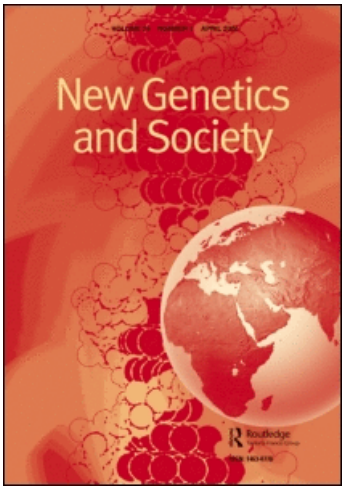

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Lay perceptions of genetic testing in Germany and Israel: the interplay of national culture and individual experience

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Lay perceptions of genetic testing in Germany and Israel: the interplay of national culture and individual experience

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Germany and Israel represent opposite regulatory approaches and bioethical outlooks regarding genetic testing. This study examines lay attitudes (including attitudes of people affected by genetic diseases) in both countries towards genetic testing of adults, focusing on the differences between cultural and personal argumentations, as well as between affected and non-affected perspectives. With regard to three major emerging themes – medical technology/technocratic medicine; economic aspects of healthcare; and personal decision-making – a national contrast was apparent on the cultural level of argumentation, but not in the personal context of decision-making or in the concerns of people affected by genetic diseases. We conclude by discussing the interplay of national culture and individual experience in constructing arguments about the harms and benefits of genetic testing, and the implications for the study of cross-cultural bioethics in the context of "genetic responsibility".

Keywords: genetic testing; lay perceptions; Germany; Israel

Introduction

We compare here for the first time lay attitudes towards genetic testing in Germany and Israel, two countries that offer much for a comparative analysis given their very distinctive approach to regulating genetic testing. Germany and Israel generally represent opposing examples of professional culture in relation to carrier screening and prenatal genetic diagnosis (Wertz and Fletcher 1989, Gottweis and Prainsack 2006, Hashiloni-Dolev 2007). The juxtaposition of these two countries is hence expected to highlight the context of national variation and pluralism in the moral assessment of genetic testing. We further ask how the effect of different nation-specific worldviews can be moderated by the lived experience of "being affected" (Kleinman *et al.* 1997, Kleinman 1999). This opens up the possibility that values shared across countries could also be culturally informed, for example by values associated with disability that transcend national contrasts.

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This study joins a growing scholarly work on how lay people, including those affected by genetic diseases, assess genetic testing, and how they develop and express their points of view (Scully *et al.* 2004, Banks *et al.* 2006). Lay perspectives on genetic testing are gaining legitimacy and influence through patients' organizations and advocacy groups (Petersen 2006, Novas 2006, 2007, Raz 2009). In this study we focus on genetic testing of adults, which includes carrier and predisposition testing. This is an important area of the new genetics usually seen as increasing the range of choices open to the healthcare consumer (Evan *et al*, 2001, Vallance and Ford 2003, Slowther 2008). Contesting lay constructions of "genetic responsibility" have been highlighted in recent studies on attitudes towards predictive testing for breast cancer and Huntington's Disease (Hallowell 1999, Konrad, 2003, 2005, Taylor 2004). The varied moral argumentations of lay people can thus provide an alternative to the Foucauldian focus on genetic testing as uniform bio-governmentality (Novas and Rose 2000, Lemke 2002, 2005).

To explore the moral arguments developed by lay people in Germany and Israel concerning genetic testing, we first introduce the comparative literature on the two countries, and then describe the themes expressed by the respondents, discussing their argumentations about the harms and benefits of genetic testing for adults. The discussion further focuses on the cultural and personal levels of argumentation, the former consisting of general arguments concerning cultural narratives and the latter consisting of concrete arguments related to personal decisions. These two levels are often intermingled, and their distinction is used here to highlight the interplay of cultural scripts and biographical experience in the interpretation of genetic disease and disability. The paper concludes by discussing the implications of this comparison for the study of cross-cultural bioethics and lay constructions of genetic responsibility.

