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ORIGINAL RESEARCH

Patients' Attitudes Towards Disclosure of Genetic Test Results to Family Members: The Impact of Patients' Sociodemographic Background and Counseling Experience

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Abstract Many factors predict the intention to disclose genetic information to relatives. The article examines the impact of patients' socio-demographic factors on their intention to disclose genetic testing results to their relatives. Data were collected in eight genetic clinics in Israel. Patients were requested to fill in a questionnaire after counseling. A convenience sample of 564 participants who visited these clinics was collected for a response rate of 85 %. Of them, 282 participants came for susceptibility testing for hereditary cancers (cancer group), and 282 for genetic screening tests (prenatal group). In the cancer group, being secular and having more years of education correlated positively with the intention to disclose test results to relatives. In the prenatal group, being married and female correlated positively with the intention to disclose. In the cancer group, being religious and with less years of education correlated positively with the view that the clinician should deliver the results to the family. In the prenatal group, being male and unmarried correlated positively with this belief. In both groups, being of young age correlated with the perception that genetic information is private. Varied sociodemographic factors affect the intention to inform family members. Thus, knowing the social background of patients will shed light on people's attitudes to genetic information and will help clinicians provide effective counseling in discussions with patients about the implications of test results for relatives.

Keywords Genetic information · Disclosure · Relatives · Israel · Family

Introduction

Many factors predict patients' disclosure or non-disclosure of genetic test results to relatives (Hallowell et al. 2005; Gaff et al. 2007; Nycum et al. 2009). However, apart from

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substantial research on the impact of gender on disclosure to relatives, there is a paucity of research on the impact of sociodemographic factors in this context (Cheung et al. 2010). Yet, knowledge of these factors and their impact is important because patients come from different backgrounds which may affect their attitudes towards disclosure to relatives. Undoubtedly, understanding the impact of sociodemographic factors on decisions about disclosure may help clinicians provide effective counseling when discussing the implications of the test results for relatives with their patients.

Consequently, the aim of our large-scale quantitative study was to examine whether and how sociodemographic factors affect patients' intentions regarding disclosure to relatives. The decision to focus on measuring people's intentions derives from the theory of planned behavior (Ajzen 1991) which argues that the central factor in predicting behavior is behavioral intention. Thus, the stronger the behavioral intention, the more likely it will be carried out, i.e. behavioral intention is the strongest predictor of actual behavior. Accordingly, measuring the intention to reveal the information can be regarded as a proxy for rates of disclosure.

The Social Context

The study was conducted in Israel, a society comprised of diverse social and ethnic communities. One way of examining Israeli society is to look at the degree of religious observance. The largest religious community in Israel is the Jewish community, which comprises 75 % of the entire population. The Jewish community in Israel can be divided into four groups according to level of religiosity: 43 % secular (non-observant), 38 % traditional (partially observant), 10 % religious Zionists (orthodox) and 9 % ultra-orthodox (Israel Center Bureau of Statistics 2012).

Significantly, the different levels of religiosity in the Jewish community in Israel influence attitudes to genetic information. For example, people who come from ultra-orthodox communities may not want to inform their wider family of their carrier status because if this is known it can harm the reputation of the family in the community and compromise the chances of young adults in such a family to marry (Hashiloni-Dolev 2006; Prainsack and Siegal 2006). For this reason, an organisation called Dor Yeshorim (Upright Generation) offers genetic screening to members of the ultra-orthodox community with the aim of minimizing the incidence of genetic disorders common to Jewish people, such as Tay-Sachs (Jewish Genetics 2015). Dor Yeshorim screens solely for recessive, early-onset genetic disorders by conducting anonymous testing for young people before marriage. The tests are processed anonymously with only a PIN linking the sample with the candidate. When two adults contemplate marriage, the matchmaker contacts the organization and enters their PINs. When both carry a mutation for the same disorder they are advised not to marry.

The system offered by Dor Yeshorim derives from the dual attitude reflected in the orthodox and ultra-orthodox communities towards genetic information. On the one hand, they appreciate that genetic testing can help couples avoid the birth of children with serious diseases in a community that does not approve termination of pregnancy, and on the other hand they want to avoid the stigma that positive test results create when one is found to carry a genetic mutation. The service offered by Dor Yeshorim provides a solution to a community whose members tend *not* to share information with relatives, based on a communal – rather than personal – perception of genetic information. This mechanism does not reflect an individual's responsibility to inform the relatives, but rather the couple's responsibility to their community not to give birth to children with a disease or disability (Prainsack and Siegal 2006).

