

Uprooting Racial Health Disparities: Genealogy as a Community Health Library Service

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ABSTRACT

Genealogical researchers are the largest user group of archives and library special collections. Although the pursuit of family history is a popular hobby in North America, the Centers for Disease Control and Prevention (CDC) reports that many patients do not collect family health history (FHH). Adequate FHH supports diagnosis and risk assessment for hereditary cancers. Referrals to genetic testing services and counseling reflect glaring racial disparities that are partially attributed to inadequate FHH. Library and information science (LIS) education may offer opportunities to introduce archives curriculum in undergraduate programs and foster synergies with community health outreach program design. Supporting the development of accurate FHH and meeting the genealogy needs of diverse communities is a critical example of the influence LIS education may wield in the reduction of racial disparities in hereditary cancer care.

ALISE RESEARCH TAXONOMY TERMS

Archives; Information use; Specific populations; Community engagement; Social Justice.

AUTHOR KEYWORDS

Genealogy and family history; health disparities; breast cancer; genetic testing; mixed methods.

INTRODUCTION

Genealogy may represent the oldest and most “public” of all history (Cox, 1984). This popular pastime and growing profession thrives globally (Aiken, 2020; Cati, 2020; Davison, 2009; de Jesús Alejandr e et al., 2022; Everett, 2011; Guerrini et al., 2021; Lima, 2019), especially in North America (Lambert, 1996). Often genealogy is considered as an act of associating generations of relatives using family tree or pedigree charts that includes dates. Whereas family history may provide more context and narrative to enrich pedigrees with biographical and historical information. Librarians may use the term “genealogy” more often than “family history” (Jelks & Sikes, 1983). Although the terms “genealogy” and “family history” have subtle differences, in this article they are used interchangeably. In the 1970s, technological advances like the rapid digitization of genealogical sources and archives increased family history information services provided by libraries and archives to genealogists. Genealogical researchers are the largest user group of archives and library special collections and in North America account for more than half of all users (Tucker, 2006). Today family historians who manage their family trees are motivated to use online services that are provided direct to consumers by companies like Ancestry.com for a fee or via a public service available to patrons of public libraries, Ancestry Library. The Ancestry Library is a smaller version of the collections of historical and genealogical information such as U.S. Census records, vital records, immigration applications and military documents. Another large source of historical family information is the Family Search service provided The Church of Jesus Christ of Latter-day Saints. These two platforms as well as the National Archive’s Access to Archival Databases (AAD) are made available to the public through libraries and institutions. As these genealogical databases and indexes continue to grow, the demand for archived data to be inclusive and accessible through library services has increased as well.

Media has contributed to interest in documenting family histories. In 1976, Alex Haley’s “Roots” stirred great interest in genealogical research and also criticisms of the historical narrative presented (Null, 1985). Roots was one of the earliest examples of Black family history as entertainment (Edge, 2017). Haley’s work introduced diverse communities to genealogical research and historical reclamation. More recently, Alondra Nelson described a celebrity effect of genealogy-themed television shows like “African American Lives” and “Finding Your Roots” hosted by Henry Louis Gates Jr., “Oprah’s Roots”, and NBC’s “Who do you think you are?” where celebrities reveal their family histories and genetic ancestries (Nelson, 2016). For many Black families in America having an adequate family history has been complicated due to the systematic censorship of information and invalidation of the personhood of their enslaved ancestors. Slavery required the dehumanization of people to reduce them to property often without names, identities, or history. The dehumanization is reflected in our documentation practices of the time. The 1870 census, which was the first census after the Civil War, is the first to include African Americans by name and is often the first official record of a surname for people who were formally enslaved (*African American History*, 2016). Prior to the Civil War many enslaved people were not recognized as human beings connected with loved ones or ancestors, rather they were connected to land and masters as property (Copeland, 2010). Enslaved people were not seen as having meaningful ties to their children or spouses and those ties were brutally broken without consideration. Enslaved women were raped and bore their masters’ undocumented children (Kemedjio, 1994). Fast forward to 2020, more than 18 million people had taken a genetic ancestry test from the direct -to-consumer service provider AncestryDNA and over 3 million people are paid subscribers to Ancestry.com platform for genealogical services (Robinson-Sweet, 2021). Ironically, due to the forced migration of the transatlantic slave trade,

African Americans are likely to get a more accurate assessment of their European ancestry than their western or central African ancestry (Graves Jr. & Goodman, 2021).

