Exploring the discourse between genetic counselors and Orthodox Jewish community members related to reproductive genetic technology

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Abstract

Objective: Genetic technology is complex, relatively new and involves sensitive issues pertaining to personhood and reproduction. While ethno cultural barriers to genetic care are well documented, little attention has been devoted to understanding religious beliefs pertaining to genetic services. This study evaluated the discourse between genetic counselors and Orthodox Jewish community members’ perceptions of reproductive genetic technology.

Methods: A cross section of the Orthodox Jewish community was sampled through purposeful and snowball recruitment for in-depth interviews with key informants.

Results: Genetic counselors felt apprehensive about serving the Orthodox Jewish population and were unaware of social norms, religious and cultural practices unique to this population. Similarly, Orthodox Jewish consumers exhibited major misgivings about genetic testing. Importantly, stereotypic expectations by both counselors and consumers exacerbated existing communication difficulties.

Conclusion: Cultural differences and poor communication between genetic counselors and Orthodox Jewish community members impeded the ability of the Orthodox Jewish community to utilize genetic services.

Practice implications: This work illuminates complex issues pertaining to medical encounters between providers and patients with ideological, social and cultural differences. In particular, issues of access to care and transcultural competence in serving religious minority groups, such as Orthodox Jews are presented. On the whole, this group is largely unrecognized in the minority health literature in spite of barriers and challenges that they face. Findings of this study may have application to other cloistered and highly observant religious groups when dealing with reproductive technology and other populations with diverse values, beliefs and behaviors pertaining to reproductive health.

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1. Introduction

Information emerging from the Human Genome Project (HGP) has revolutionized the approach to prevention, diagnosis and treatment of disease [1]. Reproductive genetic screening is the most common and earliest form of genetic intervention aimed at enhancing the management of detectable genetic diseases by generating vital information to be used in reproductive planning [2]. However, this form of reproductive genetic technology with its premise of technological manipulation of human procreation presents a great challenge to many religious and culturally distinctive groups.

Jews constitute the largest religious group in America, only second to Christians. Orthodox Jews represent the most
concerned branch of Judaism, strictly adhering to ancient Jewish law and yet, orthodoxy is the least unified and the most diverse of all branches of Judaism including strict (“Frum” or “Charedi”) and Modern branches. Orthodox Jews legitimize their normative behavior almost exclusively through rabbinical precedence and Jewish law and tend to have limited contact with the secular world [3,4]. Health care and in particular, specialized care presents one of the only contact zones in which the Orthodox Jewish community regularly interacts with the secular world. Some elements in Orthodox Judaism are uniform across affiliation, including a modest dress code for men and women, gender-specific role expectations and central values favoring the sanctity of marriage and the establishment of large families. In Orthodox tradition, the rabbi is expected to adjudicate issues of Jewish law and tradition [5]. It has been noted that as Orthodox rabbis provide mediation between modern health technology and ancient laws, they will at times make use of “loopholes” or apply legal flexibility to assist their congregants in reaching decisions that they can be comfortable with, while taking into consideration the lived experience, aspirations and convictions of the particular people involved [5].

Medical science is extolled as it is concerned with saving of human life, one of the highest decrees in Jewish law. Observant Jews are required to keep in good physical and mental health so that they can perform their religious obligations successfully. The issue of when life begins is a contentious one is Jewish law [6] with a general view of the products of conception as mere water until the 40th day after conception [7]. Prevailing views regard the fetus as an extension to the mother’s body. An abortion in that context is viewed as self-mutilation and is not permitted except when the pregnancy endangers the mother’s life. In recent years, emotional and mental anguish have been recognized as a threat to the mother’s well-being [8], and rabbinical adjudicators have been considering the issue on a case-by-case basis.

Genetic counselors are considered experts in the delivery of genetic information, psychosocial support related to the occurrence or the suspected occurrence of a birth defect and the facilitation of genetic technology to the public [9]. Some of the goals of genetic counseling include reduction of client anxiety, enhancing client understanding of genetic risk and options and facilitating coping with the outcome of genetic testing [10,11]. Because of the early ties of human genetics to eugenics, genetic providers strongly espouse autonomy, non-directiveness, informed consent and individuality [12,13].

