Women's Intention to Abort a Fetus Diagnosed with a Genetic Disease: Results from Israel, Cyprus and Germany

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Research Article

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Abstract

Background: Developments in genetics, have now enabled early detection of fetus genetic abnormalities in utero. In parallel, a woman's right to her body has led to legal changes, which permit abortions under certain conditions. The decision whether to undergo an abortion following the discovery of a fetal abnormality is affected by culture, legal regulations, and attitudes. The aim of the study was to assess the cultural influence on women's intention to undergo an abortion in case her fetus is diagnosed with a genetic disease.

Research Design: A scenario based study conducted in Israel, Germany and Cyprus. A questionnaire presented six scenarios in which a woman is pregnant and her fetus is diagnosed with a mild, moderate or severe genetic disease. For each scenario, the women were asked to rate their perceived severity about having a child with the disease, sense of control over performing an abortion and their intention to undergo an abortion. For analyzing the differences between the countries, one-way analysis of variance (ANOVA) was used with Tukey's-b post hoc tests. Multiple linear regressions were used to detect variables associated with the intention to terminate the pregnancy.

Results: A total of 358 women participated in the study 141 Israeli, 121 German and 96 from Cyprus. The results revealed that for all diseases, Israeli women were more inclined to perform an abortion than German and Cypriot women. In all cases Israeli women reported a higher sense of control over performing an abortion and Cypriot women expressed the highest perceived severity. Sense of control, severity perception, being Israeli, and increased age predicted the intention to abort.

Conclusions: The intention to abort following the diagnosis of a fetus with a genetic disease is influenced by culture. There is a greater intention to abort when women feel more control, and have a higher perceived severity, regardless of the severity of the disease.

Introduction

Developments in assisted reproduction and genetics, now enable early detection of abnormalities in the fetus and neonate [1, 2]. Diagnostic tests, which are adopted readily by prospective parents [3], hold the potential to offer information regarding the health of the fetus [4]. When the results are normal, they provide certainty, however when an abnormality is identified, the prospective parents face a dilemma and a decision about whether to continue or terminate the pregnancy [5, 6]. The accessibility of these tests and the information they provide, as well as the increasing recognition of a women's rights to her own body, place much of the responsibility for the decision whether to continue or terminate the pregnancy on the woman [6, 7]. However, it is reasonable to suppose that the severity of the genetic disease is a consideration in the decision to perform an abortion [8].

Induced abortions are now common in Western society. According to a survey conducted in sixty countries between the years 1990–2014, one out of four pregnancies ended in an induced abortion. One-tenth of the abortions were due to a genetic disease [9]. The rate of abortions differs between countries according to culture, legislation, and regulations. For example, the rate of pregnancy terminations in developing countries is much higher than in developed countries [10]. According to an Israeli Ministry of Health report [11], the rate of induced abortions in Israel is lower than the average in European Union countries, numbering 98.8 per 1000 live births in Israel compared to 198.6 in EU countries.

Israel, Cyprus, and Germany, are all Western, multicultural immigration countries, with different religious and sociopolitical contexts, have secular abortion laws that approve induced abortions in certain circumstances including when there is a risk to the mother's life or physical health, or in cases of severe fetal impairment [12, 13]. Nonetheless, differences in legislation and conduct exist between the countries. As an example, in Israel, all selective abortions, including those due to fetal impairments, require the approval of a medical center committee for termination of pregnancies in the early weeks of pregnancy. After the 24th week of gestation, approval from the high Regional Committee is required [11]. In contrast, abortions due to fetal abnormality are legal in Germany up to the 22nd week of gestation, with a three day delay before

conducting the procedure [14]. Abortions up to the 12th week of gestation can be approved after consultation with a recognized center, while after the 12th week; approval by two physicians is required. Legislation in Cyprus was recently updated to allow abortions up to 12 weeks of gestation, but requires a mandatory psychological consultation [15]. It should be noted that the law in these countries does consider the severity of the genetic defect as a factor in approving an abortion [12].

