# Clients' Interpretation of Risks Provided in Genetic Counseling

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### SUMMARY

Clients in 544 genetic counseling sessions who were given numeric risks of having a child with a birth defect between 0% and 50% were asked to interpret these numeric risks on a five-point scale, ranging from very low to very high. Whereas clients' modal interpretation varied directly with numeric risks between 0% and 15%, the modal category of client risk interpretation remained "moderate" at risks between 15% and 50%. Uncertainty about normalcy of the next child increased as numeric risk increased, and few clients were willing to indicate that the child would probably or definitely be affected regardless of the numeric risk. Characteristics associated with clients' "pessimistic" interpretations of risk, identified by stepwise linear regression, included increased numeric risk, discussion in depth during the counseling session of whether they would have a child, have a living affected child, discussion of the effects of an affected child on relationships with client's other children, and seriousness of the disorder in question (causes intellectual impairment). Client interpretations are discussed in terms of recent developments in cognitive theory, including heuristics that influence judgments about risks, and implications for genetic counseling.

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## INTRODUCTION

Individual variation in interpretation of numeric risks is a topic of concern to genetic counselors, because a client's interpretation of a risk for having a child with a specific birth defect or genetic disorder may affect reproductive behavior. Given the same numeric risk for a disorder, some clients, who may be considered "pessimists," will view their risk as higher than do other clients, who may be called "optimists." In the following analysis, we identify factors that are associated with pessimistic and optimistic client interpretations of risks for having a child with a specific birth defect provided in genetic counseling.

#### BACKGROUND

Risk interpretation (the judgment that a risk is "high" or "low") is ordinarily associated with acceptability of risk (willingness to take the risk) and with actual decision-making. All three—risk interpretation, acceptability, and decision-making—are linked in a complex interactive process whereby each one affects the other. Most of the literature on risk focuses on the "active" components: acceptibility and decision-making [1–9]. Although we recognize that the process of interpreting a risk is linked with the process of imagining whether one is willing to accept that risk, for purposes of this paper we shall leave aside acceptability and decision-making. We have considered elsewhere the reproductive decision-making of genetically counseled clients under conditions of risk [10–12]. Other researchers have developed models of rational decisionmaking under conditions of uncertainty in genetic counseling [13–18].

We have chosen instead to focus on the interpretation of a numeric risk as high, moderate, or low, without regard to whether the client considers the risk acceptable or decides to take it. The interpretation of risk is influenced by qualitative features, including, for example, whether the risk is under the individual's control, is reversible or irreversible, visible or invisible (e.g., beating a train approaching a railroad crossing vs. exposure to a possible carcinogen), or familiar or new [3, 6], or whether any cultural aspects of this risk (e.g., new technologies) threaten the person's social or religious values [2].

According to the Bayesian hypothesis, which is a rule for revising probabilistic beliefs on the basis of new information, if new evidence results in a change in a probability, our interpretation of the new probability will be affected by the direction of the change. For example, if a client goes to genetic counseling with a prior belief about her numeric risk of having an affected child, and is then given a lower numeric risk than she thought she had, her interpretation of the new risk should be "optimistic;" if she is given a higher numeric risk than anticipated, her interpretation of the new risk should be "pessimistic" [5, 7].

It is now a well-established fact in cognitive psychology that individuals violate Bayes's rule in systematic ways [19–22]. Tversky and Kahneman [20, 22] describe three heuristics or biasing factors that people frequently apply to expectations about outcomes: representativeness, availability, and anchoring. Representativeness is the degree to which an individual outcome (in the context of genetic counseling, a particular child with a particular birth defect) is

regarded as representative or stereotypical of all outcomes. Many birth defects, for example, have widely variable potentials for effective treatment. For example, if the parents of a child at the "poor" end of the treatment spectrum regard that child as "representative" of all children with the disorder in question, they will interpret a given numeric risk as "higher" than they would if they did *not* regard their child as typical of all children with the disorder.

