Knowledge, Attitudes, and Practices of Women Toward Prenatal Genetic Testing

Epigenetics Insights
Volume 11: 1–20

DOI: 10.1177/2516865718813122

Nour Abdo[1], Nadia Ibraheem[1], Nail Obeidat[2], Ashley Graboski-Bauer[3], Anwar Batieha[1], Nada Altamimi[1] and Moawia Khatatbih[4]

[1]Department of Public Health and Community Medicine, Faculty of Medicine, Jordan University of Science and Technology, Irbid, Jordan. [2]Department of Obstetrics and Gynecology, Faculty of Medicine, Jordan University of Science and Technology, Irbid, Jordan. [3]Teacher Education Department, The University of Texas at El Paso, El Paso, TX, USA. [4]Faculty of Medicine, Yarmouk University, Irbid, Jordan.

ABSTRACT

OBJECTIVES: We aim to address public knowledge, attitudes, and practices relative to prenatal genetic testing as a starting point for policy development in Jordan.

STUDY DESIGN: We conducted a cross-sectional prenatal genetic testing knowledge, attitudes, and practices survey with 1111 women recruited at obstetrics and gynecology clinics nationwide. Data were analyzed using a variety of descriptive and inferential statistical tests.

RESULTS: The overwhelming majority (>94%) of participants considered prenatal genetic testing, particularly non-invasive prenatal genetic screening, procedures to be good, comfortable, and reasonable, even when the non-diagnostic nature of non-invasive prenatal genetic screening was explained. Likewise, 95% encouraged the implementation of non-invasive prenatal genetic screening within the Jordanian health system, but most preferred it to remain optional. However, women in higher-risk age brackets, in consanguineous marriages, and with less education were significantly less interested in learning about non-invasive prenatal genetic screening. Only 60% of women interviewed were satisfied with the services provided by their obstetric/gynecologist. The more satisfied the women were, the more they are likely to adapt non-invasive prenatal genetic screening.

CONCLUSIONS: In sum, although the data support the receptivity of Jordanian women to national implementation of non-invasive prenatal genetic screening, such policies should be accompanied by health education to increase the genetic literacy of the population and to engage high-risk populations. Thus, this offers rare insight into the readiness of 1 particular Arab population to adapt non-invasive prenatal genetic screening technologies.

KEYWORDS: Prenatal genetic screening, knowledge, attitudes, and practices, non-invasive prenatal genetic screening tests, Jordan policy

RECEIVED: October 11, 2018. **ACCEPTED:** October 23, 2018.

TYPE: Original Research

FUNDING: The author(s) disclosed receipt of the following financial support for the research, authorship, and/or publication of this article: The authors would like to thank the deanship of research at Jordan University of Science and Technology for the financial support grant number 242-2016.

DECLARATION OF CONFLICTING INTERESTS: The author(s) declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

CORRESPONDING AUTHOR: Nour Abdo, Department of Public Health and Community Medicine, Faculty of Medicine, Jordan University of Science and Technology, PO Box 3030, Irbid 22110, Jordan. Email: nmabdo@just.edu.jo

Introduction

Recent scientific advances have led to commercially available prenatal genetic screening tests that use the circulating cell-free fetal DNA in a maternal blood sample to assess fetal risk for specific congenital defects.[1] These newer, non-invasive prenatal genetic screening (NIPGS) tests have many advantages over older forms of prenatal genetic testing (PGT). Not only can NIPGS technologies be implemented earlier than older screening methods, but they are less invasive and risky than diagnostic procedures like chorionic villus sampling (CVS) and amniocentesis, while still maintaining a high degree of accuracy.[1–3] Presently, NIPGS can assess risk for a long list of serious conditions, for instance, Trisomy 21 (Down syndrome), Trisomy 13 (Patau syndrome), Trisomy 18 (Edward syndrome), Monosomy X (Turner syndrome), and Klinefelter syndrome (XYY syndrome).[4] These features imbue modern NIPGS with broad appeal, as clinicians, expectant parents, and health educators share a vested interest in identifying serious fetal congenital anomalies as early as possible.[2,4] Congenital abnormalities detectable by NIPGS frequently lead to miscarriage or infant mortality, and even if non-fatal, most will significantly affect parent and child quality of life.[4,5] Thus, the primary impetus for PGT, whether screening or diagnostic, is to facilitate patient-centered health care and decision-making.[6] Non-invasive prenatal genetic screening is especially well-suited to this imperative, as through unobtrusive, early risk assessment, it can enable families and health care workers to educate themselves, make deliberated but timely and informed choices, seek additional testing, and prepare emotionally or in other ways for the likely outcomes of their pregnancy or health needs of the child.[2,5,7,8]

Based on these medical and psychological advantages, many leading maternal and child health authorities—including the American College of Medicine and Genomics (ACMG),

American College of Obstetricians and Gynecologists (ACOG), and Society for Maternal Fetal Medicine (SMFM), and the World Health Organization (WHO)—have advocated making NIPGS services accessible to all, or at least a much wide swath, of pregnant women, as soon as they begin prenatal care.[8–10] What is more, a recent WHO report[7] supports the feasibility of doing so, even in low- to middle-income population, so long as costs, cultural considerations, and public health objectives and options are carefully anticipated, balanced, and coordinated. This positioning and possibility is of extreme significance to Arab nations in the Eastern Mediterranean Region (EMR), wherein rates of several congenital abnormalities are among the leading causes of infant mortality, premature death, and disability-adjusted life years (DALYs).[11–14] In fact, at >65 cases for every 1000 live births, the rate of fatal or severely disabling congenital defects in the EMR is the highest in the world; by comparison, this rate is <51.1 per 1000 live births in Europe, North America, and Australia.[7] Several reasons contribute to the high prevalence of congenital abnormalities in Arab countries. First, blood-related marriage is one of the chief risk factors for congenital anomalies, and between 25% and 60% of all marriages in Arab countries are estimated to be consanguineous.[4,11,15] Second, certain genetically inheritable disorders are highly prevalent in the EMR, for example, thalassemia, glucose-6-phosphate dehydrogenase deficiency, and haemoglobinopathies.[7,11,12] Third, mother's age at pregnancy, whether very young or advanced, has been reported to increase the odds of congenital abnormalities, and birthrates among mothers within both of these fertility spectrum extremes are relatively high in the EMR.[4,11,14,16]

Superficially, PGT, including both screening and diagnostic services, is commercially available in most Arab EMR countries[2,4]; however, the actual accessibility and delivery of such services are another matter. Although limited, existing literature on these matters has long indicated that women in Arab EMR countries are often subjected to PGT without first being properly appraised of the implications or asked for consent; labs equipped to process PGT are few and far between in the region; health care workers in disciplines and capacities well-positioned to recommend PGT are not adequately trained or mentally prepared to do so, and genetic literacy is low among the general populace as well as relevant health and medical professionals.[17,18] In light of these concerns, another important barrier to making NIPGS services more accessible in Arab EMR countries is a dearth of research on the attitudes of the general public toward more systematic and government-supported implementation of PGT practices.

In keeping with regional norms, 30% to 50% of all marriages in Jordan are consanguineous, with 20% to 30% of all marriages occurring between first cousins.[15,18] Consequently, the toll of congenital birth defects is extremely high in Jordan, representing the second leading cause of infant mortality and the leading cause of premature death nationwide.[11,13,14] In total, the Jordanian Ministry of Health (MOH)[19] reports that about 2 out of 100 children nationwide are affected by congenital anomalies, with the highest rates occurring in rural areas of Tafeileh directorate (6.3%) and Zarqa directorate (3.1%). Furthermore, these figures likely reflect underreporting.[17,20]

Congenital diseases could be prevented, or at least decreased, by providing adequate prenatal and postnatal genetic services to the community, by performing the non-invasive prenatal testing (NIPT) during the 9th to 10th week of pregnancy.[21] Accordingly, proper genetic counseling is crucial for high-risk groups such as consanguineous marriages.[21] However, a common misunderstanding of how screening test works is still prevalent.[4] All those tests have different false positive and false negative results associated with them.[2] There are 2 misconceptions worldwide about genetic screening. First, genetic screening, like any other screening, is not diagnostic, as most of these tests do not reach 100% accuracy.[4] Second, the main purposes for genetic screening are to inform parents about the possible outcomes of pregnancy, prepare them emotionally, and provide them with the opportunity to educate themselves on how to cope with a particular birth defect.[4] Moreover, these tests can be efficiently used by physicians to plan for early post-delivery interventions. Most assuredly, genetic screening is not meant to encourage abortion. But it could be misunderstood by some which will cause an ethical dilemma.

