




SPECIAL ARTICLE

Promoting international, locally focused, and patient-oriented genetic counseling



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Introduction

The profession of genetic counseling originated in the United States in the 1970s under circumstances that were specific to the individuals involved; the institutions and

departments in which they worked; the theories, practice, science, culture, and ethnicities of the time; and local, national, and international events and history.¹ As genetic counseling expanded, first in the United States and then internationally, it broadened in many ways to meet the needs and expectations of diverse patients, as well as the ever-advancing knowledge and technologies of medical genetics.²

In the process, there have been many contributions to the theory and practice of working with individuals and communities from an increasingly wide variety of cultures and ethnicities. In some countries, such as the United States and Canada, this involved considerable interchange of individuals and ideas.³ In other countries, such as Japan⁴ and Cuba,⁵ genetic counseling was established and developed relatively independently. The patterns of integration into health care systems, legal systems, and training programs in more than 28 countries where genetic counseling is now practiced are highly complex.⁶ Nevertheless, much of contemporary literature, training, and practice is based on Western-oriented, English-based theory and practice. As genetic counseling continues to expand globally, it is essential that a body of theory, practice, training, and

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literature be developed that is grounded in the specific circumstances of the communities being served.^{4,7-10}

We conceptualize this as locally focused, patient-oriented genetic counseling. During the earlier part of the century, the faculty of North American genetic counseling graduate programs pioneered the patient-centric care model termed the reciprocal engagement model. The reciprocal engagement model aimed to train the graduate students to develop a therapeutic relationship with the counselees by providing necessary genetic information and supporting the assimilation of that information to personalize health-related decision making.¹¹ To maintain the same level of therapeutic relationship as genetic testing and counseling continue to cross continents and borders, the natural course of evolution of the profession compels professionals to explore uncharted paths to a diverse body of theory, practice, training, and literature that is grounded in the experiences of the diverse communities being served.

In this article, locally focused is defined as genetic counseling grounded in the beliefs, expectations, and norms of the community or communities being served. This does not assume that a locality is homogenous. Indeed, a diverse population may be a defining characteristic of a particular area.

Patient oriented refers to the same approach being applied to the individual being treated, which is care that is attentive to the beliefs, expectations, and norms of the patient. The profound interrelationship between the 2 terms illustrates the depth and complexity of this proposal.

This professional growth requires decentering from the predominantly White, European-American, Westernized perspective.¹² What replaces it will then be a variety of points of view and practices that adequately represent the social, cultural, ethnic, religious, and historical diversity of the individuals, families, and communities who are now offered and receive genetic counseling services worldwide. We, the authors, have diverse ethnocultural identities ([Supplemental Table 1](#)). We the authors trained in several different countries and provide or have provided genetic counseling to individuals and families from communities (both representative of and differing from our own) in the United States and in our countries and regions of origin. Thus, we present what follows from a variety of perspectives that includes the knowledge and a lived understanding of several non-Western societies and cultures, an understanding of Western-based genetic counseling, and recognition of some of the barriers that confront our decentering proposal. In developing this proposal, we encountered many instances of differing opinions and perspectives, corrections of misinformation and stereotypes, and explanations of aspects of history, culture, and clinical practice by those of us with lived experience for those of us without it. We also went outside of our collective knowledge and experience to address some topics. Thus, our varied and interlocking positionalities created a valuable microcosm for the type of transformation we are proposing.

This radical decentering involves 2 interrelated steps: first, recognition of the exclusive, harmful consequences of the assumptions of “universality,” which are due in part to the specific origin and history of genetic counseling; and second, consideration of the ways in which alternative conceptualizations of genetic counseling might be achieved based on the key differences of faiths, cultures, social constructs, and ethnicities around the world, as well as the commonly held principles of collective humanity.

