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When good news is bad news: psychological impact of false positive diagnosis of HIV — Source link

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AIDSIMPACT SPECIAL ISSUE: WHEN GOOD NEWS IS BAD NEWS: PSYCHOLOGICAL IMPACT OF FALSE POSITVE DIAGNOSIS OF HIV

Abstract:

HIV testing is known to be stressful, however impact of false positive HIV results on individuals is not well documented. This is a series of four case, who developed psychological difficulties and psychiatric morbidities, after being informed they had been misdiagnosed of HIV positive status. We look into documented cases of misdiagnosis and potential risks of misdiagnosis. The case series highlights the implications a false diagnosis HIV positive status can have, even when the diagnosis is rectified. Impact of misdiagnosis of HIV can lead to psychosocial difficulties and psychiatric morbidity, have public health and epidemiological implications and can lead to medico-legal conflict. This further reiterates the importance of HIV testing carried out ethically and sensitively, and in line with guidelines, respecting confidentiality and consent, and offering counselling pre-test and post-test, being mindful of the reality erroneous and false positive HIV test results. The implications of misdiagnosis are on the individual, their partners and social contacts, as well as for the community.

Aim:

To report the psychological impact of notification of the confirmed HIV negative status to people who had previously been diagnosed with HIV positive status. We looked into the potential sources of mistaken diagnosis with HIV testing and explored the impact of erroneous results from the psychosocial, epidemiological and medico-legal domains.

Background:

The UNAIDS/WHO 2006 AIDS Epidemic Update, with an estimated 39.5 million people are living with HIV [Global AIDS epidemic continues to grow]. There is increased initiative for HIV testing [e.g. WHO and UNAIDS issue new guidance on HIV testing and counselling in health facilities, 2007]. The United Nations and WHO published a policy statement in 2004, stating the importance of three- Cs in HIV testing- Confidentiality, Counselling, and Consent. In the United Kingdom both the General Medical Council ['Serious Communicable Diseases' 1997] and the Department of Health [Guidelines for pre-test discussion on HIV testing, 1996] had published documents with regards to HIV testing emphasizing both pre and post-test counselling.

HIV testing is taken seriously not only because of the epidemic nature and high mortality of the illness, but also the psychological impact of HIV testing itself. HIV-positive result is associated with psychological morbidity (Catalan 1995). This is acute after initial diagnosis (Leiberich 1997) with gradual adjustment over time (Pedersen and Elkit 1998). Diagnosis of HIV also affects relationships, occupation, social stigma and future planning. Suicidal ideation is associated with testing process of HIV. Though there is a reduction in suicidal ideation in testing negative, there was no increase in risk with testing positive. Suicidal ideation was

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found to persist with pre and post test counselling in over 15% of seropositive and seronegative individuals (Perry et al 1990).

We found a series of five cases (Gill et al 1991) and few case reports of erronous HIV diagnosis (Vernon 1987, Zumwait et al 1987, Tyson 1987, Wu et al 1988). The risk of false positive results increases in low risk population screens (Meyer and Pauker 1987). A newspaper article referred to a man, found to HIV negative after fourteen months of being HIV positive (Gallagher, 2005).This is of relevance in screening blood donors (Altrah et al 1995). It is important that positive results are further investigated to establish a confirmed diagnosis (Mylonakis 2000).

There were no substantial data on the impact of notification of patients of false positive HIV positive status. One of the cases reported referred above (Vernon et al 1987) was noted to require psychotherapy for 'continued adjustment difficulties related to his misdiagnoses'.

A systemic review looking into long-term effect of false positive mammograms (Brewer et al 2007)found that false positive results impacted on health seeking behaviour of women. There was one newspaper report of a man who committed suicide after being falsely diagnosed of carcinoma (Brockes, 2001). Another newspaper article, reported a man misdiagnosed with cancer, spent all his money (Tozer 2007). These reports reflect the complexity with which people can respond to a false diagnosis.

Method:

Information from four medico-legal reports of cases, with erroneous diagnosis of HIV positive status were summarized. We have kept personal information to the minimumaiming to respect confidentiality. We presented with psychological impact and psychiatric morbidity pre and post-diagnosis ychiatric conditions, post-diagnosis and following revision of diagnosis to HIV negative status.

We carried out a literature search into the topic of psychological impact on people with misdiagnosis of HIV. We found minimal data in this regard. We found some data looking into impact of misdiagnosis in other conditions. We looked into psychological impact of HIV testing and potential sources of erroneous results. We carried out literature searches through the Ovid database using keywords of 'HIV testing', 'false positive', 'misdiagnosis' and 'psychological impact'. Relevant references from articles were searched. We also searched public domain data through generic Internet search engines.

