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## On knowing and believing: Prenatal genetic screening and resistance to 'risk-medicine'

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This paper presents the concept of 'risk-medicine' through the analysis of the rejection of prenatal screening among ultra Orthodox Jews in Israel. The foundations of this phenomenon are examined, defining 'risk' as a major socio-cultural feature of late modern Western society. The authors describe eight possible components of resistance to biomedicine, some being specifically applicable to risk-medicine: cultural discrepancy, lack of information, religious prohibitions, risk-aversion, incompatible health and illness cosmologies, fear and mistrust, governmental control, and irreconcilable epistemological differences. The analysis identifies two fundamental dimensions associated with risk-medicine: its epistemological basis, and the governmental surveillance that it involves. While the former stems from diverging conceptions on the values of different forms of 'gnosis' (probabilities vs. certainty) the latter draws upon the relationship between the state and risk-medicine, portraying ultra Orthodox women's rejection of prenatal screening as a form of resistance to nationalist, secular forces. The paper advances new concepts (namely 'risk-medicine' and 'gnosis' as related to 'pro-gnosis' and 'dia-gnosis') that may constitute a ground for further research on forms of medical epistemologies and practices and their related forms of resistance, namely in the context of religious and ideological incompatibilities.

**Keywords:** risk; risk-medicine; screening; genetic screening; ultra Orthodox Jews

### Introduction

Elaborate prenatal screening tests have been recently introduced in many countries and are gradual joining the routine elements of a medicalised pregnancy (Nicolaidis *et al.* 1992, 1998, Wald *et al.* 1994, Wald and Hackshaw 1997, Nicolaidis 2005). These new procedures provide, with high predictability and relative simplicity, early information on the likelihood of chromosomal abnormalities in the unborn. In Israel, while widely accepted both within the medical establishment and among the lay public, this particular group of tests tends to be shunned by Jewish ultra Orthodox women (Chemke and Zlotogora 1997, Zlotogora 2002, Sher *et al.* 2003, Remennick 2006). For example, in 2001, almost 90% of non-religious women chose to perform screening tests, in contrast to a little above 10% of ultra Orthodox women (e.g. Haknesset 2003, Sher *et al.* 2003). Other types of testing procedures, such as foetal body screens and ultrasound check-ups, remain generally acceptable (*Kosher*) by both rabbinic authorities and the ultra Orthodox public.

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Since many ultra Orthodox women are satisfied with ultrasound-based assertions of foetal health, some pathologies (such as heart defects suggesting the presence of chromosomal abnormalities) become apparent only in the course of the elaborate ultrasound tests performed in the second trimester (IMH 2003, Sher *et al.* 2003, Gofin *et al.* 2004). In this case, the woman remains with two options: either going through more invasive and perilous procedures, or maintaining the pregnancy and hoping for the best. Naturally, postponing the examination process to the second trimester is problematical both in terms of the effects of a delayed termination of pregnancy on the woman's health, and its potential moral and religious implications (Lewando-Hundt *et al.* 2001, de Graaf *et al.* 2002, Wapner *et al.* 2002).

Jewish law (*Halacha*), as widely interpreted, prohibits pregnancy terminations unless the foetus is recognised as presenting a risk to its mother's 'well-being' (Bleich 1979, Schenker 2000). As maternal well-being is increasingly regarded as comprising states of mind as well as bodily functions, and as the birth of an unwell child is prone to put considerable strain on the mother's mental health, the categories which permit pregnancy terminations have expanded to include diagnoses of chromosomal abnormalities (such as Down's syndrome) that are foreseeable through early screening tests (Schenker 2000, Aviner 2001, Bornstein 2002). Thus, a religious rejection of artificial terminations of pregnancy does not necessarily account for the definition of tests as *Kosher*. In fact, the *Kosher* tests are equally likely to be suggestive of pregnancy termination as non-*Kosher* tests, again, generally conceived to be forbidden in Jewish religious laws.

Our analysis seeks to understand how, and on what grounds, the benefits of early screening tests are systemically overlooked by the ultra Orthodox public. In an attempt to account for this interesting phenomenon, we shall propose the implication of resistance to a particular form of biomedicine: risk-medicine. This form of medical practice and epistemology will be introduced via the particular case of the ultra Orthodox women's predisposition to reject *risk-based, statistical*, prenatal testing, while embracing other forms of follow-up and diagnosis. This shall be put into a broader delineation of forms of non-compliance to biomedicine, emphasising the distinctiveness and conceptual value of the notion of risk-medicine.

