Psychosocial aspects of anal cancer screening: A review and recommendations

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Abstract
Cancer screening programs have the potential to decrease psychosocial wellbeing. This review investigates the evidence that anal cancer screening has an impact on psychosocial functioning and outlines considerations for supporting participants. The review suggested that screening has no significant effect on general mental health but may increase cancer-specific worry. Having worse anal or HIV symptoms, being younger, higher baseline distress or worse histology results were predictive of greater worry. The findings suggest the need to increase education campaigns, particularly targeting those with HIV infection and men who have sex with men. There is a need to develop a consensus on measuring the psychosocial impact of screening and stepped care approaches for responding to any resulting distress.

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Main Title

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Abstract:

Cancer screening programs have the potential to decrease psychosocial well-being. This review investigates the evidence for anal cancer screening having an impact on psychosocial functioning and outlines considerations for supporting participants. The review suggested that screening has no significant effect on general mental health but may increase cancer-specific worry. Having worse anal or HIV symptoms, being younger, higher baseline distress or worse histology results were predictive of greater worry. The findings suggest the need to increase education campaigns particularly targeting those with HIV infection and men who have sex with men. There is a need to develop a consensus on measuring psychosocial impact of screening and stepped care approaches for responding to resulting distress.
Introduction

Early detection screening programs are recommended for a variety of cancer types. While there are well established population screening programs for other cancers, anal cancer has not been recognised as a high priority for screening until the last 5 to 10 years. High rates of HPV infection and anal cancer in HIV-infected individuals and men who have sex with men (MSM) have led to a growing concern that screening, prevention and early intervention efforts need to be implemented, similar to other cancers. Baseline and annual follow up anal cytological screening is recommended for HIV-infected individuals in the New York State Guidelines. The need for screening programs has been recognized with research studies being conducted in North America, Europe and Australia.

Progression and regression rates from HPV infection to anal cancer are unknown, but the screening process is similar to the highly effective cervical cancer model. While there is no universally accepted anal cancer screening or treatment protocol, typically, the screening process involves two stages. A swab is taken and sent for cytological analysis and if further investigation is warranted from non negative cytology results, a high resolution anoscopy (HRA; similar to colposcopy) is conducted to determine the extent of disease via biopsy and histology results. The HRA process is potentially uncomfortable and painful. Additionally it is during the waiting periods for both sets of results and for the HRA procedure that patients may experience increased distress about the potential for bad news. The severity of result may have an effect on the psychosocial response. Specifically, different results are likely to convey different levels of perceived risk of disease. For example, the distinction between cancer and pre-cancer cytological and histological results can be difficult for patients to understand. In a related area, cervical screening participants found it, “difficult to understand cell changes as anything other than a life-threatening illness”. Levels of education, personal experience with cancer (self or others) and psychological status are all possible moderators of
the psychosocial response to screening. Both researchers and clinicians’ highlight the need to understand the potential psychosocial impact of screening programs, particularly in response to uncertainty associated with screening, procedures and results 10-14.

**Potential psychosocial impacts in anal cancer screening**

The psychosocial impact of anal cancer screening has not been widely investigated in comparison to other forms of cancer. There are numerous studies and systematic reviews examining the psychological effects of cervical15, prostate16 and breast17 cancer screening programs and these provide valuable insights into the potential psychosocial effects of anal cancer screening.

The anal cancer screening process is similar to both prostate and cervical cancer screening on several dimensions. For example, they are associated with private parts of the body and related to sexuality. The screening process has two stages and is very similar to cervical and slightly different to prostate, with a blood test for prostate specific antigen (PSA) followed by transrectal ultrasound-guided and random biopsy.

Increased anxiety, worry about cancer and lower sexual well-being has been found with all grades of cervical cytology results18-20. Rates of return for repeat testing are lower in those who are most anxious 19. Men with normal PSA results were less worried than men with benign biopsies even after 12 months. Those with benign biopsies had sought more medical follow up, talked more to their partners and sought information from the internet 11, 21. It may be that repeat testing, biopsy and concern about false negative biopsies contributed to the ongoing anxiety found, particularly as random biopsy is likely to miss 10% of men with active disease 21. While HRA is more targeted than the prostate biopsy process there may be false negative rates in that process as well.

