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Public knowledge, awareness, and perception of genetic testing for hereditary diseases in the United Arab Emirates

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Abstract

This study aims to evaluate the awareness, knowledge, and perceptions of genetic testing among residents of the United Arab Emirates (UAE), recognizing the importance of genetic testing in diagnosing and managing hereditary diseases and the variability of public understanding across different populations. A cross-sectional study was conducted from November 2021 to January 2022, targeting UAE residents aged 18 years and older through convenience sampling. The sample size was determined to be 400 participants, based on a 95% confidence level and a 5% margin of error. A validated questionnaire was employed, consisting of four sections: demographics, knowledge, awareness, and perceptions of genetic testing. Data analysis was performed to identify associations with demographic variables. Ethical approval was obtained, and informed consent was secured from all participants. A total of 581 respondents participated in the study, with 73.5% aged between 18 and 26 years and 66.6% holding bachelor's degrees. Among the respondents, 56% had degrees in science-related fields, and 60% reported a family history of genetic diseases, with diabetes (32%), hypercholesterolemia (14%), and thalassemia (12%) being the most common. The study found that awareness of genetic testing was at 69%, and 85.4% acknowledged its role in diagnosing cancers. Furthermore, a significant majority (81.4%) viewed genetic testing as more beneficial than harmful. Notably, younger age, higher education levels, and backgrounds in science were significantly associated with enhanced awareness, knowledge, and positive perceptions of genetic testing. The findings indicate a strong awareness and positive perceptions of genetic testing among UAE residents, particularly among younger and more educated individuals. However, there are notable gaps in detailed knowledge and ethical concerns regarding direct-to-consumer genetic testing, which necessitate further investigation and educational outreach. The study underscores the need for targeted educational initiatives to address the gaps in knowledge and ethical considerations surrounding genetic testing. Additionally, the influence of demographic factors on public understanding and acceptance highlights the importance of developing tailored interventions to maximize the benefits of genetic testing in healthcare settings. This approach can enhance the overall effectiveness of genetic testing as a preventive measure and diagnostic tool in managing hereditary diseases within the UAE population.

Keywords: Congenital abnormalities, Consanguinity, Educational initiatives, Genetic testing, Hereditary diseases, Public awareness, Public health.

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1. Introduction

Genetic disorders are inherited conditions resulting from alterations in deoxyribonucleic acid (DNA), structural changes, or variations in chromosome number [1]. In the United Arab Emirates (UAE), common autosomal recessive conditions among Emirati nationals and residents include thalassemia and sickle cell anemia, which are prevalent due to high rates of consanguinity [2]. Certain cancers, such as breast cancer, are also associated with hereditary factors [3]. Blood-related genetic disorders like thalassemia and sickle cell anemia arise from mutations in specific genes, including those involved in hemoglobin production [2].

2. Literature Review

The prevalence of genetic disorders in the UAE is closely linked to sociocultural factors, particularly consanguineous marriages, which significantly increase the incidence of autosomal recessive disorders. In isolated populations, the introduction of new mutations can elevate the number of carriers and homozygous individuals. Research highlights a high prevalence of genetic and congenital disorders in Arab populations [4], with contributing factors including consanguineous marriages, which significantly raise the incidence of autosomal recessive disorders [5]. The high rate of consanguinity in the UAE, estimated to be between 39% and 54.2%, exacerbates the occurrence of these disorders due to the increased likelihood of homozygous disease-causing variants [5]. This phenomenon is not unique to the UAE; studies across the Arab world have consistently demonstrated a correlation between consanguinity and the prevalence of genetic disorders. For instance, a study in Saudi Arabia reported that consanguineous marriages resulted in a birth defect rate as high as 54.5% [6]. Similarly, the implications of consanguinity on genetic disorders have been documented in other Arab populations, highlighting a regional trend [7].

Additionally, advanced maternal and paternal age are linked to chromosomal abnormalities and dominant mutations, respectively, which can lead to congenital anomalies [4]. Large family sizes further amplify the chances of inheriting recessive disorders, as each additional child increases the risk of genetic transmission [4].