The uncommon choice of prenatal diagnosis, with a selective termination of pregnancy of an affected fetus, is slowly becoming an available option in most Arab countries.[22] Tunisia, for example, is the only Islamic Arab country where selective abortion of an affected fetus is accepted by parents and permitted under the civil law and the religious authorities.[23]

Given the incidence and impact of congenital defects in Jordan, it might first appear paradoxical that NIPGS have been commercially available therein for some time now, yet remain extremely undermarketed and underused within the country.[4] The key reasons for this appear to be a combination of economics and logistics: on one hand, because NIPGS is not an official standard of prenatal health care within Jordan, its market pricing remains prohibitive for many couples; on the other hand, only a few clinics and laboratories within the country are currently equipped to offer NIPGS or the appropriate pre- and post-test genetic counseling to expectant parents.[17,18]

In addition, although the MOH acknowledges the need for more widely available, comprehensive, and accessible community genetic services to help reduce the burden of congenital disorders in Jordan, little headway has been made thus far. Programming and policy efforts remain limited to the implementation of a few surveillance programs and a law mandating premarital screening to identify and advise prospective couples if both are carriers for hemoglobinopathies.[4,18,21] As yet, the impact of this policy has not been systematically reviewed, nor

to the best of our knowledge has any research been published on the attitudes of the general Jordanian public toward government-sponsored NIPGS initiatives. Moreover, although efforts like premarital genetic screening and counseling are admirable as primary interventions pursuant to enabling informed, preconception decision-making,[22] they are largely irrelevant thereafter, and especially during pregnancy, when genetic services become arguably more imperative.

However, it is certainly feasible for Jordan to meet the structural prerequisites for wider, state-sponsored implementation of NIPGS.[18] First and foremost, health care infrastructure, and specifically prenatal care, is generally well-developed within the country and among the best in the Middle East.[2] More than 95% of expectant mothers, regardless of region, receive the amount of prenatal care recommended by the WHO, and 90% exceed these standards.[24] International studies suggest that this degree of pre-existing infrastructure greatly increases the feasibility of implementing routine NIPGS for most individuals at the primary care level because the bulk of capacity-building can be directed toward provider education, and it can be more easily coordinated. Specifically, research shows that even very brief or long-distance supplemental education programs are sufficient to address the genetic literacy deficits most often cited as preventing general, primary, and midwifery health care providers, as well as allied health professionals and staff, from effectively promoting and offering genetic screening services.[23,25–31] In countries like Jordan, where vast majority of pregnant women already engage with the health care system, once providers are well-prepared to offer NIPGS, half the battle has already been won, and what remains is garnering the support and interest of the general public. Thus, pursuant to filling the paucity of research on public attitudes, practices, and knowledge toward implementing broader prenatal genetic services in Jordan and other Arab EMR nations, we developed and administered an Arabic language survey instrument to assess the PGT knowledge, attitudes, and practices (KAP) of the Jordanian public.

The study aimed mainly to assess the KAP of the Jordanian population regarding PGT. In addition, we wanted to evaluate social, cultural, religious, and other factors that influence patient's KAP of prenatal GS. Furthermore, we studied the attitudes of Jordanian women toward abortion in case the fetus is diagnosed with a congenital malformation or Down syndrome. Finally, we wanted to gauge the readiness of the Jordanian population for the adoption of new technologies available in the PGT programs applied in developed countries and to introduce the concept of GS and improve the knowledge about it.

Subjects and Methods

Survey design

A preliminary 4-section questionnaire was developed based on pertinent regional and international genetic testing literature, with special consideration given to the limited publications offering guidance for conducting such research in cultural contexts similar to that of Jordan.[22] The questionnaire was initially written in English and then translated to Arabic using forward and back translations by a certified translator. The survey was designed for oral administration by a proctor (Appendix 1).

Section 1 gathered information on the demographic and socio-economic characteristics of the participants, in addition to the cigarette and water pipe smoking pattern of the parents. Section 2 gathered information on the medical background of the participants, including certain health behavior and data about past and current pregnancies. Section 3 mainly addressed concepts and decision-making in prenatal care and was the primary section dedicated to assessing knowledge, attitudes, and anticipated behaviors regarding PGT. This section therefore included formative and scenario-type questions, some of which gauged attitudes toward abortion and blame in the context of hypothetical situations involving confirmation that a fetus was afflicted with a particular congenital defect. It should be noted that currently, abortion is not legal in Jordan except to save the life of the mother, nor is it by any means the intended purpose of PGT to encourage the termination of a pregnancy, even if a genetic abnormality is found in the fetus. However, abortion as a reproductive choice following diagnostic testing to confirm the results of prenatal genetic screening is slowly becoming an option in Middle East countries.[18,24,32,33] Thus, research on attitudes toward this potentiality in tandem with PGT is warranted.[18] The fourth section of the survey assessed patients' quality and satisfaction with the obstetric and gynecological practice provided by their clinic. This was a separate survey in itself but was later analyzed in conjunction with the KAP section based on the hypothesis that satisfaction with one's OBGYN (obstetrics and gynecology) provider might influence one's attitudes toward NIPGS. In addition, 4 questions distributed throughout the 4 different sections were included to solicit information from married women as to their husband's role in prenatal health care and decision-making.

Survey validation

The initial survey instrument was pilot tested on a sample of 30 participants; data from this testing phase were not included in the final results. Piloting of the instrument involved multiple statistical tests to determine its internal consistency, test-retest reliability, and, because the test was to be administered verbally in an interview protocol, inter-rater reliability. Minor revisions to the instrument were made based on pilot testing. The overall internal reliability of the questionnaire calculated as Cronbach alpha was 0.83, which is within acceptable ranges; KAP score test-retest inter-rater reliability using Cohen kappa test was 0.74, indicating substantial agreement. McNemar test also revealed a statistically significant agreement for test-retest KAP scores ($P = .045$). Furthermore, a significant correlation for the KAP score was estimated between test-retest results with $r = 0.83$ ($P < .001$), indicating a high construct validity.

Participant recruitment and survey administration

A cross-sectional sample of reproductive-aged women in Jordan was chosen in the waiting room from 166 governmental and private gynecology clinics in several areas across Northern and Middle Jordan, urban and rural areas. At each clinic, as many women as time allowed were approached to participate while they awaited their appointments. Participant recruitment and survey administration was conducted by qualified research assistants. All participants were provided oral and written information about the study prior to beginning the survey and informed of their option to withdraw at any time. In addition, written informed consent was obtained from all participants. The research assistants verbally administered the survey to each participant by means of a brief waiting room interview lasting approximately 10 to 15 minutes.

Data analyses

A scoring schema was developed to facilitate analysis of the close-ended, non-demographic survey questions. Specific to the section of the survey focusing on gathering information about understanding and attitudes toward PGT, questions were first classified as assessing either knowledge, attitudes, or practices. Responses were then assigned a binary number value of 1 for positive or affirmative responses or 0 for responses in the negative. This allowed for the calculations based on a total possible KAP score of 11. A parallel scoring schema was used for the satisfaction survey, allowing for analysis to determine whether correlations existed between KAP constructs and satisfaction scores. Scenario-type questions were considered an attitude assessment but were analyzed qualitatively and adjacent to the binary-coded responses.

All analyses for dependent and independent variables was conducted using PC SAS (version 9.2; SAS Institute, Cary, NC). Frequencies and percentages were used for categorical variables (demographics and socio-economics) and summary measures (means and standard deviations) for continuous variables (KAP score, age). Participants' KAP scores were calculated as described above. The participant was considered to have adequate positive KAP score if his KAP score was higher than the median KAP score of all participants.

Data from this survey are non-parametric; therefore, the Mann-Whitney, Kruskal-Wallis, and Pearson chi-square tests were used to test the differences among the variables that affect the KAP score (bivariate analysis). Mann-Whitney test was used to compare medians of 2 independent groups. The Kruskal-Wallis test was used to compare medians of more than 2 independent groups. Finally, Pearson chi-square test was used to find the association between 2 categorical variables. Factors that were found to be significantly associated with high KAP score through bivariate analysis entered into backward-stepwise-multivariate logistic regression analysis to determine the strength of association of each of the variables. All hypothesis tests were 2-sided. A P of $<.05$ was considered significant.

