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Exploring the Emotional and Behavioural Reactions to Receiving Personalised Melanoma Genomic Risk Information: A Qualitative Study

Running head: Emotional and behavioural reactions to melanoma genomic risk information

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What's already known about this topic?

- Previous research suggests there is minimal emotional and behavioural impact of delivering personalised genomic risk information (based on common, low-to-moderate-penetrance variants) to healthy individuals in the general population.
- Little is known about emotional and behavioural reactions of the general population to melanoma genomic risk information and whether this information could elicit positive sun protection and skin-examination behaviours.

What does this study add?

- This qualitative study found that participants' reported emotional and behavioural responses to receiving personal genomic risk results were linked to their expectations for their risk result, their pre-existing perception of their own melanoma risk, their existing melanoma preventive behaviours as well as their genomic risk category (low, average, high).
- Many participants experienced positive emotional reactions to receiving personalised melanoma genomic risk information and reported making subsequent positive lifestyle behaviour changes.

What are the clinical implications of the work?

- Personalised melanoma genomic risk information alongside education and lifestyle counselling is favourably received by the general public and might lead to improved sun protection and skin-examination behaviours. Any initial feelings of distress are likely to dissipate over time.
- These findings could guide the preparation of educational and support resources for clinicians, patients and the community to maximise the benefits and minimise the harms of genomic testing at a population level.

SUMMARY

Background: There is a need for greater understanding of the spectrum of emotional and behavioural reactions that individuals in the general population may experience in response to genomic testing for melanoma risk.

Objectives: To explore how individuals in the general population respond to receiving personalised genomic risk of melanoma.

Methods: Semi-structured interviews were undertaken with 30 participants (aged 24-69 years, 50% female, 12 low-risk, 8 average-risk, 10 high-risk) recruited from a pilot trial in which they received personalised melanoma genomic risk information. We explored participants' emotional and behavioural responses to receiving their melanoma genomic risk information. The qualitative data were analysed thematically.

Results: Many participants reported a positive response to receiving their melanoma genomic risk, including feelings of happiness, reassurance and gaining new knowledge to help manage their melanoma risk. Some participants reported short-term negative emotional reactions that dissipated over time. Most individuals, particularly those who received average or high-risk results, reported making positive behaviour changes to reduce their melanoma risk. Emotional and behavioural responses were linked to participants' expectations for their risk result, their pre-existing perception of their own melanoma risk, their existing melanoma preventive behaviours and their genomic risk category.

Conclusions: Personalised melanoma genomic risk information alongside education and lifestyle counselling is favourably received by people without a personal history and unselected for a family history of melanoma. Participants described increased knowledge and awareness around managing skin cancer risk and improved sun protection and skin-examination behaviours. Any initial feelings of distress usually dissipated over time.

INTRODUCTION

Personal genomic testing is increasingly being offered in clinical, research, and commercial contexts.[1-6] The mainstreaming of genomic testing offers the possibility of providing personalised risk information for common, polygenic diseases such as melanoma on a population-wide scale.[7,8] With strong evidence that the incidence and prognosis of melanoma is associated with sun protection and skin-examination,[9-11] the provision of personalised melanoma genomic risk information to the general population is a potential strategy to improve melanoma prevention and screening behaviours.

There is debate over the clinical and personal utility of personal genomic testing for healthy individuals. Studies to date suggest personal genomic testing has little emotional impact and only at best, a small effect on eliciting positive health-related behaviours.[2,5,6,12] However, the quality of the research evidence is limited, and there is a lack of evidence on skin cancer prevention and screening behaviours. Offering genomic testing for diseases with modifiable risk factors such as melanoma, alongside education and lifestyle counselling, may also yield different outcomes than previously reported when providing risk information alone.[13]

Preliminary research examining the impact of delivering personalised genomic risk of melanoma information to the public or to melanoma families has shown potential for improved preventive behaviours with minimal psychological distress.[14-16] Yet, the range of emotional responses and the potential to capitalise on these as barriers or motivators of behaviour change have gone largely unexamined.

