European Scientific Journal May 2015 edition vol.11, No.14 ISSN: 1857 – 7881 (Print) e - ISSN 1857- 7431

PERCEPTIONS OF SERVICE PROVIDERS FOR PEOPLE LIVING WITH HIV/AIDS ON CHALLENGES THEY FACE WHILE PROVIDING SERVICES

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Abstract

This study aims to analyze the perceptions of service providers related to services provided for people with HIV/AIDS and what they suggest to meet these needs. In Albania, the study focuses on services provided for PLWHA and challenges that service providers encounter. In this study a quality methodology has been used. Service providers were interviewed using 20 semi-structured interviews. Data collection took place in the University Hospital “Mother Teresa” in Tirana, in the Infective Hospital Service. Data revealed that service providers refer changes in the way services are provided for PLWHA. Medical staff of Infective Hospital Service in TUHC shows a positive attitude toward these people as information and understanding about the disease has increased in the last few years. This institution has constantly sought to raise awareness and inform other professionals, family members, relatives and PLWHA themselves about this disease. There are a lot of difficulties that medical service providers face during their work with PLWHA such as: inability of PLWHA and their family members to understand and really evaluate their disease’s level, convincing PLWHA on an emergent check-up of their partner, decrease of therapy success due to diagnosis in late stages of the disease, lack of information and low level of voluntary check-ups. Today’s challenge is not only improving the quality, but also reformulating the way medical services are provided, so as to complete social and psychological aspects of health.

Keywords: Service providers, people living with HIV/AIDS (PLWHA), challenges, services

Introduction

At the beginnings of HIV/AIDS epidemics, in many countries the intervention focused on addressing HIV as a medical issue, ignoring its social, economic dimensions and human rights that influence on prevention and care.

The approach based on human rights emphasizes that all the people should enjoy a satisfactory life, where everyone is capable of developing their human potentials. Human rights determine global standards for the well-being and development (UNAIDS 2000).

To the concerned person, learning the HIV status through laboratory diagnosis is always a traumatic experience which changes the life (Leserman, 2008). People with HIV infection have high rates of life stressful events. In particular, HIV puts the individual against many challenges that can affect their coping resources and interfere with their psychological adaptation to constant requirements to cope with this chronic and stigmatizing disease (Bouhnik, Préau et al., 2005). Reduction of social exclusion, as well as social and emotional support, can lead to a greater social cohesivety and improve health (Serovich, Brucker & Kimberly, 2000).

Living with HIV/AIDS includes a series of stresses about insecurity about the course of disease and social stigma (Antoni, Baggett et al., 1991; Fleishman &Fogel, 1994). Since the beginning of AIDS epidemics, stigma and discrimination have increased the negative impact of this epidemic. HIV-related stigma and discrimination continue to manifest all over the world, creating great barriers to its prevention, further infection treatment, mitigation the effects and guaranteeing adequate care.

There is a strong link between HIV-related stigma and reported poor medical care access. Studies show that people with high levels of stigma are more likely to lack a regular pattern of HIV medicine taking. In addition, research showed that rapid disease progress is associated with a low level of social support (Leserman, Petitto et al., 2000). Stigmatization can make PLWHA abandon the right to medical care, decrease the willingness for check-ups for HIV, affecting the efforts to prevention and early treatment (Berger, Ferrans & Lashley, 2001).

For women infected with HIV, psychosocial issues like HIV-positive results, stigma, HIV testing, care issues, poverty and gender role are unique challenges and stress (Broun, 1999; Sandelowski, Lambe & Barroso, 2004). These stress elements escalate when individual infected with HIV is a woman who at the same time copes with HIV and provides care to young children (Broun, 1999). Also, women have reported hostile and prejudicial attitudes of service providers, including check-ups without their approvaland refusal to provide service (Manchester &Mthembu, 2002).

