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Illness representations and distress in women undergoing screening for familial ovarian cancer

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Women with a familial or genetic predisposition to ovarian cancer are at significantly increased risk of developing the disease, and this warrants effective risk management strategies. A clinical trial of ovarian cancer screening (OCS) is being conducted to establish the effectiveness of this risk management strategy. This article reports data from its psychological partner study which aims to evaluate the psychological effects of OCS. Leventhal's Self-Regulatory Model provided the theoretical framework for understanding emotional responses to OCS. The revised Illness Perceptions Questionnaire (IPQ-R) is based on this model and the IPQ-R, adapted to the risk of ovarian cancer, was completed by women ($N=1999$) prior to screening. The original IPQ-R factor structure was not replicated but IPQ-R variables explained 14.70% of the variance in women's ovarian cancer-specific distress after controlling for age, general anxiety and depression. Negative emotional representations of ovarian cancer risk and general anxiety were moderately associated with greater ovarian cancer-specific distress whereas cognitive illness representations were weakly related to ovarian cancer-specific distress. Further analyses of data from the ongoing psychological evaluation are needed to determine the predictive utility of IPQ-R variables in explaining distress during OCS.

Keywords: ovarian cancer screening; Illness Perceptions Questionnaire (revised); distress; psychological; health threat; ovarian cancer risk

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Introduction

Ovarian cancer is the fourth most common cause of death from female cancer, with a 5-year survival rate of only 40%. Survival rates increase dramatically, however, if the cancer is diagnosed at an early stage (≈ 3 in 4 survive for 5 years; Cancer Research UK, 2010). Around 10% of cases are associated with a familial and/or genetic predisposition which confers an increased lifetime risk of 10–45% (Angioli, Estape, Mason, & Penalver, 1998). This increased risk warrants effective risk management strategies, including surgery (prophylactic bilateral salpingo-oophorectomy; Kauff et al., 2002) and ovarian cancer screening (OCS). Phase 2 of the United Kingdom Familial Ovarian Cancer Screening Study (UK FOCSS Phase 2) aims to determine the effectiveness of more frequent OCS in detecting ovarian cancer at an early stage and reducing mortality in women at significantly increased risk of familial ovarian cancer. The OCS offered to women participating in UK FOCSS Phase 2 comprises of 4-monthly CA125 estimation (because high levels of CA125 could indicate the presence of an ovarian tumour) and annual transvaginal ultrasound scans (TVS).

Despite the potential benefits of early detection and reduced mortality, premenopausal women can have physiological variations (e.g., menstrual cycle) and benign conditions (e.g., ovarian cysts) that can result in false positive abnormalities on TVS and CA125 and could lead to unnecessary surgery. Moreover, the clinical effectiveness of OCS in detecting ovarian cancer is not proven and OCS cannot yet be recommended as a safe alternative to surgery (Rosenthal & Jacobs, 2006). Alongside these clinical considerations, there may be psychological benefits and harms. Prior to UK FOCSS Phase 2, women were screened annually for ovarian cancer, and although the more frequent screening in Phase 2 might improve the early detection of ovarian cancer, there is a concern that it may increase distress in women who are vulnerable due to their family history (Cull, Fry, Rush, & Steel, 2001). Moreover, although in most cases, women will receive a normal result from OCS, which may alleviate ovarian cancer-specific distress (Gaugler, Pavlik, Salsman, & Andrykowski, 2006), women who undergo repeat screening following an abnormal result may experience adverse psychological consequences even if the final result is normal. False positive results from familial OCS have been associated with increased anxiety compared to normal results (Wardle et al., 1993; Wardle, Pernet, Collins, & Bourne, 1994) and with significant distress 6 months after results (Kauff et al., 2005). This article reports the baseline data from PsyFOCS, an ongoing psychological partner study to UK FOCSS Phase 2 which aims to determine predictors of ovarian cancer-specific distress during OCS and identify subgroups of women who are prone to greater distress (Brain & Lancaster, 2007).

Leventhal's Self-Regulatory Model (SRM; Leventhal, Diefenbach, & Leventhal, 1992; Leventhal, Halm, Horowitz, Leventhal, & Ozakinci, 2005) provides a comprehensive theoretical framework for predicting emotional responses to a range of health threats. The SRM conceptualises people as common-sense scientists trying to understand and manage their world. When faced with a health threat, a cognitive and emotional representation of the threat is formed by interpreting information from different sources. The representation is based around five dimensions: disease *identity* (e.g., signs, symptoms), *consequences* (e.g., physical, social, emotional), *causes* (e.g., genetic, environmental), *timeline* (acute, chronic, cyclic) and *curability/controllability* (can the illness can be cured or prevented?). Individuals then form an action plan to cope with the health threat, its implications

for their well-being and their emotional reactions. The strategies used are evaluated and modified accordingly.

