



Bridging the Gap: Genetic Counseling, Islamic Bioethics, Challenges, and Recommendations

Iqra Javaid¹, Abdul Mannan², Mariam Khan³, Aliza Fatima⁴, Muhammad Danish⁵

¹COMSATS University, Islamabad, Pakistan.

²University of Health Sciences, Lahore, Pakistan

³Bahauddin Zakariya University, Multan, Pakistan

⁴Bahawal Victoria Hospital, Bahawalpur, Punjab, Pakistan.

⁵Shahida Islam Nursing College, Lodhran, Punjab, Pakistan.

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Correspondence to: Iqra Javaid, Genetic Counselor, COMSATS University Islamabad, Pakistan.

Bahawalpur Victoria Hospital, P.O Box 63100, Bahawalpur, Pakistan.

Email: javidiqra@77gmail.com

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ABSTRACT

This paper examines the intersection between genetic counseling, testing, and Islamic bioethics, with a particular emphasis on the challenges faced by Muslim communities and the often neglected experiences of migrants and refugees. In predominantly Muslim nations, the high prevalence of consanguineous marriages significantly contributes to the burden of genetic disorders such as sickle cell anaemia and β -thalassemia. While advancements in genetic testing and prenatal diagnostics have improved early detection, there remain significant gaps in ethical guidance, accessibility, and training. Muslim communities face additional challenges, including language barriers, cultural displacement, and inconsistent healthcare. This study investigates these gaps, explores emerging ethical issues associated with technologies such as CRISPR, and proposes frameworks for culturally sensitive genetic counseling.

INTRODUCTION

Genetic counseling is a patient-centered communication practice with the objectives of facilitating individuals and knowledge to enable autonomous decision-making regarding genetic disorder (Almarri et al., 2021). In Muslim communities, this practice intersects with cultural norms and Islamic bioethics, presenting unique barriers and challenges (Bhattacharya et al., 2023). Consanguineous marriages are highly prevalent in Muslim nations, with the highest rates observed in North Africa, the Middle East, Central Asia, and South Asia; these unions significantly increase the risk of congenital anomalies and autosomal recessive disorders (Goundali et al., 2022). These marriages are highly regarded, particularly due to marital stability and reduced divorce risk, as they promote greater compatibility between spouses and other family members and foster a more affectionate relationship within the family. Consequently, such unions are respected because they strengthen family

ties, promote family stability, and reduce dowry requirements (Shoaib et al., 2023). Consanguineous marriages are influenced by multiple factors, including large families, young age at the time of marriage, lower educational attainment, rural location, unemployment, family consent, social standing, monogamous marriage, and lower socioeconomic status. Younger couples are more likely to engage in interfamilial marriages due to economic factors and less complex arrangements (Khayat et al., 2024). Therefore, genetic counseling is of pivotal in Muslim communities due to the prevalence of consanguineous marriages, which elevate the risk of genetic disorders.

Furthermore, Islamic teachings emphasize the significance of acquiring knowledge and implementing preventive measures to protect health for present and future generations. Genetic counseling for prenatal, pediatric, premarital, and cancer-related issues is of significant importance globally in promoting health and



well-being. However, prenatal genetic counseling is particularly crucial in the Arab world to mitigate the high incidence of genetic disorders in future generations (Cuckle & Maymon, 2020).⁵ Prenatal diagnosis confirms the presence of birth defects in the fetus, significantly affects a pregnant woman's health, and may potentially influence her decision to continue the pregnancy (Brun et al., 2024).⁹ The primary objective of prenatal genetic counseling is to enable couples to make informed decisions regarding reproduction, termination, and health management.

Ethnic minorities groups may experience reduced access to healthcare facilities, suboptimal treatment, stigmatization, discriminatory encounters, and challenges in accessing culturally sensitive genetic counseling due to cross-cultural communication barriers, trauma, and less patient engagement (Vela et al., 2022). The Islamic Jurisprudence Council of the World Islamic League provides consensus on hereditary illness prevention and management in Islamic society, endorsing molecular genetics, abortion, bioengineering, and premarital medical screening (Matthews et al., 2021). Despite this, Muslim countries remain significantly underrepresented in genome-wide association studies, and limited training for healthcare providers hinders the effective delivery of services (Eltyeb et al., 2024). This review aims to address these gaps and provide actionable recommendations for improving genetic counseling in Muslim communities and displaced populations.

