

ORIGINAL ARTICLE

Agreement within couples on choosing preimplantation genetic diagnosis *versus* pre-natal diagnosis: perspective from Saudi population

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ABSTRACT

Background: Couples who are at risk of having an infant with a serious genetic disorder can benefit from pre-implantation genetic diagnosis (PGD), but many couples still opt for the riskier pre-natal diagnosis (PND). Although couples make this decision together, the male and the female in the couple may have different attitudes toward choosing PGD *versus* PND. The objective of this study was to determine if men and women in the same couple with at least one child with a genetic disorder will have significantly different attitudes toward choosing PGD *versus* PND.

Methodology: In this cross-sectional clinical study, couples with at least one child with a genetic disease attending the King Faisal Specialist Hospital Research Center, Genetic Counseling Clinic, Riyadh, Saudi Arabia were asked to complete an anonymous survey about their attitudes toward PGD *versus* PND. The responses were compared between men and women in couples. The study was conducted during May 2017.

Results: A total of 38 couples provided complete surveys. In terms of preference for PGD *versus* PND, there were no significant differences in aggregate between men and women ($p > 0.05$). Over half the couples agreed (were concordant) on all the statements about PGD *versus* PND. An almost equal number of couples with members who disagreed (were discordant) had women preferring PND *versus* men preferring PND compared to PGD.

Conclusion: This study showed that the members of couples sampled were generally in agreement about their preference for PGD *versus* PND. Among discordant couples, there was no preference among women for PGD *versus* PND. Studies like this are important to help clinicians understand intra-couple dynamics in genetic counseling.

Keywords: Genetic counseling, preimplantation diagnosis, prenatal diagnosis, consanguinity, health knowledge, attitudes, practice.

Introduction

Couples who are at risk of having an infant with a serious genetic disorder can benefit from pre-implantation genetic diagnosis (PGD). In this process, multiple zygotes can be developed and tested, and only the ones who are healthy are then implanted in the woman to carry to term (1). The PGD process has been studied and found to be successful in Saudi Arabia. In one study, 137 families underwent PGD, which resulted in 802 embryos, of which only 24% were transferred to the woman to carry to term (2). Over time, couples in Saudi Arabia

have changed their attitudes toward choosing PGD. In 2006, Al-Sulaiman and Hewison (3) studied attitudes

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in Saudi Arabian couples toward PGD and found that only 8 of the 30 couples they studied would accept PGD. However, in 2010, they studied 184 parents who either had a genetically-diseased child or were visiting the *in vitro* fertilization (IVF) clinic for infertility, and found that these families were enthusiastic about PGD, and were not concerned about the technical limitations or the ethical issues behind it (4). Those who do not choose PGD instead opt for prenatal diagnosis (PND), where the woman gets pregnant first the natural way and the fetus is tested early for genetic abnormalities (4). While the study in 2006 suggested that, among Saudi Arabian couples, PND was preferred; the more recent study suggests that PGD is preferred. The King Faisal Specialist Hospital Research Center (KFSH-RC) Genetic Counseling Clinic (GCC), in Riyadh, Saudi Arabia offers PGD to couples. Couples are referred if they have a child with a genetic disorder with a known mutation, or if the woman in the couple is currently carrying an infant suspected to have a genetic disorder. The couples are given a choice between PGD and PND. The hypothesis of the current study was that among patients of the GCC, men and women in the same couple with at least one child with a genetic disorder will have significantly different attitudes toward choosing PGD *versus* PND. Thus, the study aimed to determine whether among patients of the GCC, men and women in the same couple with at least one child with a genetic disorder will have significantly different attitudes toward choosing PGD *versus* PND.