In a meta-analysis of studies using the SRM (Hagger & Orbell, 2003), the SRM showed sound construct and discriminant validity across various illnesses and cognitive representations of illness predicted psychological outcomes. The SRM has also been used to explain responses to familial or genetic risk assessment and testing (Decruyenaere, Evers-Kiebooms, Welkenhuysen, Denayer, & Claes, 2000; Kelly et al., 2005; Rees, Fry, Cull, & Sutton, 2004). The revised Illness Perceptions Questionnaire (IPQ-R; Moss-Morris et al., 2002) is based on the SRM and assesses cognitions and emotional responses to illness. The authors suggest that IPQ-R may be differentially applicable to different patient populations and encourage the adaptation of the measure in order to increase its validity and reliability (Moss-Morris et al., 2002; Rees et al., 2004).

In this study, IPQ-R items were adapted to be appropriate for women at risk of developing ovarian cancer because the cognitions and emotions engendered by the knowledge of *susceptibility* to a disease may not be the same as those arising from the *manifestation* of that disease (Fang et al., 2006). For example, in the case of ovarian cancer risk, ovarian cancer symptoms may not be at the forefront of women's minds because they have not yet developed the disease and in its earliest stages the symptoms of ovarian cancer can be vague and nonspecific (Ovacome, 2009).¹ Baseline psychological data were collected before women had the first OCS of the UK FOCSS Phase 2 screening trial. Data were examined to determine associations between elements of the SRM and ovarian cancer-specific distress at the start of screening and to determine other potential predictors (e.g., OCS history, demographic variables) that may explain variation in ovarian cancer-specific distress during OCS.

Method

Participants

Women were recruited from amongst those consenting to a clinical trial of OCS (UK FOCSS Phase 2). UK FOCSS participants were recruited from women registered with the UK Familial Ovarian Cancer Registry, attending clinical genetics centres participating in UK FOCSS, or were identified in other clinics (e.g., gynaecology clinics, medical oncology clinics) as being at high risk of ovarian cancer due to their family histories. All women recruited to UK FOCSS Phase 2 received an assessment and explanation of their ovarian cancer risk and advice about prevention and screening. The same inclusion criteria applied to PsyFOCS and the clinical trial. Women were eligible to participate if they had a specified number of close relatives (e.g., parents, siblings), with breast, ovarian, or colorectal cancer or a family member with an ovarian cancer-predisposing gene. Exclusion criteria were also the same in both studies; women were excluded if they (1) had undergone bilateral oophorectomy, (2) were <35 years of age or (3) were participating in other OCS trials.

Prior to commencing Phase 2 screening, all women consenting to UK FOCSS Phase 2 ($N = 3224$) were invited to participate in PsyFOCS, and 2130 (66.07%) consented to take part in PsyFOCS and returned a completed baseline questionnaire. Of these, 131 (6.15%) were not included in the final sample because they knew the result of their first UK FOCSS CA125 blood test when they completed the

baseline questionnaire. Because the PsyFOCS consent form and questionnaire were returned together, no psychological data are available for women who did not consent to PsyFOCS. The mean age of women in the final sample ($N=1999$) was 47.50 years ($SD=9.46$), and of those who provided demographic information about marital status, education and ethnicity (99.10%; $n=1981$), around three-quarters (76.63%, $n=1518$) were married or cohabiting and the majority had been educated at least to 16 years of age (89.20%, $n=1767$). Most women (97.12%; $n=1924$) described their ethnicity as white.

Materials

The study invitation pack included an invitation letter, information sheet, consent form and reply paid envelope and baseline questionnaire. The baseline questionnaire included measures of ovarian cancer-specific distress, anxiety, depression, demographics (age, marital status and education), clinical screening history and illness perceptions. The stressfulness of follow-up tests after any previous OCS was assessed by an item asking 'How stressful were these further tests for you?' anchored 1 (not at all stressful) and 7 (extremely stressful).

Illness representations

The IPQ-R (Moss-Morris et al., 2002) was used to measure cognitions and emotional responses to the risk of ovarian cancer. The original IPQ-R has shown strong factor structure, reliability and validity and has been used to predict reactions to a range of illnesses (Moss-Morris et al., 2002). Items were adapted to refer to ovarian cancer or ovarian cancer risk. The identity scale was not used to avoid inducing anxiety in healthy women and the timeline scale was not used as ovarian cancer risk does not have symptoms that improve, pass or fluctuate over time. In line with Moss-Morris et al. (2002), curability and controllability items assessed beliefs about personal control and self-efficacy in relation to the risk of ovarian cancer, and beliefs that OCS could control the risk of ovarian cancer. Items asking about beliefs that OCS could control risk referred to CA125 blood tests or TVS. Written instructions explained that the questions were enquiring about women's personal views regarding their ovarian cancer risk. Agreement with the items was indicated on 5-point scales anchored 1 (strongly disagree) and 5 (strongly agree). Because IPQ-R items were substantially altered, the underlying factor structure of the adapted IPQ-R was validated using principal components analyses (PCAs; Tables 1 and 2).

