

# A Qualitative Look into Israeli Genetic Experts' Insights Regarding Culturally Competent Genetic Counseling and Recommendations for Its Enhancement

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**Abstract** The aim of this study is to describe the perceptions and recommendations of Israeli genetic experts in regard to culturally competent genetic counseling. Qualitative data was collected from 15 semi-structured interviews with Israeli genetics experts. Recurring themes were identified using "thematic analysis" and coded by means of "grounded theory". Our analysis divides data from the genetic experts' interviews into four main themes: *Why* is culturally competent genetic counseling important? (Describing its contribution to individuals and to society); *who* is the recipient of culturally competent genetic counseling? (Differentiating the needs of counselees based on genetic education, cultural/religious characteristics and geographic location); *what* should we include in culturally competent genetic counseling? (Addressing the contents that counseling should convey); *how* should we perform culturally competent genetic counseling? (Addressing the methods that counseling should employ). In light of the study, we recommend lengthening the genetic counseling session so that counselors will be able to truly gauge all the prior knowledge of the counselees, their religious beliefs, norms, values and attitudes towards genetic testing. We further recommend that students continue to study genetics further into high school. Finally, we suggest adding a preparation session, similar to a prenatal course, to the genetic counseling of lay people so that their genetic knowledge, attitudes and

perceptions will be enhanced, leading to more efficient genetic counseling and more informed decisions.

**Keywords** Cultural competence · Genetic counseling · Genetic experts · Qualitative analysis · Semi-structured interview

## Introduction

Genetic counseling is a process that is affected by the counselee's values and culture. In this process the counselor promotes decision making through discussion of the client's values and beliefs, incorporating how the client or couple personalizes the genetic information passed to them during the counseling session so that this scientific information is both useful and meaningful to them (Biesecker and Hamby 2000). Thus, the aims of the genetic counseling are: 1) to deliver personalized genetic information to the client in a useful way. 2) To explore the meaning of the information with the client in light of personal values and beliefs. 3) To promote the client's preferences for reproductive options, considering the various alternatives, consequences and barriers. 4) To prepare the client for accepting the outcome of the choice(s) (Biesecker 2001). Thus, counseling must be conducted in a manner that is cognizant and respectful of the cultural differences that may exist between various counselees, and between counselees and their genetic counselors (Abad et al. 2014; Weil and Mittman 1993).

Despite these aims, it has been found that lay people often have alternative conceptions regarding genetics and that as a result their decision making following the counseling process is not always informed, often relying on prejudice and on information with no scientific basis (Condit 2010; Falcone et al. 2011; Klitzman 2010; Michie et al. 2005). These alternative conceptions and the cultural differences have recently

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led researchers to open a discussion about cultural competence in genetic counseling. In order to provide genetic counseling that is truly culturally sensitive and competent, genetic counselors must be able to build trust and rapport with their clients (Abad et al. 2014). In a study from Taiwan, for example, parents discussed their belief in the supernatural etiology of their child's condition only after a trusting relationship had been established with their health care provider (Shyu et al. 2010). In a Mexican study, parents shared pregnancy-related cultural health practices with their health care provider if they were sure that the health care provider will not be dismissive and judgmental of their beliefs (Barragan et al. 2011). These examples suggest that there is a growing understanding of the importance of providing unique culturally sensitive genomic care to individuals from any culture, race, or ethnicity (Barlow-Stewart et al. 2006; Berry 2013; Khan et al. (2010); Middleton et al. (2007); Paniagua and Taylor 2008). The ultimate aim is to make genetic counseling accessible to all populations, bridging multicultural gaps for the sake of informed decision making based on counseling that has been customized to the counselee's particular needs.

The main objective of this study is to shed light on the complex considerations undertaken by experts in genetics when they carry out counseling and when they meet with counselees. Our emphasis is on the insights of the counselors regarding the principles of culturally competent genetic counseling (as shall be discussed in the next section), and their thoughts regarding the manner in which this counseling can be done. The genetic experts' interview (attached in Appendix 2) intentionally does not mention the term "culture," so as not to direct the interviewees to a specific answer. Nevertheless, this was a topic that arose as a dominant thread in all the interviews. Based on this research, the authors aim to offer guidelines that may aid genetic experts in providing culturally competent genetic counseling. Our research questions are therefore:

1. *Why* is culturally competent genetic counseling important?
2. *Who* is the recipient of this culturally competent genetic counseling?
3. *What* should we include in culturally competent genetic counseling?
4. *How* should we perform culturally competent genetic counseling?

## Theoretical Background

### What is Culturally Competent Genetic Counseling?

"Genetic counseling is 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. The process is intended to help those counseled in making medical decisions in a non-directed manner, appropriate to their values, and is therefore called non-directed counseling" (Organization of Genetic Counselors in Israel 2015). Culture is defined as the totality of beliefs, values, behaviors and communication patterns among members of a cultural group (Parette 1999). Science education researchers cast culture as a system of implicit and explicit beliefs and values located within entities (e.g., individuals, groups), or a set of dynamic practices constructed and reconstructed through participants' engagement in community activities (Parsons and Carlone 2013). While providing genetic information to the Israeli public, genetic experts throughout the country strive to pay attention to the cultural differences of the different sectors of the Israeli multicultural society, and to "[help] the family and the individual to recognize and reconcile with their emotional and psychological needs" (State of Israel, Ministry of Health, Process for Obtaining a Status Recognition Certificate – Genetic Counseling 2016). Nevertheless, this study seeks to provide a clear and more solid characterization of genetic counseling that is customized to the values, norms and attitudes of the counselees (including both the situation as it stands today and the genetic experts' thoughts for the future) in an effort to ensure that the public's choices in these matters will be as informed as possible.

"Cultural competence" in health care involves "understanding the importance of social and cultural influences on patients' health beliefs and behaviors; considering how these factors interact at multiple levels of the health care delivery system (e.g., at the level of structural processes of care or clinical decision-making); and, finally, devising interventions that take these issues into account to assure quality health care delivery to diverse patient populations" (Betancourt et al. 2003, pp. 297). The need for cultural competence in the domain of genetic counseling has grown, as the populations in countries - including Australia, USA and Europe - have become more culturally diverse. For example, family orientated genetic services for ethnic groups practicing consanguinity can be acceptable and effective when provided in a culturally appropriate manner (Khan et al. 2010). Research has found that increased awareness of genetic counseling is extremely important, but awareness alone will not ensure access to such services (Barlow-Stewart et al. 2006). Cultural competence in genetic counseling is achieved when the patients are not focused on as an "other," in the sense of their difference from the dominant culture (Barlow-Stewart et al. 2006). The counselor has a duty to be familiar with the cultural expectations of the counselees, including the religious considerations to which the counselees may be committed. Additionally, cultural competence can be achieved if conscious attempts are made to bridge cultural gaps between the patients and the staff of the genetic counseling clinic (Barlow-Stewart et al. 2006). The

staff's ability to identify with and have an in-depth understanding of their patients can lend cultural competence to their counseling.

