Pedigree and Family History: Genetic Counseling a Lesbian Couple

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Learning Objectives

By the end of this case, genetic counselors will be able to:

1. Acknowledge personal perspectives towards gay, lesbian, bisexual or transgender (GLBT) persons.
2. Discuss the emotional, psychological, and legal barriers facing GLBT persons.
3. Use culturally appropriate language when taking a family history and counseling GLBT clients.

Brittany is a genetic counselor working in a Children’s Hospital that provides comprehensive genetic services, including prenatal genetic counseling. Lisa, age 38, was referred by her OB/GYN because of advanced maternal age. Lisa’s partner, Jamie, age 39, is also present at the genetic counseling session. The intake form notes that the couple used in vitro fertilization to conceive this pregnancy. As she always does, Brittany briefly explains to Lisa and Jamie that she will gather family history information. Then, Brittany begins to ask questions to draw the pedigree. After eliciting Lisa’s family history, Brittany asks Lisa, “Do you know about the paternal side-about the father of the baby and his family history?” Lisa corrects the genetic counselor. “Do you mean, do we know about the sperm donor? Of course, yes, Jamie and I have information about the donor’s family history.” Brittany blushes, looks uncomfortable, and says, “Sorry. Let’s just continue with the pedigree.”

Click here to view Lisa’s family history and pedigree.
Family History

Proband: Lisa Reisten is 38 years old and in good health. Lisa’s egg was used to conceive this, her first, pregnancy. Lisa has two brothers. Her older brother is 40 years old. He has no apparent health problems and no children. Lisa’s younger brother died in a car accident at age 16; he had been healthy before the accident. Lisa’s parents divorced after 20 years of marriage. Her mother is 69 years old and she has three sisters and one brother, all healthy. Lisa’s mother’s parents died of natural causes; her father at age 73 and her mother at age 76. Lisa’s father (70 years old) was an only child whose mother died in childbirth at age 24. His father is still alive at 90 years old but he has high cholesterol and high blood pressure. Lisa’s mother’s family was from Germany and her father’s family was from England. There is no known consanguinity.

Proband’s Domestic Partner: Jamie O’Hare is 39 years old and in good health. Jamie was previously married for two years; that relationship resulted in no pregnancies or children. Jamie had recently divorced from her husband when she and Lisa met through mutual friends about six years ago.

Sperm Donor: The anonymous sperm donor was identified by Lisa’s reproductive endocrinologist. Lisa was told that her physician’s donor screening protocol is rigorous. Lisa reports that the sperm donor is 32 years old and healthy, with no previous pregnancies or children. The donor’s sister and parents were reported to be in good health. The donor’s mothers’ parents were reported to have both died of natural causes. The donor’s father’s parents are reported as alive and well. The donor’s family background is French. There is no known consanguinity.

Additional Notes about the Family: Jamie and Lisa have been together as a couple for about five years. They are very excited that they are finally building the family they have dreamed about. Both Jamie and Lisa actively participate in the tasks of childrearing; they plan to cut back on taking new work responsibilities to generate more family time.
**Personal Reflections**

What are your reactions to this case?

What do you know about GLBT culture and terminology?

What thoughts do you have about Lisa’s reproductive and relationship decisions?

How is Lisa and Jamie’s relationship the same and how is it different from your relationships?

Have you ever counseled a client of a sexual minority?

What stereotypes and messages can you recall from family members and the media regarding heterosexuality, homosexuality, and bisexuality?

Are you aware of the current laws regarding GLBT rights and privileges?

**Perspectives**

How could Brittany have made Jamie feel more a part of the genetic counseling session?

How can a genetic counselor modify the pedigree intake and drawing protocol when counseling a lesbian couple?

What expectations do you think Lisa had about genetic counseling?

How do you think Brittany’s initial interactions with Lisa and Jamie set the tone for the prenatal counseling session?

**Self Assessment**

Before taking the self assessment, consider where you think you stand on the gay, lesbian, bisexual, and transgender continuum (McAuliffe, 2005).

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**Condemnation** involves viewing GLBT persons as inferior and immoral. A person who condemns same-sex attraction believes it goes against nature and supports any action to change a person back to a heterosexual sexual orientation. At this stage your feelings are preventing you from accepting and being supportive of GLBT persons. When someone recognizes GLBT persons without taking actions to include
them as an equal part of society he or she is considered to be tolerant. Acceptance of GLBT persons allows for equal rights in society, but still debase homosexualty. At the acceptance stage, you are minimally supportive of GLBT persons. A supportive person may be slightly uncomfortable with homosexuality, but this person works actively to maintain equal rights and acknowledges the current injustices in society. Admiration includes people who realize the strength that it often takes to live as a GLBT person; they examine and adjust their own personal attitudes/biases to be inclusive. At this point you are ready to be an effective supporter of GLBT persons. Lastly, when you appreciate homosexuality, you work to reduce injustice and bias in society, you believe that GLBT persons are an important part of the community, and you have affection towards GLBT persons. When you achieve appreciation, you can be a strong and willing advocate for GLBT persons.

Take another self-assessment, the Gay Affirmative Practice Scale (GAP), by Crisp, 2006.

While there are many self-assessment measures available, we have included two. The first self-assessment tool asks you to honestly define where you stand on the continuum. After taking the GAP self-assessment, go back to the first self-assessment.

- Did your perspectives on where you stand on the continuum change?
- Did you realize you were less accepting, more appreciative, or similar to where you originally placed yourself?

