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Understanding factors behind the late testing and diagnoses of HIV: A review of the international literature.

Abstract

Late diagnosis of HIV results in increased morbidity and mortality and raises the potential for onward transmission to others. It also increases costs to health service providers and impacts on national health budgets. This paper reports results from a literature review conducted to inform the conduct of an international study investigating barriers to early HIV testing from the perspectives of both patients and healthcare professionals. The literature suggests that reasons for late presentation include demographic factors such as age, sex and ethnicity; fear and stigma associated with an HIV diagnosis; and individual risk appraisal, as well as structural and organisational barriers within the healthcare system. Other key issues highlighted by the literature review include the fact that: the number of people living with HIV is increasing year on year, the proportion of people presenting with a late HIV diagnosis is increasing not only in MSMs but also in other less recognised groups such as heterosexual women and in particular, older heterosexual men and women. Reasons for late presentation and diagnosis are multifactorial, but further research into the issue of late presentation and diagnosis of HIV is required, including the exploration of reasons why people continue to present late. The review indicated that further work to raise public awareness of the benefits of early testing, together with improved education and training for healthcare professionals is vital to improve the uptake and timeliness of HIV testing.

Key words: HIV testing, late presentation, late diagnosis, risk appraisal, barriers, health education.

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Introduction

Late diagnosis of HIV is detrimental to patients, resulting in increased morbidity and mortality, increased risk of onward transmission and higher costs for national health budgets [1]. This paper outlines the results of a literature search undertaken to inform the development and conduct of the EU INTERREG IVA Channel Programme project, 'Understanding factors behind the late testing and diagnoses of HIV'. The study, recently completed, elicited both patients' and healthcare professionals' understanding and experiences of factors determining whether to ask for, or recommend an HIV test in Kent and Medway in the UK, and Picardy in France.

In 2012, Public Health England estimated the number of people living with HIV in the United Kingdom to be 98,400 [2], of which approximately 20% were unaware of their status. Forty-seven percent of the 6,360 newly diagnosed people were identified at a late stage (CD4 count <350 cells/mm³ within three months of diagnosis). In 2014, the number of new diagnoses had risen to 6,509 - the highest figure in both European Union (EU) and European Economic Area (EEA) countries [3]. This is almost twice the number of new diagnoses in Italy (3,861), Germany (3,525) or Spain (3,366), and whilst the rate of new diagnoses, 10.1 per 100,000 of the population is not the worst in either the EU or EEA area, it is still the fifth highest when adjusted for reporting delay and adjustment coefficients behind Estonia (22.1/100,000), Latvia (17.3/100,000), Luxemburg (14.8/100,000) and Portugal (11.8/100,000), which all have much smaller populations [3]. France had 6,372 new diagnoses in 2012 although it did not supply data for the later WHO data [4, 5].

If diagnosed early, HIV patients derive more benefit from the newer, highly active antiretroviral therapies [6], so that early diagnosis and treatment can result in a near-normal lifespan [2]. Recent increases in the uptake of routine HIV testing within sexual health clinics and antenatal care has significantly reduced the proportion of people diagnosed late across all

exposure groups [2]. Nevertheless, the proportion of late diagnoses in the general population remains high, underscoring the need to increase HIV testing in other healthcare settings [2]. However; substantial barriers to HIV testing remain at individual, societal, medical and public policy levels in the UK and elsewhere [7], and an understanding of such factors is critical to the development of effective programmes and treatment strategies [8]. The literature review described below was conducted therefore, to inform the development of a mixed methods study to elicit barriers to early testing so that specific guidance for clinicians and public health providers in both France and the UK could be developed and a public health campaign launched to coincide with the national HIV testing week and World AIDS Day at the end of 2014. The results of the study, which concluded in 2015 can be seen in a report published by O'Connor et al [9].

Method

The databases used to source relevant literature included PubMed Central, CINAHL, EBSCOhost, SAGE Journals, and Wiley Online Library. The literature search was conducted using the search term 'HIV' narrowed with the additional terms: 'late presentation', 'late diagnosis' and 'late testing' (Table 1). Fairly broad criteria were developed to ascertain whether the papers sourced were suitable for inclusion in the literature review including primary research describing healthcare professional or patient/service user viewpoints, literature reviews, and a range of national or international opinion papers. These were reviewed to identify key themes which would aid the formulation of semi-structured interview schedules for healthcare professionals and service users, and a retrospective patient record analysis of 240 patient records in Kent and Medway as part of the study and an equivalent number in Picardy.