Today, researchers are using family histories and ancestral ties to identify pathogenic mutations within populations (Wohns et al., 2022) to prevent and treat disease. Despite technological innovation in genomic variant detection, family health history (FHH) data remains the most accessible, least expensive, and practical assessment tool (Wildin et al., 2021). Clinically, FHH represents an abridged family history (usually just 3 generations) to describe 1st degree and 2nd biological relatives impacted by a specific disease. Collecting and using FHH for risk assessment is a part of routine clinical care (Wu et al., 2019). Yet FHH is rarely collected in sufficient detail to significantly impact healthcare decisions and referrals to genetic evaluation for hereditary diseases. Inadequate FHH is more pronounced in racialized communities and further exasperates disparities. For example, Black women are less likely to be referred to genetic evaluation for hereditary breast and ovarian cancer (HBOC) due to inadequate FHH (Jones et al., 2020). Inadequate FHH for HBOC may also negatively impact the insurance coverage for genetic testing and other risk reducing treatments (Alberty-Oller et al., 2020; Ciuro et al., 2020).

Although the pursuit of family history is a popular hobby in North America, the CDC reports many patients do not collect FHH, despite believing this information to be important to their own personal health (Cohn et al., 2010). There is great utility of FHH for diagnosis and risk assessment in clinical genetics, but existing methods of documenting FHH are not integrated with family health research or reflect the diversity of family structures in our society. The purpose of this study is to identify themes in the conceptualization of family structure and differences in genetic testing awareness in context with FHH.

METHODS

This study is an exploratory analysis of data from a semi-structured questionnaire developed and delivered in partnership with breast cancer advocacy groups. This study received IRB approval in 2018 and was completed in 2021. Participants were recruited by purposively advertising on breast cancer advocacy group listservs and social media then snowballing to connections.

Sample

The sample included 81 participants who were women or gender non-conforming adults:

- Ages 24-76
- 60% self-identified as Black
- 32% reported FHH of breast cancer

Responses were quantitatively and qualitatively analyzed to compare those with FHH of breast cancer to those without.

RESULTS

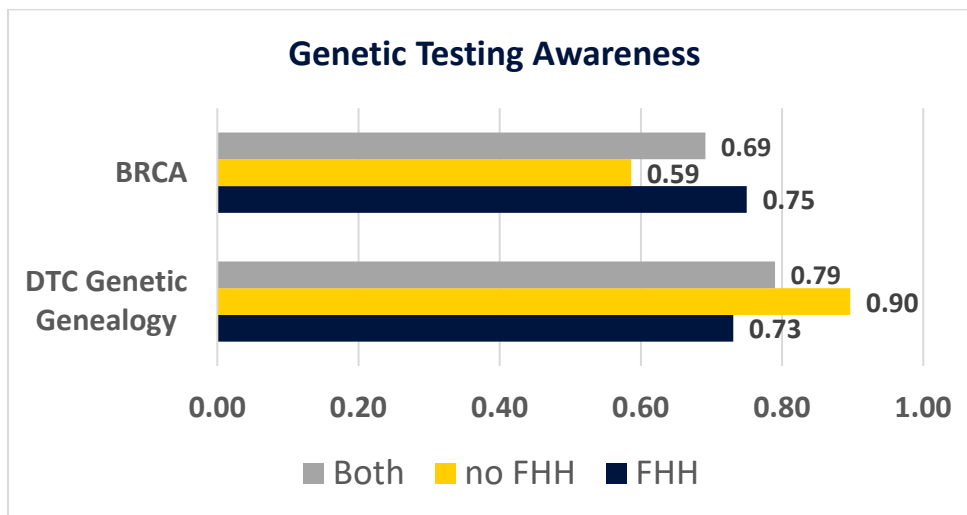
The two key findings were gaps between clinical and social worlds and connections with family structure conceptualizations on knowledge creation.

