Barriers and facilitators to HIV testing in people age 50 and above: a systematic review

Background: Approximately 13% of people living with HIV in the UK are unaware of their infection. New diagnoses among people ≥50 years is increasing. Unique factors may be associated with testing in this group. This review aims to identify patient and clinician-related barriers/facilitators to HIV testing in people aged ≥50 years.

Methods: A systematic electronic search was conducted. Papers were assessed for eligibility and data from eligible studies were extracted. Barriers/facilitators were grouped, and number of times reported was noted. Due to considerable heterogeneity, a narrative approach has been undertaken to synthesise data.

Findings: 17 studies were included. Main barriers to testing were low perceived risk, and clinicians' preconceptions about older people. Main facilitators were regular use of healthcare services or being offered/encouraged to test by a healthcare provider.

Interpretation: Although being encouraged to test was a common facilitator, clinicians' preconceptions about older people was the biggest barrier, showing a divide between clinicians' preconceptions and patient's expectations, which may impact on testing rates. This review is an important first step to identify potential barriers/facilitators for further study or to be addressed in the design of future interventions.

Key words

HIV testing
Barriers
Facilitators
Older age
Systematic Review

Introduction

Effective treatment has transformed HIV into a manageable long term condition. Despite advances in treatment, approximately 13% (95% CrI 10-17%) of people living with HIV in the UK are unaware of their infection[1]. Most new transmissions occur from someone who is unaware of their HIV infection[2] therefore

improving testing and reducing undiagnosed HIV is key to improving treatment outcomes and reducing onward transmission.

Although overall rates of new HIV diagnoses in the UK are decreasing, the number of older people (age ≥50 years) newly diagnosed with HIV in the UK is increasing.[3] Furthermore, people diagnosed with HIV aged ≥50 years are much more likely to be diagnosed late (with a CD4 count of <350 cell/mL or presenting with an AIDS defining event)[4] and continue to be disproportionately affected by late diagnosis (LD).[5] LD has significant implications for patients and health services in terms of poorer health outcomes and increased healthcare costs, both of which are increased in older age. Further, older people experience a faster clinical decline than someone younger.[6]

The high rate of LD in older people suggests unique factors may be associated with testing for HIV in this group. HIV testing guidelines suggest testing in general practice and in all general medical admissions where the HIV prevalence is high (>2 per 1000).[7, 8] However despite varied testing initiatives such as routine testing in primary and secondary care, community outreach programmes and home sampling,[9] increasing rates of LD suggest the older population are not routinely testing for HIV. Although adults remain sexually active into older age, preconceptions about a lack of sex in this group may impact on test offer rate. One UK study in a high prevalence area found that although uptake of HIV tests was high among patients admitted to hospital (>90%), older people were less likely to be offered a test by a clinician. This may partly explain the continued rise in LD among older people despite a significant proportion having seen a healthcare provider (HCP) shortly before their diagnosis.[10] This systematic review aims to specifically identify patient and clinician-related factors associated with HIV testing in people aged ≥50 years.

Method

A systematic electronic search was conducted on April 7, 2016 using MEDLINE, Embase, PsychINFO, CINAHL and the Cochrane library and relevant conference abstracts were searched. Search terms can be found in Table 1.

All retrieved articles were exported to Endnote, de-duplicated and tabulated in Excel for abstract review. Two reviewers independently reviewed abstracts to identify studies potentially meeting the inclusion criteria (Box 1). Any study published before 1997 was excluded since it was felt that attitudes towards testing would be significantly different in the pre-therapy era when an HIV diagnosis would have meant a significantly poorer outcome. Any disagreement was solved through discussion. Full text of potentially eligible studies was retrieved and assessed further for eligibility.