Other factors that have impacted psychosocial responses are having symptoms prior to testing; for example men with urinary symptoms 23 or higher anxiety at baseline 21, 24.
Having more or less knowledge about the screening and disease are also potential factors. Men who had multiple PSA testing points had increased anxiety at the second and subsequent tests. This may be due to awareness of cancer being raised by the initial PSA result and increasing with each re-test \(^{25}\). In contrast, having repeated biopsies did not increase anxiety \(^{25}\) and although speculative, it is possible that repeated biopsy was viewed as a more thorough test and increased reassurance. Being given cervical HPV results increased anxiety\(^ {15}\), in part due to poor understanding and confusion about HPV infection, particularly the difference between genital warts and high-risk HPV. When women sought information, their anxiety diminished over time \(^ {15}\). Knowing that HPV can clear on its own and that it would not cause genital warts also reduced anxiety \(^ {26}\).

Test specific psychological questionnaires (TSPQ) whether it be cervical or prostate compared to generalised psychological questionnaires (GPQ) appear to be associated with greater sensitivity to psychosocial responses to screening \(^ {11,22}\) and may explain conflicting results between different studies. A number of studies have found that PSA and biopsy results did not increase anxiety, depression or health related quality of life (QOL) using GPQ\(^ {23-25}\). It may be important for future studies to utilize TSPQ. There are psychosocial impacts from cervical and prostate screening processes and the full range of results; better information can improve psychosocial responses.

**Aims**

Screening programs have the potential to decrease psychosocial well-being and increase avoidance of health testing. There have not been many direct studies in the anal cancer field, so this systematic review will also integrate findings from other relevant cancer screening areas. The aim is to identify the likely psychosocial effects of anal cancer screening and then suggest how future screening programs could prevent or minimise any negative impacts.

**Method**
Search Strategy

A search of four electronic databases using standard research procedures was conducted in October 2011. The databases were Medline, PsychInfo, Cumulative Index of Nursing and Allied Health Literature (CINAHL) and Web of Science. Search terms were entered with combined sets of terms relating to anal cancer, screening and psychosocial impact; (anal) and (cytol* or screen*) and (psyc* or anxi* or worry). These four searches identified 200 articles, 7 were unique and directly relevant to the review. It was not possible to combine the data from these studies in order to conduct a meta-analysis due to the highly variable measures and methods used.

Inclusion and exclusion criteria

Exclusion criteria were minimal, given the scarcity of publications on this topic. All theoretical, descriptive or empirical studies on psychosocial characteristics of anal cancer screening were included. Titles and abstracts were reviewed for the following inclusion criteria:

- Presented original research on psychosocial aspects of cancer screening
- Screening was for anal cancer
- Published in English

Articles were further excluded if they described cost effectiveness, surveyed health care workers only, focused solely on patients diagnosed with cancer or the effects of cancer treatment.

In order to assess one aspect of study quality and to begin describing the diverse psychosocial domains investigated, those studies that used psychological measures with some previously assessed reliability and validity were identified. Measures assessed in other cancer screening contexts (e.g., cervical) were considered to have some established reliability and validity. Table 1 summarises the seven studies.
Results

Measures of psychosocial functioning

The articles reviewed used a combination of validated and nonvalidated self-report psychological measures which are listed in Table 1. The validated measures are indicated in Table 1, they can be categorized into GPQ’s; for example, Hospital Anxiety and Depression Scale and TSPQ’s such as, Psychological Consequences Questionnaire positive scale, developed for impact of mammography screening on physical, social and emotional domains. The non-validated measures were unique to each study and were related to knowledge of HPV, anal cancer and anal pap tests; attitudes or beliefs; willingness to seek or return to screening and evaluating screening procedures. All measures which were readily available are in Appendix 1.

Knowledge, attitudes & willingness to have screening

Knowledge

The majority of studies had a knowledge assessment component. The first published study on knowledge was in 2007 by Pitts et al. 27, who found no single item was answered correctly by more than half of the sample and awareness of risk factors was poor. For example respondents had low awareness of risk factors such as HPV, smoking and being a receptive sexual partner. While 62% had received a sexual health screen in the past 12 months this was not associated with better knowledge. Significantly higher knowledge was found in those who had higher education 27, had ever had an anal pap screen 28, 29 and among those undergoing regular screening (RF) compared to patients lost to follow up (LTF)30. Amongst participants who had higher levels of knowledge or awareness of screening availability, there was greater willingness to have screening 28, 29.

