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AN EXPANDING ROLE OF THE SOCIAL WORKER IN THE CHANGING
HEALTH CARE SYSTEM

City University of New York

D.S.W. 1985

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AN EXPANDING ROLE OF THE SOCIAL WORKER
IN THE CHANGING HEALTH CARE SYSTEM

by

Marie Cafiero

A dissertation submitted to
the Graduate Faculty in Social Work
in partial fulfillment of the requirements
for the degree of
Doctor of Social Welfare
The City University of New York

1985

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This manuscript has been read and accepted for the Graduate Faculty in Social Work satisfaction of the dissertation requirement for the degree of Doctor of Social Welfare

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Ms. Lynn Perry.

M.C.

PREFACE

The idea basic to this program, multi-family experience sharing discussion groups, has been developing over the past fifteen years as I worked with clients who were coping with the problems related to long term illness.

In 1966, I was first introduced to the concept of Multi-Family Therapy in the field of mental health. As a practicing family therapist, I began to realize that this concept has potential for use in a wider range of coping with problems. When I worked in the areas of mental health, mental retardation and physical rehabilitation, there was evidence that many of the clients lacked the necessary self confidence to manage their medical regimen. The client's input revealed considerable dissonance between what they wanted' to do and what they were able to do.

The clients had searched out and accumulated knowledge about the disease process and recommended treatment approaches for medication, diet, exercise, and preventive measures. The difficulty seemed to arise in trying to integrate this knowledge into the activities of daily living. This process of integration required continuous adjustments in the lifestyle and the ability to make numerous decisions that were formerly the responsibility of the health professional. The support of the group in helping to choose from alternatives

available and then providing reinforcement when a choice was tried, appeared to aid the client in developing confidence in his/her ability to exercise some control over the situation.

In a few isolated instances, a group of clients and their families were formed to provide support as they coped with the problems of long term illness. These groups were without any formal structure or continuity, but they did appear to have some positive results.

Eight years ago I began to work with the American Diabetes Association, the American Association of Diabetes Educators, and the New York Affiliate of the American Diabetes Association as a professional volunteer. This included a variety of positions as committee member and chairperson at the local and national level and co-director of the American Diabetes Association's Post Graduate Seminar in 1979. I became aware of the growing problem of non-compliance in the area of diabetes from both the clients and the health professionals.

The program director at New York Diabetes Affiliate had occasionally referred several clients and their families to me for counselling because they were having difficulty trying to cope with their treatment regimens. The situation was discussed with the program director when it became evident that the multi-family counselling was proving effective in resolving many of the problems experienced by the clients.

We decided that a formal program should be developed. The idea for such a program was introduced through the organizational channels at the New York Diabetes Affiliate office and we were assured of support in the implementation of such a program. The study presented here is the result of all these experiences.

It is hoped that this endeavor will produce some measure of information that will inspire further hypothesis and research in this direction.

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SECTION 1

THE UNMET NEED

INTRODUCTION

This study is concerned with the health problem of the high degree of non-compliance to medical regimens, by clients who are living with a chronic illness.

Half of the American population have one or more chronic illnesses. This study will be addressed to those individuals in our society who are diagnosed as having the chronic disease of diabetes. This choice was determined because diabetes is viewed as a major health problem, since it is the third leading cause of death in the United States. The recent statistics printed by the American Diabetes Association reveal the disabling complications that can develop from this disease process (Fig. 1).

In the last four decades the morbidity rate for chronic illness increased from 30% to 80%. This would indicate the need to increase the "care" approach rather than just being concerned with the "cure" approach to medical intervention. Cure being related to acute illnesses which are short termed. The major decisions are usually made by the health professionals and changes in life style are of short duration. Care being related to chronic illnesses, with a lifetime duration and requiring continuous lifestyle adjustments for the client and the family.

Diabetes is the THIRD leading cause of death in the U.S.A.

Known incidence of Diabetes	6,000,000
Unknown and potential cases	6,000,000

1 out of 20 people will develop Diabetes

1 out of 4 families has a history of Diabetes

Diabetes is the leading cause of blindness...

1/2 of all heart attacks

1/4 of all strokes

2/3 of all gangrene

40,000 or 37% of diabetics die from their disease each year

463,000 die as a direct or contributory cause

300,000 people die from Cancer each year

265,000 people die from Heart Disease each year.

Diabetes affects 10 million Americans or 5% of the population

Diabetes is increasing at the rate of 6% each year

The economic loss from premature death and loss of productivity is estimated to be in excess of 5 billion dollars a year.

Source: Committee on Statistics of the American Diabetes Association
 Research Statistics, National Diabetes Data Group
 National Commission on Diabetes, N.I.H. 1980.

Figure 1. Statistics Related to Diabetes

In chronic illness there is often a need for the client or family to make decisions which were previously the responsibility of the health professionals. The high technological services of the acute care system do not meet the needs of the chronically ill. There is a need for the high cost and unavailable professional care, which places new emphasis on the critical role of lay resources, namely the client, his/her family, and/or significant others in the social context. These factors must be considered and addressed in the preparation of health education programs if they are to be effective.

A seminar held at Columbia University in January 1981 on Newer Trends in Health Education," had as a guest speaker Dr. Lawrence Green, Director of Information, Department of Health and Human services. He reported the need for a shift in the paradigm of health education.¹

PARADIGM OF HEALTH EDUCATION

<u>Previous Focus</u>	<u>Emerging Focus</u>
Process	Outcome
Diagnosis	Progress
Biomedical	Biosocial
Acute	Chronic
Cure	Care
Expert	Individual

Dr. Green stated that health strategies used must focus on activities at the micro-social level, such as the family and the community. The emphasis is to be on prevention, health promotion, social diagnosis and involves some concern for risk factors.² In addition, Dr. Green expressed the belief that clients and their families must be able to anticipate the development of problems and take action or seek help in preventing their occurrence. In his opinion, the health education programs in Europe are more progressive than ours, because they place greater emphasis on social forces and the decision making skills of the individual.³

The consumer movement and the high cost of health care have been strong influences in placing health education in a position of high priority. The traditional focus on health education has been on cognitive knowledge, but recent strategies of guidance, counselling and support now focus on feelings and attitude. This focus will broaden the therapeutic activity from just diagnosis, prescription and physical treatment, to include the many problematic issues of communication, motivation and social circumstances that also play a part in the state of the client's health, and in the meaning that the illness has for the individual and his/her family.⁴

It is becoming increasingly evident that many of the health problems are related to individual behavior and the greatest potential for improving health lies in what we do

and don't do for ourselves. It appears that the goal of improving the health of the American people will not depend just on increasing the numbers of doctors and hospital beds, but rather in what people can be taught and motivated to do for themselves, in influencing their personal behavior and attitude.⁵

This added dimension in the health care scene will require skills that are therapeutic in preventing the occurrences of unnecessary illness and complications, in order to limit the disabling factors of chronic illness. In this changing order, health maintenance to promote social functioning is destined to have equal importance with the expertise now concerned solely with the treatment of the disease process.⁶ "In the final analysis, each individual bears the major responsibility for his own health. Unfortunately, too many of us fail to meet this responsibility."⁷

Extent of the Need

The recognition of a need for change has initiated investigation and research from a variety of sources. The following information provides a sample of the efforts being developed to resolve or improve the problem on non-compliance. The health care professionals today recognize non-compliance with therapeutic regimens as one of their most serious health problems.

In 1973, the Health Education Monograph #33 presented

"New Definitions," prepared by the Joint Committee on Health Education terminology. The definition of health education reads:

Health education is a process with intellectual, psychological, and social dimensions, relating to activities which increase the abilities of people to make informed decisions affecting their personal, family and community well-being. This process, based on scientific principles, facilitates learning and behavior changes in both health personnel and consumer.⁸

In 1977, the Health Systems Agency of New York stated in their Proposed Health Systems Plan that:

A greater investment must be made in health communication and education to sensitize individuals and society to the fact that their health is well within their means to govern.⁹

The plan emphasizes that an individual's choices and responsibilities extend beyond the recognition of illness. People must be taught how they can effect their health in positive ways. Information of this nature should include means that will aid the individual's decision making skills in the direction of improved health.¹⁰

A review of 100 educational programs was done by an Advisory Committee, whose members were appointed by the Health Education section of the American Public Health Association and the Society for Public Health Education. The report submitted indicated that there were gross deficiencies in the following areas:

1. The need for a holistic approach to the application of the educational process in the health field.

2. The need for a broad spectrum of skills and knowledge from all disciplines in the health care system for program planning and also for implementation.
3. The need for more extensive documentation and reporting of when, where, how and why the educational process was applied and what were the endeavors accomplished.
4. There is a need to view the goal of health education to be not just telling people what to do, but for helping them to become people who will know what to do.
5. There is a great need for more consumer participation, respect for their contributions and the recognition that individuals have a right to determine their destiny.
6. There is a need for mechanism outside as well as inside the health care system for education, specially when one is planning health care rather than just medical care. The focus of the educational program must include staying well and developing healthy habits.
7. There is a need for educational efforts to be based on the promotion of a sense of individual identity, dignity and responsibility.

8. There is a need to realize that behavior changes must be selfimposed and integrated into the individual's life pattern.¹¹

The concern for health education is also reflected in the establishment of the National Center for Health Education, and the National Disease Control and Consumer Act of 1975 and Public Law 93-641 the National Health Planning and Resources Act of 1974. All of these have health education as one of their major priorities.

The National Diabetes Advisory Board is composed of consumers and professionals and funded on a yearly basis by Congress. Their charge is to review data collected from other involved groups and to make recommendations for improved services for persons with diabetes. Yearly reports are required to be submitted to the National Institute of Health. In 1980, their report stated that, if the emotional aspects of diabetes are not adequately managed, it is impossible to manage the medical side of the disease, despite the best medical skills and knowledge applied.¹²

The American Diabetes Association is a national voluntary organization with local affiliate branches. They are dedicated to public, consumer and professional education and research. Their seminars and journals keep the consumer and professional updated on new advances in the area of diabetes.

The American Association of Diabetes Educators is an independent, interdisciplinary, and non-profit organization dedicated to improve the education of the consumer by

providing educational growth for the health professional, through use of seminars and the publication of their journal.

The Diabetes Research and Training Centers were established in 1977 by the National Institute of Arthritis, Diabetes, Digestive and Kidney Diseases. The United States is divided into eight regions and each has a center that is affiliated with a university medical center. They are involved with research and professional education to improve the delivery of care to clients with diabetes. The center at Washington University in St. Louis is currently involved in research which is focusing on the family milieu and the impact of cooperation and conflict on the rate of compliance. The target population are adolescents and the data to date indicates that family support has a positive influence on the rate of compliance. The recommendation was that more extensive investigation is needed, to develop methods to assist families in learning skills to provide support that is required. Another study is concerned with the use of groups as a therapeutic context for adolescents with diabetes. In addition, a program was developed to train aides and volunteers to go out into the community and provide basic social support and education to the elderly, home bound person with diabetes.¹³

The Ohio Department of Health, Division of Chronic Diseases, made a study of diabetes educators and the data indicated that the major part of the client's education was

performed by nurses and dieticians. They, in turn, received most of their preparation in this area from on-the-job training and workshops provided by their particular profession (70% to 80%). Only a small percentage (5% to 8%) were attending workshops or special programs presented by the Diabetes Research and Training Centers.¹⁴

The Center at Washington University in St. Louis views the role of the social worker as a very important aspect of team approach to diabetes management. They estimated that social workers seldom received formal training in diabetes management and have developed a course for social workers in order to correct this oversight. This program has three goals:

1. To increase the knowledge of diabetes and new treatment approaches.
2. Identify the interactive aspects of the physical and psychological effects of diabetes--such as impact on the family.
3. Define the role of the social worker by identifying specific tasks for hospital-based programs and community follow-up and support groups.¹⁵

It is believed that the basic professional education of the social worker focuses on skills for education, counseling, and working with groups. These areas of training are important for working with clients with chronic conditions, which involve in addition to physical changes an impact on

the client's concept of self and relationships in the social environment¹⁶ (Table 1).

The recent shift in self-management has placed additional stress on the client and the family, because it involves increased responsibility in the management of the diabetes and in the demand for daily decision making. Group approaches have been found successful in providing support and counselling to clients and their families, in the management of the treatment regimens.¹⁷

In the professional literature, social work is defined as a professionally guided system that engages people and social units in change activities for the purpose of improving the quality of life. In 1977, Manahan and Pincus stated as one of the objectives of social work practice "helping people develop their problem solving and coping resources."¹⁸

In the Hollis Taylor report in 1951, social work practice is defined as a liaison or integrating function for which no other provision is made in contemporary society.¹⁹ Gordon suggests that medical Social Work is clearly a candidate for consideration as a specialization, but it must expand its concern beyond the hospital to the total environment with which the client must deal.²⁰

We must realize that persons with diabetes may not respond with any of the therapeutic or educational compliance programs, if there is no consideration of their own psychological perspective. It is important to have a commitment to provide ongoing counselling and support to families in which diabetes is present, but how the physician in the traditional

TABLE 1
PSYCHO-SOCIAL ASPECTS OF CHRONIC ILLNESS

Medical Problems	Psychological Factors	Social Problems
Accepting the diagnosis	Fear	Public lack of knowledge, suspicions of any differences in people
Learning the treatment approach	Tension Stress Anxiety	
Developing continuous relationships with health professionals	Alienation Depression Negative self image	Problems on the job and in school --taking medicines or reactions
Decision making re diet, medication and exercise		Stigmatization or discrimination (real or imagined) causing stress and impaired social relationships
Learning tasks and skills needed for proper care		The need to adjust to limitations and changes in life style may cause family stress and tension. This may result in an environment that is destructive rather than constructive for the support needed for following the treatment regimens.
Continuous cost of care		
Length of illness-Life		
Change in degree of dependence and independence		
Uncertainty and fear of possible cumulative effects		

Source: Health Education Monograph, Supplement #1, Vol. 5, 1977, p. 49

setting can accomplish this is unclear. An obvious answer would be to use other health professionals, such as the Social Worker.²¹

Summary

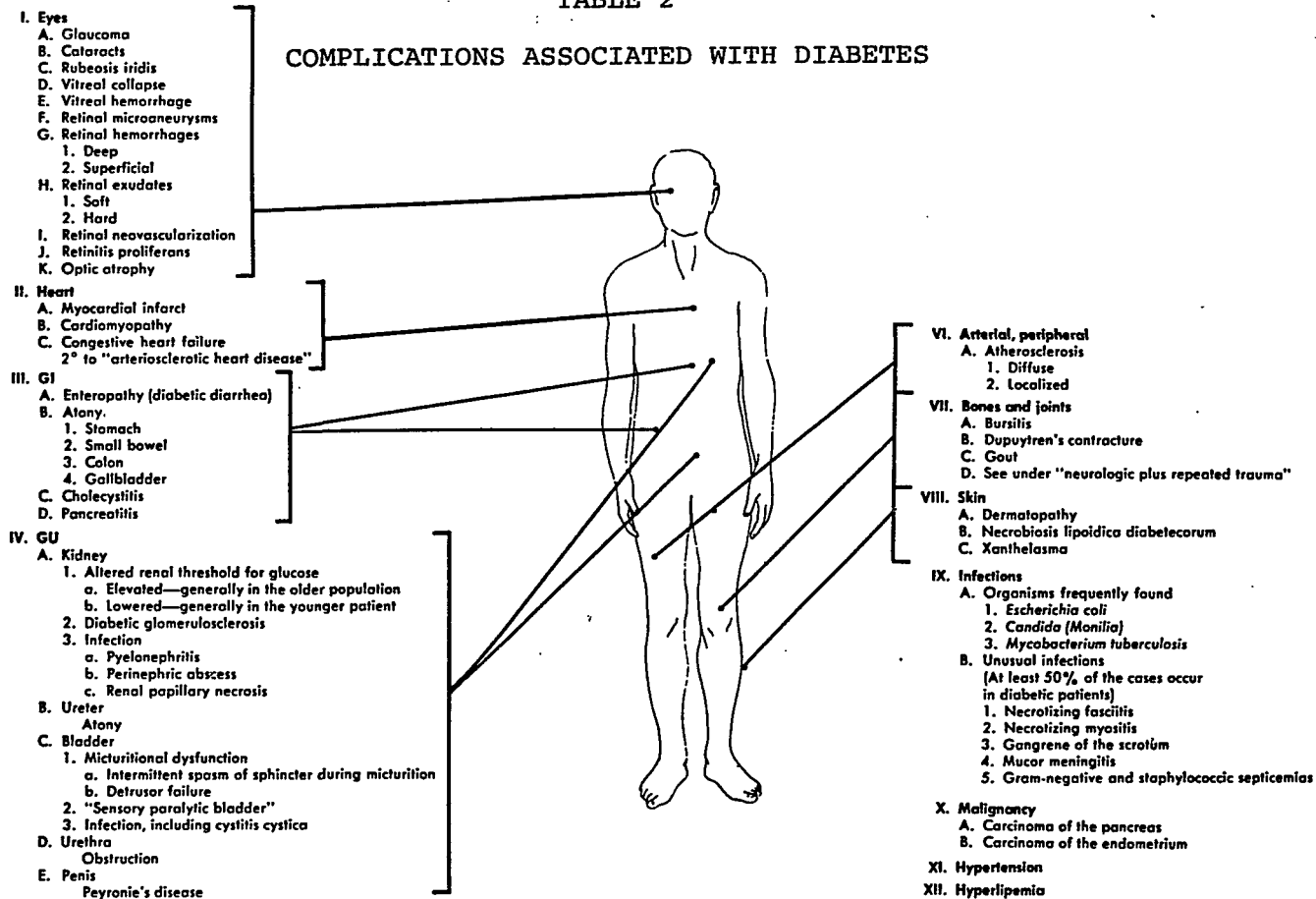
The leading causes of death in the United States are heart disease, cancer, diabetes, stroke and accidents. The reports from health professionals indicate that except for the elderly, many of these deaths could have been delayed or prevented.

In spite of the vast number of health education programs developing for clients, there continues to be a high rate of non-compliance to medical regimens, some figures quoted as high as 50% to 70%. This situation created a large high risk population for the development of complications. Some research findings suggest a correlation between lack of control (non-compliance) and the complications, and support the belief that control (compliance) can limit, prevent, and in some cases even reverse the presence of complications. Diabetes is a chronic disease that may lead to many disabling complications (Table 2). It is the responsibility of the health professionals to be concerned with the development of educational programs that will lead to improved compliance to treatment regimens.

Health education has relied heavily upon behavioral and other social sciences, related professional fields, such as

TABLE 2

COMPLICATIONS ASSOCIATED WITH DIABETES



Some complications associated with diabetes mellitus. (From Dobson, H. L.: Diagnostic dilemmas. *In* The older diabetic patient, an Upjohn monograph, Jan. 1973, Kalamazoo, Mich., The Upjohn Co., pp. 40-41.)

social work and adult education for its theories. While this eclecticism has guaranteed a broad base, there has been movement toward integration, refinement and adaptation of these imported theories into a conceptual scheme unique to health education.

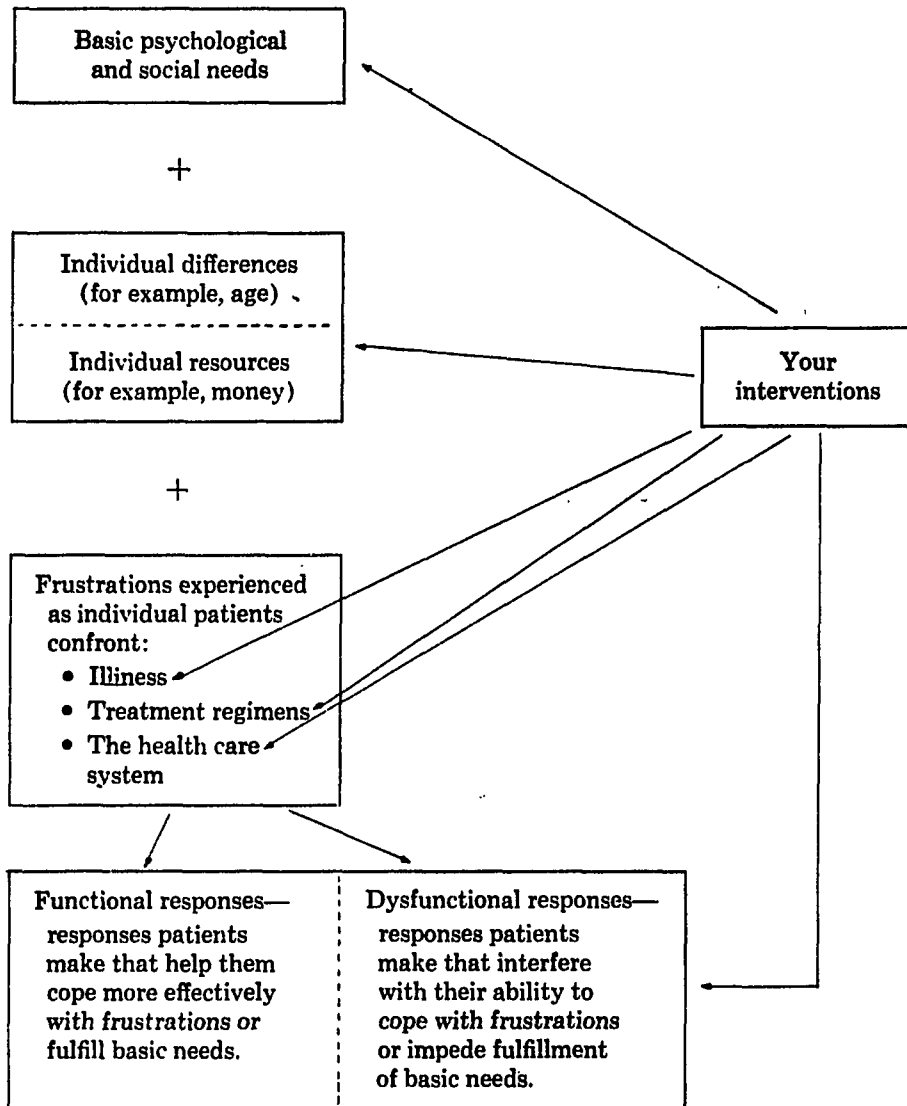
The direction and development of patient/client health education are just beginning. . Since there is no coordinated, comprehensive development of health education, it is likely that the development done by an individual profession can affect both the overall course of health education and the place of the profession in the client education activity.