We will here present two fundamental dimensions associated with risk-medicine, both of which are challenged by the ultra Orthodox woman: its scientific epistemological basis, and the secular governmental practices that it involves (Foucault 1984, 1986, Rose 1996, Turner 1997). We shall assert, thus, that the notion of risk-medicine comprises two interlaced components: first, it endorses a particular epistemology (*gnosis*) that is grounded on assessments of *future prospects* as affected by present behaviour patterns. Second, it involves processes of *governmentality* enacted through the utilisation of unique surveillance practices. This will be shown to threaten the ultra Orthodox public's desire to maintain independence as a religious group, responding in a rejection of both the surveillance practices and the underlying secular epistemology of risk-medicine.

### On risk and risk-medicine

Since the 1990s, much has been written on the notion of risk and its role in society and culture (e.g. Giddens 1991, 1998, Beck 1992, 1996, Douglas 1992, O'Malley 1996). This growing body of literature holds one relatively consistent premise: as risk has become increasingly central to discourses of late modernity, a shift of attention occurred, namely from the *actual* to the *potential* (Skolbekken 1995, Scott *et al.* 2005, Alaszewski and Burgess 2007).

In their seminal article on the characteristics of late-modern medicine, Clarke *et al.* (2003) contrast *biomedicalisation* with the earlier process known as *medicalisation*. While *medicalisation* refers to the all-encompassing rendition of social deviance to disease (Zola 1972, Conrad and Schneider 1992), *biomedicalisation* places an emphasis on the *potentially* deviant practices and lifestyles, classifying them as healthy or risky forms of living. The value in the grasping of immediate knowledge known as *dia-gnosis* (or *through-knowing*) is challenged, and is increasingly surpassed by an endeavour to grasp future events, defined as *pro-gnosis* (or *before-knowing*). In defining an individual's present health status based on the evaluation and calculation of probable futures, this favours prognostic data and predictive knowledge over the more classical pair of diagnosis-therapy (Bull 1990, Nelkin 1996, Fox 2000). Thus, risk-medicine, unlike its modern antecedent, fights its battle not only against disease, but also against uncertainty.

From a governmental viewpoint, the cultural embracing of risk has replaced *order* with *vigilance* as the founding values of surveillance practices (Crook 1999, Dean 1999). This has created a unique form of disciplinary power: while risk-medicine provides the individual with a greater level of control over his/her own health, the definition of his/her risk status (whether high or low) remains in the hands of society. Reframing issues in terms of risk involves a shift from explicit coercion to a seemingly personal, deliberate resolution to improve one's health status (Foucault 1979, Dreyfus and Rabinow 1982, Green 1997, Pilnick 2004). This will bring about a particular type of resistance, *albeit* not unrelated to the more generalised phenomenon of resistance to biomedicine.

### Mapping the grounds of resistance

According to our scheme, the first target of resistance is risk-medicine *per se* and includes public health imperatives, such as vaccinations, screening for diseases, prevention of illness through the proliferation of health-related information, and the device of specific guidelines for the attainment and maintenance of better health. A second target is Western medicine in general and involves treatment refusals or abstinence from referring to biomedical healthcare facilities. This distinction is of most importance, as we shall show here: in many cases, the responses to risk-medicine may not coincide with the public's approach to the more general level of biomedicine. In the case presented here, we shall show how crucial is the application of a more refined model of resistance to biomedicine.

Resisting groups are diverse, including ethnic minorities (e.g. the African Americans, or Americans of Mexican origins), spiritual and religious congregations (e.g. certain forms of Christianity), New Age advocates, and peoples of some developing countries (e.g. African tribes or Indian Americans) (Martin 1987, Scott and Martin 1990, Louderback-Wood 2005). The patterns of resistance vary as well, ranging from active protest to peaceful avoidance. Taking these distinctions as demanding a schematic reorganisation of the concepts of resistance to biomedicine, we sought a more profound analytical study of the subject. A thorough examination of the literature on the subject has allowed us to create what we believe to be a helpful typology of the modes of resistance and the grounds upon which it is based.

