ORIGINAL RESEARCH



# Should I Perform Genetic Testing? A Qualitative Look into the Decision Making Considerations of Religious Israeli Undergraduate Students

Merav Siani<sup>1</sup> · Orit Ben-Zvi Assaraf<sup>1</sup>

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Abstract The aim of this study is to draw a picture of the concerns that guide the decision making of Israeli religious undergraduate students and the complex considerations they take into account while facing the need to have genetic testing or to attend a genetic counseling session. We examined how the religious affiliation of the students influences their perceptions toward genetics and how these are expressed. Qualitative data were collected from 51 semi-structured interviews with students, in which recurring themes were identified using 'thematic analysis.' The codes from the thematic analysis were obtained according to 'grounded theory'. Our results show that religious undergraduate students' decision making in these issues is influenced by factors that fall under three main categories: knowledge and perceptions, values, and norms. In order to include all the components of influence, we created the Triple C model: "Culture influences Choices towards genetic Counseling" which aims to generalize the complex decision making considerations that we detected. Our model places religion, as part of culture, as its central point of influence that impacts all three of the main categories we detected. It also traces the bidirectional influences that each of these main categories have on one another. Using this model may help identify the sociocultural differences between different types of patients, helping genetic counselors to better assist them in addressing their genetic status by tailoring the counseling more specifically to the patient's cultural uniqueness.

Merav Siani sianim@post.bgu.ac.il **Keywords** Genetic testing · Decision making · Semi-structured interviews · Qualitative analysis · Religion · Norms · Values · Genetic knowledge · Genetic perceptions

# Introduction

With the scientific and the genetic progress of the last three decades, genetic diseases can now be detected before or during pregnancy, which can drastically reduce the rates of hereditary diseases, and which makes genetic counseling an essential domain in every society. And yet, the willingness to receive counseling and genetic testing is not always common in every society, and is influenced by the individual's cultural background, and by factors like family, tradition, history, privacy and religious faith (Raz and Atar 2003; Shaw 2011; Ten Have 2001). In this study we sought to portray how these elements come together in the case of Israeli religious students, and to examine the complex considerations they take into account while facing the need to undertake genetic testing or to go to a genetic counseling session. To do so we analyzed a series of in-depth interviews that we conducted with 51 religious Jewish undergraduate students who are studying in universities and colleges throughout Israel, adopting a qualitative grounded theory approach so as to capture the complexity of the decision making process.

Decision making is a complex process, especially in a domain like genetic testing, which must take numerous considerations into account. Genetic testing is a general term, encompassing a variety of available tests that can provide information about a person's genes and chromosomes. In this article we shall concentrate on prenatal genetic testing, which is used to detect changes in a fetus's genes or chromosomes before birth. It is offered during pregnancy if there is an increased risk that the baby will have a genetic or chromosomal

<sup>&</sup>lt;sup>1</sup> Science and Technology Education Department, Ben-Gurion University of the Negev, Beer Sheva, Israel

disorder (National Library of Medicine, US, http://ghr.nlm. nih.gov/handbook/testing/uses, Accessed 10 Feb 2016).

Discovering a genetic disorder through prenatal testing raises various moral questions, such as the possibility that prenatal genetic counseling and decisions could violate the future child's autonomy and rights. These rights could be violated, for instance, when prenatal testing reveals a predisposition for a late-onset disease that cannot be treated or prevented and the woman decides to continue the pregnancy, thereby deciding, in place of the child, that it will live with an incurable disease (de Jong et al. 2011). This kind of moral question does not arise when adults perform genetic testing and decide for themselves which measures to take in response to their own test results. Prenatal genetic testing also raises questions regarding the need to inform other family members of their risk (Fulda and Lykens 2006), especially those who might be pregnant, for whom this information might be crucial. The question of informing others arises in general genetic testing too, but often in a less immediate manner.

The complexity of decision making in the field of genetic testing is reflected via the complexity of the definitions offered for informed decision making on genetic issues. Briss et al. (2004) defined informed decision making in the genetic domain as occurring when individuals understand the nature of the disease or condition being addressed, understand the clinical service and its likely consequences - including risks, limitations, benefits, alternatives, and uncertainties, have considered their own preferences as appropriate, and have made a decision consistent with their other preferences and values .Rimer et al. (2004) address similar issues, claiming that informed decision making includes understanding the screening test, its risks, benefits and alternatives, understanding the pros and cons of the genetic test accordingly.

These definitions show how the procedure can be quite a complicated one for any person, but for religious individuals the considerations are even more complex. Religious undergraduate students' decision making in these issues is influenced not only by medical recommendations, but also by their religious values, their tradition, and the religious rules to which they are committed (Stephens et al. 2010; Phillips et al 2000). These two things do not always agree, adding an element of the general tension between faith and science (Dickerson et al. 2008) to the already complicated process of informed decision making in this specific domain. Because genetic counseling can sometimes contradict religious positions, it is necessary (if such counseling is to be successful) to understand the impact of this cultural element on the process of decision making in the context of genetic counseling (Weil 2001).

This is why we have chosen to focus specifically on the religious population, in an attempt to broaden our understanding of decision making in the domain of genetic testing and genetic counseling. Other researchers have already identified various factors that influence the layperson's decision making in the genetic testing domain (see Table 1). Our interviews were designed to complement the factors detected by other researchers while expanding the attention devoted to the religious factor, which has been less extensively researched.

# **Theoretical Background**

# Decision Making in the Field of Genetic Testing and Genetic Counseling

Our literature review revealed a set of factors that influence decision making in the field of genetic testing and genetic counseling. One of the more dominant of these is the explicit genetic knowledge that the counselee had previously acquired (Chen and Goodson 2007; Frets et al. 1990; Vos et al. 2012; Wilson et al. 2011), as well as the procedural knowledge of the counseling process (Biesecker and Peters 2001). These aspects also include knowledge of the statistical facts associated with the perceived risk for genetic diseases (Schwartz et al. 2000), and the reliability of the information given to the counselee (Skirton 2001), since some genetic tests give uncertain test results. Counselees' knowledge of certain genetic diseases is often influenced by their familiarity with the disorder due to their acquaintance with relatives who are affected by this genetic disease (Frets et al. 1990). From the counselor's side, knowledge includes the extent to which the counselor knows the family and is aware of all of its genetic history (Geer et al. 2001; Frets et al. 1990; Caruso et al. 2011).

Aside from knowledge, another central factor that influences decision making is the counselees' attitudes and perceptions towards complex genetic testing; how the need for genetic testing fits into their world view. This is not unconnected to knowledge, since better informed people tend to be more positively inclined towards genetic counseling (Vos et al. 2012). The relevance and authenticity of the genetic knowledge or the genetic situation to the counselee's life is influential too (Vos et al. 2012). This factor includes the counselee's attitude towards the consequences of getting results of genetic testing (e.g. how they might impact things like health insurance and employment) (Morren et al. 2007). The counselees' tolerance for the uncertainty involved in genetic testing and their perception of its reliability both influence the acceptability of the testing in their eyes. This perceived reliability depends in part upon the level of trust that has been formed between counselee and counselor (Skirton 2001).

Religion and ethnicity have also been shown to contribute to this domain of decision making. There is a connection between people's spirituality and their likelihood of receiving test results, and between their level of religiosity and the way they perceive genetic testing (Botoseneanu

#### Table 1 Literature review of the factors influencing decision making in the field of genetic testing and genetic counseling

The Factor	Reference	
A. Genetic Knowledge		
1. Explicit knowledge been acquired	Chen and Goodson 2007; Frets et al. 1990; Vos et al. 2012; Wilson et al. 2011.	
2. Procedural knowledge acquired	Biesecker and Peters 2001.	
3. Knowledge passed in the counseling session	Caruso et al. 2011; Frets et al. 1990	
4. Acquaintance of the counselor with the family's genetic history	Caruso et al. 2011; Frets et al. 1990; Geer et al. 2001.	
5. Acquaintance of the counselee to genetic disorders	Frets et al. 1990;	
6. Knowledge of the genetic statistical facts	Schwartz et al. 2000.	
7. Reliability of the information to the counselee	Skirton 2001.	
B. Attitudes and perceptions		
1. Attitudes to genetics according to the way they are informed	Vos et al. 2012.	
2. Attitude to health insurance and employment	Morren et al. 2007	
3. Relevance and authenticity to the counselee's life	Vos et al. 2012.	
4. Tolerance to uncertainty in genetic testing and the level of reliability	Chen and Goodson 2007; Skirton 2001.	
5. Attitudes towards the acceptability of abortions	Chen and Goodson 2007; Wilson et al. 2011.	
C. Religion and ethnicity		
1. Spirituality and likeliness to receive test results	Botoseneanu, Alexander, and Banaszak-Holl 2011; Schwartz et al. 2000.	
2. Level of religiosity in connection to the way people perceive genetic testing	Botoseneanu, Alexander, and Banaszak-Holl 2011; Schwartz et al. 2000.	
3. Ethnicity as a part of culture	Chen and Goodson 2007	
D. The personal factor		
1. Meeting the client's needs and expectations from genetic counseling	Biesecker and Peters 2001.	
2. Client's willingness for risk assessment and personal risk	Frets et al. 1990; Geer et al. 2001.	
3. Parity including the family structure and the desire for children	Caruso et al. 2011; Emery, 2001; Frets et al. 1990; Wilson et al. 2011.	
4. Practical motives:		
a. Cost of the tests	Chen and Goodson 2007; Geer et al. 2001	
b. Access to genetic counseling	Geer et al. 2001	
c. Time commitment	Geer et al. 2001	
5. Socioeconomic status to which the counselee belongs	Chen and Goodson 2007	
6. Privacy concerns	Geer et al. 2001	
7. Emotional factors		
a. Fear from genetic social stigma	Geer et al. 2001.	
b. Depression, over excitement and feelings towards the counseling process itself	Biesecker and Peters 2001.	
c. Internal locus of control	Chen and Goodson 2007.	

et al. 2011; Schwartz et al. 2000). The contribution of religion and ethnicity to this process is described in greater detail below.