Maintaining the social status of the family and preserving the chances to marry is also relevant for late-onset diseases such as hereditary breast cancer (Levin 2013). People from orthodox and ultra-orthodox communities face a dilemma regarding whether to conceal not only the fact that they are carriers, but also their illness when it is diagnosed (Mozersky 2013).

By contrast, the impact of genetic information on one's chances to marry is not a common concern for people who come from secular backgrounds. On the contrary, the attitude of these communities to genetic testing is positive, and the uptake of genetic screening before pregnancy, and testing during pregnancy, is high compared to other Western countries (Gilbar and Barnoy 2012). For people from secular backgrounds, undergoing testing and acquiring information which may have implications for relatives means undertaking the responsibility to inform those at risk (Gilbar and Barnoy 2012; Raz and Schicktanz 2009a; b). Thus, knowing the social background of patients will shed light on people's attitudes to genetic information and will help clinicians provide effective counseling.

The Provision of Genetic Services in Israel

The provision and use of genetic services in Israel has become increasingly widespread (Rosner et al. 2009; Sagi and Uhlmann 2013), where the main purposes are carrier screening before or during pregnancy, prenatal (foetal) diagnosis, and diagnostic and predictive testing, mainly for cancer.

Carrier Screening Before or During Pregnancy

Genetic services are part of the public health care system and are provided to all Israeli citizens at no extra cost. These services include general newborn screening, prenatal diagnosis for women at increased risk for Down's syndrome and other genetic diseases, and carrier screening for Spinal Muscular

Atrophy, Cystic Fibrosis and Fragile X for the entire Jewish population (Ministry of Health 2011). In addition, free-of-charge prenatal testing includes Tay Sachs, Canavan Disease and Familial Dysautonomia for people from an Ashkenazi background, and Thalasemia and Tay Sachs for people from a North African background. Other predictive tests are provided free-of-charge for people from other ethnic backgrounds. In addition, the public health funds to which all citizens in Israel are subscribed cover part of the costs of predictive genetic testing for other early-onset diseases, which is recommended by Israeli geneticists based on the ethnic backgrounds of the prospective parents, for example Niemann Pick and Fanconi Anemia C for people from an Ashkenazi background and Fanconi Anemia A for people from a North African background (Ministry of Health 2011). Women are usually referred by their family doctor or gynaecologist to genetic screening before or during pregnancy. Some couples request a referral for genetic testing before marriage. A genetic nurse refers the couple to the relevant tests based on the couple's or individual's ethnic origin. If the test results indicate that the individual is a carrier, a genetic counselor contacts the patient, offers to test the patient's spouse, and highlights the importance of informing other family members.

Diagnostic and Predictive Testing for Inherited Cancer

Diagnostic testing in this area is performed mainly for breast/ovarian cancers and familial/hereditary colon cancer where individuals are referred to testing by their treating doctor (e.g., oncologists, surgeons, gastroenterologists). In the Jewish community, those of Ashkenazi origin are at a greater risk of being a carrier of one of the known BRCA1 or BRCA2 mutations (Rosner et al. 2009). Among Ashkenazi Jews, three mutations, *BRCA1 185delAG*, *BRCA1 5382insC*, and *BRCA2 6174delT*, account for the great majority of inherited breast cancer. In the Ashkenazi group, 2.5 % carry one of these three mutations, and the mutations account for 11 % of breast cancer cases and 40 % of ovarian cancer cases (Gabai-Kaparaa et al. 2014). Testing and counseling are provided free of charge for patients with breast or ovarian cancer with a family history, subject to particular criteria which include the following: belonging to an ethnic group where the carrier rate of known BRCA1 and BRCA 2 mutations is 1 % or over; having either ovarian cancer or breast cancer before age 50; breast cancer in both breasts; breast cancer in males; and breast cancer at any age when at least 2 relatives (first and second degree) had breast or ovarian cancer (Ministry of Health 2004). Regarding colon cancer, no formal guidelines exist so far, although due to heightened awareness by family doctors and relevant specialists, colon cancer patients are often referred for genetic counseling (Rosner et al. 2009).

Regarding predictive testing, first- or second-degree relatives of breast cancer patients who are also BRCA1/2 carriers can be referred for BRCA testing free of charge (Rosner et al. 2009; Ministry of Health 2004). In addition, the Ministry of Health has recommended that first-degree relatives of breast cancer patients be screened by mammography annually from age 40 (Ministry of Health 2012). As for colon cancer, the Ministry of Health has recommended that first-degree relatives of patients who were diagnosed with Lynch Syndrome should undergo a colonoscopy every year from age 25 (Ministry of Health 2012).

