



Psychological consequences of cancer screening in HIV

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Purpose of review

There is a growing awareness of the increase in non-AIDS-defining cancers (NADC) in the HIV-infected population. Cancer screening is one means of reducing morbidity and mortality, but such screening may have psychological consequences across those with high and low-risk results, such as increased anxiety, worry and potential behavior change like increased self-examination or medical follow-up. This review examines the literature on psychological consequences of screening for NADC in HIV-infected populations.

Recent findings

Anal cancer is the only cancer type in which the psychological consequence of screening has been investigated in HIV-infected populations. Screening increases worry about anal cancer, particularly in those who are younger, have higher baseline anxiety or more symptoms. Participants with low-risk results show unrealistic optimism; this is a potential concern as it may lead to unrealistic beliefs about future risk, the need for healthy behaviors or follow-up screening. The lack of standardized screening protocols and programs makes assessing psychological consequences difficult.

Summary

More research is needed to determine if HIV populations differ from general population studies. Increased health promotion or symptom awareness is important for NADC with no standardized screening. Screening programs need to be aware of the potential for increased anxiety and worry and provide support as needed.

Keywords

anxiety, cancer screening, HIV, unrealistic optimism, worry

INTRODUCTION

Cancer screening has become a well established disease prevention tool for a variety of cancers. With the introduction of general population screening programs, there has been increased awareness of possible psychological consequences from testing processes, waiting periods for results, false positives and high-grade results. This review examines psychological consequences of cancer screening in the HIV-infected population.

NON-AIDS-DEFINING CANCER

A variety of cancers are becoming more prevalent in HIV-infected patients. Although AIDS-defining cancers have decreased with the use of highly active antiretroviral therapy (HAART), the incidence of non-AIDS-defining cancers (NADC) is increasing. A number of studies report that men [1,2[■],3,4[■]] and women [4[■]] infected with HIV have a greater risk than the general population of having a NADC.

Sigel *et al.* [5] report HIV-infected patients have two times the risk of having any NADC, whereas Deeken *et al.* [2[■]] report the risk as 12 times higher for those less than 40 years of age, possibly because of accelerated disease progression in this population. There is uncertainty about how the HIV virus, lowered CD4 counts or HAART contribute to this increase. Nevertheless, it seems that HAART has little impact in reducing the risk of NADC [5].

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KEY POINTS

- Non-AIDS-defining cancers are increasing in HIV-infected populations.
- There is a scarcity of research investigating the psychological effects of cancer screening in HIV-infected populations.
- Current research suggests that screening may increase cancer-specific anxiety and worry.
- Preliminary evidence suggests that receiving a negative screening result may lead to unrealistic optimism about future health.
- More research is needed in HIV-infected populations to determine the psychological consequences of cancer screening and investigate possible differences due to level of HIV management.

Lifestyle factors such as smoking, alcohol consumption, recreational drug use, multiple sexual partners, human papillomavirus (HPV) and hepatitis C or B virus (HCV, HBV) infection may explain some of the increased risk [2[■],3,5,6[■]]. The types of NADC, the increased risk levels and screening recommendations for HIV-infected patients are outlined in Table 1 [7–9,10[■],11,12[■],13].

CANCER SCREENING: TOO MUCH? WITH TOO LITTLE THRESHOLD?

As medical technology improves, the array of screening tests for cancer increases. Harris's [14]

review of cancer screening suggests that screening has become the primary and default prevention tool. He suggests that screening larger populations leads to more false positives, over diagnosis, unnecessary treatments and higher psychosocial consequences. A review of screening policy [15] lists criteria for screening programs, including the consideration of the psychological consequence of false positives, even if such consequences are small. To reduce the unnecessary negative effects associated with false positives, it has been suggested that screening should occur for smaller targeted populations who are at highest risk and to have higher thresholds for abnormality [14]. Thus, screening guidelines for HIV-infected patients should reflect the elevated relative risk in considering which tests should be recommended. There is a danger of patients being bombarded with a battery of up to six different cancer-screening tests.