Decision making in the field of genetic testing and genetic counseling is also influenced by **personal factors**. This includes meeting the client's needs and expectations from the genetic counseling process, including their requests for help or for information (Biesecker and Peters 2001). It also includes the client's willingness to undertake risk assessment and personal risk (Frets et al. 1990; Geer et al. 2001) and their family

structure - if the couple has children or not and the desire of the couple for children (Caruso et al. 2011; Chen and Goodson 2007; Frets et al. 1990; Wilson et al. 2011). Personal reasons also encompass practical concerns, like the cost of the tests (Geer et al. 2001; Chen and Goodson 2007), time commitment to the procedure (Geer et al. 2001) and access to genetic counseling. Privacy is also a relevant personal factor, reflected in the counselees' concern that the personal genetic information revealed in the process should not become public (Geer et al. 2001).

Finally, the **emotional aspect** of the counseling process is a very influential personal factor. It includes elements like fear of the social stigma that might be involved in genetic decision making (Geer et al. 2001), as well as depression, overexcitement and feelings towards the counseling process itself - all of which can influence the decision to attend (or not to attend) counseling (Biesecker and Peters 2001). Internal locus of control, meaning the extent to which individuals believe they can control events around them, including the health domain, is one of the affective factors that influence decision making, as are additional factors like socioeconomic status, ethnicity and culture (Chen and Goodson 2007).

#### **Religious Influences on Genetic Decision Making**

As mentioned above, religion and ethnicity contribute to the domain of decision making in the genetic domain (Botoseneanu et al. 2011; Schwartz et al. 2000). Religious beliefs, as part of one's cultural background, affect one's approach to science in general and to genetics in particular. It has been shown that there is a tension between science and religion, and that it is therefore necessary to integrate religious beliefs into the understanding of science (Starr 2010). A positive attitude toward science has been shown to be coupled with a strongly negative attitude toward religion (Astley and Francis 2010) The effect of religious beliefs on attitudes toward science have been shown in cases as wide ranging as Muslim society in Saudi Arabia (Aqueel 2007), Chinese society in Australia (Ota Wang 2001), Pakistani society in Great Britain (Shaw and Hurst 2008) and religious women in Italy (Pivetti and Melotti 2013). They were also noted amongst African and Latin Americans, who claimed explicitly that their faith/religion would influence their prenatal testing decision, with some patients arguing that "accepting what is given, " for example a sick child, is part of their cultural belief system, leading to these women undergoing prenatal diagnostic testing less often (Learman et al. 2003). In all these societies, religious or traditional beliefs can, at times, contradict genetic recommendations, and therefore influence decision making.

Regardless of the type of education received, most of the religious populations that have been investigated believed that only God knows why a given situation occurs, and therefore did not necessarily wish to intervene before or during pregnancy, since they believe the situation is not in their control anyway (Pivetti and Melotti 2013; Shaw and Hurst 2008). And yet, there is not always an exact correlation between belief and behavior. Though religious people usually prefer to rely on God, there are cases when - despite the fact that religious rules do not permit abortion, some religious people nevertheless choose to do so if their fetus is sick (Raz 2009). Generally speaking, religious conviction has been found to be an important influence, but not the only one, reflecting the fact that religious identity is a complex, fluid and negotiable

phenomenon (Atkin et al. 2008). This complexity has not yet been widely researched in Israel, especially among religious undergraduate students. This study therefore focusses specifically on that population, in an attempt to thoroughly understand the factors that influence these students' decision making and their considerations while making choices in this field.

## **Genetic Counseling in Israel**

The Organization of Genetic Counselors in Israel (http://www. genetic-counselors.org.il, Accessed Oct 2015 ) offers the following extended definition of genetic counseling, citing it as "an interpersonal process in which information is offered on issues connected to human genetic diseases and their nature, inheritance, implications, and recurrence in a family at risk, after the counselor has investigated the family issue and ascertained the mode of inheritance and the chances of passing it on to future generations." This counseling is referred to as "non-directed," because its purpose is "to help those counseled in making medical decisions in a non-directed manner [that is] appropriate to their values." As this definition shows, genetic counseling includes the following components: 1. Interpretation of family and medical histories to assess the chance of disease occurrence or recurrence. 2. Education about inheritance, testing, management, prevention, resources and research. 3. Counseling to promote informed choices and adaptation to the risk or condition (Resta et al. 2006).

Israel is a highly varied multicultural society, and approaches to genetic testing and genetic counseling can therefore differ strongly among the different subcultures. Israeli society also includes a large non-Jewish population, including Christian and Moslem Arabs, Druze, and Bedouins. Our study focuses only on the Jewish population, because properly and responsibly addressing the significant cultural and religious differences that distinguish all of these groups from one another is a task far greater than the scope of one study. The Jewish Israeli population consists of four broad categories of religious affiliation, namely secular, semi religious or "traditional", National Religious and Ultra-Orthodox. These categories - and the cultural connotations they imply - are familiar to the general public, and most Israeli Jews associate themselves with one of these four groups.

This study focusses on the National-Religious sector, which, based on self-declared affiliation, has been estimated to constitute roughly one-fifth (22 %) of Israel's adult Jewish population (Herman et al. 2014). This sector shares some (chiefly religious) characteristics with the Ultra-Orthodox sector, but also has others in common with the secular sector (Frumkin et al. 2011). In the field of genetic services, most of the Israeli population uses those of the genetic clinics in hospitals in addition to clinics in health insurance organizations, but the Ultra-Orthodox Jewish population is treated mainly by the "Dor Yesharim" Foundation. According to the principles of "Dor Yesharim," before a match is made by a matchmaker, the couple's genetic suitability must be checked (Abeliovich et al. 1996). This foundation does not publicize its findings, but it does alert the couple if there is a genetic incompatibility, suggesting that the couple should therefore not marry (Frumkin et al. 2011). Among the National Religious sector, young people date in a more random manner. They therefore generally find the "Dor Yesharim" approach inappropriate (Frumkin et al. 2011).

Apart from their different utilization of genetic services, differences in religious belief and custom are clearly reflected in differing genetic practices in Israel. The rejection of pregnancy termination by many religious communities often prevents participation in genetic testing (Rosner et al. 2009). In Ultra-Orthodox Jewish society, women refrain from doing amniocentesis because of religious restrictions that forbid selective abortion, whereas in secular Jewish Israeli society prenatal diagnosis and selective abortion are supported, independently of the rabbinical stance (Raz 2004). The National Religious sector shows a higher percentage of performing genetic tests than the Ultra-Orthodox, though still lower than that of the secular sector (Sher et al. 2003).

#### Life-Long Learning in the Context of Genetic Testing

In addition to a positive attitude towards taking the tests, informed decisions about genetic testing also require those who make them to have sufficient knowledge of the testing options and of their own genetic background. Lack of knowledge is sometimes the driver of negative attitudes and biased risk perceptions towards science (Bauer et al. 2007), and is even associated with more discriminating attitudes towards science in general (Evans and Durant 1995). Researchers have realized that the participation of the public in scientific decisions is crucial, since the public no longer trusts scientists blindly, and areas such as genomics and modified food are giving rise to many ethical and social dilemmas in which the scientists are trying to involve the public (Wilsdon and Willis 2004). Thus, as the public gradually becomes more involved and gains more knowledge, their decision making will also become more informed.

As a reaction to the lay public's lack of sufficient knowledge in different subjects, including biology and genetics, there has been an effort to expand education beyond high school learning, enabling the lay person to make informed decisions based on a wider scope of knowledge. This is referred to as Life Long Learning (LLL) and occurs in any situation, at many stages of life. It includes all formal, nonformal and informal learning - be it intentional or unanticipated, which occurs at any time across the individual's lifespan (Candy et al. 1994). Life-long learning can also impact our attitudes and values towards fields with which we are acquainted (Field 2000). Since we are flooded with information all the time and we cannot learn all of it at once, it is an essential challenge for societies to make life-long learning a habit for people to acquire (Fischer 2000; Coffield 2000). This is true in all subjects, especially in those that are beneficial to the population, like genetics and genetic testing. In these fields scientific progress is occurring every day, and by the time today's students become parents it may be that standard obstetrics packages will include sequencing the baby's genome (Redfield 2012).

Given the above, life-long learning should be authentic (Ashton 2010; Hamilton et al. 2013) and relevant (Hamilton et al. 2013), especially in the field of genetics (Redfield 2012), since many families deal with rates of risk for genetic diseases and genetic dilemmas during the course of their lives. Authentic and relevant long-life learning is important for informed decision making in the area of genetics, since it would allow each person to make their own decisions based on firm knowledge according to their ethnic affiliation, country of origin and the genetic diseases existing in their family.

# Relevance of Genetic Counseling for the Young Generation in Israel

It has been suggested in the literature that the evaluation of the considerations influencing decision making in the genetic testing domain should take place at an age when genetic tests and genetic counseling are relevant and immediate. For example, Frumkin and Zlotogora (2007) noted that the ideal age for screening a population for autosomal recessive diseases is before the first pregnancy, at an age in which one can make mature decisions regarding these tests. In addition, young people are exposed to current information, which increases their ability to absorb new ideas. The level of genetic knowledge tends to be inversely proportional to age, and is highest in the 18-25 age range (Ashida et al. 2011), the age of most students at universities and colleges. This therefore seems the most appropriate age to target in order to evaluate genetic decision making. Undergraduate students are at the appropriate age at which to take advantage of their genetic knowledge, to weigh the risks, limitations, benefits, alternatives, and uncertainties, and to implement all these in order to make informed decisions either immediately or in the near future.