Availability is the ease with which instances of the risked event can be brought to mind (e.g., one already has, or knows someone who has, a child with a particular birth defect). The greater the "availability" of an event, the more likely its occurrence will seem. A numeric risk of its occurrence will tend to be interpreted as higher than will the same numeric risk for an event that is not "available." In genetic counseling, Lippman-Hand and Fraser [23, 24] have speculated on the effects of clients' experiences with previous children with birth defects, including the early death of such a child, on their subsequent interpretations of risks as high.

Anchoring occurs when the person has a starting point or partial computation on which to base an interpretation of risk, for example, a prior belief that a risk is high or low. This prior belief will continue to affect the interpretation of a risk, even after a new numeric risk is provided. Therefore, we would anticipate that, for those clients who have a belief about their numeric risk prior to counseling, these prior beliefs will be reflected in their interpretations of risk after counseling.

Experiments with lotteries have demonstrated that each of these three heuristics influences subjects' interpretations of risk [25]. Cognitive psychologists have further demonstrated that, when subjects are given numeric probabilities, their estimates of the degree of risk do not increase in proportion to increases in numeric risk. Most subjects tend to "overestimate" numerically smaller risks and to "underestimate" numerically larger risks [26]. This occurs because the desire for absolute certainty makes even a high numeric probability, such as 90%, seem insufficiently certain, while at the same time the desire for impossibility of a negative outcome makes even a 5% probability seem too high. Low numeric probabilities are perceived as higher than they are, and higher numeric probabilities are perceived as lower than they are. The result is that a wide range of numeric risks is given the same interpretation.

Clients of genetic counseling face lottery situations somewhat similar to those described by the experimental psychologists. Most clients go to counseling in order to get information that will help them make a decision about whether to have a child [10]. The prize, a normal child, may be won only by taking the risk of conceiving a child with a birth defect. In some cases, clients' interpretations of their numeric risks may affect them for a lifetime, in the form of child with a birth defect living at home. Although the risk of having a child with a birth defect is given by the counselor in terms of a percentage, the outcome is *binary:* the child either will or will not be normal. As Lippman-Hand and Fraser point out, "the one in the numerator never disappears no matter the size of the denominator, and the 'one' could be the counselee's child'' [23, 24].

In the following analysis, we examine client characteristics associated with optimistic and pessimistic interpretations of numeric risk. Under real conditions, as opposed to experimental ones, is clients' interpretation of risk affected by the heuristics of representativeness, availability, and anchoring?

#### METHODS

Genetic counseling cases were ascertained between 1977 and 1979 at 47 genetic counseling clinics located in 25 states and the District of Columbia. The study employed a prospective longitudinal design. Detailed structured self-administered questionnaires were completed by clients immediately before and within 7–10 days following genetic counseling. Data on a large number of topics were collected, including client sociodemographic characteristics, reproductive history, and status, characteristics of the disorder in question, questions and concerns brought to genetic counseling, perceptions of problems associated with having a child with a birth defect, and topics discussed in genetic counseling.

Clients' knowledge of the diagnosis of the birth defect for which their children were at risk and of their numeric risk for having a child with the disorder in question was assessed before and after counseling, as were their views about the burden that a child with this defect would impose upon personal and family life. Detailed medical and genetic information on each case was provided by the genetic counselor through a structured questionnaire completed immediately after each counseling session. Counselors provided the specific diagnosis and the assigned risk of occurrence or recurrence of the birth defect in the client's children.

Clients in 1,369 cases chose to participate. Of those who completed precounseling questionnaires, 1,096 cases (83%) returned a postcounseling questionnaire. In 550 cases where the client reported that the counselor had given a numeric risk, clients were asked to report this risk. Next they were asked, "I think this risk is \_\_\_\_\_\_ (choose one) very low, low, moderate, high, very high." The following analysis deals with 544 cases where the numeric risk, as reported by the client, was less than or equal to 50%. The six clients who reported risks greater than 50% were too few for analysis.

