The facilitating role of information provided in genetic counseling for counselees' decisions

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Purpose: To investigate genetic counselees' evaluations of the helpfulness of the information they receive in genetic counseling and of their difficulty in making decisions, and to determine correlates of these two outcomes.

Methods: A field study on 108 counselees seeking genetic counseling aimed at arriving at a reproduction-related decision. Prior to counseling, questionnaires measuring individual differences in factors expected to correlate with outcomes were administered. The objective controllability of the information conveyed in counseling was evaluated by counselors. The outcomes — decision difficulty and information helpfulness — were evaluated one month after counseling in a telephone interview. **Results:** Information about consequences of options and about possible controlling actions were evaluated as most helpful; whether other information was helpful depended on the type of decision to be made. Decision difficulty was unrelated to counselees' evaluations of the helpfulness of the information. Decision difficulty was also unrelated to individual difference variables, but was related to the objective controllability of the information. **Conclusion:** These findings may help develop guidelines for identifying clients prior to counseling for whom making reproduction-related decisions will be difficult, and for tailoring information that will help such clients reach a decision. *Genet Med* 2006;8(2):116–124.

Key Words: genetic counseling, decision-making, information

Early definitions of genetic counseling saw the genetic counselor as either “information giver”¹ or “facilitator of counselees' decision-making,”² and these views have influenced genetic counseling definitions to this day.^{3,4} They dovetail with counselees' expectations from genetic counseling to receive information, half of them expecting to get advice, and about a third expecting to get help in decision-making.⁵ Accordingly, educational and decisional outcomes have been used as the main criteria for assessing success of genetic counseling over the years.^{6–8} Criticism of the limitations of these outcomes^{3,4,9} gave rise to modern approaches to genetic counseling that emphasize process factors and represent a wider range of outcomes.¹⁰

A modern definition of genetic counseling sees it as a “dynamic psychoeducational process centered on genetic information,”¹¹ in which “the goal is to facilitate clients' ability to use genetic counseling in a personally meaningful way that minimizes psychological distress and increases personal control.” Consequently, the present research focused on the helpfulness of the information received in counseling for facilitat-

ing counselees' decisions rather than on the commonly studied amount and accuracy of the information gained. We suggest that separating information from decision as outcomes of counseling is artificial, since information is provided in genetic counseling not as an end in itself, but as a means of facilitating a personally satisfactory decision. Specifically, we explored the relationships between the types of information provided and the degree of personal control granted in counseling and 1) counselees' evaluations of the information as helpful for making a decision; and 2) the difficulty they had in reaching their decision.

What makes information conveyed in genetic counseling helpful for deciding? According to classical decision-making theories,¹² an optimal decision is based on comprehensive information about expected utilities (the products of consequences and chances of occurrence) of the available options. However, Huber's model of risky decision-making in natural situations¹³ suggests that individuals in risky situations are interested mainly in information about risk-defusing operators (RDOs) — actions expected to control and decrease the risk. This includes pre-event RDOs (like vaccination against an infectious disease), and post-event RDOs (worst-case plans) that need not be initiated unless the event happens (e.g., a medical treatment against the disease).

The focus of this model on control is compatible with previous findings that information provided in genetic counseling has a significant impact on clients' perceived personal control.⁹ Three dimensions of perceived personal control were identified in the information provided in genetic counseling: behavioral control, the availability of an instrumental response that

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may directly influence or modify the physical characteristics of the stressful event; cognitive control, the processing of information in such a way as to make the potentially threatening situation less stressful; and decisional control, the opportunity to choose among various courses of action. Perceived personal control following genetic counseling was found associated with knowledge, satisfaction with counseling, and with later coping and well-being.¹⁴

However, genetic counseling sessions differ in the amount and quality of the information they can provide, and often counselees are left with a feeling of little control over the condition.¹⁵ Counseling may vary on the cognitive control dimension, depending on its ability to determine a definite diagnosis, prognosis, hereditary explanation, and an explicit risk (probability) that the genetic problem might occur in future offspring (predictability). On the decisional dimension, counseling may or may not specify choices such as not having (more) children, adopting, or fertilization by donor insemination. The behavioral control provided in genetic counseling may vary according to the availability of prenatal diagnosis of the problem, which may enable the couple to prevent the birth of an affected child in future pregnancies, and the availability of a treatment for the problem, which can prevent it or alleviate its symptoms in affected individuals. The more of the above elements in a particular genetic counseling, the more control it provides to counselees.

