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The psychological impact of anal cancer screening on HIV-infected men†

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Abstract

***Background*: Anal cancer rates are increasing in HIV-infected men. Screening programmes similar to prostate and cervical cancer have been recommended to reduce morbidity and mortality. Research shows that screening processes have psychological consequences that need to be considered. Limited investigation of the psychological impact of anal cancer screening has been conducted.**

***Methods*: A prospective longitudinal survey of 291 men was conducted at three time points over 14 weeks at a public HIV clinic in Sydney, Australia. Self-report questionnaires measuring worry, distress, depression, anxiety, stress and health-related quality of life (SF-12) were collected.**

***Results*: Those who had a biopsy recommended were significantly more worried about anal cancer, rated their anal health worse and were less optimistic about their future health than the control group who needed no further medical investigation. The group receiving high grade histology results remained worried about anal cancer at time 3. We found no evidence that general anxiety, depression or quality of life was significantly affected by the process.**

***Conclusions*: Anal cancer specific worry increases throughout the screening process. Clear communication prior to procedures about the procedure itself, potential adverse events, the recovery process and non-technical explanations of results should be implemented in anal screening programmes.**

Keywords: anal cancer screening; oncology; HIV; worry

Introduction

Increases in anal cancer prevalence, especially in specific populations such as HIV-infected individuals and men who have sex with men (MSM) have increased awareness of this disease. There is a growing concern that screening, prevention and early intervention efforts need to be implemented as they have been in cervical, breast and prostate cancers [1]. The New York State Guidelines [2] for management of HIV-infected individuals recommend baseline and annual follow-up anal cytological screening. While screening programmes have the potential to reduce morbidity and mortality in some individuals, they also have the potential to decrease psychological well-being, due to uncertainty associated with screening, procedures and results [3–7]. This aspect of anal cancer screening has not been investigated.

The anal cancer disease and screening process is similar to the highly effective cervical cancer model [1]. Psychological costs and implications of cervical cancer screening have been demonstrated by many studies. Screening increases anxiety, worry about cancer, and can be detrimental to sexual well-being [8–10]. It is not only high grade results that have adverse impacts [10]. Low grade results have also been shown to have a negative psychological impact [9], and 'inadequate specimen' results are associated with increased anxiety. In turn, return for repeat testing is lower in those who are most anxious [8].

Similar results have been found in breast cancer screening studies [11]. Worry about breast cancer persists even after receiving reassurance of a false positive mammogram, and there are increased reports of self-examination and higher interference with mood and daily functioning [12,13]. Prostate cancer screening studies report similar findings [14]. Worry about cancer persisted amongst a group of men after negative biopsy results were received, and more medical follow-up was sought by this group than the control group who did not have a biopsy [4,15].

Anal cancer and its potential burden of disease particularly in the HIV-infected and MSM population have gained prominence in the last 5–10 years [16,17].

Many screening and treatment studies have been conducted around the world [18], but little empirical research has focused on the psychological implications of the screening process. Only one study focussed on the psychological effects of screening [19]. They found that most participants were not significantly impacted by the process, and the most difficult aspect was waiting for the results. In this study, the swab and high resolution anoscopy (HRA) were completed at the same time, which may have reduced the potential effects. Typically, the screening process involves two stages: a swab and, if further investigation is warranted from swab results, an HRA to determine the extent of disease. It is during the three waiting periods for results and an HRA that patients may experience increased stress and worry about the potential for 'bad news'. There is a need to assess the psychological effects of this screening under more naturalistic conditions.

Other studies have investigated barriers and facilitators to MSMs accessing anal cancer screening [20], MSM's knowledge of anal cancer and HPV [21] and factors affecting follow-up rates after screening [22]. It is possible that being HIV-infected desensitises this population to other health issues. The aim of our study was to investigate the psychological impact of a naturalistic anal cancer screening programme. We utilised a prospective longitudinal design using standardised measures adapted from previous cervical and prostate cancer screening studies.