Results

In total, 1111 women were recruited into the study, of whom 89 completed the additional questions about shouldering blame for congenital birth defects. Tables 1 and 2 show summary demographic and medical statistics, respectively, for the study population. The mean age of participants was 31.6 ± 7.3 years, ranging from 16 to 66 years. More than half of the participants held a bachelor's degree or higher, and 35% were currently working. Three-quarters were insured, primarily through the government. Ninety-eight percent were married, more than 21% of them to a first-degree cousin, and more than 68% of them were pregnant or willing to get pregnant. Fifteen percent already had a close relative suffering from a congenital malformation, and although most had received a combination of fetal health examinations (84.4%), only 10.8% had undergone NIPGS at some point. These marital and birth statistics are in agreement with reported national estimates in Jordan, and with worldwide estimates that position the percentage of births with congenital abnormalities as high when compared with the 2% to 5% reported in industrialized countries.[12,15]

Total KAP survey scores

The minimum score obtained from the KAP survey was 0 points, while the maximum score was 11 (mean = 9.43 and median = 10). A score equal to or higher than the median (n = 700, 63%) was considered supportive of PGT as a whole. Total KAP scores were analyzed according to all socio-demographic variables listed in Table 1 except for marital status, for which the study population was too homogeneous. There was a significant association between participants' age ($P = .007$), level of education ($P \leqslant .0001$), employment status ($P = .0439$), a husband's cigarette smoking ($P = .0209$), and a family history of genetic diseases ($P = .0102$) and a higher KAP score.

Backward-stepwise-multivariate logistic regression analysis was performed using a couple's respective cigarette and water pipe smoking habits and women's satisfaction with care (section 4 of the survey), age, education, employment, ethnicity, income, insurance source and status, family history of congenital disease, marriage consanguinity, and number of born children (live and stillbirths). Satisfaction, age, and education were the only predictive variables for KAP score. The overall likelihood ratio score for the model was significant ($P < .0001$). The odds of having an adequately satisfactory KAP score were greater for women ages 20 to 40 years old versus those younger than 20 or older than 40; for women with high educational attainment versus those with low educational attainment; and for those who were highly satisfied with their health care provider compared with those who were less satisfied.

KAP toward prenatal genetic screening

Questions on the KAP survey were also grouped thematically, and responses to them analyzed accordingly. A summary of

Table 1. Participant demographics (N = 1111; category totals vary due to missing values).

CHARACTERISTIC	N (%)
Age	
15-20	30 (2.7)
20-35	779 (70.4)
35-40	173 (15.6)
>40	124 (11.2)
Place of recruitment	
Urban	896 (80.6)
Rural	215 (19.4)
Marital status	
Single	2 (0.2)
Married	1090 (98.1)
Divorced	12 (1.1)
Widowed	7 (0.6)
Education	
Less than high school	101 (9.1)
High School	246 (22.1)
Technical degree	112 (10.1)
Bachelor's degree	558 (50.2)
Master's degree or higher	94 (8.5)
Employment	
Present	390 (35.1)
Absent	721 (64.9)
Ethnicity	
Afro-Jordanian	106 (9.6)
Bedouin	140 (12.6)
Armenian/Circassian/ Chechen	2 (0.2)
White	860 (77.4)
Income	
<350	371 (33.4)
350-1000	659 (59.3)
>1000	81 (7.3)
Income assessment	
Low	37 (3.3)
Medium	1058 (95.2)
High	16 (1.4)
Insurance	
Present	840 (75.6)
Absent[a]	271 (24.4)
Type of insurance	
Governmental	638 (73.3)
Private	172 (19.8)
Other[a]	60 (6.9)

[a]Includes some women with special, temporary coverage offered only during pregnancy, hence, the incongruity in total n values for "presence" versus "type" of insurance.

each KAP question and corresponding response data are presented in Table 3, while the thematic and cross-wise results are presented below.

Two questions were included in the survey to assess participants' knowledge about prenatal genetic screening and diagnostic procedures, while another set of questions were designed to assess women's attitudes toward wider implementation of PGT within the Jordanian health care system. Results indicate that Jordanian women are more aware of NIPGS techniques than about diagnostic PGT and the risks associated with the latter type of procedures. Nearly three-quarters (74.1%) of participants were aware that PGT capable of screening for genetic abnormalities exists. However, only 39% were aware of the existence of riskier and more invasive diagnostic PGT (eg, amniocentesis and CVS). An overwhelming majority of women (94.3%) said that they supported the integration of PGT as a standard procedure in Jordan; that proportion increased to 94.7% when PGT was defined to include both screening and diagnostic tests and the practical goals of each procedure.

Although these questions indicate that women in Jordan hold attitudes quite favorable toward PGT as a whole, further analysis revealed that women felt more positively toward NIPGS than toward diagnostic PGT. When asked about NIPGS, specifically, 95.1% of the participants believed performing it would be good; 94.7% believed it would be a reasonable procedure to undergo during pregnancy; and 86.1% thought it would be physically comfortable. Furthermore, 79.7% indicate they would be willing to switch to another clinic to undergo NIPGS, and a moderate majority (65.2%) of women believed NIPGS should be obligatory in Jordan. Fewer women felt the same way about prenatal diagnostic tests: only 80.1% of participants believed prenatal diagnostic tests to be good, reasonable (81.2%), or physically comfortable (63.5%) to undergo during pregnancy. Although they were not asked about their willingness to change providers to access prenatal genetic diagnostic services, when

Table 2. Medical and pregnancy-related characteristics of all participants (N = 1111).

MEDICAL CHARACTERISTIC	N (%)
Family history of genetic diseases	
Present	171 (15.4)
Absent	940 (84.6)
Spousal smoking behaviors	
Wife, cigarette smoking	
Non-smoker	1007 (90.6)
Light smoker	64 (5.8)
Heavy smoker	40 (3.6)
Wife, water pipe smoking	
Non-smoker	948 (85.3)
Light smoker	75 (6.75)
Heavy smoker	88 (7.92)
Husband, cigarette smoking	
Non-smoker	558 (50.23)
Light smoker	86 (7.74)
Heavy smoker	467 (42.03)
Husband, water pipe smoking	
Non-smoker	799 (71.92)
Light smoker	121 (10.89)
Heavy smoker	191 (17.19)
First-degree consanguineous marriage	
Present	234 (21.1)
Absent	877 (78.9)
Number of born children (live and stillbirths)	
0	354 (31.9)
1-2	396 (35.6)
3-4	267 (24.0)
⩾5	94 (8.5)
Number of miscarriages	
0	845 (76.0)
1-2	237 (21.3)
3-4	25 (2.3)
⩾5	4 (0.4)
Types of fetal examinations received	
Ultrasound only	21 (1.9)
Blood test only	65 (5.85)
Urine test only	3 (0.27)
All of the above	937 (84.34)
Not applicable	85 (7.65)
NIPGS	
Yes	120 (10.8)
No	983 (88.5)
Income	
<350	371 (33.4)
350-1000	659 (59.3)
>1000	81 (7.3)
Income assessment	
Low	37 (3.3)
Medium	1058 (95.2)
High	16 (1.4)
Insurance	
Present	840 (75.6)
Absent[a]	271 (24.4)
Type of insurance	
Governmental	638 (73.3)
Private	172 (19.8)
Other[a]	60 (6.9)

[a]Includes some women with special, temporary coverage offered only during pregnancy, hence, the incongruity in total n values for "presence" versus "type" of insurance.

asked whether diagnostic PGT should be obligatory, only 44.5% of the women surveyed assented.

Last, as an additional attitudinal measure and a prelude to questions about health decision-making and responsibility, we asked participants outright about their willingness to be informed about possible congenital defects during pregnancy. Initially, 88.8% of the women expressed the desire to be officially informed. When women were subsequently counseled about the risk of false positives with NIPGS, 79.3% remained interested in such procedures.

Table 3. KAP survey results.

