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The Role of Genetic Counseling in the Elective Termination of Pregnancies Involving Fetuses with Disabilities

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In this study, 69 women were surveyed who, as a result of prenatal screening, knew they were at risk for carrying a fetus with a disability. Results indicated that most women were referred by their physicians for genetic counseling either because of their age or because of an abnormal blood test. The majority of women indicated they would choose to terminate a pregnancy that tested positive for a disability, but the type of disability of the fetus, either Down syndrome or spina bifida, made no difference in the decision that women believed they would make. The women's intention to terminate a pregnancy appeared to be unrelated to their overall knowledge about disabilities but was negatively related to their knowledge of disability-related services. Although women reported that genetic counseling was helpful, they revealed that they were not given information about future-quality-of-life issues for individuals with disabilities nor provided with the positive as well as the negative aspects of giving birth to a child with disabilities.

The past 20 years have seen rapid advances in the detection of genetic disorders in human fetuses. Prenatal screening has become an increasingly common procedure, particularly for women who are at risk for giving birth to an infant with a disability. Prenatal screening is concerned with the detection, and often the avoidance, of disability *in utero* (Fletcher, 1975; Kaplan, 1993) and has been found to significantly decrease the prevalence of infants born with disabilities (Bull, 1999; Forrester, Merz, & Yoon, 1998; Richards, Bentley, & Glenn, 1999).

Genetic disorders are detected through two types of tests: screening procedures and diagnostic tests. Screening procedures, such as the maternal serum alfafetoprotein (AFP) test and ultrasound, are now available to most women as routine services from their obstetrician and identify if their pregnancy is at risk for a congenital disability. Serum screening involves a noninvasive blood test that measures the amount of alfafetoprotein and other biochemical markers in the mother's bloodstream. These tests identify pregnancies at risk for disabilities such as spina bifida and Down syndrome. Diagnostic tests, such as chorionic villus sampling and amniocentesis, are considered invasive procedures but provide more detailed information than screening procedures and confirm whether a fetus has a neural tube defect or a chromosomal disorder. Both chorionic villus sampling and amniocentesis increase

the probability of miscarriage; however, this risk is minimized when an experienced physician conducts the procedure (Santalathi, Hemminki, Latikka, & Ryyänen, 1998).

In the United States, physicians commonly refer women who are at risk for giving birth to a child with a disability to a genetic counselor. Genetic counseling is composed of diagnostic, educational, and decision-making elements and is often an important source of information for women making decisions about their pregnancy (Bender, 1974). Some women, because of a family history of congenital disabilities or due to their age, are referred to a genetic counselor early in their pregnancy or even preceding pregnancy. Most women, however, are referred to genetic counseling following an abnormal ultrasound finding or serum screening result. Genetic counseling has thus become a common vehicle for discussing abnormal screening results with women for assisting them in making informed pregnancy-related decisions.

Genetic counseling is often the first exposure women and their families have to detailed information regarding disabilities. Best practice during counseling sessions is a patient's receiving unbiased and objective information from a counselor who is knowledgeable about pregnancy and disability issues (Applebaum & Firestein, 1975; Saxton, 1984). Accurate information at this stage is vital so that women's decisions are fully informed (Pueschel, 1991). However, beyond medical de-

scriptions of various disabilities, there is no agreement on what specific information should be given. Smith (1981) suggested that prospective parents be given information about the developmental potential for a child with the diagnosed disability, such as Down syndrome; other researchers believe that information should be included such as resources, educational opportunities, legislation, and employment, as well as informal supports for parents of children with disabilities (Hershey, 1994; Kaplan, 1989). In a survey of participants at risk for giving birth to a child with a disability, Elkins, Stovall, Wilroy, and Dacus (1986) found that 89% of the participants believed that both positive and negative aspects of a disability should be presented to parents prior to prenatal screening.