It is critical to recognize the issue of universalism, which is “the presumption of dominant groups that their perceptions and values are ‘universal’ in nature and application.” This has been investigated with respect to journal titles, which often include the community or population involved when it is a nondominant group but do not include the community when it is a dominant group. This can lead to the assumption that nondominant groups have specific experiences and perceptions that should be noted, whereas the world view of the dominant group is universal and requires no comment.¹² More significantly, universalism can result in a failure to recognize critical aspects of individual and group experiences, such as the impact of colonialism and racism, as well as those of deeply held social and religious beliefs.¹³ The relative paucity of concepts and understanding concerning other cultures and ethnicities are as limiting as is the comparable paucity of genomic data, the detrimental effects of which are now well understood.¹⁴

We begin our discussion of how alternative conceptualizations of genetic counseling might be achieved by asking what questions and procedures would be involved if genetic counseling were founded at the present time in communities whose beliefs, practices, and understandings differ fundamentally from those in which genetic counseling originated.

We invite readers to consider the questions in [Box 1](#). To achieve alternative conceptualizations of genetic counseling, we must examine the established fundamentals of genetic counseling practice. We illustrate this with a discussion of 2 foundational concepts within genetic counseling: decision making and consanguinity along with a discussion of issues related to providing genetic counseling services to Indigenous communities. They exemplify how the Western roots of genetic counseling can be examined and evolved. It is an opening but by no means an exhaustive discussion of these or the many other relevant foundational ideologies. These topics were chosen based on the expertise and lived experiences of the authors.

Commentary

Decision making

Decision making is fundamental to genetic counseling and thus provides an entry into a number of issues involved in promoting locally focused, patient-oriented genetic counseling.

Communal decision making is as deeply and complexly embedded in the social structure of many societies as

individual decision making is in others.¹⁵ However, because of its White, European-American, Western origins, much of international genetic counseling has been developed based on the assumption of individual decision making, regardless of the decision-making practices of the societies in which these new services are practiced.^{4,7-10} It is crucial to integrate genetic counseling theory, education, and practice in societies where communal decision making is the cultural norm. This approach would build upon the existing framework of patient autonomy, which often disregards external influences or coercion.

Communal decision making has multiple forms. In some communities or cultures, there is the expectation that a second person (such as a spouse or an in-law) is to be involved. In other settings, family members (including community elders and distant relatives), and community members (including religious leaders or those who have gained higher education) are consulted.¹⁵ As discussed below, when marriage within or between families is common, the number of individuals involved, and the aspects of personal and familial well-being that are considered may be large and complex.

In addition, chronic illnesses, including mental illness, have been associated with feelings of shame¹⁶ and stigma,^{17,18} which in some communities affects marital and reproductive decisions, as well as decisions on genetic testing and sharing of family and medical histories.^{19,20} Further, patients in some communities often rely on the health care provider to recommend or even make the decision on their behalf.^{21,22} As an example of our proposed process, one could investigate each of the questions presented in **Box 1** assuming a foundation of communal decision making. For example, within a community that values and expects shared decision making, what would be the foundational principles and practices of genetic counseling service, research, education, and training?

Consanguinity

In many cultures and societies, marriage between relatives has deep historic, cultural, familial, and economic meaning and imperatives. Sociocultural factors that contribute to this practice include the maintenance of family structure and property, ease of marital arrangements, better relationships with in-laws, and financial advantages relating to dowry.²³ Although consanguinity is generally thought of as being practiced by Muslim communities, many other faiths and some members of other communities also practice it, including Hindus, Jews, and Christians.²⁴⁻²⁶

In some communities, consanguineous marriages are thought of as a strategy of conservation of cultural values and cultural continuity. This is especially observed in minority groups in which societal change and/or political and socioeconomic instability has led to immigration and the establishment of refugee communities. There are higher risks for autozygosity and congenital malformations of about 2% to 3% above the general population risk among progeny of first cousins,²⁷⁻²⁹ which often leads to a

Box 1.