Our typology includes eight different grounds for resistance, which often combine to create each specific setting of rejection, as it does in our case. These will be referred to as: cultural discrepancy, lack of information, religious prohibitions, risk-aversion, incompatible health and illness cosmologies, fear and mistrust, governmental control, and irreconcilable epistemological differences. The first component, *cultural discrepancy*, typically involves a foreign invasion into well-established, historically-powerful,

traditional methods. The original, more authentic methods are conceived as being more in line with the population's cultural setting, thus leading to a rejection of biomedicine (Streefland *et al.* 1999, Tester and MacNicoll 2006). The intrusion of Western medical norms may also clash with local customs and cause the breaking of taboos (Sivan *et al.* 2004, Tester and MacNicoll 2006). Furthermore, biomedical institutions may be tied up to negative aspects of daily life. For instance, a hospital may be associated with death, illness, and the taking of one's freedom (Tester and MacNicoll 2006). As we shall see in the coming analysis, this aspect is of less prominence (although clearly of some salience) in the case of ultra Orthodox Jews' stance towards risk-medicine. Medical practice has traditional roots in Judaism and is generally viewed as congruent with Jewish *Halacha*.

The second component, *lack of information*, refers to a lack of knowledge or comprehension of the interventions involved, including their risks and potential benefits. This may be grounded the use of medical jargon in interactions with patients, the unavailability of sources of information, or the avoidance of exposure to these sources (Halliday *et al.* 1995, Paravic *et al.* 1999, Browner and Preloran 2000, Browner *et al.* 2003). From a biocentric viewpoint, this is often seen as a central feature of all forms of non-compliance, and resistance is expected to subside if only was the population better informed, or was it more 'rational' (e.g. Hepburn 1988, Davidov *et al.* 1994, Chaabouni *et al.* 2001, Chilaka *et al.* 2001). In the case of the ultra Orthodox community, a lack of knowledge is but a minor component in the refusal to adopt screening tests as routine. Minimal exposure to the lay media may keep the women unaware of new medical technologies; however, this public is, as a rule, well acquainted with the medical establishment and has generally no objection to learning about biomedical techniques that do not involve risk practices.

The third component, *religious prohibition*, relates to medical interventions that are specifically forbidden or frowned-upon by religious authorities, sacred texts, or spiritual leaders. These may include the rejection of blood transfusions by Jehovah's witnesses, certain Christian views on vaccines, or prohibitions of pregnancy-endangering interventions (Zlotogora and Reshef 1998, Ahmed *et al.* 2000, Herrera 2005). In our understanding of ultra Orthodox women's choices relating to prenatal testing, religious imperatives are clearly involved, although not in a straightforward manner. Ultra Orthodox Judaism will affect the propensity to be tested only *via* epistemological and ideological premises.

The fourth component, *risk avoidance*, refers to a more explicit, conscious refusal of biomedical interventions. In these cases, the population is well informed, yet the relative value of the risks suggests a stance of rejection (Markens *et al.* 1999, Moyer *et al.* 1999). The very way in which the risks or benefits are calculated may be challenged: a vaccine may be blamed for causing more serious illness, such as autism or multiple sclerosis (Streefland *et al.* 1999, Streefland 2001). We have not found this to be of significant relevance to our case; screening tests, being based on techniques of ultrasound and blood drawing, being extremely safe.

The fifth component, *incompatible health and illness cosmologies*, holds some commonalities with the definitions of the religious and cultural grounds, but is also distinct enough to be seen as a meaningful category. The biomedical model regards the body as a sum of interrelated parts, in which pathology arises from a particular malfunction. Different socio-cultural groups may hold views of the human body and self that are incongruent with this model. For instance, for some Christian congregations, illness is related to sin: Jesus holds the discretion to cure the inflicted person (Abrums 2000). Accordingly, faith and prayer become effective in the restoration or preservation of health, ultimately depending on Divine will (Baer 1981, Streefland *et al.* 1999, Herrera

2005). New Age advocates often hold alternative assumptions on the body's interaction with *nature*. This may, for example, involve a view on the immune system that is irreconcilable with the concept of vaccination (Streefland *et al.* 1999). In other cases, diseases may simply be seen as natural, inescapable features of life, thus not requiring, nor demanding, human intervention (Bierlich 2000). As shall be described later, some forms of ultra Orthodox Judaism may be interpreted to hold a somewhat different health and illness cosmology than is generally accepted in biomedicine; namely, the involvement of divine intervention.

