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Advocacy and actions to address disparities in access to genomic health care: A report on a National Academies workshop

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ABSTRACT

Background: In the United States, access to genomic risk assessment, testing, and follow up care is most easily obtained by those who have sufficient financial, educational, and social resources. Multiple barriers limit the ability of populations without those resources to benefit from health care that integrates genomics in assessment of disease risk, diagnosis, and targeted treatment.

Purpose: To summarize barriers and potential actions to reduce genomic health care disparities.

Method: Summarize authors' views on discussions at a workshop hosted by the National Academy of Medicine.

Discussion: Barriers include access to health care providers that utilize genomics, genetic literacy of providers and patients, and absence of evidence of gene variants importance in ancestrally diverse underserved populations.

Conclusion: Engagement between underserved communities, health care providers, and policy makers is an essential component to raise awareness and seek solutions to barriers in access to genomic health care for all populations.

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Introduction

Clinically actionable genomic research discoveries can improve health and wellbeing of people when they are at risk for, or have conditions with a major genomic component. There are benefits when participants in the research represent the clinical populations who are most likely to gain from the discoveries. However, that is not sufficient. Dr. Patricia Brennan, Director of the United States (US) National Library of Medicine recently noted that discoveries have little value if not delivered to the underserved (Brennan, 2018).

Disparity in genomic health care is a universal issue. Nursing has a primary commitment to using advocacy as reflected specifically in Provisions 2 and 4 of the American Nurses Association Code of Ethics which address advocacy and actions to promote health, and to provide optimal care to individuals, families, groups, or populations (ANA, 2015). Furthermore, this is a global issue, with scholars from the United Kingdom (UK) and Australia reporting that redesigning health care systems to improve access to genomic services, and raising awareness of needs of communities of people who are low-income, ethnic minority and/or from indigenous backgrounds, are needed (Mathew et al., 2017).

Current genomic health care services tend to be most accessible to those from higher socio-economic backgrounds with access "codetermined by awareness, education, and income" (Cornel & Bonham, 2017, p. 249). Nearly half of Americans are under or not insured (Sabetello, Callier, Garrison, & Cohn, 2018). Current genomic services delivery systems do not address the unresolved problem of how to deliver clinical care based on genomic discoveries to members of the US population "who may receive care on an episodic basis from community, federal, or volunteer organizations, or from multiple health care systems" (Williams, Feero, Veenstra, Starkweather, & Cashion, 2018, p. 574). In addition, some persons are gaining genomic information through consumer-driven testing, bringing this information to the care providers with commonly inadequate interpretation of the findings (Starkweather et al., 2017). However, disparities in genomic health care go beyond the location where people receive health care, and the availability of genomic specialist providers. Understanding health care coverage and health care system barriers is required to achieve the goal of appropriate genomic medicine accessibility for all.

On June 27, 2018 the National Academie's Roundtable on Genomics and Precision Health held a workshop in Washington D.C. on Understanding Disparities in Access to Genomic Medicine. The workshop was co-chaired by Vence L. Bonham, National Human Genome Research Institute and Catherine Wicklund, National Society of Genetic Counselors (National Academies of Sciences, Engineering, and Medicine, 2018). Dr. Bernice Coleman, chair of the American Academy of Nursing Genomics expert panel, and Dr. Janet Williams representing the American Academy of Nursing, also participated in the planning. Dr. Ann Cashion represented the National Institute of Nursing Research/National Institutes of Health on the Genomics Roundtable. Dr. Jacquelyn Taylor was a presenter at the workshop.

The focus of this workshop was to explore disparities in access to genomic services that exist across different segments of the population (e.g. in medically underserved areas and populations, across different racial/ethnic groups, and socioeconomic levels). The term, genomic services, broadly refers to identifying disease risk, diagnosis, and treatment based on a clinical assessment which may include genomic testing, genetic counseling, and follow-up health care.