Effective health care requires a broader perspective than are circumscribed by the emergency room, the outpatient department, and/or the hospital. There certainly seems a need for a broader definition of therapeutic activity by treatment personnel. Such a definition would not be confined to the routine neatly bounded tasks of diagnosis, prescription and physical treatment, but would seek to embrace in addition the many problematic issues of communication, motivation, and social circumstances that also play a part in the state of the client's health, and in the meaning the illness has for the client and his/her family.²²

The various points of intervention that the social worker as a health educator may have an opportunity to provide support and counselling, are illustrated in Table 3. This indicates a broader perspective of the educational scene and has potential for support in the problems that the client is confronting at the time of contact. Once the immediate problem is resolved, there is a relationship already established which could lead to further health counselling.

TABLE 3

FACTORS CONTRIBUTING TO PATIENTS' COPING RESPONSES
AND POINTS AT WHICH THE HEALTH CARE PROFESSIONAL
MAY INTERVENE



Source: Staff Manual for Teaching Patients About Diabetes.
American Hospital Assoc. Chicago, IL, 1979, p. 62.

Notes Section 1

¹L. Green, "Newer Trends in Health Education," Seminar, Columbia University Health Promotion Center, January 26, 1981.

²Ibid.

³L. Green, Health Education Planning (Palo Alto, CA: Mayfield Press, 1980), pp. 2-8.

⁴E. Warren-Boulton, "Diabetes Management--The Impact of Social Context," (Unpublished paper, Washington University Diabetes Research and Training Center, St. Louis, MO, December 1980).

⁵H. Somers, "Health and Public Policy," Inquiry, (June, 1975), 12:95.

⁶A. Rosen, "Patient Education Programs," Health and Social Work, 3, 2 (May 1978):175-178.

⁷Report of the President's Committee on Health Education, Washington, DC, 1973.

⁸Joint Commission on Health Education Terminology, "New Definitions," Health Education Monograph #33 (Washington, DC: U.S. Government Printing Office (hereinafter called USGPO), 1973).

⁹Health Systems Agency of New York City, Proposed Health System Plans (August 1977), pp. 305-06.

¹⁰Ibid., p. 310.

¹¹American Public Health Association, Special Report, Making Health Education Work (Washington, DC, 1976), p. 108.

¹²Third Annual Report of the National Diabetes Advisory Board, 1980.

¹³Warren-Boulton, p. 64.

¹⁴A. Hartman, "The Family: A Central Focus for Practice," Social Work, 26 (1981):7-13.

¹⁵S. Hopper and W. Auslander, "Training Social Workers in Diabetes," Diabetes Educator (Summer 1983), p. 24.

¹⁶Ibid., p. 23.

¹⁷L. Levin, A. Katz, and E. Holst, Self Care: Lay Initiative in Health (New York: Prodist, 1979).

¹⁸A. Minihan, A. Pincus, "Conceptual Framework for Social Work Practice," Social Work (September 1977):347-52.

¹⁹Hollis Taylor Report 1951; Statement from the U.N. Report, "Training for Social Work" (New York: United Nations, February 1950), pp. 18-20.

²⁰W. Gordon: "A Critique of the Working Definition," Social Work (October 1962):3-13.

²¹W. Wishner, M. O'Brien, "Diabetes and the Family," Medical Clinics of North America, 62 (1976):839-56.

²²F. Davis, Passage Through Crisis (Indianapolis, IN: Bobbs-Merrill, 1963), p. 171.

Section 2

THE MODEL

Selecting a Model

The need to develop more effective health education programs has been recognized. Now, our attention is focused on investigating possible approaches that might help in resolving the problem.

In problem solving, requiring decisions and choices, one can produce a shift in the preference selected, if the problem is framed in a different way. The frame a decision maker adopts is controlled in part by the formulation of the problem.

The objective is not to obtain maximum control of behavior, but rather to obtain necessary control, while preserving enough variability to permit change. The focus is on developing positive recognition that the invention of new alternatives is more important than the suppression of those that might be detrimental.

After reviewing the health education literature, it was determined that Dr. Green's "Precede" framework could offer a different way to frame the problem. Dr. Green views health education as any combination of learning experiences designed to facilitate voluntary adaptations of behavior conducive to health.¹

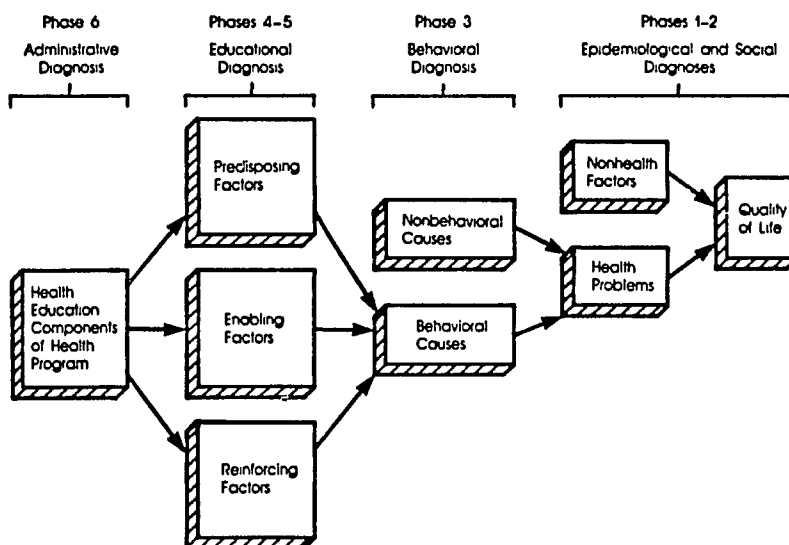
The initial attention in the Precede framework is directed to the outcome, rather than the input of the educational program. This approach is based on the belief that

factors important to the outcome must be diagnosed before any intervention is designed.² By beginning with the outcome, one must think deductively and determine what must precede that outcome (Table 4).

There are basically seven phases to this procedure:

- Phase 1: The quality of life is concerned with the social problems that the target population might experience. In this study, poor control of diabetes could lead to absenteeism, unemployment and welfare. A result of these conditions could develop feelings of hostility, alienation and discrimination.
- Phase 2: The health problems that could contribute to these problems are the incidence, intensity and duration of the morbidity rates and the degree of disability.³ Premature mortality could develop social problems for the remaining members of the family (Table 5).
- Phase 3: The identifying of the specific health related behaviors that appear to be linked to the problem, is a major factor for designing the planned intervention. In this study our concern is with self care, preventive actions and compliance. The dimensions that we will focus on are frequency and persistence.
- Phase 4: The research on health behavior indicates that three groups of factors have potential for affecting

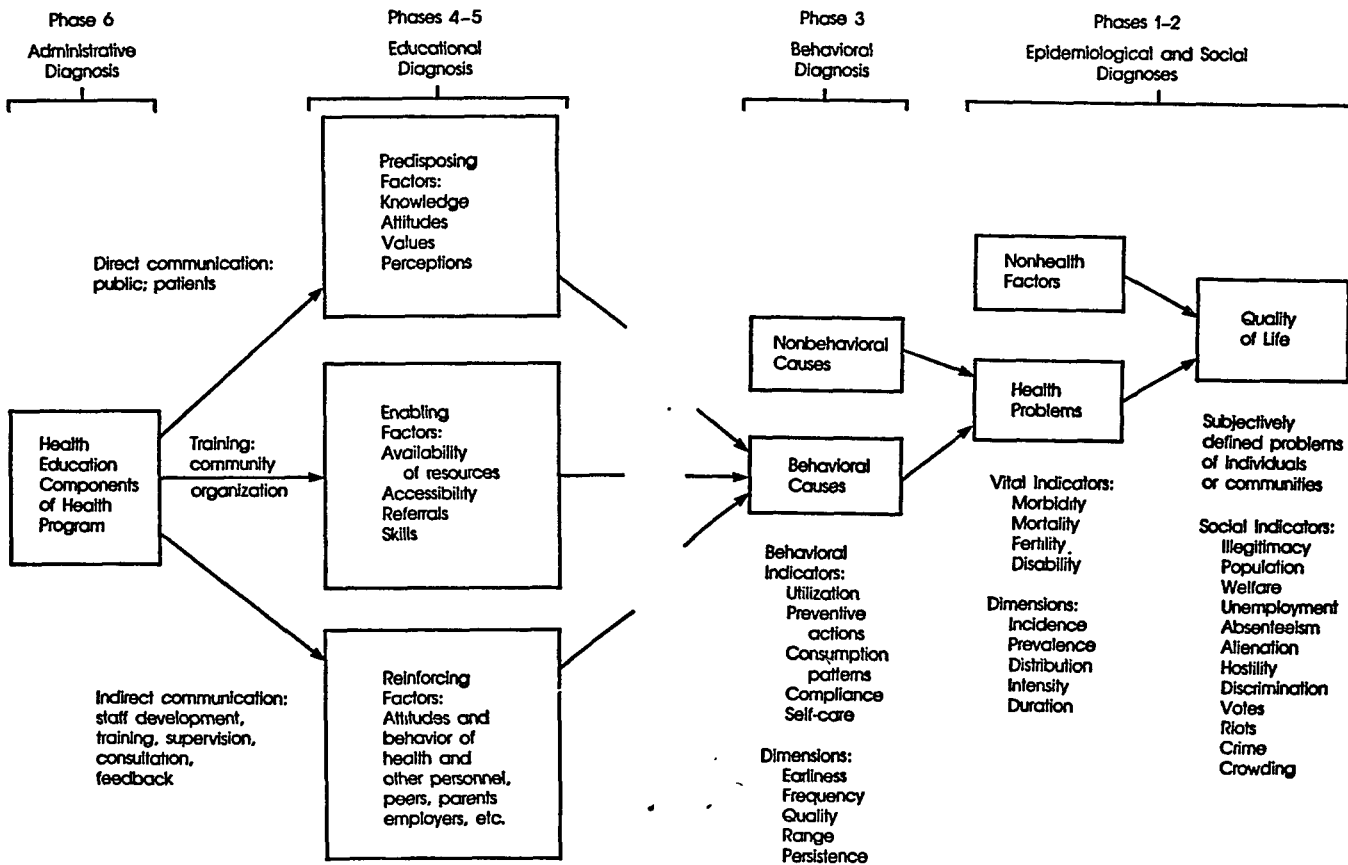
TABLE 4
THE PRECEDE FRAMEWORK FOR HEALTH EDUCATION



A health education program is seen as an intervention, the purpose of which is to enhance the quality of life through change or development of health related behavior. Precede directs the initial attention to outcomes rather than to inputs. The factors important to an outcome must be diagnosed before the intervention is designed.

Source: L.Green. Health Education Planning, Palo Alto, CA: Mayfield, 1980, p. 12.

TABLE 5
THE PRECEDE FRAMEWORK²



health behavior, predisposing, enabling and reinforcing factors (Table 6).

Phase 5: This phase consists of selecting the factors which are the focus of the intervention.

Phase 6: Development and implementation of a program
Goals
Strategies
Assessment tools
Data collection process.

Phase 7: Evaluation is an integral and continuous part of the entire model (Table 7). The criteria for evaluation develop out of the framework during the diagnostic procedure. The stating of program and behavioral objectives set standards of acceptability which are defined early in the process.

The design of a program, using this model, would be identifying the goal in phase 3. In the area of chronic illness, the goal might be in compliance with treatment approach. The strategy supported by this study would be multi-family experience sharing group counselling. This approach would have as the:

Dependent variable--the behavior that follows exposure to the program.

Independent variable--the exposure to the group counselling program.

Intermediate variable--factors that have potential for

affecting health behavior, predisposing, enabling and reinforcing factors (Table 6).

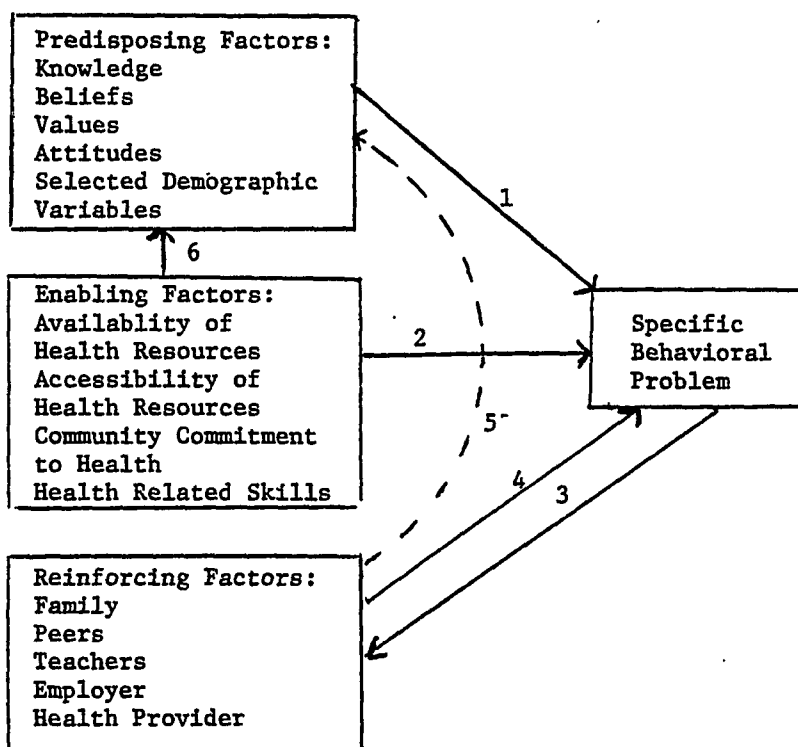
The development of assessment tools, in the form of either a questionnaire guideline or an assessment task checkoff list, or a combination of both, so that the health professional can determine:

1. What the client needs to know about the illness.
2. Whether the client believes that the illness pattern can be altered--that he/she can make a difference.
3. What the client's daily routine is, so needed changes can be planned.
4. Whether the client intends to follow a treatment plan or is denying the illness and the need for care.
5. Does the client expect and accept problem symptoms or does he/she recognize and believe that a potential for prevention exists?
6. Whether past psychological and social adjustment indicates some degree of coping with life style changes existing in the family.
7. Whether the client and the family are aware of the available health resources and what efforts have been taken to make use of them.

Tables 8, 9, and 10 illustrate the kind of assessment tools that might be utilized to determine the needs of the client.

TABLE 6
ASSESSING CAUSES OF HEALTH BEHAVIOR³

Three Categories of Factors contributing to Health Behavior:



The solid lines imply contributing influence and the dotted lines imply secondary effects. Numerals indicate the approximate order in which the actions usually occur.

TABLE 7

THREE LEVELS OF EVALUATION TO PRECEDE

Health Education Program	Predisposing Enabling Reinforcing Factors	Behavior	Health	Social Benefit
Process Evaluation	Impact Evaluation		Outcome Evaluation	

1. In process evaluation, the object of interest is professional practice
2. Impact evaluation focuses on the immediate impact that the program has on some aspect of it--Knowledge, Attitudes, and Behavior.
3. Outcome evaluation focuses on morbidity and mortality. Have the incidence and prevalence of the condition been affected by the program?

Source: L.Green, Health Education Planning, Palo Alto, CA: Mayfield Publication Co., 1980, p. 134.

Table 8 provides material for the creation of criteria related to knowledge of the disease process and the tasks and skills associated with the daily treatment approaches. This information can be utilized to develop a criteria check list specific to the individual study.

Tables 9 and 10 are resources that can be utilized to learn about the feelings, attitudes and beliefs of the participants and the effects of the disease process on the individual and his/her family or significant others. These questions identify the areas that may be acting as a barrier to the adherence to prescribed regimens. In addition, these three tables act as guidelines which will provide necessary information to establish objectives for the participants in a given study.^{5,6}

Contents of Sessions

Each session has three elements: a topic pre-planned jointly at the previous meeting, the problems presented at the beginning of the session and the attitudes presented by the client at the session. These might all be related and approached together, or a selection made because of the intensity of the presentation. The educational strategy is to use the session as a vehicle to explore the problems in relation to:

1. Appropriate use of health resources
2. Compliance/health partnership

TABLE 8
GUIDE FOR ASSESSMENT CHECKOFF LIST⁴

General Knowledge

- What are the characteristics of diabetes?
- What are the symptoms of diabetes?
- How does the pancreas work?
- How does insulin work?
- What are normal blood glucose levels?
- What do you do to maintain and control your glucose levels?
- What are the risk factors for diabetes?
- What are your particular risk factors?

Insulin

- What is the name and type of your insulin(s)?
- What is your insulin dose?
- When do you take your insulin?
- Do you take it at the same time every day? If not, why not?
- When does the insulin you use begin to act?
- When does its peak action occur?
- How long is its action?
- Where do you inject your insulin? (Have patient point to the spot.)
- How do you inject it? (Have patient demonstrate technique.)
- Have you noticed any particular reactions to insulin, such as itching, hives, or bruising?
- Do you have any difficulty using the syringe, such as seeing the numbers, getting air bubbles, etc.?
- Do you ever change or skip a dose? If so, why?

Oral Hypoglycemics

- What are the name and dose of your medication?
- Do you ever change or skip a dose? If so, why?
- How often do you measure your levels?

Urine Testing and Home Blood Glucose Monitoring

- What testing procedure(s) do you use to measure your glucose levels?
- What products do you use?
- Do you record the results?
- How do you use the results you obtain from the tests to manage your diabetes?
- How do you perform these tests? (Have patient demonstrate.)

Control Difficulties

- What are the symptoms of hypoglycemia and what causes it?
- What are the symptoms of hyperglycemia and what causes it?

- Describe the onsets of a hypoglycemic and a hyperglycemic reaction.
- What are the treatments for hypoglycemia and hyperglycemia?
- What can you do to prevent these reactions?
- Have you ever had hypoglycemic or hyperglycemic reactions? If so, what were the circumstances?
- Have you ever had emergency-room treatment for either of these reactions?
- Do you carry diabetes identification. What kind?
- Do you carry a fast-acting carbohydrate with you at all times?

For insulin-dependent patients:

- Do you know how to use glucagon?
- Does a member of your family also know?

Complications

- How often do you visit an ophthalmologist?
- How often do you go to your dentist?
- How often do you visit your podiatrist?
- Why is good foot care important?
- What are the essentials of good foot care?
- What do you do for foot care?
- Have you had any visual difficulties?
- Have you had any sensations of numbness or tingling?
- Have you had any degree of sexual impotence?

Life-style

- Do you exercise regularly?
- What kind of work schedule do you have?
- Are you able to take regular meal breaks?
- Are you married, single, or divorced?
- Do you live alone?
- Is there any situation in your life now that is causing you stress?
- Do you smoke or use alcohol? If so, to what extent?

Emotional Factors

- Where and how did you acquire your knowledge of diabetes?
- Are there people you can talk to about your diabetes, or do you keep it to yourself?
- Are there any particular problems you have in dealing with diabetes?
- Do you feel capable of managing your illness with professional help?
- How do you feel about having diabetes?
- What most concerns you about having diabetes?

TABLE 9

ASSESSMENT/INTERVENTION TOOL
IDENTIFYING THE PROBLEM

Identified by and based on the family's or significant others' perception of the client's circumstances.

1. What do you consider to be the major problem, stress area or area of concern? (Identify problem areas)
2. How do present circumstances seem to differ from the client's usual pattern of living?(Identify life style patterns).
3. Has the client ever experienced a similar situation? If so, how would you evaluate what the client did? How successful do you think it was? (Identify past coping patterns).
4. What do you anticipate for the future as a consequence of the client's present situation? (Identify perceptual factors, i.e. reality versus distortion--exceptions, present and possible future coping patterns)
5. What can the client do to help him/her self? (identify perceptual factors, i.e. reality versus distortions, expectations, present and future coping patterns)
6. What do you think the client expects from caregivers, family, friends, or other resources? (Identify perceptual factors, i.e. reality versus distortions, exceptions, present and future coping patterns).

By comparing responses of the client with the significant others, it is possible to identify some of the conflicts which exist in the social context of the client and may be contributing to areas of non-compliance.

Source: Neuman, N., Young, R. A model for teaching total approach to patient problems. Nurs.Res. 21, 3:264, May-June, 1972.

TABLE 10

ASSESSMENT/INTERVENTION TOOL
IDENTIFYING THE PROBLEM

Identified by and based on the client's perception of the circumstances.

1. What do you consider your major problem, stress area or area of concern? (Identify problem area)
2. How do the present circumstances differ from your usual pattern of living? (Identify life style patterns)
3. Have you ever experienced a similar problem? If so, what was the problem and how did you handle it? Were you successful? (Identify past coping patterns)
4. What do you anticipate for yourself in the future as a consequence of your present situation? (Identify perceptual factor, i.e. reality versus distortions, expectations, present and possible future coping patterns)
5. What are you doing and what can you do to help yourself? (Identify perceptual factors, i.e. reality vs. distortions, expectations, present and possible future coping patterns)
6. What do you expect caregivers, family, friends, or others to do for you? (Identify perceptual factors, i.e. reality vs. distortions--expectations, present and possible future coping patterns)

It is believed that this tool provides a frame of reference which is needed to establish goals that are relevant to the circumstances, from the client's perceptions. In addition, it supports the client's right to determine his own destiny and to assume a responsible and knowledgeable role in implementing his/her own care.

Source: Neuman, B.; Young, R. "A model for teaching total approach to patient problems." Nurs. Res. 21:3, May-June, 1972.

3. Observation/treatment methods/basic knowledge
4. Health promotion/self regulation
5. Increased individual responsibility/improved decision making.

The coping skills that are to be developed in the process of these sessions are:

1. Identify the problem
2. Identify alternate choices by group decision
3. Process of the selection of a plan of action/group participation
4. Process of trial/in between sessions
5. Process of feedback/support and reinforcement given by group even if trial is not effective
6. Evaluate next step/continue same plan with more time and support or the selection of another alternative for trial.

