Genetics inMedicine | SYSTEMATIC REVIEW

Ethical, social, and cultural issues related to clinical genetic testing and counseling in low- and middle-income countries: a systematic review

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Purpose: We performed a systematic review of the ethical, social, and cultural issues associated with delivery of genetic services in low- and middle-income countries (LMICs).

Methods: We searched 11 databases for studies addressing ethical, social, and/or cultural issues associated with clinical genetic testing and/or counselling performed in LMICs. Narrative synthesis was employed to analyze findings, and resultant themes were mapped onto the social ecological model (PROSPERO #CRD42016042894).

Results: After reviewing 13,308 articles, 192 met inclusion criteria. Nine themes emerged: (1) genetic counseling has a tendency of being directive, (2) genetic services have psychosocial consequences that require improved support, (3) medical genetics training is inadequate, (4) genetic services are difficult to access, (5) social determinants affect uptake and understanding of genetic services, (6) social stigma is often associated with genetic disease, (7) family values are at risk of disruption by genetic services, (8) religious principles pose barriers to acceptability and utilization of genetic services, and (9) cultural beliefs and practices influence uptake of information and understanding of genetic disease.

Conclusion: We identified a number of complex and interrelated ethical, cultural, and social issues with implications implications for further development of genetic services in LMICs.

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INTRODUCTION

Clinical genetic testing detects DNA anomalies that may have pathological consequences. A standard part of management for many inherited disorders,[7] its aim is to predict the risk of developing disease and transmitting disease-causing variants to offspring. Genetic counseling assists individuals in understanding test results and their consequences. As technology has evolved and become increasingly more cost-effective, genetic testing services have been introduced in low- and middle-income countries (LMICs), usually through research initiatives[13–18] or formal international partnerships.[19,21,22] In contrast, genetic counseling has not developed in a similar robust fashion, and remains largely a Western concept and profession. Indeed, the number of genetic counselors available globally is far lower than the need for their services, frequently resulting in physicians bearing much of the responsibility for genetic counseling.[23–25] In LMICs, where physicians have bigger patient loads and often limited training in medical genetics, it remains challenging to effectively educate and support patients.

In contrast to the push to bring genomic science from "lab to village,"[1–6,26] there is little focus on how to build clinical genetic services in LMICs in a responsible, ethical, and culturally appropriate manner. Much of the literature reporting on development of genetic services in LMICs has largely commented on capacity building and tecnical success.[8–12,20] Several experts have recognized the urgent need for a thoughtful approach, grounded in ethics, to implement genetic services in LMICs so that the unique needs of those patient populations are met.[27,28] A growing number of studies are beginning to address ethical and sociocultural issues in genetics.[29–32] This knowledge synthesis aims to determine the breadth of work done in this area, and uncover

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the ethical, social, and cultural issues that are relevant to implementation of genetic services in LMICs. The results will inspire policy recommendations and ultimately define areas of new areas of investigation.

MATERIALS AND METHODS

Protocol and registration

This study was reported according to the Preferred Reporting Items for Systematic Review and Meta-Analysis (PRISMA) checklist (Additional File 1). The protocol was registered with the PROSPERO International Prospective Register of Systematic Reviews (#CRD42016042894). The detailed protocol has been previously published.[33]

Briefly, an integrated knowledge translation approach was used to engage end-users throughout the study. An End-User Committee met three times over the course of the systematic review to (1) discuss methodology, (2) review data collection and analysis, and (3) review synthesized results. The search strategy was developed with the assistance of an information scientist, searching MEDLINE, Embase, Web of Science, PsycINFO, Cinahl, LILACs, CCRCT, CDSR, DARE, BiblioMap, HealthPromise for studies between January 1, 1990 and July 12, 2013 (Additional File 2). Studies were included if they reported on (1) clinical genetic testing or genetic counseling services (where genetic counseling refers to both formal genetic counseling, as well as other forms of communication from healthcare professional to patient regarding heritability and/or genetics of a disorder), (2) populations in LMICs as defined by the World Bank,[34] and (3) ethical, social, and/or cultural factors that influence the implementation of genetic testing and/or counseling. Studies performed in high-income countries (HICs) and/or states/territories (e.g., Hong Kong, Taiwan)[35,36] were excluded. Studies focused solely on the technological aspect of genetic testing (e.g., development and/or application of a novel technique) and studies related to basic genomic research (e.g., such as those looking at migration, ethnicity, or genomics of populations) were also excluded. Studies in languages other than English were excluded for practical reasons, as were those published before 1990, which were presumed to be outdated.

