Leadership, Literacy, and Translational Expertise in Genomics: Challenges and Opportunities for Social Work

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The transdisciplinary field of genomics is revolutionizing conceptualizations of health, mental health, family formation, and public policy. Many professions must rapidly acquire genomic expertise to maintain state-of-the-art knowledge in their practice. Calls for social workers to build genomic capacity come regularly, yet social work education has not prepared practitioners to join the genomics workforce in providing socially just, ethically informed care to all clients, particularly those from vulnerable and marginalized groups. The authors suggest a set of action steps for bringing social work skills and practice into the 21st century. They propose that good genomic practice entails bringing social work values, skills, and behaviors to genomics. With education and training, social workers may facilitate socially just dissemination of genomic knowledge and services across practice domains. Increased genomic literacy will support the profession's mission to address disparities in health, health care access, and mortality.

KEY WORDS: *genetics; genomics; social justice; social work education; translational medicine*

Genetic and epigenetic variations that predispose individuals to a variety of conditions require social workers to contend with a new concept of risk, one that begins as microscopic genetic material (Werner-Lin & Reed, 2011). New understandings about the human genome offer hope of improved well-being by identifying genetic variants that contribute to disease under certain environmental conditions. In a society where health disparities are likely to continue to widen as the genomic revolution further stigmatizes or bypasses marginalized populations, our profession's call to social justice requires that education and practice expand commensurate with 21st-century science. Yet, calls to develop social work competencies in genetics (Rauch, 1988), epigenetics, and epigenomics (Combs-Orme, 2013) have gone unheeded. To assist marginalized populations to equitably access the promise of genomic medicine, social workers must understand genetics and genomics and their social ramifications. Only then can we provide services to individuals, families, and groups who struggle with health literacy and challenging care decisions involving genetic information and diagnosis.

LITERATURE REVIEW

Trajectory of Social Work in Genetics

In the early 1900s, broad acceptance of evolutionary theory fueled public policy based on social Darwinism (Martin, 2012). This pedagogy identified "degenerate" individuals as threatening to deplete social resources and rationalized Draconian approaches to their needs. "Mental hygiene" and eugenics movements partnered (Lombardo, 2011), implicating social work pioneers in using pseudoscience to denigrate the challenges of vulnerable populations and to place responsibility for their social ills on their heredity (Kennedy, 2008). Since then, professionalization, role change, and evidence-based practice have brought social workers to ethically focused practice that supports marginalized populations in accessing medical and mental health services and reducing health disparities.

As reproductive technologies developed in maternal–fetal medicine during the 1970s and 1980s, health social workers often served as interpreters of medical information (Walther, 1990). Social work's values underscored the importance of helping populations with diverse health literacy skills and complex decisional needs. This led to the development of nondirective counseling in health contexts. Schild and Black (1984) pioneered skills to help families cope with the psychosocial implications of familial conditions newly identified as having genetic origins.

Following completion of the Human Genome Project in 2003, the National Association of Social Workers (NASW) recognized the need to integrate genetics into social work practice. An NASW task

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force mapped nine standards for competent practice in genetics focused on three tacit areas: (1) social work ethics, (2) building knowledge of genomics, and (3) practice across systems, to improve the quality and relevance of social work practice.

Today, social work's acquisition of genetic knowledge and participation in genomics research, practice, and advocacy remain limited (Combs-Orme, 2013). Some social workers perceive genomics to be of limited relevance in direct practice with populations affected by poverty, incarceration, and serious mental illness, creating a barrier to adopting genomic-literate practice. Other social workers practice in settings in which genomic information, testing, and decision making are becoming routine.

Current social work education and practice privilege the biopsychosocial–spiritual perspective and use the person-in-environment (PIE) approach to guide assessment and intervention. These frameworks fit organically with the notion that the *human genome* (the full complement of genes that form our smallest microsystem) interacts in critical ways with environments to predispose individuals to a variety of medical, psychological, and social risks that in turn affect the well-being of individuals and society. The PIE framework parallels epigenomics, which studies how gene chemistry interacts with social and physical environments to produce phenotypes (observable traits) (see http://www.genome.gov/glossary).

Implications and Implementation of Genomics in Social Work Practice

Genomic information shapes conceptualizations of health and mental health; informs treatment and reproductive decisions; potentially improves the course of treatment and reduces adverse outcomes, mortality, and costs associated with preventable disease; informs interactions with legal and social institutions; and affects health, life, and long-term care insurance. Yet genomic literacy in the health and mental health professions is fledgling, and in the general population it is nascent (Syurina, Brankovic, Probst-Hensch, & Brand, 2011). Technologies are introduced before the ethical, legal, or social implications are responsibly explored and before adequate treatment protocols evolve (Kaye et al., 2012).