Willingness
Three studies\textsuperscript{28-30} investigated factors related to intentions or willingness to participate in screening. Being HIV-infected was related to being more willing to be screened \textsuperscript{28,29}. Men indicated they were more willing to have screening that would be free (83\%) than if they incurred out of pocket costs of $150 (31\%) \textsuperscript{29}. Those with household incomes over $60,000 were also more willing to be screened than those earning less \textsuperscript{29}. Truesdale and Goldstone \textsuperscript{30} investigated factors related to men who have sex with men (MSM) with both low and high grade squamous intraepithelial lesions (LSIL & HSIL) returning to screening after 1 year. It was found that having more sexual partners led to greater rates of return, with each additional partner increasing likelihood of return by 8\%. Return to screening was related to being contacted to take part in the study, leading to 7\% of LTF having further screening and 18\% of the LTF participants returning for screening. Twelve percent of MSM indicated that the anal pap smear was “too painful to make it worthwhile” \textsuperscript{30}.

\textit{Worry}

A variety of concerns or worries were related to knowledge and willingness to have screening. Participants who described learning they had HPV as “upsetting” were 3 times more likely to have regular follow up (RF) than be lost to follow up (LTF) \textsuperscript{30}. Furthermore, when treatment was prescribed at diagnosis participants were 2 times more likely to be RF than LTF \textsuperscript{30}. Having greater worry about or higher perceived likelihood of getting anal cancer was related to being more willing to have screening. Physical symptoms were strong motivators for the RF group and those who reported physical symptoms were 10 times more likely to return to screening after being lost to follow up \textsuperscript{30}. The severity of diagnosis was related to more compliance with screening. Those in the RF group were more likely to have HSIL and those with HSIL were 4 times more likely to be to be in the RF group than those with LSIL \textsuperscript{30}. Being concerned about anal cancer was higher in HIV-infected men \textsuperscript{28} and those having a history of anal warts in the last 6 months or ever \textsuperscript{28}. Willingness to have
screening was lower when men were concerned about accuracy of the test, embarrassed about asking for or having the pap test 29.

Sexuality

Two of the studies investigated some aspect of sexual function or beliefs. The patients who participated in regular follow up (RF) were two times more likely to agree that ‘finding out I had HPV made me feel promiscuous’ 30. Those who were recalled for further investigation rated their anal health lower than those who did not need further investigation 31.

Evaluation of screening procedure

One study directly investigated the acceptability of the self collected Dacron swab screening procedure 8. The anonymous evaluation found that 53% rated the swab easy to collect, 81% rated the process highly acceptable, 65% reported no pain and 83% reported no bleeding 8. As these questionnaires were anonymous they were not able to investigate any factors associated with better or worse responses and they did not ask about participant’s willingness to repeat the test. Self-collected screening was generally acceptable and therefore has the potential to allow for home testing, which has the potential to reduce the costs of screening programs.

Psychosocial impact of screening

Two studies have investigated the psychosocial impact of the screening process longitudinally. Tinmouth et al 6 (study 1) used 4 time points over 6 months and Landstra et al 31 (study 2) used 3 time points over 3 months. These studies had different time lines for medical procedures with study 1 occurring in a research context. Study 1 6 had the swab and HRA conducted at the same time, thereby giving all participants both procedures and having only one time frame to wait for results. In contrast, study 2 31 demonstrated a more common, two stage screening process, where swab results determined who was recalled for HRA, thereby requiring some participants to return and wait for results twice. Both studies found no
general impact on psychological health in terms of depression or anxiety, nor effects on stress or QOL using GPQ’s.

There was some discrepancy between these studies regarding who is impacted and when. Study 1 found those with anal intraepithelial neoplasia (AIN) 2/3; high grade precancerous lesions were no more impacted than others with lesser results. In contrast study 2 found that being referred for HRA led to higher worry and subsequently those with high grade anal intraepithelial neoplasia (HGAIN; equal to AIN 2/3) continued to be worried. The time of most negative impact in study 1 was waiting for results to be given. In study 2 waiting for further investigation by HRA was the time of most impact. These differences may be due to study 1 using GPQ’s and study 2 using TSPQ’s. Alternatively, it may have been due to study 1 having both the swab and HRA completed in one visit while study 2 followed a two step screening process.

Other results of importance in the studies are that participants who received negative results from the HRA were more optimistic about their future health than those who did not need an HRA. Thus, negative results may lead to “unrealistic optimism”. Characteristics that were predictive of greater worry were being younger, having more HIV symptoms and greater baseline psychological distress. Both studies demonstrated that there is some psychosocial impact from anal cancer screening, namely increased worry and concern and this is similar to prostate and cervical screening.