We conducted a qualitative study among a subset of participants from a pilot randomised control trial[14] in which participants received their personal melanoma genomic risk, to better understand how this knowledge impacted their emotional and behavioural responses. These findings are important for assessing the personal and clinical utility and psychosocial consequences of genomic testing in a population setting.

METHODS

Recruitment of participants

This was a sub-study of a pilot randomised controlled trial (parent study) that examined the feasibility, acceptability and impact of delivering personalised genomic risk of melanoma information to the public.[14] Details of recruitment have been described in detail previously.[14,17] Briefly, participants were recruited to the parent study from a cancer research database, and were eligible if aged 18-69 years, had no personal history of melanoma, were residing in New South Wales, Australia, and spoke English. After completing the parent study (on average 7 months after receiving their risk results), 41 participants were invited to take part in a 30-45 minute semi-structured interview.

Procedures for providing personalised melanoma genomic risk information

In the parent study, participants provided a DNA sample for genotyping, which was used to calculate their personalised genomic risk of melanoma based on variants from 21 genes/regions known to be associated with melanoma.[14] A telephone communication protocol for disclosing the personalised melanoma risk information was developed.[18] Results were communicated by a mailed personalised hard-copy booklet along with a generic educational booklet about skin cancer prevention and early detection and a telephone call by a genetic counsellor.[18]

The hard-copy personalised booklet contained the participant's *remaining lifetime absolute risk*, a *relative risk* comparing the participant's risk to others of the same age and sex in the general population, and a *risk category*, for which participants were classified as low, average or high genomic risk.[14] The remaining lifetime absolute risks ranged from 0.2% to 9.3% (median 2.3%) for women and from 0.6% to 19.5% (median 3.9%) for men.[14] The presentation of risk results was based on disease-risk communication literature and a previous focus group study.[19-22]

Qualitative data

The interview guide was piloted with consumers and other researchers and included questions about participants' emotional and behavioural responses to receiving their genomic risk (see supplementary online-only materials). Participants were purposively sampled to obtain comparable numbers by sex, age-group and genomic risk category, to ensure a range of views. We recruited in batches until there were no new themes or sub-codes identified in the data, i.e. data saturation[23,24] after five consecutively coded interviews.

The semi-structured interviews were conducted and audio-recorded by AKS, and professionally transcribed. A thorough and systematic thematic analysis was undertaken which was grounded in constructivist methodology.[25] A coding framework was developed through an iterative process of reading the transcripts and discussion with the research team.[23] We relied on inductive reasoning to categorise phrases and paragraphs into the broad themes and sub-codes.[26] We searched for patterns in ideas and themes related to participants' responses to receiving their personal genomic risk information across the interview transcripts and according to genomic risk category. Coding was conducted by AKS and GLF, and Nvivo11 was used to facilitate the coding process. Agreement between coders was high and discrepancies were resolved through consensus. In this paper, we present the key themes related to participants' emotional and behavioural responses.

The conduct, design and reporting of this study follows the Standards for Reporting Qualitative Research.[27] Ethics approval was obtained from The University of Sydney and participants gave informed consent.

RESULTS

Participants

Of the 41 participants invited for interview, 34 agreed to participate and 30 were interviewed; 27 via telephone and three in-person. Reasons for declining included not being available or lack of time. Over a quarter (8/30) of participants self-reported a family history of melanoma and/or a personal history of other (non-skin-related) cancer (12/30) (Table 1).

Relief, reassurance, disappointment, worry: emotional reactions

When participants were asked how receiving their risk results made them feel, about half reported a positive reaction (16/30) within which four common themes were identified: (1) feeling happy or relieved; (2) feeling comforted or reassured; (3) finding the results interesting; and (4) feeling glad about contributing to research. Most participants who reported a positive reaction had received a low (8/16) or average (6/16) risk result. Among those who felt happy or relieved, many attributed this to an expectation for a higher risk result.

> "I thought I might be a high risk or a higher risk, so I was much relieved and opened the envelope with some trepidation and read the first three or four pages and went, wow, that's good, I'm pleased about that." (Male, 68, average risk)

Participants who reported feeling reassured by their results all felt that they were still at risk of melanoma (even if low) and should maintain sun protection and skin-examination habits.