For purposes of this paper, the responses of female clients have been used as the basis of analysis. Although 68% of clients were seen as couples, a chi-square analysis of the male clients' interpretations of risk revealed no significant differences from the responses of the (more numerous) female clients. The analysis focuses on identifying factors associated with clients' interpretations of a given numeric risk as low or high, controlling for actual numeric risk. An interpretation that is lower than the modal response for that particular risk in this population of counseled clients is considered optimistic; an interpretation that is higher than the modal response, pessimistic.

### RESULTS

The first step in identifying characteristics of clients who were optimistic or pessimistic about a given numeric risk was to identify the modal interpretation category for each numeric risk along a five-point scale ranging from "very low" to "very high." At every numeric risk, up to and including 50%, clients used the full range of responses (very low, low, moderate, high, very high). Changes in the modal interpretation category as numeric risk increased are reported in figure 1. The modal interpretation varied directly with risks between 0% and 15%. The modal category reached "moderate" at 15% and remained there to 50% risk. The clients' modal category of risk interpretation never reached "high" or "very high." The result is a largely "flat" curve for the modal category of interpretation of risks between 10% and 50%. The flatness of this







curve agrees with the empirical lottery research of cognitive psychologists, who have documented both (1) a tendency to give the same risk interpretation to a wide range of numeric probabilities, and (2) the absence of a corresponding increase in interpretation of level of risk as numeric risk becomes very high [25]. Genetic counselors' modal categories of interpretation also produced a flat curve between 25% and 50% risk, with the difference that they interpreted these risks as "high" as opposed to the clients' "moderate."

The percents of clients who chose each category of risk interpretation are reported for selected levels of numeric risk in table 1. The risk levels selected include  $\leq 3\%$ , which is sometimes described as the risk faced by the population at large, and the risks of 25% and 50% faced by clients who carry Mendelian genetic disorders. (Too few clients reported risks of 11%-24% or 26%-49% for meaningful inclusion in this table.) Although the modal interpretation category never rose beyond moderate, some clients chose each category of risk interpretation at every level of numeric risk.

NUMERIC RISK,	<b>Risk interpretation (%)</b>						
AS REPORTED BY CLIENT	Very low	Low	Moderate	High	Very high	No.	(Total %)
≤ 3%							
("population risk")	41.9	35.7	14.5	6.3	1.6	255	(100)
4%-5%	31.3	45.0	18.8	2.5	2.5	80	(100)
6%–10%	16.6	45.8	29.2	6.3	2.1	48	(100)
25%	2.7	19.2	37.0	27.4	13.7	73	(100)
50%	7.4	9.3	38.9	29.6	14.8	54	(100)
Total						510	

TABLE 1
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CLIENTS' INTERPRETATIONS OF SELECTED LEVELS OF NUMERIC RISK (No. = 510)

In order to identify characteristics associated with optimistic and pessimistic interpretations of risk, we ran partial correlations between clients' interpretations of risk on the five-category scale of very low to very high and all variables on client demographic background, characteristics of the disorder in question, reasons for coming to counseling, reproductive history, plans, and expectations, present and anticipated problems in caring for an affected child, and topics that clients reported were discussed in the counseling session, a total of 49 variables. Selection of these variables was partially governed by suggestions in the literature on genetic counseling that certain factors could be expected to affect risk interpretations, for example, the existence of a living affected child whose care was burdensome [23, 24]. In the course of the analysis, virtually all data gathered through client pre- and postcounseling questionnaires were examined for strength of association with risk interpretation.