The students in this study belong to the millennial generation, a term that refers to individuals born between 1982 and 2005, who constitute the newest generation to enter the workforce. Leaders across disciplines are taking note of the challenges and opportunities associated with training (as young doctors for example) this generation, which has grown up highly protected and told by their parents that they are "special" and "winners". Eckleberry-Hunt and Tucciarone (2011), for example, examined the training of young doctors in the US and found that this generation has been raised on the values of free expression and accustomed since childhood to the intensive use of technology. In addition, Twenge (2014), who researched young Americans, found that some of them see religion as "old-fashioned," and are less committed to religious rulings, feeling that they have their own personal beliefs to lead them and tell them what is right. As such, it seems that their responsibility to religious obligations is lower, while their concern for their own well-being is higher. Although each of these studies relates to a specific population, of the cultural similarities brought on by globalization give us sufficient ground to look into the possibility that their findings may be relevant to our local population as well.

#### **Research Questions**

According to Creswell et al (2007) and Yin (2009), research questions guiding case study inquiry should address 'how' and 'why' questions so as to better understand the phenomenon being observed (in Governor et al. 2013). Our research was designed to explore the students' decision making considerations, so our research questions are:

- 1. How do Jewish religious Israeli students perceive genetic testing and counseling?
- 2. How does the students' religious belief influence their perceptions regarding genetics?

#### Methods

#### Sample

The population in this research included 51 undergraduate students who belong to the National-Religious sector in Israel. Generally speaking, the Jewish religious population in Israel is currently highly integrated into secular society (Herman et al. 2014). Members of religious sector work in all places: in the high-tech industry, in the army, in the communication system and so on, and see themselves as a part of the general society, as well as observant followers of religious rules. The participants in this study came from 3 universities (78 % of the students) and 3 colleges throughout Israel. Forty three percent of them study life sciences and the rest study other subjects such as sociology, physics, economics etc. Of the interviewees, 49 % are women and 39 % are married. The age range of the interviewees is 20–29, with an average age of 23.9. Fifty seven percent of them live in large cities, 22 % in medium sized cities and the rest in small villages or other rural localities. This study was reviewed and approved by an ethics committee.

#### What Does it Mean to be a "National Religious" Jew?

Being a National Religious Jew has everyday implications to one's life. The National Religious sector is made up of many smaller, tight-knit communities ("kehilot"). The members of a community attend the same synagogue (a Jewish house of prayer), meet regularly to celebrate holidays, births, marriages etc., and aid one another at different stages of life. The community therefore plays a central role in its members' lives, as do the shared norms, values, and behavioral expectations that come with it.

It is important to note, however, that National Religious communities are not as physically and culturally separate from Israel's secular society as those of the ultra-Orthodox Jews tend to be. This sector usually lives in mixed neighborhoods, unlike the ultra-Orthodox who live in their own homogenous neighborhoods, separated from the secular population. The National Religious Jews serve in the military and are completely involved in all sectors of Israel's working life, unlike the ultra-Orthodox who usually work in their own community or study Torah (the central reference of the religious Judaic tradition) while their women go out to work.

One of the most central figures in a National Religious community is its rabbi. National Religious Jews believe that the Halacha (Jewish Law) should be observed literally, and the rabbinical authority is therefore very influential in their decision making in all aspects of life. However, because the National Religious sector is influenced by rabbinical rulings and by the modern society, the range and diversity within this sector regarding the degree to which the rabbi should be consulted is very great. The Rabbi can be consulted about all aspects of life, including number of children to have, the degree of contraception it is permissible to use, which job to take, whether and how to conduct genetic tests etc. Some members of this sector, who have studied the basic rulings or have a lower commitment to the rabbinical ruling, count on themselves to decide on these and other topics. Others consult their Rabbi on every controversial topic of their lives, while most lie somewhere in between these two extremes. This diversity has led to the formation of sub-sectors among this community, though they all define themselves as belonging to this same sector.

Belonging to one of these communities sets expectations to its followers in the field of marriage and having children. While the total fertility rate of the ultra-Orthodox sector is around 7 children, in the National Religious sector it is about 4 births per woman, compared to approximately 2 births per woman in the secular sector (Friedlander and Feldmann 1993). Regarding the age of marriage, in National Religious families the age of marriage is higher than among the ultra-Orthodox and lower than among the secular sector. All these issues are discussed daily at the community level, leading to deliberations on the personal and society levels.

#### Values and Norms in the National Religious Sector

# Values are known as one of the components that influence the making of choices between alternative courses of action (Dietz et al. 2005; Kortenkamp and Moore 2001; Oreg and Katz-Gerro 2006; Stern et al. 1999; Stern 2000). For the purpose of our study, values are defined as 'the principles people use to select and justify their actions and to evaluate people and events.' The value priorities of individuals are affected by their social experiences, such as religion, gender, education, occupation, and cultural background, but are designed by the individual. In turn, values also influence individuals' actions in domains such as religion and environment (Schwartz 1992). The values that are spoken about among the National-Religious Sector, for example, reflect the duality of their exposure to both a religious and a secular value system. The principles upon which they rely when addressing issues like genetic testing and abortions can draw on arguments from both realms; and this duality can lead to conflict because the religious rulings do not always meet the medical ones.

Values are sets of beliefs used by individuals to guide their behavior. Norms, on the other hand, are codes of conduct set by a society that dictate that society's guidelines for "normal," acceptable behavior. A working definition for norms is that they are expectations about behavior that are at least partially shared by a group of decision makers (Gibbs 1981; Moch and Seashore 1981; Thibaut and Kelley 1959). Some norms are 'social norms,' which are abstract and less definite guides to behavior, but are shared by all individuals of a group. Others are more 'personal norms,' which are expectations that people hold for themselves (Schwartz 1973).

In the context of this study, the National Religious sector is marked, for instance, by the norm that marriage is an act for which it is common practice to prepare oneself by gathering genetic information. Moreover, genetic testing is accepted as a topic that is open to personal consideration, ambivalence and deliberation. The norms of the national religious sector allow individuals room to be ambivalent about genetic testing, and to include their personal inclinations or affinities for the topic - as well as the consequences of the testing - as factors in the decision making process. Another important norm that affects the National Religious sector's relationship to the topic of genetic testing is the individual's responsibility to the family unit. This is reflected in strong considerations of how genetic information will affect the family - for instance, to what extent is the individual responsible for notifying the family of a potential common danger? Alternatively, to what extent is the individual responsible for protecting the family from the public revelation of information that might put a stigma on the family as a whole, leading to difficulties for other family members wishing to marry into other families in the sector?

#### The Qualitative Methodology

This study is based on qualitative data gathered by means of in-depth interviews. Qualitative methods are used to address research questions that require explanation or understanding of social phenomena and their contexts as well as identifying the important influences of these contexts (Ritchie and Ornston 2013). They are suited to exploring issues that hold some complexity and to studying a process that occurs over time (Ritchie 2003). The dilemmas in the field of genetic testing are complex and socially interconnected. They involve individuals as well as their close and extended family, and even their wider social circles. Moreover, decision making in this area is connected to the individual at several stages of life, and might be required of us more than once during our lives. All these sources of complexity led to the choice of a qualitative methodology as suitable for this research.

#### The Research Tool - The Interview

The construction of the interview was based on a review of the literature on decision making in relation to genetic counseling over the last 15 years (see Table 1). This review raised four main factors that are deemed most influential in the decision making process for the field of genetic testing and genetic counseling: genetic knowledge, attitudes and perceptions, religion and ethnicity and the personal factor (including the emotional factor). In light of these factors, we constructed the interview to address all these main subjects and their subtopics, so each question relates to one or more aspects of these 4 main concepts. Since the interview is open ended, the students can raise a wide range of categories for each question to reflect their personal, cultural point of view, sometimes far beyond the topics that the question had been designed to address.

A list of the interview questions, and an indication of how each question relates to the factors in the literature review, is provided in Table 2. The table is divided into two sides. The right side shows the interview questions while the left states the concept to which the research question relates. The concepts are taken from Table 1, which details the literature-based list of factors influencing decision making in the field of genetic testing. For example, Table 2 states that question number 3 relates to the concept "A1," which, as Table 1 shows, refers to the first component (1) of the first determining factor (A), or in other words, the concept 'explicit knowledge acquired,' which is part of the 'genetic knowledge' factor of the decision making process.

