GENES, ETHICS, AND LAWS: UNRAVELLING THE COMPLEXITIES OF GENETIC COUNSELLING IN INDIA

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ABSTRACT

Genetic Counselling (*hereinafter referred to as* "GC"), introduced in India in 2007, remains underutilized despite its significant potential to mitigate risks and complications associated with the country's substantial burden of genetic disorders. As of June 2023, India has only 76 genetic counsellors to serve a population of 1.3 billion, compared to approximately 4,000 counsellors in the United States for a population of 0.3 billion. This disparity underscores the systemic challenges impeding the adoption of GC in India, even as the prevalence of genetic conditions such as congenital malformations, G6PD deficiency, down syndrome, beta-thalassemia, and late-onset multifactorial diseases continues to rise. The limited adoption of GC in India is attributed to several factors, including low public awareness, high costs that make it inaccessible to many, ethical complexities, and legal challenges related to privacy, autonomy, confidentiality, and the lack of a unified regulatory framework. The Author through this research aims to critically examines the current state of GC in India, with a focus on its accessibility, ethical considerations, and legal challenges. By comparing India's approach with international practices, the study aims to identify barriers and propose actionable strategies to enhance the reach and efficacy of GC services, addressing the pressing genetic health needs of the Indian population.

INTRODUCTION

GC is a specialized professional service that provides individuals and families with comprehensive information, guidance, and support regarding genetic conditions and their potential health implications. The primary objective of GC is to enable individuals to make well-informed decisions concerning their health, reproductive choices, and the potential inheritance or transmission of genetic conditions. By elucidating complex genetic concepts, GC facilitates an understanding of risks and aids individuals in navigating available options to achieve optimal health outcomes. The GC program was introduced in India in 2007. However, as of June 2023, there are only 76 genetic counsellors available to cater to India's vast population of 1.3 billion. In comparison, the United States of America has approximately 4000 genetic counsellors for a population of 0.3 billion[1]. The shortage of genetic counsellors in India cannot be attributed to a lack of demand, in contrast, the available data suggests that effective GC shall help in mitigating risks associated to genetic conditions considering the increased number of genetic diseases found in the Indian population.

> *"Annually, it is estimated that approximately 495,000 infants are born with congenital malformations, 390,000 with G6PD deficiency, 21,400 with Down syndrome, 9,000 with beta-thalassemia, 5,200 with sickle cell disease, and 9,760 with amino acid disorders. Additionally, there is a significant prevalence of late-onset multifactorial conditions, including coronary artery disease, diabetes, hypertension, and psychiatric disorders."* [2]

A young couple sought GC before planning their next pregnancy, worried about the recurrence of Autism Spectrum Disorder in their four-year-old son, who had ASD, ADHD, seizures, and other clinical features. Initial genetic tests were inconclusive, but whole exome sequencing identified a de novo pathogenic variant in the *CHD8* gene, associated with intellectual developmental disorder with autism and macrocephaly. This confirmed the sporadic nature of the condition, reducing the recurrence risk to 1-2%. Chorionic villus sampling during the next pregnancy confirmed the foetus was unaffected, and the couple welcomed a healthy child.[3] The

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[1] Abacan, MaryAnn, et al. "The global state of the genetic counseling profession." European Journal of Human Genetics 27.2 (2019): 183-197.

[2] Verma, I. C., and S. Bijarnia. "The burden of genetic disorders in India and a framework for community control." *Community Genetics* 5.3 (2002): 192-196.

[3] "Genetic Counseling in Mumbai, Genetic Experts in Mumbai, India." *Geneticsinindia.com*, 2018, geneticsinindia.com/case-studies.php. Accessed 20 Jan. 2025.

case study highlights the role of GC in mitigating risks and complications, however, the adoption of GC in India remains limited and unsung due to several factors: *firstly,* there is a lack of awareness and sensitization among the population regarding GC, resulting in many individuals being unaware of its availability and benefits[4]; *secondly*, the high cost of GC services renders them inaccessible to the lower-income segments of the population; *thirdly,* GC presents ethical challenges[5]; and *fourthly*, GC faces numerous legal challenges, including issues related to privacy, autonomy, confidentiality, and equity, largely due to the absence of a unified framework to regulate and guide its practices[6].

