

## A Qualitative Investigation of Somali Immigrant Perceptions of Disability: Implications for Genetic Counseling

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*This study examined the potential utility of genetic counseling services for Somali immigrants by investigating their perceptions of disability. Five Somali women participated in structured interviews that assessed their perceptions of the nature, causes, and impact of disability, and care for persons with disabilities. Using a Heideggerian Hermeneutics qualitative method of analysis, six major themes emerged: (1) disability refers to both physical and mental conditions, with mental disability generally thought of first and as more severe; (2) in Somalia, the family cares for disabled family members, treating them as if they were "normal"; (3) there are major cultural differences between Somalia and the United States in how persons with disabilities are treated; (4) caring for a person with a disability is stressful for the family; (5) Allah determines whether or not a child will be disabled, and this cannot be predicted or altered; and (6) family is the primary life focus, and therefore, risk of disability does not affect reproductive decisions. These themes suggest that traditional genetic counseling may have limited utility for Somali immigrants. We recommend several modifications to traditional genetic counseling for Somali patients that also may be useful for populations that have similar beliefs.*

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**KEY WORDS:** Somali immigrants; perceptions of disability; genetic counseling.

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Culture consists of widely shared ideals, knowledge, values, and behaviors that are accepted as “right” and “correct” by individuals who identify themselves as members of a given social group (Brislin, 1990; Carrillo *et al.*, 1999; Fisher, 1996). Culture is a primary influence on how people react to their environment (Hofstede, 1980). For instance, cultural norms and values dictate appropriate types of social behaviors, including communication patterns and help-seeking behaviors. When people of different cultures interact, they operate from distinctly different cultural foundations. These differences can result in conflicts or ethical dilemmas for genetic counselors and other health care providers (Agard *et al.*, 1998; Blackhall *et al.*, 1995; Fetters, 1998; Marshall *et al.*, 1994; McCarthy Veach *et al.*, 2001; Orr *et al.*, 1995).

In the last decade greater efforts have been made to identify factors affecting the types of medical services a particular cultural community uses (Barker, 1992; Beyene, 1992; Carrillo *et al.*, 1999; Gatrad, 1994; Jecker *et al.*, 1995; Young and Klinge, 1996). These studies have found that traditional Western health care practices often are not valid for patients of non-Western cultures. For instance, disclosure of terminal illness to a patient conflicts with Ethiopian cultural practices (Beyene, 1992).

The standard of care in genetic counseling has evolved primarily in accordance with Western majority culture values and ideals (Fisher, 1996). Historically, most genetic counseling patients were upper- to middle-class Caucasians who routinely used the health care system; individuals from minority cultures rarely used genetic counseling services on a regular basis (Lum and Whipperman, 1987). However, growing numbers of individuals from diverse cultures are seeking genetic counseling services (Fisher, 1996).

There is limited information on how genetic counselors can best help families from diverse cultural groups (NSGC, 1995). A few authors have explored the impact of cultural variables on genetic counseling (Fisher, 1996; Lum, 1987; Lum and Whipperman, 1987; Mittman *et al.*, 1998; Moreno, 1987; Punales-Morejon and Penchaszadeh, 1992; Swinford and El-Fouly, 1987; Wang, 1993; Wertz *et al.*, 1990). These authors provide primarily descriptive and anecdotal information about the characteristics of specific cultural groups and underscore the necessity of genetic counselors being “culturally competent.” Swinford and El-Fouly (1987) conducted one of the few data-based investigations, studying the extent to which genetic counseling, as it is typically practiced, is useful for patients from non-Western, Islamic cultures.

Accordingly, the major purpose of this study was to investigate the potential utility of genetic counseling for Somali immigrants by gaining a better understanding of their perceptions of disability. We chose this population because our geographic area of Minneapolis/St Paul, Minnesota, is home to the largest number of Somali immigrants in the United States, 38–70% of the total 40,000 (Suzukamo, 2000). Furthermore, although Somalis have sought other types of Western medical

services, they are strikingly absent from genetic counseling (El-Hashemite, 1997). We wondered if the low numbers could be due to the incompatibility of genetic counseling with Somali worldviews, and if so, whether genetic counseling could be adapted to be more helpful for this population.

We focused our qualitative investigation on how Somali immigrants view disability, its causes, and impact. We believed that their perceptions of disability would have implications for the utility of traditional genetic counseling and would indicate ways in which current genetic counseling practices could be modified for this population. Furthermore, their perceptions and our subsequent recommendations might serve as an example for providing genetic counseling to patients who have similar beliefs.

