

"This is the peer reviewed version of the following article: Heiniger, L., Price, M., Charles, M., kConFab Psychosocial Group on behalf of the kConFab Investigators, K., Butow, P. (2012). Distress in unaffected women at increased risk of familial breast cancer who delay, decline or remain Ineligible for predictive genetic testing. *Asia-Pacific Journal of Clinical Oncology*, 8(suppl 3), 197-198. . Which has been published in final form at, DOI: 10.1002/pon.3235. This article may be used for non-commercial purposes in accordance with Wiley Terms and Conditions for Self-Archiving."

Distress in unaffected women at increased risk of familial breast cancer who delay, decline or remain ineligible for predictive genetic testing

Louise E Heiniger¹, Melanie A Price¹, Margaret Charles¹, kConFab Psychosocial Group on behalf of the kConFab Investigators, Phyllis N Butow¹

¹ *Centre for Medical Psychology and Evidence-based Decision-making (CeMPED), School of Psychology, University of Sydney, NSW, Australia*

Background: Emerging evidence suggests that women at risk of hereditary breast cancer who remain ineligible for predictive testing experience elevated distress compared with tested women, while individuals who have declined or delayed learning their result report less distress than tested individuals.

Method: This study compared women who opt for, delay, decline or remain ineligible for predictive testing with regard to cancer-related distress (CRD; Impact of Events Scale), anxiety and depression (Hospital Anxiety and Depression Scale) in 1131 unaffected women enrolled in the Kathleen Cuninghame Consortium for Research into Familial breast cancer (kConFab) psychosocial study, controlling for stressful life events (Life Event and Difficulties Schedule) and perceived risk of breast cancer. Controlling for potential confounders (age, education, perceived risk and cumulative life event stress), statistical significance and clinical relevance of differences between 120 testers (pre-notification of eligibility for testing), 56 decliners, 90 delayers and 865 women who were ineligible for testing (ineligibles) were investigated.

Results: Delayers and testers reported significantly higher CRD compared with decliners (95%CI 1.543 - 5.796, 2.795 - 6.870, respectively; $p \leq .001$) and ineligible (95%CI 0.066 - 2.891, 1.411 - 3.872, respectively; $p < .05$). Moderate-high CRD was observed in 14% of decliners, 24% of ineligible, 34% of delayers and 42% of testers ($\chi^2=24.73$, $p < .001$). Decliners reported less anxiety than delayers (-3.169 - -0.567, $p = .005$) and testers (-2.858 - -.365, $p = .011$) with possible/definite anxiety disorder in 25% of decliners, 34% of ineligible, 53% of delayers and 44% of testers ($\chi^2=19.21$, $p < .001$). No clinically significant differences in depression were observed and prevalence of depression did not differ between groups ($\chi^2=3.49$, $p = .322$).

Conclusion: Decliners and delayers have distinctly different distress profiles and should be considered as separate groups. Delayers report significantly higher levels of distress, similar to those who opt for testing, indicating that these two groups have the greatest need for psychological support and would benefit most from supportive interventions.