Bibliographic data of identified studies were managed using EPPI-Reviewer 4 (University College London, UK). A data extraction form was developed using Microsoft Excel (Microsoft Corp., Redmond, WA, USA). Quality appraisal was performed using the QUALSYST quality assessment tool, which consists of a separate checklist for quantitative and qualitative research studies that assesses "the extent to which the design, conduct and analyses minimize errors and biases."[37] The QUALSYST tool was developed specifically for assessment of studies from a wide variety of disciplines. A narrative synthesis was performed, following the framework established by the Economic and Social Research Council,[38] as described in our previously published protocol.[33] The data was organized using NVivo-11 (QSR International). Two authors (AZ, HD) independently conducted an inductive, realist analysis to generate descriptive codes. Codes were refined until consensus among authors was reached, and applied to meaningful data points to generate themes. To explore relationships within and between all studies, themes were mapped onto the social ecological model, a conceptual framework based on ecological systems theory, which proposes that individual health outcomes are influenced by interactions with the greater environmental, social, and cultural context.[39,40] Further details are provided in the published study protocol.[33]

Role of funding source

There was no funding source for this study. The corresponding author had full access to all the data in the study and had final responsibility for the decision to submit for publication.

RESULTS

Study characteristics

The search strategy identified 19,618 records, of which 13,038 remained after removing duplicates. After applying inclusion/exclusion criteria from review of titles and abstracts, 915 remained. Full manuscripts were accessible for 638/915. Review of full manuscript excluded another 447. One study was identified by hand-searching, to arrive at 192 included articles (Fig. 1, Additional File 3).

Included studies represented South Asia (40), Middle East and North Africa (38), Latin America and the Caribbean (34), Africa (32), East Asia (21), Eastern Europe (18) or a combination (9) (Fig. 2). Studies covered blood disorders (59), neurological disorders (17), chromosomal abnormalities (12), cancer (11), or other disorders (11). Studies used quantitative (136), mixed (29), or qualitative (27) methods. Observational study designs were most common (170), followed by knowledge syntheses (15) and experimental studies (7). The average QUALSYST score was 82% (median 85%; range 60–100%).

Themes

Thematic analysis revealed nine key themes: two ethical, four social, and three cultural issues.

Ethical issues

Theme 1. Genetic counseling has a tendency of being directive. Clinical genetic counseling in LMICs tends to be directive.[41–54] Caregivers and patients, especially those of low socioeconomic status, prefer clinicians to make final decisions, and have little desire to learn more about treatment options.[51–53] Some clinicians approach genetic counseling as a means to reduce birth defects and deleterious genes in the population, and improve the affected family's quality of life,[50,54–58] an attitude described as having eugenic tendencies.[55,56,58] This acceptability of eugenics is reportedly more common among clinicians in LMICs than HICs.[59]

Clinicians tend to be accepting of termination of pregnancy following prenatal detection of genetic disease.[41,42,45,47,50,60–64] The implicit or explicit advice to patients is termination of pregnancy; clinicians may use negative language to influence