Table 1: Results of the literature search

	Number of papers retrieved				
	PubMed Central	CINAHL	EBSCOhost	SAGE Journals	Wiley Online Library
Search terms					
HIV + late testing	27	9	43	13	4
HIV + late presentation	249	7	195	133	6
HIV + late diagnosis	520	22	271	135	10

Findings

A small number of papers considered the issue of late testing and diagnosis internationally though the majority of primary research papers provided single country perspectives. Four opinion papers were reviewed as these were frequently cited by other authors [7, 10, 11, 12], and 3 literature reviews were also analysed as these provided both global and European perspectives on the issue. Interestingly, primary research papers focused exclusively on patient perspectives and none elicited the views of professional health carers. These were mentioned in passing in some, although they did not form part of the sample. Most of the quantitative studies included large, non-homogenous samples, whereas qualitative studies had smaller samples which generally encompassed participants from both high and low-risk populations. Tables 2 and 3 provide a broad overview of the papers reviewed.

Table 2: Literature reviews included in the analysis

Author	No of papers reviewed	Demographic factors	Risk appraisal	Fear or emotional responses to HIV	Concerns about stigma	Perceived treatment efficacy	Specific issues for migrants	Structural and systemic barriers to testing
Adler et al (2010)	63 articles sourced 22 countries surveyed	yes	no	yes	no	no	yes	no
Mukolo et al (2012)	36 articles	yes	yes	yes	yes	yes	no	yes
Savasta (2004)	67 articles	yes	yes	yes	yes	no	no	yes

Table 3. Summary of research papers reviewed

Author	Country	Sample details			Themes covered						
		Patients	Health carers	Sample size	Demographic factors	Risk appraisal	Fear and emotional responses	Concerns about stigma/ stereotyping	Perceived treatment efficacy	Specific issues for migrant populations	Structural and systemic barriers
Antorini et al (2010)	Europe	no	no	no	yes	no	no	no	no	no	yes
Bonjour et al (2008)	Venezuela	yes	no	225	yes	yes	yes	yes	no	no	yes
Branson et al (2006)	USA	n/a	n/a	n/a	yes	no	no	no	no	no	yes
Camoni et al (2013)	Italy	yes	no	7,300	yes	no	no	no	no	yes	no
Carrizosa et al (2010)	Mexico	yes	no	362	no	no	yes	yes	no	no	no
Casau (2005)	USA	yes	no	unstated	yes	no	no	no	no	no	no
Castilla et al (2002)	Spain	yes	no	30,788	yes	no	no	no	no	no	no
Delpierre et al (2007)	France	yes	no	unstated	no	no	no	no	no	no	yes
Dowson et al (2012)	UK	yes	no	17	yes	yes	yes	yes	no	no	yes
Garcia de Olalla et al (2011)	Spain	yes	no	2,507	yes	no	no	no	no	yes	
Girardi et al (2007)	Global (various)	yes	no	unstated	yes	yes	no	no	no	no	yes
Hanf et al (2011)	French Guiana	yes	no	398	no	yes	yes	no	no	yes	yes
Johnson et al (2010)	Europe (various)	n/a	n/a	n/a	yes	no	no	no	no	no	yes
Krentz et al (2004)	Canada	yes	no	241	yes	no	no	no	no	no	
Lo et al (2011)	Taiwan	yes	no	227	yes	yes	no	yes	no	no	yes
Pereira et al (2011)	Brazil	yes	no	492	yes	no	no	no	no	no	no
Schrantz et al (2011)	USA	n/a	n/a	n/a	no	no	no	no	no	no	yes
Schwarz et al (2011)	USA	yes	no	41	no	yes	yes	no	yes	no	no
Sudarshi et al (2008)	UK	yes	no	108	no	no	no	no	no	no	yes
Sullivan et al (2005)	UK and Ireland	yes	no	977	yes	no	no	no	no	no	yes

