Investigating harms of testing for ovarian cancer - psychological outcomes and cancer conversion rates in women with symptoms of ovarian cancer: a cohort study embedded in the multicentre ROCkeTS prospective diagnostic study

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Abstract

Objectives: To investigate psychological correlates in women referred with suspected ovarian cancer via the fast-track pathway, explore how anxiety and distress levels change 12 months post-testing and report cancer conversion rates by age and referral pathway. Design: Single arm prospective cohort study Setting: Multicentre. Secondary care including outpatient clinics and emergency admissions. Participants: 2596 newly presenting symptomatic women with a raised CA125 level, abnormal imaging or both. Methods: Women completed anxiety and distress questionnaires at recruitment and at 12 months for those who had not undergone surgery or a biopsy within 3 months of recruitment. Main outcome measures: Anxiety and distress levels measured using STAI-6 and IES-r questionnaires. OC conversion rates by age, menopausal status and referral pathway. Results: 1355/2596 (52.1%) and 1781/2596 (68.6%) experienced moderate-to-severe distress and anxiety at recruitment. Younger age and emergency presentations had higher distress levels. Clinical category for anxiety and distress remained unchanged/worsened in 76% at 12 months despite a non-cancer diagnosis. OC rates by age were 1.6% (95% CI 0.5 to 5.9) under 40 and 10.9 % (95% CI 8.7 to 13.6) over 40 years. In women referred through fast-track pathways, 3.3% (95% CI 1.9 to 5.7) of pre- and 18.5% (95% CI 16.1 to 21.0) of postmenopausal women were diagnosed with OC. Conclusions: Women undergoing diagnostic testing display severe anxiety and distress. Younger women are especially vulnerable and should be targeted for support. Women under 40 have low conversion rates and we advocate reducing testing in this group to reduce harms of testing.

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