

Improving Access to Cancer Genetic Counseling through Telegenetics – A Bayhealth – University of Pennsylvania Initiative

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Introduction

Genetic testing for hereditary cancer syndromes, such as BRCA1/2 testing for Hereditary Breast and Ovarian Cancer syndrome, may have significant implications for patients and their families for cancer treatment, management, and prevention. The National Accreditation Program for Breast Centers now requires access to cancer risk assessment and genetic testing when appropriate for patients.¹ Traditionally, cancer genetics services have included in-person pre- and post-test genetic counseling (GC) with an experienced provider. Remote two-way video-conferencing (RVC) is a feasible alternative to provide genetic counseling for patients in geographically underserved populations with reduced travel burden. This alternative to traditional face-to-face counseling is also associated with high patient satisfaction and favorable cognitive and affective outcomes.²

A majority of the genetic counseling workforce is centered in academic and urban centers which may require patients to travel long distances to receive in-person services. Limited access to genetics services creates potential disparities in clinical care.³ In order to receive cancer genetic services, Bayhealth Medical Center (BHMC) patients were referred to major medical centers located outside of the southern Delaware region. Barriers, including the time and cost of travel as well as unfamiliarity with these outside centers, resulted in reduced uptake of genetic counseling and testing for patients and families with significant cancer history. BHMC has partnered with the Penn Telegenetics Program at the University of Pennsylvania to make genetic counseling accessible on-site, eliminating the need for patients to travel long distances and maintaining continuity of care within the BHMC network.

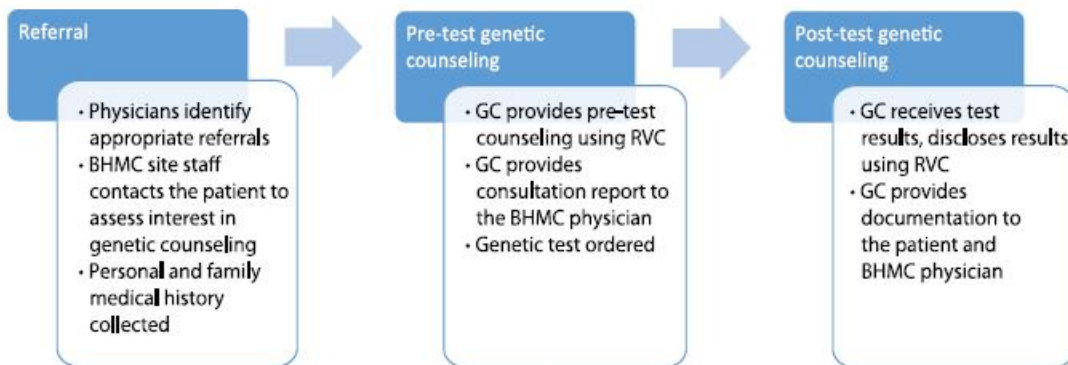
Penn Telegenetics Program at Bayhealth Medical Center

The Penn Telegenetics Program provides cancer genetic counseling services using RVC to community hospitals without access to genetic providers. BHMC was a participating site in a NIH-funded pilot-study conducted at the University of Pennsylvania, investigating the feasibility of using RVC cancer genetic services at three community practices. At the conclusion of the study, BHMC entered into a clinical contract with the Penn Telegenetics Program to maintain continuity of telegenetics services. Genetic counselors at the Penn Telegenetics Program remotely provide genetic counseling using RVC to patients located at BHMC. They work closely with on-site physicians and staff to coordinate the genetic test order and provide follow-up care when appropriate.

Serving the Community

When a physician in the community determines that a patient might benefit from genetic counseling, the patient can be referred to a Penn Telegenetics counselor (Figure 1). The types of referrals might include: patients recently diagnosed with cancer who are considering treatment options, patients with a strong personal and/or family history of cancers, patients with young age of diagnosis and patients with personal and/or family history of rare cancers or other findings. Benefits of genetic counseling include personal assessment for inherited risk factors, discussion of genetic testing options and outcomes, education on early detection and risk-reduction options, as well as addressing patients' psychosocial concerns. Discussion of these topics further fosters informed decision making. Most genetic testing is covered by patient insurance for patients meeting specific criteria. Financial aid options are available for patients who do not receive insurance coverage.