### **Why is Culturally Competent Genetic Counseling Important?**

Research has shown that comprehension of scientific and genetic information is influenced both by cultural factors (Lee et al. 2005) and by genetic knowledge and perceptions (Al-Gazali 2005; Lanie et al. 2004; Shaw and Hurst 2008). It has also been shown that religious beliefs, being part of cultural background, affect one's approach to science in general and to genetics in particular (Siani and Assaraf 2016a). For example, Jewish women have been found to be unwilling to receive genetic information from genetic testing because of their religious values, explaining their decision through their religious objections to abortion or their concern over the eugenic aspects of prenatal screening (Remennick 2006). Some Ultra-Orthodox Jewish women also refrain from doing amniocentesis because of religious restrictions that forbid selective abortion, while in secular Jewish Israeli society prenatal diagnosis and selective abortion are supported, independently of the rabbinical stance (Raz 2004). In another example, Pakistanis and other subjects deriving from South Asia and living in Great Britain have been shown to believe that a Higher Power causes congenital problems or the loss of a pregnancy (as do many other religious believers from various cultural backgrounds) (Shaw and Hurst 2008). Regardless of the type of education received, most of these subjects believed that only God knows why a given situation occurs, and were therefore reluctant to intervene before or during a pregnancy, since they believe the situation is not in their control anyway. Examples like these reflect an element of tension between science and religion, and the need to find ways of integrating religious beliefs into the understanding of science (Starr 2010).

### **Who Needs Culturally Competent Genetic Counseling?**

The need for culturally competent genetic counseling is not limited to a specific population, since the influence of culture, including religious beliefs, on scientific and genetic conceptions has been found to exist in all investigated societies. In societies that have been studied (Aqueel 2007; Ota Wang 2001; Shaw and Hurst 2008), religious or traditional beliefs have (at times) been found to contradict genetic recommendations. In Chinese-Australians, for example, barriers to communication have been detected when there was inconsistency within the family between "Western" and traditional beliefs (Barlow-Stewart et al. 2006). For that reason, in the Philippines, for instance, there is an emphasis on culture in genetic counseling training, since it has a crucial role in

shaping the counselee's comprehension of health (Abad et al. 2014). Culturally competent genetic counseling is thus needed in societies in which some of the people assimilate the genetic information in a manner that contradicts genetic theory because of their religious or traditional beliefs. An understanding of the differences between various cultures and religions, and the beliefs associated with them, will help counselors understand the manner in which individuals relate to both faith and science (Dickerson et al. 2008).

The acceptance of scientific (Bauer et al. 1994) and genetic information, as comprehended in the Jewish population in Israel (Siani and Assaraf 2015), is influenced not just by religion and beliefs, but also by interests and attitudes towards science and genetics. All populations, in particular those with less interest in genetics and less willingness to assimilate and accept new genetic information, as demonstrated in the Orthodox Jewish population in Israel, must be addressed in a culturally competent way, taking into consideration their particular fears, the barriers to their acceptance of genetic information and their desire to maintain their individual rights (Siani and Assaraf 2016b). Increased understanding of the belief systems of this population will enhance the genetic counselors' ability to better serve this unique group of patients by providing counseling that helps patients choose the testing options that they deem appropriate, while simultaneously respecting the patient's belief system (Grazi and Wolowelsky 2015).

Another important factor that can aid in acceptance of knowledge is the counselee's level of genetic knowledge, which tends to be inversely proportional to age, and is highest at the age of 18–25 (Ashida et al. 2010). This means that the age of the public's exposure to prenatal genetic counseling is also critical to its efficiency. Premature exposure, at a time when one is not ready to hear about these topics, is liable to undermine future success (Frumkin and Zlotogora 2007). These findings should be taken into account when planning culturally adapted genetic counseling to increase its chances of efficiency.

### **How Can Culturally Competent Genetic Counseling be Enhanced?**

One of the fundamental requirements for addressing the counselee in a culturally competent way is that the counselors have knowledge of the basic ethno-cultural values of patients and their families, since values motivate actions and serve as standards to evaluate them (Gschmeidler et al. 2016). This can guide healthcare providers, like genetic experts, in delivering ethno-culturally competent, culturally sensitive genomic healthcare that meets the needs of a rapidly growing diverse population (Middleton et al. 2007; Paniagua and Taylor 2008). Of course genetic experts do already refer to the cultural background of the patient, but sometimes culture is not

discussed during the counseling session because the counselors do not realize that the patient's responses are reflecting a cultural belief (Berry 2013). This demands that the issue of culture should be spoken about during the session as a rule, to increase the chances of identifying important and relevant issues.

## Materials and Methods

### Research 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 researchers to explain or understand social phenomena and their contexts, and to identify the important influences of these contexts (Ritchie 2013). These methods are suited to exploring issues that hold some complexity and to studying a process that occurs over time (Ritchie 2003). The qualitative methodology used in this research is "multiple case study", in which several cases are examined to discover the similarities and differences between them (Baxter and Jack 2008). Our research aimed to understand the complex considerations of genetic experts and their insights regarding principles of culturally adapted genetic counseling. The similarities and differences between the different interviewees were revealed through in depth semi-structured interviews, which allowed the interviewees to raise all the topics they deemed relevant, to explain their attitudes thoroughly and to give examples from the genetic clinic. "In a semi-structured interview, the researcher provides some structure based on his research interests and interview guide but works flexibly with the guide and allows room for the respondent's more spontaneous descriptions and narratives. Some interviews have very little preset structure" (Brinkmann 2014, pp. 1008). This research, which was constructed within the framework of qualitative grounded theory, deliberately did not ask the genetic experts about genetic competence, but asked generally about genetic counseling, allowing these topics to spontaneously rise (or not rise) out of the interview based on the extent to which the interviewees deemed them relevant (Charmaz 2014). Although we could not have known in advance to what extent the cultural issues would be brought up, we found that they arose in every one of the interviews, and were dominant issues throughout all of them.

