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PROFESSIONAL ISSUES

Exploring Adoption with Clients: The Need for Adoption Education Within the Genetic Counseling Profession

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Abstract Genetic counselors and other health professionals may encounter adoption during any counseling session. They must be skilled in using appropriate language and understand how to approach and discuss this topic with clients. A thorough knowledge of adoption as an option for clients facing a prenatal or postnatal diagnosis is necessary when presenting individuals with non-biased information needed for informed decision-making. However, three preliminary studies have demonstrated an absence of graduate education and lack of a professional knowledge base regarding this option (Mates 2008; Oksala 2007; Perry 2003). We discuss the impact of medical professionals' preconceptions on client decision-making, increasing early identification of fetal anomalies, deficiency of adoption knowledge and resources, and the resulting need for genetic counselors and other health professionals to develop their skills in discussing adoption with clients.

Keywords Adoption · Prenatal diagnosis · Prenatal testing · Prenatal screening · Fetal anomaly · Informed decision-making · Pregnancy options · Professional education · Graduate education · Special needs adoption

Introduction

The genetic counseling field is grounded in distinct knowledge and skilled communication, as the professionals who work within this field have an immense responsibility not only to provide their clients with accurate genetic information and support, but also to present all options in a clear, concise, nondirective manner (Marteau and Dormandy 2001). These responsibilities are intended to help clients reach a decision that is in line with their personal beliefs, abilities, and circumstances. The breadth of these responsibilities is great, as genetic counselors must possess a thorough familiarity with genetics and the biological sciences, disability management, and counseling skills to discuss sensitive situations and life-impacting options. Because a fundamental goal of genetic counseling is to aid clients in making the most appropriate decision, a deficiency of knowledge in addressing clients' needs and/or in the information presented could ultimately result in a disservice.

One area of knowledge with which genetic counselors must be familiar is that of adoption. The intersection of genetic counseling and adoption may occur while discussing a medical history, family pedigree, carrier status, or infertility. However, in our experience, we have found that adoption most commonly is discussed after a prenatal or postnatal diagnosis. Counseling clients in these situations requires knowledge about the options of parenting a child with special needs, making an adoption plan, and termination of the pregnancy for cases of prenatal diagnosis or identified fetal anomaly. In order to facilitate an informed decision, genetic counselors should provide clients in these situations with sufficient accurate information regarding every option. Nevertheless, the results of three preliminary studies (Mates 2008; Oksala 2007; Perry 2003) suggest that professional knowledge surrounding adoption wanes in comparison to the options of parenting a child with special needs and pregnancy termination.

Health professionals commonly report that adoption is a decision few clients pursue, even when this option is presented (Oksala 2007). Nevertheless, it is a relevant option and should be accurately discussed as such for a

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pregnancy or for fulfilling parenthood; however, there appears to be a lack of formal adoption education for health professionals such as genetic counselors (Mates 2008; Oksala 2007; Perry 2003). Thus, while genetic counseling sessions may include the topic of adoption, without formal training about accurate and sensitive language and general adoption facts and processes, it likely is difficult for counselors to adequately discuss this option with clients, let alone dispel common myths and misconceptions held by the general public. For instance, many believe that birth parents who make an adoption plan will know nothing about their birth child or the child's adoptive parents in the years that follow, or that birth parents who choose adoption are typically adolescents. In fact, younger individuals often decide to parent while those who consider and choose adoption are characteristically over the age of 18 (National Committee for Adoption 1985). In addition, birth parents are typically able to participate in selecting adoptive parents, and can also choose the level of contact and amount of information shared with the child and adoptive family in the years that follow (Henry and Pollack 2009). Thus, those clients who immediately refuse adoption may be basing their decision upon an erroneous perception about the option. It is our position that genetic counselors and other health professionals cannot be expected to accurately assess clients' knowledge and educate them about a topic on which they themselves have received insufficient education. In other words, health professionals would have difficulty educating about which they have limited knowledge.