A lack of standardization in information provided, or procedures used, in prenatal screening and genetic counseling gives individual doctors and counselors substantial control over what information is given to women. Gatens-Robinson (1996) suggested that as medical advances increase in the areas of pregnancy, childbirth, and conception, women's behavior in these areas also becomes more controlled by the medical community. Doctors' and other health care workers' attitudes toward prenatal disabilities can influence types of screening and diagnostic tests offered to women (Heckerling, Verp, & Albert, 1998; Santalahti et al., 1998). When women are surveyed about what types of changes they would like to see implemented in the prenatal screening process, they most frequently mention their desire to obtain more information about disabilities and diagnostic tests (Santalahti et al., 1998). Information presented in genetic counseling sessions, however, typically does not include quality-of-life issues for people with disabilities.

Genetic counseling also supports women in making decisions concerning their pregnancy. Women who are at risk for giving birth to a child with a disability must make irrevocable decisions about medical procedures in a relatively short period of time. The first decision a woman faces when she receives an abnormal test report is whether or not to participate in further diagnostic procedures (usually amniocentesis or chorionic villus sampling). However, approximately one fourth of women regard participation in these diagnostic tests as a "self-evident act" (Santalahti et al., 1998, p. 1069) and do not actively participate with their health care professional in the decision to undergo further testing. Following these diagnostic procedures, the genetic counselor typically discusses the results with the pregnant woman and, if the results are positive, provides information specific to the disability of the fetus the woman is carrying. The woman is then faced with the decision of whether to terminate the pregnancy or carry the pregnancy to term. Usually women make this decision soon after confirmation that a fetus has a disability; however, in some states, pregnancies involving a fetus with Down syndrome legally may be terminated much later in the pregnancy than those without disabilities, because these abortions are considered to be of "medical necessity" (Glover & Glover, 1996).

Glover and Glover (1996) reported that Americans are evenly divided regarding the morality of the abortion issue,

with 44% to 54% opposing abortion and 39% to 47% advocating a woman's right to choose. However, Planned Parenthood's (Survey on Attitudes, 1999) most recent statistics indicated that the majority of adults (62%) were in favor of the *Roe v. Wade* decision, whereas less than 33% of voters oppose the decision and 5% are unsure. Blendon, Benson, and Donelan (1993) reported that women were also almost evenly divided in their opinions about abortion: Forty-four percent were in opposition and 47% were in favor of choice, depending on circumstances. These percentages shifted, however, when the presence of a disability was detected: If the test returned positive for a genetic disorder, 78% of the women were in favor of abortion (Blendon et al., 1993). Similarly, two other studies (Finley, Varner, Vinson, & Finley, 1977; Robinson, Tennes, & Robinson, 1975) found that 71% and 77%, respectively, of women seeking genetic counseling responded that they would terminate a pregnancy if an anomaly was detected in the fetus. Rice and Doherty (1982) found an even higher rate (89%) of women responding that they would terminate a pregnancy that tested positive for a disorder.

The rate of deciding to terminate a pregnancy is also high when the specific disability of the fetus is known. For example, Glover and Glover (1996) concluded that over 88% of women who have a confirmed prenatal diagnosis that they are carrying a fetus with Down syndrome choose to abort the pregnancy. Williamson, Harris, Church, Fiddler, and Rhind (1996) similarly found that 88% of their sample of 302 women pregnant with a fetus with Down syndrome chose to terminate their pregnancy. Bull's (1999) study found that 50.4% of all pregnancies with fetal diagnoses of congenital heart disease were electively terminated. Brock (1996) found through screening 25,000 couples for cystic fibrosis that in the eight cases where fetuses were found to have cystic fibrosis, all eight pregnancies were terminated. In addition, Velie and Shaw (1996) interviewed 538 mothers who had pregnancies with a neural tube defect and found that 40% chose to terminate their pregnancy.