The Orthodox Jewish community is at high risk with respect to birth defects. In addition to the general population’s risk Orthodox Jews, who are largely of Eastern European descent have a cumulative chance of one in four for carrying genes for recessive conditions, such as Tay Sachs disease and Bloom syndrome [14]. In addition, a mandate to reproduce and aversion to contraception use increases the proportion of pregnancies at the end of the female’s reproductive cycle in this population, thus increasing the risk for chromosomal abnormalities, such as Down syndrome.

Scholars have pointed out that there is a wide cultural gulf between the Ultra-Orthodox community and mainstream medical providers; not only do they often espouse different cultural values, but they also maintain contradictory and clashing principles [4]. For example, genetic counseling which touts “control and mastery over life’s circumstances” [10] may especially be at odds with the world view of Orthodox Jews who strongly abide by the prohibitions of the Torah (the first five books of the Hebrew bible), and faithfully accept God’s plans. Moreover, a strong sense of community interconnectedness and the pursuit of rabbinical guidance in making decisions pertaining to health are rather antagonistic to the concepts of individualism and non-directiveness that form the core of the genetic counseling process.

In spite of the fact that genetic care is permitted by Jewish law [15], Orthodox Jews shy away from most forms of genetic services [16]. Anecdotal data suggests that Orthodox Jews seldom take part in prenatal and pediatric genetic interventions offered within the medical model [17]. This is attributed to social and religious constraints, lack of trust in genetic providers, fear of stigmatization and misconceptions related to the attainment of these services [16,18]. Premarital genetic screening through a grass roots program, Chevre Dor Yeshorim, is widely endorsed and used for arranged marriages, a pervasive practice in the Ultra-Orthodox Jewish community [16]. To date no efforts have been devoted to investigating misconceptions and bridging the cultural gap between the Orthodox Jewish community and the medical community with relation to genetic services [15].

2. Methods

Qualitative investigation was chosen for this study because perceptions related to genetic screening in Orthodox Jews are not well articulated in the medical literature. Moreover, topics related to reproductive genetic screening are sensitive in nature and given that the target community is cloistered and suspicious of medical research, personable interactions were important in establishing rapport with study participants.

2.1. Study sample

Non-probability, purposeful sampling took place followed by snowball recruitment as key informants suggested and facilitated additional contacts. Health care providers and genetic counselors serving an Orthodox Jewish community in a large metropolitan area were targeted. Genetic counselors serving communities with high concentration
of Orthodox Jews were sought nationally through the Listserv of the National Society of Genetic Counselors (NSGC). Consumers of genetic services were also targeted for interviews; these included Orthodox Jewish men and women who had genetic testing and/or counseling, parents of children with genetic conditions and persons who themselves have disease-causing traits. Lastly, rabbis and matchmakers (professional and non-professional persons acting as marriage brokers) were also sampled for interviews.

2.2. Data collection

Unstructured, one-on-one interviews either in person or by phone took place with study informants who received a token monetary reward for their participation in the study. All interviews were audiotaped and transcribed verbatim. Transcripts also included notes, comments on the demeanor of interviewees and details on the settings where interviews took place. A total of 33 interviews were used to analyze the discourse between genetic counselors and Orthodox Jewish community members (Table 1). Data collection concluded when saturation was achieved in the information derived from informants.

2.3. Data analysis

Atlas T.I. 5.0 was used to manage, organize and define the voluminous textual data retrieved through the interviews in facilitating construction of meaningful theories from the data. Analysis took place at the following levels; textual—in which word files were sorted out and text segments were coded to reflect representing themes. At the conceptual level, the relationships between themes were ascertained and compared across informants to enable data interpretation. Importantly, data collection and analysis occurred simultaneously leading to an iterative process of theory building. Texts with similar codes were examined and cross-referenced between informants. Code families were created to reflect the relationships between emerging themes and allow the construction of a conceptual framework.

Emerging themes were evaluated and reviewed, alternative interpretations were considered and revisions were made when appropriate. Importantly, individuals who described attitudes and experiences counter to those typical for the group were examined and analyzed (negative cases). Further measures to achieve interpretation credibility included member validation of emerging themes with new informants and on a few occasions with informants who articulated the sentiments that led to original interpretations. Dependability of the findings was examined through resource and subject triangulation in engaging different sources of informants and by querying the same informants on different subjects pertaining to a topic of investigation. Field notes, journals, memos and reflexivity notes were kept along the way providing an “audit trail” of what led to the development of themes and theories.