DOMAIN	QUESTION	ANSWER		% POSITIVE ANSWERS
Knowledge	Do you know there's a test for early detection of fetal malformation that is performed by a sonography to the fetus or taking a mother's blood sample?	Yes	No	74.1
Knowledge	Do you know there's a specific test that confirms if a fetus is affected by a congenital malformation, which is performed by taking a sample of the amniotic fluid surrounding the fetus or the placenta?	Yes	No	38.7
Attitude	Do you want to know if your baby could probably have a congenital malformation?	Yes	No	90.1
Attitude	If you have the opportunity to perform a test for early detection of fetal malformation, you will find it:	Good	Bad	95.1
Attitude	Performing this type of test should be	Obligatory	Elective	65.2
Attitude	Performing this type of test is	Reasonable	Unreasonable	94.7
Attitude	Performing this type of test is	Comfortable	Uncomfortable	86.1
Attitude	If a genetic test can tell you the chance of having a baby with a genetic disease (eg, Down syndrome) would you like to know that while you are pregnant?	Yes	No	88.8
Attitude	If a genetic test can tell you the chance of having a baby with a genetic disease (eg, Down syndrome) but could sometimes be wrong, would you still like to know that while you are pregnant?	Yes	No	79.3
Attitude	If genetic screening is integrated as a standard procedure in Jordan, will you support it?	Yes	No	94.3
Attitude	Prenatal genetic testing refers to tests that are done during pregnancy to either screen for or diagnose a birth defect. The goal of prenatal genetic testing is to provide expectant parents with information to make informed choices and decisions. Do you support it now?	Yes	No	94.8
Practice	If performing this type of test is available only in another hospital/clinic, would you agree moving to that hospital/clinic?	Yes	No	79.8

Abbreviation: KAP, knowledge, attitudes, and practices.

Satisfaction score

Forty percent of women who had attended governmental clinics were positively satisfied with their health care provider and services compared with 58.7% in private clinics and 1.3% in international organization sectors. We developed a satisfaction score to objectively assess the quality of gynecological visits women usually experience.

The minimum satisfaction score obtained in our study was 0 points, while the maximum score was 18 (mean = 10.9 and median = 11). Score equal or higher than the median (n = 675, 60%) was considered satisfactory regarding visits. Table 4 shows the satisfaction score results of our study.

Variables that are associated with KAP score

Table 5 details the association between the participants' sociodemographic characteristics and KAP and satisfaction scores. Our results indicate that the participants' age and level of education were significantly associated with a higher KAP score. On the contrary, age, level of education, and income were associated with a higher satisfaction score in our study population.

Health care decision-making and responsibility

To supplement the information captured by the KAP score components, 4 additional survey questions were added to help better understand the attitudes and roles of Jordanian families in pregnancy-related health decisions. In addition, women in favor of PGT (n = 1053) were asked hypothetical, open-ended questions about how they would approach the process of deciding whether to abort a fetus diagnosed either with Down Syndrome or another congenital malformation. Down Syndrome was specified in contrast to other congenital malformations because it is one of only a few genetic conditions with name recognition among the Jordanian public.

Table 4. Satisfaction score results.

QUESTIONS	N (%)			
	SCORE = 0	SCORE = 1	SCORE = 2	SCORE = 3
What prenatal tests does your doctor routinely recommend?	Ultrasound only	Urine test only Blood test only	All of them	
	21 (1.89)	65 (5.85) 3 (0.27)	937 (84.3)	
Has your doctor ever explained to you the reason beyond describing you specific tests?	No	Yes		
	215 (19.35)	816 (73.45)		
Have your doctor ever talked about diagnostic medical sonography	No	Yes		
	342 (30.78)	683 (61.48)		
Why you have chosen your doctor?	Insurance Forced	Reputation Personal experience		
	178 (16.02) 109 (9.81)	527 (47.43) 284 (25.56)		
How much time do you spend with your doctor during the visit on average?	10 minutes	20 minutes	45 minutes	More than an hour
	588 (52.93)	475 (42.75)	20 (1.8)	14 (1.26)
How long is the average waiting time at the doctor clinic?	More than an hour	45 minutes	20 minutes	10 minutes
	556 (50.05)	247 (22.23)	210 (18.9)	83 (7.47)
Is your doctor available after the visit?	No	Yes		
	560 (50.41)	524 (47.16)		
In case of emergency, how do you reach your doctor?	Call the clinic Call the hospital Other	Direct call to the physician		
	279 (25.11) 220 (19.8) 140 (12.6)	458 (41.22)		
Do you feel comfortable with your doctor?	No	Yes		
	55 (4.95)	1036 (93.25)		
How satisfied are you with your doctor performance?	Unsatisfied	Neutral	Satisfied	Very satisfied
	23 (2.07)	244 (21.96)	585 (52.66)	241 (21.69)
If you attended the interview with your partner, did the doctor make an effort to include both of you in the conversation?	No	Yes		
	231 (20.79)	848 (76.33)		
Do you find difficult reaching the clinic?	Yes	No		
	199 (17.91)	900 (81.01)		
Are you satisfied with the expenses?	No	Yes		
	214 (19.26)	88 (79.66)		
Total score	20			

Table 5. Socio-demographic characteristics of *all* participants and its association with KAP and satisfaction scores (N = 1111; category totals vary due to missing values).

CHARACTERISTIC	N (%)	KAP SCORE (*P*)	SATISFACTION SCORE (*P*)
Age		.007	.0465
15-20	30 (2.7)		
20-35	779 (70.4)		
35-40	173 (15.6)		
>40	124 (11.2)		
Place of recruitment		.8806	.2047
Urban	896 (80.6)		
Rural	215 (19.4)		
Marital status		NA	NA
Single	2 (0.2)		
Married	1090 (98.1)		
Divorced	12 (1.1)		
Widowed	7 (0.6)		
Education		<.0001	.0259
Less than high school	101 (9.1)		
High School	246 (22.1)		
Technical degree	112 (10.1)		
Bachelor's degree	558 (50.2)		
Master's degree or higher	94 (8.5)		
Employment		.0439	.3280
Present	390 (35.1)		
Absent	721 (64.9)		
Ethnicity		.7031	.4162
Afro-Jordanian	106 (9.6)		
Bedouin	140 (12.6)		
Armenian/Circassian/ Chechen	2 (0.2)		
White	860 (77.4)		
Income		.2043	.0001
<350	371 (33.4)		
350-1000	659 (59.3)		
>1000	81 (7.3)		
Income assessment		.1735	.8089
Low	37 (3.3)		
Medium	1058 (95.2)		
High	16 (1.4)		

(Continued)

Table 5. (Continued)

CHARACTERISTIC	N (%)	KAP SCORE (*P*)	SATISFACTION SCORE (*P*)
Insurance		.231	.3215
Present	840 (75.6)		
Absent[a]	271 (24.4)		
Type of insurance		.5029	.1313
Governmental	638 (73.3)		
Private	172 (19.8)		
Other[a]	60 (6.9)		

Abbreviations: KAP, knowledge, attitudes, and practices; NA, not available.
[a]Includes some women with special, temporary coverage offered only during pregnancy, hence, the incongruity in total n values for "presence" versus "type" of insurance.

Last, as a very general gauge of household attitudes and genetic literacy, we asked a subset of participants (n = 89) about who "shoulders the blame" for the conception of a child with congenital defects.

Husband's involvement in health care

A majority of women reported that their husbands are involved in their health care practices (76.3%) and are actively engaged in decision-making regarding PGT and abortion (80.8%). Similarly, most participants declared that their husbands support PGT procedures (79.3%) and accept the concept of abortion in the case that their fetus is diagnosed with a congenital malformation (86.3%). At the same time, 23.6% of the women who answered the questions about shouldering the blame for a fetus with congenital malformations reported that their husbands think the mother is at fault when a child with congenital defects is conceived, and nearly a 10th concur with this logic, believing that having a child with a congenital disorder is their own responsibility.

Hypothetical decision-making about abortion

Women's responses to the questions about abortion further elucidate the nuances of their attitudes, thinking, and decision-making processes relative to PGT. Figure 1 shows an illustration of the women's perception toward GS and the willingness to perform an abortion to a fetus having Down syndrome or congenital malformations. Explaining first that their answer would also depend on the couple facing this hypothetical situation, respondents then grounded their decision-making in religious concerns. A majority of women said that due to religious concerns, they would be unwilling to abort a fetus diagnosed with Down Syndrome (71.1%) or a fetus with another congenital malformation (67.7%); however, these numbers show a slightly higher willingness to abort a fetus with a less familiar genetic disorder.

