

The quest for the perfect baby: why do Israeli women seek prenatal genetic testing?

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Abstract Since the mid-1990s, the Israeli medical scene has witnessed a real boom in elective prenatal testing for inherited diseases that has spread beyond risk groups to the general Jewish population, especially of Ashkenazi (European) origin. This study tried to identify key social influences involved in the growing range and prevalence of prenatal genetic tests as they emerged from women's own perspective. Twenty-seven women having blood tests for genetic mutations were interviewed at two types of genetic clinics, and re-interviewed after getting test results. The names of 23 women who chose not to have elective tests were obtained from testers, and these non-testers were interviewed for comparison. Women's accounts suggest that elective genetic testing is more acceptable, if not normative, among educated middle class Ashkenazi women, and is more often questioned and refused by lower class Mizrahi women, as well as religious women of any ethnic origin. The key forces that drive women's choice of prenatal genetic diagnosis include the fear of having a sick and/or socially unfit child in an unsupportive environment; strong endorsement of testing by gynaecologists; popular and professional discourse on the common Ashkenazi mutations causing *genetic anxiety* in this ethnic group (*i.e.* apprehension of multiple known and unknown dangers hidden in its genetic makeup); and the emerging social pressure for comprehensive prenatal screening as an indispensable part of *good motherhood*. Many women described the experience of testing as frustrating because of the long wait for results and difficulty of their interpretation and subsequent decision-making. Women who rejected elective tests explained their decision by moral/religious objections to abortion and/or eugenic aspects of prenatal screening, as well as by prohibitive costs and poor understanding of the tests' meaning and implications. Yet, few informants voiced objections to the excessive medicalisation of pregnancy as such; ethno-national motives of reproductive decisions were also uncommon in this

group. More critical reflection is clearly needed from both providers and users of elective genetic screening before the more widespread uptake of this practice.

Keywords: prenatal genetic screening, medicalisation of pregnancy, Israel

Introduction

With the advancement of the Human Genome Project, the genetic base of some 4,000 human diseases has been discovered and, by the late 1990s, about 350 clinical tests had been developed for their prenatal diagnosis (Conrad 1999, Singer *et al.* 1999). At the same time, geneticisation of not only health and disability, but also intelligence, spirituality, deviance and a host of other psychosocial traits in popular biomedical discourse, have put genes in focus as a new cultural icon, invested with almost mystical powers (Nelkin 1996, Nelkin and Andrews 1999, Conrad 1999, Conrad and Gabe 1999, Kluger 2004). Driven by the preventive ethos and technological imperative of modern biomedicine, every new genetic discovery is rushed into clinical practice, increasing in geometric progression the numbers of tests offered to pregnant women – a practice viewed by some thinkers as opening a ‘backdoor to eugenics’ (Duster 1990). Some genetic tests are based on maternal blood sample, while others are invasive and may cause spontaneous abortion. The financial costs involved in genetic testing may also be rather high, which means that lower social strata are excluded from this practice (Kupperman *et al.* 1996, Learman *et al.* 2003). Since for most congenital diseases a cure is not available, the only solution to ‘defective pregnancy’ is termination, which poses a heavy moral dilemma for most women.

Prenatal testing, therefore, casts a shadow on the whole experience of pregnancy, causing many women anxiety and stress, precluding maternal bonding with the baby and turning the whole experience into what Barbara Katz Rothman has cogently called ‘tentative pregnancy’ (Rothman 1994). When pregnancy is constantly probed for normality or defectiveness, the fetus itself becomes a tentative fetus, whose birth is conditional on certain quality parameters verified by expert interventions. Although in modern maternity discourse fetuses are invested with personhood, and hence are described, for example, in maternity guides as sensitive to music, voices, and moods, having feelings, etc. (Georges and Mitchell 2000, Ettorre 2002), suspected or confirmed abnormalities may turn the fetus into a defective person or even a non-person, merely a lump of damaged biological tissues.

On a more general social level, the practice of prenatal screening is fraught with ethical dilemmas (Duster 1990, Press and Browner 1997, Rhodes 1998, Kolker and Burke 1998, Nelkin and Andrews 1999, Ettorre 2002). Many social scientists have pointed out that the emergence of new technologies of

genetic testing and manipulation far outpaces the ability of service providers and legal bodies to comprehend their implications and respond with relevant medical and social policies (Kenen and Smith 1995, Asch *et al.* 1996, Cassel 1997, Petersen 1998). The ultimate purpose of prenatal genetic diagnosis is to eliminate hereditary disease and to improve public health and individual quality of life. Yet, in practice, women and couples who take the tests face much uncertainty and anxiety in the process of 'predicting their futures' (Marteau *et al.* 1997, Tercyak *et al.* 2001, Hedgecoe 2003). By way of paradox, the expanding knowledge about genetically-based pathology produces more questions than answers, and seems to reinforce rather than abate parental anxiety in the face of tens of known and hundreds of yet-unknown threats hidden in our genes (Kolker and Burke 1998, Petersen 1998, Ettore 2002).

Genetic screening, while fully acceptable for high-risk families and in the case of potentially fatal diseases and severe malformations, becomes morally challenged when driven by the wish to avoid having babies with minor or cosmetic defects, or to select their sex. While some inherited syndromes invariably manifest as severe disabilities, others are conditional on many factors, and their severity is difficult to predict. Therefore, a positive diagnosis raises fundamental questions as to what kind of life is worth living and who is entitled to decide (Press and Browner 1997, Cassel 1997, Kolker and Burke 1998). Moreover, the routine practice of genetic testing has the potential to further diminish the social status of disabled or 'defective' children and adults. The theoretical possibility of prenatal selection of the fittest strongly adds to the stigmatisation and isolation of the people who live with disability (Weiss 1994, Cassel 1997, Parens and Asch 2003).

Another set of potential problems has to do with the dissemination, interpretation and usage of the information generated by prenatal testing. As Kaja Finkler (2000) has shown in her study of people trying to trace their genetic origins and inherent medical risks, the 'hegemony of the gene' in popular culture risks the 'medicalization' of kinship. Since hereditary defects are seen as a family problem, close and distant relatives can claim the right to know, and the disclosure of private genetic data is often inevitable. Yet in many cases women or couples wish to prevent the involvement of their relatives in their reproductive decision-making. This conflict of interests, and the need to test other family members to increase the validity of results, may become a source of tension and family conflict (Cassel 1997, Rhodes 1998). Additionally, the breach of privacy and leakage of private genetic information may be used by insurance companies as grounds for denying coverage (Laurie 1996). Genetic counsellors have a special role to play as mediators between dry laboratory data and the value-laden world of reproductive decision-making. Genetic counsellors who disclose positive findings to women and couples sometimes struggle themselves with an appropriate interpretation, while trying to offer their clients meaningful guidance (Kenen and Smith 1995). When there is more certainty as to the test outcome (*e.g.* in the case

of cystic fibrosis) the counsellors face the dilemma of a descriptive versus prescriptive model of counselling (Asch *et al.* 1996).

While most traditional tests focus on Down's syndrome, Tay-Sachs and some other classic genetic disorders, new tests for discovery of cystic fibrosis (CF), Fragile X (a frequent cause of inherited mental retardation), deafness, late-onset diseases such as Huntington's and breast cancer, as well as other rare conditions (Bloom's syndrome, Gaucher's disease, etc.) are increasingly used, especially by members of predisposed ethnic groups¹ (Kupperman *et al.* 1996). Up until the 1990s most genetic tests and consultations were offered to couples with known genetic risk in the families, but today a significant part of genetic screening is becoming elective and is chosen by low-risk women and couples. In Israel, the prevalence of elective testing has tripled every five years since 1992, and by the early 2000s this practice had become common for a broad low-risk population, especially of Ashkenazi descent (Gak 2001, Sher *et al.* 2003). Although few countries report solid statistics on the prevalence of prenatal screening, the available comparisons indicate that the scope of this practice in Israel is outstanding by any measure. Thus, in Japan, only four per cent of pregnant women over 35 years of age reported having amniocentesis; in Denmark and Holland, these figures range between nine per cent and 16 per cent (Matsuda and Suzumori 2000), while in Israeli Jewish women this rate was about 51 per cent in general and reached 94.4 per cent for secular women. About 40 per cent of secular new mothers reported having tested for Fragile X (Sher *et al.* 2003, Zlotogora and Leventhal 2000).