We were interested in examining optimistic and pessimistic interpretations of all numeric risks from 1% to 50%. Therefore, actual numeric risk, as reported by the clients, was controlled for in the partial correlation procedure. Thirty variables with a correlation coefficient of .10 or above (P < .05) with client pessimism about risk are listed in table 2, along with the P values and correlation coefficients. Among the characteristics associated with pessimistic interpretations of risk were: having an affected child living at home; the disorder in question causes intellectual (as opposed to physical or neurological) impairment; prenatal diagnosis is not available for the disorder; client is having serious problems in raising an affected child; and client anticipates serious problems raising the child in the future. Clients whose interpretations were pessimistic were more likely than optimists or those whose interpretations followed the mode to have discussed in depth with the counselor (1) whether they would have a child; (2) the effect of the affected child on their relationships with their other (normal) children; (3) the checkup and progress of the affected child; and (4) school programs for the child. They were also more likely to report that the session had not provided all the medical facts they wanted and had not helped with personal concerns. Pessimists were more likely to have believed, before counseling, that their risk was high than were those who were optimistic or whose interpretations followed the mode. Finally, pessimists were less likely to be pregnant at the time of counseling or to have planned, either *before* or *after* counseling, to have a child in the foreseeable future than were those who were optimistic or whose interpretations followed the mode.

Several client characteristics that we thought might be associated with pessimistic interpretations were not significantly associated. These were: education, income, discussion of risk during counseling session, and changes in reported numeric risk from before to after counseling.

The characteristics listed in table 2 were next put into a stepwise linear regression, in order to identify those independently and significantly associated with pessimistic interpretations. To find out whether any of these characteristics had an effect over and above numeric risk, numeric risk was also included in the regression. The results are reported in table 3. Among 427 clients in the regression analysis, the characteristics most strongly associated with pessi-

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## TABLE 2

### CHARACTERISTICS ASSOCIATED WITH CLIENTS' PESSIMISTIC INTERPRETATIONS OF RISK, CONTROLLING FOR NUMERIC LEVELS OF RISK (No. = 544; Risk $\leq$ 50%)

	<b>P</b> *	Correlation coefficient
Background:		
Have affected child living at home	.00	.14
Affected child was firstborn	.00	.12
Genetic disorder:		
Causes intellectual impairment	.00	.16
Prenatal diagnosis not available	.00	.16
Present problems raising an affected child:		
Caring for child at home	.00	.10
Feelings about child, before session	.00	.13
Feelings about child, after session	.05	.10
Effects of child on clients' social life	.02	.12
Anticipated future problems in raising child:		
Feelings about child	.00	.11
Caring for child at home	.01	.11
Medical care	.01	.11
Education	.01	.14
Financial costs	.03	.10
Content of counseling session:		
Discussed in denth:		
Whether would have (another) child	.00	.18
Relationship with other (normal) children	.00	.14
Checkup for affected child	.00	.11
School programs for child	00	.13
Client reported that session		
Did not give all the medical facts	.00	.10
Did not beln with personal concerns	00	17
Reproductive expectations before counseling		•••
Think risk is high	00	28
Not pregnant	00	15
Do not intend pregnancy in pext 2 years	.00	10
Do not intend pregnancy after 2 years	00	15
Fulfillment as parent not important	.00	10
Wishes of snouse not important	.00	10
Ideal family size not important	.00	.10
Depreductive expectations, ofter courseling:	.00	.00
Reproductive expectations, after counseling.	00	14
Do not intend programow in part 2 years	.00	.14
Do not intend pregnancy offer 2 years	.00	.21
Uncertain about ideal number of abildron	.00	.12
Uncertain about ideal number of children	.01	.10

\* Partial correlation, controlling for level of numeric risk, was used as the measure of association. Only those variables with a partial correlation coefficient  $\geq$  .10 are reported here.

mistic interpretations, in order of incremental R-squares, were: (1) numeric risk; (2) discussion in depth of the effects of an affected child on relationships with client's other children; (3) discussion in depth in counseling about whether they would have a child; (4) has a living affected child; and (5) the disorder in question causes intellectual impairment.