We asked those women who said they would consider aborting a fetus with either Down syndrome or a congenital malformation to further elucidate how they would arrive at such decisions. Religious or medical consultations emerged as the primary determinants: 96.1% responded that they would choose to abort if a religious consultation supported their decision, while 91.4% said they would do so if a medical consultation supported the decision. Only 25.5% of women said they would choose to abort depending on some other decision-making process.

In the course of analyzing the data from this study, it was also revealed that willingness to terminate a pregnancy was significantly associated with maternal water pipe smoking. That is, there was a significant association between water pipe smoking in women and their willingness to abort a fetus diagnosed with a congenital malformation ($P = .0038$) and Down syndrome ($P = .0052$).

Discussion

A number of genetic and non-genetic screenings are now available worldwide to predict or detect major birth defects or congenital syndromes prior to delivery. Non-invasive prenatal genetic screening is one type of PGT that can predict risk of a growing list of such diseases and carries with it many advantages over older forms of PGT. However, despite the availability of such tests and a uniquely high rate of congenital birth defects, NIPGS has not been officially integrated nor widely adopted electively within EMR health care systems. To be able to prepare health education and policies to better meet the PGT needs of Arab populations, we therefore conducted a study of the knowledge, attitudes, and expected practices (KAP) of the Jordanian public regarding NIPGS.

Our results produced a number of findings that support the development of health education programs about NIPGS to increase the genetic literacy and readiness of the general public to adopt such technologies; in addition, it yielded some results that warrant further research. Overall, nearly 95% of women in

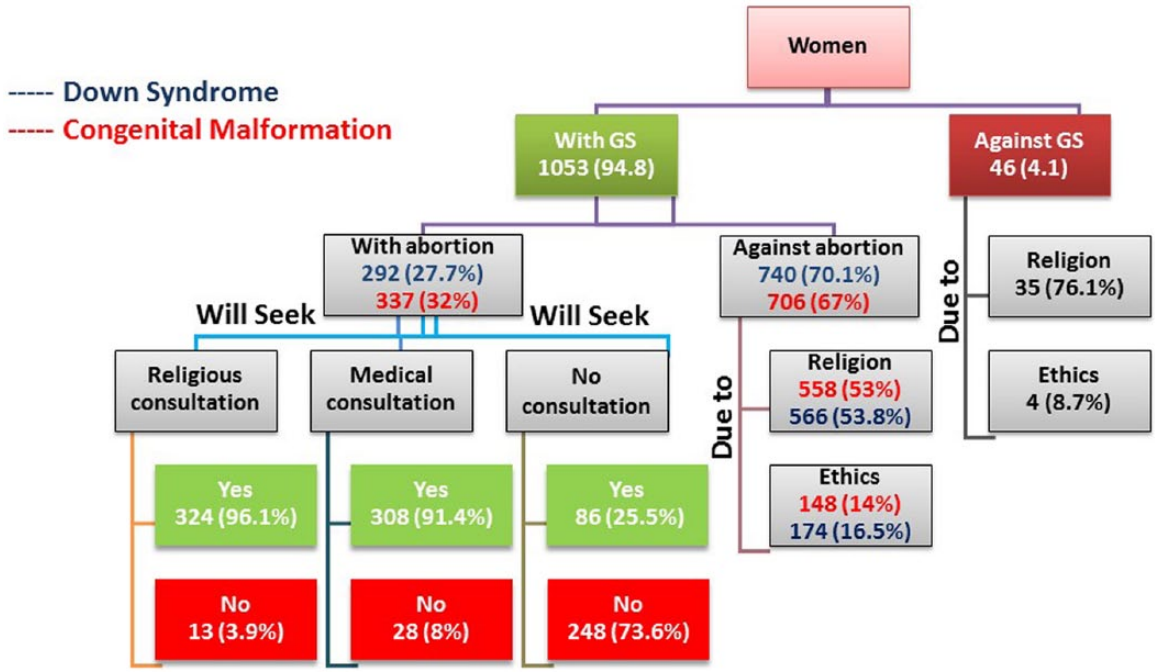

Figure 1. Hierarchy of women's perception toward GS in general, and the hypothetical act of abortion in case diagnosed a congenital disease (red) or Down syndrome (blue). GS indicates genetic screening.
The total numbers are not complete due to missing values.

our study expressed positive attitudes toward PGT overall, and NIPGS in particular, and supported the integration of such services into the national health care service. However, only a slight majority (65.2%) believed the tests should be required. Previous research supports the importance of reassuring women that the offer of NIPGS will not undermine their autonomy in any way. In studies of public attitudes toward routinizing NIPGS, participants' prevailing concerns and reasons for apprehension revolved around ensuring and protecting women's autonomy throughout the entire individualized tree of decision-making that would follow, were it offered to all clients.[6,34-36] Moreover, these studies, and related discussion of the moral grounds for NIPGS, emphasize that simply offering NIPGS on the reasoning that by providing more information, clients have more choices, or that advising physicians that informed consent should be garnered before performing the tests, is not enough to satisfy these demands for the protection and primacy of autonomy.[6,34,35,37-41] According to this literature, men and women, with and without the experience of pregnancy or a pregnant partner, articulated concern about the implications if informed consent were merely cursory, and NIPGS presented was presented to clients with provider bias, patients were not allowed to change their minds about receiving the results once tests were conducted; patients were influenced or stigmatized as to their decisions on whether to continue a pregnancy even in the event that a tests revealed the fetus was at risk for a congenital defect, and so on.[6,34–36] Although our results, taken from a context wherein congenital anomalies are especially common and salient in the lives of the study population, indicate that a slight majority of women believed NIPGS should be mandatory, they nonetheless support these assertions.

Publications have indicated that, for better or worse, popular coverage and discussion framing the "choice" of genetic testing significantly influences how the public interprets and extrapolates the concept of "risk" in the context of decision-making about these procedures.[34,36,37,39,42] No actual program to implement NIPGS on a national scale is yet in effect in Jordan, and therefore the survey instrument merely gauged beliefs and reactions to hypothetical situations, meaning that the women surveyed might feel differently were they confronted with the actual possibility of finding out their fetus' risk for genetic malformations. Thus, whereas women might only be considering medical risks as the grounds for whether NIPGS should be mandatory, and that as it carries none besides those associated with a blood draw, once NIPGS is actually available, the conceptualization of the "risks" and personalized or societal implications involved will most likely evolve and complexify, extending to more emotional and moral dimensions, such that the idea of imposing the test on someone will seem less of an obvious answer or purely noble act.[6,34,37,39,40,42–44]

Other results of this study further support the need to preemptively ensure that any policies to promote NIPGS in Jordan explicitly protect and support parents' autonomy. For example, the spread of hypothesized reactions to post-results decision-making, for example, the differing interest in abortion depending on the condition identified, and the meaningfully high proportion of women who felt they "shouldered the blame" for conceiving a fetus with congenital malformations, or that their

husbands felt they did so, raise important concerns about whether mandatory NIPGS would actually broaden and benefit all women in Jordan, or whether the involuntary imposition of such knowledge would be a burden to them. Furthermore, the issue of confidentiality, or duty to disclose genetic results to partners and family members whose reproductive planning knowledge of hereditary risk factors might benefit, is also an obvious ethical concern with genetic testing.[6,18] Our study only surveyed women and asked them to anticipate the participation and reactions of their husbands, so we do not yet know how men in Jordan feel about enacting a national NIPGS program, only that they must be given due attention in efforts to promote genetic literacy and NIPGS in Jordan. Further research should focus on the attitudes and needs of male partners, prior to the crafting of national policy on NIPGS.

A study performed in Lebanon assessed the role obstetricians play in prenatal diagnosis. It involved encouraging the parents to undergo prenatal diagnosis and to consider abortion in severe anomaly cases. Religion, age, socio-economic background, the number of previous pregnancies, "cultural norms," and "cost" were the most influential factors that affected the parents in their decision to terminate pregnancy.[33] Whereas in Israeli Arab community, parental attitude toward pregnancy termination depends mainly on the couple's stated level of religious commitment and the severity of the disease.[45] However, per the Jordanian Public Health Law in 2008, Article 12

> prohibits physicians from providing advice on abortion or from performing an abortion except when clinically necessary to prevent a threat to the life or health of the pregnant woman. Abortion must be performed in a hospital with the consent of the pregnant woman or of her husband or guardian if she is unable to write or speak. Licensed physicians or specialists must certify that the abortion is necessary, and records of the abortion must be maintained for ten years.

