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SPECIAL ISSUE

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Research to reduce inequities in cancer risk services: Insights for remote genetic counseling in a pandemic and beyond

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1 | INTRODUCTION

Genetic counseling and testing for hereditary breast and ovarian cancer (HBOC) have been in use for over 20 years. Yet, these services are largely unavailable to historically underserved populations despite known high mortality rates due to cancer (Williams et al., 2019). The COVID-19 pandemic has highlighted our society's longstanding health care inequities. Two decades of evolving practice-based research in hereditary cancer genetic counseling in underserved populations unexpectedly prepared us to respond to the COVID pandemic, and provides lessons learned that can improve access and decrease health disparities. This essay is a story of collaborations between cancer disparities researchers and providers, with far-reaching implications for the field of genetic counseling.

In 1994, BRCA1 and BRCA2 were identified as tumor suppressor genes that, when mutated, confer an exceptionally high risk for breast and ovarian cancer. These mutations are rare, occurring in only 5%–10% of individuals with breast and ovarian cancer (King et al., 2003). By 1996, genetic testing became clinically available for some families with personal and/or family histories suggestive of hereditary breast and ovarian cancer syndrome (HBOC), enabling them to learn who was and was not at increased risk for cancer. Individuals who are positive for a mutation can choose from multiple risk-reducing and potentially life-saving interventions, such as enhanced cancer screening, chemoprevention, and risk reducing surgery, including bilateral mastectomy and oophorectomy (Domcheck et al., 2010).

At our institution, the University of California, San Francisco (UCSF), genetic testing for HBOC was first offered in 1996 as part of a research protocol (CC 96,759 UCSF, 1996). To obtain genetic testing, participants were required to sign a detailed consent form and complete psychological questionnaires both pre- and post-testing. The purpose of the research was to study the implications of the new genetic counseling and testing services including psychological impact, decision-making about medical interventions, informing family about positive results, as well as concerns about privacy and insurability.

The process of genetic counseling and testing consisted of three separate in-person 60- to 90-min visits: first, an educational and family history gathering session (often including exhaustive collection of medical records and death certificates); second, a testing appointment; and the final visit included results and recommendations for cancer screening and prevention as appropriate. The length of appointments, number of required visits, need for medical records, literacy level of educational tools, consent forms, and other written material created barriers that initially prevented genetic counseling and testing for HBOC from becoming widely available outside of the research setting (American Society of Clinical Oncology, 1996). Many dynamics compounded this BRCA story including Myriad Genetics' ownership of a patent on the genes (overturned in the courts in 2013), which greatly increased the cost of testing and

limited availability (Cook-Deegan et al., 2010). Although, at our institution, testing was done through a research protocol, the research did not cover the cost of testing; insurance coverage was limited, which required some patients to pay out of pocket for these expensive tests.

By the early 2000s, genetic counseling and testing for HBOC became more readily available in many clinical oncology settings (American Society of Clinical Oncology, 2003). However, as with many medical innovations, patients with financial resources and/or access benefit, while the underserved do not, thus further exacerbating health disparities (Good et al., 2005). In 2002, a generous grant from the Avon Foundation enabled The Cancer Genetics and Prevention Program at UCSF to establish a satellite clinic at San Francisco General Hospital (SFGH, now called Zuckerberg SFGH or ZSFG); the county hospital in San Francisco which is operated by the San Francisco Department of Public Health and largely staffed by UCSF clinical faculty. The Avon funding supported free genetic counseling and HBOC testing for low-income safety net patients. To our knowledge, this was the first program in the United States to offer these clinical services at no cost. We learned quickly that free services alone do not eliminate all the barriers to risk reduction faced by vulnerable populations.