In this article I explore the driving forces behind the upsurge in elective prenatal screening for genetic conditions among Israeli Jewish women as these emerged from women's own accounts. I chose to focus on Jewish Israelis because they comprise over 80 per cent of consumers of genetic services (Sher *et al.* 2003) and because the set of issues faced by non-Jewish Israelis in the reproductive realm is rather different, calling for a separate research project. As the reader will see, there is enough variety across religious, socio-economic and ethnic lines within the Jewish sector to make data collection and analysis complex and multifaceted. This research was informed by three related theoretical frameworks: the social construction of 'good motherhood'; the medicalisation of reproduction and vested interests of the medical providers; and the rise of the consumerist paradigm of childbearing in the light of unqualified popular faith in modern biomedicine. Let me turn now to these issues and their interplay in the Israeli context as a backdrop for the following study.

The Israeli context: motherhood, medicalisation and prenatal screening

The family and motherhood are among the key social values of Israeli society: marriage is almost universal, divorce is relatively rare (albeit growing), and total fertility rates are the highest in the developed world, standing at about

2.8 nationally and ranging, among the Jews, from 2.4 in secular families to 7.5 among the Ultra-Orthodox. Israeli Jewish pronatalism is expressed at both institutional and popular levels and is driven by the religious tradition, the memory of the Holocaust, the loss of life in military conflict and terrorist attacks, and the on-going demographic competition with surrounding Arab nations (Portugese 1998, Sered 2000). While Orthodox Jews are known for their unlimited fertility reflecting the biblical commandment to 'be fruitful and multiply', in the secular Israeli discourse, too, raising a large family is often represented as a patriotic deed and a contribution to the national cause (Berkowitz 1997). Despite its post-industrial economy and Westernised lifestyle, Israeli society is known for its familism and the central role of the family (both nuclear and extended) as the primary support network. Motherhood is the chief ideological icon and primary identity for most Israeli women regardless of their education, employment and career aspirations; one child is never enough and the norm for secular couples is around three children. Childless women carry a lifetime stigma that can only be alleviated by protracted attempts to get pregnant by means of assisted reproductive technologies (ART). The latter are accessible to all Israeli women since IVF and other expensive treatments are subsidised from public funds – yet another expression of state ideology stressing the need to 'reproduce Jews' at any cost (Kahn 2000, Remennick 2000).

Medicalisation of reproduction and women's bodies has been as prominent in Israel as in the US, or even more so, reflecting universal access to all tiers of healthcare and traditional respect for medical science and doctors among the Jews (Sered 2000, Remennick 2000). Some Israeli feminists have argued that by providing public funding for most reproductive services the state also imposes various forms of social control on women's bodies via medical professionals as its agents (Amir and Benjamin 1997, Haelyon 2004). While the most recent trend in American and, especially European, obstetrics has been towards more 'natural motherhood', *i.e.* fewer interventions and less technology applied to normal pregnancies, in Israel medicalisation is still in high gear. There is little public discussion of the controversies and adverse effects of ART, Caesarean births, prenatal tests and other reproductive technologies (Kofafer and Landau 1997, Rhodes 1998, Sered 2000). If up until the early 1990s the main providers of prenatal care were maternity centres run by nurses and midwives (*Tipat Halav*), the recent trend has been to sign up with Obs & Gynae specialists (for wealthier women – a private one) for a 'more professional' pregnancy follow-up (Ministry of Health 2001). Women are given direct incentives for hospital delivery (home birth disqualifies them from the maternity bonus), are strongly encouraged to register early for prenatal care and are bombarded with popular literature, media and internet messages encouraging them to use as much medical surveillance as possible (Shavlev 2003).

With the emergence of a thriving private sector in Israeli medicine from the early 1990s (Gross *et al.* 1998), specialists in Obs & Gynae have developed additional vested interests in ordering as many tests and performing as many

procedures as possible. Another driving force behind the soaring numbers of various prenatal tests among healthy low-risk women is the nascent defensive mindset of Israeli physicians, aware of the upsurge in malpractice lawsuits that is especially prominent in obstetrics. Last but not least among the forces sustaining growth in the bulk of prenatal tests, is the direct profit of the hospitals and clinics, be they public (getting payment from Health Maintenance Organisations) or private (direct fee for service). Commercial providers of reproductive services further boost the demand via active advertising of prenatal diagnosis (Gak 2001). Alongside material revenues, medical and academic careers are being advanced as a by-product of this thriving industry. Indeed, Israel has always been on the cutting edge of research and clinical practice in reproductive medicine, producing a record number of publications and conference presentations, considering the small size of its medical corps (Sered 2000, Kahn 2000).

Just as general prenatal follow-up became routine a few decades earlier, genetic screening too is rapidly becoming part of the normative conduct of expectant mothers as the means 'to secure a healthy future for your baby' (in the language of an ad for a CF test in a popular maternity magazine). Thus, compliance with the medical requirements and the use of all available technologies to ensure a positive pregnancy outcome is emerging as a norm of 'good motherhood', *i.e.* responsibility and early investment in your children's future (Kofafer and Landau 1997). This discourse is intertwined with the prevalent social attitudes toward disability and physical imperfection. In her 1994 book *Conditional Love* Israeli social anthropologist Meira Weiss offers an analysis of the bio-politics of falling in love with your physically imperfect child. She shows how a child's appearance determines his or her parents' terms of affection and explores practices of abandonment, dehumanisation, territorial seclusion and abuse to which parents subject their appearance-impaired children. The book underscores the significance given to 'body image' in Israel and how it determines the acceptance/abandonment of the child; in a more general sense, it testifies to a low tolerance of disability in everyday Israeli Jewish culture. These attitudes are aggravated by the modest level of support given by state agencies to parents of disabled children, constantly shrinking funds for special education, and the deteriorating quality of institutions caring for handicapped and learning disabled children and adults. The general message potential parents are receiving from this prevailing social milieu is: if you have a disabled or sick child, you will face all the consequences yourself, your child will be isolated and ostracised, will be a burden on you and on society. This prospect is intimidating for every parent, but especially frightening for educated and career-oriented women, whose work life would be severely damaged by the demands of caring for a sick child. In this milieu, it is hardly surprising that many women seek to predict their future by using new genetic technologies.

Jewish parents, especially of Ashkenazi origin, have always had a higher 'genetic anxiety' than other ethnic groups due to the relatively high incidence

of certain genetic conditions as a result of many generations of endogamy in European Jewish communities (Zlotogora and Leventhal 2000, see also Note 1). The wonders of new genetics, and the related prenatal tests, ostensibly promise security and peace of mind to pregnant women. As amniocentesis, chorionic villus sampling (CVS) or complex fetal sonograms are becoming more available and routine, women who choose to forego them may be labelled as backward or irresponsible (Press and Browner 1997, Ettore 2002). The new medical gospel is welcomed by most health professionals and laypeople alike without rigorous question, such as: if there are thousands of known genetic diseases, how many tests can you realistically perform to screen them out? If you have tested negative for Fragile-X, CF and a dozen other conditions, what about the rest of potential mutations? Is there a logical criterion of how many and which tests to order for a low-risk woman? And most important, do pregnant women really benefit from exposure to genetic risk information and the ever-growing number of tests? Do prospective parents have the right *not to know* the details of their genetic makeup and willingly accept the uncertainty that has always been involved in the creation of new life?

As a recent national survey among postpartum women in Israeli maternity wards has shown (Sher *et al.* 2003), the key factors predicting performance of the prenatal tests include women's higher socio-economic status, secular background, lower number of children in the family, and doctor's referral. The main reason for non-performance of the tests was high religiosity and moral objection to abortion: less than one per cent of Ultra-Orthodox women older than 35 have had amniocentesis and other invasive tests, as against 94.4 per cent of secular women. For non-invasive (blood) tests such as Fragile X the respective figures were 40 per cent and 3.4 per cent (Sher *et al.* 2002). Thus, social inequality is apparent in women's practice of elective testing: poorer and less educated women with more children, *i.e.* in the Israeli case, Ultra-Orthodox and Mizrahi (non-European) Jewish and Muslim women, are less prone to seek prenatal diagnosis, regardless of the actual level of genetic risk. The preoccupation with 'quality of the offspring' is more typical for the upper social strata (and for wealthy low-fertility societies in general (Lock 1998)) who are willing to use all available technology in order to produce a flawless baby destined for success and prosperity (Kofafer and Landau 1997).

While biomedical research in reproductive genetics is thriving in Israel, public health experts have joined forces with the medics, defining comprehensive genetic testing as a future goal and asking how to narrow ethnic and social divides in uptake (Zlotogora and Leventhal 2000, Sher *et al.* 2002). In the face of the paucity of critical social research on prenatal testing in Israel, this study addressed the previously overlooked, women's perspective on this new practice and tried to review the balance of benefits and hazards that it entailed. Does the engagement with testing, awaiting and interpreting test results indeed grant women peace of mind and a sense of security and control over their future, as the promoters of prenatal testing persistently

assert? How can we capture the emerging 'genetic anxiety' among expectant mothers? In more general terms, the study explores psychosocial mechanisms that drive the observed expansion of prenatal screening practice from defined risk groups to the general female population.