3. Results

3.1. Referrals for genetic counseling

Barriers to communication between the Orthodox Jewish community and genetic counselors were present from the start and at times even before the encounter ever took place. Referrals of Orthodox Jewish patients to genetic counseling services were affected by assumptions made by medical providers about what would be acceptable to Orthodox Jewish patients. Interviews with health care providers suggested that Orthodox Jewish patients may be treated differently than secular patients with regard to the offer of reproductive genetic screening options as can be illustrated by the following quote.

Some physicians think that they know how the patient will respond to things, and may either not offer things or gloss over it. For example: “you are 35 you know, sometimes we offer genetic counseling for amnio, but you are not going to do anything anyway, so therefore”. And it’s sort of like saying to someone, “you have never had a sexually transmitted disease have you?” (A female allied health professional)

Genetic counselors felt that lack of referrals from medical providers and biases about the offering of genetic counseling introduce major barriers to their ability to access patients and provide meaningful services. Counselors perceived that they were getting fewer referrals of Orthodox Jews than expected.

So you know, it is how the offer is made, is there a pre-conceived or maybe not pre-conceived, an implied judgment as to the value that this will be for them? . . . even for the physicians who have fairly large Orthodox practices I am getting their other patients . . . (A female genetic counselor)

Others commented that even when patients did present for counseling they were reluctant, impatient and even hostile.

. . . It’s very frustrating for me because I do not want to feel that I am being imposed on people. The last thing you want to do is be put in a position where someone is coming in

<table>
<thead>
<tr>
<th>Group</th>
<th>Orthodox Jewish</th>
<th>Non-Orthodox Jewish</th>
<th>Total</th>
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<tbody>
<tr>
<td>Genetic Counselors</td>
<td>3</td>
<td>3</td>
<td>6</td>
</tr>
<tr>
<td>Health care Providers</td>
<td>9</td>
<td>4</td>
<td>14</td>
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<tr>
<td>Matchmakers</td>
<td>3</td>
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<td>3</td>
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<tr>
<td>Rabbis</td>
<td>5</td>
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<td>Consumers</td>
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<td>5</td>
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<td>Total</td>
<td>25</td>
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Twelve in-depths interviews were conducted by phone. Of these, eight informants lived outside the study Metropolitan area.
angry because they are here. And sometimes when even on the phone I have gotten the sense from someone that they are questioning the value [of coming in]. (A female genetic counselor)

Another important factor influencing patients’ presentation for genetic counseling were stories making their rounds in the community regarding the way people are treated when going to genetic providers. Multiple informants including consumers, community-based physicians and rabbis used the term “horror stories” when recounting these events. These stories tended to portray genetic providers as coercive, insensitive and uninformed about the religious and cultural needs of Orthodox Jews. In addition, the accuracy of genetic testing was doubted by some informants both rabbis and community members, who could recount stories about women going through emotional turmoil after being advised that their baby would have a birth defect, and after delivery found out that the baby was perfectly healthy.

It is interesting to note, that on a few occasions both counselors and consumers reported rewarding, extensive and beneficial interactions that helped counselees and their families cope. However, in most cases, reports of positive impressions of the interactions were the exception and not the norm.

3.2. Establishing rapport

Genetic counselors and Orthodox Jewish consumers exhibited little familiarity with one another, yet they were reluctant to reach out to one another for more information and a deeper understanding. Pre-conceived notions were evident in both communities and at times major issues were left unacknowledged as the “elephant in the room.” One such issue was the religious identity of the counselor and counselee. Both genetic counselors and consumers made assumptions based on surnames, dress code and even facial appearances but chose not to inquire about religious identity directly.

Simple gestures, such as culturally acceptable greetings were also an issue. One genetic counselor was unaware that physical contact between a man and a woman not married to one another was forbidden and that when greeting clients of the opposite sex verbal greeting alone would be appropriate.

... And then I turned to shake his hand I extended my hand out, and he just kept his hand down I believe and said “I don’t shake hands” and I said “OK” and kept going but I felt like ... probably my face was kind of flush I was in the waiting room and there were other people around ... I just know that I felt embarrassed that I have done the wrong thing ... (A female genetic counselor)

3.3. Genetic counselors’ perceptions

Genetic counselors perceived that they are not well received by Orthodox Jews. Moreover, some counselors perceived their interactions with Orthodox Jewish patients to be shallow and confessed that they feel inadequate in discussing psychosocial issues when counseling Orthodox Jewish patients. Interestingly, most counselors recounted that they found their interactions with members of the Orthodox Jewish community even more challenging than dealing with other cultural minority groups. Overall, genetic counselors felt uncomfortable probing about religious practices even as they relate to offered interventions. Counselors feared that probing would be construed as a value judgment and were reluctant to disrupt an already fragile relationship with Orthodox Jewish counselees.