Case Reports:

Case-1:

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33-years-old Caucasian heterosexual woman was found to be HIV positive following investigations in 1991. She had past psychiatric contact with the adolescent services and had suffered emotional difficulties in the context of relationship problems. She suffered from hyperthyroidism but did not have any ongoing psychiatric complains.

She initially suffered from an adjustment disorder following the positive diagnosis. From 1993 to 1995 she suffered from depression with hypochondriacal reassurance seeking behaviour with fear of developing AIDS. She experienced rejection in her relationship and discrimination in her job. She then gradually came to terms with the condition by 1996 and positively adapted her social life leading to improved mental state.

In 1997 she was re-investigated and found to be HIV negative, at a time when she was attempting to return to paid employment. After an initial couple of weeks of elation following receipt of this information, she developed a depressive episode. This was associated with anger over her predicament and anxiety of losing her newfound social circle which was based around AIDS support groups.

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Case-2

35-years-old Caucasian gay man was found to be HIV positive on a routine 6 monthly testing in 1996. He had past history of bulimia nervosa though his condition was on remission. His job involved direct health care delivery.

Following the diagnosis he suffered from depression with suicidal ideation. While struggling to cope, he engaged in risk taking behaviour (unprotected sex and harmful use of alcohol). He disclosed his HIV status and was moved to a non patient contact job, which he did not enjoy.

In 1999 he was re-tested after no confirmatory test was found in his notes. He was found to be HIV negative. Initial elation and shock soon gave away to low mood needing treatment with anti-depressant medication. He experienced anger towards perceived wasted time in his life.

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Case-3

25-years-old heterosexual Asian, who was a victim of torture seeking asylum was housed with a HIV positive person which made him anxious. Testing revealed positive HIV status in 1991.

Following the diagnosis he developed depression with obsessive symptoms. This gradually resolved but in 1993 he married under pressure from family. The marriage broke down within months due to his anxiety of transmitting HIV to his wife. He suffered severe adjustment disorder at this point. He suffered extreme shame and guilt at this ordeal. Thereafter he displayed resilience to reorganize his life and started working with victims of torture.

In 1996 he developed a cold, which he believed was sign of imminent AIDS. On seeking medical advice discrepancies appeared between his history and medical records, which led to retesting. The results confirmed a HIV negative status. He experienced anger and shock at

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this development, and regretted loss of years of his life. He developed depression with labile and irritable affect with suicidal ideation and PTSD type 're-living' symptoms of past torture.

Case-4

19-years-old woman was diagnosed of HIV positive status after travelling abroad in 1989. She had Anorexia Nervosa in her adolescence.

She developed acute stress reaction with hypochondriacal features, followed by mixed anxiety and depression. She received psychotherapy and treatment with antidepressants. She modified her career choice presuming a short life expectancy. She remained in a stable relationship but experienced sexual dysfunction. She received private care between 1990 and 1999.

She was re-tested when she moved to NHS care in 1999 and was found to be HIV negative. She experienced anger and regret for major life decisions and developed Acute Stress Reaction and Panic Attacks. Her relationship also suffered with the change of roles and expectations.

Comment:

We observed a pattern of psychological impact following the disclosure of the previous erroneous result. There was an initial period of shock and elation lasting couple of weeks, followed by a more chronic response associated with anger and resentment over perceived wasted time and opportunities. There was stress, associated with readjusting and psychiatric morbidities such as depression, anxiety and panic attacks.

Discussion:

Table 1. Potential Causes of Erroneous Diagnosis of HIV positive status

Serological Causes	Logistical Issues
1. Interpreting Intermediate results 2. 'True' False Positive 3. Pregnancy 4. Neonates 5. Immunological conditions such as SLE, malignancy 6. Infections with immunological overlap such as HBV 7. Volunteers in vaccination trials	1. Human Error such as mislabelling samples, erroneous recording of results or misreporting to patient 2. Screening not followed by follow-up 3. Seeking [confidential] testing under false name 4. Factitious Disorders

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The potential causes of erroneous diagnosis can be looked into those resulting from Serological causes and those from Logistical error.¶ ... [12]

With screening ELISA test [Enzyme Immunoassay] there is a potential for misinterpretation in determining the visual cut-off in a result (Kleinman 1998). With Western Blot test, often used as confirmatory test, there can be potential confusion in case of partial antigenic response, i.e. 'intermediate' results (Kleinman 1998). In such cases further testing in the form of Polymerase chain reaction (PCR) and or Nucleic Acid based tests (NAT) is recommended and tests repeated after three months. The 2006 UK National Guideline on document HIV testing claims: 'Observational data are limited, but in ten years of application of the 'three months rule' by all members of the UK HIV Laboratory Forum no reports of its failure have been received, and thus it is recommended that in general the three month rule continues to be applied'. It is worth noting in this context that all the cases in our study were diagnosed to be HIV positive before 1996.