Methods

Design and procedures

A multi-wave longitudinal study of 291 HIV-infected MSM undergoing anal cytological screening at St Vincent's Hospital in Sydney, Australia, was conducted from October 2008 to April 2010. The study was approved by the human research ethics committee of the hospital, and informed consent was obtained from all participants. Any HIV-infected MSM who attended the HIV clinic during the study period were eligible. Exclusion criteria included a significant bleeding disorder, anal pathology likely to render an anal swab significantly uncomfortable and being unable or unwilling to give informed consent.

The study consisted of three stages as illustrated in Figure 1. The medical aspects of the screening study began with a sexual health research nurse (L. P. B.) conducting a detailed history of sexual and anal health and giving instructions regarding the self-collection of swabs for anal cytology and anal bacterial sexually transmitted infections. The cytology results were delivered on the basis of participant's preferences (phone, mail, e-mail or in person). Participants whose swab yielded cytology results that were technically unsatisfactory were invited to have a second swab. Participants with negative or low grade squamous intraepithelial lesion (LSIL) cytology results formed the control group. Further investigation by HRA was offered to participants whose cytology results were high grade squamous intraepithelial lesion (HSIL), atypical squamous cells—cannot exclude HSIL or atypical squamous cells—unknown significance. The HRA procedure is similar to colposcopy investigation of cervical smear abnormalities. Following the HRA procedure, histology results were given in person or by mail, and follow-up options were discussed.

The psychological impact assessments occurred at the three stages of the medical process. The first questionnaire was given at the initial interview, to be completed that day and mailed back. The second and third questionnaires were mailed in the week the participant received their cytology and histology results, approximately 2 weeks after the respective procedure. The control group were not offered an HRA but were sent the third questionnaire at a time matched interval of approximately 10 weeks. The questionnaires consisted of a variety of well-standardised measures as outlined below and took 20–30 min to complete. Identical questionnaires were used, except questionnaire 3 for the HRA group, which contained questions about their HRA experience (Appendix 1).

Participants

The anal screening study sample consisted of 291 men, of whom 287 (99%) participated in the psychological impact study as outlined in Figure 1. The individual questionnaire response rates were 94% (271/287) at baseline, 84% (220/263) at time 2 after cytology and 79% (50/63) at time 3 for the group receiving histology results and 82% (113/138) for the control group. Some participants had an HRA ($n = 11$) off protocol for investigation of warts, some declined an HRA ($n = 5$) and others withdrew from the study ($n = 5$). These participants along with those who did not complete all three questionnaires ($n = 97$) were excluded from the analysis. Full follow-up data were available from 57% (163/287) of the participants given the baseline questionnaire as indicated in Figure 1.

Measures

The Anal Screening Questionnaire was created by modifying the Cervical Screening Questionnaire (CSQ; [10]). As no research has been conducted in the anal screening field, we sought permission to utilise this validated measure, substituting 'anal' for 'cervical'. Questions cover general and anal health, body image, sexual interest and optimism about future health, with items rated on a 44-point Likert scale. The worry questions from the Cervical Screening Questionnaire were omitted, and the adapted prostate cancer worry items from McNaughton-Collins *et al.* [4] were used. This measure assesses worry about cancer, dying soon and reassurance from testing. In the present study, Cronbach's alpha for the cancer worry scale was $\alpha = 0.71$.

The Distress Thermometer is a single item utilising a Likert type scale from 0 = No Distress to 10 = Extreme