Participants and methods

As I have mentioned, prenatal genetic screening in Israel is increasingly elective, that is, performed on low-risk women as part of routine pregnancy assessment or in planning future pregnancy. This study targeted women who sought elective testing for a number of specific genetic disorders with significantly higher frequency among Ashkenazi Jews: Fragile X, several mutations linked to CF and deafness, Canavan Disease, Gaucher's Disease, and Bloom's syndrome, Fanconi anaemia, and some other rare disorders – altogether 16 mutations at the time of the study, a package of tests that is constantly expanding². All mutations for which tests are offered (except Fragile X) are recessive ones, meaning that if a woman tests positive on one or more count, her male partner should be tested as well to define the odds for this disorder in the offspring. In some cases, testing of additional family members may be needed to increase the certainty of the outcome. Elective tests are not covered by basic health insurance and are usually paid for out-of-pocket (the costs are in the order of 30–50% of the average monthly salary). However, if a mother is found to carry one or more mutations, all subsequent counselling and testing of the father and the testing of the fetus is free. When both parents are carriers of a specific mutation, the next step in prenatal diagnosis would be fetal genetic testing in later pregnancy by means of CVS (sampling of placental tissue) or amniocentesis and late termination if mutation is confirmed.

Although most genetic tests are based on a sample of maternal blood and are ostensibly harmless, they may open a Pandora's box of practical and ethical issues. All above-named genetic disorders are rare (from 1:2,500 live births for Fragile X to 1:3,600 for CF) and their clinical manifestation can occur (with a 25% probability) only when two carriers of the same mutation parent a child. Yet the chances for testing positive for one of the so-called Ashkenazi mutations for the women belonging to this target group are not negligible (from 1:113 for Bloom's to 1:30 for CF and 1:17 for Gaucher's – Gak 2001). Moreover, the very appearance and clinical severity of these syndromes in offspring is conditional on many factors and is difficult to predict. Gaucher's and some other newly-discovered mutations manifest themselves as relatively mild and treatable symptoms. Can they justify the decision to terminate the pregnancy? Both providers and users of genetic services have to negotiate these questions.

Informants for this study were contacted in two types of medical setting in two geographic regions in order to ensure wide social representation. One group (16 informants) was located in a private Institute for Reproductive

Genetics, loosely affiliated with a major hospital in central Israel, and the other (11 informants) in a public maternity centre in a northern town that also offered additional private testing. Both facilities serve a broad range of local residents from the city and surrounding villages or kibbutzim, and are diverse in terms of religion, ethnicity and social class, although the Institute attracts a relatively more educated middle class population. About 65 per cent of the women who were initially approached ($N = 37$ in both centres) agreed to be interviewed, which is a good response rate for a study targeting sensitive and morally-charged issues (in the earlier Israeli studies on infertility stigma and abortion experiences the response rates were well below 50% (Remennick 2000, Remennick and Segal 2001)). Most women who refused to be interviewed (10 out of 37) explained this was due to the personal nature of the subject, feeling unwell during pregnancy or their general scepticism of social research (Israelis are an over-surveyed population, regularly contacted by pollsters and research institutes). In terms of the main demographics (age, urban/rural residence, ethnicity and education) the non-respondents in both centres did not vary significantly from the respondents.

Women were interviewed at two points in time: firstly while registering for the tests (to assess the reasons for this decision) and then after receiving test results (to understand women's interpretations and further actions). At the first contact in the clinic, the study goal (represented as an evaluation of certain aspects of prenatal care in Israel) was explained to the women, and they were invited to participate. Some preferred to talk while waiting for the procedure or after it was over; others left their details and were interviewed later in their homes or in other places. The interviews were conducted by me and my assistant – a female graduate student of sociology. Altogether, we interviewed 27 women ('testers') who had had a blood test for genetic disorders; 25 women were interviewed twice as planned and two women rejected the second interview for personal reasons. Among women who sought genetic tests, 21 were already pregnant (usually in the first trimester) and six were planning pregnancy in the near future. Interviews centred on one open question: 'Why did you have elective genetic tests in the absence of known genetic risks in your family?'. Depending on women's responses, they were steered by researchers to provide more details or explanations, but no direct judgmental questions were asked.

To elicit the attitudes of the women who resisted the trend for comprehensive genetic screening, a comparison group was built of 23 women who chose not to have elective tests ('non-testers'). These women were located via the personal networks of the testers, who were asked to give names of other women who did not have elective genetic tests while pregnant. This approach, resembling matching techniques in quantitative research designs, allowed the examination of individual variations in decision-making in the presence of at least some peer pressure. Testers and non-testers belonged to one social network and had probably discussed their pregnancy-related experiences. Non-testers were asked an open question to explain their decision to forego the tests.

On average, all interviews lasted about 90 minutes. They were tape-recorded with the women's consent, and consequently transcribed verbatim and analysed using repeated scanning, thematic and narrative analysis as described by Crabtree and Miller (1992). Below I discuss the main themes that emerged in the women's narratives and illustrate them with typical quotes. Women's names have been changed to ensure anonymity, but other relevant details (age, occupation, ethnicity) were left intact. Most women who tested for genetic disorders were secular or 'traditional' (*i.e.* generally secular in their outlook and lifestyle but observant of some Jewish traditions like keeping kosher and lighting candles on Shabat). Among non-testers there were more religious and a few Ultra-Orthodox women; their religiosity is mentioned before the quotes when relevant.

Findings

I begin by describing the accounts of the women who chose to perform all possible tests (the testers) and then move to the narratives of those who decided to forgo all or most elective tests (non-testers). Demographic and social profiles of the two groups were rather different (see Table 1). Women seeking elective tests were on average less religious, more educated and employed full time, carrying their first child, and more often belonging to the Ashkenazi Jewry. Non-testers were usually more religious, pregnant with their second or third child, less educated, more often homemakers or working part time, and of non-European ethnic origin. These socio-demographic differences, similar to those reported in an epidemiological study by Sher *et al.* (2003), may partly explain women's attitudes towards the medicalisation of pregnancy and their acceptance or rejection of prenatal screening. As most women in both groups stated several reasons for their decision to get tested or not, different themes inevitably intersect in the analysis reported below. Yet, Table 2 shows clear differences between testers and non-testers in the appearance of specific reasons or motives in their accounts.

The more tests the better: reasons for elective screening

From 'The doctor knows better' to 'I want to control my future'

By and large, women who chose maximum prenatal screening were those who had fully internalised the medical model of pregnancy as a high-risk condition. Out of 27 women, 25 had acted upon the advice of their gynecologist. Most informants built their narratives around two locations of 'control' – medical (trust in medicine and technology) and personal (exercising agency, making the right decisions about pregnancy). Below are several typical explanations of that type. Liat (26, librarian, mixed ethnicity) said:

Table 1 *Social and demographic characteristics of the participants*

	Testers (N = 27)	Non-testers (N = 23)
Mean age	26.2	28.3
		per cent
<i>Pregnancy order</i>		
1 st	68	50
2 nd	27	36
3 rd or more	5	14
<i>Marital status</i>		
Married	92	87
All other	8	13
<i>Ethnicity</i>		
Ashkenazi	73	45
Mizrakhi	8	28
Mixed origin	19	27
<i>Religiosity</i>		
Secular	69	45
Moderately observant (traditional)	29	40
Religious/Orthodox	2	15
<i>Education</i>		
Secondary (12 years)	25	44
Undergraduate (15 years)	62	48
Postgraduate (17+ years)	13	8
<i>Employment</i>		
Full-time	65	49
Part-time	28	40
Unemployed	7	11

As an educated person I know about all the problems involved in pregnancy. Things can go wrong at any point because few women are perfectly healthy: many of us smoke, some are overweight, we live under stress, etc. And then there are all these genetic problems with Ashkenazi Jews . . . This is my first baby and I want to do all I can to ensure its good health. Of course I am also trying to eat well, to be calm, to exercise, etc . . . but medical check-ups can never hurt.