In Appendix B, Tables 17-18, there are guides to assist in the stating of learning objectives and some techniques to reach desired outcomes. These were included because one of the methods that recurs is participation of clients and group discussion. In addition, there is an operational model for decision making, which identifies some factors which might support or block the desired behavior. These guides can be of assistance to leaders in the development of new programs.^{7,8,9}

In the process of designing a health education program,

one must consider the three major stages that should influence the contents of the material presented. The first stage occurs when the diagnosis is first made. The client needs information about the diagnosis and enough information and skills for immediate or survival management. The next stage is after the client has accepted the diagnosis and is ready to increase his/her management skills and understanding of the disease process. The third stage is one of long term goals to update skills and understanding and to involve the client in a process of continuing education (see Appendix B).¹⁰

Theoretical Concepts

The theoretical concepts for this study have been drawn from five major sources. Lewin's work on the role of group process in behavior change, Knowles' theory of adult education, Laqueur's theory of multi-family therapy, Glasser's formulation of reality therapy and the system's view of man. This selection was considered appropriate because they are all concerned with the present, responsibility for self, decision making, and the participation of the client. In addition, there is an emphasis on the importance of group support and reinforcement for the client.

The family is seen as a system, the elements of which are interdependent. It is evident that what happens to one component has consequences for other elements in the system.

Systems, like families, tend toward maintaining equilibrium. Resistance to change, in this view, stems not only from the fact that the individual has social support to continue his/her existing practices, but also that these practices are aspects of the process to maintain the equilibrium of the system, of which the individual is a part.^{11,12}

There are several key factors in Lewin's analysis of how people change their attitude and habits, that are related to this study:

1. Individual attitudes and habits do not exist in isolation, but are related to the attitudes and habits of significant others or groups to which the individual is affiliated.
2. Since behaviors are "frozen" within supportive group settings, to change those behaviors it is necessary to "unfreeze" them from their setting or alter the standards of the group.
3. To retain the new behavior, the person must be within a group context that will support rather than undermine it. This involves a process that Lewin calls refreezing--locating the new behavior in a supportive group whose standards will conform to the new behavior.^{13,14,15}

In reality therapy the focus is on responsibility of the client for his/her own behavior. The client must contribute to what is happening now. The past cannot be changed,

only the present. The belief is that this is only possible when the client is involved with other people. The major factors in reality theory considered applicable to the present program are as follows:

1. The illness factor is not accepted as an excuse for the lack of responsive behavior (non-compliance). New and improved behavior patterns can be learned.
2. The focus on reality places emphasis on daily behavior and the fact that it is not providing the maximum potential for improving the quality of life. In the effort to help the client gain more conscious, responsible control over what he/she does, we are adhering closely to the reality of the present.
3. The development of responsibility for self can be accomplished only through involvement with other responsible human beings. The support of others who care enough to accept and help him/her in their struggle to cope with the illness.¹⁶

Androgogy, a recent development in the education of adults, is based on the belief that adults learn more affectively with participatory experiential, rather than transmittal techniques. The individual feels more committed to the decisions of planning and implementations, because they are based on his/her identification of the existing need. In this process, the learner assumes responsibility for his/her own destiny.¹⁷

The central dynamic of the learning process is perceived to be the experience of the learner, experience being defined as the interaction between an individual and his environment. The art of teaching is essentially the management of these two variables in the learning process-environment and interaction which together define the substance of the basic unit of learning, "a learning experience." The critical function of the teacher, therefore, is to create a rich environment from which students can extract learning and then guide their interaction with it so as to maximize their learning from it.¹⁸

Multi-family counselling is based on the theory that improved ability in decision making will benefit the client who is concerned with changing behavior. The traditional mode of describing change is to indicate that feeling, thinking, and acting have changed. However, the only factor that can be measured with any degree of accuracy is the acting. The change as an act is preceded by the making of a decision, even the non-act requires a decision not to act.

The Latin work "decidere," from which our word "decide" stems, means "cut off." Doubt and debate are cut off when a decision is made. Another way of stating that is, that all options except one are cut off when a client makes a decision. This sorting out of options and the selection of one indicates the need for the client to be aware that different options are available, from which to choose. The problem for most clients and their families is to be able to view the choices in an orderly fashion and then to make a selection for a course of action.^{19,20,21} The use of the group provides an opportunity for the clients to learn from

experiences of others, how the selection of existing options can influence behavior. The free flow of information and the shared experiences among the families erase some of the uncertainty and develop more confidence in their ability to make the necessary decisions.²²

The assumption here is that you will learn the problem solving model and its skills experientially in the context of small groups. Small groups present certain advantages in experiential learning.

1. Observing one's own behavior and receiving feedback.
2. Developing observation skills--clients have the opportunity to develop observational skills as they watch the behavior of their fellow clients.
3. Lowering defenses--if a group becomes a working/learning community with a sense of caring, the members can experiment with lowering customary, but often self-limiting defenses.
4. Experimenting with "new" behavior and the release of emotions. The group provides a controlled environment in which members can responsibly experiment with behavior, including the expression of emotions that are kept under cover in day to day living.
5. Discovering models--clients can become models for each other. They can see in one another behavior

that they like or dislike or wish to develop themselves.

6. Giving and receiving help--the group provides an opportunity for clients to both give and receive help with their own problems, concerns and developmental issues.
7. The group provides its own system of rewards and punishments with the acceptance, support and the identification of behavior that acts as a barrier to the desired goals.
8. Group discussion is purposeful conversation and deliberation about a topic of mutual interest among 6-15 participants under the guidance of a trained participant called a leader.²³

The research design planned for this study was an exploratory method. This involved the selection of three groups (target population), presenting them with a pre-test (the scores for assessment criteria at the first session), then subjecting them to an educational program and following this with a post test (the scores on the assessment criteria at the last session). The purpose was to determine if any changes had developed in the ability to adhere to the prescribed medical regimens.

Selitz and Simon see the pre-experimental methods as having a definite place in the exploratory research, in order to provide suggestions for hypothesis for further

research. In the early stages of a study, it is often more efficient to proceed without strict controlled situations. When an idea is initiated, it should be developed in a loose fashion to check and develop the idea and provide knowledge gathering. It should not be offered as proof of casual relations, but as the exploration that it really is.²⁴

Mater and Greenwood stress the need to identify the intervening or bridging variables when concerned with the attitudes and behavior, the key being to establish a plausible sequence among the set of variables, to note their respective position in that sequence. Changes in the participants' attitudes and knowledge is sometimes hypothesized as a necessary pre-condition for change in behavior. The measure of attitude or knowledge change is then viewed as the bridging or intervening variable which links events in the program towards the desired effects.²⁵

Summary

This section presents a model and guidelines that can be applied to health education programs for any chronic illness. This model stresses the need to develop an educational diagnosis prior to the implementation of a program. In this process the specific problems of concern to the target population can be identified and included in the program contents.

The principles of adult education are followed when

issues of concern to the participants are addressed. The art of teaching according to Knowles is the management of the two variables environment and interaction, which provides a learning experience. Glasser supports this with his claim that responsibility for self can be accomplished only through involvement with others. Lewin believes that individual habits and attitudes do not exist in isolation, but are related to significant others in the environment. These concepts are the basis for Laqueur's multi-family counselling group, which provides interaction with other participants and with significant others in their respective lives, to provide a learning experience. These learning experiences create an approach to self management that can be transferred to the decision making required in the daily activities of coping with a chronic illness. The advancement toward the established goals may be slow and in small steps, therefore the leader or researcher has the responsibility to make sure that all participants recognize each step of progress along the way.

Notes Section 2

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- ⁷M. Knowles, The Modern Practice of Adult Education, Assoc. Press. (New York, 1970), p. 287.
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- ¹⁶W. Glasser, Reality Therapy (New York: Harper and Row, 1975).

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- ¹⁸ Ibid., p. 51.
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- ²⁴ C. Selitz, Research Methods in Social Relations (New York: Holt, Rinehart and Winston, 1959).
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SECTION 3
RESEARCH DESIGN

Introduction

In the development of a model that will be specific for this program, we made some minor adjustments in the Precede Model. This is illustrated in Table 11, which is a skeletal model for any chronic illness, and Table 12, which is designed for the specific disease entity of diabetes. The thinking of Mater and Greenwood, and Seltitz and Simon was influential in our plan of action. The model may include the major recognized risk factors because when they occur the control is disrupted, no matter how compliant the client may be, and additional medical control of the situation is required, until the situation is corrected.

In the preface, the steps that led to the formulation of the concept of this program are identified. The idea was discussed through established communication channels at the New York Diabetes Affiliate office. This included the Executive Director, Program Director, and members of the Patient Education Committee. The following support was provided for the program: The clerical work would be done by the New York Diabetes Affiliate office staff, the cost for mailing notices would be absorbed by New York Diabetes Affiliate, and the xeroxing of needed handouts would be done by the same staff. The counsellor would be responsible for progress reports to the Director of Programs at the New York Diabetes Affiliate. This

TABLE 11

PRECEDE MODEL APPLIED TO ANY CHRONIC ILLNESS

Program	Determinants of Behavior	Impact	Outcomes	Quality of Life
Health Education Component of Treatment	Predisposing Factors		Reduction Morbidity Mortality Disability	Improved Social and Physical Activity
	Enabling Factors	Patient Behavior		
	Reinforcing Factors			
Input	Contributing Factors	Behavior Outcome	Health Outcome	Social Outcome
Interdependent Variable	Intermediate Variable	Dependent Variable	Long Term Outcomes	

TABLE 12

PRECEDE MODEL APPLIED TO THE DIABETES PROGRAM

Program	Determinants of Behavior	Impact	Outcome
Multi- Family Group Counselling	<p>Predisposing Factors Belief in one's ability to control. Confidence in decision making</p> <p>Enabling Factors Availability and accessibility of the program. Community commit- ment to health</p> <p>Reinforcing Factors Family Peers Health Providers</p>	<p>Patient Behavior Compliance by ability to carry out self care tasks to control blood sugar Identify self as having diabetes Develop a support system in one's own social context</p>	<p>Lower Rate of Mortality Morbidity Prevent acute stage recurrence Limit disabling complications Improve social and physical activity.</p>
Input	Contributing Factors	Behavior Outcome	Health and Social Outcome
Independent Variable	Intermediate Variable	Dependent Variable	Long Term Outcome

person is a social worker and has counselling experience with clients who have diabetes. In addition, she served as a back-up person for planning and for supplying resource materials as needed.

Implementing the Program

The recruitment and selection of clients was the next step, now that the approval and support of New York Diabetes Affiliate had been obtained.

1. An announcement about the program was placed in local community papers and in the New York Diabetes Affiliate Newsletter, which is mailed to all members.
2. The program was described as a discussion group with a counsellor that was a nurse and a social worker. The title of the session was "Coping with Diabetes."
3. Interested individuals were requested to call the New York Diabetes Affiliate office to register.
4. The people who responded were interviewed by the Program Director at the New York Diabetes Affiliate office, who was a social worker.
5. The individuals were selected on a first come basis, as long as they:
 - (a) were 30 years or over,

- (b) were under the care of a licensed physician,
 - (c) were able to speak and understand English,
 - (d) were concerned with a problem in adjusting to their prescribed regimens.
6. Three groups were formed with ten clients in each of the groups.
 7. The clients were requested to bring a family member or significant other person to the meetings when they attended.
 8. The clients were informed, at the initial interview, that there would be no attempt to evaluate or criticize their physician and the treatment regimen prescribed. The program was designed to help and support the client, to comply with his/her individual regimen.
 9. A total of ten meetings was scheduled, and each session lasted about 1½ hours.
 10. The meeting place was the Board Room at Lenox Hill Hospital in Manhattan. The space was provided to New York Diabetes Affiliate on the second Monday of each month, from 6:30 to 8:30 P.M. This site is well located for all major forms of transportation and the area is well lighted and a busy intersection at these hours.

The first meeting involved explaining the purpose and goals of the program and an informal introduction of all members present. The introduction consisted of giving their

name, introducing the significant other, stating the length of time they had diabetes, explaining briefly the treatment regimen prescribed by their physician and the general range of recent blood glucose levels.

The researcher explained that an assessment form would be distributed for the participants to check off his/her knowledge of diabetes and its management. They were encouraged to be honest as this was not a test but a means of determining the areas requiring assistance. This information would help establish the direction of the group sessions. All of the participants accepted the assessment forms and appeared interested in the contents. There was a spontaneous exchange between the group members that reflected a feeling of cohesiveness. In addition to diabetes, it appeared that the check-off list provided another factor being shared by the participants.

In the process of the discussion, it was evident that the clients were knowledgeable about diabetes, the symptoms, various treatment approaches, recent literature published, and the many complications that might result from having the illness. The conversations indicated feelings of defeat and despair in applying the knowledge in the decisions needed for the activities of daily living. A discrepancy existed between what they wanted to do and what they were able to do. The major problem areas appeared to be the need for support, confidence in decision making and recognition of the "locus of control."

Format of Sessions

1. Give a general introduction to program:
purpose--goals--time--frequency
2. Have clients introduce themselves to the group:
How long have they had diabetes?
Present treatment plan
Identify their major problems.
What they hate or fear the most about diabetes.
3. Distribute assessment forms.
Explain criteria
Purpose of form to aid in planning program.
4. Review results of assessment forms.
Identify problem areas as seen in the form
Open discussion to clarify interpretation.
5. Plan for future meetings with the group.
6. Use question guidelines to initiate discussion if necessary.
7. If a client states a problem at this time--use it to start discussion and ask for suggestion from the group-- identify choices, have client make a selection for trial before the next session.
8. Get feedback at the next session and continue from there.
9. Keep criteria at hand for recording and direction.
10. At session 6 start reviewing with clients what has been accomplished.

Make referrals for additional experiences in club meetings or seminars as jointly determined.

11. At last session review assessment form again and ask clients to complete evaluation form. Review responses with group to clarify responses.

Definitions

Hypothesis Clients with a chronic illness, such as diabetes, will improve their compliance or adherence to prescribed treatment regimens, if they are exposed to a health education program that is based on the strategy of multi-family experience sharing group counselling.

Compliance (Chosen rather than alternatives, such as adherence or cooperation to be consistent with much of the literature) means the client being able to carry out assignments or tasks in the way originally planned, discussed and agreed upon by both him/her and the health professional.

Control The ability to maintain a continuous process of dealing with the problems that occur at various intervals in the disease process (not just a record of blood glucose readings). This would make compliance the ability to participate in a continuous process of control.

Health Is viewed as a fluid adjustment to circumstances.

Health
Education

A planned program to assist the client in adjusting to these continuous changes in circumstances and the problems that accompany these changes.

Client

A person who brings to the health education setting a knowledge base of personal needs and feelings and a system of beliefs and values.

Health
Educator

A person who comes to the setting with professional expertise and knowledge of the disease process, the principles of teaching and learning and the effect that both of these have on the client, the family and the entire social context.

Group
Discussion

Group discussion is purposeful conversation and deliberation about a topic of mutual interest among 6-15 participants under the guidelines of a trained participant called a leader. It is a technique which offers maximum opportunity for the individual learner to share ideas, feelings, and experiences with others and to move toward a planned action to improve the situation.

Program Variables

The model developed for the diabetes education program Table 13, identifies the three variables which are the focus

of this study.

The independent variable, the health education program using the strategy of multi-family counselling; the goal of the program being to improve the compliant behavior.

The dependent variable is the behavior of the client and the significant other following exposure to the program. The behavior being assessed by the criteria on Table 14 and the changes in scores between the first and the last session of the program.

The intermediate variables are identified as the contributing factors to the behavior of the clients and their significant others. In this study we are concerned with the predisposing factors of attitude, belief and knowledge. In addition, the program focuses on the reinforcing factors of family, peer and health provider support.

The enabling factors present at the time of this study are the providing of the program by New York Diabetes Association, the allotting of space by Lenox Hill Hospital, the support and resources from New York Diabetes Affiliate, and the availability of a clinically prepared group leader.

Establishing an Educational Diagnosis

In the initial discussion with the target population (using the Precede Model as our guide), they expressed concern about the following social problems which could affect the quality of their lives:

Phase ISocial Problemsa. Discrimination

Real or imagined feelings of discrimination, such as different, sick, disabled, or not one of the group could limit the client's social activities or be a barrier to their career development.

b. Absenteeism

The frequency and duration of morbidity rates can cause absenteeism from work or school and eventually lead to unemployment. This fear created feelings of alienation and hostility in the client and the members of his/her family.

c. Role Reversal

The major fear expressed by the clients was the possible development of disabling complications (loss of sight and/or limbs). This was viewed as a change from an independent adult to a dependent person in the activities of daily living. In addition, the client who was the main support of the family feared the loss of status and love if they could no longer function in that role.

Phase IIHealth Problems

The health problems that the clients were concerned about were the morbidity incidents, which placed them in the sick role. The belief was, that the frequency, intensity

and duration of these incidents were the initial steps leading to disabling complications. The clients openly expressed their fears, but felt that they lacked the skills and power to take any preventive actions.

Phase III

Behavior Patterns

The behavior patterns that appeared to pose problems were the skills needed to carry out the self care procedures requiring decision making. The clients were under the care of a physician, kept regular appointments, and regular visits to the podiatrist, ophthalmologist, and the dentist. In addition, they took their medications and monitored blood and/or urine as prescribed. The discussions indicated a need to develop confidence in their ability to make a difference in the situation, to recognize when there is a need for a decision, and then to carry out the decision once it has been selected.

Phases IV-V

Educational Diagnosis

In establishing the educational diagnosis, three major factors must be considered:

- (a) predisposing
- (b) enabling and
- (c) reinforcing.

The predisposing factors of knowledge, attitude and

belief were assessed in the initial stages of the assessment. The knowledge base for all three groups was greater than anticipated. The clients were well informed about the disease process and its complications. The weak area was that they did not believe that they could make a difference and were convinced that the health professional was the one solely responsible for their health status and decision-making.

The enabling factors posed no problems since all the clients lived in the metropolitan area. This meant that health resources were available for care in the private medical sector or in the clinics. In this particular study, the community resources consisted of the support of New York Diabetes Affiliate for the program and the provision of a meeting place by Lenox Hill Hospital. In addition to support for the program, New York Diabetes Affiliate provided a qualified staff person to lead the group and make available to the members of the group the resources of the association.

The reinforcing factors provided by the family, peers, employers and health providers appeared to be an area that required some attention. The clients and the significant other who attended the sessions were readily available for this action. The client, who is more confident, demands more support from other members of his/her

environment. A review of Table 6 will identify the relationship of these three factors to health problems.

Phase VI

Administrative Diagnosis

The health education program designed to meet the needs of the clients was based on the theories which were identified in section two on the model. The main strategy used was multi-family counselling. This provided a means for the client and the significant other to

- (a) identify the problem,
- (b) open discussion of the problem,
- (c) identify and review alternative choices with the group,
- (d) selecting the action for trial
- (e) deciding to implement this choice
- (f) deciding to provide feedback (positive or negative) to the group
- (g) deciding to enter into discussion about other available choices if the trial had negative results.

At each session a brief review was made of all the assessment criteria, to obtain data regarding any changes that might be taking place. In addition, a close observation was made regarding the attitude of the group members in relation to the criteria established in Table 13.

The goal is to develop skills and attitudes that can be

useful in implementing future knowledge acquired from any continuing educational experience.

The assessment tools provided a means of determining the educational diagnosis for the participants and the next step was to select the objectives for each of the three variables. The ultimate goal was to improve the quality of the life of the participants involved in the study.

A. Independent Variable

1. To provide open-end discussion groups to develop an awareness of the problems involved in coping with diabetes.
2. To provide a safe and accepting environment, where real and imagined fears can be shared.
3. To use group discussion as a technique to move toward a planned action to improve the situation, in addition to providing an opportunity to share ideas, feelings, and experience.
4. To provide a support system in the immediate social context outside of the group, by including the significant others in the program.

B. Intermediate Variable

1. To believe that diabetes is controllable through appropriate health care regimens.
2. To understand that diabetes is a family affair and the role of each member in the treatment process.

3. To develop self-confidence in decision making for effective self-care.
4. To develop and maintain resources that support and encourage appropriate self-care behavior. This would include continuing education, membership in diabetes clubs and attending seminars for clients.
5. To develop a support system in the immediate social context.

C. Dependent Variable

1. To identify self as a person with diabetes to appropriate others.
2. To base self-care plans on the interrelation of medication, diet and exercise.
3. To be able to carry out self-care tasks to control blood sugar levels.
4. To utilize the support system developed in the immediate social context.
5. To develop an awareness that extreme stress can be a barrier to adequate adjustment--to attempt to recognize one's own anxieties.
6. To develop the ability to recognize an emergency situation in diabetes and to teach significant others how to respond appropriately.

It is believed that with improved blood glucose control, the morbidity rates will decrease and the risk of disabling

complications will be lowered. The acceptance and support of the participants in the group and the lowered morbidity rates should decrease the feelings of discrimination. The quality of life of the group members should improve, since the social problems identified was concerned with discrimination, absenteeism and adjustment to the sick role.

Assessment Tools

Three assessment tools were used in this study, the criteria checklist, the attitude criteria, and the questions guideline.

The criteria checklist, Table 13, consists of 15 basic criteria to assess the needs of the clients in the program. The headings at the top of the page offer four possible responses. The clients are requested to self report their status for each category. The headings "always" and "most of the time" are interpreted to mean that the criteria is under control. The headings "some of the time" and "never" indicate a definite client need for education. This method of self-reporting is used to promote confidence and respect for the client's decision and participation in the program. In addition, the client has an opportunity to determine his/her own destiny.

These task oriented criteria are a safe and familiar vehicle through which attitudes and psycho-social problems can be introduced into the discussions. The basis knowledge

TABLE 13
ASSESSMENT CRITERIA

Criteria		Always	Most of the Time	Some of the Time	Never
1.	Takes medication as ordered				
2.	Monitors blood or urine sample as ordered				
3.	Adheres to dietary regimen as recommended				
4.	Engages in exercise daily				
5.	Wears I.D. alert badge				
6.	Recognizes & responds to early signs of hypoglycemia				
7.	Adjusts regimen to changes in stress and physical exertion				
8.	Develops a support system with family & peers				
9.	Sees self as resource person to other diabetics				
10.	Seeks information on diabetes from journals, books and seminars				
11.	Actively engages in ADA or NYDA				
12.	Carries some form of sugar at all times				
13.	Gives self special foot care				
14.	Prevents infection--flu shots, etc.				
15.	Regular visits to dentist, M.D., etc.				

of these group members was greater than anticipated. Initially, the fears expressed are related to dislike of dietary restrictions, taking injections and concern about insulin reactions. These task oriented discussions can be expanded to talk openly about fear of the disease process and its complications. In addition, it offers an opportunity to provide support and reassurance when learning that the application of the criteria to daily living can make a difference. These open discussions with peers and family lessen their anxiety which is often heightened at this time, and act as a barrier to the much needed support from these significant others.