In the present research, we hypothesized that the controllability of information given in counseling will be associated with counselees' own evaluations of the information as helpful in reaching a decision and with their reported difficulty in making a decision. Information, although essential for making an informed decision, does not guarantee an easy decision. Being better informed can both facilitate and impede decision-making. In one study, greater understanding and knowledge acquired during counseling was related to lower client concern afterward,¹⁶ while other studies found that more knowledge can increase the burden of information processing, the conflict between alternative choices, and doubts about the right choice.^{17,18} In a large survey of knowledge and attitudes about genetics, those with the highest level of knowledge expressed both more enthusiasm and more skepticism than those with little knowledge.¹⁹ Thus, whether helpfulness of information and decision difficulty are associated, and in what way, was also investigated here.

Another issue of interest was individual differences among counselees. According to an integrative model for the assessment of genetic services,¹⁰ individual differences moderate the links between counseling processes and subsequent outcomes. We chose to explore personal characteristics that are potentially associated with information evaluations and decision difficulty: desire for medical information and involvement in medical decisions, health locus of control, and perceived personal control. Persistent individual differences in the desire for information and involvement in decision-making have been documented.²⁰ A review of the literature concluded that across a wide range of medical settings, patients express desire for

detailed information about their condition and treatment, whereas the distribution of scores in desire for involvement in decision making is skewed in the direction of physician-only or at least shared decision making.²¹ Health locus of control, the degree to which individuals believe that their health is controlled by internal versus external factors,²² is another potential moderator of patient reactions to information and decisions. A recent study showed that patients with a greater belief that powerful others (e.g., doctors) control their health were less likely to want to seek information or make decisions about their health.²³ Moreover, perceived personal control over a genetic condition was found associated with genetic counselees' evaluations of counseling and counseling outcomes.^{9,14}

A prospective field study was carried out here on clients' evaluations of the helpfulness of the information they had received in genetic counseling for reaching a decision, their reported difficulty in deciding, and the relationship between these outcomes. We hypothesized that the information provided in counseling, its controllability value, individual differences in desire for medical information and involvement in medical decisions, and health locus of control and perceived personal control will predict post-counseling information evaluations and decision difficulty. Specifically, higher controllability of the information provided in counseling, and counselees' stronger desire for information, involvement in medical decisions and control beliefs will be associated with evaluations of the information as more helpful and the decisions as less difficult.

MATERIALS AND METHODS

Data consisted of individual differences measures, the information provided in counseling, its controllability and whether it answered main counselees' questions (the independent variables); and counselees' evaluations of the information they had received in counseling and their decision difficulty (dependent variables).

Participants

A total of 161 genetic counselees participated in a larger study conducted between 1999 and 2001: One hundred forty-eight from the Genetic Institute of Sheba Medical Center (a large medical center near Tel Aviv, Israel) and 13 from two other genetic centers (Hadassah Ein-Kerem, Jerusalem, and Wolfson Hospital, Holon). Individuals arriving for counseling were enrolled if they reported facing a specific decision following counseling, agreed to participate in the study, and signed an informed consent form. Participation rate was very high (95%). Reasons for declining were anxiety or lack of time. Of those who started the study, 108 were interviewed a month after counseling (only one party of each of the participating couples was interviewed). The other 14% declined for various reasons.

The 108 with complete data faced one of three prototypic decisions: whether to start a new pregnancy involving a genetic risk ($N = 31$); whether to continue a current pregnancy after

receiving an abnormal diagnostic prenatal result ($N = 44$); or whether to perform amniocentesis in the current pregnancy, a procedure carrying a small risk of miscarriage ($N = 33$). There were 84 women (78%) and 24 men (22%). Their mean age was 31.63 years ($SD = 4.98$). Mean educational level in school years was 14.78 ($SD = 2.52$). They had 0-4 children (mean 0.98, $SD = 0.93$), and 0-3 children with genetic conditions (mean 0.30, $SD = 0.52$).

Measures

Controllability

At the end of counseling, counselors rated the 'objective' degree of control they had given in counseling on a three-point scale: no control, some control, and maximum control. Counselors were instructed to base their estimates on the number of control-related information items they provided to counselees: e.g., giving a diagnosis and/or estimated recurrence risk, providing choice options, explaining available treatment and/or prenatal diagnosis. This method of measuring controllability of the information provided in genetic counseling was validated in a previous study.⁹ Re-estimates of controllability (the same scale and instructions) given after a year by one counselor who reviewed data in 30 random medical records were 100% in agreement with the original estimates. Interrater reliability on a different set of 30 random cases showed complete agreement in 25 cases (83%), and mild disagreement (difference in one score) in five cases.

