

THE ROLE OF ULTRASOUND RESULTS IN GENETIC COUNSELING FOR
AMNIOCENTESIS

by

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The present study explored whether a nontraditional method of genetic counseling for amniocentesis, in which parents received their ultrasound results before deciding on the amniocentesis, was more effective than the traditional method and whether emotions influenced the decision making process. The subjects were genetic counseling clients with high-risk pregnancies. Clients of two genetic counseling centers, each using one of the two models, completed questionnaires throughout their counseling session, measuring changes in their psychological symptoms, their emotions toward amniocentesis, and their satisfaction with the counseling services. No conclusive evidence indicated the experimental method was more effective at improving these factors; however with both methods, client anxiety, relaxation, somatic well-being, and contentment improved. Emotions toward amniocentesis successfully predicted reported likelihood of having an amniocentesis, and reported likelihood was related to actual decisions. Clients expressed high satisfaction with the counseling they received.

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The necessity of psychological counselling during the prenatal diagnostic process is apparent. Equally obvious is the need for further scientific research into the emotional facets of fetal genetic assessment. Only by acknowledging and further exploring these important issues will prenatal diagnosticians realize their full potential to serve the psychological and physical needs of an informed reproductive populace. (Falek, 1984, p. 180)

Pregnant women that show an elevated risk of having a baby with certain birth defects and other genetic disorders are offered an amniocentesis to determine if the baby is affected. Amniocentesis is a procedure in which a needle is inserted through a pregnant patient's abdomen into the amniotic cavity surrounding the fetus to draw a small amount of fluid, which can be analyzed for certain genetic disorders (Grobstein, 1979). Because the amniocentesis procedure is invasive, it carries a certain risk. Genetic counseling, a form of counseling that revolves around families who have concerns regarding genetic disorders, is provided to help clients decide if they want to undergo the amniocentesis procedure or other prenatal diagnostic methods.

This counseling is an emotional session for the expectant parents because of the risk of the procedure and the possibility of discovering that the fetus is not healthy. In undergoing this test, they face the fear of the test results, the fear of the slight risk of miscarriage or infection due to the procedure, and the fear of the procedure itself (Phipps & Zinn, 1986; Robinson, Tennes, & Robinson, 1975). Once the laboratory results return, either the family can relax or it must begin to deal with the ramifications of an abnormal

result. Some families choose to abort an affected fetus while others elect to keep the baby. Those who opt for the latter then have the benefit of time in which to prepare for a baby with possibly serious health demands.

Most families are referred by their physician for prenatal diagnosis if they have a high-risk pregnancy, which means that because of some “genetic, maternal, environmental, or fetal” factor or factors they have a higher likelihood of having a child with a disorder (Gorman 1995, p. 225). For instance, women who have previously had a child with a genetic disorder or women over 35 years old, because of the higher likelihood of the child having Down’s Syndrome, are referred to counseling. Parents who know they are at risk for having a child with a certain genetic disorder are sometimes referred for an amniocentesis to determine if the fetus has the disorder. Some parents wish to check for common neural malformations like the one that causes the disorder spina bifida (Hsia, 1977).

An ultrasound procedure is required before undergoing an amniocentesis. The ultrasound shows the parents and the medical personnel a two-dimensional image of the fetus. The physician can determine from the ultrasound the location of the fetus in order to determine where to insert the needle into the mother’s abdomen. The ultrasound sometimes contains information significant to this decision; for instance, it can indicate if there is a possibility that a fetus has Down’s Syndrome or a spinal malformation (Robinson & Henry, 1985). Traditionally, clients have a session with their genetic counselor during which they decide whether or not to have an amniocentesis. If they elect to have an amniocentesis, they then leave the session to undergo an ultrasound, which is followed without further counseling by the amniocentesis. If they choose to forego the

amniocentesis, they may still opt for other primarily screening procedures, i.e. an ultrasound or a blood test.

The present study investigates the effect of a new method of genetic counseling for amniocentesis on patient decisions to elect or decline an amniocentesis. Before elaborating on the details of the study, I provide an overview of the role of genetics in medicine. Following that is a review of previous findings in the psychological field of decision making that offer insight on the present study. Last is a discussion of the counseling method that the present study explores, relevant findings about emotions in genetic counseling and the hypotheses of the present study.

Background

Health professionals predict that in twenty to thirty years physicians will be primarily practicing preventive medicine. It will be standard practice to be able to examine the entirety of each patient's genetic blueprint to identify diseases to which that patient is predisposed. The doctor will then be able to recommend preventive therapies or other such measures to avoid these disorders. Pharmaceutical companies will then primarily develop drugs to prevent rather than to cure disease. Such predictions have been based on early feedback from the Human Genome Project, an international effort founded in the late 1980's to map the human genome (Hood, 1992). The human genome is the genetic code contained in human cells in the form of the chemical deoxyribonucleic acid, known as DNA (Kevles, 1992).

The field of medicine faces an incredible challenge in the years to come as a result of the discoveries of the Human Genome Project. Physicians now know much more about the genetics of conditions than they understand about methods of dealing with the medical reality of those conditions. Researchers have the challenge of learning to interpret the map of the genes they are assembling and of developing therapies and preventive measures to accompany that map.

While researchers are developing a broader knowledge base and while the role of physicians is evolving toward preventive medicine, the field of genetic counseling is emerging as an integral component of health care. Genetic counseling is a fairly new field; it originated when physicians allied with social workers to explain to families the intricacies of genetic disorders and to refer families to support services.¹ It was not until 1969 that it was established as a professional practice when Sarah Lawrence College offered the first graduate program for a Master of Science degree in Genetic Counseling. Today there are approximately 1000 genetic counselors practicing in the U.S. and Canada (Smith, 1993).

Using a non-directive approach, genetic counselors provide genetic information such as the probability that a couple who has a family history of a particular genetic condition will have a child with that condition. The non-directive nature of genetic counseling merits attention; the counselor's objective is to help the family make the best decision possible while not allowing her personal or professional judgment to affect the family's decision (Fraser, 1977; Kessler, 1979). For instance, a genetic counselor who has just told a pregnant woman that her child will be born with a severely debilitating condition is professionally obligated to present abortion as one of the woman's options.

The genetic counselor might personally disapprove of abortion or might have the professional opinion that abortion is an inappropriate means of dealing with the situation. Nevertheless, she must put her feelings aside when she discusses abortion as an alternative for this woman, to whom abortion could seem to be the only option with which she can live. (Rapp, 1993).

Helping families in crisis to make a decision is a delicate task. While the counselors help the family make sense of the often complicated genetic information, they also help the families deal with the emotions that arise as they consider the ramifications of the disorder in question. This enables the family to make a decision that is as rational as possible while they are dealing with emotionally charged issues such as future childbearing, the possibility of abortion,² and how to deal with an affected family member. Genetic counselors refer families to other support services if needed (Hsia, 1977; Robinson & Henry, 1985).

Much of the work genetic counselors do today is in prenatal diagnostic centers in major hospitals. One of their roles in this field is talking with clients who are considering an amniocentesis. The counseling for an amniocentesis begins with a discussion about the family medical history and about the reason the family is in for counseling. The next step is familiarizing the client with the procedure. This includes a discussion of the possible risks of miscarriage and infection. Then the counselor discusses with the family what can and cannot be found with the amniocentesis. They cover what would happen if they found an anomaly, or an abnormality, and they discuss alternate procedures that avoid amniocentesis (Grobstein, 1979). For instance, a family can choose instead to undergo an ultrasound and have blood screens that screen for certain disorders, revealing the probable

risk that the fetus has a disorder. In the case of ultrasound, the test is a diagnostic test as well as a screening test; it can detect heart problems with confidence. Clients can also elect to have only one of these procedures.

The decision to have an amniocentesis is perplexing for some families because, while the amniocentesis provides more varied and more conclusive information than the ultrasound and blood tests, it carries some risk to the fetus. Inducing abortion is the most common risk associated with amniocentesis; complications occur in approximately 1 of every 400 pregnancies (Rose, 1995). Because this decision is so difficult for and crucial to the families involved, genetic counselors are concerned with providing their patients optimal service. This is the broad aim of the present study: to aid in improving genetic counseling services.

Decision Making

Because the decision to have an amniocentesis involves grave considerations and multiple, conflicting emotions, genetic counseling is needed to help parents unravel the genetic information and then utilize that knowledge in the context of their values and beliefs (Rapp, 1993). The decision is so critical because of the far-reaching consequences of the alternatives. Regardless of which option they choose, there are possible long-lasting, negative ramifications involved with which the parents will have to live. For instance, if a couple decides to have an amniocentesis and learns the fetus is affected with Down's Syndrome, they must decide whether to keep or abort the fetus; they might also consider putting the child up for adoption. Rearing a child with a serious illness is a major

undertaking. However, the alternatives, abortion and adoption, also entail serious psychological struggles.

In order to help clients make a sound decision, incorporating the complex genetic information presented them in the counseling session, one of the key goals of genetic counseling is to “give reliable information and to hope the counselees make informed decisions based on the information they receive” (Smith & Antley, 1979, p. 257). Unfortunately, this goal is difficult to achieve partly because genetic counselors rarely have the luxury of speaking to families in absolutes. With only the information available from a family’s medical history and perhaps a blood screen or ultrasound, rarely are they sure that a child will or will not be born with an anomaly. Even with genetic screening results available, there is a certain likelihood that the outcome of the test is wrong. Usually, the genetic counselor is limited to presenting the family with a percent likelihood of the child expressing a disorder. The drawback to explaining genetic risk in terms of percentage likelihood is that people have trouble understanding the concept of probability figures and they also struggle with implementing this information in decision making (d’Ydewalle, 1987).

Genetic counselors have the troublesome task of presenting risk probabilities in a way that the clients can comprehend well enough to apply to their decision making process. Often counselors discuss risk figures using various approaches, hoping the client will relate to at least one approach. For example, a genetic counselor might tell a patient that she has a 1%, or 1 in 100, chance of having an affected child, while also pointing out that that is the same as a 99%, or 99 in 100, chance of having a healthy child. For patients who are not willing to risk having an affected child, the 1% chance of having an affected

child is the perspective that will apply. They do not want to risk being the “one person in one hundred.” Even with a relatively low risk, they could not live with the ramifications of having an affected child. Conversely, patients who are willing to accept the risk of having a child with a disorder will relate to the perspective of having a 99% chance of having an unaffected baby. Providing both perspectives is an important practice, as previous studies show that the way options are worded is influential in how decisions are made (Plous, 1993).

Not only do genetic counselors have the challenge of helping clients interpret probability figures, they also need to ensure that the clients are in a psychological state conducive to reception of this information. Several key factors that hinder the decision making process by interfering with patients’ information retention and comprehension are anxiety, anger, emotion toward amniocentesis and an exaggerated perception of the risk involved in amniocentesis (Alhakami & Slovic, 1994; Benthin, Slovic, Moran, Severson, Mertz, & Gerrard, 1994; Brown, 1948; d’Ydewalle & Evers-Kiebooms, 1987; Johnson & Tversky, 1983; Peters, Flynn, & Slovic, 1996; Peters & Slovic, 1996; Smith & Antley, 1979).

Client anxiety and anger are often connected. Frequently when parents learn their child has an elevated risk for a genetic disorder like spina bifida or Down’s Syndrome, the parents’ anxiety increases, causing the situation to escalate into a crisis. At such times, clients can become too preoccupied by their anxiety to process what the genetic counselor relates to them. Further, their reaction to this crisis state is often anger. They are then further impaired in their ability to receive information presented to them in the genetic counseling session, reducing their decision making capacity (Smith & Antley, 1979).

Negative affect, or emotion, toward the amniocentesis procedure itself also can have an adverse effect on the genetic counselor's success in helping patients make a decision to elect or decline an amniocentesis. A genetic counselor will have a difficult session if the clients have already decided against the amniocentesis because they have negative feelings toward it. While the goal of genetic counseling for amniocentesis is not to impose the test on clients, it is important that the clients be receptive to the information available to them in the session regarding their child's risk probabilities and what the amniocentesis could mean to them as parents. Parents cannot make an informed decision to reject an amniocentesis if they make up their mind before they come to the counseling session, which is designed to expose them to pertinent information regarding the procedure.

Clearly psychological affect, or emotion, toward the amniocentesis procedure is influential in a patient's decision making process. Various studies have considered this relationship between affect toward an object and decisions made regarding the object. One such study investigated the influence of people's images of objects on their preference for the objects. They found that people prefer objects with which they associate positive emotions. Peters and Slovic (1996) discuss this seemingly simplistic statement, postulating that affect is an "orienting disposition that guide[s] people's decisions about complex and risky topics" helping them "navigate in a complex, uncertain ...world" (p. 1427).

Part of the difficulty in using affect as a guide in making decisions about complex topics is the fact that this often involves ambivalence, or conflicting emotions toward one object. Several studies about emotional responses to objects have steered away from the

standard way of measuring affect toward an object, which has been to assume that it can be placed on only one scale that extends from positive to negative--that a person can only feel bad or good about something (Crites, Fabrigar, & Petty, 1994; Russell, 1980; Watson, Clark, & Tellegen, 1988, as cited in Peters & Slovic, 1996). One experiment observed the behavior of rats in a narrow alley, at the end of which was a piece of food and an apparatus that delivered an electric shock. The experimenters found that rats avoided the end of the alley less when they were hungry than when they were satiated. Thus the organism acts according to the strength of each emotional pull (Brown, 1948). When they were very hungry, their desire for food was stronger than their fear of shock. This showed that organisms can exhibit both object-seeking and object-avoiding behavior simultaneously.

The Brown study shows that the role of affect is in fact more complex than just one scale of emotion, allowing for two dimensional emotional responses, which are comprised of one negative and one positive scale. In other words, rats--and people, as well--can feel both positive and negative emotions toward something. Consider the following everyday example involving a person's affect toward a chocolate bar: The person knows that the chocolate bar is unhealthy and will contribute to his weight problem; hence, he has a negative emotional response to the candy. Nevertheless, another dimension of his feelings toward the chocolate is his positive association with its pleasant taste and texture.

One area in which these two-dimensional responses have been investigated is risk-taking among adolescents. Benthin et al. (1994, as cited in Peters & Slovic, 1996) found that positive and negative emotions the youths exhibited toward a behavior influenced

their decisions variably depending on the context of the scenario. For example, even though a teen is aware of the consequent risks involved in smoking, she adopts the habit. She is aware that it is a destructive behavior and so has negative emotions associated with this fact. Nevertheless, the positive emotions involved with the desired social feedback (i.e. peer pressure to smoke or the desire to portray a rebellious image) ultimately determine her decision. In another scenario, the teen might decide differently. If she becomes involved with a new group of friends who encourage her not to smoke, her negative affect toward smoking might prevail.