In the area of cancer genetics, a genetic counselor or a geneticist provides face-to-face counseling to the individual before the testing and discusses the results in a face-to-face meeting, particularly if the results are positive. The clinician highlights the importance of informing the relatives in both pre-test and post-test meetings.

Demographic Associations with Genetic Testing

The study examines the impact of the following background factors on patients' intention to disclosure: family history, gender, age, level of education, marital status and religiosity. In this part we review the literature on these factors, which, during the last two decades, has focused mainly on cancer genetics rather than on prenatal testing.

Family History

Having a relative with hereditary breast or ovarian cancer plays a role in patients' decisions to inform relatives (Nycum et al. 2009; Barsevick et al. 2008; Peters et al. 2011; van Oostrom et al. 2007). However, this family history can work both ways: it has been correlated with a tendency not to share test results with relatives (Dancyger et al. 2011), but also with a stronger intention to disclose (compared to patients with no previous cancer in their family) (Claes et al. 2004), and with greater openness when talking to relatives (Lafroniere et al. 2013). In some families, witnessing a relative with the disease created fear of cancer risks and led family members to evade any information about it (Dancyger et al. 2011), while in other families, knowing that cancer is curable if detected in an early stage led family members to share information (Lafroniere et al. 2013). The studies vary with regard to cancer status: some included affected and non-affected individuals (van Oostrom et al. 2007; Lafroniere et al. 2013), while others included non-affected participants only (Claes et al. 2004).

Gender

Gender has an impact on the intention to inform relatives. Women are generally more open than men about communication of genetic information in the context of hereditary cancer. Studies of affected and unaffected tested individuals for

hereditary colon cancer show that men tend to inform fewer relatives than female patients (Claes et al. 2004; Gaff et al. 2005), and they tend to inform their closest relatives, while women will also inform their extended family (Gaff et al. 2005). Additionally, female BRCA1/2 carriers are more likely to inform their children than male carriers, partly because men find it difficult to discuss the issue with their children (Hallowell et al. 2005; Tercyak et al. 2001).

Women's higher inclination than men's to share health information with their relatives derives from undertaking the role of promoting the family's health (Hallowell et al. 2005). This role leads women to gather and disseminate information in the family (Koehly et al. 2003, 2009; Hay et al. 2008). In the area of genetic testing, women tend to feel morally obliged to inform their relatives even when their spouse is the one who had the test (Nycum et al. 2009; Wiseman et al. 2010). This is explained by the good familial ties women tend to keep with their relatives, and their need to provide and receive social support (Daly 2009).

However, one report of 90 affected and unaffected female participants in a study regarding hereditary breast and ovarian cancer showed that significant numbers of women try to avoid receiving genetic information (Peters et al. 2011). In addition, two studies of BRCA1/2 carriers and non-carriers, comprised of 29 participants (Hallowell et al. 2005) and 99 participants (Kegelaers et al. 2014), indicate that men share their test results with their relatives at the same rate as women. Other studies with a similar number of participants indicate that men are as concerned about their children as their female counterparts (Hallowell et al. 2006; Keenan et al. 2005). The sense of moral duty fathers feel towards their offspring leads them to be more open about disclosure than they initially intended (Liede et al. 2007). This ultimately suggests that the impact of gender on intention to disclose is not clear-cut.

Age

Age was found to be an influential factor regarding disclosure to relatives. A study of 183 participants from BRCA1/2 families indicated that young first-degree relatives do not undertake the role of disseminating the results (Koehly et al. 2009). This report found that it is the older relatives who, upon learning about important genetic information, take on the role of disseminators because they are often the bridge between their children and older (and more distant) relatives (Koehly et al. 2009).

Yet, another study of 1103 women who underwent BRCA1/2 testing indicates that older age was a factor associated with a decreased likelihood of sharing BRCA1/2 test results with relatives (Cheung et al. 2010). In this large study, disclosure to relatives was positively associated with increased knowledge of hereditary breast and ovarian cancer screening, risk reduction recommendations, and increased satisfaction with the decision to undergo genetic testing.

Another report of 40 individuals who had predictive genetic testing for HNPCC indicated that those who informed distant relatives were younger than those who did not inform them (Claes et al. 2004). Other studies about communication of BRCA1/2 test results, which included 329 participants in one (Barsevick et al. 2008) and 215 in another (MacDonald et al. 2007), did not find significant differences regarding age between those who intended to tell all their relatives and those who intended to tell none or some relatives. Thus, the studies on the impact of age do not paint a clear picture.

Education

Years and level of education were reported in one study to have an influence on disclosure to relatives. Kegelaers et al. (2014) found that the level of disclosure to relatives among 99 carrier and non-carrier participants showed that the level of disclosure among those with fewer years of education was higher than those with more years of education.