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Current diagnostic protocols in the western world offer extremely sensitive and specific diagnosis. False positive rates are believed to be between 0.0004 to 0.0007% while false negative rates of around 0.0003% (Kleinman 1998). However concern remains in cases where the entire diagnostic protocol is not followed through. It is known people with 'evasive style' of coping, are at increased risk of psychiatric morbidity associated with HIV testing (Leiberich 1997). It can be hypothesized these are the people who are at increased risk of not following through the entire diagnostic protocol. There are case reports of emotional trauma in patients who chose to avoid confirmatory testing after testing positive on screening [Correspondence JAMA 1993; AIDS letter 1999], and people who were not reassured even after repeated negative tests.

Physiological conditions such as pregnancy [Doran and Parra, 2000] and neonatal state [Owens et al 1996] sensitivity and specificity of tests are reduced. People suffering from Systemic Lupus Erythematosus (Sommer 2004) are at increased risk of testing false positive. People who had participated in HIV vaccine trials might present with a challenge in HIV testing (Weber 1997). The issue of serological false negativity is beyond the scope of this article.

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The potential of false positive results magnify with less rigorous testing protocols. These would include testing in low and medium income countries where potentially due to resource constraints, more sophisticated tests may not routinely be available, to follow through, in all cases of ambiguous results.

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The UNAIDS document on testing endorses voluntary testing, diagnostic testing in the symptomatic and testing in high-risk groups. It does not support but recognizes the presence of mandatory testing, such as testing associated with employment, or in certain countries joining armed forces or for immigration. These settings raise concerns surrounding the ethics

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of consent, confidentiality, counselling, and the level of sensitivity with which results are feedback, as well as the rigor of testing protocols in such situations.

The United States Food and Drug Administration first approved home kits in 1996. In 2006 the FDA clarified in a public statement that The Home Access Express HIV-1 is the only home-kit it approved. Oraquick and Orasure are two other brands available in the UK. The approved home kits claim 100% sensitivity but we were not able to obtain information regarding risk of false positivity or false negativity. It is difficult to regulate the home kit market. There are brands, which have been declared fraudulent (e.g. Globus Media of Canada, Lei-Home kit from Carolina, US). There are also ethical considerations surrounding effectiveness of counselling along with self-test kits, without face-to-face contact. In the UK the Terrance Higgins Trust supports public access to self-test kits, and the UK Government posted a technology note in this regard (Medical self test kits, 2003). In 1992 the government had banned HIV self test kits in UK.

There is increased emphasis on improving access to HIV testing, such as with public health and voluntary sectors (Dialogai in Geneva). There is an increasing risk of HIV testing being carried out without the rigor it deserves, and thereby increasing risk of error. Public health authorities are promoting testing and initiating policies based on sero-status (e.g. sero-sorting). These can have immense public health implications in all countries.

Conclusion:

With recent increased emphasis on HIV testing as evident from the WHO document, there is a need for increased awareness both among public health authorities as well as in individuals of the reality of false positive test results and potential for error in diagnosis. We need to be mindful of the ethics behind HIV testing and ensure application of the rigorous testing protocols. Diagnosing someone as HIV positive has huge implications in medical, psychological and social domains for the individual. It has implications in terms of epidemiology. As obvious from the very basis of our study, there are medico-legal implications for the health care provider testing for HIV. There are also medico-legal implications for the individual in terms of insurance and disclosure.

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Zumwait, R.E., (1987) Fraudulent AIDS, Journal of American Medical Association, 257, 3231

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notification and highlights instances where this can have potential grave impact of such an event.

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Described below is a case series of four cases known from

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. Information on the cases was obtained from their medico-legal report.

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prepared by one of the authors [Cases 2, 3 and 4] and by another psychiatrist [Case -1].

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psychological impact and psychiatric morbidity,

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of informing

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patient of

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positive status.

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and diagnosis

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under current diagnostic practices around the world. Searches were

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The potential causes of erroneous diagnosis can be looked into those resulting from Serological causes and those from Logistical error.