Limitations of the studies

These studies have a number of limitations in common. All studies were completed with gay men only and did not include other at risk populations, such as women with HIV or prior HPV related cervical disease and immunosuppressed transplant recipients. Most participants were Caucasian, well educated, and in some studies most had private health insurance. These characteristics may not reflect the general MSM or HIV-infected population. The vast
majority of studies used different questionnaires and therefore could not be compared. Participants were voluntary or convenience samples which may have skewed the results towards participants who were more interested, knowledgeable or more connected to the gay community. Hypothetical statements were used by Reed and these could have failed to anticipate barriers to screening. The availability of screening was not independently determined in D’Souza’s study and therefore the lower perceived screening availability may not reflect the actual availability of screening programs. The two longitudinal screening studies used different medical process timelines and swab collection procedures (self collected vs. clinician collected), making comparison between them difficult.

Discussion

Summary of Results

Anal cancer screening appears to generate health worries specific to the procedure. Thus far, research suggests no acute or clinically significant levels of mental health problems as a result of screening. Most screening participants experienced no significant psychosocial impact, but there was some individual variation, suggesting some with particular characteristics were affected more than others. Having worse anal or HIV symptoms, being younger, higher baseline distress or worse histology results were predictive of greater worry. Worry in this context involved repetitive thoughts about the screening and the possibility of having anal cancer. Furthermore, there was generally poor knowledge of anal cancer, anal pap testing and HPV or other risk factors and low willingness or intention to screen.

Clinical implications: what to consider when setting up routine anal cancer screening

Education

Given the low levels of knowledge in the MSM’s studied and its links to screening adherence, it is important to have targeted education campaigns about the risk of anal cancer and the need for screening. This education is particularly important for high risk groups such
as HIV-infected MSM. Raising knowledge may increase concern and perceived vulnerability and therefore increase motivation to have screening. Striking the balance between raising awareness and inducing fear is important as some levels of worry may cause avoidance. For example, women at high risk of breast cancer with mild distress were more likely to have screening than those with moderate distress\textsuperscript{32}. Hay et al. \textsuperscript{32} conclude that cancer worry increases the likelihood of screening but fear of positive results or the test itself may deter screening.

Primary care physicians were the most common point for sexual health screening and potential contacts for anal cancer screening. Thus, primary care physicians are critical to educational efforts and to encouraging screening. It has been suggested that, “primary care physicians should be prepared to counsel their patients about the pros and cons of anal cancer screening and be familiar with anal health services in their local communities”\textsuperscript{28}.

Information about the costs of screening and follow up care need to be part of educational campaigns. In areas where there are few public or affordable opportunities, policy advocacy could be very important. While there are a number of research studies on anal cancer screening, there is still debate about cost effectiveness and guidelines for regular screening. Despite such debate, most countries have a need to increase the availability of screening and skilled clinicians in the follow-up of abnormal anal cytology results.

\textit{Managing the screening process}

The screening process itself needs to have clear and appropriately pitched education materials. Having communication regarding the procedure itself, expected adverse events, recovery and non technical explanations of results are essential to support the participants \textsuperscript{12, 33, 34}. The potential benefits of information are reflected in findings from cervical screening. Providing written information about the meaning of an abnormal pap smear resulted in less anxiety and fewer patients thinking they had cancer \textsuperscript{35}. Written and verbal explanations of
abnormal pap smear results led to better understanding of results and better attendance for follow up colposcopy than written information alone 36.

The choice of materials to gather the swab is also important. Such choices require a balance between the need for good quality specimens and methods that reduce discomfort as part of the collection process. Inadequate specimens have the potential to increase anxiety if results are inconclusive19. In the evaluation of self collected Dacron swabs, 35% reported some level of pain and 17% reported some level of bleeding 8. In another study, 12% reported that the screening was too painful to be worthwhile 30. Some clinics use a cytobrush which gathers more satisfactory specimens and may also be more painful and lead to more bleeding.

The vigor which is used in collecting the specimen may also have an impact. Making sure participants are sufficiently prepared for the method used, potential adverse events and level of pain is important, to increase the probability for that person to return for screening. It is also important given they may also talk within their social networks and provide word of mouth recommendations or warnings. Providing the option of self-collection rather than clinician collection may give the participant control over the level of pain. Where there is poor availability of screening, doing home screening with self-collection may be an alternative method to reach those at risk.