The Author through this research aims to critically analyse the current state of GC in India, focusing on its accessibility, ethical and legal challenges, and public awareness. The research seeks to evaluate the barriers limiting the adoption of GC, compare the Indian framework with international practices, and explore potential strategies to improve the reach and effectiveness of GC services in addressing the growing burden of genetic disorders in the country.

GENETIC COUNSELLING IN INDIA

GC in India has evolved significantly since its introduction in 2007, yet it remains largely underutilized due to systemic barriers such as inadequate awareness, accessibility issues, and ethical and legal complexities. Historically, genetic services in India existed in a fragmented manner before the formal establishment of GC programs, primarily through medical genetics departments in select institutions. With technological advancements and increasing recognition of genetic disorders, institutions such as the All India Institute of Medical Sciences and the Centre for DNA Fingerprinting and Diagnostics spearheaded initiatives to provide GC services.[7] Despite these efforts, the shortage of trained genetic counsellors has hindered its widespread adoption. As of June 2023, India has only 76 certified genetic counsellors for a population of 1.3 billion, compared to approximately 4,000 counsellors in the United States for a population of 0.3 billion.[8] This disparity highlights the urgent need to strengthen the GC

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[4] Wainstein, Tasha, et al. "Experiences with genetic counseling, testing, and diagnosis among adolescents with a genetic condition: a scoping review." *JAMA pediatrics* 176.2 (2022): 185-195.

[5] Scriver, Charles R. "Assessing Genetic Risks: Implications for Health and Social Policy." *American Journal of Human Genetics* 56.3 (1995): 814.

[6] Suter, Sonia. "Legal challenges in genetics, including duty to warn and genetic discrimination." Cold Spring Harbor Perspectives in Medicine 10.4 (2020): a036665.

[7] Abdi, Ghloamareza, et al. "Revolutionizing Genomics: Exploring the Potential of Next-Generation Sequencing." *Advances in Bioinformatics*. Singapore: Springer Nature Singapore, 2024. 1-33.

[8] *Id* at §1

infrastructure in India, especially given the country's rising burden of genetic disorders, including congenital anomalies, beta-thalassemia, sickle cell disease, and late-onset multifactorial conditions such as diabetes and coronary artery disease.[9]

Legal Framework Surrounding Genetic Counselling

GC in India operates within a fragmented regulatory framework, as there is no single, comprehensive legislation governing the profession. Instead, various laws regulate different aspects of genetic counselling, including prenatal diagnostic techniques, assisted reproductive technology, data protection, and disability rights. While these laws provide a partial framework for ethical and legal considerations in GC, the absence of a unified legal structure has resulted in inconsistencies in its accessibility and practice.[10] Unlike countries such as the United States, which have well-defined regulations for genetic counselling professionals, India lacks a standardized approach to regulating the profession, leading to challenges in professional accreditation, ethical accountability, and service delivery.[11]

The Pre-Conception and Pre-Natal Diagnostic Techniques (Prohibition of Sex Selection) Act, 1994 (*hereinafter referred to as "**PCPNDT Act**"*) plays a crucial role in regulating genetic testing during pregnancy.[12] Enacted to prevent the misuse of prenatal diagnostic techniques for sex selection, the Act mandates strict guidelines for genetic testing in pregnant women. It requires that all genetic counselling centres, laboratories, and clinics be registered and prohibits the use of genetic testing for non-medical purposes, such as determining the sex of a foetus. Furthermore, the Act mandates that genetic counselling and prenatal testing can only be performed under specific medical conditions, such as when there is a high risk of genetic disorders.[13] While the PCPNDT Act helps prevent unethical practices, its stringent restrictions can sometimes hinder access to necessary genetic counselling services.[14] The absence of clear

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[9] Noor, Farjana Akther, Kaiissar Mannoor, And Hossain Uddin Shekhar. "Beta And Hbe/Beta Thalassemia: The Most Common Congenital Hemoglobinopathies In South Asia." *Trends In Biochemistry And Molecular Biology*: 183.

[10] Modell, Bernadette, and Aamra Darr. "Genetic counselling and customary consanguineous marriage." *Nature Reviews Genetics* 3.3 (2002): 225-229.

[11] Bowles Biesecker, Barbara, and Theresa M. Marteau. "The future of genetic counselling: an international perspective." *Nature genetics* 22.2 (1999): 133-137.