Subjects and Methods

In this cross-sectional clinical study conducted during May 2017, couples who were patients at the GCC who had at least one child with a genetic disease were asked to complete an anonymous survey about their attitudes toward PGD *versus* PND. The responses were compared between men and women in couples. The study population, survey development, data collection, and data analysis plans were systematically reviewed. This study has been approved by the Alfaisal University Ethical Review Board. As a part of the approval, the survey used in the study was approved. The study participants included couples who were attending genetic counseling when considering whether or not to have the woman get pregnant. They were recruited from the GCC, in Riyadh, Saudi Arabia. Patients at this clinic included couples referred from other departments at KFSH-RC as well as from other public hospitals in Saudi Arabia. There were two types of couples referred: (1) those with an existing child with a genetic disease who were concerned about having another diseased child and (2) those couples where the wife was currently pregnant with a potentially diseased fetus. Most couples referred fall in the first category and were recruited for the study. At the GCC, referred couples meet with a genetic counselor, who describes that they can choose one of two processes: PGD or PND. If the couple chooses the PGD, they are scheduled then for their first appointment approximately 2 years in the future (due to a long waiting list at the

clinic). However, if the couple chooses PND, they will immediately be placed in the PND protocol. In terms of genetic disorders, PGD is seen as primary prevention, and PND is seen as secondary prevention.

There are some ethical issues that come up in this process. First, those at the GCC who are told that they have a diseased fetus they cannot abort because the disease is non-life-threatening may go to a private clinic to have this work done. Second, primary prevention through PGD is preferable, but due to the long waiting list, this is not possible for many couples. If the woman is over the age of 40, the clinic will not provide PGD due to concerns with ovum quality. This is because, by age 40, the chance of a woman conceiving (with her own ova) is no more than 10%–15%. Therefore, couples might be turned away over this issue. Also, couples may choose to go to an expensive private clinic for PGD services because they do not want to wait the 2 years, but those without enough funds for this are left with the choice between waiting 2 years for PGD or choosing the PND process right away.

This situation suggests that these ethical considerations may have a strong influence on the decision process of couples. The rules about aborting fetuses might drive couples to private clinics and away from the GCC. However, those who cannot afford private care may continue with the GCC. There are likely other ethical issues that are personal and might impact the couples' decisions. Detailed inclusion and exclusion criteria for this study are listed in the Supplementary Data. A literature search was performed to identify an appropriate quantitative instrument for measuring attitudes in couples toward PGD and PND. Qualitative instruments were identified, but no quantitative instruments were found. To clarify, no quantitative instruments for measuring attitudes in couples toward PGD and PND were found in the literature that had been the subject of reliability and validity tests, and therefore, no instrument was identified that could be used as an international standard. For this reason, the researchers had to develop their own survey for this study. The hypothesis was examined, and a list of domains required in the survey to answer the hypothesis was developed based on similar surveys (5). The domains and their descriptions are listed in Table A included in the Supplementary Data. Statements were designed corresponding to the different domains of the survey (Table A). The respondents were asked to rate their level of agreement with each of the statements on a scale of 1–5, where 1 strongly disagreed, and 5 strongly agreed. The statements in the survey are provided in Table B of Supplementary Data. In addition, demographic questions were developed corresponding to the demographic domains of the survey.

The survey was first written in English and then translated to Arabic. Next, it was then back-translated to English by another translator, and any issues with interpretation were addressed with minor changes. Because this was the first time this survey was used, it was not studied for validity

and reliability, although the authors intend to study and improve upon this survey in the future.

The recruitment of study subjects took place at the initial visit, where the choice between PGD and PND was explained. Couples attending a genetic consultation who appeared to qualify for the survey were approached at the end of the consultation by the clinician. If the couple was found to be eligible and consented to the survey procedures, the couple was enrolled in the study. To preserve anonymity, verbal consent was used with no documentation of consent. After consent, the couple was given a packet containing two identical copies of the survey, one labeled for the wife and the other labeled for the husband, along with an envelope that could be sealed. The surveys were numbered with randomly chosen study identification (ID) numbers (couple ID for the couple and study ID for the individual) to facilitate anonymity of the couple but to also allow the researcher to pair the surveys together during analysis. The couple was also provided writing utensils if needed. The clinician left the room while the couple filled out their respective surveys and sealed them in the envelope provided. The sealed envelopes were stored in a locked drawer and collected by the researcher at least once per week. Later, the envelopes were opened by one researcher (F. A.), and data entry was conducted into an Excel spreadsheet. This spreadsheet was de-identified because only the couple IDs and study IDs were included as identifiers.

