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ABSTRACT

This study compared the beliefs of mothers (N=36) of persons with Down Syndrome with the beliefs of genetic counselors (N=28) and nurses (N=32) about parenting children with Down Syndrome and about prenatal diagnosis. All subjects were shown a videotaped discussion by parents of persons with Down Syndrome and then responded to a questionnaire. Major findings included: 89% of mothers felt the film was an accurate portrayal of parental attitudes compared with 14% of genetic counselors and 40% of nurses; 92% of mothers thought the film was of "high" educational value compared to 30% of genetic counselors; 48% of genetic counselors felt that problems outweighed benefits in parenting a child with Down syndrome, but 94% of mothers and 83% of nurses thought that benefits predominated; and 56% of genetic counselors believed that parents of a person with Down syndrome would choose to abort a subsequent affected fetus, while only 8% of mothers and 10% of nurses agreed. Contains 30 references. (DB)

REACTIONS OF MOTHERS AND MEDICAL PROFESSIONALS TO A FILM ABOUT DOWN SYNDROME

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ABSTRACT

Parents, genetic counselors, and nurses were shown an 18 minute videotaped discussion by parents of persons with Down syndrome and asked to complete an evaluation. Some of the statistically significant differences ($p<.005$) included: 89% of mothers felt the film was an accurate portrayal of parental attitudes compared to 14% of the genetic counselors and 40% of the nurses; 48% of genetic counselors felt problems outweighed benefits in parenting a child with Down syndrome but 94% of mothers and 83% of nurses thought that benefits predominated; 56% of genetic counselors believed that parents of a person with Down syndrome would choose to abort a subsequent affected fetus while only 8% of parents and 10% of nurses agreed. It is important that medical professionals have a balanced and accurate view of the impact of this disability on families.

INTRODUCTION

Developments in the field of prenatal diagnosis continue to increase the complexity of information available to expectant parents about the well-being of their baby. The maternal serum alpha-fetoprotein assay has allowed estimates of increased risk for such conditions as spina bifida and Down syndrome.(1,2) More recently, additional maternal serum markers have been identified to refine the precision of risk assignment for Down syndrome.(3,4) Advances in ultrasonography have expanded the contributions of this technology to the assessment of fetal health.(5) In order to fully utilize these services and the information they generate, consumers require the translation of data into understandable language about consequences. This interpretation is usually provided by professionals trained in genetics, genetic counseling, nursing, or obstetrics. It is, therefore, important that these professionals not only have an accurate grasp of the technical data, but also a balanced view of the real life implications of the diagnosis in question.

Studies of the attitudes of pediatricians towards people with mental retardation have suggested unrealistically limited expectations for future functioning.(6) A majority of pediatricians were found to have no contact with people with developmental disabilities outside of the professional setting.(7) Parents of newborns with Down syndrome reflecting on the informing interview have complained about a lack of sensitivity and balanced information afforded them by medical professionals.(8,9) If physicians who care for children with developmental disabilities are incompletely informed of their future prospects, then those professionals who counsel the parents of fetuses with disabilities may also lack a well-rounded awareness.

In the preparation of a training film about parenting persons with Down syndrome, we had the opportunity to examine the views of some genetic counseling and nursing professionals. Completion of the film included its test screening before audiences of professionals and of parents of individuals with Down syndrome. These audiences were asked to complete an anonymous questionnaire evaluating the film and indicating attitudes towards prenatal diagnosis. This report compares the responses of mothers with those of genetic counselors and nurses in an effort to determine if differences exist in their beliefs about the experience of parenting a child with Down syndrome.

METHODS

Materials In the winter of 1988 with funding from the New England Regional Genetics Group a discussion by parents of individuals with Down Syndrome was recorded on video tape. The edited result, titled Down Syndrome—A Parental Perspective, was used as an 18 minute "trigger film" to introduce parental and family issues for further discussion by an audience.