Comparing Israel and Germany in the context of genetic testing

Germany and Israel represent two contrasting regulatory and bioethical models regarding genetic testing, mainly in the context of reproduction and the beginning of life. In Wertz and Fletcher's (1993–1995) international survey, German geneticists expressed extreme caution regarding the use of prenatal diagnosis (PND) for selective abortion, while Israeli geneticists advocated it. Hashiloni-Dolev (2007) demonstrated how these differences are shaped within the thriving social, legal and ethical debate concerning reprogenetics in Germany, as opposed to the non-existence of such debates in Israel. Israeli law allows eugenic abortions, even after viability, while the latest version of the German Law does not (Hashiloni-Dolev 2007). While many German political, feminist and disability rights groups oppose genetic technology (Schindele 1990), many disability activists in Israel support the use of PND to prevent life with disability (Raz 2004). While in Germany the production of human embryonic stem cells is illegal and pre-implantation genetic

diagnosis (PGD) is contested because of the moral protection of the human embryo, in Israel both issues are supported (Krones and Richter 2004, Krones *et al.* 2005, Prainsack 2006).

While predictive and carrier testing are both practiced in Germany and Israel on a personal choice basis, it is only in Israel that carrier screening of adults is regulated by the State as part of a national screening program as well as community-based screening programs for high-risk groups (Zlotogora *et al.* 2009). In Germany, the issue of carrier screening is discussed separately from and with much more caution than individual genetic testing (Schroeder-Kurth 1999, Enquete-Kommission 2002). This overarching cultural contrast has been related to Nazi eugenics and the Holocaust, although there is no consensual explanation as to why and how the unavoidable (yet commonly avoided) shared historical background of the Holocaust could result in such opposite interpretations (Caplan 1992, Winau and Wiesemann 1996, Singer 2000, Weindling 2005).

Methodology

The impetus behind this study was to explore whether the dichotomy between professional (regulatory and bioethical) cultures in Germany and Israel would also be reflected in lay and affected people's cultural and personal argumentations. To shed light on this question we analyze focus groups and interviews conducted with lay and affected people in Germany and Israel. All of the respondents (N = 48) in this exploratory and qualitative study were volunteers recruited in Germany (Berlin) and Israel (Beer-Sheva, Jerusalem and Tel-Aviv) during 2005–2007. In Germany, two focus groups were organized, one with lay people and the other with people affected by genetic diseases.[1] In Israel, three group meetings were held with lay people, and 10 people affected by genetic diseases were interviewed individually, as per their preference. Similar scenarios and questions were used in the focus groups and individual interviews (Bloor *et al.* 2001, Carter and Henderson 2005). Focus group meetings in Israel and Germany included seven to eight people and lasted about two hours; individual interviews lasted about one hour on average. In terms of education, all participants had a high school diploma; 58% and 42% of the German and Israeli respondents, respectively, had a BA-level university degree.

German respondents affected by genetic diseases were recruited from self-help and support organizations and included people who tested positive, or had children who tested positive, for a variety of genetic diseases/conditions including Marfan Syndrome, muscular dystrophy, dwarfism and cystic fibrosis. Israeli respondents affected by genetic diseases were recruited from organizations of and for people with genetic diseases and included people who tested positive, or had children who tested positive, for a variety of genetic diseases/conditions including cystic fibrosis, Prader-Willi Syndrome, Rett Syndrome, and thalassemia. The category of "being affected" in this comparative study is thus comprised of people who

either have genetic diseases or have children with genetic diseases. After finding that similar views were expressed by these two subgroups, we decided to amalgamate them for the purpose of this study into one group. Of note, while differences in attitudes between people who have genetic diseases and people who have children with genetic diseases have been found in the context of prenatal testing, our focus in this study is on carrier testing of adults. Many of the parents of children with genetic diseases have themselves gone through genetic counseling following the birth of the affected child. German and Israeli respondents not affected by genetic diseases were recruited by disseminating flyers and ads in urban public places. Table 1 summarizes the basic socio-demographic data concerning the participants.

