



## Carrier matching and collective socialization in community genetics: Dor Yeshorim and the reinforcement of stigma

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### ARTICLE INFO

#### Article history:

Available online 11 August 2008

#### Keywords:

Israel  
Premarital carrier testing  
Community genetics  
Stigmatization  
Bioethics  
Religion

### ABSTRACT

Dor Yeshorim, the premarital carrier testing program designed and implemented by the ultra-orthodox Jewish community, has succeeded in generating high uptake thus considerably reducing the number of children born with genetic diseases. Those critical of the program stress its directive and coercive features which are said to compromise personal autonomy, while those in favor emphasize its efficiency, cultural fit, and the reduction of stigma. This debate has so far, however, been addressed only from a top-down view representing the theories of community leaders and bioethicists, while the actual meaning and practice of carrier matching as experienced by community members have remained unexplored. Based on interviews with 24 ultra-orthodox women and 5 matchmakers in Israel, as well as on observations of instructions in the community, this exploratory study shows how Dor Yeshorim has been selectively incorporated into the traditional match-making process. We examine the unintended consequences of this selective assimilation, namely how messages that propagate ignorance and fear, as well as misunderstandings regarding the genetic basis of carrier matching, reinforce the continuing stigmatization of presumed carriers. The paper concludes by discussing the findings in the broader context of the social analysis of the ethics of community genetics.

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### Introduction

Community-based programs for genetic screening, testing, matching and counseling are a growing, global bio-social phenomenon. This paper focuses on *Dor Yeshorim*, the global project established by Rabbi Ekstein originally in the context of a terminal autosomal recessive disease (Tay-Sachs) and using a culture-specific premarital carrier matching scheme. This program has become for many a paradigm for the successful assimilation of new genetic technologies by a traditional community. As such, this program provides an intriguing case study for examining the manifold implications of bioethical dilemmas such as stigmatization, eugenics, medicalization, privacy and autonomy.

An ethnographic study of Dor Yeshorim has the potential to expose the unintended consequences of the interplay between 'genetic responsibility' and communal narratives (Davis, 2004). This study describes for the first time the implementation of Dor Yeshorim by ultra-orthodox Jewish community members, focusing on the emerging patterns of this utilization as an arena of negotiation. Although there are many discussions of Dor Yeshorim (e.g., Friedman Ross, 2006; Prainsack & Siegal, 2006; Wailoo & Pemberton, 2006), these discussions arguably have a common blind spot. They are informed by the public declarations of the program's founders and community leaders, while local patterns of interpretation and utilization remain outside the scope of the discussion.

We begin with an overview of the research concerning broader social and ethical aspects of community-based programs for carrier testing and matching. The cultural context, history and practice of Dor Yeshorim in the *Haredi*

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(ultra-orthodox Jewish) community are then discussed. To explore the local patterns of utilization and interpretation, the main part of the paper describes the contents of Dor Yeshorim's instruction in the community and analyzes interviews conducted with ultra-orthodox Jewish women and matchmakers.

### **Social and ethical aspects of community-based carrier testing and matching**

The manifold practices of genetic testing and screening are fraught with social and ethical dilemmas including discrimination, stigmatization, medicalization, resource allocation, accessibility, privacy, and autonomy (Chadwick, 1998; Ettore, 2002; Kolker & Burke, 1998). We focus here on a particular form of genetic testing, namely premarital carrier testing (and matching). Previous studies of carrier testing have largely focused on the *individual* level concerning uptake, compliance, stress, self-image, and so on (Friedman Ross, 2006; Frumkin & Zlotogora, 2007). However, carrier testing and counseling also involve the community (Brisson, 2000). Some scholars have proposed that communities should have the authority to approve or veto genetic research involving their members (Sharp & Foster, 2000), and that individual attitudes should also be considered in the context of community norms and values concerning, for example, marriage patterns, family planning, perceptions of selective abortion, religious traditions, and power relations of gender, age, and status (Clarke & Parsons, 1996). Our identity, as shaped by the usage or avoidance of genetic testing and by the right to know or not to know (Fanos & Johnson, 2005) reflects the interplay between autonomy and social expectations (Buchanan, Brock, Daniels, & Wikler, 2000; Rapp, 1999).

