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ORIGINAL RESEARCH

Culture and Acculturation Influences on Palestinian Perceptions of Prenatal Genetic Counseling

Rawan Awwad · Patricia McCarthy Veach · Dianne M. Bartels · Bonnie S. LeRoy

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Abstract Patient cultural backgrounds strongly influence decision-making processes and outcomes in genetic counseling. The present study investigated influences of culture and acculturation on prenatal decision making processes of native Palestinians and Palestinian Americans. Seventeen native Palestinians and 14 first-generation, Palestinian Americans were interviewed and asked to imagine themselves as patients in hypothetical premarital and prenatal situations. Five major issues were investigated: 1) Influence of family history of an inherited condition on pre-marital decisions; 2) Perceptions of non-directive genetic counselor statements regarding options; 3) Role of gender in prenatal decisions; 4) Gender differences in emotional expression; and 5) Role of family and society in prenatal decisions. Several similarities and differences in native Palestinian and Palestinian American responses were obtained. Similarities appear to be due to common cultural roots, while differences may be due to acculturation. Practice and research recommendations are provided.

Keywords Prenatal genetic counseling · Palestinian decision-making · Arab culture · Acculturation · Culture and decision-making

R. Awwad
Prenatal Diagnosis Center, California Pacific Medical Center, San Francisco, CA, USA

P. M. Veach
Department of Educational Psychology, University of Minnesota, Minneapolis, MN, USA

D. M. Bartels
Center for Bioethics, University of Minnesota, Minneapolis, MN, USA

B. S. LeRoy
Department of Genetics, Cell Biology, and Development, Institute of Human Genetics, University of Minnesota, Minneapolis, MN, USA

P. M. Veach (✉)
Department of Educational Psychology, University of Minnesota, 206 Burton Hall, 178 Pillsbury Dr., SE, Minneapolis, MN 55455, USA
e-mail: veach001@umn.edu

Introduction

Culture plays an important role in genetic counseling patients' decision making processes and outcomes. Recognizing the profound influence of cultural values, the National Society of Genetic Counselors (www.nsgc.org) encourages practitioners to educate themselves in ways that promote culturally competent service provision. Traditional Western health care approaches vary in their relevance for patients of non-Western cultures. For example, while pregnancy termination is an option until the 22nd week of gestation in most U.S. states, interruption of pregnancy after 120 days (about the 16th week) is forbidden by Islamic Law unless continuation of the pregnancy has a confirmed risk to the mother's life (Albar 1999; El-Hazmi 2004).

Although several articles in the health care literature discuss how professionals might incorporate beliefs, attitudes, and religious and family traditions of Arab Americans into their service provision (Erickson and Al-Timimi 2001; Jaber 2003; Nobles and Sciarra 2000; Sayed 2003), none are specific to genetic counseling. It is important for

genetic counselors to know how their Arab-American patients perceive genetic counseling services in general, and how culture and acculturation potentially influence their decision making. Therefore, the purpose of the present study was to identify influences of culture and acculturation on prenatal decision-making by two groups of Palestinians, Palestinian Americans and native Palestinians. It was expected that acculturation experiences would lead to differences in decision making processes for Palestinian Americans as compared to native Palestinians. However, given their common cultural roots, it was likely that some decision-making processes would be similar.

In this study, culture is defined as a shared set of beliefs, values, attitudes, behaviors, and communication patterns among members of a particular group that are learned through social membership (Parette 1999). Acculturation refers to a process of cultural socialization to the majority group (Berry 1994; Kim *et al.* 2001), and it has been found to be a powerful determinant of attitudes and behaviors (Smart and Smart 1992). Typically, members of a group with less power (e.g., an immigrant group) acculturate to a group with greater power (e.g., a host group), and they do so by giving up "old ways" and adopting new ones (Berry 1997). Acculturation occurs as individuals become more involved in the dominant group's traditions, values, assumptions, and practices (Landrine and Klonoff 1995). Factors that potentially affect the degree of an individual's acculturation include age, gender, occupation, education, socioeconomic status (SES), and length of time in the host country (Parette 1999).

Arab Americans

Individuals from various countries of the Arab World in the Middle East and North Africa comprise the Arab population in the U.S., with the largest ancestral groups being Lebanese, Syrian, and Egyptian (U.S. Census Bureau 2003). Palestinian Americans are among the approximately 2–3 million Arab Americans, including individuals born and raised in the U.S. (~75%) and recent immigrants (~25%) (Erickson and Al-Timimi 2001). According to U.S. Census Bureau (2003) data, Palestinian Americans constitute 6.1% of the Arab American population, although this percentage may be an underestimation. Their ethnic language is Arabic, a Semitic language with different dialects, and Palestinians are usually either Muslim or Christian, with Islam being the predominant religion. In comparison, there are roughly 5.1 million Palestinians inside Israel who are also predominantly Muslim. Of those, about 3.8 million live in the West Bank and Gaza Strip regions of the country (Palestinian Central Bureau of Statistics 2001–2006), and they are referred to as "native Palestinians" in this study. About 1.3 million live in the Israeli territories of the country (Israeli Central Bureau of Statistics 2003) and are commonly known as "Arab Israelies."

Stereotypes

Palestinian Americans are part of an ethnic group that is frequently misunderstood in the Western world. Various stereotypes portrayed by the media and other entertainment venues cast all members of the Arab American community in a negative light (Erickson and Al-Timimi 2001). For instance: *Most Arabs are terrorists* (Abraham 1995; Said 1997; Suleiman 1988); *All Arabs are Muslims* [In 1980, over 90% of Arabs in the U.S. identified as Christian, although recent immigration trends show a decrease in Christian Arabs and an increase in Muslim Arabs (Ali *et al.* 2004)]; *Muslims are fundamentalists, fanatical, resistant to change, and closed-minded or ignorant* (Said 1997; Shaheen 1986; Suleiman 1988); and *Arab families consist of husbands who are polygamous and mistreat their wives and children, and women who passively accept the inferior role imposed by Arab society and Islam* (Al-Mughni 1993; Suleiman 1988; Terry 1985). Stereotypes may be particularly influential on the impressions of people who lack familiarity with Arab culture. To avoid biases in clinical practice, genetic counselors need to be aware of these stereotypic images and further recognize that the Arab American population is highly diverse regarding factors such as country of origin, degree of religiosity, level of education, SES, political beliefs, length of time in the U.S., and degree of acculturation to the Western world (Erickson and Al-Timimi 2001).

Acculturation Influences

With respect to length of time in the U.S., Palestinian immigration is part of three main waves of Arab immigration to the U.S. The first wave, between the late 1800s and World War I, was comprised mainly of Syrian and Lebanese people, predominantly Christian farmers and merchants who emigrated for economic reasons (Abraham 1995). They settled in urban areas in the Northeast and in industrialized cities in the Midwest (Erickson and Al-Timimi 2001). Immigrants in the first wave tended to blend in with the general population with little difficulty (Abraham 1995; Abudabbeh 1996). A second wave began in 1948 after the formation of Israel and consisted primarily of Muslims, including Palestinian refugees. These immigrants also settled in the Northwest and Midwest, in cities such as Chicago, Toledo, Dearborn, and Detroit. Many of these immigrants were college professors and students who stayed in the U.S. after completing their education. By this time the Arab world was breaking from European colonialism and experiencing more unification, thus allowing Palestinians and other Arab

immigrants to retain more of an Arab identity. A third wave, which began after the Arab-Israeli war in 1967, is still occurring. These immigrants are coming to the U.S. to escape political instability and to pursue economic opportunities (Abraham 1995; Erickson and Al-Timimi 2001), and they have settled in various areas including the West Coast. Due to a more negative reception in the U.S. compared to earlier immigrants, these individuals have been more likely to create *closed* (segregated) communities that include their own religious schools and cultural activities (Abraham 1995). These immigration patterns have resulted in three general types of acculturation among Palestinian and other Arab Americans: 1) those who blended well in the society and do not feel a need for much connection to their cultural heritage, 2) those who adjusted to main stream society but retain their Arab identity, and 3) those who have not blended with the main stream society and live in closed communities.