Rate of termination appears to vary as a function of type of disability. Vincent, Edwards, Young, and Nachtigal (1991) found that following amniocenteses, pregnancies that involved common trisomies (21, 18, and 13) were terminated at a rate of 92% to 95%; by contrast, sex chromosomal abnormalities were terminated in only 42% of cases. In a study of pregnancy outcomes in 1,153 cases of fetuses prenatally diagnosed with disabilities, Forrester et al. (1998) noted that the percentage of affected pregnancies that were electively terminated was highest for those with anencephaly (83%) and Down syndrome (84%) and lowest for fetuses with gastroschisis abdominal wall defects (12.8%) and cleft palate or lips (28.1%). Velie and Shaw (1996) also found differential rates of termination of fetuses with different types of neural tube defects, with more elective abortions performed in pregnancies diagnosed with anencephaly (54%) than in those diagnosed with spina bifida (39%). Bell and Stoneman's (2000) survey of 166 undergraduates found that students were more

likely to consider terminating a pregnancy that involved a fetus with Down syndrome than one involving a fetus with spina bifida and were more likely to consider terminating a fetus with spina bifida than one with hemophilia.

The above literature suggests that some disabilities are perceived as less “acceptable” than others. Because research shows that most women would terminate a pregnancy if Down syndrome were present, Hershey (1994) questioned if society might be accepting of some disabilities but not others. She postulated that this phenomenon might be related to the lack of information women receive in genetic counseling. Although results from a prenatal screening test cannot determine the severity of a disorder, most prospective parents seem to consider Down syndrome as involving severe mental retardation. In actuality, 90% of all individuals with Down syndrome fall within the mild to moderate range of functioning (Glover & Glover, 1996). Smith (1981) noted that parents should be made aware during counseling that the development of a child with a disability is highly variable and that this development can be greatly influenced by early intervention programs.

A number of additional factors seem to affect a woman’s decision about whether to continue a pregnancy when the fetus has been diagnosed as having a disability. Cohen (1986) noted that supposed “low quality of life” for people with disabilities has often been the reason for terminating a pregnancy of a fetus with a disorder. Other reasons can involve a woman’s perception of disabilities, her own self-doubt as to her ability to care for a child with a disability, or her perception of a lack of the resources necessary for caring for a child with a disability (Hershey, 1994). Elkins, Stovall, Wilroy, and Dacus (1986) found that 50% of women who had previously had a child with Down syndrome would choose to terminate a similarly affected pregnancy. In contrast, Beeson and Golbus (1979) stated that of the women with a prior child with Down syndrome in their study, *all* would choose to terminate if a subsequent pregnancy tested positive for Down syndrome. These women, however, also described themselves as the primary caregivers for their child, and thus the perceived corresponding stress relating to that role may have been a factor.

The previously described research suggests that a number of factors affect women’s decisions about pregnancies with disabilities; however, few have directly questioned pregnant women about these influences. In addition, few studies have directly examined the information about disabilities that women obtain during genetic counseling sessions or how that information affects their decision-making. In this study, we questioned whether the particular type of disability—specifically, Down syndrome or spina bifida—differentially affected women’s decisions to terminate their pregnancies. We also questioned how and by whom they were referred to genetic counseling. In addition, we investigated how knowledge of disability issues and of available disability-related resources affected these women’s decisions. Finally, given the primacy of genetic counseling as a source of information used in decision making, we questioned women about their perceptions

of the counseling process and about the information they had obtained from their genetic counselor.

Method

Participants

The 69 participants in this study were contacted through a genetic counseling center located in a large metropolitan area. All women who participated were pregnant, at least 18 years of age, and considered to be at risk for giving birth to an infant with a disability. Demographic characteristics of the participants can be found in Table 1.

The genetic counseling center used in this study provided services to the local community and surrounding area and was located close to a state university in an affluent urban area. Many genetic counseling centers are tied to hospitals or religious organizations and therefore do not offer a full range of prenatal screening, counseling, and pregnancy alternatives to clients. This genetic center was an independent facility and therefore not affiliated with a hospital or religious organization. The center’s services included clinical evaluations, genetic counseling, laboratory studies, as well as prenatal diagnosis. According to the clinic staff, most women who used the clinic’s services had access to private health insurance and had received excellent prenatal care.