In Israel during 2016, 99% out of 19,283 requests for pregnancy termination were approved, where a fifth of the requests were due to fetal abnormalities [11]. The corresponding number for Germany is not known since the German "Protection of the Individual privacy" law from 1995, bans documentation of the causes for pregnancy termination [16]. In Cyprus, which does not maintain records of the abortion rate or reasons [17], studies estimate that approximately 5% of abortions are performed because of a fetal genetic disorder [18].

The decision to undergo an abortion, following the diagnosis of a genetic disorder is influenced by a wide range of culture-related factors such as religion, government policy, and customs [19]. With regard to religion, Christianity and specifically the Catholic Church, opposes abortions under any circumstance [20]. In contrast, Islamic and Jewish law permit abortion in cases where a severe condition such as Tay Sachs disease that would cause death in early childhood, is diagnosed in the fetus [21]. Religiosity is also connected to the decision to perform an abortion, with stronger religious beliefs associated with less inclination to perform selective abortions [22].

In Cyprus, where one out of seven members of the population is a carrier of βthalassemia, the government introduced quasi-mandatory premarital genetic testing for the disease, a step taken with the cooperation of the Cypriot Orthodox Church. Accordingly, couples intending to marry in church must be screened and receive counseling prior to their marriage. During counseling, the risk of thalassemia major and the options of preimplantation genetic diagnosis (PGD) or prenatal screening followed by an abortion if the fetus is affected are discussed. As a result, some couples decide to change their marital plans. This plan when implemented in 1983 dramatically reduced the birth of children with thalassemia. However, the increase in overseas workers, and the option for civil weddings have since resulted in an increase in the births of children with thalassemia [23].

In the decision-making process of whether to undergo an abortion, the severity of the genetic abnormality of the embryo is usually a consideration for the prospective parents. It has been reported that 65% of Greek women would request late pregnancy termination if a severe disease was diagnosed in the fetus. Moreover, the more negatively they perceived the ability of the future child to lead a healthy lifestyle, the more they were likely to terminate the pregnancy, one important factor was the age of illness onset [24]. As an example, a fetus diagnosed as a carrier of the BRCA gene mutation, which increases the risk of developing breast and ovarian cancer in later life, was perceived by women as less severe, so that only one third of women faced with this situation decided to abort or use reproductive technologies to ensure a healthy fetus [25]. Another study conducted in the United States reported that when the genetic disease was likely to cause severe physical disability in early life, 76% of women expressed a desire to perform an abortion [26]. Recently, a classification of the severity of genetic diseases was published that defines four categories by the age of onset and severity of symptoms. The most serious diseases are classified as profound, and diseases with more minor manifestations are classified as minor. The authors also present a flow chart for categorizing disease severity [27].

Variables found to be associated with the likelihood of selective abortions are: living in a more permissive country, being younger, secular, more educated, divorced, and employed [28]. An Israeli study found that the more a woman believes that the act of abortion is moral, justified, or desirable, the stronger her behavioral intention of carrying out an abortion regardless of the views of significant others [29]. A recent study reported of three evaluation factors when facing the decision to terminate an unwanted pregnancy: capital, values and access barriers [30].

Social pressure was reported to be a strong factor in increasing behavioral intention, especially with regard to issues with a high impact on the society, such as pregnancy [31]. In other similar fields, such as fertility, women from a variety of cultures

were shown to be influenced by their social environment. For example, in Germany, the negative context of Nazi history, as well as current legislations and statements by politicians, encourage the population to avoid selective abortions [32]. In Israel however, is there is a high fertility rate, and strong peer pressure to raise a healthy baby, so selective abortions are socially acceptable [33]. Similarly, in Cyprus, abortions in cases of thalassemia have become more acceptable with the advent of quasi-mandatory premarital genetic testing for the disease [23].

The present study was designed to examine these issues, focusing on the effect of the severity of the genetic disorder according to the published classifications [27]. In addition to perceived severity of the disease, we also examined the impact of perceived control over performing an induced abortion as defined by Ajzen & Madden [34], and the intention to undergo an induced abortion in three different countries with different abortion laws: Cyprus, Germany and Israel, as representing different cultures.

