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 Care 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 in order to provide recommendations for the development of a chatbot and online genetic education intervention.
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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

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?

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

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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References