In the Jordanian penal code of April 10, 1960, article 321 clearly states that "A woman who through any means performs an abortion on herself or consents to another person applying such means shall be punished with 6 months to 3 years of imprisonment."[46]

Our results suggest that about one-third of women would consider abortion if diagnostic PGT confirmed by diagnostic testing indicated they were carrying a fetus with Down syndrome or another congenital malformation; however, they concurrently indicated that expert opinions, whether medical or religious, continue to have a significant bearing on women's reproductive decisions. These results are in keeping with aspects of social habitus in Jordan,[17,18] and suggest the need to maintain respect and recognition for the role of religious traditions in health decision-making even as the country looks forward to adopting advanced biotechnology innovations. Studies on public attitudes toward NIPGS have also pointed out that interest depends on public perceptions of the support that is available to parents dovetailing with the need to protect clients' autonomy to truly make informed choices. People have indicated that equally robust and accessible emotional and health support programs must be in place for parents, for helping them choose and live with the consequences whether they continue or terminate a pregnancy.[6,34,35]

This conditional difference is interesting, perhaps even more so given that Islam, the predominant religion in Jordan, does not expressly forbid abortion. Rather, this faith stipulates that bioethical choices must be decided through careful reflection on historical religious teachings and clerical decisions arrived through similar deductive reasoning, some of which interpret sanction for abortion in certain cases.[11,17,18]

In light of our results about "shouldering the blame," the fact that abortion on the basis of genetic testing is not even an option for women in Jordan as yet, and the significance of religion in the lives of the population, women's interest in religious or other consultation regarding NIPGS-related decision-making must also be respected and supported within efforts to promote such technology.

We also found that positive attitudes toward NIPGS are significantly higher among women with more formal schooling than those with less, those between the ages of 20 and 40 years old, and those with at least 1 relative suffering from a congenital disorder. These were concerning results, as they indicate that women across multiple risk categories for offspring with congenital defects, that is, young mothers, those of advanced age, or those in first-degree consanguineous marriages, appear less interested in receiving information about new PGT technologies. Furthermore, women who were employed and those whose husbands smoked cigarettes were significantly more likely to be interested in NIPGS, whereas women who smoked water pipes were significantly more likely to endorse abortion in the event that their fetus was diagnosed with Down syndrome or a genetic malformation. Although we are not prepared to explain the correlations identified between house member smoking patterns, employment status, and maternal interest in NIPGS, we speculate that these could be associated with sociocultural factors as well, including higher education, the need to plan in advance for child care, and awareness of other efforts to promote health in Jordan, such as recently initiated smoking cessation research and campaigns.[47–50] Further research is most certainly needed on these associations; nonetheless, the totality of these additional findings also points to the need for a variety of well-planned, health education campaigns that target both marriage partners, particularly those in consanguineous relationships, those with lower education, and those in which the prospective or expectant mothers are in a higher-risk age bracket.

In sum, then, the results of this study support the implementation of national NIPGS programs, but only if, and only if, such programs include a heavy emphasis on health education, directed at both the general public and the health care professionals who will administer the tests and their results. As prior research has shown, if NIPGS is to be accepted in Jordan,

genetic literacy among health care professionals must also be bolstered with appreciation of and adherence to the ethical premise for enabling clients' informed decision-making; efforts must be made to inculcate genetic literacy equally in men and women; and thought paired with support must be put into what expectant parents are able, and interested in doing, with the results of NIPGS. Therefore, planning for NIPGS in Jordan must be preceded by comprehensive, multifocal health education and planning. Further research will be needed to develop and hone such programs; however, with due diligence, the future is bright and Jordan clearly has much to gain from implementing NIPGS.

We concluded that concordant with efforts to educate the public and prepare health care providers, subsidizing and offering NIPGS to expectant parents through the national health care system would greatly increase accessibility to such services and benefit Jordan's public welfare. This would be the result of allowing doctors and parents to make informed reproductive decisions and plans for the care of special needs children in advance of their birth. In light of the high incidence of congenital birth defects in Jordan, these benefits would extend beyond the level of the individual to the nation as a whole.

Conclusions

The overwhelming majority of 1111 participating women considered GS procedures aiming to detect fetal abnormalities to be good, comfortable, and reasonable. Moreover, the majority was positive toward NIPT and would like to use the test if available. In addition, only 60% of women interviewed were satisfied with the services provided by their obstetric/gynecologist. Finally, the more satisfied the women were with the OBGYN services, the more they are likely to adapt NIPGS.

Author Contributions

NoA, NI, and NO have developed the questionnaire. MK, AB, and AG-B have supervised the KAP validation and editing. Nadia Ibrahim administered the questionnaires in clinics. NoA ran the statistical analyses and managed the project. NaA helped in formatting and technical stuff.

Ethical Approval and Consent to Participate

This study followed research ethics guidelines in all of its phases. Approval to conduct the study was obtained from the Institutional Review Board (IRB) number 22/96/2016 at the Jordan University of Science and Technology. In addition, permission from the Jordanian Ministry of Health (MOH) was obtained to collect data from public gynecologic clinics.

REFERENCES

1. Leach MW. ACOG issues new prenatal testing guidelines. https://prenatalinformation.org/2016/04/29/acog-issues-new-prenatal-testing-guidelines/. Updated April 29, 2016. Accessed November 11, 2017.
2. Chandrasekharan S, Minear MA, Hung A, Allyse MA. Noninvasive prenatal testing goes global. *Sci Transl Med*. 2014;6:231fs15. https://doi.org/10.1126/scitranslmed.3008704.
3. Driscoll DA, Gross SJ. Screening for fetal aneuploidy and neural tube defects. *Genet Med*. 2009;11:818–821. https://doi.org/10.1097/GIM.0b013e3181bb267b.
4. Allyse M, Minear MA, Berson E, et al. Non-invasive prenatal testing: a review of international implementation and challenges. *Int J Womens Health*. 2015;7:113–126. https://doi.org/10.2147/IJWH.S67124.
5. Norwitz ER, Levy B. Noninvasive prenatal testing: the future is now. *Rev Obstet Gynecol*. 2013;6:48–62.
6. Gaivoronskaia G, Solem KE. Genetic testing: affected parties and decision making. *J Risk Res*. 2004;7:481–493. https://doi.org/10.1080/1366987042000146201.
7. World Health Organization (WHO). Community genetics services: report of a WHO consultation on community genetics in low-and middle-income countries, 2011. http://apps.who.int/iris/bitstream/10665/44532/1/9789241501149_eng.pdf.
8. American College of Obstetricians Gynecologists'(ACOG) Committee on Practice Bulletins—Obstetrics, Committee on Genetics, Society for Maternal–Fetal Medicine (SMFM). Practice Bulletin no. 162: prenatal diagnostic testing for genetic disorders. *Obstet Gynecol*. 2016;127:e108–e122. https://doi.org/10.1097/AOG.0000000000001405.
9. Gregg AR, Skotko BG, Benkendorf JL, et al. Noninvasive prenatal screening for fetal aneuploidy, 2016 update: a position statement of the American College of Medical Genetics and Genomics. *Genet Med*. 2016;18:1056–1065. https://doi.org/10.1038/gim.2016.97.
10. Leach MW. ACMG releases new statement on cell free DNA prenatal screening. https://prenatalinformation.org/2016/08/04/acmg-releases-new-statement-on-cell-free-dna-prenatal-screening/. Updated August 4, 2016. Accessed November 12, 2017.
11. Al-Gazali L, Hamamy H, Al-Arrayad S. Genetic disorders in the Arab world. *BMJ*. 2006;333:831–834. https://doi.org/10.1136/bmj.38982.704931.AE.
12. Hamamy H, Alwan A. Genetic disorders and congenital abnormalities strategies for reducing the burden in the region. *East Mediterr Health J*. 1997;3:123–132.
13. Khoury SA, Mas'ad DF. Causes of infant mortality in Jordan. *Saudi Med J*. 2002;23:432–435.
14. Institute for Health Metrics Evaluation (IHME). Global Health Data Exchange (GHDx): 2015 statistical reports. http://ghdx.healthdata.org/gbd-results-tool. Updated 2017. Accessed June 10, 2017.
15. Hamamy HA, Masri AT, Al-Hadidy AM, Ajlouni KM. Consanguinity and genetic disorders. Profile from Jordan. *Saudi Med J*. 2007;28:1015–1017.
16. Chen X-K, Wen SW, Fleming N, Yang Q, Walker MC. Teenage pregnancy and congenital anomalies: which system is vulnerable? *Hum Reprod*. 2007;22:1730–1735.
17. Hamamy H, Al-Hait S, Alwan A, Ajlouni K. Jordan: communities and community genetics. *Community Genet*. 2007;10:52–60.
18. Hamamy H, Bittles AH. Genetic clinics in Arab communities: meeting individual, family and community needs. *Public Health Genomics*. 2009;12:30–40. https://doi.org/10.1159/000153428.
19. Jordan Ministry of Health (MOH). Percentage of congenital anomalies among children. 2013. http://apps.moh.gov.jo/gpmch/indicatorreportresults4table.jsp?dir=&hc=&lang_parameter=english&p_directoratename=zzzzz&p_placeid=00000&p_month=1&p_year=2013&displaysum=yes&p_repid=4&group_button=Show+Summary.
20. Dababneh F, Nichols EK, Asad M, Haddad Y, Notzon F, Anderson R. Improving mortality data in Jordan: a 10 year review. *Bull World Health Organ*. 2015;93:727–731. https://doi.org/10.2471/BLT.14.137190.
21. Odeh M, Granin V, Kais M, Ophir E, Bornstein J. Sonographic fetal sex determination. *Obstet Gynecol Surv*. 2009;64:50–57.
22. Sahlin E, Nordenskjöld M, Gustavsson P, Wincent J, Georgsson S, Iwarsson E. Positive attitudes towards non-invasive prenatal testing (NIPT) in a Swedish cohort of 1,003 pregnant women. *PLoS ONE*. 2016;11:e0156088. doi:10.1371/journal.pone.0156088.
23. Goodson P, Chen LS, Muenzenberger A, Xu L, Jung E. Genomics education for health educators in Texas: the Family Health History Training Program. *Public Health Genomics*. 2013;16:233–240. https://doi.org/10.1159/000353886.
24. Chaabouni H, Chaabouni M, Maazoul F, et al. Prenatal diagnosis of chromosome disorders in Tunisian population. *Ann Genet*. 2001;44:99–104.
25. Chen L-S, Goodson P, Jung E, et al. Effectiveness of a web-based genomics training for health educators in Texas. *Genet Med*. 2014;16:271–278. https://doi.org/10.1038/gim.2013.100.
26. Rose P, Humm E, Hey K, Jones L, Huson SM. Family history taking and genetic counselling in primary care. *Fam Pract*. 1999;16:78–83.
27. Wallen GR, Cusack G, Parada S, Miller-Davis C, Cartledge T, Yates J. Evaluating a hybrid web-based basic genetics course for health professionals. *Nurse Educ Today*. 2011;31:638–642. https://doi.org/10.1016/j.nedt.2010.11.001.