Whether clients make a fully informed decision to decline adoption, or whether this option is typically rejected due to receiving deficient or inaccurate information or because the client's misperceptions are not explored, remains to be empirically determined. Regardless, clients have a right to receive relevant information about all possible options in order to make a truly informed decision. Therefore, we advocate for the development of educational opportunities regarding adoption for genetic counselors in order to increase their skills in counseling clients facing a prenatal or postnatal diagnosis. In the following sections of this paper, we discuss the prevalence of adoption in the field of genetic counseling, the influence of medical professionals, the need for adoption education, and the lack of resources in existence for expectant parents. We conclude by providing recommendations for increasing adoption knowledge among genetic counselors and students in order that they may be able to adequately discuss this option with clients.

Adoption in the Field of Genetic Counseling

Approximately three out of five Americans have a personal connection to adoption, meaning that they or someone they know was adopted, adopted a child, or made an adoption plan for a birth child (Evan B. Donaldson Adoption Institute 1997). Given its widespread nature, adoption is a fairly prevalent topic in genetic counseling sessions. For instance, counselors may have clients who were adopted, possibly complicating the process of family history intake if limited birth family information is known. An adoption in the family pedigree may also bring the topic of adoption into a genetic counseling session, or the client or a family member may have previously made an adoption plan for a birth child.

Even more commonly, genetic counselors will encounter adoption during prenatal or pediatric counseling sessions. A client's inability to naturally conceive or birth a child, possibly as a result of a genetic condition or health risk, may lead to a discussion of alternative family planning options, which should include adoption. Furthermore, adoption may be a particularly fitting option in situations in which an individual or couple wishes to create or expand a family but does not desire to risk the chance that a future child will inherit a specific genetically-linked condition. People in these situations may wish to explore alternative options for building families. In addition, adoption may be a viable option for clients who experience a pregnancy in which a fetal anomaly has been identified or suspected, or who give birth to a child with a disability. Genetic counselors must be prepared to equally offer this option along with termination and parenting. In these cases, the ultimate goal is to provide expectant and new parents with accurate information, resources, and referrals in order to allow for informed decision-making.

Options Following a Fetal Diagnosis

A diagnosis or an anomaly identified in a pregnancy or at the time of birth carries life-altering implications for individuals and families, leading to a vast array of resulting emotions such as fear, anxiety, depression, shock, and distress (Cristofalo et al. 2006; Kowalcek et al. 2003; Susanne et al. 2006). The mechanisms they use to cope during this experience may vary greatly. However, it has been suggested that a thorough knowledge of one's options, when combined with accurate resources, can lessen an individual's sense of helplessness (Kaunitz et al. 1987), and a common coping strategy in difficult situations consists of information-gathering (Garvin and Kim 2000). The importance of providing as much accurate information as possible at the time of diagnosis has been emphasized as one strategy to enable expectant parents to consider all options and make an informed decision (Carroll et al. 2000; Lalor et al. 2007; Schuth et al. 1994). This strategy has been supported by numerous studies researching earlier detection of congenital disorders (e.g., Canick et al. 2006; Saltvedt et al. 2006). As one may suspect, it is assumed that better client outcomes result from an informed choice rather than from an uninformed one (Kenen 1996; Marteau and Dormandy 2001).

Recent shifts in societal trends and the declining stigma regarding single parenthood could be credited for the vast increase in public knowledge regarding pregnancy termination and parenting a child. As a result of formal education, professional training, and internet accessibility, information regarding legal statutes, resources, and referrals is readily available to health professionals when discussing the options of termination and parenting with expectant clients. While sources diverge over the exact percentage of terminations that result after a prenatal diagnosis, most suggest that a large majority of individuals who choose to undergo prenatal testing and who face a prenatal diagnosis of Down syndrome choose to terminate their pregnancies (Cragan and Khoury 2000; Mansfield et al. 1999). Thus, it can be assumed that this option is consistently explored with clients (Oksala 2007). Although studies have yielded contradictory findings, they have succeeded in identifying variables that seemingly are associated with the decision to terminate. These variables include background characteristics of the individual or couple, the test used to determine the diagnosis and the certainty of this diagnosis, and fetal gestational age at diagnosis (Sandelowski and Jones 1996). One study concluded that expectant individuals characteristically choose pregnancy termination when a chromosome abnormality is diagnosed in the first trimester (Verp et al. 1988). Additionally, Sandelowski and Jones (1996) cited the excessive financial demands of parenting a child with special needs as another reason for an individual's decision to terminate. Above all, however, the nature and prognostic severity of the diagnosis appear to be most highly associated with the decision to terminate a pregnancy (Pryde et al. 1992).