### Participants

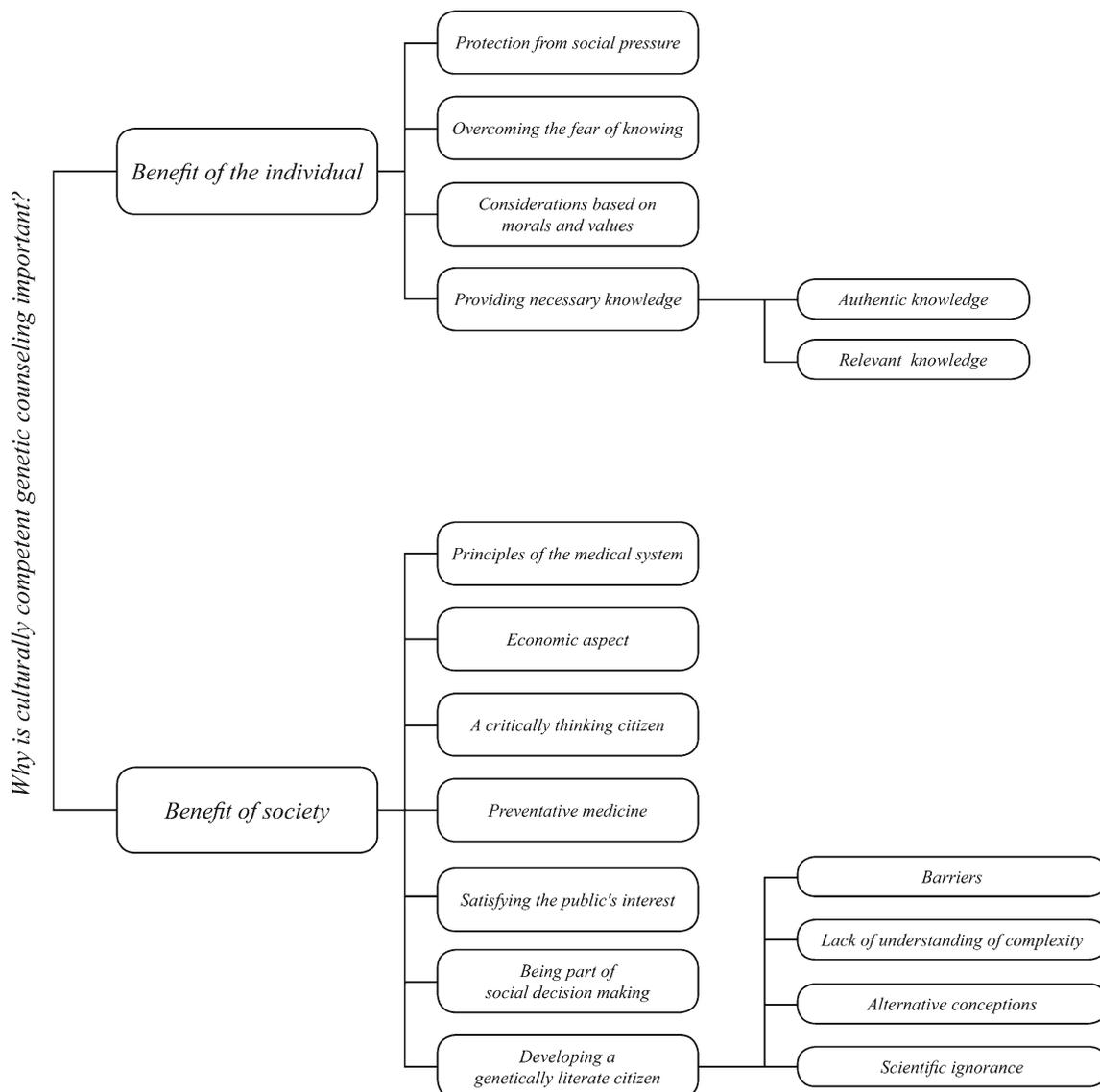
Our study population was composed of 15 genetic experts from 9 medical centers and health maintenance organizations (HMOs) throughout Israel (list of participants is attached in Appendix 1; the process for obtaining a status recognition

certificate of Genetic Counseling in Israel is attached in Appendix 3). Our interviewees work at diverse institutes throughout Israel, since the authors realized that geographic location (and the population diversity that goes with it) plays a role in the counseling process as well. The authors appealed to the genetic experts from the major medical institutions in Israel by mail, asking them to be interviewed for the study (85% of those we appealed consented to be interviewed). The authors arranged a meeting with those who were willing to do so. The in-depth interview (attached in Appendix 2) took approximately an hour and a half.

### Data Analysis

The analysis was conducted in stages. First the authors 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 the "grounded theory" analysis (Corbin and Strauss 2008; Glaser and Strauss 1967), coding the replies until saturation. The third stage started with a reflective process. After the first author conducted a few interviews and came to see some of the codes differently, both authors realized that some categories should be added. This resulted in another code refinement for all of the interviews, followed by a peer and auditor debriefing. The peers were two experts in genetics and one expert in science education, each of whom classified the answers into categories on their own (Creswell and Miller 2000). Elaborations that led to any disagreements were discussed until a 90% agreement on the elaboration categories was reached (Vedder-Weiss and Fortus 2012). In the fourth stage the authors refined the codes and produced the final categories. The first author then proceeded to recode all the interviews according to the new coding.

In accordance with the qualitative grounded theory approach, the authors' goal was to enable the respondent's voice to be heard (Kvale 1996) and not to force pre-existing categories. After listening to and transcribing the interviews, the first author conducted a line by line detailed microanalysis coding process in order to generate initial categories (Devers and Frankel 2000). The analysis produced four groups of primary categories, which together add up to the factors that genetic experts in Israel see as influences on the counseling's cultural competence. The codes were grouped into sub categories, which were grouped once again into four main categories: "Why is culturally competent genetic counseling important?" (Fig. 1); "Who is the recipient of this culturally competent genetic counseling?" (Fig. 2); "What should we include in culturally competent genetic counseling?" (Fig. 3)



**Fig. 1** The "why is culturally competent genetic counseling important" category tree

and "How should we perform culturally competent genetic counseling?" (Fig. 4).

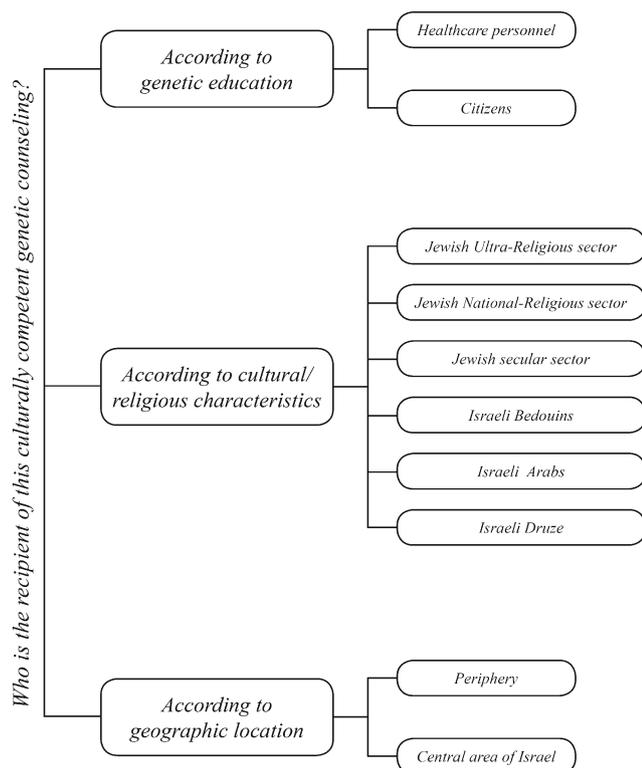
**Validation and Reliability**

During data collection the authors made an effort to maintain analysis reflexivity - to be as sensitive as possible to the ways in which the authors collected data and to minimize any bias due to prior assumptions or experience (Mays and Pope 2000). Since every researcher interprets data according to their own subjective perspective, content validation was done with the aid of experts from different areas of expertise so as to capture as wide a view as possible while defining the final codes (Elo and Kynigäs 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 how data should be categorized. This procedure took place twice, in two rounds, to assure the accuracy of the categorization.

**Results**

This section is divided according to the four category trees produced by our analysis of the genetic experts' interviews (Figs. 1, 2, 3 and 4). These summarize the main themes that came up in the interviews, demonstrating the thoughts, the examples from the clinic, and the dilemmas raised by the genetic experts. Each of the genetic experts is represented by a letter assigned by the authors (see the table in Appendix 1).