The genetic counseling clinic employed four genetic counselors who conducted a total of approximately 50 counseling sessions per week. The center provided genetic counseling through a referral from physicians and other medical professionals, through selected community programs, or by direct request from patients. According to the clinic staff, however, most women were referred for genetic counseling because of two factors: maternal age and/or an abnormal “triple screen” result. As part of medical protocol, women aged 35 and over are referred for genetic counseling because they have a higher probability of giving birth to a child with Down syndrome than do women under age 35. A “triple screen” is an elective blood test, conducted in the 15th to 20th week of pregnancy, that uses three biochemical markers— α -fetoprotein, human chorionic gonadotrophin, and estriol—to calculate whether a fetus is at risk for a neural tube defect or a chromosomal disorder. The results of this screening procedure are not precise, having a high false-positive rate, and further diagnostic tests, such as an amniocentesis, must be conducted to determine if a fetus indeed has a disability. The role of the genetic counselor in this study, therefore, included informing women about further diagnostic tests that would definitively determine whether their fetus had a disability.

Instrumentation

A survey was designed to determine the women’s (a) general knowledge about disabilities, (b) awareness of resources avail-

able for parents of persons with disabilities, (c) general satisfaction with genetic counseling sessions, and (d) decision tendencies concerning the termination or continuation of a pregnancy. The survey specifically measured the women's knowledge of spina bifida and Down syndrome. These two types of disability were chosen because (a) women over age 35, as were most women in this sample, are particularly at risk for giving birth to children with Down syndrome, (b) abnormal triple-screen test results report whether a pregnancy is at risk for either a chromosomal disorder or a neural tube defect, and (c) these two disabilities are the chromosomal disorder and neural tube defects most readily identifiable by laypersons.

To pilot study the survey, the first author selected three participants who approximated the description given by the center staff of typical clients of the genetic counseling center. These participants were over 18 years of age, were pregnant, used English as their first language, and were seeking genetic counseling. The three participants and the researcher analyzed the survey by reading through each question silently and then together, and discussed each question's ability to elicit the information desired by the researcher. Participants were also asked to review the procedures that would be used to distribute the survey. The first researcher then revised the survey design and the survey questions based on the participants' recommendations.

Procedure

Surveys were distributed to pregnant women who were having their first appointment at the genetic clinic. A partner accompanied most of these women. As women waited for their counselor, the researcher introduced herself and explained the purpose of the study. Face-to-face contact with the participants was chosen so that the researcher could explain the importance of the study and reassure participants about confidentiality, and so that the participants could ask questions about the study. If a woman volunteered to participate, she was given a survey packet, which contained an introductory letter; a questionnaire; and an addressed, stamped return envelope. She was asked to complete the survey within 2 weeks after participating in her genetic counseling session and before she had received a definitive diagnosis about her pregnancy. These materials also included the name of a contact person, should the participant become emotionally stressed while completing the survey, and an explanation of how anonymity would be maintained.

Analysis

The statistical procedures used in this study included correlational analysis and descriptive statistics. The point biserial correlation allows the researcher to correlate continuous and dichotomous data (Huck & Cormier, 1996). Internal consistency of the survey was assessed via use of Cronbach's alpha

TABLE1. Participant Characteristics

Variable	<i>n</i>	(%)
Ethnicity		
White	60	87.0
Black	3	4.3
Japanese	3	4.3
Latino	3	4.3
Income		
25,000–34,999	3	4.3
35,000–49,999	18	26.1
50,000–74,999	24	34.8
75,000–99,999	15	21.7
> 100,000	9	13.0
Educational level		
High school diploma	6	8.7
Some college	9	13.0
Undergraduate degree	24	34.8
Master's	27	39.1
Doctorate	3	4.3
Religion		
None	23	33.3
Catholic	21	30.4
Other	13	18.8
Nondenominational	6	8.7
Baptist	3	4.3
Lutheran	3	4.3

Note. Categories are as used by the U.S. Census Bureau (1990).