Culture Influences

Being Palestinian means being part of Arab culture which is characterized by a number of themes. Four cultural themes are particularly relevant to the present study:

1) *Family is the central structure of Arab culture*. A strong sense of community and interdependence among family members makes Arab culture more collectivistic (group-oriented) than individualistic. Developing an individual identity separate from that of one's family or community is neither encouraged nor welcomed (Abudabbeh 1996). Family well-being tends to be valued over individual happiness, and guilt may be experienced if personal needs are given priority. Family honor is highly regarded, and individuals are encouraged to attain this honor for their families by hard work, pursuit of education, and economic stability (Erickson and Al-Timimi 2001; Nydell 1987). Extended family members are important, and individuals of the same family are continually encouraged to stay connected. Extended family members often live in close proximity to one another, sometimes with two or three generations residing in the same household (Abraham 1995). Children grow up respecting their elders and they are expected to take care of them.
2) *There are gender differences in decision making*. Although factors such as level of education and religious conservatism result in some variability, men generally are regarded as head of the household and as decision maker for their families. Women influence family decisions more covertly (Abudabbeh and Nydell 1993; Jackson 1997), for instance, by expressing an opinion in private or behaving in ways that indirectly express an opinion, such as avoiding talking to the family when upset. These behaviors contribute to Western misperceptions that Arab women are passive and oppressed by their husbands (Erickson and Al-Timimi 2001).
3) *Marriage is a family affair.* It is common practice for family members to arrange their children's marriages. A prospective partner is selected based on family reputation and values, and the couple meets and decides after one or more meetings whether to pursue a marriage (Abraham 1995; Abudabbeh 1996). Individuals in arranged marriages do not expect their partner to meet all of their emotional needs, but they do expect to maintain strong connections with both families of origin. Marriage is highly valued, and the divorce rate among Arab Americans is significantly lower than that of the general U.S. population (Abraham 1995).
4) *Religion is integral to Arab culture*. Although not all Arabs are Muslim (and not all Muslims are Arab), Arabic culture is heavily influenced by the religion of Islam (Patai 1973). Basic Arab religious tenets, grounded in the Qur'an (holy book for Muslims) include: a) Everyone believes in God (or Allah) and has a religious affiliation; b) Humans cannot control everything—some things depend on God [e.g., The expression *inshallah* (God-willing) denotes God's plan of what will happen to each person]; c) Piety is one of the most highly admired individual characteristics; d) There should be no separation between church and state; and e) Religious tenets should not be liberally interpreted or modified because such modifications threaten established beliefs and practices (Nobles and Sciarra 2000; Nydell 1987).

Purpose of the Present Study

This study investigated influences of culture and acculturation on prenatal decision making processes of Palestinians, a population chosen in part due to the intimate familiarity of the first author with the Palestinian culture. Two groups were studied: 17 native Palestinians living in the Palestinian Territories in Israel; and 14 Palestinian Americans who were born and raised in the U.S. Participants responded to hypothetical premarital and prenatal genetic counseling scenarios posed during semi-structured individual interviews. Five major research questions were investigated: 1) How would a family history of an inherited condition influence pre-marital decisions among Palestinians? 2) How do Palestinians perceive a genetic counselor message that is intended to be non-directive? 3) What is the role of gender in prenatal decision making? 4) Are there gender differences in emotional expression? and 5) What is the role of family and society in prenatal decision making?

Materials and Methods

Participants

Sample Recruitment

The sample was recruited from two different Palestinian populations: 1) native Palestinians living in the Palestinian Territories in Israel, either in the city of Ramallah or nearby village of Kharbata; and 2) first generation Palestinian Americans living in Minnesota, Illinois, Oregon, North Carolina, California, Georgia, or the District of Columbia. To control for some factors found to influence degree of acculturation, only first generation Palestinian Americans (i.e., first to be born in the U.S. to parents who emigrated from the Palestinian Territories in Israel) were recruited.

Upon receipt of approval by a University of Minnesota institutional review board, the first author began recruitment. A *networking* procedure for participant recruitment was used because the culture is collectivistic (individuals offer help by connecting one another to resources), and the Palestinian community is relatively small. In Israel potential participants were approached either randomly at their work place or through referral from personal contacts or members of a cultural organization and asked to voluntarily participate in a study of Palestinian perceptions of prenatal genetic counseling services. Initially two acquaintances from the first author's neighborhood were approached and asked to participate. Upon completion of their interviews, one offered to approach co-workers and ask them to participate. Subsequent participants were asked to refer others. Most individuals who were invited to participate indicated that they felt comfortable doing so because they were referred through a known/trusted source. Of 20 individuals who were approached, 17 consented to the interview, while three declined, citing either discomfort with an audiotaped interview or lack of interest in participating.

Palestinian Americans were recruited initially through a local cultural group that focuses on issues for Arab Americans. These participants then referred acquaintances from various U.S. locations. Five individuals were interviewed locally, and nine non-local participants were interviewed by phone. Of 16 individuals who were invited to participate, 14 consented and two declined**.** It is important to note that the participants interviewed in this study represent a small portion of the populations of Arabs and Palestinians worldwide.

Procedure

After providing consent, participants completed a demographic form (those interviewed by phone responded verbally to these questions). Next, they were interviewed by the first author who has extensive knowledge of the Palestinian culture and is fluent in the Arabic language. Consistent with a semi-structured interview (Patton 1990), the same order of questioning was followed, with occasional prompts or questions to draw out participant experiences. All interviews were audiotaped and ranged in length from 30 to 60 min (Mdn=50 min). They were later transcribed verbatim, with all identifying information removed. Interviews with native Palestinians were conducted in Arabic and translated into English. The translation was verified by a physician and academician who is fluent in the Arabic language. The interviewer had the impression that most participants were forthcoming and sincere, although one male native Palestinian and one female Palestinian American seemed somewhat guarded in their responses.

Instrumentation

Demographic Form

We developed a brief demographic form to elicit information regarding participant age; sex; marital status; religious affiliation; level of religiosity [assessed by the item: "How often do you practice your religion?" (Scale: 1=Never/Rarely, 2=Sometimes, 3=Often, 4=Usually/Always)]; household income; highest level of education achieved; number of children; and, for Palestinian Americans, their generation.

Interview Protocol

Prior to development of the interview protocol, we engaged in a process of *bracketing of our biases***,** that is, stating our expectations about how participants would respond. Specifically, we expected that across the sample there would be gender differences in emotional expressiveness, with females more likely to report being openly demonstrative, and males more likely to report being restrained; that decision making power would reside in the male; and that family history of a genetic condition would play a role in marital arrangements.

We designed a semi-structured interview consisting of five hypothetical premarital and prenatal situations followed by open-ended questions and prompts, and questions about how a genetic counselor could be most and least helpful in the event of an affected pregnancy (See Appendix). Interview questions are based on the primary investigator's experience with the Palestinian culture and on cultural elements described in the literature as specific to

Arabic culture, including interdependence and strong family structure (Erickson and Al-Timimi 2001; Nobles and Sciarra 2000).