2 | AN 18-YEAR ONGOING MULTIDISCIPLINARY COLLABORATION

That same year, ZSFG genetic counselors initiated an ongoing collaboration with experts from UCSF to study strategies to increase awareness of HBOC and access to care. A multidisciplinary team was formed that included public health and health communication researchers, social scientists, oncologists, social workers, research associates, genetic counseling assistants, and patient navigators. To facilitate referrals and successful collaboration at our public hospital where both patients and staff were unfamiliar with genetic counseling, we spent time with staff to become familiar with the patient populations and the challenges they faced. Genetic counselors attended oncology clinics, tumor boards, provided in-service training, and devised a self-administered family history questionnaire that could be used in the mammography clinic (Lee et al., 2005). Initially, we met a measure of resistance from staff who expressed unease about genetic testing and the financial resources required in a population in which many faced compounding issues such as homelessness, substance abuse, chronic health conditions, and mental illness. At the same time, a few medical oncologists were eager to have specific patients tested, suspecting hereditary cancer conditions that might impact treatment decisions. The initiation of clinical services in this setting led our team to several research questions that addressed the key barriers of ineffective communication and limited access to genetic risk services. Clinical care, genetic testing, and research during this initial phase were generously funded by The Avon Breast Cancer Crusade.

What is known about this topic

HBOC genetic counseling and testing have been largely unavailable to historically underserved populations despite known high mortality rates due to cancer. The COVID-19 pandemic has highlighted our society's longstanding health care inequities.

What this paper adds to the topic

Two decades of evolving practice-based research in hereditary cancer genetic counseling in underserved populations unexpectedly prepared us to respond to the COVID pandemic and provides lessons learned that can improve access and decrease health disparities. This essay is a story of collaborations between cancer disparities researchers and providers with far-reaching implications for the field of genetic counseling.

3 | COMMUNICATION IN GENETIC COUNSELING

Our initial work focused on tools needed to provide appropriate education to a multi-lingual population with lower health literacy (Lubitz et al., 2007). Our early research findings made clear that the conventional model of genetic counseling would not meet the needs of patients in this setting. For example, excessive technical information was provided in the initial genetic counseling visit, and many concepts did not translate well, if at all, to patients' native languages. Medical interpreters also had difficulty with specific words, concepts, and analogies (Joseph & Guerra, 2015; Lara-Otero et al., 2019). Gathering prior medical records was also difficult, particularly for patients experiencing family separation due to immigration and complicated social situations. This research, which included patient focus groups and qualitative interviews with patients and interpreters, led us to re-think our informed consent procedure, patient education, and requirements for genetic testing with greater sensitivity to culture, language, and health literacy.

A key collaboration at that time was a partnership with Dr. Galen Joseph, Medical Anthropologist at UCSF, who was integral to the research detailed below. Dr. Joseph was particularly interested in communication between genetic counselors and patients, and she collaborated on one of our first projects to develop patient educational materials. The final products were informed by patient focus groups that examined genetic education terms and presentation strategies based on patients' stated preferences (Lubitz et al., 2007). The results led us to develop a Cancer Risk Educational Tool (CREdIT), a 15-min video (with English and Spanish versions) intended to orient patients prior to their initial pre-test genetic counseling visit. We evaluated CREdIT using pre- and post-questionnaires and patient interviews. We found that

genetic counseling and testing for breast/ovarian cancer was a new concept, and CREdIT's use of a family story to explain hereditary cancer risk was particularly appealing. However, changes in participants' perceived risk for breast cancer varied; and some misunderstandings about individual risk and heredity persisted after CREdIT and counseling (Joseph, et al., 2010).

Given these results (especially the persistent misunderstandings), and the challenges of implementing CREdIT consistently in a busy clinic, our next project aimed to assess the strengths and limitations of genetic counseling communication practices with Latinx patients (Joseph, et. al. 2015). This pilot project identified both strengths and limitations of the observed communication about family health history, education regarding genes and genetics and patient information needs, the purpose of the genetic test, genetic test results and cancer risk, building rapport and providing support, and medical interpretation for monolingual Spanish speakers. A subsequent in-depth study included a more diverse population with English-, Spanish-, and Chinese-speaking patients to further examine communication between genetic counselors and patients from the patient perspective (Joseph, et al. 2017). Analysis of over 170 genetic counseling sessions found a substantial mismatch between the information provided to patients and the information patients needed and wanted. To address that finding, we designed an intervention for genetic counselors (rather than patients) by adapting evidence-based communication methods for effective communication with patients of low health literacy such as limiting the amount of information and using teach-back to assess comprehension (Schillinger et al., 2003; Weiss, 2007) for the genetic counseling context (Joseph et al., 2019). The findings from these studies have been presented at several national and local educational events and workshopped with genetic counselors and genetic counseling students. Adapted for the context of returning exome sequencing results, the intervention, which is now called ARIA (Accessible, Relational, Inclusive, Actionable), is currently being tested in a randomized controlled trial as part of the Clinical Sequencing Evidence-Generating Research (CSER) consortium (Amendola et al., 2018; Riddle et al., 2020).