Perceived Personal Control—PPC

Counselees⁹ recorded their subjective perceptions (in contrast to the objective controllability measure described above) of how much control they believe they have regarding their genetic problem on a scale made up of nine items representing three dimensions of control: cognitive-interpretive (e.g., "I feel I understand the problem that brought me to genetic counseling"), decisional (e.g., "I feel I can make decisions that would influence future outcomes"), and behavioral (e.g., "I know what I can do to alleviate the problem"). In the version used in this study, counselees rated these items on a five-point scale: (1 = very little control to 5 = very high control). A total score ranging from 1 to 5 represented the average of raw scores. The scale was found reliable and valid in measuring counseling effectiveness in previous research.⁹ In the current study, the mean PPC score was 3.09 ($SD = 0.78$), and the reliability of the scale was high (Cronbach $\alpha = 0.85$). PPC measured after counseling correlated 0.43 ($N = 161$; $P < 0.001$) with counselors' estimations of the 'objective' controllability provided. This significant but moderate correlation indicates that variance in postcounseling PPC scores is not entirely explained by the information provided in counseling, but by additional factors like PPC before counseling.¹⁴

Multidimensional Health Locus of Control—MHLC Form C

The MHLC²² measures beliefs about control by assessing the extent of agreement or disagreement with a series of items,

such as: "If I take care of myself, I can avoid illness." The instrument consists of three 6-item subscales: Internal Health Locus of Control (IHLC), Powerful Others Health Locus of Control (PHLC), and Chance Health Locus of Control (CHLC) scales. Subjects responded to the items using a six-point Likert response scale ranging from 1 (strongly disagree) to 6 (strongly agree). The scores were obtained by averaging the scores on each of the subscales. Numerous studies with these scales have shown high internal reliabilities and good construct and predictive validity.²² In the present sample, the mean scores were 3.94, 3.22, 3.34 ($N = 161$, $SDs = 0.78$; 0.97; 0.90) for the Internal, Chance and Powerful Others subscales, respectively, and internal consistencies were 0.70, 0.76, 0.75 (Cronbach α), respectively.

Krantz Health Opinion Survey—KHOS

The KHOS²⁰ is a 16-item questionnaire comprised of two subscales: the information subscale that measures the desire to ask questions and be informed about medical conditions, and the self-treatment subscale concerned with active behavioral involvement of patients in medical care. These scores were associated with information seeking and behavioral adjustment in health care settings.^{20,24} We developed a five-point version of the questionnaire (replacing the binary agree/disagree original version), asking subjects to indicate the extent to which they agree (1 = not at all; 5 = very much) with each of the items ("Instead of waiting for them to tell me, I usually ask the doctor or nurse immediately after an exam about my health"). The scores were obtained by averaging the scores on each of the subscales. A confirmatory factor-analysis of the new version in the present sample ($N = 161$) yielded an information factor (eigen value 2.35) that included four items that showed internal reliability of 0.72, and a self-treatment factor (eigen value 3.82) that included 10 items with reliability of 0.81 (Cronbach α). Reported inter-item reliabilities of the original scales were 0.76 and 0.74, and test-retest reliabilities were 0.59 and 0.71.²⁰ The mean scores in the present sample were 3.55 ($SD = 0.93$) and 2.74 ($SD = 0.63$) for the information and the self-treatment subscales, respectively.

Telephone interview

About a month after counseling, participants were called by the interviewer and asked what they have decided (all had reached a decision by then). In addition, they were asked to indicate the information they had received in counseling that was most helpful for their decision. Finally, interviewees were asked to evaluate whether counseling provided answers to their most important questions (1 = not at all to 10 = completely), the helpfulness of information received in genetic counseling (from 1 = not at all helpful to 10 = very helpful), and their decision difficulty (from 1 = not at all difficult to 10 = very difficult).

Answers to the open-ended question about which information was most helpful were classified according to a two-dimensional coding system based on Huber's decision-making model,¹³ and components of the illness schema^{25,26}: identity,

consequences, causes, duration and cure. Three main content categories were coded: 1) Identity, including items about the diagnosis, its prevalence in the population and its cause; 2) Consequences, either of the genetic condition or the alternative option, like the consequences of diagnostic procedures; 3) Control, including pre-event and post-event (worst case plans) risk-defusing operators (RDOs). In addition, each answer was coded on a certainty-uncertainty dimension, depicting the use of exact probability terms versus general uncertain or certain terms.

This coding system was developed on a sample of 60 genetic counselees from the same clinic (not included in the main sample) that embodied the theoretical constructs to be investigated as well as specific themes elicited by participants. Two independent coders (second author and a psychologist) coded 223 items (information bits mentioned by participants) and reached 86% agreement (Kappa 0.82). In cases of disagreement, the coding decision was based on discussion and consultation with a third coder (first author). Inter-coder median correlations between numbers of items coded to each category were 0.97 and 0.77 for the content and uncertainty dimensions, respectively. Table 1 presents definitions of the coding categories and sample items for each of them.