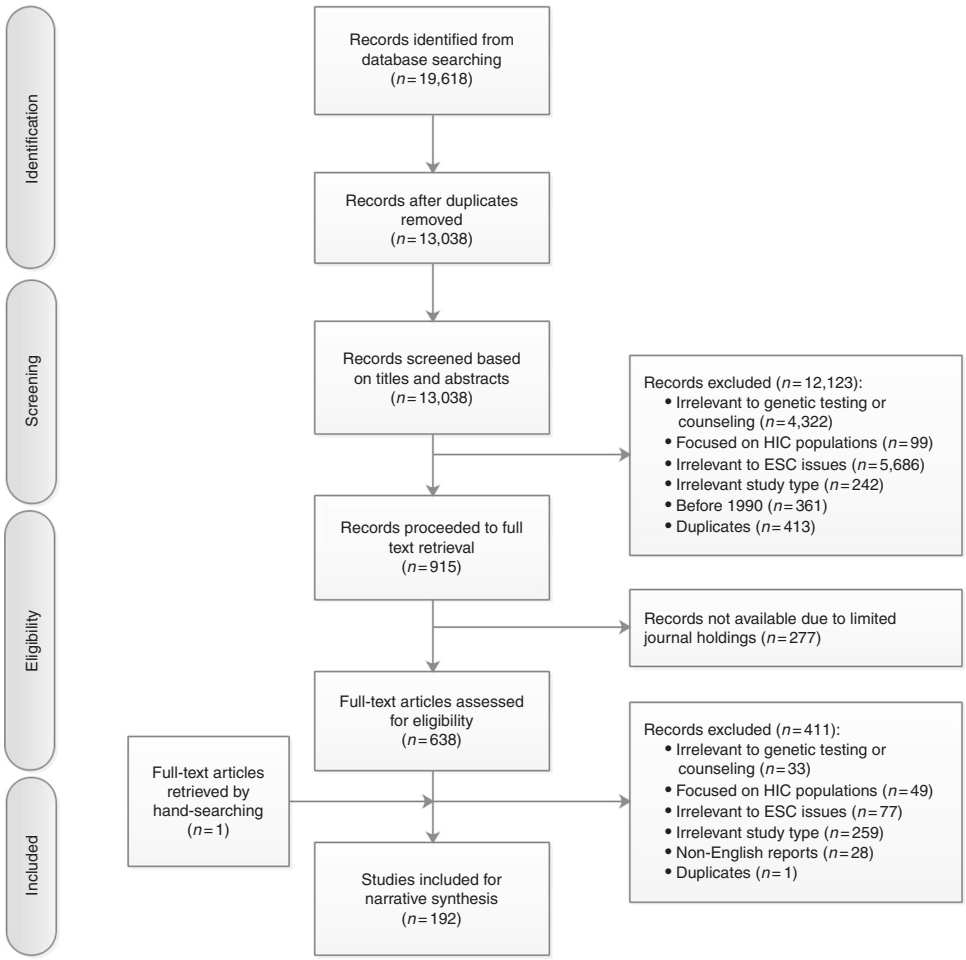

Fig. 1 Preferred Reporting Items for Systematic Review and Meta-Analysis (PRISMA) flow diagram. This PRISMA flow diagram depicts the number of records identified at different stages of the systematic review study selection. HIC high-income country, ESC ethical social cultural.

the patient's choice to terminate pregnancy, without directly suggesting it.[58] Information leaflets studied in LMICs were significantly more negative in their description of genetic diseases as compared with similar material in HICs.[58,65,66]

Theme 2. Genetic services have psychosocial consequences that require improved support. Studies investigating the psychological effects of genetic services found that patients were commonly in denial of their risk, contributing to an unwillingness to undergo genetic screening.[67–69] Fear and anxiety is associated with genetic testing, particularly related to the implications of a positive test result.[46,48,51,59,70–82] Psychological distress affects extended family members.[46,67,71,74,76,83–89] Individuals with a genetic diagnosis feel like a burden to their families, and experience guilt or blame.[49,67,83,86,90–92]

Studies identify a need to address psychological effects of a genetic diagnosis and enhance patient coping.[73,84,85,93–97] Patients commonly express a need for genetic counseling following testing, are generally willing to join a support group, and desire psychological follow-up.[73,80,84,94,98]