Gaps between clinical and social worlds.

Overall, 79% were aware of ancestry testing and 69% were aware of genetic testing for BRCA. Over half (64%) the participants reported FHH. Participants with FHH had greater awareness of BRCA testing (75%) compared with those without FHH (59%).

Figure 1

Genetic Testing Awareness



Knowledge creation.

Among those with FHH, 29% identified a first degree relative and 38% identified a second degree relative. Interestingly, 19% included non-biological family members (best friends, godmothers, stepparent's siblings, etc.). Participants described their foundational knowledge about breast cancer beginning in childhood when a relative was diagnosed or when a celebrity discussed their own diagnosis in the news, or during OB/GYN visits. Similarly, many became aware of genetic testing in grade school, through advertisements related to ancestry, or clinically due to a personal breast cancer diagnosis.

DISCUSSION

This study, which was oversampled for Black people, describes gaps between clinical and social realities. Participants having FHH of breast cancer appear to have greater awareness of clinical genetic testing, while those without FHH have a greater awareness of DTC genetic genealogy services. Also, participants described non-biological relatives as kin and experiences in youth or with media shaped their foundational knowledge about breast cancer and genetic testing. There is an information chasm in family history for Black Americans who are descended from enslaved African people. Clinically, referrals to genetic testing services and counseling often depend on having an adequate family health history yet

racial disparities are great and information insufficiency leads to deadly outcomes. Libraries have an opportunity to address this problem by training librarians and engaging family history researchers.

Traditionally, the academic and medical communities have looked askance at genealogy. The practice has been written off as an egotistical hobby with little merit because the accuracy of ancestry is questioned (Kirkpatrick & Rashkin, 2017) and those compiling the archives have been criticized as being socially pretentious (Null, 1985). Yet, those perspectives appear to be softening due to innovative techniques for risk assessment and genomic research and public access to digital archives. The study of family lineages and the foundation of archives are intertwined and shaped by the educational and technological revolution of the twentieth century (Tucker, 2006). With respect to library and information science education, some have called for libraries to provide training and formalized workshops to support advanced features of the Ancestry Library and FamilySearch (Biggs, 2013). Others recommend changes to LIS curriculum to offer more archives courses at the undergraduate-level because most archives education is designed for graduate-level students in library schools who are interested in becoming professional archivists. Still others have called for genealogists to be recognized professionally for their information contributions (Tasker & Liew, 2020). These approaches may expand educational and workforce development resources to introduce new actors to archives related to family history and community health. Expanding community health training for library staff opens the door for library staff to lead a broad range of health-related programming to address health screening and disease management (Morgan et al., 2018).

There have been numerous advances in personal access to online services and archives, and librarians continue to support family history information searches and play a critical role in community health. Librarians provide patrons with resources to assess validity, legitimacy, and accuracy health information (Alligood, 2019) and there may be opportunities to build economies of scale between services for family history researchers and community health initiatives. The challenge faced by LIS educators and scientists is to learn new ways to overcome institutionalized barriers to achieve more equitable outcomes. People who have been marginalized, racialized, and oppressed feel the generational impacts of having scant family history. They are turning to public and private services to repair their broken family trees. For many Black Americans the act of collecting their family history is the first step toward reconciliation of their identities and we have a chance to generate greater value from the effort.

LIS has a role to play in addressing racial health disparities. Supporting the development of accurate FHH and meeting the genealogy needs of diverse communities is a critical example of how we must “go back and get it”. Through family histories, we discover how societies evolve, how communities protect narratives, and how researchers can use old information to reveal new insights. As individuals gain greater access to archives and contribute to history, libraries must become progressively more inclusive by providing and promoting access to less-documented narratives. Through supporting everyday acts of information seeking and provision among family historians we can decrease health inequities and improve access to genetic testing services.

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