Hypothetical Scenarios

Situation 1 was designed to assess how information about a genetic problem provided during pre-marital genetic counseling might impact marital decisions. Participants are presented with a family history of mental retardation in their future spouse's family and asked to explain how it would affect their decision to marry that person. Participants also are told about the availability of a test that would predict with 100% accuracy whether their pregnancy will be affected with mental retardation. Although a 100% accuracy rate is rarely quoted in actual practice, it was provided to emphasize to participants that the test was *diagnostic*, rather than a screening test with associated false positives and negatives.

In situation 2, designed to assess perceptions of genetic counselor directiveness/nondirectiveness, participants are asked to imagine that their pregnancy has just tested positive for β-thalassemia. The genetic counselor presents information regarding the nature of the condition, its genetic cause, and expected prognosis. Participants then are asked about their perceptions of the extent to which the counselor provided information in a neutral way (non-directive) versus conveyed a message that directly or indirectly favored either pregnancy termination or continuation (directive). Situation 3 was designed to assess: a) whether Palestinians are comfortable expressing their emotions about an affected pregnancy to a counselor or whether there would be a stigma about displaying emotions in the presence of a stranger/professional, and b) whether there is open communication of emotions between Palestinian spouses.

Situation 4 was designed to assess how comfortable participants would be sharing news about an affected pregnancy with others. Participants are asked with whom they would choose to discuss the situation, including the counselor, spouse, nuclear family, friends, and other patients going through a similar experience. Situation 5 was designed to assess any concerns about pressure by people both within and outside the family, (e.g., social stigmatization) because their baby would have a birth defect.

Data Analysis

Interviews were transcribed by the first author who then used an inductive analysis method to manually extract themes (Lincoln and Guba 1985; Patton 1990). First, each transcript was read thoroughly, and major comments by participants were noted. Responses to each of the hypothetical situations were analyzed separately using cross-case analysis (Patton 1990) to identify recurring themes and to compare responses between native Palestinians and Palestinian Americans, and between males and females.

Specific data analysis steps include: 1) Participant responses for each situation were noted on a spreadsheet; 2) Next, responses within each native Palestinian and Palestinian American group were cross-compared for each situation, and recurring themes and emerging patterns were noted; 3) Then responses of all males and all females were cross-compared; 4) Where possible, themes were extracted on the basis of participant educational level, SES, and religiosity (although lack of variability limited this type of analysis); 5) Next responses for native Palestinians were compared and contrasted to those of the Palestinian American group; 6) Finally, the analysis was independently confirmed by the second author who served as data auditor.

Results

Participant Characteristics

The sample consisted of 17 native Palestinians (11 females, six males) and 14 Palestinian Americans (six females, eight males). The two groups were comparable in age (Mdn= 28 years, *R*: 19–50 and Mdn=29 years, *R*: 19–38, respectively). More native Palestinians (10/17) than Palestinian Americans (6/14) were married and had children (8/17 and 2/14, respectively). Most of the native Palestinians (15/17) and Palestinian Americans (11/14) were Muslim, while the rest were Christian. A majority of native Palestinians (11/17) indicated high religiosity versus only two of the Palestinian Americans. More Palestinian Americans (12/14) than native Palestinians (8/17) had a high educational level (*R*: bachelor degree to graduate degree), while the remaining participants had a low educational level (*R*: some school to some college). All of the Palestinian Americans and just over one half of the native Palestinians (9/17) were in a high SES group. Figures 1 and 2 illustrate some of the demographic characteristics that have been shown to influence decision making: SES, self-reported level of religiosity, and gender (Erickson and Al-Timimi 2001).

Previous Knowledge of Genetic Counseling

The interview began with a question about prior knowledge of genetic counseling. No native Palestinians reported having previously heard of genetic counseling. Only four Palestinian Americans reported prior knowledge from being offered the option of meeting with a genetic counselor during prenatal testing (second trimester quad screen).

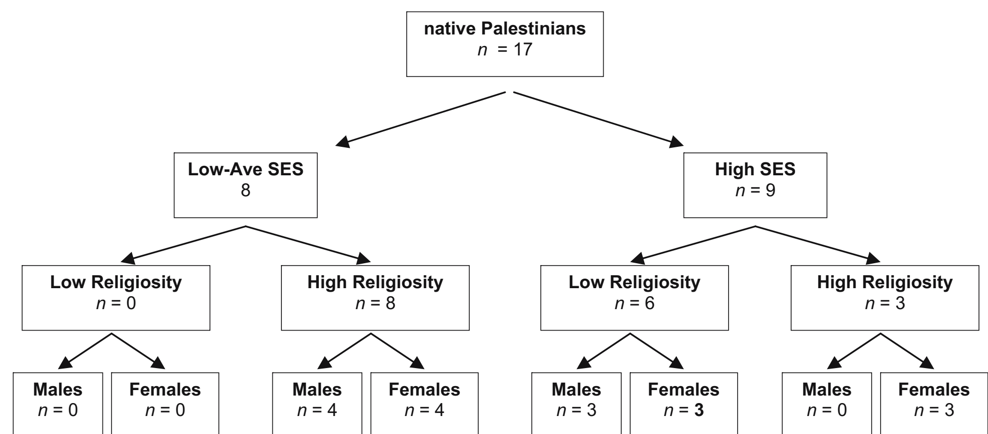

Fig. 1 Demographic information for native Palestinian participants. *Note*. SES was determined by the national average annual income which is $3,500 (United Nations, Report on the Palestinian Economy 2001). Religiosity was based on self-reported frequency of faith practice: *usually/always*=high religiosity, and *never/rarely* or *sometimes*=low religiosity

However, none of these participants had an actual session with a genetic counselor.

In the following sections, themes in participant responses to each situation are reported and sample quotes are provided. It should be noted that there were no apparent differences in responses of participants interviewed by phone versus face-to-face. Themes for the Palestinian American group are reported first, followed by those for the native Palestinian group. When applicable, apparent differences in responses based on gender, and occasionally, those based on educational level and SES, are noted. Table I contains a summary of themes extracted from participant responses.

Pre-Marital Decisions

Palestinian Americans

The first situation involves a family history of mental retardation present in the family of the participant's future spouse. Every Palestinian American stated that a family history would not affect the decision to marry; however, most (11/14) said that it might affect their decision to have children. Eight participants stated that they would undergo the pregnancy test and choose to terminate an affected pregnancy. Several indicated that they would inquire about their partner's position regarding pregnancy termination prior to marriage, and if s/he was opposed to it, they would end the relationship:

- *Female Participant*: *It wouldn't affect my decision to marry him. I think it would affect the decision to have children...I would have children and use the test available...If [*it is*] positive, I probably wouldn't want to have* [the baby].
- *Male Participant*: *I would certainly consider this information...It would be a major concern for me...I think much of the concern would be alleviated by the testing if I had a sense that my future wife is not opposed to abortion. But if it became apparent that* [this] *was a position she wouldn't compromise, I would find it difficult, and that would decrease my likelihood to marry that individual.*

Three participants stated that because they are against abortion, they would not see the point in undergoing the