We have previously speculated (Perry and Henry 2009) that as a likely result of common misconceptions, preconceived notions, and limited education, resources, and referrals accessible to health professionals regarding adoption, this option is often not discussed in great detail, if at all, with clients. Nevertheless, adoption may be an appropriate option for many individuals and couples who do not feel prepared or able to parent a child with special needs, but for whom termination may not be a viable option. Skotko (2005b) found that the decision not to terminate a pregnancy may first be influenced by a mother's conscience, followed by religion and the opinion of her partner. In addition, severity of the disability, coping capacity of the expectant parent(s), and the value placed upon the life of the fetus are also linked with continuation of the pregnancy (Chaplin et al. 2005), as are uncertainty surrounding the diagnosis, a favorable prognosis, or the possibility of intrauterine or neonatal therapy (Pryde et al. 1992; Sandelowski and Jones 1996). A client's perception of the pregnancy and connection to a human life, however, either through feeling fetal movement or as a result of ultrasound examination, could also serve as influences during the decision-making process (Van der Zalm and Byrne 2006). While ultrasound imaging greatly increases medical capacity to detect fetal anomalies, studies have demonstrated that women often identify the fetus as a "baby" following ultrasound examination (Kowalcek et al. 2003; Van der Zalm and Byrne 2006). Considering these potential influences and the fact that most individuals will undergo ultrasound to detect anomalies prior to making a pregnancy decision, it is possible that pregnancy termination may not be an option for some expectant parents, despite their feeling unprepared to parent a child with special needs.

The Rising Trend of Fetal Anomalies

Three percent of pregnancies in the United States every year result in the birth of a child with significant birth defects (Centers for Disease Control and Prevention [CDC] 2007); however, we have previously hypothesized that a rising trend in this number may soon be noted as a result of current societal practices (Perry and Henry 2009). Specifically, women are placing greater emphasis on education and career establishment before having children, resulting in a notable rise in maternal age at conception. The mean maternal age at first birth has risen to over 25 years in 2005 from approximately 21 years in 1970 (Martin et al. 2007; Mathews and Hamilton 2002), a direct result of a growing number of women conceiving after the age of 30. In fact, the number of births for women over 30 years old continues to steadily rise each year (Martin et al. 2007). Even more noteworthy, however, is the rate at which these numbers are increasing. The number of births to women between the ages of 35 and 39 years [the age range at which counseling for advanced maternal age (AMA) begins], increased 52% between 1990 and 2005 (Martin et al. 2007). The escalating risk of fetal chromosome abnormalities as maternal age progresses implies that greater numbers of women and their families may be faced with a pregnancy in which a fetal anomaly is diagnosed, resulting in an increase in the number of cases for which genetic counselors may be consulted for potential pregnancy options (Perry and Henry 2009).

Further, assisted reproductive technologies have recently been linked to a possible increase in the occurrence of some congenital abnormalities (Reefhuis et al. 2008). In a systematic review of 25 studies, two-thirds of these studies demonstrated an increased risk of birth defects of at least 25% in infants conceived with assisted reproductive technologies (ART) (Hansen et al. 2005); however, despite this heightened risk, births resulting from ART treatment in the United States nearly tripled between the years of 1996 and 2005 (CDC, American Society for Reproductive

Medicine, and Society for Assisted Reproductive Technology 2007). Thus, the mounting use of reproductive technology as a means to conceive may ultimately result in an increase in the number of identified fetal anomalies. Despite feelings of anxiety and grief after a fetal diagnosis, it is possible that individuals and couples who have undergone reproductive treatments may not wish to terminate a pregnancy they have struggled to conceive; however, they may feel overwhelmed with the idea of parenting a child(ren) with special needs.