**Fig. 2** The "who is the recipient of this culturally competent genetic counseling" category tree

## Why is Culturally Competent Genetic Counseling Important?

This category contains the genetic experts' descriptions of the many potential benefits that they associate with access to genetic information and tests. These can be broadly divided into two primary sub-categories (see Fig. 1): "for the benefit of the individual" and "for the benefit of society".

The first of these sub-categories reflects the interviewees' understanding that individual citizens need to be addressed specifically, according to their personal background and agenda, so that they can make informed decisions about their own welfare:

"When standing before the wedding or before pregnancy, we suggest that people do genetic testing according to their particular genetic background and origin and sometimes people do not choose the tests that are recommended for them. [i.e. they insist on tests for illnesses for which they are not at risk, or they avoid tests despite the fact that they are recommended]" (A).

The "for the benefit of the individual" category is further divided into subcategories, noting the various contributions genetic counseling can make to addressing personal issues that influence individuals' ability to fully benefit from it.

One of these is "providing necessary knowledge" – meaning both "authentic knowledge" (up to date though complex genetic information) and "relevant knowledge" (information relevant to the specific patient based on their genetic problem learning ability). For example, one expert pointed out that:

"What tests are done or not done has to be a conscious choice of the specific person and that conscious choice can be done only by someone who understands - who has the relevant knowledge" (H).

In other words, genetic counseling is necessary because it provides individuals with the knowledge they need to make informed decisions regarding their genetic situation.

Another subcategory that addressed the "benefit of the individual" is "overcoming the fear of knowing." It included examples like:

"If this woman was a carrier of the two mutations, her family members sometimes say that they do not want to be tested because this information will not add to them, just make them more anxious" (D).

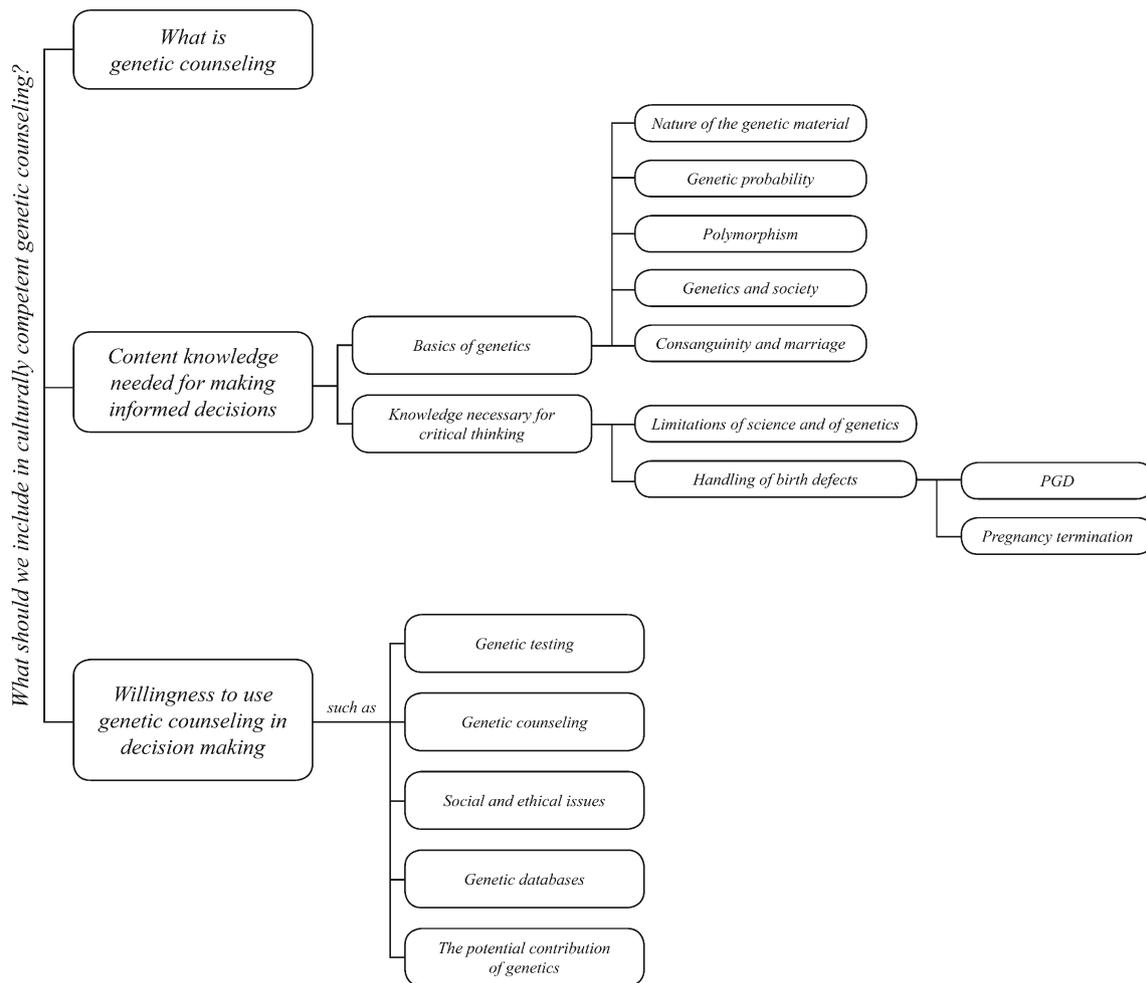
This passage reveals that some counsees are very anxious about genetic results, feeling in many situations that it is preferable not to know at all. This feeling is also connected at times to their culture - to the background the counsees come from, the principles accepted in their family and the support they get for their decision to perform or not to perform a genetic test. Thus, as a cognitive, emotional characteristic, it is a part of culturally competent genetic counseling.

The second main category of considerations that are intended to make sure that everyone has access to genetic counseling is the "benefit of society" as a whole, rather than just of individuals. For example, the subcategory, "principles of the medical system" addresses the moral implications of genetic counseling for the medical community:

"How have we set our boundaries? Why don't we check for everything? Which diseases do we check for? I mean people should understand the medical system, why we check what we check" (O).

"If the couple doesn't fully understand what the risk of continuing a pregnancy with a given genetic finding is, then ultimately it is the genetic expert who decides for them, and that seems like too much power to me"(F).

Another sub category in the "benefit to society" main category addresses the importance of "preventative medicine":



**Fig. 3** The "what should we include in culturally competent genetic counseling" category tree

"There's a government program for testing newborns, and that's going pretty well. It's moving into public awareness; we're working on it all the time and the numbers (of newborns tested) are going up" (L).

"We say 'go tell your family'. If we find a woman who's carrying a gene for breast cancer, we say 'tell your family before someone else gets sick, and you could have saved her life if you'd have told.'" (N).

