The Daffodil Centre

Communicating Melanoma Polygenic Risk Information: Genetic Counselling Experiences In A Community-based Study

Conclusion

In this study, the Australian community had high satisfaction with a genetic counselling phone call after receiving personal polygenic risk of melanoma information alongside educational information on melanoma prevention and early detection. The phone call provided an opportunity for participants who had questions about their personal risk to raise these with the genetic counsellor. Variations in levels of satisfaction and in discussion topics highlight a need to explore educational and support preferences for communicating polygenic risk information among population subgroups, including diverse literacy levels.

Background

Personalised polygenic risk information may be used to guide risk-based melanoma prevention and early detection at a population scale, but research on communicating this information is limited. This mixed-methods study aimed to assess the acceptability of a genetic counsellor (GC) phone call in communicating polygenic risk information in the Melanoma Genomics Managing Your Risk randomized controlled trial.

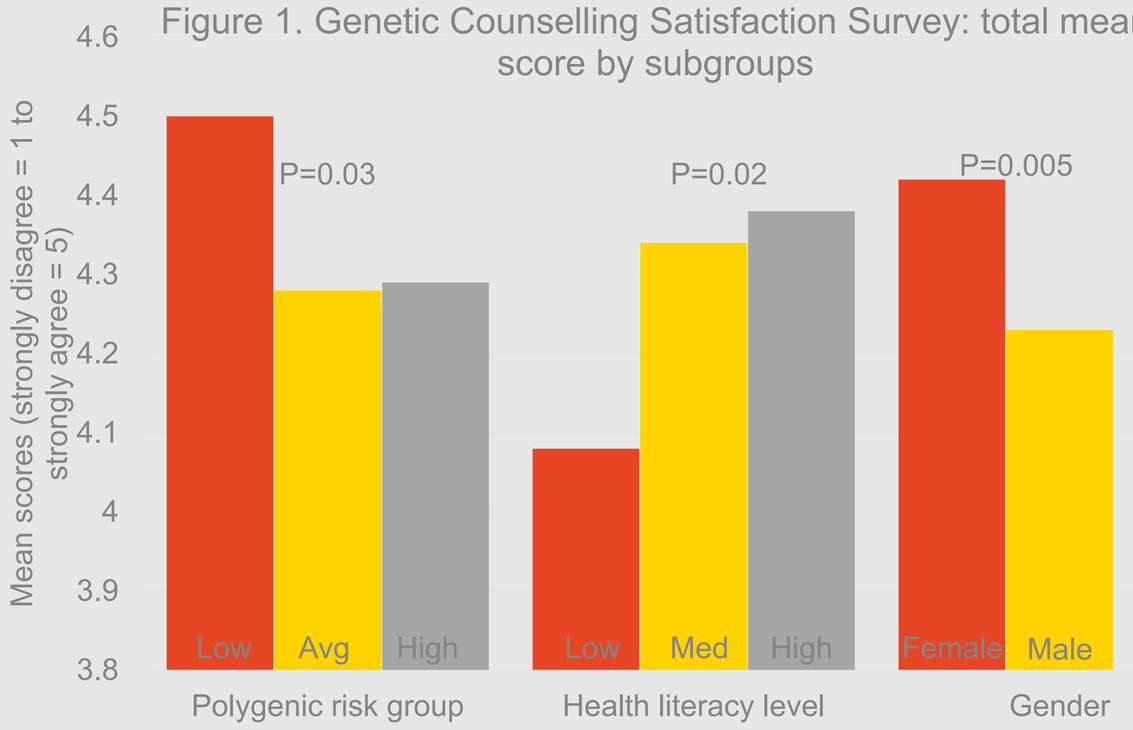
Methods

Participants (n=509) received personalised melanoma polygenic risk information, an educational booklet on melanoma prevention and a GC phone call, which was audio-recorded. Participants completed the Genetic Counselling Satisfaction Survey 1-month after receiving their risk information (n=346). A subgroup took part in a qualitative interview post-study completion (n=20). Survey data were analyzed descriptively using SPSS, and thematic analysis of the qualitative data was conducted using NVivo 12.0 software.

Results

The survey showed a high level of acceptability for the GC phone call with a mean satisfaction score overall: 4.3 out of 5 (standard deviation: 0.6) with differences according to gender, health literacy and polygenic risk group (Figure 1).

Figure 1. Genetic Counselling Satisfaction Survey: total mean score by subgroups



During the GC phone calls, discussion predominately related to the impact of past sun exposure on personal melanoma risk and explaining how the risk information was calculated.

"I grew up in the times when you just baked in the sun when you were a kid. I don't now, but I have damage, there's no doubt about that" (Female, 65 years, low risk)

"I'm surprised by my relatively low risk because my sister has had loads of melanoma cut out in her late 20s, but they may have been lower grade ones" (Female, 44 years, average risk)

Participants who described positive experiences with the genetic counselling call felt that it had provided them with an opportunity to ask questions and clarify their personal risk information:

"I think the one-on-one contact and to be able to listen to a professional talk about the topic was very good and not being [a] medical, scientific person [myself], it's good to hear that and [it] gave you a chance to ask a couple of questions along the way." (Male, 59 years, high risk)

The study was funded by a National Health and Medical Research Council (NHMRC) project grant (1129822) and endorsed by Melanoma and Skin Cancer Trials (ANZMTG 03.17). AKS received a Research Training Program (RTP) Stipend Scholarship and a Merit Top Up Scholarship from the University of Sydney, and a Melanoma Institute Australia Postgraduate Research Scholarship. AEC was funded by fellowships from the NHMRC (1147843 and 2008454). AKS received conference registration support from Sydney Cancer Partners via a grant from the Cancer Institute NSW

Proudly supported by Cancer Institute NSW

Sydney Cancer Partners
Collaboration, Translation, Impact

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