

Genetic Counseling for β -Thalassemia Trait Following Health Screening in a Health Maintenance Organization: Comparison of Programmed and Conventional Counseling

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SUMMARY

Providing adequate counseling of patients identified in genetic screening programs is a major responsibility and expense. Adults in a health maintenance organization, unselected for interest, were screened for β -thalassemia trait as part of preventive health care. Counseling was provided by either a trained physician (conventional counseling) or by a videotape containing the same information followed by an opportunity to question a trained physician (programmed counseling). Immediately before and after counseling, knowledge of thalassemia, knowledge of genetics, and mood change were assessed by questionnaire. Comparable mood changes and similar learning about thalassemia and genetics occurred with both counseling methods. Thus, as judged by immediate effects on knowledge and mood, videotaped instruction can greatly reduce professional time required for genetic counseling and facilitate the incorporation of genetic screening into primary health care.

INTRODUCTION

This is the second report of a longitudinal project designed to compare two methods of genetic counseling: programmed and live physician counselors. Details

Received October 10, 1980; revised March 5, 1981.

This study was supported by grant R01-HL-17465 from the National Institutes of Health and New York State grants 146 and 664 from the Health Research Council.

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of the rationale and design of the study have been previously presented [1] and will not be duplicated here. Briefly, however, all members aged 18 to 65 of a health maintenance organization (HMO) were screened for β -thalassemia trait when a phlebotomy was undertaken for any reason, usually for an initial health assessment. An individual who tested positively was recruited by letter and asked to participate without mentioning the specific disorder. Consequently, patients were unselected for interest and were naive to the condition prior to counseling.

We previously reported that, compared with nontrait controls, trait subjects demonstrated significant learning about thalassemia and genetics, and recorded acceptable mood changes (viz., increased surprise and alertness, and decreased skepticism) [1]. This report compares a physician counselor on videotape to one in person to determine the pedagogic effectiveness of the two methods given the differences in required physician time and cost.

METHODS

Selection of Subjects

The population screened was the Genesee Valley Group Health Association (GVGHA) located in Rochester, New York. Each patient with an elevated hemoglobin (Hb) A₂ ($\geq 3.5\%$) [1] was recruited, and of the 103 subjects invited to participate, 93 consented (92%). This high participation rate enhances the degree to which the results of the study may be generalized.

A nontrait, control population, matched on several demographic variables (table 1), was studied to determine if any changes occurring in counseled subjects between precounseling testing and postcounseling evaluation were due to counseling and not to the testing, the passage of time, or information from other sources. For the control subjects, the same pattern of pre- and postcounseling evaluations was undertaken. However, a film dealing with general health maintenance was substituted for counseling about thalassemia.

Test and Counseling

As described in [1], the protocol consisted of pre- and postcounseling assessment of mood (Nowlis Mood Adjective Checklist [2]), knowledge of thalassemia, and knowledge of genetics. The mood checklist was administered immediately after informed consent and a second time immediately prior to counseling so as to assess the effects of approximately 2 hrs of precounseling personality and attitude assessment.

Trait subjects were randomly assigned to programmed or conventional counseling groups with care taken to match them on the basis of sex, marital status, and childbearing status. The *programmed* counseling method employed a specially produced 40-min color-sound videotape showing an actual counseling session. Following viewing, a physician-counselor entered to answer questions. In the *conventional* counseling method, five general internists, GVGHA physicians, were trained to present the same information as presented by the videotape. Details of the content of the videotape and the live counseling have been presented in [1].

Table 1 presents a comparison of all subject groups on demographic variables. Each counseling group was closely matched to its control group, and there were no significant differences among the four groups on any demographic variable.

Data Analysis

Subject responses to tests of both knowledge and mood were scaled as percent correct (or percent positive). An arc sine transformation was applied to the data to expand the tails of the distributions, truncated by expression as percentages.

TABLE 1
DEMOGRAPHIC COMPARISONS OF SUBJECT GROUPS

	PROGRAMMED		CONVENTIONAL	
	Counselees	Controls	Counselees	Controls
Sex:				
Males	23	21	26	27
Females	20	19	27	23
Total	43	40	53	50
Age (yrs):				
Mean	38.79	38.33	35.60	35.54
SD	12.80	12.74	13.72	13.27
Marital status:				
Single	4	4	12	11
Married	36	33	38	37
Divorced	3	3	3	2
Social class*:				
Mean	3.29	3.08	3.37	3.40
SD90	.83	.88	.86
No. children:				
Mean	1.63	2.20	1.43	1.78
SD	1.50	1.80	1.68	2.14

*Social class computed by Hollingshead and Redlich 2 factor index.

Because of the relative instability of adjective checklists, the scores on the 13 Nowlis mood scales for each of 71 trait subjects were factor analyzed using a principal-components analysis with oblique rotation. Five factors accounted for 71.5% of the variance: (1) sociability (26.7%) = social affection + pleasantness + nonchalance, (2) depression (16.3%) = deactivation + depression I + depression II, (3) fear (11.4%) = anxiety + skepticism + startle, (4) defensiveness (9.6%) = aggression + egotism, and (5) active concentration (7.5%) = concentration + activation.