Premarital carrier screening is one of the common strategies for community-based genetic counseling. Carrier screening for thalassemia has been carried out since the 1970s in Cyprus, with the State and the Church actively discouraging marriages between carriers (Angastiniotis & Hadjiminis, 1981). Once prenatal diagnosis became possible for thalassemia it was made available within the Cypriot health service. It was then found that 98% of couples at risk detected prior to marriage proceeded to marry, even though Cypriot parents often have considerable influence on choice of partner. Nevertheless, couples used the information on genetic risk in a variety of ways to obtain a healthy family and the annual number of new births of thalassemic children has fallen almost to zero in Cyprus (Angastiniotis, Kyriakidou, & Hadjiminis, 1986). In Canada, a program of information and screening for carriers of Tay-Sachs disease or thalassemia in high schools has proved highly acceptable to the study participants (Scriber, 2006; Zeeman, Clow, Cartier, & Scriber, 1984). Normal fertility rates were maintained in the families at risk, while incidence of these two diseases declined by more than 90% in the communities (Mitchell, Capua, Clow, & Scriber, 1996).

Perhaps the most widely-known example of successful community-based premarital carrier screening and matching is *Dor Yeshorim*, the program developed by Rabbi Josef Ekstein and implemented by ultra-orthodox Jewish communities in the US, Europe and Israel (Abeliovich

et al., 1996; Broide, Zeigler, Ekstein, & Bach, 1993; Ekstein & Katzenstein, 2001; Merz, 1987). Because of the Jewish objection to abortion, ultra-orthodox women – in stark contrast to secular Israeli women – do not use prenatal testing; for example, less than 1% of ultra-orthodox women older than 35 have had amniocentesis and other invasive tests, as against 94% of Israeli secular women (Sher, Romano-Zelekha, Green, & Shohat, 2003). Jewish law (*halacha*) is usually interpreted to forbid abortion (unless the woman's life or health is at stake) thus making prenatal genetic testing irrelevant. *Dor Yeshorim* extends the traditional norm of pre-arranged matchmaking to include carrier matching for genetic diseases that are prevalent in the Ashkenazi Jewish population (the system is detailed below). The uptake is over 95% (Ekstein & Katzenstein, 2001; Sagi, 1998) and according to Ekstein, since *Dor Yeshorim* began no genetically diseased children were born to the parents who used the tests (New Scientist, 2004). An Arab-Bedouin community characterized by consanguinity, high prevalence of genetic diseases, arranged marriages and a Muslim ban on abortion was recently targeted by a group of Israeli geneticists and health professionals for the implementation of premarital carrier matching inspired by the *Dor Yeshorim* system. However, this project – which tested a relatively mild disease (congenital hearing loss) – failed to engage the community (Raz, 2005).

Carrier testing and matching are an important loci for identity formation or “genetic couplehood” (Prainsack & Siegal, 2006). The case of carrier matching encapsulates the broader issues of “genetic responsibility” or “genetic citizenship”, namely our perceived responsibility towards ourselves, our children and our reproductive partner, vis-à-vis our knowledge of what is in our genes (Davis, 2000, 2004). Carrier matching as advocated by *Dor Yeshorim* arguably involves at least three major ethical dilemmas. First, the *Dor Yeshorim* system raises ethical questions regarding the seeming violation of the individual's lawful right to obtain information about him- or herself. Second, non-directiveness and autonomy are seemingly compromised by a scheme in which two carriers are termed “genetically incompatible” and advised not to marry (for similar criticism on the Cyprus program, see Hoedemaeker & ten Have, 1998). Third, while few would debate the severity of Tay-Sachs, the clinical severity of other diseases which were added to *Dor Yeshorim* is conditional on many factors, difficult to predict, and can be even relatively mild and treatable, such as in the case of Gaucher's disease. Israeli geneticists and health professionals working with *Dor Yeshorim* usually acknowledge these dilemmas, but justify the compromise by claiming that (a) carrier matching was selected by the community, (b) the program decreases the potential of stigmatization, and (c) above all, it is “the only way the orthodox community can avoid the agony caused by the birth of babies affected by very devastating diseases” (Sagi, 1998: p. 427).

### **Dor Yeshorim and the *Haredi* community: cultural context, history and practice**

In the ultra-orthodox (*Haredi*) community in Israel, which comprises about 800,000 people (out of 5.4 million

Jews living in Israel, a country of 7.2 million), average fertility rates reach 7–7.5 births per woman (Remennick, 2006), compared to a fertility rate of 2.8 children per woman in the general Israeli population (Landau, 2003). The ultra-orthodox community, although usually seen from the outside as a homogenous enclave, is actually comprised of many sub-groups, struggling at times over material resources and religious hegemony (Grilek, 2002). Social differentiation is mainly along ethnic lines (e.g., Ashkenazi, namely of European origin, vs. Sephardi/Mizrahi, originating in North Africa, the Mediterranean and Asia); and along different spiritual movements going back to the 18th and 19th centuries (e.g., Hassidim vs. Lithuanians). The Ashkenazi groups in particular are still quite diversified in relation to these movements (Heilman, 1992; Idel, 1995; Nadler, 1997). We focus in this study on the Ashkenazi groups – the Hassidim and Lithuanians.

