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Sickle Cell Trait Counseling—Evaluation of Counselors and Counselees

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SUMMARY

In this study, information about both counselee and counselor performance was obtained from taped recordings of 193 structured counseling sessions with persons diagnosed as having sickle cell trait. The data provide evidence that: (1) lay persons can understand essential sickle cell information; (2) trained lay persons using a structured format can transmit successfully sickle cell information; (3) only education and age, among counselee characteristics studied, were related to successful learning; (4) the evaluation of information transfer in counseling programs cannot be limited to counselees' comprehension but must also consider other variables such as counselor performance and curriculum content; (5) a reduction in negative feelings associated with a diagnosis of sickle cell trait is an immediate effect of counseling; and (6) audio-taping of counseling sessions is client acceptable and useful for evaluation, quality control, and counselor training.

INTRODUCTION

During the past several years, considerable time, effort, and money have been expended to provide counseling for persons who are carriers of the sickle cell gene. A wide range of procedures and different types of personnel have been used in these programs that usually aim to provide information needed for making in-

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formed decisions about marriage and reproduction as well as to help clients avoid any adverse psychosocial side effects of being identified as a carrier of sickle cell disease. With the development of these genetic counseling programs, there is a growing need for evaluations to determine the extent to which programs are meeting their objectives. For both the individual program director who is interested in using the most effective method of counseling in a particular institution or agency and the social policy maker who is concerned about the utilization of resources, it is important to know whether activities are achieving their intended results.

A review of the literature reveals that some assessment of the outcome of genetic counseling has been conducted for a number of genetic diseases. The outcomes measured have included the information acquired, information retained, reproductive behavior, and changes in attitudes and feelings. However, all of the reported studies have a major flaw in that they do not include an assessment of the counseling process.

Evaluations of outcomes are essential, but possible hazards are presented if the results of evaluations are used for policy decisions without consideration of the curriculum content and the quality of the instructional activities of the counselors, each of which is an important factor in the outcomes.

This report provides data on a sickle cell trait counseling program with a structured curriculum, the implementation of which permitted assessment of the counselees' comprehension of the information transmitted, as well as the quality of the counselors' performances and the relationship between the two. It also provides data on the effect of counseling on counselees' feelings regarding their being told that they have sickle cell trait.

PROCEDURES

Subjects

The counselees were adults who have sickle cell trait or were parents of a child with sickle cell trait. (Some of the parents also have the trait.) The counselees were recruited for testing through: a public awareness campaign achieved through media presentations (newspaper, radio, and TV) and visibility of a mobile unit throughout the city; presentations at meetings of social and civic organizations; presentations in high schools and literature and consent forms sent to parents of kindergartners and high school students; and the requirement for sickle cell testing in the Medicaid Early Periodic Screening, Diagnosis and Treatment (EPSDT) Program.

The diagnosis of sickle cell trait was established by hemoglobin electrophoresis and a solubility test performed on individuals tested through the Sickle Cell Detection and Information Program, a community-based unit of Wayne State University's Comprehensive Sickle Cell Center. Testing was done at the various sites where the EPSDT Program was being conducted, at the Sickle Cell Detection Center, or on the Detection Center's mobile unit. The mobile unit is designed and equipped to enable clients to receive education (slide-sound program), testing, and counseling. It was used in public schools (kindergarten and grades 10–12), at various community sites such as churches and supermarkets, and at special events such as public meetings and the State Fair.

Counseling Program

The goal of the program is to enable individuals with sickle cell trait to make informed decisions with respect to marriage and family planning that the person believes are in his or her best interest. The specific objective of the counseling session was for at least 80% of the counselees to be able to answer satisfactorily a question about each of the following topics: (1) Genotype—as reflected in the major types of hemoglobin present in red blood cells of normal individuals and individuals with sickle cell trait and sickle cell anemia. (2) The risk of sickle cell anemia in each pregnancy of trait-trait couples. (3) The incidence of sickle cell anemia in families with trait-trait parents. (4) The health status of individuals with sickle cell trait. (5) The life span of individuals with sickle cell trait. (6) The symptoms of sickle cell anemia. (7) The variability of occurrence of symptoms in sickle cell anemia. (8) The life span of individuals with sickle cell anemia. (9) The options available to individuals with sickle cell trait with respect to marriage and family planning. (10) The reasons individuals or couples with sickle cell trait might decide to have or not have children.