To assess whether the scores on a given scale for the subjects receiving programmed counseling compared with their controls were significantly different from the scores for subjects receiving conventional counseling compared with their controls, the scores from the two knowledge scales, the 13 Nowlis scales, and the five mood dimensions underwent separate 2 × 2 analyses of covariance. Since subjects differed as to their precounseling scores, these were used as the covariate for the adjustment of the postcounseling scores so as to statistically equate all subjects for initial values. One main effect compared the counseling vs. control experience; the second main effect compared the two counseling methods with their combined controls; and the interaction term referred to the comparison of programmed and conventional groups relative to their respective controls. The interaction term was therefore used to determine primary differences between immediate outcome of counseling methods.

RESULTS

Table 2 presents knowledge and mood scores before and immediately after counseling for each counseling method. Relative to the appropriate control groups, the two counseling methods were equally effective in teaching about both thalassemia and genetics. As reported in [1], both counseling groups taken together demonstrated significant learning. The present findings indicate that this learning was not specific to a particular counseling method (i.e., no two-way interaction term reached or approached significance).

TABLE 2
EFFECT OF TYPE OF COUNSELING RECEIVED ON CHANGES IN KNOWLEDGE AND MOOD

SCALE	PROGRAMMED						CONVENTIONAL						
	COUNSELEES		CONTROLS		COUNSELEES		CONTROLS		COUNSELEES		CONTROLS		
	Pre	Post	Pre	Post	Pre	Post	Pre	Post	Pre	Post	Pre	Post	
Knowledge:													
Genetics.....	55.05	88.45	60.73	62.91	41.55	79.63	58.52	60.53	42.09	45.17			
Thalassemia.....	44.92	86.97	43.73	44.87	34.42	84.67							
Mood scales:													
Pleasantness.....	19.98	21.48	30.95	28.98	13.68	25.30	32.39	19.79	0.98	1.14			
Aggression.....	0.81	1.53	1.17	.00	2.52	2.42							
Concentration.....	69.66	64.59	84.53	77.41	64.64	52.36	79.43	70.99	24.90	16.70			
Social affection.....	27.36	20.50	35.33	29.99	22.38	14.62	24.90	16.70	13.71	10.59			
Nonchalance.....	14.65	8.81	18.14	12.02	11.48	6.70							
Depression I.....	1.84	3.27	1.14	1.53	3.13	2.22	0.43	0.61					
Depression II.....	18.19	12.77	6.94	5.57	21.23	11.29	5.18	5.66					
Anxiety.....	1.96	1.76	2.75	1.83	1.76	2.47	1.66	1.53					
Egotism.....	18.18	4.80	17.25	5.90	26.74	6.70	14.31	6.94					
Skepticism.....	1.43	2.44	1.17	4.33	2.93	2.36	0.53	1.19					
Depression I.....	22.00	13.06	17.23	22.52	16.69	17.61	16.51	20.12					
Deactivation.....	2.82	6.39	1.36	1.00	3.94	16.34	0.75	1.08					
Startle.....	27.81	28.35	53.51	47.46	26.08	17.69	38.66	28.58					
Activation.....													

NOTE: Scores reflect mean percentages for each group on each scale. These scores underwent an arc sine transformation for purposes of analysis to counter effects of truncated distributions related to use of percentages.

With regard to the 13 mood scales, there were no significant differences in pre or post changes at the 5% level between the two counseled groups compared with their controls on any of the 13 Nowlis mood scales; that is, trait patients in both counseling groups had similar mood changes following counseling. Similarly, no differences between the groups occurred in comparisons of the five mood dimensions (table 3).

It will be recalled that following informed consent, approximately 2 hrs of precounseling personality and attitude assessment occurred prior to counseling for trait subjects or to viewing a film in the case of controls. To assess the effects of the assessment period on trait and nontrait subjects, the Nowlis scale was administered immediately prior to and after precounseling assessment. Postassessment mood scales and dimensions were analyzed by a trait-nontrait analysis of covariance with the preassessment score used as a covariate so as to equate groups for initial values. Only two mood scales reached statistical significance: anxiety ($F = 7.17$; $P < .008$) and pleasantness ($F = 3.77$; $P < .05$). Trait subjects scored significantly higher on the anxiety scale after assessment than did nontrait controls, and similarly, trait subjects scored significantly lower on pleasantness than did controls. No mood dimension reached or approached significance.

To determine whether the increased anxiety that occurred with trait subjects during precounseling assessment influenced subsequent learning or mood change, the trait subjects were divided into high-anxiety and low-anxiety groups on the basis of their change scores. These two groups were then compared using a 2×2 , group by counseling method analysis of covariance on thalassemia and genetic knowledge, and the five mood dimensions. The high- vs. low-anxiety groups were not discriminated on any dependent variable. Also, t tests run between these two groups on a variety of demographic and personality variables also yielded nonsignificant findings. Therefore, although trait subjects tended to react to precounseling assessment with more anxiety than nontrait subjects, the effect did not influence the outcome data studied nor could particular characteristics be identified on the basis of initial demographic information.