I am certainly not comfortable enough with them to step back and say “Can you explain to me you know what it is that we are doing that is making the community uncomfortable?” or “Is there something that we can be doing differently to optimize accessibility?” Whereas you know there have been other people from other ethnicities that I have been comfortable enough to step back and be able to have that conversation with ... What I would not want to be doing (sighs) is making them feel uncomfortable about coming to me again in the future. I would not want to insult them or anger them. (A female genetic counselor)

Genetic counselors were aware that they are perceived by Orthodox Jewish consumers as being directive and defended their obligation to mention all available options including abortion.

... if I have got a baby with multiple birth defects, I am going to say either from the beginning depending on the severity of the abnormalities that ending this pregnancy is an option ... I am still going to say that to these families but I think you have to be careful how you present this information depending upon who it is that you are speaking to, and I think that it may very well be that they are assuming that “that genetic person is going to be telling us what she thinks we should do and telling us we should abort the baby. ” So I’m not sure that there is an understanding of truly what my role is. (A female genetic counselor)

3.4. Consumers’ perceptions

While genetic counselors felt frustration around their inability to connect with Orthodox Jewish consumers on a deeper level, consumers tend to view the genetic counseling encounter as mostly an educational process and felt that genetic counseling offers little utility as it states the obvious:

... But there I felt like what was there really more to say. You know, we know our chances are one in four if we are going to do this test. We’ll send the labs out to who ever it is and it will take this amount of time to come back. I just felt like for whatever long it took, I didn’t need to sit there for that amount of time just because I knew it already. (A female consumer)

Moreover, consumers expected that the major role of a genetic counselor was to discuss termination of pregnancy,
where counselors felt that their role was to discuss all options in a non-biased way facilitating a decision that the family can be comfortable with.

She found them [genetic counselors] not helpful at all. You know it was just being a Frum person she felt, “well, I am not having an abortion so, what are you talking to me about?” Because that’s you know a lot of [the nature] of the genetic counseling in terms of later issues is whether or not to keep the child. (A female consumer)

Importantly, these notions were articulated not only by consumers but also by community-based physicians and rabbis who provide counsel related to health care practices.

And many a time I’ve heard horror stories where you know a doctor will convince a patient you know, whose life is going to be miserable having a child like that. Therefore putting some kind of pressure on them to try to go through an abortion. And that’s not right, it’s just not right on the part of the physician doing something like that. (A rabbi)

3.5. The rabbi as a gate keeper

In the Orthodox Jewish community, consultation with a rabbi or multiple rabbis who act as adjudicators in cases of conflict is common practice, and ranges from mundane issues such as nutrition laws to very delicate intimate family matters. It certainly involves interactions with the secular medical system, and especially with regard to the sensitive and evolving field of reproductive genetics.

Genetic counselors were at times challenged by the prospect of bringing the rabbi into the conventional counseling dyad. A genetic counselor expressed her frustration in the following excerpt:

…but the process of what are we going to be doing for this baby after delivery, was driven by the rabbi, as opposed to what we are used to as driven by the family … and the medical people that are involved in taking care of that baby. And, again this was difficult to try and bring into perspective the ethical considerations of this physician with the ethical and parental [in the face of] the advice and recommendations that they were getting from the rabbi … (A female genetic counselor)

Another informant, following up on a ruling provided by her rabbi, shared her frustrating encounter with a genetic counselor she saw for a prenatal management issue, who disagreed with the rabbi’s counsel:

After, I said “I am aware, I am aware,” she said “well, even after all of these risks you are going to do [repeats patient’s decision]?” And I said “we went to the rabbi”, and I didn’t want to have to go through the whole (issue) because the woman wasn’t Jewish. I said “We made our decision with our rabbi that this is what we are going to do, [repeats her decision].” And she said “Your rabbi is also a doctor?” I said “No, he is a rabbi”. And then she sort of left the room. (A female consumer in her twenties)

Interestingly, medical providers who were Orthodox Jewish themselves reacted differently in the face of a conflict with rabbinical counsel:

So, I went and talked to the rabbi and the rabbi said that he doesn’t believe in amniocentesis, whatever, he came up with his reasons, which I disagreed with but that’s OK, that’s the rabbi. So I came back and said “You know what, I don’t agree with your rabbi (laughs) but this is what your rabbi said. What would you like to do?” She said “I am not going to do the amniocentesis” so I said “OK” and then we forgot about it. (A male physician)

Most counselors interviewed, including those who worked at sites serving large volumes of Jewish patients, have not involved rabbis in the counseling interactions, and some assumed that there was rabbinical counsel on site, but have never actually queried their institutions about this matter. However, from the standpoint of consumers, consulting with a rabbi was a matter of fact. Moreover, some consumers articulated great relief in having a difficult decision made for them. The following quote illustrates the experience of a consumer facing a complex, heart-wrenching decision in reproduction:

So, my feelings were so interesting because I think I was the happiest person there. … I mean people were crying, were sobbing. It was just so distressing but when I went, this is after weeks of Halachic discussions and rabbis and back and forth, and when my decision was made, it’s like in a way, it was a copout, it’s like “I am free, I don’t have to make this decision.” Because once the decision has been made I never looked back with regret … I never for one split second of my life had a “what if”, I don’t think I ever will because it just wasn’t my decision. (A female consumer)

4. Discussion and conclusion

4.1. Discussion

Immigration patterns, age demographics and population growth trends in general contribute to an accelerating ethnic/racial diversity in the U.S. Sociocultural differences between patients and providers impact communications and effect quality of care [19–21].

The vast attention to culturally discordant patient–provider encounters and issues of cultural competency in the medical literature in the past decade tends to focus on “visible” ethnic and racial groups. Largely neglected are religious minority groups who have very distinct social norms, practices and morals that may challenge the ethos and beliefs of healthcare providers.

The case study of the Orthodox Jewish community illuminates a sub-culture of a population disproportionately
targeted in genetic research, yet is vastly under-represented in social research about the impact of genetic interventions and health care in general as well as patient–provider communications. This population is high risk for genetic conditions and under-utilizes the extensive system of genetic care.

4.2. Conclusion

A wide gap exists between genetic counselors and Orthodox Jewish community members. Lack of awareness pertaining to patients’ preferences needs and values as well as misconceptions related to the nature and logistics of genetic services both contribute to this gap. This seems to result not only in a perceived poorer quality service but to limited access to genetic services by Orthodox Jews to begin with.

Stereotypic labeling of religiously pious communities as opposing modern health interventions and reproductive technology, may deny those in the community who desire to take advantage of these interventions the opportunity to do so. Health care providers serving religious groups should recognize the diversity of practices and circumstances within these groups and should make available standard of care options allowing individuals to make their own informed decisions. Discussions about patients’ cultural convictions and preferences should take place openly as communications initiate. Community leaders should recognize the broad utility of medical interventions and should discourage the uninformed and inaccurate portrayal of those.

Issues related to the cultural identity and practices of religious minority groups need to be addressed openly and at the initiation of the medical encounter. Health care providers should form a working alliance with community gatekeepers about the provision of services and identify cultural brokers who can help alleviate misconceptions, and ease access to services. Moreover, while providers should emphasize the gamut of available medical options to communities who are guided by diverse world views they should recognize their unique religious, social and cultural stipulations and support their decisions even if they are at odds with their views.

4.3. Practice implications

Although the study targeted a specific sub-group, an Orthodox Jewish community in North America, various emerging themes and concepts learned may be transferable to other Jewish communities around the world who adhere to similar written and oral guidelines, as well as non Jewish populations with strict religious convictions, and other unique social and cultural circumstances. Orthodox Jews, who live in segregated communities, adhere to special dress and dietary codes and have distinct gender roles are not dissimilar from other religious minority groups and cloistered communities, such as Muslim, Hindu, Buddhist, Old Order Amish and various Orthodox Christian denominations. This work contributes to increased awareness among health care providers to unique cultural and social needs of patients which is essential in improving the quality of care and reducing health and health care disparities.

Lastly, this work provides important lessons for targeting identifiable communities in medical research. As human genome scientists hone in on the genetics of common and complex disorders by targeting socially identifiable groups, it is imperative that they recognize the delicate intricacies of targeting such communities and apply culturally competent methodologies when doing so.

As a note of disclosure, I confirm that all patient/personal identifiers have been removed or disguised so the patient/ person(s) described are not identifiable and cannot be identified through the details of the story.

References