We conducted in-depth, semistructured interviews with five Somali immigrant women. Our research questions were (1) What is a disability or handicap? (2) Who cares for individuals with disabilities? (3) What is the impact of disability on the family? (4) How would having a child with a disability affect future reproductive decisions? (5) What is the cause of disability? and (6) How can health care professionals be helpful to families who have a child with a disability?

Before moving to a more detailed description of our methods, we first provide background information on the Somali culture. Somalia's primary social structure is the family clan, people related through a single common male ancestor. Individuals typically make friends and marry within their own clan. About 98% of Somalis are Muslim, primarily Sunni Muslims. The Koran, the most sacred of the books sent by Allah, and the Prophet Muhammed's Hadith, or speeches, serve as guidelines for this life and the life to come (Braswell, 1997; Lippman, 1995).

Parents are obligated to cherish, educate, and train their children and to provide optimal prenatal conditions (Hamid, 1989). The Islamic view is that the fetus has a soul after 120 days (Braswell, 1997). Prior to that point, circumstances will determine if an abortion is allowed. Abortion in the case of a disabled child remains uncertain (Braswell, 1997; Swinford and El-Fouly, 1987), although Muslim Jurisconsults (Sunni and She-at) have agreed that if a genetic test proved definitely that a fetus was affected by a serious and permanently disabling condition, abortion would be permissible and lawful before the 120th day (El-Hashemite, 1997).

Fertility is greatly valued, and infertility treatment and assisted reproduction are generally acceptable if both parents are genetically related to the child (Serour *et al.*, 1995). Because birth control generally is not acceptable, pregnancy may occur at any time, and is often unplanned (Hamid, 1989). The only widely accepted birth control practice is child spacing. Couples are told that it is unhealthy to bear another child while the last one is still breast feeding, and they abstain from intercourse during this time.

Since the 1960s, Somalia has been plagued by civil war and family clan rivalry. Nearly 45% of the estimated 7.7 million people have either been displaced inside Somalia or have fled to other countries, and another 400,000 have died of

famine and disease or have been killed in the war (Putman and Noor, 1993). During their immigration, most Somalis were separated from other family members who either live in other host countries or have remained in Somalia. Many immigrants have no friends or family nearby, which is particularly problematic because they tend to rely on these individuals for information about resources and available services (Rode, 1999).

## METHODS

### Sample

The participants were five adult, English-speaking women from the Somali immigrant population who were living in the Minneapolis/St Paul, Minnesota, metropolitan area. Women were interviewed because they are both the primary storytellers in the Somali culture and the primary caretakers of children. A member of the Somali population, a visiting instructor at the University of Minnesota, served as our cultural contact for this research project. She approached members of the local Somali population and invited them to participate in an interview study about children with disabilities.

Recruitment was extremely challenging due to cultural barriers. For instance, a number of individuals declined because they were concerned about their immigration status and the confidentiality of information they might provide. Because of these recruiting difficulties, we decided to interview the minimum number of individuals needed to achieve saturation (redundancy) of the data. Qualitative researchers (e.g., Patton, 1990) have identified saturation as a valid criterion for determining sample size.

We obtained institutional review board approval before beginning this study. Prior to conducting each interview, the cultural contact and the primary investigator, Greeson, informed participants that the purpose of the study was to understand how people from Somalia perceive and cope with disability in their families. This study was conducted from October 1999 through March 2000.

### Data Collection

#### *Instrument*

We designed a series of open-ended questions to allow participants to reflect upon their experience in their own words. The questions, listed in Appendix, elicited information about perceptions of disability, its definition and impact on the family, causes of disability, ways that health care providers can assist families who have a child with a disability, knowledge about genetic counseling, and participant demographics. These questions are based upon our clinical experience

and on literature about the Somali culture. We consulted with our cultural contact when developing the questions to insure that they were neither too invasive nor culturally offensive.

### *Procedures*

We used a semistructured, face-to-face, interview method that invites participants to share their perspectives (Patton, 1990). Each interview was conducted by Greeson, an advanced genetic counseling student who had previous knowledge of the Somali culture. The interviews occurred at a location chosen by the participant, most commonly the participant's home. They lasted approximately 1 h, and all interviews were audiotaped. Consistent with a semistructured interview process, the interviewer asked questions in approximately the same order to allow for consistency of topics discussed and to facilitate comparison of participant responses in subsequent analyses (Patton, 1990). She occasionally gave prompts or posed additional questions to draw out participant experience. Interpreters were used for two of the five interviews, upon participant request. The interviewer transcribed the interviews verbatim, and verified transcription accuracy by comparing text with audiotapes.