The counseling sessions were preceded by an education session consisting of a 15-min slide-tape presentation providing an overview of sickle cell anemia and sickle cell trait. The format for all counseling sessions was the same—the counselors were instructed to follow precisely the following 10 steps.* Step 1. Introduce yourself, explain your role, explain use of tape recorder, and obtain permission to tape. Step 2. Give test results. Step 3. Ask the five opening questions. Step 4. Ascertain feelings about the individual having or his or her child having sickle cell trait. Step 5. Review and explain the essential features of sickle cell anemia and trait by pointing to and discussing 26 graphics. (The graphics cover the concepts and facts the program attempts to teach.) Encourage the counselee to ask questions and attempt to establish a dialogue with the counselee. Step 6. Explain program goals. Step 7. Describe the options persons with sickle cell trait have with respect to marriage and child bearing. Step 8. Provide reasons couples with sickle cell trait might decide to have or not have children. Step 9. Ascertain the counselees' grasp of the information presented about each of the 10 topics through asking specific open-ended questions in relationship to rolls of a pair of sickle cell dice. (The dice have sperm and eggs labeled for normal or sickle hemoglobin and represent a mother and father with sickle cell trait.) Step 10. Ascertain feelings about the individual having or his or her child having sickle trait.

All sessions for which counselees' permission had been obtained were audiotaped. If an individual indicated unwillingness, counseling was conducted without taping. The counseling sessions required about 45 min to complete, at the end of which the counselees were given a brochure and fact sheet that contained some of the salient points and illustrations presented in the session. Counseling was conducted by lay persons who, although they had some college education (at least 2 years) or a college degree, had no previous training as health professionals. They received their training as counselors at the Sickle Cell Center. The key elements of the training program (developed by the senior author†) follows. The trainee: Completes a programmed self-instructional unit on the basic aspects of sickling. Learns acceptable answers to 50 questions that have been frequently asked by our counselees. Learns importance of counseling and goals, objectives, content, and format of counseling session from a syllabus and discussions with the counseling supervisor. Is instructed on the handling of "difficult" counselees and problem situations. Reviews tapes of model counseling sessions conducted by counselors in the program that contain a variety of counselee responses, reactions, and styles. Reviews tapes of counseling sessions conducted by counselors in the program that contain previously identified errors in technique, contact, etc. Reviews a training film with built-in errors that requires trainee to identify and comment on the errors. Conducts an unspecified number of taped practice counseling sessions

* A detailed description of the counseling format can be obtained from the senior author.

† Syllabus available on request.

with a counselor serving as the counselee and critic, and is permitted to begin counseling of clients when his or her performance under these circumstances is satisfactory.

The counseling took place either immediately after the laboratory test was completed or at some later date. When testing occurred at the Sickle Cell Center or in the mobile unit, the laboratory tests were performed immediately and subjects were counseled at that time unless they indicated that they had insufficient time. In the EPDST Program, specimens from all the health care collection sites were sent to a central laboratory for analysis and, therefore, counseling was delayed. Appointments were scheduled by letter and by phone.

Evaluation

The evaluation was accomplished through the analysis of the tapes of approximately 20% of the counseling sessions conducted in 1976, a total of 193 tapes. Approximately two tapes per month from each of the eight counselors were randomly chosen for transcription, coding, and analysis. This amounted to either 25 or 26 sessions for each counselor except for one counselor who was employed for less than 1 year and had only 16 tapes analyzed.

A counselee's success in learning the material was determined by ascertaining whether the counselee's answers to the series of questions asked during the dice review were satisfactory. There was a question for each of the 10 information components (see objectives) that the counselors were required to cover in the earlier part of the counseling session, making it possible for each individual to answer anywhere from zero to 10 questions correctly.

Adequacy of counselor performance was determined for each information component that counselors were required to cover during the counseling session. The coverage of each of the 10 informational components was judged to be satisfactory or not satisfactory on the basis of specific criteria for each component. For example, satisfactory coverage of topic no. 8—the life span of individuals with sickle cell anemia—requires the counselor to include and elaborate on three statements: (1) the average life span is shortened; (2) a specific figure for the average life span is not available; (3) it is not true that the vast majority fail to reach adulthood. Satisfactory coverage of topic no. 10 requires the counselor to cover at least three factors, giving in each case the reasons parents might decide for or against having children. The factors include: desire to have children of their own, their ability to cope with adversity, their desire to have perfect children, their views on the prospects for a cure, their views on the prospects for the severity of the disease in their child, and their willingness to take chances.