(Huck & Cormier, 1996). A targeted minimum sample size of 66 was based on a power analysis utilizing alpha level = .05, a medium effect size of .30 (Cohen, 1977), and power = .70. Due to the exploratory nature of this study, an effect size of .30 was chosen by the researcher: When the researcher is unable to make an educated guess as to the effect size present in the population or when there is little prior research in an area or if the researcher is using a new measuring instrument, the researcher may set the effect size based on the level of desired detection of difference (see Huck & Cormier, 1996).

Of 149 surveys (see Roberts, 1998) distributed to the women, 71 were returned, for a return rate of 48%. Of these 71 surveys, 69 were analyzed. Two surveys were omitted from the sample, as they contained unanswered questions. In the interest of maintaining confidentiality, the researcher did not gather information on women who chose not to return the survey.

The Fry test of readability (Vaca & Vaca, 1996) indicated that the survey required a ninth-grade reading level. Internal consistency of the survey was assessed by using Cronbach's alpha (Gay, 1996). Internal consistency of questions relating to knowledge of disability in general was .83. The internal consistency of other groups of questions was moderate: For knowledge of Down syndrome, $r_{\text{total test}} = .77$, for knowledge of spina bifida, $r_{\text{total test}} = .77$.

TABLE 2. Sources of Influence for Women Seeking Genetic Counseling

Source	<i>n</i>	%
Doctor recommended	60	87.0
Own decision	36	52.2
Other reason	6	8.7
Spouse	3	4.3
Friends	0	0.0
Family	0	0.0

Note. Women were encouraged to select as many responses as they believed applied to their situation; therefore, the percentage of women in the categories totals more than 100.

TABLE 3. Sources of Concern for Women Seeking Genetic Counseling

Source	<i>n</i>	%
Age	45	65.2
Doctor recommended	27	39.1
Other	18	26.1
Prior child with a disability	3	4.3
Genetic disorder	3	4.3
Abnormal ultrasound	0	0.0

Note. Women were encouraged to select as many responses as they believed applied to their situation; therefore, the percentage of women in the categories totals more than 100.

Results

Reasons for Seeking Counseling

To determine the participants' reasons for seeking genetic counseling, we asked, "Women who go to genetic counseling have chosen to go on their own or are referred by their doctor. How were you influenced to see a genetic counselor?" Eighty-seven percent of the women stated that their doctor had referred them to genetic counseling, whereas 52.2% said it was their "own decision" (see Table 2).

The women also were asked about the concerns about their pregnancy that led them to seek genetic counseling: "Women usually seek genetic counseling because of a particular concern. What is the concern that has made you seek genetic counseling?" As had been previously described by the clinic staff, over 65% of the women stated that they came to the clinic because of their age (over 35), while 39.1% stated that they had been referred by their doctor (see Table 3). For

the women who selected "other," "abnormal blood test" was their most frequent handwritten answer.

Factors Associated with the Decision to Terminate

When asked, "Would you terminate a pregnancy if a disorder was present in the fetus?" the majority of the women (65%) indicated that they would. However, there was no difference in the decision to terminate as a function of the two specific types of disabilities: The decision to terminate was 60.9% for Down syndrome and 65.2% for spina bifida, a statistically nonsignificant difference.

The women were asked to identify sources that they found helpful in deciding whether to terminate their pregnancy. Consistent with the high educational and economic status of the women in this study, the most often cited source (82%) was "books and articles." "Genetic counselor" was chosen by 74% of the women (see Table 4); and of the women who identified "other" as a source, most cited their own education as being helpful.

Sixty-six (95.7%) of the women indicated that they foresaw themselves as being the primary caregiver of their child, should they carry their pregnancy to term. The women were then asked if this role as primary caregiver would affect their decision to terminate. Forty-two (60.9%) of the women indicated that it would.

Effect of Knowledge of Disability Issues on Termination

The survey contained a subscale of questions that emphasized traditional medical knowledge about disabilities, such as physical differences, severity of disability, additional health risks to mother and fetus, and pregnancy options. A woman's intention to terminate or continue a pregnancy did not appear to be related to her overall level of knowledge about disabilities. A point biserial correlation revealed a nonsignificant relation between a woman's decision to terminate her pregnancy and her score on overall knowledge about disabilities on the survey. The scores obtained by women in this sample ranged from 0 to 6, with the mean score being 1.34 out of 12 points possible ($SD = 1.69$).