Dor Yeshorim means in Hebrew “generation” (*dor*) of “the righteous” (*yeharim*) or “upright generation”; *yeshorim* is the Ashkenazi pronunciation of the Hebrew word *yesharim*. It was founded by Rabbi Josef Ekstein, an ultra-orthodox Jew from Brooklyn, NY, in 1983, after losing four of his own children to Tay-Sachs disease. Dor Yeshorim representatives visit ultra-orthodox high schools and draw blood samples from students, who are then issued a number. The blood samples are screened for several genetic diseases (the list is detailed below) and the results stored in Dor Yeshorim’s offices. When young men and women reach a marriageable age, and receive a recommendation from a *shadchan* (matchmaker) about a potential mate, they or their parents make a phone call to a representative of Dor Yeshorim, who retrieves the assigned numbers for each member of the potential couple and checks to see if they are carriers of the same genetic disease. If they are, they are told that a union is not advisable. The only result that the tested individuals receive is either “advisable” or “nonadvisable” for marriage. They do not receive their specific carrier status, either at the time of the examination or at the time of the check. In this way, most carriers never find out what gene they carry and thereby are supposed to avoid being seen as defective. The match is considered to be compatible if both parties are not carriers of the same recessive trait. Each member of the couple may be a carrier for a different disorder, but that information is not revealed, as it does not affect their compatibility as a couple. This system is also called “integrative” (as opposed to individual) disclosure. If marriage is deemed inadvisable, genetic “counseling”<sup>1</sup> (by phone only) is available to these individuals. Consulting the Dor Yeshorim database is meant to transpire very early in the matchmaking. If individuals have received testing anywhere other than Dor Yeshorim, or are already engaged or married, they will not be able to use the Dor Yeshorim system. The tests cost about \$200, and results typically take between two and three weeks. The tariff

changes according to the response time, with higher prices for more urgent response.

Dor Yeshorim tests for several genetic disorders – Tay-Sachs disease, cystic fibrosis, Gaucher disease type I, Canavan disease, familial dysautonomia, Bloom syndrome, Fanconi anemia, glycogen storage disease type 1a, mucopolysaccharidosis type IV, and Niemann–Pick disease type A – most of which have significantly higher frequencies among Ashkenazi Jews (Zlotogora & Leventhal, 2000). Dor Yeshorim has been endorsed by religious community leaders and became a standard prerequisite in ultra-orthodox matchmaking. Since its inception, over 220,000 individuals have been tested and over 500 incompatible couples identified (Ekstein & Katzenstein, 2001). Recently Dor Yeshorim has aimed at increasing its activities, reaching out to other religious communities within Jewish society, such as the “modern orthodox.”

## Methodology

To shed light on the assimilation of Dor Yeshorim by members of the ultra-orthodox Jewish community and its emerging patterns of utilization and interpretation, interviews were conducted with ultra-orthodox women and matchmakers. Data collection and analysis conducted in this study reflect the exploratory nature of the research. As a result, a naturalistic, qualitative mode of inquiry was preferred. Interviews (which lasted 1–2 h) were semi-structured, containing questions regarding matchmaking practices and expectations, the place and timing of the genetic criterion in the assessment of the desirability of a match, the perceived meaning of “genetic incompatibility,” the effect of genetic diseases in the family on the marriage prospects of people from such families, and the effect of Dor Yeshorim on the situation of individuals from families with genetic diseases that are looking to find a match. These questions were developed after a review of the literature on Dor Yeshorim and on matchmaking in the ultra-orthodox Jewish community. Questions were asked in the same way but in an open-ended manner, without offering specific options for responses, so as to let respondents express and clarify their opinions. While the interview was structured around similar questions, open discussions also developed and the respondents were encouraged to share their stories. Prior to the interview it was explained to respondents that the study is about Dor Yeshorim and how the program is being used and understood by community members. All participants had the right to refrain from answering any question and could also withdraw from the interview at any time. Responses were thematized by the authors and discussed until reaching agreement. Data analysis followed an inductive, grounded theory development process (Denzin, 1978; Glaser & Strauss, 1967). Interpretations and work concepts were thematically and inductively developed from the interviews, textual analysis, and observations by combining and comparing information and interpretations between interviews.

An attempt was made to build a sample of respondents reflecting the relevant parameters of the population, namely Hassidic as well as Lithuanian women stratified

<sup>1</sup> The word “counseling” is bracketed since in standard professional view, counseling should not be done through the telephone but requires a personal meeting.

by age and marital status. We wanted to hear the opinions of younger, single or married women who have recently underwent genetic testing by Dor Yeshorim, as well as to hear the views of older, married women, whose adolescent children will be undergoing the test soon. Table 1 describes the socio-demographic characteristics of these respondents, dividing them into categories of age and marital status that emerged from the field. Respondents were recruited during 2004–2005 using the snowball method, building on the natural access of the second author, whose family belongs to the ultra-orthodox community. Since the seclusion of an unmarried couple (man and woman) is prohibited by Jewish law (*isur yichud*), this greatly hampered the possibility of interviewing *Haredi* men by the second author, who is a woman. In addition, five ultra-orthodox matchmakers were interviewed. Interviews were conducted by the second author in the homes of the respondents as well as in public meeting places, and tape-recorded with their consent.

