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ORIGINAL ARTICLE

Perception of the general public towards the ethical and legal issues surrounding DNA paternity testing in Lebanon

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Summary
Background. — DNA paternity testing constitutes a challenging area, particularly in Lebanon where there is no existing law to cover the different aspects of the test. This study aimed at exploring the perception of the general public on the various ethical and legal issues surrounding DNA testing, as an initial elementary step towards creating an appropriate legislative framework for paternity testing in Lebanon.
Methods. — Data were collected from 300 Lebanese individuals aged 18 years and above through an online self-reported questionnaire.
Results. — The majority of the respondents insisted on giving their informed consent prior to DNA testing, regardless who is requesting the test. Around three-quarters of participants think that paternity tests should be carried out in accredited laboratories, and almost all subjects (97.3%) highlighted the importance of creating a Law that regulates paternity tests in Lebanon. In terms of results communication and incidental findings disclosure, 66.3% of participants think that the results should be preferably communicated to the concerned person(s), and 64.0%

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required the presence of a psychologist. The vast majority of respondents prefer to be notified about misattributed paternity (90.3%) with women being significantly less comfortable with the disclosure than men (86.9% vs. 94.4%; $P = 0.0492$). Nevertheless, only 23% of individuals think that such results could be reported without prior consent to their family for the sake of beneficence. Moreover, both men and women had comparable perception towards reporting a misattributed paternity and the risk of violence against women (90.3% vs. 93.8%; $P = 0.28$). Finally, 78.7% of participants accepted the use of residual samples in future genetic analyses, but on condition of anonymity.

Conclusion. — Our findings shed the light on Lebanese individuals' perception towards the protective role of the informed consent and the need for a legislative background in terms of privacy, autonomy, confidentiality, rights and guarantees in the context of DNA paternity testing.

Introduction

DNA Paternity testing has been and still is a contentious area of privacy and consent [1]. In contrast to several countries such as the United Kingdom, France and Australia, where restrictions are made on non-consensual use or appropriation of genetic material, the ease of taking a paternity testing in other countries including Lebanon without the necessity of involving a doctor and/or without the consent of the concerned parties (father, child, etc.) has raised ethical concerns in terms of privacy of the person [2]. Furthermore, there is currently no established law regulating DNA theft in Lebanon, thus enabling any person to have access to another's individual genetic material without its knowledge and permission.

Paternity can be revealed either directly from paternity testing or, in some cases, indirectly while searching for a specific mutation or condition in the family, hence increasing the chance of incidental findings. Misattributed paternity is one of the most common incidental findings that may be encountered by clinicians in a genetic research setting [3]. Existing guidelines about how to handle and report the discovery of misattributed paternity offer contradictory advice, and this may plausibly lead genetic health professionals to vary considerably in their perspectives and practices [4—8]. Most genetic professionals are against disclosure unless there is a clear medical benefit that outweighs the potential harms that may result from revealing the information to the child and the mother [5,8,9]. However, according to bioethicists the disclosure of material information is a general duty for clinicians, and not-disclosing may cause loss of trust in medical professionals [10].

In this regard, regulations and guidelines governing the conduct of genetic research require the presence of an informed consent, considered as one of the most important aspects of bioethics. The purpose behind such a document is to protect the autonomy of a human subject by providing him/her with sufficient information, in a language which is easily understood by him/her, so that he/she can make a voluntary decision regarding ''to'' or ''not to'' realize a test or participate in a research study [11].

Another important step before undertaking a DNA testing is to have a genetic counselling with a specialized clinician. Having such a dialogue would help to ensure that each relevant family member provides truly its informed consent about whether or not he/she would like to proceed with the test, and would explore the potential outcomes of the results on the family members [12].