Procedure

Upon arrival at the clinic, potential participants were approached by a female genetic counselor (second author) who invited them to participate in a study "about decision-making in genetic counseling." After checking for eligibility (that a decision was considered), and obtaining informed consent to

participate in the study, each participant was given an individual interview about the kind of information that could help him/her make a decision. Details about this part are presented elsewhere.²⁷ The participant then filled out the individual-differences questionnaires (PPC, MHLC, KHOS). The whole procedure took about 20 minutes. The counseling session was conducted by the staff of the clinic in the usual way, with the interviewer present. Following the counseling session the counselor completed the Controllability measure. About a month later the interviewer conducted the telephone interview.

Analyses

Descriptive statistics were used to represent evaluations of information helpfulness and decision difficulty. The possible effects of the type of decision (whether to start a new pregnancy, whether to continue a current pregnancy, or whether to perform amniocentesis) and the specific choices that were made, on participants' evaluations of the information and decision difficulty, were explored by inter-group comparisons using chi-square and ANOVA statistics. Significant results were followed by Posthoc analyses (Scheffé) and by separate descriptive statistics for each decision type and choice. Pearson product-moment correlations were used to analyze associations between continuous variables, and Regression analyses were used to predict outcomes (information helpfulness and decision difficulty) by demographic variables, individual differences and counseling variables (counseling provided answers and controllability).

RESULTS

Mean scores of the evaluated helpfulness of information received in genetic counseling was 7.14 (SD = 2.10) and mean reported decision difficulty was 6.90 (SD = 2.52) on scales ranging from 1 to 10. The distributions of both outcomes (Fig. 1) show that a minuscule number of counselees evaluated the information unhelpful and the decision easy. Almost everyone

Table 1
Coding of interview items

Content dimension	
Category	Example
Identity	
Diagnosis	"What is the name of the disorder?"
Prevalence	"How often do you see this syndrome?"
Cause	"What causes this problem?"
Consequences	
Genetic condition	"Does it include mental retardation?" "Is the condition fatal?"
Alternative	"Can the test cause a miscarriage?" "What can be the results of using sperm donation?"
Control	
Pre-event	"Is it possible to select normal eggs pre-implantation?" "Is it possible to make prenatal diagnosis of the disorder?"
Post-event	"Is it possible to treat the disease?" "Can the defect be corrected by surgery?"

A. Information helpfulness (1-10)

B. Decision difficulty (1-10)

Fig. 1. Distributions of outcome variables (n=108)

evaluated the information as at least moderately helpful. Reported decision difficulty had two peaks: low-moderate difficulty (10%) and extremely difficult (14%). The fact that even when information received in genetic counseling was helpful, the decision could still be difficult was also demonstrated by the negligible correlation between these two outcomes ($r = 0.04$).

In response to the question about which information they received in counseling was most helpful for their decision, 75% of the respondents reported information coded as “consequences” (of both the genetic condition and the alternative option), 40% noted information about control (both prevention and treatment), and 35% mentioned information coded as “identity of the genetic condition” (e.g., label, symptoms, causes) (percentages add up to more than 100 because many mentioned more than one piece of information as most helpful). Forty-four percent reported that information (across content categories) expressed in probability terms was most helpful.

The frequency of items coded as “identity of the genetic problem” as most helpful differed significantly by type of decision to be made ($\chi^2 = 17.56$, $P < 0.01$): this category was considered most helpful for deciding by 43.5% of those considering having more children, 25% of those considering amniocentesis, and only 10% of those deciding about pregnancy continuation. The helpfulness assigned to probability terms was similarly related to decision type ($\chi^2 = 9.04$, $P < 0.05$): 61% of those considering having more children, 49% of those considering amniocentesis, and only 27% of those deciding about pregnancy continuation. There were no significant inter-group differences in reported helpfulness of information coded as “consequences” and “control.”

Next, we looked for differences in outcomes (rating scales of information helpfulness and decision difficulty) between groups of counselees who faced different types of decisions (Fig. 2).

ANOVA results showed that the decisional groups differed significantly on both outcome measures (Information helpful: $F = 7.61$, $P < 0.01$; Decision difficulty: $F = 10.70$, $P < 0.01$). According to post hoc analyses (Scheffé), those deciding about pregnancy termination and amniocentesis evaluated the information given in counseling as more helpful compared to those deciding about having more children. With regard to decision difficulty, amniocentesis was a less difficult decision than preg-

Fig. 2. Outcome variables by type of decision.

nancy termination and having more children. It is noteworthy that the pregnancy termination group evaluated the helpfulness of the information similarly high as the amniocentesis group, but the difficulty of the decision similarly high as the group deciding about having more children.