This ambivalence toward simple objects, such as chocolate bars and cigarettes, hints at the ambivalence involved in responses to more complicated objects like amniocentesis. Obviously, the feelings associated with amniocentesis are opposing and render decision making a difficult process. The reason for the presence of ambivalence in deciding to accept or reject an amniocentesis are apparent. Parents express negative affect toward amniocentesis due to the physical risks such as miscarriage and due to threatening information that could be revealed by the test. On the other hand, parents experience positive emotions toward amniocentesis if they look forward to the information as a benefit or if they desire the opportunity to elect an abortion if the results are unfortunate.

Clearly, a patient's affect toward amniocentesis affects her decision to undergo the procedure. Perceived risk is another factor involved in the patient's decision making process that can hinder her reception and comprehension of complex genetic information. Further, a person's perception of a risk is influenced by her affect toward that hazard (Peters & Slovic, 1996). Johnson and Tversky (1983, as cited in Peters & Slovic, 1996) found that a tragic story created negative affect toward an involved object or act, causing

subjects to inflate estimates of risk in events involving that object or act not related to the tragic story. This can be applied to the genetic counseling setting. If a woman has previously miscarried after having an amniocentesis or if she knows someone who has had this experience, the resulting negative affect she experiences toward amniocentesis may raise her estimate of the perceived risk of miscarriage associated with amniocentesis compared to women without the same experience. Her perceived risk may be higher than the actual statistical risk, which will then be reflected in her decision to accept or reject the amniocentesis.

On the other hand, a patient who knows several people who have had uneventful amniocenteses might perceive the risk of miscarriage to be a 0% chance and make her decision accordingly, i.e., without considering the physical risks, because her acquaintances reported no troubles with their amniocenteses. If this woman then has a miscarriage, she will not only be shocked, but perhaps regretful of her decision to undergo the amniocentesis.

A study by Alhakami and Slovic (1994) about the inverse relationship between perceived risk and perceived benefit supports the fact that women's perceived risk of amniocentesis is related to their willingness to undergo the procedure. They found that if people perceive a risk to be very high, they will consider the benefits of the hazard to be low, and the opposite also holds true. In the case of genetic counseling for amniocentesis, if a patient believes the risk of the procedure is high, they will perceive the benefit as low and will then be more likely to decline one. Conversely, if they think the risk is low, they are more likely to elect an amniocentesis.

Another element that perhaps influences patient decision making in genetic counseling is the availability of the appropriate opportunities for the patient to pose questions to the genetic counselor. Two studies have investigated the situational and social factors involved in medical decision making within the context of the physician-patient relationship. Beisecker and Beisecker (1990) found that patients did not seek as much information as they wanted until they had interacted with their physician for at least 19 minutes (as cited in Hodne, 1995). Waitzkin (1985) also asserts that patients' requests for more information correspond with increased length of acquaintance with the physician (as cited in Hodne, 1995). Further, Waitzkin found that uncertain or poor prognoses led to greater information sharing between patient and physician.

When applied to the genetic counseling situation, these studies perhaps demonstrate how an additional meeting with the genetic counselor after the ultrasound, but before a decision about the amniocentesis has been made, could be more effective in patient decision making in genetic counseling for amniocentesis. With increased time with the genetic counselor, the patients might reach the desired comfort level necessary for them to ask as many questions as they have in mind. Further, if the ultrasound conveys the possibility of an anomaly, analogous to what Waitzkin called an uncertain or poor prognosis, the patients theoretically would seek more information thereafter, in which case, an additional meeting with the genetic counselor after the ultrasound might be beneficial to allow clients to ask further questions. Longer interaction with patients and uncertain or poor prognoses might increase patient information-seeking behavior in the genetic counseling setting, enabling the patient to make a more informed decision.

The Present Study

At most fetal diagnostic centers, the family decides whether or not to have the amniocentesis at the end of their genetic counseling session. If they decide to proceed with it, they then have an ultrasound followed by the amniocentesis. The ultrasound results are not included in the genetic counseling session unless the clients specifically request to discuss the ultrasound results with their genetic counselor before they make their decision. If they decline to have an amniocentesis, the options of having an ultrasound or a blood test remain. At Sacred Heart Medical Center in Eugene, Oregon, this order is different in that the ultrasound is performed in the middle of the counseling session. Clients undergo an initial counseling session, have an ultrasound, and then meet again with the genetic counselor to discuss the meaning of the ultrasound results and to decide to accept or reject the option of the amniocentesis.

Meeting again after the ultrasound is advantageous in that the family has one more piece of information with which to make a decision. The ultrasound can show if the fetus has an anomaly and it can help the family become more comfortable with the idea of undergoing a diagnostic medical procedure. Furthermore, the ultrasound is a reassuring experience for patients if no anomaly is detected. Reading, Cox and Campbell (1988) comment that the ultrasound process “makes patients feel more confident, informed, involved, reassured, and relieved” (p.169).

One of the goals of the present study is to examine whether the procedure modification adopted by Sacred Heart has an effect on the way families choose to have an amniocentesis. We also attempted to determine which psychological factors play a role in

decision making in this situation. It may seem that the simple hypothesis that emotion is involved in decision making in genetic counseling is obvious. However, for the most part, although past studies of decision making in genetic counseling regarding amniocentesis do mention the emotional aspect of genetic counseling, they tend to focus on outcomes (e.g., Did the family elect to have an abortion or to continue with the pregnancy?) in evaluating the effects of genetic counseling. Much of the available literature on genetic counseling indicates that there is a need for more studies regarding the effectiveness of genetic counseling in regard to how families make decisions. With this information genetic counselors could provide more effective services (Beeson & Golbus, 1979; Hsia 1977; Shaw, 1977).

There are a few studies that have employed psychological scales to measure emotional reactions to ultrasound and amniocentesis. One such study measured the psychological reactions to ultrasound of women with low-risk pregnancies (Michelacci, Fava, Grandi, Orlandi, & Trombini, 1988). Michelacci et al. measured the women's anxiety, depression, somatic (physical) symptoms, and hostility before undergoing an ultrasound each trimester. They found that the women's levels of anxiety, depression, somatic symptoms, and hostility decreased after each ultrasound performed. It should be considered that no abnormalities were found. If abnormalities had been found, it is probable the researchers would have found a rise in negative symptoms after the ultrasound.

Like the Michelacci et al. study, the present study measures the same four psychological reactions to ultrasound, utilizing the same measure, the Symptom Questionnaire, to analyze the women's reaction to ultrasound; however, the present study

considers women in higher-risk pregnancies, i.e. older women or women with a history of genetic problems. The Michelacci et al. study is useful, therefore, to show the behavior of these symptoms in women with low-risk pregnancies undergoing ultrasound. This gives us some clue as to what can be expected from women in higher-risk pregnancies. One would expect that these high-risk women would have similar, but elevated, negative reactions to the ultrasound procedure in general because the women with high-risk pregnancies would have similar concerns about possible problems detected by the ultrasound as the low-risk women had. The women with higher-risk pregnancies would simply be more worried because of their awareness of their elevated risk status.

Fava, Kellner, Michelacci, Trombini, Pathak, Orlandi, and Bovicelli (1982) also used the Symptom Questionnaire to measure the psychological reactions of pregnant women, but they examined the women's reaction to amniocentesis instead of to ultrasound. They compared the anxiety, depression, somatic symptoms, and hostility of a group of pregnant women with low-risk pregnancies and a group of pregnant women who had been offered an amniocentesis due to higher-risk pregnancies. They showed that in the high-risk group, after the physician recommended an amniocentesis, women's anxiety, depressive symptoms, and hostility were significantly elevated as compared to after the amniocentesis was performed. After the amniocentesis was performed, the women's anxiety, depressive, and hostility levels dropped while their relaxation, contentment and somatic well-being increased (Fava, et al., 1982). In summary, the Michelacci et al. and Fava et al. studies show that one would expect women with high-risk pregnancies to show elevated negative psychological symptoms and depressed positive symptoms before having an ultrasound, after which the negative symptoms would decrease and the positive

symptoms would increase, but the negative symptoms would remain somewhat elevated and the positive symptoms would stay somewhat depressed before the amniocentesis procedure takes place.

Given that negative psychological symptoms are elevated and positive symptoms are depressed in patients referred for genetic counseling for a high-risk pregnancy and that these symptoms improve after having a normal ultrasound, one would expect Sacred Heart patient symptom levels to improve more during their genetic counseling session, which includes having ultrasound results, than symptoms of patients at genetic counseling centers that do not provide ultrasound results during their session. The present study examined this premise, investigating whether meeting with the genetic counselor before and after the ultrasound, thus giving families in genetic counseling their ultrasound results before they make their decision to have an amniocentesis, affects the role that psychological affect, or emotion, plays in the amniocentesis decision making process. Further, it investigated the likelihood that the family would elect to undergo an amniocentesis. Last, we investigated whether counseling procedures affect client satisfaction with the genetic counseling experience. These inquiries are important to the way that patients receive and understand genetic information presented to them in genetic counseling services. This is pertinent in that clients need to be prepared to apply this information to their decision making process in order to enable them to make an informed decision with which they can live.

To achieve these goals, clients of the Fetal Diagnostic Center, Sacred Heart Medical Center in Eugene, Oregon and of the Department of Medical Genetics at Legacy Emanuel Hospital and Health Center in Portland, Oregon completed a series of

questionnaires about their emotional and physical well-being, about their emotional reactions toward amniocentesis, and about their satisfaction with the genetic counseling services provided.

The specific hypotheses tested were: 1) that throughout the genetic counseling session, Sacred Heart participants would exhibit a greater overall decrease in negative psychological symptoms (anxiety, depression, somatic symptoms, and hostility) and a greater overall increase in positive psychological symptoms (relaxation, contentment, somatic well-being, and friendliness) than Emanuel participants, 2) that negative psychological symptoms would be lower and positive psychological symptoms would be higher after the ultrasound test results than before the ultrasound results except for those who have abnormal results, 3) that the Sacred Heart patients would show a greater overall increase in positive affect toward the amniocentesis than the Emanuel patients, 4) that affect toward amniocentesis (positive/negative) would predict reported likelihood of having the procedure (very likely/not likely) 5) that the Sacred Heart group would display higher satisfaction with the genetic counseling process than the Emanuel Hospital group.

METHODS

Participants

This study compared two groups of pregnant women who had been referred for genetic counseling for amniocentesis to the Fetal Diagnostic Center, Sacred Heart Medical

Center in Eugene, Oregon and to the Department of Medical Genetics at Legacy Emanuel Hospital and Health Center in Portland, Oregon. The Emanuel group was selected to be compared to the Sacred Heart group because it employs the traditional method of genetic counseling for amniocentesis while the center at Sacred Heart does not. The two centers have essentially the same method of conducting amniocentesis counseling except for the variable of whether or not having an ultrasound and discussing the ultrasound results are an integral part of the genetic counseling session. The two hospitals were also selected because they are both major hospitals located in urban locations in Oregon, serving a diverse clientele.

Although these two large hospitals are in urban centers, they have a substantial referral radius from both rural and urban areas of Oregon. For instance, Sacred Heart has clients from as far away as northern California and Emanuel sees clients from Alaska, which illustrates that the populations served by the Eugene and Portland hospitals are considerably more diverse than they would be if they were exclusively from Eugene and Portland.

The genetic counseling centers recruited subjects from their clients who had been referred to genetic counseling for the amniocentesis procedure. We sought clients over eighteen years of age. Twenty-two subjects participated in this study. Although originally we intended to survey the patients' partners, few women came to their sessions with partners, rendering any analysis of partner data useless.

The subject samples consisted of five women from Emanuel Hospital and 17 women from Sacred Heart Medical Center. Three women in the Emanuel Hospital group were white, while one was Asian/Pacific Islander and another indicated she was both white

and American Indian/Alaskan Native by checking two categories on the survey. Only one woman was not a native speaker of English; she had been speaking English for 15 years. The Sacred Heart subjects were also primarily white women whose native language was English. The Sacred Heart group consisted of 17 native English-speaking women all of whom were white except for one who indicated she was Hispanic and another who indicated she was white as well as Hispanic.

Two Emanuel participants and 15 Sacred Heart patients disclosed the size of the city in which they resided. One Emanuel patient lived in a semirural town and one was from an urban center. Of the Sacred Heart subjects, one was from a rural area, four lived in semirural towns, and seven lived in urban communities. Five Emanuel patients reported their income. Two women reported earnings of \$15,000 to \$30,000, one woman had an income range of \$30,000 to \$45,000, another had an income of \$45,000 to \$60,000, and the last woman reported an income of \$60,000 to \$75,000. Fourteen Sacred Heart participants disclosed their income range. Two patients had an income range of \$0 to \$15,000, four reported earnings of \$15,000 to \$30,000, and one had an income of \$30,000 to \$45,000. Four reported to fall in the range of \$45,000 to \$60,000 while two had an income of \$60,000 to \$75,000. One woman from Sacred Heart reported an income of over \$75,000.

Two Emanuel subjects gave their age; both were 35 years old. Twelve Sacred Heart participants indicated their age. The average age, which was close to that of the women in the Emanuel group, was 31.8 years. The Sacred Heart participant age range was from 19 to 38 years. Both hospitals had only one woman who indicated that she had undergone an amniocentesis previously.

The purpose of obtaining demographic data was to show that the two hospitals draw generally similar client populations. The two groups are mostly white, English-speaking women with geographically and economically diverse backgrounds. They are of elevated maternal age, mostly without previous amniocentesis procedures. Although reassurances of the confidentiality of their responses were stressed to women during the recruiting process, many subjects chose not to answer some or all of the demographic questions.

Procedures

Questionnaire Overview

The primary aim of this study was to investigate client decision making about amniocentesis by measuring key psychological factors at different stages in the differing genetic counseling processes employed by Sacred Heart and Emanuel Hospital. Patients were asked to complete a series of self-report questionnaires over the course of their counseling session. After reading and signing the consent form, the subjects completed the sequence of questionnaires in the following manner: If the clients consented to participate, the genetic counselor assigned each participant an experimental code number. Participants then received an envelope containing the series of questionnaires they would be completing. The participants' experimental code numbers were written on their respective questionnaires. The genetic counselor advised them throughout the session when to fill out each questionnaire. When the participants finished a questionnaire, they

returned it to its envelope. At the conclusion of the study, the participants were instructed to seal the envelopes and give them to an administrative assistant, who then mailed the envelopes to the principal investigator.