Following a brief introduction, the film records an informal, leaderless discussion among 10 parents (4 couples and 2 individual parents) of several general themes. All of the parents participating in the film were from New Hampshire and Vermont. Their ages ranged from 28 to 65. All parents had more than one child, and their children with Down syndrome ranged in age from 2 years to 24 years old. One child had been placed in temporary foster care soon after birth, but reclaimed by the birth parents at six weeks of age. One child had undergone bowel surgery and heart surgery, the others had been free of major medical complications of Down syndrome. All but one of the parents had more than 12 years of education. Among three of the couples, both parents worked. One mother was a single, working parent. The discussion themes, which included recollections of the initial diagnosis (of Down syndrome) and the informing interview, decision-making about subsequent prenatal diagnostic tests, attitudes of medical professionals, and how medical education might address these issues, were introduced at 30 minute intervals. Some of the discussion of medical professionals was critical, particularly around topics like "breaking the news" (of the diagnosis) and preventive medical care. All of the parents said they would not abort a subsequent fetus with Down syndrome, though two couples had chosen a prenatal diagnostic test in a subsequent pregnancy. All of the parents felt having a choice about testing and abortion was important, and that such a choice required balanced information. The film concluded with several minutes of informal footage of two families of children with Down syndrome at a winter outing. About two hours of raw footage were eventually edited to the final version.

Subjects In the course of evaluating the film's quality and usefulness, a number of screenings were held before audiences assembled for other purposes. These audiences included gatherings of genetic counseling, nursing, and other medical professionals for continued medical education and of parents of persons with Down syndrome for workshops and meetings. The same film was presented to each audience with the minimal introduction that it was a teaching film portraying parents of people with Down syndrome discussing some of their experiences. Immediately after the film and prior to any discussion, viewers were asked to complete a three page anonymous evaluation form requesting demographic information, impressions of the film, beliefs about prenatal diagnosis, and predicted behavior in response to several scenarios. The evaluation was organized in a Likert scale format with responses of 1, 2, 3, 4, and 5 signifying the respondent's degree of disagreement (1) or agreement (5) with each statement. An area for narrative comment was also provided.

The evaluation responses from the three largest, distinct groups (parents, genetic counselors, and nurses) were compared. Responses from members of other professional categories were too few to create additional groups and too diverse to combine. Since all of the members of the nurses group and most of the members of the other two groups were female, the responses of males were excluded for the purposes of this study. A total of 155 evaluation forms were completed and returned. An assortment of medical students, pediatric residents, social workers, cytogenetics laboratory technicians, and educators accounted for 44 responses which were excluded from this study. The 5 male respondents among the genetic counselors and the 9 male respondents among the parents were also excluded. The remaining 97 evaluation forms were reviewed. The three respondent groups included 36 mothers, 29 genetic counselors, and 32 nurses. (see Table I) All of the nurses and mothers and all but five of the genetic counselors were from New England. The mothers and both groups of professionals were of similar ages, educational levels, and socioeconomic backgrounds. The nurses were all obstetrical care nurses. Data about parenthood among the professionals was not gathered, but it may be assumed that some were not mothers. None of the nurses and genetic counselors had personal, as opposed to professional, experience with Down syndrome.

Due to the relatively small sample size, the data was dichotamized on the basis of the median Likert scale response of the entire population (3.43). This resulted in responses of 1, 2, and 3 being recoded as "disagree" (with the statement) and responses of 4 and 5 being recoded as "agree" (with the statement). Each of the responses were examined by three individual Chi square analyses comparing each group to each of the remaining groups.

RESULTS

In general, differences were found among all three groups in their responses to the statements on the film evaluation. Most of the statistically significant differences occurred when the responses of the mothers of individuals with Down Syndrome were compared with those of the genetic counselors. Often the nurses' responses fell between the other two groups differing, but not significantly, from each. Within group differences in the number of responses to some item occurred because of occasional omissions by respondents.

Initial statements on the evaluation form related to the content of the film. They were divided between those addressing the usefulness of the film and those probing the viewer's perceptions of the film's accuracy. In the first category were statements regarding the film's applicability to various audiences, its overall educational value and emotional impact, and its usefulness (see Table II). The second category included statements about the accuracy of the film's portrayal of parents, of medical professionals, and of genetic counseling (see Table III).

Over 90% of the mothers thought the film had high educational value and would be appropriate for use by professionals-in-training. Genetic counselors, on the other hand, differed significantly ($p<.005$), with 29% regarding the educational value highly and 56% feeling that professionals were an appropriate audience. Among the nurses, 84% felt that professionals were an appropriate audience and 56% thought the educational value was high. Nearly 90% of the mothers thought the film would be useful to stimulate discussion while only half of the genetic counselors agreed ($p<.005$).