Finally, advancements in the accessibility and accuracy of prenatal diagnostic and screening techniques such as ultrasound, maternal serum screening, chorionic villus sampling, and amniocentesis have resulted in an increased ability to detect many genetic and congenital anomalies earlier in gestation (Strauss 2002). The ever-continuing development of new technology ultimately results in escalating numbers of expectant parents faced with the decision to terminate or continue the pregnancy (McCoyd 2007). These advancements, in combination with the expected rise in fetal anomalies, require genetic counselors and other health professionals to be prepared to discuss adoption as a possible option for pregnancies with a suspected or identified congenital disorder.

The Prenatally and Postnatally Diagnosed Conditions Awareness Act

Congressional bill *S.1810*: *The Prenatally and Postnatally Diagnosed Conditions Awareness Act*, signed into action as Public Law No: 110-374 on October 8, 2008, further speaks to the continuing movement for health professionals to be familiar with all options associated with a prenatal or postnatal diagnosis. This bill was a response to escalating concern about the high rate of pregnancy terminations resulting after a prenatal diagnosis (Brownback 2008). Members of various disability communities stress the benefits that individuals with disabilities provide to society (Reilly 2009). They contend that with the increased number of terminations, the population will have fewer individuals with specific conditions, leading to decreased research into these conditions and into bettering the lives of those who are affected (Harmon 2007).

This act addresses the educational deficiency of health professionals by calling for increased training in presenting accurate and thorough scientific and support service information to clients receiving any prenatal or postnatal diagnosis. Further, it requires the establishment of a national registry of families who wish to adopt an infant with a diagnosed condition, recognizing that this option is not routinely discussed with individuals and that health professionals are unaware of the number of families waiting to adopt children with disabilities.

Role of Health Professionals and the Need for Professional Education

Influence of Medical Personnel

Genetic counselors, obstetricians, maternal-fetal medicine sub-specialists, midwives and health center social workers have the responsibility to remain unbiased and nondirective when providing information to clients (Perry and Henry 2009). Because these health professionals are often the first resources that expectant parents encounter after a fetal diagnosis, the impact that genetic counselors and other health professionals have on parental response and decision-making has been demonstrated to be so great as to potentially influence whether clients decide to terminate or to continue their pregnancy (e.g., Schuth et al. 1994). Perhaps this placement of responsibility on others for the decision to terminate is, in fact, a coping mechanism for dealing with the stress and grief associated with an emotionally difficult choice, as has been shown in some studies (e.g., Bijma et al. 2005; Sandelowski and Jones 1996). In times of uncertainty, individuals may choose to place responsibility for a decision on family members, friends, health professionals, or others to avoid the pain of bearing complete responsibility for the outcome. Regardless of the reason(s), clients often rely upon medical personnel for guidance and information regarding the possible outcome of a pregnancy, the extent of life quality the child will likely be able to experience, and the options available for the pregnancy or for the child's care.

Despite health care profession codes of ethics that articulate the necessity of presenting information in a nondirective manner, a considerable number of expectant parents have reported the professionals they encountered when faced with a prenatal diagnosis openly expressed negative views, while seemingly promoting termination of the pregnancy (Abramsky et al. 2001; Helm et al. 1998; Schuth et al. 1994; Skotko 2005a). Relatedly, some studies lend support to the notion that medical caregivers may question why expectant parents choose to undergo prenatal testing when termination is not an option for them (Hunt et al. 2005; Sandelowski and Jones 1996). Some health professionals may communicate an inability to understand the decision to continue a pregnancy in which a fetal diagnosis has been made, and reveal personal beliefs that termination is a more appropriate decision under such circumstances (Lalor et al. 2007). Additional studies even question the ability of health professionals to remain unbiased in *any* medical situation, not only those including pregnancy counseling (Williams et al. 2002). While these studies do not necessarily reflect the attitudes and practices of genetic counselors in particular, they illustrate the influence that medical professionals in general can have on client decision-making. When health professionals express personal biases and make assumptions regarding decisions that should be made, clients can be left feeling abandoned by the medical system (Lalor et al. 2007), and they may be influenced to make a decision that is not the best option for them merely because they are led to believe that it is the most widely accepted choice.