Some of the challenges discussed by the planning committee and explored during the workshop, included: Community experiences with barriers to access, Health care systems efforts to reduce health care disparities, health care provider efforts, models of success, and unmet needs (National Academies of Sciences, Engineering, and Medicine, 2018). This article summarizes key points from the workshop that the authors believe are relevant to nursing across all health care settings (Table 1). The key points also include a summary of barriers from the authors' perspectives, and, where identified, potential strategies to reduce these barriers. The strategies proposed by the

Table 1 – Major Barriers with Selected Nursing Advocacy Actions

Language Matters
Document meaning of genomic health terms with recipient.
Involve the experts preferred by the patient or at-risk community member, which may include advocacy organization members, or family.
Use culturally appropriate genomic health educational materials.
Recognize risk for societal harm from unintended interpretation of genomic information.
Access
Evaluate navigator model to minimize barriers to effective genomic health care.
Partner genomic specialists with health care providers at point of care.
Quality
Engage community leaders in addressing gaps in quality care.
Determine what outcomes matter to underserved communities, health systems, and payers.
Develop or apply existing measurement instruments as common data elements to build evidence base to document these outcomes.

authors are listed after discussion of each of the five major themes that follow.

Discussion

Throughout the workshop it became clear that each person can have a unique experience of disparity or unsatisfactory genomic health care, and that the solutions rest with taking a broad and open-minded view of implicit bias and barriers created by health care providers, health systems, and society. Although the details varied within the individual experiences, many shared a common theme of experiencing lack of access to, or benefit from, genomic health care. These experiences formed the basis for three major themes were apparent throughout the presentations and were to be central to the discussions.

Language Matters

The messages of miscommunication and lack of communication provided by workshop presenters and participants are not new to nursing or health care providers. Yet, components of use of language in communication regarding genetic aspects of risk, diagnosis, care plan, implementation, and expected outcomes, were central in the experiences of people who attempt to overcome barriers to access genomic health care.

Meaning

Although on the surface this may seem to be an obvious expectation, an overarching theme in the entire workshop was the need for education and culturally appropriate communication of meaning of terms between genomic clinicians and the public. Although communication is an element of nursing, as well as many other health care education programs, the issues raised by representatives of the public were a stark reminder of what can go wrong when these communication principles are not used in health care practice. Health care providers may be very familiar with the concept of genomic testing to clarify risk for a disease, as well as a tool useful in making a diagnosis, or a component of guidance for selection of a treatment plan. However, words such as genetic, genomic, variant, or mutation may have different meanings in a community experiencing health care disparities. Examples provided by a panel of community members included the unintended interpretation by males that gene variants associated with hereditary breast or ovarian cancer are only of concern to women (National Academies of Sciences, Engineering, and Medicine, 2018). Some genetics and genomic research and services are associated with perceived heightened risk for harm based on community knowledge of historic research abuses, for example, the US Public Health Services Syphilis study (Gamble, 1997) and utilization of Henrietta Lacks' cells without the family's knowledge for research and economic profit (Gamble, 2014; Lee et al., 2018).

Another barrier to genomic access is the fear of misuse of genetic information. For example, the genomic information may result in a greater risk for discrimination in the workplace, insurability, impact on social identity, loss of privacy or harm from law enforcement (Hull & Vassy, 2018; National Academies of Sciences, Engineering, and Medicine, 2018). Due to these perceived risks, people may not attend a genetic counseling appointment even if one is offered.

Furthermore, communication of terms is only part of the process, with the risk for mismatch of what is desired by each party. A recent report of communication mismatch between genetic counselors and underserved patients with cancer noted that patient expectations were not met due to patients receiving too much information, information being difficult to understand, information not perceived as being relevant to the patient, limited opportunity for patients to ask questions, and lack of guidance for what to do next regarding further screening or prevention actions (Joseph et al., 2017). While this study focuses on one genetic counseling setting, these missed opportunities for clear communication that reflects an understanding of the needs of the patient, between a health care provider and a patient, and recognizing expectations of each, may not be limited to one health care situation and is also relevant for recruitment to participate in genomic research studies.

Strategies. Primary care providers and advocacy groups may be helpful in explaining what happens at a genetic counseling appointment and address concerns about risk for harm.

The Patient Perspective

Health care providers are limited in their effectiveness when they do not understand the community member's perspective. The importance of health care providers' awareness of patient and community concerns is acknowledged in a scientific statement addressing cardiovascular health in African Americans, issued by the American Heart Association. It includes the statement that understanding perspectives of patients is an essential element of higher-quality patient interactions (Carnethon et al., 2017). Furthermore, the use of language requires delicacy and empathy (National Academies of Sciences, Engineering, and Medicine, 2018) when the health care provider uses such words as genetic, genomic, germline, or somatic.