> “Well it provides a lot of reassurance. Having said that, it doesn't mean that I won't develop melanoma, but it suggests that my chances are very low, which is very, very reassuring.” (Male, 60, low risk)

Pre-existing expectations were described by participants as influencing their responses to the risk results. Participants who described their results as interesting explained that they had gained new, unexpected information.

> “I hadn't really thought about the genetic risk aspect and the lifestyle risk aspect; I'd kind of pushed them all in together a bit. So yeah, this process has been interesting to separate those out a bit and to kind of go, oh okay, so if this bit is a known and that bit I can't change, this bit I can.” (Female, 44, average risk)

Some (10/30) expressed initially negative reactions to receiving the risk result and two key themes were identified: disappointment and stress/worry. The majority of these participants had received a high-risk result (8/10), one had received an average-risk result and one had received a low-risk result. Among participants who expressed disappointment, some attributed this to expecting to receive a lower risk result.

> “It wasn't great. I mean it would have been nice to be, oh no, you've got an average risk, you know, that would have been lovely; I didn't expect that, but it's always nice if you get better news.” (Female, 51, high risk)

> “At first I was sort of disappointed that I didn't have a lower chance of it and I was like, oh well and I sort of just put it out of my mind. But then as the summer went on and then I came across the booklet again, I was like, no, I've got to be more sensible, you know, like I said, I have just as greater risk as anyone else, so I should make more of an effort.” (Female, 24, average risk)

Some participants who anticipated a high-risk result based on their previous perception of their own melanoma risk, either due to their skin colour or their family history of melanoma, felt disappointed when this result was confirmed.

> “Ah, probably - certainly disappointed and I say that because I would love to go outside and not have to cover up or whatnot… so probably reading that information is a bit upsetting, to be honest because when my mates are going out there doing different things and I go, oh I'll meet you later ... But yeah, that probably restricts me and this booklet just cemented that, I suppose.” (Male, 36, high risk)

Although these participants described initially feeling stressed or worried, they all felt that over time these emotions diminished and they started perceiving their result more positively.

> "I remember being a bit apprehensive… When I got it, I thought, oh I'm a bit nervous about opening it. But it's interesting, yeah, because I think it just makes you more aware. I think it's made me know that I have to go and keep seeing the skin specialist, just to keep an eye on it all so at least you catch anything early..." (Female, 51 high risk)
>
> "It was a little bit stressful, but as long as you can - you do the right things and you're just trying to manage sun exposure and all that kind of thing, I think it's okay. For me it was just very useful finding out the risk factor, because otherwise you've got no idea and you sort of think, well maybe I don't need to be so careful... But now I definitely know, so it's kind of useful in that respect, I make sure I'm pretty careful all the time now with the sun." (Female, 29, high risk)

Knowledge is Power

Over half of all participants (19/30) described feeling satisfied about undertaking the testing because they had: 1) gained new knowledge about their risk or about preventative behaviours; 2) reinforced their existing sun protection and screening knowledge, awareness or behaviours; 3) contributed to research. Participants across all risk groups who felt they had gained knowledge also felt better equipped to make decisions around managing their skin cancer risk.

> "Um, well at first I - I felt a little bit concerned, like about, oh no, I'm high risk, you know, what does this mean for me? But double checking the information and also looking at prevention and early detection information, I felt glad that I was armed with that knowledge so that I can actually do something to try and prevent what's happened." (Male, 38, high risk)
>
> "So since receiving the result, I thought it had a lot more information than I was expecting and I was surprised that I was average, I thought I would have been - had a lower risk. So since then I've definitely been more cautious… And it definitely made me think, okay I should get long sleeved shirts for in the sun and also made me think, okay I better go get my skin checked again." (Female, 24, average risk)

'The damage has already been done': Fatalistic attitudes

Many older participants (>44 years) described feeling regret about their childhood sun exposure (14/23), which was prompted by their risk results. Several participants used the phrase “the damage has already been done” and many described their melanoma risk using the terms “lottery” or “luck”. Although half of the participants expressing this fatalistic attitude had received a high-risk result (7/14), this theme was raised across all risk levels (3/14 low-risk; 4/14 average-risk). Nevertheless, most of these participants also reported making behaviour changes in attempt to reduce their risk of developing melanoma (11/14).