Vives et al (2012)	Spain	yes	no	4,651	yes	no	no	no	no	yes	no
Wohlgemut et al (2012)	Scotland	yes	no	165	yes	no	no	no	no	no	yes
Yang et al (2010)	USA	yes	no	unstated	yes	no	no	no	no	yes	no
Yazdanpanah et al (2010)	Europe (various)	n/a	n/a	no	yes	no	yes	no	no	yes	yes

The main themes elicited from the literature review regarding the factors behind late testing and diagnosis tended to cluster around the following:

- Demographic factors

- Individual risk appraisal

- Fear and emotional responses to a possible diagnosis

- Concerns about stigma and/or stereotyping

- Specific issues for migrant populations

- Structural and systemic barriers to testing

Demographic factors

Age was a consistent demographic correlate. Each of the 36 studies reviewed by Mukolo et al [8] associated older age with late presentation. This concurs with primary research data showing that older individuals generally do not perceive themselves to be at risk, and consequently, are less likely to be tested for HIV than young people [13, 14]. Low socio-economic status as indicated by employment/occupational status or level of education was also widely correlated with late presentation, often overlapping with racial, ethnic and immigration status which, together with language barriers or lack of knowledge about the services available made it harder for subjects to access testing.

Although men who have sex with men are at the highest risk for HIV infection overall, they are often less likely to present late [11]. Mukolo et al [8] and Adler et al's [15] literature reviews show that males (particularly heterosexual males) are consistently at greater risk of being diagnosed late in most countries. This could be due to womens' higher perception of risk, a greater propensity to access health services; or the likelihood that they will be offered HIV testing during pregnancy leading to earlier diagnosis as posited by Garcia de Olalla et al. [16].

Living in a region with low prevalence of HIV increases the risk of late HIV diagnosis [15]. This is certainly true in the UK where the highest rates of late diagnosis may occur outside London [9]. Similar patterns have been found in other countries, for example, in France, where late presentations may also be higher outside Paris and the Île-de-France area. Suggested explanations for this pattern are provided in Adler et al's literature review [15], which inferred that risk is perceived to be lower in areas with low prevalence and where stigma of having a test may also be present. A variety of primary studies have identified additional variables associated with late HIV testing or delayed diagnosis, including lower levels of educational attainment [17, 18], and having previously tested negative for HIV prior to a subsequent positive result [18].

Delpierre et al's French study [19] found that HIV infection was more common among women and in people identified at higher risk of infection, such as men who have sex with men, young people and those with multiple sexual partners. Conversely, those who were detected late tended to be older, heterosexual males in stable relationships. Other studies in both Italy and the US also conclude that older people, non-nationals and heterosexuals are at higher risk of being diagnosed late [20, 21]. These populations are not generally included amongst priority groups for testing on either side of the Atlantic, even though they may benefit from targeted programmes to encourage timely HIV testing when exposed to risk of the virus.

Risk appraisal

Denial of risk factors was a common reason for not being tested in studies carried out in the UK, French Guiana and a number of European countries [7, 22, 23]. The latter study showed a positive correlation between those who had never had an HIV test and their perceptions about the perceived efficacy of medical interventions for the illness. Johnson et al's paper [11] pointed out that being a member of a group perceived to be at low risk (i.e. anyone other than

men who have sex with men or black African) is itself a risk factor for late testing since HIV is not at the forefront of the minds of those individuals. Vives et al also recognised barriers related to lack of awareness by health professionals about the sexual history of their patients, lack of time to assess risk, and to offer or perform the test [24]. The importance of perception is also borne out by the studies reviewed by Mukolo et al, which indicate that cognitive appraisal of actual or potential risk can influence the timeliness of presentation [8]. It also shows that adolescents who considered themselves to be at high risk of infection are more likely to seek HIV testing than adults with comparable risk perceptions.

Fear and emotional responses to HIV

One study in Mexico found those who 'preferred not to know' their status had more than double the risk of late testing than those who were prepared to know the results of their test [25]. Fear of the consequences of a positive test, including anticipated pain, death, discrimination, feeling socially devalued or isolated, and diminished capacity to be economically productive can all contribute to late presentation [8, 22, 23]. Fear of HIV as a barrier to testing was also highlighted in qualitative service-user interviews conducted for our own study [9].