A. Having more children

B. Pregnancy termination

C. Amniocentesis

Fig. 3. Outcome variables by chosen alternatives.

Next, within each decision type, we analyzed differences in outcome variables between those who chose each of the alternative options (Fig. 3).

ANOVA results showed that those who decided not to have more children felt that the decision was more difficult than those who decided to have more children ($F = 6.81$, $P < 0.05$). These two groups did not differ in their evaluations of the helpfulness of the information provided in counseling. Those who chose to terminate a pregnancy evaluated the information received in counseling as more helpful ($F = 12.90$, $P < 0.01$) and the decision as more difficult ($F = 26.10$, $P < 0.01$) than those who chose not to terminate. Finally, those who decided to perform amniocentesis evaluated the information as marginally more helpful than those who declined the test ($F = 3.67$, $P = 0.06$). Performers and decliners of amniocentesis did not differ in their reported decision difficulty ($F = 0.23$, n.s.).

Our next step was to find correlates of both outcomes: evaluated helpfulness of information received in counseling and decision difficulty. Table 2 presents the correlations between

Table 2
Pearson correlations between predictors and outcomes (N = 108)

Predictor	Total sample (N = 108)		Having children (N = 46)		Pregnancy termination (N = 71)		Amniocentesis (N = 44)	
	Information helpful	Decision difficulty	Information helpful	Decision difficulty	Information helpful	Decision difficulty	Information helpful	Decision difficulty
Age	-0.13	0.25 ^a	0.12	0.03	-0.08	0.30 ^a	-0.24	-0.07
Education	0.01	0.03	-0.14	-0.11	0.05	-0.15	0.09	0.23
Number of children	-0.19 ^m	0.27 ^a	-0.15	-0.01	-0.02	0.28	0.06	0.03
Number of affected children	-0.40 ^b	0.20 ^a	-0.29	0.18	-0.20	0.03	-0.06	—
Internal locus of control	0.06	0.08	0.12	0.15	0.04	-0.03	0.11	0.14
External locus of control powerful-others	-0.23 ^a	0.08	-0.13	0.31	-0.23	-0.07	-0.25	-0.03
External locus of control-chance	-0.04	0.02	0.00	0.08	-0.21	-0.01	0.08	0.02
Desire for medical information	0.05	-0.03	-0.05	-0.16	0.01	-0.19	0.02	0.29
Desire for involvement in medical decisions	0.20 ^a	-0.13	0.16	-0.40 ^a	0.25	-0.15	0.13	-0.04
Perceived personal control	0.05	-0.12	0.45 ^a	-0.14	-0.25	-0.19	0.07	-0.01
Counseling provided answers	0.45 ^b	-0.19 ^m	0.38 ^a	-0.25	0.34 ^a	-0.06	0.42 ^a	0.16
Objective cognitive control	0.21 ^a	-0.32 ^b	0.24	-0.16	0.04	-0.23	0.13	-0.13
Objective decisional control	0.43 ^b	-0.04	0.18	0.05	0.34 ^a	-0.04	0.42 ^a	0.36 ^a
Objective behavioral control	0.25 ^a	-0.31 ^b	0.08	0.21	-0.04	-0.10	0.29	-0.13
Objective control-total	0.38 ^b	-0.25 ^b	0.18	0.04	0.18	-0.15	0.51 ^b	0.10

^a $p < 0.05$.

^b $p < 0.01$.

^mMarginal.

outcomes and continuous variables (demographics, individual differences, counseling providing answers and control).

The findings in Table 2 indicate that having fewer children, especially affected children, and counseling that provided more control and more answers were associated with both outcomes: evaluations of counseling as more helpful and reports of the decision as less difficult. Some variables had differential associations with both outcomes: older age was related only to higher decision difficulty; lower external locus of control (powerful-others) and stronger desire for involvement in med-

ical decisions were associated only with more favorable evaluations of information given in counseling. These findings partly support our hypotheses.

Two regression analyses were performed to predict evaluations of information helpfulness and reported decision difficulty by demographic variables (step 1), individual differences (step 2), and counseling variables (step 3). The results (presented in Table 3) show that 35% of the variance in the evaluations of information helpfulness and 30% of the variance in reported decision difficulty could be explained by the predictor

Table 3
Regression model summary (N = 108); dependent variables: decision difficulty and information helpful

Predictors ^a	R	R Square	R Square Change	F Change	P
Decision difficulty					
Model 1—demographic variables	0.30	0.09	0.09	3.35	0.02
Model 2—psychological variables	0.40	0.16	0.07	0.95	0.48
Model 3—counseling variables	0.55	0.30	0.14	3.50	0.01
Information helpful					
Model 1—demographic variables	0.41	0.17	0.17	6.88	0
Model 2—psychological variables	0.51	0.26	0.09	1.31	0.25
Model 3—counseling variables	0.60	0.35	0.10	2.63	0.03

^a Step 1: age, number of children, number of affected children; Step 2: locus of control (3 scores), desire for medical information, desire for involvement in medical decision-making, perceived personal control (4 scores); Step 3: counseling provided answers, objective control provided in counseling (4 scores).

variables. For both outcomes, counseling variables (providing answers and control) had significant independent contributions to predicted variance, above the demographic factors, while individual differences did not have a significant contribution.