Potential Strategies. One common suggestion that was mentioned throughout the workshop was an expectation that materials prepared for patient education should be read and understood by their health care providers, and that health care providers use the words presented in the materials. Further, the person most preferred to provide information about genomic

aspects of a health risk, diagnosis, or treatment may not be a genomic specialist, but rather a physician the person knows, someone else in the family, another person who has had the same condition, or a care coordinator (Kaphingst & Goodman, 2016; National Academies of Sciences, Engineering, and Medicine, 2018). Research participants also report that they want information about research and clinical trials from their primary health care providers (Persaud & Bonham, 2018).

Racism

Finally, the potential continues that use of genomic information in risk assessment, diagnosis, or treatment information may deepen racism, violate privacy, and further erode trust in health care providers and the services they attempt to deliver. Due to some underserved populations that may only have health information from one to two generations back or have experienced harms associated with receiving substandard health care, a gap exists in accuracy of family history. During the workshop Dr. Taylor noted that it is not the social construct of race that is the underlying factor in health disparities, it is racism of how people are treated and the stress that results from maltreatment (National Academies of Sciences, Engineering, and Medicine, 2018). For example, it has been shown that the interaction of perceived racism and discrimination with genetic and epigenetic factors is significantly associated with increased cardiovascular risks for African Americans (Barcelona de Mendoza, Huang, Crusto, Sun, & Taylor, 2018; Taylor et al., 2017).

Disparities in access to genomic health care are also intertwined with the under representation of genetically diverse populations in genomic research. This extends beyond enrollment and maintenance in research studies. It is apparent in experiences of interactions by African immigrants, as documented by a team of nurse researchers, with health care providers who lacked a genuine connection with their communities. This experience was described by participants as perceiving US health care providers as acting from stereotypes, or being uninformed about communities and their cultures; and a perception that health care providers focused more on racial and country of origin stereotypes than focusing on each person as an individual (Buseh, Stevens, Millon-Underwood, Kelber, & Townsend, 2017).

The use of race as a variable in research and in health care is an issue important to nurses. Individual patients look to nurses for information about their health care which may be influenced by how the concept of race is viewed by the nurse in assessing risk for disease or managing treatment plans for individuals.

Strategies. Nurses need to be informed regarding the implications of employing racial categories within the context of genomic research (Jaja, Gibson, & Quarles, 2013). In order to provide care that can decrease racial and ethnic disparities in care, nurses, who are often at the front line of health care encounters, should develop a stronger foundation of knowledge about genetic ancestry, population genetics, and the role of the concept of "race" and "perceived racism and discrimination" in clinical decision-making (Sellers et al., 2016).

Access Is More Than a Location

Genomic health care is commonly located in major medical centers, nationwide telephone genetic counseling services, and, in some locations, through telemedicine services. In some cases, genomic services are connected to communities through outreach programs linked with local care providers such as community health nurses or physicians. Members of the public also access a genomic testing component through commercial driven testing programs. Workshop participants highlighted efforts to bridge genomic specialists with populations who seldom access any genomic health care services.

Navigators

Several presenters emphasized that access may be enhanced by people within a health system who are focused on the underserved person or community. Barriers include lack of guidance through the entire process from initial genomic testing to completion of follow-up care.

Strategies. One such option suggested at the workshop is the use of navigators, to decrease fear of the information or its consequences on the person and their family. Elements of this concept are that a navigator connects an individual with appropriate providers and extends the focus of patient-centered care across the health care settings. The navigator helps the individual identify barriers to care and provides information to improve the person's access to care needed (Peart, Lewis, Brown, & Russell, 2018). A variety of lay and health care personnel fill this role. One example is nurse navigators in oncology care who contribute to improved outcomes such as shorter time to diagnosis and treatment, increased patient and caregiver knowledge, improved adherence to care, and improved quality of life (Oncology Nursing Society Statement, 2018).