> “In our younger days, you ran around the yard naked with your undies on and jumping under the sprinkler with no sun protection. So the damage has already been done.” (Female, 58, low risk)
>
> “So when I look back on it and reading this booklet, I think, well I've been a silly boy and I just hope that my lottery stays with me and I never develop anything serious.” (Male, 65, average risk)
>
> “Probably before this [receiving the result] I thought in the back of my mind, it happened years ago, there's nothing I can do about it… but I also realise now that I can still be careful and stop any new damage and possibly stop some old damage getting any worse. So I am very careful now with the sunblock.” (Female, 64, high risk)

‘It's confirmed what I had already felt was likely’: reaffirming existing personal risk perception

Some participants (4/30; that included all risk-groups) felt that they had received the risk results that they had anticipated, and the result did not trigger a strong emotional reaction for them.

> “I guess I wasn't surprised… It's confirmed what I had already felt was likely. I still think that general lifestyle and type of time we spend in the sun and times we fail to follow the common sense advice of protecting yourself means that genetic risk is probably small compared to the lifestyle risk I'm putting on top of that.” (Male, 33, average risk)
>
> “It sort of turned up and I thought, oh okay, great… It's not terribly worrying to me, it's just something that I'm going to be aware of and perhaps just make sure that I'm, you know, continue to be careful with sunscreen and hats and that sort of stuff.” (Female, 58, average risk).

Behavioural reactions: sun protection and skin examinations

Many participants reported that since receiving their risk result, they had made behaviour changes to reduce their risk of melanoma (18/30). The majority of these participants had received an average or high-risk result (14/18), although positive behaviour changes were still described by 4 of 10 participants who had received a low-risk result. The four changes in behaviour described by participants were: (1) spending less time outdoors during the middle of the day; (2) wearing more protective clothing whilst outdoors; (3) increasing sunscreen use and 4) undergoing clinical skin examinations.

> "I have increased the SPF rating of the sunscreen that I use from 30 to 50, which, yeah, has kind of been a thing; my skin is quite sensitive to some of the chemicals that are in sunscreens, but I've found one that doesn't have the preservatives in it that irritate my skin and is a 50. So that was a direct result of this." (Female, 44, average risk)
>
> "Yeah, well I always wear a wide-brimmed hat now, all the time, every time I go outside... Like I used to love the sun, I used to love to sit out in the sun, but now I sit in the shade all the time... I'll seek out shade more than sit out in the sun talking to somebody. If we're up the street talking, I'll stand under an awning instead of standing on the side of the footpath talking out in the sun. I'll move to the shade, even if it's only for a couple of minutes." (Male, 57, high risk)

Among participants who did not report positive behaviour changes (12/30), half had received low-risk results (6/12); a quarter had received average risk results (3/12) and a quarter had received high-risk results (3/12). The majority attributed this to feeling that their sun protection and skin examination habits prior to their participation in the study were already adequate, and their capacity to improve these behaviours was limited. This theme was evident in interviews with participants from all risk groups.

> "Because I think I'm pretty sensible and I take a lot of precautions, so it hasn't, you know, there's nothing that I'm not already doing that I should be really." (Female, 48, average risk).

One individual spoke about how participating in the study had triggered intentions to undergo a skin check.

> "I mean, just probably it's nagging me in the back of my mind, I should go check all my moles…. that's probably the thing that keeps on coming back." (Female, 50, low risk)

All participants who received a low risk result and reported not making any behaviour changes stated they would have made lifestyle changes, such as wearing more protective clothing and using sunscreen more frequently, if they had received a higher risk result.

> “Oh, I think [receiving a high risk result] would have probably made me have second thoughts about some of the things I might be doing. I'm pretty confident it would have changed the way I thought about protecting myself.” (Male, 57, low risk)

One participant felt that her sun protection behaviours had become more lax since receiving a low risk result.