To understand the ultra-orthodox stance as expressed by Rabbis and community leaders regarding premarital carrier matching, we analyzed recent relevant religious texts and rabbinical references and lectures given on this subject and interviewed four representatives of religious Institutes established in Jerusalem to provide authoritative orthodox counseling on reproductive issues. To understand the messages and public presentation of Dor Yeshorim in the community, three Dor Yeshorim's instruction sessions in orthodox educational settings were observed in 2007.

### Carrier matching as collective socialization

For all the respondents, utilization of Dor Yeshorim was a taken-for-granted matter crossing group affiliation, age and socio-economic status, as the following quotes illustrate:

"The success of Dor Yeshorim – for us this is very simple, because in our community there aren't many choices. God forbid, if there is a baby like that, you cannot abort, so you must do what you can to prevent it. I did the test when I was 17. Everyone in my class did it, it's a routine" (27, married + children, Lithuanian).

"You do the test without asking questions. My son did it when he was in the process of matching. Dor Yeshorim came to the *yeshiva* and offered them a deal for the entire school. My daughter did it at school, too. We heard about it from the children, who were instructed about it at school" (49, married + children, Lithuanian). "Dor Yeshorim is the solution of the *Haredi* community. Abortion is not an option, and PGD is expensive and difficult. So this is what you have. People who don't do the genetic test will be blamed for that" (49, married + children, matchmaker, Hassidic).

These positive attitudes illustrate how premarital carrier matching in the form offered by Dor Yeshorim became a taken-for-granted part of life in the *Haredi* community. It remains to be seen, however, whether this high compliance represented genetic literacy and followed the original rationale of the program.

To understand the messages and public presentation of Dor Yeshorim in the community three Dor Yeshorim's instruction sessions in orthodox educational settings were observed in 2007. What follows is a description of the common features that characterized all the instructions, illustrated through quotes that were repeated and stressed by the instructor. The instructions began with a description of the life story of Rabbi Ekstein, the founder of Dor Yeshorim, and his four children who died of Tay-Sachs. The instructor, a married *Haredi* woman around 40, stressed the difficult characteristics of the disease. She then quoted Rabbi Ekstein as saying "how difficult it was to raise sick children and to depart from four of them, but even more difficult to find a match for the healthy ones. All the family was labelled as carrying a terrible disease, and this frightened away everyone." This was followed by basic explanations concerning genetics and heredity of recessive traits. The instructor stressed, for example, that when "someone carries a recessive trait, he or she have 25% risk which is high enough to be afflicted by the disease." She then explained that secular people undergo a DNA test and receive an individual answer concerning their carrier status. But this system, she said, "is wrong because in this way people are stigmatized. We don't want the people of Israel to be divided into categories of carriers and non-carriers, thus putting a blemish on a large part of the public. The religious leaders of the Jewish people (*gedolei Yisroel*) have forbidden it. This is how the system of Dor Yeshorim came into existence. One is tested and receives a code, but not an answer. The information is stored in Dor Yeshorim's computer. When you consider a match, you just call Dor Yeshorim and find out if the two codes are compatible or not. Dor Yeshorim recommends not marrying in case of incompatibility." Then she showed a series of pictures concerning the genetic diseases tested in the program, each disease being presented with its frequency and with graphic illustrations of children who were deformed, sick and suffering. The taxing effect of the illustrations was evident. "One of five people is a carrier," continued the instructor, "this is a fact. One of seven has one of the seven diseases I mentioned. Is it then not necessary to do the test? If you don't take genetics into account, you can suffer from this." The program, she

**Table 1**  
Socio-demographic characteristics of the respondents

|                                   | Hassidim        | Lithuanians     |
|-----------------------------------|-----------------|-----------------|
| Young with no children            | 5               | 3               |
| Age (range in years)              | 18–20, mean: 19 | 19–23, mean: 20 |
| Education (range in years)        | 12–14, mean: 13 | 12–15, mean: 13 |
| Young and married (with children) | 5               | 3               |
| Age (range in years)              | 25–35, mean: 28 | 27–34, mean: 30 |
| Education (range in years)        | 12–15, mean: 13 | 12–15, mean: 13 |
| Married with adolescent children  | 3               | 5               |
| Age (range in years)              | 49–51, mean: 50 | 49–53, mean: 51 |
| Education (range in years)        | 12–18, mean: 15 | 12–18, mean: 15 |
| Total                             | 13              | 11              |



explained, was not meant for those who were already married or engaged: “we will not provide answers after the engagement. Our intention is that you call Dor Yeshorim before the engagement.” She concluded by saying that those who do the test must sign a declaration stating that they have not been tested before and do not know their carrier status concerning the diseases tested by Dor Yeshorim. “95% of the matches,” she said in closing, “are done with Dor Yeshorim.”