Social exclusion of people living with HIV causes negative results not only for affected individuals, but for all the societies in general. Inappropriate medical services and lack of medicine to save the life directly contribute to high levels of mortality and, therefore, to a lower level of life expectancy, greater medical expenditures and truncated family and community. Data show that antiretroviral therapy improves significantly life quality of the people living with HIV, if they start immediately the treatment (Wang, Vlahovet la., 2004). Social exclusion, which brings about deprivation of anti-retroviral treatment, or, even worse, prevention of anti-retroviral treatment due to the fear of revealing their condition, can dramatically and unnecessarily reduce life expectancy of people living with HIV and, as a result, affect the Index of Human Development.

Definition of social support and HIV/AIDS

Social support is particularly related to HIV because of the opportunities to address such issues as gender inequality which are encountered by the populations more at risk of infection (UNAIDS, 2010b). Social support for PLWHA is directly related to life quality and health (Nunes, Raymond et al., 1995). Withdrawal, refusal and isolation can threaten the hope and well-being of PLWHA (Miller, 1989). Supporting social environments, especially family and friends, directly influence on the increasing of life quality of PLWHA (Friedland, Renwick & McColl, 1996; Ichikawa & Natpratan, 2006). Informal support is the support provided by the family, friends and community as a whole.

Aim of the study

To analyze the perceptions of service providers in reference to services provided for people living with HIV/AIDS and what they suggest for meeting these needs.

Objective of the study

To analyze services that are provided for PLWHV in Albania.

To identify challenges that service providers are faced with during their work with PLWHA and their family members.

To analyze their perceptions on gender differences and service access

Background and methods

This study was conducted in the Ambulatory Center near the Infective Services, which is located in the University Hospital Center “Mother Teresa” in Tirana.

Sample

The cohort in the study consists of service providers who work in the Infective Service, as well as other service providers working in key institutions that provide services for PLWHA. The study was based on a sample of 20 semi-structured interviews with people who provide services for PLWHA. The key individuals selected for this study were professionals in the field of HIV/AIDS who work at policy and service areas for PLWHA. In fact, they were medical service providers in Infective Service Unit in TUHC, representatives of HIV/AIDS National Programme (PHI), representatives of national and international organisations working in the field of HIV/AIDS.

Semi-structured interview

Semi-structured interviews were considered as an appropriate approach to obtain free information about a series of important issues. The interviews are more flexible in obtaining information about a certain event or context, revealing the reality, attitudes and experiences expressed by the participants. Interviews were the mainstay of quality and quantity research over the decades, and, in essence, they are “conversations with an aim” (Burgess, 1984) although their form and structure can vary.

Gathering and analyzing the data

To record the sessions a digital dictaphone was used, allowing the researcher to concentrate on moderating discussion and not continually keeping notes. This enabled accurate session recording, protecting both the researcher and the participant. The transcripts were encoded and then used in analyses. Data analysis in quality research is the most challenging part, since it must be a systematic and carefully organised process. The researchers must be careful to distinguish between their observations and interpretations and what is directly expressed by the participants in the study. For this, they should follow a clear path to manage unprocessed data, their encoding (not numerically, but using expressions) so the data can be understood in the actual context and beyond it (Soafer 2002). Data were manually encoded. Transcripts were read many times, so that the researcher could become familiar with and understand thoroughly the gathered information. After the transcription, a list of all the topics mentioned in each sentence was recorded. After this process was completed for all the interviews, main topics were selected on a basis of the most important topics appearing in all the texts and the aims of research questions.

I.

Services provided for people living with HIV/AIDS

Service providers claim that they have noticed changes in the way services are provided for PLWHA. Medical staff in Infective Services in TUHC is much more supporting and cooperative with PLWHA, compared to the beginnings when stigma and discrimination of this group were much higher. Different medicines provided for free have improved life quality of PLWHA. However, some state that stigma and discrimination are still an interfering factor with the discovery of the condition so that they can seek and receive various services. PLWHA prefer to receive services mainly in Infective Service Unit in TUHC, since medical staff awareness on AIDS is greater. Services provided are not stigmatizing and the service enables medicine provision.