G Power software was used for the sample size calculation (6). The power calculation was designed to estimate how many couples would be needed to show a statistically significant difference between men and women with respect to the response to the survey statement, “If I had to choose today, I would choose PGD over PND.” It was hypothesized that the mean response in men would be lower, and the mean response in women would be higher.

Effect sizes were calculated by subtracting the estimated mean of the men’s rating of the statement from the estimated mean of the women’s rating of the statement. Assuming an alpha of 0.05 and a power of 80%, the sample needed was estimated at various effect sizes. An effect size of a difference of approximately two to four points was targeted. Ultimately, given the time available, clinic flows, and estimated sample at various effect sizes, a target recruitment goal of 45 couples (45 men and 45 women, total = 90 participants) was set.

Descriptive analysis (means and percentages) was done on all the data from couples and individuals in the couples. To answer the research question, answers to the

preference for PND *versus* PGD and the various reasons were compared between men and women. Participants were considered to have “agreed” with each statement if they answered 4 or 5 to each statement. Rates of men and women agreeing with the various statements, both in aggregate and within couples, were analyzed. Chi-square and Fisher’s exact tests (where cells included less than five units) were used to compare differences in rates of agreement between men and women and between couples.

Results

A total of 40 couples agreed to complete the surveys. The surveys from one couple were not returned, and another couple was found to not qualify for the survey after completing it, making the total number of couples included in the analysis equal to 38. Table 1 and Figure 1 represent couple demographics.

As shown in Table 1 and Figure 1, there was wide variability in the number of children the couples reported having. Demographics of the men and women in the couples in the study are presented separately in Table 2.

Table 2 shows column percentages. As shown in Table 2, women in couples were younger than the men. There were no men in the lowest age group, 18–25 years old, but there were four women (11%). There were more men in the age 36–55 group ($n = 16$, 42%) compared to women ($n = 11$, 29%), and there were only men in the oldest age group of 55+ ($n = 3$, 8%). PGD is limited to women under age 40, so women in this study would be expected to be in younger age groups. The highest level of education was similar among men compared to women, in that 20 men (53%) and 20 women (53%) reported having achieved at least a bachelor’s degree. For both men and women, the primary reason stated for visiting the GCC was because of an existing child or children with a genetic disorder (men $n = 32$, 84%, and women $n = 31$, 82%). However, two women (5%) and two men (5%) indicated their primary reason for visiting was concern about multiple abortions, while three women (8%) and two men (5%) said they were primarily concerned that they themselves may have a family history of a genetic disorder. Also, both men ($n = 16$, 42%) and women ($n = 18$, 47%) listed family and friends as the main influencers in their decision between PGD and PND, with the second most common answer in both being from what was learned in the counseling session (men $n = 15$, 39%, and women $n = 11$, 29%). Equal percentages of women (6, 16%) and men (6, 16%) listed the media and internet as the main

Table 1. Couples information.

	1 (n, %)	2 (n, %)	3 (n, %)	4 (n, %)	5 or more (n, %)	Unknown (n, %)
Number of children	6 (16%)	10 (26%)	7 (18%)	6 (16%)	9 (24%)	0 (0%)
Number of children born with genetic disorder	22 (58%)	9 (24%)	4 (11%)	1 (3%)	0 (0%)	2 (5%)