We believe that biases and assumptions regarding adoption as an option in cases of fetal anomaly may primarily stem from one question: Who would want to adopt a child with a disability? Peter and Joyce Forsythe of Ann Arbor, Michigan encountered this same question in the early 1960s (Sullivan 1996). Their desire to adopt a child who was considered "unadoptable" by agency standards was met with hesitation and questioning. The challenges faced by the Forsythes led to the establishment of the Council on Adoptable Children (COAC) whose ultimate goal was to change the definition of adoptable. In the wake of the establishment of this organization, numerous other organizations were formed to promote the adoption of children with special needs. As a result of the efforts of the COAC and other adoption organizations, today there are a significant number of families willing and waiting to specifically adopt a child with a disability. These families may feel physically, emotionally, or financially better prepared to parent a child with special needs for countless reasons. Some may have another child with a disability; others may have work experience or personal experience with individuals who have special needs. Regardless of the reasons behind the families' willingness to adopt these children, research has shown that adoptive families may not experience the severe initial reactions of shock, denial, despair, and depression that birth parents often do in parenting a child with a disability (Glidden 1990). These findings are thought to stem from the fact that adoptive parents make the choice to parent children with special needs and can determine the extent to which they feel able to care for a child with a particular disability. Adoptive parents also have time, typically, to prepare for the child's arrival and health needs, while birth parents may not have this opportunity. As a result, the Child Welfare League of America (CWLA) maintains that regardless of how serious children's needs are, families will nearly always come forward to care for them (Sullivan 1996).

Deficiency of Professional Adoption Knowledge and Graduate Education

An unpublished study conducted in 2003 (Perry) revealed that many genetic counselors, upon questioning, reported feeling unprepared to equally offer the option of adoption in addition to those of pregnancy termination and parenting a child with special needs to clients facing a pregnancy in which a fetal anomaly has been identified. They were not aware of current adoption practices and laws, and they were unsure of where to locate additional resources and referrals. In fact, many health professionals are not even aware that families are currently waiting to adopt infants with certain disabilities (Lindh et al. 2007). In one study, Lindh and colleagues (2007) found that 88% of those families waiting to adopt a child with Down syndrome agreed that health professionals must be informed about the availability of such families and individuals. Henry and colleagues (2006) have found that undergraduate and graduate medical education across the United States typically excludes adoption education, particularly regarding special needs adoptions. Mates (2008), in an unpublished master's thesis, questioned genetic counseling graduate programs across the United States. She similarly found that adoption education generally received less emphasis than education surrounding parenting a child with special needs and pregnancy termination. It follows therefore, that this option is often not explored during counseling sessions unless a client inquires, or it is added as an alternative to termination and parenting rather than as an equal option (Perry and Henry 2009).

The lack of a focus on adoption as an equal option is also evident in a search of current literature. For example, when discussing prenatal diagnosis and pregnancy counseling, authors often refer to the options of pregnancy termination or parenting of the child (e.g., Strauss 2002; Verp et al. 1988). While outlining an effective model for counseling and providing information, Marteau and Dormandy (2001) assert the importance of including parents of affected children and parents who chose to terminate an affected pregnancy as resources. There is no mention of the inclusion of parents who chose to make an adoption plan for a child with the condition in question. Taken together, these examples suggest that adoption is rarely mentioned as a possible option for individuals and families facing a prenatal or postnatal diagnosis.

Educational Needs of Genetic Counselors

Educational efforts should aim to increase awareness, knowledge, and skills regarding adoption as an option for clients. Professionals should be aware both of personal predispositions and misconceptions and those of others, and of the immense impact these biases and assumptions may have on clients' decision-making abilities. Genetic counselors and other health professionals must possess not only a thorough knowledge of options, referrals, and resources, they also must be skilled in using language during a counseling session that allows them to convey an unbiased and nondirective attitude and interventions.

Adoption-sensitive language is essential when discussing this option with clients. Such commonly used phrases as "give up for adoption" and "keep the child" may convey a negative portrayal of this option to clients who may otherwise see adoption as a fitting choice (Henry and Pollack 2009). Table 1 details additional adoption word choices with negative, insensitive connotations, while offering more accurate and respectful alternatives and explanations of the language.