Social Issues

Theme 3. Medical genetics training is inadequate. For clinicians, a lack of knowledge about genetic diseases is a common barrier to their capacity in counseling patients.[51,70,99,100] Clinicians do not feel confident in providing information or counseling patients regarding genetic disease,[49,101] and can be dismissive when patients and families ask many follow-up questions.[70,102,103] Many clinicians report that their medical education in genetics was insufficient.[70,104–112]

Studies reveal an absence of practice guidelines and ethical codes for genetic services.[54,57,101,113–120] Informed consent and protection of patient rights are underdeveloped in many LMICs.[48,65,66,99,121–123] There is little recognition of genetic counseling as a profession, so the responsibility is nearly always the physician's.[49,54,91,120] A number of studies explored opportunities for medical staff other than physicians, such as nurses and midwives, to be involved in genetic services.[73,106,107,110] Medical staff and physicians are accepting of additional educational programs to enhance their genetic knowledge.[100,105,108,112,124]

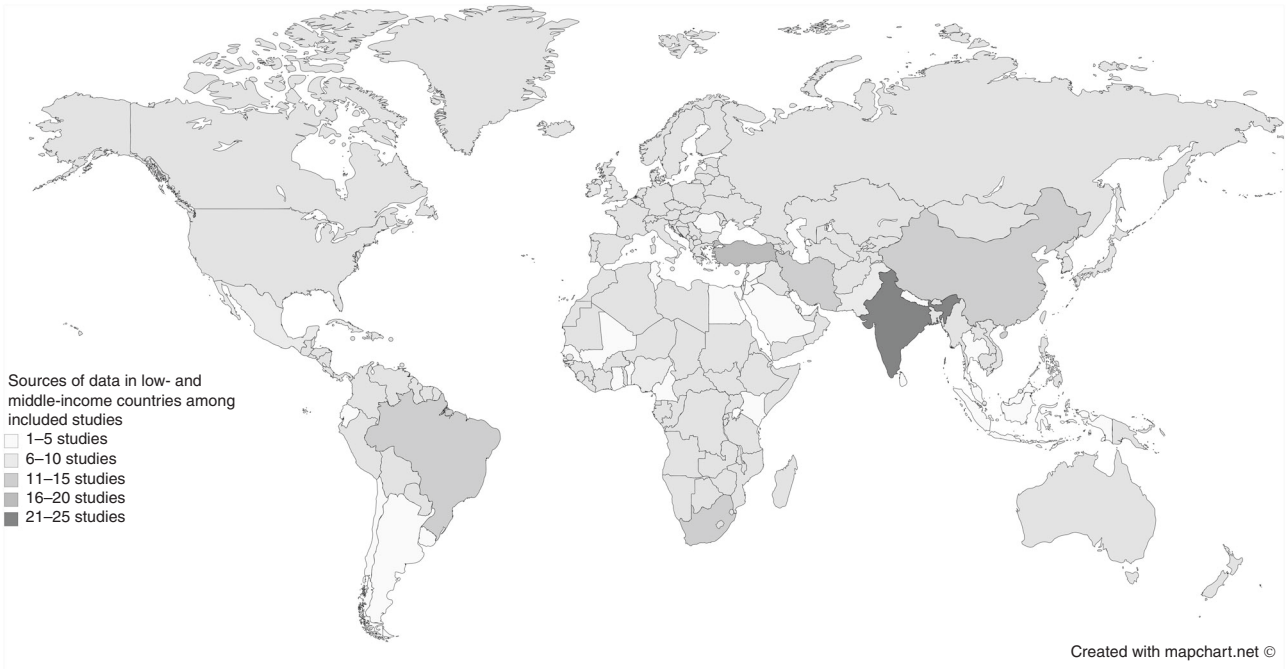

Fig. 2 Sources of data in low- and middle-income countries (LMICs) among included studies. This map shows the sources of data among the included studies in the systematic review