This process differed in the two counseling centers due to their different amniocentesis counseling formats, one of the main variables considered in this study. The Emanuel Hospital group completed only two questionnaires. After they signed the consent form, the subjects completed the first questionnaire before their counseling session. They filled out the second after the counseling session was over. (See included Questionnaire Timeline in Appendix A.) The mother then left to another part of the hospital to have her ultrasound if she had chosen to undergo an amniocentesis or if she elected to have only an ultrasound. She could change the decision to elect or decline the amniocentesis that she made in the genetic counseling session if the ultrasound results motivated her to reconsider her earlier decision. If she needed to, she could page the genetic counselor to discuss the ultrasound results before making a final decision.

At Sacred Heart the genetic counseling session paused midway for the patient to have the ultrasound, which took place in the Diagnostic Center and which afforded immediate results. After the ultrasound the genetic counselor and the family always reconvened to discuss the ultrasound results and whether they wanted to elect or decline the amniocentesis procedure. Thus the procedure for Sacred Heart participants was slightly different. The Sacred Heart subjects filled out three questionnaires about amniocentesis. They completed the first after giving consent to participate, the second after the ultrasound, and the third after the second part of the genetic counseling session, which was before the opportunity for amniocentesis.

The time before the genetic counseling session at which patients completed their first questionnaire will be referred to as Time 1. Time 2 corresponds to when Sacred Heart patients had just undergone their ultrasound procedure, at which time they completed their second questionnaire. Emanuel Hospital subjects did not fill out a questionnaire at Time 2 because they did not have an ultrasound. Both hospital groups completed a questionnaire at Time 3, which corresponds to the point after the entire counseling session had ended.

Recruitment Process

The Department of Medical Genetics at Legacy Emanuel Hospital and Health Center sent a letter to each client before their appointment, explaining that they might be approached to participate in this study. The letter included the consent forms to familiarize the clients with the study's procedure. Also, only clients from Emanuel Hospital who arrived early for their appointment were approached to participate in order to make it possible for the center to remain on schedule. When the clients arrived at the Department of Medical Genetics for their amniocentesis counseling appointment, the center's administrative assistant solicited their participation. She verbally assured the clients that participation was voluntary and confidential and that they could withdraw participation at any time without penalty.

At the other participating clinic, the Fetal Diagnostic Center, Sacred Heart Medical Center, the subject recruitment process differed slightly. Sacred Heart did not send out a preclinic letter and patients who were less than 15 minutes early were not necessarily

excluded. Sacred Heart had already begun the study when Emanuel decided to modify the recruiting process at their center. In order to maintain consistency within the Sacred Heart data, we chose not to switch to Emanuel's recruiting procedure. Aside from the initial difference in recruitment, the administrative assistant at Sacred Heart proceeded in the same manner as the administrative assistant at Sacred Heart, discussing with clients the issues of confidentiality and their right to withdraw from the study.

Questionnaire Components

The Sacred Heart subjects completed a series of three questionnaires and the Emanuel group completed a series of two questionnaires. Each of the questionnaires contained three primary psychological scales: a likelihood scale, a bipolar emotion scale and a symptom checklist. In addition to these three components, which will be described in greater detail later, the first questionnaire of each series also included demographic questions. The second questionnaire for the Emanuel participants and the third questionnaire for both hospital groups included a satisfaction survey. (All questionnaires can be found in Appendix B.)

The first key psychological scale included in each questionnaire was a 7-point Likert rating scale that asked clients at that point in time how likely they were to undergo an amniocentesis. This indicated if patients were becoming more or less likely to have an amniocentesis and if and when clients changed their minds about going through with the procedure.

The second element contained in each questionnaire was a bipolar emotion scale that required the clients to rate their emotional reactions to amniocentesis on seven point bipolar emotional scales such as good/bad and like/dislike (Peters & Slovic, 1996). The purpose of this measure was to show if the patients' emotional reactions to amniocentesis changed during the session, which in turn may have affected their decision to have an amniocentesis.

A symptom checklist called the Symptom Questionnaire was a third component in each of the questionnaires (Kellner, 1987). The Symptom Questionnaire evaluates the anxious, depressive, physical, hostile, relaxed, contented, physical well-being, and friendly symptoms a client currently expresses. It was included in all of the questionnaires administered in order to determine how the patients' emotional and somatic symptoms changed throughout the counseling process. The Symptom Questionnaire was adapted in two minor ways to make it applicable to this study. The phrase, "headaches" was modified to "Headache" and "Takes a long time to fall asleep" was changed to "Feels like it will take a long time to fall asleep." These changes were adopted because the Symptom Questionnaire was originally developed to question patients about a period of time preceding an appointment, whereas this study measured the client's symptoms at the time they filled out the questionnaire.

The Shiloh questionnaire was included with the second questionnaire administered to each hospital group (Shiloh, Avdor & Goodman, 1990). The Shiloh questionnaire is a 32-item satisfaction survey that was specifically designed to measure patient satisfaction with genetic counseling services. The survey gauges satisfaction with the emotional, instrumental, and procedural aspects of genetic counseling. In other words, it evaluates

client satisfaction with the genetic counselor's approach and the operational details of the session (i.e. how long clients waited to see the counselor). This is an important measure for the genetic counselors involved, as the results could suggest improvements to their respective genetic counseling centers, and could also reveal differences in satisfaction caused by the two different counseling procedures.

It was necessary to change some of the wording of the Shiloh questionnaire to make it relevant to the genetic counseling services involved in the study. The original Shiloh questionnaire refers to the genetic counseling provider as "doctor" in its questions. For instance, it asks, "Did the doctor explain your condition to you clearly?" (Shiloh et al., 1990, p. 525). Because the counseling in this study is provided by genetic counselors, the words "genetic counselor" replaced "doctor" throughout the questionnaires. Also, the doctor is referred to as "him" and "he" in the original measure. The genetic counselors involved in the present study were women, hence the words "her" and "she" replaced the masculine terms.

At Sacred Heart the Shiloh survey was included in the second questionnaire, which was delivered after the ultrasound and before the final amniocentesis decision was made (Time 2). At Emanuel the satisfaction measure was a part of the last questionnaire, which was delivered after their genetic counseling session ended (Time 3). Therefore, the satisfaction data collected for the Sacred Heart subjects are only reflective of client attitudes toward the genetic counseling experience prior to the final interaction with the counselor. The data are consistent within each hospital group, but they are not exactly equivalent across hospitals in terms of when they came in the counseling session. This is because the Emanuel group had completed their genetic counseling session and had made

a decision by the time they completed their Shiloh survey while the Sacred Heart group had covered only part of their genetic counselor's agenda since they had yet to reconvene after the ultrasound. They had discussed neither their ultrasound results nor their final decision regarding the amniocentesis.

Ultrasound Results

In addition to the questionnaire data, dichotomous ultrasound results (normal, not normal) and choice on amniocentesis results (elected, declined) were obtained. The genetic counselors sent the results to the principal investigator identified only with the subject's experimental code number to maintain patient confidentiality. These data were then utilized in the data analysis to determine how positive and negative results affected the decisions families made.

RESULTS

Psychological responses to amniocentesis

Patient responses to the 92-question Symptom Questionnaire were categorized into eight subscales, four negative (anxiety, depression, somatic symptoms, and hostility) and four positive (relaxation, contentment, somatic well-being, and friendliness). There were 17 possible points in the four negative subscales while there were six possible points in the four positive subscales. An elevated score indicated increased expression of that

symptom. The means were then compared at two times using a 2 (Sacred Heart vs. Emanuel) x 2 (before counseling session vs. after counseling session) within-between ANOVA (see means in Table 1).

The hypothesis that Sacred Heart patients would exhibit a greater decrease in negative psychological symptoms and a greater increase in positive psychological symptoms than Emanuel patients over the course of the genetic counseling session was confirmed only in the relaxation subscale. The interaction of hospital and time on the relaxation scale was significant, $F(1, 16) = 4.81, p = .043$, such that Sacred Heart patients became more relaxed over time, whereas Emanuel patients stayed about the same (session means in Table 1). It must be noted that there was a main effect of time on relaxation scores, $F(1, 16) = 4.81, p = .043$, but this was driven entirely by the changes in the Sacred Heart scores because Emanuel scores were approximately the same over time while the Sacred Heart patients became more relaxed.

Patients at both hospitals showed a decrease over time in the anxiety scores, $F(1, 16) = 9.05, p = .008$. In addition, patients at both hospitals showed an increase in contentment scores, $F(1, 16) = 7.33, p = .016$ and somatic well-being scores, $F(1, 16) = 7.29, p = .016$ (see means in Table 1). However, there was no effect of hospital and no interaction effect on either of these three variables; thus, both hospitals' counseling procedures were successful in making patients more comfortable according to these scales, but Sacred Heart's procedure was no more successful than Emanuel's.

There was a marginal effect of hospital on the friendliness scale, $F(1, 16) = 3.80, p = .069$, with patients at Emanuel expressing marginally greater feelings of friendliness toward others (see means in Table 1). There were no effects of hospital or time, and no

interaction effects on the depression, hostility, or somatic scales. In all cells scores on these scales were very low, suggesting a possible floor effect. Essentially a floor effect is a situation in which the initial scores are so low that any drop would be negligible.

Sacred Heart clients after ultrasound results

Because the Sacred Heart group was measured three times, it was possible to investigate more specifically at what point psychological symptoms changed. As predicted, in Sacred Heart patients there was a significant decrease in some negative psychological symptoms and a significant increase in some positive psychological symptoms after ultrasound for the entire participant population, as well as for the population excluding those with abnormal ultrasound results. In the entire sample of thirteen participants, including those with abnormal ultrasound results, anxiety dropped significantly between Time 2, that is to say, after the ultrasound procedure, and Time 3, which is after the genetic counseling session and the amniocentesis decision, $F(1, 24) = 9.67, p = .005$ (see means in Table 1).³ There was no significant difference in anxiety from Time 1, which is before the counseling session, to Time 2. A significant increase in relaxation occurred between Time 1 and Time 2, $F(1, 24) = 5.99, p < .003$, as well as between Time 2 and Time 3, $F(1, 24) = 4.53, p < .05$. The friendliness and contentment subscales displayed no significant change between Time 1 and Time 2, but between Time 2 and Time 3, there was a significant rise in friendliness, $F(1, 24) = 5.99, p < .03$, and a significant increase in contentment, $F(1, 24) = 10.30, p < .004$. Also, somatic well-being experienced a marginally significant increase from Time 2 to Time 3, $F(1, 24) = 3.85, p <$

.07. Contrary to prediction, there was no significant decline after ultrasound in Sacred Heart patients in depression, hostility, and somatic symptoms, again, probably due to a floor effect.

Adjusting for patients with abnormal ultrasound results by removing the data of the one participant who had abnormal results did not change the data for the entire participant population. Although we had planned to study the psychological reactions of women with abnormal ultrasound results, the data for the one participant with abnormal results could not be utilized because one subject is not a statistically relevant sample size.

Affect toward amniocentesis

After reversing the responses to some questions such that all low scores corresponded to high positive affect toward amniocentesis, the means of the scores for each hospital's group of the semantic differential scale measuring client affect toward the amniocentesis procedure were found by summing each participant's responses to the eight bipolar scales. A 2 (Sacred Heart vs. Emanuel) x 2 (before session vs. after session) within-between ANOVA was conducted on participant affect (see means in Table 2).

There was a marginal effect of time, $F(1, 16) = 3.33$, $p = .087$, such that patients expressed greater positive affect toward amniocentesis at the end of their counseling sessions than they did at the beginning (see means in Table 2). However, there was not a main effect of hospital. Furthermore, contrary to the hypothesis that Sacred Heart participants would show a greater overall increase than Emanuel participants in positive affect toward amniocentesis, no interaction of time and hospital effect was found. When

Sacred Heart patients who received irregular ultrasound results and Sacred Heart patients for whom there were no ultrasound results were removed from the sample, the results were very similar.

Again, because Sacred Heart patients were assessed three times, it was possible to see if there was a particular point at which affect toward amniocentesis became more positive. The change from Time 1 to Time 2 was not significant, nor was the change from Time 2 to Time 3. However, the overall change from Time 1 to Time 3 was significant, $F(2, 13) = 3.28, p = .05$, suggesting that affect became gradually more positive over time (see means in Table 2). Removing the data of the participant with abnormal ultrasound results and the data of those participants with no ultrasound information yielded similar results: no significant change in affect toward amniocentesis was found.

Reported likelihood of undergoing an amniocentesis

A 2 (Sacred Heart vs. Emanuel) x 2 (before session vs. after session) within-between ANOVA was conducted on participant reported likelihood to undergo an amniocentesis (see means in Table 2). The reported likelihood to undergo an amniocentesis that Sacred Heart and Emanuel patients experienced were not significantly affected by time, hospital, or interaction between hospital and time.

In order to control for abnormal ultrasound results and those with no ultrasound results, a 2 (Sacred Heart vs. Emanuel) x 2 (before session vs. after session) within-between ANOVA was conducted on patient reported likelihood to undergo an amniocentesis, excluding the subject at Sacred Heart who had abnormal ultrasound results

and two Sacred Heart participants who had no ultrasound results (see means in Table 2). After altering the sample in this manner, patient reported likelihood to have an amniocentesis experienced a marginally significant decrease as an effect of time, $F(1, 14) = 4.39$, $p = .055$ (see means in Table 2). However, there was no effect of hospital and interaction between hospital and time.

Examination of only Sacred Heart clients at all three times showed that although reported likelihood means appeared to drop, there was no significant effect of time (see means in Table 2), $F(2, 28) = .97$, $p < .393$. This was confirmed by a within-subjects ANOVA performed on Sacred Heart patient reported likelihood to undergo an amniocentesis (see means in Table 2).

Affect predicts reported likelihood of undergoing an amniocentesis

A regression equation with Sacred Heart participant affect toward amniocentesis at Time 1, Time 2, and Time 3 as predictor variables was able to predict reported likelihood at Time 3 to undergo an amniocentesis, explaining 77.9% of the variance in likelihood responses, $F(3, 9) = 10.59$, $p = .0026$. Affect toward amniocentesis at Time 1 was a significant predictor of reported likelihood at Time 3 of having the procedure ($\beta = -.933$, $p = .0004$), showing that high positive affect indicated high reported likelihood of having an amniocentesis. Conversely, affect at Time 2 was also a significant predictor of reported likelihood at Time 3 ($\beta = .774$, $p = .029$), but as affect rose, reported likelihood dropped. Affect at Time 3 was similar to that at Time 1 in that it was

marginally significant as a predictor of reported likelihood, ($\beta = -.622$, $p = .0581$), and that as positive affect increased, so did reported likelihood.