Attitudes toward PGD *versus* PND among Saudi Arabian couples

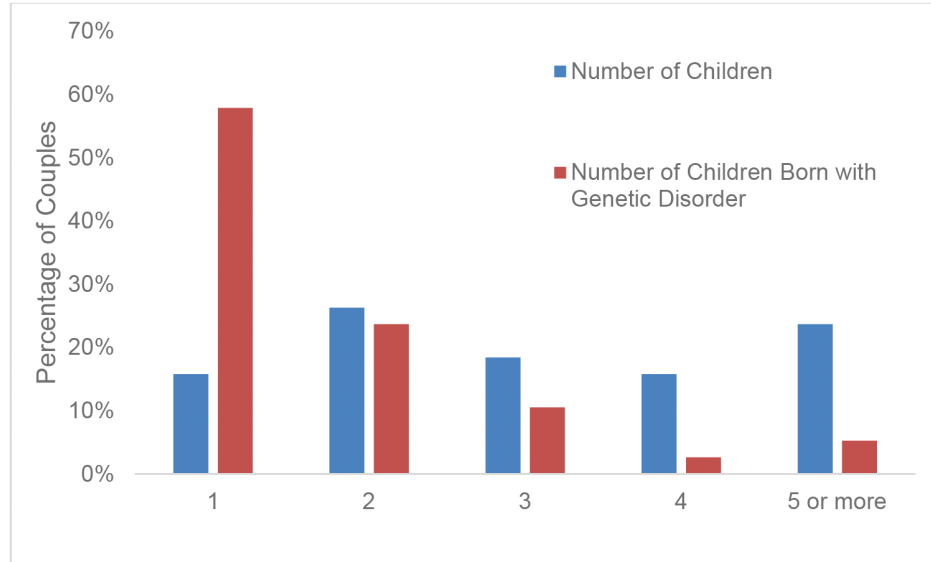


Figure 1. Couples information.

Table 2. Demographics of women and men in the study.

Variable	Level	Men		Women	
		<i>n</i>	%	<i>n</i>	%
Age groups	All participants	38	100	38	100
	18–25	0	0	4	11
	26–35	19	50	23	61
	36–55	16	42	11	29
	56+	3	8	0	0
	Missing	0	0	0	0
Highest education level	Primary education	1	3	3	8
	Intermediate	1	3	6	16
	High school	14	37	9	24
	Bachelor's degree	19	50	19	50
	Other*	2	5	1	3
	Missing	1	3	0	0
Primary reason for visiting clinic	I have a child/children with a genetic disorder	32	84	31	82
	Multiple abortions	2	5	2	5
	Family history of a genetic disorder	3	8	2	5
	Other**	1	3	3	8
	Missing	0	0	0	0
Main influence(s) for decision***	From what I learned in the counseling session	15	39	11	29
	From family and friends	16	42	18	47
	Media and internet	6	16	6	16
	Other influence****	3	8	3	8

*Other education includes Men—PhD (1), Diploma (1), Women—Master's degree (1).

**Other reasons include: Men—Preterm birth plus congenital anomalies in the baby (1), Women—Because my husband has a family history of a disease called beta thalassemia (1), my husband has a genetic disease called Albert's disease (1), preterm birth plus congenital anomalies in the baby (1).

***More than one answer was accepted for this question.

****Other influences include Men—Wife (2), personal experience with PGD (1). Women—Made decision alone (1), personal experience with PGD (1), not listed (1).

Table 3. Attitudes of men and women toward PGD and PND.

Variable	Level	Men		Women		χ^2 p-value
		n	%	n	%	
Overall preference	Would choose PGD today	21	55	22	58	1.0000
	Would choose PND today	17	45	12	32	0.3449
PGD preference—positive aspects	Want to be sure of the outcome	30	79	33	87	0.5424
	Want to avoid abortion	32	84	26	68	0.1773
	Do not want waiting period during pregnancy not knowing the status of the baby.	25	66	27	71	0.0851
	Only 3% level of misdiagnosis	22	58	19	50	0.6453
PGD preference—negative aspects	Only 40% chance to get pregnant the first time	24	63	24	63	1.0000
	Takes 2 years to get an appointment	19	50	21	55	0.8183
PND preference—positive aspects	Outcome sooner than with PGD	25	66	23	61	0.8120
	Only 1% miscarriage risk	24	63	22	58	0.8145
	Fewer appointments than PGD	28	74	27	71	1.0000
	The couple has full control over the process, not the medical system	16	42	17	45	1.0000
	No potential mistakes in the father's identity	18	47	16	42	0.8175
PND preference—negative aspects	The fetus may be affected and be aborted	22	58	23	61	1.0000
	The infant may be affected and die after delivery*	3	8	5	13	0.7110
	The infant may be affected and have disability*	2	5	3	8	1.0000
	The infant may be affected but not qualify for an abortion	7	18	8	21	1.0000

* Due to small cells, Fisher's exact test was used.

influencer. Table 3 represents the attitudes of men and women in aggregate.

As shown in Table 3, in aggregate, men and women did not show any statistically significant differences in their overall agreement with statements indicating a preference for PGD *versus* PND, as well as in their agreement with specific statements indicating a preference for PGD *versus* PND.