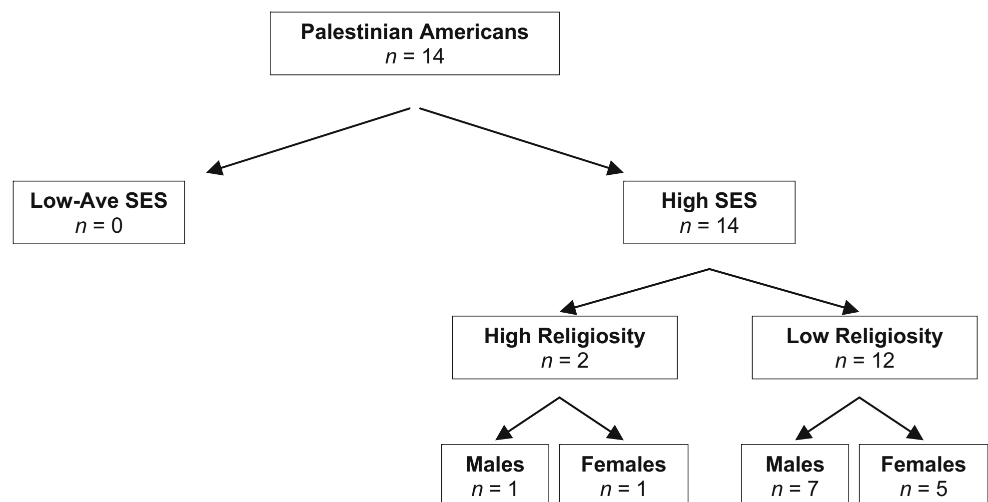

Fig. 2 Demographic information for Palestinian American participants. *Note*. SES was determined by the national average annual income which is about $44,389 (US Census Bureau 2004, www.census.gov). Religiosity was based on self-reported frequency of faith practice: *usually/always*=high religiosity, *never/rarely* or *sometimes*=low religiosity

Table I Summary of Themes in Participant Responses to Hypothetical Scenarios

Hypothetical Scenario	Theme
Pre-Marital Decision	For Palestinian Americans, family history of mental retardation was relatively irrelevant when considering marriage, whereas more native Palestinians reportedly would **not** marry within families with such a history.
	Most Palestinian Americans preferred a long-term relationship before marriage, while the majority of native Palestinians preferred traditional (arranged) marriage.
	Having children is a vital component of marriage for both groups. For native Palestinians who would end a relationship with a partner based on family history, their reason often was connected to a desire to have healthy children. Some Palestinian Americans reportedly would consider adoption as a viable alternative, while none of the native Palestinians mentioned this option.
	More native Palestinians than Palestinian Americans reported that they would consider religious restrictions on abortion in making their decision regarding the course of their pregnancy.
Nondirectiveness and Decision Making	More native Palestinians than Palestinian Americans interpreted the counselor's message as directive, with some viewing it as encouragement to terminate the pregnancy, and others viewing it as encouragement to continue the pregnancy.
Role of Gender in Decision Making	Most Palestinian Americans and native Palestinians endorsed joint decision making. However, a majority of Palestinian Americans stated that in the event of disagreement, the final decision should be made by the woman. In contrast, native Palestinians either stated that the final decision should remain shared, or that the man would make it.
	Among native Palestinians, more participants from lower SES and educational levels endorsed a male-dominated decision making process. Lack of variability in SES and education precludes assessment of their effects on Palestinian American responses.
Expression of Emotions	There were no major differences in responses between native Palestinian and Palestinian American groups.
	Females were more likely than males to state that they would express their emotions, including in the genetic counselor's presence; males reportedly were more likely to withhold negative emotions from their wives, viewing their *stoicism* as a form of support.
Role of Family	Every participant reportedly would share information with their nuclear families about the course of an affected pregnancy, either immediately or eventually.
	Most Palestinian Americans and native Palestinians indicated that they would not disclose to extended family members. Distant relatives are viewed as part of the society and as such, might be judgmental and/or fail to maintain confidentiality.
	More Palestinian Americans than native Palestinians reported being comfortable sharing information about an affected pregnancy with friends or patients going through a similar situation.
Role of Society	A majority of native Palestinians and Palestinian Americans indicated that they would worry about societal perceptions regarding an affected pregnancy, a concern that was even more prevalent among native Palestinians.

prenatal test; instead they would choose not to have children and would consider adoption. Another three participants stated that they would proceed with marriage, get pregnant, and keep the pregnancy regardless of outcome.

When asked about marriage preference, all 14 Palestinian Americans indicated a preference for a long-term premarital relationship rather than an arranged marriage. However, several (5/14) said that they would consider, and had previously considered, both means of marriage. Four of these participants indicated that their responses would not differ if they chose a traditional marriage, while one participant indicated that she would not proceed with a traditional marriage, given the information regarding family history.

Native Palestinians

About three-fourths of the native Palestinians (11/17) indicated that a family history would affect their marriage decision because they would rather avoid a marriage in which there is any risk of having affected children. All but one of these participants stated either that they do not believe in abortion as an option at any point in the pregnancy, or, in accordance with Islamic law, beyond 120 days gestation.

> *Female Participant: I won't be willing to risk marrying this person...For me to be pregnant and to find out that my pregnancy is affected would greatly affect me psychologically. I'm not willing to risk it at all.*

> *Female Participant: Personally, the major reason why I want to get married is to have children...I would rather avoid this situation if I can.*

> *Male Participant: It's a confusing situation, but if I'm sure, or somewhat sure, that there will be a problem with my children, then I won't marry her.*

The remaining six participants indicated that family history would not affect their decision about marriage if they were marrying out of love, but four commented that they would not have children at all or would abort any affected pregnancy.

Male Participant: If I marry her out of love and I'm convinced she's the one for me, it won't affect the decision to marry her, but it would definitely, 100%, affect my decision to have children with her. I would choose not to have children and not to use the test. Even if there is a 1% chance of having a handicapped baby, I would still choose not to have a baby. That's the extent to which I don't want this to happen. Because once I bring a handicapped child to this world, I cannot choose to abandon it, and the whole course of my life would change due to a mistake I'm responsible for...

Female Participant: If I love him I imagine I would marry him, but I will try with the first child. I will get tested, and if he turns out to be retarded, I will not repeat the pregnancy... if I discover the risk to be high and from the first pregnancy this danger is present, I will not have kids. And for sure, this will be based on an agreement between him and me because having kids is very important in this society. So if he really wants kids, then for sure it won't be with me, because I don't want to take the risk.

Two participants indicated that this information would not affect either their decision to marry their partner or to have children together because they would leave everything up to Allah. However, one of them said that the number of children would be fewer than expected.

Male Participant: You never know what will happen. If I marry her, Allah determines whether the children will be handicapped or not, not medicine. So if I know someone that I care for and love, and it so happens that she has a health issue, I don't think I would give up on her.

Nine native Palestinians stated a preference for an arranged marriage, 5 indicated a desire to get to know their partner by dating, and 3 reportedly would consider both types of marriage.

Nondirectiveness and Decision Making

Palestinian Americans

The second hypothetical situation involves a pregnancy that tested positive for β-thalassemia and perceptions of genetic counselor nondirectiveness. Every Palestinian American stated that information provided by the genetic counselor was objective, intended to inform them about the medical situation and what to expect if they continued with the pregnancy. Responses to the interview question, "Why do you think the counselor is giving you this information?" include:

Male Participant: In order for us to make an educated decision about the pregnancy.

Male Participant: To decide whether you want to deal with: a)...the inconvenience of having frequent blood transfusions for the child...that's just on a personal level; b)...inconvenience and hardships on the child for getting blood transfusions every 2 weeks to the extent that they can be normal, but it would still not be a normal life; c)....a life expectancy of less than half that of a normal human being...Is any life better than no life at all?"

All but one Palestinian American also mentioned that the counselor's statements were intended to help them make an informed decision that is right for them:

Female Participant: I don't think she's telling me this in order to push me to not have the baby. I think she's telling me this so I can make an educated decision on what I want to do.