Choice to elect or decline amniocentesis

Between the two hospital groups there was not a significant difference in whether patients chose to elect or decline the amniocentesis procedure, $t(16) = .20$, $p = .841$. Out of curiosity, we examined patient choice to have amniocentesis and its relationship with affect toward amniocentesis and reported likelihood of having an amniocentesis.

For participants at both hospitals, using affect toward amniocentesis at Time 3 to predict the participants' choice to undergo amniocentesis resulted in correctly classifying 57.14% of the choices the women made, which was not significantly different from chance, $\chi^2(1, N = 14) = .460$, $p = .498$. However, when patient affect toward amniocentesis at both Time 1 as well as Time 3 were used to predict choice 92.86% of the choices the women made were correctly predicted, $\chi^2(1, N = 14) = 15.518$, $p = .0004$. Patient affect ratings at each of these times were not individually a significant predictor of amniocentesis choice.

There was a strong relationship between reported likelihood at Time 3 to undergo an amniocentesis and whether the patient chose to have an amniocentesis. A regression equation found reported likelihood of having the procedure was able to correctly predict 87.50% of the choices the women made, $\chi^2(1, N = 16) = 11.044$, $p = .0009$. Those who chose to have an amniocentesis reported to be more likely to have the procedure at Time 3. When we add reported likelihood at Time 1 to the regression equation, we found that

reported likelihood at Time 1 was not a significant predictor of amniocentesis choice. In fact, the predictions made by Time 1 and Time 3 together were slightly weaker than those made by Time 3 alone, only able to predict 86.67% of choices made, $\chi^2(1, N = 16) = 10.2952, p = .0058$.

Satisfaction with genetic counseling

As some questions were written such that low scores were associated with high satisfaction, the answers to these questions on the Shiloh satisfaction scale were reversed such that high scores (scores ranged from one to four) indicated higher satisfaction. With this adjustment, we found the mean score for each hospital group by summing each participant's responses and dividing by the number of questions. Contrary to prediction, a t-test showed that the Sacred Heart satisfaction scores ($M = 3.72$) were not significantly higher than the Emanuel scores ($M = 3.75$), $t(16) = .41, p = .69$. In fact, the scores for the two hospitals were nearly the same.

DISCUSSION

Few of the hypotheses of the present study were substantiated. This is not necessarily because they were incorrect; rather, unforeseeable limitations in the study resulted in a lack of participants. The original goal of this project was to have 150 patients from each hospital. However, staffing issues at each site caused subject recruitment to falter. Unfortunately, with low subject numbers statistical analyses are often inconclusive.

Small sample designs may lack the power to detect significant differences. In addition, extreme scores can influence means exceedingly with small samples. Not only did both hospitals have a very low number of participants, the subject sample sizes were vastly different in the two hospitals. Unbalanced sample sizes and very small samples violate the assumptions of many statistical tests, rendering suspect any conclusions drawn from a test with unbalanced or small samples.

Psychological responses to amniocentesis

The hypothesis that throughout the counseling session Sacred Heart patients would experience a greater overall decrease in psychological symptoms (anxiety, depression, somatic symptoms, and hostility) and a greater overall increase in positive psychological symptoms (relaxation, contentment, somatic well-being, and friendliness) than Emanuel patients was designed to determine whether the Sacred Heart method was more effective than the Emanuel method. However, we were unable to show that the Sacred Heart method of including ultrasound results in genetic counseling was more effective at improving seven of these eight measures of emotional and physical health. Only in the relaxation subscale were ultrasound results found to be more effective at improving a subscale score.

Furthermore, the greater change in relaxation in Sacred Heart participants is an unclear result because, although Sacred Heart showed a significantly greater change in relaxation, they began at a lower relaxation level and rose only to the approximate level of the Emanuel patients. Therefore, it is not conclusive whether the Sacred Heart method

was more effective at increasing relaxation than Emanuel's traditional method or whether something else was happening at Sacred Heart to cause the low initial relaxation scores. (This will be discussed in greater detail later.)

The greater change in relaxation in Sacred Heart participants does, however, possibly confirm the findings of Reading, Cox and Campbell (1988) that ultrasound has a relieving influence on parents when the test's results are normal. This is consistent with the Sacred Heart sample in the present study because all but one patient had normal results, and relaxation in Sacred Heart patients increased significantly after the ultrasound. Increasing relaxation is important in the context of genetic counseling in that patients who are less nervous and thus more relaxed are better able to receive complex information than anxious patients (Smith & Antley, 1979).

It is noteworthy that Sacred Heart patients began their counseling sessions with somewhat less positive and more negative psychological symptoms than Emanuel patients in all of the subscales and the Emanuel patient scores did not change as much as Sacred Heart scores throughout the counseling process. For instance, patient friendliness was marginally different in the two hospitals. Although its level of friendliness dropped slightly over the course of the counseling session (see means in Table 1), the Emanuel group still had higher friendliness scores after the counseling session than the Sacred Heart group. The lower scores in the Sacred Heart participants before the counseling session could be the effect of some stressor on Sacred Heart patients. For instance, the Sacred Heart clients could have been referred to genetic counseling for more serious reasons. Another possibility is that something was initially upsetting clients at Sacred Heart like disorganization or a frustrating parking system.

Regardless of why the Sacred Heart sample began their counseling sessions in a more negative manner, they were nearing or surpassing the scores of the Emanuel sample by the end of the counseling session. Despite whatever caused the initial negativity in psychological symptoms, it is possible that the Sacred Heart method of including ultrasound results in genetic counseling for amniocentesis was more effective at improving psychological symptoms, causing the women to become more positive to a greater degree than the Emanuel women and thus closing the initial gap between the two hospitals. Another possibility is that if a stressor before the session started was causing the Sacred Heart scores to be lower at the beginning of the session, the tension was relieved simply by being removed from the upsetting situation, improving the patients' psychological symptoms. In this case, Sacred Heart's ability to "catch up" would be caused by removal of the stressor, not by including ultrasound results in the counseling session.

Another potential explanation for the lower Sacred Heart scores before the counseling session is that for Sacred Heart patients, the ultrasound procedure was imminent. For Sacred Heart clients, having an ultrasound is part of genetic counseling for amniocentesis so the Sacred Heart participants knew an ultrasound was definitely going to take place during their approaching counseling session. Consistent with the Michelacci et al. study's (1988) findings that maternal psychological symptoms were elevated before the ultrasound indicate, it is possible that Sacred Heart mothers had elevated psychological symptoms before the genetic counseling session in anticipation of the ultrasound procedure. Conversely, Emanuel patients were going to have an ultrasound after the genetic counseling session was over and only if they elected to have an amniocentesis. Therefore, Sacred Heart's lower positive symptoms and higher negative symptoms could

be due to the fact that their ultrasound was impending while the prospect of having an ultrasound was more removed for the Emanuel patients. In this case, the changes in Sacred Heart psychological symptoms during the session would be due to the ultrasound procedure. They were worse before the session in anticipation of the ultrasound and better after the ultrasound with relief and perhaps confidence from the normal results. Thus, Sacred Heart's procedure of dividing the counseling session may produce greater variability in patient reactions throughout the session. Similar variability may appear in the Emanuel clients who were planning on have an ultrasound. Perhaps less improvement was observed in Emanuel patients than Sacred Heart clients over the genetic counseling session because some Emanuel clients were

Yet another possible explanation for the lower initial scores seen in Sacred Heart participants is the slight difference in the participant recruiting processes at the two hospitals. As described previously, the Emanuel hospital staff sent out a preclinic letter to all possible participants to familiarize them with the study itself and to advise them that they would be approached to participate when they arrived at the clinic for their appointment. Also, the Emanuel center only recruited patients who arrived early for their appointment in order to accommodate their busy schedule. When Emanuel chose to make this change, Sacred Heart had already begun the study, recruiting patients as they arrived in the center for their appointment. To maintain consistency within the Sacred Heart subjects, Sacred Heart did not switch to the Emanuel procedure.

Possible ramifications of this difference could have been that the Sacred Heart patients had more negative and less positive psychological symptoms before the counseling session because they were already anxious about their appointment with the

genetic counselor and being recruited for a study exacerbated those symptoms, whereas Emanuel participants had an opportunity to consider the study and its consent form days before their appointment when their emotions would not have been as volatile. In the future, it would be ideal to avoid this possible problem by implementing the same recruitment process at both hospitals.

The critical test between the two counseling methods would be to examine the changes in psychological symptoms of each hospital group, matching each Sacred Heart patient with an Emanuel patient with similar reasons for referral and similar demographics, using the same recruiting process at each hospital. Even more effective would be to compare two groups at one hospital, using the two methods and only one genetic counselor, which would preclude any differences in stressors at the clinics and in genetic counseling styles.

Aside from the lower initial psychological subscale scores in the Sacred Heart group, both hospital groups experienced a decrease in anxiety and increases in contentment and somatic well-being as a main effect of time, although Sacred Heart did not exhibit greater changes than Emanuel as a result of their counseling method, as was hypothesized. This means that both hospital groups were changing in the same direction over time and that these symptoms were significantly influenced by the genetic counseling itself. Hence, both hospitals were doing a good job of improving these symptoms. Perhaps patients generally experience negative emotions while anticipating seeing a health care practitioner or while anticipating the possibility of learning negative information at the counseling session. Having the session behind them would alleviate these anxieties regardless of which counseling model was in use.

It is not surprising that the hypothesized decreases in depression, somatic symptoms and hostility over the span of the genetic counseling session were not confirmed. Patients reported very few depressive, somatic and hostile symptoms before the session started; therefore, it would be unlikely to find a significant reduction in those symptoms after the session, i.e., there was a possible floor effect. One explanation for this possible floor effect is that the Symptom Questionnaire was developed to differentiate between groups of people. For instance, one study by the author of the Symptom Questionnaire compared psychiatric versus nonpsychiatric patients (Kellner, 1987). It is possible that the difference in symptoms found in these two widely varying groups would be more pronounced and that the symptoms found would be more severe in ill patients than the symptoms found in the groups tested in this study, whose symptoms were caused by concerns about genetic testing rather than by illness.

Sacred Heart clients after ultrasound results

Because they had three questionnaires, three data points were available for the Sacred Heart group. Hence, we examined the Sacred Heart group's data alone to test when their psychological symptoms changed significantly over time. It would be expected that if the ultrasound results were significantly influencing the psychological state of the patients, there would have been greater changes in psychological symptoms from Time 2 to Time 3, i.e. between the ultrasound and the end of the session, than from Time 1 to Time 2, i.e. between the initial counseling session and the ultrasound. It was predicted that the Sacred Heart participants' negative symptoms would decline if the ultrasound

results were normal and that they would increase if the results were abnormal. Similarly, it was expected that the positive symptoms would rise in the case of normal results and fall if the results were abnormal. As predicted, anxiety, relaxation, contentment, and friendliness improved significantly from Time 2 to Time 3. There was a marginally significant increase in somatic well-being in that time period as well. Only in the relaxation subscale was there a significant change from Time 1 to Time 2. Thus, most significant changes took place after the ultrasound. This lends weight to the premise that ultrasound results influence psychological responses to genetic counseling and the decision making process except in the case of relaxation, which appears to be increasing steadily throughout the counseling session without significant influence from the ultrasound results.

Removing the data of the one participant with abnormal results and those who did not have ultrasound data did not affect these results. Although we had planned to study the psychological reactions of Sacred Heart participants with abnormal ultrasound results after the ultrasound, this was impossible because only one woman had abnormal results. One subject's data is insufficient to characterize the behavior of a group. Again, had there been a larger number of women with abnormal ultrasound results, they would have been expected to show an increase in negative symptoms and a decline in positive symptoms.

The fact that Sacred Heart patient anxiety decreased after the genetic counseling session is consistent with previous findings by Michelacci et al. (1988), that women experience a decline in anxiety after an ultrasound. Michelacci et al. studied low-risk pregnancies while this study considered higher-risk pregnancies. It was suspected that women with higher-risk pregnancies would respond similarly to ultrasound as the low-risk women in the Michelacci et al. study responded, which was confirmed by these results.

Further, the decline in anxiety in both hospitals as a main effect of time shows that counselors at both hospitals were moving toward the goal of reducing anxiety, which along with reducing hostility is key to improving client decision making capacity. As was previously introduced, anxiety and hostility impair parents' ability to receive complex genetic information and to then apply that knowledge to their decision making process (Smith & Antley, 1979). Both hospitals had negligible hostility levels, which showed little or no change over time.

Affect toward amniocentesis

Contrary to prediction, Sacred Heart patients were not shown to have a greater overall increase in positive affect toward the amniocentesis procedure itself than Emanuel patients throughout the counseling process. Thus, ultrasound results do not appear to influence affect toward amniocentesis. However, both hospitals demonstrated an increase in positive affect toward amniocentesis that was marginally significant as a main effect of time. As a result, both centers appear to be effectively teaching and reassuring clients about the amniocentesis procedure. It is plausible that both of the hospitals demonstrated only a marginally significant increase in affect toward amniocentesis because client attitudes toward the procedure were already fairly established before the session started, limiting how much counselors could improve client perception of the procedure.

To correct for any influence on the overall affect toward amniocentesis that abnormal ultrasound results could have elicited in Sacred Heart patients, we examined patient affect toward amniocentesis for both hospital groups together, excluding one

Sacred Heart subject with abnormal ultrasound results and two subjects with no ultrasound information. Affect toward amniocentesis was not significantly different from the results for the whole sample. As was true in studying the psychological responses to amniocentesis, we were unable to examine the role of ultrasound results in affect toward amniocentesis in the Sacred Heart patients who had abnormal ultrasound results because there was only one such patient. If we had been able to do so, we would have expected a decrease in positive affect, perhaps due to fear or dread of the procedure because of the physical risks involved or because of the negative information it could reveal (Phipps & Zinn, 1986; Robinson, Tennes, & Robinson, 1975). On the other hand, affect toward amniocentesis could rise because the procedure might be perceived as a helpful tool that would bring some closure to parents' uncertainty about the health of the fetus.