Methods

Tools

We collected demographic characteristics including age, marital status, having children, religion and religiosity, country of birth, years of education, and the presence of known genetic diseases in the close or extended family.

The questionnaire was scenario based, with each scenario representing a situation where the fetus of a pregnant woman is diagnosed with a genetic abnormality. We classified fetal abnormalities into three groups as described by Lazarin et al [27], who defined four degrees of severity of genetic disease from profound to mild. Because profound disease was very likely to result in an abortion, we selected diseases that fall into the three categories of severe, moderate, and mild. Accordingly: 1. Fragile-X and thalassemia were classified as severe disorders. 2. Albinism and a carrier of the BRCA mutation were classified as moderate diseases, and 3. Triple X, and Van der Woude, syndromes were classified as mild. Six scenarios were presented to the women participants, who were requested to imagine that she is pregnant and has received genetic test results indicating that her fetus is affected with one of the diseases described above, accompanied by a short description of the disease symptoms. The participants were requested to indicate their perceived severity of the disease ranked on a six-point scale ranging from not at all severe = 1 to very severe = 6. They were also asked to rate their intention to perform a selective abortion if the disease was detected in their fetus, on a 6 point scale ranging from strongly disagree = 1 to strongly agree = 6. The results of each group of questions were averaged according to the type of disease (severe, moderate, or mild). The Cronbach's alpha of the internal consistency of the questionnaire ranged from 0.88 to 0.92.

Statistical Analysis

Data were analyzed using SPSS for windows (version 25). Statistical tests included $\chi 2$ for categorical variables. In order to determine whether there were any statistically significant differences between the means of the groups, one-way analysis of variance (ANOVA) was used with Tukey’s-b post hoc tests. Multiple linear regressions were used to detect variables associated with the intention to terminate the pregnancy.

Procedure

Prior data collection, in order to evaluate the questionnaire, a pretest among 10 women in each country was conducted, which revealed no need for changes. After, data were collected from women visiting gynecological clinics for routine checkups in the center of Israel (Tel- Aviv), Germany (Berlin), and in the Greek speaking region of Cyprus (Nicosia). The questionnaire was translated to Greek and German, and women who were not fluent in the local language were excluded from the study. Women were requested to participate in the study; those who gave their oral consent received a short explanation regarding the aim of the study and completed the questionnaire. Altogether, 358 questionnaires were collected: 96 in Cyprus, 121 in Germany, and 141 in Israel. The response rate was 90%.

Results

Sample

Sample size was calculated using G*power program [35], the sample size required for achieving power of 0.90 and α of .05 was 91 participants in each group. The sample consisted of 358 women from Cyprus (N = 96), Germany (N = 121), and Israel (N = 141) that visited gynecological clinics for routine checkups. Their ages ranged between 18–45 years with the women from Germany being younger and with fewer children than those from Israel and Cyprus. Women from Cyprus had more years of education than the participants from Israel and Germany. About half the women were married or living with a partner, with the lowest number of single women in Cyprus. About a third of the sample was secular, with most of the women in Cyprus defining themselves as religious. Most women from Israel were Jewish, from Cyprus, Christian, and about 40% of German participants said they were Christian with about 50% defining themselves as atheists. Only 23 and 27 of the participants (the majority from Israel) reported the presence of a genetic disease in their close and extended family respectively. Table 1 presents the socio-demographic details of the sample.