Legal problems, such as heritage matters and parents' obligations towards their child, may also arise from genetic tests [13—15]. A DNA test result do not stand as evidence. It should be officially recognized so that necessary measures are taken, hence bringing justice and law into the process. In France for example, DNA paternity testing should be solely performed on decision of a judge, and private tests are illegal [16]. In contrast, in other countries including Belgium, Canada, China and Philippines, where home test kits are available, false results can be obtained due to the low sensitivity of the tests [17,18]. In this regard, the presence of accredited laboratories, such as in Australia, Canada, France and Germany [19—24], is very important to provide accurate results and to ensure that confidentiality is respected and information is protected and kept private.

In Lebanon, the subject of genetic testing is regulated by the Law No. 625 drafted by the Lebanese National Consultative Committee on Ethics (LNCCE), and approved by the Ministry of Health, the Council of State and the Council of Ministers. Despite bringing insight to health professionals towards the various applications of genetic and genomic technologies, the law did not tackle regulations of DNA paternity testing [25].

Given the relevance of this ethical dilemma and its significance to the general population, this study was designed to assess the hypotheses that (1) Lebanese individuals acknowledge the importance of the informed consent and the necessity of a legal framework to regulate DNA paternity testing and information disclosure, and (2) women and men have different perceptions towards misattributed paternity disclosure. Addressing the attitudes and concerns of the general public towards the various aspects of DNA paternity testing may broaden the scope of ethical considerations surrounding this topic, and consequently help in

the development of an appropriate legislative framework for paternity testing in Lebanon.

Materials and methods

Study design and population

The study was carried out between May 2019 and May 2020 according to the Declaration of Helsinki and in agreement with standards of the Ethical Committee of the Lebanese University.

The research involved Lebanese individuals aged 18 years and above. The survey was sent to approximately 1000 participants randomly selected (friends/families, university students, professionals, co-workers, etc.). However, only 302 responded and accepted to participate in the research. Two respondents did not meet the inclusion criteria and were therefore excluded from the study.

Questionnaire

Data were collected over the entire period of the research through an online structured questionnaire using Google forms, appended to it the study information and consent form. The link of the questionnaire was sent by e-mail or WhatsApp message to the contacts of the investigators who were encouraged to send the survey to as many people as possible in order to include individuals with different backgrounds and socio-demographic characteristics.

After reading the information sheet, participants were asked to give their explicit consent by indicating that they understand the nature and objectives of the study and they agree to participate voluntarily to the research project. They were then invited to fill out a self-reported questionnaire consisting of 25 items. The first part of the questionnaire included socio-demographic characteristics of participants, mainly their age, gender, civil status, and current status (Student, employed, etc.). The second section focused on participant's perception in terms of ethical and legal aspects and considerations related to genetic research and DNA paternity testing. The questionnaire was reviewed by various experts, including a clinical geneticist and a general practitioner, who have considerable experience in the field.

Confidentiality and privacy of participants' data

In order to preserve the confidentiality and privacy of participants' data, appropriate safeguards were applied during data collection, transfer and storage. Indeed, information collected to meet our research objectives were kept anonymous and did not include personal data such as name, identification number, telephone number, address, etc.. Survey responses were directly exported to a study-specific excel sheet in which data were coded, and records were saved and secured through the use of password protected files to prevent unauthorized access or use of information. Moreover, passwords were appropriately protected and data were only accessible by the principal investigator upon the need. Information related to data protection measures was stated in the informed consent in a clear, accurate and understandable manner.

Table 1 Socio-demographic characteristics of participants.

Variable	*N* (%)
Gender	
Men	176 (58.7)
Women	124 (41.3)
Marital status	
Single	104 (34.7)
Married	185 (61.7)
Divorced	8 (2.6)
Widowed	3 (1.0)
Age group	
18-25	48 (16.0)
26-35	68 (22.7)
36-45	99 (33.0)
46-60	72 (24.0)
>60	13 (4.3)
Work status	
Student	46 (15.3)
Employee	180 (60.0)
Employer	48 (16.0)
Unemployed	26 (8.7)

Statistical analysis

Study data were analyzed using the GraphPad Prism software version 6 (GraphPad Software, Inc., USA). Descriptive statistics were performed for all variables using means, standard deviations, range and frequency analysis. Fisher's exact test was applied to find the association between two categorical variables by comparing frequencies between groups. For all analyses, a 95% confidence level was used, and a P-value < 0.05 was considered statistically significant.