### *Design and Analysis*

The interviews were analyzed for themes using the Heideggerian Hermeneutics qualitative method of analysis. Hermeneutic phenomenology is a branch of philosophical hermeneutics (Annells, 1996). Hermeneutics concerns a theoretical attitude toward the practice of interpretations of texts and involves a process of interpreting for the purpose of disclosing an underlying theme within a text (Plager, 1994; Rohde, 1996). In the hermeneutic approach, the absence of objectivity allows a researcher to understand others; her or his prejudices and perspective are critical components, as they give the researcher the ability to identify what is different (Annells, 1996). Hermeneutic phenomenology addresses potential bias by remaining close to the text and by uncovering any biases for scrutiny (Plager, 1994).

The main aims of hermeneutic phenomenology are to identify and understand "the variety of constructions that exist about a phenomenon and to bring them into consensus. The interpretation is open to reinterpretation and is dialectical in nature" (Annells, 1996, p. 708). This approach is valuable in its emphasis on moving past the written text to search for the deeper meaning and insights that the experience of communication can provide (Leonard, 1994; Robertson-Malt, 1999).

Hermeneutic phenomenology has been used in nursing research (e.g., Annells, 1996; Duke, 1998; Koch, 1996; Robertson-Malt, 1999; Rohde, 1996; Ruangjiratain and Kendall, 1998) when the goal was a better understanding of the patient's experience and point of view. Given that understanding the patient's experience is a

**Table I.** Rohde's (1996) Seven Stage Process of Hermeneutic Analysis

Stage 1	Transcripts are examined as a whole to obtain an overall understanding.
Stage 2	Sections of transcripts are sorted by question and summarized. Possible themes are identified, and support for the themes is obtained from interview excerpts.
Stage 3	Transcripts are further analyzed. Themes are compared to the transcripts for similarities and differences between interviews. Any differences are clarified by referring to the original transcripts.
Stage 4	Relational themes are identified. Relational themes are defined as those which reveal themselves in all of the narratives. They are supported by referring back to the original interpretations to look for any discrepancies.
Stage 5	The constitutive patterns emerge. These patterns express the relationship among the relational themes and are the highest level of hermeneutic analysis.
Stage 6	The analysis is validated by other investigators who read the transcripts, independently identify possible themes, and discuss any similarities and differences in their interpretations with the principal investigator.
Stage 7	A final report is prepared using interview excerpts as validation of themes.

common goal in genetic counseling research and practice, this qualitative approach to analysis was considered appropriate for the present study.

In order to understand the participants' experience, Greeson used Rohde's seven stage process (Rohde, 1996), described in Table I, to guide the analysis of the text of the interviews. Validation (Stage 6) was provided by the other investigators, LeRoy, an experienced genetic counselor, and Veach, a licensed psychologist.

## RESULTS

### Sample Characteristics

All participants were from Somalia, and ranged in age from 25 to 53 years (mean = 35 years). They had been in the United States an average of 5 years (range 2–9 years). Only two participants reported being married (the interviewer did not ask the others if they had ever been married or if they were widowed due to the private nature of these questions). They reported an average of 2–3 children (range 0–7). The interviewer did not clarify if the participants had children who were deceased, nor did she ask how many pregnancies they had due to the private nature of such questions. Clan identification was not asked due to the sensitive nature of the question (the civil war in Somalia is essentially the result of clan rivalries).

Four of the participants reported being college-educated in Somalia, and one individual stated that she had gone as far as "intermediate school" (similar to U.S. high school). Two participants currently worked outside of the home, one as an interpreter, and one as a janitor; one participant was a student; and two participants did not have an occupation outside of the home.

Every participant had personal experience in Somalia with someone who had a disability. None of the participants had heard of genetic counseling or met a genetic

counselor prior to their participation in this study. Before proceeding to subsequent questions, the interviewer provided a brief explanation of genetic counseling.

In the following section, themes are organized according to the interview questions, differences when they occurred, are described, and interview excerpts are provided to validate each theme.

### **What is Disability or Handicap?**

#### *Theme #1*

Disability occurs when an individual lacks something that others have, such as mental or physical ability. Mental disability was always mentioned first, and the participants distinguished between mental and physical disabilities. In particular, physical disabilities (e.g., visual and hearing impairments) were viewed as less severe than mental disabilities. Participants reported that there is great respect for individuals who have disabilities, and that an effort is made to focus on the abilities they do have.