Liat's quote reflects several reasons for genetic testing: perception of any pregnancy as a high-risk condition, attempts at healthy lifestyle, apprehension of having a less than perfectly healthy baby, and the reliance on medical control as the answer. She is also trying to connect this attitude to her being an educated professional and therefore upper class, maybe reflecting class ambiguity to her mixed ethnicity. Shelly (24, law student, Ashkenazi) reflected along the same lines:

Table 2 *Frequencies of appearance of specific themes and motives in women's narratives (as rounded % of all testers and non-testers)*

<i>Theme or motive</i>	<i>Testers</i>	<i>Mentioned by</i>	
		<i>Non-Testers</i>	
		per cent	
Doctor's advice to get tested, full trust in biomedical model	85	30	
Agency and wish to control pregnancy outcome	90	20	
Peer pressure, social norm	90	65	
Family interests and pressure ('medicalization of kinship')	60	20	
Good motherhood, responsibility	90	25	
Fear of having a disabled child	100	30	
Mistrust in social support from state and/or family in raising a sick child	80	50	
Questioning/rejecting excessive medicalization of pregnancy	15	80	
Financial barriers to testing	20	70	
Opposition to eugenic aspects of prenatal screening	10	60	
Rejection of abortion on moral or religious grounds	5	70	

I have found an experienced doctor and I'll go with all his advice. If modern science offers help in preventing deformity and disease it is simply wrong not to use it . . . There are no genetic problems in my family, but I am not so sure about that of my husband . . . You know, Ashkenazi Jews have more mutations than others, so you cannot be too careful.

Galit, (29, lab technician, mixed ethnicity):

What do I know? I just rely on my doctor's advice. If he says that these tests are worth doing I'll do them, even if I have to borrow money to pay for it [laughs]. It gives me peace of mind to know that I've done all possible things to prevent trouble. I know that there are many other diseases for which there are no reliable tests so far, but we can't help this, can we? You use the available tests and hope for the better . . .

These quotes reflect three related themes: apprehension at potential troubles hidden in the Ashkenazi gene pool, an unlimited trust some women have in their physicians and in biomedical science, and women's attempts to attain control over their future motherhood by ruling out major congenital disorders.

The pursuit of 'peace of mind' via prenatal screening – which is typically heralded by physicians and medical geneticists as a major 'side benefit' of testing – is a controversial issue, as many other narratives suggest. Karen (27, school teacher, Mizrahi) said:

It is tricky, this testing issue. On one hand, you want to gain control over your pregnancy outcome, to make sure the baby is OK, but on the other, testing itself keeps you worried and tense all the time. I trust this clinic and I know that, if I need to do amniocentesis, the abortion risk is low but still this procedure is very scary . . . And then you have to wait three weeks for the results – it is pure hell! I hope this is the very last test I'll do . . .

Tamar (26, sales manager, Ashkenazi):

It is my first pregnancy and I have no experience, so I act on other women's advice, and that of my doctor of course. Two of my close friends are pregnant as well, and both have had genetic tests at this Institute. One was OK, but the other had some problem and went for genetic counselling. So I decided that I also need to check my genes, to make sure I don't carry some defect that I can pass to my baby . . . Truth is, I will worry till I get the results, only then I'll be able to sleep quietly . . . for some time at least, since I have many other tests waiting ahead . . .

Karen and Tamar's comments suggest that being in the process of constant testing of one's genetic material and probing for the pregnancy's quality may be highly stressful for the women and may in fact lead to anxiety and perceived loss of control over one's life and body rather than enhanced confidence and wellbeing.

The theme of controlling one's fate came out strongly in Hagit's account (she is 38, having her third pregnancy, Ph.D. and Ashkenazi):

Most women I know do these tests for the same reason: we are trying to control and shape our future at least where possible. Look, in this country we are forced to live under constant risk and fear for our loved ones: we have no choice about sending our kids to the military or letting them drive cars, terror attacks strike randomly at anyone, and young people get killed or maimed all the time. You cannot prevent many diseases like cancer in later life . . . in brief so much of what happens is beyond your control. Now, when you can try to prevent at least some of the life-threatening outcomes in your offspring – how can you forego this opportunity? At least you've done all that is humanly possible and won't blame yourself if there is a problem with the baby . . .

Hagit provides an excellent nexus between the macro-level socio-political context and private choices made by Israeli women. The tensions and fears

ambient in the everyday life of most Israelis shadowed by an on-going military conflict with Palestinians make women feel helpless and unable to protect their children (and other close ones) from danger (this theme has also emerged in women's narratives on reproduction cited by Sered in her 2000 book). The ambient danger fortifies women's drive to exhaust all possible means to gain at least some control of the future wellbeing of their unborn children.

Peer and family pressure

As most previous quotes show, peer groups are an important source of normative pressure to undergo elective testing. Partner, parents and other family members also often persuaded women to get tested 'just for the peace of mind'. Limor (24, student, Ashkenazi) recounted in a similar vein:

When I first heard about these new genetic tests I did not intend to do them as none of my relatives had genetic diseases. But then I mentioned this to my husband, and he spoke with his parents – and at the next family gathering they tried to convince me to have these tests, just for the peace of mind. They even offered to pay for them . . . So I decided – why be obstinate? It is after all just another blood test.

Thus, the decision to get tested becomes a family matter; parents and other relatives seem to have personal stakes in checking the 'genetic quality' of a future mother, with the ensuing ramifications for the whole family. Thus, 'medicalization of kinship' (Finkler 2000) finds its vivid expression here, augmented by the strong familism of Israeli society and the role of kin networks in childrearing and mutual support.

Good motherhood

Good motherhood is another concept that finds its way into women's accounts of prenatal testing. Motherhood begins in utero – women assume full responsibility for the outcome of their pregnancy and wish to live up to the role of an enlightened and caring mother as early in a pregnancy as possible. Many women emphasised that their self-image as prospective mothers would be damaged if they did not act in a 'responsible way.' This responsibility meant first and foremost preventing the suffering and misery that a child's disability inevitably entails, according to most informants' belief. In the words of Miri (28, nurse, mixed ethnicity):

Look, if anything is wrong with my baby, I will never stop blaming myself for not doing these tests, all that are available at the moment. It is so hard to raise a child with disability; I am not prepared for that. Our society is rather cruel towards deformed or just different kids and not really supportive of their parents, the welfare system has dwindled lately . . . If the test results are bad, I will terminate this pregnancy. So my credo is – I'd rather be safe than sorry.

In Miri's quote, several motives intersect: fear of having a sick child, mistrust in public aid, the wish to avoid future self-blame and live up to the standard of responsible motherhood. Responding to the wave of ambient genetic anxiety, some women had concerns arising even before pregnancy and saw it as their 'duty before their future children and the family' to clarify whether they carried potentially 'bad genes' in order to screen out problematic pregnancies. Anat (28, computer analyst, Ashkenazi) said:

I think it's a good idea to know what your genes may potentially contain. If I know I am negative on all these tests then I will not concern myself with my partner's genetic makeup. But if I am positive on some mutation (G-d forbid) then my partner will need to be tested too and then we'll decide how to act . . . I think this new possibility offered by genetic science is very positive, it gives parents control over their future destiny . . . I think it is in the best public interest to reduce the amount of disability in society, given how much of our scant resources goes into special education, medical treatments and residential care.

Departing from her personal fears, Anat is concerned with some general social issues around disability and new genetics, in fact endorsing the medicalisation of kinship and eugenic rationale for screening out the unfit. Like most preceding quotes, Anat's words bring us back to the key incentive for genetic screening – the fear of having to raise a sick or retarded child.

'I cannot raise a disabled child'

The theme of the difficulties of raising a disabled child, exemplified by Miri and Anat, surfaced time and again in most narratives, pointing to low acceptance of disability and the lack of will to raise a child with medical or mental problems, even mild ones. Often this stance was expressed indirectly or tacitly as all women realised that blatant intolerance of disability and 'defectiveness' is indecent and beyond shared social conventions. Noa (23, officer in the army, Ashkenazi) said:

My neighbour has a disabled kid whom she still takes around in a carriage at the age of five or six. She cannot work or study, they live on her husband's small salary and some miserable allowance from Social Security . . . It is so hard to see their suffering. I don't think I could cope with such a bleak life. When I imagine this child, I rush to do all pregnancy tests possible to ensure this doesn't happen to me . . .

Rita (26, hair stylist, Mizrahi) offered the following, along similar lines:

Yes, I want a perfect baby, healthy and happy as in the movies. Why not? I am not going to have 10 kids but only two, three at most. Each one will be precious. If science can help me to find trouble before birth I'd rather

not take the risk and have this pregnancy interrupted. We can try again later . . . Abortion is painful but a sick child is much worse.

Rita is indirectly referring to the ethno-religious and generational split in fertility levels, saying that she will have a small number of 'quality' children, who will not grow up in a crowded household (like her own Moroccan mother and maybe herself) and get all the attention and resources they need. Her quote also resonates with the motif of reproductive consumerism – the sense of entitlement to a genetically pure offspring destined for a great life. Hadass (25, medical student, Ashkenazi) expressed the same motif in a stronger way: 'I am kind of a superwoman who can achieve it all – a career, a good husband, popularity with friends . . . and I don't see why not take the same active attitude in childbearing. I cannot comply with just any destiny and raise a sick or retarded child. It's a must to screen out all possible problems'. This informant, again, ties together the themes of agency, securing a successful future and rejection of unfitness in children that may severely damage all her glorious lifestyle as a superwoman.