The sixth component, *fear and mistrust*, is related to a vision of biomedical agents as dishonest and malicious, operating through a systematic deception of the public. The African American community, for example, will draw on an historical case where treatment for syphilis was denied to men of colour in an attempt to study the natural progression of the disease (Gamble 1997 cited Abrams 2000). This case has become constitutive in characterising the medical establishment as discriminative (Schnittker 2004). Another instance is found in the Catholic Church's accusing the World Health Organization (WHO) of distributing tetanus vaccines (known to endanger pregnancies) with the concealed aim of controlling birth rates. Mistrust may also stem from a vision of biomedicine as related to political and economical interests. For instance, the health care system may be said to be ruled by drug conglomerates, and to be reinforcing existing social inequalities (Abrams 2000). This component is of relatively marginal importance in the case at hand, as it does not entail a resistance that is specific to risk-medicine.

The seventh component, *governmental control over private matters*, draws on the right to privacy, free choice, and self-determination (Swartz 1985). State requirements to undergo vaccinations or screening tests may be seen as a breach of this very right, and will thus be at best rejected, and at worst actively disputed (Streefland *et al.* 1999, Durbach 2000). This includes feminist rejections of biomedicine and technology (as seen in homebirth movements), perceived as forms of male dominance (e.g. Bush 2000, Kornelsen 2005, Parry 2006). This also involves ethical and political issues as to the state's mandate over its citizens' health-related decisions (Scott and Martin 1990). Our analysis will seek to link this component to the ultra Orthodox women's resistance to risk-medicine, namely by presenting the latter's governmental facet. The eighth and final component, *irreconcilable epistemological differences*, is, by far, the least studied. As we shall show here, understanding discrepancies as to what constitutes knowledge is much valuable when seeking the fundamental grounds of resistance.

### **The ultra Orthodox and nationalist-religious communities**

Landau (2003) draws on Heilman and Friedman (1991) to position the ultra Orthodox Jews in the contra-acculturation end of the acculturation continuum. This community, comprising roughly 8% of Israel's Jewish population (approximately 560,000) tends to remain secluded in both its cultural and socio-economic practices (Friedlander and Feldman 1993, ICBS 2006). The ultra Orthodox cultivate their otherness as a way of life in a secluded niche in Israel, a state to which they do not feel any ideological belonging (Friedman 1986, El-Or 1997). This segregation is sustained by a reluctance to partake in institutions that define identity around hallmarks of citizenship, i.e. the mandatory military service and the national schooling system. This seclusion, which, in turn, entails a strong inner closeness and exclusivity, reinforces the group's tendency to high consensus and a relatively homogeneous healthcare behaviour (Geertsen *et al.* 1975). As a constituent of a community's lifestyle, health-choices are thus both expressive and

formative of socio-cultural boundaries between the ultra Orthodox and the state (Cockerham 2001, Cockerham *et al.* 1997).

The study of another population will be essential to our analysis, namely the nationalist-religious Jews. This group, comprising about 10% of the Israeli Jewish population, practices a pious, orthodox, form of Judaism, although, as a rule, somewhat more moderately than the ultra Orthodox. The distinction between the two groups is principally founded on one characteristic: while the ultra Orthodox are generally anti-nationalist and tend to be secluded from the general Israeli public, the nationalist-religious take part in all aspects of Israeli citizenship. They have a strong commitment to the state and are very much *acculturated* (Landau 2003, Prainsack 2006).

## Methodology

Our goal was to achieve an in-depth understanding of an evidently broad phenomenon, which demanded, beyond the report of frequencies and variances, a consideration of the social, institutional, and ideological distinctiveness of the ultra Orthodox community as a segregated cultural and religious group. With the aim of grasping some of this complexity, as well as assemble the multiple aspects of prenatal care and genetic screening, we reviewed and qualitatively analysed a range of written sources: authoritative texts on Jewish religious law, articles published in community newspapers and websites, and statistical reports on practices of prenatal testing (Hepburn 1988, Parsons and Atkinson 1993). A theological analysis of Judaism's views on pregnancy was beyond the scope of our research. Religious teachings and laws, as interpreted by different rabbinic authorities, are numerous and often conflicting, their popular conceptions tend to be utilised in ways that are selective and, at times, based on expediency (Goldscheider 1971, Jakobovits 1979). Here, we shall focus on the manners in which informants, placed in strategic positions, have achieved unique interpretations of these laws.

We complemented this study with in-depth interviews of several key informants from the different ends of the dialogue, including four heads of obstetrics departments, three social workers involved in critical locations of our field, two members of religious institutes on pregnancy and childbirth, and a group of three women having had particular pregnancy-related experiences. The list of potential interviewees was gathered through snowball recruitment. Potential interviewees were contacted (in the case of women, only after the referring person has obtained consent to communicate their personal details), and all expressed a willingness to take part in the research.