To understand agreement and disagreement within couples with each statement, couples were placed into one of four categories: (1) Both husband and wife agree with the statement, (2) neither husband nor wife agrees with the statement, (3) husband agrees but wife does not agree, and (4) wife agrees but husband does not agree. The distribution of couples categorized this way by the statement is presented in Table 4.

As shown in Table 4, over half of the couples were concordant on all the statements, meaning they either both agreed with the statement or they both did not agree with the statement. The results for the discordant couples, or couples where the husband and wife answered differently, are presented in Figure 2A for PGD statements and Figure 2B for PND statements.

As shown in Figure 2A, with respect to the PGD statements, almost the same percentage of couples was in both discordant groups. As shown in Figure 2B, there was a similar pattern with respect to PND statements, with about half of discordant couples having the husband agreeing with PND statements, while the wife disagreed, and the other half vice versa.

Discussion

The results of this study show that the members of Saudi Arabian couples who were patients of the GCC who had

Table 4. Distribution of couples by attitudes toward PGD and PND.

Variable	Level	Both Agree		Both Do Not Agree		Husband Agrees, Wife Does Not		Wife Agrees, Husband Does Not	
		<i>n</i>	%	<i>n</i>	%	<i>n</i>	%	<i>n</i>	%
Overall preference	Would choose PGD today	15	39	10	26	6	16	7	18
	Would choose PND today	6	16	15	39	11	29	6	16
PGD preference—positive aspects	Want to be sure of the outcome	27	71	2	5	3	8	6	16
	Want to avoid abortion	24	63	4	11	8	21	2	5
	Do not want waiting period during pregnancy not knowing the status of the baby.	18	47	4	11	7	18	9	24
	Only 3% level of misdiagnosis	14	37	11	29	8	21	5	13
PGD preference—negative aspects	Only 40% chance to get pregnant the first time	16	42	6	16	8	21	8	21
	Takes 2 years to get an appointment	11	29	9	24	8	21	10	26
PND preference—positive aspects	Outcome sooner than with PGD	18	47	8	21	7	18	5	13
	Only 1% miscarriage risk	15	39	7	18	9	24	7	18
	Fewer appointments than PGD	22	58	5	13	6	16	5	13
	The couple has full control over the process, not the medical system	8	21	13	34	8	21	9	24
	No potential mistakes in the father's identity	12	32	16	42	6	16	4	11
PND preference—negative aspects	The infant may be affected and be aborted	15	39	8	21	7	18	8	21
	The infant may be affected and die after delivery	1	3	31	82	2	5	4	11
	The infant may be affected and have a disability	0	0	33	87	2	5	3	8
	The infant may be affected but not qualify for an abortion	2	5	25	66	5	13	6	16

at least one child with a genetic disorder did not have significantly different attitudes toward choosing PGD *versus* PND. Although it had been hypothesized that the largest percentages of discordant couples would be the ones where the wife preferred PGD and the husband preferred PND, this was not the case in this study. Although for some questions, as high as 45% of the couples were discordant on their answers, discordant couples were found to be roughly equal with respect to the wife preferring PGD and the husband preferring PND, and vice versa. No strong trends were found to suggest that there were a greater number of discordant couples where the wife preferred PGD and the husband preferred PND. In previous studies of Saudi couples' preferences for PGD *versus* PND, the couples were studied together, and individual opinions of each member of the couple were not gathered. For example, Alsulaiman and Hewison (3) reported that of the 30 couples they surveyed, only 8 (27%) accepted PGD, and four (13%) accepted PND, but

did not query the members of the couples individually to probe for differences in opinions. A 2010 study by Alsulaiman et al. (4) again examined attitudes toward PGD and PND (as well as IVF) in terms of Saudi couples' attitudes rather than individual attitudes of the members of the couple. While quantitative data were presented in both of these articles, they were derived from the results of semi-structured interviews (3,4). This makes it difficult to compare the results of the present study with previous studies, as the current study quantitatively gathered information, and compared attitudes of individual members of the couples. One comparison could be made, however, between a trend toward greater acceptance of PGD that was found and noted by authors when comparing findings from the 2006 paper and the 2010 paper (3,4). While only 27% of the couples accepted PGD in the 2006 article, in the 2010 article, the authors reported "families were enthusiastic about PGD and relatively unconcerned about its technical limitations";

