Psychosocial consequences of skin cancer screening

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ABSTRACT

Screening for melanoma may save lives, but may also cause patient distress. One key reason that preventative visual skin examinations for skin cancer are not currently recommended is the inadequate available evidence to assess potential harm to psychosocial wellbeing. We investigated potential psychological harms and benefits of skin examinations by conducting telephone surveys in 2015 of 187 screened participants; all were ≥ 35 years old. Participants had their skin examined by practitioners who had completed INFORMED, a validated web-based training for detection of skin cancers, particularly melanoma. Participants underwent the Spielberger State-Trait Anxiety Inventory (STAI), Psychological Consequences of Screening (PCQ), Hospital Anxiety and Depression (HAD) scale, and the 12-Item Short Form Health Survey (SF-12). Analyses were conducted in 2017. Of the entire study sample, 40% were thoroughly screened as determined by patient-reported level of undress and skin areas examined. Participants who were thoroughly screened: did not differ on negative psychosocial measures; scored higher on measures of positive psychosocial wellbeing (PCQ); and were more motivated to conduct monthly self-examinations and seek annual clinician skin examinations, compared to other participants ($p < 0.05$). Importantly, thoroughly screened patients were more likely to report skin prevention practices (skin self-examinations to identify a concerning lesion, practitioner provided skin exam), recommend skin examinations to peers, and feel satisfied with their skin cancer education than less thoroughly screened individuals ($p < 0.01$). Our results suggest that visual screening for skin cancer does not worsen patient psychosocial wellbeing and may be associated with improved skin cancer-related practices and attitudes.

1. Introduction

Melanoma incidence continues to increase and accounts for over 79% of skin cancer-related deaths (Trask et al., 2001; de Vries et al., 2007). The 5-year survival rate is very high among early stages; > 96% for *in situ* melanomas and 92% at stage I (Balch et al., 2009; Balch et al., 2011). However, survival decreases markedly to 67% at stage II, and 49% at stage III (Balch et al., 2009; Balch et al., 2011). Thus the importance of early diagnosis of melanoma is paramount. Full-body visual skin examination is the primary tool for secondary prevention of skin cancer, particularly melanoma. Regular whole-body skin examinations are associated with reduced melanoma thickness at diagnosis and improved survival rate (Aneja et al., 2012), which has been found for both

provider (Berwick et al., 1996) and self-administered skin exams (Aitken et al., 2010).

Though many providers use whole body skin exams as a standard method of skin cancer detection (Tsao & Weinstock, 2016), surprisingly little research has examined additional benefits, or potential harms of screening (Bibbins-Domingo et al., 2016; Wernli et al., 2016). This relative gap in the literature contributed to consecutive "insufficient" ("I") ratings by the US Preventative Services Task Force (USPSTF) (Bibbins-Domingo et al., 2016). In 2016, the USPSTF issued another "insufficient" statement regarding the utility of visual skin examinations for skin cancer screening of asymptomatic healthy adults (Bibbins-Domingo et al., 2016) in primary care settings. Some of the concerns mentioned by USPSTF included the over-diagnosis and an increase in

unnecessary skin biopsies, which we addressed in previous work (Weinstock et al., 2016). They also cited an inability to adequately compare the benefits and harms of skin examinations, including potential harm on psychosocial wellbeing (Bibbins-Domingo et al., 2016).

Potential psychosocial effects of cancer screening, such as anxiety and distress have contributed to revised screening recommendations for some cancer types, including breast and colon cancer (Chad-Friedman et al., 2017; Brennan & Houssami, 2016). Screenings for several types of cancer have been found to be associated with largely beneficial or non-harmful results (Niv et al., 2012; Taupin et al., 2006; McCaffery et al., 2010; Wardle et al., 2015). However, the effects on these outcomes have not been reported for skin cancer screening.

The purpose of this paper is to document the results of a survey assessment of the positive and negative psychosocial consequences, as well as post-screening skin cancer prevention attitudes and behaviors of patients who were screened by primary care providers at the University of Pittsburgh Medical Center (UPMC) initiative to screen for melanoma. Prior assessments of this initiative have shown that skin surgery and dermatology visits are not increased among patients seen by participating providers (Weinstock et al., 2016) and detected melanomas were more numerous and thinner among screened patients (Ferris et al., 2017).

As has been described elsewhere (Weinstock et al., 2016), the screening was conducted by primary care providers (PCPs; ie, physicians and other clinicians) during routine visits. These clinicians were offered online training using a modified version of the INFORMED (INternet course FOR Melanoma Early Detection) program (Eide et al., 2013). INFORMED (available at www.visualdx.com/educational-resources) has been previously shown to improve PCP skills related to melanoma detection, including the ability to appropriately reassure patients who have benign lesions that may resemble melanoma, such as seborrheic keratoses (Mykletun et al., 2001; Singer et al., 2009). It was anticipated that the ability to appropriately reassure patients would reduce the risk of screening-induced harms.