Affective reactions to learning that one has sickle cell trait was assessed by asking individuals at the beginning and end of the counseling session, "How do you feel about having sickle cell trait?" or, if it was more appropriate, "How do you feel about your child having sickle cell trait?" The answer to these questions were coded as expressing: (1) no feeling, (2) negative feelings such as anxiety, concern, or disavowal, (3) acceptance, or (4) positive feelings. For example, the feeling was classified as a negative feeling when the response was: "I am so worried about this"; as acceptance if an individual responded: "Well, it is just one of those things"; and as a positive feeling if he or she said: "I feel good knowing it is just the trait." The responses were coded independently by two coders (the senior author and F. Koen, PhD, an educational psychologist, Dept. of Community Medicine, Wayne State University) who experienced a high level of agreement. Disagreements in the coding of a specific response were resolved by mutual consent.

RESULTS

Counselee Performance

Overall, 78.8% of the answers were satisfactory, 19% of the counselees answered all of the questions satisfactorily, and nearly 80% answered seven or more questions satisfactorily (table 1). In terms of specific questions, our objective was to

TABLE 1

COUNSELEE PERFORMANCE IN TERMS OF NO. CORRECT ANSWERS

NO. CORRECT ANSWERS	COUNSELEES		CUMULATIVE		TOTAL CORRECT ANSWERS
	No.	%	No.	%	
0	0	0			
1	2	1.0	193	100.0	2
2	2	1.0	191	99.0	4
3	1	0.5	189	98.0	3
4	3	1.6	188	97.5	12
5	11	5.8	185	95.9	55
6	23	11.9	174	90.1	138
7	24	12.4	151	78.2	168
8	41	21.2	127	65.8	328
9	49	25.4	86	44.6	441
10	37	19.2	37	19.2	370
Total	193	100.0	...	...	1,521*

* 1,521 is 78.8% of the 1,930 possible correct answers.

have each question answered satisfactorily by 80% of the counselees. This objective was met for five of the questions. The range for the other five was 74%–77% (table 2).

Counselor Performance

Our objective was for counselors to perform satisfactorily on the average for at least 90% of all the topics covered in the counseling session, as well as for each of the informational components considered separately. Overall, the counselors

TABLE 2

% COUNSELEES WITH CORRECT ANSWERS FOR EACH INFORMATION COMPONENT; % COUNSELORS THAT PERFORMED SATISFACTORILY FOR EACH COMPONENT

COMPONENT	CORRECT ANSWER (COUNSELEES)		SATISFACTORY PERFORMANCE (COUNSELORS)	
	No.	%	No.	%
Genetics	170	87.5	185	95.9
Risk of sickle cell anemia	141	76.2	176	91.2
Incidence of sickle cell anemia	138	74.6	177	92.2
Health status—sickle cell trait	171	90.9	189	99.0
Life span-sickle cell trait	179	98.9	177	92.2
Symptoms-sickle cell anemia	171	92.9	188	97.4
Variability of symptoms	128	77.1	175	91.1
Life span—sickle cell anemia	137	75.3	165	85.5
Options—sickle cell trait	156	86.2	164	85.0
Reasons for decisions	131	75.7	173	90.1
All components	1,522	83.6 (No. 1,817)*	1,769	92.0 (No. 1,924)*

* Totals were less than the 1,930 possible answers because of no answers or inaudible sections of tapes in a few instances.

presented the material and reviewed the graphics according to our criteria for satisfactory counseling 92% of the time (table 2). The 90% objective was also reached for individual subject areas with two exceptions: the options for marriage and reproduction available to individuals with sickle cell trait (85.0%) and the life span of persons with sickle cell anemia (85.5%).

Relationship between Counselee Characteristics and Performance

The relationship between selected characteristics of the counselees and their ability to answer questions satisfactorily was analyzed by multiple regression and chi-square statistics. Multiple regression analysis revealed that the various counselor characteristics (i.e., age, sex, education, marital status, number of children, whether they were being counseled because they had sickle cell trait as opposed to their child having it, and when they were counseled—immediately, after the identification of the trait or at some later date) minimally predicted the number of correct answers ($R = .3147$) accounting for only 9.9% ($R^2 = .099$) of the total variance in the scores. The best predictor, education, accounted for only 4.6% ($R^2 = .046$) of the total variance.

To further determine whether a significant relationship existed between counselee characteristics and their ability to answer questions, the counselees were divided into two groups depending upon whether they answered fewer than eight or eight or more questions satisfactorily. Chi-square analysis showed a significantly higher number with eight or more correct answers among the counselees who had finished high school than among those who did not and among those who were less than 30 years of age. There were no significant differences in the numbers of counselees who scored 80% or higher as opposed to less than 80% with respect to the other characteristics (table 3).

Relationship between Counselor and Counselee Performance

A significant difference in counselee performance among different counselors was determined for four of the subject areas, that is, genetics, the risk of sickle cell anemia in children of a trait-trait couple, the life span of persons with sickle cell anemia, and the options for marriage and reproduction available to persons with sickle cell trait (table 4).

