Telegenetics in Oncology Care

Cara Cacioppo, MS, LCGC Genetic Counselor Penn Telegenetics Program University of Pennsylvania Cara.Cacioppo@uphs.upenn.edu





Applying Telemedicine to Genetic Counseling

- Genetic Counseling: the process of advising individuals and families affected by or at risk of genetic disorders to help them understand and adapt to the medical, psychological, and familial implications of genetic contributions to disease (Resta et al., 2006)
- Telegenetics: an evolving definition, but often includes the delivery of genetic consultations via telephone and videoconferencing



Access to genetic services is limited

- Genetic counseling is associated with outcomes that foster risk reduction behaviors and improved outcomes (risk perception accuracy, increase in genetics knowledge)
- A 29% growth in the GC profession is forecasted from 2016-2026 by the US Bureau of Labor Statistics



- Access to GC services can be limited due to geographic or financial barriers
 - For instance, BRCA1/2 testing is standard-of-care but only 37% of patients undergoing BRCA1/2 testing meet with a GC



Need for Telegenetics

- Genetic counseling is recommended, but the traditional two in-person visit model presents barriers
- In-person outreach models are costly, inefficient, and limited
- Alternative, non-traditional technology-based service delivery models have emerged to fill gaps in care



(Platten et al. 2012; Iredale et al. 2012; Lea et al. 2005; Peshkin et al. 2016; Buchanan et al. 2015; Sutphen et al. 2010)



The Penn Telegenetics Clinical Program

• 3 Clinical Sites Currently:

- Bayhealth Medical Center (DE)
- Shore Medical Center (NJ)
- Chester County Hospital (PA)
- Patient Access Pilot:
 - GC by phone/video in the home
- Currently only clinically offer cancer genetic counseling/testing





Telegenetics Service Delivery Model

Technology Platform

Expertise Center



Access Need Center/Home



Penn Genetic Counselor

Patient

Cancer Telegenetics Workflow

Referral

- Site receives referral
- Site assesses patient interest in genetic counseling
- Obtain medical & family history information

Pre-test genetic counseling

- GC provides pretest counseling via video or phone
- Remote sample collection
- GC orders test & provides consultation report to site physician

Post-test genetic counseling

- GC receives test results
- Disclose results via video or phone
- Documentation provided to patient and physician

Patient Telegenetics Experience

- Previous studies have demonstrated that methods of telegenetics are valid and effective ways to educate, evaluate, and support patients undergoing a genetics assessment
- Providing telegenetics services has also been correlated with a higher attendance rate for individuals receiving telegenetics and increased convenience for patients when compared to in-person genetic counseling.

(Platten et al. 2012; Iredale et al. 2012; Lea et al. 2005; Peshkin et al. 2016; Buchanan et al. 2015; Sutphen et al. 2010)

Oncology Patient Telegenetics Experience

General Benefits of Oncology Genetic Counseling/Testing

- Information may impact cancer risk reduction and treatment options
 - Surgical decisions, medications, clinical trial eligibility
 - Personalized screening recommendations
- Information may benefit relatives (cascade testing)

Benefits of Access to Telegenetics

- Reduces geographic barriers
- Accommodates potential physical limitations
- Increases convenience
- Facilitates cascade testing



Oncology Patient Telegenetics Experience

"The convenience of not having to travel. I felt it was as personal as a person to person consultation. I also received information regarding my medical history that was previously not explained to me."

> -Penn Telegenetics cancer genetic counseling patient

Oncologist Telegenetics Experience

- Research shows that many physicians have incomplete or inaccurate knowledge about the inheritance and characteristics of hereditary cancer syndromes and interpretation of genetic test results (Hamilton et al., 2017)
- Telegenetics offers physicians and genetics professionals the ability to collaborate, partner, and offer multidisciplinary care to patients
- Do not need to refer patient to an outside institution
- "Tele-colleagues" such as telegenetic counselors can participate in case conference/tumor boards and efforts to increase program referrals

Oncologist Telegenetics Experience

"Sometimes genetic testing is very straightforward, but sometimes it isn't [...] By having this affiliation with the University of Pennsylvania we have access to Penn's immense database and we can ask them what experience they have in this particular situation, what recommendations can they offer."

