

Effect of Receiving Genetic Counseling On Pre-Event Anxiety in Genetic Amniocentesis Patients

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Abstract: None available.

Full Text: Headnote ABSTRACT: Data were obtained as part of a larger experimental study of 48 genetic amniocentesis patients, ages 21 to 40. Information about genetic counseling was obtained through the demographic data questionnaire. State anxiety was measured before the procedure. Pre-event anxiety scores of women who had received genetic counseling before the day of the procedure were compared with those who had not received counseling before their appointment day. T-test for independent means revealed that those women who had counseling before the day of the procedure reported significantly less anxiety before the procedure than those who had no previous counseling. Prior counseling offers needed time for information integration and truly informed choice. The results are discussed in the context of the theoretical relationship between high anxiety levels before a threatening event and disruptions in emotion and coping during and after the procedure. INTRODUCTION Genetic amniocentesis is a procedure performed in the second trimester of pregnancy to diagnose genetic problems of the fetus. The current increased use of this procedure is directly related to the following factors: the large number of genetic disorders that can be diagnosed prenatally, the relative safety of the procedure, as well as increased public awareness and acceptance of the procedure. Although emotional arousal related to genetic amniocentesis has been reported in the literature over the last decade, little attention has been focused on variables which impact this psychological response. Included among these variables are cognitive interpretation, perception of personal control and planned intervention. The beneficial effect of genetic counseling as an intervention to alter the emotional arousal has been assumed, however a search of medical and nursing literature (Cumulated index medicus and Cumulative index to nursing and allied health literature) indicate this outcome has not been documented. One important purpose of genetic counseling is to identify women and couples who are candidates for genetic amniocentesis and other methods of prenatal genetic diagnosis. Ideally, genetic counseling should be offered to individuals and couples before pregnancy. Early counseling offers the opportunity for understanding those potential problems that may arise, and also permits the opportunity for identifying the best method for diagnosis (e.g. parental testing, chorionic villi sampling, amniocentesis, etc.). This provides the individual or couple with sufficient time to assimilate the information they have been given and to make informed decisions for the future. In reality genetic counseling seldom takes place before pregnancy has already been established and genetic amniocentesis may be the only option available. In genetic amniocentesis patients, it has been documented that in many cases genetic counseling does not take place until the day of the procedure (Loranz, Willard & Botti, 1986), further limiting the possible choices and imposing forced decisions on the woman or couple. These decisions may be further influenced by what Rothman (1986) believes is a "compulsion to 'choose' the socially endorsed alternative" (p. 12) in reproductive choices. Medical geneticists are ethically obligated to provide complete information for each individual case. Ideally, the counselee then carefully considers this information before making an autonomous decision (Fletcher, Berg & Tranoy, 1985). Time is an essential element in arriving at this decision. Counseling on the day of the procedure may contain little more than sufficient information for informed consent. Even an in-depth same-day session will still differ qualitatively from one that takes place earlier than the day of the procedure. In reality, Lorenz and colleagues (Lorenz, Botti, Schmidt & Ladda, 1985) found that patients who were counseled before the day of amniocentesis chose the procedure less often than those who received counseling on the day of the procedure. These authors (Lorenz, Botti, Schmidt & Ladda; 1985) have suggested that time to consider options is necessary for this complex and potentially confusing decision. Counseling

should separate the decision to have amniocentesis from the decision to terminate the pregnancy. The decision making related to these procedures is a complex process, and therefore time is needed to arrive at these decisions (Rothman, 1986). This is consistent with Temple's (1983) earlier recommendation that a minimum time of two weeks would lapse between genetic counseling and the procedure. A potential psychological side effect resulting from the combination of genetic risk, amniocentesis and forced decision making is anxiety (Phipps & Zinn, 1986; Temple, 1983). In addition, when information, assimilation time, and understanding are insufficient, the cognitive appraisal of threat is increased. Thus the emotional arousal will also be increased.