The use of individual interviews provided an opportunity for detailed investigation of people's personal perspectives and context (Lewis and McNaughton Nicholls 2013; Patton 2005; Ritchie 2003). We used a standardized open-ended interview because we wanted to minimize the variation between

#### Table 2 Semi-structured student interview

General Questions:	Decision making factors addressed by this question (see Table 1)
1. Some argue that science is important in our lives. What do you think?	Scientific knowledge
2. Do you think that science gives us definitive answers following its research? Is there a difficulty with this (according to your answer)?	Scientific knowledge; B4
3. What does the term genetics mean to you?	A1
4. Do you think genetics relates to you personally?	A2; A5
5. When do you think genetics can be useful for you during your life?	B3
6. Are you acquainted with the field of genetic counseling? (If not, the interviewer explains what it is).	A3; D4b; D1
<ul><li>7. Today it is possible to make a variety of genetic tests before and during pregnancy. Do you think one should take maximum genetic tests to rule out fetal diseases?</li><li>8. Is there a particular test you would like to take for your own child during or before pregnancy?</li></ul>	B4; A6; A7; D4a; C2 D1; D4c
9. Do you understand why people prefer not to receive genetic information?	D7a; D6; B2
10. There are people who are afraid of genetic information. What do you feel about that information?	D7a; D7b
11. Are there any genetic issues that you take into consideration when you choose (or have chosen) a mate?	D5; A6
12. Do you know people who take genetic considerations into account when choosing a mate? Can you understand this approach?	D3
<b>Case 1</b> : Rachel comes to a genetic counseling session during her first pregnancy. During the consultation session she confesses that she has a mentally retarded brother. She was always told by her family that her brother's birth occurred with an abnormal supply of oxygen, and therefore he was mentally retarded. Rachel is interested in doing all possible genetic tests to determine whether her fetus has a risk of mental retardation, but does not want her family to be aware of the genetic testing she is conducting. She has brothers and sisters who do not have children yet and she is aware of the fact that not only her parents but also her brothers and sisters might be carriers of the gene for mental retardation. She does not want to share the fact that she has performed genetic tests, and what their results were. She is tested and found to be a carrier of a gene that causes mental retardation. Happily, her fetus is tested and found to be normal.	
1. In your opinion, what ethical questions arise from this case?	C3; B5
<ol> <li>What considerations and dilemmas can rise from this case, assuming we know that the syndrome causes inherited mental retardation?</li> <li>Case 2: Huntington's disease is a genetic disease caused by a dominant gene mutation. Symptoms of the disease usually begin in adults from the age of 40. Until then there are no signs of illness. The disease</li> </ol>	
is fatal after a period of suffering.	
1. Do you think every child should be checked for this disease as soon as he is born? What is your dilemma?	B4
<ol> <li>Assuming the disease exists in a family, do you think the fetus should be checked even if the test itself imperils the pregnancy?</li> <li>Do you agree that it is better the person does not know if he has the gene for this disease?</li> </ol>	B5
Case 2: Some kinds of desfrees have been found to be equived by mutations. Nowedays it is possible to	<i>D</i> / <i>C</i> , C1
examine a fetus prenatally for mutations that cause deafness.	
1. If you find in genetic testing that your fetus would be deaf, do you think you should have an abortion?	В5
2. Do you think that you should check the genes for deafness and allow the family to cope with the information?	C1; D2
3. Do you think the state should fund research that deals with diseases such as deafness, which do not cause death?	D4a
<b>Case 4:</b> Nowadays, researchers use an in vitro procedure called Pre-implantation Genetic Diagnosis (PGD) to test embryos for inherited diseases that exist in the family before they are introduced into their mother's womb. In this method, only the healthy embryos will be implanted into the mother's womb.	
1. Do you think this test has future ethical dangers?	C3
2. Do you think the ethics committee of the hospital is competent to decide whether to carry out these tests rather than individual?	A4; A6
Case 5: Thanks to genetic research early detection of genetic diseases is now possible.	
1. Assuming there is no treatment for the disease; do you want to be tested for the genetic disease?	A6; A7
2. Would you inform your family about genetic test results that you have done?	A4; A5; B1
3. Would you want a genetic survey to inform you that you are at risk for a genetic disease?	D7c; A5

The letters and numbers in the right hand column refer to the factors influencing decision making that are summarized in Table 1. For example, factor B4 refers to the major factor B: 'attitudes and perceptions', and to sub-factor no. 4: 'tolerance to uncertainty in genetic testing and the level of reliability,' and factor D4b refers to the major factor D: 'the personal factor' and sub-factor no. 4:' practical motives', which includes the further sub002Dcategory b: 'access to genetic counseling

the different interviewees (Patton 2005). In addition, the interviewer, like the interviewees, is a member of the National-Religious sector, and is therefore personally attuned to the sensitivities and nuances in the students' words. This also contributed a measure of identification between interviewees and interviewer, allowing the interviewees to feel free to speak in terms the interviewer would understand.

The students volunteered to be interviewed after we advertised on the notice boards of their institution that we are looking for religious students for an interview on genetic issues. The interviews were held during the 2013 academic year, and the students were told that the interview is confidential and that its findings would be used for research purposes only. Each interview lasted 45–50 min, and took place in a quiet place at the university, for the students' convenience.

We decided to interview a large amount of students, since we wanted a sample of both genders as well as a sample of different domains of study and different marital status. We wanted to grasp the complexity of decision making in the genetic domain, but also maintain a comparison between the different groups, which we would not be able to do if we had interviewed fewer students. We continued interviewing more participants so long as we were getting different answers (Baker and Edwards 2012). After conducting 51 interviews, we reached a point in which we sensed, as suggested by Baker and Edwards (2012), that we had encountered a sufficient amount of repetition with which to confidently make analytical generalizations.

#### **Data Analysis**

The analysis was conducted in stages. First we conducted a "thematic analysis" (Boyatzis 1998; Dey 1999) in order to obtain the main themes that arose from the answers. The second stage was obtaining the codes from the thematic analysis. This was done according to "grounded theory" analysis (Corbin and Strauss 2008; Glaser and Strauss 1967), taking into account our literature review while coding the replies according to codes that were modified until saturation. The third stage started with our reflective process. After we had conducted a few interviews, we came to see some of the codes differently, and realized that some categories should be added. This resulted in another code refinement for all the interviews, followed by a peer and auditor debriefing. The codes were validated by peers that were involved in the research and by external researchers (Creswell and Miller 2000), and based on the validation process the codes were refined again. In the fourth stage we refined the codes (a total of 67), and produced the final categories. We then proceeded to recode all the interviews according to the new code scheme using ATLAS-ti, the Qualitative Data Analysis & Research Software.

"ATLAS.ti offers myriad analytic tools that allow the researcher to quantify qualitative information through coding, data query, cross-tabulation, and networked visualization of project design" (Scales 2013). Most of the interviews were used in ATLAS.ti as audio files. ATLAS.ti can code segments, integrate material, attach notes and find them again, count the number of codes and more; all this makes it much easier to analyze data systematically, while doing so manually would have been much more time consuming and less accurate (Friese 2014).

In accordance with the qualitative grounded theory approach, our goal was to enable the respondent's voice to be heard (Kvale 1996) and not to force our pre-existing categories. After listening to and transcribing the interviews, we conducted a line by line detailed microanalysis coding process in order to generate initial categories (Devers and Frankel 2000). The analysis produced three groups of primary categories, which together add up to the factors influencing the decision making process of the Israeli religious student in the domain of genetic testing. The codes were grouped into sub categories; knowledge, perceptions and attitudes towards genetic testing (Fig. 1) norms (Fig. 2) and values (Fig. 3).

Each category tree is divided into a several major categories and their respective sub-categories. The **knowledge and perception** tree (Fig. 1) includes the 3 major categories: 1) "Perceptions towards science in general" (included the subcategories, "perceptions regarding what science does" and "criticism towards science"). 2) "Knowledge and understanding of genetics" (included "perceptions regarding what genetics is" and "perceptions regarding the practical applications of genetics"). 3) "Factors involved in decisions to undergo/ act upon genetic testing" (included five sub categories, among them "consequences of raising a sick child," "reference to the severity of the genetic disease" and "perception of risk").

The norms tree (Fig. 2) includes 4 major categories. The first, "Genetic preparation for marriage," included genetic preparation both with and without the "Dor Yesharim" program. The second and third categories ("adapting genetic testing to what is acceptable in the community" and "individual responsibility towards the family") reflected the influence of the individuals' relations with their religious community and with their family on their decision making. The fourth and largest category, "genetic testing is open to personal consideration, ambivalence and deliberation" reflected the range of personal thoughts and feelings that, in their recurrence, seemed to be an acceptable and "normal" part of the interviewees' decision making process. This category included an acknowledgement that various aspects of this topic could be seen as sources of ambivalence; it also included an awareness of the personal impact of decisions in this field, as reflected in the importance of "personal inclination to undergo testing" and the "personal consequences of genetic testing."

The values tree (Fig. 3) includes 4 major categories, which together reflect the dual presence of both religious





and secular values in the National Religious students' lives. The first two categories reflect the students' "Philosophical religious considerations" (such as the religious arguments in the for and against humanity's intervention in nature) and their "practical religious considerations" (including "relying on religious doctrine as a guide in decisions relating to genetic testing and procedures"). The third and fourth categories reflect the students' more secular value set. This is divided into "'universal' ethical considerations" (like basing the termination of a pregnancy on criteria like the severity of disease, or basing one's attitude towards genetic testing on whether or not it constitutes a " slippery slope"), and "considerations based on 'rights" (like the "rights of the family" and "the right of life").

Each of the sub-categories in the category trees unites several codes that emerged from the students' interviews. Using the Atlas software, we counted the number of students that mentioned each code during the interview. The numbers beside each code represent the percentage of students who mentioned it during their interview.

#### Validation and Reliability

During the data collection we made an effort to maintain analvsis reflexivity - to be as sensitive as possible to the ways in which we collected data and to minimize any bias due to prior assumptions or experience. As Mays and Pope (2000) advised, personal and intellectual biases were made plain at the outset of the research report to enhance the credibility of the findings. Since every researcher interprets the data according to their own subjective perspective, content validation was done with the aid a few experts from different areas of expertise, so as to capture as wide a view as possible while defining the final codes (Elo and Kyngäs 2008). These included two specialists in genetics and in science education and a researcher from the science education field, all with extensive experience in qualitative analysis. In addition, as Graneheim and Lundman (2004) have suggested, a dialogue took place between the researchers to agree on the way in which the data is categorized. This procedure took place twice, in two rounds, to assure the accuracy of the categorization.



