Empowering Women to Prevent Breast Cancer: Research Agenda & Preliminary Findings

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One in eight U.S. women will be diagnosed with breast cancer in her lifetime, and this risk can rise to 60% or higher for women with mutations of the *BRCA*1/2 genes or a strong family history of the disease. Effective mechanisms exist to prevent breast cancer among these women, but we have very limited knowledge of how women choose among their options; which women choose which prevention methods; or the psychosocial impacts of these processes. At the same time, we know that women rarely receive the systematic information and support that would allow them to make educated, health-protective choices fully aligned with their values. Missing from our ability to effectively leverage available methods of prevention is an understanding of the decision-making processes women utilize in the time between learning that their risk is elevated and choosing a course of preventive action. Absent this link, we do not know (a) how women decide among the prevention pathways available; (b) to what degree they are able to implement choices that reflect accurate knowledge and their own preferences; (c) what motivations, interactions, and constraints most forcefully shape their choices; (d) how the features of decision-making affect physical and psychosocial health; or (e) how these dynamics vary across sub-groups defined by race-ethnicity, socioeconomic status, and severity of breast cancer risk.

This paper has two central goals: to articulate a research agenda, and to report early findings from an initial study. The research agenda articulated here is designed to trace the dynamics through which diverse women navigate pathways to all potential prevention behaviors, and to illuminate the relationships among decision-making factors, prevention choices, and health outcomes for various subgroups. Original qualitative and quantitative research is urgently needed to add the perspectives of women at elevated risk into a field of research that has so far been dominated by medical perspectives, and largely fragmented into separate studies on groups of women who have *already chosen* their course of preventive action. This literature leaves a range of important questions open; answering these questions will provide the critical foundations for the project of empowering women at elevated risk to make health-protective decisions that reflect informed preferences and personal values. The first half of this paper catalogues the specific gaps in the existing literature, and articulates a multi-stage research agenda to fill these gaps.

Prophylactic mastectomy, prophylactic oophorectomy, chemoprevention, and enhanced surveillance have all been shown to dramatically reduce the risk of breast cancer among high risk women (Freedman et al. 2011; Kuhl et al. 2010; Lostumbo, Carbine, & Wallace 2010; Razzaboni et al. 2012; Warner et al. 2011). Existing research also illuminates some of the specific physical or psychological side effects these prevention methods may cause (Lostumbo et al. 2010; Shuster et al. 2008; Tuttle et al. 2010). The dearth of studies illuminating women's own perspectives, however, means that there are also serious gaps in our knowledge of the toll these methods take on women's sense of well-being and social relationships; the conditions under which women experience them positively; and what kinds of information, interaction, and support can facilitate empowered decision-making that protects women's psychosocial and physical health.

Our current understanding of which women choose which prevention methods is extremely limited; and we know even less about *why* women make the choices they do. Only a few studies have used qualitative data that explores women's choices in their own words. These studies reveal that both women's conceptualizations of risk and their prevention decision making differ substantially from those of the medical community (Salant et al. 2006); that exposure to cancer in primary relatives influences women's understanding of their own risk and prevention options (Hallowell et al. 2001); that a complex array of communications with health care providers, family, friends, and patient communities helps shape women's decisions (Klitzman & Chung 2010); and that women's perceptions of personal risk and preventive behavior evolve over time (Hallowell et al. 2001). Neither the relative importance of these factors nor their associations with physical and psychological outcomes has yet been explored. The cancer prevention and health decisions literatures, and the work of peer support communities, suggest other potential drivers of women's choices that have not been explored, including access to and usability of health information; access to and communication style of health care providers; quality of support from family, friends, and cancer survivors; desire to control one's health; self-worth; cancer-related stigma; and financial considerations (FORCE 2013; McQuirter et al. 2010; Vodermaier, Esplen, & Maheu 2010).

Existing literatures on prevention decisions and their health effects also lack attention to racial and ethnic disparities, despite the documented importance of such disparities in many related areas. African American women have a lower incidence of breast cancer, for instance, but suffer significantly higher breast cancer mortality rates than non-Hispanic Whites (Hall & Olopade 2006), and these mortality rates have fallen significantly less for African Americans than Whites in recent years (American Cancer Society 2007). Racial-ethnic variations also exist in adherence to screening guidelines (Gerry 2011); access to and utilization of genetic testing and counseling (Hall & Olopade 2006); and the use of breast conserving surgery to treat early stage cancer (Gomez et al. 2004).

After diagnosing the serious gaps in the existing literature and articulating the research necessary to remedy these, the second half of this paper will report early findings from a study designed to address the initial stage of this research agenda. This study involves conducting in-depth, open-ended interviews with African American and non-Hispanic white women who are living with elevated risk of breast cancer but have never been diagnosed with cancer. Fifty women will be interviewed during Winter and Spring of 2015 by the author, funded by the first year of a K01 grant from the National Cancer Institute. In order to be eligible to participate in the study, women must be at least 18 years of age, have never been diagnosed with cancer, and know they are at elevated risk of breast cancer as a result of (a) a positive test for a BRCA1 or BRCA2 genetic mutation, or (b) family history of breast or ovarian cancer. Because one important objective of this research is to compare processes, behaviors, and outcomes across diverse groups, recruitment will aim for pre-defined target proportions of women in specific categories of race-ethnicity, socioeconomic status, severity of risk, and time since becoming aware of elevated breast cancer risk. Participants will be recruited from the patient populations of the High Risk Breast Cancer Prevention and Clinical Genetics Clinics at the Stefanie Spielman Comprehensive Breast Center at the Ohio State University; these participants will also suggest other eligible women, who will be recruited through a snowball sampling procedure.

By exploring decision-making dynamics in the words of women who are diverse in terms of race-ethnicity, social class, and severity of risk, this research offers the opportunity to gather two novel but important types of information. First, the interview approach (semi-structured protocol with minimal guidance in the first phase of women's storytelling and then systematic follow-ups) is ideally suited to illuminate decision-making factors and psychosocial dynamics that are powerful from women's perspectives, but have not been explored in previous research. Second, the inductive analytic approach will trace the full range of dynamics by which women navigate pathways to *all* potential prevention behaviors. This novel research starts with women who are dealing with elevated risk – instead of women who have already made a specific prevention choice – in order to catalog the "real" options women perceive and explore the psychological, relationship, and medical dynamics that lead to both prevention decisions and psychosocial health outcomes.

Subsequent stages of the research agenda will build on the findings of this initial study, using original survey data to test specific hypotheses about relationships among decision-making factors, prevention behavior, physical and psychosocial health outcomes, and patient characteristics. By revealing women's decision-making processes and their effects, this body of work will ultimately illuminate modifiable target points for tailored decision support interventions. The final stage of the proposed research agenda will involve designing and testing such interventions, with the aim of empowering women to implement decisions that reflect their own preferences and values by providing high quality information, interaction, and support.