4 | EXTENDING THE REACH OF GENETIC COUNSELING

Even though genetic testing was becoming more widely available in the early 2000s, the technology was improving, and the cost of testing was decreasing, historically underserved patients continued to be left behind (Beattie et al., 2012; Wang et al., 2011). This inequity led us to extend our collaboration to include experienced cancer disparities researchers to explore and assess mechanisms to extend the reach of genetic counseling from our academic medical center to diverse low-income patients throughout the San Francisco Bay Area. Together we developed two successive National Cancer Institute-funded research trials: *Statewide Communication to Reach Diverse Low-Income Women* (NCI R01CA129096, 2007–12) and *Comparison of 3 Modes of Genetic Counseling in High-Risk Public Hospital Patients* ('GC3 study', NCI R01CA197784, 2016–21), under the direction of Principal Investigator Dr. Rena Pasick, Professor of Medicine and a cancer disparities researcher at UCSF.

The goal of the State-wide study was to ascertain whether an existing program that provides free breast and cervical cancer screening to low-income communities throughout California could be expanded to also identify women at high risk for HBOC and connect them with free genetic counseling and testing. We partnered with *Every Woman Counts (EWC*), a trusted toll-free phone service of the California Department of Public Health that is called by thousands of diverse underserved women every year (https://www.dhcs.ca.gov/services/cancer/EWC). We targeted callers within geographic reach of the UCSF Cancer Genetics Program to assess their risk of HBOC. Callers who were eligible for genetic counseling by virtue of personal or family risk were invited to join the study and randomly assigned either to immediately schedule a genetic counseling appointment or to be sent information about their risk and how to make an appointment themselves. For this study, we adapted the Pedigree Assessment Tool (PAT) to create a 'Six-Point Scale' designed for ease of administration over the phone (Joseph et al., 2012; Stewart et al., 2016; Teller et al., 2010).

Participation in the study included reimbursement for travel to San Francisco from nearby counties for in-person counseling. However, it quickly became apparent that transportation and travel distance were barriers preventing patients from completing counseling. As a result, we modified our study protocol to include phone counseling for the first visit; patients who met criteria for genetic testing were encouraged to present in person for genetic testing. As expected, this strategy enabled many more high-risk women to participate. Over a 14-month period, of 23,619 callers, 1,212 (5%) met initial study criteria; of those callers, 88 (7% of 1,212) were identified as high risk, 13 (15%) of whom had a personal history of breast cancer. Clinic records were used to assess receipt of genetic counseling after a 2-month period. During this period, 17 participants (39%) randomized to the intervention arm received genetic counseling compared with 2 participants (4.5%) in the control group. At the end of the study period, all women were contacted and offered genetic counseling, eventually 51 participants (58%) received genetic counseling (Pasick et al., 2016).

Concurrent with the State-wide study, we sought to explore more deeply the issues of access to HBOC education and services in the community experiencing the highest rate of mortality due to breast cancer, African American women. With funding from Susan G. Komen for the Cure (2010–15, PI: Pasick), and building on a longstanding African American faith-based initiative at the UCSF Comprehensive Cancer Center, we developed the *Family History Project* to assess the feasibility of training church health ministry leaders on cancer family history including collection of self-administered screener forms using another adaptation of our Six-Point Scale, and encouragement of those found to be at high risk to obtain free genetic counseling at UCSF. Our findings showed that through trained health ministry leaders, lay and low literacy adults received the information they needed to assess their family history and to act on that information

if they were at risk for hereditary breast and ovarian cancer. We identified 84 women at high risk from 751 screener forms, 50% of whom obtained genetic counseling (manuscript under development). In both the Statewide and Family History projects, those counseled were unlikely to obtain HBOC genetic counseling any other way.

