Project iCare: Fighting Disparities in Cancer Treatment through Technology

Grace Simmons 2022, Neuroscience
Rutgers Cancer Health Equity Institute
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Introduction

Hereditary Cancer Syndromes
- BRCA1/2 gene mutations increase risk of Breast and Ovarian cancer (females) and prostate cancer (males) significantly
- Lynch syndrome mutations increase the risk of endometrial cancer (female carriers) and colorectal cancer for all who are diagnosed
- Cancer risks can be managed if carriers are aware of their status,

Importance of Family Communication
- HIPAA prevents care providers from informing patient relatives that they may have a pathogenic mutation
- Cascade testing (identifying mutation carriers) relies heavily on family communication of test results

Disparities in Utilization of Genetic Testing Services
- Cause many preventable deaths
- Gender (males less likely to seek testing), racial/ethnic (Black individuals most underserved), socioeconomic, and cultural

Chatbots as an Alternative Care Delivery model
- Can address the national shortage of genetic counselors, disparities in genetic testing and awareness, and save lives

Internship Objective

Synthesize literature regarding cancer health disparities in family communication and cascade testing, focus group data, and research detailing existing technological interventions in order to provide recommendations for the development of a chatbot and online genetic education intervention.

Work Profile

Rutgers Cancer Health Equity (CHE) Objectives:
- "To advance the achievement of equitable access, improved health care quality, and better outcomes across the cancer continuum – prevention, early detection, treatment, survivorship, and end-of-life care – through research, education and training, community engagement and outreach, and public policy advocacy."

Project iCare Objectives:
- Recruit diverse focus group cohorts, including males and those underrepresented in research
- Gain feedback for a technological intervention (website and chatbot) that facilitates cascade testing through enhancing family communication of genetic test results

General Internship Deliverables and Tasks:
- Conduct literature reviews on chatbots, decision aids, online interventions and family communication tools for genetic testing, and relevant disparities and cultural and gender issues.
- Attend virtual meetings with research team and genetic counselor
- Code qualitative data related to chatbots from de-identified focus group transcripts
- Write a paper summarizing the literature reviews and focus group data, and providing recommendations for research using chatbots in online genetic education interventions

Resources Participants Would Use to Share Genetic Test Results with Family
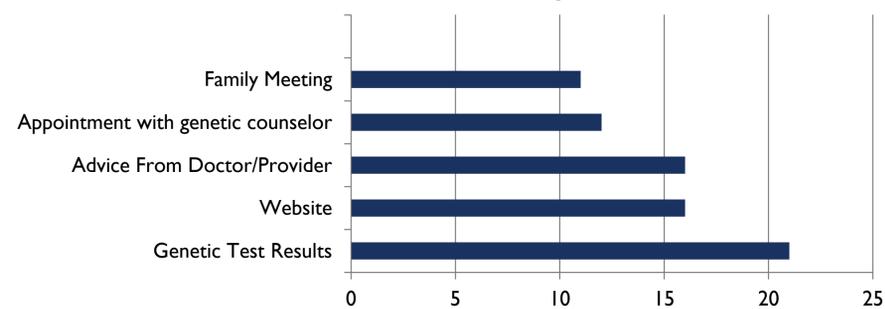
Results

iCare Focus Group Findings
- Website geared toward helping those with BRCA1/2 mutations and Lynch syndrome share their results with family members well received
- Chatbot less well-received (due to AI hesitancy and bad personal experiences with consumer chatbots), but most participants reporting a willingness to use a chatbot-based intervention

Research Contributions:
- Presented a flash talk at the Cancer Health Equity Institute Retreat
- Compiled a list of cancer organizations to aid with recruitment
- Conducted a thorough literature search, organized by study type, citation, title, principle finding, and relevance of 90+ journal articles
- Recruited and consented focus group participants
- Sent out surveys and study reminders
- Created a Microsoft Teams participant user guide and attended focus groups
- Conducted quality assurance (QC) on participant surveys
- Attended weekly research team meetings
- Created an *apriori* codebook, coded, and analyzed focus group transcripts
- Synthesized existing literature and focus group results into a 36-page report detailing significant findings and technological recommendations
- Presented paper findings and suggestions to research team and other CHE researchers

Table 1: Demographic Data

Characteristics	July 7th (n=12)	July 21st (n =7)	July 23rd (n=6)	Total (n= 25)
Sex				
Female	7	6	4	17
Male	5	1	2	8
Race				
White	11	7	5	23
Black	0	0	1	1
Asian	1	0	0	1
Other	0	0	0	0
Hispanic	1	0	0	1
Ashkenazi Jewish	7	4	2	14
Diagnosis				
BRCA1/2	12	5	4	21
Lynch Syndrome	0	2	2	4

Looking Ahead

How this experience has impacted my future plans:
- Increased my desire to forge a career that merges clinical practice, research, and health equity
- Looking forward to engaging in more interdisciplinary clinical research endeavors
- Speaking to genetic counselors and conducting literature reviews made me aware of many physician's lack of training and awareness regarding genetic testing and counseling services.
- I am looking forward to seeing the eventual iCare chatbot and website intervention

Reflection

Skills Developed:
- Community-based and cold call recruitment
- Consenting participants
- Familiarity generating and running reports in redcap
- Thematic Analysis using NVivo
- Endnote proficiency

Lessons Learned:
- Importance of partnering with the community one seeks to serve when designing interventions
- When conducting clinical research, considering whose voices are being left out of the conversation may reveal whose needs are not being met
- Most studies do not run smoothly. Especially, when their protocols are updated to reflect new pandemic-caused restrictions
- Healthcare is multifaceted

Unanswered Questions

- What are the best ways to address the lack of diversity in research?
- How might the decision-making process for the family communication of genetic testing results differ for gender minorities?
- What are culturally sensitive recruitment approaches?
- In the increasing development and employment of new technologies, who is getting left behind?
- What are the best ways to make technological health tools available for those who need it the most?

Table 2: 18 Digital Universal Precautions to promote eHealth (1)

Conclusions & Acknowledgments

I am extremely grateful for the opportunity to have worked with Dr. Kinney's team. I learned a lot during my 8-week internship and gained many skills that I will carry over to my future research and clinical endeavors.

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Contact

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References

1. Smith B, Magnani JW: New technologies, new disparities: The intersection of electronic health and digital health literacy. Int J Cardiol 292:280-282, 2019