Fig. 2 The norms category tree

#### Results

Our main findings are organized in the three category trees (Figs. 1, 2 and 3) from which we have derived most of our results. The trees raise insights as to the issues that concern, interest or trouble the students, all of which influence their considerations while making decisions regarding genetic counseling and genetic testing. The result analysis shall be divided into two parts: the first will deal with the complex decision making and considerations of the students as a whole, in which we shall lay out **three main claims** that we have formulated in light of our findings. The second part will focus on 3 of the students for which faith is a central value, showing the complexity of their concerns and addressing the diversity of the students that belong to this sub-sector. Throughout the results section the quotations from the interviews will be followed by the students' code, their field of study and their age.

The first claim we shall try to demonstrate in our portrayal of the students as a whole is that Israeli religious

undergraduate students, despite their adherence to the rules and traditions of a religious way of life, are - in their approach to issues of genetic testing - ultimately very close to what might be broadly characterized as 'Western' thought, in the sense that they show a considerably high level of trust in science and in scientific innovations. Our findings showed that, at least when it comes to this particular context, science is an integral part of these students' lives, while their commitment to family and religious society is a less significant influence. In addition, the participants' desire for a healthy child comes across strongly as a central concern.

Nearly all of the students we interviewed agreed that science contributes to the world's development (96.1 %) and that science explores things that help society (84.3 %) (see Fig. 1, perceptions towards science in general, perceptions regarding what science does). Their knowledge comes from diverse sources such as television, radio and the internet, as indicated by responses like, "*Science can improve quality of life. I heard yesterday on the radio that there was a breakthrough cure for* 



Fig. 3 The values category tree

*cancer. Research in science helps people" (PL, education, 23).* Moreover, the students' belief in the benefits of science is not limited to the field of medicine: "*the world is nurtured by science also in the field of communication, transportation" (YN, accounting, 25).* 

The interviews suggest that these students' opinions are guided by a belief in scientific progress and a liberal, 'Western' sense of morality, and not necessarily by religious considerations. This argument is supported, for example, by the fact that students refer to the "slippery slope of genetic testing" argument as a universal moral issue rather than as a religious concern: "you shouldn't enable the public to check anything they want (in genetic testing) since it can lead to checking eye and hair color. That's not ethical, it's like making an army of robots" (SA, biology, 25). The same is true of the opinions they expressed regarding the universal right of the disabled to live in society.

The claim that the students were more strongly influenced on this issue by 'Western' considerations than by traditional or religious ones was further supported in the "norms" category tree (Fig. 2), which showed that most of the students (80.4 %) think that genetic background is not a relevant factor in choosing a mate (Fig. 2, genetic preparation for marriage, looking into the partner's genetic background). It is worth noting here that in the Israeli religious population it is very common to find a spouse with the aid of a matchmaker. In addition, the Ultra-Religious population is a very closed one, and therefore this population is very concerned about recessive genetic diseases for which they understand that they are at greater risk. As such, the Ultra-Religious community and part of the National-Religious sector choose partners for marriage according (in part) to genetic criteria.

In the National Religious sector, the issue of choosing a mate is not just a personal issue belonging only to the individual. Its social aspects include the potential involvement of the rest of the individual's family and other members of the community in the decision making process, which makes it part of the "norms" category tree. Nevertheless, it seems that the religious students that we interviewed think that their choice of mate should be based on personal preference, rather than on the prospective partner's ethnicity, community or genetic history. They speak about love and the personal connection as central concerns: "There is a test that checks a genetic match and begins to make a match, but we do not do these tests because if I meet a guy (randomly) no matter what the tests say I will be with him. The tests don't affect my partner selection" (LH, mechanical engineering, 21). LH is referring to the genetic tests done in the ultra-Religious sector prior to marriage (the "Dor Yesharim" program). Only 25.9 % of the students (Fig. 2, genetic preparation for marriage, going to "Dor

Yesharim") accept the ideology of this program as suitable for the National Religious society to which all these students belong. Not all of these 25 % will even conduct these tests. The students therefore represent a generation for which personal well-being is more important than their society's expectations or norms.

Despite their seeming faith in science, however, the students' level of genetic knowledge is not high enough to allow them to make informed decisions in the domain of genetic testing. For example, one student claimed that "a genetic disease will come if two of the parents are from Eastern Europe" (NG, geology, 24). Misconceptions like this one reveal a fundamental misunderstanding of the potential we all have to carry a genetic disease. A fair percentage of the students (62.8%) have some knowledge concerning the uses of genetic methods (see Fig. 1, knowledge and understanding of genetics) and some of the basic principles of genetics were known to a relatively low percentage of students (Fig. 1, 'genetics is the human rule book' (47.1 %) and 'genes determine but people can change their destiny' (43.1 %)). Insufficient knowledge of this sort leads to uninformed decisions, as reflected by the fact that only half of the students (54.9 %) see the family history of genetic disease as relevant (Fig. 1, factors involved in decisions to undergo act upon genetic testing, perception of risk).

The lack of knowledge is also reflected in the fact that only half of the students expressed a desire to conduct genetic testing before marriage (Fig. 2, genetic testing is open to personal consideration, personal inclination to undergo genetic testing). While some expressed sentiments like: "It suits me. We did genetic tests before we got married and before we had children" (YD, computational biology, 27). Others did not understand the importance of these aspects as measures to prevent and discover genetic diseases: "I think it's unnecessary to examine everything. All this area is new. Everything was fine until now so let's let life to flow and it will be okay" (LC, Hebrew literature, 22).

Furthermore, 43 % of the students expressed criticism towards the number of genetic tests performed, criticism that might lead to failure in the informed decision making process (Fig. 1, factors involved in decisions to undergo genetic testing, lack of faith in genetic testing): "I don't think that people should spend so much money on genetic tests and then they will be told that something is wrong...leave space for God. We do not know everything, and we don't need to know everything. There have been enough cases when doctors said things that were not true. Do not trust science" (ST, special edu*cation*, 21). This suggests that although the students do reflect the strong influence of modernization and Westernization, their lack of sufficient genetic knowledge and their criticism towards genetic testing limits their trust in scientific-genetic innovations.

This second claim that arises from our findings is that this population of students - despite its adherence to the laws and traditions of religious life - still reflects the characteristics that have been associated with the "millennial generation," which refers to children born in the '80s and '90s. This generation is characterized by individuals who have been exposed to technology from a young age. Moreover, it consists of people who are accustomed to caring about and prioritizing their own well-being, but who are also concerned with social rights. This claim can be demonstrated by the students' values (Fig. 3), which focus on rights - like the right to choose not to know ones' genetic profile (84.3 %), the right for privacy of information versus the rights of the family to know (74.5 %) and the rights of the family decide what tests and actions to take (84 %), "there are diseases that are a torture that ... you must avoid, torture for your own child and for the family, I think if you can avoid it in advance... it is your right to do it" (RN, biomedical engineering, 23). The students also referred to the rights of the fetus, and displayed a reluctance to conduct genetic testing that endangers it (Fig. 3, practical religious considerations, 56.9 %). For instance, RN said, "Before pregnancy I am in favor of testing, but during it is very problematic...because even if the fetus had a genetic defect, it has the right to live". This sentiment was echoed by other students, for example: "If someone thinks she isn't going to do anything with the fetus test results, she shouldn't do the genetic testing for the fetus. It's needless, because she probably wants to keep the fetus' right to live" (LH, mechanical engineering, 21). These elaborations describe the fetus as an entity with rights, whose right to live should be carefully considered.

Another characteristic of the millennial generation, which has been exposed to science and technology from a young age and therefore understands the importance of collecting all the information in order to make decisions, is their need to check the scientific details regarding the genetic disease, including what the treatment options for the disease are (Fig. 1, factors involved in decisions to undergo/ act upon genetic testing, perception of risk, 76.5 %). This student, for example, sees the decision to test for a genetic disease as conditional, explaining that the choice "depends [on] if there is anything to do with it. If there is some way to heal the disease" (YD, computational biology, 27). The will to know in order to avoid uncertainty is part of the broad knowledge base that a millennial student wants to have in order to make decisions: "On the one hand, one's medical information is very confidential, but on the other hand, if you supply that information (to your family) you can prevent a person from suffering in the first place, and I think it's very problematic not to have all your genetic information" (AC, medicine, 26).

In addition to their desire to have all the genetic information, the students also reflected a millennial concern for their own well-being in the fact that they addressed the economic aspect of genetic testing and of raising a sick child. They realize that one's economic situation is a crucial factor in wellbeing, as is the financial and mental strength required to deal with a sick child. "*There are diseases that I think I would choose to have an abortion for, because I think I won't be able to deal with the serious illness of the child*" (*SV, biology and social work, 23*). SV expresses the fact that not every person is able to deal with raising a child with special needs, since it requires special traits that not everyone possesses.

The students' concern about their well-being was also reflected when the students were asked to explicitly state their readiness to perform genetic procedures. More than half of them (56.9 %) thus expressed ambivalence about whether to conduct genetic testing and genetic procedures (Fig. 2, genetic testing is open to personal consideration, ambivalence and deliberation, genetic testing as a source of ambivalence). These hesitations were usually not based on religious grounds, but rather on fear, stress and concern about the stigma that genetic information might create (Fig. 2, genetic testing is open to personal consideration, ambivalence and deliberation, the positive/negative personal consequences of genetic testing). One student said, "Some people are afraid that they will not be considered as good because of their genetic background. For example, I do not want to marry that person because of his genetic condition" (MR, biology and education, 20). Other students noted that the genetic knowledge itself could be a source of fear, suggesting that fear of dealing with the complex situation might lead them to prefer not to know at all: "First of all there is the fear of knowing. If a couple wants to get married and goes to genetic counseling and they will be told that there is a problem in terms of genetic match and there is a high chance that their children will have a problem, the couple faces a difficult dilemma" (YN, accounting, 25).

