

Participants' discussions were recorded only with their agreement (hence, not all the interviews and FGDs were recorded). During the sessions, the researchers stopped recording whenever participants asked not to record their voice. When it was not possible to record, notes were taken and the conversations were summarized on paper. Moreover, the participants were assured that the collected data would remain strictly confidential and would be used only for research purposes. Participants had complete freedom to leave the study at any stage they wished and to protect their identity a code was used instead of their actual names.

Data handling and analysis

Using OpenCode software for qualitative data analysis, the transcripts were first reviewed and initial themes were extracted. Care was taken to use the participants' own responses for the wording of the initial themes, which were subsequently categorized according to their content; that is, those extracts which had similar thematic content were grouped together. In order to reduce the number of categories, these were further clustered to form a number of macro-categories. During the process of theme extraction and categorization, each newly extracted theme was carefully compared with the previous ones in order to further enhance the reliability of the study.

The researchers utilized various bias reduction techniques in order to minimize the factors that threaten the internal and external validity of the analysis (14). To secure the trustworthiness of the analysed data, the 4 indices of credibility, dependency, conformability and transferability were checked. In order to enhance credibility the participants were selected from among those who had experience of contact with HIV care services. Dependency was improved by taking the ideas of the research team into account with regard to the review, theme extraction and analysis of transcripts and so the research reports were given to various researchers and experts who provided feedback. To increase the conformability of the research members of the research team discussed any conflicting findings and came to an agreement. The transferability of the findings was improved by providing a rich description of the data and by ensuring that individuals with different responsibilities and educational backgrounds participated in the study.

Results

The themes of the study were analysed within the 4 stakeholder groups: policy-makers and managers; physicians and counsellors; PLHIV; and relatives of PLHIV. In general, the findings were categorized into 24 themes. Further analysis of these themes indicated that they could be clustered into various groups based on stakeholders' ideas; i.e. 5 themes belonged to the policy-makers and managers, 6 to the physicians and counsellors, 7 themes to the PLHIV and 6 to PLHIV's relatives. Tables 1 and 2 show the identified categories (themes) in each stakeholder group, illustrated by examples of quotes from participants, and the macro-categories which were formed by clustering themes with similar content. The findings have been ordered based on their frequency, i.e. the findings with the highest frequency of responses have been placed higher than those with lower frequencies.

The following macro-categories were determine based on the views of the different groups of stakeholders: PLHIV's lack of complete access to the service centres; incomplete coverage of PLHIV health services in these centres; lack of access to the required specialized care services; lack of awareness and training in the community; substance abuse by PLHIV; problems associated with methadone maintenance therapy (MMT) for PLHIV; stigma perceived by patients; burnout of personnel that provide care for PLHIV; employment problems of PLHIV; excessive bureaucratic processes; inconsistency of services provided across the country; dissatisfaction with some of the services provided in counselling centres; and dissatisfaction with hospital care.

Similar themes were identified by the different groups of stakeholders. From the perspectives of managers, policy-makers, physicians and counsellors, there were a number of problems in common: difficulties for PLHIV in accessing the centres that provide services; inadequate and incomplete coverage of PLHIV treatment services; lack of awareness in the community; substance abuse by PLHIV; PLHIV's fear of stigma; and burnout by medical personnel (Table 1).

PLHIV and their relatives also identified a number of problems in common: patient's fear of stigma; dissatisfaction with some of the services provided by counselling or medical centres; violation of confidentiality by medical staff; difficulties in accessing specialized services; inequity in services provided in different centres across the country; financial difficulties of PLHIV and their families; lack of employment for PLHIV; and substance abuse by PLHIV (Table 2).

According to participants' responses, while some of these problems were mentioned by all

groups of stakeholders, others were pinpointed only by specific groups. For instance, all 4 groups believed that fear of stigma was one of the major problems for PLHIV in receiving care services. However, closer inspection of the 4 groups' views showed that from the perspective of managers, policy-makers and relatives, the stigma originated only from the community, whereas physicians and counsellors also believed that it could originate from medical staff. On the other hand, patients themselves claimed that the strongest stigma came from their family, followed by the community and medical personnel.

Discussion

Even without a vaccine against HIV, the effectiveness of antiretroviral therapy in treating and preventing HIV infection, and the increased availability of resources for HIV programmes in low- and middle-income nations, are reasons for optimism (15). Nevertheless, this study has drawn attention to a number of health-care problems for PLHIV in the Islamic Republic of Iran, in terms of service provision issues (incomplete coverage of services, especially specialized services, patient dissatisfaction); access problems (patients' inability to pay for transport or for services); staffing problems (burnout, confidentiality violations); low community awareness; patients' fear of stigma; patients' financial/employment problems; and patients' drug use. These problems may be common to other countries of the EMR, due to these countries' cultural and social similarities, and the study may provide evidence which can also be applied in other parts of the world.