Limited genetic testing facilities in the UAE reflect inadequate venting of genetic disorders during and before pregnancy [8]. Genetic testing is essential for the early detection, prevention, and management of hereditary conditions [9]. However, limited awareness about its significance contributes to the persistent prevalence of these diseases. Although clinical genetic services, including counseling, testing, and diagnosis, are being introduced, public understanding and acceptance of genetic testing in the UAE remain low [9, 10]. Recent advancements in genetic testing, driven by genomic data and technological innovations, offer opportunities to prevent conditions like cancer, cardiovascular diseases, and Type 2 diabetes. Yet, the clinical utility of genomic data and its integration into healthcare remain debated, with health literacy gaps hindering the effective use of genomic risk information [11].

Previous studies have reported low public awareness of genetic testing globally [12, 13], particularly regarding prenatal genetic testing. This underscores the need for enhanced health education, improved facilities, and non-invasive testing methods [11]. In the UAE, the integration of genetic testing into public health strategies is crucial, especially given the cultural context that often influences health-seeking behaviors and perceptions of genetic disorders [2]. This study aims to evaluate the knowledge, awareness, and perceptions of genetic testing for hereditary disorders in the UAE. It further seeks to identify factors affecting public understanding to inform future educational and preventive strategies.

2.1. Objectives

- To assess public awareness, knowledge, and perceptions of genetic testing for hereditary disorders in the UAE.
- To identify factors that influence individuals' perceptions of genetic testing.

3. Methodology

3.1. Study Design

A cross-sectional study was conducted from November 2021 to January 2022, targeting residents of the United Arab Emirates (UAE) using a convenience sampling method. With an estimated population of approximately 10 million, as reported by the UAE Department of Statistics, the required sample size was calculated using the Raosoft sample size calculator (Raosoft, Inc., 2004, http://www.raosoft.com/samplesize.html) with a 95% confidence level and a 5% margin of error [14, 15]. The required sample size was determined to be 385 responses; however, to account for potential redundancies, the target was set at 400 responses.

3.2. Inclusion and Exclusion Criteria

- Inclusion criteria: Individuals of both genders aged 18 years and older.
- Exclusion Criteria: Individuals of both genders aged below 18 years.

3.3. Questionnaire Design

The questionnaire was developed based on insights from validated research studies [16-18]. It was divided into four sections.

1. Demographic Information: Focused on the respondents' demographic characteristics.
2. Knowledge of Genetic Testing: Assessed the respondents' understanding of genetic testing.
3. Awareness of Genetic Testing: Explored respondents' awareness of genetic testing processes and applications.
4. Perception of Genetic Testing: Investigated attitudes and perceptions regarding genetic testing.

3.4. Data Validation

The survey questions were reviewed by three Ph.D. holders in Genetics and Molecular Biology to ensure validity and relevance. Recommendations from these experts led to the inclusion of additional questions to enhance data collection. Their responses were excluded from the final statistical analysis.

3.5. Ethical Considerations

The research was approved by the ethical research committee from Dubai Pharmacy College for Girls (DPC-REC) NO: REC/UG/2021/9. Confidentiality of the respondents' information was strictly maintained. Before participation, respondents were asked to provide informed written consent and were informed that their participation was entirely voluntary and that the study was conducted solely for academic purposes.

4. Results

4.1. Basic Demographic Data

A total of 581 respondents participated in the survey. The majority of respondents (73.5%) were aged between 18 and 26 years. Among the participants, 66.6% held a bachelor's degree, and 56% of these degree holders were from science-related fields.

Additionally, 60% of the respondents reported a family history of genetic diseases. Among these, diabetes was the most common disorder (32%), followed by hypercholesterolemia (14%) and thalassemia (12%).