General anxiety and depression

The Hospital Anxiety and Depression Scale (HADS; Zigmond & Snaith, 1983) was used to assess the presence and severity of general anxiety (seven items) and depression (seven items). Women rated the extent to which statements assessing anxiety (e.g., I feel tense or wound up, I feel restless as if I have to be on the move) or depression (e.g., I have lost interest in my appearance, I feel as if I am slowed down) were true of the way they had generally felt in the past week. Total subscale scores yielded cut-off values for mild (scores 8–10), moderate (11–15) or severe (>16) depression or anxiety (Zigmond & Snaith, 1983). The HADS showed strong

Table 1. PCA of IPQ-R items.

IPQ-R subscale	Factor I	Factor II	Factor III	Factor IV	Factor V	Factor VI	Factor VII
<i>Personal control</i>							
There is a lot I can do to control risk of OC	0.715						
What I do can determine whether my risk of OC gets better or worse	0.753						
My risk of getting OC depends on me	0.588						
My actions have no affect on my risk of OC	− 0.746						
Nothing I do will affect my risk of OC	− 0.736						
I have the power to influence my risk of OC	0.743						
Little can be done to reduce my risk of OC	− 0.706						
Nothing which can help my risk of OC	− 0.664						
<i>Emotional representations</i>							
I get depressed when I think about risk of OC		0.844					
When I think about my risk of OC, I get upset		0.869					
My risk of OC makes me feel angry		0.752					
My risk of OC does not worry me		− 0.690			0.306		
Being at risk of OC makes me feel anxious		0.825					
My risk of OC makes me feel afraid		0.837					
<i>Illness coherence</i>							
My risk of OC is puzzling to me			0.838				
My risk of OC is a mystery to me			0.871				
I do not understand my risk of OC			0.871				
My risk of OC does not make any sense to me			0.817				
Have a clear picture/understanding of risk of OC			− 0.711				
<i>Prevention/control</i>							
Negative effects OC prevented/avoided: CA125						0.781	
Negative effects OC prevented/avoided: ultrasound						0.792	
CA125 blood tests can control my risk of OC						0.863	
Ultrasound scans can control my risk of OC						0.867	

(continued)

Table 1. Continued.

IPQ-R subscale	Factor I	Factor II	Factor III	Factor IV	Factor V	Factor VI	Factor VII
<i>Nonspecific consequences</i>							
OC is a serious condition					-0.750		
OC would have major consequences on my life					-0.794		
OC would not have much effect on my life					0.699		
<i>Specific consequences</i>							
OC would strongly affect the way others see me						0.705	
OC would have serious financial consequences						0.710	
OC would cause difficulties for those close to me						0.691	
<i>Detection/control</i>							
CA125 blood tests effective in detecting OC							0.881
Ultrasound scans effective in detecting OC							0.882

Note: Bold factor loadings indicate that the item was included in the factor concerned.

Table 2. PCA of IPQ-R causal items.

	Factor I	Factor II	Factor III	Factor IV
<i>Psychological attributions</i>				
Family problems	0.872			
Emotional state	0.870			
Overwork	0.805			
Mental attitude	0.784			
Stress or worry	0.756			
My personality	0.655		0.362	
Altered immunity	0.365	0.316	0.314	
<i>Risk factors</i>				
Smoking		0.840		
Alcohol		0.801		
Diet or eating habits	0.309	0.652		
Pollution	0.310	0.510	0.319	
Own behaviour	0.416	0.434		
<i>Harm/neglect</i>				
Germ or virus			0.706	
Poor medical care			0.622	
Accident or injury	0.370		0.529	
<i>Separate items</i>				
Hereditary			-0.579	0.454
Chance or bad luck				0.756
Ageing		0.472		0.520

Note: Bold factor loadings indicate that the item was included in the factor concerned.

reliability and validity in women at increased genetic risk of breast cancer (Van Dooren Rijnsburger et al., 2004). The reliability of the anxiety ($\alpha = 0.86$) and depression ($\alpha = 0.82$) subscales were good.

Ovarian cancer-specific distress

The Impact of Event Scale (IES; Horowitz, Wilner, & Alvarez, 1979) comprised of 15 items. Written instructions asked women to consider how frequently in the last week they had experienced intrusive thoughts about their ovarian cancer risk (e.g., I thought about it when I did not mean to, I had dreams about it) and how frequently they had avoided such thoughts (e.g., I stayed away from reminders of it, I was aware that I still had a lot of feelings about it, but I did not deal with them). Horowitz (1982) identified thresholds for low (<8.5), medium (8.6–19) and high (>19) distress, corresponding to levels of clinical concern using the IES total score. The IES has been used as a measure of cancer-specific distress in several studies (e.g., Kent, Howie, Fletcher, Newbury-Ecob, & Hosie, 2000; Tiller et al., 2002) and showed good internal consistency and test–retest reliability amongst women at high risk (Thewes, Meiser, & Hickie, 2001). The reliability of this measure in this study was good ($\alpha = 0.93$).

