

Awareness and Perceived Importance of Genetic Counseling in the Prevention and Management of Genetic Disorders among Residents of Derna District, Libya

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ABSTRACT

Purpose: Genetic counseling plays an important role in identifying individuals and families at risk of inherited disorders and supporting informed reproductive and healthcare decisions. In Libya, evidence regarding public awareness and attitudes toward genetic counseling remains limited. This study assessed awareness, attitudes, and perceived barriers related to genetic counseling among residents of Derna District.

Materials and Methods: A descriptive cross-sectional study was conducted among 278 participants aged 17–45 years in Derna District, Libya. Data were collected using a structured questionnaire covering sociodemographic characteristics, awareness and self-rated knowledge of genetic counseling, attitudes toward its use, and perceived barriers to access. Data were analyzed using SPSS version 26.0 and summarized using descriptive statistics.

Results: The mean age of participants was 24.65 ± 4.70 years; 79.9% were female and 93.5% had university-level education. Overall, 58.3% had previously heard of genetic counseling, while 65.5% rated their knowledge as moderate, good, or excellent. Most participants considered genetic counseling important in preventing or reducing the risk of genetic disorders (90.6%), and 90.3% stated that they would consider undergoing counseling if recommended by a physician. In addition, 79.1% supported premarital genetic counseling. The most frequently reported barriers were fear of results (39.9%), lack of awareness (30.9%), high cost (20.1%), and cultural beliefs (18.0%).

Conclusion: Participants demonstrated generally favorable attitudes toward genetic counseling, although important gaps in awareness and several psychosocial, financial, and cultural barriers remain. Targeted public education, culturally appropriate communication, and improved access to affordable genetic counseling services may support informed reproductive and healthcare decision-making in Derna District. (*Open J Biomed Res* 2026;5:131-138)

Keywords: Genetic counseling, awareness, attitudes, genetic disorders, premarital counseling, Derna.

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AUDIOABSTRACT



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INTRODUCTION

Congenital and genetic disorders represent an important global public health concern. The World Health Organization estimates that approximately 240,000 newborns die each year within the first 28 days of life because of congenital disorders.¹ Although congenital disorders may arise from genetic, environmental, infectious, nutritional, or multifactorial causes, advances in genetics and genomic medicine have improved the ability to identify individuals and families at increased risk of inherited conditions and to provide appropriate screening, diagnosis, risk assessment, and preventive or risk-reducing interventions.

Genetic counseling is a patient-centered communication process through which trained professionals help individuals and families understand the medical, psychological, and familial implications of genetic conditions. It includes assessment of personal and family history, estimation of genetic and recurrence risks, explanation of available genetic tests, and support for informed and autonomous decision-making.² Depending on the clinical situation, genetic counseling may assist individuals and couples with carrier screening, prenatal testing and diagnosis, reproductive planning, and medical management of hereditary conditions.³⁻⁵ It may also support risk assessment and surveillance decisions in disorders such as hereditary cancers.⁶

The public health importance of genetic counseling is particularly evident in populations where inherited disorders are relatively common or where consanguineous marriage is prevalent. Consanguinity increases the likelihood that both partners carry the same pathogenic recessive variant and, consequently, increases the risk of autosomal recessive disorders among their offspring.⁷ In such settings, genetic counseling and appropriate screening can help identify at-risk individuals

and couples and enable them to make informed decisions regarding reproduction, testing, and healthcare. Genetic counseling should therefore be viewed not as a means of preventing all genetic disorders directly, but as an important component of risk identification, informed reproductive decision-making, early diagnosis, and appropriate disease management.

Despite advances in genomic medicine, access to genetic counseling services remains uneven across different regions of the world. In several Middle Eastern and North African countries, the availability of trained genetic counselors and specialized genetic services remains limited.⁸ Regional studies have also identified gaps in public knowledge and several barriers to the use of genetic services. For example, research conducted in Egypt reported limited genetic knowledge among a substantial proportion of participants and identified concerns about test results, financial cost, and personal beliefs as possible barriers to seeking genetic services.⁹ Similarly, studies of premarital screening in Saudi Arabia have highlighted the importance of public beliefs and attitudes in determining acceptance and use of preventive genetic services.¹⁰

Evidence from Libya is still limited. A 2024 study among students at the University of Tripoli found generally positive attitudes toward premarital screening, although knowledge of the specific hereditary diseases targeted by such programs was limited. The study also noted that genetic testing and counseling services were not widely available in Libya.¹¹ However, because the study focused on university students in Tripoli, its findings cannot be assumed to represent other populations or regions of the country. In particular, there is limited published evidence concerning awareness and perceptions of genetic counseling among residents of Derna District.