The instruction illustrates the public message of Dor Yeshorim regarding premarital carrier testing and matching, separating the occasion of the DNA test from the actual answer, which is meant to be provided only concerning the compatibility of two people and only *before* engagement. The instruction also highlights the directive and preventive aspects of the program by its blunt emphasis on the negative aspects of life with a genetic disease – as well as of life as a presumed carrier, namely someone with genetic diseases in the family. The latter message is arguably two-pronged. The instruction repeatedly stresses the stigma of presumed carriers and its intent to help them find a compatible match. This was done by stressing the importance of using Dor Yeshorim as part of the process of matchmaking. The emphasis appeared to be on doing rather than understanding. The stigma of presumed carriers was in itself not questioned or countered, but rather ascertained and even reinforced through negative statements. It appears that while well-intended, the instruction could be interpreted by its audience in a manner that reproduces stigmatization. The views of the respondents, which are further examined in the following sections, support this conjecture.

### Misunderstandings and ignorance regarding the genetic basis of carrier matching

A growing debate over the (mis)representation of genetic knowledge in the media and among the public has emphasized the need to counter genetic determinism and prevent the use of genetics to reinforce discriminatory messages (Condit, 2007; Nelkin & Lindee, 1995). Indeed, what do ‘gene for’ or ‘carrier’ mean to lay people? The question of what does a ‘gene for’ mean is influenced by community norms and cultural preconceptions. For example, some of the respondents said that a ‘carrier’ is afflicted by a disease which is in a ‘dormant’ state. Moreover, community instruction on genetics is not always objective or neutral (Raz, 2005). While a minority (5 of 24) of the respondents, four of them younger women, explained the scientific rationale behind “carrier matching” correctly, the majority, and especially older women, did not.

The respondents understood that a reply from Dor Yeshorim regarding ‘incompatibility’ meant that the match had to be broken, and that each person needed to look for another partner. However, when asked what the basis for genetic incompatibility was, many simply said they preferred not to know. As one of the younger respondents (18, single, Hassidic) said: “why do I need to understand all these details? This will bring me nothing but stress.” Those who tried to provide a more detailed explanation demonstrated the extent of the misunderstanding. It

appears that the message of Dor Yeshorim regarding the benefit of “not knowing” one’s carrier status was so strong that it spilled over to the interpretation of carrier matching:

“I don’t know exactly the source for this so-called genetic incompatibility. One of the couple has a problem, but they don’t tell you who it is” (49, married + children, Lithuanian).

“The meaning of the genetic test is to see if the blood is compatible” (20, married, Hassidic).

“They test if the two of us can together create a defective gene” (23, married, Lithuanian).

“We don’t have to get to the bottom of this. I was told by the Rabbi, and also read in the [community] newspapers, that compatibility means there is no problem with the match. I don’t understand the meaning behind it, and who the carrier is exactly” (35, married + children, Hassidic).

Such misunderstandings and deliberate ignorance, derived from the dictum ‘not to know,’ were very common among the majority of our respondents. They were probably also expressed in the emerging patterns of utilization that are incongruent with the original rationale of the program, as the following section demonstrates.

### Carrier matching and the matchmaking process

In strictly Orthodox Jewish circles, dating is limited to the search for a marriage partner. Both sides (usually the parents, close relatives or friends of the persons involved) make inquiries about the prospective partner, e.g. on his/her character, intelligence, level of learning, financial status, family and health status, appearance and level of religious observance. Matchmaking guidebooks for the *Haredi* community warn that the matchmaking process can be in favor of the “wealthy and healthy” and against all others (Jacobs & Marks, 2006). Perceived negative aspects of the candidate include, for example, medical or psychiatric issues of the candidate or in their family, financial issues, broken homes, orphans, or converts.

The following interview excerpt illustrates a typical matchmaking ‘checklist’ and the place of carrier matching within it:

“My expectations from my match were that he would be *tzadik*, very Hassidic, that’s the most important thing. Then I wanted to know about his family – what is their style, are they suitable for us or not. After that – how he looks like, I didn’t want him to be too fat.”

Q: “How then was the matchmaking process conducted?”