These criteria were reviewed briefly at the beginning of each session to determine if a problem existed, requiring more knowledge or reassurance and reinforcement. In Appendix C, there is an outline which presents more detail regarding each criteria and can act as a guideline for the leader. The major aspects of each criteria are identified so that they can be approached in more depth. These criteria were adapted from an assessment criteria established by the Michigan Diabetes Research and Training Center in Ann Arbor for a community research program and the guidelines in Table 8.

The scores for each session indicate the number of participants who have the specific criteria under control (Appendix C2, Fig. 21). These scores are recorded from the self-reporting of the participants that the criteria is being managed "always" or "most of the time."

The responses in all three groups indicated that there was full compliance of adherence for items 1, 2, 14, and 15. These items or criteria revealed that the clients took their medications and monitored their urine or blood as prescribed. In addition, they took preventive measures such as regular visits to the podiatrist, dentist, and ophthalmologist. Infections were prevented by following good personal hygiene practices, receiving flu shots and seeking medical care as soon as there was any indication of a problem developing.

The areas identified as needing the most attention were items 3 through 8 and 12 and 13. These areas were related to the daily activities of coping with diabetes, such as regulating diet, exercise, knowing the signs of hypoglycemia and corrective action necessary, the effect of stress on diabetes and the need for a support system with family and friends. The preventive measures needed are identified in items 12 and 13, which stress the need to carry some form of simple sugar at all times and to develop the daily habit of special foot care.

Items 9 through 11 are concerned with continuing education and the use of self as a resource person to other persons with diabetes can be dealt with after the other fundamentals are being practiced on a daily basis (Table 13).

The attitude criteria Table 14 was adapted from the many health education programs sponsored by Johns Hopkins University and illustrated in the publications of Dr. L. Green. The

TABLE 14
CRITERIA FOR ATTITUDE ASSESSMENT

The majority of the clients come to the program seeking help from the professional and have little or no understanding of their role in the management of their diabetes. An important aspect of obtaining and maintaining control is based on the client's positive attitude toward his ability to make the necessary decisions in daily living and the fact that what he/she does can make a difference.

Category P Positive reaction is identified by feelings of confidence in the performance of self-care tasks and the making of necessary decisions. The belief that control can be obtained; that one can make a difference in the situation; that the experience of the individual is of value as a resource to others with diabetes.

Category N Negative reaction is identified by the feelings of what I do does not matter; my family and friends do not give me support, why would strangers do this? If the professional cannot control the situation, how can I as a lay person? I don't have the skills to handle a crisis. I don't know how to make all the decisions needed. How will I know what is right to do?

examples provide a means of coding the responses of the participants into two categories. The objective being to move from a negative towards a positive position in relation to the ability to exercise self-management and assuming responsibility for making a difference by controlling the situation. As the scores increased for the criteria checklist, it is assumed that the attitudes will be moving toward a more positive category.

The question guideline illustrated in Table 15 is an adaptation from Tables 9 and 10 to meet the objectives of this particular study. It is believed that this tool provides a frame of reference which is needed to establish goals that are relevant to the circumstances, from the clients' perceptions. In addition, it supports the clients' right to determine his/her own destiny and to assume a responsible and knowledgeable role in implementing his/her own care. By comparing the responses of the client with the significant others, it is possible to identify some of the conflicts which exist in the social context and may be contributing to the problem of not adhering to the prescribed regimens.

Data Collection

The process of data collection consisted of the use of three methods. The first was the use of work sheets on which the reactions were recorded at each session by the group leader. The samples of these work sheets are in Appendix C hereof.

TABLE 15

ASSESSMENT/INTERACTION TOOL IDENTIFYING THE PROBLEM
QUESTION GUIDELINES

1. How did you find out that you had diabetes? What was your first thought when you were told the diagnosis?
2. Has the recommended regimen been a hassle?
3. What bothers you most about having diabetes?
4. Have you ever known anyone with diabetes?
5. What is the most frightening aspect of having diabetes?
6. What aspect of care is hardest for you to follow?
7. What do you see as the doctor's responsibility with respect to your health? Your own responsibility?
8. What is it like to have diabetes? To live with diabetes?
9. What things have the health professionals done for you that have been helpful? What has not been helpful?
10. The family or significant other should be asked the following:
 - a. What is it like to live with someone who has diabetes?
 - b. Has it changed your life?
 - c. What worries you most?
 - d. How do other family members or friends respond?
 - e. What positive effects has this experience had on the family?

The responses are coded at each meeting as explained on page 144. The scores are then transferred to a data collection sheet for any planned analysis. This information is then available for a variety of data analyses, such as graphs and tests of significance as used in this study (Figs. 2,3 & 4).

In order to obtain a clear view of the changes that might have transpired between the first and last session, a profile was developed of the scores of these two sessions. See Figure 5. This profile indicates that some change had occurred in each of the categories.

In addition to the collection of data scores a progress record was developed to keep a log of the reactions of clients and families in relation to each criteria. A summary was made of the reactions of the families or significant others and any changes in attitude that might have taken place in the group sessions (pp. 77-87).

The demographic statistics are recorded in Fig. 6, stating the composition of the groups in reference to age, sex, vocation, and the attendance record.

Criteria

	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	N	P	Remarks
1	9	8	4	6	1	3	1	2	0	7	3	3	2	5	6	10	0	
2	10	10	4	6	1	3	2	2	0	7	3	4	4	5	6	10	0	
3	10	10	4	6	2	4	2	2	0	7	3	5	4	5	6	9	1	
4	10	10	5	7	2	5	4	3	1	7	3	5	5	6	7	9	1	
5	10	10	5	7	3	6	4	3	3	8	3	7	5	6	7	8	2	
6	10	10	6	7	4	6	5	5	4	8	3	7	5	6	7	7	3	
7	10	10	6	7	4	7	5	5	4	9	4	7	5	6	9	6	4	
8	10	10	6	8	5	7	5	5	5	9	4	8	6	7	9	5	5	
9	10	10	7	8	5	8	6	5	6	9	4	8	6	7	9	5	5	
10	10	10	7	8	5	8	6	5	7	9	4	8	6	7	9	4	6	

Session

Fig. 2. Data Collecting Sheet Group 1

Criteria

Session	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	N	P	Remarks	
	1	10	10	5	4	2	2	0	1	0	6	3	4	3	6	7	10	0	
	2	10	10	5	4	2	2	0	2	0	6	3	5	4	6	7	10	0	
	3	10	10	5	5	2	3	1	2	0	6	3	5	5	7	7	8	2	
	4	10	10	6	5	3	4	2	3	0	7	3	6	5	7	8	8	2	
	5	10	10	6	6	4	5	4	4	1	7	3	6	5	7	8	7	3	
	6	10	10	7	6	4	5	5	4	1	7	4	6	6	8	8	6	4	
	7	10	10	7	7	4	6	6	5	1	8	4	6	6	8	9	5	5	
	8	10	10	8	7	5	6	7	5	2	8	5	7	7	8	9	4	6	
	9	10	10	8	8	5	7	8	6	2	8	5	7	7	9	9	4	6	
10	10	10	8	8	5	7	8	6	2	8	5	8	7	9	9	3	7		

Fig. 3. Data Collection Sheet Group 2

		Criteria																	Remarks
Sessions		1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	N	P	
	1	10	10	5	4	3	3	1	3	1	6	2	4	3	6	7	9	1	
	2	10	10	5	4	3	3	1	4	1	6	2	5	5	6	7	9	1	
	3	10	10	5	4	4	4	2	4	1	6	2	5	5	6	7	8	2	
	4	10	10	6	5	5	4	2	5	2	7	2	6	6	7	8	7	3	
	5	10	10	7	5	6	5	3	5	2	7	3	6	7	7	8	7	3	
	6	10	10	7	6	6	5	3	6	3	7	3	7	8	7	9	6	4	
	7	10	10	7	7	7	6	3	6	4	8	3	7	8	8	9	5	5	
	8	10	10	8	7	7	7	4	6	4	8	4	8	8	8	9	4	6	
	9	10	10	8	7	8	7	4	6	5	9	4	8	9	8	9	3	2	
10	10	10	8	7	8	7	4	6	5	9	4	8	9	8	9	3	7		

Fig. 4. Data Collection Sheet Group 3

		Group 1		Group 2		Group 3			
Criteria	Sessions			Sessions			Sessions		
		1	10	1	10	1	10		
	1	9	10	10	10	10	10		
	2	8	10	10	10	10	10		
	3	4	7	5	8	5	8		
	4	6	8	4	8	4	7		
	5	1	5	2	5	3	8		
	6	3	8	2	7	3	7		
	7	1	6	0	8	1	4		
	8	2	5	1	6	3	6		
	9	0	7	0	2	1	5		
	10	7	9	6	8	6	9		
	11	3	4	3	5	2	4		
	12	3	8	4	8	4	8		
	13	2	6	3	7	3	9		
	14	5	7	6	9	6	8		
	15	6	9	7	9	7	9		

Figure 5. Profile of data collected from assessment criteria, a comparison of scores from session 1 and session 10.

	<u>Group 1</u>		<u>Group 2</u>		<u>Group 3</u>	
Clients	10		10		10	
<u>Sex</u>	M	F	M	F	M	F
	3	7	2	8	5	5
<u>Age</u>	32-62		30-60		32-68	
<u>Mean</u>	43		47		45	
<u>Mean Attendance</u>	9.3		9.2		9	
<u>Occupation</u>						
Housewife	2		2		3	
Social Worker	1		1		0	
Teacher	3		3		2	
Managers	3		2		3	
Counselors	1		0		1	
Office Worker	0		2		1	
<u>Significant Other</u>						
	Husband--Fiance--Friend--Son--Daughter--Wife--Neighbor					
<u>Attendance Mean</u>	8.2		8.9		9	

Sessions: Second Monday of every month for ten months
Time: 6:30 to 8:30 PM
Place: Lenox Hill Hospital Board Room

Fig. 6. Demographic Statistics

Progress RecordCriteria

#1 This item "takes medication as ordered"

<u>Session</u>	<u>Group 1</u>	<u>Group 2</u>	<u>Group 3</u>
1	9	10	10
10	10	10	10

This criteria was adhered to by all members of the groups, except for one discrepancy. The problem was that the couple slept late on Sundays and then went out to brunch about noon time. The regular meal schedule was disrupted and one dose of medication was omitted. With the help of the group a revised meal plan was made for these occasions and the medication was taken as prescribed.

#2 "Monitors blood or urine as prescribed"

<u>Session</u>	<u>Group 1</u>	<u>Group 2</u>	<u>Group 3</u>
1	8	10	10
10	10	10	10

This monitoring was carried out as prescribed, except for two incidents. The client in item #1 omitted the monitoring when the medication routine was disrupted. The designing of a new meal plan resulted in correcting the situation. Another client felt that if there were dietary indiscretions, that it was useless to monitor. The group support in stressing the need

to be consistent, influenced the client to monitor on a daily basis, especially when the diet had been altered.

#3 "Adheres to dietary regimen as prescribed"

<u>Session</u>	<u>Group 1</u>	<u>Group 2</u>	<u>Group 3</u>
1	4	5	5
10	7	7	8

The members of the group had acquired a large number of facts related to diet, but were unable to integrate this knowledge into their daily meal planning. Some of the clients who were not having a problem, had been following one sample menu without any variation. This limited the foods eaten and isolated the client from sharing with the family at meal times. The basic education that had been given to them on diet appeared to be inadequate or not understood. The four basic food groups were reviewed and suggestions planned for trial in between sessions. They eagerly awaited to share in the feedback presented and eventually were able to develop more satisfying meals. In addition, the whole family was starting to eat the same foods. The families and significant others were able to provide support when they were aware that the diet planning could fit into their individual preferences. The word diet had most of the members of the group originally believing that only special foods could be served the person with

diabetes. It was also an important factor in their lives as they learned how easy it was to select foods in restaurants and when going out to special affairs. Additional resources were recommended, such as books (approved by the New York Diabetes Association) and seminars locally available on diabetes meal planning. Two clients had made plans to work with a private nutritionist to help improve their skill in the selection and preparation of foods.

Criteria

#4 "Engages in daily exercise"

<u>Session</u>	<u>Group 1</u>	<u>Group 2</u>	<u>Group 3</u>
1	6	4	4
10	8	8	7

This item refers to a specific time designated each day (or at least three times a week) for some planned exercise.

The first group started out with six members engaged in some form of exercise anywhere from 3-5 times a week. Only two additional clients developed some formal plan of exercise during the sessions. The remaining two clients felt that walking to the subway each day, the subway stairs, and their daily household chores were all they could manage at present. They did indicate that they would try to develop some plan for scheduled exercises, even if only for weekends.

The original six members with an exercise plan did not establish this as a result of their diabetes. They had established this pattern prior to developing diabetes, but reported that they would continue now that they realized that it was important to their treatment regimen.

Group 2 had four clients involved in formal exercise at the onset of the sessions. Two clients had been exercising prior to the onset of diabetes and two clients started on the recommendation of their physician when the diagnosis of diabetes had been made. The four clients who developed exercise patterns stated they did so because they were influenced by the positive reports from the original four clients. The fact that they reported feeling better as a result of regular exercise, and noticed a change if for any reason it was omitted from their daily schedule. The remaining two clients offered the same reason as those in Group 1 for not having any designated time for exercise. They did verbalize their understanding of its importance and hoped to develop some pattern of exercise for weekends in the near future. Group 3, the original four clients involved in a daily exercise program had started their activity as a result of reading literature about the importance of exercise for the person with diabetes. The three clients who had started exercising during the sessions

stated that they did so because of the enthusiasm of the group members who were actively involved in a formal program of exercise regimen, and hoped to take some action in this direction in the near future. All clients in this group reported having read about the value of exercise for the person with diabetes.

Criteria

#5 "Wearing an ID band"

<u>Session</u>	<u>Group 1</u>	<u>Group 2</u>	<u>Group 3</u>
1	1	2	3
10	5	5	8

The wearing of the medical alert band is vital in that it identifies the person with diabetes to any medical staff in an emergency. All clients verbalized recognition of its importance, but were reluctant to publicly display their identity as a person with diabetes. They were alerted to the fact that carrying this band in purse, pocket or wallet was of little value. In an emergency, such items are not searched. In case of an emergency when the individual is unconscious, a medical alert bracelet, identifying the person as a diabetic, would provide treatment direction that could be life-saving. Most of the intravenous solutions used in emergency situations contain sugar, and if the knowledge of the presence of diabetes is not available, the patient's medical

situation could be critical or even fatal.

The purchase of the band was a simple procedure.

The application forms were provided. The cost was minimal and within the means of all members.

At the end of the sessions, only half of the clients were wearing the bands. In Group 3, two members stated they were reluctant to wear their bands because they did not tell anyone at work that they had diabetes.

The members who started wearing their bands at work found, much to their surprise, that no one even noticed their presence on the arms.

Criteria

6 "Recognizes and responds to signs of hypoglycemia"

<u>Session</u>	<u>Group 1</u>	<u>Group 2</u>	<u>Group 3</u>
1	3	2	3
10	8	7	7

At the onset, only a few of the clients had experienced episodes of hypoglycemia and were familiar with the symptoms that they presented at the time of the incident.

In the process of the sessions, the members were alerted to the relationship of medication, monitoring, diet exercise, and stress on the blood glucose levels. For the first time some clients were aware that they had been experiencing episodes of hypoglycemia

but had not recognized the symptoms. The initial signs were not the same for everyone, and when in doubt it is a good idea to take a small portion of simple sugar.

An awareness developed, as the session progressed, that hypoglycemia is a potential problem for "all diabetics" on medication. The families and significant others were beginning to learn their role in observing for early signs, sometimes before the person with diabetes is aware of the change taking place. An acute situation can be avoided if some form of simple sugar is taken in time.

Criteria

- #7 "Adjust regimen to changes in stress and physical exercise"

<u>Session</u>	<u>Group 1</u>	<u>Group 2</u>	<u>Group 3</u>
1	1	0	1
10	6	8	4

At the onset of the sessions, the clients saw stress only in relation to death, severe illness, divorce or any very negative events. The objective was to introduce them to other forms of stress and develop their ability to recognize those situations that might be stressful to them.

The clients were requested to recall incidences when their blood sugars were unstable, even though they

had adhered to their regimens. As they began to describe the incidents, an awareness developed about what situations might be stressful to the individual, Some of these situations were: Having special company for dinner, dealing with the behavior problems of children, waiting for the results of diagnostic tests, and severe traffic jams. Some of the clients made specific identification of stressful situations that were occurring at the time of the sessions.

The group as a whole was able to verbalize an awareness of the possible effects of stress and additional physical activity on the blood glucose level, and the fact that some adjustment in their regimen might be required for such occasions. Any changes required by the client should be reported to the physician. The family members began to develop awareness of helping the client to identify stressful situations and to offer support in the client's coping process.

#8 "Develop a support system with family and peers"

<u>Session</u>	<u>Group 1</u>	<u>Group 2</u>	<u>Group 3</u>
1	2	1	3
10	5	6	6

In the initial session, when the clients brought a family member or significant other with them, only a small number saw their role as a support to reinforce the treatment regimen. They were concerned for the

clients, but saw the treatment regimen as an agreement between the physician and the client. The role of the family and peers as support groups was readily accepted verbally. As the members of the group began to understand the relationship between all of the criteria, it was easier to develop the support roles. In the work situation, the support from fellow workers provided a feeling of reassurance to the family. Some of the clients related about episodes of hypoglycemia at work, where their peers had helped to correct the situation. Similar reports began to be heard from the families about such incidents at home. It appeared easier to develop the support system at home than at work, because some clients were still reluctant to identify to others that they had diabetes. At the end of the sessions, at least half of the group members had developed a support system at work and at home.

Criteria

#9 "Sees self as resource person to other diabetics"

<u>Session</u>	<u>Group 1</u>	<u>Group 2</u>	<u>Group 3</u>
1	0	0	1
10	7	2	5

Each time a member of the group offered an example from their own experience or from the literature that they had read, it was identified as being an act of

a resource person. The group was very verbal in offering assistance to each other, but had difficulty accepting the label of resource person. This title was viewed as belonging to the professional and not the lay person. There was a gradual increase in the number of clients ready to accept this label. The family members and peers were also slow in viewing themselves as resource persons, even though they were able to provide effective contributions to the group.

Criteria

#10 "Seeks information about diabetes from journals, books and seminars"

<u>Session</u>	<u>Group 1</u>	<u>Group 2</u>	<u>Group 3</u>
1	7	6	6
10	9	8	9

In all three groups, over half the members had established the habit of seeking out information about diabetes. They readily shared this information with other members and were interested in the opinions of other members on the topics introduced.

At the end of the sessions, some members were still reluctant to seek out information. The feeling seemed to be that it only added to the confusion they were still experiencing about diabetes. Their lifestyle did not include the introduction of new

concepts or controversial issues. The focus was to direct the client to recognize the importance of continuous education as part of their treatment regimen.

Criteria

#11 Actively engages in American Diabetes Association and New York Diabetes Association activities.

<u>Session</u>	<u>Group 1</u>	<u>Group 2</u>	<u>Group 3</u>
1	3	3	2
10	4	5	4

The clients, who were members at the onset of the sessions, had joined mainly with the purpose of supporting any research being done for diabetes. They were informed that membership also offered a resource for continuing education through seminars, club programs, newsletters, and other publications. The value of this resource was that it had been reviewed by professional committees for the validity of the source and the facts.

The clients who started to participate in the activities offered made enthusiastic reports to the groups about their experiences. In spite of this, about half of the group members did not enter into any of the scheduled activities. Some expressed the view that these organizations were for the professionals. They did not perceive the place for the lay person to be directly involved.

Criteria

#12 "Carries some form of sugar at all times."

<u>Session</u>	<u>Group 1</u>	<u>Group 2</u>	<u>Group 3</u>
1	4	3	4
10	8	8	8

The clients who had established the habit of carrying some form of simple sugar with them at all times, had been advised to do so by health professionals. The majority carried some life savers or hard candy with them and readily shared with the group how it had come in handy on several occasions to prevent an attack of hypoglycemia. At the last session, all but two clients were carrying some form of simple sugar with them at all times. The remaining clients remained unconvinced of the need. They felt that their environment was one that would always have some sugar available when needed. The other members tried to convince them that this was a necessary precaution for all diabetics on medication, but they did not respond to the efforts of the group members to comply.

#13 "Gives self special foot care"

<u>Session</u>	<u>Group 1</u>	<u>Group 2</u>	<u>Group 3</u>
1	2	3	3
10	6	7	9

This item is a major preventive measure, because people with diabetes are a high risk for foot infection and ulcers. It is recommended that the clients wash their feet daily, dry them thoroughly, and apply some lubricant to the skin. At this time the entire foot must be inspected for any breaks in the skin. This is necessary because many persons with diabetes have suffered a loss of feeling in their feet and cannot feel a cut or injury when it occurs. Only a few clients had been advised of this procedure by a health professional. The general feeling was that if the feet don't bother me, why should I give them special care?

The clients were advised to attend a seminar on foot care for those with diabetes, which was sponsored by New York Diabetes Affiliate. The change was a gradual one, and the support of the family and significant others helped to encourage the members to adhere to this practice. The input from the members as they started to care for their feet, was an incentive for the others to follow. The remainder of the clients indicated awareness of the need and indicated intent to follow the routine, but had not started by the time the sessions were completed.

Criteria

- #14 Prevents infections by good personal hygiene, daily change of underclothing and gets flu-shots.

<u>Session</u>	<u>Group 1</u>	<u>Group 2</u>	<u>Group 3</u>
1	6	5	6
10	8	7	9

At the onset of the sessions, about half of the clients had knowledge of and were practicing these preventive measures. Most of the members had obtained their information from reading related literature and not from a health professional.