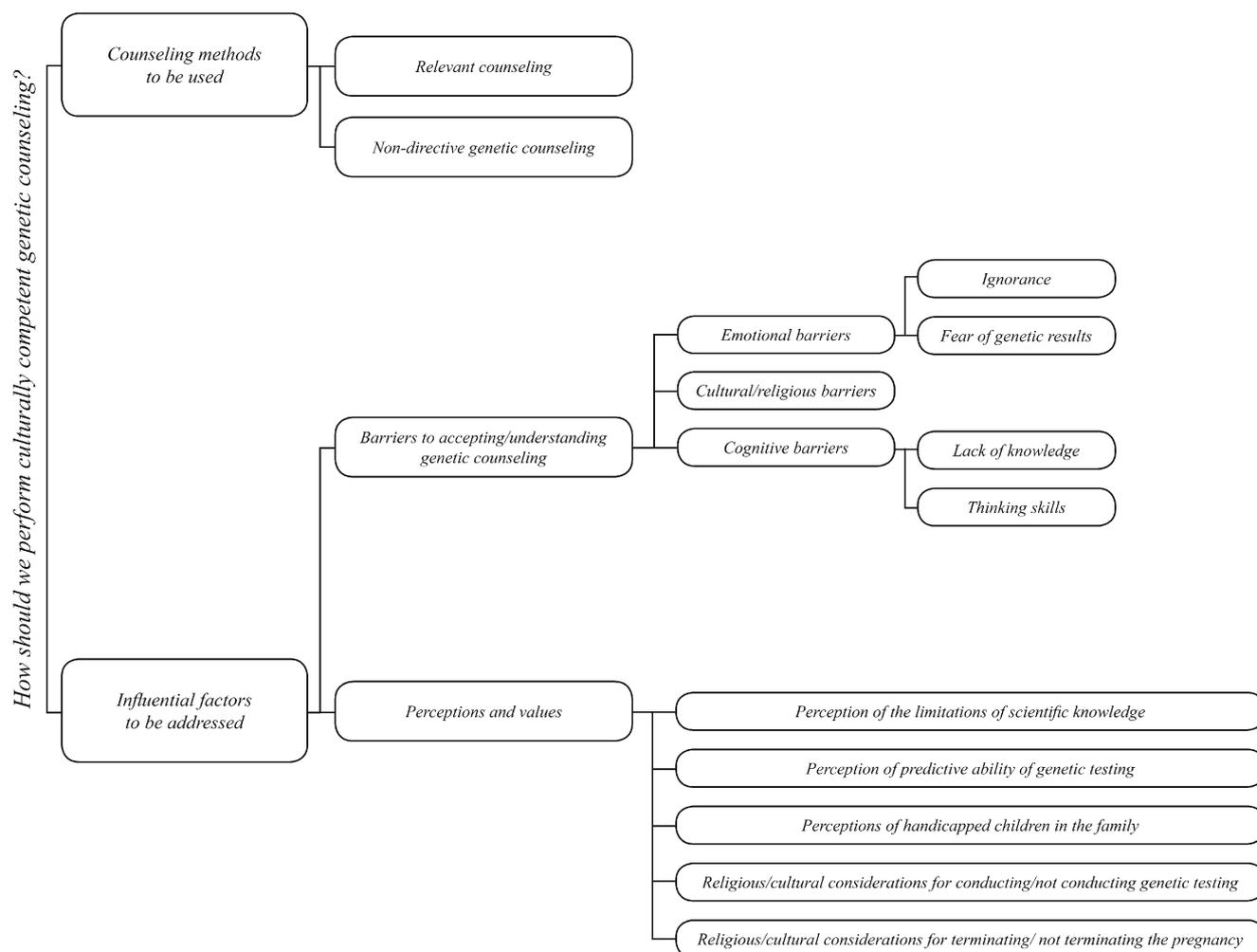
An additional sub category derived from this main category is "being part of social decision making", meaning that culturally competent genetic counseling is needed to help counsees acquire the knowledge they need to be a part of the public discourse in these issues:

"To acquire basic genetic knowledge is quite a duty so that the person can say: I can debate about genetic dilemmas at some point" (B).

According to this quote, part of being an involved citizen is being able to debate about dilemmas that are

not part of one's expertise. Some of these are crucial topics to the health and well-being of every person, including understanding, debating and even making decisions in the genetic domain.

As the examples above show, even when the counsees' culture is not addressed directly, there is an implicit reference to the importance of cultural competence and sensitivity in the strong implication that genetic counseling should be available to *everyone*, and that an individual's cultural background affects the form and extent of their access to genetic information and tests. Cultural barriers such as fear, lack of appropriate knowledge, different values etc., can prevent some populations from gaining full access to the genetic counseling process and from fully considering the options it provides. As the contents of this category suggest, access to these things should be as broad as possible, making the counseling dialogue culturally sensitive enough to allow diverse populations to make use of genetic information and procedures in a manner and to an extent that conforms to their own specific needs.



**Fig. 4** The "how should we perform culturally competent genetic counseling" category tree

### Who is the Recipient of this Culturally Competent Genetic Counseling?

The interviewees identified several characteristics that should be taken into account when adapting genetic counseling to particular populations. They mentioned three major categories that address the issue of who will be the counseling's recipient, dividing prospective counselees "according to genetic education", "according to cultural/religious characteristics" and "according to geographic location" (see Fig. 2).

The first main category, "according to genetic education" includes two sub categories of populations who need culturally competent counseling: healthcare personnel and citizens. The need of "healthcare personnel" to receive more knowledge regarding up to date genetic counseling is clearly addressed in the genetic experts' interviews. For example:

"She had two healthy children and she was pregnant when she came to the doctor, who told her that she does not have to take genetic tests because she already has

two healthy children. This is a terrible mistake. She gave birth to a child with Fragile X and for that I say she could have prevented it all. That is the problem if the doctor is not updated.

Some doctors are very aware but some doctors don't even send to do tests like Tay–Sachs. That's bad. It can really save families" (I).

The second main category addresses the need to acknowledge the diversity potential counselees, and the potential influence of "cultural/religious characteristics" on the counseling situation. This category consists of sub categories that reflect different sectors of Israel's extremely multicultural population, based on the interviewees' references to how their distinctiveness can affect the counseling process. For example:

"In the Ultra-Orthodox sector which is a very traditional one, many tests must not be done since terminating pregnancy is prohibited" (F).

"It seems to me that among the National Religious public there is great importance to the issue of genetic screening, since they are not aware of it. The last time I saw children with Tay-Sachs disease was among that community. They are not aware of doing genetic tests" (I).

"Among the Bedouins, after 120 days it is forbidden to terminate the pregnancy. In every society there are expectations but this is rare. The great majority [of Bedouins] do not terminate after 120 days" (J).

These three citations express the differentiation that is very common amongst the different sub populations, suggesting that if each sector received genetic counseling with the right approach, their decision making could be informed and based on genetic facts that take religious and cultural considerations into account, while also taking into consideration the individual's position and perspective within their specific "sector."