In a separate subscale, the relation between a woman's intention to terminate or continue a pregnancy and her level of knowledge of resources available for people with disabilities was examined. A point biserial correlation ($r^{pb} = .48$) indicated a moderate positive relation between the decision to terminate and knowledge of resources available for people with disabilities. As the level of such knowledge increased, the choice to continue the pregnancy was more likely. Scores obtained on this subscale ranged from 0 to 9, with the mean score being 2.59 out of 9 points possible ($SD = 3.20$).

The women were asked if they had been encouraged to meet with a parent of a child with a disability during the pre-

natal screening process. The majority of women (91.3%) indicated that they had not been encouraged to meet with a parent by either the genetic counselor or any other medical personnel.

Helpfulness of the Genetic Counseling Process

Three questions were asked to assess how the genetic counseling helped women to make decisions about pregnancy, and how helpful the process actually was. The first question asked if women found genetic counseling helpful in providing information about prenatal disabilities. Ninety-one percent of the women stated that genetic counseling provided helpful information about prenatal disorders. In response to the second question, 87% of the women indicated that genetic counseling did not give them information about future-quality-of-life issues for a child with a disability. On the third question, 82.6% of the women indicated that the genetic counselor did not provide them with both positive and negative aspects of giving birth to a child with a disability. These findings suggest that although women found genetic counseling to be helpful as a source of information regarding disabilities, they did not believe that they received information regarding the quality of life for people with disabilities, nor did they believe that they received a balanced view of parenting a child with a disability.

Discussion

As has been previously reported in research on prenatal screening (Heckerling et al., 1998; Henifin, Hubbard, & Norsigian, 1989; Saxton, 1987), we found that most women are influenced to participate in genetic counseling by their physicians. As a result, much of the information they receive about disabilities is obtained in conjunction with decisions about medical procedures. Although genetic counseling is designed to provide nonbiased information about disabilities, the medical profession refers women to genetic counseling primarily to assist them in making decisions about medical procedures, and it is not unreasonable to assume that this medical focus then influences the perceptions about disabilities that pregnant women develop.

Also similar to earlier work (Bell & Stoneman, 2000; Glover & Glover, 1996; Velie & Shaw, 1996), the majority (65%) of women in this study stated that they would terminate a pregnancy that tested positive for a developmental disorder. Although this stated termination rate is substantially less than has been found in studies of actual termination rates of fetuses with disabilities (see Forrester et al., 1998), it is slightly higher than that reported by nonpregnant college students (Bell & Stoneman, 2000). Taken together, these results suggest that the actual termination rate of pregnancies with disabilities is higher than women's declared termination intentions.

TABLE 4. Sources of Information Women Viewed as Helpful During the Genetic Screening Process

Source	<i>n</i>	%
Books/articles	57	82.6
Genetic counselor	51	73.9
Obstetrician	30	43.5
Other	21	30.4
Friends	18	26.1
Family members	12	17.4
Television	12	17.4
Nurse	6	8.7
Other medical personnel	6	8.7
Spouse	0	0.0

Note. Women were encouraged to select as many responses as they believed applied to their situation; therefore, the percentage of women in the categories totals more than 100.

In contrast to other studies (Bell & Stoneman, 2000; Velie & Shaw, 1996), the intention by women in the present study to terminate a Down syndrome pregnancy did not differ from their intent to terminate a pregnancy with spina bifida. This departure in the current findings may be a result of the relatively small sample size of women in this study. Similarly, no difference in the decision to terminate a pregnancy was found in connection with the ethnicity, household income, religion, or education level of the participants, which, again, may be a result of the small number of women within some of these subgroups.