Another review [5] suggests that individual risks be taken into account in recommending screening, such as life expectancy, the benefits and harms of screening and potential outcome or treatment options. A review of cervical screening [16] has suggested that benefits in reduced mortality are linked to organized screening programs with quality controls and ongoing research to optimize screening strategies rather than opportunistic screening. Such considerations are important as awareness of the need for better detection of NADC amongst the HIV-infected population grows.

Screening does not need to be the only method of reducing cancer-related mortality and

Table 1. Non-AIDS-defining cancers, relative risk for HIV-infected population, screening recommendations and psychological consequences

Cancer type	Relative risk	Screening recommendation	Psychological consequences of screening
Colorectal	0.5–1.3 [1,4 [■] ,5]	Normal population guidelines, ensure full colonoscopy [2 [■] ,5,6 [■] ,7]	Anxiety, failure to attend follow-up [8]
Melanoma	0.1–4.3 [1,2 [■] ,4 [■]]	–	Not known
Prostate	0.6–1.0 [1,5]	Normal population guidelines [2 [■] ,5,6 [■] ,7]	Worry, increased testing, unrealistic optimism [9]
Breast	0.4–1.7 [4 [■] ,5]	Normal population guidelines [2 [■] ,5,6 [■] ,7]	Anxiety, increased self examination [10 [■]]
Lung	1.2–7.7 [1,2 [■] ,3,4 [■] ,5]	Still experimental; possibly helpful for heavy smokers [2 [■] ,5,6 [■]]	Not known
Hepatocellular (Liver)	1.8–11.2 [1,2 [■] ,3,4 [■] ,5]	HIV + HCV or HBV 6 months–2 yearly [5,7]	Not known
Cervical	3.0–13.0 [5]	No consensus, 6 months–3 yearly [5,6 [■] ,7]	Anxiety, worry, lower sexual well-being [11]
Hodgkin lymphoma	7.5–31.7 [1,2 [■] ,3,4 [■]]	No reliable screening available [3]	Not known
Anal	15.0–148.8 [1,2 [■] ,4 [■] ,5]	1–3 yearly [5,7]	Worry, unrealistic optimism [12 [■] ,13]

HBV, hepatitis B virus; HCV, hepatitis C virus.

morbidity. As seen in Table 1, a variety of cancer types have no organized screening programs. Rather than increasing emphasis on screening, one can increase awareness of symptoms and increase programs targeting known risk behaviors that contribute to these cancers. For example, programs can promote smoking cessation, moderation of alcohol use for those with HCV or HBV, uptake of HPV vaccine for young men and women and safe sex behaviors [2^a,6^a]. In summary, screening programs are a valuable tool, but should not be considered the only tool, nor are they devoid of adverse consequences.

PSYCHOLOGICAL CONSEQUENCES FROM SCREENING

Reviews of the psychological consequences of breast [17], prostate [9] and cervical [11] cancer screening in the general population have shown psychological effects associated with inadequate smears, false positives and both high and low-grade results. The effects include anxiety, worry about cancer and lower sexual well-being. There are also changes in behaviors such as, increased or reduced medical follow-up, breast self-examinations and information seeking from the internet [17–19]. Some studies have found that baseline screening can identify those who are more likely to be affected, such as those with symptoms or higher baseline anxiety [13,20–22]. These individuals can be offered additional support through the screening process, particularly as screening programs typically require regular follow-up testing for ongoing monitoring when indicated. A person's knowledge about the screening and disease can also influence their psychological response to screening. Studies in the prostate field show that repeat prostate-specific antigen (PSA) tests raise anxiety [23,24], whereas repeat biopsy does not [23]. It is thought that awareness of cancer was increased by the initial PSA result and anxiety increased with each retest [23]. In contrast, it is suggested that repeated biopsy was viewed as a more thorough test and increased reassurance.

Questionnaires assessing generalized psychological states (e.g. anxiety) show little to no change in response to screening compared with cancer-specific psychological questionnaires (e.g. worry about cancer [18,20,21,25]). There is inconsistency in evidence for psychological effects of cancer-screening processes and responses to different screening results, but there is consensus that measurement of the psychological consequences of cancer screening needs to be more standardized [20,21,24–27].