Another method of ascertaining clients' interpretation of risk is to compare

### TABLE 3

Characteristic	Beta	P value	R-square			
Numeric Risk	.47	.00	.218			
Discussed in depth, effects of affected child on relationship with other children	.11	.01	.248			
Discussed in depth whether to have a child	.14	.00	.264			
Has a living affected child	.12	.01	.279			
Disorder in question causes intellectual impairment	.09	.03	.287			

Results of Stepwise Linear Regression Analysis Identifying Characteristics Associated with Pessimistic Interpretations of Risk

(No. = 427)

their reported numeric risk with their estimates of the probability that their next child will be normal or abnormal. In posing this question, we asked clients to interpret their reproductive futures in terms of a zero-sum game [23, 24] in which their child either will or will not have a birth defect, rather than interpreting a numeric risk. Their answers, for clients at selected levels of self-reported numeric risk, are summarized in table 4 (there were 471 clients who answered this question). Their answers parallel the risk interpretations reported in table 1, with the difference that, as numeric risk increases, "pessimism" is expressed in terms of uncertainty about the child's normalcy rather than responses indicating that the child will probably or definitely have a birth defect. Even at population risk (3%), few (12.6%) were prepared to state that the next child would "definitely" be normal. Fewer still were ready to state that the

**TABLE 4** 

Clients' Expectations about Normalcy of Next Child, by Selected Levels of Numeric Risk (No. = 471)

	EXPECTATIONS ABOUT NEXT CHILD					
NUMERIC RISK AS REPORTED BY CLIENT	Definitely normal	Probably normal	Probably have defect	Definitely have defect	Not sure	Total clients
$\leq$ 3% ("population risk")	33 (12.6)*	182 (69.7)	10 (3.8)	0	36 (13.8)	261
4%-5%	2 (2.4)	53 (63.9)	3 (3.6)	0	25 (30.1)	83
6%-10%	2 (4.0)	36 (72.0)	1 (2.0)	0	11 (22.0)	50
25%	2 (2.7)	25 (33.3)	14 (18.7)	3 (4.0)	31 (41.3)	75
50%	4 (7.0)	19 (33.3)	14 (24.5)	0	20 (35.1)	57
Total clients	43	315	42	3	123	526

\* Percentage in parentheses.

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child would "definitely" have a defect, even at risks as high as 50%. Instead, clients interpreted their risks in terms of probabilities (as child will "probably" be normal or "probably" have a defect) or uncertainties ("not sure"). The basic uncertainty of their situation is expressed in their modal category of expectation. At risks below 10%, the modal category is "probably normal." At 25%, the modal category of expectation about the next child's normalcy becomes "not sure" rather than "definitely" or "probably" would have a defect.

### DISCUSSION

Numeric risk itself, as reported by the client, accounted for most of the explained variance in risk interpretation. Four additional characteristics, over and above numeric risk, emerged from the regression as significantly associated with the interpretation of risk, accounting for 6.9% of the explained variance. The total explained variance of 28.7% compares favorably with the percent of variance explained in other studies of health behavior and outcomes. Part of the unexplained variance may result from interpersonal communication factors, including possible client disagreement with or refusal to accept the numeric risk given by the counselor. Such factors are beyond the scope of our data.

Another factor in the unexplained variance may be that clients who interpret a risk pessimistically may be interpreting the seriousness or burden of the risked disorder rather than the numeric probability of its occurrence. The variable we used to assess seriousness of the disorder (causes intellectual impairment) was a general ranking for each disorder given by a medical geneticist independently of the client's individual case; it is possible that some clients and counselors assessed seriousness and treatment potential in a more pessimistic light than did our medical geneticist. Nevertheless, the emergence of four characteristics, over and above numeric risk, as significant suggests that risk interpretation is affected by two client background and two session characteristics. The two background characteristics ("has living affected child" and "disorder in question causes intellectual impairment") are examples of Tversky and Kahneman's "availability," in this case, a readily visible negative outcome that influences the client's interpretation toward pessimism.