Therefore, this study aims to assess the level of awareness of genetic counseling among residents of Derna District, evaluate their perceptions of its importance in the prevention and management of genetic disorders, and identify perceived barriers to accessing genetic counseling services. The findings may provide locally relevant evidence to support public education initiatives and future planning of genetic counseling and related healthcare services in the district.

MATERIALS AND METHODS

Study Design

This study employed a descriptive cross-sectional design to assess awareness, attitudes, and perceived barriers related to genetic counseling among residents of Derna District, Libya. The cross-sectional approach was considered appropriate because it allows data to be collected from a defined

population at a specific point in time, thereby providing an overview of existing levels of knowledge, perceptions, and attitudes toward genetic counseling.

The study was conducted in accordance with accepted ethical principles for research involving human participants. Before participation, individuals were informed about the purpose of the study, the nature of their involvement, and their rights as participants. Participation was entirely voluntary, and respondents were informed that they could decline to answer any question or withdraw from the study at any time. Written informed consent was obtained from all participants before data collection. Confidentiality and anonymity were maintained throughout the study, and collected information was used solely for research purposes. The overall study framework is presented in Figure 1.

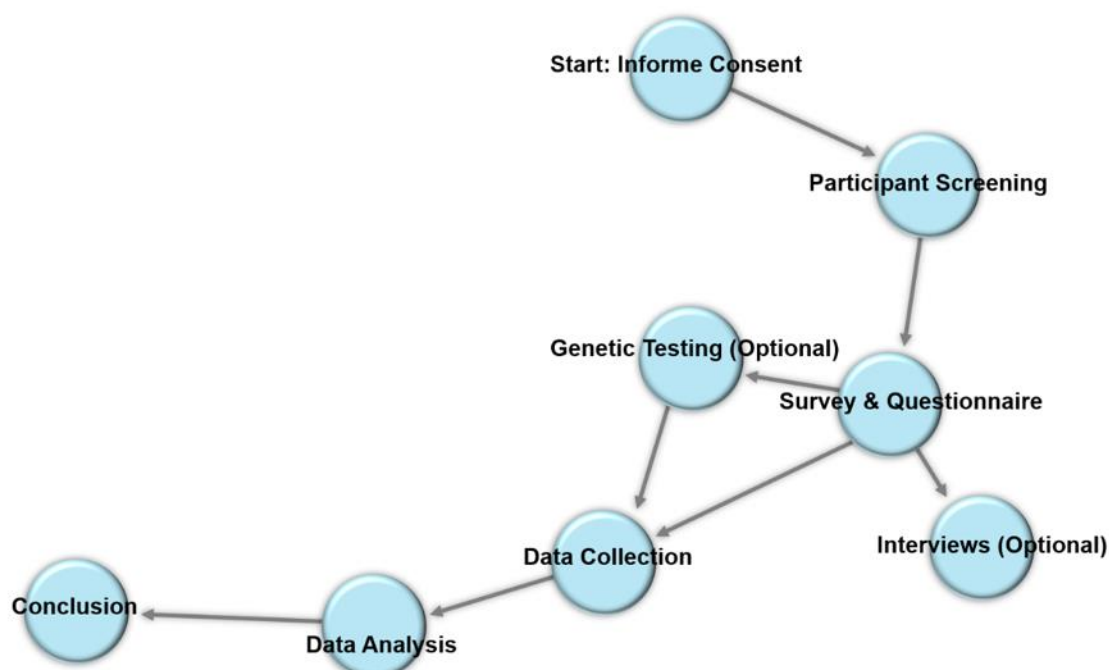


Fig 1. Study design framework for assessing awareness of and attitudes toward genetic counseling among residents of Derna District.

Study Setting and Population

The study was conducted in Derna District in northeastern Libya. The target population consisted of adult residents of the district, with particular attention to individuals of reproductive age, including recently married couples and engaged couples, because genetic counseling may be particularly relevant to decisions concerning marriage, family planning, reproductive risk, and inherited disorders.

A stratified sampling approach was used to obtain participants from different demographic groups and geographical areas within Derna District, including both urban and rural communities. The sampling strategy was intended to improve coverage of population subgroups and reduce the likelihood that the sample would be concentrated within a single demographic or residential category. Particular attention was given to individuals of reproductive age, especially recently married and engaged participants, because these groups may be more likely to encounter decisions in which genetic counseling, premarital screening, or reproductive genetic services are relevant. A total sample of 300 participants was initially targeted. After data collection and screening for completeness and eligibility, 278 participants were included in the final analysis.