The film's portrayal of parents was felt to be accurate by 89% of the mothers, by 41% of the nurses, and by only 14% of the genetic counselors. The nurses' and genetic counselors' responses differed significantly ($p<.005$) from the mothers'. Nearly all of the narrative comment by the genetic counselors complained that the film was a too positive view of parenting a child with Down syndrome. 70% of mothers felt the film provided an accurate view of genetic counseling and 78% felt the film portrayed the attitudes of medical professionals accurately. Less than 10% of the genetic counselors agreed. The nurses also differed significantly from the mothers on these statements.

Though over 65% of both mothers and nurses found the film helpful, 86% of the genetic counselors did not ($p<.005$). The majority of all three groups said the film caused little change in their attitudes about Down syndrome. The groups also did not differ significantly in their opinions of the emotional impact of the film which a majority felt was "high."

The remainder of the evaluation form involved statements concerning the viewers' beliefs about prenatal diagnosis, Down syndrome, and predicted behaviors under conditions of altered health in the fetus. These statements included several about the timing and value of genetic counseling, about the "burden" of a person with Down syndrome, about choices parents would make in future pregnancies, and about circumstances under which the viewer would choose abortion. (See Tables IV, V, and VI)

With notable exceptions there was more agreement among the groups on the "beliefs and choices" statements of the evaluation form. Mothers were less positive about the usefulness of prenatal diagnosis to prevent birth defects than were the other two groups ($p>.05$). However, most members of all three groups agreed that genetic counseling before amniocentesis and before prenatal screening with maternal serum alpha fetoprotein was desirable. A majority of all three groups believed that parents of a fetus with Down syndrome should be given the same information as parents of a newborn and should be offered the opportunity to meet other parents. While 62% of the genetic counselors felt that genetic counseling was unbiased, only 18% of the mothers' group agreed ($p<.005$). Agreement among 36% of the nurses was intermediate to, but not significantly different from, the other two groups.

The choice of abortion by parents of a child with Down syndrome when a subsequent fetus is found to have Down syndrome was predicted by 56% of the genetic counselors and by only 8% and 10% of the mothers and nurses. The latter results differed significantly from the genetic counselors ($p<.005$). 48% of the genetic counselors felt that problems outweigh the benefits of parenting a child with Down syndrome while only 6% (p<.005) of mothers and 17% (p<.05) of nurses agreed.

Concerning their own choices, only 9% of the mothers compared to 46% of the genetic counselors (p<.005) and 29% of the nurses predicted that they would choose to abort a fetus with Down syndrome. While small numbers of each group predicted that they would choose abortion for any fetal abnormality (however, minor), greater numbers felt they would abort a fetus with a lethal condition. None of the groups differed significantly on these statements. Finally, a significantly larger number of the mothers (34%) than the genetic counselors (0%) would never choose abortion under any conditions.

DISCUSSION

We have compared the reactions of mothers of individuals with Down syndrome with those of genetic counselors and nurses to a film of families discussing their experiences with Down syndrome. Important differences among these groups were found in several areas: perceptions of family life involving a person with Down syndrome; perceptions about future reproductive choices of parents; and opinions about the usefulness of this film as an educational tool.

The genetic counselors in our study viewed the parenting and family life of a person with Down syndrome in a significantly more negative light than the mothers or, in some cases, the nurses. According to many of the genetic counselors, the burdens outweigh the benefits of having a child with Down syndrome and parents would choose to abort a subsequently affected fetus. Though mothers and nurses disagreed, a large majority of genetic counselors felt the film did not accurately portray the experience of parents. In fact, it was on this point that many counselors commented at length, complaining that the film's parents were too well-adjusted, too positive, and did not include single parents, parents of adults with Down syndrome, or parents of medically complicated children . (In fact, the film's parent discussion group included representatives of each of these groups.) None of the mothers' or nurses' evaluation forms contained similar comments.

The addition of a child with Down syndrome to a family is not a neutral event. Though the literature on the impact of such a child is full of conflicting results, there is general agreement that unique stresses are involved.(10) The initial diagnosis of Down syndrome in a newborn is usually an unanticipated tragedy for most families accompanied by intense feelings of shock, grief, guilt, and despair.(11) The ensuing adjustment has been called a "values crisis," and is often a period of high risk for marital discord.(12) Gath compared the families of 30 children with Down syndrome matched with the families of 30 "normal" children from birth to age 2 and found no differences in the physical or emotional health of parents. Marital stress was increased in the families of children with Down syndrome, but over half of these parents felt their marriages were strengthened by the experience.(13) A six year follow-up study of these groups demonstrated "few differences in the family lives of the two groups" or in the amount of serious psychiatric illness.(14) By personal communication, Feingold reports a survey of 382 New England parents of backgrounds similar to our group. Of his sample, 89% stated that their child with Down syndrome had exceeded their expectations.(15) The vast majority of Feingold's subjects found that their child did not have a negative effect on family relationships. Medical complications had no influence on these responses. Marital and family conditions before the birth of a child with Down syndrome must be determined retrospectively in most cases, but some studies suggest that the impact of the child is determined by prior characteristics of the family.(16) Furthermore, community factors and other supportive resources may be playing an increased role in the determination of a positive family adjustment.(17)