Questions asked in the focus groups and interviews included attitudes towards genetic testing of adults, such as: Who influences the decision to test (family members, partners, health professionals, the state and so on), when and how; who is seen as responsible for making the decision and why; who is seen as having the authority to decide and what are the sources of such authority (religion, morality, the law and so on). Respondents were not provided with any preliminary instruction. A short case study regarding carrier testing of adults (for example in the context of breast cancer) was used in Germany and Israel to provide a concrete narrative that invites participants to imagine a real case, to consider what other

Table 1. Characteristics of participants (N = 48).

	Country			
	Germany		Israel	
Characteristics	N	%	N	%
Male	5	31	15	47
Female	11	69	17	52
Age				
18–30 years	5	31	14	44
31–45 years	4	25	9	28
46–60 years	5	31	6	19
>60	2	13	3	9
Religion				
Protestant	7			
Catholic	0			
Buddhist	1			
Muslim	1			
Jewish*			7	
Atheist	7		25	
Affected people	8	50	14	43
Total	16		32	

Note: *All Israeli participants were Jewish by birth but only seven defined themselves as being religious.

information they would need to know to make a judgment, to consider the reasons and motives of significant others, and so on. Group discussions and interviews were audio recorded and transcribed. The transcripts from each country were analyzed thematically by the authors, then translated from Hebrew and German into English and compared cross-nationally in order to uncover discursive themes and categories of themes recurring within and across groups (Denzin and Lincoln 1994). The quotations given illustrate the range of responses with regard to the emerging themes.

Views of medical technology and technocratic medicine

The majority of German respondents (including those affected by genetic diseases) voiced criticism and skepticism concerning medical technology in general. This view, which we refer to as "dystopian", was expressed, for example, in regard to the perceived limited knowledge of medical science and its technocratic outlook:

> Scientists change their minds every 10 years. The only thing you shouldn't do is to consider the scientific result as definite [. . .] Well, my body is damaged. I take it to a workshop, fix it please and then it's mended. That's the way many doctors think of themselves. [. . .] You always have the impression that they are not listening. (Male, German, affected by hereditary disease)

In contrast to the dystopian German view, the majority of Israeli respondents (including those affected by genetic diseases) did not voice critical opinions and were generally positive of the progress and benefits inherent in medical science and predictive/carrier testing:

> I am definitely in favor of testing, for the purpose of therapy and prevention [. . .] We seek to reduce human suffering. We therefore encourage genetic testing. This is a good thing! (Female, Israeli, with family members affected by a genetic disorder)

Some participants in Germany and Israel referred to their religious belief in justifying their stance. German respondents who were generally critical of the potential misuse of medical technologies also referred to religion as setting limits on medical interventions that verge on "playing God".

> But what is it good to me to be informed then, and when it is incurable? [. . .] According to my Christian faith, I think, God created me like this and my life is up to him. (Male, German, not affected by genetic disease)

This view was less common among German respondents affected by genetic diseases. Many Israeli respondents (including those affected by genetic diseases) explained that their positive view of genetic testing was supported by Jewish religion:

> Speaking as a religious person, there can be no contradiction between medical technology and God's will. God has created everything – including medical technology. Since we are not speaking here on prenatal testing but on testing of adults, this is

> much easier for me to accept on religious terms. (Male, Israeli, not affected by genetic diseases)

The dystopian view of medicine was also linked by some German respondents to the lessons of Nazism:

> I think the Third Reich and genetic tests are definitely things that are related to each other. This is a view of man which hasn't been wiped out to this very day. (Female, German, cystic fibrosis patient)

However, some of the German respondents affected by genetic diseases expressed a different view, stressing the benefit of genetic research and criticizing the linkage to Nazism as too simplistic:

> I do think that Germany should be [. . .] a bit a more relaxed. And they shouldn't always let the time of the Nazi regime spoil everything. [. . .] I think that what they did at that time doesn't compare with genetic research done today. [. . .] Germany lags behind in the field of genetics. Because they carry that burden of the past. I think one has to/you should promote genetic research. Of course, you should never forget that caution is called for. (Female, German, Marfan Syndrome patient)

In contrast to German respondents, Israelis did not speak about "the lessons of Nazism" in the context of genetic testing. Not speaking about the Holocaust could in itself be regarded as part of what we termed as a "utopian" discourse of genetic testing.