"*Relationship to the patient is better, understandably...that is, follow-up is better with the patient; medical follow-up. Communication has improved. You consider them sick people, like all the others, not with that famous nickname that they have HIV. There is greater care for them. Understandbly, because we know even their greater problem, since, well...their immunity is weaker. Other...even from the psychosocial viewpoint it seems to me that there is greater support provided. The therapy they receive is for free.*" (Infective Service in TUHC, doctor, 7)

All the interviewed service providers are worried about the frequent lack of medicines or various reagents. On the other hand, there has been a great effort from medical staff themselves in Infective Services in TUHC to provide the medicines taking into consideration the severe health consequences due to the lack of medicine.

"*Qualitatively yes, in the world and even in Albania, considering that ambulatory service here has been established only recently for the systematic follow-up of these patients starting with the first cases where their follow-up was sporadic and not so properly planned or scheduled. Recently, the follow-up of people with AIDS is done in the most perfect way possible based on the objective conditions or opportunities in Albania, considering even the frequent lack of reagents to determine patient's immune condition, as well as the lack or shortage of medicines and their arrival.*" (Infective Service in TUHC, doctor, 2)

Medical staff of Infective Service in TUHC that works with and continually supports PLWHA takes a positive attitude towards these people as information and understanding about this condition has increased in the last few years. The services, attitudes and information level about HIV/AIDS have changed for medical staff and there is a continuous effort by this institution to inform and make other professionals, family members, relatives and PLWHA themselves aware of this condition.

At the beginning of the treatment of this disease, nurses were most afraid since they were less informed about it. Gradually, they started to accept it as they are now more informed, but nowadays they also are offered positive and nondiscrimination models of providing services by the doctors.

"*In the past we were afraid, we couldn't touch them. We used to get away, whereas now we don't.*" (Infective Service in TUHC, nurse, 11)

There are greater difficulties when PLWHA have to receive medical service outside the Infective Center in TUHC. There are cases reported by medical staff and psychosocial service providers which show how medical services have been refused for PLWHA. Often, administrators and medical staff in Infective Center in TUHC need long periods of time to communicate and negotiate with other specialists outside Infective Center in TUHC in order to provide the appropriate service for PLWHA.

Challenges that service providers encounter

Medical service providers face many difficulties on their work with PLWHA since there are lots of barriers and difficulties that are associated with the disease. Difficulties can arise from PLWHA themselves because they fail to really understand and evaluate their level of morbidity; from their relatives or other formal or informal sources as the level of stigma and discrimination continue to be high. The majority of PLWHA are diagnosed at late staged of the disease and this makes the therapy less likely to being successful. Lack of information and the very low level of volunteer check-ups make PLWHA ask for infective service only when they have severe health problems, for which they could not get proper care in other hospitals/health care centers or when they have been referred by different professionals to be treated in Infective Service in TUHC. Low rate of volunteer check-ups in other towns of Albania is associated even to the fear of inconfidentiality as the likelihoods to be recognized or identified are greater compared to Tirana.

"*We still have a diagnosis in late stages, and this is the reason that the rate of therapy success is not very high. In over 90% of the cases, diagnosis is at a stage when there are changes, either immune ones or clinical. This is because of the lack of information, lack of provision or access to volunteer check-up. In Albania, there isn't any mere check-up strategy to instruct us on what we should do to identify these individuals as soon as possible and send them to treatment.*" (Infective Service in TUHC, doctor, 1)

There are also cases when partners have postponed the check-up of their partners due to the fear of them leaving the family, their reaction, attitude, etc. Medical and psychosocial staff should put a lot of effort into convincing PLWHA on how important it is for their wives/partners to have a check-up. There is a continuous insistence on the partner himself to understand and bring the partner as soon as possible to be diagnosed and evaluated and it could be necessary even for the children to have check-ups.