Support after screening and results
Waiting for results and further investigation were the times of greatest psychosocial distress. It is these times that participants could benefit from support. Different types of support may be needed by different people. Where possible it would be helpful to have a variety of support options available such as written information, support staff available by phone or email, patient support groups or access to a psychologist or social worker. We have developed a stepped care model outlined in Table 2 to offer suggestions for how to triage those who may need extra support beyond information37. Recognition of risk factors for
psychosocial distress is an important part of this process (e.g., younger age, physical anal symptoms, more HIV symptoms, higher baseline distress, worse screening results). Using TSPQ was more sensitive than GPQ. For example, the distress thermometer, cancer worry scale, or impact of events scale may be quick and easy ways to check level of distress or concern at the time of screening. Those with higher levels of baseline distress should be linked to available supports or encouraged to call for support. Other indicators that participants are at risk of a more negative response to screening might include a lack of information seeking (raising concerns of avoidance) or the expression of excessively negative emotions about their results.

Similar to the lack of universally accepted protocols for screening, treatment protocols are also not well established as there is an absence of data from randomized treatment trials of HGAIN showing reduction of anal cancer. One post screening option is active surveillance with no active treatment but ongoing monitoring and assessment. It is estimated that half the men diagnosed with early prostate cancer have unnecessary treatment that has many physical side effects and negative effects on QOL. Similar concerns may be present for precancerous anal lesions which have significant natural regression rates suggesting they may not worsen with time. Some clinicians may take an active surveillance approach rather than treatment. If this is the case there are some strategies which can be implemented to support the patient. In a review of active surveillance for early prostate cancer Pickles et al. found that this option creates anxiety, but audio-taping treatment consultations for the patient improved understanding and decision making. The doctor’s role in creating clear “rules” about when to initiate treatment and ways to gain quality information were also important. Another strategy is to actively manage the anxiety that may be created by uncertainty and withholding active treatment. Options such as support groups or therapeutic groups focused on teaching mindfulness, stress management and other psychological therapies could be
offered. One promising therapeutic approach is Acceptance and Commitment Therapy, which helps participants to focus on accepting uncertainty and living a vibrant and valued life even with the ongoing threat of cancer. Use of acceptance based coping strategies, after receiving abnormal cervical pap smear results was associated with lower psychological distress.\textsuperscript{38}

Supporting return for repeat screening

Empirically supported screening guidelines have not been clearly established but, as with other cancer screening programs, regular screening may be important. Therefore being able to motivate participants to return is imperative. Finding the balance between reassurance and complacency is essential.\textsuperscript{25,31} A concern in the screening process is the phenomenon of “unrealistic optimism” which has been found to hinder protective health behaviours. Intentions to participate in breast screening were lower when unrealistic optimism was higher.\textsuperscript{39} Three years after colorectal screening, the group who were reassured with negative results had significant increases in their body mass index compared to those with positive results.\textsuperscript{40} This may reflect unrealistic optimism and a resulting tendency to be less vigilant in following protective behaviours after being reassured. To protect against this phenomenon, clinicians could emphasize known risks such as HIV and HPV infection, numbers of sexual partners, unprotected receptive anal intercourse, and potential consequences of progression to anal cancer. Truesdale and Goldstone\textsuperscript{30} highlight the need to stress the importance of repeat screening so the participant “hears” the message without becoming too alarmed. They found participants who were more emotionally upset at diagnosis returned for regular follow up. They also recommend a reminder system be “more extensive than a mailed reminder card or short telephone call”. Unnecessary mortality might be prevented by setting clear expectations for regular screening at the initial screening and result-giving stages and then following up with detailed information and reminders including assertive follow up of those who do not return.
Future directions

Areas needing further research are impacts of screening on HIV-infected women, women with prior HPV related cervical disease and immunosuppressed transplant recipients, who are also at high risk. Research is also needed to examine the impact of screening on sexual functioning and related emotional responses, such as shame, embarrassment and self-stigma, as both cervical and prostate cancer have shown this to be an issue. For example, does self-stigma prevent people from seeking screening, and if so, how can this barrier be addressed? There is a need to determine what types of support are most effective and we propose the stepped care model outlined in Table 2 as a starting point to develop this research, with a particular focus on motivating regular screening.

Conclusions

Anal screening does not appear to have a general impact on mental health, but in some instances does appear to increase health-related worry. A small proportion of people will need support and the most effective ways to do this have not yet been empirically tested. In order to identify those who will need support, it would be useful to have consensus on a core set of psychosocial screening measures and to establish cut off points that provide guidance about appropriate levels of response. Similar suggestions emerged from a review of prostate cancer screening. As anal cancer screening is not yet well established there is an opportunity to set up a consistent and evidence-based approach to measuring and responding to the psychosocial effects of screening.

Conflicts of Interest

None declared
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