If you admire GLBT persons, but you simply have not had a lot of experience with this culture, you may want to review the resources listed at the end of this case for more information regarding GLBT persons, current legal updates, and suggestions for showing your support.

**Defining the Elements of GLBT**

*Sexual orientation* is defined as the direction of romantic, sexual, and emotional feelings. This orientation can be towards the same sex, the opposite sex, or both. No exact factors have been found to explain the development of sexual orientation, but scientists have examined the interaction of cognitive, biological, and environmental factors as possible contributors (American Psychological Association, 2008). The process by which a person establishes their sexual identity is very complex. McAuliffe (2005) describes a model of gay and lesbian sexual identity development. The first phase, Being Different/Identity Confusion, involves feeling different than peers and beginning to wonder if one is lesbian or gay. Identity Acceptance/Coming Out is the second phase and involves sharing a preferred sexual orientation to oneself and others. The third and final phase is Identity Synthesis, which allows assimilation of one’s sexual identity into other aspects of the self (McAuliffe, 2005).

Sexual orientation is a continuum ranging from exclusively heterosexual to exclusively homosexual; individuals may identify with either extreme or one or more places in-between (Gilbert, 2003). Usually emerging in adolescence, sexual attraction occurs without any sexual experience (Szymanski, 2008). **It is vital to consider a person’s sexual identity as an orientation, not a preference.** A preference implies that there was a choice in a person’s orientation, which is not supported by empirical evidence. An orientation implies that the person was created to be gay, lesbian, bisexual, or transgender. According to the American Psychological Association (2009), when describing orientation, it is best to use terms such as “gay male sexual orientation” and “lesbian sexual orientation” over “lesbianism” and “homosexuality.” To describe behaviors, it is appropriate to use terms such as “same-gender behavior” or “female-female behavior” (American Psychological Association, 2009).

The language describing persons of homosexual sexual orientation is often misused. Homosexuality is correctly defined as the sexual orientation of any person who is attracted to the same sex. A gay person is defined as a male attracted to a male, while a lesbian is a female attracted to a female. However, the term gay has been used to describe all gay, lesbian, and bisexual persons. Some people may be used to seeing gay and lesbian in literature and the media, and assume that gay only refers to men; others may believe it refers to men and women alike. **It is important to use the same terminology as your client.** Bisexuality describes persons who currently have or have previously had relationships with members of
both genders. There are several myths about bisexuality that have arisen out of societal assumptions. They include the idea that bisexuals are “closeted” gays or lesbians, they are stuck in transition between a homosexual and a heterosexual, that they are incapable of monogamy, and that they have relationships with both genders for their own personal satisfaction (Szymanski, 2008). A pansexual person has the potential to be attracted to any person, independent of their sex or gender.

The terms gender and sex are often used interchangeably; however, they have different meaning. Sex is the anatomy of a person’s genitalia along with his or her genetic makeup. A person can be male, female, transitioning, or intersex. Intersex is the sex designated to persons born with ambiguous genitalia. Gender is defined as who one believes oneself to be emotionally and psychologically, whether it agrees with one’s assigned sex or not. A person can feel that they are a male or a female or may not identify with either gender. Gender assignments are merely a social construct, created and enhanced by culture to designate behaviors to male or female (Gama, 2002). These behaviors are enforced by media, politics, law, religion, and most of all, family. The so-called “norms” for male or female genders cause difficulty for people who self-identify themselves with the gender that is not their sex or those who do not identify with any sex at all. Individuals who do not identify with their assigned sex are transgender. Transgender persons challenge the conventional descriptions of male and female. Transgender is not a sexual orientation; rather transgender persons can be heterosexual, homosexual, pansexual or bisexual, including both males and females and pre-operative and post-operative persons. The scope of this module does not include further discussion of issues related to counseling transgender persons.

Marriage and Family Legal Aspects

Same-sex attraction occurs in humans across all cultures, educational levels, career paths, socioeconomic levels, religions, and personalities (Szymanski, 2008; McAuliffe, 2005). In fact, 5-10% of the United States population report significant same-sex attraction. According to the Catalyst, in 2009, an estimated 13-17 million persons of the U.S. population are gay, lesbian, or bisexual (Gates, 2006). The potential stigma surrounding coming out as a gay, lesbian, bisexual or transgender person may result in underreporting.

According to Gay & Lesbian Advocates & Defenders (2008), marriage is defined as “a unique legal status conferred by and recognized by governments the world over”. Not only does a marriage offer certain rights and protections, it declares to the world a couple’s love and commitment for each other. A civil union provides legal protection to couples at the state law level, but omits federal protections as well as the dignity, clarity, security and power of the word “marriage” (Gay, 2008). Depending on the state, a domestic partnership can ensure some protection similar to marriage or simply allow same-sex couples to declare their commitment and pledge to be responsible for the other person’s financial obligations. States that allow domestic partnerships are California, Washington, Oregon, Hawaii, Maine, and the District of Columbia (National, 2009).