Education of providers who interact with and can inform the general public is key for ensuring that the benefits of genomic advances are equitably distributed. Lower-cost personal genome sequencing is becoming a reality, paving the way for an era of personalized, prevention-based medicine for most Americans (Collins & Varmus, 2015). Social workers can advocate for policies ensuring that marginalized populations have adequate access and information by participating in development of federal initiatives, such as the Precision Medicine Initiative (Gehlert, Collins, Golden, & Horn, 2015). Now, nearly all pregnant women are screened for genetic and chromosomal conditions by their obstetricians, and increased newborn genetic screening will more rapidly identify risks to child and adult health (Timmermans & Buchbinder, 2013). In oncology, tumor genotyping can predict a patient's chemotherapeutic response and recurrence, and the body's own immune system can be leveraged to fight tumor cells (Roychowdhury & Chinnaiyan, 2014). Gene therapy using viral vectors and stem cell transplantation is being explored for any number of conditions (Ginn, Alexander, Edelstein, Abedi, & Wixon, 2013). In short, genomic medicine is integrated across the life span.

Social work's values, such as the dignity and self-worth of every person, are critical to shifting public dialogue about genomics from a bench science to a population concern intimately intertwined with social justice. Yet a comprehensive strategy for engaging the public in awareness and utilization of genomic information remains absent, raising concerns about the potential for exclusion, misunderstanding, and discrimination. Previous strategies for engaging the public reached primarily well-resourced groups (Geronimus, 2000). Genomic discovery is moving too rapidly to allow for the slow-paced, social evolution of knowledge. People are harmed when they cannot understand the personal import of genetic screening and diagnostic technologies (Kingsberry, Mickel, Wartel, & Holmes, 2011).

For over a century, the social work profession has practiced at the nexus of scientific discovery and health disparities. Gehlert et al. (2015) recently surveyed social workers to determine the social work presence in Accountable Care Organizations (ACOs). They found a growing workforce of experienced health social workers on health care teams on which they were often the only social worker. Training social workers for new health care environments like ACOs and patient-centered medical homes allows us to demonstrate the contribution of social work in the new genre of health care teams. Although we recognize the shortage of social workers in many health arenas, we knowingly set a high bar for the profession, to

advance the provision of such services in the light of growing capacity and need. Ideally, all individuals grappling with genetic screening and diagnosis would have access to a genomically literate, compassionate social worker who can accurately help process information, assist in values clarification, and aid in the complex decision making this information requires. Here we propose strategies to increase the dissemination and responsible use of genomic knowledge by the social work profession across the many settings in which clinicians, clients, and families interact (see Table 1).

Developing Genomic Competencies in Social Work

Genome-based health literacy and skills will enable social workers to participate fully in direct practice, research, and advocacy on behalf of clients and society. We propose action steps to improve social workers' knowledge of genomics, comfort in genome-based health communication, and other skills for translating such knowledge to vulnerable and marginalized clients. The larger goals for social work genomic competency are to

- Build a consumer base with accurate expectations about state-of-the-art science as it affects health, mental health, gene x behavior/environment interactions;
- Increase knowledge of genomic concepts and consumption of genomic services across ethically contested domains (for example, direct-to-consumer advertising and reproductive technology);
- Improve the efficacy of consumer communication with providers;
- Develop consumer capacity to make informed, autonomous choices about genomic services;
- Reduce harm in the translation of genomic services to mainstream medicine, particularly for conditions understudied in racial and ethnic minority groups.

Hence, our "upstream" focus on growing a genomically literate professional body will support a variety of "downstream" outcomes across contexts.

In Health and Mental Health Contexts. Genetics and genomics are increasingly integrated into primary and specialty care settings (Guttmacher, Porteous, & McInerney, 2007). The Patient Protection and Affordable Care Act and other initiatives are placing more social workers in health settings and increase social work visibility as health navigators and integrative behavioral health specialists, among other roles (Gehlert et al., 2015). Familiarity and comfort with genomics varies widely in both patient and provider populations (Khoury et al., 2007). Patients make decisions based on rudimentary and inaccurately deterministic understandings of the information physicians provide (Sankar, 2009). Social workers who understand genomic and medical information can assess the patient's and family's understanding, ensure that adequate information has been transmitted from health care providers, and support informed decisions.