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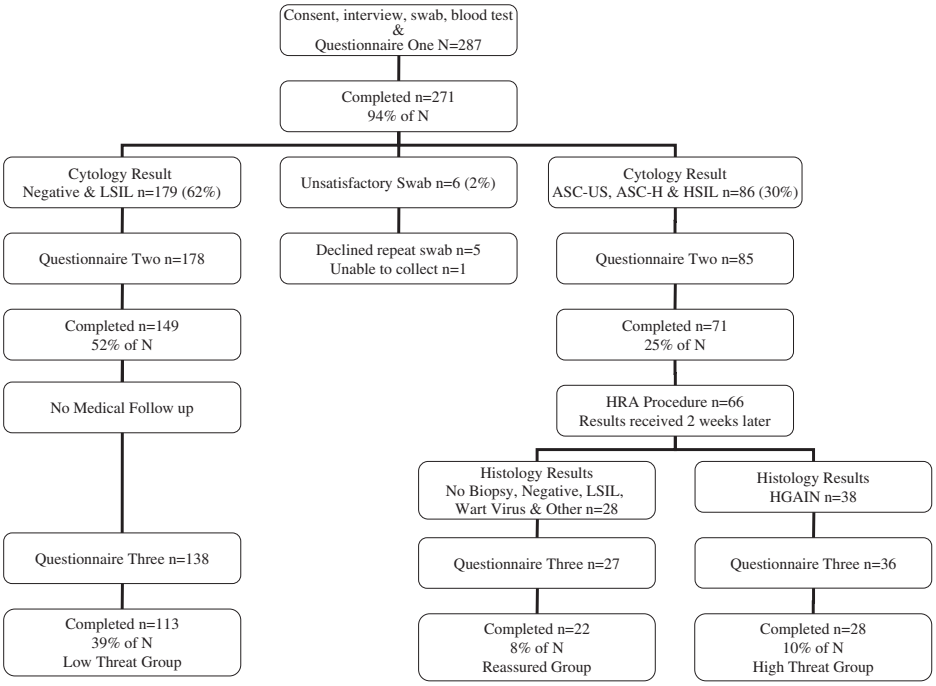

Figure 1. Study flow diagram. Percentages are of original sample ($N = 287$) at each subsequent time point. LSIL, low grade squamous intraepithelial lesion; HSIL, high grade squamous intraepithelial lesion; ASC-US, atypical squamous cells—unknown significance; ASC-H, atypical squamous cells—cannot exclude HSIL; HRA, high resolution anoscopy; HGAIN, high grade anal intraepithelial neoplasia

Distress [23]. It measures subjective distress in relation to specific aspects of the screening process such as, 'waiting for the swab results' or 'since the HRA results'. A similar distress measure is used in Oncology [23] and has demonstrated the ability to quickly and easily identify distress levels. A cut-off score of 4 yielded optimal sensitivity and specificity relative to established cut-off scores on the Brief Symptom Inventory and Hospital Anxiety and Depression Scale [23].

Medical Outcomes Study Short Form Health Survey (SF-12) is a measure of health-related quality of life that is well validated in Australia [24,25]. Two summary scales of physical and mental well-being are generated using the brief integer scoring method developed by Andrews [24].

The Depression Anxiety Stress Scale (DASS 21; [26]) measures depression, anxiety and stress. Items such as, 'I felt scared without any good reason', are rated on a 4-point Likert scale. The measure has been used with general, clinical and HIV-infected populations and has good internal consistency, validity and test–retest reliability [26,27]. In the present study, Cronbach's alpha for the depression scale was $\alpha = 0.94$, the anxiety scale $\alpha = 0.88$ and the stress scale $\alpha = 0.92$.

Statistical analyses

The principal analysis was repeated measures ANOVA to investigate mean scores and differences between groups at each time point. We also performed chi-squares to compare our results with similar studies in other health domains. All analysis was completed using SPSS version 17 for Windows (SPSS Inc., Chicago, IL, USA) with a significance level of $p < 0.05$.

Results

Participants

Missing value analysis revealed no significant differences between those who completed every wave of the study (completers) and those who did not complete every wave (non-completers) on the psychological impact variables, all ps > 0.05. There was a significant age difference, $F(1, 279) = 12.46$, $p < 0.001$, between the completers (52 years) and non-completers (48 years). There were no significant differences in demographic characteristics between the control and HRA groups. Therefore, the demographic details for participants included in the analysis have been summarised as a total group (Table 1).

Group differences

On the basis of cytology and histology results, three groups were formed. The 'low threat' group ($n = 113$) received cytology results of negative or LSIL. The 'reassured' or false positive group ($n = 22$) required an HRA and either needed no biopsy or had reassuring histology results such as negative, warts or 'other inflammation'. The 'high threat' group ($n = 28$) required an HRA and received high grade anal intraepithelial neoplasia (HGAIN) histology results.