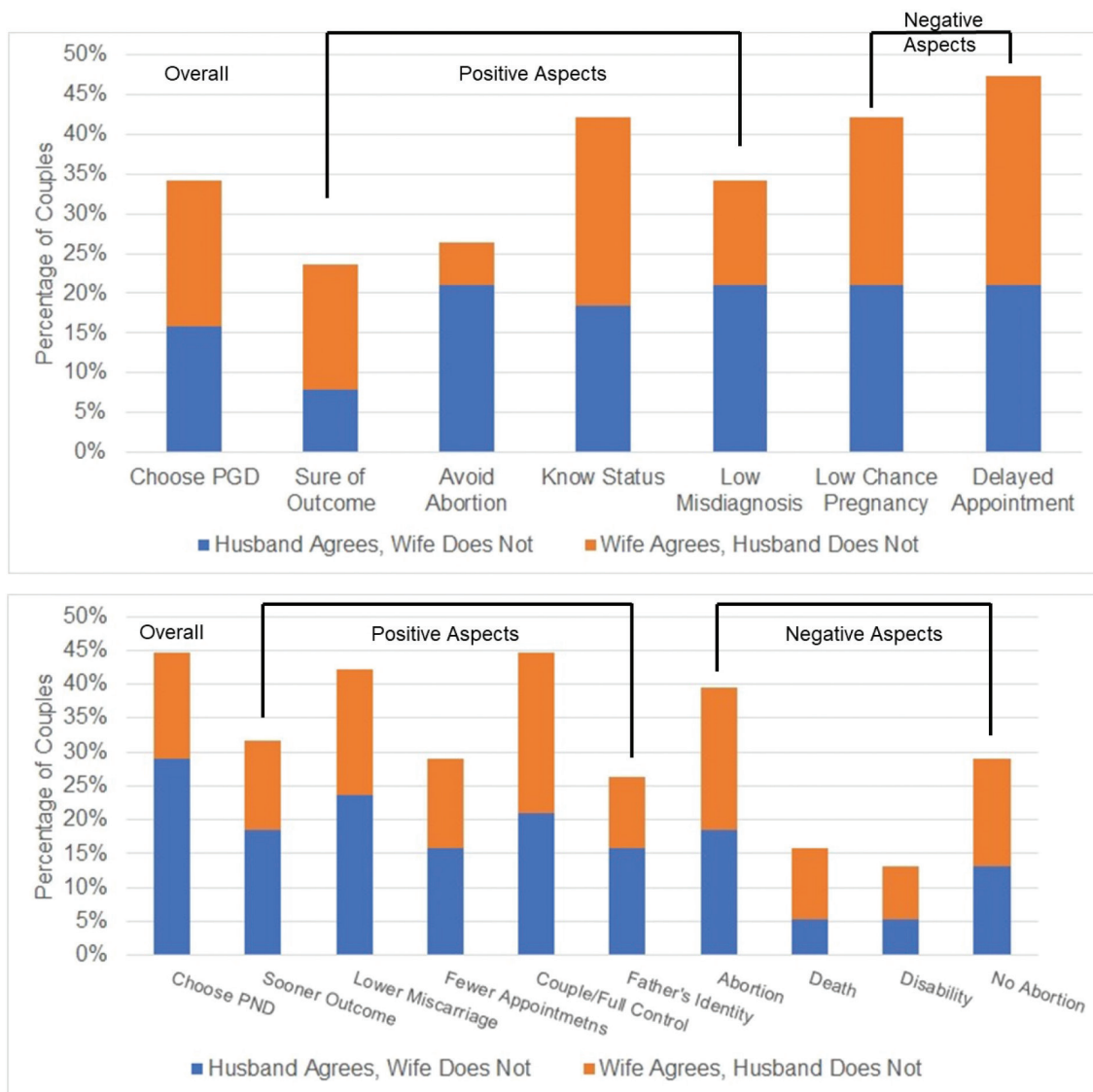


Figure 2. (A) Discordant attitudes in couples: PGD statements. (B) Discordant attitudes in couples: PND statements.