*Male Participant: It seems like there were both negatives and positives mentioned. Positive being [*the baby*] would live a normal life, and negative being it would [*live*] up to 30 years. So there was good and bad news all mixed together. So I would say 'neutral.'*

One participant added a caveat that the counselor's decision to end her statements with information about the baby's life expectancy communicated a message that continuation of the pregnancy was not a good option.

*Male Participant: She's giving you an option of a wasted investment in the child. By the time you're ready to 'let it go,' the child would die. So your 20 years of nurturing and learning and teaching will be wasted. In a way she's telling you [*that*] you're a fool for going with that decision [*of keeping the baby*].*

Native Palestinians

Nine of the native Palestinians described the information as neutral, objective, and intended to help them make their own decisions, while eight stated that the counselor was

conveying a directive message, either to abort (6/17) or keep the pregnancy (2/17).

> *Female Participant*: *You were implying what my solution would be based on the information you gave me. Meaning, based on what you told me it is better for the fetus to be aborted, right?*

> *Female Participant: If she's giving me the information in the way you presented, she's trying to be positive, so I could keep the baby and have awareness on how to deal with him once born.*

> *Male Participant*: *She was suggesting that I should leave the baby untouched and let it live its life, and leave my situation in the hands of Allah.*

Role of Gender in Decision Making

Palestinian Americans

For hypothetical situation 2 (β-Thalassemia) participants were asked to describe how a decision would be reached about the course of the pregnancy. Every Palestinian American participant stated that it would be a joint decision. However, when asked who would have the *final word* if there was an irreconcilable disagreement, three of the six females, and five of the eight males stated that it would have to be the woman, primarily because it is her body and she could not be coerced.

> *Male participant*: *Ultimately it would come down to her. Nobody can force someone else to do something they don't want to do. Since I wouldn't be carrying the child, there's nothing I can do. At the end of the day if she's opposed to my decision, my hands are tied. I may be resentful and probably would hold a grudge.*

> *Female participant: I honestly feel that it should be with the woman...because in all honesty, the woman would be the primary caretaker of the child. Even if she's a working woman, the baby always wants the mom...You don't want her feeling resentment towards her child.*

Four participants stated that it would remain a joint decision, and two said the man would have a larger share of the decision.

> *Male Participant*: *We will make the decision together, but I will push to keep the child and follow through with the pregnancy. I can't really choose to accept certain things that God gives me and decide I don't want other things he gives me. You have to go with what you have.*

> *Male participant:...I would like for us to come to a general agreement. But if we totally disagree, then I would like for it to be my word. It's not like she says what she says and I'm going to take my decision and run with it. I would like to hear what she has to say, and then it is nice to have the final word.*

Native Palestinians

Most native Palestinians (14/17) stated that the decision would be made jointly, while only three participants (two men, one woman) stated it would be made by the man. When asked about an irreconcilable disagreement, ten participants indicated that it would continue to be a joint decision, and one male stated that the decision would mostly be with his future wife

> *Male Participant:...In the end we must come to consensus. It's not like we'll get divorced or something. I feel like it would be 70% her decision and 30% mine.*

Six participants (three males and three females), all from average-low SES and low educational backgrounds, stated that the man would have the final word:

> *Female Participant*: *Yes, I would agree with him [husband], because some men are very religious and say that all these matters are in the knowledge of Allah not the doctor, so they don't believe the doctor. Then they go and consult a sheikh who says the same thing. So the woman ends up not being consulted [for her opinion] because the consultation is for the man because this baby is more for the man than for the woman. So the man might feel like you killed the baby's soul.*

> *Female Participant*: *My husband decides, because a woman must obey her husband in everything, no matter how big or small.*

> *Male Participant*: *We will discuss it together, and always in these situations the decision falls with the man because the woman would be completely devastated, weak, and emotional. Therefore, the man makes the decision in these situations after convincing his wife of the decision*.

Two of these women commented that if the woman made the decision, she would *get away with* what she wants, but she would risk abandonment by her husband:

> *Female Participant*: *Some of them say to their wives 'If you abort I will divorce you.' So, some women, poor women, are forced to keep the baby..."*

Perceptions of the Genetic Counselor's Role

When asked whether the genetic counselor would have a role in the case of disagreement, participants were mixed. Most native Palestinians (10/15) viewed her as a mediator, whereas Palestinian Americans were fairly evenly split between preferring to make their own decision (8/14) and viewing the genetic counselor as a mediator (6/14).

Expression of Emotions

Palestinian Americans

In hypothetical situation 3, participants are asked to imagine that the genetic counselor has just informed them that their baby will have a birth defect and to describe their expression of emotions. As expected, there were obvious gender differences. Three of the six female participants, and none of the eight males stated that they would cry and discuss their feelings in front of the genetic counselor. Six of the men said they would first like to get more information and then *let it sit* for awhile.

Female Participant: I would probably cry... discuss it, and express how I feel about it. I think it would be more sadness than anger for me.

Male Participant: I tend not to express emotions. I tend to hold it inside until I break down. I reflect on my own.

All of the women and half of the men indicated that they would express their feelings to their spouse. The other men said they would discuss the situation rationally with their wives but probably not show emotions. These men reasoned that they would be more supportive by not showing emotions because their wife would be carrying the baby and therefore would be more affected by the situation.

*Male Participant: I probably wouldn't express any of those emotions in front of my wife just because she's probably more broken up about it than anybody [*else*], and it wouldn't help the situation.*

Male Participant: I would probably not cry in front of her or something. I figure I must be the strong person in the relationship.

Native Palestinians

Over half of the women (7/11) said they would express themselves in clinic by crying or looking bothered. None of the men said they would cry or react in an overtly emotional way, although a few mentioned that they might feel sad and bothered. The remaining participants stated that they might react minimally but would express their emotions later at home. Almost every participant (15/17) indicated that they would share their emotions with their spouse, while two males said they would not do so because they wished to be *protective*.

Male Participant:... she would be dealing with enough. I don't want to add to her worry. Instead, I would try to alleviate her worry.

Role of Others

Palestinian Americans

In hypothetical situation 4, participants are told that their baby will have a birth defect and asked with whom they would choose to discuss the situation. All of the Palestinian Americans responded that they would initially share the news with their spouses, and most (10/14) would also disclose to members of their nuclear family, while the rest indicated that they would not do so immediately.

*Male Participant: [*My wife*] would be the first person to find out...Not initially [*for immediate family members*]. I don't know what initially they can provide, but for emotional healing after all the facts are ascertained, then yes, maybe.*

When asked about distant relatives (cousins, aunts, and uncles), almost all of the participants (12/14) stated that they would not share this information with them.

Male Participant: Right off the bat, no. After me and my family decide what to do about it, I would tell them. I don't consult their opinion.

Male Participant: No, I wouldn't bring it up. If it gets around, as you know it would in Arab families...then maybe.

Female Participant: Not right away. Not unless they have a medical degree and can help me out.

When asked about friends, almost all of the Palestinian American participants (12/14) said they would share the news with those who are close, who have children, and/or have specialized degrees that could help them. Most (12/14) also indicated that they would be comfortable contacting patients going through a similar situation.

Native Palestinians

A great majority of the native Palestinians (13/17) indicated that they would initially share the news with spouses and

members of their nuclear family, three participants stated a preference to make a decision regarding the pregnancy before talking to family members, and one participant had deceased parents. Only one participant reportedly would disclose to extended family members.

> *Male Participant: Sharing this info outside the* [nuclear] *family is wrong. Women sit down and gossip about it and change the story to their liking in the process. I would only tell people who would directly be impacted by the situation. My wife would be the most impacted, since I might leave the house and go to work, but she has to stay and take care of the baby.*

> *Male Participant: No, it is better not to branch out to the family because each person would have a different opinion, and everyone would become a preacher.*

Most participants said they would share the news with friends who are close (9/15) and that they would contact patients going through a similar situation (10/15). Due to interviewer error, two participants were not asked these questions.