Another strategy to enable people to access needed care is the use of a state department of health phone service in which a screening tool is administered over the phone by staff, with free genetic counseling and testing available to low income and ethnically diverse women at risk for hereditary breast cancer (Joseph et al., 2012). Finally, there are national programs with the mission to eliminate obstacles on behalf of patients in accessing needed treatment with health insurance plans (Patient Advocate Foundation, 2018).

Partnerships

The wise use of genomic information may require closer partnerships across health care providers and

community members. These include not only genomic specialists and genetic counselors but also partners such as ministers, teachers, and other respected community members who are aware of quality of life issues that may or may not be affected by genomic health information.

Strategies. An early pilot program documented that partnerships among local providers, public health nurses, and genomic specialists improved access in a rural state (Lea et al., 2005), and current programs partner genetic specialists and local providers through telehealth platforms (Kubendran, Sivamurthy, & Schaerfer, 2017). A more recent survey of 20 genetic counselors practicing in rural areas in the United States reported that lack of awareness and skepticism from local providers and from the community were barriers to provision of genetic counseling services (Emmet, Stein, Thorpe, & Campion, 2018) providing further evidence for the importance of open and ongoing engagement with the community. Specialist and local provider partnerships also can have the advantage of delivering genomic health risk, diagnostic or treatment information at the point of care, when and where it is needed. An additional benefit of improved access to the person in the community is the elimination of multiple referral steps each of which can involve time, travel, and money.

A partnership approach is also necessary when developing research into health care disparities. Researchers should establish collaborations early on with community partners and leaders. It is essential that researchers provide a service to community in some way and not just function as a "data collector." As in any relationship, reciprocal useful actions are appreciated on both ends of the partnership. For example, while community partners may assist with recruitment and retention of the target sample into omics studies, the research team may lend their talents to community action activities such as health fairs, blood pressure checks, health presentations at local churches, community forums, and parent meetings. It is also important for researchers to disseminate the findings from research studies to local community partners via newsletters and/or presentations at community meetings or national meetings of such organizations (e.g., National Association for the Advancement of Colored People, Historically Black Sororities and Fraternities, Churches, Barber Shops, etc.). Nurse researchers can build upon knowledge of nursing and health to increase understanding of environmental, sociocultural, genomic factors behind why disparities exist, and develop actions to reduce disparities in genomic health care (Taylor & deMendoza, 2018).

Cost

The costs of the tests, clinical visits, time lost from work, travel, and subsequent clinical care are barriers. Genomic testing, genomic clinical care, and follow-up procedures are all expensive and insurers may or may not cover these costs (Hull & Vassey, 2018). Medicaid policies vary, as some policies are made on the local level, and both private and Medicaid policies are likely to develop their own individual approaches to coverage of genomic health services (Phillips, 2018). In a survey of three state-based public health genomics programs, the most common barrier across programs was financial; with insufficient third party payer coverage dividing those who could afford genomic services from those who could not (Senier, Tan, Smollin, & Lee, 2018). Despite having an increased incidence for early onset breast cancer, Black women are less likely to receive BRCA testing and counseling. Black women in Pennsylvania and Florida were less likely than White women to receive appropriate genomic breast cancer screening. Black women were less likely to know their risk and the potential benefits of genetic testing, and face cost and other administrative barriers (Jones, McCarthy, Kim, & Armstrong, 2017). A review of barriers to access to genomic health care in state-based public health programs, notes that individuals may be geographically as well as financially far away from specialty care (Senier et al., 2018).

Strategies. Mechanisms such as telehealth, mobile health, and research vans that are part of the community are strategies that may be valuable in genomic health care. However, other factors in addition to the location of health care providers may influence outcomes. Unrecognized factors may also influence quality of genomic health care access. A study of genomic testing uptake among women at risk for hereditary breast/ovarian cancer revealed differences in use of genetic testing was conducted in which women were randomized to receive either telephone counseling or in-person counseling. Women receiving the telephone counseling were less likely to be tested. Potential reasons were burden of travel to a clinical site to provide a DNA specimen for genomic testing, distress related to the counseling and testing, and unrecognized bias on the part of the person providing telephone counseling (Butrick et al., 2015).