The third major category in this topic is "geographic location." It is important to note in this context that in Israel (as indeed, in many other places), different geographic locations are dominated by particular populations, with specific cultural, religious and socioeconomic characteristics. For example, the primary distinction made by our interviewees is the common Israeli distinction between "center" and "periphery." "Center" is a term generally applied to Tel Aviv and its suburbs, the population of which tends to be wealthier, more secular and more educated than that of the rest of the country, known as the "periphery." The implication of this is that the genetic experts' references to geographic location actually reflect references to the particularities of particular cultural and socioeconomic groups. It should be noted that in the "center" the proximity to genetics services is a little better than in the "periphery". We have maintained the distinction of these references in a separate category because the genetic expert themselves described these differences in geographic terms, for example:

"There are sectors that do a crazy amount of tests. Tel Aviv for example, is an extreme case. Women want to do all the tests that are possible. This is typical to non-religious, educated woman. They hear about the tests from their neighbors and come with genetic data" (M).

"There are the Orthodox religious patients from Netivot (a peripheral town in the south of Israel) that won't do almost any genetic tests" (H).

Examples like these suggest that the different sectors of the population, coming from diverse areas in Israel, need different types of culturally competent counseling, since their awareness of the possibilities and the consequences of genetic testing is not the same. While the precise geographic distinctions made by our genetic experts in Israel may not be directly

applicable to a broader audience, the general premise that geographic location should be taken into account as an indicator of cultural, religious and socioeconomic particularity could certainly be useful in other contexts. Geographic location is also related to the accessibility of genetic services, since people who live further from centers of population generally have less access to health services (including genetic ones). This reduced access can translate into less genetic knowledge, as well as reduced chances of prevention, diagnosis, and treatment.

### **What should We Include in Culturally Competent Genetic Counseling?**

The third research question, which addresses the issue of what the content of culturally competent genetics counseling should be, produced 3 main categories (see Fig. 3): "what is genetic counseling", "content knowledge needed for making informed decisions" and "willingness to use genetic counseling in decision making".

The following citation reveals how important it is to clarify the intentions and aims of genetic counseling to the lay population in order to overcome objections to receiving genetic information and to understanding one's genetic situation.

"We had a Bedouin couple with their first pregnancy, and they were both carriers of thalassemia. She had amniocentesis, and it turned out that the fetus is sick and they kept the pregnancy. During the second pregnancy the fetus was tested and found to be ill again. Then they stopped the pregnancy and the father told me: I'm glad that we didn't stop the first pregnancy because if we stopped it and now you would have told me again that I have a sick child, I would have thought that you don't want me to have children, because I am a Bedouin" (J).

This quote indicates that the first stage for an efficient counseling process is cultivating the counselees' trust in the counselor and in the counseling process. To this end, counselees must be made to understand what genetic counseling is and what its goals are. As the interpretation suggested by this Bedouin father shows, this is especially important when dealing with minorities, since, if they feel unwanted or even persecuted by a ruling majority, they may not necessarily trust their government (and by extension also government-funded medical services like genetic counseling) to have their best interests at heart. The second main category states that there is "content knowledge needed for making informed decisions":

"A person must have a body of knowledge in order to make informed decisions for himself. The difficulty for

me as a genetic counselor is to see someone making a very un-informed decision because he doesn't understand the genetic facts. For example, he might tell me: 'I do not believe in your results', or, 'everything will be all right'." (J).

As part of this main category, the genetic experts made reference to "the basics of genetics" that counselees are usually missing, the lack of which is problematic if we want them to make informed decisions in the genetic domain. As the quote below shows, these basics include more than just pure genetic knowledge, but also additional types of relevant knowledge like an understanding of probability, which is difficult to understand and which there is not enough time to explain:

"For several years I have been trying to bring couples to genetic counseling before pregnancy, meaning to think that pregnancy is an important step in life and you need to plan it and design it in terms of health. I do not think that the problem of the couples is the understanding the genetics itself. The problem is all the statistics; the subject of probabilities, and the significance of probability. When you talk about a risk of one in a hundred, that sort of thing is very difficult for people to grasp and I usually don't have enough time to explain it"(O).

The content knowledge category also includes a sub-category containing the "knowledge necessary for critical thinking". This includes the ability to understand the "limitations of science and of genetics":

"We need to emphasize the fact that with everything we know, we cannot guarantee that everything will be OK. There may more problems that we have not checked and therefore it is impossible to be 100% confident that the fetus will be healthy" (H).

Another part of critical thinking is the understanding of the various options for "handling birth defects":

"I think that genetic counseling should include informing about PGD for example, it is important especially for religious populations. They should be aware of this genetic procedure because it opens options, so that they won't say: 'Well if I am a carrier I will not marry'"(G).

The third main category in this category tree (Fig. 3) is "willingness to use genetic counseling in decision making":

"I prefer that people won't say- 'we do not agree at all to pregnancy termination because of our religion'. I hope

that people will develop skills of understanding, being informed, and will understand that a decision in one place has different implications in another place."(E)

As this quote indicates, culturally competent genetic counseling must be able to overcome an initial cultural tendency to reject all genetic testing and information outright. Counselors must develop their counselees' receptiveness to various aspects of the counseling and testing process, helping them understand that this process could present them with options, even within whatever boundaries their cultural background might impose.

This main category includes various sub-categories, including the development of openness to the discussion of "social and ethical issues" in genetics:

"Genetics cannot be taught without reference to ethical questions. There is no black and white. I always say that if a child broke his arm and went to an orthopedist; obviously it needs to be fixed. But if a woman has a risk of having a sick child, there is no right and wrong. What she thinks needs to be done with this situation is equally right" (B).

The complexity of genetic decision making is completely different than in other fields of medicine, which makes the necessity for a good attitude and willingness to receive the information much more relevant.

Another sub category of this topic is developing an awareness of "the potential contribution of genetics":

"There are areas of genetics that have a lot to offer. There are also areas that don't. In these areas there is also the importance of the environment, and we cannot control everything"(A).

Genetic knowledge has its limitations, and it is not the only factor that influences our lives. Nevertheless, it is important not to see these limitations as a reason to write genetics off completely, but to acknowledge and embrace the essential contribution that genetics can still have on our lives.

## How should We Perform Culturally Competent Genetic Counseling?

The considerations that the genetic experts think we should take into account when performing counseling can be divided into two main categories (Fig. 4): "counseling methods to be used" and "influential factors to be addressed". Together, these two categories and their sub categories constitute a set of guidelines regarding how counselees should be addressed

so as to tailor the counseling to each individual's specific needs.

The recommendation for "counseling methods to be used" refers to methods such as "non-directive counseling" (i.e. making sure the counseling does not direct the counselee's decision to any particular decision) and "relevant counseling" (i.e. the ability to tailor, translate and communicate complex information in a simple, relevant way for a broad range of audiences, <http://nsgc.org/p/cm/ld/fid=94>). The meaning of the latter is that part of the success of a counseling session rests on whether the counselor is able to be sensitive enough to transfer *only* the relevant information to a specific counselee, which is not necessarily all the genetic information about their genetic situation:

"You have to be careful when you pass the genetic information not to throw the knowledge on to the people and let them deal with it" (M).

"I think it's a skill that we shouldn't downplay, because on the one hand we have to give people the information but on the other hand we cannot give them information that they cannot handle" (L.).

This category reflects the genetic experts' opinion that if such accepted methods are used during the counseling session, the counseling is more likely to be culturally competent.