Role of Society

Palestinian Americans

In hypothetical situation 5, participants are told their baby will have a birth defect and are asked what would worry them the most in this situation. All but one Palestinian American mentioned issues such as the baby's quality of life, how their spouse would handle the situation, how a decision regarding the pregnancy would be reached, and possibility of recurrence. For example:

> *Female Participant: If the child would be able to live a normal life and how happy they would be.*

> *Male Participant: The future of the child and addressing your own weaknesses...Am I man enough to handle it?*

> *Male Participant: My wife's response and how the information will affect our relationship. Also, I would worry about recurrence* [in future pregnancies].

Only one participant initially mentioned "social stigma" as a worry. When specifically asked if societal perceptions would be of concern, another four participants said "Yes," four said they would only worry about perceptions of their child, and five said "No."

> *Male Participant: Yeah, one doesn't like to admit it. You worry about these things, people bragging about their kids, and you have nothing to brag about.*

> *Female Participant: I don't think I would think so much what people would perceive me as, but I would take into consideration what people would perceive that child as.*

Native Palestinians

A vast majority of native Palestinians (14/17) initially mentioned the welfare of the baby. Other concerns included risk of recurrence and the spouse's reactions. Four female native Palestinians initially mentioned societal perceptions as a worry.

> *Female Participant: The baby's situation, the extent of society's acceptance of the baby. I would also worry about the way the baby's life would be.*

> *Female Participant: I might start thinking "Is it possible that I will bring all my children to life like this?" Another thing I would fear is people, especially the close ones like my husband's family. People always blame the woman in these situations...They might start contemplating the idea of their son marrying a second wife. So this is something I really fear.*

When specifically asked if they would worry about societal perceptions, a majority (11/17) said "Yes," and placement of blame on the mother by family and/or society was a prevalent concern for these participants. Two participants said they would only worry about perceptions of their child, and another five said they would not worry.

Genetic Counselor Behaviors

Participants provided a number of suggestions of how a genetic counselor could be helpful and unhelpful if they had an affected pregnancy. There were no apparent differences in native Palestinian and Palestinian American or male and female participants' suggestions.

Helpful behaviors

Helpful behaviors included providing as much honest information as possible; instilling/maintaining hope; and being objective in a non-coercive, compassionate, and empathic way. One native Palestinian described a constellation of helpful behaviors:

> *Female Participant: The most important thing is to give people hope and not to destroy their determination and optimism. The counselor has to possess a certain style that reduces the problem, no matter how*

big, into something that the patient can deal with. I want the counselor to give me hope and optimism. If one of my children will be affected, then to tell me that my other children will turn out ok. All doctors are very rough and give the news 'as is.' They don't try to make it easier for the patient. The genetic counselor combines both medicine and psychology. So the counselor has to know how to deal with people psychologically and to reach into their psychological states. It depends on the personality of the patients, as some do not really need a lot of counseling and can make their decisions with ease. But the most important thing is to give hope...Even if my baby will die soon, the counselor should try to give me psychological relief/help, because the psychological state of the patient plays a huge role in their well-being.

Unhelpful behaviors

Unhelpful behaviors generally are the opposite of helpful ones. Prevalent suggestions of what *not to do* include distorting the situation by withholding information or making the situation seem either better or worse than it is; being biased/directive about what the patient should do; being cold, distant, or insensitive; and making patients feel as if it is their fault.

Discussion

In the present study 17 native Palestinians and 14 Palestinian Americans responded to hypothetical pre-marital and prenatal genetic counseling situations. Themes extracted from their responses suggest that both culture and acculturation factors influence their decision making processes and outcomes.

Acculturation Affects How Family History Influences Pre-Marital Decisions

The native Palestinian participants generally indicated reluctance to marry someone with a family history of mental retardation, while Palestinian Americans primarily reported that family history would not be particularly influential. Their reasons appear to be related to the nature of the marital relationship. All of the Palestinian Americans indicated a preference for a long-term relationship prior to marriage, whereas a majority of the native Palestinians preferred arranged marriage, a difference that may be due to acculturation. In Arab culture *arranged marriage* involves a social and economic contract between two families (Erickson and Al-Timimi 2001; Nobles and Sciarra 2000). *Family fit* is an important criterion in prospective partner selection and often is based on compatibility of values, reputation, and religion (Rashad *et al.* 2005). It follows that a known family history of a medical condition might be stigmatizing, especially for women known to be affected with, or carriers of, a genetic condition (Raz and Atar 2004). Currently in the Palestinian Territories, carrier screening for Thalassemia is mandatory prior to completion of a marriage contract, and many couples choose not to proceed with marriage if both are carriers (Thalassemia Patients' Friends Society, personal communication, 2006). The present results suggest that knowledge of family history similarly may influence marital decisions for some individuals.

Both native Palestinians and Palestinian Americans considered having healthy children as an integral part of marriage. Knowledge of a family history of a genetic condition appeared to have more negative repercussions for native Palestinians who described more religious and societal restrictions regarding pregnancy termination. In addition, none of the native Palestinians mentioned adoption as an option, an omission possibly due to culturally-based attitudes. Specifically, Islamic Law allows adoption only if the child retains the same lineage and family name as the biological parents (Albar 1999). For some native Palestinians, the most viable option was avoidance of the potential marriage partner. In contrast, more Palestinian Americans identified options such as pregnancy termination and adoption, suggesting acculturation influences.

Demographic factors may also influence decisions. Jaber *et al.* (2000) studied Arab women in Israel to assess attitudes regarding pregnancy termination after prenatal diagnosis of a major congenital malformation. They found that women who considered termination were more likely to have more education and a higher SES than those who opposed it. In the present study, a majority of Palestinian Americans and native Palestinians who mentioned termination as an option at any stage of pregnancy were from a higher educational level and SES. However, lack of variability in education and SES for the Palestinian American group does not allow for definitive comparisons.

Acculturation Affects Perceptions of Genetic Counselor Non-Directiveness

All but one Palestinian American viewed information provided by the genetic counselor as nondirective, while half of the native Palestinians perceived it as directive, either encouraging termination or continuation of the pregnancy. These results are consistent with those of Raz and Atar (2003) who studied Arab Bedouins in the Negev in the southern district of Israel and found they generally viewed non-directive messages by a prenatal genetic counselor as directive. Wertz (1998) found that in non-English speaking countries, especially Asian and African

countries, genetics professionals are more directive, and she concluded that a more directive approach fits with cultural expectations. The present findings suggest that non-directive genetic counseling, as currently practiced in the U.S., may be more *culturally congruent* for Palestinian Americans who are acculturated to Western health care practices.

Both Culture and Acculturation Affect Views Regarding Decision Making Roles

When asked about decision making processes, a majority of participants in both groups preferred to obtain as much information as possible and then to reach a decision jointly at home. However, in the event of an irreconcilable disagreement, most Palestinian Americans stated that the decision should be made by the woman because she carries the baby, and "no one can be forced to do something they do not want." Their reasons reflect Western values of individual freedom (individualism) and personal autonomy. In contrast, most native Palestinians preferred that the decision either remain a joint one, or that the man decide. Within the native Palestinian group, more participants from lower SES and educational levels indicated a preference for male-dominated decision making, which may reflect both concordance with dominant cultural values and the financial necessity of maintaining a harmonious relationship with one's husband.