Results

Socio-demographic characteristics of participants

The study included 300 subjects, of whom 58.7% were females and 61.7% were married. The age range 36—45 represented the highest category in the study (33%), and 60.0% of participants were employee. Details related to the socio-demographic characteristics of participants are presented in Table 1.

Informed consent request

The majority of the participants (88.7%) reported that DNA paternity testing should be performed with the consent of all concerned persons (father, mother and the child if aged 18 years or older), and 86.0% think that a fourth person, other than the mother, the alleged father and the child, has not the right to apply for a paternity test without having their own consent. Similarly, 77.3% of participants do not accept

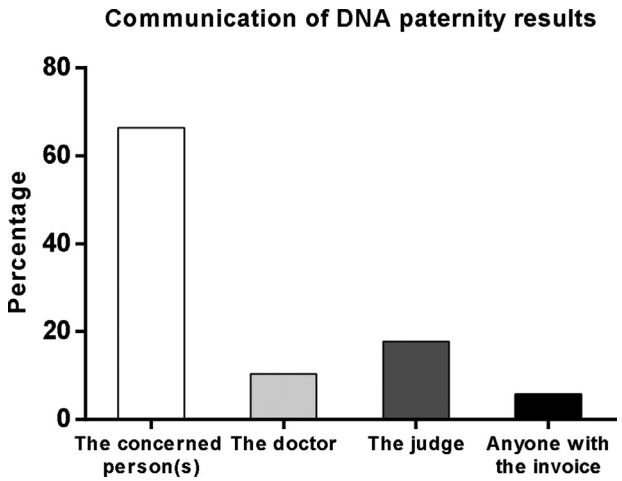

Figure 1. Perception of participants on how DNA paternity results should be preferably communicated.

that the spouse does the paternity test of the child without the consent of the other partner. Finally, a vast majority of participants (95.3%) expressed their rejection towards the extraction of DNA without their consent.

Knowledge and Perception in terms of existing regulations and accredited laboratories

A remarkable percentage of respondents (80%) do not know if there is any existing law that regulates paternity testing in Lebanon, whereas approximately half of the participants (52%) recognized the existence of accredited Laboratories that perform the test in Lebanon. Interestingly, around three-quarters of participants (74.0%) think that paternity tests should be carried out in specialized laboratories approved by the government, and almost all of them perceived the importance of creating a Lebanese Law that regulates genetic tests in general (98.7%) and paternity tests in particular (97.3%). In agreement, 96.7% of subjects prefer to be informed about the new guidelines related to the performed test before analysis.

Communication and disclosure of information

As shown in Fig. 1, 66.3% of participants perceived that results of the paternity test should be preferably communicated to the concerned person(s). Nevertheless, a non-negligible percentage of participants (17.7%) prefer that results be communicated through a judge, if following a trial. Moreover, 64.0% of individuals think that the presence of a psychologist is needed during results communication.

In terms of information disclosure, our findings revealed that the majority of participants (88.3%) do not agree on the right of health professionals to share DNA genetic results with another doctor or with third parties without their written consent. Likewise, 66.0% were against the use of their proper genetic test results or those of the child for the interpretation of DNA tests in other family members without taking their consent, whereas 23.3% stated to give their approval on condition that their identity be hidden.

Interestingly, when it comes to incidental findings that may be encountered in genetic analyses of family members, 90.3% of participants prefer to be notified about unrecognized biological links such as adoption or misattributed paternity. Yet, only 23% of individuals think that such valuable results could be reported without prior consent by the doctor to their family for the sake of beneficence. Unfortunately, 92.3% of participants think that reporting a misattributed paternity result may expose the mother to a risk of violence.