Although not intended to provide statistically representative data, the participants turned out to be highly informative, and provided rich sources for thick description and interpretation. Much of the material gathered became redundant as the interviewing process advanced and much agreement was found amongst the interviewees in each group. We have therefore chosen to take on a hermeneutic, detailed analysis of a limited number of transcripts, thus gaining a level of interpretation non-otherwise achievable (there is no coding system, since the analysis is more interpretative, hermeneutic than 'grounded theory' oriented, or based on 'content analysis').

The empirical stage of the research began in August 2005, and lasted approximately 6 months. The first author conducted semi-structured interviews lasting 1–1½ hours, typically at the informant's workplace or, in cases where the interviewees were not professionals, i.e. the women, in public spaces. The sessions were recorded and later transcribed verbatim. The transcripts consequently formed the database for analysis and interpretation. The texts were carefully discussed amongst the two authors with insights

continuously exchanged and corroborated. This was followed by the application of a triangulation method, superposing the transcripts interpretations with the literature review produced in advance. We shall now turn to quotes from the interviews in order to illustrate our analysis. We have provided contextual information for the respondents and use pseudonyms to indicate sources.

## The dual aspect of resistance

### *Epistemological conflicts: faith and risk-medicine*

#### *Questioning the value of pro-gnosis*

Almost by definition, when divine decree is considered as the definitive force of future events, risk-assessment practices are of little or no assistance. As Rabbi Lepek (a pseudonym), an expert on Jewish religious laws and procreation, stated, a human intervention can only be considered if it is based on empirical (*dia-gnosis*), and not merely prospective (*pro-gnosis*) knowledge: the decision to proceed with a termination of pregnancy 'can only be based on a test that is 100% accurate.' In other words, knowledge of the *actual* is both acceptable and valuable, while knowledge of the *possible* is vain. Professor Goldberg (head of a neonatal service and head-researcher in an institute of Jewish medical ethics) attempted to explain what he considered to be the main position in religious laws quoting a famous Rabbi:

We do not speak of a chicken [a case where the termination of pregnancy is considered], whether it is *Kosher*, not *Kosher*, and so on. What do you tell a woman? Bring the chicken to me, and only then will I tell you whether you can eat this chicken or not.

According to this view, no issue can be resolved solely on the grounds of abstract statistical information. Knowledge must be actual and factual, based on a present state of affairs, and not on the future, however predictable it may be. Thus, risk science which aims to imagine future situations and their probabilities is nothing but futile: a prospective medicine is as unsatisfactory as a probable chicken.

#### *The downside of gnosis: implicit miracles*

Asked to his view on the possible reasons on which ultra Orthodox women may base their decisions to refrain from prenatal testing, rabbi Lepek told us:

There is a spiritual approach that says it is better not to know. Meaning that if you are not aware that there is a problem, it is better not to know [...] Why is it better not to look for the problem? Because, spiritually, we believe in the power of prayer to change things. God hears the prayer and when needed, or when deemed important, miracles happen. So Rabbis say, when a woman is pregnant, she naturally prays for her foetus to be safe and sound [...] and if she prays, has her merits, and God has good reasons to answer her prayer, he will answer her prayers and the foetus will be safe and sound without anyone ever knowing that he was not so healthy to begin with. This is simple. But if she knows there is a medical problem and now she prays ... changing what is already known is an explicit miracle and explicit miracles are at another level. It is not like implicit miracles. Not everyone who gets an implicit miracle can get an explicit miracle.

The notion of 'implicit miracle' is much instructive. This idea, much like the idea of risk-medicine, represents a form of control over a chaotic future, an attempt to undertake the challenges of the unknown. There is, however, one clear distinction between the two



epistemological forms. If seeking to alter a future result, risk-medicine pictures the individual as obliged to adopt an active, well-informed role. The concept of divine intervention demands the strict opposite: taking an uninformed, passive stance. Moreover, divine determinism undermines the very *raison d'être* of risk-medicine, namely, its power to control through knowledge, or more essentially, its power to control through prediction. Thus, the relative power assigned to either 'believing' or 'knowing' play a distinct role in defining the locus of control (divine or biomedical) over both reality and eventuality.