Data Collection

Data were collected using a structured questionnaire administered either through face-to-face interviews or by self-administration, depending on participant circumstances. The questionnaire was designed to assess three main domains. The first domain evaluated participants' awareness and knowledge of genetic counseling, including whether they had previously heard of genetic counseling and how they perceived their own level of knowledge. The second domain assessed attitudes toward genetic counseling, including participants' perceptions of its importance and their willingness to use genetic counseling services when appropriate. The third domain

explored perceived barriers that might limit access to or utilization of genetic counseling services.

The questionnaire also collected sociodemographic and background information, including age, gender, educational level, marital status, place of residence, and family history of genetic disorders. These variables were included to allow comparisons in awareness and attitudes across different population subgroups. Eligible participants were approached and provided with an explanation of the study objectives and procedures. After obtaining written informed consent, the questionnaire was completed either independently by the participant or with assistance from the researcher during a structured interview when required. Completed questionnaires were reviewed for completeness before data entry. Questionnaires containing substantial missing information or failing to meet the study eligibility criteria were excluded from the final analysis.

Statistical Analysis

Data were entered, coded, and analyzed using the Statistical Package for the Social Sciences (SPSS), version 26.0. Descriptive statistics were used to summarize participants' characteristics and responses. Categorical variables were presented as frequencies and percentages, while continuous variables were summarized using means and standard deviations where appropriate. Chi-square tests were used, where applicable, to examine associations between categorical sociodemographic characteristics and participants' awareness or attitudes toward genetic counseling. Statistical significance was determined according to the predefined significance level used in the study.

RESULTS

Participant Characteristics

A total of 278 participants were included in the analysis. Their ages ranged from 17 to

45 years, with a mean age of 24.65 ± 4.70 years. Approximately two-thirds of participants were younger than 25 years (67.3%), and females represented the majority of the sample (79.9%). Most participants had a

university-level education (93.5%). The demographic characteristics of the study population are summarized in [Table 1](#).

Table 1: Sociodemographic characteristics of the participants (N = 278).

Characteristic		n	%
Gender	Female	222	79.9
	Male	56	20.1
Age group (years)	<25	187	67.3
	25–35	83	29.9
	>35	8	2.9
Educational level	Secondary	13	4.7
	University	260	93.5
	Postgraduate	5	1.8

A family history of genetic disorders was reported by 71 participants (25.5%), whereas 207 (74.5%) reported no such history ([Table 2](#)).

Table 2: Sociodemographic characteristics of the participants (N = 278).

Family history of genetic disorders	n	%
Yes	71	25.5
No	207	74.5

Awareness and Knowledge of Genetic Counseling

Overall, 162 participants (58.3%) reported that they had previously heard of genetic counseling, while 116 (41.7%) had not. Self-rated knowledge varied considerably: 17.3% described their knowledge as excellent, 24.5% as good, 23.7% as moderate, 13.3% as poor, and 21.2% reported having no knowledge of genetic counseling ([Table 3](#)).

Table 3: Awareness and self-rated knowledge of genetic counseling among participants (N = 278).

Item	Response	n	%
Have you ever heard of genetic counseling?	Yes	162	58.3
	No	116	41.7
How would you rate your knowledge of genetic counseling?	Excellent	48	17.3
	Good	68	24.5
	Moderate	66	23.7
	Poor	37	13.3
	None	59	21.2

Attitudes Toward Genetic Counseling

Participants generally expressed favorable attitudes toward genetic counseling. Most respondents (90.6%) considered genetic counseling important in preventing or reducing the risk of genetic disorders, and a similar proportion (90.3%) indicated that they would

consider undergoing genetic counseling if recommended by a physician. Support was somewhat lower for making genetic counseling mandatory before marriage, although 79.1% of participants agreed with this proposal (Table 4).

Table 4: Participants' attitudes toward genetic counseling (N = 278).

Attitude item	Yes, n (%)	No, n (%)
Genetic counseling is important in preventing or reducing the risk of genetic disorders	252 (90.6)	26 (9.4)
Would undergo genetic counseling if recommended by a physician	251 (90.3)	27 (9.7)
Genetic counseling should be mandatory before marriage	220 (79.1)	58 (20.9)

Perceived Barriers to Genetic Counseling

Fear of receiving unfavorable results was the most frequently reported barrier to genetic counseling (39.9%), followed by lack of awareness (30.9%) and high cost (20.1%). Cultural beliefs were reported by 18.0% of participants (Table 5).