Reported likelihood of undergoing an amniocentesis

Although the mean, or average, reported likelihood of having an amniocentesis for each hospital group dropped over time, the results were not significant (see means in Table 2). The results were similar after removing the data of the Sacred Heart patient with abnormal ultrasound results and the Sacred Heart patients with no ultrasound data. The likelihood of having an amniocentesis that Sacred Heart participants reported was also investigated individually because the group had three data points, but again, there was no significant decrease. A larger sample size could elicit different, more conclusive results as to whether reported likelihood of having an amniocentesis decreases significantly over time. On the other hand, it is possible that a larger sample would not produce different

results; perhaps clients had formulated their decision about whether to undergo an amniocentesis before their session, as was possible with the results for affect toward amniocentesis. In this scenario, the session served to reinforce established client attitudes and, because most patients had normal ultrasound results, occasionally to help some patients recognize that amniocentesis might not have been a justifiable risk for them (Jackson, Farmer, Katz, Murray, Graveline, & Jensen, 1996).

There was only one abnormal ultrasound result in the sample, precluding any analyses of results of Sacred Heart women with abnormal results. In a larger sample, it would be valuable to examine reported likelihood of having amniocentesis results of those participants with normal results in contrast to those with abnormal results. One would expect those with normal results to behave as the participants in the present study, decreasing in reported likelihood of having an amniocentesis as they discovered there was less reason for worry about genetic anomalies. Those with abnormal results would be expected to increase in reported likelihood of having an amniocentesis because they would perceive amniocentesis as important in obtaining more feedback on the health of the fetus (Jackson, et al., 1996).

Affect predicts reported likelihood of having an amniocentesis

It was hypothesized that affect toward amniocentesis would predict the scores of the reported likelihood of having an amniocentesis. Consistent with this, Sacred Heart's affect toward amniocentesis at Time 1, Time 2, and Time 3 correctly predicted 77.9% of the participants' reported likelihood of having an amniocentesis. High positive affect

toward amniocentesis generally predicted a higher reported likelihood to have an amniocentesis, but interestingly, after the ultrasound in Sacred Heart participants, higher positive affect toward amniocentesis predicted low reported likelihood of having the procedure. Perhaps after the ultrasound, for which all but one woman received normal results, the Sacred Heart clients were feeling optimistic about their pregnancy and less likely to have an amniocentesis. However, how affect toward amniocentesis and reported likelihood to have the procedure are related is unclear because clients became slightly less likely to have an amniocentesis over time.

The reason for investigating whether affect predicted reported likelihood of having an amniocentesis was to determine if affect toward amniocentesis is associated with reported likelihood to undergo the procedure. A key goal of this study was to consider if emotions toward amniocentesis influenced patient decision making and it appears they do. We now know that affect toward amniocentesis and reported likelihood of having the procedure are related, but we do not know how. Thus, negative affect toward amniocentesis should be considered a target for improvement in amniocentesis counseling and for future research into the relationship between affect toward amniocentesis and reported likelihood of having an amniocentesis.

As Peters and Slovic (1996) had found that positive affect toward an object determines preference for that object, we had expected reported likelihood of having an amniocentesis to change in the same direction as a respective change in affect toward amniocentesis. However, the amniocentesis counseling situation is more complex, as evidenced by the fact that reported likelihood to undergo the procedure declined somewhat even though positive affect toward amniocentesis increased marginally. Thus,

as patients became more familiar with the amniocentesis procedure, they felt more positive towards it and yet they were not more likely to undergo it. It is plausible that participants were generally finding the amniocentesis procedure to be less threatening than they did before the session, but that was not the only determining factor in their decision.

Despite this possible decrease in the clients' perception of the risk of amniocentesis and its subsequent increase in their estimation of its benefits, (Alkhami & Slovic, 1994), the participants' reported likelihood of undergoing an amniocentesis declined slightly. Perhaps clients also realized they did not need the amniocentesis, regardless of their more positive view of the amniocentesis. Of course, if more patients had received abnormal results, perhaps reported likelihood of having an amniocentesis would have risen because some patients who were not planning on having an amniocentesis at the beginning of the session changed their decision because they had abnormal ultrasound results (Jackson et al., 1996).

Choice to elect or decline amniocentesis

Although it was not included in the hypotheses, we explored participant choice to undergo an amniocentesis and its relationship to affect toward amniocentesis and reported likelihood of having the procedure. No significant difference was found between the hospitals in whether participants elected or declined an amniocentesis. This is not particularly conclusive in that we did not know which hospital found more serious problems in the parents' medical histories or how serious the problems found in the

ultrasounds performed at Sacred Heart were. Moreover, we knew the amniocentesis choice for very few Emanuel participants.

For the Sacred Heart group, clients' affect toward amniocentesis at Time 1 and Time 3 could be used to correctly predict 92.86% of the choices clients made to elect or decline the amniocentesis. The reported likelihood of having an amniocentesis at Time 3 could be used to correctly predict 87.5% of the choices made. Thus, affect is associated with the participants' actual behavior. Furthermore, at the end of the session reported likelihood of having an amniocentesis is an effective predictor of the choice participants will make regarding amniocentesis. It is interesting to note that participants were generally behaving as they had reported they would.

Satisfaction with genetic counseling

Client satisfaction was high at both hospitals so the genetic centers were providing excellent services. Nevertheless, contrary to hypothesis, the satisfaction results for each hospital were nearly the same, lending some weight to the fact that perhaps the Sacred Heart method is not more effective than the Emanuel method. However, because the satisfaction questionnaire was administered at different times in the counseling session at each hospital, the satisfaction results were not an ideal comparison. As described previously, the Emanuel group completed the satisfaction survey with their second, final questionnaire at the end of their counseling session. At this time, they had completed their genetic counseling session and had already made their decision about amniocentesis. The Sacred Heart group also completed the satisfaction survey with their second

questionnaire, which took place after their ultrasound, but before they reconvened with the genetic counselor to discuss the ultrasound results and their final amniocentesis decision. Because Sacred Heart completed the survey in the middle of their session and Emanuel filled theirs out at the end of the session, the two groups' data are different in terms of when they took place during the genetic counseling process, making comparisons less meaningful.

Future directions

With a larger sample size, it would be interesting to examine what psychological factors are correlated with changes in reported likelihood to undergo an amniocentesis as a participant changes her decision about amniocentesis. Studying the role of psychological symptoms in reported likelihood of having an amniocentesis would be valuable to counselors in that they would know which factors to attempt to improve during the counseling sessions. For example, if I found that an increase in friendliness is highly correlated with an increase in positive affect toward amniocentesis and with changes in reported likelihood to have the procedure, counselors could adopt the strategy of identifying clients who have unfriendly feelings in order to work on increasing feelings of friendliness in those clients. This would be an appropriate plan because it would help bring their hostile clients to a state in which the clients could make the decision most appropriate for them.

It would also be interesting to explore the data of the partners of women who participate. Possible investigations would be whether the partner's affect toward

amniocentesis is consistent with the mother's. I would examine if either the mothers or the partners are generally less positive toward amniocentesis before the genetic counseling session. Determining if one group changes in affect toward amniocentesis more than the other group and in which direction might indicate if one group is affecting the attitudes of the other group. An example of this would be if the partners started out with less positive affect toward amniocentesis than the mothers, but by the end of the counseling session they had increased in affect toward amniocentesis, rising to a level approximately as positive as that of the mothers. This might indicate that the mothers' affect toward amniocentesis influenced the partners' perception of the amniocentesis procedure.

The results of the present study might be valuable to genetic counselors as they attempt to improve their counseling for amniocentesis. They would be interested to know that their efforts to reduce anxiety and increase relaxation have been successful. Their patients are better able to receive and process complex genetic information by the end of the genetic counseling session when they need to make a decision about amniocentesis. Furthermore, Sacred Heart might be interested to know that their model is not necessarily more effective than the traditional model, as it could be more cost effective for Sacred Heart to only offer ultrasound to women who choose amniocentesis. Another consideration for Sacred Heart staff would be to evaluate their presession performance to determine if there are any stressors on clients, using any negative responses from the Sacred Heart client satisfaction data from the present study as a feedback source.

Counselors might also consider the results of the present study as a potential model for a research project. Knowing that reported likelihood to undergo amniocentesis does change during the session and that it is associated with actual client behavior (e.g.,

whether they elect or decline the amniocentesis), counselors might hope to explore the factors that influence these changes. This study showed that affect toward amniocentesis is related to changes in reported likelihood of having an amniocentesis, which predicts actual behavior. This suggests that clients' affect toward amniocentesis is an important factor in decision making in genetic counseling for amniocentesis. It is thus possible that attempts to change client affect toward amniocentesis could change client decisions to accept or deny an amniocentesis. The role of psychological symptoms in relation to these findings would be important information in the pursuit of improving patient decision making capacity. The results found in this study were an exploration into what a funded project with a paid research assistant, who could recruit high numbers of participants, could determine.

Conclusions

The present study investigated Sacred Heart's method of genetic counseling for amniocentesis, attempting to determine if it was more effective than the traditional method used at Emanuel by exploring the difference in the two groups in psychological reactions to amniocentesis, affect toward amniocentesis, and reported likelihood of undergoing the procedure. We also examined the clients' actual amniocentesis choices. Few of the investigations of the present study yielded conclusive results, largely due to the crippling, small sample size.

There was little indication that the Sacred Heart method of including ultrasound results in the genetic counseling session was more effective than Emanuel's traditional

method at improving client psychological symptoms because both hospitals produced similar outcomes. It is unclear whether the Sacred Heart method was more effective than the Emanuel method; however, both hospitals were successfully improving their clients' anxiety and relaxation, thus improving their decision making ability. The hospitals produced elevated contentment and somatic well-being, which also indicates that the counseling centers are succeeding at helping their clients improve their psychological symptoms throughout the session. We found that both centers using different methods were making their clients more comfortable with amniocentesis and clients were satisfied with the care they received.

Affect toward amniocentesis is related to changes in reported likelihood of undergoing the procedure, which is an effective predictor of actual client behavior. Thus, affect, or emotions, are possibly an integral part of decision making in genetic counseling for amniocentesis. Therefore, it is possible that attempts to modify client affect toward amniocentesis could influence decisions to elect or decline amniocentesis.

Further research into how emotions are involved in decision making in amniocentesis counseling could prove fascinating. Intuitively, one assumes that emotions are important in making crucial decisions. Studies such as the present study set out to prove this and to determine which emotions are involved in decision making. As we learn about how emotions affect decision making in genetic counseling for amniocentesis, we can determine which emotions hinder client decision making abilities and how then to counteract any negative influence and enhance any positive influence of these emotions in order to aid clients in receiving and utilizing complex genetic information with which to make a decision with which they can live.

Table 1

Mean scores for Sacred Heart and Emanuel client psychological reactions to amniocentesis

Subscale	Hospital		Entire Sample (n = 18)
	Sacred Heart (n = 13)	Emanuel (n = 5)	
Anxiety*			
Time 1	.367 (SD .225)	.341 (SD .222)	.359 (SD .218)
Time 2	.357 (SD .254)	--	--
Time 3	.113 (SD .153)	.188 (SD .244)	.134 (SD .178)
Relaxation**			
Time 1	.462 (SD .273)	.800 (SD .361)	.556 (SD .328)
Time 2	.654 (SD .284)	--	--
Time 3	.821 (SD .292)	.800 (SD .183)	.815 (SD .261)
Depression*			
Time 1	.104 (SD .125)	.082 (SD .067)	.098 (SD .111)
Time 2	.063 (SD .100)	--	--
Time 3	.023 (SD .057)	.059 (SD .059)	.033 (SD .058)
Contentment**			
Time 1	.474 (SD .303)	.600 (SD .149)	.509 (SD .271)
Time 2	.564 (SD .277)	--	--
Time 3	.782 (SD .350)	.767 (SD .279)	.778 (SD .323)
Somatic Symptoms*			
Time 1	.127 (SD .170)	.153 (SD .202)	.134 (SD .173)
Time 2	.118 (SD .132)	--	--
Time 3	.068 (SD .131)	.082 (SD .122)	.072 (SD .125)
Somatic Well-being**			
Time 1	.577 (SD .358)	.633 (SD .139)	.593 (SD .309)
Time 2	.641 (SD .279)	--	--
Time 3	.795 (SD .320)	.833 (SD .167)	.806 (SD .282)
Hostility*			
Time 1	.077 (SD .145)	.024 (SD .032)	.062 (SD .125)
Time 2	.036 (SD .078)	--	--
Time 3	.023 (SD .045)	.024 (SD .053)	.023 (SD .046)
Friendliness**			
Time 1	.564 (SD .406)	.967 (SD .075)	.676 (SD .390)
Time 2	.590 (SD .358)	--	--
Time 3	.782 (SD .284)	.933 (SD .091)	.824 (SD .252)

Note. n = the number of participants in the sample; SD = the standard deviation from the mean, representing the range of responses

* Negative psychological symptom (0 = lowest score, 17 = highest score).

** Positive psychological symptom (0 = lowest score, 6 = highest score)

Table 2

Sacred Heart and Emanuel mean affect toward amniocentesis and reported likelihood of having an amniocentesis

Group	Affect toward amniocentesis				Reported likelihood of undergoing an amniocentesis			
	Time							
	n	1	2	3	n	1	2	3
Sacred Heart								
All	13	3.740 (SD .816)	4.130 (SD 1.209)	4.519 (SD 1.117)	15	2.800 (SD 2.042)	3.067 (SD 2.344)	3.400 (SD 2.586)
Normal only*	10	3.588 (SD .799)	--	4.263 (SD 1.035)	11	2.909 (SD 2.300)	--	4.273 (SD 2.494)
Emanuel								
All	5	3.850 (SD .715)	--	4.225 (SD 1.418)	5	3.000 (SD 2.550)	--	3.800 (SD 2.775)
Normal only*	5	3.850 (SD .715)	--	4.225 (SD 1.418)	5	3.000 (SD 2.550)	--	3.800 (SD 2.775)
Entire Sample								
All	18	3.771 (SD .770)	--	4.438 (SD 1.171)	20	2.850 (SD 2.110)	--	3.500 (SD 2.565)
Normal only*	15	3.675 (SD .757)	--	4.250 (SD 1.124)	16	2.938 (SD 2.294)	--	4.125 (SD 2.500)

Notes. High affect scores indicate positive affect (0 = lowest, 7 = highest).