DISCUSSION

A main finding of the current study was that counselees' evaluations of decision difficulty were unrelated to their evaluations of the helpfulness of the information they received in genetic counseling. Experiencing the decision as very difficult does not imply that the information is perceived as unhelpful, and evaluating the information as helpful does not imply that the ensuing decision is experienced as easy. Information helpfulness and decision difficulty should be regarded as independent constructs. This conclusion corresponds with other findings about the specificity of outcomes in genetic counseling; for example, that meeting clients' expectations for information and help with decision-making were not associated with post-counseling state anxiety, satisfaction with information given, and concern about the problem for which they were referred.⁵ Decision difficulty is most probably related primarily to the diagnosis of a genetic condition itself, to limitations in genetic knowledge representing the state of the art, to uncertainties inherent in genetic risks, and to moral dilemmas involved in some of the decisions. However, despite the fact that counselees' subjective evaluations of information helpfulness were unrelated to their evaluations of decision difficulty, the content of the information given in counseling had an impact on both evaluations.

According to our findings, the degree of control provided in counseling (reported by counselors) contributed to the variance in counselees' evaluations of information helpfulness and decision difficulty beyond demographic variables. This is consistent with arguments about the centrality of control issues in genetic counseling,^{9,14} and with findings that lack of control-related information leads to decision difficulties in genetic counseling.²⁸ In contrast to our findings, Michie et al.¹⁶ failed to find significant counseling process predictors (e.g., length of consultation, number of social and emotional issues raised) of patient outcomes (satisfaction with information, concern, anxiety) in multivariate analysis of data from a prospective study of genetic counselees. The authors suggested that the process and outcome measures they used might have been irrelevant or inadequate. We suggest that the problem is not inadequacy but incompatibility between predictors and outcomes. The process variables we measured (e.g., controllability) were well-matched with counselees' evaluation of information helpfulness and their reported decision difficulty.

Decisions about pregnancy continuation/termination and having more children were evaluated as more difficult than amniocentesis. These differences cannot be attributed to structural (complexity) and contextual (time pressure) factors, since the amniocentesis and pregnancy termination decisions are similarly complex and under time pressures. However, the severity of consequences, moral issues and the nature of the

conflict involved may explain the variance in difficulty judgments among decision types. Deciding to terminate a pregnancy or to avoid having children implies moral dilemmas and a stronger sense of loss and definiteness, especially for older clients with affected children, in contrast to the risk combined with hopes involved in the amniocentesis decision. Experimental studies showed that independent of information processing demands, decisions are more difficult when alternatives are unattractive or attribute trade-offs are large.²⁸ As maintained in the Prospect Theory,²⁹ in loss situations there is preference for risk taking (choosing uncertain results like amniocentesis) compared to sure loss like that involved in termination of pregnancy or avoidance of having more children. The special difficulty attached to the decision to have biological children can also be attributed to temporal differences among decision types in the unfolding of decision outcomes. While the results of amniocentesis are immediate, the outcomes of the decision to have biological children may take years to be known. Knowledge of outcomes influences retrospective decision evaluations,³⁰ and since our one-month follow-up assessment could not assess the outcomes of the decision to have biological children, this decision may have been evaluated as more difficult compared to the other.

Psychological differences in desire for involvement in medical decisions and locus of control correlated with evaluations of the helpfulness of information received in counseling, but did not add to its explained variance above demographic variables. Older clients with more affected children reported having more difficulty deciding. These findings correspond with other reports that couples with an affected child were more likely to see the decision as difficult.³¹ Thus, while showing the predicted theoretical associations between individual difference factors and information evaluations, for practical purposes, age, medical factors and decision type may be sufficient to identify clients susceptible to decision difficulties.