The differences in psychological responses were investigated between these groups across the three time points. One way ANOVAs and analysis of mean

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Table 1. Demographic characteristics of participants

Characteristic	Frequency
Mean age (SD; range)	52 (9; 28–73)
Education (%)	
High school or less	56 (34)
Certificate/diploma	25 (16)
Bachelor's degree	54 (33)
Post-graduate	28 (17)
Relationships (%)	
Currently in a relationship	78 (49)
Time in relationship > 5 years	65 (83)
Median sex partners in the last 12 months (SD; range)	5 (31; 0–240)
Employment (%)	
Full time	86 (53)
Part time/casual	25 (16)
Student	1 (1)
Retired	15 (9)
Unemployed	35 (21)
HIV characteristics (SD; range)	
Mean years HIV-infected	15 (8; 1–27)
Antiretroviral medication (%)	151(93)
Mean years on antiretroviral medication	10 (6; 1–22)
Median current CD4 count (cells/μL)	486 (230; 69–1634)
Median current HIV viral load (copies/mL)	50 (22 001; 5–265 000)
Current anal symptoms (%)	
Pain	17 (10)
Discharge	7 (4)
Bleeding	47 (29)
Itch	38 (23)
Lumps	21 (13)
Past history anal disease (%) (self-report)	
Anal HPV	75 (46)
Anal fissures	24 (15)
Anal intraepithelial neoplasia	3 (2)
Current smoker (%)	44 (27)
Illicit drug use in last 24 months (%)	80 (49)
Current alcohol drinker (%)	138 (85)
Antidepressant medication (%)	12 (7)

HIV, human immunodeficiency virus; HPV, human papillomavirus.

scores were used to investigate the group differences. There were no significant differences at baseline (Figures 2, 3 and 4). At times 2 and 3, there were significant group differences for cancer worry, anal health ratings, optimism for future health and distress after receiving histology results. The differences in cancer worry can be seen in Figure 2. At time 2, the groups recommended for HRA (reassured and high threat) had higher levels of worry than the low threat group, $F(1, 143) = 37.56$, $p < 0.001$, $\eta^2 = 0.21$. At time 3, the high threat group continued to have higher levels of worry, whereas the reassured group dropped below the high threat group but remained significantly above the low threat group, $F(2, 159) = 16.59$, $p < 0.001$, $\eta^2 = 0.17$. Figure 3 illustrates that anal health ratings were only significantly different at time 2, with anal health rated significantly worse by the HRA groups, $F(1, 157) = 14.22$, $p < 0.001$, $\eta^2 = 0.08$. Optimism for

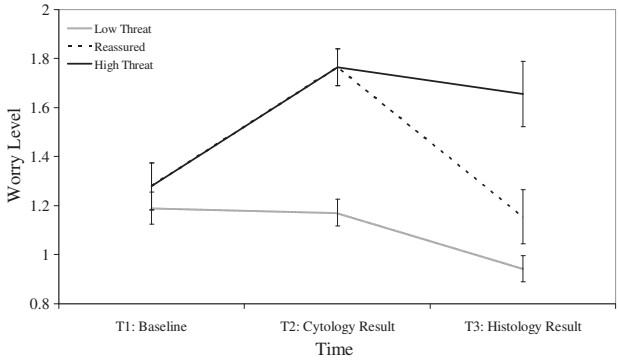

Figure 2. Cancer worry by threat groups at three time points. T1, time 1; T2, time 2; T3, time 3. The reassured (dashed line) and high threat (solid line) groups were both recommended for HRA; therefore, the groups are merged at T1 and T2. Cancer worry scale consisted of six items. The time interval between T1 and T2 is 2 weeks and between T2 and T3 is 10–12 weeks

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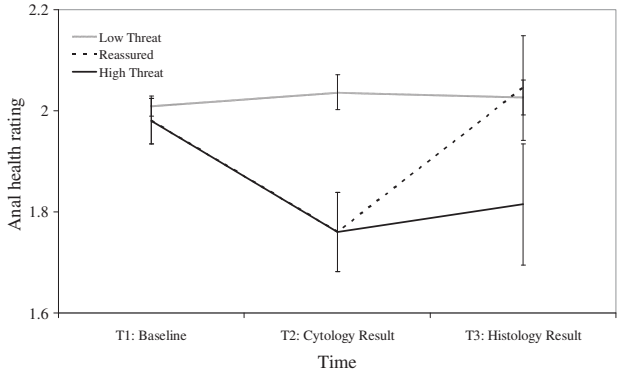