#### *Interview Excerpts.*

- Disability is when someone has not functioning very well. He or she lacks some of other parts of organs or sensations that other people have . . . I thought that people would describe disabled if the person is mentally disabled. Like when you see someone who is blind or someone who is deaf, I don't think that many people would consider them severely disabled. But when person is mentally ill, then they would say that this person is. Or, when person is crazy, or whatever, you describe, "Oh, that is disability."
- So, disability means they are able people, who as human being they can do things, but because of their disability, patients, they have disability which won't allow them to do things which a lot of people can . . . When I see someone who's in a wheelchair, I don't look at them like they are less or anything. They just have disadvantage of, you know, what we take for granted.

*Differences.* Some of the participants categorized disabilities more concretely than others. For instance, one participant mentioned that different disabilities are not necessarily related to each other (e.g., someone may have a physical disability and not have a mental disability).

#### *Theme #2*

The family cares for people with disabilities, treating them with respect and as if they were "normal." If they are able, they attend school and interact with nondisabled children.

*Interview Excerpts.*

- I remember one . . . my . . . in my neighbor, he was disability, and his mom died; and also his father have another family, but his aunt takes care of him, you know. And he was very very smart, very strong. His family, and especially his aunt and her children, takes care of him, you know, and he lived normal. Nobody discarded him, or . . . saying something that affects him.
- There are no day cares, no nursing home. So, if I am old, and I have kids, my kids will take care of me. If I don't have any kids, then the kids of my brother or sister . . . Either you're sick or healthy, it is all about family, the immediate family.

*Differences.* One participant described a family friend whose daughter was mentally delayed. She did not describe this daughter as either "normal" or leading a "normal life." However, this is the only participant who explicitly discussed an individual with a mental disability.

*Theme #3*

Treatment of individuals with disabilities in the United States is very different from treatment in Somalia. The participants could not recall any special schools in Somalia that helped people with disabilities. However, there is family, neighborhood, and community help. The participants recalled that people with disabilities received respect and emotional support and were not isolated as they are in the United States. There is much less emotional support and help from communities in the United States because everyone is busy.

*Interview Excerpts.*

- [In the U.S.] they bring you car, you go to school, you come home and use wheelchair, you know, and you don't have friend. You are missing psychological. Because you don't feel . . . when you are disability in my country, you go everywhere with your friends, and they are not disability . . . go to movie. They just, you don't feel, you know, isolated. You feel like the way they feel.
- . . . but I am sure that they are better off [in America], because they can now go to facilities and get help. But, I don't know if they would be happy with that. I think they would be isolated.
- *Regarding her aunt who was deaf:* She was considered . . . In fact, people would give . . . again when I say people, different . . . different people have different kindness, different level of kindness in the way they treat people. In general, people would treat her just every person, very respectful . . . even kindly. . . . And even if they are young, if person is disabled we treat very respectful.



- In general, the religion will tell you, “Be kind,” because in Islam you are supposed to be kind to those who are weaker than you or even those who are the same as you are, but be kind to children, be kind to animals, so you should really be a lot kinder to people with disability because they are weaker than you.
- . . . you know, [in] America what I am most surprised, if you are disability you can only have disability friends.

### **Who Cares for Individuals With Disabilities?**

#### *Theme #1*

In Somalia, the family cares for people with disabilities. Other family members, friends, and neighbors are responsible for helping people who care for persons with disabilities.

#### *Interview Excerpts.*

- *Translator:* Neighbors also help. It is like a charity. Relatives who live away from them when they hear that the child is disabled, they come or send something to him or to her. Even the person who takes care of this disabled person gets attention from other family or relatives. They give money or whatever they can cause they know this person is doing great job helping this person.
- *Translator:* She just explained to me if the child who is disabled, his parents dies, his family relatives would take care of him or her . . . If someone dies or gets older, then another family member comes in and takes care of that person until they die. They will never be alone. They will always have someone.

### **What is the Impact of Disability on the Family?**

#### *Theme #1*

Although a Somali family caring for a child with a disability may not express it, caring for this person is difficult and places stress on the family. Since the bulk of the responsibility for care is on the family, disabilities within the immediate family and/or more severe disabilities may create greater stress.

#### *Interview Excerpts.*

- It definitely does [change how the family interacts], because it is a burden to them. And unless your parents are very religious and very nice people, extremely nice, whoever has a disability can feel in his heart that he is

being a burden. Like if you are blind, when all the kids go to school, you have to stay back. Maybe your mother wants to go to the market while kids are in school, and she has to drag you wherever she goes. So, I think . . . I would say that people with disability would have these kinds of feelings. And their parents, too, because they are not, they are not able to do what other kids can.

