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Is attendance at an ovarian cancer screening clinic a worry-reducing event? Findings from pre- to post-screening

Joshua L. Ruberg [a,c,e,f,*], C. William Helm [a,c,1], Benjamin I. Felleman [e], Jane E. Helm [a,c], Jamie L. Studts [a,b,c,d]

[a] University of Louisville, Louisville, KY 40292, United States
[b] University of Kentucky College of Medicine, Lexington, KY 40536-0086, United States
[c] James Graham Brown Cancer Center, 529 South Jackson Street, Louisville, KY 40202, United States
[d] Lucille P. Markey Cancer Center, 800 Rose Street, Lexington, KY 40536-0293, United States
[e] VA San Diego Healthcare System, 3350 La Jolla Village Dr., San Diego, CA 92161, United States
[f] Department of Psychiatry, University of California, San Diego, 9500 Gilman Dr., La Jolla, CA 92093, USA

HIGHLIGHTS

- Worry was assessed before, during, and after an annual cancer screening visit.
- Worry about cancer was highest in the weeks prior to screening.
- Mere attendance at ovarian screening clinic seems to be a worry-reducing event.
- Psychological reactions to screening results vary depending on assessment method.

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ABSTRACT

Objective. Many studies have examined the relationship between worry and cancer screening. Due to methodological inconsistencies, results of these studies have varied and few conclusions can be made when generalizing across studies. The purpose of the current study was to better understand the worry-cancer screening relationship using a prospective research design.

Method. 180 women enrolled in an annual ovarian cancer (OC) screening clinic completed surveys at three time points—pre-screening, day of screening, and post-screening—using three measures of cancer-specific worry.

Results. OC worry was highest in the weeks prior to screening and mere presentation at a screening clinic was associated with a significant worry decline. Observed elevations in worry following abnormal screening were not universal and varied by the instrument used to measure worry.

Conclusions. In contrast to our hypotheses, it appears that mere presentation at a cancer screening clinic may be a worry-reducing event. Receipt of abnormal results was not necessarily associated with increased worry.

1. Introduction

Ovarian cancer (OC) ranks fifth in cancer deaths among women, accounting for more deaths than any other cancer of the female reproductive system [1]. The American Cancer Society estimates that approximately 21,290 women received a new diagnosis of OC in 2015. The two most frequently used methods of early-disease detection include transvaginal ultrasound/sonography (TVS) and CA-125 tumor marker sampling, both of which have been a source of controversy due to high false-positive rates and low positive predictive values [2]. However, there remains supporting evidence for rigorous adherence to screening schedules for women at high genetic risk [3].

There are a number of individual determinants of cancer screening participation. While some variables such as socioeconomic status [4] have a relatively clear relationship with individual screening behavior, less is known regarding psychological factors such as cancer-related worry. Much of the extant research has focused on the role of cancer worry in terms of being either a facilitator or barrier to screening uptake. The consensus to date is that the relationship between cancer worry and screening is characterized by a U-shaped relationship, whereby moderate levels of cancer worry facilitate screening and mild and severe levels inhibit it [5,6]. Because cancer screening is optimally

* Corresponding author at: VA San Diego Healthcare System, Psychology Service, 116A4Z, 3350 La Jolla Village Dr., San Diego, CA 92161, United States.
E-mail address: joshua.ruberg@va.gov (J.L. Ruberg).
[1] Present address: Northern Gynaecological Oncology Centre, Queen Elizabeth Hospital, Gateshead, Tyne and Wear NE9 6SX, United Kingdom.

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effective when repeated at regular intervals, worry plays an important role in screening practices as it can affect whether one attends screening for the first time, but also has the potential to influence participation in critical subsequent screenings [7]. In the context of regular cancer screening, cancer worry has the potential to vary at different time points during the process; therefore, it is advantageous to understand not only the effects of worry prior to screening, but also at the time of screening and upon receipt of results.

A major methodological concern of all known studies examining worry associated with OC screening is that all have compared post-screening worry to worry at a single pre-screening time point, either on the day of screening e.g. [8] or the day immediately prior e.g. [9]. No known study has assessed worry about OC screening more than one day *prior* to presentation at the screening clinic—when decisions to attend the screening clinic may be heavily influenced by psychological factors—and then continued to assess this worry at multiple points over time throughout the screening process.