The clients were influenced to follow these measures by the model set by the members who were initially adhering to such a pattern and from the support received from family members and significant others.

- #15 "Makes regular visits to the physician, dentist, podiatrist, and ophthalmologist"

<u>Session</u>	<u>Group 1</u>	<u>Group 2</u>	<u>Group 3</u>
1	6	7	7
10	9	9	9

All clients in the three groups made regular visits to the physician and the dentist. The areas that needed more concern were visits to the podiatrist and the ophthalmologist. The pattern was to visit these professionals only when a problem had already developed, rather for routine preventive care.

At the end of the sessions, all but one client in each group reported a change in this area. The support and reinforcement of the other members appeared to influence their behavior.

Attitude Assessment

Initially the members of the group directed all of their questions and remarks to the counselor. They were seeking information and answers only from the professional. Any effort on the part of the members to make a contribution was usually ignored. The members did not view themselves as resource persons with valuable experiences.

The counselor directed the interaction towards the group by asking (around the table) what experiences they might have had in relation to the topic being discussed. In this manner, a role model was established to identify the value of feedback from the group. The members gradually began to listen to the contributions of the group members and then would address their questions to both the professional as well as group members. At the end of the last few sessions, the greatest problem was breaking up the group, when it was time to close the sessions. As they began to leave the conference room, they formed small groups and continued to exchange knowledge and experience. This activity continued as they walked together to the bus or subway. They appeared to have developed confidence in their ability to contribute

some assistance to others. In addition, this activity reflected a belief that they could make a difference. This also indicated increased confidence in the decision making for themselves, first in deciding to give or accept assistance, second the decision to try out the suggestions given, and finally the reporting back to the group the results of the trials at home.

Significant Others

At the beginning of the sessions, the family and the significant others looked to the counselor as the only person responsible for any change. They made statements such as "tell him/her what to do," "make them follow orders," or "tell him/her what will happen." They came with the client because that was part of the program. As the session progressed, the discussions included their feedback about the trials at home and questions about their support actions at this time. The questions asked were, "were you able to provide some support during this situation?" "Were you able to act as a resource person and remind the client of the plans made?" "Were you able to encourage the client and recognize the tasks that were improving?" Toward the end of the sessions members of the group felt comfortable asking any of the family "and what did you do at this time to help?"

The clients stated that in times of stress it was easier to follow the plans made in the group, when the significant

other was able to provide the much needed support.

Two of the husbands in the group became active in their place of business, seeking out employees with diabetes. They provided them with information about health resources available in the community and spent time talking and listening to provide emotional support. They earned quite a reputation for themselves and people began to seek them out for assistance. The family and the significant others were more aggressive in discussing diabetes in the community than the clients. They were not hindered by fears of rejection or discrimination, since they were not considered the "sick one." Towards the end of the sessions, more of the clients began to follow suit and talked about themselves, as people with diabetes. In addition, they offered information about resources available in the community without any real discomfort.

Data Analysis

The scores of the individual sessions have been summarized and recorded in Figures 2, 3, and 4. A profile of the first and last scores of the three groups are then presented in Figure 5. This data was then used to develop line graphs, which are presented in Appendix C3. These line graphs were difficult to follow, so bar graphs were constructed and seemed to present the data in a manner that made it easier to follow the path of the scores.(Figs. 7-18).