- What would be the foundational principles and practices of genetic counseling service, research, education, and training?
- When developing a training program, what would be the most important courses and what qualifications, skills, and experiences would one look for in faculty, clinical supervisors, and applicants?
- How would the practice be integrated within their health care system, and what would the scope of practice of a genetic counselor be within that health care system?
- What would be the most important issues to address in a Genetic Counseling Code of Ethics?
- With which professionals and community members would one consult concerning these questions and the more specific topics we now discuss?

stigmatization of the practice. However, as some of the authors have observed when providing genetic counseling, members of consanguineous marriages may choose to proceed with conceiving naturally even in the presence of 1 or more familial hereditary conditions. In some communities, the idea of fatalism, which is the belief that all events are predetermined and therefore inevitable, may guide these principles.^{9,30} Similarly, there are other reasons for choosing to have children despite challenges. In certain cultures, societal norms and expectations dictate that having children is not a personal choice but simply a social requirement to fulfill familial obligations and preserve lineage. Additionally, for many families, children serve as a means of strengthening marital and familial bonds, fostering a sense of unity, and passing down traditions and values through generations. Embracing parenthood despite potential risks may also be driven by a source of immense pride and content, a symbol of continuity and legacy.^{31,32}

In some instances, the individuals may even be up against their “government/national policies.” For example, in countries with high consanguinity rates, consanguinity is an established contributing factor to the incidence of (genetic) diseases, which are, in turn, considered to constitute a psychological, medical, and economic burden. In some Middle Eastern countries, premarital screening (PMS) is mandatory and is considered by policymakers to play a role in mitigating psychological, medical, and economic burden of genetic diseases for which consanguinity is thought to be a contributing factor. However, in studies assessing attitudes and knowledge of PMS, even when participants agreed that genetic diseases constitute a psychological and economic burden, not only was the awareness of PMS low, but most participants also expressed they would be unwilling to cancel marriages or interfere with destiny. In fact, cultural norms and expectations may be so deeply ingrained that they preclude, or appear to preclude, consideration of

alternatives, a consideration that also applies to societies that are based on individual decision making.^{33,34}

Counseling should be grounded in the beliefs and cultural practices of the patient population being served, as opposed to utilizing the same strategies followed elsewhere in the world. Efforts should be geared toward understanding the balance between the reproductive risks and social benefits of consanguinity and avoiding stigmatization of this practice. There needs to be an effort towards recognition of microaggressions that can occur when counseling consanguineous patients.

Indigenous communities

Despite many differences among Indigenous and First Nation communities and cultures around the globe, many share a holistic view of the individual within the community, living in harmony with the earth, and the animate and inanimate entities on and in it.³⁵ This world view is radically different from that upon which genetic counseling is based. Thus, it presents major challenges to the provision of culturally appropriate genetic counseling and genetic testing. It also necessitated the conceptualization of genetic counseling from a fundamentally different set of assumptions and expectations.³⁶ The authors confronted this because the concepts and lived experience are in large part outside our knowledge and experience. In addition to knowledge and worldviews from millennia living in intimate connection with the land, the historical, political, and social consequences of colonization are fundamental to Indigenous and First Nation peoples' experience, survival, and resilience.³⁵

Responding to longstanding concerns about the quality of health care provided to Māori patients and communities in New Zealand, the concept of cultural safety was developed by Māori nurses in the 1990s. It is now used more broadly with respect to other health care professions and to Aboriginal and Torres Strait Islander patients and communities in Australia. It focuses on the ways in which colonization, racism, and power inequalities affect the health and health care of Indigenous individuals and communities, emphasizing that non-Indigenous providers must examine their roles critically. As Curtis and coauthors state (p. 14), “[Cultural safety] requires individual health care professionals and health care organizations to acknowledge and address their own biases, attitudes, assumptions, stereotypes, prejudices, structures, and characteristics that may affect the quality of care provided.”³⁷ Cultural safety thus challenges genetic counseling to undertake a radical, self-reflective decentering from its White, European-American, western origins.

