CASE SERIES

Disclosure of Human Immunodeficiency Virus Serostatus to the Patient; Issues for Laboratory Staff

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ABSTRACT

Background: The disclosure of positive HIV status to a patient is not an easy task. In the developed world with established protocols for doing this, it becomes relatively simpler to present the results to the patient. In the underdeveloped countries like Pakistan, it is not easy for the laboratory personnel in particular to convey such results to the patient.

Case Presentation: The problem has been discussed in the light of two cases presenting to Shalamar Teaching Hospital. The first case is an example of "Provider referral" and the second one the "Self-referral". At the end, recommendations are made to effectively handle the situation in an underdeveloped setup like Pakistan.

Discussion: Complete knowledge of the disease is an essential requirement for anybody from the pathology department contemplating this responsibility. In addition, all communications should be in local language and the counselor must be able to address all the questions/concerns raised by the patients and/or their families. The counselor learns the skill more through supervised training rather than a taught course.

Conclusion: This responsibility should be accepted only if the laboratory staff has no other option.

Key Words: Laboratory staff, HIV serostatus, Disclosure of Result, Positive result

INTRODUCTION

The disclosure of HIV positive blood test to an infected person has never been an easy task for health care workers (HCWs). In the developed world, most of the healthcare systems have a dedicated facility like Sexually Transmitted Infections (STI) Clinic, Genitourinary Medicine (GUM) Clinic or Sexual-Health Clinic, where testing and counseling services are provided for HIV and other STIsby properly trained and experienced staff[1]. Once the diagnosis and treatment/management options have been discussed with the patient, the services of an HIV-AIDS counselor are also at hand to provide self- and family support to the newly infected individual so that he/she can cope with unexpected HIV diagnosis and its associated social and psychological repercussions[2].Recently, on-line counseling services have also been made available for those living with HIV in UK[3].In contrast, the situation is very different in our set up. Although dedicated HIV-AIDS Clinics have now been established in some public sector hospitals in large cities like Lahore, many patients may still be unaware of the existence of these facilities and end up presenting directly to Out-patient Departments (OPD) of hospitals as "self-referrals". Once the HIV test has been initiated in the laboratory and found to be reactive, the staff will have to request a second sample from the patients to confirm the results. After the reactive HIV antibody status is confirmed by repeating test on the second sample, laboratory personnel are expected to disclose and explain the HIV results to the patient. Some of the issues faced by the laboratory staff at the time of disclosure of sensitive HIV antibody status, to the patient, will be discussed in relationship to the two case reports below:

CASE 1

A 32-year-old male, farmer by profession, married for six years and having two children aged five and two years, had been having fever for six months. He noticed gradual loss of weight and increasing fatigue. Lately, fatigue was so severe that he was

unable to do his daily chores without the help of his parents and pregnant wife. He was clinically diagnosed as a case of Typhoid fever by a General Practitioner, who prescribed many antibiotics but without much relief. At this stage, screening tests were carried out for Hepatitis B virus (HBV) and Hepatitis C virus (HCV). He was referred to the Tertiary Care Hospital in Northern Lahore, after he tested positive for HCV. Here, he was advised to have the HIV antibody test also. In the Pathology lab, the initial results revealed that he was reactive for both HCV and HIV. As the HIV antibody reactive results require confirmation by repeating test on a freshly drawn sample as explained above, the patient was contacted by the laboratory staff to submit the sample. It was at this time that all clinical information narrated above was obtained from the patient by the Consultant Pathologist. The confirmed HIV antibody reactive result was later disclosed to the patient in the presence of his parents and wife, on his request. The patient had been escorted by his family to collect the results as he was too unwell to do this on his own and the laboratory would not release the reactive HIV antibody results to any other person except the patient. (The patient was then referred to the public sector HIV-AIDS clinic for further management).

CASE 2

A sample was submitted at the Pathology laboratory of a Tertiary Care Hospital by a 30-year-old male, for determining the serostatus for HBV, HCV and HIV. He had no symptoms and the only reason he was submitting a sample was to reassure his wife who discovered after getting married three months back, that her husband was an intravenous drug user. When the laboratory called for submission of a fresh sample from the patient for confirming reactive HIV antibody result, it was his wife who took the message for him. She informed the laboratory staff that although her husband had provided the first sample he was not willing anymore to submit another sample for confirmation of results. As the laboratory requires a repeat sample for confirmation of HIV serostatus, the unconfirmed HIV result had to be released with a disclaimer. In this case, sensitive HIV antibody reactive results had to be shared with the wife of the patient, on the phone.

DISCUSSION

The first case presented here is an example of "Provider-initiated HIV Testing" as mentioned in 2013 document published by National AIDS Control Program[4]. These cases are the ones for which HIV testing has been suggested by a healthcare provider as a result of medical care in any healthcare institution. In contrast, the second case is an example of "Client-initiated HIV Testing"[4]where a client is actively seeking HIV testing of her spouse after discovering that he is an intravenous drug user. Both these cases highlight a specific issue relating to the disclosure of reactive HIV antibody statusto the patients or their families, in the laboratory environment. Currently, there are no guidelines or documents available that provide specific information to the laboratory staff involved in such encounters. In the West, before contemplating HIV testing, Pre-HIV test counseling covers aspects like the patient's access to all types of information in the form of frequently asked questions before he/she decides to go ahead with the test. The patient knows exactly what to expect from the laboratory results and how to get further help in case he/she is found to be infected with HIV. In contrast, in Pakistan, situation is quite complex. Firstly, the patients do not have any idea about the type of infection they have contracted or how it was transmitted to them and where to seek medical help. Secondly, many cases are direct referrals by the patient himself/herself. The lab staff is, therefore the first to inform patients about HIV reactive results. Because of the awareness campaigns and high literacy rate in the developed societies, almost everyone understands the gravity of such a diagnosis and also knows his/her rights as far as the confidentiality issues are concerned. As, there is a legal binding on the HCW these results cannot be divulged or discussed even with close family members[5]. If a Clinical Laboratory Specialist or Microbiologist has to disclose the result to a patient testing positive for Anti-HIV antibodies, he/she must have the required knowledge about not only the diagnostic criterion but also the treatment options available and how to

reach them[6]. The expertise may be gained more with supervised counseling rather than undergoing a formal training program[7]. In addition, knowledge of the local language(s) may be an asset to good communication. The counselor should start the discussion with open ended questions and must allow the patient to describe his/her condition first as it may lay the foundation for further discussion. Moreover, the counseling session should be used as an opportunity to fit the immediate needs (treatment issues), concerns (informing the partner(s) and/or family), or challenges of a client (job, transmission to near ones, getting pregnant etc)[8]. Out of a total (36.9 million) global burden of HIV infected individuals, Pakistan is estimated to have 150,000 people living with this infection. The burden of HIV newly infected individuals has increased from 14,000 in 2010 to 20,000 in 2017. In the same period, the annual mortality has increased from 1,300 to 6,200, clearly showing an upward trend. On the other hand, only 15% of these infected individuals know their HIV status and only about half of them (8%) are receiving antiretroviral therapy[9].Thisleaves a staggering figure of 85-90% of HIV infected individuals who are either undiagnosed or untreated. This clearly reflects the gravity of situation and necessitates the need of well-designed and well-placed counseling and testing services, if we wish to run a successful HIV prevention program in countries like Pakistan.

CONCLUSION

Breaking the news to a newly diagnosed HIV infected client/patient is a difficult task. A Pathologist/Microbiologist should undertake this responsibility only, if it is unavoidable. Complete and accurate knowledge of the disease is a key to successful counseling and adds to the confidence of the counselor to talk about it.

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