There are over 1,049 legal protections and responsibilities that accompany a marriage, the majority of which are denied to same-sex couples (Gay, 2008). These benefits include affordable housing programs, employee benefits, tax laws, and death benefits among many others. Partners in a civil union receive rights based on the state in which they are partnered. While a marriage is recognized worldwide, civil unions are not recognized from state to state. Divorce proceedings too are different for married couples versus those in a civil union. Partners in a civil union must be a resident of the state that granted the union in order to receive a divorce; married couples can be a resident of any state. Similarly, a spouse can make any medical decisions regarding their partner. If a partner in a civil union is injured in a state that doesn’t recognize their partnership, this person may not be recognized as a family member, may not be allowed to make medical decisions, and may not be able to even visit the patient. If the patient should die, the partner may be denied the right to plan a funeral or receive bereavement (Herek, 2006). With marriage being the primary source for health insurance other than employment, many gay and lesbian couples go without health coverage. Even when employers do extend health insurance to same-sex partners, the coverage is often taxed as income (Herek, 2006; Gay, 2006). Fortunately, these challenges are attaining national recognition and are slowly improving. On April 15, 2010, President Barack Obama issued an Executive Order “Respecting the rights of Hospital Patients to Receive Visitors and to
In 1996, Congress passed the Defense of Marriage Act (DOMA) which specifies marriage as the union of one man and one woman. Many states have since voted for their own versions of DOMA, disallowing same-sex marriage (Herek, 2006). As of June 2009, only six states allow same-sex marriage: Massachusetts, Connecticut, Iowa, Maine, Vermont, and New Hampshire. Many of these states have only made this decision very recently – after January 2008. Rhode Island, New York, and the District of Columbia recognize same sex marriages, but do not allow them to be performed in their own state. Three states allow civil unions with spousal rights including Vermont, New Jersey, and New Hampshire. H.R. 3001: Ending LGBT Health Disparities Act was introduced to the 111th Congress on June 23, 2009 by Representative Tammy Baldwin. This bill sets forth provisions concerning the health of lesbian, gay, bisexual, and transgender individuals, and was in committee at the time this case was written. The bill includes provisions for expanding the definitions of “spouse” and “married” for purposes of Medicare, and prohibits discrimination on the basis of sexual orientation or gender identity under Medicaid and other federal programs. The bill also provides support for demonstration projects and research to improve the health and health care of sexual or gender minorities.

Formation of Families by GLBT Persons

The desire for children is a basic human instinct felt by lesbians, gay men, and heterosexuals alike. Humans desire to be parents for the same reasons regardless of their sexual orientation (Ames & Chabot, 2004). Currently, 25% of gay men and 55% of lesbian and bisexual women are parents. Many of these clients decide to have children through adoption (allowed in every state but Florida), surrogacy, foster parenting, and/or assisted reproductive technology (Sue & Sue, 2003; Amadio & Perez, 2004). Artificial insemination by a known or anonymous donor using fresh or frozen semen is also common (Steele & Stratmann, 2006). In addition, there are many types of assisted reproductive technology (ART) available to couples who are infertile or in same-sex relationships.

The ART technique used in this case by Lisa and Jamie is called in vitro fertilization (IVF), which involves combining a woman’s eggs and man’s sperm outside of their bodies in a laboratory. After the egg(s) are fertilized, the embryos are transferred to the woman’s uterus. All types of IVF may be done with the couple’s own eggs and sperm or donor eggs or sperm. Donor eggs and sperm are typically obtained from a donation bank and undergo extensive medical and genetic screening (American Society, 2008). If a pregnancy is carried by the egg donor, the woman is considered a traditional surrogate. If the pregnancy is carried by a woman who has no relation to the baby, she is considered a gestational carrier. Lesbian couples typically allow one partner to be the egg donor and the traditional surrogate. For gay males to parent, they may use an egg donor who can also be a surrogate or an additional female to be the gestational carrier (American Society, 2008). Due to common stereotypes, acceptance of gay fathers is not universal. ART programs throughout the United States have been found to widely accept lesbian couples, but are less likely to accept gay male couples (Greenfeld, 2007).

There are medical risks associated with IVF for each step of the procedure. Women preparing to undergo IVF or ovum donation receive ovulation induction or fertility drugs to allow for growth of multiple eggs in the ovaries each month. These women are at risk for ovarian hyperstimulation syndrome (OHSS) which can lead to the development of fluid in the abdominal cavity, excessive weight gain, over-concentration of the blood, and even kidney failure or death. There are also risks associated with retrieval of eggs similar to any general surgery that requires anesthesia. Additional risks involve the possibility of the aspirating needle causing damage to the bladder, a blood vessel, or the bowel during egg retrieval. After fertilization, embryo transfer can cause cramping and bleeding with the rare chance for an infection (American Society, 2008). Anytime multiple embryos are inserted into the uterus, there is a higher chance for multiple pregnancies. The risks involved with a multiple birth pregnancy include premature delivery, maternal hemorrhage, gestational diabetes, and early or prolonged bed rest. Miscarriage rates after IVF are very similar to the general population. The rate of a miscarriage when the mother is in her twenties is 15%. If a mother is in her forties the rate is 50% (American, 2007). According to Correa et al. (2009), among single births, ART was found to be associated with septal heart defects, cleft lip with or without cleft palate, anorectal atresia and esophageal atresia. ART resulting in multiple

Designate Surrogate Decision Makers for Medical Emergencies”. See the Presidential Memorandum at: http://www.whitehouse.gov/the-press-office/presidential-memorandum-hospital-visitation
births was not found to be significantly associated with these birth defects. The mechanisms are not yet clear as to why these birth defects are more common in babies conceived via ART (Correa et al., 2009).

It is important to consider the financial, physical, and emotional effects IVF has on a couple. The treatments are expensive and patients are known to hold high expectations. Failure is common, however, leaving couples feeling resentful and frustrated. Couples are often encouraged to seek psychological counseling to help manage the stress of the situation. Many ART clinics have mental health professionals on site to work with couples who are dealing with anxiety and grief (American Society, 2008).