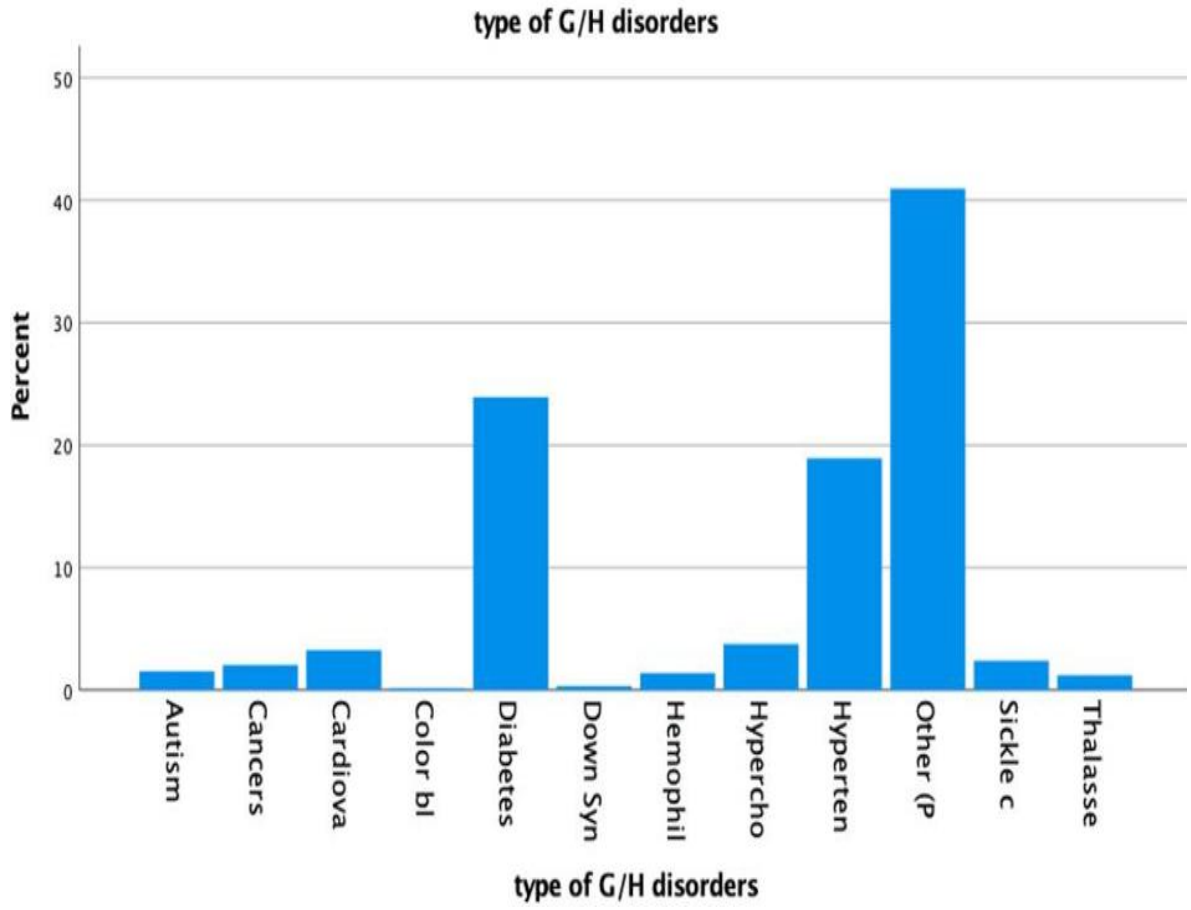

Figure 1.
Family history of various types of genetic disorders among respondents.

Table 1.
Respondents' knowledge regarding genetic testing.

Respondents' knowledge regarding genetic testing	Yes (N, %)	No (N, %)
Did you hear about genetic testing?	401 (69)	180 (31)
Genetic testing has the potential to reduce the occurrence of genetic diseases.	423 (72.8)	158 (27.2)
Genetic testing can help determine an individual's genetic makeup.	410 (70.6)	171 (29.4)
The risk of genetic or hereditary diseases can be predicted using a person's DNA sequence.	477 (82.1)	104 (17.9)
Genetic testing can help detect specific diseases that are hereditary.	490 (84.3)	91 (15.6)
Genetic diseases are transmitted through generations within a family.	470 (80.9)	111 (19.1)
Prenatal diagnosis is the process of testing a fetus or embryo for disorders before birth.	447 (76.9)	134 (23)
During pregnancy, genetic testing can be performed to determine whether the baby will have diseases such as sickle cell disease, thalassemia, or neural tube defects.	478 (82.3)	103 (17.2)
One of the methods used in genetic testing is a blood test or DNA analysis.	452 (77.8)	129 (22.2)
Cancers such as blood cancer and breast cancer can be detected through genetic testing.	496 (85.4)	85 (14.6)

Out of the 581 respondents, 401 (68%) had heard about genetic testing, with the internet being their primary source of information (41%). As shown in Table 1, many respondents recognized that genetic testing could be used to identify genetic or hereditary diseases. Additionally, they were aware that certain types of tumors could also be diagnosed through genetic testing (Table 1).

Table 2.
Respondents' awareness of genetic testing.