Box 1: Inclusion criteria

Criterion 1: Articles published since 01/01/1997
Criterion 2: Studies describing barriers and facilitators to HIV testing
Criterion 3: Analysis in adults age ≥50 years
Criterion 4: Published in the English language
Criterion 5: Published papers/reports and conference abstracts were included
Criterion 6: Studies utilising any study design were eligible for inclusion

Once relevant articles had been identified, reference and citation searching were conducted to identify any additional articles. Data from all eligible studies were independently extracted by two reviewers and tabulated in Excel from published reports. Factors associated with HIV testing reported by each study were also independently extracted and tabulated. Thematic analysis was conducted to identify systematically recurring themes/factors across the studies. Significant heterogeneity meant a narrative approach was used to synthesise data in order to identify factors associated with testing. Although an estimation of effect size was not investigated, number of times each factor was reported was noted as a way of identifying repeatedly recurring factors.

Data were then assessed for study quality by two reviewers using the standardised Critical Appraisal Skills Programme (CASP) tools. This consisted of 10 criteria each rated as met (scored 1) or not met/can't tell (scored 0). Scores were summed for each paper and they were graded as high quality (scores 9-10), moderate quality (5-8) or low quality (1-4). Any disagreement was solved through discussion.

Results

Electronic database searching identified 1752 potentially relevant papers. After removal of duplicates (n=655), 1097 were subjected to abstract review, of which 204 met the eligibility criteria (Box 1). Full text review was conducted, resulting in 14 eligible papers to be included in the review. Reference and citation searching of eligible papers yielded a further 3 papers to be included (Fig 1).

The majority of included studies were conducted in the USA (n=14), with the remainder conducted in the UK (n=1), Brazil (n=1), and Uganda (n=1) (Table 2). Studies were mainly descriptive and data were both qualitative and quantitative using a range of methodologies. Sample sizes ranged from 11 to >143,000. Studies tended to include a greater proportion of men, although 3 studies were conducted solely in women.[11-13]

Study quality ranged from 2 to 10 (Table 3). Of the 17 included studies, 2 (12%) were good quality and 12 (71%) moderate quality. Included quantitative studies lacked information on whether potential confounding factors were identified and taken into account, and whether participants were recruited in an acceptable way to avoid selection bias. Included qualitative studies lacked detail on the methodology used and reported little information on the interaction between the researcher and participants, including how this interaction may impact on bias. Three studies (18%) were low quality.

Percentage uptake of HIV testing were reported in 9 studies. Three studies reported testing rates over the previous 12 months; ranging from 3%-56%. Seven studies looked at whether participants had ever had an HIV test; which ranged from 25%-77%. One study investigated length of time since last test and found that of those who had reported a previous test, 70% had last tested >5 years before. Several factors associated with a decision to test for HIV in older people were identified (Table 4). Patient and clinician factors were separated into perceptual and practical factors as suggested in the Perceptions and Practicalities approach[14].

Perceptual factors

Patient-related factors associated with testing for HIV

Three studies found HIV testing to be associated with high perceived risk of HIV.[15-17] Conversely, one study[11] reported low perceived risk as a factor associated with testing. HIV knowledge/awareness was another commonly reported factor, described in four studies; one found people with higher HIV knowledge scores were significantly more likely to have tested for HIV,[12] and three found having greater awareness of HIV, or knowing someone with AIDS or Tuberculosis was associated with testing.[13,15,17] Two questionnaire-based studies found testing was significantly associated with reporting high-risk behaviours.[18,19] Similarly, testing to protect a partner or because a partner was HIV-positive or at high-risk were also reported as associated with testing for HIV in studies using qualitative interviews, survey or case note review.[12,17,20]

Two studies[12,17] reported testing because of 'curiosity' for example, to eliminate uncertainty about status.[12] Experiencing symptoms attributed to HIV was related to testing emerging from qualitative studies,[17,21] and perceived poorer health status was also reported as a factor associated with testing.[22] Further, belief in AIDS-related conspiracy theories was found to be a factor associated with testing in one study from the USA.[19]