The potential benefits of improved access to genetic counseling through remote channels led to our recently completed GC3 study. While phone counseling greatly increased access in the State-wide study, we knew little about the effectiveness of communication through that channel, particularly for women of low health literacy. As a result, we designed GC3 to compare three modes of counseling delivery: telephone, video conferencing, and the gold standard – in person. Prior research compared GC in person to telephone counseling and found no difference in impact. However, those studies included predominantly insured White patients, and study recruitment suffered due to potential participants who refused randomization (Kinney et al., 2014; Schwartz et al., 2014).

In comparing the modes, we wanted to learn what is gained and lost with each. We designed a mixed-method partially randomized preference non-inferiority trial, and recruited ethnically diverse, high-risk patients at three public hospitals in the San Francisco Bay Area. Patients were eligible if they were at high risk for HBOC but had not received genetic counseling previously and spoke English, Spanish, Cantonese, or Mandarin. To identify potentially high-risk patients, our Six-Point Scale (described above) was distributed throughout multiple clinics in two of the hospitals. In the third hospital, a mammography registry form was used. High-risk patients were also identified by direct referral from providers. Research staff obtained completed forms from clinic personnel, identified those forms indicating high risk, and placed recruitment telephone calls to those patients. Informed consent was obtained from patients who agreed to participate, followed by administration of a baseline survey. Patients were asked if they would agree to be randomized ('let the computer choose') to telephone, in-person, or video counseling appointments (at their local clinic), if not, they were able to request a specific mode. Up to 100 patients could be enrolled per counseling mode by their preference. We needed a total of 270 randomized participants to complete the study (90 per counseling mode) to yield the statistical power required for our main outcome comparisons.

Counseling appointments were made for patients upon assignment to counseling mode. Once they completed counseling, participants were called to complete a follow-up survey. Outcomes measured at baseline and follow-up included: knowledge, cancer-specific distress, decisional conflict, risk perception, and (at follow-up) satisfaction with counseling. A subset of patients was interviewed in-depth after the follow-up survey.

Our quantitative data for the randomized trial showed that telephone and video counseling were as effective as in-person genetic counseling. All outcomes that were measured pre- and post-counseling improved significantly between baseline and follow-up surveys. However, knowledge increases were lower for those with less than a high school education (a final detailed report is currently under development). Counseling attendance varied by assigned mode, with many more telephone counseling appointments completed compared with in person or video. Respondents overwhelmingly rated every mode as 'very convenient', and satisfaction with counseling as 'very high'.

The ability to receive genetic counseling remotely by telephone or video provided important access to care and was well received by patients. Video counseling provided many similarities with in-person sessions, including the formation of meaningful connections and the opportunity to see visual aids used by the counselor. However, preliminary analyses of case studies revealed more nuanced limitations from both patient and counselor perspectives, particularly regarding telephone counseling, including abbreviated sessions, distractions, and less effective communication overall. In all modes, key messages were often not recalled by patients.

It is important to note that patients eligible for testing were less likely to complete the test if they were counseled by telephone because they were not physically in clinic to provide a sample. It is likely that this would have also been the case for video-counseled patients but in order to ensure uniform access to video, patients in that mode received appointments at their local medical clinic, where a research assistant met them, set up the video visit with the genetic counselor (who was at the UCSF clinic), facilitated the visit, consent form, and sample collection if appropriate. Thus, this was a test of video counseling as a communication medium, rather than an assessment of home video conferencing. Video counseling can combine the best features of in-person and telephone counseling, allowing greater access without losing the quality and satisfaction of in-person appointments. However, immediate access to testing may be lost if not anticipated and addressed in that process.