There is little published data about the actual choices of parents of a child with Down syndrome confronted with a recurrence in a subsequent pregnancy. One study found that 48 of 71 mothers predicted that they would abort a future affected pregnancy.(18) However, others have found lower predicted rates. Elkins et al found in a survey of mothers of children with Down syndrome that 50% opted for prenatal diagnosis in subsequent pregnancies. Of those having prenatal testing, about half would consider aborting an affected fetus, but none were actually confronted with the choice.(19) Oetting and Steele reported that only 17% of their group of parents of a child with Down syndrome availed themselves of prenatal diagnosis during the next pregnancy.(20) Feingold's survey reports that 42% of parents of a child with Down syndrome predict that they would have amniocentesis in a future pregnancy, but only 13% would terminate an affected pregnancy.(15) Furthermore, Feingold found that of 224 mothers of children with Down syndrome who had a subsequent pregnancy, 73% elected not to have amniocentesis. In our study, 52% of the mothers would choose prenatal diagnosis, but only 9% predicted that they would abort a fetus with Down syndrome. In contrast, 93% of genetic counselors would utilize prenatal diagnosis, and 46% would abort a fetus with Down syndrome. Of course, what people predict that they would do in the future may differ from their actions. Therefore, collaborative effort is needed to prospectively follow the reproductive choices of a larger group of families affected by Down syndrome.

Why do the genetic counselors in this study have such a pessimistic view of family life for a child with Down syndrome? First, selection bias may have influenced the mothers participating in the study. Mothers with more negative points-of-view may have been less likely to attend workshops and parent support group meetings where the film was screened. However, representation from 36 families in a small, rural state is, at least, a substantial minority voice worthy of consideration. Second, the work experience of genetic counselors may involve more contact with families during the intensely negative crisis of initial diagnosis and less longitudinal contact with crisis resolution and families finding balance. Third, the education of genetic counselors may come predominately from members of their own or related professions whose experience has been similarly limited. A respected and recently revised medical genetics textbook still refers to people with Down syndrome as "mongols" and contains such erroneous and negative statements as "50% die before age five years."(21) This text predicts an IQ range of 25 - 50, substantially less than the mean IQ of 48 in Gath's study group.(13) Finally, some genetic counselors involved in the process of prenatal diagnosis may feel that its goal is a reduction in the birth incidence of Down syndrome (rather than offering choices to individual families). For example, at a recent meeting, Dr. Sumner Yaffe of the Center for Research for Mothers and

Children at the National Institute of Child Health and Human Development stated, "The Foundation (for Blood Research) has embarked on another prenatal screening program that has, and will play, a significant role in removing another significant cause of mental retardation—Down syndrome."(22) It may be difficult to reconcile a more positive view of Down syndrome with a personal belief in a policy of reduced birth incidence.

The suggestion that bias might play a role for professionals in the discrepant reactions to our video can also be made for parents. Parents have invested considerable time and emotional energy in the nurturance of their children with Down syndrome. For some parents, resolution of the added stress that their child brings to family life requires a hopeful, positive view. Hope, in fact, has been suggested as one of the healthy forces that facilitates a family's initial adjustment to the birth of a child with Down syndrome.(23) However, bias among professionals, when it exists, may have more far-reaching impact. Bias may be overtly expressed, though this violates the genetic counseling tenet of "non-directiveness." A recent survey of physicians in southern France found that 78% favored termination of pregnancy for Down syndrome and that 33% would voice their opinions to counselees.(24) Perhaps more importantly, bias may be unacknowledged or hidden and still influence services such as prenatal diagnosis. In editorial comment upon a study finding less than expected use of bone marrow transplantation by children with Down syndrome for treatment of acute lymphoblastic leukemia(25), Churchill states: "Prejudice need not be conscious to be present. Unintended bias against DS (Down syndrome) children can be all the more powerful for being unarticulated, especially among professionals who hold high ideals."(26)