> “I probably don't slop as much sunscreen on as I should… Well I'm relaxed about it a bit I think, like about not putting a hat on but I know I should. Well [that is because of] the less than one per cent risk… ” (Female, 63, low risk)

DISCUSSION

In this qualitative interview study with recipients of personal genomic risk of melanoma information, we found that reported emotional and behavioural responses were linked to participants’ expectations for their risk result, their pre-existing perception of their own melanoma risk and their previous melanoma preventive behaviours. Emotional and behavioural responses were also influenced by participants’ genomic risk category (low, average, high). A family history of melanoma did not appear to influence the emotional and behavioural responses described by participants.

We found that many participants experienced positive emotional reactions to receiving their risk results, similar to other genetic testing studies.[1,2,4,6,28] Sanderson et al. [6] and Wasson et al. [9] found that the most common emotional responses were feeling happy, pleased, or relieved, especially if participants had received lower risk results. Gordon et al.[1] reported that participants’ most common emotional reaction was reassurance, which was identified in our study, but only among recipients of low or average risk results and participants who felt that their risk result matched their expectations.

We found that for some participants, high risk results or results higher than expected initially evoked emotions of disappointment, stress or worry, which dissipated over time. This finding provides context to the survey results from the parent trial, which found no evidence of increased skin-cancer related worry or general psychological distress at 3-months follow up,[14] but higher distress and uncertainty based on the Multidimensional

Impact of Cancer Risk Assessment (MICRA) for participants who received a high risk result.[16] Acute negative reactions that diminish over time have been commonly reported in individuals undergoing genetic testing, particularly for higher penetrance variants such as BRCA1/2.[29,30] Our novel findings indicate that this emotional response may also be experienced by recipients of melanoma genomic risk information based on common variants with low-moderate penetrance, although our MICRA survey results[16] suggest that this emotional response is lower than reactions to receiving higher-penetrance risk information. Further research on pre-testing expectations of risk may assist in identifying those who may experience initial concern or distress.

There is limited evidence to date on significant impacts on motivation or behaviour change following either direct-to-consumer personal genomic testing (DTC-PGT) or genomic testing in a research setting.[2-5] However, many of these studies are limited by high risk of bias, provided risk information based on single variants and provided little/no genetic counselling or education on risk-modifying behaviours.[4,5] In contrast, our parent trial was grounded in behaviour change theory and the risk results were accompanied by a generic educational booklet on skin cancer prevention and early detection, and reinforced by the genetic counsellor. The changes to prevention behaviours described by some participants in this study (including those at low and average risk) suggests that the education and counselling aspect of result disclosure may help motivate behaviour change. Additionally, in the parent trial most participants' (79%) risk results were sent (with permission) to their general practitioner, which may enhance its clinical utility.[17]

Our findings provide a novel insight into how reported behaviour change was often linked to participants' genomic risk level and their expectations. Behavioural theory identifies a range of cognitive mechanisms that influence responses to health information (including perceived risk, perceived benefits and self-efficacy)[31] which could be explored in the context of understanding behaviour change after receiving genomic risk information. A strength of our study is its general population focus and communication of genomic risk based on a comprehensive set of gene variants. A limitation is that the study sample had higher than average education levels and an interest in cancer research, which may influence participants' health literacy and level of motivation for behaviour change, and therefore the transferability of these results to all population subgroups. Further research is underway to quantitatively assess the impacts of genomic risk information on melanoma prevention and screening behaviours.[32]

As genetic testing becomes more widespread, these results are important for informing the types of behavioural and emotional responses that might be stimulated by delivering melanoma genomic risk information to the general population. They will also guide the preparation of educational and support resources for clinicians, patients and the community to maximise the benefits and minimise the harms of genomic testing.

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Table 1: Qualitative interview participant characteristics

Characteristic	Interviews (n=30)
Age, mean (range)	53 (24-69)
Female, N (%)	15 (50%)
Highest level of education	
High school or equivalent	7 (23%)
Trade/diploma	9 (30%)
University degree or higher	14 (47%)
Family history of melanoma, N (%)	8 (27%)
First degree relative	4 (13%)
Second degree relative	3 (10%)
Third degree relative	1 (3%)
Personal history of other cancer	12/30 (40%)
Genomic risk category, N, (%)	
High	12 (40%)
Average	8 (27%)
Low	10 (33%)