PSYCHOLOGICAL CONSEQUENCES IN HIV-INFECTED POPULATIONS

Relatively few studies have investigated the psychological consequences of cancer screening on HIV-infected populations for a variety of reasons listed below. There are well established general population screening programs for cervical, breast, prostate and colorectal cancers. These screening programs are the source of most psychological effects research. The guidelines listed in Table 1 suggest that HIV-infected patients do not require additional testing for these cancers because the increased relative risks are not significantly higher than the general population [1,4^a,5]. Therefore, the research describing the effects of cancer screening in other general populations (outlined above) is likely to be broadly applicable to those who are HIV-infected. Table 1 outlines the known psychological consequences for the various NADC.

There are no general population screening programs for melanoma, anal, hepatocellular and lung cancers or Hodgkin lymphoma. The lack of programs is somewhat related to the lack of technology or ability to screen successfully. For example, there is no reliable screening for Hodgkin lymphoma [3], screening for lung cancer is in experimental stages [5,6^a], melanoma screening is done by visual inspection and hepatocellular screening is not routine or standardized [28]. Given the lack of screening programs available for these NADC, it may be useful to increase awareness of symptoms and health promotion programs targeting the relevant lifestyle risk factors in HIV-infected patients.

Anal cancer screening studies have been focused on HIV-infected men who have sex with men (MSM), because this disease has the highest prevalence in this population. Screening programs are mainly in the research phase and no standardized general MSM population screening programs are available. The anal cancer screening process is similar to cervical cancer with an initial cytological swab taken to triage those who need further investigation by high-resolution anoscopy (HRA), in which biopsy samples are taken, similar to colposcopy. One of the preeminent researchers in the field has noted that performing HRAs is a skill that develops over time and because of the 'paucity of providers' (p. 586), new clinicians are unlikely to have mentors [29]. This is clearly one hindrance to more widespread screening. Anal cancer screening has been focused on HIV-infected patients and there have been two studies investigating the psychological consequences of that process on HIV-infected men [12^a,13].

PSYCHOLOGICAL CONSEQUENCES OF ANAL CANCER SCREENING

The two studies [12¹¹,13] prospectively investigating the psychological consequences of anal cancer screening were conducted within research studies of medical aspects of anal cancer screening, and the methodology was different in each study.

Tinmouth *et al.* [13] (study 1) used four time points over 6 months (1 week prescreen, 1 week postscreen, 1 week postresults, 1 week prior to 6-month follow-up) with all participants having the cytology swab and HRA conducted at the same time. This group had to wait for results only once. The measures were completed on paper or online and comprised the Impact of Events Scale, Illness Intrusiveness Ratings Scale, Psychological Consequences Questionnaire, Hospital Anxiety and Depression Scale, HIV Symptom Index and Knowledge items. The study had 104 participants (response rate 67%), with an average age of $M = 44$ years (41–50) and 11% had anal intraepithelial neoplasia 2/3.

Landstra *et al.* [12¹¹] (study 2) used three time points over 3 months (at screening, 1 week postswab result and 1 week post-HRA result), with a two stage screening process, in which cytology results determined who was recalled for HRA. Some participants had to wait for results twice and generally had to wait 10 weeks for the HRA procedure due to limited clinician time to perform the HRA. The measures were completed on paper and comprised the Anal Screening Questionnaire, Cancer Worry Scale, Distress Thermometer, Medical Outcomes Study Short Form 12 (MOS SF-12) and Depression Anxiety Stress Scale. The study had 163 participants (response rate 60%), with an average age of $M = 52$ years (28–73) and 17% had high-grade anal intraepithelial neoplasia (equivalent to anal intraepithelial neoplasia 2/3).

Both studies found an increase in worry about cancer. Being younger, having more HIV symptoms and greater baseline psychological distress predicted those who were more worried in study 1 [13]. Neither study found a general impact on psychological health in terms of depression or anxiety [12¹¹,13], nor effects on stress or quality of life [12¹¹] using general psychological questionnaires not specific to cancer.