Question	Strongly disagree N (%)	Disagree N (%)	Neutral N (%)	Agree N (%)	Strongly agree N (%)
I possess adequate knowledge about genetic testing.	59 (10.2)	57 (9.8)	92 (15.75)	273 (47.8)	92 (15.75)
I would like to undergo genetic testing.	45 (7.7)	18 (3.1)	76 (23.1)	362 (62.4)	76 (23.1)
Genetic testing reduces the risk of developing certain diseases.		155 (26.7)		423 (72.8)	
I understand that not all genetic disorders are curable.	6 (1)	37 (6.4)	206 (35.5)	310 (53.4)	17 (2.9)
Genetic testing could only be performed at a hospital with a doctor's prescription.	36 (6.2)	22 (3.8)	85.5 (14.7)	347 (59.7)	85.5 (14.7)
Genetic testing is available for purchase on the Internet.	62 (10.7)	348 (59.9)	60.5 (10.4)	61 (10.4)	45 (7.7)
Genetic testing can be available in stores.	49 (8.4)	96 (16.5)	61 (10.5)	308 (53)	61 (10.5)
Genetic testing relates to science and medicine.	34 (5.9)	96 (16.5)	173 (29.8)	205 (35.3)	67 (11.5)
There are technologies for recording genetic profiles for various genetic disorders.	37 (6.4)	59 (10.2)	128 (19.7)	247 (42.5)	130 (19.7)
The public perception and awareness of genetic testing are important.	76 (23.1)	76 (23.1)	174 (29.9)	170 (29.3)	80 (13.8)
The lack of education and awareness regarding genetic testing causes ethical problems.	61 (10.4)	93 (16.0)	121 (20.8)	239 (41.1)	61 (10.4)

4.2. Awareness of Genetic Testing for Hereditary Disorders

A majority of respondents (59.7%) believed that genetic testing should be conducted in hospitals under a doctor's supervision, while a significant proportion opposed the availability of genetic testing kits online (59.9%) or in retail stores (16.4%). Additionally, 43.1% of respondents emphasized the importance of public awareness and acceptance of genetic testing (Table 2).

Table 3.
Perception of genetic testing for hereditary disorders.

	Strongly disagree N (%)	Disagree N (%)	Neutral N (%)	Agree N (%)	Strongly agree N (%)
A genetic test is more advantageous than detrimental.	28 (4.75)	28 (4.75)	47 (8.1)	288 (49.6)	185 (31.8)
During pregnancy, genetic testing may be conducted.		100 (17.2)		447 (82.3)	
Genetic testing can help improve an individual's quality of life.	52 (8.95)	118 (20.3)	168 (28.9)	186 (32.0)	52 (8.95)
Newborns should undergo genetic testing.	44 (7.6)	49 (8.4)	149 (25.6)	311 (53.5)	23 (4.0)
Pregnant women should undergo genetic testing.	33 (5.7)	39 (6.7)	194 (33.4)	270 (46.5)	39 (6.7)
Religious beliefs and genetic testing can be seen as contradictory.	71 (12.2)	114 (19.7)	167 (28.7)	109 (18.8)	114 (19.7)

The majority of respondents (81.4%) believed that genetic testing is crucial, as its benefits outweigh potential harms. Furthermore, 57.5% agreed that genetic testing should be mandatory for all newborns, while 53.2% supported its requirement for pregnant mothers (Table 3).

Table 4.
Respondents' knowledge of genetic testing in relation to demographic factors.

Variables	Knowledge level - inadequate	Knowledge level - adequate	Total	P Value
Gender				0.107
Female	70	234	304	
Male	85	189	274	
Age				<0.001
18-25	120	307	407	
25-29	24	55	79	
30-35	21	37	58	
Above 35	12	2	14	
Marital status				0.488
Married	48	93	141	
Unmarried	107	330		
Education status				0.681
Postgraduate	37	94	131	
Graduate	124	261	385	
General secondary	14	40	54	
Primary	2	6	8	
Illiterate	0	0	0	
Field of study				0.033
Science related	48	288	336	
Another field	40	202	242	

Based on the provided Table 4, here is an interpretation of the results regarding respondents' knowledge levels about genetic testing concerning various demographic factors.