Economic aspects of genetic testing of adults

Another important theme for both German and Israeli respondents was the issue of access to healthcare. Most German respondents voiced concern that because of its costs, only the rich would have access to genetic tests of adults. German respondents affected by genetic diseases also supported this criticism with their personal experiences regarding the refusal of private health insurance companies to insure them. Most Israeli respondents, in contrast, expressed the view that carrier testing will have to become a public matter, made available to everyone through state-supported and subsidized screening programs:

> We are all in the same boat in this matter so I expect testing will be subsidized by HMOs [Health Management Organizations]. It is a simple cost-benefit calculation for the State or the health organization. It should be cheaper to test and prevent suffering than not to test and then treat. (Female, Israeli, affected by genetic disease)

Personal decision-making

For the majority of German respondents, genetic testing without the option of an ensuing therapy was regarded very skeptically, as a potential cause of disease escalation due to stress as well as social surveillance. Carrier testing that only produced

statements of risk probabilities was regarded by the majority of German respondents as inadvisable:

> I believe that if you get signs in that manner, then it will be somehow/this will also lead to a state of panic or perhaps even to paranoia. And I believe that this is not necessarily positive for the/for your quality of life. (Female, German, not affected by genetic disease)

However, as long as the genetic test could lead to an improvement in the individual's quality of life via prevention or therapy, most of the German participants were in favor of it. Most agreed that even though genetic testing will not prevent the outbreak of a disease, at an early stage of detection it could prolong life and increase one's opportunities:

> In my case this Marfan Syndrome [. . .] Well, it has affected my vascular system. That's why I had to have a heart transplant 8 years ago. I mean, if you know right from the start that you have a certain disease, you'll cope with it differently. For example not participating in sports in order not to overstrain yourself. (Female, German, affected by genetic disease)

Many German participants related to breast cancer as a disease which is potentially curable if detected early, stating they would like to take a test, especially if there were further signs such as for example the occurrence of breast cancer in their family:

> If for example you come from a family with a history of breast cancer and if it was possible to say with the help of a genetic test whether it could be passed to your own children, you would keep an eye on everything right from the outset. (Female, German, affected by genetic disease)

In a similar manner, most Israeli respondents considered the benefit of carrier as well as predictive testing on the basis of its therapeutic or preventive benefit:

> If you tested positive for it, then you become more watchful for additional medical examinations. Instead of having mammograms once a while, you have one every six months. (Female, Israeli, not affected by genetic disease)

Some Israeli respondents also supported testing on the basis of belonging to a perceived risk group:

> There are no genetic problems in my family at present, but I am not so sure about previous generations since many have gone in the Holocaust. You know, Ashkenazi Jews have more mutations than others, so you cannot be too careful. It is better to do the test, just to be on the safe side, and then see what are the implications. (Female, Israeli, not affected by genetic disease)

This view of "collective risk", which means that belonging to a certain group such as Ashkenazi Jews results in a higher genetic risk for the group member, was also expressed by a few Israeli respondents in the form of what they regarded as a "duty to know":

> Even if in my own family there are no cases of cancer, just being an Ashkenazi woman means that I am under greater risk. It can make sense to pay for the predictive test since if you are a carrier it means that you have to do the screening more frequently, and maybe the State will subsidize it in case you are a carrier. (Female, Israeli, not affected by genetic disease)

While the majority of the respondents in Israel and Germany shared a pragmatic outlook of personal decision-making that took into consideration both the pros (therapeutic and preventive benefit) and cons (stress, futility, social surveillance) of testing, a minority view that also existed in each country presented a cultural contrast that could be termed as the duty to know (in Israel, demonstrated above) versus the right not to know (in Germany). A small group of German respondents, mainly non-affected, who also presented themselves as Christian, expressed a resigned stance stressing their will to "take things as they come". If no concrete actions or consequences were deducible from the test, according to these respondents, they would object to "knowing what destiny holds":

