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Communicating risk of hereditary breast and ovarian cancer with an interactive decision support tool

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ABSTRACT

Objective: Women with hereditary breast and ovarian cancer syndrome (HBOC) face a higher risk of earlier, more aggressive cancer. Because of HBOC's rarity, screening is recommended only for women with strong cancer family histories. However, most patients do not have accurate history available and struggle to understand genetic concepts.
Methods: *Cancer in the Family*, an online clinical decision support tool, calculated women's HBOC risk and promoted shared patient–provider decisions about screening. A pilot evaluation (n = 9 providers, n = 48 patients) assessed the tool's impact on knowledge, attitudes, and screening decisions. Patients used the tool before wellness exams and completed three surveys. Providers accessed the tool during exams, completed exam checklists, and completed four surveys.
Results: Patients entered complete family histories (67%), calculated personal risk (96%), and shared risk printouts with providers (65%). HBOC knowledge increased dramatically for patients and providers, and many patients (75%) perceived tool results as valid. The tool prompted patient–provider discussions about HBOC risk and cancer family history (88%).
Conclusions: The tool was effective in increasing knowledge, collecting family history, and sparking patient–provider discussions about HBOC screening.
Practice implications: Interactive tools can effectively communicate personalized risk and promote shared decisions, but they are not a substitute for patient–provider discussions.

1. Introduction

Hereditary breast and ovarian cancer syndrome (HBOC) is a dominant inherited condition that typically is caused by a mutation in the BRCA1 or BRCA2 genes [1]. Women with HBOC have up to an 85% lifetime risk of breast cancer and 50% lifetime risk of ovarian cancer, compared to the 7% and 1% lifetime risks of women without the syndrome [2–4]. The tumors of BRCA1 mutation carriers, in particular, are more likely to be aggressive, resistant to hormone-based treatment, and fatal than tumors in women without a family history of cancer [3]. Women with HBOC may opt for intensive breast cancer screening, prophylactic chemotherapy, or prophylactic mastectomy or salpingo-oophorectomy [5].

The risk of having a BRCA mutation is only 1 in 400 in the general population, although the risk is higher (1 in 40) in the Ashkenazi Jewish population [3]. BRCA mutations—and, by extension, HBOC—can be identified through genetic testing, and in 2005, the United States Preventive Services Task Force (USPSTF) recommended that providers refer women who have a family history consistent with HBOC for genetic counseling and possible testing [4,6]. USPSTF also recommended against genetic counseling or testing for women without such family histories.

However, there are a variety of challenges to identifying women for HBOC testing in primary care. First, primary care providers' knowledge of HBOC is limited, and very few have experience referring women to genetic counselors [7,8]. Second, providers do not systematically collect cancer family history, and many patients are unsure of this history, needing time to gather it with family

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members [9,10]. Third, women are often confused about HBOC, the genetic testing process, and the information provided by genetic tests [11]. For example, many women incorrectly believe that BRCA tests diagnose cancer, and women with any family history of breast cancer overestimate their risk of having a BRCA mutation [11–14]. Finally, providers struggle to communicate genetic risk concepts to patients [15–17]. Patients have rated primary care providers poorly on knowledge of genetic conditions, and many providers are unsure how to convey risk information in a way that helps patients make informed screening decisions [10,18].

Clinical decision support (CDS) tools with artificial intelligence (AI) offer one strategy for overcoming such challenges. CDS tools collect and organize medical information and, using AI components such as risk algorithms or message tailoring, can produce patient-specific educational information, risk assessments, and screening or treatment recommendations [19,20]. These tools are especially valuable when medical history is not easily available, when patients or providers lack critical knowledge, and when clinical recommendations vary based on a patient's risk profile [21]. CDS tools also can facilitate patient–provider discussions and shared decision making by sharing risk results and clinical recommendations with both parties [22].