In some cases, the students' doubtful and critical stance towards genetic testing reflects their lack of understanding of its essence. One said, "It doesn't relate to me (genetic diseases), since I feel that among my community, I am Moroccan, it's less common. The chance for genetic diseases is low, so we didn't go to do genetic testing" (AG, psychology, 26). AG, like others, has the misconception that genetic diseases are common only in certain ethnic groups. He does not understand that different genetic diseases are characteristic of different communities. This misconception might lead to problematic decision making, since it does not take all the genetic possibilities into consideration.

Until now we have focused on the students' "Western" and "non-religious" considerations, but our interviews clearly show that these were not the only aspects of the students to come up. In addition to the points of similarity that they may share with their more secular counterparts, the students in our study also conveyed a significant connection to faith and to religious considerations, which emerged as influential aspects of their decision making.

The third claim we shall consider is therefore that although only a third of the students (Fig. 3, philosophical religious considerations, priority for religiosity, 35.3 %) mentioned faith as a central value in their life, for this sub-group religious belief is a significant guiding factor. This means that although these religious students resemble the more secular elements of Israeli society in several important ways, they also have unique features that characterize them as religious. The findings also suggest that even among the 65 % of the students who did not claim faith as a central value in their lives, 79 % did mention some practical religious explanations and 67 % used philosophical religious explanations in their interview. This use of religion to explain their decision making suggests that their concerns are also often related to religious explanations, even though these are not always explicitly mentioned in the context of faith as central to their lives. In other words, the students mention the components of their faith without mentioning the faith itself.

The presence of religion as an influence in the students' decision making process is also reflected in their elaborations and explanations, in which 31 % of the students admit that they would make their decision regarding genetic testing only after consulting a rabbi or rabbinical ruling (Fig. 3, practical religious explanations, relying on religious doctrine as a guide in decisions relating to genetic testing and procedures). This is made clear, for instance, in the following dialogue:

"Interviewer: Today it is possible to do a variety of genetic tests before and during pregnancy. What do you think about the genetic tests that can be done during a pregnancy?

SZ: I think it's good so that you know where you stand, what you can do, but... on the other hand it depends which tests.... For diseases?

Interviewer: Yes.

SZ: I think it's good, especially in cases when you can prevent a disease, but... I don't know if I'll do these tests.

Interviewer: If you think it's good, why aren't you sure you'll do the tests?

SZ: Because there are things that you cannot do anything about. I think what I will do is much consultation with my Rabbi. I have heard a lot of stories about people that did the tests and in the end everything was fine and I believe in these things, really. It depends on my community, if we do these tests, and what the rabbi says."

SZ (bioengineering, 23) clearly admits that in order to make decisions while pregnant she will definitely consult her Rabbi and not make any decision otherwise. She understands the importance and the consequences of genetic testing, but is not willing to conduct them during pregnancy without getting confirmation from a rabbinical authority.

Some of the students clearly declared that their religious faith would directly affect the decision they would make, and that they would subordinate their personal preferences to what they perceived to be the will of God. This was clear from detailed answers like this one: "If it's already there (the fetus) there is nothing to do with it. If it's there it's there. If I was allowed to have an abortion I would like to, but it's not ethical to have an abortion. You can't decide that you don't feel like raising this child. If it happens to you then that's probably what God wanted. But if not speaking about God, then I would want to do have an abortion. If that's what God gave you so that's what it should be. It's very selfish to have an abortion. You want the good life. You don't want a child to need you all the time (BF, industrial engineering and management, 24). It was equally clear, however, from such shorter examples, like: "Leave room for God. We do not know everything and we do not need to know everything. We should believe" (ST, special education, 23). Examples like these reinforce our impression that for some of the students the belief in God overrides the desire to know more or to prioritize their own lives over that of the fetus; their faith, as they perceive it, does not allow them to rely only on their own will, but requires them to rely primarily on "God's plan."

These religious considerations were involved most prominently (43.1 %) in the decision whether or not to have an abortion (Fig. 3, practical religious explanations, relying on religious doctrine as a guide in decisions relating to genetic testing and procedures), an area in which students seek "outside" help to make a decision regarding this controversial subject. One student told us: "what would I do if I have a fetus with a genetic defect? I would ask my Rabbi. It's too big for me to decide whether to have an abortion in the case of deafness. I don't know how to handle it" (RM, biology, 21).

They were also raised in connection to intervention in nature, though the students' faith did not always lead them to similar conclusions (Fig. 3, philosophical religious explanations). For example, 33.3 % of the students were in favor of intervention in nature as part of their religious view. One said: "I think that it should be a convention to do genetic tests. Maybe this is a liberal approach, but God gave us technology and science to use it and not to be afraid of it or to rely on miracles" (AI, physics, 27). On the other hand, 51 % of the students were against interference in God's creation, claiming that genetic procedures that interfere with the natural course of the world were not allowed or not needed. These expressed opinions like: "I think that our limit as human beings is diseases that we can deal with. We should not interfere with the creation of God" (SA, biology, 25), or "Having an abortion for a deaf fetus is to get into the place of playing God. I worked a bit with deaf people. It's very difficult, but still, to abort? I don't think so" (PL, education, 23). The interference in God's creation seems to these students inappropriate, and is inconsistent with their values.

In conclusion, our results raised three main claims. First of all, the religious Israeli students in this study are very close to what might be termed "Western" mentality; they trust science, and it is a central part of their lives. Secondly, the students displayed traits associated with the "millennial generation" into which they were born – a generation of individuals that have been taught to prioritize their own well-being and be concerned about their rights. Third, though faith was noted as a central factor by only part of the students, for that part belief is a highly significant factor and the religious considerations of those particular students are certainly an influential part of their decision making in the domain of genetic testing.

# An in-Depth Look at Three Students' Religious Worldview

After considering these three claims, we must admit that the qualitative study of 51 students is not fully reflected in them. Each of the students in the study ultimately represents a separate story, and each interview provided us with an entire narrative of that student's world view. We therefore also wish to supplement our general conclusions with the personal stories of three students, each of whom represented religion from a different perspective. We realized that we cannot simply relate to all of the religious students in our population as a homogenous whole, since each of them has their own personal perspective, influenced by their prior studies, the customs of their family and community, and by their own personality. In this variety, we can nevertheless distinguish three "types" in the relationship between religious commitment and genetic decision making. While, as we have noted, the students who did not mention faith as a central value also revealed religiously centered claims, we have nevertheless concentrated on the subgroup of students that did mention faith as a central value, looking more closely at the subtleties of their different outlooks.

# **Type 1: The Religious Ideologist**

**ZG** (23), an unmarried physics student at a university, has a very firm religious ideology. He is a theological thinker, not willing to compromise when a religious value clashes with a scientific one. He is not willing to accept any scientific innovations, especially if these do not align with his beliefs about religious rules. Though many Rabbis have offered halachic rulings that have been updated according to scientific improvements, ZG is not willing to consider them as an option. He told us that:

If you have a defective gene in the embryo, an abortion is forbidden religiously. But if I was not religious, I would permit the parents make the decision as to whether to have the baby or not until the soul enters the body of the child. But because I'm religious I can say that I oppose abortion. If the soul has already entered the body of the child, then no abortion can be done under any circumstances, even if it endangers the mother.

ZG takes an extreme view of Jewish law, showing no interest in negotiating and taking the medical situation into account: "Genetics has given rise to possibilities that contradict moral principles. If the mother knows her child is born deaf and mute, who said that she is allowed to end his life? And if a person is born retarded, who says that this child wants to die? Who gave you right kill this child? It is totally forbidden by Jewish law." His approach does not leave space for individuals to decide such things for themselves at all. It is an approach completely ruled by God's written rules.

# Type 2: The Informed Yet Religiously Oriented Social Conformist

**PL** (23), an unmarried teacher training college student, thinks emotionally. She wants to please the social and familial system in which she lives. She does not think of her own interests, but of what is in line with the expectations of her family, as reflected by statements like "My mother told me that she does not agree that I continue dating with this guy before I go to do genetic tests." PL is willing to accept the social system she belongs to and what is customary in it indisputably, openly claiming: "I think that the opinion of **the private person** regarding termination and the implications of genetic testing should not be considered, if someone has to decide it is a Rabbi."

This denial of individual will has caused PL to pay a personal price for her religious beliefs and her willingness to obey rabbinical expectations. She and her boyfriend checked their genetic suitability by means of "Dor Yesharim" tests and were told that they are both carriers of a recessive genetic disorder. She decided to part from her boyfriend, as "Dor Yesharim" recommended. It was a very difficult step to take as the relationship with her boyfriend had been serious, yet she did not want to continue the relationship and get married since it would mean risking every future fetus by taking a genetic test during her pregnancies.

Importantly, her commitment to her religion and her community is accompanied by a sincere readiness to be exposed to what science has to say in these fields. She told us: "I called 'Puah Institute' [deals with counseling, guidance and assistance to couples who have gynecology and infertility problems] and asked them what options there are if we are both carriers of a recessive disease. I also investigated and found that there is genetic counseling in hospitals and even telephone counseling, which is free." Nevertheless, her commitment to her faith outweighs her trust in science: "The fact that I am religious, a believer, is very influential. If I was secular I would look at more data and statistics. But as a religious person I don't think everything has to be checked... I really believe in God, it's something very significant in my life. For example the whole thing I had (the separation from the boyfriend), at first it was very difficult and I said - I might transfer the disease to my children...but I believe that everything is from God. Maybe I'll marry a normal person [i.e. someone who is not also a carrier]."