"*We have quite a lot of couples with quite a lot of problems. And I have had cases that were, in general men firstly, who haven't brought their partners for a long time. They haven't brought or said that we are...we don't have partners, then later they have become aware and told the truth. But there are even cases when they said "we are married" and only after a lot of effort they brought them, because it is a great challenge to him. Often it gets them to split up*."(Infective Service in TUHC, doctor, 9)

Continuing antiretroviral therapy is a great challenge as PLWHA should receive it during all their lifetime and should follow regularly every piece of advice given by medical staff. Level of perception on the disease and the importance of regular regime of medicine, frequent examinations, a healthy sexual life, etc., varies from one person to another. There are individuals who are very collaborative since the beginning and establish a strong belief relationship to medical staff, but there are also individuals neglect or avoid contact to the doctor, do not understand their condition and do not take their medicines regularly, and this makes their health condition worse and makes their treatment difficult.

Like PLWHA that need medical, social, psychological support, even their family needs a constant care. Behavior and health condition of PLWHA should be considered in complexity and its impact in family environment. Family should be supported in order to continue its normal functioning and to provide support for PLWHA.

"*There are patients who are really open-minded, and there are patients who are so withdrawn and who don't complain or say anything and then you learn that a major disease has broken out, which are associated with HIV, and this happened only because the person didn't complain. Of a great value is the doctor who communicates with the patient. If you don't create a warm environment, where he can come and feel comfortable, and have confidence...confidence is the key. Each patient has his own specific points, that is, somebody needs to talk, somebody else needs only a visit, so you should get to know the patient in many aspects, to provide help and provide the maximum.*" (Infective Service in TUHC, doctor, 9)

There isn't any national programme on the prevention of transmission from mother to child, hence, there are still children being diagnosed with HIV/AIDS. Stigma and discrimination are considered as two causes for pregnant women not having check-ups.

Frequent medical inconveniencies add to the difficulties that medical staff encounter as they should face even the reactions and dissatisfactions of the patients and their families. Medical staffs themselves are dissatisfied with the delays of medicines since they know that discontinuing the treatment has serious consequences on the health condition of PLWHA.

"*Difficulties start from medical inconveniencies and so on. Difficulties in communication with family members, with the patient, we have to plead for 2 examinations, although it is easier now*." (Infective Service in TUHC, doctor, 8)

Referring PLWHA to other specialists is associated with some difficulties due to the fear and unwillingness shown by these professionals to treat PLWHA. Medical staffs of Infective Service in TUHC and the administrators very often have to do a convincing and informing job so that PLWHA can be accepted and provided services even in other health care centers. There are rare cases when, despite the medical staff of Infective Service in TUHC insistence to convince other specialists, PLWHA have not been provided the necessary treatment.

"*We have problems of course with other colleagues when there is a need for their intervention, surgery for example. When they learn about it, it's very difficult to convince them, or obstetrician, or...however, we have positive results. The situation has changed, but it has been an absolutely divorce. They didn't touch them, didn't operate on them, they didn't do it, because they dreaded it, because the blood spread, etc. We have had such problems that, to be honest, are improving*." (Infective Service in TUHC, doctor, 6)

Cases of patients discontinuing the therapy are not rare, despite the great job by the medical staff to explain them the consequences of that. Reasons for discontinuing the therapy can be various like economic problems to pay for the transportation when they don't live in Tirana, fear of being detected by the family in cases when their family haven't learned about their condition yet, as when they feel better and they think that they have cured, lack of proper information by medical staff, their job if they are employed, etc. There are even cases when PLWHA should start the therapy immediately since they arrive at late stages of the disease, so the time available to inform and make them aware of the importance of a regular regime of medicines is limited.

Communicating the diagnosis is still one of the most difficult moments because the dramatic way it is expected is very severe. The doctor is still considered as one of the most reliable figures by the patient and communicating the diagnosis causes other reactions compared to the case when the diagnosis is communicated by a social worker. The doctor is considered more acceptable by HIV-positive individuals to communicate and discuss about their condition as PLWHA come into contact firstly with the doctor. Communicating the diagnosis requires time and training for the doctors in the way they are going to share the information with PLWHA or their families, if this is approved by the HIV-positive patient. Medical staff doesn't always have the required time available and the necessary skills to share the information.