The information received in counseling was evaluated by counselees as generally very helpful. This should not be confused with real helpfulness, since people are biased in their evaluations of their knowledge and cognitive processes.³² In another qualitative study,³³ information was also deemed a very helpful aspect of genetic counseling by all participants, who looked at information as a means of optimizing certainty and relieving feelings of vulnerability. Our participants reported that some pieces of information provided in counseling had a special value in helping them reach a decision. As predicted by Huber's model of risky decision-making,¹³ they appraised information about potential consequences of choices and of possible controlling actions (prevention and treatment) as most helpful. However, the value of identity information (diagnosis, cause, prevalence) and probability expressions varied according to the type of decision to be made. These types of information were reported to be most helpful among those considering having more children, of intermediate helpfulness among those considering amniocentesis, and least helpful among

those deciding about pregnancy continuation/termination. These information types are characterized by being more abstract, "scientific," and emotionally detached. It seems that they are evaluated as more helpful only when the decision to be made is less pressing and the child that is considered is still not real. But, when the decision is to be made about an existing pregnancy, these types of information are perceived as less helpful.

Limitations of the study

Participants in this study were a subgroup of genetic counselees who, before the counseling started, had described themselves as having to make decisions. It is important to note that they do not represent all genetic counselees. Other counselees may attend genetic counseling and benefit from the information received even when there is no decision to be made. Cognitive and behavioral types of control can be as helpful as decisional control. The sample was also mainly female, which limits generalization to male clients. It should also be noted that the study was conducted on one cultural group, Israeli Jews. Reproductive decisions, especially those surrounding pregnancy terminations, have been shown to be heavily influenced by cultural norms.³⁴ More studies among different populations are therefore needed to validate the generality of our findings regarding information usefulness and decision difficulties in genetic counseling. Another limitation is the choice of evaluations of information usefulness and decision difficulty as the only outcomes. More outcomes of genetic counseling should be considered for future assessments: for example, clients' satisfaction or regret with their decisions.³⁵

CONCLUSIONS

Researchers and counselors should be aware that genetic counseling can be assessed in terms of several different outcomes that are not necessarily interrelated. Some of the outcomes, like decision difficulty, may be inherent to the situation the counselees face and less affected by the counseling process.

The types of information counselees found most helpful lead to important clinical implications. Counselors should be aware that information about consequences of having an affected child and of alternative options is considered by all clients as most helpful. Information about possible controlling actions (prevention and treatment), when available, is also very helpful. Also, among those considering having more children, identity information (diagnosis, cause, prevalence) and probability expressions are most helpful. These latter details are least helpful among those deciding about pregnancy continuation. Better understanding of counselees' informational needs and tailoring the counseling process accordingly promises better outcomes. However, varying the information provided in counseling according to clients' needs can create a professional dilemma. Legal requirements to convey all relevant information, and counseling goals, may lead to different decisions about what infor-

mation needs to be shared with clients. In order to partly circumvent this dilemma, it has been suggested that in the initial stage of counseling the patient be informed by the counselor about what information can be provided and what decisions can be made on the meta-level, so that he or she can decide whether or not to be told about it in more detail.³⁶

Practically, prior identification of clients at risk for experiencing difficulties in deciding can be made on the basis of demographic variables (older age and having affected children) and the type of decision to be made (having more children and pregnancy continuation/termination). Counseling clients of these groups should therefore be more intensive, provide more decisional support, and require more counseling skills.³⁷

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References

1. Hsia EY. The genetic counselor as information giver. In, Capron AMML, Murray RF, Powledge TM, Twiss SB, Bergsma D, editors. Genetic counseling: facts, values and norms. Vol 15. New York: Alan R. Liss, 1979:169–186.
2. Antley RM. The genetic counselor as facilitator of the counselees's decision process. In, Capron AMML, Murray RF, Powledge TM, Twiss SB, Bergsma D, editors. Genetic counseling: facts, values and norms. Vol 15. New York: Alan R. Liss, 1979:137–168.
3. Bernhardt BA, Biesecker BB, Mastromarino CL. Goals, benefits, and outcomes of genetic counseling: client and genetic counselor assessment. *Am J Med Genet* 2000; 94:189–197.
4. Biesecker BB. Goals of genetic counseling. *Clin Genet* 2001;60:323–330.
5. Michie S, Marteau TM, Bobrow M. Genetic counselling: The psychological impact of meeting patients' expectations. *J Med Genet* 1997;34:237–241.
6. Evers-Kiebooms G, van den Berghe H. Impact of genetic counseling: a review of published follow-up studies. *Clin Genet* 1979;15:465–474.
7. Kessler S. Current psychological issues in genetic counseling. *J Psychosom Obstet Gynaecol* 1990;11:5–18.
8. Pilnick A, Dingwall R. Research directions in genetic counselling: a review of the literature. *Patient Educ Couns* 2001;44:95–105.
9. Berkenstadt M, Shiloh S, Barkai G, Katznelson MBM et al. Perceived personal control (PPC): A new concept in measuring outcome of genetic counseling. *Am J Med Genet* 1999;82:53–59.
10. Wang C, Gonzalez R, Merajver SD. Assessment of genetic testing and related counseling services: current research and future directions. *Soc Sci Med* 2004;58: 1427–1442.
11. Biesecker BB, Peters KF. Process studies in genetic counseling: Peering into the black box. *Am J Med Genet* 2001;106:191–198.
12. Edwards W. Behavioral decision theory. *Annu Rev Psychol* 1961;12:473–498.
13. Huber O, Wider R, Huber OW. Active information search and complete information presentation in naturalistic risky decision tasks. *Acta Psychol* 1997;95: 15–29.
14. Shiloh S, Berkenstadt M, Meiran N, BatMiriamKatznelson M, Goldman B. Mediating effects of perceived personal control in coping with a health threat: The case of genetic counseling. *J Appl Soc Psychol* 1997;27:1146–1174.
15. van Zuuren FJ, van Schie EC, van Baaren NK. Uncertainty in the information provided during genetic counseling. *Patient Educ Couns* 1997;32:129–139.