Marital Status

In the rigorous literature review conducted for the study, no research was found showing marital status as a significant factor regarding intention to disclose BRCA1/2 to relatives (Barsevick et al. 2008).

Religiosity

No studies were found on the correlation between patient's level of religiosity and attitudes towards disclosure to relatives.

To conclude, past experience with the disease, female gender, and age are associated with disclosure to relatives. As one report indicates, women with personal experience of the disease, and from older generations in the family, will probably be disseminators of genetic information in their families (Koehly et al. 2009). However, as the review in this part indicates, the picture is not clear about the impact of these factors. In addition, the literature so far has barely examined the impact of religiosity, marital status and level of education. It appears, therefore, that more research is needed regarding the impact of socio-demographic factors on the intention to inform relatives.

Methods

Sample

The convenience sample consisted of participants who visited genetic clinics for two different purposes: (1) susceptibility testing for hereditary cancers (the cancer group), and (2)

genetic testing for carrier status of recessive early-onset conditions either before or during pregnancy (the prenatal group). We decided to focus on these two groups for the following reasons: (1) they represent the vast majority of patients who receive genetic services in Israel; (2) we believe it is important to examine the similarities and differences which exist between these two groups regarding disclosure to family members, so that clinicians who provide their services to both groups would be better informed when offering counseling; and (3) it is important to know whether the socio-demographic criteria cited above have the same impact on these two different groups of patients. If, for example, level of religiosity has an impact on the attitude to disclosure in both groups, such a finding will be highly significant for clinicians.

Research Tools

A questionnaire was constructed for the study and was reviewed for internal validity by four genetic counselors and a geneticist. The questionnaire contained the following parts:

- Participants' demographic details and reasons for referral to the clinic. This includes age, gender, marital status, level of education, years of education, religious belief (Judaism, Islam, Christianity), level of religiosity (secular, traditional, orthodox, ultra-orthodox), place of birth, reasons for referral to the clinic (e.g., for hereditary cancer, prenatal testing/screening), whether there is a family history of a genetic disease, and if yes, what type of disease.
- A section consisting of 12 statements based on a previously published study (Gilbar and Barnoy 2012), comprising three topics: (i) views about the nature of genetic information (personal vs. familial), consisting of 2 items with a high inter-correlation (r=0.63), where higher scores indicate a higher perception of genetic information as private (see supplement 1, items 1 and 5); (ii) attitudes towards the responsibility to disclose (is it the patient's or the clinician's responsibility), consisting of 2 items with a high inter-correlation (r=0.65), with higher scores indicating a higher perception that it is the physician's responsibility to disclose the information to their families (see supplement 9, items 12); and (iii) intention to disclose the information to relatives, consisting of 8 items (see supplement 1 items 2,3,4,6,7,8,10,11), where higher scores indicate greater intention to disclose (Cronbach α=0.77). Participants were requested to indicate their views on each item on a scale ranging from 1 (completely disagree) to 6 (completely agree). Averages of the item scores were calculated for each section and were used for the analysis of the three scales: the nature of genetic information private/familial, intention to disclose test results to the family, and the responsibility to disclose self/physician. In addition, a yes/no question relating to the general intention to inform relatives was included. Respondents who stated that they do not intend to inform were asked to select from a given list their main reason for non-disclosure. Questionnaire items can be found in Supplementary Table 1.
- The counseling experience was measured by two yes/no questions: First, whether during counseling the clinician *explained* the implications of genetic information for the relatives' health, and second, whether the clinician *encouraged* the study participant to disclose the test results to the relatives.

Procedure

Data were collected in eight of the 19 outpatient clinics that offer genetic services in Israel. Following receipt of ethical approval, a pilot study was conducted among 56 participants, which yielded minor amendments in the questionnaire. Thereafter, data were collected once a week in each clinic over a period of 3 to 4 months. The clinicians in the relevant clinics worked 5 days a week. The patients were scheduled for counseling randomly according to available appointments. Hence, there was no bias in choosing a specific day each week to collect the data. Patients at the clinics were approached by a

Table 1 Demographic variables of the study participants (N=564)

Variable	Sample	Prenatal	Cancer
Age (Mean±SD)	39.1±13.15	32.79±10.18	45.38±12.78
Years of education (Mean±SD)	15.52±2.94	15.07±2.63	15.95±3.15
Number of children (Mean±SD)	2.22±1.93	1.32±1.70	2.83±1.84
Range	0–15	0–11	0–15
Gender (N=564)			
Male	124	100	24
Female	440	182	258
Place of birth (N=552)			
Israel	429	235	194
Other	123	41	82
Marital status (N=563)			
Married	461	233	228
Single	102	49	53
Religion (N=552)			
Jewish	519	252	267
Other	33	22	11
Religiosity (n=564)			
Secular	363	171	192
Traditional/Religious	201	111	90
Family history (N=550)			
Yes	214	53	161
No	336	224	112

research assistant with the request to fill in the questionnaire after counseling. The type of counseling varied, depending on the internal policy of the clinic. Patients in the cancer group received pre-test counseling from a genetic counselor or a geneticist in all the clinics. In the prenatal group, some patients received pre-test counseling, while others watched a video or were given information sheets to read before the test. Patients who agreed to take part in the study were given an oral and written explanation by the research assistant.