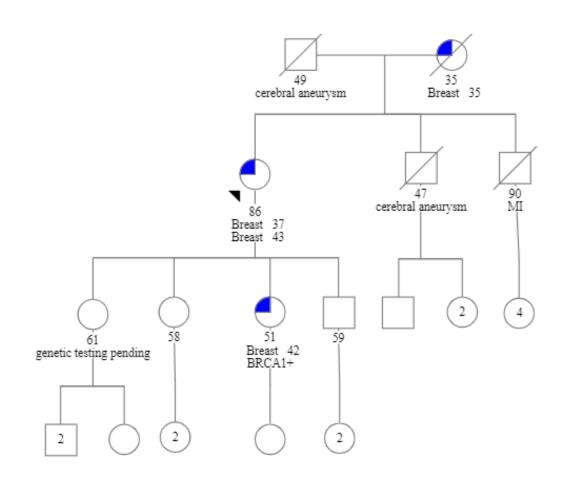
> -Dr. Rishi Sawhney, Medical Oncologist at Bayhealth Medical Center in Dover, DE

Telegenetics Genetic Counselor Experience

- Just over 2% and 8% of GCs report "always" or "often" using video or telephone to provide genetic counseling, respectively
- While those who commonly practice via telemedicine see the utility of this service, genetic counselors recognize there are unique differences and challenges associated with these alternative delivery models
- Telemedicine allows more efficient use of provider time while expanding breadth of practice

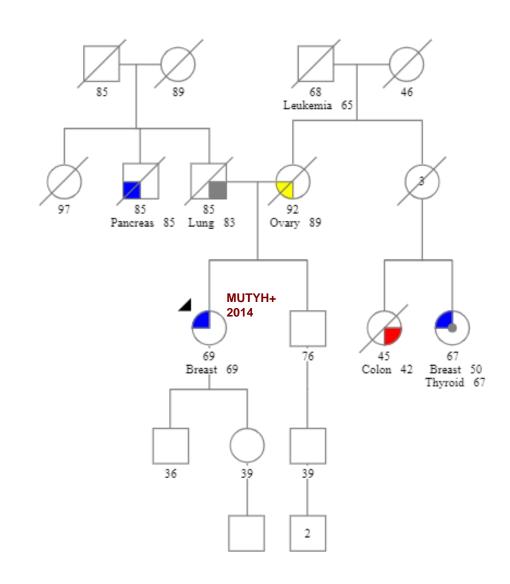
(Cohen, 2013; Burgess, Carmany, & Trepanier, 2015; Cohen et al., 2012; Cohen, Huziak, Gustafson, & Grubs, 2016)

Case Example (C.B.): Ease of Access



- CB, 86y female, rural PA.
 BRCA1 mutation identified in her daughter.
- An in-person GC appointment was not an option for CB due to early stage dementia and multiple health issues/physical limitations
- CB received telegenetics services at home and tested BRCA1 positive, providing information for her siblings and relatives

Case Example (S.P.): Providing Expertise



- SP, 69y female, rural DE.
 Referred to telegenetics due to recent breast cancer dx.
- SP's oncologist noted in her medical record that SP has Lynch syndrome and is screened accordingly
- GC reviewed SP's previous genetic test results
- GC explained that SP does <u>not</u> have Lynch syndrome and does not need additional genetic testing

Conclusion

- Increased demand for genetic services requires alternative service delivery model options
- Telegenetics allows patients to receive quality care in their local community sites while reducing travel burden, costs, time, and disruptions to their daily routine
- Telegenetics has demonstrated the ability to improve access to genetic services without compromising quality of care





Acknowledgments

- Angela Bradbury, MD
- Colleen Sands, MPH
- Beth McCarty Wood, MS, CGC
- Nicolette Sookar, MS, CGC
- Claire Leifeste, MS, CGC
- Dana Falcone, MS, CGC
- Dominique Fetzer
- Syeda Abbas
- Demetrios Ofidis

- Telegenetics clinic site patients, oncologists, and support staff
 - Bayhealth Medical Center
 - Shore Cancer Center
 - Chester County Hospital
 - Patient Access Pilot team





Thank you!

Cara.Cacioppo@uphs.upenn.edu