16. Michie S, Axworthy D, Weinman J, Marteau T. Genetic counselling: Predicting patient outcomes. *Psychol Health* 1996;11:797–809.
17. Redelmeier DA, Shafir E. Medical Decision-Making in Situations That Offer Multiple Alternatives. *JAMA* 1995;273:302–305.
18. Shiloh S, Koren S, Zakay D. Individual differences in compensatory decision-making style and need for closure as correlates of subjective decision complexity and difficulty. *Pers & Individ Diff* 2001;30:699–710.
19. Jallinoja P, Aro AR. Does knowledge make a difference? The association between knowledge about genes and attitudes toward gene tests. *J Health Commun* 2000;5:29–39.
20. Krantz DS, Baum A, Wideman M. Assessment of Preferences for self-treatment and information in health care. *J Pers Soc Psychol* 1980;39:977–990.
21. Auerbach SM. Do patients want control over their own health care? A review of measures, findings, and research issues. *J Health Psychol* 2001;6:191–203.
22. Wallston BS, Wallston KA. Social psychological models of health behavior. In: Baum A, Singer JE, editors. *Handbook of psychology and health*. Vol 4. Hillsdale, NJ: Erlbaum, 1984:23–53.
23. Braman AC, Gomez RG. Patient personality predicts preferences for relationship with doctors. *Pers & Individ Diff* 2004;37:815–826.
24. Auerbach SM, Martelli MF, Mercuri LG. Anxiety, information, interpersonal impacts and adjustment to a stressful health care situation. *J Pers Soc Psychol* 1983;44:1284–1296.
25. Lau RR, Hartman KA. Common-sense representations of common illness. *Health Psychol* 1983;2:167–185.
26. Nerenz DR, Leventhal H. Self-regulation theory in chronic illness. In: Burish TGLAB, editor. *Coping with chronic disease: research and applications*. New York: Academic Press, 1983:13–38.
27. Shiloh S, Gerad L, Goldman B. Patients' information needs and decision-making processes: what can be learned from genetic counselees'? *Health Psychol*. In press.
28. Chatterjee S, Heath TB. Conflict and loss aversion in multiattribute choice: the effects of trade-off size and reference dependence on decision difficulty. *Organ Behav Hum Perform* 1996;67:144–155.
29. Kahneman D, Tversky A. Prospect theory: an analysis of decision under risk. *Econometrica* 1979;47:263–291.
30. Baron J, Hershey JC. Outcome bias in decision evaluation. *J Pers Soc Psychol* 1988;54:569–579.
31. Frets PG, Duivenvoorden HJ, Verhage F, Peters-Romeyn BM, Niermeijer MF. Analysis of problems in making the reproductive decision after genetic counselling. *J Med Genet* 1991;28:194–200.
32. Rozenblit L, Keil F. The misunderstood limits of folk science: an illusion of explanatory depth. *Cog Sci* 2002;26:521–562.
33. MacLeod R, Craufurd D, Booth K. Patients' perceptions of what makes genetic counselling effective: An interpretative phenomenological analysis. *J Health Psychol* 2002;7:145–156.
34. Sagi M, Meiner V, Reshef N, Dagan J, Zlotogora J. Prenatal diagnosis of sex chromosome aneuploidy: possible reasons for high rates of pregnancy termination. *Prenat Diagn* 2001;21:461–465.
35. HolmesRovner M, Kroll J, Schmitt N et al. Patient satisfaction with health care decisions: The satisfaction with decision scale. *Med Decision Making* 1996;16:58–64.
36. van Zuuren FJ. The standard of neutrality during genetic counseling: an empirical investigation. *Patient Educ Couns* 1997;32:69–79.
37. Kessler S. Psychological aspects of genetic counseling. XIV. Nondirectiveness and counseling skills. *Gen Testing* 2001;5:187–191.