The nature of the relationship between counselor and counselee performance was also examined by considering counselee performance for only those occasions when counselor performance had been satisfactory according to our criteria. A significant difference in counselee performance for different counselors was ascertained for three subject areas: genetics, risks, and options (table 4).

Finally, on the basis of data presented in table 2, we identified those subject areas for which, on the average, both counselors and counselees performed at a level that met the program's objectives (80% satisfactory answers for counselees and 90% satisfactory performance by counselors). Those areas in which counselors, counselees, or both failed to meet the objectives were also identified. As shown in table 5, both counselees and counselors successfully met the objectives for four of the subject areas. In four areas, counselees were unsuccessful even though the

TABLE 3

COUNSELEE PERFORMANCE RELATED TO SELECTED COUNSELEE CHARACTERISTICS

COUNSELEE CHARACTERISTIC	80 OR ABOVE No.	80 OR ABOVE %	LESS THAN 80 No.	LESS THAN 80 %	TOTAL	
Education:						
Less than 12 yrs	24	51.1	23	48.9	47	$\chi^2 = 6.52$
12 or more yrs	100	71.4	40	28.6	140	$P < .01$
Sex:						
Female	100	65.4	53	34.6	153	$\chi^2 = .61$
Male	27	69.2	12	30.8	39	N.S.*
Marital status:						
Single	40	61.5	25	38.5	65	$\chi^2 = .08$
Married	43	69.4	19	30.6	62	N.S.
Other	36	65.5	19	34.5	55	
Age:						
Less than 30 years	70	72.2	27	27.8	97	$\chi^2 = 4.4$
30 years or older	45	57.0	34	43.0	79	$P < .05$
Person with sickle cell trait:						
Counselee	55	69.6	24	30.4	79	$\chi^2 = .72$
Child, only	49	61.3	31	38.7	80	N.S.
Child, counselee	23	69.7	10	30.3	33	
No. children:						
None	25	73.5	9	26.5	34	$\chi^2 = 1.81$
1–3	71	64.5	39	35.5	110	N.S.
More than 3	21	58.3	15	41.7	36	
Time of counseling:						
At time of testing	52	65.0	28	35.0	80	$\chi = .08$
Later	75	67.0	37	33.0	112	N.S.

* N.S. = not significant.

counselors had performed satisfactorily. In one area, neither counselors nor counselees met our objectives, and for one subject, counselees were able to meet the program's objectives when the counselors had not performed adequately by our criteria.

TABLE 4

CHI-SQUARE VALUES FOR RELATIONSHIP BETWEEN COUNSELOR AND COUNSELEE PERFORMANCE FOR EACH SUBJECT AREA

SUBJECT	ALL COUNSELOR PERFORMANCES χ^2	ALL COUNSELOR PERFORMANCES P	ONLY SATISFACTORY COUNSELOR PERFORMANCES χ^2	ONLY SATISFACTORY COUNSELOR PERFORMANCES P
Genetics	16.6	.05	18.1	.05
Risk	16.5	.05	19.6	.01
Incidence	2.9	N.S.*	3.4	N.S.
Health status—sickle cell trait	12.5	N.S.	12.0	N.S.
Life span—sickle cell trait	9.1	N.S.	6.3	N.S.
Symptoms—sickle cell anemia	8.6	N.S.	8.5	N.S.
Variability—sickle cell anemia	6.7	N.S.	7.5	N.S.
Life span—sickle cell anemia	21.3	.005	10.8	N.S.
Options—sickle cell trait	22.5	.005	18.8	.01
Reasons—sickle cell trait	8.6	N.S.	6.2	N.S.
Average	2.5	N.S.	2.5	N.S.

* N.S. = not significant.

TABLE 5

SUBJECT AREAS WITH SATISFACTORY OR UNSATISFACTORY PERFORMANCES BY COUNSELORS AND COUNSELEES

	Satisfactory by counselees (80% or above)	Unsatisfactory by counselees (Less than 80%)
Satisfactory by counselors (90% or above)	Genetics	Risk
	Health status—sickle cell trait	Incidence
	Life span—sickle cell trait	Variability—sickle cell anemia
	Symptoms—sickle cell anemia	Reasons
Unsatisfactory by counselors (less than 90%)	Options	Life span—sickle cell anemia

Affective Responses

Table 6 contains data pertaining to the affective reactions of individuals to learning that they or their child has sickle cell trait and the immediate effects of the counseling sessions upon these expressed feelings. At the beginning of the session, 29% of the individuals expressed no feelings about their diagnosis of having sickle cell trait, 36% expressed positive or acceptance feelings, and 35% expressed feelings of anxiety. A comparison of feelings expressed before and after counseling showed a decrease from 35% to 17% in those who expressed anxiety about having sickle cell trait (a 53% decrease). The percentage of persons who expressed positive or acceptance feelings more than doubled, increasing from 36% before the counseling to 74% after the counseling session. Only 6.3% (four) of the 63 persons who had positive or acceptance feelings at the beginning expressed anxiety after the counseling session was over.