Figure 1. Telegenetics Work Flow



Telegenetics allows patients to receive quality care in their local community sites while reducing travel burden, costs, time and disruptions to their daily routine. In addition, local providers gain access to services and information without having to refer their patients outside of their practice. For many, access to telegenetics services may be invaluable, as the information may impact risk reduction and treatment options. This information may also benefit family members of patients. When an individual is found to have a gene mutation, family members are eligible for genetic counseling and testing to learn about their personal cancer risk. Through our services, we have identified families with several hereditary cancer syndromes, such as: Hereditary Breast and Ovarian Cancer syndrome, Lynch syndrome, Cowden syndrome, Li-Fraumeni syndrome, and other gene mutations conferring increased cancer risk. These patients and their family members can now receive personalized screening and prevention options to manage increased cancer risk due to a gene mutation.

Telegenetics Program Overview

Since the start of the program, 290 patients have been referred by on-site physicians (n=178), local community doctors (n=88) and self-referral (n=24) (Figure 2). The majority of referrals are from oncologists (57%) and surgeons (29%) (Figure 3). To date, 135 patients have been seen for pre-test counseling; of the remaining 155 referrals not seen for genetic counseling, reasons include patient refusal of services, lost to follow-up or pending decision to receive services. One hundred and nine patients elected to have genetic testing and completed disclosure sessions, resulting in the identification of 15 positive mutation carriers (Figure 4).