As expected, the analysis of frequency distribution with regard to gender revealed a significantly lower percentage of women who prefer to be notified about misattributed paternity as compared to men ($P = 0.0492$) (Table 2). Nevertheless, both men are and women held comparable perception in terms of non-paternity disclosure and risk of violence against women ($P = 0.28$) (Table 3).

Table 2 Perception of participants towards the desire of being notified about misattributed paternity according to gender.

	Yes *N* (%)	No *N* (%)	*P*-value
Desire of being notified about misattributed paternity			0.0492
Men	117 (94.4)	7 (5.6)	
Women	153 (86.9)	23 (13.1)	

P-value based on Fisher's exact test.

Table 3 Perception of the relationship between misattributed disclosure and risk of violence against women according to participant's gender.

	Yes *N* (%)	No *N* (%)	*P*—value
Misattributed paternity disclosure and risk of violence against women			0.2800
Men	112 (90.3)	12 (9.7)	
Women	165 (93.8)	11 (6.2)	

P-value based on Fisher's exact test.

Collection, storage and use of DNA samples in future research studies

Around two-thirds of the participants (67.7%) reported to know the various biological sources that can be used for DNA isolation and genetic testing. On the other hand, 47.7% preferred that their sample be stored and/or used for future research purposes, rather than being completely destroyed, but on condition of anonymity (Fig. 2). Furthermore, according to 78.7% of subjects it is acceptable to use their stored samples for genetic purposes (identification of new genes and new technologies, validation of technical procedures, etc.) once an authorization is provided (Fig. 3).

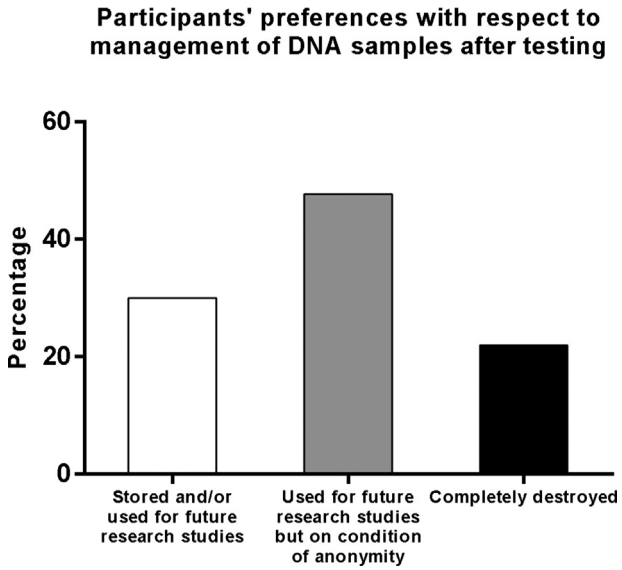

Figure 2. Participants' preferences with respect to management of DNA samples after testing.

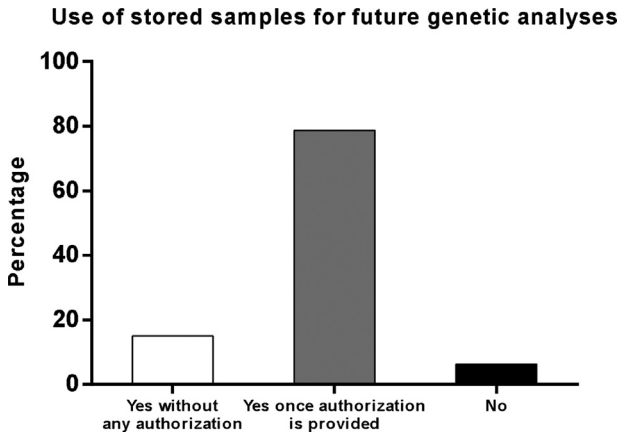

Figure 3. Participants' preferences regarding the use of stored DNA samples for future genetic analyses.