Concerns about stigma and stereotyping

Wohlgemut et al. warn against the danger of healthcare professionals stereotyping 'at risk' patients since one fifth of diagnoses in their study occurred in those without recognisable transmission risks [26]. Fear of disclosure, and subsequent social or legal stigma was a common reason for migrants to avoid testing in Yazdanpanah et al's study [7]. This may be a well-founded conclusion however, since Mukolo et al. suggests that decisions about testing are often made within social contexts characterised by hostility towards people living with HIV and AIDS due to deficits in knowledge about HIV transmission, prevention and treatment; and prevailing social norms and values which may stigmatise the individual [8]. Improvements in

treatment efficacy may result in some de-stigmatisation of HIV/AIDS by rendering it less threatening or disabling in key domains of life, although this area is not well researched and more evidence is needed, particularly in relation to testing [8].

Specific issues for migrant populations

Yazdanpanah et al suggest that specific barriers exist for migrants, including stigmatisation within some African communities in the UK [7]. The study showed that many still considered HIV to be a deadly disease in these communities which, aligned with the belief that HIV tests may not remain confidential would reduce an individual's chance of gaining permanent residence in the UK. Others feared that it would bring them to the attention of immigration services, but as an issue it also featured less highly than housing, childcare and employment for many of their sub-Saharan respondents. Language barriers were also found to distort health messages, in that migrants may not understand what healthcare services are available or their entitlement to them. Adler et al. on the other hand showed that a lack of advocacy for HIV infected migrants living in the UK combined with much negative publicity about UK taxpayers having to support so-called 'health tourists' also increased risk of late presentation [15]. As a consequence of these fears, the National Institute for Health and Clinical Excellence (NICE) published guidance to promote cultural awareness of these fears among men who have sex with men and black African communities in the UK with similar guidance issued at a European level [27].

Structural and systemic barriers to testing

In many countries, patient-initiated approaches continue to be the primary model for providing HIV testing and counselling. However, health facilities represent a key point of contact for people with HIV who are unaware of their HIV status [7]. Other evidence suggests that many opportunities to diagnose and counsel individuals at health facilities are being missed [28, 29].

Barriers highlighted in these studies include consent and how this should be gained, the necessity for pre-test counselling, logistical barriers such as competing priorities and policy objectives, language barriers; and lack of knowledge, education and training for healthcare professionals who may be unaware of various factors indicative of HIV infection. These include non-typical risk groups such as heterosexual men or women, older people of both sexes; and non-specific symptoms which might be indicative of HIV infection including recurrent opportunistic infections, malaise, lethargy, anorexia, nausea, myalgia, arthralgia, diarrhoea, generalised lymphadenopathy or other health problems [28, 29]. Perceived failure of primary care practitioners to address HIV-related topics with their patients can exacerbate the issue of late presentation, as can the lack of accessible testing facilities [22].

Health policy in the UK has traditionally targeted those at 'high risk' of infection, and therefore provision and funding is aimed at certain groups. For example, the Terrence Higgins Trust (THT) was only funded to offer postal HIV testing kits to African people and gay or bisexual men who live in England [30], and the majority of targeted HIV prevention excluded heterosexual males, meaning they had less information and fewer opportunities for an early test than injecting drug users, MSMs, or women attending antenatal care [8]. Indeed, most studies show that injecting drug users have lower rates of late diagnosis than heterosexuals [15], and in the UK, these make up only 2% of new diagnoses [2].

Discussion:

Although quite dated, World Health Organisation guidance recommends an 'opt-out' approach to testing, including the provision of simplified pre-test information, and an increase of HIV testing and counselling facilities [31]. In this model, individuals attending a given healthcare setting should be offered an HIV test as standard, but can decline. It is clear from evidence that this strategy is being put into place. However, many studies still argue for the need to develop

interventions that increase HIV testing and facilitate earlier entry into care, including routine screening in healthcare and non-clinical settings for patients at risk for HIV where this does not yet take place [1, 10, 16, 20, 32]. Branson et al's US study suggests that it might be feasible to include HIV testing as a routine part of healthcare practices for all adults and adolescents aged 13-64 years, as proposed by the US Centers for Disease Control and Prevention [10]. Another US study on the implementation of an HIV testing model in an Emergency Department showed that it was effective in identifying new patients, notification of results and integrating newly diagnosed patients into existing clinical care and procedures [13].