Table 1
Sample characteristics by country and comparison between the samples

Variable	**Germany (n = 121)**	**Israel (n = 141)**	**Cyprus (n = 96)**	
	Mean ± SD	Mean ± SD	Mean ± SD	One way ANOVA
Age	27.79 ± 7.61	30.30 ± 7.73	30.69 ± 6.72	F = 5.1; p = 0.006
Years of Education	14.10 ± 2.18	14.99 ± 2.56	16.14 ± 2.33	F = 17.64; p < 0.000
Number of children	0.49 ± 0.99	0.88 ± 1.20	0.84 ± 1.17	F = 4.00; p = 0.019
	Germany (n = 121)	Israel (n = 141)	Cyprus (n = 96)	
	N	N	N	χ^2
Marital Status	36	68	71	Pearson Chi-square = 45.52
Married/living with partner	75	68	20	p < 0.001
Single	10	5	5	
Divorced/widow				
Religion	3	115	1	Pearson Chi-square = 397.68
Jewish	49	4	92	p < 0.001
Christian	10	20	1	
Muslim	59	2	2	
Atheist				
Religiosity	17	11	67	Pearson Chi-square = 207.83
Religious	3	31	24	p < 0.001
Traditional	44	79	1	
Secular	59	18	4	
Atheist				
Economic Status	44	31	18	Pearson Chi-square = 40.14
less than average	58	59	63	p < 0.001
Average	16	51	13	
above Average				
Genetic Disease Close Family	116	122	93	Pearson Chi-square = 11.82
No	5	19	3	p = 0.003
Yes				
Genetic Disease Extended Family	116	128	91	Pearson Chi-square = 3.12
No	5	13	5	p = 0.209
Yes				

One way ANOVAs between countries were performed with Tukey's-b post hoc analyses to investigate the cultural differences in perceived severity of having a child with the disease, perceived control over performance of an abortion, and the intention to terminate the pregnancy. The results reveal that, across the three disease types, severity perception was significantly lower in the German women while the Cypriot women had the highest severity perception. Again, for all disease types, Israeli women had a higher sense of control over performing an abortion than German and Cypriot women. Tukey's-b post hoc analyses revealed that these differences were significant. For the intention to perform an abortion, the intention to terminate the pregnancy in all types of disease, was the highest among Israeli women, and lowest among German women. Tukey's-b post hoc analyses showed that for severe and mild diseases Israeli women had a significantly higher intention to abort compared to both German and Cypriot women, while, for moderate diseases, Israeli women differed significantly only from German women. The results are presented in Table 2.

Table 2
Intention to abort the pregnancy and perceived severity of the disease by country and type of disease

	Germany M ± SD (n = 121)	Israel M ± SD (n = 141)	Cyprus M ± SD (n = 96)	F; p
Intention to Abort Mild Disease	2.38 ± 1.42	3.20 ± 1.52	2.74 ± 1.37	10.74; <.0001
Intention to Abort Moderate Disease	2.23 ± 1.44	2.90 ± 1.39	2.53 ± 1.27	7.62; =.001
Intention to Abort Severe Disease	2.98 ± 1.51	4.08 ± 1.51	3.41 ± 1.70	16.25; <.0001
Perceived Severity Mild Disease	3.18 ± 1.42	3.65 ± 1.25	4.01 ± 1.14	11.18; <.0001
Perceived Severity Moderate Disease	2.98 ± 1.38	3.45 ± 1.20	4.30 ± 1.10	30.04; <.0001
Perceived Severity Severe Disease	3. 91 ± 1.39	4.18 ± 1.47	4.78 ± 1.26	10.71; <.0001
Perceived Control Mild Disease	3.62 ± 1.82	4.30 ± 1.59	3.41 ± 1.86	8.71;<.0001
Perceived Control Moderate Disease	3.55 ± 1.75	4.25 ± 1.58	3.33 ± 1.85	9.64;<.0001
Perceived Control Severe Disease	4.05 ± 1.69	4.55 ± 1.50	3.51 ± 1.84	11.25;<.0001

Three multiple stepwise linear regression analyses were carried out to examine the variables related to the intention to abort for the three types of disease severity. The variables entered were perceived severity, perceived control over carrying out an abortion, age, years of education, number of children, marital status, and country. For country, two dummy variables were computed, one where Israel = 1 and Germany and Cyprus = 0, and the second where Germany = 1 and Israel and Cyprus = 0. As there was a high correlation (Spearman's Rho) between the country and religiosity, and a significant difference in the distribution of religion between the counties, only the country was entered into the regressions. The results are presented in Table 3, and show that only perceived control over performing an abortion, perceived severity of the diseases, country (Israel), and age, were significant. For all disease types, higher control and higher perceived severity and being Israeli predicted the intention to terminate the pregnancy. Age predicted the intention only for mild and moderate diseases. The models explained between 24–32% of variance.