A: “We listened to the suggestions of the matchmaker. We found out about the candidates. We called people and asked about the candidate. Then, if he proved to be a good match, we met. Then we called Dor Yeshorim” (20, married, Hassidic).

A vast majority of the respondents (20 of 24) said that as far as they knew, the matchmaking process first proceeds according to the traditional criteria. Finding out about genetic compatibility was done only after everything else had been agreed on. Most people discontinued the process once they heard about the existence of genetic diseases in

the candidate's family, and therefore did not get to the point of asking Dor Yeshorim about genetic compatibility. The following quote illustrates this.

"First we hear about the candidate, from a matchmaker or someone else we know. They give us the basic details, like who is the family, religiosity, personality, medical background. After two meetings, if we see that we want to continue, we call Dor Yeshorim" (34, married + children, Lithuanian).

Similar answers were given by younger as well as older respondents. For example:

"The matchmaker called our house and told my parents about the candidate. They also asked other people who knew the family. I think my parents called Dor Yeshorim after they met with his parents and reached an agreement about how to proceed in terms of who is giving how much money" (20, married, Hassidic).

When asked if they would discontinue the match in case of genetic incompatibility, the respondents – Hassidic and Lithuanian, older and younger, with or without children – answered unanimously. The following quote illustrates this answer:

"Yes. If there is a genetic problem, we break up the process. There are no social sanctions because the match has not been decided yet and we simply discontinue, only the families know about it" (35, married + children, Hassidic).

When asked why the genetic criterion was not the first to be examined, answers were ambiguous. A few acknowledged that "maybe it's a mistake not to do it in the very beginning. But usually the answer is okay" (31, married + children, Hassidic). It appeared that while everyone spoke about the importance of using Dor Yeshorim, it was done only after the traditional checks.

### **The misunderstood rationale of Dor Yeshorim and the power of presumed carrier stigma in the *Haredi* community**

The vast majority of the respondents (22 of 24) expressed the view that a genetic disease in the family was a stigma which greatly reduced the prospects for matching. As one of the respondents (19, married, Lithuanian) said:

"This is well-known. You do Dor Yeshorim so that the genetics will be good. So that you don't have children who suffer. I have in my class a friend with three brothers who are sick with CF and she tells everyone: Do the test!"

Q: "Is your friend married?"

A: "No and it is difficult for her to find a match. Since both of her parents have the defective gene, it is very difficult for her. People do not understand this. She will have to compromise."

Q: "How about you, would you consider a match with such a family?"

A: "No, I wouldn't. I know it is a stigma. But – I wouldn't go for it because it is frightening."

Respondents spoke about the concept of 'marriage value' in a normative and taken-for-granted, sometimes even business-like manner:

"You see, genetic diseases reduce the value of candidates for matching. People will not listen. Those who are aware would be prepared to listen if it's not hereditary, but those who don't want, would not listen. Many in the public are unaware" (34, married + children, matchmaker, Hassidic)

Some of the respondents became uneasy when speaking about the 'compromise' or the 'price' paid by families in which hereditary diseases reduced the 'marriage value' of family members:

"Would I marry my son to a girl from a family with genetic diseases? To begin with, no. Let's say, hypothetically, the family is really good, but still if it's genetic... you know in many cases unfortunately it turns out that they need to give more money, I don't know how to tell you... Maybe if they give more money [as dowry] it might be a consideration. Look, it's only talking, God help us, for this we have the community leaders" (27, married + children, Lithuanian).

The following quote was told by a Hassidic matchmaker based on her personal as well as professional experience:

"Dor Yeshorim is the final indication. I would not go beyond that. First thing we need to check is health. *If there is a genetic problem [in the family], don't proceed to matching*" (26, married + children, Hassidic, matchmaker; emphasis in the original).

Were those with a genetic disease in the family more accepting of the possibility of a match with a similar person? Out of the 10 respondents who had genetic disease in their family, 8 expressed a negative view concerning this possibility. It appears that living with the burden of stigma did not make these women more critical of stigmatization. Rather, their attitudes reflected and reinforced the very stigma with which they were labelled. In fact, some of them expressed a more extreme position regarding the need to "bring better genes to the match" (in the words of one of the respondents). Despite being aware of the stigma, none of the respondents expressed overt criticism towards the community responsible for that hierarchy of matching, or towards Dor Yeshorim.

### **The twofold view of disability: testing and supporting**

Yet another theme that emanated from the interviews concerned perceptions of disability in the community. All of the respondents spoke, on the one hand, about the increased acceptance of and support for people with disabilities in the ultra-orthodox community, and on the importance of premarital genetic testing on the other hand. Most of them acknowledged this gap between testing (before marriage) and supporting (a child born with a disability) by stressing the suffering imposed by the disability on the child as well as on the family:

"Children and people with disabilities are well accepted in the *Haredi* community; maybe their acceptance is

even better than in secular society. It is different than before, when there was shame and denial and people were afraid to go out with their disabled child. Today there is much more openness and acceptance. I am talking for example about Down's. But concerning genetic diseases that run in the family – this will no doubt affect matching prospects. People don't take a chance" (50, married with children, Lithuanian).