[12] Patnaik, A. Murali Mohan, and Gouri Shankar Kejriwal. "A perspective on the PCPNDT Act." *Indian Journal of Radiology and Imaging* 22.02 (2012): 137-140.

[13] Mohanty, Tapan Ranjan. "Law, Liberty and Life: A Discursive Analysis of the PCPNDT Act." *Rev. Eletronica Direito Sociedade* 3 (2015): 97.

[14] Tandon, Neha Pruthi, et al. "The unmet needs of PCPNDT act in the women of the general population in North India." *International Journal of Community Medicine and Public Health* 7.12 (2020): 5044.

guidelines distinguishing legitimate medical genetic counselling from potential misuse for sex selection creates ambiguity for genetic counsellors and medical professionals.

In the domain of fertility treatments, the Assisted Reproductive Technology (Regulation) Act, 2021 (*hereinafter referred to as "**ART Act**")* plays a significant role in regulating genetic testing in assisted reproduction.[15] This Act governs procedures such as in-vitro fertilization and mandates ethical guidelines for pre-implantation genetic testing. It requires informed consent from individuals undergoing genetic screening and emphasizes the role of genetic counselling in helping couples understand the implications of genetic testing before embryo implantation. However, despite its regulatory framework, the ART Act does not provide specific accreditation requirements for genetic counsellors, leading to inconsistencies in service delivery.[16] Unlike in the United States, where genetic counsellors are certified professionals with well-defined roles[17], India lacks a standardized qualification framework for genetic counsellors under the ART Act. This gap results in variability in counselling quality, affecting patients' ability to make fully informed reproductive decisions.

The increasing reliance on genetic testing and digital health records has raised concerns about the privacy and security of genetic data. The Digital Personal Data Protection Act, 2023, along with the Information Technology Act, 2000, classifies genetic data as "sensitive personal data" and mandates strict safeguards for its collection, processing, and storage.[18] These laws require genetic counselling centres to obtain explicit consent before collecting genetic information and ensure that such data is not shared or processed without the individual's authorization. Additionally, individuals have the right to access and correct their genetic information under the Digital Personal Data Protection Act, reinforcing principles of autonomy and confidentiality.[19] However, while these laws provide a broad framework for data privacy, their enforcement across India's genetic counselling landscape remains inconsistent, especially in private healthcare settings where data protection policies may not be uniformly implemented.

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[15] Kashyap, Soumya, and Priyanka Tripathi. "Assisted Reproductive Technology (Regulation) Act 2021: Critique and Contestations." *Asian Bioethics Review* 16.2 (2024): 149-164.

[16] Banerjee, Sneha, and Prabha Kotiswaran. "Regulating reproductive technologies: A blow to inclusive family forms." *Economic and Political Weekly* 56.25 (2021): 21-24.

[17] Zuckerman, Shachar. "The emergence of the "genetic counseling" profession as a counteraction to past eugenic concepts and practices." *Bioethics* 35.6 (2021): 528-539.

[18] Tyagi, Amit Kumar, ed. *Privacy Preservation of Genomic and Medical Data*. John Wiley & Sons, 2023.

[19] Coquet, Margaux, and Nuria Terrado-Ortuño. "Forensic DNA phenotyping: Privacy breach, bias reification and the pitfalls of abstract assessments of rights." *International Journal of Police Science & Management* 25.3 (2023): 262-279.

The lack of clear sector-specific data protection regulations for genetic counselling further adds to the complexity of ensuring patient confidentiality in genetic health services.

Another critical legislation impacting genetic counselling is the Rights of Persons with Disabilities Act, 2016, which recognizes genetic disorders as a category of disability.[20] This recognition emphasizes the importance of early genetic diagnosis and counselling to provide appropriate healthcare and support for individuals with genetic conditions. The Act mandates that healthcare services, including genetic counselling, should be made accessible to individuals with disabilities and promotes awareness campaigns on genetic disorders to improve public understanding.[21] However, accessibility to genetic counselling services remains a major challenge, particularly in rural and underserved areas, where trained professionals and infrastructure are limited. Despite the Act's provisions, there is still no state-funded national genetic counselling program that ensures equitable access to these services for individuals at risk of genetic disorders.