*Patient-related factors associated with **not** testing for HIV*

Five studies reported low perceived risk to be associated with not testing for HIV.[12,13,15,17,23] This included the perception HIV was a young person's disease or not feeling part of a high-risk group.[17] Two qualitative studies found not having symptoms or not attributing symptoms to HIV was associated with not testing.[17,21] Stigma either relating to HIV or being older with HIV, was reported by two studies.[17,24] The same studies also reported fear of a positive result as a barrier to testing. Other factors, reported once, included government mistrust[19] and hopelessness associated with a lack of treatment.[17]

*Clinician-related factors associated with **not** testing for HIV*

Three studies using surveys or qualitative methods reported preconceived ideas about older people as a barrier to offering an HIV test to an older person. This included the perception that older people lack understanding regarding HIV,[25] that they are at less risk[16,26] or that they are not comfortable discussing sexuality.[16] Similarly, HCP feeling uncomfortable with risk factor questioning or addressing risk of older people was reported by two studies.[25,26]

Practical Factors

Patient-related factors associated with testing for HIV

The most commonly reported practical factor associated with testing for HIV was regular use of healthcare services, reported by 8 studies.[15,16,18,20,23,26-28] This included having a usual source of care,[23,27] having seen a clinician within the last year,[18] testing during hospitalisation,[26-28] as part of a routine health screen,[16,28] sexual health screen,[20] or because of blood donation.[28] Further, being offered/encouraged to test by a HCP was reported by 3 studies using survey[13,28] or qualitative methodologies.[17] Similarly, experiencing physical symptoms was associated with a decision to offer an HIV test. [17,27] Having health insurance or financial means to pay for healthcare was significantly associated with a decision to test for HIV in studies from the USA.[19,22,23]

*Patient-related factors associated with **not** testing for HIV*

People who had tested for HIV previously were less likely to test again.[12] One study acknowledged that older, menopausal women did not attend for antenatal care resulting in a lost opportunity for HIV testing[28]. Not having an HIV test suggested by a HCP was significantly associated with not testing in one survey study.[13] Finally, not liking needles was reported by one study as a barrier to testing.[12]

Clinician-related factors associated with offering an HIV test

HCPs were more likely to offer a test when a patient presented with symptoms or disclosed high-risk behaviours, indicated in a survey study[16] and study utilising a case notes review design.[20] Offering an HIV test as part of a routine check-up was reported by one survey study as a facilitator.[16]

*Clinician-related factors associated with **not** offering an HIV test*

A lack of HIV-related information, including not being able to identify an HIV clinical indicator disease and a feeling that HIV-related information was not available to older people were reported as factors associated with not offering an HIV test.[16,20,25] One study reported lack of time as a barrier.[25]

Discussion

Several factors associated with a decision to test for HIV in older age have been identified. The most commonly reported patient-related factors associated with test were frequently using healthcare, high perceived or actual risk of HIV, having some HIV-related knowledge and being offered/encouraged to test by a HCP. Conversely, the most commonly reported patient-related factor associated with not testing was low perceived risk of HIV.

Low risk perception is a commonly cited barrier to HIV testing regardless of age, highlighted in a previous review.[29] However despite disclosing HIV risk behaviours, some patients still perceive themselves to be low risk[30,12]. In the older population, this low perceived risk may be exacerbated by the perception HIV is a young person's disease.[17] Despite public opinion, evidence shows that many older people remain sexually active; one study indicated the main reason for lack of sex in this group may be due to physical limitations, not because of lack of desire or opportunity.[31] Indeed, there has been an increasing emergence of online dating sites aimed at older people.[32] Although this is not unique to older people, relationship transitions, common in older age may increase the likelihood of meeting new partners after an established relationship.[33] Studies indicate condom use among older people is low[34] which may be due to a lack of confidence in negotiating condom use when starting a new relationship, or because postmenopausal women no longer worry about pregnancy.[28] Additionally, availability of drugs such as Sildenafil mean erectile dysfunction may no longer be a barrier to sex for older men. Physiological changes in older age such as vaginal dryness, may actually put older women at increased risk of HIV.[35]

Misconceptions about older people was the most commonly identified barrier to offering an HIV test to older people, however greater engagement with healthcare was associated with testing. It is therefore salient that