The matchmakers also related to this issue from their professional point-of-view. As one of the matchmakers (26, married + children, Hassidic) said:

"Today there is much more awareness. Once there was much more fear. A family with Down's syndrome – that was something I was afraid of handling. Today there is much more awareness, Down's children are admitted into normal classes, there is special education. Of course, the value for marriage decreases. The families know about it very well. I once had a family where the candidate had a brother with mental retardation. They carried with them papers confirming that they have done all the tests to prove it was not genetic. In each meeting they would pull out the documents and show them... In case of retardation, this is half the trouble. But in case of genetic disease, people would be afraid of entering a match."

Similar accounts of preventing disability through prenatal testing were found to characterize secular Israeli women (Remennick, 2006), who also perceived this as an indispensable part of "good mothering." The *Haredi* respondents, however, also made a distinction, unique to them, between disability in general and disability inherited through genetic diseases – stressing the latter's negative effect on matchmaking.

## Discussion

The purpose of this study was to explore the views of members of the ultra-orthodox community regarding premarital carrier matching. Although the sample in this study reflected relevant parameters of the population, namely Hassidic as well as Lithuanian women stratified by age and marital status, given its small size it is not possible to make any firm conclusions whether the views of this group are representative of the entire community. Furthermore, our study focused on ultra-orthodox women (community members and matchmakers); it would be interesting to compare their views with the opinions of ultra-orthodox men. Additional, comparative studies are also needed in order to examine whether the pattern observed in this study is unique to the ultra-orthodox community in Israel or whether it also characterizes this community in other parts of the world, for example in the US and the UK. The major finding of this study is that the actual meaning and practice of carrier matching as experienced by community members hinge on misunderstandings regarding the genetic basis of carrier matching, and differ from the original design and public messages of the program. Carrier matching is not done at the earliest stage of the matchmaking (as recommended by Dor

Yeshorim) but rather late in the process and only after the traditional examination of other criteria has already been completed. This means that the existence of genetic diseases in the family can disqualify a candidate well before the occurrence of carrier matching, which in such cases does not take place because the match has already been discontinued. These interpretations characterized the majority of respondents, cutting across age, marital status and group affiliation. While Dor Yeshorim has argued that its compromise of autonomy and non-directiveness can be morally defended by the reduction of individual stigmatization, in practice the utilization of Dor Yeshorim reproduces this very stigmatization through propagating a culture of ignorance and fear.

Dor Yeshorim is a well-intended and sophisticated scheme. Its establishment and global institutionalization reflect the efforts and concerns of many people. Furthermore, this program has the potential to reduce stigmatization. However, this study shows that the actual ways in which it is being utilized differ from the original intentions of its designers. Dor Yeshorim arguably carries at least some of the responsibility for this situation. By building itself on the dictum of "not knowing one's genetic identity" (expressed in the nondisclosure of each individual's carrier status), Dor Yeshorim also inadvertently reinforces the message that being a carrier is something which one is better off *not* knowing, and hence that being a carrier is *bad*. This message, implicit in the Dor Yeshorim system and in its directive instructions, was interpreted by community members through the explicit stigma traditionally associated with genetic diseases.

## Dor Yeshorim and Israeli society

At first glance, Dor Yeshorim appears to be conducted in a cultural bubble. The *Haredi* community studied here, although living in Israel, separates itself culturally from secular Israeli society. Indeed, the principle of premarital testing, as opposed to prenatal diagnosis, reflects the difference between orthodox and secular communities. Because abortion following prenatal diagnosis is usually forbidden, the ultra-orthodox Jewish community developed its own screening program, namely Dor Yeshorim, based on premarital carrier screening and matching. Furthermore, genetic counseling in Israel outside of Dor Yeshorim generally espouses the same patient-centred, autonomy-oriented norms as in the US, thus making the contrast with the authoritarian Dor Yeshorim extremely striking.