28. Cragun DL, Couch SC, Prows CA, Warren NS, Christianson CA. Success of a genetics educational intervention for nursing and dietetic students: a model for incorporating genetics into nursing and allied health curricula. *J Allied Health*. 2005;34:90–96.
29. Metcalf MP, Tanner TB, Buchanan A. Effectiveness of an online curriculum for medical students on genetics, genetic testing and counseling. *Med Educ Online*. 2010;15:4856. https://doi.org/10.3402/meo.v15i0.4856.
30. Skirton H, Lewis C, Kent A, Coviello DA. Genetic education and the challenge of genomic medicine: development of core competences to support preparation of health professionals in Europe. *Eur J Hum Genet*. 2010;18:972–977. https://doi.org/10.1038/ejhg.2010.64.
31. Smets E, van Zwieten M, Michie S. Comparing genetic counseling with non-genetic healthcare interactions: two of a kind? *Patient Educ Couns*. 2007;68:225–234. https://doi.org/10.1016/j.pec.2007.05.015.
32. Eldahdah LT, Ormond KE, Nassar AH, Khalil T, Zahed LF. Outcome of chromosomally abnormal pregnancies in Lebanon: obstetricians' roles during and after prenatal diagnosis. *Prenat Diagn*. 2007;27:525–534.
33. Saleem R, Gofin R, Ben-Neriah Z, Boneh A. Variables influencing parental perception of inherited metabolic diseases before and after genetic counselling. *J Inherit Metab Dis*. 1998;21:769–780.
34. Kelly SE, Farrimond HR. Non-invasive prenatal genetic testing: a study of public attitudes. *Public Health Genomics*. 2012;15:73–81.
35. Lippman A. Prenatal genetic testing and screening: constructing needs and reinforcing inequities. *Am J Law Med*. 1991;17:15–50.
36. Seavilleklein V. Challenging the rhetoric of choice in prenatal screening. *Bioethics*. 2009;23:68–77. https://doi.org/10.1111/j.1467-8519.2008.00674.x.
37. Allyse M, Sayres LC, Goodspeed T, Michie M, Cho MK. "Don't want no risk and don't want no problems": public understandings of the risks and benefits of non-invasive prenatal testing in the United States. *AJOB Empir Bioeth*. 2015;6:5–20. https://doi.org/10.1080/23294515.2014.994722.
38. Allyse M, Sayres L, Havard M, et al. Best ethical practices for clinicians and laboratories in the provision of non-invasive prenatal testing. *Prenat Diagn*. 2013;33:656–661. https://doi.org/10.1002/pd.4144.
39. Kamenova K, Ravitsky V, McMullin S, Caulfield T. Media portrayal of non-invasive prenatal testing: a missing ethical dimension. *J Sci Commun*. 2016;15:1–19.
40. Minear MA, Alessi S, Allyse M, Michie M, Chandrasekharan S. Noninvasive prenatal genetic testing: current and emerging ethical, legal, and social issues. *Annu Rev Genomics Hum Genet*. 2015;16:369–398.
41. Stasiuk K, Bar-Tal Y, Maksymiuk R. The effect of physicians' treatment recommendations on their epistemic authority: the medical expertise bias. *J Health Commun*. 2016;21:92–99. https://doi.org/10.1080/10810730.2015.1049308.
42. Markens S, Browner CH, Press N. "Because of the risks": how US pregnant women account for refusing prenatal screening. *Soc Sci Med*. 1999;49:359–369. https://doi.org/10.1016/S0277-9536(99)00097-0.
43. Bates BR, Templeton A, Achter PJ, Harris TM, Condit CM. What does "A gene for heart disease" mean? A focus group study of public understandings of genetic risk factors. *Am J Med Genet A*. 2003;119A:156–161. https://doi.org/10.1002/ajmg.a.20113.
44. Collins RE, Lopez LM, Marteau TM. Emotional impact of screening: a systematic review and meta-analysis. *BMC Public Health*. 2011;11:603. https://doi.org/10.1186/1471-2458-11-603.
45. Proposed international guidelines on ethical issues in medical genetics and genetic services (part II). World Health Organization, Human Genetics Programme. *Rev Derecho Genoma Hum*. 1998;9:239–251.
46. Abortion Law. Article 321; 1960.
47. Bader RK, Shihab RA, Al-Rimawi DH, Hawari FI. Informing tobacco control policy in Jordan: assessing the effectiveness of pictorial warning labels on cigarette packs. *BMC Public Health*. 2017;18:84. https://doi.org/10.1186/s12889-017-4642-8
48. Salloum RG, Abu-Rmeileh N, Hamadeh R, et al. Policy-relevant context of waterpipe tobacco smoking among university students in six countries across the Eastern Mediterranean region: a qualitative study. *Asian Pac J Cancer Prev*. 2017;18:2533–2540. https://doi.org/10.22034/APJCP.2017.18.9.2533.
49. Dar-Odeh NS, Bakri FG, Al-Omiri MK, et al. Narghile (water pipe) smoking among university students in Jordan: prevalence, pattern and beliefs. *Harm Reduct J*. 2010;7:10. https://doi.org/10.1186/1477-7517-7-10.
50. Eshah NF, Froelicher ES. Knowledge, attitudes, beliefs and patterns of waterpipe use among Jordanian adults who exclusively smoke waterpipes. *Eur J Cardiovasc Nurs*. 2018;17:85–92. https://doi.org/10.1177/1474515117719592.

Appendix 1

Questionnaire *(English version)*

Consent Form

I'm a research assistant student at Jordan University of Science and Technology.

I am working on a project whereby I need to collect information on how people know and act toward Prenatal Genetic Testing. I am therefore asking if you would agree to participate in my research by answering a questionnaire.