Culture Influences Gender Differences in Emotional Expression

Across the sample, females were more likely than males to report that they would express their emotions in the presence of the genetic counselor, and males were more likely to report withholding negative emotions from their wives, viewing their actions as a form of support. More native Palestinian males reasoned that they needed to be "the strong one" by containing their emotions. While these gender differences are congruent with general sex role research (cf. Williams and Best 1990), they might be magnified in Arab culture due to a strong expectation for the male to be the head of the household and the primary decision maker. Gender expectations may place men in a *double bind*. If they openly express their grief, it may be suggested (subtly or otherwise) that their reaction will upset their partner and *violate* their supportive role, whereas if they do not show their feelings, they may be perceived as uncaring (Puddifoot and Johnson 1997).

Culture Affects the Role of Family Members in Dealing with Genetic Information

When seeking advice about personal problems, Arabs tend to refrain from discussion with individuals outside their family support system (Jackson 1997). In the present study, a majority of participants reported that they would share information only with their nuclear families (parents and siblings). The specific member(s) of the nuclear family chosen for involvement in this process varied from one participant to another and appeared to be based on individual family dynamics.

Distant family members (e.g., cousins, aunts, and uncles) are also important in Arab culture (Abraham 1995), and maintaining continuous contact and good relationships is encouraged. Interestingly, almost all of the participants in this study said that they would choose initially **not** to involve their distant relatives. They viewed distant relatives as part of society which is prone to judgment or pressure regarding sensitive issues such as an affected pregnancy. Thus, Palestinian patients might refrain from involving distant relatives in decisions involving genetic issues, and they might even be secretive about information they receive in clinic.

Acculturation Influences Concern Regarding Societal Expectations

Given the collectivistic (group-oriented) nature of Arab culture (Erickson and Al-Timimi 2001), family reputation and honor are highly regarded. In that regard, individuals often find themselves pressured to *live up to* societal expectations. Some participants stated that eldest male children, in particular, are expected to carry on the family name, and therefore they experience even more societal pressure to have healthy, successful children. The native Palestinians expressed greater concern about societal perceptions than the Palestinian Americans, suggesting that they were more strongly influenced by their Arab culture. Their worries included: minimal or non-existent support from professional societies or specialized services to support the care of affected children; women are expected to stay at home to care for affected children, which might cause social isolation; women bear a majority of blame for having an affected child; and, having a childless marriage or unhealthy children is often pitied. Palestinian Americans were generally more comfortable looking to friends and other patients for support.

Limitations of the Study

Several aspects of this study should be considered when drawing conclusions from the findings. Qualitative data are not intended to be generalized to all members of a population, in this case all Palestinians. Furthermore, the findings should be generalized with considerable caution to other Arab individuals. In addition, participants' responses to hypothetical situations may not reflect their

actual behavior. Finally, the interviewer is Palestinian, and it is possible that participants provided answers that fit prevalent cultural expectations due to concern about being judged.

Prenatal Counseling Practice Considerations

Results of this study highlight possible culture and acculturation factors that influence Palestinians' decision making. Based on these findings, the following strategies might be considered when counseling Palestinian patients:

- Describe the genetic counseling process and potential outcomes since virtually none of the participants had heard of genetic counseling prior to their involvement in this study.
- Assess whether Palestinian Americans are recent immigrants and, if not, what generation they are in the U.S. It is important not to generalize across all patients, as their levels of acculturation will vary. Information that might provide clues about acculturation level include how long the patient has lived in the U.S., proximity to other family members, who generally makes major decisions in the household, and the patient's religion and SES.
- In premarital genetic counseling, determine the type of marital relationship the couple would enter into (arranged or not) since this factor may affect the relevance of family history in making marital decisions.
- Remember that traditional cultural views define the man as head of household. Therefore, he may be expected to make decisions for his family. However, women may influence decision making processes less overtly.
- When engaging couples in decision making, recognize that most will prefer a joint process. However, some patients may prefer a male-dominated process, especially if there is disagreement about what to do.
- Consider incorporating opinions of nuclear family members when discussing options as they may be can integral part of the decision making process for a Palestinian couple. Ask, "What is the impact of this decision on your family?"
- Decide how much attention to devote to extended family members' opinions as they may be less important than those of nuclear family members and perhaps even unwanted.
- When faced with a decision regarding an affected pregnancy, assess the patient's personal, religious, and cultural beliefs regarding pregnancy termination. Is termination ever permissible? For what reasons? Within what time frame?
- Similarly, assess personal, religious, and cultural beliefs regarding adoption.
- Acknowledge the importance of having healthy children as part of Arab culture.
- Do not misinterpret a couple's silence as a sign of a dysfunctional relationship. They may wish to discuss the information later at home.
- Realize that you may be perceived as directive when providing genetic information. Consider prefacing your information provision with the statement, "I'm not trying to influence you one way or the other."
- Provide relevant information in a direct but empathic way, bearing in mind that preservation of *hope* appears to be an important patient goal.

Research Recommendations

Research is needed that compares Palestinians at varying levels of acculturation. For instance, in the present study, only first generation Palestinians from less segregated communities were interviewed. Future research might yield a different pattern of results for Palestinian Americans who reside in *closed communities* (i.e., those that are more segregated). In this study, the genetic counselor was a female in a prenatal setting. Additional studies should assess the effects of counselor gender and patient setting (e.g., pediatrics, cancer, etc.). Investigations of the influence of cultural elements for Palestinians in actual genetic counseling sessions are also recommended. Finally, research with larger samples would allow for determination of the effects of demographic variables such as SES, education, and religiosity on genetic counseling processes and outcomes for Palestinian patients.

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Appendix

Interview Questions

Opening Question

Have you heard of genetic counseling? [If yes, what have you heard?]

Definition of Genetic Counseling

Interviewer provides this definition to each participant: Genetic counseling is a health care profession that serves

individuals and families who are either affected with, or are at risk of being affected with, a genetic condition. Genetic counselors answer patients' questions, provide support, and communicate genetic and medical information in a clear, understandable manner.

Hypothetical Situation 1

Imagine that before you married your husband/wife [For single participants, say "Imagine you are about to marry your husband/wife, and..."] you discover that s/he has a family history of mental retardation. One of your husband/wife's siblings is mentally retarded, as well as a few of his/her cousins. This means that there is a chance that you and your husband/wife could have children affected with mental retardation. Although there is no cure for mental retardation, there is a pregnancy test that would predict with 100% accuracy whether the baby would be affected when it is born. Let's talk about how this might affect your decision about marriage.

[Prompts: Would you proceed with the marriage anyway and test each pregnancy? Proceed with the marriage and not chose to test each pregnancy? Or would you pick a different partner and avoid this process all together?]

Hypothetical Situation 2

This situation I will read to you is unrelated to the first. Imagine that you and your partner are expecting, and your baby has tested positive for beta-thalassemia very early in the pregnancy. Beta-thalassemia is a common blood disorder in the Middle East where normally both parents are carriers of the genes causing the condition but are not themselves affected. At the genetic counseling clinic the counselor says: "Individuals affected with beta-thalassemia have anemia and their blood cannot deliver oxygen efficiently to their body. This results in life-threatening complications early in life. Treatment is available in the form of frequent blood transfusions which allow individuals to live a normal life. Patients undergoing treatment have normal intelligence and can attend school and hold regular jobs. However, due to potential complications from iron accumulation, the life expectancy is 20–30 years." Why do you think the counselor is telling you this information? What do think the counselor is telling you regarding your choices for this pregnancy?

[Prompts: Do you think the counselor is giving you information to help you make an informed decision that is right for you, or is s/he directly suggesting a specific option for you (pregnancy termination or continuation)?]