There was inconsistency in the timing when the most negative consequences were apparent. The highest level of distress was observed when people were waiting for results in study 1 [13], and waiting for the HRA test in study 2 [12¹¹]. Another difference related to whether groups with higher grade screening results were more impacted. Study 1 [13] found no difference related to higher grade results, study 2

[12¹¹] found those with higher grade results were more worried. Unfortunately, these differences are confounded by variations in the screening procedures used and differences in the use of general versus cancer-specific psychological questionnaires. Participants who received negative results from the HRA were more optimistic about their future health than those who did not need an HRA [12¹¹]. Thus, it was hypothesized that negative results may lead to 'unrealistic optimism', a phenomenon that has also been found in colorectal cancer screening [8].

DISCUSSION

More research is needed across different aspects of screening for NADC in the HIV-infected population. Research needs to identify the best screening methodologies, subsequent treatments and their interaction with HAART regimens and the psychological consequences of these processes on the participants [2¹,3,5,12¹¹,13]. The psychological consequences of screening in the general population for cervical, prostate, breast and colorectal cancer include increased anxiety, worry about cancer and lower sexual well-being. Screening for anal cancer in HIV-infected MSM also increases worry about anal cancer. Future research needs to further explore the ways HIV-infected populations may react differently to the general population in response to screening.

For example, HIV-infected populations may differ from other groups in that they are familiar with regular medical testing of their HIV and therefore may not be as upset by waiting for test results or receiving 'bad' news. This possibility has not been investigated. Neither has behavior change in response to results. Studies in breast and prostate screening have shown that increased worry and anxiety are associated with increased medical follow-up, self-examinations or information seeking from the internet [17,18,27]. In contrast, studies in cervical [30] and colorectal screening [31] have shown that increased anxiety is associated with avoidance of follow-up. Given the higher risk of NADC in the HIV-infected population and the potential for accelerated disease progression, it will be important to ensure adequate follow-up. Potential differences in the reaction to screening amongst people with HIV-infections have not been assessed. One possible reaction may be unrealistic optimism.

Unrealistic optimism is the phenomenon in which a negative test result leads to lower anxiety or higher optimism for future health. This may hinder return for testing, lead to unrealistic beliefs of not developing cancer or a reduction in

health-promoting behaviors [8,26]. Unrealistic optimism may also be related to relief that a thorough test has shown a 'good' result and the person does not need to worry [12,21] or engage in health-protective behaviors. Landstra *et al.* [25] outline steps to reduce the impact of unrealistic optimism, by explicitly stating the frequency of screening at the outset and having an effective reminder system. More research is needed to determine how prevalent unrealistic optimism is and the best steps to be taken to increase follow-up testing.

Health promotion and increasing symptom awareness is another avenue to reduce cancer mortality and morbidity and should also be implemented, especially given few organized and standardized screening programs are available for the highest risk NADC. It would be useful to have general health promotion in HIV services focused on smoking, drug and alcohol cessation and promotion of the HPV vaccine in young gay men.

CONCLUSION

There is a growing awareness of the rise of NADC in HIV-infected populations. Cancer screening has become the default response, but such screening is not possible for all the cancer types that have greater incidence in this population. There have been only two studies focused on the psychological consequences of cancer screening in the HIV-infected population. These show similar results to general population studies, specifically increased worry about the cancer being screened. The variability of screening processes and lack of consistency in psychological measures used between studies make comparisons difficult. Higher risk and lack of clear guidelines for screening or the availability of standardized screening programs may increase the worry felt by HIV-infected patients. We expect that increasing screening programs will be accompanied by an increased need for participants to receive some form of psychosocial support. More research is needed to optimize the ability to identify the support needs of participants depending on their results and psychological response. A stepped-care approach is outlined in Landstra *et al.* [25] and future research could test the utility of this methodology.

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Conflicts of interest

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Papers of particular interest, published within the annual period of review, have been highlighted as:

- of special interest
- of outstanding interest

Additional references related to this topic can also be found in the Current World Literature section in this issue (pp. 581–582).

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