Several informants (all of Mizrahi origin) said that their husbands were less enthusiastic about genetic tests because they did not understand their usefulness or were angry about the costs to cover. Two women said that they had borrowed money and been tested without informing their husbands. These women made a point that the major burden of care for a sick child falls on mothers, so it is in their best interests to avoid this trouble. Mazal (35, social worker, Mizrahi) said:

Men are not as intimidated by having a disabled child as women are. It's not that they don't care, of course they do, but let's face it: most of hands-on care for such a child will be on me. I also have two other children to think of: it will be hard on them to have a retarded or sick sibling and I won't be able to give them that much time . . . I can maybe count on my sister's or my mum's help, but not so much on him – he is out there running his business all day long.

Some women expressed their reservations about the expanding practice of genetic testing, but still chose to do the tests. Maya (27, pharmacist, Ashkenazi) summarised current pregnancy experience under the shadow of constant medical supervision:

Throughout nine months of pregnancy all you do is get appointments for the tests, then get tested, and then await the results. It keeps you preoccupied with things that may go wrong and kind of creates a negative bias. Pregnancy should be pleasurable and relaxed, and medical counselling often spoils this experience. My mother's generation had a nurse check their weight gain and fetal heart rate, and that had seemed perfectly enough . . . now there is no limit, they add new tests all the time.

Maya cogently taps on the essential aspects of the increasing medical control of pregnancy and questions the actual benefits women gain from medical interventions, but she is unable to take her protest one step further and to refuse elective screening altogether.

In sum, most informants gave multiple reasons for choosing genetic screening, but an overarching motif in most accounts was the inherent fear of disability and misery for one's child and the intimidating prospect of facing the burden of care for that child alone, virtually unsupported by larger society. The apprehension at the potential disruption of all major aspects of everyday life with the arrival of a disabled child was especially prominent among upwardly mobile women with established or just-started careers. The existence of supportive husbands and extended families did not alleviate this fear; on the contrary, parents and other relatives were often the agents of pressure to get tested. On a more immediate level, the forces that propelled women in this study to seek prenatal diagnosis included physician's advice and peer pressure, as well as the incipient genetic anxiety inflated by the media and medical professionals. Preventing disability was perceived as an indispensable part of good motherhood, an expression of responsibility towards one's own future, existing children and other family, as well as society at large. In either explicit or tacit ways, several women expressed their sense of entitlement to perfect motherhood as an attainable asset as a result of new genetic technologies. Although a few women in this group have questioned excessive medical interventions in normal pregnancies, none conveyed reservations as to the moral acceptability of elective prenatal screening and the range of potential defects that may justify termination of a new life.

Whatever next? The meaning of test results

In limbo: awaiting the results

Women who had had a full set of genetic tests were interviewed for the second time shortly after receiving their test results in order to elicit their reactions to the genetic information given to them by the medical establishment. At the beginning of the second interview, most informants told us about the tension and anxiety they had been through while awaiting their test results, largely as a result of their poor understanding of these tests. While waiting to give a blood sample, these women had read leaflets about CF, Fragile X and other tests included in the set. All these materials (a sample is given in Appendix 1) were written in the complex language of medical genetics, describing mutations, and citing probabilities of clinical expression of mutations in the carriers. Many women said that they gave up reading in the middle feeling dizzy and intimidated: 'Who do they think I am – an MD or a scientist? I don't know every other word in this flyer; what's the point in reading it? It only gets scarier . . . I'd rather give the blood and be done with it as soon as possible. I'll ask the questions later on, if something turns up' (Liora, 22, student).

Women who sought further explanation from the clinic's personnel were usually told that in the case of a positive finding they would get genetic counselling, and that otherwise there was no reason to worry. Some women were rather annoyed by this attitude: 'This is their favourite answer – not to worry. If we didn't have to worry about our babies, what the hell are we doing in this clinic? Either don't send the women for the tests or explain what they are all about . . . This approach is so patronising!' (Tamar, 27, computing). Some women believed that the stress they experienced because of this testing was excessive and redundant and had second thoughts about their decision. Ilana (28, medical clerk) thus described her feelings:

Rationally I knew that everything should be normal, but I still lost my sleep for these three weeks. Especially after I called for the result and the clerk told me that there was some kind of doubt about my test and they had to run it again. It took almost another week for them to have it ready and let me know it was all right. I was sick with worry for all this time and afraid of miscarriage . . . With hindsight, this test was a waste of my energy, money and emotions. I don't think I'll do it again with my future pregnancies. I'd rather accept any baby than comes out of my womb.

In both clinics, the only staff members to whom such women could turn for explanations were receptionists, who over time had learnt how to answer some typical queries about test outcomes. While most women were not curious about the details when the result was negative, some were rather offended by the lack of access to more expert knowledge and said that they had a right to know about their genetic makeup even when it was not deemed 'problematic', especially given that they had paid a direct fee for this service. 'They could at least have handed us some kind of a written answer, with an explanation or a simplified genetic map so that we learn something new about our bodies' (Liat, 24, arts student). Thus, on top of the protracted and troubled wait for results, women were not treated as informed clients deserving of an explanation, so this encounter with new genetics was rather uninformative and unpleasant for many of them.

Interpreting genetic information

Three women tested positive or borderline for one or more of the genetic mutations included in the test kit and were invited for counselling. Although they comprise a small minority in this study, their experience of digesting complex and inconclusive genetic information (covered in more detail in other studies, for example, Tercyak *et al.* 2001) merits some brief consideration. All the three women were dissatisfied with the counsellor's neutral and non-directive attitude, which they interpreted as avoiding responsibility or sheer incompetence. The above-cited Miri (28) recalled:

I wish the counsellor would be more concrete and specific about the meaning of all these percentage values and probabilities. 'If your husband

also has this mutation, then the probability of its expression in your offspring is 25 per cent' – so what? What am I supposed to do about it? Is this condition [Gaucher's Disease] treatable? How severe would be the symptoms? We had an impression that this counsellor was trying to avoid direct answers, saying things like 'it depends on many factors', or 'there is not enough scientific data on this' . . . If you don't really know how to use this information, then why seek it at all?

Gila (29, social worker) offered a similar comment:

The counsellor's task is to help us arrive at the right decision, not just explain to us statistical patterns of genetic disease. These issues are so complex and we don't have any relevant education about the genes and inherited disease, so how can we decide what to do all alone? Maybe there is nothing we can do but terminate this pregnancy . . . but is this disease bad enough? And what if it doesn't have a clinical expression after all?

For all women with positive test results testing of the husband was needed, and in one case of his sibling as well, in order to achieve more definite results. Miri, whose brother-in-law had to be tested, was rather upset about the need to share her genetic problem with the extended family and to involve relatives in the couple's reproductive decisions. The negative implications of the medicalisation of kinship came out strongly in her account: 'This information is very private. Now I need to share it with my in-laws who are not so friendly to begin with, and furthermore – to ask them to be tested as well. They will always see me as a genetic liability for the family in the future, no matter what happens with this pregnancy. I really don't know how to act now'.

All three women who had tested positive for rare genetic disorders struggled with the question: What is considered a serious abnormality justifying termination? Ahuva tested borderline for Fragile X, Gila borderline-positive for Gaucher's, and Miri borderline positive for Bloom's mutation (for Gila and Miri the interpretation of results was dependent upon testing of their male partners and their next-of-kin). While Fragile-X typically causes mental retardation in a varying degree, Gaucher's and Bloom's syndromes have a relatively mild expression, and their symptoms are treatable. All three women were in their mid to late twenties and pregnant with their first baby, so theoretically they had some future reproductive opportunity and could decide to terminate their current pregnancy. Another option was to carry this 'tentative pregnancy' till 17 weeks, and then have amniocentesis. But having to terminate an advanced pregnancy is definitely harder than ending one that has just started. All the women had learned from genetic counsellors that they and their partners could transfer the same mutation to their future fetuses as well.