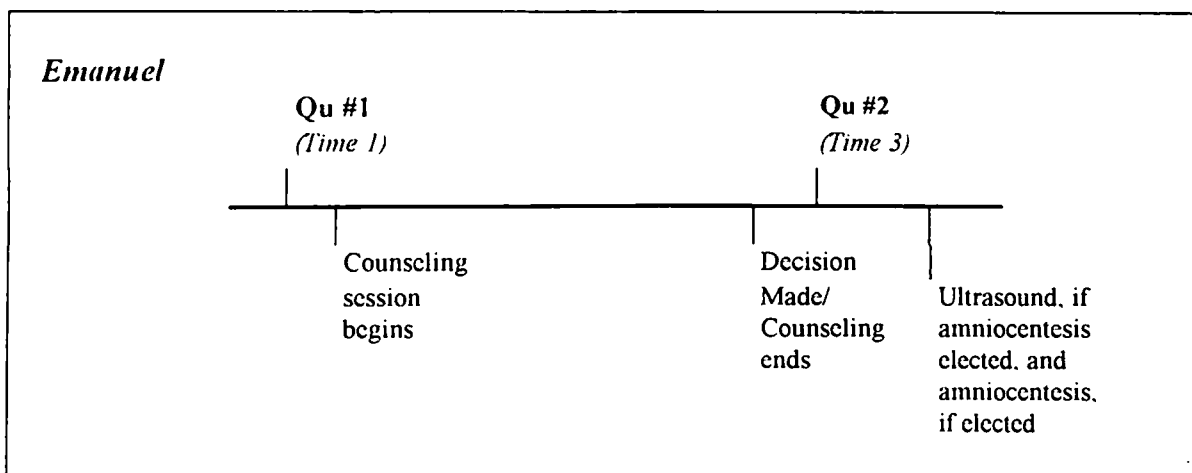
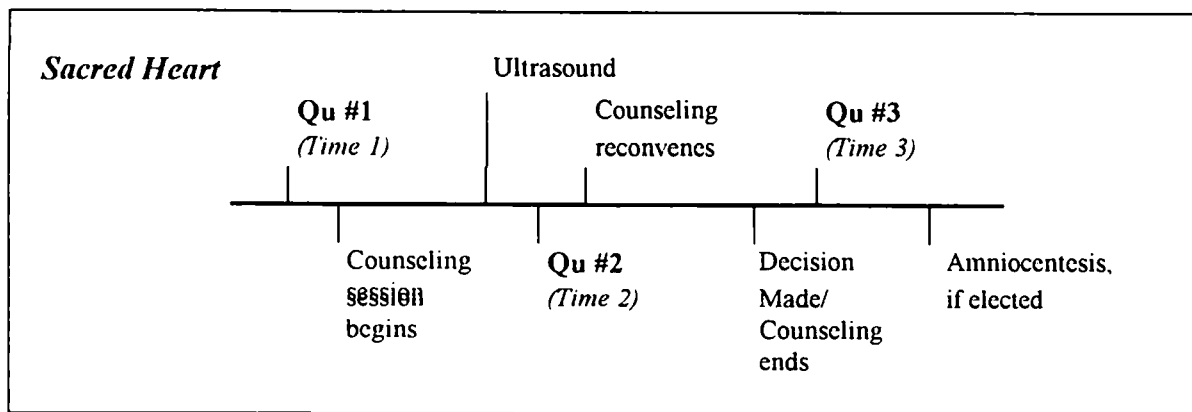
High reported likelihood scores indicate low likelihood (0 = highest, 7 = lowest).

n = the number of participants in the sample; SD = the standard deviation from the mean, representing the range of responses.

* This sample excludes Sacred Heart patients with abnormal ultrasound results and those with no ultrasound results.

APPENDIX A

QUESTIONNAIRE TIMELINE



Qu = Questionnaire

Note: Emanuel patients completed questionnaires at Time 1 and Time 3, not at Time 2.

APPENDIX B

QUESTIONNAIRES

The Sacred Heart Questionnaires

QUESTIONNAIRE #1, PAGE 1: EXPECTANT MOTHER ONLY

(These are the demographic questions.)

Age: _____ Number of children: _____ City of residence: _____

Number of previous amniocentesis procedures: _____

Race/Ethnic origin: _____ Household income: _____

(you may choose more than one)

Asian/Pacific Islander	_____	\$0 - \$15,000	_____
Black (not of Hispanic origin)	_____	\$15,000 - \$30,000	_____
Hispanic	_____	\$30,000 - \$45,000	_____
American Indian or Alaskan	_____	\$45,000 - \$60,000	_____
Native	_____	\$60,000 - \$75,000	_____
White (not of Hispanic origin)	_____	\$75,000 or more	_____

Are you a native speaker of English? Yes No

If not, for how many years have you been speaking English? _____

(This is the likelihood scale.)

On this scale, please rate whether, at this point in time, you think you will have an amniocentesis.

definitely will 1 2 3 4 5 6 7 definitely will not

(This is the bipolar emotion scale.)

*Using the following adjective scales, please rate as best you can how you are feeling right now about amniocentesis:***amniocentesis**

love	1	2	3	4	5	6	7	hate
miserable	1	2	3	4	5	6	7	delighted
sad	1	2	3	4	5	6	7	happy
pleased	1	2	3	4	5	6	7	annoyed
afraid	1	2	3	4	5	6	7	calm
relaxed	1	2	3	4	5	6	7	tense
interested	1	2	3	4	5	6	7	bored
angry	1	2	3	4	5	6	7	content

QUESTIONNAIRE #1, PAGE 1: PARTNER ONLY

(These are the demographic questions.)

Age: Number of children: City of residence:

Number of previous amniocentesis procedures:

Gender: Relationship to expectant mother:

Race/Ethnic origin: Household income:

(you may choose more than one)

Asian/Pacific Islander

Black (not of Hispanic origin)

Hispanic

American Indian or Alaskan

Native

White (not of Hispanic origin)

\$0 - \$15,000

\$15,000 - \$30,000

\$30,000 - \$45,000

\$45,000 - \$60,000

\$60,000 - \$75,000

\$75,000 or more

Are you a native speaker of English? Yes No

If not, for how many years have you been speaking English?

(This is the likelihood scale.)

On this scale, please rate whether, at this point in time, you think you will have an amniocentesis.

definitely will definitely will not

1 2 3 4 5 6 7

(This is the bipolar emotion scale.)

*Using the following adjective scales, please rate as best you can how you are feeling right now about amniocentesis:***amniocentesis**

love

1 2 3 4 5 6 7

hate

miserable

1 2 3 4 5 6 7

delighted

sad

1 2 3 4 5 6 7

happy

pleased

1 2 3 4 5 6 7

annoyed

afraid

1 2 3 4 5 6 7

calm

relaxed

1 2 3 4 5 6 7

tense

interested

1 2 3 4 5 6 7

bored

angry

1 2 3 4 5 6 7

content

QUESTIONNAIRE #1, PAGE 2
(This is the Symptom Questionnaire)

Please circle the response that applies most accurately to how you are feeling right now.

(T = True; F = False; Y = Yes; N = No)

- | | |
|---|--|
| Y N Nervous | Y N Feeling of courage |
| Y N Weary | Y N Enjoying yourself |
| Y N Irritable | Y N Breathing difficult |
| Y N Cheerful | Y N Parts of the body feel numb or tingling |
| Y N Tense, tensed up | Y N Feels like it will take a long time to fall asleep |
| Y N Sad, blue | Y N Feeling hostile |
| Y N Happy | Y N Infuriated |
| Y N Frightened | Y N Heart beating fast or pounding |
| Y N Feeling calm | Y N Depressed |
| Y N Feeling healthy | Y N Jumpy |
| Y N Losing temper easily | Y N Feeling a failure |
| Y N Feeling of not enough air | Y N Not interested in things |
| Y N Feeling kind toward people | Y N Highly strung |
| Y N Feeling fit | Y N Cannot relax |
| Y N Heavy arms or legs | Y N Panicky |
| Y N Feeling confident | Y N Pressure on head |
| Y N Feeling warm toward people | Y N Blaming yourself |
| Y N Shaky | Y N Thoughts of ending your life |
| Y N No pains anywhere | Y N Frightening thoughts |
| Y N Angry | Y N Enraged |
| Y N Arms and legs feel strong | Y N Irritated by other people |
| Y N Appetite poor | Y N Looking forward toward the future |
| Y N Feeling peaceful | Y N Nauseated, sick to stomach |
| Y N Feeling unworthy | Y N Feeling that life is bad |
| Y N Annoyed | Y N Upset bowels or stomach |
| Y N Feeling of rage | Y N Feeling inferior to others |
| Y N Cannot enjoy yourself | Y N Feeling useless |
| Y N Tight head or neck | Y N Muscle pains |
| Y N Relaxed | Y N No unpleasant feelings in head or body |
| Y N Restless | Y N Headache |
| Y N Feeling friendly | Y N Feel like attacking people |
| Y N Feeling of hate | Y N Shaking with anger |
| Y N Choking feeling | Y N Mad |
| Y N Afraid | Y N Feeling of goodwill |
| Y N Patient | Y N Feel like crying |
| Y N Scared | Y N Cramps |
| Y N Furious | Y N Feeling that something bad will happen |
| Y N Feeling charitable, forgiving | Y N Wound up, uptight |
| Y N Feeling guilty | Y N Get angry quickly |
| Y N Feeling well | Y N Self-confident |
| Y N Feeling of pressure in head or body | Y N Resentful |
| Y N Worried | Y N Feeling of hopelessness |
| Y N Contented | Y N Head pains |
| Y N Weak arms or legs | |
| Y N Feeling desperate, terrible | |
| Y N No aches anywhere | |
| Y N Thinking of death or dying | |
| Y N Hot tempered | |
| Y N Terrified | |

QUESTIONNAIRE #2, PAGE 1

On this scale, please rate whether, at this point in time, you think you will have an amniocentesis.

definitely will 1 2 3 4 5 6 7 definitely will not

Using the following adjective scales, please rate as best you can how you are feeling right now about amniocentesis:

amniocentesis

love	<u>1</u> <u>2</u> <u>3</u> <u>4</u> <u>5</u> <u>6</u> <u>7</u>	hate
miserable	<u>1</u> <u>2</u> <u>3</u> <u>4</u> <u>5</u> <u>6</u> <u>7</u>	delighted
sad	<u>1</u> <u>2</u> <u>3</u> <u>4</u> <u>5</u> <u>6</u> <u>7</u>	happy
pleased	<u>1</u> <u>2</u> <u>3</u> <u>4</u> <u>5</u> <u>6</u> <u>7</u>	annoyed
afraid	<u>1</u> <u>2</u> <u>3</u> <u>4</u> <u>5</u> <u>6</u> <u>7</u>	calm
relaxed	<u>1</u> <u>2</u> <u>3</u> <u>4</u> <u>5</u> <u>6</u> <u>7</u>	tense
interested	<u>1</u> <u>2</u> <u>3</u> <u>4</u> <u>5</u> <u>6</u> <u>7</u>	bored
angry	<u>1</u> <u>2</u> <u>3</u> <u>4</u> <u>5</u> <u>6</u> <u>7</u>	content

QUESTIONNAIRE #2, PAGE 2

Please circle the response that applies most accurately to how you are feeling right now.

(T = True; F = False; Y = Yes; N = No)

- | | | | |
|-----|-------------------------------------|-----|--|
| Y N | Nervous | Y N | Feeling of courage |
| Y N | Weary | Y N | Enjoying yourself |
| Y N | Irritable | Y N | Breathing difficult |
| Y N | Cheerful | Y N | Parts of the body feel numb or tingling |
| Y N | Tense, tensed up | Y N | Feels like it will take a long time to fall asleep |
| Y N | Sad, blue | Y N | Feeling hostile |
| Y N | Happy | Y N | Infuriated |
| Y N | Frightened | Y N | Heart beating fast or pounding |
| Y N | Feeling calm | Y N | Depressed |
| Y N | Feeling healthy | Y N | Jumpy |
| Y N | Losing temper easily | Y N | Feeling a failure |
| Y N | Feeling of not enough air | Y N | Not interested in things |
| Y N | Feeling kind toward people | Y N | Highly strung |
| Y N | Feeling fit | Y N | Cannot relax |
| Y N | Heavy arms or legs | Y N | Panicky |
| Y N | Feeling confident | Y N | Pressure on head |
| Y N | Feeling warm toward people | Y N | Blaming yourself |
| Y N | Shaky | Y N | Thoughts of ending your life |
| Y N | No pains anywhere | Y N | Frightening thoughts |
| Y N | Angry | Y N | Enraged |
| Y N | Arms and legs feel strong | Y N | Irritated by other people |
| Y N | Appetite poor | Y N | Looking forward toward the future |
| Y N | Feeling peaceful | Y N | Nauseated, sick to stomach |
| Y N | Feeling unworthy | Y N | Feeling that life is bad |
| Y N | Amoyed | Y N | Upset bowels or stomach |
| Y N | Feeling of rage | Y N | Feeling inferior to others |
| Y N | Cannot enjoy yourself | Y N | Feeling useless |
| Y N | Tight head or neck | Y N | Muscle pains |
| Y N | Relaxed | Y N | No unpleasant feelings in head or body |
| Y N | Restless | Y N | Headache |
| Y N | Feeling friendly | Y N | Feel like attacking people |
| Y N | Feeling of hate | Y N | Shaking with anger |
| Y N | Choking feeling | Y N | Mad |
| Y N | Afraid | Y N | Feeling of goodwill |
| Y N | Patient | Y N | Feel like crying |
| Y N | Scared | Y N | Cramps |
| Y N | Furious | Y N | Feeling that something bad will happen |
| Y N | Feeling charitable, forgiving | Y N | Wound up, uptight |
| Y N | Feeling guilty | Y N | Get angry quickly |
| Y N | Feeling well | Y N | Self-confident |
| Y N | Feeling of pressure in head or body | Y N | Resentful |
| Y N | Worried | Y N | Feeling of hopelessness |
| Y N | Contented | Y N | Head pains |
| Y N | Weak arms or legs | | |
| Y N | Feeling desperate, terrible | | |
| Y N | No aches anywhere | | |
| Y N | Thinking of death or dying | | |
| Y N | Hot tempered | | |
| Y N | Terrified | | |

QUESTIONNAIRE #2, PAGES 3 & 4
(This is the Shiloh satisfaction survey.)

Please rate the following questions on a scale of 1 to 4.