> I myself wouldn't like to know. And I think, what is the good of having this forecast? And the first question would be whether this is bound to come true. (Male, German, not affected by genetic disease)

In contrast, some of the German respondents who were affected by genetic diseases also spoke – in a similar manner to Israeli respondents – about the duty to know and to tell close family members:

> I'd consider it to be my duty. Yes. Well, I've always kept my relatives informed of how my disease made its way through the genes of my family [. . .] When everything, I mean, all the trouble has started, well, I told her [my sister] that it's a thing which can be transmitted by men. But if these women have babies themselves, this may/their children may be, well, disabled. (Male, German, affected by hereditary disease)

Comparing the themes between the groups and cross-culturally

A comparison of the three themes that emerged from the cross-national comparison (summarized in Table 2) supports the following generalizations.

(1) National contrasts characterized the themes of medical technology and economic aspects. In these themes, lay attitudes generally mirrored the national contrast expressed in professional outlooks. Of note, these themes consisted of more general references that focused on abstract views (e.g. medical progress/technocracy, the health market, lessons of Nazism). Religion was also found to contribute to this national contrast; religiosity was perceived by some German Christian respondents as setting limits to medical technology while some Israeli respondents considered Judaism as supportive of medical progress. In the third and more concrete theme of personal decision-making, however, we saw a difference between professional and lay outlooks, and a common practical

Table 2. Emerging inter-group and cross-cultural comparisons of major themes concerning genetic testing of adults.

	Medical technology		Economic aspects		Decision-making	
Respondents	Germany	Israel	Germany	Israel	Germany	Israel
Not affected	General dystopian view of technocratic medicine; Christianity as setting limits; critical lessons of the Third Reich.	General utopian view; supportive role of Judaism; Holocaust not mentioned.	Fears of unequal accessibility and health disparities, difficulties with health insurance.	Expectations of equal accessibility following the model of State-supported and subsidized carrier screening programs.	Shared pragmatic outlook considering the pros (therapeutic and preventive benefit) and cons (stress and futility) of testing. In addition, a minority view in Israel regarding "the duty to know" (shared by some German affected respondents) versus a German non-affected minority view regarding "the right not to know".	
Affected	Some affected respondents stressing the benefit of genetic research and criticizing the reference to Nazism as too simplistic.					

Note: In cases of views shared by the majority among groups, their respective cells were merged.

view considering the pros and cons of predictive and carrier testing emerged in both countries.

(2) "Being affected" is a factor that generates a common voice among respondents from different national cultures who are furthermore affected by different genetic diseases. In contrast to the general dystopian view of a technocratic medicine shared by the majority of German lay respondents, German respondents affected by genetic diseases stressed the benefits of genetic research and criticized the references to Nazism as too simplistic. This view was similar to the view generally shared by Israeli respondents.

(3) In Israel, all the respondents – those affected by various genetic diseases and those not affected – generally expressed support of the responsibility of individuals and society towards promoting genetic screening and testing. The Israeli view regarding the "duty to know" emphasized this by constructing a collective sense of genetic risk linked with the "Ashkenazi Jewish gene pool". In Germany, in contrast, "the right not to know" was unique to respondents who were not affected by genetic diseases, while some respondents affected by genetic diseases spoke about the duty to test and share information with close relatives. These findings present a plurality of lay moralities regarding duties and rights related to genetic testing, thus complementing and extending previous studies of affected people in which the moral duty to test was found to characterize women in the context of testing for breast cancer (Hallowell 1999), whereas a moral conflict whether or not to know and tell was found in the context of Huntington's Disease (Konrad 2003, 2005).

Concluding remarks

People in Germany and Israel have a wide range of views about genetic testing of adults, and this study touched on the complexities and variability of these perspectives. Our study mainly contributes to the understanding of lay views of highly educated, middle-class people – a bias common in many research settings. Our data demonstrate that national contrast remained apparent in the cultural level of argumentation characterizing the themes of medical technology and economic aspects of access to healthcare. Some of the contrast in the argumentations concerning medical progress was influenced by religious outlooks (see also Walter 1999, Gross and Ravitsky 2003, Prainsack and Firestine 2006). However, generalizing these differences to the level of "Christianity" or "Judaism" should be made with caution, since these terms do not imply a single view and their articulation is made in the context of other cultural, political and historical narratives.