Also of concern are the counseling issues that may develop when adoption is considered. Genetic counselors must be aware of the effects of decision-making in cases of fetal anomalies on relationships and the differences in beliefs surrounding adoption that may surface between partners in such situations. Social, financial, religious, and situational factors such as age may all influence whether an individual chooses to make an adoption plan (Henry and Pollack 2009). Genetic counselors should be aware that these factors may differ from individual to individual and, thus, the needs and concerns of all involved parties should be addressed. Preparation is also necessary for ethical debates surrounding the separation of multiples when one fetus is affected while another is not. Genetic counselors and other health professionals must be skilled in counseling clients and families dealing with the issue of parenting one child while making an adoption plan for another.

In addition, siblings and extended family may present another dilemma for expectant parents who choose to make an adoption plan after receiving a fetal diagnosis. Clients often turn to health professionals for guidance in explaining the situation and their decision to family members, particularly to young children who are aware of the pregnancy. In these instances, it is important to determine what the child is able to comprehend, as a child's capacity to understand changes with age, and different explanations may be appropriate at different points in the child's life. For example, when explaining the situation to young children, it may be helpful to refrain from focusing on the fetal diagnosis, as children may then wonder whether they will be adopted by another family if they become sick. Genetic counselors should feel comfortable referring clients to resources, local adoption agencies, or other professionals for support with these difficult conversations and decision-making.

Table 1 Respectful and Accurate Adoption Language

Hurtful choice	Wise choice	Explanation
Gave up	Chose or made an adoption plan	The decision to make an adoption plan is extremely difficult and thoughtful.
Given up Put up Surrendered for adoption	A child for whom an adoption plan was made	Children who were sent on the orphan trains from New York to the west during the mid- 1800s were "put up" for display on a platform so that prospective adoptive parents would be able to see them to better decide which child would meet their needs.
Keep the child	Parent the child	People who choose adoption are not discarding their children but are unable to parent them.
Real or natural parents	Birth parents	There are no imaginary or unnatural parents.
Real or natural child Illegitimate child	Birth child Child born to unwed parents	All children are real, natural, and legitimate. Lack of a genetic link does not make someone unnatural or illegitimate.
Own children	Birth children or children who were adopted	All parents consider their children their own regardless of how they became a family.
Is adopted Adoptee	Was adopted Person who was adopted	Using the present tense implies an ongoing "condition." An adoption is an event or process, not an enduring quality of a person, a diagnosis, or a condition. It should not be used by others as a defining characteristic.
Unwanted	Unable to be parented by a birth parent	There can be a variety of reasons people are unable to parent their children. Desire is usually not a common reason and being described as "unwanted" is detrimental to a child's sense of self.
Tracking down relatives	Search for information or relatives	Tracking down people could imply that they are unwilling to be found. Conducting a search can take many forms and can mean searching for information, people, or both.

Adapted from Henry, M. J., & Pollack, D. (2009). Respectful and Accurate Language. *Adoption in the United States: A reference for families, professionals, and students.* Chicago, IL: Lyceum Books

Lack of Resources for Expectant Parents

Expectant parents who receive a diagnosis or medical suspicion of a fetal disability or anomaly suddenly face life-altering decisions. It is essential that they receive accurate information concerning the diagnosis and all possible options, as well as the emotional support needed for making such decisions. However, verbal information alone is often insufficient for expectant parents who may be experiencing a wide range of emotional responses to such unexpected information; they may be unable to fully comprehend the options available to them and, as a result, their retention of the information discussed is limited. Numerous sources, therefore, acknowledge the need for supplementary written materials to enhance recall, communicate information to others, and to further understand the diagnosis in order that a decision can be reached (Lalor et al. 2007; Skotko 2005b).

A search of current literature on fetal anomaly and pregnancy options, identified through the use of databases such as PubMed and Google Scholar™, reveals a wealth of information regarding parenting children with disabilities as well as pregnancy termination. Additionally, a great deal of information exists in both print and throughout the internet concerning general adoption. Adoption of children with special needs is also a topic that has been widely explored, although the term “special needs” often refers to older children within the public foster care system or any child considered difficult to place (e.g., Rosenthal and Groze 1994). Search engines such as Google™, often a first choice by the general public for uncovering information, identify adoption-related websites that discuss the process of adopting, existing services for families adopting children with special needs, support groups available for families who adopt, and legal implications of adoption. However, there is significantly less information accessible to expectant parents and families regarding making an adoption plan for a child with disabilities. The information that does exist on adoption planning focuses primarily on unplanned and single-parent pregnancies. Few resources are available for expectant parents faced with a pregnancy in which a fetal anomaly has been newly diagnosed or suspected. These pregnancies are often desired (McCoyd 2007), and individuals and couples face an overwhelming decision concerning the pregnancy outcome.