(1 = low/strongly disagree 4 = high/strongly agree)

- _____ Did the genetic counselor show interest in your personal problems beyond what is medically required?
- _____ Did you consider turning to another genetic counselor regarding your problem?
- _____ Did the genetic counselor explain your condition to you clearly?
- _____ Did the genetic counselor meet your expectations of her?
- _____ Do you think the genetic counselor cares for you as a person?
- _____ How comfortable would you feel to call the genetic counselor to ask another question?
- _____ Did the genetic counselor reassure you?
- _____ Did the genetic counselor listen to what you had to say?
- _____ Was the genetic counselor considerate of your emotional state during the meeting?
- _____ How satisfied are you with the way in which information was transmitted to you?
- _____ Did the genetic counselor show enough dedication in treating your problem?
- _____ How would you rate the level of service that you received?
- _____ Did the genetic counselor understand what was really bothering you?
- _____ Do you think that you could get more considerate care from a private doctor?
- _____ Did the genetic counselor make you feel you are "in good hands"?
- _____ Did the genetic counselor make you feel that she knows how to handle problems like yours?
- _____ Did the genetic counselor give you enough of her time?

- _____ Was the genetic counselor sensitive and tactful during your conversation?
- _____ Did the genetic counselor give you the necessary treatment?
- _____ Do you think the genetic counselor is an expert in the field in which you need help?
- _____ Can the counseling that you received help you cope better with your problem?
- _____ Did the genetic counselor lessen your worries?
- _____ How do you rate the length of time you waited since you first contacted the clinic and until your visit (documents, lines, etc.)?
- _____ How do you rate the length of time you waited since your arrival at the clinic and until you entered the genetic counselor's office?
- _____ If an acquaintance of yours needed a similar help, would you recommend this clinic to him/her?
- _____ Do you think you could get better treatment from a private doctor?
- _____ How satisfied are you with the treatment you got from the medical staff, besides for the doctor--the nurse, the secretary, etc.?
- _____ Do you think that the counseling was given in the appropriate setting for the sort of problem you had?
- _____ In summary, how would you rate your satisfaction with the counseling?

QUESTIONNAIRE #3, PAGE 1

On this scale, please rate whether, at this point in time, you think you will have an amniocentesis.

definitely will 1 2 3 4 5 6 7 definitely will not

Using the following adjective scales, please rate as best you can how you are feeling right now about amniocentesis:

amniocentesis

love	<u>1</u>	<u>2</u>	<u>3</u>	<u>4</u>	<u>5</u>	<u>6</u>	<u>7</u>	hate
miserable	<u>1</u>	<u>2</u>	<u>3</u>	<u>4</u>	<u>5</u>	<u>6</u>	<u>7</u>	delighted
sad	<u>1</u>	<u>2</u>	<u>3</u>	<u>4</u>	<u>5</u>	<u>6</u>	<u>7</u>	happy
pleased	<u>1</u>	<u>2</u>	<u>3</u>	<u>4</u>	<u>5</u>	<u>6</u>	<u>7</u>	annoyed
afraid	<u>1</u>	<u>2</u>	<u>3</u>	<u>4</u>	<u>5</u>	<u>6</u>	<u>7</u>	calm
relaxed	<u>1</u>	<u>2</u>	<u>3</u>	<u>4</u>	<u>5</u>	<u>6</u>	<u>7</u>	tense
interested	<u>1</u>	<u>2</u>	<u>3</u>	<u>4</u>	<u>5</u>	<u>6</u>	<u>7</u>	bored
angry	<u>1</u>	<u>2</u>	<u>3</u>	<u>4</u>	<u>5</u>	<u>6</u>	<u>7</u>	content

QUESTIONNAIRE #3, PAGE 2

Please circle the response that applies most accurately to how you are feeling right now.

(T = True; F = False; Y = Yes; N = No)

- | | |
|---|--|
| Y N Nervous | Y N Feeling of courage |
| Y N Weary | Y N Enjoying yourself |
| Y N Irritable | Y N Breathing difficult |
| Y N Cheerful | Y N Parts of the body feel numb or tingling |
| Y N Tense, tensed up | Y N Feels like it will take a long time to fall asleep |
| Y N Sad, blue | Y N Feeling hostile |
| Y N Happy | Y N Infuriated |
| Y N Frightened | Y N Heart beating fast or pounding |
| Y N Feeling calm | Y N Depressed |
| Y N Feeling healthy | Y N Jumpy |
| Y N Losing temper easily | Y N Feeling a failure |
| Y N Feeling of not enough air | Y N Not interested in things |
| Y N Feeling kind toward people | Y N Highly strung |
| Y N Feeling fit | Y N Cannot relax |
| Y N Heavy arms or legs | Y N Panicky |
| Y N Feeling confident | Y N Pressure on head |
| Y N Feeling warm toward people | Y N Blaming yourself |
| Y N Shaky | Y N Thoughts of ending your life |
| Y N No pains anywhere | Y N Frightening thoughts |
| Y N Angry | Y N Enraged |
| Y N Arms and legs feel strong | Y N Irritated by other people |
| Y N Appetite poor | Y N Looking forward toward the future |
| Y N Feeling peaceful | Y N Nauseated, sick to stomach |
| Y N Feeling unworthy | Y N Feeling that life is bad |
| Y N Annoyed | Y N Upset bowels or stomach |
| Y N Feeling of rage | Y N Feeling inferior to others |
| Y N Cannot enjoy yourself | Y N Feeling useless |
| Y N Tight head or neck | Y N Muscle pains |
| Y N Relaxed | Y N No unpleasant feelings in head or body |
| Y N Restless | Y N Headache |
| Y N Feeling friendly | Y N Feel like attacking people |
| Y N Feeling of hate | Y N Shaking with anger |
| Y N Choking feeling | Y N Mad |
| Y N Afraid | Y N Feeling of goodwill |
| Y N Patient | Y N Feel like crying |
| Y N Scared | Y N Cramps |
| Y N Furious | Y N Feeling that something bad will happen |
| Y N Feeling charitable, forgiving | Y N Wound up, uptight |
| Y N Feeling guilty | Y N Get angry quickly |
| Y N Feeling well | Y N Self-confident |
| Y N Feeling of pressure in head or body | Y N Resentful |
| Y N Worried | Y N Feeling of hopelessness |
| Y N Contented | Y N Head pains |
| Y N Weak arms or legs | |
| Y N Feeling desperate, terrible | |
| Y N No aches anywhere | |
| Y N Thinking of death or dying | |
| Y N Hot tempered | |
| Y N Terrified | |

The Emanuel Questionnaires

White (not of Hispanic origin)

If not, for how many years have you been speaking English?

definitely will 1 2 3 4 5 6 7 definitely will not

Using the following adjective scales, please rate as best you can how you are feeling right now about amniocentesis:

amniocentesis

love	<u>1</u>	<u>2</u>	<u>3</u>	<u>4</u>	<u>5</u>	<u>6</u>	<u>7</u>	hate
miserable	<u>1</u>	<u>2</u>	<u>3</u>	<u>4</u>	<u>5</u>	<u>6</u>	<u>7</u>	delighted
sad	<u>1</u>	<u>2</u>	<u>3</u>	<u>4</u>	<u>5</u>	<u>6</u>	<u>7</u>	happy
pleased	<u>1</u>	<u>2</u>	<u>3</u>	<u>4</u>	<u>5</u>	<u>6</u>	<u>7</u>	annoyed
afraid	<u>1</u>	<u>2</u>	<u>3</u>	<u>4</u>	<u>5</u>	<u>6</u>	<u>7</u>	calm
relaxed	<u>1</u>	<u>2</u>	<u>3</u>	<u>4</u>	<u>5</u>	<u>6</u>	<u>7</u>	tense
interested	<u>1</u>	<u>2</u>	<u>3</u>	<u>4</u>	<u>5</u>	<u>6</u>	<u>7</u>	bored
angry	<u>1</u>	<u>2</u>	<u>3</u>	<u>4</u>	<u>5</u>	<u>6</u>	<u>7</u>	content

QUESTIONNAIRE #1, PAGE 1: PARTNER ONLY

Age: **Number of children:** **City of residence:**

Number of previous amniocentesis procedures:

Gender: **Relationship to expectant mother:**

Race/Ethnic origin: **Household income:**

(you may choose more than one)		\$0 - \$15,000	_____
Asian/Pacific Islander	_____	\$15,000 - \$30,000	_____
Black (not of Hispanic origin)	_____	\$30,000 - \$45,000	_____
Hispanic	_____	\$45,000 - \$60,000	_____
American Indian or Alaskan	_____	\$60,000 - \$75,000	_____
Native	_____	\$75,000 or more	_____
White (not of Hispanic origin)	_____		

Are you a native speaker of English? Yes No

If not, for how many years have you been speaking English?

On this scale, please rate whether, at this point in time, you think you will have an amniocentesis.

definitely will definitely will not
 1 2 3 4 5 6 7

Using the following adjective scales, please rate as best you can how you are feeling right now about amniocentesis:

amniocentesis

love	<u> </u> <u> </u> <u> </u> <u> </u> <u> </u> <u> </u> <u> </u>	hate
	1 2 3 4 5 6 7	
miserable	<u> </u> <u> </u> <u> </u> <u> </u> <u> </u> <u> </u> <u> </u>	delighted
	1 2 3 4 5 6 7	
sad	<u> </u> <u> </u> <u> </u> <u> </u> <u> </u> <u> </u> <u> </u>	happy
	1 2 3 4 5 6 7	
pleased	<u> </u> <u> </u> <u> </u> <u> </u> <u> </u> <u> </u> <u> </u>	annoyed
	1 2 3 4 5 6 7	
afraid	<u> </u> <u> </u> <u> </u> <u> </u> <u> </u> <u> </u> <u> </u>	calm
	1 2 3 4 5 6 7	
relaxed	<u> </u> <u> </u> <u> </u> <u> </u> <u> </u> <u> </u> <u> </u>	tense
	1 2 3 4 5 6 7	
interested	<u> </u> <u> </u> <u> </u> <u> </u> <u> </u> <u> </u> <u> </u>	bored
	1 2 3 4 5 6 7	
angry	<u> </u> <u> </u> <u> </u> <u> </u> <u> </u> <u> </u> <u> </u>	content
	1 2 3 4 5 6 7	

QUESTIONNAIRE #1, PAGE 2

Please circle the response that applies most accurately to how you are feeling right now.

(T = True; F = False; Y = Yes; N = No)

- | | | | |
|-----|-------------------------------------|-----|--|
| Y N | Nervous | Y N | Feeling of courage |
| Y N | Weary | Y N | Enjoying yourself |
| Y N | Irritable | Y N | Breathing difficult |
| Y N | Cheerful | Y N | Parts of the body feel numb or tingling |
| Y N | Tense, tensed up | Y N | Feels like it will take a long time to fall asleep |
| Y N | Sad, blue | Y N | Feeling hostile |
| Y N | Happy | Y N | Infuriated |
| Y N | Frightened | Y N | Heart beating fast or pounding |
| Y N | Feeling calm | Y N | Depressed |
| Y N | Feeling healthy | Y N | Jumpy |
| Y N | Losing temper easily | Y N | Feeling a failure |
| Y N | Feeling of not enough air | Y N | Not interested in things |
| Y N | Feeling kind toward people | Y N | Highly strung |
| Y N | Feeling fit | Y N | Cannot relax |
| Y N | Heavy arms or legs | Y N | Panicky |
| Y N | Feeling confident | Y N | Pressure on head |
| Y N | Feeling warm toward people | Y N | Blaming yourself |
| Y N | Shaky | Y N | Thoughts of ending your life |
| Y N | No pains anywhere | Y N | Frightening thoughts |
| Y N | Angry | Y N | Enraged |
| Y N | Arms and legs feel strong | Y N | Irritated by other people |
| Y N | Appetite poor | Y N | Looking forward toward the future |
| Y N | Feeling peaceful | Y N | Nauseated, sick to stomach |
| Y N | Feeling unworthy | Y N | Feeling that life is bad |
| Y N | Annoyed | Y N | Upset bowels or stomach |
| Y N | Feeling of rage | Y N | Feeling inferior to others |
| Y N | Cannot enjoy yourself | Y N | Feeling useless |
| Y N | Tight head or neck | Y N | Muscle pains |
| Y N | Relaxed | Y N | No unpleasant feelings in head or body |
| Y N | Restless | Y N | Headache |
| Y N | Feeling friendly | Y N | Feel like attacking people |
| Y N | Feeling of hate | Y N | Shaking with anger |
| Y N | Choking feeling | Y N | Mad |
| Y N | Afraid | Y N | Feeling of goodwill |
| Y N | Patient | Y N | Feel like crying |
| Y N | Scared | Y N | Cramps |
| Y N | Furious | Y N | Feeling that something bad will happen |
| Y N | Feeling charitable, forgiving | Y N | Wound up, uptight |
| Y N | Feeling guilty | Y N | Get angry quickly |
| Y N | Feeling well | Y N | Self-confident |
| Y N | Feeling of pressure in head or body | Y N | Resentful |
| Y N | Worried | Y N | Feeling of hopelessness |
| Y N | Contented | Y N | Head pains |
| Y N | Weak arms or legs | | |
| Y N | Feeling desperate, terrible | | |
| Y N | No aches anywhere | | |
| Y N | Thinking of death or dying | | |
| Y N | Hot tempered | | |
| Y N | Terrified | | |

QUESTIONNAIRE #2, PAGE 1

On this scale, please rate whether, at this point in time, you think you will have an amniocentesis.

definitely will 1 2 3 4 5 6 7 definitely will not

Using the following adjective scales, please rate as best you can how you are feeling right now about amniocentesis:

amniocentesis

love	<u>1</u> <u>2</u> <u>3</u> <u>4</u> <u>5</u> <u>6</u> <u>7</u>	hate
miserable	<u>1</u> <u>2</u> <u>3</u> <u>4</u> <u>5</u> <u>6</u> <u>7</u>	delighted
sad	<u>1</u> <u>2</u> <u>3</u> <u>4</u> <u>5</u> <u>6</u> <u>7</u>	happy
pleased	<u>1</u> <u>2</u> <u>3</u> <u>4</u> <u>5</u> <u>6</u> <u>7</u>	annoyed
afraid	<u>1</u> <u>2</u> <u>3</u> <u>4</u> <u>5</u> <u>6</u> <u>7</u>	calm
relaxed	<u>1</u> <u>2</u> <u>3</u> <u>4</u> <u>5</u> <u>6</u> <u>7</u>	tense
interested	<u>1</u> <u>2</u> <u>3</u> <u>4</u> <u>5</u> <u>6</u> <u>7</u>	bored
angry	<u>1</u> <u>2</u> <u>3</u> <u>4</u> <u>5</u> <u>6</u> <u>7</u>	content

QUESTIONNAIRE #2, PAGE 2

Please circle the response that applies most accurately to how you are feeling right now.