Procedure

Ethical approval for PsyFOCS was granted by the Eastern Multi-Centre Research Ethics Committee. Women were sent the baseline questionnaire pack on receipt of

their consent for UK FOCSS Phase 2 screening and were sent a reminder questionnaire pack if they did not respond about the psychological study within 2 weeks. Consent was sought for PsyFOCS researchers to access relevant clinical information from the UK FOCSS database (e.g., CA125 and TVS results). Women were advised that they were not obliged to participate in PsyFOCS, that they could opt out of further contact from PsyFOCS researchers and that their decision about the psychological study would not affect their medical care.

Data analysis

Descriptive analyses were conducted on all variables. Missing data on psychological variables (<6% of cases per variable) were replaced with the mean for that item or subscale. Missing data on demographic and ovarian screening history variables were not replaced and *N*s differ for these variables. PCAs with Varimax rotation were conducted on IPQ-R items. Zero-order correlations were conducted on IPQ-R subscales, and between IPQ-R subscales and the other psychological variables. A hierarchical multiple regression was conducted on ovarian cancer-specific distress to test the relative contribution of adapted IPQ-R subscales in explaining ovarian cancer-specific distress after controlling for demographic and clinical variables, anxiety and depression. Age was entered on Step 1, and anxiety and depression on Step 2. IPQ-R illness representations (excluding emotional representations) were entered on Step 3 and all IPQ-R subscales were included on Step 4. A second hierarchical regression was conducted for a subset of women ($N=276$) answering a question about the stressfulness of further tests after their most recent TVS. Age was entered on Step 1, the stressfulness of further tests on Step 2, anxiety and depression on Step 3, IPQ-R illness representations (excluding emotional representations) on Step 4 and all IPQ-R subscales on Step 5. Due to the large sample which can mean that weak effects are statistically significant, a conservative alpha ($p<0.001$) was used for analyses involving the full sample and very weak correlations <0.10 will not be discussed.

Results

OCS history

Most women (81.86%, $n=1620$, $N=1979$) had undergone TVS before. The majority (77.65%, $n=1258$, $N=1620$) had received a normal result from their most recent screen, whereas 9.63% ($n=156$, $N=1620$) had undergone further tests ($M=1.29$, $SD=0.68$, $N=192$) before receiving a normal result. Those answering the question about the stressfulness of follow-up tests had found these moderately stressful ($M=3.19$, $SD=1.93$, $N=276$). Around one-fifth of women (20.10%, $n=321$, $N=1595$) had undergone further tests after OCS in the past.

PCAs on IPQ-R items adapted to the risk of ovarian cancer

The PCA on IPQ-R items (excluding Causes) yielded seven factors which together explained 65.04% of the variance (Table 1). All but one of the 31 items loaded onto a single factor. Factor I comprised of eight items asking about perceptions of control over ovarian cancer risk and explained 15.37% of the variance. Two of these items

were adapted from the Moss-Morris et al. (2002) treatment control subscale and the remaining items assessed perceptions of personal control. This subscale was labelled Personal Control ($\alpha = 0.86$). Factor II ($\alpha = 0.90$) comprised of six adapted Emotional Representations items and explained 15.07% of the variance, whilst Factor III ($\alpha = 0.89$) comprised of five Illness Coherence items identified by Moss-Morris et al. (2002) and explained 11.98% of the variance. Factor IV comprised of four items referring to control of ovarian cancer risk by CA125 blood tests or TVS. This subscale (labelled Prevention/Control) explained 8.48% of the variance ($\alpha = 0.88$). Factor V explained 6.06% of the variance and Factor VI explained 4.10%. Each comprised of three Consequences items adapted from the original Moss-Morris et al. (2002) solution. Factor V ($\alpha = 0.66$) comprised of items that did not specify particular consequences of ovarian cancer (labelled Nonspecific Consequences) and Factor VI ($\alpha = 0.62$) comprised of items that did (labelled Specific Consequences). Finally, Factor VII contained two items asking about beliefs that CA125 blood tests or TVS would detect ovarian cancer. This factor (labelled Detection/Control) explained 3.98% of the variance and showed good reliability ($\alpha = 0.82$).

The PCA on IPQ-R causes yielded four factors which together explained 60.79% of the variance (Table 2). Ten items loaded onto a single factor with the remainder showing cross-loadings (>0.3) with other factors. Factor I comprised of seven items and explained 39.17% of the variance. These were mainly attributions about psychological causes for ovarian cancer risk (labelled Psychological Attributions; $\alpha = 0.90$). Factor II (labelled Risk Factors; $\alpha = 0.81$) had five items asking about lifestyle risk factors for ill-health and an item enquiring about pollution and explained 8.17% of the variance. Factor III comprised of four items and explained 7.62% of the variance. This factor comprised the heredity item which was inversely related to items enquiring about poor medical care, germs and accidents. The reliability of this subscale (labelled Harm or Neglect) was low ($\alpha = 0.45$). Removing the heredity item improved reliability ($\alpha = 0.64$) and heredity was used as a single item. Finally, Factor IV was a 2-item factor explaining 5.82% of the variance. Factor IV was not reliable ($\alpha = 0.27$) and was decomposed into its constituent items, Chance or bad luck and Ageing.