Thus, these women could not escape major decisions about having children at all, having them with the current male partner, and defining their personal

red line between acceptable and unacceptable abnormality? 'Given all this uncertainty, I regret that I went for this testing at all. It would be much easier just to proceed with the pregnancy not seeking genetic information, and accept the outcome, whatever it is. Sometimes it's better not to know in advance' (Miri). As we see, Miri's initial enthusiasm about prenatal diagnosis turned into doubt and criticism in the aftermath of her positive (but still ambiguous) test outcome. Ahuva spoke along the same lines:

It wasn't easy for us to get pregnant, we have been waiting for over three years . . . Now we face this dilemma: to take the risk of having a retarded child, try again later or remain childless? I realise that nobody can decide for us, but it's so hard to decide! And what if this 'borderline probability' is never expressed after all, and we would have destroyed our baby for nothing? The only thing I know is that right now it's a nightmare for us . . . In fact I wish I had not had this test at all, this so-called genetic knowledge may be so destructive.

Ahuva's last emotional comment resonates with the often-discussed bioethical question about *the right not to know* in the light of multiple disruptions in personal and family life that advance knowledge of an impending disease can introduce. This is especially true of reproductive genetics with its built-in uncertainties and probability-based conclusions (Conrad 1999, Bennett 2001, Ettore 2002).

In sum, most women experienced anxiety while awaiting test results, and, even though most results were negative, some women felt frustrated, being unable to make sense of the procedures they underwent and to get clear answers about their genetic makeup from the medical professionals. Women who received borderline or positive results were in the most confusing position, grappling with uncertainty and the need to involve others in their difficult reproductive decisions. Carrying 'tentative babies' until the final 'clearance' is a harsh experience for all women, and some informants had second thoughts about genetic knowledge and its alleged benefits.

Women who said no to elective testing

I will turn next to the attitudes of 23 informants who had limited their prenatal follow-up to the established medical tests covered by basic insurance. All these women had heard about elective genetic tests from their medical providers, the media or friends, so that their decision did not reflect a lack of information. Table 1 indicates that, compared with testers, non-testers were more often of lower socio-economic status, more religious, of non-European origin, and already had children (usually more than one). These personal features had a clear bearing on the stated reasons for avoiding elective genetic tests. The main reasons for rejection fell into several

themes: moral/religious objections to abortion, financial limitations, dissent from the medicalisation of pregnancy and eugenic practice, and/or doubt as to the utility of these tests. Let me comment briefly on each reason and illustrate them with interview highlights, noting again that women often stated more than one reason for their decision.

Moral and/or religious objections to abortion and prenatal selection

Although only six women out of 23 defined themselves as religious or Ultra-Orthodox, 40 per cent were observant of the Judaic religious norms to some extent (that is, belonged to the broad category called in Israel 'traditional'). Informants who identified with religious moral and behavioural norms usually asserted that they were not prepared to abort their pregnancies in case of genetic abnormalities, making prenatal testing pointless. Rina (25, receptionist, Mizrahi, second child) asserted: 'I grew up in a culture where abortion is not an option no matter what. Every marital pregnancy must be carried to term and every child is welcomed to the Jewish family'. Many women in this group believed that the selection of fit babies and discarding of the 'defective' ones was as immoral before birth as after it; every fetus has a right to live and humans cannot interfere with the superior will in these matters. Sarah (31, homemaker, Ashkenazi, third child) put it like this: 'Even if my future baby has some kind of deformity or illness I'll accept it and raise it with love. I am only human and cannot decide whether it is better for it to be born and live or to die in the womb. These matters are in the hands of Divinity'.

Moral objections to prenatal screening, linking this practice to eugenics and the social status of disabled persons, were also voiced by some non-religious women. Linda (29, chemical researcher, Ashkenazi, second child) said:

I think that this new fashion to check the genetic material before birth against every known defect is de-facto reintroducing 'selection of the fittest' and the 'improvement of the race' in the sense that Nazis used in the 1930s and 1940s. The official backing-up of this practice is about sparing children and families suffering, but I don't see much of a difference. I guess the main tacit goal is to save public money that goes into medical and welfare services for the disabled.

Talia (26, teacher, Ashkenazi, first child) expressed similar news:

Who can decide that living with Down's syndrome or some genetic disorder is necessarily bad? If it was not for the isolating attitude of our society towards such people, they could be perfectly happy, and maybe some of them are in their hearts . . . It is certainly hard to raise such a different child, and s/he may grow as an outcast among 'normal' children . . . , but still no one can define that his or her life is not worth living at all.

Alma (28, second child, secular, mixed ethnicity, lawyer) said: 'I think the right investment is not to check every prospective mother for defective genes and abort the unfit fetuses, but develop social services for the children with special needs and alter social attitudes to allow their greater inclusion in society'.

Thus, most religious non-testers and some secular ones (usually educated and professional) disapproved in principle of genetic screening, albeit for different reasons. While religious women were deterred by the excessive interference with the natural or Divinely-regulated processes of reproduction and deemed abortion unacceptable, the criticism of this practice from the liberal secular perspective stemmed from the rejection of eugenics and, further, the social exclusion of disabled children and adults. Secular women also criticised the hidden social-policy agenda underlying prenatal diagnosis.

Financial limitations and perceived lack of utility

High costs as a barrier to testing were mentioned by two-thirds of the non-testers, usually alongside other reasons including disapproval of prenatal selection. Over half of these women were employed part time or unemployed and had, on average, larger families than the testers (Table 1). Thus, Ruti (29, third pregnancy, Ashkenazi, nursery school teacher) offered her general reflections about the futility of prenatal screening in view of the unpredictable outcomes of parenting:

All these optional tests recommended by private doctors are a luxury for women with lots of spare time and money. They shop around for perfect babies as they shop for perfect homes, dresses and cars. And you know what? It may all be an illusion in the end, because there is no such thing as a perfect baby. Even if it is healthy and has all the right genes only G-d knows what might grow out of it. Criminals and maniacs also come from good homes, as we know . . . So in a sense all this frantic activity is about chasing illusions and wasting money. I'd rather buy some new toys for my living children or send them to a music class instead of digging into the genes of the unborn one.

Tali (24, student, mixed ethnicity, first child) said: 'I am not sure I'd do these tests even if they were free, because I am the sort of person who prefers not to know bad news in advance. But I am surely not going to pay half of my monthly wage for these blood tests. I don't even know what these results would mean . . .?'

Some other women said that they would go for elective testing if it was included in the services basket or at least subsidised. Dana (23, part-time legal clerk, first child) said 'I know that two of my pregnant friends have done genetic tests at the . . . hospital. I wanted to follow in their steps, but when I heard how much it would cost, I gave up. It is really an extra, and you can also have a healthy baby without going that far . . .' Some women suggested that it was unfair of the healthcare system not to fund these tests

if they were deemed important. 'If these tests have been proved useful, they should be offered to everyone for free, and if they are just experimental – then women should not be brainwashed to participate in this experiment and also pay for it out-of-pocket' (Ruti).

Some other women expressed more general social and economic concerns: 'It is silly to save maybe thousands of shekels needed to cover the costs of genetic tests and then to face much heavier expenses to provide for the disabled children in boarding schools, special education programmes, etc. As usual, our state has no broad economic vision and does not invest in prevention' (Dina, 28, nurse). Thus, some women were rather dubious as to the value and inherent risks of elective screening in pregnancy to begin with, but price was the final argument that deterred them from these procedures.

Expectations of the available social support

Some women, usually more religious, less educated, living in a small town and/or of Mizrahi origin (these characteristics are often interlinked), said that they had full confidence in receiving help in case of having a sick child. The most cited source of support was the immediate or extended family where any child, sick or healthy, belongs. Limor, 24, Mizrahi sales clerk, said: 'Of course I am scared at the idea of having a child with Down's syndrome or any other major defect, but on the other hand, it is not the end of the world. I will not have to struggle alone, my family will surely give me a hand. My mother doesn't work, and she is still young, she will shoulder part of the burden with me. Then one of my older sisters has no family of her own, she would also help in case of need. A sick child is a family problem in our community, not just mother's'.

Another woman from a small northern town said she believed in the help of her neighbours and friends from their local community: 'My neighbours on the block are also my friends, we are used to giving a hand to each other in difficult times. When both my husband and I were unemployed a few years ago, people here collected money, cooked food for us, brought clothes for my son . . . I am sure if something really bad happens I will not be left alone' (Shira, 28, religious, mixed ethnicity, second pregnancy).

A few other interviewees expressed their belief in the helping role of the welfare agencies in raising a disabled child. Mira, a 30-year-old daycare worker, commented: 'Of course, our *revaha* [social security] has dwindled in the past years, but it is still present. And don't forget that we have free healthcare with good pediatric services. With a disabled child you get access to various special facilities – physiotherapy, respite services, schools for children with special needs, etc. If it comes to the worst and you cannot cope any more, you can place your child in a special institution . . . this is very sad of course, but life goes on even in these places'.