(T = True; F = False; Y = Yes; N = No)

- | | |
|---|--|
| Y N Nervous | Y N Feeling of courage |
| Y N Weary | Y N Enjoying yourself |
| Y N Irritable | Y N Breathing difficult |
| Y N Cheerful | Y N Parts of the body feel numb or tingling |
| Y N Tense, tensed up | Y N Feels like it will take a long time to fall asleep |
| Y N Sad, blue | Y N Feeling hostile |
| Y N Happy | Y N Infuriated |
| Y N Frightened | Y N Heart beating fast or pounding |
| Y N Feeling calm | Y N Depressed |
| Y N Feeling healthy | Y N Jumpy |
| Y N Losing temper easily | Y N Feeling a failure |
| Y N Feeling of not enough air | Y N Not interested in things |
| Y N Feeling kind toward people | Y N Highly strung |
| Y N Feeling fit | Y N Cannot relax |
| Y N Heavy arms or legs | Y N Panicky |
| Y N Feeling confident | Y N Pressure on head |
| Y N Feeling warm toward people | Y N Blaming yourself |
| Y N Shaky | Y N Thoughts of ending your life |
| Y N No pains anywhere | Y N Frightening thoughts |
| Y N Angry | Y N Enraged |
| Y N Arms and legs feel strong | Y N Irritated by other people |
| Y N Appetite poor | Y N Looking forward toward the future |
| Y N Feeling peaceful | Y N Nauseated, sick to stomach |
| Y N Feeling unworthy | Y N Feeling that life is bad |
| Y N Annoyed | Y N Upset bowels or stomach |
| Y N Feeling of rage | Y N Feeling inferior to others |
| Y N Cannot enjoy yourself | Y N Feeling useless |
| Y N Tight head or neck | Y N Muscle pains |
| Y N Relaxed | Y N No unpleasant feelings in head or body |
| Y N Restless | Y N Headache |
| Y N Feeling friendly | Y N Feel like attacking people |
| Y N Feeling of hate | Y N Shaking with anger |
| Y N Choking feeling | Y N Mad |
| Y N Afraid | Y N Feeling of goodwill |
| Y N Patient | Y N Feel like crying |
| Y N Scared | Y N Cramps |
| Y N Furious | Y N Feeling that something bad will happen |
| Y N Feeling charitable, forgiving | Y N Wound up, uptight |
| Y N Feeling guilty | Y N Get angry quickly |
| Y N Feeling well | Y N Self-confident |
| Y N Feeling of pressure in head or body | Y N Resentful |
| Y N Worried | Y N Feeling of hopelessness |
| Y N Contented | Y N Head pains |
| Y N Weak arms or legs | |
| Y N Feeling desperate, terrible | |
| Y N No aches anywhere | |
| Y N Thinking of death or dying | |
| Y N Hot tempered | |
| Y N Terrified | |

QUESTIONNAIRE #2, PAGES 3 & 4
(This is the Shiloh satisfaction survey.)

Please rate the following questions on a scale of 1 to 4.

(1 = low/strongly disagree 4 = high/strongly agree)

- _____ Did the genetic counselor show interest in your personal problems beyond what is medically required?
- _____ Did you consider turning to another genetic counselor regarding your problem?
- _____ Did the genetic counselor explain your condition to you clearly?
- _____ Did the genetic counselor meet your expectations of her?
- _____ Do you think the genetic counselor cares for you as a person?
- _____ How comfortable would you feel to call the genetic counselor to ask another question?
- _____ Did the genetic counselor reassure you?
- _____ Did the genetic counselor listen to what you had to say?
- _____ Was the genetic counselor considerate of your emotional state during the meeting?
- _____ How satisfied are you with the way in which information was transmitted to you?
- _____ Did the genetic counselor show enough dedication in treating your problem?
- _____ How would you rate the level of service that you received?
- _____ Did the genetic counselor understand what was really bothering you?
- _____ Do you think that you could get more considerate care from a private doctor?
- _____ Did the genetic counselor make you feel you are "in good hands"?
- _____ Did the genetic counselor make you feel that she knows how to handle problems like yours?
- _____ Did the genetic counselor give you enough of her time?

- _____ Was the genetic counselor sensitive and tactful during your conversation?
- _____ Did the genetic counselor give you the necessary treatment?
- _____ Do you think the genetic counselor is an expert in the field in which you need help?
- _____ Can the counseling that you received help you cope better with your problem?
- _____ Did the genetic counselor lessen your worries?
- _____ How do you rate the length of time you waited since you first contacted the clinic and until your visit (documents, lines, etc.)?
- _____ How do you rate the length of time you waited since your arrival at the clinic and until you entered the genetic counselor's office?
- _____ If an acquaintance of yours needed a similar help, would you recommend this clinic to him/her?
- _____ Do you think you could get better treatment from a private doctor?
- _____ How satisfied are you with the treatment you got from the medical staff, besides for the doctor--the nurse, the secretary, etc.?
- _____ Do you think that the counseling was given in the appropriate setting for the sort of problem you had?
- _____ In summary, how would you rate your satisfaction with the counseling?

APPENDIX C

STUDY INSTRUMENTS

CONSENT FORM: SACRED HEART

Consent Form

Approved by the Sacred Heart Medical Center Institutional Review Board this 11th day of July, 1997.

Purpose:

You are invited to participate in a research study conducted by Amy Hudkins from the University of Oregon Honors College with participation from Sacred Heart Medical Center and Emanuel Hospital. The purpose of this study is to learn more about how people make decisions and about client satisfaction with the genetic counseling process here at the Fetal Diagnostic Center. The results of this study will contribute to my senior thesis. You were selected as a possible participant in this study because you are presently undergoing genetic counseling.

Procedure:

If you decide to participate, you will fill out three questionnaires about the amniocentesis procedure. You will complete the first after you give your consent to participate, the second after your counseling session, and the third after your ultrasound. Each questionnaire should take approximately five minutes to complete during your appointment. You have the right to refuse to participate or to withdraw your participation at any time. This will not affect your relationship with anyone at Sacred Heart Medical Center.

Benefits:

Though you will receive no direct benefits from this research, your answers to the questionnaires could shed light on decision-making and on your satisfaction with the genetic counseling process. In so doing, it will help genetic counselors provide improved service in the future.

Risks:

There is no known risk associated with participation in this study. One possible inconvenience to you is the additional time required to complete the questionnaires. Your genetic counselor will not see the questionnaires so the counseling you receive will not be affected by your answers. You are welcome to discuss with your genetic counselor questions or concerns you might have regarding the questionnaires you will complete.

Confidentiality:

Any information that is obtained in connection with this study and that could possibly be identified with you will remain confidential and will be disclosed only with your permission. The questionnaires will not contain your name and they will not be stored with your hospital records. In addition I (Amy Hudkins) will obtain your ultrasound results from your genetic counselor; however, these results will be labeled only with a participant code number, not with your name.

Again, your genetic counselor will not see your questionnaires as a part of this study. After you complete your questionnaires, you will put them in an envelope, seal the envelope and give it to a

secretary who will mail it. It is possible that in the future your genetic counselor will contact you in order to extend this research. At that time she might ask you for access to your questionnaires. If you decide not to participate at that time, your genetic counselor will never see your questionnaire. If you do decide to participate in the follow-up study, then, as now, you have the right to refuse to participate or to withdraw your participation at any time.

It is possible that the Food and Drug Administration could choose to inspect these records.

Alternatives:

Your participation is voluntary. Your decision whether or not to participate will not affect your relationship with anyone at Sacred Heart Medical Center. If you decide to participate, you are free to withdraw your consent and discontinue participation at any time without penalty. Once you are involved in your counseling, if you feel that this research is interfering, please let the genetic counselor know that you would like to withdraw from the study.

Compensation:

Sacred Heart Medical Center will not be financially responsible for any services rendered for an adverse event resulting from this study.

Contacts:

If you have any questions regarding the research, please feel free to contact me, Amy Hudkins, (541) 302-6734, or my advisor from the University of Oregon Psychology Department, Dr. Sara Hodges, (541) 346-4919. If you have questions regarding your rights as a research participant, contact the Research Compliance Office, University of Oregon, Eugene, OR 97403, (541) 346-2510. You will be offered a copy of this form to keep.

Your signature indicates that you have read and understand the information provided above, that you willingly agree to participate, that you may withdraw your consent at any time and discontinue participation without penalty, that you will receive a copy of this form, and that you are not waiving any legal claims, rights or remedies.

Participant Signature

Date

Witness Signature

Date

CONSENT FORM: EMANUEL

Consent FormPurpose:

You are invited to participate in a research study conducted by Amy Hudkins from the University of Oregon Honors College with participation from Sacred Heart Medical Center and Legacy Emanuel Hospital and Health Center. The purpose of this study is to learn more about how people make decisions and about client satisfaction with the genetic counseling process here at the Department of Medical Genetics. The results of this study will contribute to my senior thesis. You were selected as a possible participant in this study because you are presently undergoing genetic counseling.

Procedure:

If you decide to participate, you will fill out two questionnaires about the amniocentesis procedure. You will complete the first after you give your consent to participate, the second after your counseling session. Each questionnaire should take approximately five minutes to complete during your appointment. You have the right to refuse to participate or to withdraw your participation at any time. This will not affect your relationship with anyone at Legacy Emanuel Hospital and Health Center.

Benefits:

Though you will receive no direct benefits from this research, your answers to the questionnaires could shed light on decision-making and on your satisfaction with the genetic counseling process. In so doing, it will help genetic counselors provide improved service in the future.

Risks:

There is no known risk associated with participation in this study. One possible inconvenience to you is the additional time required to complete the questionnaires. Your genetic counselor will not see the questionnaires so the counseling you receive will not be affected by your answers. You are welcome to discuss with your genetic counselor questions or concerns you might have regarding the questionnaires you will complete.

Confidentiality:

Any information that is obtained in connection with this study and that could possibly be identified with you will remain confidential and will be disclosed only with your permission. The questionnaires will not contain your name and they will not be stored with your hospital records. In addition I (Amy Hudkins) will obtain your ultrasound results from your genetic counselor; however, these results will be labeled only with a participant code number, not with your name.

Again, your genetic counselor will not see your questionnaires as a part of this study. After you complete your questionnaires, you will put them in an envelope, seal the envelope and give it to a secretary who will mail it. It is possible that in the future your genetic counselor will contact you in order to extend this research. At that time she might ask you for access to your questionnaires. If you decide not to participate at that time, your genetic counselor will never see your questionnaire. If you do decide to participate in the follow-up study, then, as now, you have the right to refuse to participate or to withdraw your participation at any time.

Alternatives:

Your participation is voluntary. Your decision whether or not to participate will not affect your relationship with the Department of Medical Genetics at Emanuel Hospital. If you decide to participate, you are free to refuse to participate or to withdraw from participation in this study at any time and it will in no way affect your relationship with, or treatment at Legacy Health Systems. Once you are involved in your counseling, if you feel that this research is interfering, please let the genetic counselor know that you would like to withdraw from the study.

Contacts:

If you have any questions regarding the research, please feel free to contact me, Amy Hudkins, (541) 302-6734, or my advisor from the University of Oregon Psychology Department, Dr. Sara Hodges, (541) 346-4919. If you have questions regarding your rights as a research participant, contact Casey Bush at the Office of Research Administration, (503) 413-2474, or you may call the University of Oregon Human Subjects Compliance Office, (541) 346-2510. You will be offered a copy of this form to keep.

Your signature indicates that you have read and understand the information provided above, that you willingly agree to participate, that you may withdraw your consent at any time and discontinue participation without penalty, that you will receive a copy of this form, and that you are not waiving any legal claims, rights or remedies.

Signature

Date

LETTER OF EXPLANATION
(Given to clients after completing the final questionnaire)

Dear research participant,

I would like to thank you for your participation in this research study. The series of questionnaires you have just completed are designed to estimate your emotional reactions toward amniocentesis at different points of your counseling session and your satisfaction with the genetic counseling process. The results will hopefully shed light on how clients make decisions about undergoing an amniocentesis procedure. The following is an explanation of the procedure and the hypothesis of the project.

As you know, amniocentesis counseling is an emotional session for clients because of the dilemma of weighing the risk of the procedure and the possibility of determining if the fetus is healthy or not. In order to help clients make this decision, the genetic counselor provides as much information as possible. The Fetal Diagnostic Center at Sacred Heart Medical Center in Eugene believes that the information available from an ultrasound should be included as part of the information available to clients before they make their decision. This is because the ultrasound sometimes contains information significant to this decision: For instance, an ultrasound can indicate if there is a possibility that a fetus has Down's Syndrome or a spinal malformation.

The diagnostic center at Sacred Heart includes ultrasound results in all amniocentesis counseling sessions. That is, expectant parents at Sacred Heart receive their ultrasound results before they make the decision to have an amniocentesis. In contrast, the Department of Medical Genetics at Legacy Emanuel Hospital and Health Center in Portland has expectant parents make their decision about whether to have an amniocentesis without ultrasound results unless the parents request to have their ultrasound results before they decide. This project seeks to determine if including ultrasound results as part of the information given in amniocentesis counseling influences the decisions made to elect or decline the amniocentesis procedure.

We are curious how your attitude toward amniocentesis changes at various stages of the decision process. This is why we had you fill out the questionnaires with the adjectives more than once. We are also interested in comparing responses of participants at the two hospitals. If there is a significant difference in when and how clients are making their decision, we may be able to determine how the counseling process affects the decisions made about amniocentesis.

Again, I am grateful for the time you have given to participate in this project. If you have any questions or concerns regarding this research study, please contact me, Amy Hudkins (541) 302-6734, c/o Clark Honors College, Eugene OR 97403-1292 or your genetic counselor at the Department of Medical Genetics, (503) 1-800-452-7032 x4726. If you have any questions regarding your rights as a research subject, please contact Casey Bush (503) 413-2774.

Respectfully,

Amy Hudkins
University of Oregon Honors College student

ENDNOTES

- 1 Physicians and geneticists provide genetic counseling as well as genetic counselors. Here I refer to genetic counseling as the profession held by non-MDs with a masters degree specifically designed for the practice of genetic counseling.
- 2 It should be noted that, although Sacred Heart Medical Center, one of the hospitals involved in the present study, is a Catholic institution, Sacred Heart physicians and genetic counselors are free to discuss all medical alternatives available--including abortion.
- 3 The subject sample size (n) occasionally varies between analyses because several participants were missing some data.

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