Initiatives by the Government

In terms of accessibility, GC services in India are concentrated in metropolitan areas, leaving a significant portion of the rural and semi-urban population without access. The cost of GC services further exacerbates the issue, with sessions ranging between INR 5,000 and INR 25,000, making them unaffordable for lower-income groups, especially in the absence of insurance coverage. Government initiatives such as the *Rashtriya Bal Swasthya Karyakram* (*hereinafter referred to as "**RBSK**"*)[22] aim to provide genetic screening and counselling for children, but these efforts remain limited in scope. Some non-profit organizations, like the *Organization for Rare Diseases India*, have been actively working to increase awareness and advocate for improved GC services.[23] Additionally, private healthcare providers have begun

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[20] Singh, Chandan, Yogendra Pandey, And Dinesh Kumar. "Types Of Disability As Per Rights Of Persons With Disabilities Act, 2016: A Theoretical Perspective." *European Journal Of Special Education Research* 7.3 (2021).

[21] Wolbring, Gregor, and Lucy Diep. "The discussions around precision genetic engineering: Role of and impact on disabled people." *Laws* 5.3 (2016): 37.

[22] Singh, Arun K., et al. "Moving from survival to healthy survival through child health screening and early intervention services under Rashtriya Bal Swasthya Karyakram (RBSK)." *The Indian Journal of Pediatrics* 82 (2015): 1012-1018.

[23] Kumar, Niraj, et al. "Challenges, barriers, and good practices in the implementation of Rashtriya Bal Swasthya Karyakram in Jodhpur, India." *Annals of the National Academy of Medical Sciences (India)* 57.04 (2021): 237-243.

offering tele-genetic counselling to enhance accessibility; however, these services are often costly and limited to those with internet access.

ETHICAL AND LEGAL ISSUES IN GENETIC COUNSELLING

Ethical Issues in Genetic Counselling

Genetic Counselling involves intricate ethical dilemmas, as it deals with highly personal and predictive medical information.[24] Ethical principles such as autonomy, beneficence, non-maleficence, and justice guide the practice of GC.[25] However, challenges arise when these principles come into conflict with societal, familial, or regulatory considerations.

Autonomy and Informed Consent

A fundamental ethical principle in GC is respect for patient autonomy, which requires that individuals make voluntary and informed decisions regarding genetic testing and the disclosure of genetic information.[26] Genetic tests can reveal predispositions to serious conditions, and individuals must have the right to decide whether they want to undergo testing and what information they wish to receive.[27] The principle of informed consent is central to ensuring autonomy in GC. Patients must fully understand the purpose, risks, benefits, and limitations of genetic testing before making a decision.[28] However, in India, low public awareness about genetics and limited genetic literacy often pose barriers to informed consent. Many individuals may not fully comprehend the probabilistic nature of genetic risk, leading to potential misinterpretations or undue anxiety about test results. Moreover, in cases of prenatal genetic counselling, family and societal pressures can sometimes override an individual's autonomous decision-making, particularly in patriarchal family structures.[29]

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[24] Vinson, Norman, and Janice Singer. "Getting to the source of ethical issues." *Empirical Software Engineering* 6.4 (2001): 293-297.

[25] Harper, Joyce, et al. "Current issues in medically assisted reproduction and genetics in Europe: research, clinical practice, ethics, legal issues and policy." *Human Reproduction* 29.8 (2014): 1603-1609.

[26] Loriga, Leandro. "The right to choose: A comparative analysis of patient autonomy and body integrity dysphoria among Czech healthcare professionals." *Ethics & Bioethics* 14.1-2 (2024): 41-60.

[27] Quill, Timothy E., and Howard Brody. "Physician recommendations and patient autonomy: finding a balance between physician power and patient choice." *Annals of internal medicine* 125.9 (1996): 763-769.

[28] Tonelli, Mark R., and Cheryl J. Misak. "Compromised autonomy and the seriously ill patient." *Chest* 137.4 (2010): 926-931.

[29] Gupta, Jyotsna Agnihotri. "Exploring Indian women's reproductive decision-making regarding prenatal testing." *Culture, health & sexuality* 12.2 (2010): 191-204.