Quality of Genomic Health Care Delivery Is Not Documented

A third common theme throughout the workshop was that genomic health care must be tailored to meet the needs of the individual, family, and/or community. Accountability and documentation of evidence are components of quality assessment in health care delivery.

Strategies. Possible solutions to reaching more equitable access to genomic health care include developing guidelines for identifying those patients who need to see genomic specialists, are candidates for genomic tests, and require follow-up care some of which can be managed through primary care. Agreed upon

measures, and means to collect necessary data to document quality genomic health care are needed. However, these will be of little use without effective health care provider and patient interactions.

Quality of Health Care Provider Interactions
A health care provider, or system, that can maintain an open mind, and be prepared to depart from usual plans or delivery of care may result in improved quality of care. This is illustrated by recognition at the workshop that a health care provider's attitude of caring can be more effective than attempts to match ethnicity of health care providers with that of the communities. It can also be illustrated by presence and engagement by health care providers coming to the community organizations and daily lives of people who typically do not access genomic health care.

Strategies. Developing relationships that embed the researchers/clinicians in the communities they serve are key to building and maintaining trust. Examples include partnerships with Historically Black Sororities and Participant Resource Pools (Taylor, 2009), and partnering with Head Start programs (Crusto, Barcelona de Mendoza, Connell, Sun, & Taylor, 2016). Not only accessing patients/participants from community partnerships, but agreeing to serve on action committees and boards for such organizations to increase familiarity and continuity of intentions and follow through. Long-term commitments and interactions with community partners build trust and reliability with clinicians.

Measureable Outcomes
Outcomes of genomic health care need to be clearly defined, measurable, and meaningful to the community. They are integral to the entire process of recognizing barriers and devising strategies to decrease them.

Strategies. The use of common data elements is one means to document answers to the question, did you get the help you needed, when determining the value of genomic health care to the health of people. A component of documenting quality is obtaining perspectives of leaders in underserved communities to explain what works and what does not. Assessing community needs by attending community forums, talking directly with community leaders and reviewing research agendas based on these needs prior to beginning any project is essential to building these trusting partnerships and identifying community-vetted measurable outcomes. One example is a pilot program operated by the Department of Veterans Affairs. This project uses principles of a learning health care system to devise a Point of Care Oncology Program to overcome system barriers and decrease disparities in access to care across the system. Components included enabling molecular analysis of tumors, offering opportunities to enroll in clinical trials, and enabling use of genomic information in clinical care (Fiore et al., 2016).

Variables Missing in EHR
Another aspect of assessing genomic health care is examining what data are necessary and what can be obtained from the Electronic Health Record. Examples of potentially necessary data are pertinent social and environmental data, genomic data, and ancestral data from diverse populations. These, and other data that are necessary to identify crucial components of equity in health care, may be useful in processes used by learning health care systems in their own evaluations of quality (Blizinsky & Bonham, 2017). Social and behavioral data are not collected from patients in a consistent manner in electronic health care record platforms. These data are commonly unstructured and highly variable clinical narratives in the Electronic Health Record (Hollister & Bonham, 2018). Advances in health care built upon the use of pertinent health data are limited when these data are not readily accessible and useable by clinicians (Starkweather et al., 2018).

Conclusion

Multiple gaps exist between genomic research and provision of genomic health care services to communities experiencing limited access to genomic health care. Use of terms that do not have a common meaning, inaccessibility to traditional genomic health care services, and paucity of evidence of quality genomic health care across health care settings all limit equitable genomic health care. Health providers and researchers need to go where the people are in their communities instead of waiting for individuals to come to the clinic to request genetic testing. When entering the community, providers and researchers should acknowledge that they have been invited, and that they are expected to use plain language, treat community members with respect, deliver on promises, and listen to what is said. Individuals underrepresented in genomic services are interested in the benefits of genomic health care. Clinicians must seek to engage these communities to benefit from the promise of genomics. Nurses are part of health care systems and health care services in underserved communities. Nurses can participate in creating solutions to link people in underserved communities with needed genomic health care services. Recognition of these barriers is an initial step in mobilizing resources and creating innovative solutions through clinical care, research, and health policy.

Supplementary materials

Supplementary material associated with this article can be found in the online version at doi:10.1016/j.outlook.2019.06.004.

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