As opposed to the less educated and Mizrahi women, endowed with significant resources of family and community support, middle class secular Ashkenazi women who rejected prenatal testing more often expected help (if

any) to come from their male partners, and sometimes from best friends. Dalia, 27, history postgraduate student, said: 'However unlikely this is, I am rather scared at the prospect of raising a sick child. My next-of-kin are all very busy – my husband is an international lawyer and he travels a lot, my parents are both young and working long hours. If this happens, G-d forbid, I will have to take care of the child pretty much by myself. I'll have to quit my research and dissertation perhaps . . . No, I must not even think in this way, everything should be fine'. Middle and upper class women were also less certain of any assistance they might get from the health and welfare agencies: 'I have heard that in Western Europe parents of disabled children get a lot of help from the state – special pensions, medical services, good education facilities for handicapped children . . . Here in Israel all this exists in theory, but you have to fight the bureaucracy tooth and nail to get any financial or medical aid you are entitled to. Unless you are very well off and can buy all these services privately. At the end of the day, the mother is the main carer of a sick child . . .' (Carmela, 33, high-school teacher).

Thus, most women who decided to forego genetic testing counted on some sources of support in case of having a child with a disability. While lower class Mizrahi and religious women expected to get support from the extended family and their residential or religious community, middle class Ashkenazi women (usually secular) expected limited help from their husbands and friends, and rarely from their parents. The two categories of women also differed in their trust in the formal support system run by social security. The less educated women were appreciative of any public support they could get, however limited, while more educated ones compared the Israeli services for disabled children and their parents with better versions abroad. Thus, in a way, lower class Mizrahi women perceived their potential support networks as more extensive and accessible than their upper class Ashkenazi counterparts.

Resistance to the medical control of pregnancy

Resistance to the medical control of pregnancy and rationale for refusing pre-natal diagnosis was voiced by a minority of women (six out of 23), all of whom were Ashkenazi or of mixed ethnicity, college educated. They also expressed some feminist ideas in other parts of the interview. These women believed that the ever-growing medicalisation of pregnancy is against the true interests of women and children, and that the main beneficiaries of the expansion of the 'genetic testing race' were doctors and the biomedical industry.

Nobody is against prenatal care in general, but in Israel they just go way overboard with it. Doctors control every breath of pregnant women and push on them more tests and procedures every year, some of purely experimental nature. Is our pregnancy experience any better due to permanent contact with the labs and doctors? Are our babies born any

healthier than before? I don't think so, at least nobody has proved it (Lina, 30, first pregnancy, psychologist).

Of course doctors would advise us to have more tests because they share in the revenues of this industry. They also want to avoid suing in case of a 'missed' congenital problem, so the more tests the better as far as they are concerned. I don't think they always have the best interests of the women at heart (Alma, 28, second child, lawyer).

One of these women was an example of a critical and informed patient, ready to challenge doctors and make independent decisions: 'Most women I know have unlimited faith in their doctors and always do what they are told. As I've been chronically ill for many years and met many doctors on my way, I know better than that. When they suggest some test or procedure, I go check it myself in the medical lit, on the internet, etc. Only if I find enough external proof of its value, I'll go for it' (Carmit, 28, first pregnancy, graduate student). All these women were supportive of the incipient natural child-bearing movement, viewing pregnancy as a natural and potentially enjoyable part of women's lifecycle. As Gali (27, first child, architect) cogently remarked:

I don't want to be defined as 'at risk' and a patient just because I am pregnant. If I am healthy and had no genetic problems in my family, I don't see any reason for rushing to the clinics and labs every two weeks. It's much more important to lead a healthy life, not to gain much weight, not to smoke – these simple wisdoms are still the bedrock of healthy pregnancy (and more difficult to stick to!). Doctors and tests only stress you out, and this is the worst thing that can happen to a woman carrying a baby. Positive emotions are essential, and the rest is bullshit.

Some non-testers turned to traditional women's wisdom on how to behave in pregnancy as the bottom line for their choices. Liora (27, second child, cook, Mizrahi) said:

Look at our mothers' generation. They had much harder lives than we have, fewer good things to eat, lived in cramped apartments . . . and still they took their pregnancies easy, carried on with their life routine. And so what? We were born healthy and grew up normal people without all these medical tests and doctoral visits. I think this obsession with prenatal tests is sheer excess, and nothing good will come of it.

Most secular non-testers faced social disapproval of their decision expressed in open and tacit ways by their social networks. Israeli everyday culture is very informal and the boundaries between public and private are often trespassed, especially in women's talk (Remennick 2000), so it is difficult for these women to avoid discussing their reproductive decisions with colleagues, relatives and

other women. Margalit (30, first pregnancy, primary-school teacher, mixed ethnicity) shared her frustration about people's curiosity and judgmental attitudes:

It's very hard to keep your business to yourself among the women; every now and then my colleagues at school would ask me about how my pregnancy was going, if I had various tests done, what my doctor said, etc. When I told one of them that I don't intend to have the new genetic tests, she got upset and started telling me that I am wrong and would regret it for the rest of my life . . . After that, other teachers too told me horror stories about some relatives or neighbours whose children were born with sick hearts or lacked a limb . . . In brief, every colleague of mine took issue with my prenatal care and tried to convince me to have the tests, and later on – the amniocentesis . . . When I still did not yield, they gave up of course, but from that time on they treated me differently, as a rebel or a half-wit . . . something has changed in their attitude.

Other women told similar stories about their co-workers, friends and relatives, who often assumed that foregoing the tests was a merely financial issue and offered to help out. When the women criticised prenatal screening as such, they were labelled as irresponsible or not caring enough about their future babies (this happened more often to educated women who rejected excessive medical interventions).

In sum, these narratives illuminate a range of reasons for the women's decision to abstain from elective testing, ranging from conscientious objection to abortion and/or prenatal selection of the fittest, to financial barriers, to dissent concerning the growing medical control of women's bodies and reproduction. The explanations put forward by these non-tested women included their personal life philosophy but also, in some cases, different social placement, that is, tendency to lower income and social status; the need to tend to existing children's needs first; their husbands' objection to the 'wasteful expense'; and other features of their daily lives. In many cases the dissidents rejecting the new cult of reproductive genetics faced negative stereotyping as 'irresponsible mothers' but were still sticking to their decision to avoid the tests. Their ability to undermine this emerging social norm reflected a host of possible variables, including the reliance on the extended family for support and hands-on help in case of having a disabled child, lesser importance of career and other individual pursuits, greater trust in the Israeli health and welfare system for formal support, or a more relaxed and natural attitude towards the body, pregnancy and health.

Discussion and conclusion

This study is one of the first attempts to understand the social mechanisms underlying the rapid expansion of prenatal screening beyond traditional genetic risk groups, explored from the women's own perspective. Israeli society is an ideal 'laboratory' for the study of social implications of genetic technologies

because of the central place of reproduction on the public agenda (Amir and Benjamin 1997, Berkowitz 1997), its unchallenged medicalisation (Remennick 2000, Haelyon 2004) and high genetic awareness of the Ashkenazi Jewry (Zlotogora and Leventhal 2000). Few medical systems offer comprehensive genetic screening to women with low-risk pregnancies and no family history of genetic disease. The emphasis on the quality of offspring and prenatal exclusion of abnormal children, termed 'backdoor eugenics' by some authors (Duster 1990) and 'genetic consumerism' by others (Henn 2000), has multiple expressions among secular Israelis. Responding to this social demand and further reinforcing it, the Israeli medical system is happy to offer prenatal testing at the cutting edge of modern biomedical science, reaping fat revenues on the way.

Perhaps the root of the mass acceptance of prenatal diagnosis in Israel is an inherent deep intolerance of physical and mental disability and the ensuing fear of having a sick or deformed child. In this respect, women's narratives in this study support the findings of Meira Weiss (1994) who observed that parents of appearance-impaired children found it difficult to bond with their 'defective' offspring and love them on a par with their 'normal' peers. It seems from some women's narratives in this study that their love for future children is also conditional on their health, physical perfection and achievements. Within this understanding of parenthood, the pregnancy and the fetus itself remain 'tentative' until fully screened for all known defects and proved 'normal'. On a more general level, the mechanism propelling prenatal screening reflects not only pan-consumerism, but also the emerging middle class ideology of full control of one's life-course and environment. Embracing the realm of reproduction, this aspiration gradually turns babies into custom-designed products (Kofafer and Landau 1997). However, as uncertainty is inherent in reproduction and parenting, these goals are hardly feasible, turning the race for perfect offspring into a frustrating and futile endeavour. Many of the women's narratives in this study add more evidence to this view.