this trend was also seen in the results of the current study. In the 2010 study, 94% of couples in one study group and 100% of couples in another study group responded “yes” to the question, “If PGD was offered to you, would you accept it?” (4). While the current study had lower rates of members of couples preferring PGD to PND, there was still a higher interest overall in PGD compared to PND in this study, which matches the general trend seen in these past studies. Another study by Alsulaiman and Hewison (7) published the results of a quantitative questionnaire given to 200 parents (100 couples) about PND and termination of pregnancy for a range of different genetic disorders. While the questionnaire employed did not ask questions about PGD, the results were analyzed in men and women separately, and the authors found that although men and women held similar attitudes toward PND diagnosis, mothers’ attitudes toward termination of pregnancy were more favorable” (7). This remains

consistent with the findings of the current study which showed that women in the couples overall did not seem as concerned with termination of pregnancy under PND as men in the couples did. Although the attitudes of men and women both within couples and in aggregate did not show any differences in this study, overall, the high levels of agreement with some technical statements about PGD and PND, as well as other results in the survey suggest that the counseling session was helpful in imparting knowledge to the participants. This is a positive signal, given that a 2013 study by Abolfotouh et al. (5) found knowledge about IVF was low in Saudi patients making decisions about IVF. However, the extremely low rates of agreement on the statements reflecting negative aspects of PND suggest that this area of education in the counseling session may be weaker. Participants felt much less favorable to PND when presented with the negative aspects, so perhaps these should be more emphasized

in the counseling session so they are considered more carefully in the couples' decision.

There are both strengths and limitations to this study. Strengths include that the study was completely anonymous, and collected and analyzed data in terms of both couples as well as independent members of the couple. Limitations of the study include that the questionnaire needed to be developed since one did not exist, and the newly designed questionnaire was not tested for its validity and reliability. Although results in this study were not statistically significant, it is acknowledged that 38 couples were below the recruitment target, and perhaps including more couples in the study would have provided a clearer picture. Some differences may be statistically significant with enough data gathered. Also, the study took place at only one clinic in Saudi Arabia; results might be different at a different clinic in Saudi Arabia, or in a different country. Future studies should be conducted considering the current study as a base. Furthermore, a reliable and valid questionnaire for measuring couples' attitudes toward PGD and PND should be also developed.

Conclusion

In conclusion, contrary to what was hypothesized, when Saudi couples in this study with at least one child with a genetic disorder attending a counseling session at the GCC disagreed on their preferences for PGD *versus* PND, the men in the couples were not more likely to prefer PND with the women preferring PGD. As the study showed, there were no gender-related trends among couples who disagreed, with PGD and PND being preferred equally by both men and women. The study also suggested that the counseling sessions at the GCC were helpful in couple decision-making and impart knowledge to them necessary to make the decision. Future studies should continue to examine couples' attitudes toward PGD and PND and look at individual answers to questions separately, as well as work on further developing the questionnaire used in this study to document and improve its validity and reliability.

List of Abbreviations

ID	Identification
IVF	<i>In vitro</i> fertilization
GCC	Genetic Counseling Clinic
KFH-GCC	King Faisal Hospital, Genetic Counseling Clinic
PGD	Pre-implantation genetic diagnosis
PND	Pre-natal diagnosis

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None.

Declaration of conflicting interests

The authors of this article have no affiliations with or involvement in any organization or entity with any financial interest or non-financial interest in the subject matter or materials discussed in this manuscript.

Ethical approval

This study was considered exempt from the Alfaisal University Ethical Review Board (ERB), which is the ethics board of record for KFSH-RC.

Consent for publication

Informed consent was obtained from the study subjects.