PL's interview reflects her firm faith in God, her willingness to obey the family rules regarding genetic testing even if these imply she must make personal sacrifices, her willingness to entertain information from scientific research and her belief that science has its limitations. Her priorities are very clear: "I have faith in God, he plans everything, even before the genetics, and I have faith that prayer can change any decree." Her attitude towards genetic testing that can risk the fetus is unambiguous, and accompanied by a tendency to be critical of the medical genetic system: "The tests that endanger the fetus should not be done. I heard that amniocentesis can endanger the fetus. Why do it? There are lots of things that are checked and they tell you for example it would be a boy or girl and eventually the opposite sex is born. There are things that don't need to be checked. We don't need to know everything. Not everything is in our control anyway."

### **Type 3: The Religious Rationalist**

**DR** (25), an unmarried medical student, shows a firm religious approach, yet it is clear that scientific and medical discoveries are part of his religious worldview. He is a rationalistic thinker who believes that science is consistent with religion and seeks for the connection between them. "*There is a religious view that says that what God wants is what will be, and who am I to interfere in his decisions? I understand where this view comes from but I don't agree with it. I think that science is religiously blessed. Should we not use cars? I strongly believe in genetic tests and I will do them when it becomes relevant."* 

DR believes that genetics is a central part of our life, but that according to the Jewish religion we can improve our life quality even though our genetics determine many of our features: "Your genetics is your fate. Many things that will influence your future are because of your genetics. These are things that apparently can't be changed, but according to religion, there is always an option to change, like in the case of health, you can be healthier if you eat differently and do sports."

DR proclaims that his religious opinions are more liberal when speaking about abortions, and he is not willing to accept a sick child at any price: "One should know to expect as much as possible in order to prepare oneself and if necessary end the pregnancy. There is a law in Israel that if Down syndrome is diagnosed even a week before birth there is no problem to abort. On this issue I'm a bit more liberal, religiously open. I don't think that you should bring life at any cost. I see people who have genetic problems, it changes their lives." He expresses a more complex approach to the relationship between religion and genetic testing, taking a wider range of considerations into account.

The three students above represent three types of religious approaches to dealing with genetic decision making. The first type is represented by ZG, who is not willing to hear anything other than Jewish law. He feels committed to the most extreme views of Judaism. He is willing to hear only scientific and religious issues that meet his radical views. The second, PL, is a type that on the one hand is willing to make a personal sacrifice in view of her obligation to Jewish law, but on the other is prepared to be exposed to scientific information and actions, even though she is sometimes critical towards them. Moreover, PL is committed to her family and community and lives according their expectations, ready to give up her personal wishes. The third type is DR, a student who understands the complexity of science and faith and takes into consideration both Jewish laws and scientific recommendations in his decision making. He is a rationalist thinker, looking for a match between science and his religious views.

#### Discussion

The goal of this study was to probe the decision making considerations of Israeli undergraduate students in the field of genetic testing and genetic counseling. Our study is a cultural one, designed to capture the students' complex thoughts, dilemmas and deliberations through in-depth interviews. Our interviewees all defined themselves as religious, belonging to the National-Religious sector in Israel. They study in diverse faculties at different higher education institutes throughout Israel and half of them are women.

Our results produced a complex picture of the numerous factors that affect this type of decision making. In order to achieve a comprehensive view of that picture that would enable us to see the similarities between different students and to project our conclusions to other students as well, we created the Triple C model: "Culture influences Choices towards genetic Counseling" (Fig. 4). Our model places religion, which is part of culture, as a central aspect of influence on our three main categories of 'knowledge and perceptions', 'norms,' 'values'. These categories serve as the three vertexes of our model, since they are influential factors in genetic decision making, as shown in the results section.

We shall start each part of our discussion by defining one of these three vertexes, and then look into the mechanism that explains the interaction between that vertex and religion. These three main categories are also influenced by one another, and their mutual influence will also be addressed in the discussion. The impact of religion on each of these main



Fig. 4 The Triple C Model: Culture influences Choices towards genetic Counseling

categories lies in the center of the model, with a condensed description of the link between them in italics both in the model and in the following descriptive text. Sub categories from the three category trees (Fig. 2, 3 and 4) will also be addressed throughout the discussion.

The first main category connected to religion in the triple C model is norms. Norms are developed in the process of socialization. Each community contains knowledge of what counts as "correct" or "appropriate" behavior, which constitutes that community's shared norms (Schäffner 1999; Svensson 2013). Therefore, in our model, religion creates expectations as to the norms to which a person who belongs to a religious society should conform. These expectations pertain to many aspects of the religious person's daily life. For example, previous studies have noted the expectations religious authorities have from their followers on issues like accepting or rejecting organ donation (Stephenson et al. 2008) or alcohol consumption (Neighbors et al. 2013). Others have found positive relationships between the importance of religion or religious faith and the perceived influence of religious factors on one's choice of occupation, decision about whether or whom to marry, etc. (Sigalow et al. 2012). Such expectations can extend to decisions about genetic testing as well.

Religious expectations in the genetic field reflect the community's norms regarding the performance of the genetic tests, with some communities expecting testing more or less than others. Moreover, the genetic preparation for marriage and the use of "Dor Yesharim" genetic tests is a norm that is accepted to varying degrees in different parts of the National Religious sector. Norms shared by the community might lead to fear of going through genetic procedures that are not acceptable in the society one belongs to, leading to conflicts and deliberations about whether to conduct genetic procedures or genetic testing.

**Values**, our second main category, refer to the principles that people use to select and justify their actions and to evaluate people and events. The value priorities of individuals are affected by their social experiences, such as religion, gender, education, occupation, and cultural background (Schwartz 1992). In the genetic counseling field, as in other fields of western health care, there are four principles that guide the values and practice of the medical service: (1) autonomy which involves respecting an individual's intrinsic right and capacity to think, make decisions and take actions based on their values and beliefs (Gillon 1986), (2) minimizing harm, (3) promoting benefits and well-being, and finally (4) the principle of justice, which involves promoting care that is fair, equitable and appropriate (Hawkins, and Ho 2012).

As this research concentrates on religion as part of culture, we comprehend that religion shapes the moral *world view* of the students, thereby influencing their perspective towards issues in genetics. For instance, patients have been found to be unwilling to cooperate in genetic procedures because of religious beliefs, stating that scientists are "playing God" or expressing fears that human genetic research and genetic technologies are being used inappropriately (Harris et al. 2004). The meaning of these findings is that religious values are central to the involvement and acceptance of genetic counseling, as indicated in our own study, in which philosophical religious considerations such as: "I am against interference in the creation of God" and "religion conflicts with science" were noted.

In the field of abortions, religious factors have been shown to influence values related to abortion policies (Ellison et al. 2005; Emerson 1996). This was also reflected in our model, where students declared that religious doctrine would guide their decisions on such issues, stating: "I will terminate the pregnancy or not depending on religious considerations." This reliance on doctrine and rabbinical guidance extended to other aspects of genetic decision making too, indicating that the students' values, as reflected in their *world view*, are affected by their religion, which thus influences their considerations in the genetic domain.

The third main factor influenced by religion is the students' knowledge and perceptions. This factor includes attitudes and perceptions towards scientific and genetic issues as well as knowledge and criticism of scientific and genetic issues. For example, perceptions towards genetic counseling include recollections and interpretations of the genetic risk and the likelihood that the genetic disease in the family is heritable (Vos et al. 2012). People are more likely to make use of genetic counseling when they feel that counseling has helped them feel more educated about genetics in general and has improved their understanding of their own genetic results (Darst et al. 2013). In our model, the students' criticism of science and genetics is influenced by religious standing, as well as other factors. It has been largely discussed that perceptions towards science are influenced by religion, especially when science and religion offer competing accounts of an issue (Evans 2011; Dickerson et al. 2008; O'Brien and Noy 2015). The students in our study also reflected previous findings according to which religious students tend to be more critical towards science and express lack of faith in genetic testing. This was expressed, for instance, by their criticism that today too many tests are performed, and that genetic tests' results are not always reliable. Allum et al. (2014) and Siani and Assaraf (2015a) have pointed out that religious students, especially those who have less scientific knowledge, are more critical towards performing genetic testing. This once again places religion as a central and significant factor that influences the decision making of students towards genetic testing and genetic counseling.

In light of this research and the relevant scientific literature, a variety of mechanisms and interactions have risen between the three basic themes - norms, values and knowledge/ perceptions - in the context of genetic counseling and genetic testing. We shall now discuss the mutual effects that occur between each pair. In this part of the discussion sub categories from the three category trees (Fig. 2, 3 and 4) will also be mentioned.

The Triple C model shows that the link between 'norms' and 'knowledge and perceptions ' is two-directional. The addition of knowledge, which is part of the scientific-medical aspect, enables a change and adjustment of norms known as *cognitive dissonance*. Cognitive dissonance is a motivational state brought about when a person holds two cognitive elements that oppose one another (Wicklund and Brehm 2013). The addition of new knowledge opens the possibility of greater flexibility in one's norms, making room for additional norms in the behavioral arsenal. This has been found, for example, among pre-service teachers who gained the ability to accept students who were unlike them thanks to the additional knowledge they gained about the students' personalities and beliefs (Eisenhardt et al. 2012).