Among females, 234 had adequate knowledge, and 70 had inadequate knowledge out of 304 respondents. Among males, 189 had adequate knowledge, and 85 had inadequate knowledge out of 274 respondents. The difference in knowledge levels between males and females was not statistically significant ($p = 0.107$). The majority of respondents aged 18–25 had adequate knowledge (307 out of 407). Respondents in older age groups showed lower levels of adequate knowledge: 25–29 years (55 out of 79), 30–35 years (37 out of 58), and above 35 years (2 out of 14). The difference in knowledge levels across age groups was statistically significant ($p < 0.001$), indicating that younger respondents were more knowledgeable about genetic testing.

93 Married respondents had adequate knowledge, whereas 48 had inadequate knowledge. 330 Unmarried respondents had adequate knowledge, and 107 had inadequate knowledge. The difference in knowledge levels between married and unmarried respondents was not statistically significant ($p = 0.488$). Respondents with postgraduate education had the highest proportion of adequate knowledge (94 out of 131). Graduates also had a significant proportion of adequate knowledge (261 out of 385). Respondents with lower levels of education (general secondary, primary) showed lower levels of adequate knowledge. The difference in knowledge levels based on education status was not statistically significant ($p = 0.681$). Respondents with a science-related field of study had a significantly higher proportion of adequate knowledge (288 out of 336). Those from other fields showed comparatively lower levels of adequate knowledge (202 out of 242). The difference in knowledge levels based on the field of study was statistically significant ($p = 0.033$).

Table 5.
Respondents' awareness of genetic testing in relation to demographic factors.

Variables	Total	P value
Gender		0.187
Female	304	
Male	274	
Age		<0.001
18-25	427	
25-29	78	
30-35	58	
Above 35	15	
Marital status		0.761
Married	141	
Unmarried	437	
Education status		<0.001
Postgraduate	131	
Graduate	385	
General secondary	54	
Primary	8	
Illiterate	0	
Field of study		<0.001
Science related	336	
Another field	242	

Based on the data in Table 5, here is the interpretation of the relationship between demographic variables and awareness of genetic testing.

Respondents aged 18–25 were the largest group (427), followed by those aged 25–29 (78), 30–35 (58), and above 35 (15). Age was significantly associated with awareness levels about genetic testing ($p < 0.001$), indicating that age plays an important role in knowledge acquisition, with younger groups likely having better awareness. Married respondents totaled 141, while unmarried respondents numbered 437. The difference in awareness levels between married and unmarried individuals was not statistically significant ($p = 0.761$). Graduates constituted the largest group (385), followed by postgraduates (131), those with general secondary education (54), and primary education (8). There were no illiterate respondents. Education status had a significant impact on awareness levels ($p < 0.001$), suggesting that higher education correlates with a better understanding of genetic testing. Respondents from science-related fields totaled 336, while those from other fields numbered 242. The field of study was significantly associated with knowledge levels ($p < 0.001$), with science-related fields showing higher awareness.

Table 6.
Respondents' perceptions of genetic testing in relation to demographic factors.

Variables	Total	P value
Gender		0.019
Female	273	
Male	303	
Age		<0.001
18-25	427	
25-29	78	
30-35	57	
Above 35	14	
Marital status		0.006
Married	139	
Unmarried	437	
Education status		<0.001
Postgraduate	129	
Graduate	385	
General secondary	54	
Primary	8	
Illiterate	0	
Field of study		<0.001
Science related	334	
Another field	242	

The analysis of respondents' perceptions of genetic testing in relation to demographic factors revealed significant associations. Gender showed a statistically significant difference (p=0.019), suggesting that perceptions may vary between males and females, possibly influenced by biological or societal roles. Age was a highly significant factor (p<0.001), with younger respondents (18-25 years) dominating the sample, indicating that they might have greater exposure to and acceptance of genetic testing due to familiarity with modern technology and science. Marital status also exhibited a significant difference (p=0.006), with married individuals likely perceiving genetic testing through the lens of family planning or hereditary health concerns. Education level had a profound impact (p<0.001), with postgraduates and graduates showing a greater understanding and acceptance, reflecting the influence of scientific literacy. Lastly, the field of study was a critical determinant (p<0.001), with science-related respondents more supportive of genetic testing, likely due to better awareness and knowledge of its applications and benefits. These findings highlight the importance of demographic factors in shaping perceptions and acceptance of genetic testing (Table 6).

5. Discussion and Findings

This study highlights significant findings on the demographic determinants, awareness, knowledge, and perceptions of genetic testing among respondents. The results indicate a promising level of awareness and acceptance of genetic testing, albeit with some demographic variations.