- *Translator:* [The parents of a girl with a disability] will be very sorry about their girl, and then they will be stressed, and that is a problem. Although the family are very religious people, and still, they feel sorry for their girl.
- . . . they are not able to do what other kids can. And another thing might be financially it is a burden, too, because if it is a girl . . . when she reaches a marriageable age, she can't move on with her life. She has to stay with her family forever. But, not many people are willing to marry a woman with a disability . . . Actually I have two, two of my cousins, they are two girls, they are twins, and they are deaf. They were really, really pretty girls, but nobody would have marry them. Because . . . just because they were deaf.

*Differences.* Some of the participants very openly and directly discussed how difficult it would be to raise a child with a disability. Others mentioned it within the context of how important it is to provide the child and/or the caretakers of that child with extra attention. Some participants talked about how individuals with disabilities are not always treated with respect and esteem. Despite what Islamic teachings say, they are ill-treated and even abandoned.

### **How Would Having a Child With a Disability Affect Your Plans for Future Children?**

#### *Theme #1*

While parents may worry, having a child with a disability would not change their plans for future children.

#### *Interview Excerpts.*

- I know one family, they have four deaf children. They go, they have fun with 3 boys and 1 girl.
- I don't know about now in America, but in Somalia [it would not change their plans to have more children]. Families keep having children. They don't stop and say, "I am worried about the next one." I don't think people have the same affect the one. I know people who have 3 or 4 kids who all have different kinds of disabilities. They don't stop and say, "This is it. I can't have anymore."

*Theme #2*

Every participant stated that family, and large families, are important in Somalia. It is not unusual for families to have 10 or more children. Thus, a family would want more children.

*Interview Excerpts.*

- I don't know in America, but in my country they don't, if they have . . . 5 or 7 is small, you know, family. We have, . . . if you have 5 children, you have small family in my country. Very small family. Average 10 or more than that. They don't care they got disability child . . . still they need a lot of . . . many.
- Family is . . . you cannot survive without a family in Somalia. Especially immediate family. It's having a relationship with a person, and his/her immediate family is very important. Yeah, your family would do anything for you . . . Family is very important.

*Theme #3*

There are virtually no reproductive plans. Couples leave the decision to have more children and the health of their children to Allah. They trust in Allah to give them whatever he will.

*Interview Excerpts.*

- In Somalia, everything is . . . living is very important, and you leave everything up to God. You don't know. You can't prevent this; you just see what happens."
- *Translator*: "There aren't any regrets after having this child as a Muslim. People believe that whatever they get . . . whatever that comes from God, we have to accept.
- So, those people who are really tied to their religion, if they are married they should not be concerned, because they don't know. This child may be disabled, and next child may be healthy. You know, it happens many times. . . . Yes, they have 1, 2, 3 child consecutively who has disability. Then they might be fearful, thinking that might . . . whatever they have might be disabled again . . . and that means couple needs to have strong faith in God. So, they hope that the next child would be healthy child. Continue having children . . .

*Differences.* Some of the participants talked about how, in the United States, practices might change. For instance, some Somali women are starting to use birth control. They said that any chemical form is a sin. Nonchemical forms such as child-spacing are allowed, although not looked upon favorably. One participant

talked about abortion. She stated that she was prochoice because she recognizes that it is a personal choice, but she also stated that Islam forbids abortion. There was some sentiment that, in the future, some individuals might try to prevent disabilities, although at present no one knew any person who would do so.

### **What Do Most Families Consider to be the Reason a Child is Born With a Disability?**

#### *Theme #1*

Disability comes from Allah.

*Interview Excerpts.*

- But if I somehow have a child with a disability, I don't think, "I will make any research to find out why"... I would just think that is the way of God make him or her. That is the way God created. I don't think we would go back and look as far as medicine is concerned. It is just, you are blind, you are blind. God decided to make you blind. It is not because your great grandfather had the same genetic problem.
- *Translator:* I can not talk about that. I can only say that God knows that.
- *Translator:* She says that she doesn't... she did not hear of any specific cause of disability. Only thing that we believe is that this came from God, Allah. And then that is it.

*Differences.* Some of the participants talked about how disability is a test from Allah to see if you appreciate what you have, while others did not discuss this aspect.