This religious viewpoint makes *gnosis* not only not useful but also potentially harmful. In contrast, risk-medicine holds a consistent view of *gnosis* as an asset, where choosing not to know does not seem to represent a valid option (Press and Browner 1997, Dormandy and Marteau 2004). This leads to a situation well described by Darya, the social worker of a pregnancy termination committee<sup>1</sup>:

Paradoxically, I think it's ultimately more difficult [to delay the decision on the termination of the pregnancy ...]. You hear [ultra orthodox women say]: 'I knew there was some kind of problem but I waited, perhaps it will eventually pass, maybe it would get better.' Like any of us, when we want something, we want to believe. It is still surprising sometimes to hear: 'I prayed a lot' or 'everyone prayed for me and we hoped it will work out by itself, so we waited a bit longer to see if it worked out.' And often faith makes them [the ultra Orthodox women] hold on a bit longer and a bit longer until [medical intervention] is not an option anymore ...

#### *Gnosis and the nationalist-religious woman*

Where nationalist-religious women are involved, the dichotomy of prediction-action vs. divine determinism is somewhat dissolved. In the course of our data collection, we observed a phenomenon of some interest, namely the creation of a theologically-correct risk-medicine, fusing risk-medicine into religion. Maya, a nationalist-religious interviewee stated:

It's not a mistake. I still think God doesn't make mistakes. God doesn't make mistakes. Why? Because it [Down's syndrome] is a mistake: you have one extra chromosome. What, god can't fix chromosomes right!? [...] With me, he was merciful in telling me on time [that I have a Down's syndrome foetus].

This theologically-correct risk-medicine can be related to these women's fidelity to both religious and medical institutions. Their opting for prenatal screening tests demonstrates the internalisation of pregnancy as a high-risk condition (Remennick 2006). Thus, if they do comply with risk-group assigning, it is not out of lesser faith in God, but rather out of a greater commitment to state and personal priorities, expressed in the performance of genetic tests. Merav, a nationalist-religious woman, performed every genetic testing proposed by the medical establishment, describing her relationship with her doctor in the following:

From the moment I found out I was pregnant, I went to the doctor because he tells me what to do. [...] I did all the usual things that you do.

For some women, such as Merav, even when *gnosis* has no practical implications, it remains valuable as such. Risk-medicine regards *gnosis* as an asset, and 'choosing not to know' (while accepting some kind of divine fate) is an unimaginable option (Press and Browner 1997, Dormandy and Marteau 2004). This stands in contrast to the scheme of *implicit miracles* where 'knowing' turns potentiality into facts.

Using the narratives of *implicit miracles* and *epistemological chickens*, we have examined the ways in which medical and religious models of gnosis may be either irreconcilable when applied to prenatal testing, or consistent when adopting a concept of theologically-correct risk-medicine. In this regard, a clear gap is revealed between ultra Orthodox and nationalist-religious positions. In an attempt to provide a further account for this divergence, we shall introduce another aspect of this problem: risk-medicine's and religion's roles as designers of procreative cultures (Berkovitch 1997).

### ***Contextualising risk-medicine: a battle for a nation's procreative culture***

Although conceived as a purely scientific practice, prenatal testing is still clearly related to specific ideologies (Cowan 1994, Lippman 1994, 1999, Lowry 2004, Williams *et al.* 2005). Social collectivities tend to form primary decision-making units on patterns of reproduction (Goldscheider 1971, Etzioni 1988, Granberg 1991, Okun 2000). In this context, the extent of adoption of nationalist ideals is likely to play a considerable role in the determination of women's reproductive choices.

Carol, the social worker of a neonatal unit, explains:

I think we should be very careful about the Israeli demand—which I believe to be problematic—of the foetus' two-hundred percent health. It says something about our society if we cannot accept something or someone that is not perfect.

A number of facts support the premise that, in Israel, nationalism and procreative ideologies are strongly intertwined. In the non-religious public, there seems to be, following a deliberate choice of some of the foetus' traits, an increasing emphasis on the quality of offspring versus their sheer quantity (Henn 2000, Remennick 2006). In contrast, the ultra Orthodox procreative ideology takes at its word the Biblical commandment to be fruitful and multiply' thus advocating an ideal of having as many children as possible (Sandiuk *et al.* 1983, Goodman 1993, Hetsroni and Remennick 2001, Landau 2003). Accordingly, prenatal medical care, and the procreative ideology associated with it, represent important arenas in which the ultra Orthodox community resists (and the nationalist-religious adopts) risk-medicine as a form of governmental control. We shall present here the latter's relation to what we will here refer to as *procreative ideologies* as well as to a broader stance of nationalism (Kahn 2000).