In the coming years, increasing numbers of genetic conditions are likely to be identified. Full

Table 1: Applying Genomic Concepts in Competent Social Work

CASE: Valerie and Jacob, a mixed-race heterosexual couple, present for counseling due to disagreement about whether to have children. Since the death of Jacob's Jewish mother when he was six, he has been adamant that he does not want children. Valerie desperately wants a child, despite feeling fearful and preemptively guilty a child might "get sickle cell like my sister has." Valerie is not worried about the possibility that their child might develop breast cancer as she believes that the fact that it is on the child's paternal side would eliminate breast cancer risk. Jacob's reluctance and Valerie's excited ambivalence have led to a rift in their marriage.

SCENARIO 1	SCENARIO 2
Focus on exploring the couple's thoughts and experiences around parenthood and parenting. Social worker does not address ambivalence about parenting. She explores Jacob's memories of his mother and complicated grief involving the culture of silence around her illness and death. Social worker explores Valerie's experience of her sister's condition without awareness of inheritance patterns or current reprogenetic technologies available for family planning. Social worker tells Jacob, "One in three Americans get cancer, so you can't predict anything." She refers them to a perinatologist for help with getting pregnant.	*Focus on patterns of illness and child bearing in both families.* Social worker explicitly asks Jacob whether he would be interested in children if health issues were not present, putting the abandonment hypotheses aside. Social worker reviews rudimentary genetics information and lets the couple know about reprogenetic treatments and the possibility of adoption. Social worker refers them to a perinatal geneticist to explore options. She works with the couple as they identify their tolerance of health risks, make decisions, and manage their grief about family illness and death as well as the loss of innocence about child bearing.

genome/exome sequencing is now interrogating the entire genome. Driven by an interest in identifying disease-specific gene variants and subsequent risks, sequencing is *also* identifying gene variants with uncertain impact (Berg, Khoury, & Evans, 2011). This creates a group of patients who are asymptomatic but have information about genetic variants associated with health and mental health conditions that may or may not be treatable, or for which evidence is based on small samples without adequate minority group representation (Johnson & Gehlert, 2014). Although, research using genomic sequencing may improve understanding of the etiology of such conditions and the development of effective therapies, genomic sequencing often leaves individuals anxious about the meaning of these variants. Since the days of Ida Cannon, social workers have helped clients process health information (Praglin, 2007); it is time to expand that role to include genomic competencies.

In Social Contexts. Genomic discovery is challenging notions of human agency, identity, heredity, and privacy. Genomic research may inadvertently (or deliberately) promote essentialist thinking in which sociological or epigenomic mechanisms are obscured in favor of explanations that seem deterministic and "inevitable" (Sankar, 2009). As gene variants linked to stigmatized disorders (mental illness, addictive personality traits) are better understood, the ability to identify genetic predispositions comes with potent ethical, social, and personal implications. Mental illness develops like other complex disorders (Tsankova, Renthal, Kumar, & Nestler, 2007); many genes, each associated with a small increase in risk, contribute to disease in combination with environmental factors (Wermter et al., 2010). Social workers can help patients process this challenging information and understand the uncertainty inherent in many of the potential outcomes. Social work's call to promote social justice extends to ensuring that marginalized groups have equal access to novel technology, and the support to understand and use the information (Matthews-Juarez & Juarez, 2011).

In Academic and Research Settings. Social workers can ask novel questions at the nexus of genes and environments, and test interventions that advance care for underserved and stigmatized populations affected by genetic conditions. Our systems perspective promotes partnerships beyond the academy to engage consumer groups, disease-specific advocacy groups, providers from multiple disciplines, and industry in studying the translation of genomic information and technologies into mainstream medicine.

Integration of genomics into social work curricula may attract a new generation of social work students, infusing energy into scholarship addressing the ethical, practice, and policy issues associated with the dissemination and implementation of genomic discovery. Professional preparation must enhance skills that already have roots in social work practice, while attending to the ways genomic information is acquired, owned, understood, and used. Social work education teaches students to map family illness legacies, address beliefs about disease risk and susceptibility, identify challenges in family and medical communication, distinguish important and urgent decisions, promote client self-determination, and engage with policy practice. Genomic concepts must be infused across social work education, increasing content that addresses health and behavioral health and leading the charge away from essentializing genetic contributions to race, sexuality, privilege, and mental health (Dupre, 2008).

Social work scholarship integrates science and social action. Just as the profession made research methods a required domain of knowledge (Drisko, 2014), we contend that genomic knowledge and risk concepts must be part of contemporary social work training. Although it is challenging to incorporate the complex and rapidly evolving knowledge base of genomics into expansive social work curricula, this is necessary for ethical social work practice.