Genetic Disorders in Muslim Communities

Muslims constitute approximately one-quarter of the global population, with significant and diverse communities situated in regions such as the Middle East, Northern Africa, and South Asia. In addition, a substantial minority population also exists in Europe and North America (Naofal et al., 2023). The prevalence of congenital and genetic disorders in Arab countries is high because genetic testing services are inadequate. The risks of genetic disorders, including spinal muscular atrophy, pseudo rheumatoid dysplasia, Down syndrome, and epilepsy, were determined to be approximately 20 percent higher in consanguineous marriages. (Younis et al., 2018). Several studies have indicated a strong correlation between genetic disorders and consanguinity, detrimental effects on reproductive health, and an increased incidence of affected offspring (Shaheen et al., 2014). Conditions such as β -thalassemia, sickle cell anemia, Tay-Sachs disease, and cystic fibrosis are prevalent in Muslim countries (Alshamlani et al., 2024). For instance, the United Arab Emirates, Bahrain, Saudi Arabia, and Pakistan have recently implemented mandatory premarital screening tests for marriage licenses. Prospective couples are required to undergo screening for common genetic blood disorders and infectious diseases, including thalassemia, sickle cell anemia, cystic fibrosis, hepatitis B, hepatitis C, and HIV/AIDS, prior to marriage (Saffi et al., 2015).

Despite these efforts, acceptance of genetic counseling remains low. The majority of couples identified as unaware of the inheritance patterns and risk factors of genetic diseases proceed with marriage despite

counseling, which poses additional challenges for implementing genetic services for this population (Yousefi, 2012). Migrants and refugees face even greater risks due to language barriers, lack of legal status, fear of deportation, disrupted healthcare access, and absence of familial medical histories, rendering them particularly vulnerable. Consequently, health professionals consider religion an essential coping strategy for assisting Muslim patients in accepting their diagnosis (Bakur et al., 2020) and enhancing their psychological well-being.

Islamic Bioethics

Islamic bioethics provides a foundation for addressing the ethical challenges of genetic counseling. For adherents of Islam, religious beliefs and values are informed by the Shari'ah, which etymologically signifies "way to the water" and refers to Islamic moral law. Shari'ah emphasizes guidance concerning obligations and duties, harm prevention, and the preservation of dignity, which aligns with the objectives of genetic counseling (Arda & Rispler, 2011). U \mathring{u} l al-fiqh, the science of Islamic ethico-legal knowledge and moral reasoning, derives fiqh (law) from material sources, specifically the Quran and Sunnah (Prophet Muhammad practices), as well as formal sources (Mohiuddin et al., 2020).

Variability in Fatawa

A total of 16 fatwas were found, which provided certain conditions for the permissibility of genetic testing and termination of pregnancy. Termination of pregnancy before the 120th day of gestation (ensoulment) is often permitted according to fatwa in cases of severe fetal anomalies but remains forbidden after this period (Matary et al., 2014). The lack of a centralized clergy in Islam and inconsistencies in fatawa can lead to confusion for families and clinicians (Shoab et al., 2023). Standardizing guidelines through collaboration among medical professionals, Islamic religious scholars, and bioethics boards can provide high-quality clinical care free from prejudice and facilitate clearer decision-making (Cortezzo et al., 2023).

Emerging Ethical Challenges

Clustered regularly interspaced short palindromic repeats (CRISPR) and CRISPR-associated protein 9 (CRISPR-Cas9) represent some of the most promising emerging technologies that have been employed to prevent a diverse array of genetic diseases, including β -thalassemia, hemophilia A, cystic fibrosis, and Duchenne Muscular Dystrophy (Yusof, 2017). However, their application in human embryos and reproductive cells raises significant concerns, particularly regarding the potential for genetic mutations such as mosaicism in offspring (Segers, 2023), thus introducing new complex ethical considerations (Wiley et al., 2024). The CRISPR-Cas9 technique alters and modifies human genomes, which may be interpreted as altering God's creation and is consequently considered a violation of Islamic principles (Alsomali & Hussein, 2023). As CRISPR/Cas9-mediated human germline editing has the potential to modify the human genome in ways that are heritable, the question of its permissibility necessitates thorough and careful consideration from an Islamic perspective (Isa et al., 2020). An additional ethical concern

is the potential presence of undesired mutations in the twin genomes due to the occurrence of both modified and unmodified cells in their bodies, potentially causing off-target effects or mosaicism, and incomplete modification in one twin, which may result in health complications for the children (Reyes & Lanner, 2017; Isa et al., 2020). These concerns emphasize the need for further research to mitigate the risk of genetic mutations in future clinical applications involving human embryos.

While these genetic tools offer the potential for identifying and preventing genetic disorders, they necessitate evaluation within Islamic frameworks to ensure alignment with ethical guidelines, oversight, and additional policies to improve health and prevent disease.