Several CDS tools already exist for calculating women's HBOC risk, yet they do not fully address the above challenges [23–27]. Most existing tools are not designed for primary care populations, focusing instead on women referred for genetic counseling, and no existing tool has both patient and provider interfaces, which limits the information shared between the two parties. Moreover, evaluations of existing tools have focused almost exclusively on risk prediction accuracy. Only one tool has been evaluated for usability and risk result comprehension, and no evaluation has examined how tools affect HBOC knowledge, screening decisions, or patient–provider discussions. Other tools exist for collecting cancer family history in primary care settings, but few capture enough information to estimate HBOC risk and none contains a CDS component [28].

The goal of this study was to create *Cancer in the Family*, an online CDS AI-enabled tool for identifying and counseling women at increased risk for HBOC in primary care settings, and to conduct a pilot evaluation of the tool. The study sought to answer four research questions:

(1) To what extent did patients and providers use the tool to collect cancer family history?
(2) Did the tool improve patient and provider knowledge of HBOC and the genetic testing process?
(3) Did patients understand the personal risk assessments produced by the tool and, if so, how did the assessments influence perceived risk of HBOC?
(4) How did the tool influence patient and provider discussions and referrals related to HBOC and other health issues?

2. Cancer in the Family tool

We developed the *Cancer in the Family* tool to facilitate referral to genetic counseling for women who are at increased risk for HBOC based on USPSTF guidelines. The tool educated patients about HBOC, used an AI algorithm to analyze patients' cancer family history and calculate their risk of having a BRCA mutation, and provided personalized risk results to patients and their primary care providers. The tool also recommended AI-selected resources to help providers counsel patients on their risk results and encouraged shared decisions about genetic counseling and testing.

The tool's AI components included

(1) A sophisticated algorithm that examined each patient's cancer family history, assessed her risk of having a BRCA mutation, and provided personalized HBOC risk results.
(2) Messages and resources, including risk result implications and screening recommendations, that were based on each patient's personalized risk results and that providers were encouraged to share with patients.
(3) A worksheet for patients that recommended questions and discussion topics to raise in one's clinical exam, based on each patient's personalized risk results.

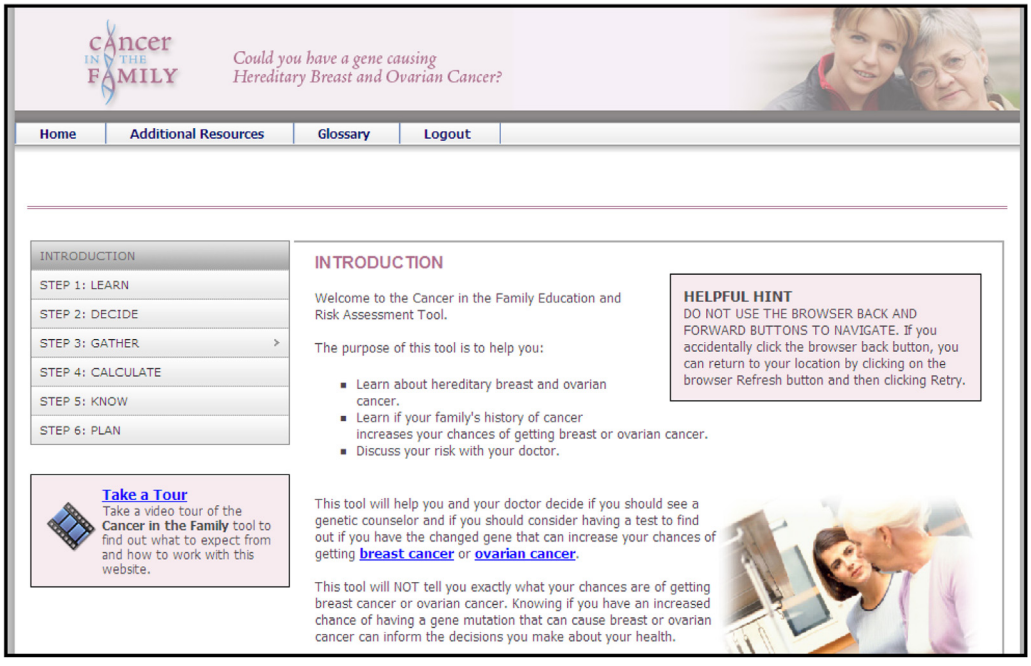

Fig. 1. *Cancer in the Family* patient interface.