Genomics Is a Transdisciplinary Science

Geneticists, physicians, genetic counselors, bioethicists, nurses, mental health professionals, public health and public policy experts, and others are expected to work collaboratively for discoveries to travel from bench to community. The National Institutes of Health is encouraging "team science" (McBride et al., 2010) research proposals that integrate multiple principal investigators from varied disciplines to increase the impact and reach of federally funded research endeavors (Collins, Green, Guttmacher, & Guyer, 2003). Interprofessional education and focus on transdisciplinary practice allow social workers to bring social work values to geneticists, genetic counselors, physicians, and others to enlighten them to concerns about equitable access, research with marginalized groups, health disparities, and other psychosocial aspects of genomic care. We concur with nursing (Jenkins & Calzone, 2007) and public health professionals

(Beskow, Khoury, Baker, & Thrasher, 2001) who asserted that increasing genomics knowledge among professionals will allow social workers to improve public health indicators over time. Multiple health and mental health professions are facing the challenge of acquiring genetic and genomic knowledge in their respective practices (Skirton, Lewis, Kent, & Coviello, 2010). At present, professional governing boards operate in isolation. Yet the challenges of integrating genomics into professional education curricula are shared. Across disciplines, educators and policymakers can shape professional agendas and support institutional buy-in, and faculty require protected time to develop genomic knowledge and lesson plans for modifying existing curricula and teaching new curricula (Gehlert & Browne, 2013).

ACTION STEPS

Here, we outline steps to ensure social work's informed involvement in the research, design, and delivery of high-quality genomic services. Our measurable goals relate to developing genomic literacy and skills among educators in social work programs, practicing social workers, social work students, and licensed social workers attaining continuing education units (CEUs). The Council on Social Work Education (CSWE) have ensured that social work curricula are infused with knowledge about aging, disability, sexual minority identity, race, economic justice, and other issues as the needs for that information were recognized (CSWE, 2015). Together with our students and readers, we will agitate for curricular revisions so that genomic skills can be similarly incorporated into our standard educational fare. To that end, four targets of change are set forth with the intent that we and our readers will pursue these goals:

1. Develop collaborations with organizations and institutions that provide genetics education and resources for professionals. We must leverage relationships with cross-disciplinary teams in educational institutions, hospitals, and leadership organizations (NASW with nursing, genetic counseling, medical, and public health organizations). Seeking collaborations with organizations such as the Genetic Alliance will support such efforts. Measurement of such partnerships includes setting and meeting benchmarks for formal communication. The development of a yearly summit, including thought leaders from different disciplines to identify and implement core competencies in genetics for nongeneticists, is another measurable outcome. Social work involvement on regulatory, advisory, and ethical boards at national and international levels can be fostered through active advocacy.

2. Include genomic and epigenomic content in core competencies within future revisions of CSWE's Educational Policies and Academic Standards (EPAS). Social work education includes a commitment to the biopsychosocial perspective. Human behavior in the social environment (HBSE) courses typically include information about reproduction, physical development, and psychological development. The incorporation of genetic, genomic, and epigenomic concepts into social work education has already begun (see Table 2) and will enable social workers to respond to epigenomic contexts that shape practice, policy, and research.

Incorporating knowledge about genomics into social work curricula is feasible using existing core competencies (NASW, 2003) that are updated regularly by the National Coalition for Health Professionals Education in Genetics (NCHPEG). Foundation knowledge requires proficiency in the components and structure of DNA; reproductive and structural variation; patterns of inheritance; epigenomics; and understanding of the ethical, legal, and social implications of genomic discovery. Advanced practice social work competencies will include health literacy and skills in epigenetics, translational principles, quality-of-life ethics, values clarification, and mastery of decisional aids developed to help with genetic decision making. Piloting nuanced genomic content in elective classes will reach faculty and students with health care interests. Later, faculty can integrate modules from NASW and NCHPEG into core practice, policy, and diversity and racism courses. See Table 2 for suggested teaching materials, listed by course and target content.

As widely adopted HBSE texts include more genomics content, CSWE can include genomics with EPAS requirements of material to be infused across the curricula (as they have for aging, sexual minorities, race, and economic and social justice) and identify incentives for institutions who adopt such curricula. At the institutional and faculty levels, CSWE and NASW media can recognize "cutting-edge educators" who include genomics information in their coursework.