HCPs preconceptions about older people or feeling embarrassed in terms of addressing their risk may prevent them for offering older patients an HIV test. This shows a mismatch between what clinicians perceive older people feel regarding HIV testing, and what they may actually feel. This phenomenon may in part be due to fear of harming the doctor-patient relationship or a lack of training on how to initiate a conversation with a patient around HIV testing.[36] This is in line with evidence from one study indicating that GPs do not feel sexual health is a suitable topic to discuss with older patients.[37] Not having a HCP discuss HIV with this group may actually reinforce their perception that they are not at risk. However, HIV tests have been repeatedly found to be acceptable to patients; one study found >90% of patients (all ages) accepted an offer of a routine HIV test, however older people were significantly less likely to be offered a test by a clinician.[9]

The themes identified in this review may be useful in designing interventions to increase testing rates in the older population. In order for intervention(s) to be successful, they will have to address patient and clinician-related barriers. Routine screening in secondary care may overcome some of the identified barriers; it would help to normalise HIV testing and expose the older population to health promotion messages, salient since a lack of HIV knowledge was also shown to be a barrier to testing in this group. This would also overcome a need for self-identifying as at-risk as everyone would be eligible to test, and may alleviate any uncomfortable feelings HCPs may have in risk factor questioning with this group. Additionally, this approach would overcome having to identify a clinical indicator disease in order to offer an HIV test, which has been suggested as one of the biggest barriers associated with non-adherence to testing guidelines in the UK.[38] However, HIV testing guidelines already suggest routine screening of all acute admissions in high prevalence areas[7,8] but increasing rates of LD among the older population suggests this is not occurring. Clinicians would therefore need adequate training and encouragement to routinely offer HIV tests.

Routine screening in primary care may also be appropriate to increase testing rates in older adults. Many interactions with healthcare services in older age occur in primary care,[39] for example for the management of comorbidities. Also familiarity with the GP may make conversations regarding HIV easier, although there is little evidence about how a relationship with a clinician might affect willingness to discuss sexual health in this group. Despite this, primary care may present a more appropriate venue for testing. However, since GPs don't always proactively address sexual health in older populations,[37] specific training or incentives may be required in order to achieve this although potential cost implications will have to be considered.

Limitations

Reviewed studies used diverse methods assessing different aspects of care meaning it was not possible to compare findings across studies, or between different populations. As a result, a narrative approach was

undertaken to synthesise data. Although this methodology is most appropriate, there is the potential for bias in terms of over or under representation of study data.

Included studies were mostly from the USA and so findings may not be generalisable, particularly to settings were healthcare services are not privatised. Further, some included studies were conducted several years ago and it is acknowledged that ongoing advances in HIV may mean factors associated with a decision to test for HIV identified in these studies may not still be relevant. Lastly, it is also acknowledged that sexual behaviour and attitudes to HIV testing is likely to vary between people age ≥50 years. However, there is little research in this area and so this review is an important first step.

Conclusion

Clinicians' beliefs that people ≥50 years are not at risk of HIV, or feel uncomfortable discussing risk were the most commonly cited barriers to test offer. Conversely, being offered or encouraged to test by a HCP was among the most commonly cited facilitators to testing. This shows a divide between clinicians' preconceptions and patient's expectations, which may impact on testing rates. These findings suggest that it is important for clinicians not to make preconceptions about risk of HIV in older people. Further, routine test offer regardless of patient age would encourage more of these patients to test for HIV. A gap between patients' perceived risk and actual risk may also need to be addressed. However there is a lack of evidence and more work is needed to verify these findings and establish which factors are relevant to the UK setting.

References

1. Kirwan P, Chau C, Brown A, Gill O, Delpech V, and contributors. Hiv in the uk - 2016 report. In: Public Health England, editor. 2016.

