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‘Knowledge is power’: coping with the risk and uncertainty of familial breast cancer.

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Background: Studies of how individuals living with increased risk for disease cope with being ‘at risk’ regard optimal psychosocial functioning as evidence of adaptation, yet the strategies and processes that precede adaptation have been predominantly unexplored. This study investigated social, cognitive and behavioural efforts to adapt to familial risk of breast cancer in a sample of unaffected women.

Method: Adopting a Grounded Theory approach to data collection and analysis, semi-structured interviews with 27 women enrolled in the Kathleen Cuningham Consortium for Research into Familial breast cancer (kConFab) psychosocial study explored women’s understanding of their risk and their experiences in adapting to familial risk. Participants were sampled to include a range of genetic testing statuses (tested, eligible untested and ineligible for testing) and patterns of distress (identified from existing quantitative data).

Results: Two themes – risk identity and managing uncertainty and risk – illustrated the approaches adopted by women in attempts to cope with being at risk, and a number of personal, family and healthcare characteristics that facilitated and challenged adaptation were identified. Knowledge of familial risk was seen as an opportunity to engage proactive strategies, while subconscious use of social comparisons, intuition and desensitisation facilitated the integration of ‘being at risk’ into self concept. The impact and experiences related to familial breast cancer shaped women’s perceptions of risk and their ability to adapt, as did confidence in healthcare. Most regarded personal satisfaction with risk management efforts, acceptance and a ‘day-by-day’ attitude as crucial to maintaining a positive outlook. A range of views on the value of genetic testing emerged and adaptation was facilitated through preservation of autonomy and provision of information in a manner appropriate to the individual’s needs.

Conclusion: At-risk women adopt strategies for coping with increased risk to match their personal and social resources. These findings will be used to guide the development of interventions for and communication with individuals at increased risk who experience difficulty adapting to this knowledge.