Figure 3. Anal health rating by threat groups at three time points. T1, time 1; T2, time 2; T3, time 3. The reassured (dashed line) and high threat (solid line) groups were both recommended for HRA; therefore, the groups are merged at T1 and T2. This single item was rated with a 4-point Likert scale, better than usual to much worse than usual. The time interval between T1 and T2 is 2 weeks and between T2 and T3 is 10–12 weeks

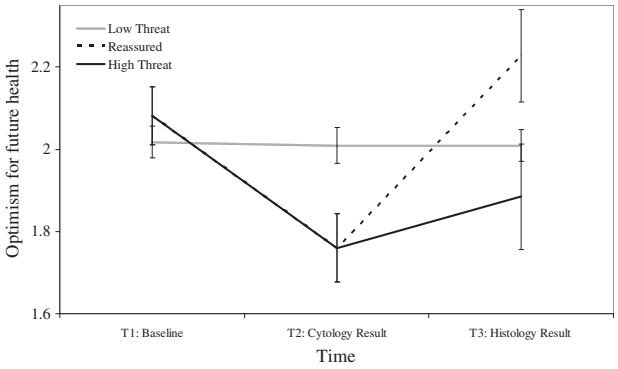

Figure 4. Optimism about future health by threat groups at three time points. T1, time 1; T2, time 2; T3, time 3. The reassured (dashed line) and high threat (solid line) groups were both recommended for HRA; therefore, the groups are merged at T1 and T2. This single item was rated with a 4-point Likert scale, better than usual to much worse than usual. The time interval between T1 and T2 is 2 weeks and between T2 and T3 is 10–12 weeks

future health (Figure 4) was significantly different at time 2, with the low threat group rating higher optimism compared with the HRA groups, $F(1, 158) = 8.40$, $p = 0.004$, $\eta^2 = 0.05$. At time 3, the reassured group became *more* optimistic about their health than either the low threat or high threat group, $F(2, 158) = 3.19$, $p = 0.04$, $\eta^2 = 0.04$. Distress levels after receiving HRA results revealed that the high threat group experienced more distress than the reassured group, $F(1, 43) = 5.65$, $p = 0.02$, $\eta^2 = 0.12$. There were no significant differences between the groups at any time point for ratings of depression, anxiety, stress and physical or mental quality of life, $p > 0.05$.

Discussion

We investigated the psychological impact of an anal cancer screening programme using prospective self-report questionnaires at three time points in the medical process. The high threat and reassured groups who were invited to have an HRA were significantly more worried about anal cancer, rated their anal health worse and were less optimistic about their future health than the control group who did not need further investigation. These findings are similar to women receiving cervical cytological screening [10] and men receiving prostate biopsy screening [4]. Our results could not be directly compared with the Tinmouth study [19] of anal cancer screening as the measures and order of medical processes were different. Tinmouth *et al.* [19] used the Impact of Events Scale, measuring stress; the Illness Intrusiveness Ratings Scale, measuring psychosocial impact on quality of life; and the positive questions from the Psychological Consequences Questionnaire adapted from mammography.

We found no evidence that general anxiety, depression or quality of life was significantly affected by the process. Thus, the psychological consequences appeared restricted to health-related concerns. The participants were all HIV-infected, which may have contributed to the finding that general mood states did not differ throughout the process. The distressing aspects of this process could be perceived as minor in comparison to what they have dealt with during their HIV diagnosis and management. Additionally, they may be accustomed to regular testing regarding their HIV infection such that this was just another routine screening process and their overall well-being was not threatened.

Interestingly, in the ratings of optimism for future health, the reassured group rebounded in optimism and indeed was more optimistic than both the high threat group and the low threat group who had not received a health scare. One possible explanation for this is that a negative result after a thorough screening for a physical problem (reassured group) is more reassuring than a negative result after a brief screen (low threat group). This possibility is supported by a study showing that 30% of asymptomatic individuals invited to have colorectal screening showed significant mental health benefits 5 weeks after screening [28]. Men with a family history of prostate cancer or who believed they had a greater chance of developing prostate cancer were more reassured by the thorough testing option than the brief screen when rating hypothetical scenarios [29].