Theme 4. Genetic services are difficult to access. Financial barriers were reported to be a common hindrance to patients' acceptance and utilization of genetic services.[41,50,69,78,80,85,89,91,95,102,116,119,125–134] Although insurance coverage and subsidies paid by the government in some LMICs improve access to these services, high cost of genetic services remains a barrier, especially for low-income and rural patients.[83,116,125,135–137] When genetic services are not widely available, patients often must travel long distances to access them, incurring high costs.[41,83,85,117,129,137] It is also a financial challenge for the healthcare system to provide the services to meet demand.[48,54,99,109]

Many patients do not undergo genetic testing due to their perception that genetic disorders cannot be treated.[49,60,61,102,138] The perceived lack of medical support and treatment options also contributes the decision to terminate a pregnancy after a positive prenatal diagnosis.[132,139,140]

Theme 5. Social determinants affect uptake and understanding of genetic services. Awareness and knowledge of genetic diseases and genetic services is correlated with education and socioeconomic status.[48,127,130,141–146] Educated individuals seek out diverse resources to understand their condition, including service providers, websites, and books; conversely, those with lower literacy ask fewer questions, and find it challenging to cope.[48] Simplified communication tools, such as charts, and using lay terminology in the local language, can overcome socioeconomic barriers and improve understanding.[83,91,147]

Acceptability of genetic testing and counseling is also positively correlated with education and socioeconomic status.[29,53,83,90,97,126,148–150] Individuals from rural areas and from lower socioeconomic backgrounds face financial and other challenges in accessing genetic services or termination of pregnancy.[85,116,137]

Theme 6. Social stigma is often associated with genetic disease. Patients worry about the effects of social stigma associated with genetic disease.[46,48,67,74,76,77,81,103,119,144,151–156] Patients are hesitant to disclose their genetic results to extended family and community, and many experience social isolation after such disclosure.[76,77,81,103,134,152,155] Affected individuals and their families experience discrimination when seeking marriage prospects.[48,57,81,103,134,154] The negative portrayal of genetic diseases in the media (e.g., "children who should not have been born") is a significant factor contributing to stigma.[70,91]

Cultural issues

Theme 7. Family values are at risk of disruption by genetic services. For many families, having an "ideal family size" is important to family planning.[78,89,102,137,139,145,157,158] Regardless of the number of children affected by a genetic disease, families continue to have more children so that the number of healthy children reflects the average family size in the general population.[102,145]

Family members and spouses, especially mothers-in-law and husbands, hold strong influence over decisions following prenatal diagnosis.[31,46,55,59,86,122,139–141,144,152,159] The Western model of individual autonomy may not be appropriate for collectivist cultures, where the individual's choice incorporates opinions of others.[65,74,89,122,152,160] Patients often feel it is

the clinician's responsibility to inform their family members of their risk;[59,74,76,88,103,134,144,153,160–162] however, clinicians often feel this is the patient's role.[55,88,163] Where consanguinity is common, family members are primarily in control of marriage and reproductive decisions.[68,164] Consanguineous couples are often less aware of genetic risks than nonconsanguineous couples.[131,157,165,166]

Women often face family pressure to give birth to healthy children, and experience blame when a child is born with a genetic disease.[46,48,49,80,86,139,143,157,167] Marital problems, including divorce, often occur if a child is affected or if the wife is a carrier.[78,86] Where arranged marriages are common, women with carrier status have fewer marriage prospects.[48,57,75,81,132,134,168]

Theme 8. Religious principles pose barriers to acceptability and utilization of genetic services. A number of studies identify religious principles that oppose termination of pregnancy as significant barriers to acceptance and utilization of genetic services.[29,45,47,69,89,97,128,134,148,151,167,169–171] Some individuals are hesitant to utilize genetic services to avoid the recommendation to terminate a pregnancy.[45]