When performing a psychosocial assessment and providing psychosocial counseling, it is important to remember that all relationships share many of the same attributes, regardless of the sexual orientation of those involved. Members of both same-sex and heterosexual relationships form strong emotional attachments and face challenges concerning loyalty, intimacy, stability, and love. Same-sex couples’ behaviors towards the household labor and family values fall into two patterns: specialized and shared (Patterson & Tasker, 2007). In the specialized pattern, one partner focuses on paid employment while the other focuses on unpaid family work. This pattern is typical among heterosexual couples, with the male focusing on paid employment. Among homosexual couples, the household work is typically split more evenly, consistent with the shared pattern.

There are four hypotheses regarding how couples determine divisions of labor. The Relative Resources hypothesis suggests that labor will be divided depending on the discrepancy in the resources available to one partner over the other. In heterosexual couples, the male often tends to have a greater access to resources, and thus earning potential. The smaller the resource discrepancy between partners, the more the paid and unpaid work will tend to be shared. If both partners are of the same sex, they are more likely to have access to equal resources and thus be more likely to equally share unpaid labor. The Structural hypothesis proposes that the partner who works fewer hours in paid employment will do more unpaid family work, due to greater availability and flexibility. However, if there is a great need for unpaid family work, such as a large number of children or a child with health concerns, the other partner will be expected to do more unpaid work regardless of hours in paid employment. The Ideological hypothesis suggests that couples that do not follow traditional gender roles will more commonly enlist the father’s help with childcare. There has not been research on lesbian or gay couples for this hypothesis. In the Family Systems hypothesis, the dynamics of the couple’s relationship will determine division of paid versus unpaid labor. For heterosexual couples, fathers who are more highly satisfied in their marriage will do more unpaid family labor. There has been no research in homosexual couples regarding relationship dynamics and the division of labor (Fulcher, Patterson, & Sufin, 2004).

Homophobia and Its Effects: Past and Present

Homophobia refers to the irrational fear of or discrimination against homosexuals. This prejudice, along with institutional influence, results in heterosexism. “Heterosexism refers to attitudes and behaviors that deny, devalue, or stigmatize any non-heterosexual form of community, relationship, identity, or behavior and can manifest on individual, familial, institutional, political, and cultural levels” (Szymanski, 2008).

Some examples of heterosexism include rejection by family or religious affiliation due to sexual orientation, refusal of marriage rights and associated protections by the government, harassment and violence, anti-gay jokes, and discrimination of employment and housing.

Homophobia was rampant in the 1960’s; this was evident by frequent police raids of gay establishments. However, members of the GLBT community were quickly growing tired of being treated as lesser persons. In the early morning of June 28, 1969, the typically pacifist gay and lesbian community fought back. Police officers conducted a raid at the Stonewall Inn, a popular gay bar in New York City. Their raids were common and usually followed the same pattern of events including: police entrance and announcement, checking of IDs, arrest of any “deviant” customers, and arbitrary dismissal of patrons. That night, as each patron was allowed out of the bar and onto the street, the crowd grew from being cheerful to being angry. The on-lookers began to throw coins at the police to symbolize the payoffs that gay bars were expected to make to the police to stay in business at the time. Coin throwing turned into throwing bottles and stones. Riot-control police officers were alerted to break up the demonstration, but it
went well into the night before the crowd could be controlled. For the next week, demonstrators continued to riot and protest for gay and lesbian rights each night (Matzner, 2004).

Shortly after Stonewall, the Gay Liberation Front was formed as a politically focused organization. Other groups were created and gay and lesbian publications increased dramatically; although groups existed prior to Stonewall, they did not have as dramatic an effect. Beginning in 1970, the gay pride marches were held every year on the date of the Stonewall riots. Stonewall Inn is now a national historic landmark. Stonewall means different things to different people, but the GLBT community agrees that it played an influential role in the Gay Pride Movement (Matzner, 2004).

Both homophobia and heterosexism are cultivated by society through media and government regulations. GLBT persons continually surrounded by these attitudes may internalize stereotypes and develop low self-esteem and self-hatred. They may live closeted lives in order to avoid harassment and discrimination. The fear of lifelong stigma can lead to depression, chronic stress, anxiety, and other mental health issues for GLBT persons (Evans, 1991). Research has shown that the fear of discrimination keeps many GLBT persons away from the health care system. Studies illustrate that 45% of lesbian and bisexual women and 44% of gay men have not disclosed their sexuality to their physicians (GLBT, 1999). In order to minimize underutilization of essential health care services, providers must make their settings safe, welcoming places if all men and women are expected to make truthful disclosures about their health and sexual histories (Gay, 2006). A health care provider may need to inquire about a patient’s sexual orientation to identify risk factors. Information recorded in the medical record could be used out of context to stigmatize the patient. The provider should obtain permission from the client to include information in the medical record on her sexual orientation.