Of the studies that assessed cancer worry on the day of or day prior to OC screening, two also assessed cancer worry as a long-term consequence of receiving abnormal screening results and found that this worry increased and persisted at one-year [10] and two-year [8] follow-up. Two studies [8,9] also assessed the presence of participants' intrusive thoughts about cancer after screening, but neither group reported persistent elevations regarding intrusive thoughts among women who had received abnormal screening results. Rather, Andrykowski and colleagues reported that intrusive thoughts were elevated two weeks after the TVS screening, but returned to baseline levels within four months [9]. A similar transient increase in anxiety and distress among women who received false positive results was reported by Wardle and colleagues [11]. None of the studies found any long-term psychological sequelae among participants who received normal screening results. However, because of methodological design, none of these studies have been able to determine the psychological consequence of merely presenting to the screening clinic.

We sought to gain a more comprehensive understanding of how worry is experienced by women throughout the OC screening process. Using a prospective design with three waves of data collection, this study investigated the trajectory of OC related worry by assessing worry twice prior to screening and again following screening. To draw better comparisons to the existing literature, three commonly used but distinct instruments were administered to assess cancer worry. Several specific hypotheses were proposed. Because we anticipated that participants would largely screen negative for OC during the screening visit, our primary hypothesis focused on those screeners. It was hypothesized that (1) reports of cancer worry among women who received normal scans would follow a curvilinear trend, whereby worry would be at the highest level on the day of cancer screening and be significantly lower before and after screening. We also hypothesized that (2) reports of cancer worry among women who received an abnormal scan would remain elevated at follow-up and be significantly higher than pre-screening levels. Finally, we hypothesized that (3) differences in cancer worry trajectory between those who received normal scans and those who received abnormal scans would result in a significant time by group (normal vs. abnormal) interaction, suggesting different worry trajectories.

2. Methods

2.1. Participants

Participants were drawn from women participating in an ongoing parent study of OC screening – *The University of Louisville Ovarian Cancer Screening Study* (*ULOCSS*). ULOCSS was a prospective longitudinal study based at the James Graham Brown Cancer Center in Louisville, Kentucky. Participants received an annual TVS screening and provided an annual blood sample for laboratory studies. Women with an abnormality on ultrasound were either asked to return for a repeat scan at a 6-week to 6-month interval or referred for surgical removal of the ovaries. Eligible women included: (A) asymptomatic ≥46 years of age with one or both ovaries in situ; or (B) ≥26 years of age with one or both ovaries and having: (a) a personal history of breast, colon, or endometrial cancer, or (b) a personal history of positive BRCA1 or BRCA2 genetic test result, or (c) one or more first degree relatives (mother, sister, daughter) with OC or breast cancer, or (d) multiple family members with either breast or OC, or (e) a mother, sister, daughter, grandparent with a positive BRCA1 or BRCA2 genetic test result, or (f) were treated with fertility drugs such as clomiphene citrate or gonadotrophins for more than one year.

2.2. Procedure

The following sections refer to methods for enrollment and data collection from a sub-study, entitled *The University of Louisville Ovarian Screening Experiences Study* (*OSES*). The OSES examined the acute trajectory psychosocial responses to participation in ovarian screening and focused attention on roughly a one-month window before and after ovarian screening test administration. The overarching aim was to explore factors that might facilitate or hinder adherence to the screening program algorithm. All references to "the study" will heretofore refer to the OSES sub-study.

2.3. Enrollment

Participants were contacted by the ULOCSS coordinator (JEH) by telephone to schedule an annual screening visit (ASV) and were offered the opportunity to participate in OSES. Those who indicated interest in participating in the sub-study during telephone contact with the screening coordinator were then telephoned independently by a research assistant (JLR) 7 to 30 days prior to the screening appointment. During this telephone call, candidates were read a brief consent preamble explaining the OSES study and their expected experiences and rights as participants. Those who consented verbally were enrolled in OSES, and all participants subsequently provided written consent on the day of screening.

2.4. Data collection

Data was collected at 3 time points: (a) time 1, 7–30 days before ASV; (b) time 2, on the day of ASV; and (c) time 3, 14–30 days after ASV. Enrolled participants completed self-report questionnaires assessing cancer-specific worry at each time point. At the screening visit (time 2), participants also completed a battery of self-report measures examining additional psychosocial variables, medical history and demographic data prior to TVS examination. Participants were notified of their TVS results within 7 days of ASV. Data were collected by telephone at times 1 and 3 and in-person at time 2.

2.5. Cancer-specific worry measures

Only data from the three cancer-specific worry questionnaires are described here. Information regarding the additional measures can be obtained from the corresponding authors.

2.5.1. Magnitude Worry Measure (MWM)

One single-item measure assessed the *magnitude* of worry by asking "How worried are you about developing ovarian cancer?" using a seven point Likert-type scale with the following anchors: 1 = "not at all worried" and 7 = "extremely worried." Similar instruments assessing the magnitude of worry on a Likert-type scale have been utilized previously in the literature [12–15].

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