The other main category, "influential factors to be addressed" (Fig. 4) reflects additional elements that genetic experts see as necessary to culturally competent counseling: "barriers to accepting/understanding genetic counseling" and "perceptions and values".

The "barriers" sub category includes "cultural/religious" barriers, which are very diverse and often interconnected. We therefore did not subdivide these barriers into just a few subcategories, but gathered them together in one large group. To cite just a few examples:

"Resistance is often on religious grounds. 'Everything is from God'. To me the question is what does it mean everything is from God? If it means 'I accept all that God says'; that's OK for me. That's one thing. Or does it mean 'leave me alone,' or 'my husband told me?'" (J).

"We have communities that do not want us to bother them. Everything will be fine. It is a faith-based approach. I had a 35-year-old patient who was pregnant, and her husband said: "everything shall be fine; if you believe everything will be all right". She didn't do any genetic survey tests or ultrasound testing" (D).

"Some populations hear the word 'genetics' and afraid of labels, especially religious populations who do not want to be labelled as having a genetic defect"(E).

"I meet those who don't want to get the genetic information because of ignorance, or ... because of prejudice.

They say that in their religious sector is not appropriate to take genetic tests since anyway there is nothing to do with that information" (B).

All of these examples reflect the interconnected influence of religious beliefs and cultural/social norms and restrictions, which often cannot be entirely separated even by the interviewee who describes them. As "J" notes in the first example, it is sometimes difficult to determine whether a woman who says "everything is from God" is expressing her own religious belief, her community's antipathy towards medical intervention, or a cultural compliance with her husband's decision on the issue. These quotes, and others like them, suggest that performing competent counseling may often require counselors to elaborate further on the statements that they make so that the particular factors involved in each case can be better understood. These declarations might mean that there are religious barriers that limit the scope of the genetic testing these counsees are "free" to perform, but they might also reflect a fallacy – a misapprehension based on word of mouth that counselors may be able to correct. The example provided by "B," for instance, reflects a common misapprehension in religious communities that they are not allowed – in any circumstance – to act upon information gathered by genetic tests. If such a misapprehension is preventing counsees from undertaking genetic tests, counselors can provide them with guidance *in religious terms* regarding options that are open to them within the boundaries of their faith, of which they may not be aware. In the US, the genetic counselor might strive for further discussion and insight into the client's beliefs and encourage the client to speak with a member of the clergy to address the religious aspects. In Israel, the genetic counselors should be familiar with the major religious laws that could impact the issues they discuss with their clients. While they cannot be expected to know *all* the religious laws of *all* the religious sectors in Israel, they could at least benefit from understanding those of the populations with whom they come into daily contact. It is recommended that the counselors speak with religious experts to gain an idea of the fundamental religious principles of their patients. This will help counselors to know how the genetic information they have to offer corresponds with the religious laws of the patient.

The acceptance of genetics is also influenced by "cognitive barriers" like the counselee's "lack of knowledge":

"I think that people who know more think more. When your mind has already acquired knowledge, not just genetics, it is easy for you to acquire more knowledge more easily and I can go on to further explanations relevant specifically to this patient, but I don't always have time to reach these levels of explanation" (C).

This suggests that the former scientific, genetic and general knowledge of the counselee will alter the kind of counseling they require and will be able to receive. For example, counselors will be able to extend the counseling to include more in-depth explanations if the basic genetic knowledge is already known to the counselee and if the session time allows it.

The second sub category contains the various “perceptions and values” that can affect the counselees’ experience of genetic counseling:

"Today we're talking about a more active consultation that will help people organize the information they receive according to the advantages and disadvantages for them, according to their values. In that way we can understand what is important to them and should be careful about it" (E).

This sub category includes, for instance, the counselees’ “perception of the limitations of scientific knowledge”:

"Today when we do genome screening we get a lot of information that we do not know what it means. You should discuss with the counselee the significance of the genetic test result and the fact that we cannot interpret all the results we get, so that people will be more aware of the possibilities of what to do with these test results"(I).

The “perceptions and values” sub category also includes counselees’ “perceptions of handicapped children in the family”:

"If you have a fetus with a very difficult genetic problem, and you say: 'this is what I received from God, and I will deal with it', it is your right"(K).

"The Ministry of Health has decided that life with CF is severe enough to perform screening of the population for this disease. But the decision is ultimately the couple's. Some of the couples want to have the child" (E).

The implication of this sub category is that some counselees may – for whatever reason – choose to take on the challenge of raising a sick child. Counselees have the right to make choices based on their own perceptions and values, and counselors must therefore understand what these are, respect them as legitimate, and take them into account.

## Discussion

The goal of this study was to probe the insights of Israeli genetic experts regarding culturally competent genetic counseling. Our study is designed to capture the genetic

experts’ complex thoughts, dilemmas and deliberations regarding the counseling process through in-depth interviews. The interviews managed to capture a complex picture of different ideas and approaches, while also describing a fairly uniform line regarding the basic standards of genetic counseling.

One of our main findings in this research is that genetic experts have a very complex view of their role during the counseling session. As the interviews show, genetic experts are required to teach their counselees the basic principles of genetics, but must also be able to mediate between the up to date genetic knowledge and the needs of each specific counselee, taking into account their former knowledge and perceptions (Shaw and Hurst 2008; Lanie et al. 2004; Al-Gazali 2005; Bauer et al. 1994). These perceptions are most influenced by the counselees’ cultural background, by their fears and by what they already know. Genetic counselors are taught to provide counselees with the genetic information available (NSGC- National Society of Genetic Counseling), but not every counselee is able to fully understand all the genetic details in a way that is beneficial to the procedure of decision making (Ormond et al. 2010). If the counselees’ cognitive situation prevents them from grasping all the information being conveyed to them, they will not use it anyway and will leave the counseling confused, overloaded by having received too much information in a very short time (Donley et al. 2012).

In addition to the counselee’s cultural background and values, the cultural context of the genetic expert also affects the delivery of culturally competent counselling. In health care, and especially in counselling settings, the values of patients and professionals are equally important or influential (Gschmeidler et al. 2016). Value conflicts between counselor and counselee have been connected to different stressful situations on the counselors’ side, when family decisions did not meet the counselors’ values, leading at times to negative emotions in the counselor, such as guilt, helplessness, anger, or inadequacy (Bernhardt et al. 2010). One study showed that in the case of deaf clients, genetic counselors’ attitudes could affect information provision and the decision making process of the clients, recommending cultural sensitivity workshops in genetic counseling training programs that incorporate personal interactions with deaf individuals to familiarize counselors with this population and thus reduce the effect of personal attitudes (Enns et al. 2010). On the whole, studies have suggested that the communication process with culturally diverse patients may be improved if the counselors learn about the family’s beliefs and culture by first establishing a sense of trust and maintaining a nonjudgmental attitude so as not to dismiss the patient’s beliefs (Barlow-Stewart et al. 2006).

