CANCER PREVENTION & RESEARCH INSTITUTE OF TEXAS

Award ID:
PP160110

Project Title:
Use of Genetic Patient Navigators to Help Mutation Carriers Comply with the NCCN Guidelines and to Enable Healthy Behaviors

Award Mechanism:
Cancer Prevention Promotion and Navigation to Clinical Services

Principal Investigator:
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Entity:
The University of Texas Southwestern Medical Center

Lay Summary:

Need: Patients with Hereditary Breast and Ovarian Cancer syndrome (HBOC) and Lynch syndrome (LS) have elevated lifetime risk for cancer. Our service area, Health Service Region 3 and 7, has one of the highest breast cancer incidence rates in the state, and greater than average incidences of ovarian, endometrial, and colorectal cancer [1]. Based on the frequency of mutated genes, 72,280 individuals in Texas have HBOC or LS, and 22.6% (16,303 affected individuals) live in our service area. If cancer risk reduction strategies are maximized, these individuals have the opportunity to achieve primary cancer prevention or early detection of curable cancers. In CPRIT-funded project (PP110220), data analysis demonstrated suboptimal uptake in HBOC and LS cancer risk management recommendations in uninsured versus a private hospital population (39% and 40% HBOC underserved adhered to breast and ovarian cancer risk management strategies; 81% of LS underserved utilized colonoscopy screening recommendations) [2]. We propose to use a dedicated genetic patient navigator (GPN) to promote adherence to recommended management strategies via targeted intervention with the identified patients. We have found that our indigent populations have unique needs, such as requiring assistance to obtain registration into county hospital systems and transportation limitations that impact appointment attendance. As 32% of our patient volume is indigent, a GPN would be able to facilitate care. Our program has identified over 2,400 mutation carriers to date. Many of these patients have not received systematic follow-up and at-risk family members have not been tested. Typically, patients are sent back to their referring providers for ongoing medical management needs, but studies have shown that many non-genetic healthcare providers have low genetic health literacy [3, 4].

Overall Project Strategy: The GPN will contact all our HBOC/LS mutation carriers from 1999-2011, as well as those who were identified outside of our previous CPRIT grant award from 2011 to present. The GPN will: 1) obtain updated medical history, 2) ascertain the need for services and current compliance with NCCN recommendations [5, 6], and 3) navigate to services and education regarding cancer risk factor minimization. The GPN will follow-up with patients after scheduled screenings or risk-reduction efforts and obtain information on relatives tested. The GPN will be available to navigate relatives to genetic counseling and testing. Finally, the GPN will promote the enrollment for applicable ‘previvors’ into the Moncrief Cancer Institute survivorship program with cancer

prevention strategies, such as exercise and nutritional counseling. Educational opportunities for targeted clinician and patient populations will be pursued to disseminate awareness regarding HBOC/LS patient identification and management, as well as understanding the GPN role.

Specific Goals: 1. Increase compliance of HBOC patients to NCCN cancer risk management guidelines (1,114 served) 2. Increase compliance of LS patient to NCCN cancer risk management guidelines (228 served) 3. Increase identification of at-risk relatives of HBOC and LS probands (2,684 served) 4. Influence lifestyle behaviors to reduce cancer risk by decreasing tobacco use in LS carriers (1,342 served) 5. Expand awareness of HBOC/LS and the GPN's role and impact in clinical care within targeted populations (10,250 reached)

Innovation: To our knowledge, there is not a current GPN position at any facility that focuses solely on following mutation carriers and identifying at-risk family members. Most clinicians are only managing a few patients with hereditary cancer syndromes, so they are less likely to be up-to-date with current NCCN guidelines [3, 4]. Most clinical genetic counselor (GCs) must focus on new patients and more immediate clinical needs rather than retrospective follow-up. Additionally, there is not a healthcare provider dedicated to providing general cancer risk reduction counseling systematically to patients at high cancer risk. Another unique aspect will be promoting the enrollment for 'previvors' into a survivorship program with cancer prevention strategies such as exercise and nutritional counseling. To our knowledge, there are no known formalized previvorship programs in existence.

Significance and Impact: The GPN role has the potential to drastically impact cancer incidence in our target population. Although this is a small, unique population, with a higher cost per patient ratio, the impact will be high. In a previous study, we utilized statistical modeling to measure the impact of cancer risk reduction strategies on cancer incidence. [2] Using our baseline data from the previous study and measuring the effect of our compliance goals, we estimate we will detect 80 new early-stage breast cancers, and prevent 14 ovarian cancers and 4 colorectal cancers.