Challenges Faced by Migrants and Refugees

Muslim migrants and refugees experience health-related disparities and encounter barriers in accessing genetic counseling. The identified obstacles for providing genetic testing include limited knowledge of cultural variations, social stigma, and language barriers, which impede patient engagement. Legal restrictions and financial constraints in host countries further exacerbate these challenges. The use of co-design model in healthcare enhances patient engagement and fosters trust between Muslim communities, including refugees and immigrants, and counselors (Martin et al., 2020; Pimentel et al., 2019). Implementing co-design also addresses crucial challenges by bridging cultural and linguistic gaps that impede effective communication and trust between patients and providers.

Trauma-informed care is essential for addressing health-related burdens of displaced populations. Genetic counseling for migrants needs to account for their experiences of loss, separation from extended families, and limited understanding of local healthcare systems (Sheteet al., 2024). Incorporating culturally sensitive genetic counseling and modifying or developing new researched strategies is necessary to overcome these barriers for ethnically and racially diverse populations (Fan et al., 2018).

Training for Genetic Counselors

Genetic counselors should be equipped to provide appropriate services. The absence of culturally sensitive training approaches to address personal implicit biases represents a significant gap in genetic counseling (Handtke et al., 2019). Training programs must incorporate Islamic bioethics, cultural competence, and effective communication strategies to overcome limitations associated with practicing genetic counseling in languages other than English (Altemura et al., 2018). Genetic counselors should address religious concerns in a non-judgmental manner by establishing a relationship with patients through clear and empathetic communication, maintaining a non-directive yet culturally congruent approach (Abacan et al., 2018). Strategies such as implementing tailored interventions through standardized guidelines, enhancing public awareness, and comprehending cultural considerations are essential to address the challenges of genetic counseling in the Middle East (Tayoun & Rehm, 2018).

The development of counselor training modules through collaboration with Islamic scholars and understanding the legal frameworks in Muslim-majority countries can prepare counselors to navigate complex bioethical dilemmas and clinical challenges. Specifically, preconception counseling, antenatal testing, termination of pregnancy, and emerging technologies are critical considerations in Muslim populations (Shoib, 2024). Consequently, a more profound understanding of Islamic religious perspectives can assist counselors in providing medical treatment that aligns with patients religious and cultural values (Shoib et al., 2023).

Public Awareness and Education

Awareness of genetic counseling (GC) and the counselor profession influences access to genetic services for Muslim communities. Low genetic literacy and stigma surrounding genetic diseases constitute significant barriers among them. Public awareness campaigns, education about genomics, and family health history can reduce disparities and improve acceptance of genetic services (Maio et al., 2013).

Programs such as premarital screening in Saudi Arabia, Pakistan, and Qatar can identify and decrease the prevalence of certain genetic diseases by demonstrating the effectiveness of targeted education. Public awareness about the importance and effectiveness of telemedicine among the general population is very necessary (Talmesany et al., 2023). Adapting telehealth options for migrant and refugee populations, including the utilization of telecommunication methods such as videoconferencing and telephone counseling, as well as partnerships with non-governmental organizations (NGOs), can expand their impact (Danylchuk et al., 2021).

RECOMMENDATIONS

Improving access to genetic counseling necessitates policy interventions and addressing clinical barriers. Integrating genetic diagnosis and screening into primary healthcare routines through population-based testing is essential for Muslim (Dusic et al., 2022). Expanding access to genetic testing and counseling through subsidies can mitigate financial barriers, while the integration of telehealth services can connect underserved populations to clinicians, with reported benefits including enhanced individual convenience, reduced travel time, and associated costs (Breen et al., 2022; Dratch et al., 2021). Moreover, telehealth counseling enhances genetic healthcare inclusivity and efficiency, potentially improving health outcomes and quality of life for a wider population (Gilbert et al., 2021). Individual intervention strategies can increase the diagnosis of fetal hereditary risk, ensure accessibility of genetic testing uptake, and facilitate subsequent follow-up care (Bednar et al., 2022; McCuaig et al., 2018).

By addressing health inequities through the reduction of financial barriers for Muslim communities and improving individual genomic literacy will empower them to make informed health decisions. Language discrepancy between patient and genetic counselor is a unique attribute that warrants consideration in counseling. Therefore, culturally trained counselors equipped with

multilingual capabilities can address geographic challenges for remote areas (Mills et al., 2021).

CONCLUSION

Genetic counseling in Muslim communities necessitates addressing disparities in accessibility, ethics, and professional development to meet the requirements of both migrant populations and established communities. By incorporating Islamic bioethical principles, establishing culturally appropriate training programs, and enhancing

service accessibility, healthcare professionals can improve the quality and equity of genetic counseling services. Future initiatives in healthcare ethics and accessibility should prioritize the development and implementation of standardized ethical protocols across medical institutions to ensure consistent, high-quality care for all patients, regardless of geographical location or socioeconomic status. Furthermore, enhancing public awareness regarding healthcare rights, available resources, and informed decision-making processes is crucial.

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