Discussion

To the best of our knowledge, this is the first study to explore the knowledge and attitudes of Lebanese adults towards the ethical and legal aspects associated with DNA paternity testing.

Interestingly, our findings revealed that the majority of the respondents insisted on giving their informed consent prior to DNA extraction and genetic test, as well as before a paternity testing. According to a study conducted by Turney et al. in 2003 on a random sample of 1044 Australians over the age of 18 years, participants undertaking a paternity testing felt more comfortable when all parties have provided their consent [16]. Indeed, many individuals do feel victimized when their DNA is used in ways that were not originally consented for. Therefore, the informed consent may be perceived by individuals as a mean to protect their autonomy and privacy and a document to have access to the information necessary to understand the nature and purpose of the test, its associated risk and benefits, as well as their own rights and guarantees.

On the other hand, most of the participants acknowledged the importance of performing DNA paternity testing in accredited laboratories, and almost all of them were for the creation of a Lebanese Law that regulates genetic paternity tests. Our results are concordant with those reported by Turney and his colleagues who noted that the most important considerations for participants were the « accuracy », « validity » and « confidentiality » of the test itself. Women in particular wanted correct information obtained through legal institutions and accredited laboratories to prove without doubt the paternity of their children [16]. Taken together, our findings support the first hypothesis and highlight the need for establishing a legal framework to create a flexible environment that is conductive to genomic/genetic research and DNA paternity testing.

Even though 66.3% of participants found that it is better to communicate the results directly to the concerned person(s), 17.7% of them preferred that findings be reported through a judge following a trial. This may be attributed to the fact that in Lebanon a DNA paternity testing is mainly requested by a judge to prove biological lineage in families where children are not registered at birth. On the other hand, the majority of respondents did not approve the right of health professionals to share their DNA genetic results with another doctor or with third parties without their written consent. Also, 66.0% were against the use of their proper results or those of the child for the interpretation of DNA tests of other family members without taking their consent. Previous studies have addressed the subjects' concerns related to communication of genetic information to individuals and families [26,27]. They have concluded that findings should be preferably released to the concerned person or to individuals for whom the test recipient has given consent. In addition, the method of communication should be chosen in advance to preserve genetic privacy and minimize the likelihood that results will be shared with unauthorized persons or organizations [28,29]. The misuse of genetic information is an issue often reported because it may lead to discrimination, stigmatization, dignitary concerns, psychological harm and family disruption, particularly in countries where cultures differ widely in their traditions of gender roles, marriage, parenthood, and family life [26,27,29].

The presence of a psychologist while communicating results was recorded by 64.0% of the participants. Indeed, many studies have showed that individuals may experience a significant influence of DNA testing on their psychological wellbeing. Moreover, findings might reveal sensitive information that can damage relationships and cause serious harm to beneficiaries, especially children, hence the necessity of the assistance of a psychologist in this context [30—32].

When addressed about incidental findings disclosure, 90.3% of participants stated that they prefer to be notified about unrecognized biological links such as adoption or misattributed paternity. Only one prior study has addressed the public's attitude regarding disclosure of misattributed paternity [16]. The research conducted on 1000 random Australians revealed a ''higher-than-average'' level of comfort with disclosure of misattributed paternity to the

presumptive biological father. Interestingly, the analysis of frequency distribution revealed a significantly higher percentage of men respondents wishing to be informed about misattributed paternity as compared to women, thus confirming our second hypothesis that women and men have different perceptions towards misattributed paternity disclosure (94.4% *vs.* 86.9%; $P = 0.0492$). This can be attributed to the fact that women are probably afraid of getting violated or murdered in the name of so-called ''honour'' if misattributed paternity was proved. This explanation was further supported by the strikingly high percentage of both men and women (90.3% and 93.8% respectively) perceiving that disclosure of misattributed paternity can be harmful for women. Indeed, in countries where women are subject to discrimination and often lack social power, misattributed paternity can have serious social repercussions such as social stigma, divorce, or physical violence [33], thus emphasizing the importance of referring to a judge for disclosure incidental findings. The gender difference evident in our data is important since it may help in the way of reporting misattributed paternity among the Lebanese population, and highlights the necessity of creating legislative framework dealing with genetic explorations in the context of DNA paternity testing.