5 | COVID-19 AND REMOTE SERVICE DELIVERY

Due to the pandemic, health care systems transitioned to telehealth, but this initial effort showed that even then inequities to access to care persisted (Chunara et al., 2021). On March 17, 2020, the San Francisco Bay Area instituted a stay-at-home order because of the COVID-19 pandemic. Overnight, our clinic, like many others was forced to scale up the use of video appointments. Our primary clinic at UCSF had been offering video visits for some time, so essential infrastructure was largely in place. For our under-resourced patients, this allowed us to put into immediate practice lessons that we learned through the GC3 study. The GC3 study demonstrated that video visits had many of the same benefits as in-person visits, so we sought to schedule all remote visits by video. Video genetic counseling in the GC3 study was conducted hospital to hospital, which did not allow us to study if patients would be able to access counseling via video from their homes. With the stay-at-home order in place under COVID-19 restrictions, we had the opportunity to learn how video visits would work under the pandemic conditions.

At the time that patients schedule these visits, a genetic counseling assistant helps them remotely download the video program and practices with them in using the program if needed. Patients

continue to be assisted with the video technology as needed; however, we have noticed a higher comfort level with video technology in general as the pandemic has continued, particularly since many people use video technology to stay in touch with family and friends. A further advantage to this mode of counseling is our ability to use video medical interpreters for limited English-speaking patients, and to actively train genetic counseling students simultaneously in real time. Seeing our patients' home environment also gives us a window into their daily lives and living situations.

Although most patients have been successful in using video, the most common barriers for not using video include: no access to device, device being used by others in the household such as children attending school remotely, or other technical difficulties. For those patients who can only access telephone counseling, we are actively working to put into practice what we learned from the limitations of telephone visits in the GC3 study. Some of these modifications include scheduling longer visits (increasing appointments from 30 to 60 min), using more counseling techniques that attend to the psychosocial needs of our patients, and using tools such as teach-back to ascertain patients' understandings, which provide an opportunity to clarify information.

We now encounter the problem with completion of testing with home video visits similarly with telephone counseling as we experienced in GC3; many patients who agree to testing still do not return the test kit. Instead, extensive follow-up is required to obtain samples; in many cases, a sample is never received. We continue to seek solutions to this ongoing problem. Even once the pandemic is behind us, the benefits from our research and real-time pandemic practice will continue to inform our efforts to increase access to cancer risk services for patients who remain underserved by their current health care system.

6 | SUMMARY

Over the past 18 years, our cancer genetics and prevention program has continued to evolve as a result of research and collaborations. We view our patients as individuals living within cultural, socioeconomic, and familial contexts, and we understand the importance of access to services, in terms of both availability and content. Integrating what we have learned through research into our clinical care is vital not only for the practice of genetic counseling but also for the training of new generations of genetic counselors if our field is to make meaningful progress toward equitable access to high-quality genetic counseling services. The need for training students in all medical professions on how to proficiently provide telemedicine is going to be critically important (Pourmand et al., 2020–2021). The devastation of COVID-19 is beyond comprehension, but it has also provided a fuller realization of the deep inequalities in health care. This tragic pandemic has created opportunities for deeper discussions and critical review of our practices and models of counseling. As the US population becomes increasingly diverse, it is critically important that we continue to research how best to provide genetic counseling for all those who might benefit from it.

AUTHOR CONTRIBUTIONS

Authors Lee, Joseph, and Pasick confirm that they had full access to all the data in the study and take responsibility for the integrity of the data and the accuracy of the data analysis. All of the authors gave final approval of this version to be published and agree to be accountable for all aspects of the work in ensuring that questions related to the accuracy or integrity of any part of the work are appropriately investigated and resolved.

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COMPLIANCE WITH ETHICAL STANDARDS

CONFLICT OF INTERST

All authors have no conflict of interest declare.

ANIMAL STUDIES

No animal studies were carried out by the authors for this article.

HUMAN STUDIES AND INFORMED CONSENT

All studies discussed in this manuscript received IRB review at the participating institutions and informed consent was obtained by all study participants.

DATA AVAILABILITY STATEMENT

Data sharing is not applicable to this article, as no new data were created or analyzed in this study.

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