### **What Can Health Care Professionals Do to Help Families Who Have a Child With a Disability?**

The participants offered three types of suggestions:

- Talk to patients to see what they are open to considering. For example, it is permissible to have one's fertility tested, or to be tested for STD's prior to having children: *You know, it is permissible that they go to doctors to test their fertility, if there are sexual transmitted diseases. If they have this kind of problems, then they have to know beforehand.*
- Try to obtain the patient's trust and confidence. Some Somali people do not feel comfortable telling their problems to health care professionals. For example: *Like right now, let's just say that you are a doctor, and I come to you and tell you my problems. I might not be honest with you.*

- Be sensitive to the fact that Somali immigrants face acculturation issues. For example: *We cannot evolve into a whole new personality or a whole new way of the world in a few years. This whole things is new to us.*

### Interviewer Impressions

During the interviews, four dynamics were apparent: (1) Initially, the participants seemed to be uncomfortable. For instance, they were reserved when answering questions, giving short responses. However, as the interview progressed, they became more verbal, volunteering more personal and detailed information about their experiences; (2) The participants were most vocal about Islamic views of disability and Islamic beliefs about how they should treat people with disabilities; (3) They seemed to be most comfortable when giving examples of other people's experiences rather than their own experiences; and (4) They were hesitant to assert their perceptions and opinions as fact. A commonly stated caveat was that they could only speak for themselves, not for all Somali people. For instance: *Still, I apologize if I misrepresent the people of Somalia, but I think, and this is just what I think . . .*

### DISCUSSION

This study was designed to assess the potential utility of genetic counseling for Somali immigrants by eliciting their perceptions of disability. We believed that our findings and suggested modifications to genetic counseling might also serve as an example for patients with similar beliefs such as patients from other non-Western, Islamic cultures. Six major themes emerged from the structured interviews.

*Disability refers to both physical and mental conditions, with mental disability generally thought of first and as more severe.* The participants' definitions of disability appear to be consistent with Western definitions, and probably are compatible with those held by most genetic counselors. Both physical and mental disabilities were included as distinct forms of disability, with mental disability considered to be more severe. These results suggest that Somalis may place more emphasis on mental ability rather than physical disability. Furthermore, families may experience greater stress if their child is mentally disabled than, for instance, if the child has a visual or hearing impairment. When taking a family history from Somali patients, genetic counselors should be aware that patients might not mention physical disabilities without prompting since they may regard them as less severe. Also, when describing a genetic condition, the genetic counselor may want to carefully differentiate between its mental and physical outcomes in order to better explain the implications.

*The family cares for the individual with a disability, and the individual is "normalized" within the culture.* The results suggest that Somali families play

a central role in caring for individuals with disabilities, attempting to treat them as normal family members. For instance, children with disabilities are strongly encouraged to participate in activities similar to their siblings. If a parent is unable to care for the individual, then an aunt, a grandmother, or another extended family member assumes responsibility. Community members generally show great respect toward persons with disabilities.

Nonfamilial organizations or agencies are regarded as unacceptable, and therefore are nonexistent in the Somali culture. Therefore, common Western services such as nursing homes, extended care facilities, group homes, institutions, and adoption placements may not be viable options. Somali patients might be very offended, for instance, if asked about their interest in placing their child in a supported living environment. Inquiries into such options should be done indirectly, for example referring to what other patients have chosen to do.

*There are major cultural differences in how persons with disabilities are treated.* Every participant discussed her perceptions of the clear differences between how U.S. and Somali societies treat people with disabilities. A major difference concerns the provision of material versus emotional support. In Somalia, individuals and their families receive substantial amounts of emotional support and respect along with tangible assistance from other family members, friends, and neighbors. Additionally, families are held in high-esteem because of their struggle with what some participants described as a “test of one’s faith in Allah.” In contrast, although material support is available in the United States, social support is lacking. Most of the participants expressed disgust with their perception that people in the United States isolate and ostracize individuals with disabilities.

A significant issue concerns the availability of support for Somalis in the United States, since many families have been broken up, and neighbors are less accessible. On a related note, in Somalia a mother would usually care for a disabled child, with the support of other neighborhood mothers. However, in the United States, many Somali women are either the sole or major economic provider for their families, and they may not be able to stay at home to care for a disabled child.

*Caring for an individual with a disability is stressful for the family.* Somali immigrants face numerous burdens in caring for disabled family members. The burdens may be particularly great when the disabled individuals are female because they typically are not regarded as suitable marriage partners. Each participant, in some manner, stated that having a child with a disability is difficult, and the impact is even greater in the United States. Some participants were very open about the difficulties, telling stories from both Somalia and the United States of friends whose husbands had abandoned them and their children because of the stress, and about friends with a disability who were picked on and beaten. These stories indicate some discrepancy between what is said (e.g., people with disabilities are afforded great respect), and what is done (e.g., they are picked on and beaten).

*Allah decides whether a couple will have more children and whether those children will be healthy.* A strong finding was that having a disabled child would not impact a couple's decision to have more children. While parents may worry about a next child, pregnancy planning is not part of traditional Somali culture because all reproductive decisions are left to Allah. However, some participants questioned whether this would change with the influence of Western culture.