In Islam, *fatwas* (religious laws) guide decisions regarding termination of pregnancy, dependent on the severity of the condition and gestational age.[134,172,173] In Pakistan, *fatwas* allow for termination of pregnancy in cases where the healthcare professional advises it.[154,172,174]

Theme 9. Cultural beliefs and practices influence uptake of information and understanding of genetic disease. Karma, curses, superstitions related to certain behaviors during pregnancy, and perceived punishment from God are commonly held beliefs regarding the origins of genetic diseases.[46,51,67,72,74,78,139,143,160,164,175,176] Without a biological understanding of genetic disease, cultural beliefs can deeply affect attitudes toward affected individuals.[136,175] Cultural beliefs are more familiar, and traditional medicine is more accessible in the community.[143,177] Traditional healers are viewed as integral members of the community, with affordable and relatable service; they may be the health service provider of choice due to a perception that there is nothing more effective available.[143]

Cultural beliefs and practices may impede understanding of genetics.[47,57,72,178,179] Cultural beliefs can be effectively integrated and confronted in the clinical setting. Clinicians can directly speak about these misconceptions to assuage guilt.[91] Incorporating traditional cultural practices, such as symbols, can facilitate understanding of genetics among patients.[161]

The social ecological model for improvement of genetic services

The nine themes were mapped onto the five levels of the social ecological model: individual, interpersonal, institutional/organizational, community, and public policy (Fig. 3).