Confidentiality and Privacy of Genetic Information

Genetic information is highly sensitive, as it does not only affect the individual but also their biological relatives. Maintaining strict confidentiality is essential to protect individuals from potential discrimination or stigma.[30] Ethical concerns arise when genetic information is shared with family members, insurers, or employers without the patient's explicit consent. One major ethical dilemma is whether genetic counsellors should disclose genetic risks to at-risk family members when a patient refuses to do so. For example, if an individual tests positive for a hereditary cancer syndrome but chooses not to inform their siblings, the counsellor faces a conflict between respecting patient confidentiality and preventing potential harm to others.[31] While international guidelines suggest that disclosure should be encouraged but not forced, Indian law does not provide clear directives on such situations, leading to ethical ambiguity for genetic counsellors. Additionally, the rapid growth of genomic databases and digital genetic records has raised concerns about data privacy. If genetic data is not adequately protected, it could be misused by third parties such as insurance companies or employers, leading to genetic discrimination, a situation where individuals face differential treatment based on their genetic predisposition to certain diseases.[32] In India, while the Digital Personal Data Protection Act, 2023, and the IT Act, 2000, provide some level of protection, there is no specific law governing genetic data privacy, leaving gaps in regulatory oversight.

Non-Directiveness in Genetic Counselling

Ethical GC is based on the principle of non-directiveness, meaning that counsellors should provide information without influencing or coercing the patient's decision. The goal is to empower individuals to make choices aligned with their personal values and circumstances.[33] However, in certain cases, achieving true non-directiveness can be challenging. For instance, when counselling prospective parents about serious genetic conditions, counsellors may struggle to maintain a neutral stance if they believe that the condition in question would

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[30] Sariyar, Murat, Stephanie Suhr, and Irene Schlünder. "How sensitive is genetic data?." *Biopreservation and biobanking* 15.6 (2017): 494-501.

[31] Kenny, Joanna, et al. "Ethical issues in genetic testing for inherited cancer predisposition syndromes: the potentially conflicting interests of patients and their relatives." *Current Genetic Medicine Reports* 8 (2020): 72-77.

[32] Seaver, Laurie H., et al. "Points to consider to avoid unfair discrimination and the misuse of genetic information: A statement of the American College of Medical Genetics and Genomics (ACMG)." *Genetics in medicine* 24.3 (2022): 512-520.

[33] Arribas-Ayllon, Michael, and Srikant Sarangi. "Counselling uncertainty: genetics professionals' accounts of (non) directiveness and trust/distrust." *Health, risk & society* 16.2 (2014): 171-184.

significantly impact the child's quality of life.[34] Similarly, in cultures where medical decisions are often made by families rather than individuals, ensuring genuine patient choice without external influence can be difficult.[35] In India, societal and familial expectations often play a dominant role in reproductive decisions, which can create moral distress for counsellors attempting to balance respect for autonomy with cultural realities.

Legal Issues in Genetic Counselling

In addition to ethical concerns, GC in India is also shaped by various legal challenges, particularly regarding reproductive rights, genetic discrimination, medical liability, and data protection. The absence of a dedicated Genetic Counselling Act means that GC is governed by a combination of existing laws, many of which do not fully address the complexities of modern genetic testing.

Legal Regulation of Genetic Testing and Reproductive Rights

Genetic counselling is closely linked to reproductive decision-making, particularly in cases where genetic disorders may be passed on to offspring.[36] However, the legal framework surrounding prenatal genetic testing in India is primarily shaped by the PCPNDT Act, which strictly regulates prenatal diagnostic procedures to prevent sex-selective abortions. While the PCPNDT Act serves an important purpose, its stringent regulations have also created barriers for genetic counselling in prenatal settings.[37] Genetic tests that detect serious inherited conditions such as thalassemia, cystic fibrosis, or down syndrome are subject to bureaucratic restrictions, making it difficult for couples to access necessary genetic information.[38] Furthermore, the Act does not distinguish between ethical genetic screening for medical purposes and its potential misuse for sex selection, leading to legal uncertainties for medical practitioners. The Medical Termination of Pregnancy Act, 1971 (as amended in 2021) (*hereinafter referred to as "**MTP Act**"*) also intersects with GC, as it governs abortion rights in India. If a foetus is diagnosed with a severe genetic disorder, parents may seek termination

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[34] Moore, Jordan Elaine Mallory. *Moral Distress in Genetic Counseling Imposed by Colleagues and Patients*. MS thesis. The University of Oklahoma Health Sciences Center, 2024.