Zero-order correlations amongst IPQ-R variables

Table 3 presents the mean scores (SD in parentheses) and intercorrelations for IPQ-R subscales. Most Causes subscales were positively correlated with each other. The heredity item, however, showed negative and weak relationships with most other causes items except ageing, with which it was positively related. Intercorrelations between the remaining IPQ-R subscales were at most weak to moderate. Stronger beliefs about personal control over ovarian cancer risk were positively related to beliefs that OCS could prevent or control ovarian cancer risk, and to causal factors more amenable to personal control (risk factors, psychological factors, harm or neglect). More negative emotional representations of ovarian cancer risk were inversely related to illness coherence, and positively related to beliefs about the negative consequences of ovarian cancer and to beliefs that psychological factors, heredity and ageing could cause ovarian cancer.

A greater sense of coherence about ovarian cancer risk was negatively related to beliefs that OCS could prevent ovarian cancer and to all causes of ovarian cancer

Table 3. Means, SD (in parentheses) and intercorrelations for IPQ-R subscales.

IPQ-R subscale	Mean (SD)	1	2	3	4	5	6	7	8	9	10	11	12
1 Personal control	3.00 (0.76)	—											
2 Emotional representations	3.03 (0.87)	-0.02	—										
3 Illness coherence	3.84 (0.78)	0.02	-0.14***	—									
4 Prevention/control	2.86 (0.90)	0.20***	0.03	-0.19***	—								
5 Nonspecific consequences	4.72 (0.48)	-0.04	0.19***	0.14***	-0.14***	—							
6 Specific consequences	3.58 (0.83)	-0.05	0.32***	-0.03	-0.10***	0.31***	—						
7 Detection/control	3.77 (0.71)	0.06	-0.06	0.00	0.34***	0.00	-0.03	—					
8 Psychological attributions	2.60 (0.80)	0.21***	0.11***	-0.16***	0.12***	-0.02	0.14***	-0.01	—				
9 Risk factors	2.86 (0.74)	0.31***	0.09***	-0.12***	0.04	0.01	0.06	-0.01	0.64***	—			
10 Harm/neglect	2.22 (0.68)	0.14***	0.08	-0.25***	0.17***	-0.12***	0.04	0.04	0.53***	0.48***	—		
11 Heredity	4.58 (0.60)	-0.04	0.10***	0.21***	-0.06	0.26***	0.10***	0.05	-0.05	-0.02	-0.16***	—	
12 Chance/bad luck	3.18 (1.17)	-0.06	0.05	-0.10***	-0.01	0.04	0.08	-0.03	0.10***	0.11***	0.17***	-0.02	—
13 Ageing	3.37 (1.01)	0.08	0.13***	-0.04	-0.01	0.11***	0.13***	-0.03	0.32***	0.40***	0.22***	0.10***	0.16***

Note: *** $p < 0.001$.

other than heredity, with which it was positively related. Greater illness coherence was related to a greater sense of the nonspecific, negative consequences of ovarian cancer. Perceptions about the specific and nonspecific consequences of ovarian cancer were moderately correlated and positively related to beliefs that heredity and ageing could cause ovarian cancer. There was some differentiation in the relationships between the separate consequences subscales and other causes. Perceptions about the specific negative consequences of ovarian cancer were positively related to beliefs that psychological issues could cause ovarian cancer, but perceptions about nonspecific consequences were not. Instead, beliefs about nonspecific consequences were negatively related to beliefs that harm or neglect could cause ovarian cancer whereas perceptions about specific consequences were not.

The PCA had separated items referring to CA125 and TVS screening into those asking about *prevention* of ovarian cancer, and those asking about the *detection* of ovarian cancer. These subscales were moderately related but distinguished themselves in their relationships with other variables. The detection/control subscale showed very weak or nonsignificant relationships with other IPQ-R variables, whereas the prevention/control subscale was negatively related to beliefs in the negative consequences of this disease and to stronger beliefs that harm or neglect or psychological factors might cause ovarian cancer.

Zero-order correlations between psychological predictors and ovarian cancer-specific distress

Means and standard deviations (SD) for the anxiety and depression and ovarian cancer-specific distress scales, and zero-order correlations between these and IPQ-R variables are given in Table 4. Anxiety and depression were strongly correlated ($r=0.64$) and the majority of women's scores were in the normal range for anxiety (62.00%, $n=1239$) and depression (89.70%, $n=1793$), according to cut-off scores. Few women had scores indicative of moderate or high levels of depression (2.80%, $n=55$), but almost 17% of women ($n=336$) were categorised as moderately or highly anxious. A little more than half of the women (56.80%, $n=1136$) reported low levels of ovarian cancer-specific distress, but more than a quarter of women (27.30%, $n=545$) were highly distressed. Examination of OCS and demographic variables with one-way analysis of variance showed that women experiencing high levels of ovarian cancer-specific distress were significantly younger ($M=45.91$, $SD=8.83$) than those in low ($M=48.26$, $SD=9.56$) or moderate ($M=47.51$, $SD=8.83$) distress, $F(2, 1996)=11.46$, $p<0.001$. Of those women ($N=276$) who answered the question about the stressfulness of further tests, women experiencing high levels of ovarian cancer-specific distress had found these more stressful ($M=3.63$, $SD=2.04$) than those in low ($M=2.91$, $SD=1.76$) or moderate ($M=3.00$, $SD=2.00$) distress, $F(2, 273)=4.38$, $p=0.013$. No other OCS history or demographic variables were related to ovarian cancer-specific distress.