While books such as *Shattered Dreams-Lonely Choices* (Finnegan 1993), which discusses the concerns, expectations, range of emotions, and experiences of parents who have considered or chosen adoption for their child with a disability, have been well-received by the community of parents they address, there has also been an increasing demand, in this age of technology, for an internet resource. Additionally, electronic resources may be more easily updated and widely distributed. Indeed, genetic counselors have supported the idea of a web-based resource of adoption information for clients facing a prenatally-diagnosed pregnancy. In an unpublished graduate student survey (Perry 2003), 95% of genetic counselor respondents agreed that an informational website on the option of adoption would be useful for expectant parents as well as health professionals. These respondents also reported feeling unprepared to provide appropriate referrals for clients in such situations. Another graduate study focusing upon the experiences of genetic counselors presenting adoption as an option for pregnancies in which a fetal anomaly has been identified (Oksala 2007) found that, in one instance, 39% of respondents did not offer the option of adoption because they did not think of it, or they lacked resources and information that would help them discuss this option. It can be assumed that increased availability of resources for both clients and health professionals could result in a greater awareness of this option, possibly leading to the consistent discussion of adoption as an equal option in cases of fetal anomaly.

Practice and Training Recommendations

It has been suggested that those who undergo brief training can not only gain a greater knowledge of adoption, but can also improve their ability to provide information (Smith et al. 1995). However, a study conducted by Marteau and Dormandy (2001) lends support to the idea that those who are most in need of such training are typically the least likely to attend (Michie and Marteau 1999), suggesting that such adoption education should consistently be required of genetic counselors and other practicing health professionals in order to maximize its effectiveness. Accordingly, we recommend that adoption education be integrated into core curricula for genetic counseling graduate programs, as well as offered to practicing counselors through conferences and courses for continuing professional education.

Beginning with adoption-sensitive language education, genetic counseling graduate students should be given the opportunity to practice counseling with accurate and respectful language through the use of in-class role plays. Program directors and instructors, as well as practicing counselors, should also be sure to model sensitive language when discussing topics related to adoption (a list of phrases, positive alternative language choices, and explanations can be found in Table 1). The use of positive language should be observed not only during prenatal counseling sessions but for any counseling session in which adoption plays a role.

In addition to adoption-sensitive language, genetic counseling graduate curricula should routinely include general information about the adoption process, types of adoption, state and federal laws and policies, adoption resources, professional roles and responsibilities, and emotional aspects of adoption. Local adoption agencies and national organizations such as the Down Syndrome Association of Greater Cincinnati Adoption Awareness Program may be useful in identifying resources to supplement this education, including adoptive and birth parents of children with disabilities who are willing to share their experiences. Personal accounts of client decision-making and thought processes may be the most impacting when discussing the presentation of this option to clients. In addition, adoption agencies can provide information about the processes of making an adoption plan and of adopting a child, as well as about national and regional policies. It is recommended that genetic counseling program directors communicate and share information and contacts with the common goal of further promoting and developing adoption education at the graduate level.

It is our position that all potential pregnancy options be discussed after a prenatal diagnosis. It may be appropriate to only explore in detail those options for which the client shows interest. However, genetic counselors should question what the client knows about each option in order to ensure that he/she has an accurate basic understanding of adoption as well as termination and parenting as they enter the decision-making process. In addition, written resources about all viable options should be provided to clients facing a decision about a pregnancy. While clients may seem to favor one option initially, they may reconsider and wish to learn more about another option at a later point.