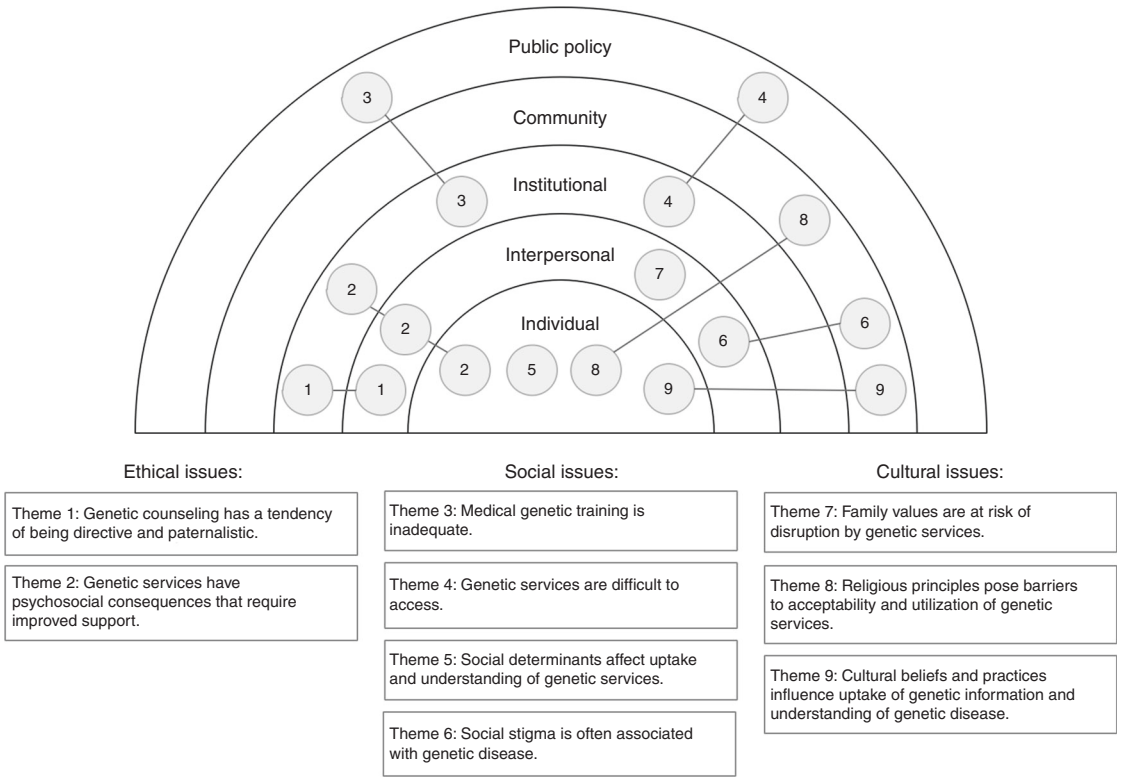

Fig. 3 Social ecological model of identified ethical, social, and cultural issues related to clinical genetic testing and counseling in low- and middle-income countries (LMICs). The five levels of the social ecological model (individual, interpersonal, institutional, community, and public policy) and the corresponding ethical, social, and cultural issues identified through this systematic review

At the individual level, a patient's socioeconomic status (theme 5), religious principles (theme 8), cultural beliefs (theme 9), and psychosocial wellbeing (theme 2) were all factors that shaped attitudes toward and affect access to genetic services. Interpersonal factors included the effect of family values (theme 7), psychosocial effects on family members (theme 2), marriage prospects (theme 6), and directive counseling (theme 1). Institutional/organizational factors were issues regarding genetic service provision and affordability (theme 4), lack of clinical guidelines for genetic counseling (theme 3), lack of psychosocial support (theme 2), and the eugenic tendency of genetic services (theme 1). At the community level, issues include social stigma of individuals and families with genetic disease (theme 6), religious principles (theme 8), and cultural beliefs and practices (theme 9). Factors at the public policy level include inadequate medical training and guidelines (theme 3), and healthcare costs for genetic services (theme 4).

DISCUSSION

Genetic counseling is an educational and communication process for individuals and families who have, or may be at risk for, a genetic disease. It is meant to help families cope with their disease, and understand the meaning and consequences of genetic testing. In many parts of the world, largely in HICs, genetic counseling is a formal process, delivered by professionals with graduate degrees in genetic counseling or medical genetics. In LMICs, genetic counseling is generally delivered less systematically; healthcare practitioners have limited training in genetics, and the added knowledge provided from genetic testing is often not available in those settings.

Yet, things are changing. The introduction of genomic technology in LMICs is expanding capacity in clinical genetic testing and genomic research with the potential to revolutionize the understanding, care, and clinical treatment for communicable and noncommunicable diseases.[180–182] However, without sufficient attention paid to the ethical, social, and cultural implications of such services, technological advances may fall short of their potential. Our narrative synthesis uncovered a number of ethical, social, and cultural issues that are associated with genetic services in LMICs, with implications for implementation and delivery of such services. On the ethical side, the study revealed that genetic counseling in LMICs is often paternalistic, potentially threatening patient autonomy. Also, communication of genetic health information can have serious psychosocial consequences for the patient, and it is unclear if the appropriate supports are in place to support patient psychological wellbeing. In terms of social issues, genetics education of medical professionals is limited, and patients face difficulty accessing genetic services. Furthermore, uptake and understanding of genetic risks are affected by social determinants, and individuals face social stigma related to having a genetic disease. Regarding culture, religion and local customs may pose barriers to uptake of genetic services and understanding of results, while family structure and unity may become threatened by communication of genetic testing results.

The World Health Organization (WHO) provides some guidance on the implementation of community genetic services in LMICs to prevent congenital disorders and genetic diseases.[183] Our findings were consistent with several issues outlined in the WHO report, such as financial barriers that limit access to genetic services, legal restrictions surrounding abortion, inadequacy of medical training in clinical genetics, stigmatization of individuals with genetic disease, and lack of standardization or practice guidelines for genetic testing.[183] While the WHO report emphasizes the need to sensitize health professionals, public policy makers, and general public to these issues, there are no additional recommendations for how to address these issues.