The GLBT community’s fear of harassment is not irrational. According to the U.S. Department of Justice (2008), 1,460 hate crime offenses based on sexual orientation occurred in 2007. These hate crimes made up 15.9% of the total hate crimes in the United States in 2007. The Matthew Shepard and James Byrd Jr. Hate Crimes Prevention Act was signed into law October 2009, attached to the 2010 Department of Defense Appropriations Bill (H.R. 3326). This bill was named after Matthew Shepard, a gay Wyoming college student who was kidnapped, tortured and killed in 1998, and James Byrd Jr., a gay Black man who was chained to a pick up truck and dragged to his death the same year. The legislation expands on hate crimes federal laws to prosecute acts of bias-motivated violence against Americans due to gender, sexual orientation, gender identity or disability. (H.R. 1913–111th Congress: Local Law Enforcement Hate Crimes Prevention Act of 2009. (2009). In GovTrack.us (database of federal legislation). Retrieved March 1, 2010, from http://www.govtrack.us/congress/bill.xpd?bill=h111-1913)

Some families may be even less accepting than the general public. When coming out to a family member or close friend, GLBT persons often take the risk of losing or damaging relationships. Extent of acceptance of others can depend on a person’s culture or religious beliefs (Gilbert, 2003). Family members and friends often respond in a variety of heterosexist ways. They could be in denial or insist that the person was just “going through a phase.” Sometimes the family might even try to “cure” the person or encourage them to be more heterosexual. Certain families will disown their relatives because they are angry that the person has rejected their family’s values. Other families simply feel depression, guilt, and grief for the person who has lost their expected heterosexual lifestyle (Szymanski, 2008). In a 2000 survey, 34% of respondents stated that at least one member of their family had refused to accept them due to their sexual orientation. Many people feel the need to hide their sexual orientation from their relatives rather risk rejection (Herek, 2006). Due to these reactions, GLBT persons often have nontraditional systems of support created in place of or in addition to their biological families. These support systems are commonly made up of other GLBT persons in their community or close friends who understand and recognize their life choices (deVries, 2009). Reactions like these can negatively impact future family relationships.

The Genetic Counseling Session

An initial step for effectively counseling a GLBT person is to become aware of your own perspectives. The American Psychological Association Guidelines (2000) encourage psychologists to acknowledge their opinions and understanding of gay, lesbian, and bisexual issues. Similarly, each genetic counselor
needs to be aware of his or her limitations and how they might affect individual clients positively or negatively. Some may have conscious objections to homosexuality while others have more unconscious aversions (e.g., always assuming that people are heterosexual). Others are completely aware of and open to people of different sexual orientations. It is important to be continually self aware of your beliefs, and to challenge yourself, your biases, and your limitations in working with GLBT clients (Szymanski, 2008). It is essential to respect the client’s choices, despite your own personal feelings.

Using culturally appropriate language is critical to developing trust between a client and a genetic counselor. Counselors need to make language inclusive, avoiding terms that assume heterosexuality. When interviewing clients for intake information, a genetic counselor should always ask questions such as “Do you have a partner?” rather than “Are you married?”. It is also important not to assume that previous partners have been of the same gender as a current partner (Szymanski, 2008). During a counseling session, take note of the language the client uses. For example, listen whether the client mentions a partner versus a spouse or a partnership versus a marriage, or two mothers instead of a mother and a father, or other variations on parenting and family relationships. Whenever possible, the genetic counselor should use the basic interviewing technique of promoting shared language by mirroring the client’s language (Baker, 1998).

Given the lack of acceptance individuals may have experienced from their families and others, genetic counselors can serve as a role model by expressing acceptance of our clients within the counseling session. For example:

Brittany (Genetic Counselor): “Do you have a partner?”

Lisa: “Yes, I do. Jamie and I have been together for five years and we are so excited about becoming pregnant!”

Brittany: “Congratulations! It’s wonderful to see your enthusiasm for becoming parents! Let’s talk about your family and this current pregnancy.”

This is a liberal response that can lead to more discussion of the client’s sexual orientation, only if is the wish of the client. The liberal response includes the necessary element of being open to the client’s sexuality. Lisa is seeking information about advanced maternal age, but her case is unique and individual approaches are needed in order to provide effective client-centered genetic counseling. As with any genetic counseling session, let your client set the agenda. The genetic counselor wants to keep the focus on the reason for referral without ignoring cues from the client.

Culturally inclusive language should be used in both written and oral communications with the client. When a client first arrives for an appointment, an intake form is completed by the client in the waiting room or during the appointment as part of the client interview process. The intake form is a crucial communication tool, and it may determine the client’s first impression of your office. Reviewing and completing this form can ease the client’s concerns about the reason for referral or it may exacerbate her worries (Gay, 2006). The intake form should be free of heterosexual bias and use neutral language (Sue & Sue, 2003). One of the first details asked on an intake form is typically regarding the client’s gender. In order to be inclusive of all people, we recommend that the options include: Female, Male, Transgender, and Intersex (Gay, 2006). Instead of questioning someone’s marital status, the intake form should inquire about relationship status. The suggested options are: Single, Married, Domestic Partnership/Civil Union, Separated from Spouse/Partner, and Divorced or Permanently Separated from Spouse/Partner (Gay, 2006). Some institutions include sexual orientation on the intake form. The development and use of intake forms that are culturally inclusive sends the message to clients that your center will respect and accept everyone (GLBT, 1999). Changes in office procedures may take some time to implement, but when interviewing and counseling the client, the genetic counselor should always use inclusive language.

Pedigrees and Genograms

In 1995, the Pedigree Standardization Task Force of the National Society of Genetic Counselors proposed a system of pedigree nomenclature (Bennett, Doyle, French, & Resta, 2008). In 2008, Bennett
et al. assessed those recommendations to ensure that they were meeting the current needs of health professionals. The thirteen year time lapse between the initial article and this review brought about a few changes pertaining to the GLBT community specifically. A diamond is now being used to represent transgender persons as well as persons who do not specify a gender and those who have congenital disorders of sex development. Bennett et al. also depicted the current nomenclature and symbols for assisted reproductive technology pregnancies. The same sex relationship can be noted in the pedigree, by using two female symbols joined with a relationship line.