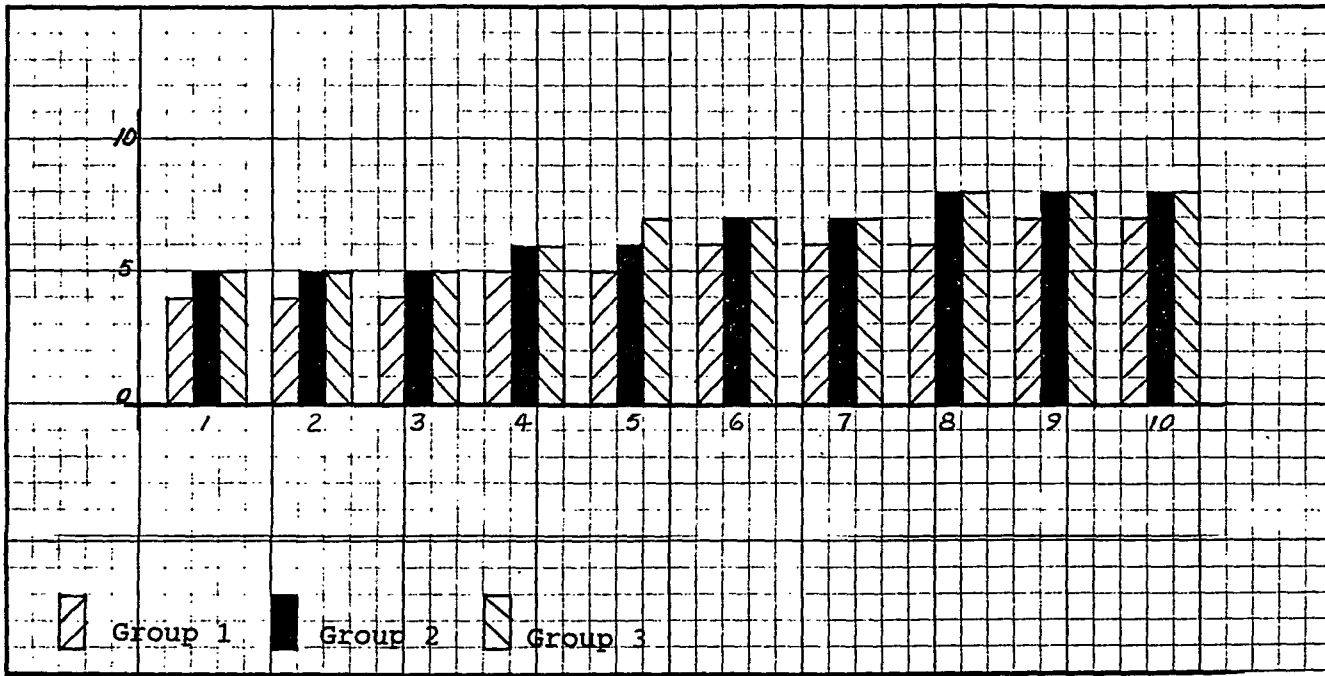


Fig. 7. Criterion #3 Follows Diet as Prescribed

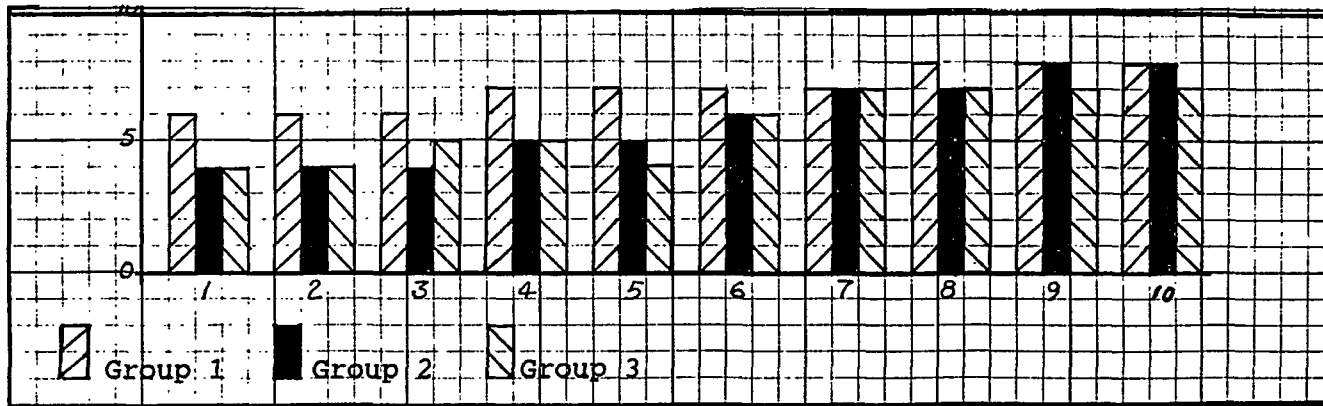


Fig. 8. Criterion #4 Has an Exercise Program

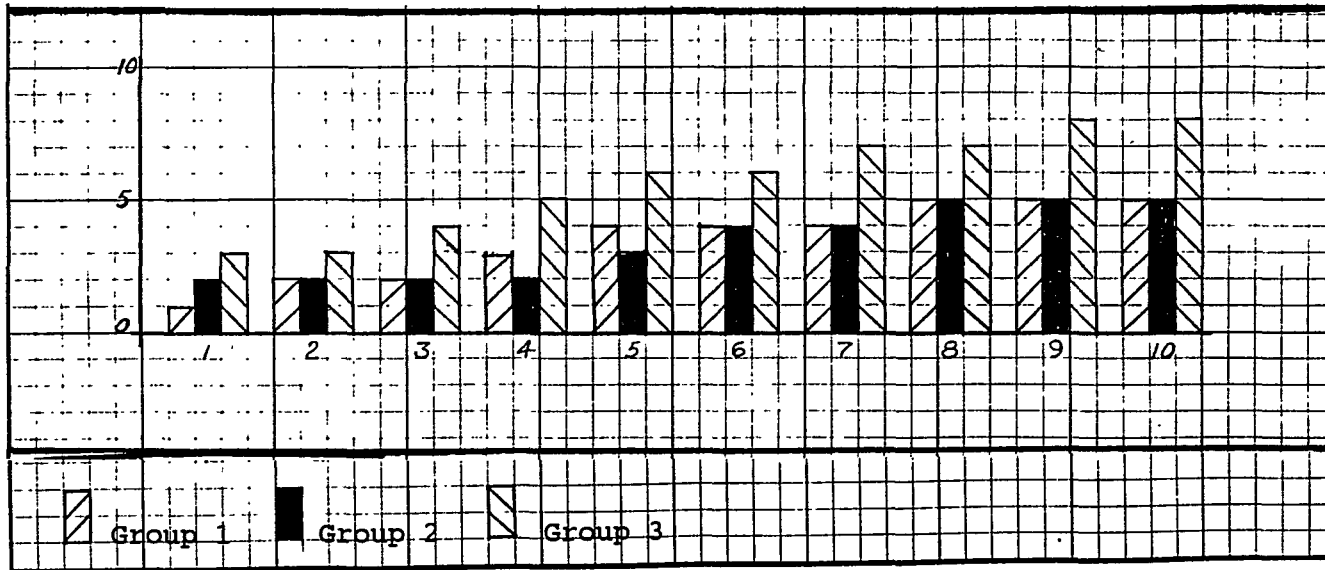


Fig. 9. Criterion #5 Wears an ID Band

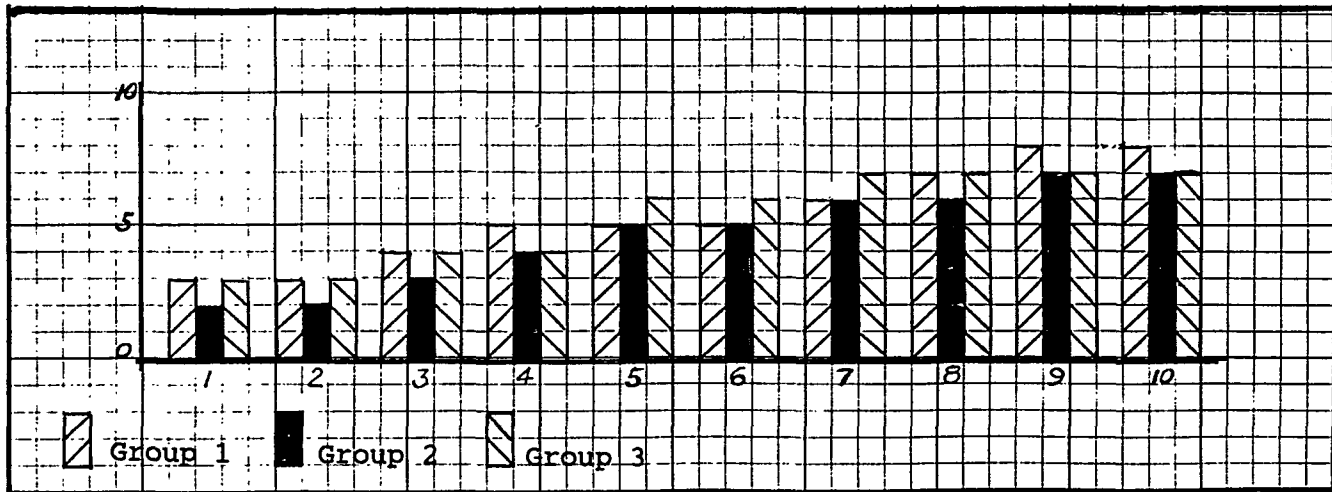


Fig. 10. Criterion #6 Knows Signs of Hypoglycemia

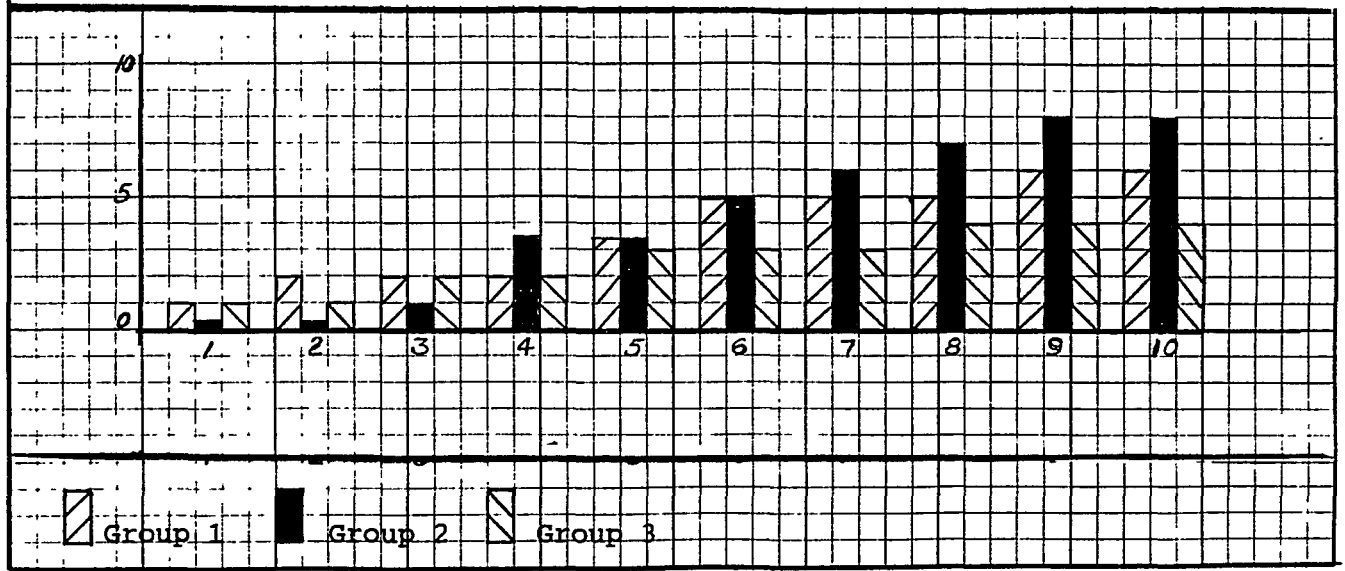


Fig. 11. Criterion #7 Knows Effect of Stress on Diabetes

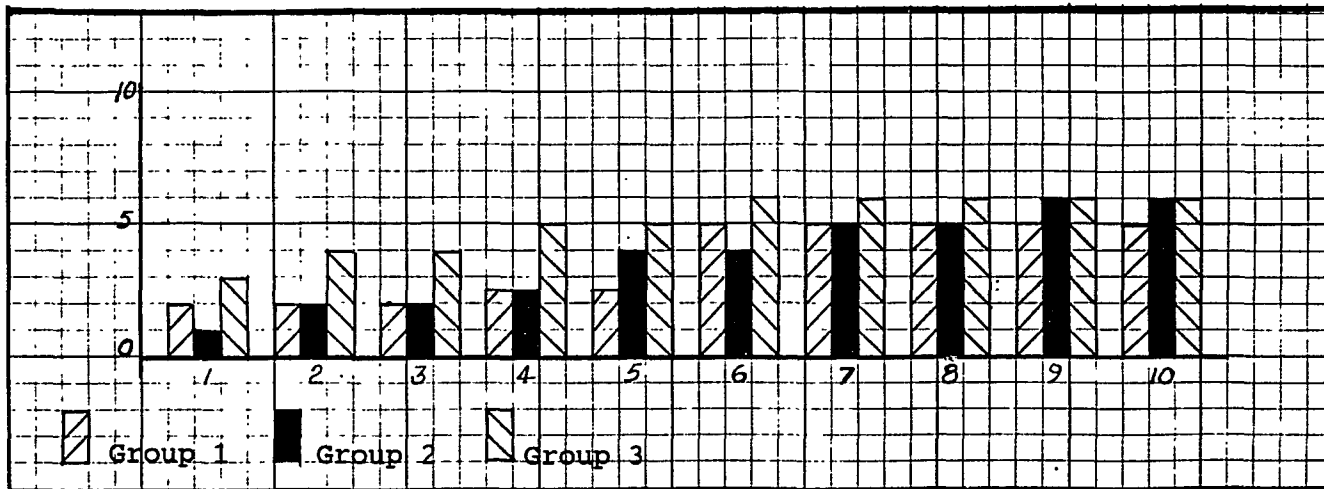


Fig. 12. Criterion #8 Known Need of Support from Family and Peers

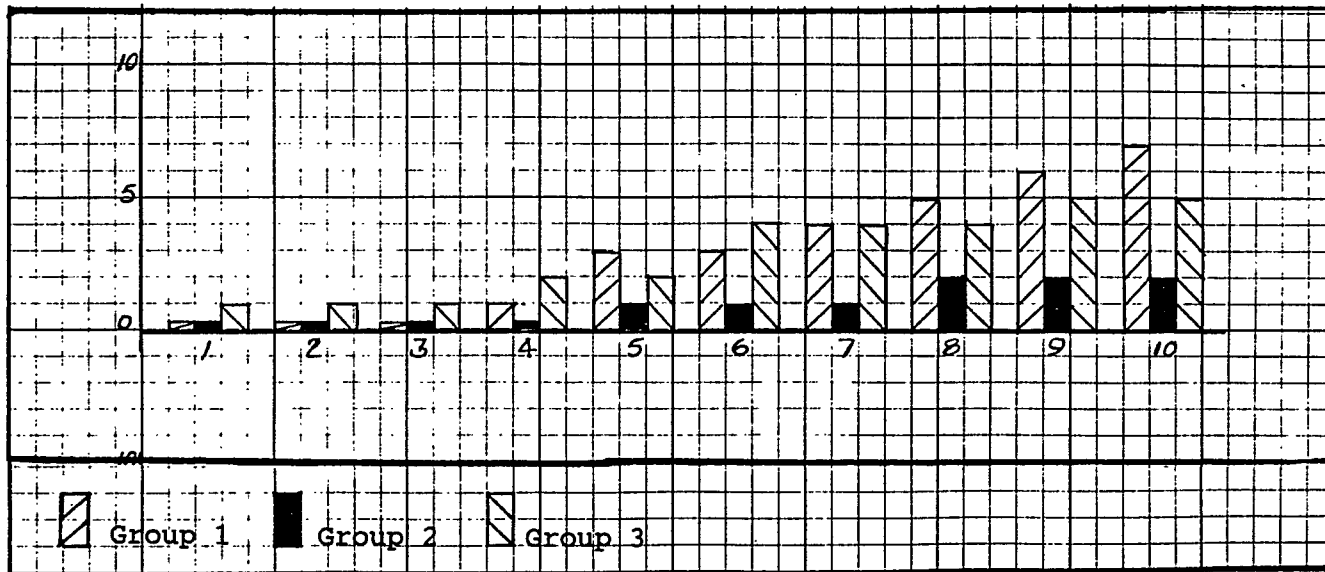


Fig. 13. Criterion #9 Aware of Self as a Resource Person

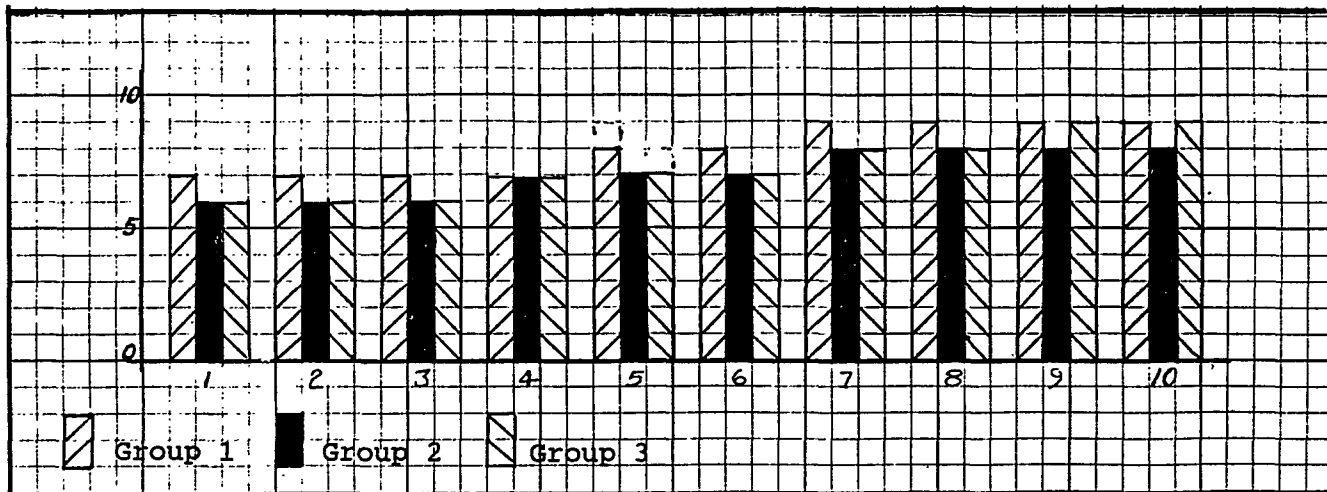


Fig. 14. Criterion #10 Seeks Information About Diabetes

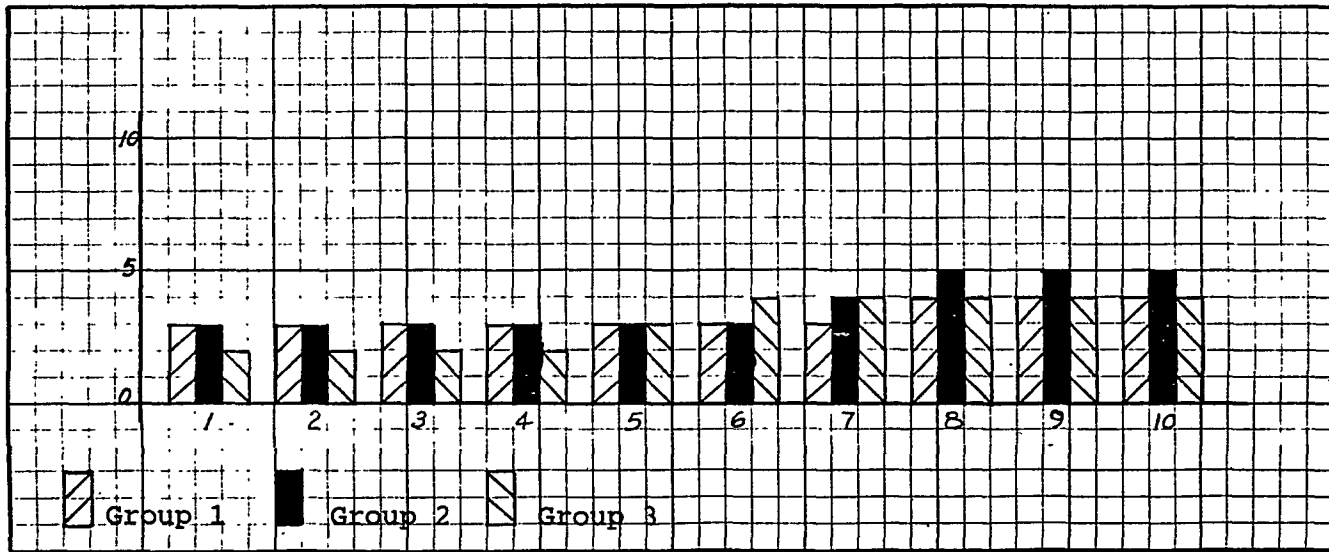


Fig. 15. Criterion #11 Active in ADA and NYDA

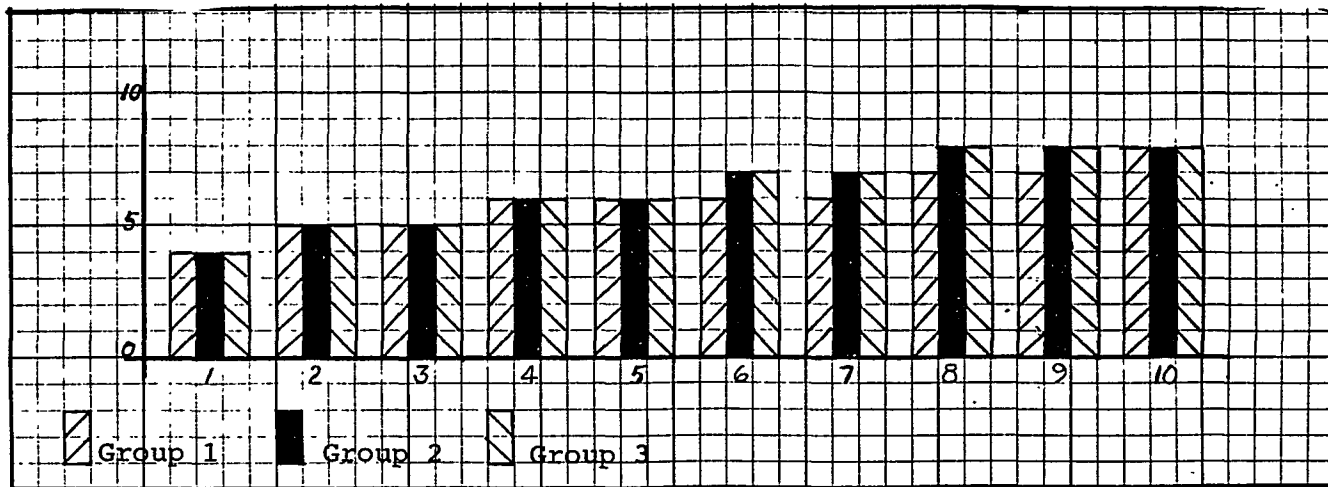


Fig. 16. Criteria 12 Carries Sugar at All Times

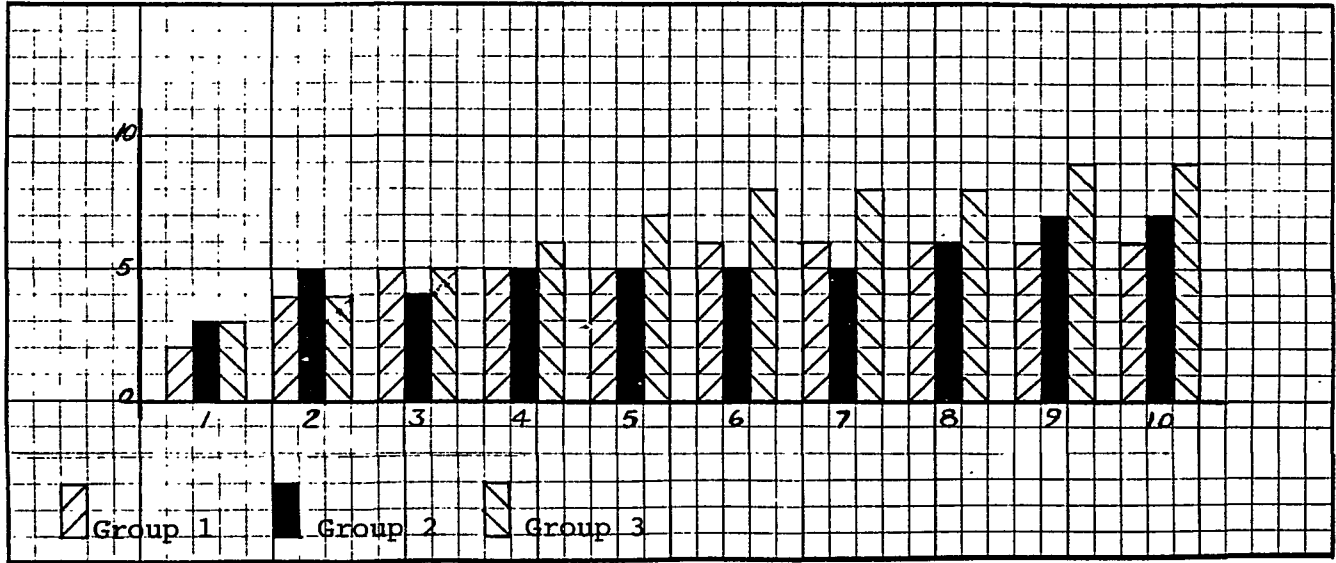


Fig. 17. Criteria #13 Performs Special Foot Care

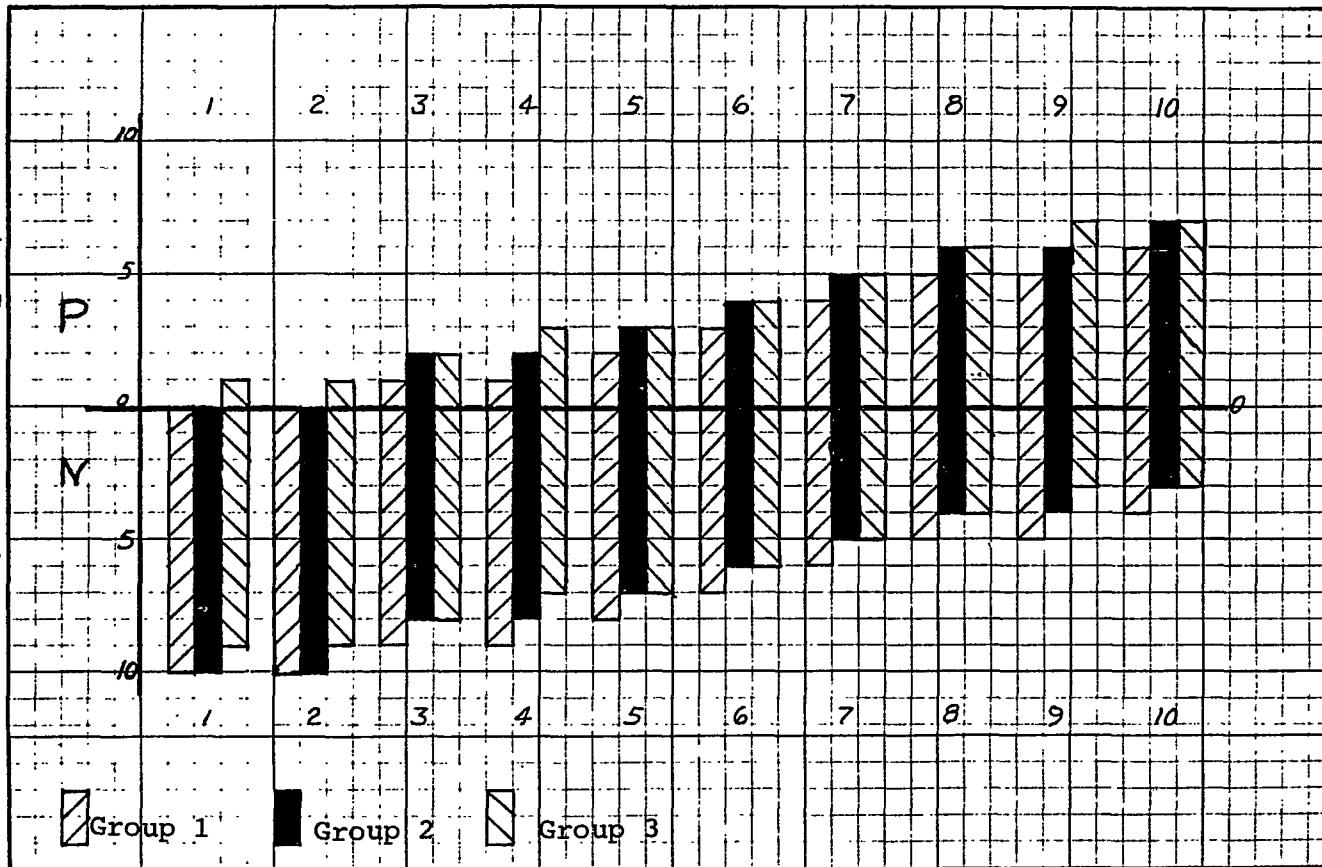


Fig. 18. Attitude Criteria: N - Negative; P - Positive

This study states a hypothesis that exposure to the strategy of multiple family counselling would make a difference in the behavior of the clients in the sample groups. The null hypothesis asserts that the exposure will not make any difference in the behavior. This study, hopefully, is to disprove the null hypothesis.

The first step in hypothesis testing is to state the null and alternative hypothesis, which was done in the previous paragraph. The next step is to select the criterion or level of significance, represented by α . The level selected for this experiment was $\alpha = .05$, which gives us a probability of .05 or less.

Having selected a criteria of significance, the data was reviewed and an appropriate statistical test was chosen.

The t -test for matched samples was the statistical technique selected, since the same group was tested twice, by the pre and post scores of the exposure to the program strategy.

To analyze matched pair data, the following procedure is used:

1. Since each score in sample $1X_1$ (before) has a paired counterpart in sample $2X_2$ (after), we subtracted X_2 from X_1 and obtained a difference score D .
2. The next step is to compute the mean difference score obtained from the sample, D :

$$D = \frac{\sum D}{N}$$

where $N = 10 =$ number of clients observed.

3. The sampling distribution--the t-table--is given in terms of degrees of freedom rather than sample size. In this situation there are $N-1$ df, or $10 - 1 = 9$ df.
4. Critical region: t-value, with a significance level of 0.05 and 9 df is 2.26. If the obtained value of t is greater than 2.26, we reject the null hypothesis. If the obtained value of t is less than 2.26, we accept the null hypothesis.
5. The statistical test for the difference between two means in a matched sample uses the following computing formula.

$$t = \frac{\Sigma D}{\sqrt{\frac{N\Sigma D^2 - (\Sigma D)^2}{N - 1}}}$$

The analysis of variance, ANOVA, is a technique of statistical analysis that permits us to overcome the ambiguity involved in assessing significant differences when more than one comparison is made. It helps us to see if there is any indication that the experimental strategy is producing differences among the means of the various groups involved.

In ANOVA, we test the null hypothesis about means by testing the variances. The procedure is based on the sample data yielding two independent estimates of the population variance, such as:

SCORES OF THE TEN SUBJECTS IN A
BEFORE-AFTER DESIGN

GROUP 1

Criteria	Before	After	Difference	
	X_1	X_2	D	D^2
1	9	10	-1	1
2	8	10	-2	4
3	4	7	-3	9
4	6	8	-2	4
5	1	5	-4	16
6	3	8	-5	25
7	1	6	-5	25
8	2	5	-3	9
9	0	7	-7	49
10	7	9	-2	4
11	3	4	-1	1
12	3	8	-5	25
13	2	6	-4	16
14	5	7	-2	4
15	<u>6</u>	<u>9</u>	<u>-3</u>	<u>9</u>
	60	109	-49	201

$$N = 10$$

$$\frac{df}{a} = \frac{9}{0.05}$$

$$t = \frac{\sum D}{\sqrt{\frac{N\sum D^2 - (\sum D)^2}{N-1}}}$$

$$t = 7.44$$

SCORES OF THE TEN SUBJECTS IN A
BEFORE-AFTER DESIGN

GROUP 2

Criteria	Before	After	Difference	
	X_1	X_2	D	D^2
1	10	10	0	0
2	10	10	0	0
3	5	8	-3	9
4	4	8	-4	16
5	2	5	-3	9
6	2	7	-5	25
7	0	8	-8	64
8	1	6	-5	25
9	0	2	-2	4
10	6	8	-2	4
11	3	5	-2	4
12	4	8	-4	16
13	3	7	4	16
14	6	9	-3	9
15	<u>7</u>	<u>9</u>	<u>-2</u>	<u>4</u>
	63	110	-47	205

$$\begin{aligned} N &= 10 \\ df &= 9 \\ \alpha &= 0.05 \end{aligned}$$

$$t = \frac{\sum D}{\sqrt{\frac{N \sum D^2 - (\sum D)^2}{N-1}}} \quad t = 11.2$$

SCORES OF THE TEN SUBJECTS IN A
BEFORE—AFTER DESIGN

GROUP 3

Criteria	Before	After	Differences	
	X_2	X_2	D	D^2
1	10	10	0	0
2	10	10	0	0
3	5	8	-3	9
4	4	7	-4	16
5	3	8	-5	25
6	3	7	-4	16
7	1	4	-3	9
8	3	6	-3	9
9	1	5	-4	16
10	6	9	-3	9
11	2	4	-2	4
12	4	8	-4	16
13	3	9	-6	36
14	6	8	-2	4
15	<u>7</u>	<u>9</u>	<u>-2</u>	<u>4</u>
	68	112	-44	166

$$\begin{aligned}
 N &= 10 \\
 df &= 9 \\
 \bar{a} &= 0.05
 \end{aligned}$$

$$t = \frac{\sum D}{\sqrt{\frac{N\sum D^2 - (\sum D)^2}{N-1}}} \quad t = 7.95$$

	Group 1	Group 2	Group 3
Obtained value of \underline{t}	7.44	11.20	7.95
Degrees of Freedom	9.00	9.00	9.00
a-Value	0.05	0.05	0.05
Table value of \underline{t}	2.26	2.26	2.26

Fig. 19. \underline{t} -Test for Matched Samples

The obtained value of \underline{t} was greater in each situation than the tabled value, so we can reject the null hypothesis. We can support the alternate hypothesis that there is a significant difference between the pre and post scores in all three groups.

1. Within group variance estimate--based on how different each of the scores in a given sample (or group) is from other scores in the same group.
2. Between group variance--based on how different the means of the various samples (or groups) are from one another.

The first step in the ANOVA design is to compute the sum of squares between groups (SS_B) the sum of squares within groups (SS_W) and the total sum of squares (SS_t),

$$SS_B + SS_W = SS_t.$$

The formula for computing the total sum of squares is:

$$SS_t = \Sigma X^2 - \frac{(\Sigma X)^2}{N}$$

N = the total number of observations.

The formulas for computing SS_B and SS_W are as follows:

$$SS_B = \frac{(\Sigma X_1)^2}{N_1} + \frac{(\Sigma X_2)^2}{N_2} + \frac{(\Sigma X_3)^2}{N_3} - \frac{(\Sigma X)^2}{N}$$

$$SS_W = X_1^2 - \frac{(\Sigma X_1)^2}{N_1} + X_2^2 - \frac{(\Sigma X_2)^2}{N_2} + X_3^2 - \frac{(\Sigma X_3)^2}{N_3}$$

or $SS_W = SS_t - SS_B$

The next step is to divide the SS_B and SS_W by the appropriate degrees of freedom. The values obtained are called the mean squares and are estimates of the population variance.

The degrees of freedom for between groups (df_B), are obtained by the following formula:

$$DF_B = k-1 \quad k = \text{the number of groups}$$

The degrees of freedom for the within groups (df_w) are obtained by the following formula:

$$df_w = N-k \quad N = \text{the total number of observations.}$$

This results in $\frac{SS}{dfw} = MS_w$ the mean square within the groups

and in $\frac{SS}{dfb} = MS_B$ the mean square between the groups.

Having computed the mean squares, the last step is to compute the F ratio, where $F = \frac{MS_B}{MS_w}$.

It is customary to summarize the results of the analysis variance in a table, such as the one shown in Figure 20.

ANALYSIS OF VARIANCE
PRE-PROGRAM FOR ALL THREE GROUPS

Criteria	Group 1		Group 2		Group 3	
	X_1	X_1^2	X_2	X_2^2	X_3	X_3^2
1	9	81	10	100	10	100
2	8	64	10	100	10	100
3	4	16	5	25	5	25
4	6	36	4	16	4	16
5	1	1	2	4	3	9
6	3	9	2	4	3	9
7	1	1	0	0	1	1
8	2	2	1	1	3	9
9	0	0	0	0	1	1
10	7	49	6	36	6	36
11	3	9	3	9	2	4
12	3	9	4	16	4	16
13	2	4	3	9	3	9
14	5	25	6	36	6	36
15	<u>6</u>	<u>36</u>	<u>7</u>	<u>49</u>	<u>7</u>	<u>49</u>
	60	344	63	405	68	420

$$\begin{aligned} X_2 &= 191 \\ X^2 &= 1169 \end{aligned}$$

$$F = \frac{MS_b}{MS_w}$$

$$\begin{aligned} K &= 3 \\ N_+ &= 30 \\ N_1 &= 10 \\ N_2 &= 10 \\ N_3 &= 10 \end{aligned}$$

$$\begin{aligned} K - 1 &= 2 \\ N_t - K &= 27 \\ dfb &= 2 \\ dfw &= 27 \\ a &= 0.05 \end{aligned}$$

Source of Variation	SS	df	MS	F
Between Groups	3.3	2	1.65	.91
Within Groups	-50.3	27	-1.80	
Totals	-47.0	30		

Fig. 20. Summary of ANOVA Calculations

The null hypothesis is that the samples were drawn from the same population.

The alternate hypothesis is that the samples were not drawn from the same population

For the present problem we cannot reject the null hypothesis.

The obtained value of -0.91 is less than the critical value of 3.35 ; therefore, using $\alpha = .05$, we retain the null hypothesis and conclude that there is no significant difference among the three population means.

Summary

The purpose of using the statistical technique was to test the null hypothesis and determine either to reject or retain the inference. In the first situation, the t-test for matched samples was used to learn if there was any significant difference between the pre and post scores. We selected the level of significance or alpha (α) as 0.05. This is the cutoff point as the basis for inferring the operation of non-chance factors. The area of rejection or critical region is equal to the level of significance and in this study we chose the 0.05 criterion. The t-test indicated that the post scores were statistically significant at the .05 level of confidence and we rejected the null hypothesis and preferred the alternative hypothesis. Since each score X_1 (before) in the three groups has a counterpart in the X_2 (after), we subtract each X_2 from X_1 and obtain a difference score. Each subject, therefore, served as his/her own control and each pair of scores was matched by coming from the same subject. It would have been desirable to have additional control groups in this study, but this was beyond the present situation. The sample was small and we can only infer that for these specific clients there appeared to be a significant difference between the pre and post scores.

The second test was analysis of variance, a procedure for testing the differences among three or more means. The

null hypothesis tested by ANOVA is that the means of the populations from which the samples were drawn are all equal. The results of the ANOVA indicated that the obtained value of F was less than the critical value, at the 0.05 criterion; we retain the null hypothesis and conclude that there is not sufficient reason to believe that there are any significant differences between the means. If the null hypothesis is retained, the result is not statistically significant at the 0.05 level.

If the F -value was significant, then further analysis might be initiated by using the protected t -test. In this test any or all of the paired means may be compared by the t -test using the usual design rule.

It is hoped that the inferences obtained may act as an incentive for further investigation into the potential for multi-family counselling as a means of improving adherence to prescribed medical regimens.

If this study were to be repeated, it would be important to increase the number of samples tested, establish a control group, and refine the tools of measurement and data collecting.

The work sheets for these calculations on the two tests can be reviewed in Appendix C4.

Section 4

CONCLUSION

CONCLUSION

This study was an exploratory design and therefore can not provide any causal relationships, but the response of the participants when exposed to the program is of concern to the researcher.