Alongside these contrasts there is also an intriguing parallel underpinning the secular and the orthodox perspectives. This parallel can be termed the "twofold view of disability." This view encourages genetic testing in order to prevent the birth of children with genetic diseases, while supporting children already born with a disability. Secular Israeli society is characterized by a twofold view of disability based on the separation of prenatal (preventive testing) and postnatal services (supporting disability) (Raz, 2004). The *Haredi* respondents in this study presented a similar twofold view, with one important difference – in their case, it was the separation of premarital (rather than prenatal) preventive testing

from the postnatal support of disability. Despite the prevalence of prenatal testing in Israeli society, and of premarital testing in the ultra-orthodox Jewish community, in both no public debate regarding disability rights and genetic testing has developed. Prenatal genetic testing, according to the disability perspective (Parens & Asch, 2000), expresses negative or discriminatory attitudes about both impairments and those who carry them (Buchanan, 1996). Saxton (1997, p. 391) commented in this context how “the message at the heart of widespread selective abortion on the basis of prenatal diagnosis is the greatest insult: some of us are ‘too flawed’ in our very DNA to exist; we are unworthy of being born.” This criticism could also be relevant to the case of Dor Yeshorim’s premarital carrier testing which has been extended to include, in addition to the original test for Tay-Sachs, tests for genetic diseases which are less severe and represent medically treatable genetic conditions (e.g., Gaucher). The support offered to Dor Yeshorim activities by the Israeli establishment could perhaps be culturally linked (in addition to more practical reasons concerning politics and managed care) to a common utopian view of eugenics. This parallel, which requires further sociological examination, could be viewed as a deep-seated linkage connecting Judaism and modern, secular Israeli society (cf. Gross & Ravitsky, 2003).

### Implications for the social analysis of the ethics of community genetics

Many geneticists, in Israel and the US, cooperate with Dor Yeshorim since they view it as a necessary adaptation of modern genetic technology to ultra-orthodox Jewish culture. However, the findings shed new light on the ethical price of this compromise. Dor Yeshorim advocates a communitarian, culturally bound concept of “genetic responsibility.” Another view of genetic responsibility, related to the “standard view” of North-American and European genetic counseling, would emphasize transparency and knowledge – namely full *individual* disclosure coupled with community education and individual counseling – as a way to liberate presumed carriers from their stigma. As the findings show, one of the consequences of the selective assimilation of Dor Yeshorim in the *Haredi* community has been to retain and reinforce the stigmatization of presumed carriers. On the other hand, it would be misleading to argue that we can rely exclusively on the liberal democratic rhetoric of individual free choice and non-directiveness to counter worries about the eugenic implications of widespread genetic testing. Research on prenatal testing in general has shown the emergence of new regimes of eugenics, rooted in the free-market economy of contemporary capitalism rather than in top-down legislation aimed at controlling reproduction (Duster, 1990; Parens & Asch, 2000; Rapp, 1999).

Another ethical charge concerns the issue of eugenics. Even if the concept of premarital screening may be acceptable for Tay-Sachs, since the technology exists to uncover more and more diseases, the process can be said to shift perilously close to “backdoor” eugenics (Duster, 1990). It should be stressed that the formal *Haredi* approach to premarital screening embodies a communal belief in the

obligation of this generation to the next rather than the eugenic imperative to eliminate the unfit. But as the system of genetic screening expands to relatively mild and medically treatable genetic conditions, for example Gaucher’s disease, the ethical boundaries become more amorphous (Kolata, 1993; Wailoo & Pemberton, 2006).

What can the case of Dor Yeshorim teach us in general about the promises and perils of community-based management of genetic information? Dor Yeshorim functions in an insular community guided by a particular moral sense regarding the individual’s religious obligations, deference to parents and elders in choosing a spouse, and opposition to abortion. Such a worldview is quite foreign to the larger secular society. As a result, the Dor Yeshorim model does not translate easily outside this particular community. Indeed, the African-American community rejected in the 1970s sickle-cell carrier screening because of worries that such screening would result in discrimination or lend support to claims of genetic inferiority. Some African-Americans, skeptical of government intervention in family life and reproductive choice, worried that the state was attempting to limit the African-American population (King, 1992; Wailoo, 2001).

Others may be troubled by Dor Yeshorim due to more general, liberal concerns (Slifka, 2007). But is it valid to judge Dor Yeshorim according to generalized secular/liberal ethical standards? This question can also be framed within the liberal/communitarian debate (Strike, 2000) as well as within the recent debate in cross-cultural bioethics (Ainslie, 2002; Lai Po-Wah, 2002; Marshall & Koenig, 2004). The case of Dor Yeshorim illustrates how ethical debates should be informed by what is actually taking place within the community. By focusing on a ‘pedestrian’ analysis of community genetics as an arena for negotiated order, we can move beyond ethical paradigms to their meanings-in-use, whose analysis can provide important insights for dialogue and mutual observation.

### Acknowledgements

The authors would like to thank all the respondents who participated in this study. We are grateful to Silke Schicktanz, Barbara Prainsack, Yael Hashiloni-Dolev, Joel Zlotogora, David Leiser, Ayala Frumkin and Sari Lieberman, who provided important suggestions. Thanks also to the journal’s editor and anonymous reviewers for their helpful comments.

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