5.1. Awareness and Knowledge of Genetic Testing

The findings demonstrate that a majority of respondents (69%) had heard about genetic testing, primarily through the Internet (41%), showcasing the importance of digital platforms in spreading awareness. This aligns with previous research emphasizing the Internet as a pivotal tool for public education on genetic technologies [19]. Additionally, over 80% of participants recognized the ability of genetic testing to detect hereditary diseases, predict genetic risks, and diagnose conditions like cancer. This finding concurs with studies highlighting the public's understanding of genetic testing's diagnostic capabilities [20]. However, only 47.8% of participants felt they had sufficient knowledge about genetic testing, indicating a knowledge gap. Educational interventions, particularly in non-science fields, could improve comprehension, as evidenced by the significant association between the field of study and knowledge level ($p = 0.033$) [21, 22].

5.2. Demographic Influence on Knowledge and Awareness

Demographic factors played a critical role in shaping respondents' awareness and knowledge. Younger respondents (aged 18–25) exhibited significantly higher knowledge and awareness ($p < 0.001$). This may reflect greater access to digital resources and education in genetics. Similarly, respondents from science-related fields demonstrated a statistically significant edge in knowledge ($p = 0.033$), underscoring the role of academic background in fostering understanding [23, 24]. Education level was another pivotal factor; graduates and postgraduates showed better awareness and knowledge compared to those with lower education levels, consistent with findings that link education to improved health literacy [25] .

5.3. Perception of Genetic Testing

The majority of respondents (81.4%) perceived genetic testing as more beneficial than harmful. There was strong support for its use during pregnancy (82.3%) and for newborn screening (57.5%), reflecting awareness of its preventive and diagnostic potential. This aligns with reports highlighting public endorsement of genetic screening in prenatal care [16]. Interestingly, perception varied significantly by gender ($p = 0.019$), age ($p < 0.001$), and marital status ($p = 0.006$). Married individuals may view genetic testing through the lens of family health, a perspective supported by studies on family planning and genetic health concerns [17].

5.4. Challenges and Ethical Considerations

Despite the positive outlook, concerns about ethical implications, accessibility, and misinformation persist. Nearly 41.1% of respondents acknowledged the role of education in mitigating ethical issues related to genetic testing. The resistance to online genetic testing kits (59.9%) further indicates apprehensions about accuracy and misuse, consistent with research that highlights the risks associated with direct-to-consumer genetic testing [18, 26].

This study underscores the importance of targeted educational initiatives to bridge the knowledge gap and enhance public understanding of genetic testing, particularly in populations with varying demographic backgrounds.

6. Implications and Recommendations

The findings underscore the need for targeted educational programs, particularly for older adults and non-science professionals, to bridge knowledge gaps. Policy interventions should ensure the regulation of online genetic testing services and promote hospital-based genetic testing under professional supervision to maintain credibility and trust. Furthermore, addressing ethical concerns through public awareness campaigns can enhance acceptance and reduce stigma.

7. Conclusion

In summary, this study provides valuable insights into the awareness, knowledge, and perceptions of genetic testing among residents of the United Arab Emirates (UAE). The findings reveal a commendable level of awareness, particularly among younger individuals and those with higher education, indicating a positive trend towards the acceptance of genetic testing as a crucial tool in the diagnosis and management of hereditary diseases. However, the study also identifies significant

gaps in detailed knowledge regarding the implications and ethical considerations of genetic testing, particularly concerning direct-to-consumer options.

The positive perceptions of genetic testing, coupled with the high recognition of its role in diagnosing conditions such as cancer, suggest that there is a foundation upon which to build further educational initiatives. These initiatives should aim to enhance public understanding of genetic testing, addressing not only the technical aspects but also the ethical implications and potential consequences of genetic information.

Moreover, the influence of demographic factors on awareness and perceptions highlights the necessity for tailored interventions that consider the diverse backgrounds and educational levels of the population. By implementing targeted educational programs and regulatory measures, healthcare providers and policymakers can ensure that the benefits of genetic testing are maximized while minimizing potential risks associated with misinformation and ethical dilemmas.

Ultimately, fostering a well-informed public will enhance the utility of genetic testing in healthcare, leading to improved disease prevention and management strategies. As the field of genetics continues to evolve, ongoing research and dialogue will be essential to adapt educational efforts and policies to the changing landscape of genetic testing and its implications for public health.

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