

Factors influencing and modifying the decision to pursue genetic testing for skin cancer risk

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Background: Across cancers, the decision to pursue genetic testing is influenced more by subjective than objective factors. However, skin cancer, which is more prevalent, visual, and multifactorial than many other malignancies, may offer different motivations for pursuing such testing.

Objectives: The primary objective was to determine factors influencing the decision to receive genetic testing for skin cancer risk. A secondary objective was to assess the impact of priming with health questions on the decision to receive testing.

Methods: We distributed anonymous online surveys through ResearchMatch.org to assess participant health, demographics, motivations, and interest in pursuing genetic testing for skin cancer risk. Two surveys with identical questions but different question ordering were used to assess the secondary objective.

Results: We received 3783 responses (64% response rate), and 85.8% desired testing. Subjective factors, including curiosity, perceptions of skin cancer, and anxiety, were the most statistically significant determinants of the decision to pursue testing ($P < .001$), followed by history of sun exposure (odds ratio 1.85, $P < .01$) and history of skin cancer (odds ratio 0.5, $P = .01$). Age and family history of skin cancer did not influence this decision. Participants increasingly chose testing if first queried about health behaviors ($P < .0001$).

Limitations: The decision to pursue hypothetical testing may differ from in-clinic decision-making. Self-selected, online participants may differ from the general population. Surveys may be subject to response bias.

Conclusion: The decision to pursue genetic testing for skin cancer is primarily determined by subjective factors, such as anxiety and curiosity. Health factors, including skin cancer history, also influenced decision-making. Priming with consideration of objective health factors can increase the desire to pursue testing. (J Am Acad Dermatol <http://dx.doi.org/10.1016/j.jaad.2016.11.050>.)

Key words: genetic testing; health behaviors; prediction; risk; skin cancer; survey.

Genomewide association studies have discovered more than 200 single nucleotide polymorphisms associated with skin disease, including 33 associated with melanoma and 10

associated with nonmelanoma skin cancers, and genetic testing for familial melanoma syndromes is readily available.¹⁻⁵ Advances in genetic sequencing technologies may allow us to identify individuals at

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Conflicts of interest: None declared.

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risk for cancer development, which could enable improved targeted prevention, early detection, and treatment efforts.⁶⁻⁹

Combining genetic testing with physician-led educational efforts has been shown to stimulate the adoption of disease risk-lowering behaviors in patients with familial melanoma syndromes.^{2,10} It is therefore hoped that population-level genomic screening efforts could produce similar results.⁶ Previous research from high-risk melanoma families with cyclin dependent kinase inhibitor 2A mutations suggests that patients are generally interested in learning more about their genetic skin cancer risk, and that genetic risk information enhances patient acceptance of preventative health measures and increases screening adherence.¹⁰⁻¹²

However, the factors that influence the decision to pursue genetic testing for skin cancer are not well understood. Although consensus has not yet been reached, for genetic testing across multiple cancers, including breast cancer,¹³ ovarian cancer,¹⁴ colorectal cancer,¹⁵ and prostate cancer,¹⁶ subjective factors, such as worry and perceived risk of disease development, may influence the decision to pursue testing more so than objective factors, such as personal and family health history.¹⁷ Subjective factors, such as perceived risk of developing melanoma and perceived concerns about testing and its psychological implications, were also found to influence patients with rare familial melanoma syndromes with identified genetic mutations.¹⁸ However, data on the decision to pursue genetic testing in the general population for skin cancer risk are limited. Furthermore, skin cancer, by virtue of being exceedingly common, being influenced by many factors both environmental and genetic, resulting from many polymorphisms, and being intrinsically visual or external, differs from many other internal malignancies in salient ways. Thus, there is reason to believe that the decision to pursue genetic testing for skin cancer may be influenced by different or additional variables from those observed in other cancers.

As genetic testing becomes increasingly common in clinical practice, it will be essential to understand which factors are associated with the decision to

pursue genetic testing to allow physicians to better engage and communicate with their patients. To study this topic, we administered a survey to characterize the motivational, demographic, and health factors influencing desire to pursue genetic testing for skin cancer risk.

METHODS

Survey construction

We developed an anonymous survey to assess the motivations and demographics of individuals who would elect to receive genetic testing to determine their risk of skin cancer. To ensure clarity and appropriateness, surveys were reviewed by nonparticipant colleagues before implementation; questions were modeled on potential motivators identified in prior studies from the fields of genetics, dermatology, and oncology, and that used standardized and well-defined

terminology from validated assessments.^{11,13,14,18-20}

Participants were asked whether or not they wished to receive genetic testing to determine their risk of developing skin cancer, along with questions assessing motivations, demographics, medical history, and health-related behaviors such as smoking and tanning. In addition, given the potential influence of priming effects in survey-based research, we randomly assigned participants to 1 of 2 versions of the survey to assess whether prior queries on health and demographic factors influences participant decision to pursue genetic testing.²¹ The first version asked participants whether they wished to receive genetic testing before discussing personal medical history and demographics; the second version started with medical history and demographics questions, and then asked about genetic testing. Other than question order, the 2 versions of the survey were identical.

Survey distribution and data collection

Data collection methods and analysis were approved as exempt by Stanford University's Institutional Review Board. Surveys were distributed through the online platform ResearchMatch, a disease-neutral, institution-neutral web-based recruitment registry intended to facilitate the process

CAPSULE SUMMARY

- The factors influencing the decision to pursue genetic testing for cancer risk vary across cancers, but in general, subjective factors outweigh objective health factors.
- For skin cancer risk, the decision to pursue testing is influenced most significantly by subjective factors, such as anxiety, curiosity, and perceived health status.
- Understanding patients' motivations will allow dermatologists to educate and guide patients on decisions regarding genetic testing.

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