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Psychological correlates of *not* undergoing genetic testing: a systematic review

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Background: Reviews on the psychosocial aspects of genetic testing for hereditary diseases typically focus on outcomes for carriers and non-carriers of genetic mutations. However, the majority of unaffected individuals from high-risk families do not undergo predictive testing. Recent empirical focus on these groups indicates a review of distress among these individuals is warranted.

Method: Medline, CINAHL, PsychINFO and PubMed were searched to identify studies investigating psychological distress in unaffected individuals who delay, decline or remain ineligible for predictive genetic testing. Reference lists of eligible articles and relevant reviews were also searched to identify additional articles for review. After screening 1898 potentially eligible articles, 23 articles reporting on 19 different studies were systematically reviewed and assessed for quality.

Results: Most studies were of a high quality ($n=19$), with some of moderate ($n=2$) and adequate quality ($n=2$). Findings of this review suggest the definition of delaying and declining is not always clear cut and few studies have investigated psychological distress among individuals who remain ineligible for testing. Findings related to distress in delayers and decliners have been mixed, but more studies reported comparatively lower distress in decliners than studies reporting higher distress in this group. A number of psychological, personality and family history vulnerability factors were identified for decliners and individuals who are ineligible for testing. Prospective studies suggest decliners and those who remain ineligible for testing may be at risk for poorer psychological outcomes, although the small number of studies and methodological limitations make it difficult to draw definitive conclusions.

Conclusion: Subgroups of those who remain untested appear to be at increased risk for psychological morbidity. As the majority of unaffected individuals do not undergo genetic testing, further research is needed to better understand the psychological impact of being denied the option of testing, declining and delaying testing.