2. Methods

In the UPMC melanoma screening program (described elsewhere (Weinstock et al., 2016)), UPMC PCPs completed a modified version of the INFORMED training beginning in January 2014 to improve the early detection of melanoma and keratinocyte carcinomas (basal and squamous cell carcinomas of the skin) (Eide et al., 2013; Shaikh et al., 2012). The electronic medical record (EMR) included a health maintenance function (a new check box) to indicate screening for melanoma. For this study, UPMC staff drew a sample of all patients ≥ 35 years of age who were indicated in the EMR having a visit where a screen was done in the 2 PCP practices.

Letters were sent to patients offering an opportunity to opt out of the survey. Consent for the survey was conducted by telephone at the time of the survey. The protocol for obtaining verbal consent from all participants was approved by the appropriate IRB committees. Baseline surveys, representing the first contact with patients, were conducted in 2015 in batches to minimize a response bias of only completing surveys of easy-to-reach patients. Initial surveys were conducted an average of 5 months after the index PCP appointment, with a second survey following three months after the baseline contact or after a subsequent dermatology appointment.

Despite the consistent EMR presence of a checked box to indicate screening, not all patients reported in their baseline survey that they had had their skin thoroughly examined for early detection of cancer. Screening was then defined based on patient responses to several questions including: whether screening was performed, the level of undress during examination and whether certain body parts were examined. One hundred and twenty-two patients (65%) reported having their skin examined; 60 patients reported that their entire skin was examined specifically for skin cancer, and 76 patients reported being

screened, and reported being completely undressed with or without undergarments and had at least two out of three body parts examined (the back, abdomen, and calves). For the purposes of these analyses, "thoroughly screened," patients were those 76 (41%) and, "not thoroughly screened patients," were those 111 patients (59%) who did not indicate that they had their whole body screened for skin cancer, did not disrobe or have two of the three body parts examined.

2.1. Measures

Demographics: Characteristics queried in the baseline survey included: gender; household composition (lived with both adults and children, just children, just adults, you live alone); education (8th grade or less, some high school, high school graduate or General Education Degree (GED), technical school or junior college graduate, some college, college graduate, post graduate or professional degree, other); ethnicity (Hispanic, yes or no); Race (American Indian/Alaska Native, Asian, Native Hawaiian or Pacific Islander, Black or African American, White/Caucasian or other); Household income ($< \$20,000$, $\$20,000–\$40,000$, $\$40,001–\$80,000$, $> \$80,000$).

The Hospital Anxiety and Depression rating scale (HADS) is a 14-item questionnaire, with 7 questions measuring anxiety (HADS-A) and 7 questions measuring depression (HADS-D) on a self-reporting scale running from 0 to 3 (Snaith & Zigmond, 1986; Mykletun et al., 2001; Singer et al., 2009). Total scores ranged from 0 to 21, with higher scores indicating more severe anxiety or depression. Based on previous data, a cut-off score of 8 or more is considered to be optimal for allocating patients into groups with high and low depressive and anxiety symptoms (Bjelland et al., 2002).

The Spielberger State-Trait Anxiety Index – form 6 (STAI-6), is a validated 6-item version of the State Trait Anxiety Inventory, a self-administered measure to assess general anxiety. Scores range from 20 to 80 with higher scores indicating more severe anxiety. An individual is considered highly anxious with a score of over 44 (Millar et al., 1995; Marteau & Bekker, 1992).

Psychological Consequences Questionnaire (PCQ) is a self-administered questionnaire designed to measure positive and negative psychological impact of a mammogram (Cockburn et al., 1992; Rijnsburger et al., 2006). The PCQ measures the consequence of screening on three major life domains: emotional, defined as the psychological aspects of a person's behavior; physical, defined as the impact on a person's physical functioning, including activities of daily living; and social functioning, defined as the effect on a person's social functioning and how she relates to others. Scoring of the negative consequences within each dimension vary from 0 to 3 with higher score indicating more distress associated with screening (PCQ – negative). Cumulative scores could range in the emotional dimension from 0 to 15, physical from 0 to 12, and social from 0 to 9.

The positive emotional, physical, and social functioning consequences of the screening experience (Cockburn et al., 1992) are also queried with scores in each dimension varying from 0 to 3 with higher score indicating less distress and more positive consequence associated with screening. Cumulative scores could range in the emotional dimension from 0 to 15, physical from 0 to 9, and social from 0 to 6.

The 12-Item Short Form Health Survey (SF-12) is a self-administered questionnaire developed to measure health-related quality of life across age, disease, and treatment group (Gandek et al., 1998). The SF-12 consists of 12 items in the physical and mental domains referring to thoughts and feelings in the past. The original form refers to one week as the reference time period; this study modified to ask about thoughts and feelings in the past four weeks. The Physical Component Summary (PCS) is an index of overall physical functioning and the Mental Component Summary (MCS) is an index of emotional and mental health. Standardized scores range from 0 to 100, with higher scores indicating better self-perceived health.

Other questions included the experience of their skin exam