The two session characteristics (discussion of whether client would have a child and discussion of effects of affected child on client's relationships with her other children) suggest that counseling can affect the interpretation of risk, particularly if decision-making in the face of risk and burdens associated with a negative outcome are discussed in depth. Although it is possible that pessimistic clients may push the counselor harder to discuss these topics, it is also possible that counseling could increase clients' pessimistic interpretations of risk if all aspects of the burden of raising an affected child—including financial costs, strain on the marriage, and care of the child as an adult—were to be presented by the counselor. Whether it would be ethical for counselors to attempt to influence client interpretations by these means is questionable. A more ethical approach would be to present *both* positive and negative scenarios—examples of the best and worst outcomes for a child with the disor-

der in question, illustrated by the clearest means possible—and to try to avoid purposive influencing of risk interpretations. In any case, counselors should realize that giving or even discussing a numeric risk does not necessarily affect the client's actual interpretation of that risk. Clients are more likely to appreciate the seriousness of a risk if that risk is discussed in terms of the client's actual behavior, in this case, whether the client would have a child. The educational value of giving a risk may be enhanced if that risk is described in behavioral terms.

Counselors should not overlook the effects of "prior beliefs" (Tversky and Kahneman's "anchoring") upon risk interpretation. A regression on a subset of 251 clients who reported an interpretation of their numeric risk prior to counseling documented that, among these particular clients, their precounseling interpretation of risk preceded *all* other variables, *including* numeric risk, in its strength of association with postcounseling interpretation of risk. Those who were pessimists or optimists before counseling tended to retain the same views after counseling.

The effects of the counselor's providing a new numeric risk to a subset of 138 of these clients did not support the Bayesian hypothesis about the revision of probabilistic beliefs on the basis of new information. According to Bayes's theory, learning that your risk is higher or lower than you had previously anticipated it to be should affect your interpretation of the new risk. This was not the case for clients in our study. Changes in clients' reported numeric risks from before to after counseling were not significantly related to optimism or pessimism about risk.

The results of our analysis have implications, not only for genetic counseling, but for health education in general. In genetic counseling, how clients interpret their risk is important because the interpretation of a risk as high or low is associated with subsequent reproductive intentions and behaviors [11, 12]. Clients who were pessimistic about their risk were less likely to plan future pregnancies than were clients who were optimistic. The interpretation of risk was a better predictor of client reproductive intentions than was numeric risk itself.

Client and counselor often approach the counseling situation with different agendas [10]. Clients most frequently give as their major reason for coming to counseling: "to get information that will help me to make a decision about whether to have a child." Counselors are likely to think that clients come to counseling to learn their risk [27]. Some counselors may believe that providing the client with a numeric risk that the counselor considers "high" will act as a deterrent to childbearing. The client, however, is likely to interpret that numeric risk as lower than does the counselor. Clients are not necessarily impressed by what counselors or educators usually consider "high" levels of risk, say 25%-50%. This is perhaps because clients feel that they have control over their own reproductive processes and decisions. Risk analysis research [21] suggests that people are likely to underestimate behavioral risks over which they think they can exert control. For many clients, the effect of higher numeric risk, given the uncertainties inherent in genetic counseling, is to produce more uncertainty about the normalcy of the next child. This leads to reproductive uncertainty [12] rather than reproductive restraint.

Provision of numeric risk in and of itself is not sufficient to reach genetic counseling's goal of providing information on which clients can base informed reproductive decisions. Clients' decisions are based on their own personal interpretation of the risk and their expectations about the normalcy of the next child, rather than on the numeric risk alone. Our results suggest that interpretation of a numeric risk as "high" is more likely to occur if: (1) an example of a risked negative outcome is readily "available" to the client; and (2) the potential burdens of a negative outcome are discussed in depth with the client, along with implications for the client's behavior. Counselors cannot provide clients with the absolute certainty that most people desire. They can facilitate informed decision-making, however, and perhaps reduce reproductive uncertainty, by providing and discussing examples of the risked outcome.

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