The strongest correlation was between emotional representations and ovarian cancer-specific distress, with moderate correlations found between emotional representations and anxiety and depression. Cognitive illness representations were weakly correlated with anxiety, depression and ovarian cancer-specific distress. A greater sense of coherence about ovarian cancer risk was related to lower anxiety, depression and ovarian cancer-specific distress, whereas beliefs about specific

Table 4. Zero-order correlations between IPQ-R subscales, anxiety, depression and ovarian cancer-specific distress.

	Mean (SD)	PC	ER	IC	Pr/C	NSC	SC	DC	PA	RF	HN	H	CBL	A
Anxiety	6.63 (4.03)	-0.02	0.48***	-0.15***	0.04	0.10***	0.22***	-0.06	0.18***	0.16***	0.12***	0.06	0.03	0.14***
Depression	3.08 (3.11)	-0.06	0.30***	-0.13***	0.05	0.02	0.17***	0.01	0.14***	0.11***	0.16***	0.01	0.04	0.10***
Ovarian cancer-specific distress	11.96 (15.00)	0.02	0.57***	-0.11***	0.08***	0.11***	0.21***	-0.03	0.09***	0.07	0.07	0.09***	0.02	0.08***

Notes: *** $p < 0.001$. PC, personal control; ER, emotional representations; IC, illness coherence; Pr/C, prevention/control; NSC, nonspecific consequences; SC, specific consequences; DC, detection/control; PA, psychological attributions; RF, risk factors; HN, harm or neglect; H, hereditary; CBL, chance or bad luck; A, ageing.

negative consequences of ovarian cancer were related to higher scores on these variables. Beliefs about nonspecific consequences were related to greater anxiety and ovarian cancer-specific distress, but not to depression. There were weak positive relationships between risk factors, psychological factors and harm or neglect as causes of ovarian cancer, and anxiety and depression. Relationships between IPQ-R causes items and ovarian cancer-specific distress were very weak.

Table 5 presents the results of the regression conducted on psychological predictors and ovarian cancer-specific distress. Model 1 was significant and women's age was significantly associated with ovarian cancer-specific distress. Model 2 was also significant and general anxiety was significantly associated with ovarian cancer-specific distress. Model 3 was significant and anxiety and beliefs about specific consequences of ovarian cancer were associated with ovarian cancer-specific distress.

Table 5. Hierarchical multiple regression on ovarian cancer-specific distress.

		β	Adjacent R^2	R^2 change	F
Model 1	Age	-0.11***	0.01	—	25.06***
Model 2	Age	-0.06			
	Anxiety	0.46***			
	Depression	0.03	0.24	0.23	212.79***
Model 3	Age	-0.05			
	Anxiety	0.43***			
	Depression	0.03			
	Personal control	0.02			
	Illness coherence	-0.04			
	Prevention/control	0.09***			
	Nonspecific consequences	0.04			
	Specific consequences	0.10***			
	Detection/control	-0.04			
	Psychological attributes	-0.02			
	Risk factors	-0.02			
	Harm/neglect	0.03			
	Hereditary	0.06			
	Chance/bad luck	-0.01			
	Ageing	0.00	0.26	0.02	47.83***
Model 4	Age	0.00			
	Anxiety	0.26***			
	Depression	0.03			
	Personal control	0.03			
	Illness coherence	0.00			
	Prevention/control	0.06			
	Nonspecific consequences	-0.01			
	Specific consequences	0.02			
	Detection/control	-0.02			
	Psychological attributes	-0.02			
	Risk factors	-0.01			
	Harm/neglect	0.02			
	Hereditary	0.04			
	Chance/bad luck	-0.01			
	Ageing	-0.02			
	Emotional representations	0.43***	0.39	0.13	80.02***

Note: *** $p < 0.001$.

The final model was also significant and 38.80% of the variance in ovarian cancer-specific distress was explained by age, general anxiety, depression and IPQ-R variables. In the final model, only general anxiety and emotional representations were associated with ovarian cancer-specific distress at the $p < 0.001$ level. Whereas cognitive illness representations accounted for 1.9% of the variance in ovarian cancer-specific distress after controlling for age, general anxiety and depression in model 3, emotional representations accounted for a further 12.8% of the variance in ovarian cancer-specific distress in the final model.