[35] Smets, Ellen, Myra van Zwieten, and Susan Michie. "Comparing genetic counseling with non-genetic health care interactions: two of a kind?." *Patient Education and Counseling* 68.3 (2007): 225-234.

[36] Shiloh, Shoshana. "Decision-making in the context of genetic risk." *The troubled helix: Social and psychological implications of the new human genetics* (1996): 82-103.

[37] Kipgen, Josephine. "Abortion and Sex-Selective Abortion in India: History, Law, and Policy." *Reproductive Politics in India: The Case of Sex-Selective Abortion*. Cham: Springer International Publishing, 2023. 41-72.

[38] Reilly, Philip. *Genetics, law, and social policy*. Harvard University Press, 1977.

under the MTP Act, which allows abortion for "substantial foetal abnormalities" up to 24 weeks of gestation. However, the law requires approval from a Medical Board, creating procedural delays that can be stressful for parents making time-sensitive decisions.

Genetic Discrimination and Lack of Legal Protections

Genetic discrimination, where individuals face unfair treatment due to their genetic predisposition to a disease is an emerging legal concern worldwide.[39] In countries like the United States, the Genetic Information Non-discrimination Act, 2008, prohibits the use of genetic information in insurance and employment decisions.[40] However, India has no specific law prohibiting genetic discrimination, making individuals vulnerable to unfair denial of health insurance or employment opportunities based on genetic test results. For example, if a person tests positive for a BRCA1 gene mutation (linked to breast cancer), an insurance company could increase premiums or deny coverage, even though the individual may never develop the disease.[41] The lack of legal safeguards places individuals at risk of financial and social disadvantages due to their genetic profile.

Legal Liability of Genetic Counsellors

Genetic counselling involves complex risk assessments, and misinterpretation of genetic test results can have significant consequences. If a counsellor provides inaccurate information or fails to disclose important genetic risks, they may be held legally liable for medical negligence.[42] However, since GC is not formally recognized as a licensed medical profession in India, the legal liability of genetic counsellors remains unclear.[43] In cases where misinterpretation leads to wrongful birth claims, where parents argue that they would have avoided conception had they been properly informed courts in India lack precedent-setting

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[39] Derks-Smeets, I. A. P., et al. "Decision-making on preimplantation genetic diagnosis and prenatal diagnosis: a challenge for couples with hereditary breast and ovarian cancer." *Human Reproduction* 29.5 (2014): 1103-1112.

[40] Beyer, Melissa. "The Genetic Information Non-Discrimination Act: Protecting Privacy and Ensuring Fairness in Health Insurance and Employment Practices." (2009).

[41] Prince, Anya ER. "Prevention for those who can pay: insurance reimbursement of genetic-based preventive interventions in the liminal state between health and disease." *Journal of Law and the Biosciences* 2.2 (2015): 365-395.

[42] Nelson, Heidi D., et al. "Risk assessment, genetic counseling, and genetic testing for BRCA-related cancer in women: a systematic review to update the US Preventive Services Task Force recommendation." *Annals of internal medicine* 160.4 (2014): 255-266.

[43] Weitzel, Jeffrey N., et al. "Genetics, genomics, and cancer risk assessment: state of the art and future directions in the era of personalized medicine." *CA: a cancer journal for clinicians* 61.5 (2011): 327-359.

cases to establish clear legal standards.[44]

CONCLUSION

India lacks a dedicated legal framework that clearly defines the profession's scope, ethical obligations, and professional accreditation standards. The absence of a Genetic Counselling Act results in ambiguity regarding the role of genetic counsellors, their liability in medical decision-making, and the ethical guidelines they must adhere to. Without a standardized regulatory framework, GC services in India remain inconsistent and inaccessible to many who may benefit from them.[45] To address these challenges, India must consider enacting a comprehensive Genetic Counselling Act that establishes clear professional accreditation requirements, defines ethical standards for genetic testing, and integrates GC into public healthcare programs.[46] Such a framework would not only improve the accessibility and effectiveness of genetic counselling services but also ensure that genetic data is handled ethically and securely, ultimately benefiting individuals and families at risk of genetic disorders.