The level of general knowledge that these women had about disabilities was not related to their intention to continue or terminate their pregnancy or to their knowledge specific to Down syndrome and spina bifida. It should be noted, however, that women in this study had very limited knowledge of disabilities, as measured by the survey, even after receiving genetic counseling. This finding is particularly interesting given the demographics of the participants: The education level of these women was very high (78% had at least a college-level degree), as was their economic status (69% had a household income of over \$50,000). Additional studies that examine knowledge of disability issues using a more diverse sample of women would add to this area of study.

Although general disability knowledge did not appear to influence decisions to terminate, knowledge about available disability-related *resources* was related to stated intentions to terminate pregnancy. Women who had knowledge of resources and programs that assist with the education, training, and care of a child with a disability were more likely to consider continuing their pregnancy. It may be that as women become more informed about the associations, agencies, and

individuals available to assist people with disabilities, they start to view the task of raising a child with a disability as less overwhelming.

Despite the limited knowledge base that women in this sample had about disabilities, they reported that genetic counseling was the primary source of the information they did have about disabilities. However, most women reported that they did not receive information about disability resources or quality-of-life issues from their genetic counselors. In addition, they did not believe that their counselor presented them with both the positive and the negative aspects of having a child with disabilities. This finding suggests that pregnant women make decisions based on limited information even after participating in genetic counseling. Hershey (1994) similarly noted that "women are unlikely to receive information about community resources or be encouraged to meet with parents of a child with a disability" (p. 31). She suggested that all relevant information, not just medical information, be presented to prospective parents of children with disabilities. An appropriate role for the genetic counselor may be to refer clients to a wide variety of additional sources, such as individuals with disabilities and agencies that provide disability-related services, for alternative viewpoints. The genetic counselor could then encourage women to integrate information from these sources to form a complete picture from which to make an informed decision.

Women who are at risk for giving birth to a child with disabilities are faced with the difficult decision of whether to terminate a pregnancy that has tested positive for a disability. A narrow timeline exists after diagnostic testing in which a woman must make this decision. Most genetic counseling centers, such as the one in this study, do not routinely discuss information pertaining to specific disabilities, including quality-of-life issues, until the definitive diagnostic results from the amniocentesis or chorionic villus sampling are known. Delaying information about specific disabilities and available community resources obligates women to gain a large amount of knowledge quickly in order to make an informed choice as to whether they should terminate or continue their pregnancy. It may be that genetic counselors need to begin early in the prescreening process to provide women with information about disabilities. Additional research is needed to ascertain whether the timing of information provided about disabilities influences women's choices to terminate a pregnancy.

Women in this study who saw themselves as the future primary caretaker of their child reported that this status contributed to their decision to terminate a pregnancy with a disability. Women often carry the majority of the responsibility for childcare, and the perceived stress of caring for a child with a disability may be a determining factor when deciding whether to continue or terminate a pregnancy. In contrast, women who feel they share, or who are strongly supported in, child rearing may be more likely to continue a pregnancy in which the fetus is diagnosed with a disability.

With respect to future research, qualitative data, obtained from personal interviews, are needed to gain further under-

standing of the complexity of women's individual decision making during pregnancy. It should be noted that women in this study represented a sample of convenience and were referred to counseling for a variety of reasons that limit the generalizability of these findings. Women who were referred to counseling due to their age, rather than to an abnormal blood test, may have, as did those in the Santalahti et al. (1998) study, viewed their genetic counseling session as a "self-evident act" and thus might not have been as alarmed about the referral as women who had received an abnormal test result. In addition, women who have access to prenatal screening may differ from those who do not have a similar level of prenatal care. Additional studies are needed to further investigate the genetic screening process and its relationship to women's decision making.

As Rothman (1993) pointed out, "decisions to continue or terminate a pregnancy are never medical decisions. They are always social decisions" (p. 63). The choice about whether to give birth to a child with a disability is an important one, both for the family and for the child. Choice includes having knowledge of quality-of-life issues about disability as well as access to the resources and support services necessary for those who live with disabilities. Only when women are fully informed about disabilities and disability issues can they make informed and ethical choices regarding their pregnancies.

AUTHORS' NOTE

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