Multiple regression analysis with pre- and post-feelings expressed ordinally (1 = anxiety, 2 = no feeling, 3 = acceptance, 4 = positive feelings) revealed that pre- and post-feelings accounted only for 1.6% (R^2 = .0166) of the total variance in the ability of counselees to answer questions satisfactorily.

In addition, the feelings expressed by counselees at either the beginning or at the end of the session did not differ significantly (chi-square analysis) among counselees depending on whether they answered eight or more or fewer than eight questions satisfactorily.

TABLE 6

FEELINGS AT BEGINNING AND END OF SESSION

FEELINGS AT END OF SESSION	FEELINGS AT BEGINNING OF SESSION							
	NO FEELINGS		POSITIVE/ACCEPTANCE		ANXIETY		TOTAL	
	No.	%	No.	%	No.	%	No.	%
No feelings	8	16.0	4	6.3	5	8.1	17	9.7
Positive	18	36.0	22	34.9	23	37.1	63	36.0
Acceptance	17	34.0	33	52.5	16	25.8	66	37.7
Anxiety	7	14.0	4	6.3	18	29.0	29	16.6
Total	50	100.0 (28.6)	63	100.0 (36.0)	62	100.0 (35.4)	175	100.0 (100.0)

Changes in feelings that occurred during the counseling session were also examined in terms of whether there was a relationship between the changes and the level of comprehension based upon whether the counselees answered more or less than 80% of the questions satisfactorily. The proportion of individuals who expressed anxiety before counseling and continued to express anxiety after counseling was completed was approximately the same for the two levels of comprehension (30.0% and 20.6%, respectively). A similar finding occurred when we compared those who changed from positive and acceptance feelings to either feelings of anxiety (6.3% and 6.4%, respectively).

Finally, we determined whether there were differences among the eight counselors in terms of how successful the counseling sessions had been in relieving anxiety as reflected by the counselees' responses to: "How do you feel about having sickle cell trait?" asked at the end of the counseling sessions. We found no significant differences.

DISCUSSION

Information Transfer

One of the basic objectives of genetic counseling programs is for counselees to acquire accurate information about the disease and the carrier state. Our success in transmitting information was excellent considering that some of the concepts are difficult to teach, the length of the counseling session, and the educational background of the counselees. At least 75% of the counselees were able to provide satisfactory answers in each of the 10 subject areas, and almost 80% answered seven or more questions satisfactorily.

Nearly all of the counselees gave satisfactory answers for the questions that dealt with the effect of sickle cell trait on health status and life span. This suggests that most of our counselees did understand that sickle cell trait is not a disease.

While counselees failed to meet our objective of 80% satisfactory answers in five of the subject areas, results never fell far from our objective. These results include those for two subjects, that is, incidence and risk, which require an understanding of probability, a concept that has been reported to be difficult for counselees to grasp [1–3]. These results are in sharp contrast to the only reports in the literature on the success in transmitting information about sickle cell disease and sickle cell trait.

The National Research Council Committee for the Study of Inborn Errors of Metabolism [3] concluded on the basis of their examination of sickle cell trait counseling programs that "a significant number of people fail to remember what they have been told." The committee also reported that "it is difficult to teach some carriers that they do not have a disease." No data (or references to data) are provided to indicate the basis for these conclusions.

Hampton et al. [4], in a study confined to a comparison of misconceptions about the significance of having sickle cell trait between counseled parents of children with sickle cell trait and noncounseled parents of children without the trait, obtained mixed results, with the counseled group having fewer persons with misconceptions about sickle cell trait in some, but not all, areas studied.

Novick et al. [5] assessed the success of counseling in terms of the questions that counselees asked after their counseling sessions. They reported that "many of these questions, coming at the close of the counseling session, indicated little understanding of the benign nature of trait and continued confusion of trait with disease."