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References

1. Fasouliotis SJ, Schenker JG. Preimplantation genetic diagnosis principles and ethics. *Hum Reprod Oxf Engl* 1998; 13(8):2238–45. <https://doi.org/10.1093/humrep/13.8.2238>
2. Abotalib Z. Preimplantation genetic diagnosis in Saudi Arabia. *Bioinformation* 2013; 9(8):388–93. <https://doi.org/10.6026/97320630009388>
3. Alsulaiman A, Hewison J. Attitudes to prenatal and preimplantation diagnosis in Saudi parents at genetic risk. *Prenat Diagn* 2006; 26(11):1010–4. <https://doi.org/10.1002/pd.1544>
4. Alsulaiman A, Al-Odaib A, Al-Rejjal R, Hewison J. Preimplantation genetic diagnosis in Saudi Arabia: parents' experience and attitudes. *Prenat Diagn* 2010; 30(8):753–7. <https://doi.org/10.1002/pd.2532>
5. Abolfotouh MA, Alabdrabalnabi AA, Albacker RB, Al-Jughaiman UA, Hassan SN. Knowledge, attitude, and practices of infertility among Saudi couples. *Int J Gen Med* 2013; 6:563–73. <https://doi.org/10.2147/IJGM.S46884>
6. Faul F. Universität Düsseldorf: G*Power [Internet]. Germany: Universitat Kiel; 2014 [cited 2014 Aug 14]. Available from: <http://www.gpower.hhu.de/en.html>
7. Alsulaiman A, Hewison J. Attitudes to prenatal testing and termination of pregnancy in Saudi Arabia. *Community Genet* 2007; 10(3):169–73. <https://doi.org/10.1159/000101758>

Supplementary Data

Inclusion and Exclusion Criteria

Couples were recruited to participate in the survey if they met the following qualifications:

Inclusion Criteria

1. Both members of the couple needed to be Saudi Arabian by ethnicity.
2. Both members of the couple needed to be age 18 or older.
3. The couple must already have conceived and given birth to a child with a genetic disorder, and have

been referred to the clinic for genetic counseling prior to conceiving the next child.

4. The couple must have been attending a clinic visit at GCC.

Exclusion Criteria

1. Couples with the unclear genetic diagnosis were excluded from the study.
2. Couples with a child with a birth defect were excluded from the study.

Because data were collected anonymously, this study was found to be exempt from oversight by the ERB.

Survey Domains and Items

Table A. Survey domains and descriptions.

Domain	Data collected
Demographics	Gender, age, number of children/live births with and without the genetic disorder, the highest level of education, consanguinity status, reasons for attending clinic visit.
Overall Preference	PGD <i>versus</i> PND
Preference for PGD: Positive aspects	Want to be sure of the outcome, want to avoid abortion, do not want to wait during pregnancy to know the status of baby, only 3% risk of misdiagnosis.
Preference for PGD: Negative aspects	Only 40% chance to get pregnant the first time, delay of 2 years in beginning appointments.
Preference for PND: Positive Aspects	Outcome sooner than with PGD, only 1% miscarriage risk, fewer appointments than PGD, couple (not medical system) has full control over the process, no potential mistakes in father's identity.
Preference for PND: Negative Aspects	The fetus may be affected and aborted, the infant may be affected and die after delivery, the infant may be affected and have a disability, the infant may be affected and not qualify for an abortion.

Table B. Statements in the survey and their domains.

Statement	Domain
If I had to choose today, I would choose PND over PGD.	Overall preference
If I had to choose today, I would choose PGD over PND	
I want PGD and I know that 40% chance to get pregnant from the first time	PGD preference—negative aspects
I want PGD even though it takes 2 years to get the appointment	
I want PGD because I will be 97% sure of the pregnancy outcome	PGD preference—positive aspects
I want PGD because I don't want to go through the abortion debate	
I want PGD because I don't want to go through the anxiety period until the result come back if my baby is affected or normal	PGD preference—positive aspects
I want PGD and I know there is a 3% of medical misdiagnosis	

Statement	Domain
I want PND and if my child is affected with a genetic disease I don't mind aborting the baby	PND preference—negative aspects
I want PND and I know that my child might be affected with a genetic disease that can lead him to death after delivery	
I want PND even though my child might be affected with a genetic disease will disable him	
I want PND even though my baby might be affected with genetic disorder but cannot not be aborted	
I want PND because it is easier and the results come out in a short period of time	PND preference—positive aspects
I want PND because the miscarriage risk from this procedure is only 1%	
I want PND because it requires less appointments than PGD.	
I want PND because I do not want to give control of the pregnancy process over to the medical system.	
I want PND because it will ensure that there are no mistakes and the male of the couple is truly the father.	