The social ecological model may be one way to surpass the limitations of the WHO report and provide a practical way forward in implementing genetic services in LMICs. The social ecological model is a theory-based framework that recognizes the dynamic interrelation of an individual's health and wellbeing with their greater environmental, social, and cultural context.[39,40] Our use of the social ecological model to frame the issues identified in this study revealed how future recommendations for policy and practice can maximize the potential for service improvement, namely by targeting multiple levels of influence (Fig. 3). For example, on the public policy level, introducing medical practice guidelines for both genetic testing and counseling could change clinical practice (institutional level), including the issue of directive counseling within the patient–clinician relationship (interpersonal level). Additionally, policy changes to government health insurance schemes to include coverage of genetic testing could tackle the financial barriers associated with accessing genetic services. Admittedly, LMICs may contend with various political, social, or economic barriers that may make this difficult or a lower priority.

At the community level, public health advocacy and awareness could increase the general public's acknowledgement of genetic services as both valuable and beneficial. Community health workers (CHWs) could be involved advocacy and other aspects of genetic health service delivery. In many LMICs, CHWs have been shown to be cost-effective in facilitating healthcare access and utilization for populations in resource-limited areas.[184] CHWs have improved disease prevention and long-term screening for noncommunicable diseases.[185] In India, the establishment of a community genetic outreach worker to raise awareness of autosomal recessive disorders associated with consanguinity, support affected individuals, identify families at risk, and increase uptake of local genetic services demonstrated a successful and sustainable community-based genetic service model.[186]

At the institutional level, effective coordination and referral between psychosocial services and genetic counseling could help support individuals and families in coping with disease. Increasing awareness for genetic testing at the institutional

level could increase demand and thus streamline operating costs of laboratories. It is imperative also to identify in which LMICs formal medical genetics and genetic counseling programs are offered, to help address training gaps, potentially through international collaboration. Additionally, inclusion of more genetics education into the curriculum of medical professional training can improve clinician awareness and competency when dealing with genetic diseases (improving care on the interpersonal level). Specialized training could assist in dispelling myths and stigma surrounding genetic diseases.

The effects of a genetic diagnosis extend beyond the individual concerned and affect their interpersonal sphere. Western models of individual informed consent have been challenged in some LMICs; for instance, in India, the ethical guideline in health research states that the entire family must give permission for a woman to participate in a study.[187] A study on Asian and Pacific Islander culture describes decision-making as a family-oriented and shared process, where physicians have adapted their communication approach to ensure that all family members receive equivalent health information.[188] These interpersonal models of counseling may be key to eliminating stigma and family conflict that are commonly reported consequences of a positive genetic diagnosis.

One potential limitation of this study is that the issues uncovered may be representative of individuals from a higher socioeconomic status, given that they are likeliest to access genetic services in the first place. Furthermore, by limiting the review to English language studies published in peer-reviewed journals, we may have missed important insights from non-English language or gray literature. A major strength of our study is the diverse collection of articles and methodologies it referenced, which facilitated capture of ethical, social, and cultural factors from a variety of perspectives (e.g., patient, health provider, etc.). It is also relevant to note that the issues identified in our review may not be exclusively relevant to LMICs; our End-User Committee highlighted that human experiences of genetic services can be universal and, in their experience, the issues identified in this review are also relevant in HICs, where clinical genetic services have become the standard care. Finally, the fact that the majority of studies uncovered by our systematic review were quantitative in nature suggests that the literature falls short of adequately addressing the psychosocial and behavioral issues that could influence implementation and uptake of genetic services. This is a challenge that could be overcome by conducting more qualitative studies to explore knowledge gaps.

In summary, our study is an important first step toward informing the development of evidence-based, ethical, and culturally appropriate genetic services in LMICs. As genetic testing and counseling become the norm in LMICs, it will become necessary to prioritize ethical, social, and cultural issues of genetic services alongside scientific and technological development to ensure patients with genetic disorders in LMICs receive the highest quality of clinical care.

ELECTRONIC SUPPLEMENTARY MATERIAL

The online version of this article (https://doi.org/10.1038/s41436-018-0090-9) contains supplementary material, which is available to authorized users.

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DISCLOSURE

The authors declare no conflict of interest.

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