A second explanation is that the reassured group might have felt that they 'dodged a bullet', and this led them to feel particularly optimistic. The phenomena

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of 'unrealistic optimism' UO has been found to hinder protective health behaviours. Intentions to participate in breast screening were lower when UO was higher [30], UO was higher in older smokers who inaccurately rated their health risks and they had less intention to quit than those with no UO [31]. Three years after colorectal screening, the group who were reassured with negative results had significant increases in their body mass index compared with those with positive results [32]. This may reflect UO and a resulting tendency to be less vigilant in following protective behaviours after being reassured. Future research could investigate these possible explanations in screening studies. Information about future risk could be important to encourage reassured individuals to repeat testing as recommended.

We found that although the screening increased cancer specific worry, it did not raise general levels of anxiety or mental health problems. These results are different from what has been found with cervical screening, which shows threatening Pap smear results are associated with subsequent increases in general anxiety [9,10,33]. However, our results are similar to findings by Essink-Bot *et al*. [33] that general anxiety was not altered by the prostate screening process. Future research is needed to investigate whether the difference was due to sex, site of problem or other aspects of the population. Studying HIV-infected women undergoing anal cancer screening is one possible way of investigating these differences.

Similar to prostate and breast screening studies [4,12], we also found that worry specific to the process and disease was different between the three groups. As we had baseline data, we were able to measure the influence of the procedures on worry levels. We found that the reassured group were more worried than the control group at time 3, but that their worry levels had dropped considerably since being referred for HRA.

Our results need to be viewed with caution, as the sample was of mainly well-educated Caucasian men living in the inner city. While response rates were adequate, the attrition rate through the various processes meant that only 57% of the initial participants were included in the analysis; this may have biased our results towards those who were more or less affected. We did not have an experimental control group who did not have any screening or the ability to screen the low threat group with the same thorough process. Our study used self-collected swabs, which is not always the method used; however, 81% of the participants who completed the anonymous evaluation form rated self-collection as acceptable [34]; self-collection could have added an additional element of fear or worry about correct collection. Further, Chin-Hong *et al*. [18] found that self-collection versus clinician collection yields comparable specificity, but clinician collection has higher sensitivity. We did not gather health or information seeking behaviour, which may have been a coping mechanism, and therefore moderated the impact of the procedures. For example, patients with a benign prostate biopsy had more PSA tests and doctor visits in the follow-up period than the control group who had no biopsy [15]. Patients who had an interest in HPV may have self-selected into the study.

Screening programmes for anal cancer need to consider the psychological impact on participants, particularly due to the likelihood of higher proportions of HSIL and HGAIN results in anal screening compared with cervical screening [1,35]. Our results indicate that the impact is likely to be specific to health-related worry. Future studies could investigate ways to ameliorate this health worry. One potential strategy is clear communication, demonstrated by prostate and cervical studies of cytology and histology results processes [9,10,15,36]. Providing written information about what an abnormal Pap smear meant led to less anxiety and fewer patients thinking they had cancer [37]. 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].

Future screening programmes need to optimise communication regarding the procedure itself, expected adverse events, recovery and non-technical explanations of results [5,38]. For example, the distinction between cancer and pre-cancer cytological and histological results can be difficult for patients to conceptualise, and cervical screening participants have found it 'difficult to understand cell changes as anything other than a life-threatening illness' [39].

Future research would benefit from using a community-derived sample of MSM, experimenting with communication styles and investigating health seeking behaviours, especially with the reassured group, as past research suggests that they may decrease their protective health behaviours [32]. In addition, having a longer follow-up period such as 6 months may give valuable information about the continuation of distress. Use of experience sampling for day to day emotions with smart phone apps or handheld computers would give richer data.

Our results show that specific worry about anal cancer increases throughout the medical process. They also suggest that receiving some threatening information and then reassuring information may produce greater optimism than never receiving threatening information. Further studies are needed to examine the best way to present information to these patients.

Supporting information

Supporting information may be found in the online version of this article.

Acknowledgements

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Conflict of interest

The authors have declared that there is no conflict of interest.

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