In our case, the genetic counselor's family history intake protocol should include eliciting information on both members of the couple, Lisa and Jamie, as well as inquiring about the health and family history of the sperm donor. The genetic counselor demonstrates respect for the couple's relationship by asking about Jamie's previous relationships and whether she had any pregnancies or children (step-siblings to Lisa and Jamie's current pregnancy). The pedigree is created based on biological relationships, but when drawing the pedigree, the genetic counselor should also use the conversation with the couple as an opportunity to identify family dynamics (Hampel et al., 2009).

Family is not a standard term with a uniform definition that is agreed upon by all. It is helpful to ask every client which people he or she considers to be family. These people may be an essential part of the client's life during his or her pregnancy, testing, diagnosis, or treatment. Further documentation of family dynamics can be made by creating a genogram. Many family therapists, family physicians, and other healthcare providers regularly use genograms. While genograms are similar to pedigrees in that they include biological relatives, they also include information about the sociocultural context of relationships (Estrada & Haney, 1998). Genograms cover at least three generations and have been used to clarify family patterns and roles, to engage the family in a session, to change the focus on certain issues, and to connect families to their history of spirituality, immigration, education or other factors under discussion. Genograms span three time perspectives—past, present, and future—which can help clients draw on previously unnoticed strengths in relationships, realize differences in previous generations, and consider current accomplishments (Kuhl, Barnard, & Nelson, 1998). Genograms can identify relationships with immediate family, coworkers, acquaintances, partners, and friends (Gerson, McGoldrick, & Petry, 2008). Genograms can cover marriage and divorce patterns, extramarital relationships, infertility and adoption, health and illness, self-esteem, birth order, and addictions (DeMaria, Hof, & Weeks, 1999). They are useful because they are clear illustrations of complex family patterns. Genograms portray the family's relationships and functioning in a format that is much easier to understand than reading notes in a chart (Gerson et al., 2008).

A genogram can focus on various themes. Cultural and sexual genograms are two important types. Technically, genograms should always include information about a client's cultural background, as it affects his or her daily behaviors; however, a basic genogram does not usually provide extensive details (Gerson et al., 2008). A person may belong to a culture by birth, marriage, or choice and these experiences shape a person's beliefs and attitudes about life. All of these aspects can be included in a genogram to fully understand the client's history (DeMaria et al., 1999). Cultural genograms can include information such as race, ethnicity, immigration, religion, and social class. Sexuality is also a factor in cultural genograms because it is viewed differently by various cultures. Sexual development can be influenced by family messages and behaviors, evolving throughout life based on experiences.

Similar to the standardization of human pedigree nomenclature, there are standard symbols for genograms (p. 136, Miller et al., 2006). Examples of genograms and common notations/symbols are noted below.
The following is an example of a pedigree/genogram composite including family communication patterns.
Brad and Jake are seen in genetics clinic regarding their daughter, Kim. She is currently 4 years old and has documented developmental delays in speech and language. Kim was referred for a genetics consultation due to dysmorphic features identified by a developmental pediatrician.

Brad and Jake have been married for five years. Their family consists of two children, Kim and Sam. Their four year old daughter, Kim, was adopted from China one year ago. Kim has two sisters who were placed in adoption and a brother, who lives with the parents in China. One of Kim’s sisters has no contact with her biological family. The second sister was reportedly abused and neglected while under the biological family’s care. The children are not known to have birth defects or health concerns.

For their second child, Jake and Brad used in vitro fertilization. Jake’s sister agreed to be the ovum donor, and Brad’s sperm was used to conceive Sam, who is now two years old. Both Brad and Jake’s parents are alive and well. Brad’s family is from Ireland. Jake’s family is from France. There is no known consanguinity.

While providing information for the pedigree, Brad and Jake revealed that Kim had been neglected and possibly abused while in China. They wonder if this oppressive early family environment contributed to Kim’s current developmental delays. The couple also revealed that Jake’s sister Jennifer did not approve of the surrogacy arrangement, creating hostility in the sibship.

Summary: Pedigree and Family History

Current genetic counseling job tasks were determined by the American Board of Genetic Counseling as the outcome of a Genetic Counseling Practice Analysis (Hampel et al., 2009). The following lists the Pedigree and Family History tasks:

1. Tailor questioning for the individual case
2. Elicit history
3. Facilitate recall (e.g., symptoms, diagnoses, treatments)
4. Document ethnicity and consanguinity
5. Construct a complete pedigree using standardized pedigree nomenclature
6. Identify the following:
   a. family dynamics
   b. emotional responses
c. diagnoses requiring confirmation.

This case discusses the dynamics of taking a family history and drawing the pedigree for a lesbian couple in prenatal genetic counseling. Genetic counselors on the pathway to increasing their cultural competence should first engage in self-assessment on the GLBT continuum. We suggested two self-assessment measures. These self-awareness activities help a genetic counselor honestly evaluate his/her willingness and ability to work effectively with a lesbian couple, or with other clients whose sexual orientation is not heterosexual. If the counselor is not where he/she wants to be, he/she might consider talking to other counselors in peer supervisory venues, engaging in cultural immersion activities, or learning more about this culture by reviewing the suggested resources.

When meeting with a lesbian couple, the genetic counselor should only ask questions that will be directly relevant to the session. By using open-ended questions, the counselor allows clients opportunities to respond in ways that are most comfortable and salient to their particular situation. Because genetic counselors frequently discuss reproductive and relationship issues with their clients, they need to be comfortable assessing clients’ past experiences related to their sexual orientation and current sexual identity. The genetic counselor should use the pedigree taking activity to promote trust and understand the clients’ definition of family. The couple’s current and past relationships should be acknowledged by using the appropriate pedigree nomenclature in an atmosphere that conveys openness to client’s personal preferences and decisions. It is important to assure genetic counseling clients about the confidentiality of the session.