DISCUSSION

This study is consonant with two authoritative committee reports on genetic screening and counseling. The first, sponsored by The National Academy of Sciences, recommended that genetic screening be regarded as one among several preventive health measures and that its development take place in the context of the evolution of health care in general [3]. The second, sponsored by the National Institutes of Health, set forth guidelines for the design of studies evaluating genetic counseling [4].

Our previous report [1] demonstrated that genetic counseling of β -thalassemia trait subjects in a primary health-care setting demonstrated significant learning about thalassemia and genetics without untoward changes in mood. Our present report analyzes these effects in terms of the two methods of genetic counseling: programmed and conventional.

TABLE 3
EFFECT OF TYPE OF COUNSELING ON CHANGE IN MOOD

SCALE	PROGRAMMED						CONVENTIONAL					
	COUNSELEES		CONTROLS		Pre	Post	COUNSELEES		CONTROLS		Pre	Post
	Pre	Post	Pre	Post			Pre	Post	Pre	Post		
Sociability	20.44	16.44	27.95	23.07	15.59	14.72	20.11	15.49				
Depression	6.02	5.46	4.52	7.42	6.47	5.91	3.40	4.65				
Fear	10.76	7.70	7.15	3.74	15.72	11.14	4.91	4.09				
Defensive	1.31	1.64	1.88	2.13	2.12	2.45	1.29	1.32				
Active concentration	48.56	46.21	70.12	63.02	44.97	34.14	59.99	49.76				

NOTE: See note, table 2.

Regarding knowledge, the two counseling methods were equally effective in teaching about thalassemia and about genetics. The systematic presentation of information, whether from carefully constructed videotapes or from well-trained physicians, are each effective in this kind of educational interaction. Physicians commonly assume that their physical presence is critical to the communication of health-care information. These data suggest that, at least in this particular setting, the presence of the physician is not necessary for the successful communication of health-related information, and that no untoward patient reactions occur, at least with respect to immediate outcome. It should be recalled, however, that each member of the programmed counseling group saw a physician following presentation of the videotape. So while educational material was communicated via videotape, a physician was at hand to answer questions and provide support.

Regarding effects on mood, our previous report [1] demonstrated that thalassemia trait subjects receiving genetic counseling by either method recorded decreased skepticism and increased alertness and surprise, compared with controls. As shown here, there was no significant difference in mood scores between the two counseling groups relative to their respective controls; that is, the mood changes reported earlier are not a function of live vs. programmed counseling.

Compared with conventional counseling, programmed counseling with live physician support was thus found to be pedagogically as effective and without any definite disadvantages with regard to mood effects. The economic advantage of programmed counseling is great since physician time required was only 5 to 10 min (to answer questions) compared to 45 min for the conventional method. Videotaped instruction may thus lower the chief practical barrier to widespread genetic screening in the primary care setting by reducing the large amount of professional time required for the genetic counseling of identified carriers.

Trait subjects completed precounseling assessment with higher scores on anxiety and lower scores on pleasantness than did controls. This is understandable considering the fact that trait subjects were aware that they had an "unusual laboratory finding" and were awaiting counseling with some concern. Indeed this finding seems appropriate given the reality of the situation and the trait subjects' anticipation of counseling. Data analysis revealed that the increased levels of anxiety did not affect knowledge or mood scores, nor were high-anxiety patients identifiable on the basis of personality or demographic data.

Two cautionary notes are relevant to any application of these findings. First, the data may be attributable to certain features of the counseling and of the setting in which it occurred. Regarding the counseling, only the essential facts were chosen for transmission, great effort was invested in presenting them clearly, and the choice among alternative courses of action was left to the counselee [1]. Regarding the setting, the fact that the counseling was done as part of primary health care at an HMO may have reduced chances for negative mood effects by assuring the counselee of confidentiality in a warm, familiar setting, and by reducing the chances of stigmatization [5, 6].

The second cautionary note is to emphasize that the results reported here describe only immediate responses which, while important in and of themselves, may

not be similar to a long-term outcome. Follow-up studies are in progress to determine the degree to which this counseling experience (1) results in knowledge retention, (2) affects attitudes about self, mate, and children, and (3) leads to action, in particular to the referral of mate or other family members for screening.

ACKNOWLEDGMENTS

We thank Dr. James S. Roberts, former Medical Director of the Joseph C. Wilson Health Center, Genesee Valley Group Association; physician-counselors Michael Buck, Richard Morris, Dennis Novack, John Robbins, Michael Udkow, and Porter Welbourne; and the entire medical and ancillary staff for their generous cooperation. We thank Dr. Paul Grover, previously of the Division of Medical Education, and Dr. Sanford Meyerowitz (deceased), Departments of Psychiatry and Medicine, for wise counsel. Starlene Dick, project coordinator, and Andrea Feldman, Judith Lee, and Carol J. Sutera, research assistants, contributed immeasurably.

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