### ***Risk-medicine and procreative ideologies***

Although non-unanimous in regard to the moral acceptance of non-vital pregnancy, the nationalist-religious public is more consumerist in terms of genetic testing (Wilder 2000, Remennick and Hetsroni 2001). Having made the decision to terminate her pregnancy when testing indicated that her foetus probably had Down's syndrome, Maya, a nationalist-religious woman, argued that:

I'm saying, whoever is not normal, let's go, [have an abortion] [...] I'm almost saying ... I'm exaggerating, but I'm not. I'm not. I think that what can be ... I'm not like the Nazis who killed them [Down's syndrome children] alive, [but] what can be avoided, should be.

Maya commented on Shofit, the nationalist-religious town in which she lived:

I told [my children], 'Why do you think there aren't any Down's syndrome children in Shofit? Do you think they were not conceived? That they didn't exist?' [...] I told them: 'There aren't

any in Shofit because people have tests and they perform abortions. We don't know what everybody had or didn't have. But the fact that they don't have [Down's syndrome children] is not because they didn't exist.' Maybe it's because it's the norm [to have an abortion].

These quotes illustrate nationalist-religious women's tendency to comply with this rule of 'two-hundred percent health' (Poutanen 2002, Remennick 2006). The data in our study indicates the acceptance of testing more closely related to political nationalist ideals than to religious ideas (Quah 1993, Amir and Benjamin 1997, Guttman 1999, Landau 2003).

### *Resistance and indignation*

The role of society in women's decision making in the field of pregnancy was often raised in our interviews. For example, Darya, a social worker, told us:

There is something about secularity, and surely in the medical system, that is very angry at all those mothers who do not have abortions.

A pregnant body is a body that is supervised by the collective, to ensure the health of the growing potential member of society (Haraway 1991, Mitchell 2001). Prenatal genetic diagnosis contributed to turning the pregnant body from private to public, and to a focal point where notions of responsibility and risk are negotiated and discussed (Amir and Benjamin 1997, Petersen 1999, Brown and Webster 2002, Webster 2002). 'Good motherhood' is a concept that is increasingly associated with leading a responsible or medicalised pregnancy, where its future outcome (risk) is taken into account as early as possible (Tsing 1990, Chadwick 1999, Poutanen 2002, Remennick 2006). Simcha, who made the decision not to go through invasive testing after Down's syndrome was suspected, depicted the postpartum period as the 'worst four days of [her] life':

The hospital gave me a feeling that I was a criminal: how did I dare do this terrible thing? Every nurse that saw me, every doctor that went in, the first question [was] 'You didn't have an amniocentesis [an invasive test]?' ... 'How could you do this?!' [...] I was shocked [...] how come it's everyone's business?

The importance of acquiring the biomedically-acceptable type of gnosis is exemplified by Gil, a social worker at a neonatal unit. She describes how she implores ultra Orthodox women to obtain information:

I tell them [the ultra Orthodox women]: go get a genetic opinion. Hear what is to be heard and decide what needs to be decided. But at least have some information.

Mary Douglas's (1985) notion of 'indignation' is useful in this context. Indignation stems from a group's failure to accept dominant definitions of risk. As already acknowledged, risk involves surveillance practices which seek to gain control over events that can only be foreseen in terms of statistical terms of probability. In not accepting this notion of risk as conceived and accepted by the dominant social group, these women separate themselves from the collective, by not accepting this type of 'governmental surveillance' (Foucault 1984, Lupton 1999). This rejection of the dominant discourse elicits indignation, thus reinforcing perceptions of the ultra Orthodox community as deliberate outsiders.

### *Institutionalising procreative norms*

A predominant element in the resistance to risk-medicine is the establishment of an institutional alternative, the *Ultra Orthodox Organisation for Premarital Genetic Screening*

(the *Organisation*). Established in 1984, the *Organisation* is a non-profit enterprise working almost exclusively within the ultra Orthodox community (Haknesset 2003). Its goal is to eradicate certain recessive genetic diseases by preventing marriages involving persons carrying mutations in the same gene, thus turning risks and probabilities into absolute (or near-absolute) preclusion of future predicaments (Eckstein and Katzenstein 2001, Raz 2004, Raz and Atar 2004). Although incapable of predicting diseases that can be detected through some foetal screening practices, the battery of testing provided by the *Organisation* do seek to ensure future health through the elimination of risks, thus being only seemingly based on risk-medicine epistemology.