Regression analyses involving a subset of women ($N = 276$) who answered a question about the stressfulness of further tests showed that model 1 was not significant, $F(1, 274) = 0.06$, $p = 0.81$, model 2 was significant, $F(2, 273) = 9.41$, $p < 0.001$, model 3 was significant, $F(4, 271) = 33.83$, $p < 0.001$, and model 4 was significant, $F(16, 259) = 9.89$, $p < 0.001$. The final model was significant, $F(17, 258) = 14.78$, $p < 0.001$, and explained 46.00% of the variance in ovarian cancer-specific distress. The stressfulness of further tests was significantly associated with ovarian cancer-specific distress in models 2 ($\beta = 0.26$, $p < 0.001$), 3 ($\beta = 0.14$, $p = 0.008$) and 4 ($\beta = 0.12$, $p = 0.02$) but not in the final model ($\beta = 0.04$, $p = 0.42$). In model 4 (excluding emotional representations), significant correlates of ovarian cancer-specific distress were general anxiety ($\beta = 0.39$, $p < 0.001$), beliefs about the specific consequences of ovarian cancer ($\beta = 0.15$, $p = 0.006$), and beliefs that ovarian cancer could be caused by harm or neglect ($\beta = 0.17$, $p = 0.006$) or heredity ($\beta = 0.12$, $p = 0.02$). In the final model (including emotional representations), women's age ($\beta = 0.10$, $p = 0.04$), general anxiety ($\beta = 0.27$, $p < 0.001$), harm or neglect ($\beta = 0.18$, $p < 0.001$) and emotional representations ($\beta = 0.44$, $p < 0.001$) were significantly associated with ovarian cancer-specific distress. Cognitive representations accounted for 1.8% of the variance in ovarian cancer-specific distress after controlling for age, the stressfulness of further tests, and general anxiety and depression and emotional representations accounted for a further 11.9% of the variance in ovarian cancer-specific distress in the final model.

Discussion

The aim of this study was to determine the demographic, clinical and psychological factors associated with ovarian cancer-specific distress in women undergoing OCS because of a family history of ovarian cancer. The results of analyses involving the whole sample initially suggested that younger women may experience greater distress about their risk of ovarian cancer but age was not associated with ovarian cancer-specific distress when illness representations were included in regression analyses. Similarly, although a subsample of women who found follow-up tests after previous OCS more stressful reported greater ovarian cancer-specific distress, this OCS variable was not related to ovarian cancer-specific distress when illness representations were included in regression analyses. General anxiety and emotional representations showed the strongest relationships with ovarian cancer-specific distress and, of the cognitive illness representations, only beliefs about the specific consequences of ovarian cancer were (weakly) related to ovarian cancer-specific distress in the full sample. Beliefs that harm or neglect could cause ovarian cancer were weakly related to ovarian cancer-specific distress in the subsample.

It has been argued that the emotional representations construct has conceptual overlap with distress or worry outcomes and the emotional representations scale has been excluded from analyses which aim to determine the relationship between illness perceptions and measures of psychological well-being (e.g., Gould, Brown, & Bramwell, 2010; Rees et al., 2004). In this study, zero-order correlations between emotional representations on the one hand and anxiety, depression and ovarian cancer-specific distress on the other were indeed moderate or high, which offers some support for this contention. However, none of these relationships exceeded $r = 0.57$ (similar to the relationship between emotional representations and worry about the risk of venous thrombosis, Kaptein et al., 2007), and our results do not therefore suggest multicollinearity (i.e., $r > 0.7$; Tabachnick & Fidell, 2001) between emotional representations and ovarian cancer-specific distress. Moreover, our measure of ovarian cancer-specific distress assessed women's propensity to experience intrusive thoughts and dreams about their risk of ovarian cancer and to use avoidant strategies to deal with their worries, whereas the emotional representations scale asks about how upset, angry, depressed, anxious, afraid and worried they are about their risk. We believe that our measure of ovarian cancer-specific distress is statistically *and* conceptually distinct from the emotional representations scale. Indeed, intrusive thoughts and avoidance would seem to be likely consequences of feeling upset or angry about an increased risk of ovarian cancer. We would argue that it is too soon to conclude that the emotional representations scale is a proxy measure of distress which warrants its exclusion from analyses involving psychological well-being as an outcome. Instead, we believe that research should continue to explore the unique and shared variance between emotional representations and general and specific distress in various illness and at risk populations.

The only cognitive illness representations that were related to ovarian cancer-specific distress in our final regression models were beliefs about the specific, negative consequences of ovarian cancer and beliefs that harm or neglect could cause ovarian cancer. Moreover, these relationships were weak. Personal control beliefs and beliefs in the ability of OCS to prevent or control the risk of getting ovarian cancer were only very weakly related to ovarian cancer-specific distress, which was somewhat unexpected. The detection of abnormal ovarian morphology at an early stage may bolster optimism about a better prognosis (Sheppard, Fry, Rush, Steel, & Cull, 2001), and therefore it would seem likely that faith in the effectiveness of OCS would reassure women and reduce their distress. The lack of relationships between cognitive illness representations and ovarian cancer-specific distress in this study raises questions about the possibility of measurement error and about the utility of cognitive illness representations in explaining distress in women at increased risk of ovarian cancer.