Table 5: Perceived barriers to accessing genetic counseling services (N = 278).

Perceived barrier	n	%
Fear of results	111	39.9
Lack of awareness	86	30.9
High cost	56	20.1
Cultural beliefs	50	18.0

DISCUSSION

This study assessed awareness, attitudes, and perceived barriers related to genetic counseling among residents of Derna District, Libya. Overall, participants expressed favorable attitudes toward genetic counseling, although important gaps in awareness and access-related concerns were identified. While 58.3% of participants had previously heard of genetic counseling, 41.7% had not. In addition, 65.5% rated their knowledge as moderate, good, or

excellent, whereas 34.5% reported poor or no knowledge. Because knowledge was self-rated, these findings reflect perceived rather than objectively measured genetic knowledge.

The awareness findings are broadly consistent with regional evidence showing that public familiarity with genetic services does not necessarily translate into adequate understanding. Studies from Egypt and Saudi Arabia have reported substantial gaps in knowledge despite generally favorable views toward genetic and premarital screening services.^{9,12} The relatively high level of self-reported awareness in the present study may partly reflect the educational profile of the sample, as 93.5% of participants had a university-level education. Nevertheless, the proportion who had never heard of genetic counseling indicates that further public education remains necessary.

Attitudes toward genetic counseling were strongly positive. More than 90% of participants considered genetic counseling important in preventing or reducing the risk of genetic disorders, and a similar proportion stated that they would consider counseling if recommended by a physician. These findings are consistent with Libyan and regional studies reporting favorable attitudes toward premarital screening and genetic counseling.¹⁰⁻¹² In

addition, 79.1% supported making genetic counseling mandatory before marriage. This finding indicates strong perceived importance of premarital genetic services, although it should be interpreted cautiously because genetic counseling is generally based on informed and autonomous decision-making.²

Despite these positive attitudes, several barriers were identified. Fear of results was the most frequently reported barrier (39.9%), followed by lack of awareness (30.9%), high cost (20.1%), and cultural beliefs (18.0%). Similar psychosocial, informational, financial, and cultural barriers have been described in previous studies and systematic reviews of genetic services.^{6,13,14} Fear of receiving unfavorable genetic information may reflect concerns about disease risk, marriage, reproduction, or stigma, while limited awareness may reduce the likelihood that individuals recognize when genetic counseling could be beneficial.

These findings suggest that improving genetic counseling services in Derna should involve more than increasing service availability. Public education, culturally appropriate communication, affordable access, and appropriate psychosocial support may help translate favorable attitudes into informed use of genetic services. Integration of counseling with primary care, premarital screening, and reproductive health services may also improve accessibility.

This study has several limitations. The sample was predominantly young, female, and university educated, which may limit generalizability to the wider population of Derna District. The cross-sectional design captures perceptions at a single point in time and does not allow causal conclusions. In addition, reliance on self-reported knowledge and attitudes may have introduced recall or social-desirability bias. Future studies should include more demographically balanced samples and use validated objective measures of genetic knowledge.

Despite these limitations, the study provides useful local evidence on perceptions of genetic counseling in Derna. The combination

of high stated acceptance and identifiable informational, psychological, financial, and cultural barriers highlights the need for targeted educational initiatives and accessible, culturally appropriate genetic counseling services.

CONCLUSION

This study found generally favorable perceptions of genetic counseling among residents of Derna District, with most participants expressing positive attitudes and willingness to use such services when recommended by a physician; however, important gaps in awareness remain, as a substantial proportion had never heard of genetic counseling or reported limited knowledge. Fear of genetic test results and lack of awareness were the most commonly reported barriers, followed by financial and cultural concerns. These findings highlight the need for targeted public education, culturally appropriate communication, psychosocial support, and improved access to affordable genetic counseling services. The strong support for premarital genetic counseling suggests that such services may be well accepted in the community, although future initiatives should emphasize informed and voluntary decision-making. Strengthening awareness and access to genetic counseling may support better reproductive and healthcare decisions and contribute to improved prevention and management of genetic disorders in Derna District.

AUTHOR CONTRIBUTIONS

Bashir M. Lakhal : Writing – original draft, literature review, investigation, data curation, and manuscript preparation. **Mohammed Al-Ghazali**: Writing – original draft, literature review, investigation, data curation, and manuscript preparation. **Sideena A. Ehmeedah**: Conceptualization, methodology, validation, critical review, writing – review & editing, and final approval of the manuscript.

CONFLICT OF INTEREST

The authors declare no conflicts of interest concerning the research, authorship, and publication of this article.

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