2. Hall HI, Holtgrave DR, Maulsby C. Hiv transmission rates from persons living with hiv who are aware and unaware of their infection. AIDS. 2012 Apr; 26(7):893-6.
3. Yin Z, Brown A, Hughes G, Nardone A, Gill O, Delpech V. Hiv in the united kingdom 2014 report: Data to end 2013. In: England PH, editor. 2014.
4. Antinori A, Coenen T, Costagiola D, Dedes N, Ellefson M, Gatell J et al. Late presentation of hiv infection: A consensus definition. HIV Med. 2011 Jan; 12(1):61-4.
5. Public Health England. United kingdom. National hiv surveillance data tables. In: HIV: surveillance dam, editor.: Public Health England; 2015.
6. Collaboration C. Differences in cd4 cell counts at seroconversion and decline among 5739 hiv-1-infected individuals with well-estimated dates of seroconversion. J Acquir Immune Defic Syndr. 2003 Sep; 34(1):76-83.
7. British HIV Association, British Association for Sexual Health and HIV, British Infection Society. Uk national guidelines for hiv testing. 2008.
8. NICE. Hiv testing: Increasing uptake among people who may have undiagnosed hiv (joint nice and public health england guideline). In: NICE P, editor. 2016.
9. Health Protection Agency. Time to test for hiv: Expanding hiv testing in healthcare and community services in england. 2011.
10. Ellis S, Curtis H, Ong EL, (BHIVA) BHA, sub-committee BCAaS. Hiv diagnoses and missed opportunities. Results of the british hiv association (bhiva) national audit 2010. Clin Med (Lond). 2012 Oct; 12(5):430-4.
11. Wigfall LTR, D. L.; Torres, M. E.; Annang, L.; Lindley, L. L.; Swayampakala, K.; Sebastian, N.; Glover, S. H.; Duffus, W. A. Hiv testing among midlife women in the deep south: An analysis of the 2008 behavioral risk factor surveillance system survey data. Journal of Women's Health. 2011 01 Jun; 20(6):933-41.
12. Akers A, Bernstein L, Henderson S, Doyle J, Corbie-Smith G. Factors associated with lack of interest in hiv testing in older at-risk women. Journal of Womens Health. 2007; 16(6):842-58.
13. Akers A, Bernstein L, Doyle J, Corbie-Smith G. Older women and hiv testing: Examining the relationship between hiv testing history, age, and lifetime hiv risk behaviors. Sexually Transmitted Diseases. 2008; 35(4):420-3.
14. Horne R, Weinman J, Barber N, Elliott R, Morgan M. Concordance, adherance and compliance in medicine taking: A conceptual map in research priorities. London: National Institute for Health Research (NIHR) Servicy Delivery and Organisation (SDO) Programme; 2005.
15. Adekeye OAH, H. J.; Onyeabor, O. S.; Hyacinth, H. I. The new invincibles: Hiv screening among older adults in the u.S. PLoS ONE. 2012 27 Aug; 7 (8) (no pagination)(e43618).
16. Barnett LC. Factors contributing to the increase in hiv/aids and late diagnoses of the virus among older adults. 2012; 72:2572-.
17. Lekas HMS, E. W.; Siegel, K. Pathways to hiv testing among adults aged fifty and older with hiv/aids. AIDS Care. 2005; 17(6):674-87.
18. Ford CLG, D. C.; Mulatu, M. S.; Gaines, T. L. Recent hiv testing prevalence, determinants, and disparities among u.S. Older adult respondents to the behavioral risk factor surveillance system. Sexually Transmitted Diseases. 2015; 42(8):405-10.
19. Ford CLW, S. P.; Newman, P. A.; Lee, S. J.; Cunningham, W. E. Belief in aids-related conspiracy theories and mistrust in the government: Relationship with hiv testing among at-risk older adults. The Gerontologist. 2013 Dec; 53(6):973-84.
20. Mensforth SG, L.; Bodasing, N.; Coultas, J. Late diagnosis among our ageing hiv population: A cohort study. Journal of the International AIDS Society. 2014 November; 3):130.
21. Siegel K, Schrimshaw E, Dean L. Symptom interpretation: Implications for delay in hiv testing and care among hiv-infected late middle-aged and older adults. AIDS Care. 1999; 11(5):525-35.
22. Wigfall L, Williams E, Sebastian N, Glover s. Hiv testing among deep south residents 50 to 64 years old with cardiovascular disease and/or diabetes. Journal of the National Medical Association. 2010; 102(12):1150-7.