THEORETICAL FRAMEWORK Lazarus (1966) identified stress as a psychological problem, and cited the environment, crisis, and threatening situations as being among the stimulus factors. He later defined stress as "a relationship between the person and the environment that is appraised by the person as taxing or exceeding his or her resources and endangering his or her well being." (Lazarus & Folkman, 1984, p. 21). Initial appraisal depended on cognitive interpretation of a potential threat, with further appraisal necessary for one to decide what to do when judged to be in jeopardy. This model emphasized the importance of cognition in the response and management of stress. Cognitive interpretation may be influenced by available information and perceptions of choice about the stimulus. Averill (1973; Cornelius & Averill, 1980) has used the term cognitive control to refer to the way an individual interprets a potentially harmful situation, while decisional control reflects agreement with the course of action that must be taken. The purpose of this study was to compare subjective anxiety of subjects who reported receiving genetic counseling before the day of genetic amniocentesis with those subjects who reported they had not been previously counseled. These data represent serendipitous findings from a larger experimental design to investigate the interaction effect of intrasubject variables (pre-event anxiety and preference for involvement in health care) and informational interventions (sensation information and behavioral instruction in a relaxation technique) on emotional arousal and coping with genetic amniocentesis. During a preliminary study at the data collection site, most women reported that they had not been counseled before the day of the procedure. A question was added to the pre-intervention subject data questionnaire for the explicit purpose of describing differences between subjects who were counseled before the day of amniocentesis and those who were not counseled before their appointment day. While the weaknesses of this design were recognized, it was felt that the data would provide beginning information concerning this complex response. In the present study genetic amniocentesis was defined as transabdominal needle aspiration of amniotic fluid for the purpose of diagnosis, which occurred during the second trimester of pregnancy. Preevent anxiety was the subjective feeling of apprehension and tension present before genetic amniocentesis. Genetic counseling referred to the subject's perception of having been counseled, without specification of place, type of counselor or content.

METHOD Subjects consisted of a convenience sample of 48 women in the second trimester of pregnancy who were scheduled for genetic amniocentesis at the private offices of a fetal-maternal medicine specialist in the perinatal center of a moderate-sized midwestern hospital. Selection criteria included: (1) pregnancy at 14 to 20 weeks gestation, (2) scheduled for genetic amniocentesis, (3) age 18 or over, (4) written and verbal fluency in English, and (5) unimpaired hearing. Data were collected between January and April, 1987. Subjects were between the ages of 21 and 40 years, with a mean age of 32.6 years. The majority of the subjects were married (75%), and the principal reason for the genetic amniocentesis was advanced maternal age (56.3%). This sample was well educated, with 75% reporting higher education. Measures All measures were made by self-administered pencil-and-paper tests. The subject data form contained a yes/no question asking subjects whether they had received prior genetic counseling. Pre-event anxiety was measured by items from the State-Trait Anxiety Inventory (STAI) with reported internal consistency reliability of .91 and validity of .93 (Spielberger, Gorsuch, Lushene, Vagg & Jacobs, 1983). Because of time constraints in the setting, a short form consisting of four items from the state scale of the 20-item STAI was used. These items consisted of short statements followed by a four-point scale (not at all to very much so) which indicated how the subject felt at that moment. This short form has been used in other research studies (Auerbach, Kendall, Cuttler & Levitt,

