

Communicating about family health history: heredity, culture, iatrogenesis and the public good

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Family health history is the genetic and ecological contributions and interactions, or what others may refer to as the genomic and bionomic inputs, affecting the life course of family members. The adage to 'know your family history' promoted in public health and clinical settings emphasises having awareness of first and second degree relatives' health status, including causes and outcomes of morbidity and mortality. An overarching aim of promoting awareness of family health history resides in making health a public good accessible to all through informed decisions about resource allocation in personal and societal realms, including effort, time and money. Evidence of the promise associated with family health history awareness emerges in studies such as the 'Family Healthware Impact Trial' conducted in the USA. Findings demonstrated that risk-tailored messages associated with self-reports of personal lifestyle behaviours and familial risk for coronary heart disease, stroke, diabetes, and colorectal, breast, and ovarian cancers related to self-reported modest improvements in fruit and vegetable intake, increases in exercise, and greater likelihood of receiving cholesterol screening.¹ Messages thus leveraged awareness of lifestyle and family history to increase personal and clinical prevention practices without promoting genetic testing. Emphasising family health history in public health and clinical settings primarily in terms of heredity and genetic testing may have a number of iatrogenic effects, including violence and family dissolution in the wake of parental discrepancy associated with test results.² Such effects emerge explicitly when considering health and heritage, while others lurk more implicitly in the background of epidemiological data guiding community health endeavours that incentivise some policies associated with genetic testing and newborn screening programmes related to identifying genetic disorders.

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One overarching presumption of promoting family health history awareness relates to the assumed view that individuals have access to their biological family. This ignores the reality of a growing number of displaced global citizens who lack the opportunity to know health history due to political, geopolitical and climate-related events. Moreover, framing family in terms of biological parents or 'parents of origin' neglects the many meanings of family and traditions that emerge from evolving norms, culture and practices relating to father absence and lack of connexion to paternal kin, limiting what individuals know about biological family and health history. In some cultures, for example, one side of the family is emphasised over the other, so awareness related to heredity will have a greater likelihood of being known for one parent of origin.³ Even one-sided awareness depends on family members talking about health, a culturally and socially determined practice layered within the meaning of family overall. Conversations to promote awareness encompass a broad scope of events, including the burdens of worry and fear for self, family and community linked to stigma and discrimination, and feelings of grief for loss linked to identity and reproductive, relational, recreational and occupational choices.⁴ Positive test results for non-treatable or partly treatable hereditary diseases may provide a more accurate picture of the prevalence of a condition and perhaps prompt policies to increase research related to treatment. However, results in these cases may be particularly likely to lead to depression and substance abuse, contributing to diminished capacity for work and additional healthcare costs related to maladaptive coping.

A primary focus on heredity may miss opportunities to emphasise the importance of family health history linked to contexts in which families live, and in which the fetus develops, including nutritional, behavioural and ecological environments that contribute to health status and how genes express themselves.⁵ Understanding that heredity may increase susceptibility to and severity of disease, but does not

absolutely determine health status, forms a critical principle for communicating about family health history.⁶ With cardiovascular disease (CVD) identified as the leading cause of mortality worldwide, for example, and nearly 80% of these deaths in low-income and middle-income countries,⁷ CVD risks related to tobacco, diet and exercise, and prevention screenings may get lost in translating the focus to heredity, which also decreases individuals' perceived control over health.⁶ As with the meaning of family itself, expectations associated with diet, exercise and smoking that may contribute to family health history emerge in families, often based on cultural norms. Chinese Americans living in the USA illustrate this reality, with higher rates of lung cancer attributed to smoking, a culturally indoctrinated practice especially among men.⁸

Tensions associated with promoting family health history emerge in developed and developing countries, as illustrated by Slovenia, a developing country. Self-reported family history within a sample of 1340 healthy Slovenian respondents found 280 (or 20%) at moderate or high risk for developing CVD, 154 (11.5%) for diabetes, and 163 (12.1%) for cancer, leading to the recommendation to offer genetic evaluation.⁹ This response aligns with clinical intervention, including genetic testing, while neglecting consideration of whether available and affordable resources for evaluation and follow-up exist. It also ignores the roles of diet and exercise, as well as access to both. Privilege extends to diet and exercise, with the poorest neighbourhoods, for example, found to have the greatest levels of physical inactivity.¹⁰ Societal resources applied to genetic testing and clinical intervention associated with heredity reduce the availability of resources to build safe environments that support exercise.

The refrain to consider family health history within cultural frameworks intersects with community genetics and public health genomics initiatives in which epidemiological evidence associated with a 'community' may lead to broad-based screening initiatives. In nations with resources, including healthcare at the societal level, and health insurance and education at the individual level, affected groups may organise and advocate to attain resources and care, and/or to limit risk linked to use of tissue samples. The Dor Yeshorim programme illustrates this response, providing a confidential system for screening related to genetic conditions appearing with increased frequency among Ashkenazi Jews.¹¹ The latter

reflects awareness of past liberties taken to advance science without addressing needs to protect communities in ways that the Belmont Report's principles protect individuals, raising the question of where to draw the line in testing.⁴ For example, sons may carry the genetic mutations associated with increased risk linked to breast and ovarian cancers in Ashkenazi women, pass it on to their daughters, and be at increased risk for breast and prostate cancers themselves.¹² Should sons be tested in initiatives designed to assess risk? Biobanking with prospective consent, an innovative approach to informed consent, acknowledges risk and reward associated with using tissue samples collected for one purpose that are additionally used in other research. Data collected from the Havasupai tribe for diabetes research reveals such a situation, as it was also used for schizophrenia and inbreeding research, posing discrimination and stigma risks to the community.¹³