What could explain why some Germans refer to the Nazi history of their country when discussing genetic testing, while Israelis generally do not? This could be linked to a general German interpretation of the lessons of Nazism as morally universal and highly relevant to current bioethical dilemmas (Winau and Wiesemann 1996,

Weindling 2005) – leading, for example, to German political, feminist and disability rights groups blaming genetic testing as "the new eugenics" (Schroeder-Kurth 1999). German expert commissions such as the National Ethics Council or the interim parliament commission on "Ethics and Law in Modern Medicine" refer consistently, when discussing genetic testing or end of life decisions, to the historical responsibility of German doctors' support of Nazism. Many Israelis, in contrast, generally interpret the lessons of Nazism by focusing particularly on Jewish victimization and heroism (Segev 1991) – hence perhaps being less interested in the general moral relevance of the Holocaust to the bioethics of genetic testing. Many Israeli Holocaust survivors further emphasize the singularity of the Holocaust as an event beyond comprehension and comparison, thus cautioning against drawing bioethical lessons from the Holocaust (Leichtentritt *et al.* 1999). In contemporary Israeli society, genetic testing and screening are broadly seen positively as reducing suffering and increasing the reproductive options of individuals genetically at risk (Raz 2004, 2009).

In the more personal and concrete theme of decision-making we found a pragmatic outlook shared by Germans and Israelis concerning the pros (therapeutic and preventive benefit) and cons (stress and futility) associated with testing. This practical line of reasoning was also found in other studies among various populations, showing that in making such a decision people take into account factors such as the predictive value of the test and control over the disease (Shiloh *et al.* 1999, Shaw and Bassi 2001, Barnoy 2007). German professionals, especially when perceiving themselves as gate-keepers, are far more restrictive in their attitudes than the general German public (see also Krones 2005, Illes *et al.* 2006). In Israel, such a gap between gate-keeping professionals and lay people did not emerge. Rather, Israeli health professionals have been shown to stress the notion of "genetic risk" (Hashiloni-Dolev 2007) which is matched by a collective sense of susceptibility expressed by the majority of our Israeli respondents, and further highlighted by what some of the Israeli respondents called the "duty to know". Why is this "duty to know" more pronounced among Israeli respondents than among German respondents? This difference could be linked to a communitarian sense of belonging to an "at-risk population". In Israel, where the "Ashkenazi Jewish gene pool" has been constructed by health professionals as especially prone to inherited disorders, "genetic anxiety" (or "responsibility", depending on one's perspective) has been boosted, creating a collective sense of risk in which the "elective" uptake of genetic testing is exceptionally high and seen by many as a moral duty (Sher *et al.* 2003, Remennick 2006).

Another important finding was that being affected can generate a common voice regarding genetic responsibility among respondents from opposing national cultures, who were furthermore affected by different genetic diseases. Some affected German respondents voiced – in a similar manner to Israeli respondents in general – an attitude supporting a moral duty to inform relatives and protect children from being affected. This affected construction of responsibility contrasted with the

"right not to know" expressed by German lay (not affected) respondents. Further research is needed to determine to what extent being affected constitutes a uniform and distinct moral view on genetic responsibility (Schicktanz *et al.* 2008). A similar pragmatic emphasis on using medical technology for the individual's benefit was also voiced by American adults with physical disabilities who claimed that genetic diagnosis "was not a problem but a tool to be used for everyone's benefit" (Chen and Schiffman 2000, p. 147). In a similar manner to the knowledge claims of feminist (Harding 2004) or disability (Johnstone 2001) studies, affected people thus appear to warrant a special place for their own situation and concerns (Badcott 2005). This carries important implications for future research on moral arguments concerning genetic testing, which is grounded not just in the professionals' viewpoint but also in the perspectives of patients and lay people.

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