ANOVA tests were performed to elucidate the characteristics of those who intended to disclose the information, those who perceived genetic information as private, and those who thought that it is the clinician's responsibility to inform their relatives. Once age was entered, linear regression tests were performed. Logistic regressions were performed to analyze the participants' counseling experience. Since several categories in the sociocultural factors were small, they were grouped and used in analyses as dichotomous variables: married/single; secular/religious.

Results

Sample Demographics

All 664 patients who visited genetic clinics on the days data were collected were asked to participate in the study. The response rate was 85 %, namely 564 participants took part in the study. The main reason given for declining to participate was lack of time. Of the participants, 95 % came from the Jewish community. The remaining 5 % were Muslims and Christians. Since the Jewish community in Israel comprises only 75 % of the population, the sample is not representative, but it does represent the various groups in the Jewish community.

In the study sample, 282 participants attended the clinics for hereditary cancers and 282 for prenatal screening/testing. The majority in the cancer group were healthy and had not developed the disease, but 161 (57 %) had a family history of cancer: 94 had a history of hereditary breast cancer in the family, one participant indicated having hereditary colon cancer in the family, and the rest did not specify which hereditary cancer they had in their family. In terms of religiosity, the majority in both groups were secular (68 % in the cancer group and 61 % in the prenatal group). In the cancer group, about 7 % were ultra-orthodox, while in the prenatal group only 2.5 % were ultra-orthodox. Demographic data is presented in Table 1.

Intention to Disclose

Based on the categorical yes/no measure, the rate of the intention to share genetic test results with relatives was high in both groups (94.7 % overall). In the cancer group, 97.2 % of the participants stated that they would disclose the information to their relatives, and in the prenatal group the rate was 92.2 %. The percentage of those who did not intend to disclose was higher in the prenatal group (7.8 %, N=22) than in the cancer group (2.8 %, N=8). A chi-square test revealed that the difference between the groups was significant (p<.01). The overall percentage of participants who did not intend to share test results with their relatives was 5.3 % (N=30). The main reason for nondisclosure of the results that was indicated by the participants was that the information is private and personal (70 %; N=21). Demographic data of those who intended/did not intend to disclose are presented in Table 2.

In addition, based on the intention to disclose index, the results show that in the cancer group, education and religiosity correlated positively with intention to disclose test results to relatives ($F_{(2241)}$=14.8, p<.01, and $F_{(1241)}$=4.37, p<.05, respectively). Being secular (Mean±SD of the intention to disclose: secular 5.09±1.00, religious 4.51±1.21), and having more education (Mean±SD for the intention to disclose: high school level 4.16±1.89, tertiary education 4.61±1.86 and academic education 5.22±1.24) correlated positively with the intention to disclose. However, in the prenatal group, marital status and gender correlated with the intention to disclose test results ($F_{(1249)}$=3.80, p<.05 and $F_{(1249)}$=6.72, p=.01, respectively). Namely, married (Mean±SD of the intention to disclose: married 5.32±.11, single 4.99±.06) and female (Mean±SD of the intention to disclose: females 4.95±.87, males 4.49±.89) participants had a greater intention to disclose.

Is Genetic Information Private?

The perception of genetic information as private information was similar in both groups, with both groups scoring similarly on the perception of genetic information as private index (cancer group Mean±SD of 3.98±1.71; prenatal group participants Mean±SD of 4.18±1.48). Stepwise linear regression tests were applied to examine the characteristics of those who perceived genetic information as private rather than familial. The variables entered to the model were age, gender, education, marital status, religion, religiosity and having a genetic disease in the family. The results showed that in both groups only age correlated with the perception of the information as private: the younger the patient, the higher the perception that genetic information is private and belongs to the patient only (cancer group: $F_{(1279)}$=6.86, p<.01; prenatal group: $F_{(1277)}$=4.08, p<.05).

Who Bears the Responsibility to Disclose?