3. Develop and disseminate educational programs. Social work education must include basic genetics in addition to addressing how genetic

Table 2: Infusing Genetic and Genomic Learning into Social Work Curricula: Getting Started

Elective Course	Content	Selected Materials
Social work in health care	Inheritance, common conditions Gene × environment Genetic technology and life course Direct practice skills with uncertainty	• Gehlert, S., & Browne, T. (2011). *Handbook of health social work* (2nd ed.). Hoboken, NJ: John Wiley & Sons. • Kerson, T. S., & McCoyd, J. L. (2010). *Social work in health settings: Practice in context* (3rd ed.). New York: Routledge. • National Human Genome Research Institute. (2015, March 20). *Online genetics education resources.* Retrieved from http://www.genome.gov/10000464
Social work with families	Family planning and reprogenetics Mutigenerational family caregiving and coping	• Miller, S. M., & McDaniel, S. H. (2006). *Individuals, families, and the new era of genetics: Biopsychosocial perspectives.* New York: W. W. Norton. • Tercyak, K. P. (2010). *Handbook of genomics and the family.* New York: Springer.
Health policy	Patient Protection and Affordable Care Act of 2010 Genetic Information Nondiscrimination Act of 2008 Precision Medicine Initiative	• American Society of Human Genetics. *Policy & advocacy overview.* Retrieved from http://www.ashg.org/pages/policy_overview.shtml • National Human Genome Research Institute. (2014). *Genetic discrimination.* Retrieved from http://www.genome.gov/10002077 • WhiteHouse.gov. (2015, January). *The Precision Medicine Initiative.* Retrieved from https://www.whitehouse.gov/precision-medicine

risk is conveyed; identifying disparities in access and uptake of genomic testing across marginalized groups; considering the multifactorial, complex nature of most genetic and genomic information; and conveying the limits of such information to provide diagnostic or treatment possibilities. Existing education materials explain the interactions and influences of genes (along with environments) on behavioral and medical conditions. Education must also address variations in insurance coverage for genetic counseling, testing, and public policy. The NCHPEG-developed training programs for health professionals (NCHPEG, 2007) can be used along with guidelines outlined by NASW (2003). NASW recently began a "Health" Special Interest Group at the Society for Social Work and Research, an organizational venue providing over a decade of support to the dissemination of research at the nexus of social work and genetics and genomics. In partnership with others, social work's efforts to move genomic literacy into mainstream social work practice have begun.

Webinars

Initial educational efforts should target faculty interested in developing their confidence in delivering genetic and genomic material already available in current HBSE texts and can easily be delivered in webinar formats. As more faculty and practitioners develop comfort with genetic material, as consumers (students and their clients) request such material, and as President Obama's Precision Medicine Initiative rolls out, the level of complexity for continuing education (CE) offerings can expand. High-quality resources already exist, enabling social work educators to bring content into the classroom and the field (see Table 2).

CEUs

Social work programs must be encouraged to develop CE programs that allow exposure to genetic, genomic, and epigenomic material for clinicians in practice prior to implementing new CSWE competencies. The Association for Social Work Boards (ASWB) and NASW provide portals to CE programs and can provide support to PhD-prepared social workers and other allied health professionals seeking to increase the scope of existing programming and to create innovative and interdisciplinary training modules. Other public, private, and not-for-profit groups provide teaching modules for many aspects of genomics (Gehlert & Browne, 2013), such as the Personal Genetics Education Project (pgED.org). These provide easy access for clinicians, academics, and others to gain genomic competency and CEs simultaneously.

Certificate Programs

We propose CSWE and the ASWB support building certificate programs that provide advanced knowledge and credentialing to support and document transdisciplinary competencies in genomics for social workers, especially in perinatal, risk diagnostic, and preventive health settings, such as those at Simmons College and Brandeis University. We challenge our educational institutions to develop certificate programs throughout the United States, including at least one such certificate program in each major U.S. region.

4. Track genomics in social work literature as well as in social and news media. We propose creation of a listserv or Twitter feed to increase circulation of publications that highlight the interplay of genomics with social work practice, behavioral and public health. Online venues, such as ResearchGate, enable scholars endorsed in social work and genetics to share resources, build knowledge, and track publications across initiatives. NASW, CSWE, or an individual institution could also provide a supportive organizational home for such data.

CONCLUSION

The expansion of personalized and precision medicine into primary care settings, public media that report inaccurate genetic information, and the growing movement toward genetic pharmacology mean that genomics is permeating the populace before professionals are adequately informed about the implications for ethical, socially just practice. Wide gaps in health care already exist, not the least of which is access to sound genetic services. Social workers are ethically committed to ensure that the gulf between privileged and marginalized groups does not continue to expand. Of all the professional groups engaged in genomics, only social work has guiding frameworks that permit fluid movement across systems, values that ensure client primacy, and skills to advocate for populations who may not otherwise have a voice. Social workers already have the skills and values to help; social workers' challenge is to ensure that they have the knowledge about genomics to provide this guidance to clients as they encounter the uncertainty, rapid evolution, and decisions required of them in this new societal context. **HSW**

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