Discussion

The fundamental issues just discussed demonstrate the importance of grounding genetic counseling in the beliefs and cultural practices of the patient populations being served rather than adapting Western-based practices to address those beliefs and practices.

As the previous presentation and sources cited demonstrate, the process of promoting international genetic counseling that meets the historical, cultural, and ethnic needs and expectations of the individuals and communities it serves is underway to varying degrees in many locations internationally.^{7,8,10,21,38-42} This is a worldwide undertaking and effort, which will be promoted by communication and analysis, including discussion and debate concerning common practices and goals, as well as diversity in perspectives and implementation.⁴²

Some of the barriers we perceive to be fundamental in overcoming to achieve our decentering proposal is the expansion of training programs and hiring of genetic counselors worldwide. This will require a financial and vocational commitment from universities and governments internationally to dedicate resources to the recruitment of talent and the decentering of genetic counseling practice from the Western world to areas in dire need in local communities. Most of us, authors, have left our countries of origin and work with underserved communities in the United States and Canada. This is not to say that our decentering proposal is not universal and is valid no matter the location of practice. But in order for this movement to gain momentum, it will be important for genetic counselors to be able to practice locally and serve their communities' needs. This starts with the development of training programs internationally that are grounded in the communities that they would serve.

The bulleted questions presented in [Box 1](#) above are useful for anyone interested in this process. Indeed, every genetics professional today practices in a world that has changed since the original conceptualization of genetic counseling. However, for genetic counselors and related professionals in countries or communities where clinical services and training are in the planning or early developmental stages,^{7,8,10,21,38-42} they can serve as valuable operational questions.

As genetic counseling continues to expand internationally, it is important to include individuals with strong relationships with the communities involved and familiarity with the environments in which program development is set to occur. Training programs should first acknowledge the limitations of the current curriculum, and that rotations and practices students are engaging in are primarily based on a model developed in the United States. They can equip genetic counselors to engage effectively with diverse populations and to navigate cross-cultural communications. This can be done through revisions to curricula to incorporate modules on cultural competencies, humility, and global health perspectives, teaching self-reflection of one's biases and limitations in exposure to their patient's cultural norms. In the near future, programs could offer international rotations, immersion experiences, or community-based placements for first hand exposure. The thought is to foster empathy, cultural sensitivity, and an appreciation for the complexities of delivering genetic counseling across different settings.

Recording and analyzing data from this iterative process may inform theory and practice in meeting the needs of patient populations that potentially represent the vast diversity of humanity. Research should be encouraged to grow organically in regions implementing genetic counseling services for the first time. Mindful attention to local cultural considerations when clinical services and training are in the early stages of development will be especially useful. Genetic counselors can be key players in collaborating with community-based organizations and religious institutions to ensure that research materials (including consent forms) are available in multiple languages and are culturally sensitive to the norms and traditions of different populations and that recruitment strategies, incentives, and compensation are in alignment with community preferences and values. These strategies will be crucial to implement to build trust between genetic counseling researchers and the local communities, and address existing and ongoing barriers to research participation.

In conclusion, we propose that identifying locally focused, patient-oriented genetic counseling, decentered from its Western origins as an organizing principle will promote the exchange of ideas and experience in a manner that will benefit genetic counseling worldwide.

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Ethics Statement

This research does not include human participants, individual-level data collected from humans, or bio-samples collected from humans.

Conflict of Interest

Aisha Furqan holds stocks in Natera, Inc, and is a cofounder of the nonprofit Pakistani Society of Medical Genetics. Smita K. Rao is the cofounder of Genexsure LLC, which is a genetic counseling telemedicine company. Rawan Awwad is one of the cofounders of Arab Society of Genetic Counselors. All other authors have no conflicts of interest.

Additional Information

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