Several challenges continue to hinder the widespread adoption of GC in India. A significant barrier is the lack of public awareness, as many individuals remain unfamiliar with the concept and its benefits, often seeking medical intervention only after a genetic disorder is diagnosed.[47] Moreover, ethical and cultural concerns, including social stigma surrounding genetic conditions and reproductive choices, create resistance to seeking genetic counselling.[48] Legal uncertainties further complicate the landscape, with the absence of standardized guidelines resulting in varied practices across different institutions. Ethical and legal challenges in genetic counselling highlight the need for a more structured regulatory framework in India. Ethical concerns such as patient autonomy, confidentiality, and non-directiveness must be carefully balanced with legal considerations regarding reproductive rights, genetic data protection, and

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[44] Vadaparampil, Susan Thomas, et al. "Psychosocial and behavioral impact of genetic counseling and testing." *Breast Disease* 27.1 (2007): 97-108.

[45] Harper, Peter. *Practical genetic counselling*. CRC Press, 2010.

[46] Patch, Christine, and Anna Middleton. "Genetic counselling in the era of genomic medicine." *British Medical Bulletin* 126.1 (2018): 27-36.

[47] Muthuswamy, Vasantha. "Ethical issues in genetic counselling with special reference to haemoglobinopathies." *Indian Journal of Medical Research* 134.4 (2011): 547-551.

[48] Bowles Biesecker, Barbara, and Theresa M. Marteau. "The future of genetic counselling: an international perspective." *Nature genetics* 22.2 (1999): 133-137.

liability.[49] Addressing these challenges requires a multi-faceted approach. A unified Genetic Counselling Act could provide a structured framework to regulate and streamline GC practices, ensuring consistency and ethical compliance. Expanding training programs to increase the number of certified genetic counsellors is crucial to meeting the rising demand for GC services. Additionally, nationwide public awareness campaigns can help educate individuals about the benefits of genetic counselling, particularly in rural areas where misconceptions about genetic disorders persist.[50] Integrating GC into primary healthcare services would further enhance accessibility, ensuring that individuals receive timely genetic risk assessments and support.[51]

India stands at a critical juncture in its approach to genetic counselling. While advancements in medical genetics and regulatory frameworks have set the foundation for GC, significant gaps remain in awareness, accessibility, affordability, and ethical governance. Strengthening the GC infrastructure through policy reforms, capacity-building, and public engagement is imperative to addressing the country's growing burden of genetic disorders. A concerted effort from the government, healthcare institutions, and civil society will be essential in ensuring that GC becomes a widely accessible and effective service, empowering individuals to make informed health and reproductive decisions.

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[49] Shah, Minit, Nandini Menon, and Ajaykumar Singh. "Genetic counselling in India: The state of affairs." *Cancer Research, Statistics, and Treatment* 6.3 (2023): 484-485.

[50] Bhat, Meenakshi. "Social and cultural issues in genetic counselling." *Journal of Biosciences* 40.2 (2015): 217-220.

[51] Mohanty, Dipika, and Kishalaya Das. "Genetic counselling in tribals in India." *Indian Journal of Medical Research* 134.4 (2011): 561-571.

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4. Banerjee, Sneha, and Prabha Kotiswaran. "Regulating reproductive technologies: A blow to inclusive family forms." *Economic and Political Weekly* 56.25 (2021): 21-24.

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10. Genetic Counseling in Mumbai, Genetic Experts in Mumbai, India. *Geneticsinindia.com*, 2018, geneticsinindia.com/case-studies.php. Accessed 20 Jan. 2025.

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14. Kashyap, Soumya, and Priyanka Tripathi. "Assisted Reproductive Technology (Regulation) Act 2021: Critique and Contestations." *Asian Bioethics Review* 16.2 (2024): 149-164.
15. Kenny, Joanna, et al. "Ethical issues in genetic testing for inherited cancer predisposition syndromes: the potentially conflicting interests of patients and their relatives." *Current Genetic Medicine Reports* 8 (2020): 72-77.
16. Kipgen, Josephine. "Abortion and Sex-Selective Abortion in India: History, Law, and Policy." *Reproductive Politics in India: The Case of Sex-Selective Abortion*. Cham: Springer International Publishing, 2023. 41-72.
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21. Mohanty, Tapan Ranjan. "Law, Liberty and Life: A Discursive Analysis of the PCPNDT Act." *Rev. Eletronica Direito Sociedade* 3 (2015): 97.

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