Promoting family health history largely in terms of heredity rather than situating it in contextual and cultural meanings results in public expectations outdistancing available technologies and therapies relating to the efficacy of genomic medicine.¹⁴ DNA sequencing methods designed to automate the process of imaging chemiluminescent samples and providing accurate results enhance the ability to accurately tell a woman that she has BRCA1 or BRCA2 mutations. Options relating to this information, however, do not include replacing, manipulating, or supplementing the genes—gene therapy. Clinical trials associated with gene therapy in humans that introduce corrected copies of disease genes into somatic cells of an affected individual, likened to treatment of individuals by organ or tissue transplantation, afford promise though innovations in mass spectrometry.¹⁵ Eliminating disease genes in offspring requires transgenic experiments, which introduce exogenous genes into the germ line of an organism to inject a gene of interest into the nucleus of a fertilised egg, a process successfully used in plants and livestock but ethically questioned when it comes to human eggs.

Promoting family history awareness based on heredity may be beneficial if pharmacogenomic research revealing genetic variants' contribution to medication efficacy accompanies access to reliable genetic tests and affordable medications, together with patients' willingness to be tested and use medications linked to test results. Warfarin therapy for treatment of blood clotting disorders illustrates the promise linked to such research, revealing

that several gene variants explain variance in warfarin dose requirements.¹⁶ Sometimes, when expectations outpace the science, however, accurate genetic testing is not yet available. The private sector only invests with clear evidence of an existing profitable market worthy of the lengthy and costly development phase, as illustrated by the development and application of commercial BRCA testing.¹⁷ Culture may also affect responses to products, including testing and therapies. The symbolic meaning of blood and the body in China, for example, relates to an era when unhygienic blood collection led to an AIDS crisis with as many as 80% of adults being HIV-positive in some villages, and resistance to giving blood in the nation overall¹⁸—perhaps contributing to less likelihood of seeking genetic testing and therapies.

The push associated with genetic testing and therapies aligned with promoting awareness of family health history and heredity may bring products to market prematurely.¹⁹ The regulatory science struggles to keep pace, independently reviewing the accuracy and reliability of testing and claims. These struggles climaxed in the latter part of 2013 in the USA, as the Food and Drug Administration ordered '23andMe', a company that offered genetic testing for DNA ancestry, to stop selling genetic tests due to inconsistent testing results (<http://www.23andme.com>).²⁰ In the wake of removing products and services such as '23andMe' from one market, less informed publics, ranging from communities seeking advancements to developing nations seeking aid, may become sources for product development and testing. Too little research has focused on investigating how pharmaceutical companies market products in developed versus developing nations and whether promotional materials given to physicians vary, exaggerating benefits and minimising risks for some countries as compared with materials provided in other nations. In developing nations, health and medical aid could be tied to policy associated with favourable regulatory environments linked to new markets and testing grounds relating to genomic products, much like the documented links between food aid and efforts to gain new markets for genetically modified foods.²¹

When newborn screening provides opportunities for genetic counselling and clinical care for infants diagnosed during screening, individual and public health benefits often emerge in support of the public good with families and society benefiting in terms of citizens' well-being.

There may even be the potentiality for lower lifetime costs linked to healthcare. Promoting family health history awareness may merge, however, with decisions to expand newborn screening programmes based on uninformed or misinformed emphases on heredity, and/or citizens' passive acceptance. In the case of harms linked to genetic testing and newborn screening, the potential to violate the informed consent process linked to genomic medicine or exaggerate benefits to patients and physicians exists. When unequal access to counselling and care follows diagnosis, or prenatal screening emerges as a practice promoted to women regardless of their ability to make an informed decision, the consequence may be reducing the prevalence of particular conditions or diseases associated with some individuals or groups. These may include disabilities ranging from physical to intellectual that occur in individuals,²² or diseases such as alcoholism being associated with a community, as with Native Americans in the USA.²³ Rather than a new era of wellness, identifying groups with genetic defects may lead to a modern era of eugenics, with groups associated with a genetic condition, and even groups associated with a behaviour linked to gene expression and disease, being targeted for testing, as well as policies and programmes limiting reproductive choice.

Promoting family health history awareness aims to motivate individuals, families, communities and societies to manage inputs to health status, including factors that range from clean air and clean water to food quality and hygienic habits. Focusing on family health history and heredity related to clinical decision-making implicitly promotes 'clean genes' as a way to achieve health as a public good. Leveraging resources and quality to treat clean air and clean water as public goods with equitable indivisible benefits for all challenges decision makers; defining 'quality' when it comes to human genes and heredity presents itself as a tension in policy and practice, with ethical dilemmas ranging from coercion and targeting to forced sterilisation.²⁴ While history affords us examples of violations of human rights through eugenic practices such as those practiced during the Third Reich, subtle violations may cast a shadow over the benefits to be realised from knowing our family health history associated with heredity. What 'life' we will honour through our policies and behaviors to protect and nurture may shift with reformation in attitudes about prenatal selection and genetic perfection.

What is thus to be avoided in promoting family health history awareness is an implicit move towards making ‘better’ babies and calling them ‘healthier’ babies. The underlying philosophy suggests a harbinging back to programmes such as the US Indiana State Fair Infant and Child Hygiene ‘Better Babies Contest’ inaugurated in 1920 and lasting for 12 years, bringing together public health and animal breeding.²⁵ A primary argument in support of genomic healthcare is that individuals can make more informed decisions about care and be motivated to behave in health promoting ways. This depends on how genetic information is communicated and communicating that medical innovation has risk. The cutting edge of technology is often the bleeding edge of technology; communities globally and locally may not know that they are pioneers in a frontier of genomics and participate unknowingly in research linking heredity to promoting family health history awareness.

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