*Risk does not affect reproductive decisions because Allah determines outcomes and because family is so central.* The absence of reproductive planning is due to one's religious faith that what comes from Allah, one accepts, and to the overriding importance of family in Somali culture. Allah's role in determining reproductive outcomes was highly evident. For instance, one participant said, "I cannot talk about that [cause of disability]. I can only say that God knows that." Common genetic counseling concepts such as risk factors and recurrence rates were strikingly alien to the participants. One individual scoffed at the idea that a person could be blind because his great grandfather had the same condition, saying, "God decided to make you blind."

### **Participant Suggestions for Increasing Health Care Provider Effectiveness**

The participants offered three major suggestions for helping families who have a child with a disability. Their first two suggestions are valid for all clients, regardless of culture. First, offer culturally acceptable services. The option of genetic testing to aid in diagnosis may be very acceptable to a Somali family because of the importance placed on medical care and management for a diagnosed disease. Several participants talked about the importance of teaching parents about a disability and helping the family find resources. Thus, the role of patient advocate could be very important to a Somali family.

Second, build patient trust. One participant openly stated that trust is so influential that Somali patients frequently withhold information or lie to physicians if they do not trust them. Mistrust and fear of disclosure are major issues for Somali immigrants. They may not believe that confidentiality can be maintained and are likely concerned about their immigration status if they reveal certain information to a genetic counselor. Limits to confidentiality will need to be clearly stated. Additionally, empathy will be important for building rapport. For instance, the genetic counselor might comment on how "alien" genetic counseling is for the patient. The genetic counselor should also ask questions to elicit patient perceptions of genetic counseling, and how the counselor can be helpful.

Third, there was a lot of discussion about being sensitive to the variability of Somali immigrants with respect to the influence of American culture. The participants stressed that each patient is an individual with varying cultural and religious beliefs. Additionally, as within any cultural community, there may be a difference between what is said in theory and what occurs in actual practice.

## Implications for Genetic Counseling

The present findings challenge the utility of traditional genetic counseling for Somali immigrants. In the following sections we discuss ways that the genetic counselor could meet these challenges.

### *Acculturation Issues*

Somali immigrants face a number of issues including the feasibility of large families in the United States, birth control, abortion, and use of Western support services (e.g., adoption, extended care facilities). It is uncertain whether they will retain their Somali cultural values and practices, adopt Western values and practices, or integrate the two. Genetic counselors should be aware that patients may be caught between Somali and Western beliefs when making decisions. Another major issue concerns the lack of culturally appropriate tangible and social support. Genetic counselors should provide psychosocial support and consider referrals to support groups. However, they must carefully consider the nature of the support group, the ethnocultural competence of the group members, and the receptivity of the particular patient.

### *Medical Issues*

In the present study, the interviewer had difficulty obtaining basic demographic data (e.g., it was too invasive to inquire about being previously married or widowed because many men were killed in the civil war). Genetic counselors will have to proceed very carefully and sensitively with history-taking, explaining why certain information is necessary and acknowledging that some questions may be uncomfortable. Data may be limited because some patients may withhold information, and also because a great deal of information is viewed as unimportant in the Somali medical system and is therefore not recorded (e.g., birth dates). Additionally, some information given in Somalia is diametrically opposed to information presented in the United States (e.g., the "pill" causes diseases). Genetic counselors will need to carefully assess their patients' knowledge and attempt to correct inaccuracies.

Most Somali immigrants will pursue genetic counseling only through referral from another health care provider because they do not know about genetic counseling and its potential benefits. Genetic counselors will need to educate them about the nature of genetic counseling (see Jacobson *et al.*, 2001, for a discussion of informed consent for the genetic counseling session itself).

Traditional risk/inheritance counseling should be modified. As the present findings suggest, if patients believe that only Allah determines what will happen to a child, then why would they believe that the genetic counselor would know the cause? Before providing scientific explanations, it may be effective to first ask the



patient what she/he believes causes a disability or a specific genetic condition. Kleinman (1980, as cited in Fadiman, 1997) developed a series of questions for use in cross-cultural medicine: (1) What do you call the problem? (2) What do you think has caused the problem? (3) Why do you think it started when it did? (4) What do you think the sickness does? How does it work? (5) How severe is the sickness? Will it have a short or long course? (6) What kind of treatment do you think the patient should receive? What are the most important results you hope she receives from this treatment? (7) What are the chief problems the sickness has caused? and (8) What do you fear most about the sickness?