Genetic knowledge and increased awareness of risk may at times make individuals more likely to challenge their previous norms and start investigating their own family histories or seeking genetic counseling (Hall and Olopade 2005). This additional knowledge can change norms that prevent people from undertaking genetic testing by reducing fear and by undermining the stigma that genetic testing can sometimes cause. It can thus be a source for increased control of one's genetic situation, which finds expression in the students' emphasis on the fact that knowing can prevent the state of uncertainty.

Research has also shown that there are significant advantages to receiving genetic information at an early stage of life. It enables the patients to prepare themselves and allows them to avoid uncertainty (Rhodes 2006), which are both concerns that were frequently mentioned by our students. The potential benefit of additional genetic knowledge in terms of improved health has been proven to be a strong motivator for conducting genetic testing (Phillips et al. 2000). That said, one must also be wary of the danger becoming overwhelmed by an excess of genetic information that one does not know what do with, – as in the case of prenatal whole genome sequencing (Donley et al. 2012). The fear of receiving more information than one can handle – or of discovering problems that science does not yet know how to solve - can in itself be a source of ambivalence regarding the extent to which one wishes to engage in genetic testing.

In the other direction, when there is a conflict between norms and scientific-genetic information or perceptions, it generates an opposition to receiving knowledge in the genetic domain because it violates one's norms. Genetic information is not like all other medical information, which is private. In medical genetics, there is always the question of who does the genetic information belong to? What responsibility do people have to tell others in their family of their own test results and inform them of their risks? (Finkler 2011). Such queries can generate opposition towards getting genetic information, since it clashes with social and familial norms regarding the individual's responsibility towards his family. Cultural differences, such as norms among Italian women for example, lead to seeking less health care and going to less genetic counseling than among the general society (Pivetti and Melotti 2013), meaning, the cultural norms oppose the acceptance of genetic knowledge.

The Triple C model also shows bi-directional relationships between 'values' and 'knowledge and perceptions'. Genetic knowledge influences one's values. Genetic knowledge has recently become more accessible, and can now easily be shared on a global basis (Kaye 2015). This greater ease in distribution can increase people's understanding the consequences of genetic situations, which in turn encourages them to consider the *moral consequences* that are involved in using - not using - genetic testing and genetic procedures. These considerations of moral consequences are influenced by the knowledge of the individual, and by that individual's values (Sadler and Zeidler 2004; Siani and Assaraf 2015b). For example, the awareness and attention to moral consequences can lead to reliance on values that highlight the 'rights' of the individual, the family, or the community, and values that emphasize the right of life. All of these seemed highly important to the students in our research.

In addition to knowledge influencing values, we can find evidence that values influence the willingness to accept medical information and to use it. When there is a conflict between the medical information and individual's values, that individual may be unwilling to even receive that information, let alone act upon it. Evidence of such *antagonism* has been observed amongst women who were not willing to receive genetic information from genetic testing because of their religious values, and who explained this decision through their religious objections to abortion or their concern over the eugenic aspects of prenatal screening (Remennick 2006). Religious believers have been known to assume that in cases when there is a conflict between scientific and religious claims about the world, the religious claim is correct (Evans 2011). This conflict, and the antagonism it sometimes created, was evident throughout our interviews in the expression of religious values like "religion conflicts with science; I am not willing to conduct genetic tests during pregnancy." This value is based on the Jewish law that takes into account the stage of pregnancy, among other considerations, when deciding if a termination of the pregnancy can be performed. It also supports the idea that opposition to prenatal genetic testing could be related to a religion-based belief in the intrinsic value of human life, which has been noted amongst Catholics (Pivetti and Melotti 2013), and which Judaism believes in too (Baeke et al. 2011). Religious values can thus influence knowledge and perceptions by leading to an unwillingness to receive genetic information, which in turn can cause such individuals to misunderstand genetic issues and genetic tests.

The link between values and norms is also reflected bilaterally in this model (Fig. 4). Norms influence values in the domain of marriage for instance. In western society, marriage has become a private decision to be made by the couple, as part of the belief in liberty, equality and autonomy (Witte 2012). This influence is reflected by the fact that most of our students opposed the "Dor Yesharim" tests that make matches according to genetic suitability (Frumkin et al. 2011). This norm of marriage as a matter of personal choice, as opposed to marriage that is dictated by the community, is part of the empowerment of individual rights. Our students' opinions largely reflect the notion that "genetic background is not a relevant factor in choosing a mate," rather love and their own will. These western influence-based norms correlate to values that are also part of this western trend, such as the right one has not to know one's genetic profile and the right to decide who to tell and who not to tell about it.

In addition to the influence norms can have on values, values can also provide moral justification for norms, as in the case of religious values that influence behavioral norms (Beauchamp, and Childress 2001). Religious values mediate decisions about prenatal diagnosis. Consequently, the decision about whether or not to have diagnostic testing is generally related to attitudes towards the termination of pregnancy (Atkin et al. 2008). In our research, we observed that religious values, like 'consulting the Rabbi when deciding about genetic testing' and 'terminating the pregnancy based on religious considerations', influenced norms regarding the acceptability of having an abortion. It has been found that religiously motivated people are relatively more able to accept the idea of raising a sick child. Believers have stated that their faith/ religion would influence their prenatal testing decision and that "accepting what is given" is part of their cultural belief system (Learman et al. 2003). Parents of sick children felt they received support from their spiritual communities and from

God (Hexem et al. 2011). Thus, religious values provide *moral justification* for norms such as not conducting genetic procedures during pregnancy since these procedures may cause the loss of the fetus, taking a life that is not ours to take.

#### **Study Limitations**

Since the students we interviewed volunteered to do so after reading the notice about looking for religious students for an interview on genetic issues, it might be that the students who volunteered were those who are not averse to addressing genetic issues, or students who are specifically interested in this domain, or alternatively students who had previously been exposed to a genetic dilemma. In some of the interviews, the interviewees raised personal genetic dilemmas with which they had dealt in the past. This factor might have biased our findings in some way, though during our analysis it did not seem to be particularly influential on the decision making elements raised by the interviewee.

Another limitation is that the unique characteristics of the National Religious community that we have investigated are specific to Israel. Despite this specificity, the combination of the involvement of a religious sector in the general society allows to parallel it in future to other populations around the world while considering the three sides of the model as a universal application.

#### **Practical Implications**

The mechanisms of mutual interaction described in the Triple C model show the complexity of the decision making that takes place in the genetic testing domain, and the multiplicity of the considerations that were raised by the National Religious Israeli undergraduate students in this study. The Triple C model illustrates the fact that genetic counseling is a complex challenge because many issues have to be taken into consideration during the counseling process. Given these findings, it is understood that sociocultural aspects are influential and that decision making must be tailored to each target population according to its background, based on their relevant exposure to and knowledge of the domain (Peters and Petrill 2011).

This model could have useful practical applications in other populations around the world, especially in religious ones, since the central axis of this model is religion. The model can be used to identify and analyze decision making considerations in the genetic counseling domain and to better address counselees at a genetic counseling session. For example, the model can be used to identify the *expectations* of a certain religious community towards their members, expectations that influence the norms of the members regarding genetic decision making. In addition, if the *worldview* of religious patients, their *criticism towards genetics* due to religious affiliation and the *expectations* of their religious community could thus be known to the counselor, it could make the counseling session potentially much more efficient and more suited to the norms, values and genetic knowledge of the counselee. The model can also be used to identify reasons underlying *opposition* to accepting genetic knowledge when these arise from the counselees' norms. Finally, it can serve to highlight the *moral consequences* counselees may be considering when debating the question of using or not using genetic testing and genetic procedures. These considerations of moral consequences are influenced by the individuals' knowledge and their values, and their analysis can once again lead to more useful genetic counseling that is adapted to the personal set of values and the knowledge of the counselee.

In order to promote the awareness of genetic counselors to this complexity, we suggest a pedagogical approach that is based on SSI (Socio-scientific Issues), an approach that allows the student to make decisions while taking into account his ethical dimensions of science and the values (Sadler and Fowler 2006; Sadler and Zeidler 2005). According to this approach, counselees can be introduced to relevant case study dilemmas, leading them to start a dialogue likely to bring forth evidence of their prior values, norms and knowledge. The counselors will be able to use this information to address the diversity of the population they are dealing with, relating to the personal perspective of each pair and accepting the different perspectives of different counselees according to the different characteristics of each family.

If religion is a central issue in the counselee's life, the topic should be raised during the counseling session and connected to each of the three main categories of the model. In Israel, counselors may find the National Religious sector as a mediator between the secular and the ultra-Religious society, and that one can be religious and at the same time be sensitive to other values. Understanding the full spectrum of the elements in place can help genetic counselors ensure that they are accounting for as many as possible of the aspects that can form barriers to informed decision making. Using this model may help us identify the sociocultural differences between different types of patients and thus better assist them in addressing their genetic status (de Souza et al. 2014).

#### **Research Recommendations**

Although our model is based specifically on a narrow religious society in Israel, we propose implementing it in other diverse societies around the world. Furthermore, the model should be applied in additional research to a larger amount of people with varied educational background, since we have applied it only to a specific population of undergraduate students. Such research would serve to further validate the model, and would allow comparisons between the genetic decision making considerations of different populations around the world according to their culture, values, norms, perceptions and knowledge.

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#### **Compliance with Ethical Standards**

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**Human Studies and Informed Consent** All procedures followed were in accordance with the ethical standards of the responsible committee on human experimentation (institutional and national) and with the Helsinki Declaration of 1975, as revised in 2000 (5). Informed consent was obtained from all patients for being included in the study

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

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