How will a decision be reached? Who will make the decision?

[Prompts: *What do you envision your role in the decision making process would be? What if you and your partner disagree? What role, if any, would you like the counselor to play in your decision*?]

Hypothetical Situation 3

You and your partner attend a genetic counseling session. The counselor is presenting you with information about your pregnancy telling you that your baby has a birth defect. You feel a range of emotions (sadness, anger, fear, etc.). How would express these emotions? What would you do?

[Prompts: Would you turn to your partner and discuss the situation? Would you turn to the counselor and discuss the situation? If yes, what would you want the counselor to say? Do? Would you wait until the session is over to discuss the situation with you partner? Would you choose not to express those emotions and deal with them on your own?]

Hypothetical Situation 4

A genetic counselor calls you up and delivers bad news about your current pregnancy. Your baby has a birth defect. With who would you chose to discuss the situation?

[Prompts: Would you choose to discuss it with the counselor? Your partner? Your family? Who in your family? A friend outside the family? Other patients in a similar situation?]

Hypothetical Situation 5

If you were to learn that your baby does have a birth defect, what would worry you the most?

[Prompts: Would you worry about the perception of others in your family? Perceptions of people outside the family? The relationship between you and your partner? The welfare of your child and his/her future life?]

Final Questions

Let's assume that you do go for genetic counseling for an affected pregnancy. What would be the most helpful/least helpful things the counselor could say or do?

Do you have any final comments?

References

Abraham, N. (1995). Arab Americans. In R. J. Vecoli, J. Galens, A. Sheets, & R. V. Young (Eds.) *Gale encyclopedia of multicultural America, volume 1* (pp. 84–98). New York: Gale Research.

Abudabbeh, N. (1996). Arab families. In M. McGoldrick, J. Giordano,

& J. K. Pearce (Eds.) *Ethnicity and family therapy*, (2nd ed., pp. 333–346). New York: Guilford.

Abudabbeh, N., & Nydell, M. K. (1993). Transcultural counseling and Arab Americans. In J. McFadden (Ed.) *Transcultural counseling: Bilateral and international perspectives* (pp. 261–284). Alexandria, VA: American Counseling Association.

Albar, M. A. (1999). Counseling about genetic disease: An Islamic perspective. *East Mediterranean Health Journal, 5*, 1129–1133.

Ali, S. R., Liu, W. M., & Humedian, M. (2004). Islam 101: Understanding the religion and therapy implications. *Professional Psychology, Research and Practice, 35*, 635–642.

Al-Mughni, H. (1993). *Women in Kuwait: The politics of gender*. London: Saqi Books.

Berry, J. W. (1994). Acculturation and psychological adaptation: An overview. In A. Bouvy, F. J. R. Van De Vijver, P. Boski, & P. Schmitz (Eds.) *Journeys into cross-cultural psychology* (pp. 129–141). Berwyn, PA: Swets & Zeitlinger.

Berry, J. W. (1997). Immigration, acculturation, and adaptation. *Applied Psychology, 46*, 5–34.

El-Hazmi, M. A. F. (2004). Ethics of genetic counseling: Basic concepts and relevance to Islamic communities. *Annals of Saudi Medicine, 24*(2), 84–92.

Erickson, C. D., & Al-Timimi, N. R. (2001). Providing mental health services to Arab Americans: Recommendations and conclusions. *Cultural Diversity and Ethnic Minority Psychology, 7*, 308–327.

Israeli Central Bureau of Statistics (2003). *The Arab population of Israel*. www.cbs.gov.il.

Jaber, L. A. (2003). Barriers and strategies for research in Arab Americans. *Diabetes Care, 26*, 514–515.

Jaber, L., Dolfin, T., Shohat, T., Halpern, G. J., Reish, O., & Fejgin, M. (2000). Prenatal diagnosis for detecting congenital malformations: Acceptance among Israeli Arab women. *IMAJ, 2*, 346–349.

Jackson, M. (1997). Counseling Arab Americans. In C. Lee (Ed.) *Multicultural issues in counseling: New approaches to diversity*, (2nd ed., pp. 333–349). Alexandria, VA: American Counseling Association.

Kim, B. S. K., Atkinson, D. R., & Umemoto, D. (2001). Asian cultural values and the counseling process: Current knowledge and directions for future research. *The Counseling Psychologist, 29*, 570–603.

Landrine, H., & Klonoff, E. A. (1995). The African American acculturation scale II: Cross-validation and short form. *Journal of Black Psychology, 21*, 124–152.

Lincoln, Y. S., & Guba, E. G. (1985). *Naturalistic enquiry*. Beverly Hills, CA: Sage.

National Society of Genetic Counselors. www.nsgc.org.

Nobles, A. Y., & Sciarra, D. T. (2000). Cultural determinants in the treatment of Arab Americans: a primer for mainstream therapies. *American Journal of Orthopsychiatry, 70*, 182–191.

Nydell, M. (1987). *Understanding Arabs: A guide for westerners*. Yarmouth, ME: Intercultural Press.

Palestinian Central Bureau of Statistics (2001–2006). *Projected mid-year population in the Palestinian Territory by governorate*. www.pcbs.gov.ps.

Parette, P. (1999). Transition planning with families across cultures. *Career Development for Exceptional Individuals, 22*, 213–211.

Patai, R. (1973). *The Arab mind*. New York: Charles Scribners.

Patton, M. Q. (1990). *Qualitative evaluation and research methods*. Newbury Park, CA: Sage.

Puddifoot, J. E., & Johnson, M. P. (1997). The legitimacy of grieving: The partner's experience at miscarriage. *Social Science & Medicine, 45*, 837–845.

Rashad, H., Osman, M., & Roudi-Fahimi, F. (2005). Marriage in the Arab World. *Population reference bureau* (pp. 1–8). Washington, D.C.

Raz, A. E., & Atar, M. (2003). Nondirectiveness and its lay interpretations: The effect of counseling style, ethnicity, and culture, on attitudes towards genetic counseling among Jewish and Bedouin respondents in Israel. *Journal of Genetic Counseling, 12*, 313–332.

Raz, A. E., & Atar, M. (2004). Cousin marriage and premarital carrier matching in a Bedouin community in Israel: Attitudes, service development and educational intervention. *Journal of Family Planning and Reproductive Health Care, 30*, 49–51.

Said, E. W. (1997). *Covering Islam: How the media and the experts determine how we see the rest of the world*. New York: Pantheon Books.

Sayed, M. A. (2003). Psychotherapy of Arab Patients in the West. *American Journal of Psychotherapy, 57*, 445–459.

Shaheen, J. G. (1986). The Hollywood Arabs: 1984–86. *Mideast Monitor, 3*, 1–6.

Smart, D. W., & Smart, J. F. (1992). Cultural issues in the rehabilitation of Hispanics. *Journal of Rehabilitation, 58*, 29–37.

Suleiman, M. W. (1988). *Arabs in the mind of America*. Brattleboro, VT: Amana Books.

Terry, J. (1985). *Mistaken Identity: Arab stereotypes in American popular writing*. Washington, DC: American-Arab Affairs Council.

United Nations (2001). *Report on the Palestinian economy*.

U.S. Census Bureau (2003). *The Arab population: 2000*, 1–9, December.

U.S.Census Bureau (2004). www.census.gov.

Wertz, D. (1998). Eugenics is alive and well: A survey of genetic professionals around the world. *Science Context, 11*, 493–510.

Williams, J. E., & Best, D. L. (1990). *Sex and psyche: Gender and self viewed cross-culturally* pp. 118–133. Newbury Park, CA: Sage.