Overall, the participants who saw a genetic counselor in both groups (N=198 in the prenatal group and N=282 in the cancer

Table 2 Demographic variables of the participants according to the intention to disclose

Variable	Intention to disclose	No intention to disclose	*p*-value (t)
Age (Mean±Standard deviation)	39.46±13.17	31.68±9.77	0.00
Number of children (Mean±Standard deviation)	2.25±1.94	2.00±1.97	0.42
Years of education (Mean±Standard deviation)	15.54±2.92	14.46±2.91	0.03
			p-value ($\chi 2$)
Gender (*N*=564)			
Male	116	8	0.52
Female	418	22	
Place of birth (*N*=552)			
Israel	409	20	0.13
Other	113	10	
Marital status (*N*=563)			
Married	436	25	0.83
Single	97	5	
Religion (*N*=552)			
Jewish	495	24	0.01
Other	27	6	
Religiosity (*n*=564)			
Secular	350	13	0.01
Traditional/Religious	184	17	
Family history (*N*=550)			
Yes	194	20	0.00
No	326	10	

group) stated that it was not the clinician's responsibility to inform the relatives (Mean±SD in the prenatal group was 2.12±1.43; Mean±SD in the cancer group was 2.11±1.53).

ANOVA tests were applied to examine the characteristics of those who thought that it is the clinician's responsibility to inform their relatives. All the participants were requested to answer these questions. In the cancer group, religiosity and education correlated with this variable ($F_{(1247)}=6.96$, $p<.05$ and $F_{(2247)}=12.80$, $p<.01$, respectively), namely more religious participants and those with less education thought that the clinician should disclose the test results to their family. In the prenatal group, gender and marital status correlated with this belief ($F_{(1239)}=6.72$, $p=.01$ and $F_{(1239)}=3.59$, $p=.05$, respectively), with more male and unmarried participants stating that it is the clinicians' responsibility to inform the relatives.

Additionally, when analyses by positive/negative family history were performed, the groups did not differ significantly in the intention to disclose index ($p=0.90$); the perception of genetic information as private index ($p=0.24$); and the responsibility to disclose index ($p=0.40$).

Experiencing the Meeting with the Genetic Counselor

Regarding the patient's experience of the consultation with the genetic counselor before testing, 92 % of the participants in the cancer group (*N*=282) and 75 % of the participants in the prenatal group (*N*=198) reported that the clinician (usually a genetic counselor) *explained* the implications of disclosing the genetic information to their relatives. In addition, 73 % of the participants in the cancer group and 37 % of the participants in the prenatal group stated that the clinician *encouraged* them to disclose the information to their relatives.

Four logistic regressions were performed to analyse the participants' counseling experience. The variables entered in the regressions were: age, education, having children, marital status, religion, religiosity, having a genetic disease in the close family, and having a genetic disease in the extended family. The results show that for the participants in the cancer group, having a genetic disease in the close or extended family correlated positively with the patient's recall of the counselor's explanation of the implications of the genetic information for the family's health. In other words, when there was a genetic disease in the patient's family (close or extended), more patients reported that the counselor gave an explanation regarding implications of genetic information for the relatives' health. Results are presented in Table 3. Concerning the counselor's encouragement to disclose the test results to relatives, age and having a disease in the close family correlated positively with this variable, namely younger participants and those who reported a genetic disease in the close family felt

Table 3 Logistic regression: patients' perception of the counselor's explanation about the implications of the genetic information for the family: cancer group characteristics

	Odds ratio	95 % confidence interval	P
Genetic disease in the close family			
Yes	5.32	2.64–10.70	0.00
No	1		
Genetic disease in the extended family			
Yes	5.02	1.37–18.62	0.00
No	1		

that the counselor gave them more encouragement to disclose the results to their relatives. Results are presented in Table 4.

For the participants in the prenatal group, no variables correlated with the patients' recall of the counselor's explanation regarding the implications of genetic information for the relatives' health. As for the counselor's encouragement to disclose, gender, religiosity, and having a genetic disease in the close family correlated significantly with this factor, namely participants who were secular, female, and reported a genetic disease in the family felt that the counselor gave them more encouragement to disclose the results to their family. Results are presented in Table 5.

Discussion

The findings show that background factors may predict attitudes about genetic information and intention to disclose.