A variety of studies looking at healthcare professionals' perspectives stress the need to increase awareness and identify populations which are at risk [24]. These often support the use of mass media campaigns in raising awareness and increasing uptake of testing and signposting to services, and there is an emerging evidence base for the delivery of targeted HIV prevention messages using the internet and social media. Such technologies potentially offer greater reach in certain target populations [33]. Current examples of health promotion interventions along these lines include National HIV Testing Week in the UK in the run up to World AIDS Day. Other suggestions include improving recognition of HIV symptoms [7], financial incentives, and education programmes to motivate healthcare professionals to discuss the need for HIV testing with their patients [22, 34]. Pereira et al. suggest that nurses are important carers in this regard and could be used to increase the capacity for counselling and educational messages targeted at increasing the number of HIV tests [35]. This is in line with Dowson et al's research which suggests that a more proactive approach by healthcare professionals, including general practitioners, would increase the frequency of earlier diagnosis [22].

Schwarz et al. assert that public health campaigns to increase testing should emphasise the effectiveness, tolerability and relative low cost (free for many patients in some health systems) and the benefits of early diagnosis [36]. Greater emphasis should be made that anyone engaged

in unprotected oral, anal or vaginal intercourse should consider their need for testing even where ejaculation does not take place. Persons thus tested should be reassured that the results of their test will be kept private. In line with the WHO recommendations and research findings discussed above, current national guidelines from Public Health England additionally recommend that HIV testing should be offered routinely to everyone admitted to hospital and people registering with a GP surgery in areas of the country with HIV prevalence greater than 2 per 1000 people [2]. The guidelines also suggest that the introduction of home testing kits would also increase the uptake of early testing.

Conclusions and recommendations

The literature reviewed in this paper suggests that many opportunities to identify, counsel and test individuals at risk of developing HIV are being missed. Barriers highlighted include over complicated consenting processes and pre-test counselling requirements in some countries, lack of knowledge or information about transmission risk, concerns about confidentiality or inadequate opportunities for testing, as well as logistical barriers such as limited consultation times, competing healthcare priorities (such as diabetes or cardiovascular screening), language and other cultural barriers. It is necessary however, to increase the rate of HIV testing and facilitate speedier entry into the care system for those subsequently diagnosed with HIV.

Traditional healthcare settings will play a significant role in these developments, but there is also need to include non-clinical settings and innovative strategies to reach 'hard to reach' groups including older heterosexual men and women embarking on new relationships after bereavement or divorce, migrants who may be wary of accessing formal healthcare services, and social or cultural groups for whom discussion about HIV is still a taboo subject and where a positive diagnosis is likely to lead to stigma or exclusion. Much of this work could be led by appropriately trained nurses who could also deliver culturally appropriate health education and

promotion campaigns and point of care testing for MSMs, migrants, and black and minority ethnic groups in a wide variety of non-clinical settings. These services should be co-designed with the communities themselves, but may include campaigns or awareness raising in compulsory, further and higher education settings, pubs, clubs, saunas and other areas where sexual interest or activity may be initiated, and churches, community groups or workplaces, where more generic information might be provided to reduce the stigma associated with HIV testing and encourage people to receive a free and confidential test where they believe themselves to have been at risk of HIV transmission. These should include education about the increased prevalence of HIV in the general population as well as information about the benefits of early testing, improved treatment efficacy, and better health outcomes for those diagnosed early. They should also highlight the fact that treatments are far more tolerable and have fewer side-effects than earlier medications, and can be obtained at little or indeed no cost in most countries.

Finally, it is important to acknowledge how a lack of sensitivity, awareness or courage on the part of healthcare professionals might limit the number of early HIV diagnoses, and the need to increase their confidence and competence to offer testing to all those they consider to be at risk, as there is evidence that fear of upset or embarrassment still holds many back from making such a suggestion. There also needs to be greater willingness to explore sexual risk factors, especially in heterosexual males with unexplained symptoms indicative of HIV which continue to be missed in many cases, and better awareness of local patterns in HIV transmission, the location and availability of testing opportunities for those reluctant to visit a sexual health or genitourinary medicine clinic; and an increased willingness to discuss and carry out such tests when (for instance), registering a new patient as a means of 'normalising' such activity so that it becomes the norm rather than the exception in such cases.

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