In some cases there are patients who do not approve of speaking to social worker or psychologist despite the insistence of the doctor on meeting and talking to them. There is some resistance initially since the fear of being exposed in many patients is considerable. There is great pressure on doctors by the families to communicate them the diagnosis of their family member, while it is the patients' right to communicate their disease.

In the beginning, the patient has to communicate his/her partner the diagnosis and it is often hard to convince them to talk with their partners as soon as possible. According to the law, the result of HIV-positive testing is communicated to the spouses or cohabitates of the examined individual. There are patient who do not return to continue their treatment or check-ups as their health condition is good event though they are diagnosed HIV-positive. Service providers report a lack of Acts which would enable law enforcement for HIV/AIDS and meeting the needs of PLWHA and their families. Even local government structures in other towns of Albania don't have the necessary capacities and abilities for the administration of HIV/AIDS cases and to provide social and psychological support.

"*There are no guidelines to enforce laws. There is a lack of Acts. Laws must be accompanied by financial means to enforce the law. Theoretically it is Ok, but practically there is no benefit.*" (Public Health Institution, employee, 19)

Gender differences

Women and girls are more prejudiced, stigmatized and discriminated than men when they are diagnosed with HIV/AIDS. This is related to gender roles that women and girls play in the family and society, and to expectations that they should be available to create healthy families. The presence of HIV/AIDS in women and girls is considered as societal norms' violation and family code's violations, whereas in boys and men it is considered more acceptable and normal.

"*It is very difficult for a woman, because stigmatization is much greater. We are Albanian and when you learn that a man has a relationship there is no fuss, but when you learn about a woman having a relationship it is a great issue. I mean, even when this is not associated with the disease.*" (Infective Service in TUHC, nurse, 15)

In most cases, the infected women are victims of transmission from their husbands, partners and they are not the infection source themselves.

"*Women are known to be more stigmatized, that is, for a woman they say 'she has had a lot of men'. While men are seen in a different way.*" (Infective Service in TUHC, doctor, 7)

In most cases, the woman is supportive and takes care of her partner during all her lifetime. The care and support that she offers is very important and in general women are seen as the first source of support for HIV-positive partners and they consider them to be the most reliable people with whom they share information about their condition.

"*Taking into consideration the case when the husband is ill and the wife is ill, it is absolutely dominated by the perfect care the wife takes of her husband when he is ill, and it is less when the wife is ill. I would say for sure that women take invaluable care and they deserve much greater things compared to males, toward the patients.*" (Infective Service in TUHC, doctor, 4)

Conclusion

Overcoming difficult situations is easier if there are formal and informal supporting networks. Social support guarantees extra benefits that compensate negative situations. Regarding HIV/AIDS morbidity, there are differences in family attitudes due to considerable stigma, discrimination and prejudice associated with this disease. Service providers report even some cases when family members abandoned PLWHA because of their incapability to understand and accept this condition. HIV/AIDS in considered as a big punishment for inappropriate sexual behavior and societal norms' violation, which is perceived more unacceptable for girls and women than men and boys. Service providers claim that in most cases the infected women are victims of transmission from their partners and they are not the source of infection themselves.

Medical service providers claimed that detection of HIV is a difficult moment due to the lack of information and the presence of unjustified stigma among population in general. Fear of being exposed negatively influences on personal behavior. People avoid check-up because they doubt the loss of privacy by corresponding services. People avoid taking antiretroviral treatment because this can lead to their recognition by accident if the others see them taking the medicine.

Formal support is occasional and very individual as it is based on the possibilities and specific characteristics of each family. Formal services are more organized and serve to specific needs of PLWHA. Medical formal services in Infective Services in TUHC have offered a modern model of medical support for PLWHA. Despite the frequent absences, engagement and commitment of medical staff is much greater since they acknowledge the barriers and difficulties that are associated with HIV/AIDS morbidity.

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