The *Organisation* is highly influential within the ultra Orthodox community. Once the head of the *Organisation* obtained endorsements from prominent ultra Orthodox rabbis, it became widely accepted, with a participation rate of 95% of the ultra Orthodox public and around 10,000 people are tested yearly (Haknesset 2003). A test is offered to young girls and boys, typically in the course of their last year of schooling, around 17–18 years old. After obtaining parental consent, a blood sample is drawn from the subjects, and is assigned a code. When a possible marriage of two individuals is considered, their codes are fed into a specialised computer programme. The *Organisation* will then give its blessing to couples holding compatible genetic profiles, while advising against unions where mutations in the same genes were found (Zlotogora and Leventhal 2000). This system requires that the tests be completely anonymous, and neither of the potential spouses is permitted to know who holds the bad genes. Hannah, the representative of the *Organisation*, told us:

[In the case of a couple where each is a carrier of a different genetic disease] we tell the couple: everything is compatible, everything is alright and there is no risk for sick children [...] and they will never know that they carry these diseases. Which means, we have reached the goal of preventing the birth of sick children and we have skipped the phase that could have make their life difficult.

Hannah further explains that knowledge *as such* has no value, that is, you have to 'bring the chicken.' For her, it is absurd to seek information on a couple's risk to having diseased children if one was not to act upon it directly and turn this probability into certainty. Even more absurd for her would be to acquire knowledge as to the genetic disposition of a person, if the very alliance with a non-carrier precluded the birth of an unwell child. One has to hold a certain view on the value of gnosis in order to be part of the *Organisation's* system. The latter serves not only as an alternative to secular institutions with a similar function, but also complies with, and reasserts, a specific epistemological stance of translating statistics into facts. The *Organisation* is extremely strict as to the information given to the couple, leaving undisclosed any statistical results that may be described as sets of possible eventualities. The *Organisation* turns probabilities into certainties, for the sake of their clientele, turning a risk-medicine practice into a biomedical one, thus releasing oneself from the burden of dealing with pro-gnosis.

## Conclusion

This research points to the significance of the relative values of dia-gnosis and pro-gnosis, and their understanding as unique forms of knowledge: all pertaining to the definition of 'risk-medicine' as distinct from the more general stance of 'biomedicine.' As shown here, there is some value in the deeper understanding of this form of medicine, and its socio-cultural context. Prenatal screening procedures form an arena where risk-medicine is both

enacted and resisted. As such, a study of the ultra Orthodox public's religious and ideological dismissal of these procedures is likely to be instructive in the understanding of the grounds and socio-cultural consequences of this particular type of medical epistemology and practice. The governmental implication of risk-medicine's and its underlying epistemological premises are of outmost significance in the study of resistance to its application. The challenges may be defined as twofold: first, involving epistemological incompatibilities between risk-medicine and some forms of theological systems and practices; second, involving aspects of governmentality (and more particularly, tendencies to affirm nationalist ideas) that may be involved in risk-medicine in general, and in prenatal screening in particular.

A wide-ranging classification of the grounds of this rejection is further proposed. This typology includes eight different components: cultural discrepancy, lack of information, religious prohibitions, risk-aversion, incompatible health and illness cosmologies, fear and mistrust, governmental control, and irreconcilable epistemological differences. Each case of resistance may involve some, or all, of these components. Yet, as suggested where risk-medicine is the target of this resistance, the last two of these aspects may be of more relevance. These eight components are to be studied further in the future, both as analytical categories and as potential foundations for empirical studies. These aspects of risk may be studied in the context of different religious, ideological, or national groups, and would gain from comparative analyses, as well as from particular case-studies.

Beyond its contribution to the understanding of processes of resistance, risk-medicine, as defined and detailed here, seems to constitute a meaningful and potentially useful concept. More generally, it provides a scheme on which to define the interactions between medicine, religion, and nationalism. It binds governmental practices with a hierarchy of underlying epistemologies, and relates socio-cultural developments of late-modernity with medical culture and practice. Hopefully, this will be taken on beyond this particular empirical case and contribute to our understanding of a wide range of socio-cultural phenomena.

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### Note

1. In Israel, a hospital-based committee must approve all artificial terminations of pregnancy. The approval is almost invariably accorded (ICBS 2003).

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