You do not have to participate at all, or, even if you agree now, you can terminate your participation at any time without prejudice. Your name will not be attached to the questionnaire and I will ensure that your participation remains confidential.

I can tell you that your response may be included in the thesis I will write at the conclusion of this study; however, your responses would be anonymous and nobody could connect your responses with you as an individual.

A benefit you may experience by participating in this study is greater knowledge of your perceptions/feelings about Prenatal Genetic Testing in Jordan.

By participating in this study, you risk being upset or made uncomfortable by the questions asked.

If you have any questions or concerns, please feel free please feel free to contact the research PI.

_____ _____

Participant signature Date

Date: **Clinic:**
Out-patient file number:

Section 1: basic information

Name:

1. Date of birth:
2. Husband's date of birth
3. Weight:
4. Height:
5. Home Address:

   Urban Rural
6. Telephone number (optional)
7. Marital Status:

   Single Married Divorced Widowed
8. Do you have a health insurance?

   a. Present b. Absent c. Other:
9. What is the type of your Health Insurance?

   a. Private b. Governmental c. Other
10. How much does your health insurance cover?

    a. 100% b. 90% c. 80%
11. Education:

    a. Less than High school c. Institutional Degree e. Bachelor's Degree

    b. High School d. Master Degree f. PhD or MD

12. Are you working?

    a. Yes (please identify) b. No

13. What is the average monthly income of the household?

14. How do you consider yourself?

Very poor	
Poor	
Lower middle income level	
Middle income level	
Higher middle income level	
Rich	
Very rich	

15. Do you smoke cigarettes?

    a. Less than 10 cigarettes/d c. More than 1 packet/d

    b. 1 packet (20 cigarettes)/d d. More than 2 packets/d

16. Does your partner smoke cigarettes?

    a. Less than 10 cigarettes/d c. More than 1 packet/d

    b. 1 packet/d d. More than 2 packets/d

17. Do you smoke water pipe?

    a. Once monthly c. Once daily

    b. Once weekly d. More than 1 a day

18. Does your partner smoke water pipe?

    a. Once monthly c. Once daily

    b. Once weekly d. More than 1 a day

Section 2: genetic background

1. Are you and the baby's father related to each other (eg, cousins)?

    a. Yes b. No

2. Are you or the baby's father from any of the ethnic backgrounds listed below?

Afro-Jordanian	
Bedouin	
Armenian Circassian Chechen	
Other (specify)	

3. Do you have children?

    a. Yes b. No

If yes, please fill the table below.

NUMBER OF PREGNANCIES	SEX	DATE OF BIRTH	DELIVERY	CONGENITAL DISEASE	STILLBIRTHS	WEIGHT AT BIRTH	LATE ON TIME EARLY
1							
2							
3							
4							
5							

4. Does anyone in your family or the family of the father of the baby have a condition that has been diagnosed as a genetic or inherited, including:

	YES	NO		YES	NO
Thalassemia			Hemophilia		
Neural tube defects (spine bifida, anencephaly)			Muscular Dystrophy		
Down Syndrome			Cystic Fibrosis		
Tay-Sachs			Huntington Chorea		
Sickle Cell Disease			Mental Retardation		

Section 3: prenatal care

1. What prenatal tests does your doctor routinely recommend?

   a. Urine test b. Blood test c. Ultrasound

2. Has your doctor ever explained to you the reason beyond describing you specific tests?

   a. Yes b. No

3. Has your doctor ever talked about diagnostic medical sonography?

   a. Yes b. No c. Not applied

4. Do you want to know if your baby could probably have a congenital malformation?

   a. Yes b. No

5. Do you know there's a test for early detection of fetal malformation by performing a sonography to the fetus or taking a mother's blood sample?

   a. Yes b. No

6. If you have the opportunity to perform a test for early detection of fetal malformation, you will find it:

   a. Good b. Bad

7. Performing this type of test should be:

   a. Obligatory b. Facultative

8. Performing this type of test is:

   a. Reasonable b. Unreasonable

9. Performing this type of test is:

   a. Comfortable b. Uncomfortable

10. If performing this type of test is available only in another hospital/clinic, will you agree moving to that hospital/clinic?

    a. Yes b. No

11. Do you know there's a specific test that confirms that the fetus is affected by a congenital malformation (By taking a sample of the amniotic fluid surrounding the fetus or the placenta collected either using a needle through the abdomen or a tube through the vagina, knowing that this test could result in miscarriage in 1 case out of 100 cases (1%))

    a. Yes b. No

12. Do you think that performing this type of test is:

    a. Good b. Bad

13. Performing this type of test should be:

    a. Obligatory b. Facultative

14. Performing this type of test is:

    a. Reasonable b. Unreasonable

15. Performing this type of test is:

    a. Comfortable b. Uncomfortable

16. Do you think Genetic Screening is an invasive procedure?

    a. Yes b. No c. Don't know

17. Have your doctor ever told you to take a genetic screening test?

    a. Yes (Why) b. No

18. Have anyone helped you taking a decision to perform a genetic screening test?

    a. Yes (Who) b. No

19. Was he/she…?

    a. Supporting the examination b. Against the examination

20. If a genetic test can tell you the chance of having a baby with a genetic disease (eg, Down syndrome) would you like to know that while you are pregnant?

    a. Yes b. No

21. If a genetic test can tell you the chance of having a baby with a genetic disease (eg, Down syndrome) but could sometimes be wrong, would you still like to know that while you are pregnant?

    a. Yes b. No

22. Do you have a reservation on abortion in case the fetus has a congenital malformation?

    a. Yes (Reason): Emotional Religious

    b. No

23. Do you have a reservation on abortion in case the fetus has Down Syndrome?

    a. Yes (Reason): Emotional Religious

    b. No

24. If the screening test was positive for a genetic disease, will you consult your doctor to do abortion?

    a. Yes b. No

25. If yes, has your spouse helped you taking this decision?

    a. Yes b. No

26. Was he/she…?

a. Supporting the examination b. Against the examination

27. Will you visit more than 1 gynecologist before inducing abortion?

a. Yes b. No

28. If your doctor advices you to abort, would you do it?

a. Yes b. No

29. If religious consultant allowed abortion, will you agree?

a. Yes b. No

30. If religious consultant did not allow abortion but your doctor strongly suggested you to abort, will you agree?

a. Yes b. No

31. If it is prohibited to abort your baby with a serious fatal disease, would you try different approaches, like abortion pill?

a. Yes b. No

32. If genetic screening is integrated as a standard procedure in Jordan, will you support it?

a. Yes b. No

33. If genetic screening is implemented, will it increase the abortion rate in Jordan?

a. Yes b. No

34. If genetic screening is implemented, will it decrease the rate of children born with genetic disorders in Jordan?

a. Yes b. No

35. Do you think genetic screening is available in your health care center in Jordan?

a. Yes b. No

Section 4: obstetric/gynecologist visit

1. Are you pregnant or trying to get pregnant now?

a. Yes b. No

2. Why you have chosen your doctor?

a. Reputation c. Forced

b. Insurance d. Personal experience

3. How often do you visit your doctor?

a. Daily c. Every 2 weeks

b. Weekly d. Monthly

4. How much time do you spend with your doctor during the visit on average?

a. 10 minutes c. 45 minutes

b. 20 minutes d. More than 1 hour

5. How long is the average waiting time at the doctor clinic?

a. 10 minutes c. 45 minutes

b. 20 minutes d. More than 1 hour

6. Is your doctor available after the visit?

   a. Yes b. No

7. In case of emergency, how do you reach your doctor?

   a. Direct call to the physician c. Call the hospital

   b. Call the clinic d. Other

8. Do you feel comfortable with your doctor?

   a. Yes b. No (please explain why)

9. How satisfied are you with your doctor performance?

   a. Unsatisfied c. Satisfied

   b. Neutral d. Very Satisfied

10. If you attended the interview with your partner, did the doctor make an effort to include both of you in the conversation?

    a. Yes b. No

11. Do you find difficult reaching the clinic?

    a. Yes b. No

12. How are you satisfied with the expenses?

    a. Yes b. No

- **Prenatal genetic testing** refers to tests that are done during pregnancy to either screen for or diagnose a birth defect. The **goal** of prenatal genetic testing is to provide expectant parents with information to make informed choices and decisions.

Do you support it now?