Remarkably, only 23% of individuals think that incidental findings of important value could be reported without prior consent by the doctor to their family or relatives. In general, families are opposed to doctors informing at-risk members without their consent, even in cases where the disease is easily preventable [26]. Accordingly, the international ethical guidelines recommend that health care professionals should respect patient's confidentiality and should not contact at-risk relatives directly [13]. Instead, they can encourage disclosure to at-risk members by informing the patient of the potential consequences for the health of their relatives [34,35].

Finally, our research registered a generally positive perception regarding the storage of DNA samples and their use in future genetic analyses. However, conditions of anonymity and authorization were reported in 47.7% and 78.7% of participants respectively. In agreement with our findings, a study done by Botkin et al. concerning the general public attitude on the use of residual new-born screening specimens for research showed that participants supported the retention and use of residual samples to research purposes, but with a clear preference for an informed permission process for parents regarding these activities [35]. On the other hand, in an interview with 1193 patients from several different medical disciplines in five U.S. academic medical centers, Hull and his colleagues found that 57% of respondents who wanted to know about research using their sample would require researchers to seek their permission, regardless of whether the samples were identifiable or ''anonymized'' [36]. Nevertheless, according to Stegmayer and Asplund, anonymity increases people's readiness to contribute to genetic research [11,37].

The fact that our research was limited to a specific category of the population represents a selection bias in the study, and may influence the generalizability of the results. Moreover, subjects lacking digital literacy and those who do not understand French or English were not able to participate to the study, hence limiting somehow the recruitment of participants.

Conclusion

Our findings highlight the importance of designing an informed consent for patients considering DNA paternity testing as a vital part of the decision-making process. Items included in the consent should be mainly related to the voluntary nature of testing, collection and storage of DNA samples, modalities of communication of the results and incidental findings, level of confidentiality and privacy, the risks and outcomes associated with inappropriate disclosure information, and the use of residual specimens and data for future genetic research (Informed consent as supplementary file). Furthermore, the establishment of legal norms and the performance of paternity tests in accredited laboratories were perceived as essential to guarantee a secured environment that is conductive to DNA paternity testing, and a way to facilitate a greater protection of the individual and his family.

These findings need to be validated on a larger and more heterogeneous sample. Moreover, conducting multi-theme genomic studies on a cohort of patients and individuals from the general population would be of great importance to generate a massive amount of data that may be useful for determining factors associated with individuals' attitudes, preferences and concerns, and subsequently for establishing an appropriate legal and ethical framework for paternity testing in Lebanon [38].

Authors' contribution

Myrna Azoury drafted the manuscript, contributed to the conception and design of the study as well as to the acquisition, analysis and interpretation of data. Fadi Abou Mrad and Issam Mansour contributed to the conception and design of the study and revised the manuscript critically for important intellectual content. José-Noel Ibrahim and Zahi Abou Rjeily contributed to the analysis and interpretation of data and revised the manuscript critically for important intellectual content. Grégory Schmit contributed to the conception and design of the study as well as to the analysis and interpretation of data, and revised the manuscript critically for important intellectual content. All authors approved the final version of the manuscript.

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Appendix A. Supplementary data

Supplementary data associated with this article can be found, in the online version, at https://doi.org/10.1016/j.jemep.2021.100640.

Disclosure of interest

The authors declare that they have no competing interest.

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