In general, the views of managers/policy-makers and physicians/counsellors were similar. Both groups believed that the main obstacles to providing services for PLHIV were access difficulties for patients; the incomplete coverage of health-care services, particularly special services for PLHIV; insufficient awareness and training in the community; and substance abuse by PLHIV. The most important common factors in this regard are patients' financial problems, including inadequate insurance coverage, and substance abuse. Furthermore, in most parts of the world HIV/AIDS-infected people are co-infected with hepatitis B and/or C virus (16) and this increases the costs of their treatment. As a result, financial problems and inadequate insurance coverage are the main obstacles to patients' continuing treatment. In addition, physicians and counsellors at the counselling centres for behavioural disorders believed that staff burnout was one of the problems in offering adequate services. The same point was raised by PLHIV themselves, who were not satisfied with some of the services provided by the personnel at the centres. These findings are echoed in studies in Zambia (17) and in Malawi (18).

The views of PLHIV and their relatives were also somewhat similar. Aside from the fear of stigma, both groups claimed that the main problem was with some of the services provided in counselling centres and they expressed dissatisfaction with counselling sessions and frequent changes of medication and medication side-effects. Furthermore, PLHIV believed that some of the medical staff, especially hospital nurses, did not respect them and had violated their

confidentiality. The same issue (i.e. patient confidentiality and its violation by physicians and nurses) was mentioned in other HIV-related studies (19–21).

All 4 groups of stakeholders mentioned that stigmatization of PLHIV was a major problem in providing services for patients. As indicated in a number of other studies such stigma has clearly existed from the very early days when HIV/AIDS was diagnosed in various parts of the world (7,22,23).

The results further indicate that lack of sufficient awareness within the community and among the medical staff was another major problem from the perspective of PLHIV. They felt not only that members of the public were unwilling to be in contact with them, but also that many of the medical staff were not interested in providing health services for them. This is a bitter reality, despite the fact that in recent years physicians and nurses in the Islamic Republic of Iran have become accustomed to providing health care for PLHIV. Although nowadays, people with HIV receive more free care and health services from the public sector, they still suffer from lack of adequate specialized services. There are 3 main reasons for this: financial problems of patients; stigma attached to PLHIV especially by medical staff; and inadequate coverage of insurance services (many of the PLHIV either do not have any insurance, or if they have it, the insurance cannot cover specialized services such as dental services or certain types of surgery).

Another major category of problem for PLHIV was their inability to access the counselling centres for behavioural disorders due to the small number of centres; the long travelling distances; and their inability to cover the commuting costs. It is inferred from the present study that patients' financial difficulties were the key factor in this problem. A study in Los Angeles in the United States came to the same conclusion regarding the costs of services and transport for PLHIV (24). Moreover, in research in suburban and rural areas of California, it was suggested that physical and transport issues were the main problems in accessing health services for PLHIV. They proposed that setting up transportation systems or mobile clinics can be helpful for individuals with physical disabilities (25). In another study, it was indicated that solving patients' transport problems would simplify access to HIV services and other peripheral services, which in turn can have a positive influence on the health of PLHIV (26). Patients' financial difficulties were also one of the main obstacles to their receiving some services. This is due to structural defects in the Iranian health system, so that in spite of the presence of insurance organizations, the costs of health care and hospital services are generally high both for the general population and PLHIV (27).

Another problem identified in this study, and one which was mentioned in another study, is the issue of relationships between service providers and clients. It seems necessary that all the staff

who provide services for PLHIV should be trained about effective communication with patients (28).

A major problem of people with HIV/AIDS in the Islamic Republic of Iran is substance abuse, a subject that was mentioned by all groups of participants except the PLHIV themselves. Since most of the individuals who have been diagnosed with HIV in this country are substance abusers (3), the lack of effective planning and services for substance abuse treatment will cause problems for patients in receiving other health and treatment services, an issue that has also been highlighted in some other studies (29,30).

Conclusions and recommendations

This research adopted a qualitative methodology to collect the ideas of various groups of stakeholders (both service providers and recipients). The results highlight the need to pay attention to the problems that hinder service provision for PLHIV and to consider possible solutions.

We suggest that there is a need to promote advocacy among policy-makers to make necessary changes in the health system to provide services effectively to PLHIV. The advocacy must be initiated by the relevant international and national organizations affiliated with the Joint United Nations Programme on HIV/AIDS and WHO. Since a major obstacle to receiving appropriate services was the stigma perceived by PLHIV and their relatives, training strategies are needed to reduce stigma originating within the community. The Iranian Ministry of Health also needs to take action to tackle stigmatization of PLHIV by therapists. Another major obstacle to providing services was the difficulty for PLHIV in accessing services. Patients' access must become geographically and economically feasible. Because most PLHIV in Islamic Republic of Iran are IDUs, appropriate measures are needed to provide them with access to harm reduction services. Considering the increasing burden of HIV/AIDS in the Islamic Republic of Iran and other countries, we suggest that integrating HIV-related services into primary health services could be a beneficial way to improve services to patients.

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