Why did we have greater success in our program than achieved in the reported studies? Our data on the relationship between counselee and counselor performances indicate that poor counselee performance can at least partially be explained by counselor performance and curriculum content. We found that overall the counselors met our objectives (satisfactory performance in 90% of the sessions) in eight of the 10 areas; the counselees met our objectives (80% satisfactory answers) in five areas. In four of the five areas in which our objectives for counselees' performance were not met (risk of sickle cell anemia, incidence of it, variability in occurrence of symptoms, and reasons for decisions), our objectives for counselors were achieved, suggesting that counselee failure to learn the material presented in these areas may have been due to curricular content. But in one of these subject areas, the life span of persons with sickle cell anemia, both counselors and counselees performed at an unsatisfactory level, suggesting that the lower than desired counselee performance may have resulted from a poor presentation of the material rather than from an inability to learn the material as it was presented. Also, it is important to note that counselees' performance in this subject varied significantly for different counselors, and that this relationship between counselor and counselee performance disappeared when the analysis was done for those situations in which counselors performed satisfactorily. This suggests that the overall unacceptable counselee performance in this area may have resulted from poor counseling by individual counselors.

Our data also suggest that there are other aspects of the counselor-counselee relationship besides the curricular components that can affect the counseling process. Considering only those encounters in which a subject had been adequately covered by the counselors according to our criteria, counselee performance differed significantly among counselors for three subjects: genetics, risk, and options. Additional work needs to be done to ascertain why these differences occur.

In summary, our analysis suggests that the failure of counselees to perform satisfactorily is sometimes related to poor counselor performance and that other counselor-counselee factors may also be operating in such a way that counselee performance is affected. We believe that an evaluation of the counseling process needs to be a part of the evaluation of all genetic counseling programs, because if it is found that counseled persons had insufficient or inaccurate information, had become fearful or apprehensive after counseling, or had made decisions that were not likely to be in their best interest, these results could imply or be interpreted as limitations in the ability of the counselees to learn, adjust, or make appropriate judgments. Furthermore, testing and counseling programs might be discontinued on the grounds that they are not likely to overcome such basic defects. These responses would be inappropriate if the real reason for the poor results is the failure of program curricula or individual instructors to cover completely and accu-

rately the material that the counselee is expected to learn. At least one sickle cell screening program has been discontinued because of counselee misconceptions after counseling, yet there was no assessment of the aforementioned factors [4].

But it is not only to avoid unwise decisions that the counseling process should be studied. When counseling programs are shown to be effective, the details of the counseling process should be studied and made available so that other programmers can attempt to replicate favorable results. To date, developers of genetic counseling programs have not had available evaluated models of genetic counseling protocols that provide information about the subjects covered, the instructional methods used, and the quality of the counselors' performances in successful programs. In only one study are substantive data provided on any of these three critical features, that is, subjects covered [6].

Affective Responses

Several authors [7–11] have expressed concerns about the labeling effects that being identified as the carrier of a genetic disorder such as sickle cell anemia may produce and they see counseling as a possible way to minimize self-stigmatization upon diagnosis. In the only study of these factors as they relate to sickle cell conditions, Novick et al. [5] reported that 61% of the persons whom they studied reported anxiety upon the discovery of sickle cell trait either for themselves or for their child. They also showed an inverse relationship between knowledge and amount of anxiety. The authors did not investigate whether counseling reduced the level of anxiety.

We recognize that complete assessment of psychological status cannot be achieved by our technique of asking persons before and after counseling: "How do you feel about having sickle cell trait?" or "How do you feel about your child having sickle cell trait?" However, we do believe that counselees' answers reflect many of their feelings. Their answers as reported in the results suggest the following: First, counseling usually reduced anxiety and seldom created anxiety in those who were previously free of this type of feeling. Of the individuals who had expressed anxiety before being counseled, 71% no longer expressed these kinds of feelings when their counseling was completed, and only four individuals among the persons who had positive or acceptance feelings prior to counseling (6.3%) expressed anxiety when the session was complete. Second, relief from anxiety was not related to the overall knowledge level achieved during counseling. Third, the counselee's ability to answer questions satisfactorily does not appear to be affected by the psychological state at the beginning of the session.

The above findings were derived from the statistical analysis of the types of feelings expressed and the level of overall comprehension determined by the review of knowledge using the sickle cell dice. A study of the content of the responses to the questions suggests that knowledge of a specific subject had more influence on counselees feelings than overall knowledge. We speculate that the three major causes of anxiety or concern over having sickle cell trait are the effects that the trait may have or is believed to have on: (1) health status or life span, (2) marriage and reproduction, and (3) self-image. Further, we assume that if the

anxiety is related to concerns or misconception about life span and the counselee learns that sickle cell trait has no appreciable effects on these parameters it is highly likely that the anxiety would be relieved. If the anxiety is related to concerns or misconceptions over the extent to which the carrier is at risk of having a child with sickle cell trait, increasing the counselees' understanding of the precise degree or circumstances under which the carrier might have a child with sickle cell anemia could resolve anxiety in some, but in others it might persist because even the accurate risk is undesirable for them. Finally, if anxiety is related to the individual's distaste for having any imperfection whether or not there are consequences, then more or accurate knowledge will not be effective in relieving anxiety or concern.