Table 3: Stepwise Linear regressions for the intention to abort a fetus with mild, moderate, and severe diseases

	Mild Diseases				Moderate Diseases				Severe Diseases			
	B	SE	β	t	B	SE	β	t	B	SE	β	t
Variable												
Perceived Control	0.29	0.40	0.35	7.37***	0.25	0.38	0.31	6.72***	0.40	0.04	0.42	9.42***
Perceived Severity	0.25	0.53	0.22	4.71***	0.32	0.05	0.30	6.57***	0.31	0.05	0.27	6.22***
Age	0.02	0.01	0.12	2.67*	0.03	0.01	0.14	3.14**				
#Country Israel	0.38	0.14	0.12	2.63**	0.32	013	0.11	2.39*	0.62	0.15	0.18	4.13***
R-squared	0.24				0.26				0.32			
Adjusted R squared	0.24				0.25				0.31			
F												
	28.32				30.99				54.39			
No. of observations	353				329				353			

***p<0.05; **p≤0.01; ***p≤0.001**

#Country dummy variable; Israel = 1; Cyprus and Germany = 0

Discussion

The present study examined severity perception and sense of control over performing an abortion, and the intentions to perform an abortion in case of a fetal abnormality, among women from three cultures (Israel, Germany, and Cyprus). The results show that the intention to terminate the pregnancy, regardless of the severity of the illness, was higher among Israelis than either Cypriot or German women. This phenomenon might be related to the influence of unique Israeli cultural features on the decision to carry out abortions. In Israel, where the society is pro-natalist, giving birth is considered a natural and even necessary stage in life. Israeli society is family oriented, and childbearing is perceived as a national institution. In addition, the memory of the holocaust, and the continuous wars, underlie a social and medical emphasis on the importance of producing healthy, strong, and surviving offspring. This is promoted by encouraging diagnostic tests and the approval of pregnancy termination [29, 36]. Moreover, the understanding that there is poor governmental support for a baby with special medical needs might be another reason that affects a woman's decision to abort [37]. Interestingly, for moderate diseases, Cypriot women conveyed similar intentions to terminate the pregnancy as Israeli women. This finding may be due to the fact that one of the moderate diseases in the study was thalassemia, which is very common in Cyprus, and for which, abortions have become more acceptable [23]. German women exhibited the lowest intention to terminate the pregnancy for all types of illnesses. This result might be explained by the fact that in the shade of World War II, the German government is very cautious about any issue that can be interpreted as improvement of race or Nazism, and therefore has fostered appropriate expectations and standards [32, 38]. The results of the study revealed that the German women had the lowest severity perception of the three cultures. Since the more severe the genetic problem is perceived, the more confident women have been reported to feel about their decision to abort [24], this might explain the low intention of German women to terminate the pregnancy in all types of diseases. Again, this should be seen in the context that in Germany after World War II, selective termination of pregnancy and genetic improvement were seen by the population as an undesirable act [33], and German women tried to conserve pregnancies in any price [38]. As a consequence, a woman who wanted to undergo an abortion required a strong reason to ask for a pregnancy termination. This policy might have influenced the perception of disabled and sick children and promoted the development of tolerance towards such children. The finding that Cypriots exhibit the highest severity perception might stem from the fact that most of the women in Cyprus are Orthodox Christians

for whom abortions are forbidden [39]. So they feel that in any case the burden of raising the child will be the family's responsibility.

Another finding was that Israeli women felt a higher sense of control over performing an abortion for all disease types than did women from Cyprus and Germany. We suspect that this high sense of control can be explained by the fact that almost every Israeli woman who wants an abortion is likely to be successful, since the abortion medical committees approves 99% of the requests for pregnancy termination [11]. Furthermore, this higher sense of control might also stem from the notion that if they have future fertility problems, they will receive support from the government, as the Israeli health system provides more free fertility treatments than either Germany or Cyprus [40]. We can also learn from the study results that the lowest sense of control was reported among Cypriot women. This might be explained by the intervention of the government, Church, and other health organizations in preventing the marriage of two thalassemia carriers, which may have a strong effect on a woman's sense of control over her body [41].