The Impact of Religiosity

To our knowledge, the impact of religiosity on intention to disclose has not been investigated in previous studies so far. Yet, significantly, the study shows that in the context of hereditary cancer, being secular is associated with the intention to inform relatives, while having strong religious beliefs are associated with the view that it is the clinician's responsibility to inform them. These findings accord with the significance that people from all Jewish communities attribute to genetic information, but particularly those with an orthodox or ultra-orthodox

Table 4 Logistic regression: patients' perception of the counselor's encouragement to disclose the results to the family: cancer group characteristics

	Odds ratio	95 % confidence interval	P
Age	1.06	1.02–3.08	0.00
Genetic disease in the close family			
Yes	3.85	1.49–9.92	0.00
No	1		

Table 5 Logistic regression: patients' perception of the counselor's encouragement to disclose the results to the family: carrier group characteristics

	Odds ratio	95 % confidence interval	P
Gender			
Female	4.40	1.62–11.17	0.00
Male	1		
Religiosity			
Secular	2.84	0.74–10.86	0.03
Religious	1		
Genetic disease in the close family			
Yes	2.12	1.26–4.34	0.01
No	1		

background where a carrier status of early onset recessive diseases and late onset diseases compromise chances to marry.

Moreover, the low number of participants from an ultra-orthodox background in the prenatal group (2.5 %), compared to the 7 % of participants in the cancer group, can also be explained. Many ultra-orthodox Jews do not attend genetic clinics for genetic screening for early-onset recessive disorders either because they utilize the Dor Yeshorim option, which is outside the public health care system, or they know – based on the prohibition imposed in Jewish law – that they will not terminate a pregnancy even if the foetus is diagnosed with a genetic disease. Yet, they do attend genetic clinics for counseling in cancer genetics – even though being a carrier of a hereditary form of cancer has the same negative impact on the social status of adults and their families in these close-knit communities – because the Dor Yeshorim option does not provide services for hereditary cancers, and the issue of termination of pregnancy is not relevant.

Discovering the association between level of religious observance and attitude to disclosure is highly significant in light of the substantial impact religious beliefs can have on identity, moral views, and decisions about health (Helman 2007). The findings suggest that clinicians should be aware that patients with strong religious beliefs may prefer not to communicate genetic test results to relatives, thereby preventing the spread of this information beyond the immediate family. Clinicians might be advised to find out how patients define themselves in terms of religiosity, which will help the clinician assess whether more efforts are needed to encourage the patient to inform relatives.

The Impact of Education

Our findings regarding the correlation between level of education and intention to disclose in the cancer group are important in light of the paucity of studies on the subject. A recent study indicates that higher education may predict a lower level of disclosure to relatives (Kegelaers et al. 2014), yet we found

that a high level of education is associated with a strong intention to inform relatives. We speculate that a high level of education may increase patients' understanding of the complex and detailed information delivered to them by the clinician, and the implications for their relatives. It thus enables patients to appreciate the importance of telling relatives that they should be aware of an increased risk in the family. The findings suggest that clinicians might need to make greater efforts to encourage patients with less awareness to undertake the responsibility to disclose the test results to their relatives.

The Impact of Gender

The close correlation in the prenatal group between female gender, intention to disclose, and undertaking the responsibility to disclose accords with studies which show that generally women take on the role of disseminating health information in their families (Koehly et al. 2009; d'Agincourt-Canning 2001).

A possible explanation for this finding is that decisions about pregnancy and birth might be perceived as the territory and responsibility of women, and collecting the relevant information and disseminating it to relatives as an extension of this domain. This may explain our findings that female participants in this group intend to take on the "traditional" gendered role of disseminating health information in their close and extended family. It may also prompt clinicians to devote more efforts to encourage male patients to share test results with their relatives.

The Impact of Marital Status

The finding that marital status is associated with the intention to disclose and undertaking the responsibility to disclose the results of prenatal screening, is important in light of the paucity of studies on this subject. It is also significant in Israel, where a substantial group of people attend genetic clinics for prenatal screening before marriage. Clinicians should be aware that the willingness of these people to inform their relatives is lower in comparison to those who are married.

The Impact of Age

The findings suggest that younger adults perceive genetic test results as more personal and private information, which may predict their reluctance to inform their relatives. This is a notable finding in light of the tendency of young people to share personal information in social networks. These findings correspond, to a certain extent, with findings from previous studies which indicate that older adults tend to be more active in informing relatives (Cheung et al. 2010; Koehly et al. 2009). Yet, young age has also been associated with a high level of openness towards disclosure to relatives (Claes et al. 2004). Clearly, more research is needed. Our findings suggest that, at least in Israel, clinicians may have to devote more time with younger patients to discuss the importance of informing relatives.

The Impact of Family History

Our findings about the impact of family history suggest that patients who had past experience with cancer in their family felt that they received more information and encouragement to inform their relatives in the initial encounter with the clinician. Our findings also indicate that patients in the prenatal group who had experience with a genetic disease in the family felt that the clinician encouraged them to inform their relatives. A possible explanation for these findings is that when there is a hereditary disease in the family, the patients themselves may raise this issue in the medical encounter, initiate a discussion about disclosure, and feel morally obliged to disclose. These findings suggest that clinicians will have to invest efforts to inform patients with no previous experience of a genetic disease about the importance of disclosure to relatives.