An analysis of the comments supports our speculations. Many comments suggest that achieving a better understanding of the distinctions between sickle cell anemia and sickle cell trait helped relieve anxiety. One mother, for example, said before the session began, "It makes you worry. I have a cousin who has sickle cell and she is in and out of the hospital," but after her session was completed, she said, "I don't feel bad about it since I know more about it and I will explain it to her when she gets older. When she gets married she will decide." Another typical comment after a session was: "I feel a lot better; I thought I had the disease." As indicated above, practically all of the counselees at the end of the counseling session appeared to understand that sickle cell trait does not alter life span or overall health status.

While the data showed a large reduction in the number of persons who expressed anxiety, most anxieties that continued to be expressed after the counseling was completed dealt with marriage and reproduction issues. Two typical responses by persons who continued to feel anxiety were: "It's not a great feeling. It's just thinking of the possibilities; I'm not sure whether my wife has the trait or not," and "I feel terrible, because the chances are that she (the daughter) could run into somebody with the trait and I would have to tell her not to have any children."

Two clients at the end had unrelieved negative feelings that clearly implied that they felt that sickle cell trait was, in itself, a negative characteristic. One young man said after the counseling session, "I still don't like it. I understand I won't have any problems, but it's just the idea," and one mother commented, "It's just that every mother wants her child to be perfect."

Features of the Sickle Cell Counseling Program

The sickle cell trait counseling process that we have described in this paper had several key features. The reasons we adopted these features are worthy of comment.

First, the process is systematic, but not rigid. Because we believe that an unstructured format would allow too many variations in approach from session to session and counselor to counselor to permit consistently effective counseling or valid evaluation of results, counselors are required to cover the same basic points in a required order of steps. They are encouraged to individualize their approach and to do whatever is necessary to establish good rapport with a client between

steps, but they must always return to the prescribed format as they continue the counseling session. The strict adherence to this format has led to consistent achievement of objectives and has enabled the evaluation of the counseling process that we have described.

Second, the counseling format does not permit counselors to give advice to clients. While there may be times when it is appropriate for health professionals to offer advice, we believe that advice-giving is not appropriate unless a substantial personal relationship has been established and detailed information about the client is available. Since this is not possible in the short encounter of the counseling session, the overall goal of the program is informed decision-making and the curriculum attempts to provide the entire range of information necessary to achieve this goal. Sickle cell disease, for example, is not presented only in terms of its severe manifestations and undesirable psychosocial effects, but in terms of the entire spectrum of manifestations of the disease that can occur. The reasons why persons may decide to take the risk of having children with sickle cell anemia are given as well as the reasons why they may not. The possible alternatives with respect to marriage and reproduction available to a person with sickle cell trait are also presented in the session.

Third, because biological facts may be confusing and difficult for the lay person to comprehend, we have incorporated three features in the format to expedite learning. (1) The language used is simple and consistent with the vocabulary of a large majority of the counselees. (2) To avoid an overloading of details, which may cause individuals to miss key points, complicated explanations and exact scientific details are simplified or avoided. (3) Figurative illustrations are used for each concept since some of the complex and unfamiliar concepts are difficult for the lay person to understand with only verbal explanations.

Fourth, the format repeats the same body of information at different times and allows for ongoing assessment of the counselees' comprehension of the material. We thought that learning would be facilitated by repeating information and that an important function of asking the clients questions is to identify misconceptions that they have retained so that these can be cleared up. Before counselees meet with their counselors, they watch a 15-min slide presentation that uses the same graphics and covers the same material that will later be covered in a more personal way by the counselor. At the beginning of the counseling session and again at the end, counselees are quizzed about their knowledge of sickle cell anemia and sickle cell trait. Questioning occurs as part of the interaction between the counselor and the counselee and attempts are made to avoid creating a testlike situation that might inhibit the client. The dice that are used help in this respect by making the question-answering appear to be a game. The questions require narrative answers that help the counselor to identify the nature of misconceptions that can then be dealt with by spending additional effort in the troublesome areas. As a final reinforcement, clients are given literature to take home that contains the same language and graphics that were used in the slide presentation and in the counseling session.