The participants were adamant that Allah, not inheritance, makes a person disabled. We believe that many individuals from Western cultures mesh science and religion by saying, for instance, that given a 1/4 recurrence risk for cystic fibrosis, God decides to make one particular child in 4 affected with the disease. However, the Somali participants did not make this type of connection. Perhaps genetic counselors could help Somali patients consider risk by using the example that Allah decides which gene the child gets, but that there are four choices.

Participants repeatedly stated that risk/inheritance knowledge would not affect their reproductive practices, because they do not make reproductive decisions. As previously stated, birth control is not widely used with the exception of child spacing. Thus, even if a couple were to accept that they are at increased risk, and wanted to consider reproductive options, few are acceptable.

The utility of genetic testing will vary greatly depending on its purpose. Prenatal testing may be acceptable, although options of what to do with positive results are limited. If abortion is acceptable until 120 days (about 17 weeks), then theoretically, one would be able to do genetic testing or chromosomal analysis on either chorionic villi or amniocytes and get a result within the time that termination is acceptable. However, many factors limit this in practice. Most pregnancies are unplanned, the prenatal care of Somali women is poor, and many do not seek medical care until much later in the pregnancy. As with all patients, individual views of abortion may vary greatly, and some couples may refuse any test or procedure that would put the fetus at risk. Because Muslims often turn to religious scholars for guidance, the genetic counselor might recommend that a couple consult a "Fikh" Islamic jurisprudence committee to see if termination is a viable option in their situation.

## LIMITATIONS

The credibility of this study is supported by the use of rigorous methods for data collection and analysis, on-going consultation with a cultural contact, and the investigators' cross-disciplinary credentials. Nevertheless, the present findings should be generalized with caution. Although the present sample ( $n = 5$ ) was sufficient to provide a rich perspective, qualitative data are not intended to generalize to the population (Patton, 1990). In addition, all participants were female and were recruited by one cultural contact, possibly introducing bias.

The interviewer's cultural background differs from the participants, and possibly decreased their trust and disclosure. Also, an interpreter's presence in the last two interviews appeared to interrupt the flow of conversation and resulted in noticeably shorter, less detailed interviews. However, the interviewer had worked with interpreters in her genetic counseling, so she was comfortable with the process. She also compared participant responses in the presence and absence of an interpreter and determined that there were no major differences.

## **FURTHER RESEARCH RECOMMENDATIONS**

This preliminary exploration of Somali perceptions of disability is a first step toward assessing the potential utility of genetic counseling for Somali immigrants and for suggesting modifications to typical genetic counseling practices. To fully address these issues, additional research is necessary. A more comprehensive understanding of how Somalis use medical services and what obstacles prevent their use is required. In addition, an understanding of the perspectives of Somali families who have children with genetic conditions and those who have seen a genetic counselor could support our preliminary findings. Longitudinal studies should be conducted to determine whether Somali immigrants retain traditional values and practices regarding disability, adopt U.S. values and practices, or blend the two cultural views. Studies that address the differences and similarities between first generation and second generation Somali immigrants will be of great importance as the second generation enters the medical system.

The effectiveness of modifications to genetic counseling practices needs to be studied with samples of Somali patients. Investigations of the specific aspects of genetic counseling which are and are not useful may provide valuable insight into how this population could be better served by the genetic counseling profession. Investigations of the reasons that at least some Somalis regard all abortions as against Islamic views would help genetic counselors understand viable options for Somali patients. Finally, it is not possible to ascertain the extent to which participants' perceptions were a function of their Islamic religious beliefs versus other aspects of their Somali culture. Studies comparing Muslims from different cultures could help to determine the role of religious beliefs versus other cultural variables in perceptions of disability and genetic counseling utility.

## **APPENDIX: INTERVIEW QUESTIONS**

1. Can you talk a little about what you think of when I use the term "disability" or "handicap"? Describe a personal experience with a child with handicap or disability (Examples: mental retardation, in a wheelchair, sickle cell anemia).

2. Can you talk about what happens to the family when a child with a disability is born? Who cares for the child? How did it affect the family?
3. How do you think having a child with a disability would change your family? How would your daily life change? Who would help care for the child?
4. Would having a child with a disability change your plans for future children? Would you want to have more children? Would you worry about the next child having the same disability?
5. How do most families think about the cause or reason for a child being born with a disability?
6. Can you think of something that a health care professional could do to help families who have a child with a disability?

### ACKNOWLEDGMENTS

This study was completed in partial fulfillment of the requirements for the first author's master's degree from the University of Minnesota. The authors gratefully acknowledge the assistance of O. Ahmed, O. Hannan, D. Pryce, and our interview participants.

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