Genetic counselors’ standard of practice is to take detailed family history information and draw pedigrees on all clients. The time and resources available to enter family history data is already a documented concern for primary care providers (Scheuner, 2009). With our experience, we have the opportunity to demonstrate to other healthcare professionals the details and complexities of this task. Standards of pedigree nomenclature are changing over time due to new reproductive technologies and choices and social and legal factors. The imminent emergence of electronic medical records as the universal standard for medical documentation in U.S. health care settings challenges genetic counselors to develop streamlined family history intake and pedigree drawing methods (Bennett, 2008). In addition, we suggest that genetic counselors should not overlook tools used in other professions to document family dynamics and emotional responses, such as genograms. Genograms may be a useful working tool for exploring biological, sexual and cultural issues in genetic counseling. However, it is important for the genetic counselor to obtain explicit permission for all personal and relationship information included in the medical record. The culturally competent genetic counselor is able to confidently anticipate and accommodate all variations and complexities of sexual orientation and family structure. According to Epstein (2008), parents and prospective parents in LGBTQ communities want health professionals to take on a positive demeanor when helping them to build and nurture their family. This positive attitude "requires a deep level of knowledge translated into behaviors and practices that recognize and acknowledge the histories, cultures and values of LGBTQ communities. This is what is sometimes referred to as ‘cultural competency’".

Cultural Competence

- Self-assess your views on the gay, lesbian, bisexual and transgender continuum.
- Engage in advocacy to eliminate homophobia and other forms of prejudice.
- Use neutral and inclusive language (in intake forms and verbal discourse) that does not imply bias of universal heterosexuality. Review and modify clinical forms as needed.
- Listen to the words used by clients to describe their relationships.
- Use questions such as “what is your relationship to...?” to gain clarity about everyone attending the genetic counseling appointment.
• Let the client set the agenda. Unless expressed by the client, discussion of sexual orientation may, or may not be, a relevant topic to the genetic counseling session.

• It may be appropriate to elicit the family history for both members of the lesbian couple, and the sperm donor. Explore the couple's past relationships and offspring.

• Explore the meaning of family with your clients.

• Be able to draw a pedigree for all clients using standardized pedigree nomenclature, Keep a copy of the guidelines handy in case you need to refer to it.

• Integrate assessment and documentation tools developed by other fields, such as genograms, to enhance genetic counseling practice.

References


Resources

Healthcare Needs

http://www.glma.org
The Gay & Lesbian Medical Association (GLMA) has been working to bring about equality in healthcare for GLBT people since 1981. This website educates patients and providers about the healthcare needs of GLBT patients. Resources for patients and their providers are available.

The Healthcare Equality Index aspires to educate healthcare policymakers to eliminate barriers that keep GLBT persons from receiving adequate care.

Laws and Regulations

http://www.hrc.org/laws_and_elections/state.asp?state=&btnG.x=9&btnG.y=4
The Human Rights Campaign offers descriptions of all laws regarding GLBT issues by state.

http://www.glad.org
Gay and Lesbian Advocates and Defenders (GLAD) has been advocating for equal justice for GLBT persons regarding sexual orientation, gender identity and expression, and HIV status since 1978. Their website discusses current projects, recent achievements and current laws regarding GLBT persons in the United States. Resources regarding the rights of GLBT persons in specific states are provided.

http://www.aclu.org/lgbt
The American Civil Liberties Union (ACLU) works with legislatures and communities to protect the individual rights that the Constitution guarantees all Americans. The ACLU strives to extend these rights to those who have been denied including but not limited to sexual minorities, racial minorities, people with disabilities and prisoners. This website includes lesbian and gay rights publications, legal and legislative documents, various resources and fact sheets, as well as current and past court cases regarding gay and lesbian rights.

http://www.transgenderlaw.org
The Transgender Law and Policy Institute (TLPI) works with advocates to create laws that support transgender equality.

Fact Sheets and Additional Resources


http://www.lgbthealth.net
The National Coalition for Lesbian, Gay, Bisexual, and Transgender Health works to increase the quality of health services for GLBT persons, to increase the cultural competency of health providers, and to reduce disparities due to community and government policies. Their website provides GLBT health updates, information on their goals and progress towards improving GLBT health, as well as additional resources to learn more about GLBT health. These resources include information on Academic Journals, City Commissions/Departments of Health, Gay and Lesbian Health Centers, HIV/AIDS Agencies & Organizations, National Organizations, Trans Health Organizations, Bisexual Organizations, Lesbian Health Organizations, Aging Organizations, and more.

http://www.gaydata.org
Created for individuals and organizations who want to find scientific information about GLBT persons.
http://www.sart.org
This website created by The Society for Assisted Reproductive Technology (SART) helps patients find and contact infertility clinics and view IVF success rates. Includes fact sheets and step by step guides.

http://www.algbtic.org/index.htm
The Association for Lesbian, Gay, Bisexual and Transgender Issues works for the improvement of counseling services to GLBT patients, the increase of awareness of GLBT issues, and the implementation of equal treatment for GLBT persons. This website includes numerous resources useful to GLBT persons, providers, and the general public.

http://www.hrc.org
The Human Rights Campaign has been continually working for GLBT rights since 1980. Their website provides information about the issues, laws and elections, how to get involved and events going on in your community.