Figure 2. Monthly Referrals to the Telegenetics Program at BHMC

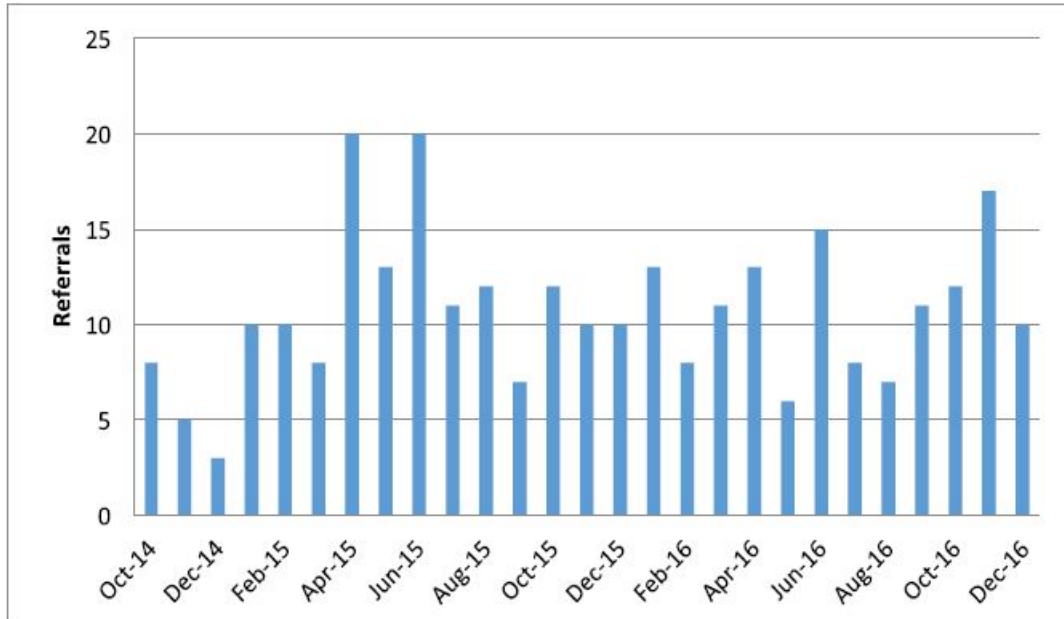


Figure 3. Referral Sources by Specialty

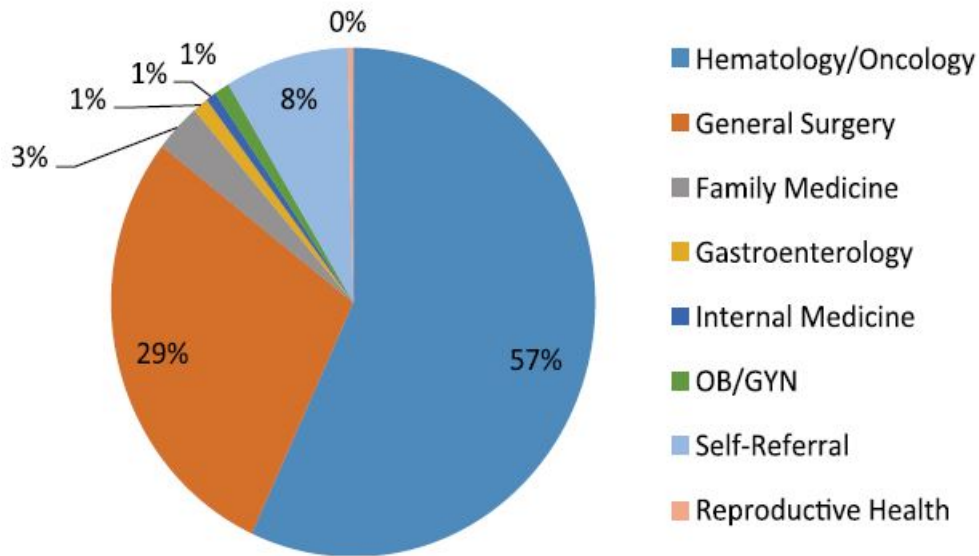
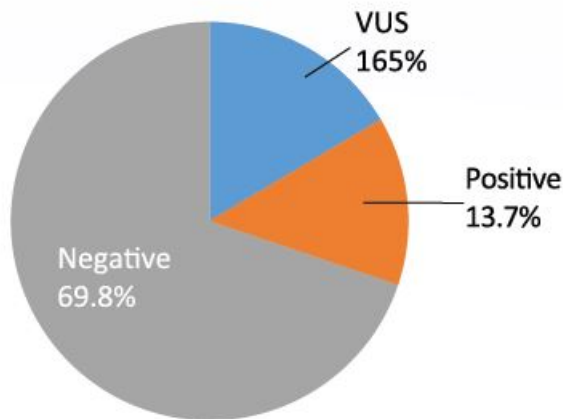


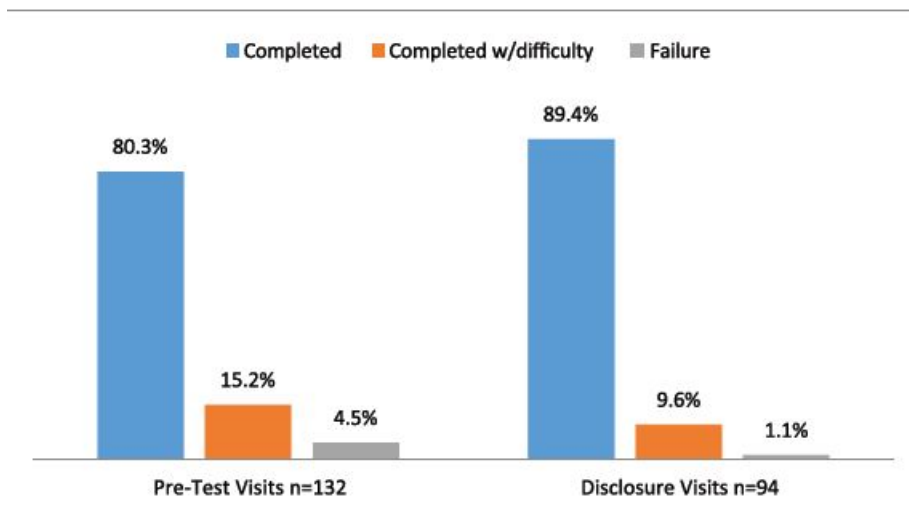
Figure 4. Summary of Genetics Tests Results



Patients are located at BHMC and connect with Penn genetic counselors using RVC platforms. To assess performance of technology used, data was obtained on 132 pre-test sessions and 94 post-test sessions.

The majority of sessions were completed successfully (80% pre-test, 89% post-test). Technology disruptions occurred in some sessions (15% of pre-test and 9% post-test), and few sessions required a secondary RVC platform or telephone to be completed successfully (4% pre-test and 1% post-test) (Figure 5). In addition, patients were offered the option of telephone services in some circumstances. Patients have verbally expressed high satisfaction with telegenetics due to ease of access, reduced travel burden and continuity of care in their community.

Figure 5. Videoconferencing Completion Rates



Conclusion

Knowledge about the presence of increased risk for cancer can provide important, sometimes life-saving options to patients, such as increased cancer screening, prophylactic surgeries, and personalized medication regimens. Previous studies have demonstrated that meeting with a genetic counselor increases patient knowledge, understanding and satisfaction.^{4,5}

The limits of in-person consultation become apparent as demand for genetic counseling increases. Penn Telegenetics and Bayhealth Medical Center strive to fill this gap efficiently, helping both patients and their physicians. We will continue our efforts to reach patients and families who may benefit from genetic counseling, and improve our services by implementing innovative approaches to care.

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