90% of the mothers in our study felt that the film Down Syndrome—A Parental Perspective was of high educational value, would be useful to stimulate discussion, and would be of value to the education of medical professionals. Perhaps the medical professionals dealing with the impact of disability on families require broader exposure to those families. Curricular changes are needed that include parents as valued experts and place students in their midst at home and in the community. Genetic service-providing agencies need to incorporate input from consumers of their services and from families affected by genetic conditions. Models for developments such as these exist and continue to evolve. For example, the New England Regional Genetics Group, which is part of a national network of collaborating medical genetics professionals, has recently provided for significant consumer participation on its steering committee. The genetics curriculum at many medical schools includes presentations by parents and families. Medical genetics educators are developing guidelines that provide substantial attention to the issues of attitudes and communication skills.(27,28)

The past decade has brought multidimensional change to the prospects and lifestyles of individuals with Down syndrome. These individuals can expect to be nurtured in a loving family, to be afforded comprehensive, anticipatory health care, to receive an appropriate education, and to lead useful and productive lives.(29) Their life expectancy has increased.(30) At the same time, services are becoming more holistic, functionally oriented, and responsive to the observations and needs of families.

During the same decade, developments in prenatal medicine have allowed increasingly accurate risk assignment and increasingly safe and early diagnosis of Down syndrome in the fetus. Identification of the majority of affected pregnancies is both technically and economically possible. It is important that these simultaneous developments not become contradictory trends or polarizing processes. The experience of families affected by Down syndrome bears valuable insights both for professionals providing prenatal genetic counseling and for expectant parents utilizing those services.

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Table I: Composition of Study Groups

Group	Number	Mean Age(Range)	Mean Age (yrs) of Child with DS (Range)
Mothers	36	37.3 (26-60)	7.5 (.5-29)
Nurses	32	36.1 (20-58)	——
Genetic Counselors	29	35.7 (25-51)	——
TOTAL	97	36.4 (20-60)	——

Table II: Usefulness of Film — Percent Agree with Statement

Statement	Mothers	Gen. Couns.	Nurses
High Educational Value	91*	29	56*
High Emotional Impact	83	64	72
Appropriate for			
Medical Professionals	92*	56	84
Parents of Fetus with DS	72*	15	50†
Parents of Child with DS	86*	32	72*
Film Stimulates Discussion	89*	52	62
Film Helpful to Me	67*	14	66*
Film Changed My Attitudes	14	10	19

Significant difference vs. genetic counselors: * p<.005; † p<.05

Table III: Accuracy of Film — Percent Agree with Statement

Statement	Mothers	Gen.Couns.	Nurses
Portrays Parental Attitudes	89*	14	41†
Portrays Medical Attitudes	78*	10	23
Portrays Genetic Counseling	70*	4	13

Significant difference vs. genetic counselors: * $p<.005$; † $p<.05$

Table IV: Beliefs about Genetic Counseling — Percent Agree with Statement

Statement	Mothers	Gen. Couns.	Nurses
Prenatal Dx Useful for Prevention of Disability	47†	78	81
Need Genetic Counsel. Pre-amnio	81†	100	81†
Need Genetic Counsel. Pre-MSAFP	72	86	72
Genetic Counsel. is Unbiased	18*	62	36

Significant difference vs. genetic counselors: * p<.005; † p<.05

Table V: Beliefs about Down Syndrome — Percent Agree with Statement

Statement	Mothers	Gen. Couns.	Nurses
Newborn Information to Parents of Fetus with DS	81	56	63
Parents of DS Fetus Should Meet Parents of DS Child	64	52	69
Parents of DS Child Choose to Abort Later DS Fetus	8*	57	10*
Problems Exceed Benefits of Having Child with DS	6*	48	17†

Significant difference vs. genetic counselors: * p<.005; † p<.05

Table VI: Predicted Choices — Percent Agree with Statement

Statement	Mothers	Gen. Couns.	Nurses
I Choose Prenatal Diagnosis	52*	93	70
I Would Abort Fetus with DS	9*	46	29
I Would Abort Fetus with Lethal Condition	49†	79	55
I Would Abort Any Abnormal Fetus (however minor)	6	12	13
I Would Never Abort	34*	0	16

Significant difference vs. genetic counselors: p<.005; † p<.05