Taking all these considerations into account, we would like to offer a few suggestions, based on the voice of Israel’s genetic experts, for improving the genetic counseling procedure

in multicultural countries such as Israel, while taking into account the complex background of the counselee. Israel, like USA, UK, Australia and many other places around the world, is a highly varied multicultural society, and approaches to genetic testing and genetic counseling can therefore differ strongly among the different subcultures that make up its population. As such, our recommendations might apply to other places whose candidates for genetic counseling come from multiple cultural, religious and educational backgrounds. Moreover, Arasaratnam (2013) reviewed 35 articles dealing with multicultural societies around the world and showed that they have characteristics in common - such as multicultural education, attitudes toward multiculturalism and even multicultural identity. In the field of genetic counseling, a "universal" approach regarding multicultural societies has been suggested, stating that: "all clients will experience some form of anxiety when faced with a genetic condition; the counselor must transcend racial, ethnic, and cultural barriers in locating anxiety and helping the client to negotiate this anxiety in ways that are consonant with individually held values" (Lewis 2002 pp. 202). All these findings together indicate that the suggestions raised in this paper, though based on interviews with Israeli genetic experts who work with one particular multicultural population, can be relevant to other multicultural societies as well.

*First* of all the authors would like to suggest lengthening the genetic counseling session so that the counselor will be able to truly gauge all the prior knowledge of the counsees, their ability to accept new information, and especially their religious beliefs, norms, values and attitudes towards genetic testing. The best way to provide culturally competent genetic counseling is by means of individualized assessment: exploring the thoughts, wishes and values of the counsees with them and then working together to arrive at an outcome or decision. All this takes time. The current length of genetic counseling sessions in Israel, in USA and in Canada is usually 30–50 min. In a session of this length the genetic experts have admitted that they cannot analyze the exact position in which the counsees stand. Moreover, they are not always able to pass on the complicated information regarding the statistics involved in genetics and the full meaning of probability, which are essential terms in many genetic diseases (Fig. 3), as reflected in the sub-category "content knowledge needed for making informed decisions," which includes essential topics such as "genetic probability." Additionally, this time frame is insufficient to allow counselors to understand the emotional state of the patient such as that reflected in the category "overcoming the fear of knowing" (Fig. 1), as well as their religious expectations, in light of their "cultural/religious characteristics" (Fig. 2). The characteristics of these specific sectors (Jewish Ultra-religious, Israeli Bedouins and so on) are relevant in Israeli society, but the importance of allocating sufficient time to identify and account for social,

cultural and religious specificity is applicable to multicultural societies around the world. Our suggestion is therefore raised in response to the frustration expressed by the genetic experts that the medical dialogue in which they must engage is so complex - including "emotional barriers," "cultural/religious barriers," "cognitive barriers" and the patients' "perceptions and values" - that it *cannot* be both effective and short (Fig. 4). Combining all of the elements effectively takes time, especially when one is dealing with patients with a lower oral literacy who require greater dialogue interactivity and more personally contextualized information (Roter et al. 2009).

We are aware of the fact that lengthening the counseling session requires substantial systemic changes and the allocation of more human resources. However, since the number of genetic counselors in Israel is rising every year, we do think it is an applicable recommendation. We are also aware of the fact that lengthening the counseling session would require additional funding. But today, as health services are becoming increasingly convinced of the fundamental importance of genetics to advances in medicine, especially with the rise of interest in personalized medicine, we do think that the idea of raising the budget is feasible, in hope that this innovation might increase the chance of patients getting the full treatment they need.

Our *second* suggestion is that every high school student should study genetics. Currently most of the students in Israel study genetics in 9th grade (Israel Ministry of Education, Life science curriculum for junior high school, 2016). Only a small percentage of the students continue to study genetics in 12th grade. By the time the majority of the population reaches the time for genetic counseling, they probably will not remember anything that they may have learned superficially in 9th grade. Moreover, although most students do have some genetic knowledge, it has mostly been acquired in a cognitive manner, with no connection to social and cultural context (Tal et al. 2011). The genetic experts that were interviewed here see it as a crucial issue to teach up-to-date relevant genetics, including the basics of genetics and the use of genetics in personalized medicine (Frueh and Gurwitz 2004). They often noted the importance of making sure individuals are equipped with "necessary knowledge" that is both "authentic" and "relevant" (see Fig. 1). They also noted the social benefits of generating citizens who are capable of "thinking critically" about such issues, and of taking part in "social decision-making" (Fig. 1). These themes were raised during the interviews, leading us to this recommendation, since "basics of genetics" and "critical thinking" are essential prerequisites for informed decision making (Fig. 3). This recommendation is partly applicable in Israel, since in the updated high school biology curriculum for high schools (Israel Ministry of Education, Life science curriculum for high school, 2015), all biology students must learn Mendelian inheritance, the difference between recessive and

dominant diseases, ethical issues of genetics and more. These issues were part of the elective subjects for high school biology major students but not part of the core as they are today. This solution is a partial one, since only approximately 15% of Israeli high school students are biology majors and study biology after 9th grade. The situation in the US is similar, since genetic issues are covered in the high school biology curriculum, but not all students are required to study biology.

Our *third* suggestion as part of the genetic experts' voice is that the lay person needs an additional preparation session, similar to a prenatal course, before attending genetic counseling. This preparation will make genetic counseling much more efficient and increase the counselees' chances of making an informed decision. The genetic experts spoke about the need for "providing necessary knowledge" to allow them to deepen their explanations and provide each patient with the "relevant knowledge" for their needs, rather than having to explain general genetics in the short session available (Fig. 1). The preparation can help by laying out theoretical genetic dilemmas, so that when counselees are confronted with dilemmas that are relevant to them, it might be easier for them to deal with them because they would not be confronting them for the first time. It has recently been suggested that more effort should be put into explaining the benefits, risks, and limitations of genetic testing, particularly at the social and personal levels, to ensure informed decision making (Haga et al. 2013). This preparation can also refresh the genetic terms that are studied at the high school level, since the lay population is usually largely unfamiliar with them (Lanie et al. 2004). Finally, the advantage of this "advance" preparation is that the actual genetic counseling session will be more personalized, with less need to discuss the "basics of genetics" (Fig. 3).

We are aware of the fact that the implementation of this suggestion is difficult, that it requires a special budget in order to organize accessible preparation sessions throughout the country. Moreover, plenty of thought is needed in order to target the sessions to the right population at the relevant age and the relevant level of genetic knowledge (or lack of knowledge). We think it is possible to find a place for such sessions, maybe as a part of marriage preparation courses conducted by the rabbinate in Israel, which are attended by many people in the country prior to marriage. All these subjects require further research to more fully assess their viability and usefulness.

### Study Limitations

Our interviewees were those who were willing to participate and be interviewed after the authors appealed to a large proportion of the genetic experts throughout Israel. They were told that we are researching the work of genetic experts. As such, the authors might assume that only those who are willing to share their professional work and maybe even their conflicts, were willing to go ahead and be interviewed.

Moreover, this study only reflects information that the participants were willing to volunteer, so it may conceivably not be reflective of issues that counselors prefer not to discuss. Our choice of interviewees and the exclusively voluntary nature of our information might have tilted the results, raising topics that would not have been raised if we had chosen a different sample, while overlooking other topics that might have come up.

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### Compliance with Ethical Standards

**Conflict of Interest** Author Merav Siani and Author Orit Ben-Zvi Assaraf declare that they have no conflict of interest.

**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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