1976; Kendall, Williams, Pechacek, Graham, Shisslak & Herzoff, 1979, OTCeil, Spielberger & Hansen, 1969; Sime & Libra, 1985) and has shown a correlation of 0.91 to scores on the entire scale (Sime, 1984). Procedure Potential subjects were contacted by phone before their scheduled appointment and invited to participate in the study. On the day of their appointment, they were met in the perinatal center by the investigator, and written informed consent was obtained. Subjects then completed the subject data form and the anxiety scale. This was followed by additional procedures related to the larger experimental design previously described (Ruiz-Bueno, 1988). At the conclusion of these experimental procedures, and prior to the genetic amniocentesis, counseling with a medical geneticist was available. RESULTS Seventeen subjects reported they had received counseling before the day of their genetic amniocentesis appointment; thirty-one subjects reported they had not been counseled. The counseled group had a preevent anxiety mean score of 7.65; the mean score of the uncounseled group was 9.81. Using the t-test for independent means, it was found that the difference between the means was significant ($t = 3.27$, $df = 46$, $p = .002$). Discussion It is not surprising that subjects who received counseling before the day of amniocentesis reported less anxiety than those who were not previously counseled. A combination of factors may contribute to anxiety in amniocentesis patients (Finley, Varner, Vinson & Finley, 1977; Golbus, Conte, Schneider & Epstein, 1974; Nielson, 1981; Rothman, 1986). While the study design did not provide for identification of other factors, lack of counseling before the day of amniocentesis is of great importance (Finley, Varner, Vinson & Finley, 1977; Golbus, Conte, Schneider & Epstein, 1974; Nielsen, 1981). Not only must the decision for amniocentesis be separated from the decision to terminate the pregnancy, but a complete understanding of the choices, with the fullest information possible is required to make a responsible decision (Rothman, 1988). It is the ethical obligation of the health care profession to provide the needed information in a timely manner, which allows for assimilation and understanding. Reproductive choices in our complex society are considered personal matters; understanding is essential for individuals to make these difficult decisions (Rapp, 1988). The data reported in this study support the need for genetic counseling before the day of the procedure, allowing time to assimilate information and promote understanding of the choices available with possible implications for the future. This will decrease the emotional arousal associated with forced decision making. The pre-event anxiety mean score for women who had received genetic counseling before their appointment day was similar to the mean scores for subjects undergoing other threatening diagnostic events as measured by the same instrument (Kendall et al, 1979; Sime & Libra, 1985). The finding of even higher anxiety levels in women who had no previous counseling suggests that these women are forming a cognitive appraisal of amniocentesis as a greater threat than counseled women or persons undergoing events such as cardiac catheterization (Kendall et al, 1979) or dental surgery (Sime & Libra, 1985). Such a cognitive appraisal would seem to place these persons in a vulnerable position. Other research has consistently demonstrated that high threat appraisals (high preevent anxiety levels) are associated with emotional arousal and impaired coping during the threat event, and with emotional and coping disruptions after the event (Kendall et al, 1979; Sime, 1976; Sime & Libra, 1985). Limitations The study was not designed to estimate the effects of preappointment day counseling upon psychological adjustment during or after amniocentesis. However, the findings suggest such a study is warranted. The major limitations of this study were directly related to the fact that the data were serendipitous findings from an experimental design. In this sample there was neither random selection nor random assignment, which imposes limitations on interpretation and generalization. In addition, the type of genetic counseling (group or individual, provided by whom, nature of content, etc.) was unknown; thus differential effects could not be examined. Implications Genetic counseling provides patients with appropriate information to make informed decisions for reproductive health; it may also have a role in controlling anxiety associated with the genetic amniocentesis procedure. In this sample of amniocentesis patients, it was found that prior genetic counseling was associated with significantly lower anxiety scores before the procedure. While many other factors are recognized as contributing to pre-event anxiety, lack of prior genetic counseling is one factor that can be readily controlled. Health care professionals

involved in the care of women of reproductive age must recognize the importance of genetic counseling for women who may be candidates for genetic diagnosis. Those who are not qualified to provide counseling should refer the patient to an appropriate counseling source as early as the question of genetic diagnosis arises. Antepartal women identified as possible candidates for genetic amniocentesis should have genetic counseling as early in the pregnancy as possible. In some cases, for example pregnant patients with abnormal serum alpha fetoprotein levels, the time element may produce a situation in which it is difficult to provide in-depth counseling in advance. Nonetheless, an attempt should be made to provide counseling at least 24-28 hours before the scheduled procedure.

Recommendations for Further Study Because the data reported here were a serendipitous finding, they must be confirmed in a study designed specifically for this purpose. Design should include randomization, and genetic counseling should also be defined according to method, content, type of counselor, and number of days/weeks before the procedure. The differential effects of group versus individual counseling needs further study, as well as the effects of counseling on emotional arousal and coping during the postamniocentesis period. Investigation of other interventions that may aid in alleviating anxiety, such as specific psychological preparation for the procedure (Ruiz-Bueno, 1988), is also suggested.

Conclusion Genetic amniocentesis is an anxiety-provoking procedure. Subjects who had not received genetic counseling prior to the day of the procedure reported more anxiety before the procedure than those who had already been counseled. While it is recommended that women at risk should receive genetic counseling before pregnancy, it is recognized that this is not always practical or even possible, as risk is not always identified early. Thus genetic counseling is most often offered after pregnancy has occurred. Counseling before the day of genetic amniocentesis is beneficial because it allows time for assimilation of information, consideration of options, and informed decision making. Another important advantage of early counseling is that it may also reduce the emotional arousal associated with the cognitive appraisal of the procedure.

SUMMARY Anxiety is one of the side-effects of screening and testing procedures performed antenatally. Genetic amniocentesis is a procedure about which many patients experience high anxiety. Health care professionals are continuously seeking methods of reducing that anxiety. Genetic counseling is believed to play an important part, but this role has not been documented in the literature. In a sample of 48 women undergoing genetic amniocentesis, it was found that those women who reported having genetic counseling prior to the day of the procedure had significantly less anxiety before the procedure than those who had not been previously counseled. This study supports the beliefs that (1) genetic counseling prepared patients psychologically for genetic amniocentesis by providing information to assist them in the decision making process, and (2) sufficient time must be allowed for the assimilation and full comprehension that is necessary for informed consent and truly personal decisions.

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