Fifth, the counseling sessions are taped because we believe that it is important to have detailed information regarding counselor and counselee performances in the

counseling session. Objections have sometimes been raised to the taping of genetic counseling sessions because it is believed that this represents an invasion of privacy, will not be acceptable to clients, or that counselees will not reveal or discuss many of their personal concerns if their remarks are recorded. We have not found these objections to be valid. At the beginning of each session, clients are asked for their permission to tape the sessions. Over 8,000 counseling sessions have been conducted in the past 7 years, and, without any coercion, over 98% of the clients have agreed to have their sessions taped. Since clients are not asked to explain their decisions, no data are available on the reasons for the refusals. Counseling proceeds for these persons with an untaped session.

Without a comparison group, it is impossible to ascertain whether personal concerns are less likely to be expressed in taped sessions. However, our random review of the tapes and discussions with counselors reveal that many counselees do discuss a wide range of personal concerns when sessions are taped.

Overall, our experiences have indicated that there are some very important advantages to taping sickle cell trait counseling sessions. Most importantly, taping permits an assessment of whether and how the counselors transmitted the desired information. Another advantage of taping is that tapes can be used for quality control. Weekly, in our program, a tape or two, selected at random from the total number done by each counselor during the previous week, is played and critiqued at a session attended by all counselors and the counseling supervisor. Counselors have found these sessions helpful in improving their individual performances, and the ongoing reviews are invaluable in maintaining overall quality of performance. Review of the tapes have also been valuable for improving the structure and content of the counseling format. Finally, tapes of sessions are very useful for training purposes. Trainees can review and learn from actual counseling sessions in a way that is not possible with artificially contrived situations.

Sixth, the format features lay counselors. It has been argued that only trained geneticists or physicians should do genetic counseling [8], but this was basically impossible in our program if we were to provide the level of service that was needed in our community. Generally, there is an inadequate number of health professionals to meet the need for sickle cell trait counseling and use of highly trained health professionals for this purpose can be an improper use of limited health care personnel. Our results show that properly trained and monitored lay persons can do an adequate job of sickle cell trait counseling with respect to our format. Lay persons may even be preferable to health professionals who, because they are accustomed to flexibility in the clinical setting, might be unwilling to adhere to a highly structured approach to counseling. The extent to which these conclusions are applicable to all forms of genetic counseling needs to be examined.

CONCLUSION

The data presented in this paper provide evidence that: (1) lay persons can understand essential sickle cell information, (2) trained lay persons using a structured format can transmit successfully sickle cell information, (3) only education and age, among counselee charascteristics studied, were related to successful learning, (4) the evaluation of information transfer in counseling programs cannot be

limited to counselees' comprehension but must also consider other variables such as counselor performance and curriculum content, (5) a reduction in negative feelings associated with a diagnosis of sickle cell trait is a short-term effect of counseling, and (6) audio-taping of counseling sessions is client acceptable and useful for evaluation, quality control, and counselor training.

REFERENCES

1. Garrison DW: Parents understanding of genetic risk data in genetic counseling. *J Am Med Assoc* 240:2631–2632, 1978
2. Leonard CO, Chase GA, Childs B: Genetic counseling: a consumer's view. *N Engl J Med* 287:433–439, 1972
3. National Research Council Committee for the Study of Inborn Errors of Metabolism: *Genetic Screening Programs, Principles and Research*. Washington, D.C., National Academy of Science, 1975, p. 176
4. Hampton ML, Anderson J, Lavisso BS, Bergman AB: Sickle cell "non-disease." *Am J Dis Child* 128:58–61, 1974
5. Novick L, Mustalish A, Eidsvold G: The New York City Department of Health: establishment of a sickle cell screening program. Presented at the 101st annual meeting of the American Public Health Association, San Francisco, November 4–8, 1973
6. Rowley PT, Fisher L, Lipkin JM: Screening and genetic counseling for β-thalassemia trait in a population unselected for interest: effects in knowledge and mood. *Am J Hum Genet* 31:718–730, 1979
7. Beutler E, Boggs D, Heller P, Miumauer A, Motulsky A, Sheehy T: Hazards of indiscriminate screening for sickling. *N Engl J Med* 285:1485, 1971
8. Fost N, Kaback M: Why do sickle screening in children? *Pediatrics* 51:742–745, 1973
9. Fraser FC: Genetic counseling. *Am J Hum Genet* 26:636–639, 1974
10. Kenen H, Schmidt RM: Stigmatization of carrier status: social implications of heterozygote genetic screening programs. *Am J Public Health* 68:1116–1120, 1978
11. Pearson H, O'Brien R: Sickle cell testing programs. *J Pediatr* 81:1201–1204, 1972