Our results indicate that age predicted the intention to abort only for moderate and mild diseases, and was not a factor in considering an abortion in the case of a severe disease. It has been reported that older women believe they have positive social support when they decide to have an abortion in case of fetal anomalies [42]. It is possible that with the age comes the understanding of the expected burden of raising a child with special needs. However, it should be remembered that age had no effect on the intention to abort a fetus with severe genetic problems. This might be connected to the fact that in such cases there is stronger certainty in the decision regardless of age.

Interestingly, the variables that predicted the intention to terminate a pregnancy in all types of diseases were perceived severity of giving birth to a child with the disease, and perceived control over the act of abortion. This supports the views expressed in the "theory of reasoned action" [34] that in order to predict how individuals will behave, we should understand their pre-existing attitudes, subject norms, and perceived behavioral control. Accordingly, the more favorable the attitudes and the greater the perceived control, the stronger is the person's intention to perform the behavior. Attitudes in these theories represent the degree to which a person evaluates and judges a particular situation or behavior and its consequences [34]. For example, a perception of high severity related to a genetic problem may suggest an intention to undergo an abortion. Moreover, the sense of control represents the individual's perception of his/her ability to succeed in conducting the behavior. Thus, the more the individual believes that he/she has the opportunity and resources to carry out the behavior, the less he/she will feel threatened by obstacles and will exhibit higher intentions to actually perform the behavior. Translating this to the current study, a higher severity perception and higher sense of control, predict the intention to terminate a pregnancy in cases of diagnosed fetal genetic abnormality.

Limitations

The main limitation of the present study is that it is scenario based and only simulates reality so that the participants responded theoretically with actions that they would have taken in each case. However, previous studies using scenarios to simulate real situations have shown that they do represent a suitable method for predicting respondents' actual behavior [43, 44]. In addition, the finding that more severe disease was perceived by the respondents as more severe, validate our approach.

Conclusions

The intention to abort when a fetus is diagnosed with a genetic disease is influenced by culture. When women feel that they have more control, and have a higher severity perception of giving birth to a child with the disease, there is more intention to terminate the pregnancy regardless of the severity of the disease. Hence, when an abnormality is identified in a fetus, it is important to explain the situation and discuss the specific implications of the disease with the family. Specific

consideration should be given to the severity of the disease while taking into account cultural aspects. It is also important to highlight all legal options and rights regarding abortions.

The current results call for further studies. Firstly, in order to understand whether the same variables influence the decision to terminate pregnancies in other cultures, it worthwhile to evaluate these elements in additional cultures. Examining a wide range of genetic problems would help in understanding more about the features of the genetic abnormalities that might influence the intention to terminate pregnancies. In addition, it would be very interesting to measure the research variables in immigrant women in order to discover whether their opinions are more influenced by their original or their adopted culture. Finally, it would be very informative to conduct a similar study with women who face an actual diagnosis and must decide whether an abortion is warranted.

Declarations

Authors' contributions

Both authors, SK and SB, made substantial contributions to the conception and design and drafting of the article. Data collection was performed by SK. Data analysis, and interpretation of data were performed by SK and SB. All authors have read and approved the manuscript.

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Availability of data and materials

The dataset supporting the conclusions is available from the corresponding author on reasonable request.

Ethics approval and consent to participate

All methods were carried out in accordance with the guidelines and regulations of the Helsinki Committee of the HMO where data were collected and the Tel-Aviv University ethics committee that approved the study. These approvals were acceptable by the clinics where data were collected in Germany and Cyprus; with no further need for regional ethical approvals. The women were fully informed and voluntarily decided to participate in the study. Informed consent was obtained by verbal agreement to participate in the study. Data were collected and managed to protect the privacy and confidentiality of the participants.

Consent for publication

Not applicable.

Competing interests

The authors declare that they have no competing interests.

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