The Impact of the Counseling Experience

The finding that the majority of the participants in the prenatal group did not feel that they were encouraged to inform their relatives is important in light of the significant rate of intention not to disclose in this group (7.8 %), which is relatively high compared to other studies (Clarke et al. 2005).

Yet, it is not surprising that only 37 % of the participants in the prenatal group stated that the clinicians encouraged them to disclose. If prenatal screening does not reveal a gene mutation or chromosome rearrangement that has implications for other relatives, there is no medical reason for the patient to convey their prenatal test results to their relatives. In addition, in many cases, the information communicated by the clinician to the patient or the couple in the medical encounter is relevant only to the pregnancy and not to relatives.

To sum up, the findings presented above should lead clinicians to devote more efforts to encourage unmarried young male patients with no previous family history to inform their relatives of the results if they undergo prenatal testing. In addition, clinicians should devote more effort to encourage young patients with strong religious beliefs, and those with less education, to undertake the responsibility of informing their relatives when undergoing genetic testing for hereditary cancer.

Study Limitations

The study did not follow the actual disclosure of genetic information to the patients' relatives, but rather measured patients' intention to disclose only. In addition, the study neither ascertains the percentage of patients being tested for familial

gene mutation, nor the percentage of patients who had results disclosed to them by relatives.

However, according to the theory of planned behavior (Ajzen 1991), the main factor in predicting behavior is behavioral intention. Based on our findings, we believe that the vast majority of patients who undergo prenatal testing or genetic testing for hereditary cancers would share the test results with at least one relative, but whether this is the case remains to be seen until studies are conducted to examine patients' actual behavior. Such studies would examine whether and how patients inform relatives, and how frequent non-disclosure is in practice.

Moreover, as any society, Israel has unique social and cultural characteristics, which may make it difficult to apply all our findings to other societies. However, our main findings suggest that in the context of disclosure to relatives, the attitudes of our respondents are not exceptional: in accord with study samples in other countries, the vast majority of our study participants indicated their intention to inform their relatives. Thus, while we believe that our findings about the impact of religiosity may be relevant to other societies, further studies on the impact of religiosity should be conducted on patients from other religious backgrounds to support the study results.

Since the study does not comprise a random sample of participants, our findings can only mark a trend which should be studied further. This in itself might pose a problem with the generalization of the results. Yet, internal validity remains strong in light of the following factors: the sample was large (N=564), the data were collected weekly on a random basis in the clinics participating in the study, the clinics were located in hospitals in both rural and urban areas, and the clinics treat patients from varied sociodemographic backgrounds. We believe, therefore, that these factors point to the representative nature of the results.

Lastly, the pre-testing counseling experience was not identical for all participants. The participants in the cancer group were given face-to-face counseling before testing, while the participants in the prenatal group watched a short video followed by a short meeting with a genetic counsellor, or received an information sheet to read.

Practice Implications

Despite its limitations, the findings have important implications for clinicians in genetic counseling. Our study shows that the patients' personal, social and demographic characteristics affect their attitudes towards disclosure to relatives. Knowing that certain sociodemographic factors influence the patients' intention to disclose may require clinicians to shape the medical encounters based on the patient's particular characteristics, and discern the attitude of the particular patient to disclosure.

Thus, clinicians will have to initiate a discussion to understand the patients' views about disclosure to relatives and the reasons for their reluctance to do so. The clinician might need to spend more time with some patients, emphasizing that genetic information is not only personal but also familial, that it is important to inform relatives, and that it is primarily the patient's responsibility to do so. Yet, the clinician must also be sensitive to the influence of the cultural values of the community to which the patient belongs.

Recently, there has been a shift in prenatal screening in Israel from a face-to-face meeting with a genetic counselor before testing, to a face-to-face meeting with a genetic nurse who informs the couple or the individual regarding the tests they may choose to undergo based on their ethnic origin. In our view, the genetic nurse should also discuss the importance of disseminating genetic test results to relatives, especially with unmarried males or couples with no family history of genetic disease, taking into account the impact of relevant social and demographic factors.

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Conflict of Interest The authors declare that they have no conflict of interest.

Ethical Approval All procedures performed in studies involving human participants were in accordance with the ethical standards of the institutional and/or national research committee and with the 1964 Helsinki declaration and its later amendments or comparable ethical standards.

Informed Consent Informed consent was obtained from all individual participants included in the study.

Animal Studies No animal studies were carried out by the authors for this article.

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