23. Ford CLL, S. J.; Wallace, S. P.; Nakazono, T.; Newman, P. A.; Cunningham, W. E. Hiv testing among clients in high hiv prevalence venues: Disparities between older and younger adults. AIDS Care - Psychological and Socio-Medical Aspects of AIDS/HIV. 2015 01 Feb; 27(2):189-97.
24. Kuteesa MOS, J.; Cumming, R. G.; Negin, J. Older people living with hiv in uganda: Understanding their experience and needs. African Journal of AIDS Research. 2012; 11(4):295-305.
25. Iyer KVA, V.; Castor, T.; Malik, R.; Ehrlich, A. Physicians' screening for hiv risk factors in older adults. Journal of the American Geriatrics Society. 2011 April; 59:S200.
26. Alencar R, S IC. Late diagnosis and vulnerabilities of the elderly living with hiv/aids. Revista da Escola de Enfermagem da USP. 2015; 49(2):227-33 7p.
27. Zingmond D, Wenger N, Crystal S, Joyce G, Liu H, Sambamoorthi U et al. Circumstances at hiv diagnosis and progression of disease in older hiv infected americans. American Journal of Public Health. 2001; 91(7):1117-20.
28. Mack K, Bland S. Hiv testing behaviors and attitudes regarding hiv/aids of adults aged 50-64. The Gerontologist. 1999; 39(6):687-94.
29. Deblonde J, De Koker P, Hamers F, Fontaine J, Luchters S, Temmerman M. Barriers to hiv testing in europe a systematic review. European Journal of Public Health. 2010; 20(4):422-32.
30. Pringle K, Merchant R, Clark M. Is self-perceived hiv risk congruent with reported hiv risk among traditionally lower hiv risk and prevalence adult emergency department patients? Implications for hiv testing. AIDS Patient Care. 2013; 27(10):573-84.
31. Lindau S, Schumm P, Laumann E, Levinson W, O'Muircheartaigh C, Waite L. A study of sexuality and health among older adults in the united states. The New England Journal of Medicine. 2007; 357:762-74.
32. McWilliams S, Barrett A. Online dating in middle and later life: Gendered expectations and experiences. Journal of Family Issues. 2014; 35(3):411-36.
33. Sherman C, Harvey S, Noell J. "Are they still having sex?" Sti's and unintended pregnancy among mid-life women. Journal of Women and Aging. 2005; 17(3):41-55.
34. Schick V, Herbenick D, Reece M, Sanders S, Dodge B, Middlestadt S et al. Sexual behaviors, condom use, and sexual health of americans over 50: Implications for sexual health promotion for older adults. The Journal of Sexual Medicine. 2010; 7(s5):315-29.
35. Durvasula R. Hiv/aids in older women: Unique challenges, unmet needs. Behavioural Medicine. 2014; 40(3):85-98.
36. Arya M, Patel S, Kumar D, Zheng MY, Kallen MA, Street RL et al. Why physicians don't ask: Interpersonal and intrapersonal barriers to hiv testing-making a case for a patient-initiated campaign. J Int Assoc Provid AIDS Care. 2016 Jul; 15(4):306-12.
37. Gott M, Hinchliff S, Galena E. General practitioner attitudes to discussing sexual health issues with older people. Soc Sci Med. 2004 Jun; 58(11):2093-103.
38. Hunter EP, M.; Leen, C.; Premchand, N. Hiv testing: Getting the message across-a survey of knowledge, attitudes and practice among non-hiv specialist physicians. Postgraduate Medical Journal. 2012 February; 88(1036):59-65.
39. Gregory S. General practice in england: An overview. 2009 [accessed.