While no specific guidelines exist for working through counseling issues that may arise when discussing adoption with clients, we recommend that graduate students be encouraged to utilize mock counseling sessions to explore and prepare for potential situations. Using appropriate and respectful language, students should learn to promote an accurate understanding of adoption and be able to respond to objections raised which may be based on myths and misconceptions. In doing so, previous notions about adoption can be explored and accurate information provided to clients. For instance, when clients suggest that children who were adopted experience emotional and psychological issues as a result of the adoption, genetic counselors should recognize this inaccuracy and provide assurance that individuals who were adopted typically demonstrate no further long-term psychological issues than those who were not adopted (Borders et al. 2000). Role plays can benefit clients as well by preparing them to speak with family members, children, and other individuals about their decision.

We further recommend that genetic counselors assure clients that they may use an adoption agency as a resource without feeling obligated to make an adoption plan. Agencies can provide additional adoption information and will explore all pregnancy options with expectant parents through pregnancy counseling prior to any final decision-making. In addition, genetic counselors (and all health professionals) should familiarize themselves with local adoption agencies and organizations upon beginning practice in an area. Adoption providers can be located through state licensing agencies (if applicable), the internet, or phone directory; contact should be made to ensure that adoption professionals respond in a timely manner and have previous experience placing children with disabilities. Because adoption is state-specific, understanding state laws and policies is necessary in order to accurately present this option to clients. Any health professional responsible for discussing adoption with a client should be knowledgeable about adoption policies specific to the state or states in which they practice.

Professional organizations can play a significant role in promoting increased adoption education among genetic counselors. Further integrating adoption education into graduate curricula and developing practice guidelines may promote standards of competence and foster education, research, and policy to promote genetic counselors' professional development and provision of quality genetic services. National organizations including the National Society of Genetic Counselors (NSGC) should seek to partner with experts in the field of adoption to promote continuing education opportunities through conferences and other professional development activities.

Courses offered through the internet have the potential to reach a wider audience, enabling a much greater number of genetic counselors to access this type of education. The University of Massachusetts Medical School's Office of Foster Care and Adoption (OFCA) currently educates medical students and genetic counseling graduate programs about adoption and foster care, and it is in the process of developing a web-based training curriculum aimed at educating health professionals, particularly genetic counselors, about adoption. The primary goal of this course is to provide medical professionals with the knowledge necessary to adequately discuss adoption with clients facing a pregnancy decision, as well as to work with individuals and families with whom adoption or foster care plays a role.

Advances in adoption knowledge should also be encouraged through expanded research, in particular needs assessments of medical professionals and clients. These assessments would hopefully lead to further development of written and internet-based adoption resources and educational materials for students and health professionals, as well as for families.

Conclusion

Because clients often rely on medical professionals to guide their decision-making (Levinson et al. 2005), inadequate professional education may result in clients' ill-fitting decisions based upon erroneous or omitted information. Recent debate and legislation highlight the importance of educating genetic counselors and other health professionals about adoption, as they are likely to encounter this topic in various aspects of their clinical practice. In particular, genetic counselors are expected to offer this option to individuals experiencing a pregnancy in which a fetal diagnosis has been made. However, preliminary studies have demonstrated that genetic counselors (as well as other health professionals) lack a thorough knowledge of adoption, specifically regarding policies, resources, and referrals; thus, many admittedly feel unprepared to discuss this option with clients (e.g., Mates 2008; Oksala 2007; Perry 2003). This lack of knowledge is a likely result of a deficiency of written resources for health professionals and for clients, as well as minimal education on this topic in graduate programs throughout the United States. Thus, the development and integration of adoption education for both graduate students as well as practicing professionals is imperative in order for genetic counselors to be able to discuss all options with clients facing a prenatal or postnatal diagnosis and, ultimately, to allow for their fully informed decision-making.

Recommended Resources

The resources listed below can provide additional information about general adoption and about the adoption of children with disabilities.

Child Welfare Information Gateway
http://www.childwelfare.gov

Down Syndrome Association of Greater Cincinnati Adoption Awareness Program
http://www.dsagc.com/programs_adoption.asp

Finnegan, J. (1993). *Shattered dreams—lonely choices: Birthparents of babies with disabilities talk about adoption.* Westport, CT: Bergin & Garvey.

Henry, M. J., & Pollack, D. (2009). *Adoption in the United States: A reference for families, professionals, and students.* Chicago, IL: Lyceum Books.

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