Our adaptation of the IPQ-R was substantial and one explanation why cognitive illness representations were not related to ovarian cancer-specific distress might therefore be that our measure of illness representations was unsatisfactory. Indeed, there were several differences between our subscales and those developed by Moss-Morris et al. (2002). Items expected to form a single 'treatment control' subscale according to the original model loaded instead onto three factors and we did not replicate the original IPQ-R causes subscales. Overall, however, our results suggest that our adaptation of the IPQ-R was successful. Our factor solutions explained 60.79% and 65.04% of the variance (causal and other IPQ-R items, respectively), comparable to that explained by Moss-Morris et al. (2002; 57% and 64%,

respectively). In addition, at the zero-order level, most of our PCA-derived subscales were related in theoretically meaningful ways to each other and to ovarian cancer-specific distress. Finally, most of our subscales were reliable, although results obtained using our consequences and harm or neglect subscales should be interpreted with caution as their reliabilities did not reach the accepted level of $\alpha = 0.70$. We do, however, believe that the differences between our solution and that of Moss-Morris et al. (2002), whose samples included patients diagnosed with asthma, diabetes and chronic pain, suggest that the underlying factor structure of the IPQ-R should be established when the measure is adapted for different patient populations.

Another explanation for the weak relationships between cognitive illness representations and ovarian cancer-specific distress is that cognitive illness representations are not as useful at explaining adjustment to the risk of ovarian cancer as they are at explaining adjustment to an actual incidence of disease. The results of previous research offer some support for this proposal. Relationships between the same cognitive illness representations used in this study and distress were all ≥ 0.3 in patients diagnosed with gynaecological cancer (Gould et al., 2010), whereas Rees et al. (2004) and Kaptein et al. (2007) found weak relationships between these cognitive illness representations and worry in individuals at risk of breast cancer or venous thrombosis. Theoretically, the reality of actually experiencing a disease may engender different evaluations and reactions than the potential that one *might* experience the disease in the future. Reactions to the former reflect a response to the actual damage caused by the disease (i.e., harm appraisals and emotions), whereas the latter represents anticipation of the possible harm caused by a disease should it occur (i.e., threat appraisals and emotions; Lazarus & Folkman, 1984). Because cognitive illness representations may be differentially applicable to individuals undergoing different types of medical experiences, we support the commitment of Moss-Morris et al. (2002) to establishing the relevance of IPQ-R constructs in different patient populations.

Our results suggest that general anxiety is another potential predictor of ovarian cancer-specific distress during OCS. Cull et al. (2001) also found that a predisposition to anxiety was related to clinically significant psychological distress in women with a family history of ovarian cancer. In this study, although the majority of women were not anxious, around 17% were moderately or highly anxious prior to OCS and anxiety remained a significant predictor of ovarian cancer-specific distress in the final regression models. This suggests that women who are more anxious in general may be prone to greater intrusive thoughts and avoidance about their ovarian cancer risk. Raised anxiety is an expectable concomitant of ongoing, unresolved and potentially threatening life-experiences (Lazarus & Folkman, 1984) and living with a significantly increased risk of ovarian cancer is certainly a strong example of such a life-experience. Moreover, depending on whether or not women opt for prophylactic surgery, this life-experience and attendant anxiety could be life-long. In line with Cull et al. (2001), we would suggest that women at increased risk of familial ovarian cancer should be offered psychological assessment and intervention, in order that those women who are prone to greater distress receive appropriate support.

The final regression models accounted for 38.80% and 46% of the variance in ovarian cancer-specific distress, suggesting that variables which were not assessed may also explain ovarian cancer-specific distress. For example, women's individual family histories of cancer, and dispositional characteristics such as neuroticism

(e.g., Eysenck & Eysenck, 1975), and coping style (e.g., Carver & Scheier, 1994) may explain individual differences in distress about an increased risk of ovarian cancer. We restricted the variables in this study to those of particular theoretical interest in order to minimise participant burden and maximise engagement and retention with the ongoing study. However, dispositional and coping measures would be a valuable addition to future research in order to delineate the relative impact of personality, coping and illness perceptions on the psychological well-being of individuals living with an increased risk of ovarian cancer.

In conclusion, our results suggest that anxious women and those with more negative emotional representations of their ovarian cancer risk may be prone to greater ovarian cancer-specific distress. The IPQ-R and ovarian cancer-specific distress measures were completed concurrently, however, and prospective analyses of data from the ongoing psychological evaluation are needed to fully determine the predictive validity of adapted IPQ-R subscales. Importantly, our results showed that almost one-fifth of women were highly anxious and more than a quarter reported high levels of ovarian cancer-specific distress. The provision of interventions designed to support efforts to cope with ongoing, unresolved and stressful medical experiences (e.g., Bennett, Phelps, Brain, Hood, & Gray, 2007; Lancaster & Boivin, 2008) may be an appropriate means of responding to the emotional needs of women at increased risk of ovarian cancer.

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Note

1. At the time of adapting the IPQ-R to ovarian cancer risk (2006), it was generally thought that ovarian cancer symptoms were nonspecific. More recent research, however, suggests that the onset and frequency of certain symptoms are linked to ovarian cancer (e.g., Andersen et al., 2008).

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