The participants were all adults and the approach used was Knowles' theory of adult education as management of the environment and interaction, creating a learning experience. The family was viewed as a system, the elements of which are interdependent and what happens to one component has consequences for the other elements of the system. The significant others were included in the groups, supporting Lewin's belief that habits and attitudes do not change in isolation, but are related to the habits and attitudes of the significant others or the groups that the individual is affiliated with. Glasser's concept that illness was not an excuse for lack of responsible behavior and that each individual must assume responsibility for his/her behavior today was a major factor stressed by the researcher. In addition, his belief that this process can only take place with involvement with other responsible persons supported the strategy selected for this study. Laqueur's multi-family aspect created an awareness of the various options available and an opportunity to observe the process of selection and decision making

of the various members of the groups. The creation of the basic concept in adult education, management of environment and interaction, was the area that the participants stated was most important to them when they evaluated the program. They expressed the need for this experience on an ongoing basis as well as at the onset of the disease process. The opportunity to interact with other diabetics, receive feedback and support, and to have professional resources available for clarifying issues that were confusing.

If this program were to be repeated, the same strategy would be used, but an effort would be made to establish some form of control group and to use individual blood glucose monitoring as a tangible means of collecting more specific data about the changes taking place. If the blood glucose monitoring were to be included, this would require the cooperation of the participants' physician. This might also provide an additional support person and help to reinforce the habits and attitudes that were desired.

The t-test for matched samples was the first statistical technique selected for the data analysis, since the same group was tested twice, by the pre and post scores. The purpose was to determine if any significant differences appeared in the scores following exposure to the program.

The analysis variance test for the F ratio was selected next, to determine if any significant difference existed between the means of the pre score data of the three groups.

The results obtained from the t-test indicated a significant difference between the pre and post scores for all three groups and the researcher rejected the null hypothesis. In the analysis variance test for the F-ratio there was no significant difference between the means of all three groups and the researcher accepted the null hypothesis.

The process of data collecting was not disturbing to the group members and they were anxious to hear what the respective scores were, even though it was explained that no causal relationship could be concluded. The data analysis indicated that the pre-scores of the three groups showed no significant difference. This might imply some common denominator present, but the circumstances of the program did not offer an opportunity to investigate this factor.

There was a significant difference between the pre and post scores of all three groups, but there was no one specific factor that could be attributed to the change in the scores.

The scoring was done solely by the researcher, so that the objectivity was limited by the individuals' subjective interpretations. On the other hand, the scoring was done as each session was in progress and this may have tended to minimize the potential threat to validity in an exploratory design. The confidence of the findings could be increased, if similar programs were replicated and the data revealed similar results.

The unexpected findings were as follows:

1. Several of the significant others became resource persons in their community and at work on information about diabetes and the various community resources available.
2. The participants developed the ability to ask more pertinent questions about their condition and to expect definite answers from their physicians.
3. The participants expressed the desire to have the groups continue on an ongoing basis, with the opportunity to come when they felt the need for support and interaction.
4. The need to inform physicians that this kind of group experience is available, so that referrals can be made early in the disease process.
5. Those who started to wear the medical alert wrist bands were surprised to find that they were not discriminated against, but that their peers did not even notice its presence.

At the present time, we can only state that for these participants

1. There appears to be no significant difference in the pre score means of the three participating groups.
2. There is evidence of a significant difference

between the pre and post scores of all three groups.

3. The participants stated that the strategy used, multi-family, experience sharing, group counseling was a positive experience, lowering the feelings of anxiety and providing direction in what could be done to improve the situation.

All programs sponsored by the New York Diabetes Affiliate must have the participant fill out the standard evaluation form (Appendix C5). The contents of the forms were discussed informally with the members of each group. They expressed feelings of agreement and satisfaction with the final summation of their evaluation forms. Knowles supports the use of informal evaluations by the participants of an educational program (Appendix C5).

The request for follow-up sessions will be discussed with the staff at the New York Diabetes Affiliate and the group members will be notified if additional meetings are to be scheduled.

This study does not provide any causal relationships, but the data suggests that further investigation, in the same direction, may be warranted. The goal is to develop more Hypotheses and additional research to furnish more definitive data toward resolving the problem of non-compliance or non adherence to prescribed treatment regimens in chronic illness.

APPENDICES

APPENDIX A

APPENDIX A1

The following pages were included in the appendix of this study because they provide vital information for a group leader, who is working with clients with a chronic illness. The psycho-social factors identified in Table 1 were often recognized by the client and introduced into the discussion as an existing problem.

The content of the following extract from the Health Education Monograph introduces problems that might exist without the client being consciously aware of their existence. These situations, when they exist, can have a strong influence on the behavior of the client and the family.

It would be the group leader's responsibility to have a reference of these situations available, as a reminder of potential barriers to compliance to prescribed treatment regimens.

The following statements were extracted from an article in the Health Education Monograph on "Chronic Illness."

The factors to be dealt with are threats to the former life style, such as the possible recurrence of the acute stage of the illness, possible reduced earning power, sexual impotence, decreased activity, and the possibility of disability.

Thus, in addition to survival, there is the problem of facing the question of how well he/she will live. The total situation is full of proscriptions.

Where there are no actual physical limitations (loss of limb, immobility or paralysis), there is a wide latitude of action. The freedom can be complex and confusing when one is on their own, in interpreting what appear to be vague and ominous warnings and directions, which require the establishing of new limits of action.

What changes are really necessary?

What will be most effective in preventing another attack?

These questions may not have clear cut answers. The harder dimension is that sudden death may be the consequence of overstepping the unclear boundary line of safety.

Important activities are learning to interpret bodily signs, dealing with divergent interpretations of what is possible and expected, among various consequential people in one's life, developing balancing equations and finding specific ways of changing behavior. Interpreting vague indicators and correcting these interpretations are based upon perceived consequences to the client.

A sense of confidence in one's ability to read cues is needed not only to assess the degree of impairment, gauge progress, but also to anticipate and recognize crisis in order to summon help and to establish limits of action for specific activities. There are two problematic aspects of cutting back, the interdependence of activities and their differential valuation by others who are involved with the client. The activity itself may not be valued by the client. The concern may be with what is associated with it. It may be prized by a person important in the immediate social context of the client. The perception may be that change will affect the relationship negatively.

In some cases, the absence of clear symptoms or the invisibility of impairment (client passes as well), are major factors in the definition of the situation for the family, peers, co-workers, health care personnel, and the client. These perceptions act as outside controls in shaping the needed changes. In addition, the personal resistance of the client to any form of change, may act as an internal control and thus limit the development of change.

Source: "Chronic Illness," special report of Health Education Monograph, Vol 6, #3 (1978): 299-304.

APPENDIX B

APPENDIX B1

The following Tables 17 and 18 are submitted as potential guides for group leaders in the organization of their objectives from their assessment tools. They provide a means of classifying the data collected into specific categories and then selecting the techniques best suited to achieve the desired outcomes. The information helps to plot the course of action and later to evaluate those areas which might need further development.

These tables are samples that may be used as they are or which might inspire the creation of innovative variations that would serve the specific program that is being planned.

Clients should always be informed of the desired objectives and share in the design of plans to resolve the problem areas. The purpose of the multi-family groups is to provide a large resource of experiences that can be tapped for the group members to utilize in their efforts to cope with the disease process.

TABLE 17

WORKSHEET FOR STATING LEARNING OBJECTIVES

Behavioral Aspect	Content Areas
To develop knowledge about	1.
	2.
	3.
	4.
	5.
	6.
	7.
To develop understanding of	1.
	2.
	3.
	4.
	5.
	6.
	7.
To develop skill in	1.
	2.
	3.
	4.
	5.
	6.
	7.
To develop attitudes toward	1.
	2.
	3.
	4.
	5.
	6.
	7.
To develop interest in	1.
	2.
	3.
	4.
	5.
	6.
	7.
To develop values of	1.
	2.
	3.
	4.
	5.
	6.
	7.

Source: M. Knowles, The Modern Practice of Adult Education,
Associated Press, NY 1970, p. 287.

TABLE 18

MATCHING TECHNIQUES TO DESIRED BEHAVIORAL OUTCOMES

Type of Behavioral Outcome	Most Appropriate Techniques
<i>Knowledge</i> (Generalizations about experience; internalization of information)	Lecture, television, debate, dialog, interview, symposium, panel, group interview, colloquy, motion picture, slide film, recording, book-based discussion, reading.
<i>Understanding</i> (Application of information and generalizations)	Audience participation, demonstration, motion picture, dramatization, Socratic discussion, problem-solving discussion, case discussion, critical incident process, case method, games.
<i>Skills</i> (Incorporation of new ways of performing through practice)	Role playing, in-basket exercises, games, action mazes, participative cases, T-Group, nonverbal exercises, skill practice exercises, drill, coaching.
<i>Attitudes</i> (Adoption of new feelings through experiencing greater success with them than with old)	Experience-sharing discussion, group-centered discussion, role playing, critical incident process, case method, games, participative cases, T-Group, nonverbal exercises.
<i>Values</i> (The adoption and priority arrangement of beliefs)	Television, lecture (sermon), debate, dialog, symposium, colloquy, motion picture, dramatization, guided discussion, experience-sharing discussion, role playing, critical incident process, games, T-Group.
<i>Interests</i> (Satisfying exposure to new activities)	Television, demonstration, motion picture, slide film, dramatization, experience-sharing discussion, exhibits, trips, nonverbal exercises.

The first step in the use of this guideline is to match the technique to the objective. Certain techniques are more effective in helping to bring about certain types of behavioral change than others. For example, a lecture may be effective technique for increasing knowledge, but it has little impact on attitudes. The second step is the principle of participation; given a choice between the techniques, choose the one involving the client in the most active participation.

Source: M. Knowles, The Modern Practice of Adult Education, Associated Press, NY, 1970, p. 294.

APPENDIX B2

Table 19 presents in some detail, the areas of concern for each of the three stages of health education for any chronic illness as identified by Dr. Etzweiler. It provides a guide to help the group leader focus on the major needs in each stage of coping with the disease process.

When the diagnosis is first made, survival techniques have priority. Following this is a need for lifestyle adjustment and when this is accomplished, the need for continuing education assumes an appropriate place in the educational process. Through all three stages there may be a need to review and reinforce basic knowledge and skills to maintain accurate procedures and motivation for compliance to regimens.

This information can be a guide for setting priorities in the implementation of health education programs and may also serve in the development of assessment tools.

TABLE 19
DIABETES EDUCATION PROGRAM

Goals and Objectives

Initial Goals and Objectives: After diagnosis, the first goals are to inform the client about the diagnosis, and provide him/her with the information and skills necessary for immediate management

To accomplish this the health professional must:

1. Explain the diagnosis
2. Assess the clients understanding of the disease
3. Explain the importance of client participation in management.
4. Help the client obtain the necessary education and skills for immediate management.

Intermediate Goals and Objectives

After the client has accepted the diagnosis and is ready for more responsibility, the goal is to increase the client's management skills and understanding of the disease of the disease process.

To accomplish this the health professional must:

1. Help the client obtain in-depth information on all aspects of diabetes.
2. Provide the client with skills for controlling blood sugar levels under unusual circumstances.
3. Develop a long range management program for the client
4. Provide necessary support to aid client in following a long term program.
5. Provide the client with a plan for continuing education

Long Term Goals and Objectives

After the client has the necessary information and skills to manage his/her disease in all situations, the goal is to maintain and update the client's management skills and understanding as necessary.

To accomplish this the health professional must:

1. Continue to assess the client knowledge and skills
2. Provide remedial education and skills training as necessary.
3. Provide open discussion for problem questions
4. Provide continuing support and motivation
5. Provide a continuing plan for update education.

Adapted form Etzwiler, D. Education of the patient with diabetes.
Med. Clin. North Am. 62:857-866. 1978.

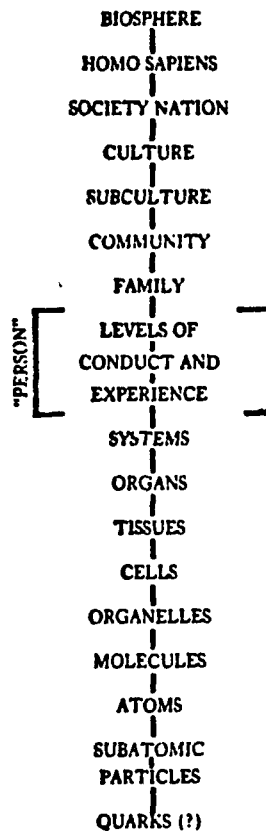
APPENDIX B3

The basis of this study is the systems view of man. Tables 20, 21, and 22 illustrate that in health there is a harmonious interaction of all the hierarchy. In disease there is a disruption of this harmony, which results in the inability to perform complex, coordinated physical and mental activities. The result is the development of emotional trauma in the family and in the immediate social context. This emotional stress often requires role re-alignment for the family. In addition, the client must reaccess self worth and learn new skills and living patterns.

This study present a program the goal of which is designed to resolve the disruptions of the family system, which are caused by a chronic illness, specifically diabetes.

TABLE 20
SYSTEMS VIEW OF MAN

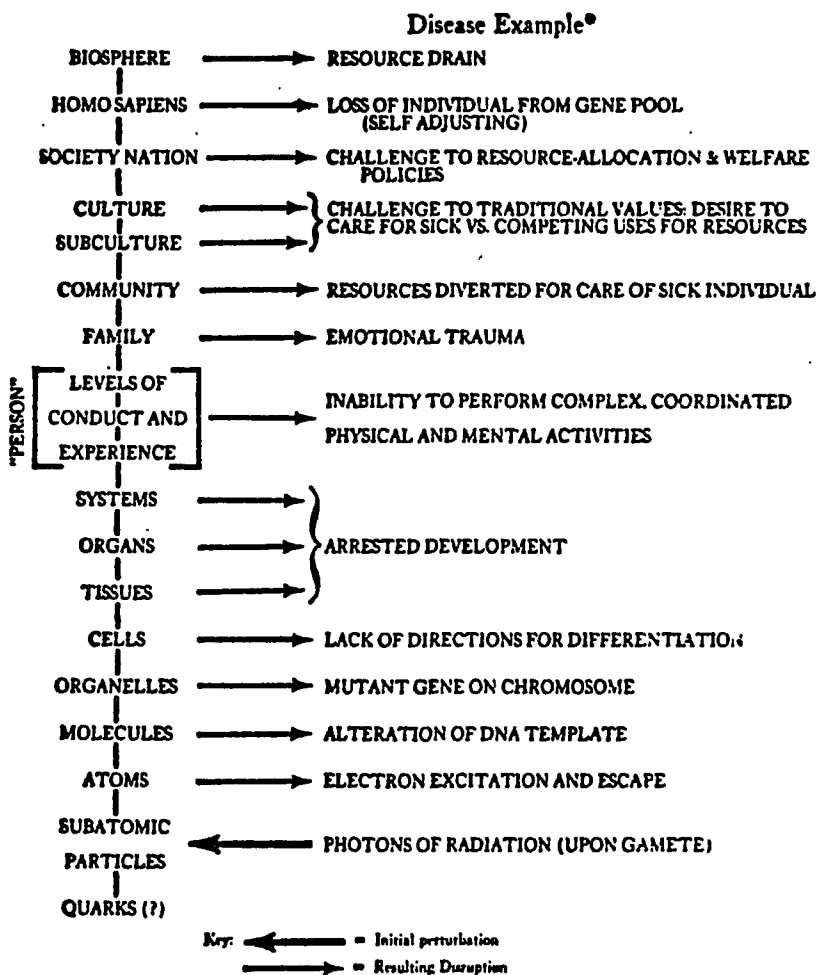
Hierarchy of Natural Systems Constituting Man*



* Reprinted by permission. Howard Brody, "The Systems View of Man: Implications for Medicine, Science and Ethics," *Perspectives in Biology and Medicine* (Autumn 1973). ©1973 by the University of Chicago. All rights reserved.

Source: R. Egdahl, P. Gertman, Quality Assurance in Health Care, Germantown, MD: Aspen Press, 1976, p. 263.

TABLE 21
SYSTEMS VIEW OF MAN
(cont'd)

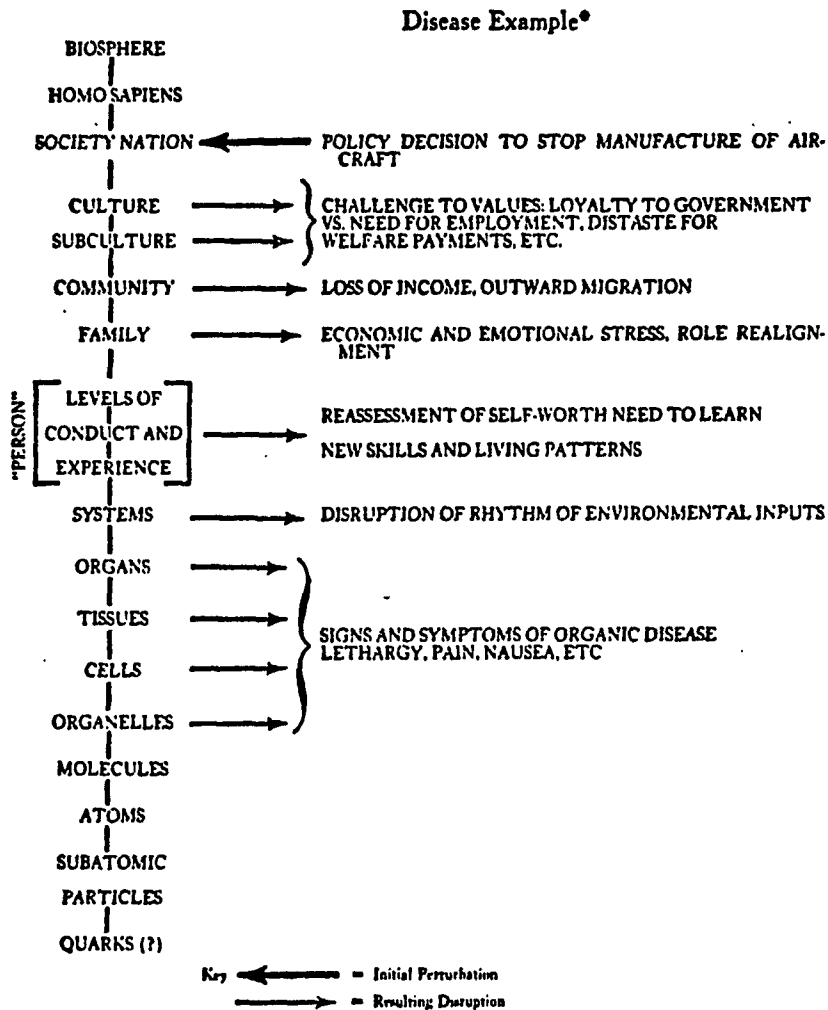


* Severe physical and mental retardation caused by a radiation-induced mutation in the gamete: example of spread of disruption upward through the hierarchy.

* Reprinted by permission. Howard Brody, "The Systems View of Man: Implications for Medicine, Science and Ethics," *Perspectives in Biology and Medicine* (Autumn 1973). ©1973 by the University of Chicago. All rights reserved.

Source: R. Egdahl, P. Gertman, Qualitative Assurance in Health Care, Germantown, MD: Aspen Press, 1976, p. 264.

TABLE 22
SYSTEMS VIEW OF MAN (cont'd)



* Stress-related psychosomatic illness in an unemployed aerospace engineer: example of spread of disruption downward through the hierarchy.

* Reprinted by permission. Howard Brody, "The Systems View of Man: Implications for Medicine, Science and Ethics," *Perspectives in Biology and Medicine* (Autumn 1973). ©1973 by the University of Chicago. All rights reserved.

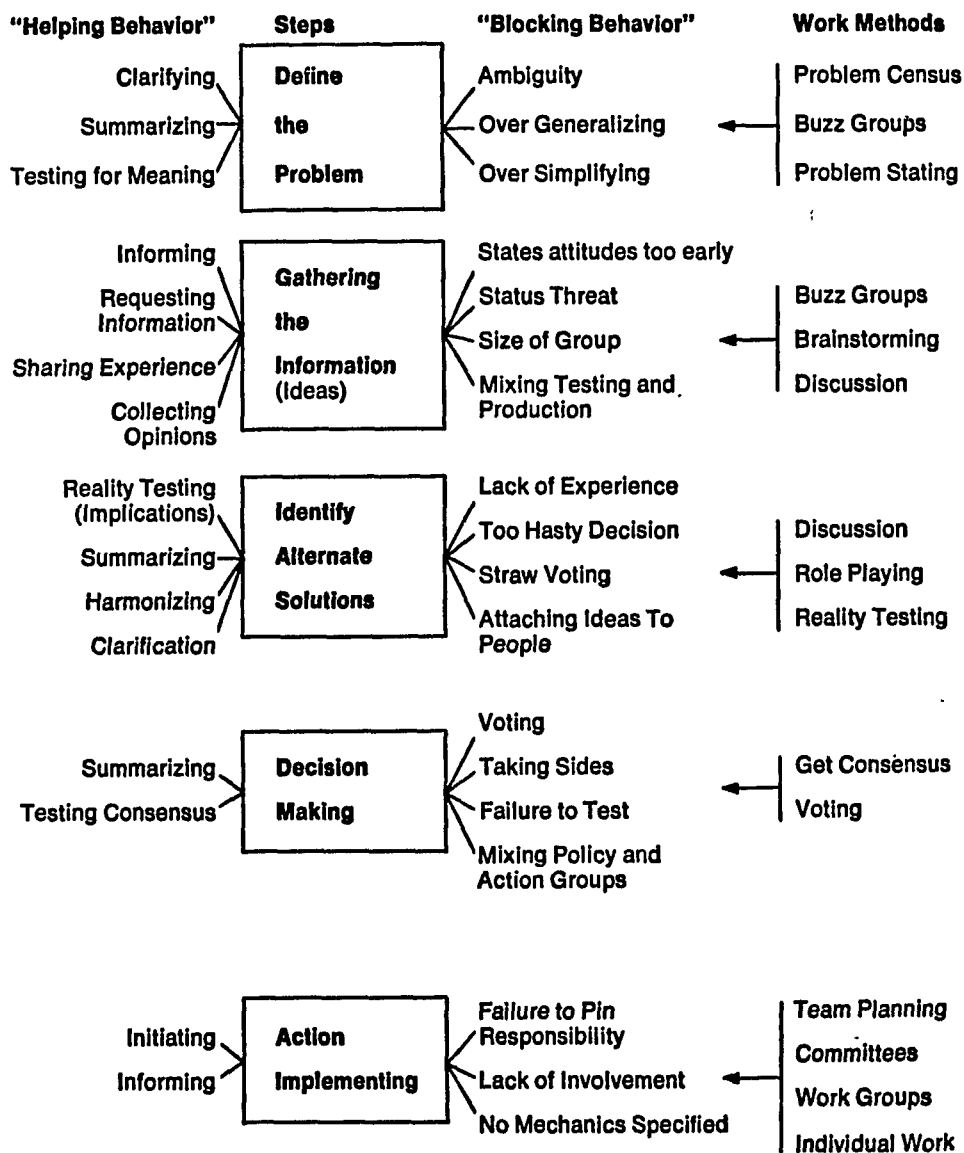
Source: R. Egdahl, P. Gertman, Qualitative Assurance in Health Care, Germantown, MD: Aspen Press, 1976, p. 265.

