Editorial

Informational Quest

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Understanding the impact of knowledge of genetic risk has been a key area of study for some time. This is not a singular impact because it includes clinical outcomes, patient behaviors, provider behaviors, and psychological impact for the patient and family. The sequelae and range of behaviors and outcomes can vary substantially, impacted in turn by multiple personal characteristics and health provider and system factors, creating a complex network of influences. For many of the common, complex diseases for which the genetic underpinnings are being revealed and tests developed, clinical outcomes will greatly be determined by patient behaviors. In turn, patient adoption of healthy behaviors will be affected by several factors, notably their understanding of the disease, their perceived risk, and knowledge of options available to reduce risk. Patient understanding will, thus, be impacted by their interest and ability to find informational resources to improve their understanding. Although genetics maintains a steady presence in the media and pop culture, it is likely that many patients remain unfamiliar about the complexities of genetic testing and clinical significance of genetic risk, triggering a quest for information.[1]

See Article by Brown et al

In this issue of *Circulation: Cardiovascular Genetics*, Brown et al[2] present their work on information sharing and seeking behaviors following receipt of risk for coronary heart disease (CHD) as part of the MI-GENES study (Myocardial Infarction Genes). In the MI-GENES study, participants were randomized to receive a conventional risk score (CRS) or CRS plus a genetic risk score.[3] At the conclusion of the study, participants in the CRS arm were offered the opportunity to learn of their genetic risk. They report that about a third of participants sought information online about CHD and genetic risk factors, with no significant difference between the conventional risk and the genetic risk arm at 3 months after receipt of their risk score. But by 6 months, participants in the genetic risk arm were significantly more likely to seek further information, although the percentage of participants seeking information had decreased. Information seeking also includes sharing of their results with others to gain further information about the significance of the result and what they should do about that risk. The majority of participants (77% in the CRS arm and 90% in the genetic risk score arm) shared their CHD risk with friends, coworkers, and family.

Challenges of Information Seeking

When faced with a suggestion or recommendation to undergo genetic testing or to make sense of a test result, many will understandably search online for more information. This behavior certainly is not unique to genetics, with >70% of American adults having searched for health information online.[4] Patients' ability to actually locate, evaluate, and understand information on genetics and disease will be key in realizing the benefits of testing. For the first step of locating online resources, participants in the study were provided with a list of recommended websites, thereby eliminating this step. In a typical clinical setting (not staffed with a genetic counselor), however, such a recommended list of recommended resources is not likely to exist. Thus, the search for information may be difficult and time consuming for some patients, potentially leading to frustration and anxiety. Patients may swing from a flood of information (as is the case for CHD where a Google search yields thousands of hits) to an information desert. For every genetic test or gene associated with a disease, suitable patient educational materials (PEMs) are not likely to exist. Of the PEMs that are available, they have been developed by a variety of authors from government, industry, academic medical centers, and patient advocacy groups and may or may not be comprehensive and up-to-date. Some are written at high reading levels.[5] PEMs may not only benefit patients but providers can use PEMs as a basis for their discussion. One study reported that family members with access to PEMs were more likely to meet with genetic specialists to discuss their risks and options for testing.[6]

Although several databases and catalogs on genetic diseases, genes, and gene variants have been developed, most are intended for researchers, geneticists, and laboratorians—an accurate and reliable catalog of PEMs about genetics, genetic testing, and the clinical significance of test results does not currently exist. Thus, more attention is needed to balance the effort between establishing centralized researcher resources and patient resources to insure that these new clinical tools and the information they yield are being understood by patients. Otherwise, patients will be left to their own accord to find these resources and evaluate their credibility—a task likely to be hampered by their limited knowledge of the topic. One potential option to helping patients identify information about diseases and genetic risk is a tailored knowledge acquisition approach, whereby patients provide some information about their current understanding of the topic and desired information.[7]

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Tailored materials have also shown some benefit with respect to informed decision making and self-efficacy.[8]

In addition to the availability of PEMs, the search for information will be impacted by patients' ability to identify online sources of information, referred to as e-health literacy. Reported differences in e-health literacy may impact patients' interest to search for or ability to identify credible resources.[9] Searching for health information online is more common among women, younger ages, and higher education status.[9,10] Participants in the MI-GENES study may have been motivated to search for information about CHD and genetic risk factors given their age (45–60 years) and the higher likelihood for conditions to develop during this time or to better understand the familial implications for their children.

Once an online resource is located, comprehension of the information will be impacted by health literacy.[11,12] Compounding the problem is the use of values and probabilities, which are abstract concepts for a substantial proportion of the public to grasp because of low numeracy.[13] An incomplete or inaccurate understanding of genetic risk can lead to misguided decisions to reduce overall disease risk. Although research has shown little-to-no impact on patient behaviors,[14] it is not clear how much of this inertia might be because of lack of understanding about genetic risk, the fact that genetic factors are only one type of risk factor, and the options available to reduce overall risk. Accurate patient comprehension may help establish more realistic expectations of disease risk in the context of other risk factors, including family health history and lifestyle factors and understanding of what actions can be taken to reduce risk. Knowledge of genetic risk might have a negative impact on patient attitudes, self-efficacy, and likelihood to engage in healthy behaviors, but evidence has not conclusively supported this assumption.[15,16]

In the MI-GENES study, the process of participants' learning of their CRS or genetic risk score results—through a genetic counselor—is not likely to mirror an actual clinical experience, given the limited number of counselors available. The communication of results to a nongeneticist provider, particularly in the absence of PEMs, is of concern given the providers' reportedly limited knowledge of genetics and genomics, inundation with the rapid growth of test development, limited time to help patients understand testing options and make informed decisions, and limited patient educational resources.[17] Thus, a brief office visit may likely leave patients with unanswered questions or confusion. Furthermore, it is unclear if, in this study, the standardized results session in the MI-GENES protocol precipitated more or less desire to seek additional information than would a more typical clinical encounter.

Social Media

Brown et al reported that MI-GENES participants shared their results with others, particularly family members, friends, and coworkers. However, they did not share their results through social media, although the majority of participants belonged to social networks and used social media to discuss health with family/friends or to find health information. As part of both information seeking and information sharing, ever increasingly, patient education and support are derived from social media.[18–20] Although the accuracy of the content or type of support gained from social media may vary, use of social media seems beneficial on multiple levels.[18,20] Thus, providers might consider referring patients, particularly younger patients, to groups that have established accurate resources via social media to facilitate information seeking and connections to other individuals with similar disease risks. This may help fill the information gap if PEMs are not available.

Conclusions

Because the use of genetic and genomic testing for disease diagnosis, susceptibility, prognosis, and drug response is anticipated to increase, mostly outside of the genetics specialty, we should also anticipate increased information seeking related to these application and understanding the significance of the results. More effort is needed to expand the availability of PEMs about the role of genetics for common, complex disease, particularly for specific genes, and to facilitate patient searches for such information or encourage the development of accurate resources through social media. In the absence of accurate, patient-friendly informational resources, the risk of uninformed decision making, anxiety/stress, failure to comply with recommended follow-up care, or pursuing unnecessary medical care are likely to occur. Although this study represented an optimal clinical situation whereby participants reviewed their results with a genetic counselor and were provided with recommended online resources, a substantial number still sought additional information. Thus, we should expect many more will be seeking information in a more typical clinical setting.

Disclosures

None.

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