Counseling and Cultural Competency

http://apastyle.apa.org/sexuality.html
This website lists the problems with current terminology regarding GLBT persons and suggests the appropriate language for use in counseling.

http://www.genopro.com
See this website for more information on creating pedigree and genogram composites.

Videos and Books

A primer on pedigree drawing and interpretation for genetic counselors and other health professionals.

Story of Chastity Bono’s, identity development as a lesbian, and daughter of superstars Sony and Cher Bono. The book provides helpful insights into issues related to coming out, and dealing with the negative and positive perceptions of family members and others.

Popular movie about Harvey Milk, the first openly gay man elected to public office in the U.S. The movie uses actual footage documenting the prevalence and impact of rampant homophobia in the 1970’s on Harvey Milk’s failures and successes running for a position on the San Francisco Board of Supervisors.

“Cultural Issues in the Clinical Setting” is a collection of scenarios depicting common problems that arise in the clinical setting dealing with the clashing of different cultures, communication barriers, and misconceptions of ideas and beliefs. Along with the videos is a facilitator’s guide that is designed to raise discussion and understanding of each issue. There are two scenarios depicting gay and lesbian patients that are excellent resources.

Cultural Immersion Activities

The National Coalition for LGBT Health
http://www.lgbthealth.net
This organization works to improve the health of GLBT persons through education, advocacy, research, and community building. They need volunteers to work in groups to plan their Awareness Week, annual meetings, and assist with legislative priorities. Being a part of these working groups will increase your
knowledge and experience with GLBT persons. They also host an annual meeting to network with other persons who are curious about GLBT health and to discuss advocacy opportunities. Their website allows you to sign up for a bi-monthly email updated regarding research, legislative decisions, and new ways to be involved.

The Gay and Lesbian Medical Association
http://www.glma.org
The Gay Lesbian Medical Association also holds an annual conference that nonmembers can attend. This conference is the world’s largest gathering of GLBT healthcare professionals and offers presentations and workshops discussing substance abuse, GLBT health, aging, HIV/AIDS, intersex health, legal issues, and family and relationships.

The International Association of Lesbian, Gay, Bisexual, Transgender and Intersex Pride Coordinators
http://www.interpride.org
If you can’t afford to travel to a national conference, you can find events in your own area. This website lists all upcoming events throughout the U.S.

Gay and Lesbian Pride Month
The month of June is Gay and Lesbian Pride Month, and many cities hold parades and/or festivals; be on the lookout for events in your area during this time. If you are looking for an event that is not in June, conduct a simple search online using keywords such as the name of your city along with “gay and lesbian events.”
Assessment and Evaluation Questions

Pedigree and Family History: Genetic Counseling a Lesbian Couple

1. True/False
   Sexual identity is a preference, not an orientation.

2. True/False
   Same-sex attraction occurs in humans, across all cultures, educational levels, career paths, socioeconomic levels, religions, and personalities.

3. True/False
   Partners in a civil union have the same rights as married couples.

4. True/False
   Sexual orientation is simple; a person is either homosexual or heterosexual.

5. True/False
   When considering McAuliffe’s continuum, a genetic counselor should “admire” or “appreciate” homosexuality in order to provide effective genetic counseling to a lesbian couple.

6. True/False
   When appropriate, the genetic counselor should mirror the client’s language regarding his or her sexuality.

7. True/False
   A lesbian or gay person’s family may include biological relatives, friends, members of the GLBT community, adopted children, and surrogate mothers.

8. True/False
   In 1995, the Pedigree Standardization Task Force of the National Society of Genetic Counselors proposed the entire set of pedigree nomenclature genetic counselors will need when working with families.

9. True/False
   Features of genograms may be of some use in genetic counseling sessions for documenting family communication patterns or social relationships.

10. True/False
    Studies illustrate that almost ½ of lesbian and bisexual women and 44% of gay men have not disclosed their sexuality to their physicians.

The following questions are for CEU learners only:

1. I feel I have achieved the following objective as a result of this learning activity:
Acknowledge personal perspectives to Gay, Lesbian, Bisexual or Transgender (GLBT) persons.

4= Great extent   3= Moderate extent   2= Slight extent   1= Not at all

2. I feel I have achieved the following objective as a result of this learning activity:

Discuss the emotional, psychological, and legal barriers facing GLBT clients.

4= Great extent   3= Moderate extent   2= Slight extent   1= Not at all

3. I feel I have achieved the following objective as a result of this learning activity:

Use culturally appropriate language when counseling GLBT persons.

4= Great extent   3= Moderate extent   2= Slight extent   1= Not at all

4. Please rate the overall effectiveness of this case in promoting learning.

4= Great extent   3= Moderate extent   2= Slight extent   1= Not at all

5. Please rate the overall quality of this case.

4= Great extent   3= Moderate extent   2= Slight extent   1= Not at all

6. The content of this case was presented without bias of any commercial drug or product.

4= Great extent   3= Moderate extent   2= Slight extent   1= Not at all

7. The technology used was appropriate and effective.

4= Great extent   3= Moderate extent   2= Slight extent   1= Not at all

Disclaimer

The purpose of the Genetic Counseling Cultural Competence Toolkit (GCCCT) is to improve the delivery of culturally responsive, client-centered genetic counseling to diverse populations and to reduce health disparities. The GCCCT is an educational resource; any suggestions do not define the standards of clinical or educational practice. All cases and scenarios are hypothetical. The JEMF, NSGC and Nancy Steinberg Warren, MS, CGC will not be liable for any medical or psychosocial applications connected with the use of or reliance upon any information obtained from this website or associated links and resources.

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