Women's stories shed new light on the reasons for the growing compliance with the emerging 'genetic imperative', discussed by Press and Browner (1997). These researchers have shown that strong institutional or provider support was the major predictor of acceptance of prenatal diagnostic screening by American women. As certain tests become routine, women's critical stance and ethical doubts begin to wane. Similar conclusions were drawn by Bernhardt *et al.* (1998) in their study of interactions between women and their obstetricians. In our study, providers of prenatal services were the major force behind the routinisation of prenatal genetic diagnosis, referring women to all possible tests, regardless of actual need, as an insurance policy against post-natal malpractice suits. An additional benefit is in the increasing population basis of genetic research. As most Israeli women have already surrendered to the medical control of pregnancy (Remennick 2000), adding more procedures and tests to the existing menu is perceived as an advancement bringing them closer to the perfect baby. Social construction of the Ashkenazi genetic pool as especially prone to inherited disorders boosts 'genetic anxiety'

among Ashkenazi and mixed couples, and sustains a steady flow of clients for genetic clinics. The uncritical acceptance of prenatal diagnosis is especially remarkable given that most women in this study (as well as in the population-based survey by Sher *et al.* 2003) admitted to their poor understanding of even the basics of medical genetics and the elective tests they took. It seems that the Israeli public is ready to accept eugenic applications of new genetics as long as it remains uneducated and uninvolved in its public policy aspects. Judging from the survey data, the public in the US and other Western countries seem to be more critical about prenatal screening (Lock 1998, Singer *et al.* 1999, Markens, Browner and Press 1999, Tercyak *et al.* 2001).

The study has confirmed our assumption about the emerging new norms of 'good motherhood' that include 'genetic responsibility' before future offspring and other family members (resonating with Finkler's 'medicalization of kinship'). However, 'good motherhood' in our data did not carry the explicit ethno-national overtones discussed by some other researchers of gender and reproduction in Israel (Yuval Davis 1997, Berkowitz 1997). I explain this by the nature of the research questions tapping the qualitative aspects of parenthood (via prenatal diagnosis and elimination of pathology) rather than fertility, birth control and family size – which indeed remain a politically-charged issue in the Israeli stratification system (Portugese 1998). The interviews tried to elucidate women's attitudes towards genetic risks and child disability, with the ensuing decision-making about getting tested. Women in this study perceived good motherhood as based on responsibility towards one's own future, their family and personal relationships, rather than the nation and its collective goals. The absence of Zionist or other ethno-national motives in the narratives can also reflect the seminal change of period and generation: most of the studies pointing to perceptions of fertility and motherhood as a patriotic duty were conducted in the early 1990s, while by 2004 young Israelis had become much more individualistic and their behaviour was driven mainly by personal rather than political or public agenda. Ethnic background was reflected in these women's narratives, but its role was definitely smaller than that of religion, education and type of employment (or social class, in other words). As ethnic and socio-economic divisions are closely intertwined in Israeli society, it is hard to isolate the influence of ethnic origin on women's attitudes and decisions. Moreover, many informants were of mixed ethnicity (common in younger Israelis), which has also subdued ethnic overtones. The role of ethnicity came to the fore in higher genetic anxiety among Ashkenazi women, aware of higher rates of certain inherited diseases in their group. At the same time, the limited personal resources of Mizrahi women and their more 'down-to-earth' philosophy of childbearing often helped them resist excessive medicalisation. Reflecting their ethnic traditions, these women's extended families and communities provided a more extensive safety net for any sick child they might have.

The alternative sources of resistance (found mostly among non-testers) were, on the one hand, religious norms rejecting prenatal screening and abortion, and

on the other, liberal anti-eugenic discourse of secular women. Women who did not comply with excessive medical surveillance for various reasons often faced the disapproval of their social network and negative labelling as 'backward' and/or 'irresponsible', especially if they belonged to the middle class where genetic testing was rapidly becoming routine. At this time a socio-economic differential is still apparent in prenatal screening practice in Israel (Sher *et al.* 2003) as in the US (Kupperman 1996, Learman *et al.* 2003), but it will soon narrow as middle class practices become more widespread, and tests become cheaper and specially geared for various ethnic groups. It is plausible that if all elective tests were covered by state health insurance and offered in multiple locations, the numbers of testers would rise dramatically. Israeli women who question prenatal screening and advocate more natural and women-controlled models of childbearing are currently in a minority, and their voice is seldom heard.

Given the rarity of genetic diseases, the actual public health benefits of prenatal screening among low-risk women are questionable (Zlotogora and Leventhal 2000), while the experience of 'tentative pregnancy' is certainly disruptive for many women. The narratives collected in this study strongly suggest that genetic screening procedures significantly aggravated women's pregnancy experience, keeping them on a low-flame of anxiety while awaiting test results and trying to interpret them. These concerns were certainly worsened by borderline or positive results, which opened a Pandora's box of questions about family loyalties, the need to share genetic information and, worst of all, whether to have this baby at all. With hindsight, quite a few women asserted that they would have preferred not to know about their genetic risks, and that testing was a mistake. In this respect, the results of this study endorse the findings from Shavlev's series of interviews with young Israeli mothers (Shavlev 2003) who often said that genetic and other medical tests were the main factor casting a shadow over their overall pregnancy experience. In a similar vein, several studies in the US and Britain that explored popular reactions to the nascent geneticisation of prenatal care (Tercyak *et al.* 2001, Bennett 2001, Ettorre 2002) reported that a significant percentage of the public opts for 'the right not to know'.

To conclude, the current expansion of prenatal testing, boosted by thriving genetic research, needs critical reappraisal by all actors involved in this practice, including gynaecologists, medical geneticists and counsellors, health policy-makers, and – most importantly – pregnant women and the wider public. The Israeli example should compel medical providers and bio-ethicists to re-examine the actual benefits that women and their offspring can glean from comprehensive genetic testing and establish more stringent referral criteria in relation to the risk level. Genetic education of the general public would also help couples make more informed choices while contemplating prenatal diagnosis.

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Notes

- 1 There has been much more genetic research on some ethnic groups (*e.g.* Ashkenazi Jews) than on others (*e.g.* Mizrahi Jews and Arabs), reflecting their differential social status, involvement in the scientific world and other factors. As a result, genetic mutations in the researched groups are well mapped, widely publicised and testing is increasingly offered for the affected groups. Yet, in other ethnic groups, specific mutations may be as common, but they do not receive similar attention from researchers and genetic counsellors. Thus, the boom around so-called Ashkenazi mutations may reflect a selective focus, social construction and other 'soft' factors, besides pure 'genetic facts'.
- 2 Given the different prevalence of some known disorders in various ethnic groups of Jews, many Genetic Centres have designed special testing packages geared for non-Ashkenazi and mixed origin groups (Yemenite, Moroccan and some others). Yet the bulk of women seeking genetic tests are of Ashkenazi origin, reflecting the social construction of Ashkenazi genetic makeup as rife with risks (Gak 2001).

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Appendix

Information flyer on genetic screening for carrier status of cystic fibrosis (CF) (translated from Hebrew by the author)

This flyer (along with others) is handed out to women who register for a set of prenatal genetic tests at one of the large Genetic Institutes in Central Israel.

CF is a serious inherited illness, which is relatively common (about 1:3,600 children suffer from it). Clinical expressions of CF include recurrent pneumonia, digestive symptoms reflecting poor absorption of food in the intestines caused by pancreatic dysfunction, and high salt content in sweat causing skin irritations. The prevalence of CF is similar in both sexes. This disease is caused by genetic mutation and is passed in autosomal recessive fashion, *i.e.* the carrier him/herself is healthy, but his/her cells carry one copy (allele) of a normal gene and one copy of a gene with mutation. In the absence of CF cases in the family, the risk of being a carrier of CF mutation is about 1:30. The chance of having a baby with CF exists only if both parents carry a gene with CF mutation. Such a couple will have a 25 per cent chance of having a baby suffering from CF from every pregnancy they may achieve.

There are multiple possible mutations in the relevant gene, of which most can be identified today. Among Ashkenazi Jews, about 95 per cent of all carriers of one or more of these mutations can be discovered via checking for five most common mutations. Among Jews of other ethnic origin, the chances of identifying carriers are lower and the percentage of mistakes is higher.

At the first stage, only one parent has to be tested for CF. If s/he does not carry one of the common CF mutations, the chances of having a baby with CF are very low (among Ashkenazi Jews – less than 1:50,000). If one parent is found to be a carrier of CF mutation/s, then the other parent must be tested. If both parents have one or more known CF mutation, they should seek genetic counselling. At 10 weeks of pregnancy the mother can take a CVS test in order to know if the fetus is a carrier of CF; alternatively she can have amniocentesis at 17 weeks for prenatal diagnosis of CF. These tests allow verification of the presence or absence of CF mutations in the offspring, and parents can make a decision about continuing or terminating the pregnancy.

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