APPENDIX B4

The focus of the multi-family counselling is to develop skill in making decisions in the problem solving process, in this program specifically for diabetes.

Table 23 is submitted as a guide for the group leader, so that he/she can be alerted to the potential barriers and the helping behaviors in the problem solving process. The coping skills of problem solving are involved in each session of this study. This table can assist in planning the direction of the sessions for the group leader with limited experience. It may also be useful for instructors who are teaching the process to new group leaders. The work methods suggested are in the areas of group discussion and in this respect further support the procedure utilized for this particular study.

TABLE 23
STEPS IN DECISION-MAKING MODEL



Source: M. Knowles, The Modern Practice of Adult Education (New York: Associated Press, 1970), p. 358

APPENDIX C

APPENDIX C1

This outline is included to provide a sample of the key factors to be included when a specific criteria is being reviewed or discussed. This is an adaptation of the criteria used by the Michigan Diabetes Research and Training Center in Ann Arbor, when they assessed client needs in a recent community research study on diabetes.

An important factor is to emphasize to the family and the clients that all of these criteria are interrelated and not handled as isolated issues.

A similar outline could be designed for use for any chronic illness. It serves as a reference for the group leader and as a guide for review sessions. Instructors who are teaching new group leaders can refer to such an outline to stress the many facets to be considered in the planning of a health education program related to chronic illness.

Each person working with clients may find information from their own experience which finds needs to be added in order to meet the needs of their target population. This guide is only a basic reminder for those involved in health education.

Sample Education Outline

If a problem was presented in relation to hypoglycemia, the topics of medication, monitoring, diet, exercise, stress, carrying some form of sugar, the wearing the ID band are all involved in the resolution of the problem. The process includes alerting the client into seeing the interrelationship of all the assessment criteria. They are not isolated issues to be learned.

The following is a sample of the content that is used when discussions are held on the assessment criteria.

The 15 criteria selected were adapted from those originally developed by Michigan Diabetes Research and Training Center in Ann Arbor. They were used to assess the clients' needs in their research studies.

1. Medications

Purpose

Action

Administration: oral, subcutaneous, IM

Peak absorption times

Side effects

What to report to the physician

2. Monitoring

Purpose

Procedure--blood or urine

Record keeping

What to report to the physician

Client and MD should decide when monitoring data
indicates the need for extra sugar or insulin

3. Diet

Understanding "diabetic diet"

Learning to read labels

Review lists of sugars--circular flier

Explain absorption rates of foods

What to report to the physician

Refer to New York Diabetes Affiliate Club diet
program as resource

Refer to individual consultant as
needed

Establish sample trials for praactice
between sessions

4. Exercise

Importance for general health

In relation to food intake

In relation to medication

Place in total treatment approach

Consult physician for possible limitations

Effect on blood glucose levels

Carry some form of sugar when exercising

5. Wear ID bracelet
 - Importance for emergencies
 - Emotional adjustment of identity to others as a diabetic
 - Offers a chance to be a resource person regarding diabetes
 - Have forms available for purchase

6. Hypoglycemia
 - What it means
 - Identify individual symptoms
 - Actions to take--options available
 - What to report to the physician
 - Individual assignments for trial inbetween sessions with feedback for group sharing

7. Identify stress
 - Positive and negative causes of stress
 - Effect on the blood glucose levels
 - Individual responses to stress
 - What makes you anxious?
 - Relaxation procedures
 - Feedback from personal experiences

8. Support systems
 - Importance of significant others
 - Diabetes is a "family affair"
 - Need for support in total social context

Relate to hypoglycemia and psycho-social
problems

Develop individual plans for reinforcement in
changing life styles

Importance of feedback and group participation

9. Resource person

Identify contributions from group as resource acts

Importance to self and others

How can this be enlarged in the broad social
context

Helps to review own knowledge base

Chance to share experiences

10. Seeks information

Reviews sources available

Members share information acquired

Topics for discussion

Source of continuous education

11. Actively engaged in American Diabetes Affiliate
& New York Diabetes Affiliate

Means of updating knowledge base

Opportunity for continuing education

Chance to share in program planning to meet their
(clients') needs

12. Carries sugar at all times

Relate to diet, medication, monitoring,
exercise, stress and hypoglycemia

Display and explain forms of sugar the clients
are carrying now

13. Special foot care

Purpose

Procedure

Review "Do's and Dont's"

Preventive measures

When to consult a Podiatrist

What to report to the physician

14. Prevent infections

General Hygiene

Diet--Rest

Adequate fluids

When and what to report to the physician

Consult MD regarding flu and pneumonia vaccines

15. Regular health visits

Purpose

Prepare questions in advance

Practice writing questions--clear and specific

Request answers

Dental visits

Ophthalmologist visits

Podiatrist visits

APPENDIX C2

The work sheets are included to illustrate how data was collected at the individual sessions. The 15 criteria are listed across the top line with abbreviated indicators. The lines scored in the boxes indicate the responses of the clients at that session. This would be measured by self-reporting, using the terms "always" and "most of the time" as an indicator that control was being exercised for the particular item scored. The terms "some of the time" and "never" would indicate that the criteria needed to be the focus of the group discussion.

The first page records the first four sessions. The first session is scored from the client's original response to the assessment sheet at the first meeting. The second page reproduces the original scores from session one and those obtained from the last meeting on the previous page. This provides the group leader with a quick view of the progress being made and indicates those items requiring more attention. The third page follows the same pattern, the original scores, those of the last previous meeting and those that follow (Figs. 21, 22, 23).

The data collected on these work sheets can be used in a variety of data analysis procedures, such as graphs, profiles, and tests of significance (Figs. 24 through 35).

P	Positive	0	0	1	1
N	Negative	### ###	### ###	### ###	### ###
15	Dental Pod. Etc.	### 1	### 1	### 1	### 11
14	Preventive	###	###	###	### 1
13	Foot Care	"	###	###	###
12	Carries Sugar	###	###	###	###
11	ADA NYDA	###	###	###	###
10	Inform. re Diab.	### 1	### 1	### 11	### 11
9	Resource	0	0	0	1
8	Support Family	"	"	11	111
7	Stress	1	11	11	111
6	Hypogly - cemia	###	###	###	###
5	ID Band	1	1	11	11
4	Exercise	### 1	### 1	### 1	### 11
3	Diet	###	###	###	###
2	Monitors	### ###	### ###	### ###	### ###
1	Meds.	### ###	### ###	### ###	### ###
		1	2	3	4

Fig. 21. Sample Work Sheet for Group 1

1	Meds.	9	10	###	###	###	###	###	###
2	Monitors	8	10	###	###	###	###	###	###
3	Diet	4	5	###		###	1	###	1
4	Exercise	6	7	###	"	###	"	###	"
5	ID Band	1	2	###		###		###	
6	Hypoglycemia	3	5	###	1	###	1	###	"
7	Stress	1	3	###		###		###	
8	Support Family	2	3	###		###		###	
9	Resource	0	1	###		###		###	
10	Inform. re Diab.	6	7	###	"	###	"	###	"
11	ADA NYDA	3	3	"		"		"	"
12	Carries Sugar	3	5	###	"	###	"	###	"
13	Foot Care	2	5	###		###		###	
14	Preventive	5	6	###	1	###	1	###	1
15	Dental Pod. Etc.	6	7	###	"	###	"	###	"
N	Negative	10	9	###	###	###	"	###	1
P	Positive	0	1	"		"		"	

Fig. 22. Sample Work Sheet for Group 1 (cont'd)

1	Meds.	9	10	###	###	###	###	###	###
2	Monitors	8	10	###	###	###	###	###	###
3	Diet	4	6	###	,	###	###	###	###
4	Exercise	6	7	###	###	###	###	###	###
5	ID Bands	1	4	###		###	###	###	
6	Hypoglycemia	3	7	###	###	###	###	###	###
7	Stress	1	5	###		###	###	###	###
8	Support Family	2	5	###		###	###	###	
9	Resource	0	4	###		###	###	###	###
10	Inform. re Diab	6	9	###	###	###	###	###	###
11	ADA NYDA	3	4	###		###	###	###	
12	Carries Sugar	3	7	###	###	###	###	###	###
13	Foot Care	2	5	###	###	###	###	###	###
14	Preventive	5	6	###	###	###	###	###	###
15	Dental Pod. Etc.	6	9	###	###	###	###	###	###
N	Negative	10	6	###		###		###	
P	Positive	0	4	###		###		###	

Fig. 23. Sample Work Sheet for Group 1 (cont'd)

APPENDIX C3

The line graphs were the first step in developing an analysis of the data collected from the work. The coding of the scores in this manner indicates the similarity and differences in the direction each group took in relation to the criteria.

In reviewing these graphs, it is easy to determine which criteria were under control and which ones still needed more reinforcement and review (Figs. 24 through 35).

The information extracted from these graphs may be used in a variety of data analysis procedures, depending on the specific objectives of the program. In addition, the information may be used in the planning of future sessions or programs.

The line graphs in this study were used to develop the bar graphs (Figs. 7-18). Although based on the same score, they appear to present the facts from a different perspective.

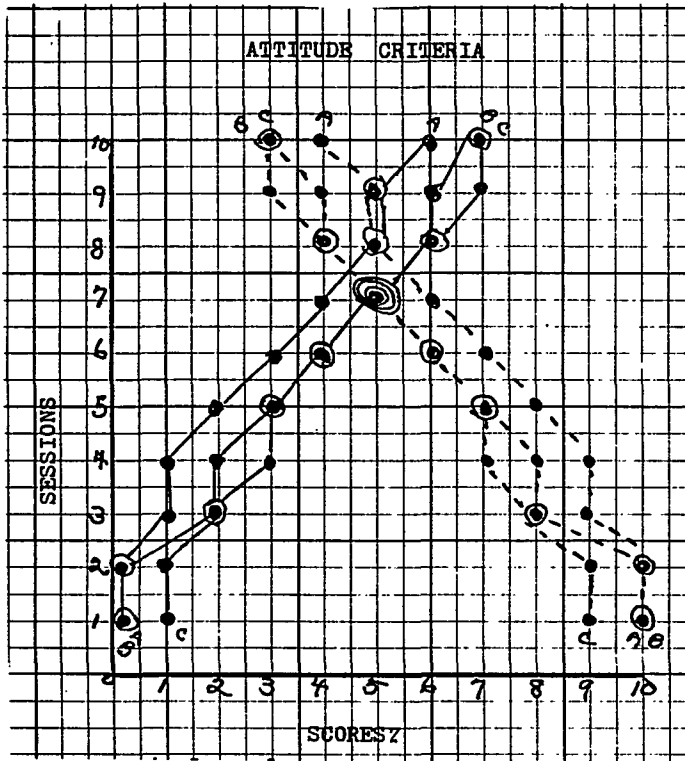


Fig. 24

A - Group 1
 B - Group 2
 C - Group 3

Solid Line - Positive
 Dotted Line - Negative

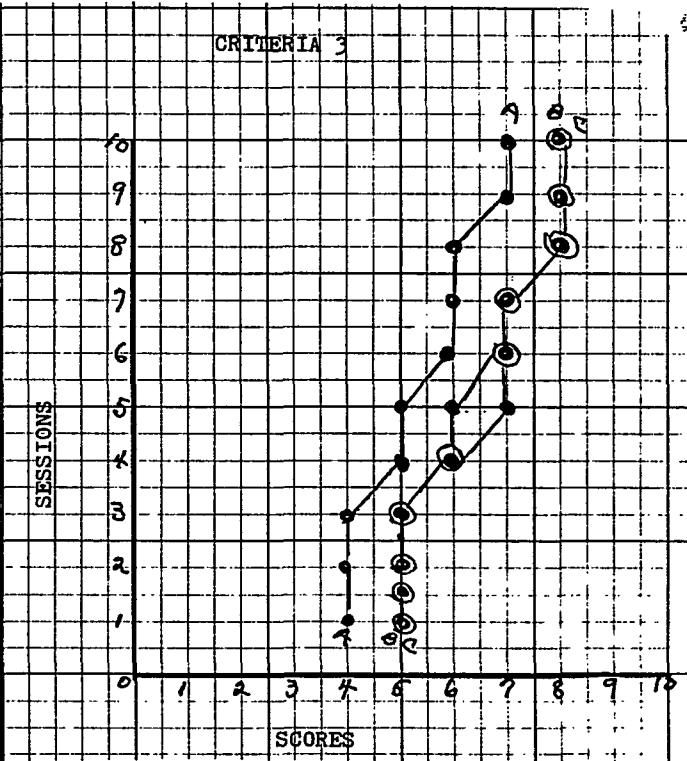


Fig. 25

Criteria #3 Follows Diet as Prescribed

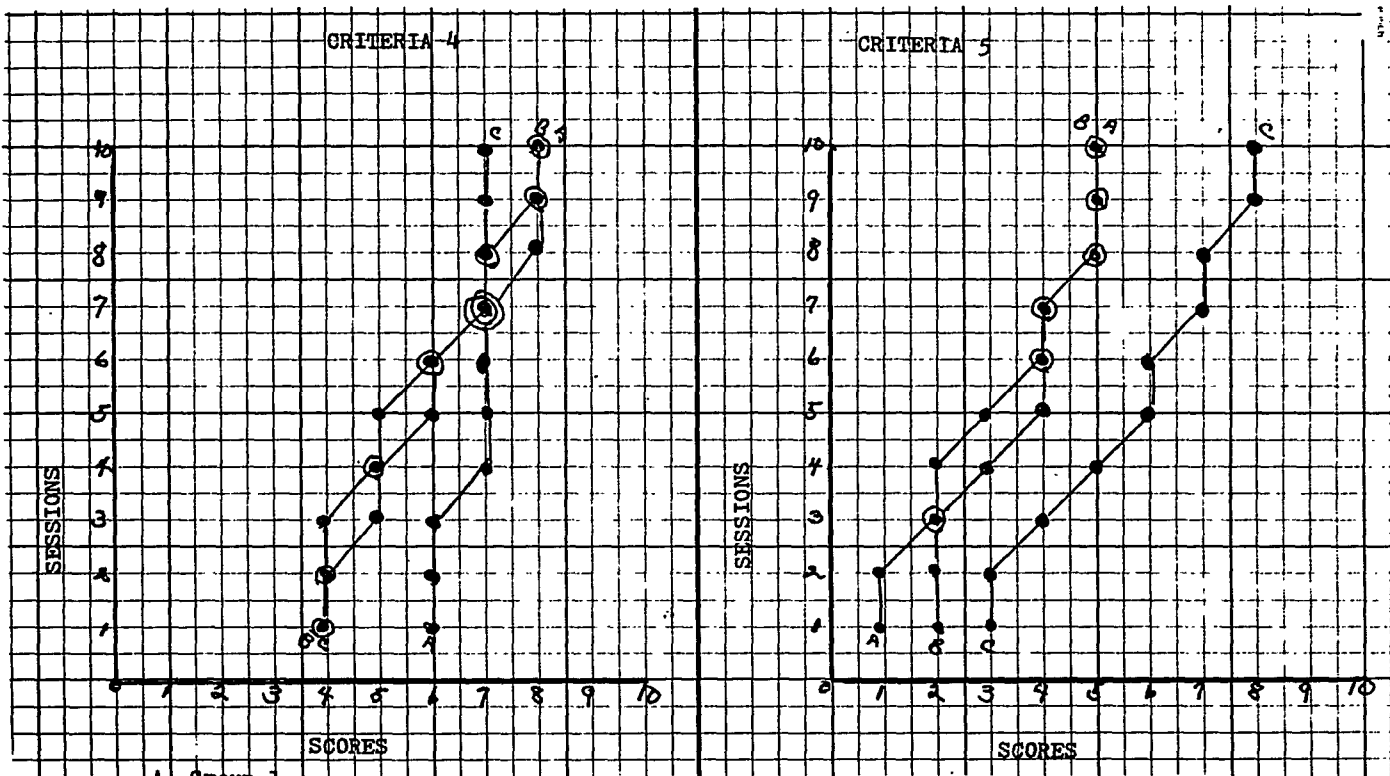


Fig. 26

Has an Exercise Program

Fig. 27

Wears an ID Band

- A - Group 1
- B - Group 2
- C - Group 3

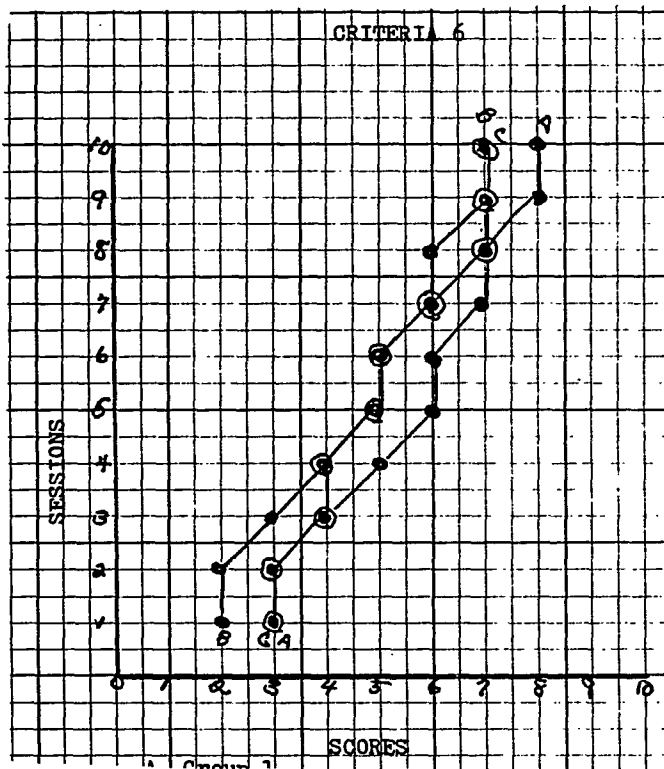


Fig. 28

Knows Signs of Hypoglycemia

- A - Group 1
- B - Group 2
- C - Group 3

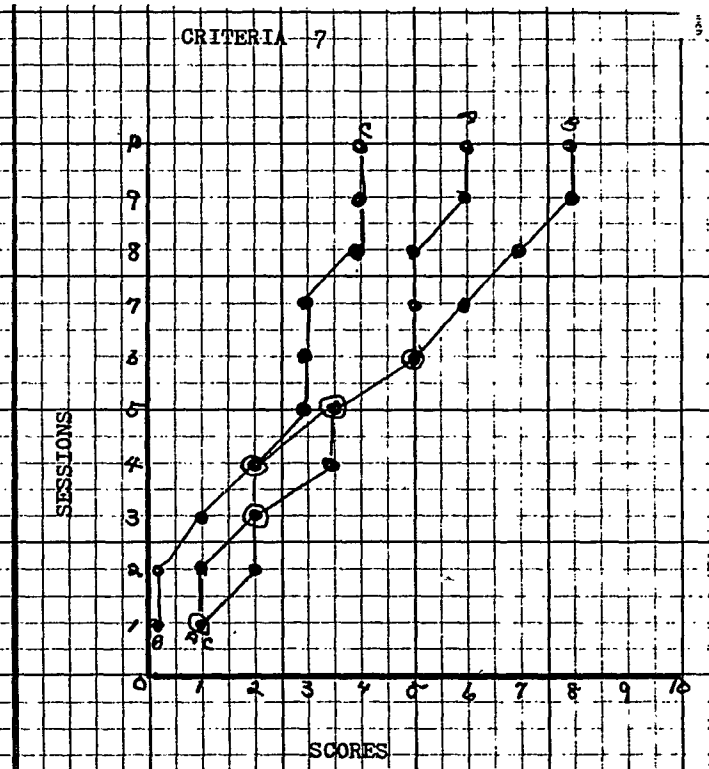


Fig. 29

Knows Effect of Stress on Diabetes

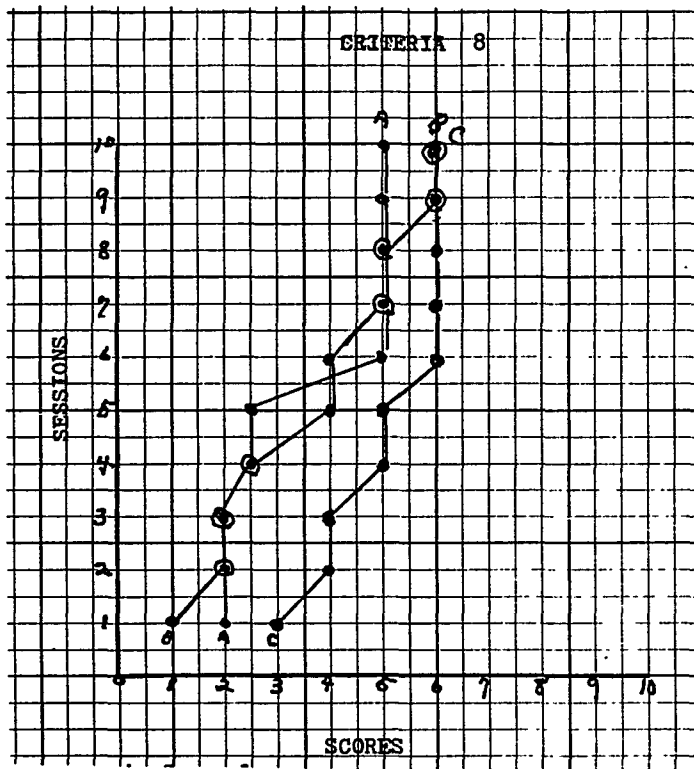


Fig. 30

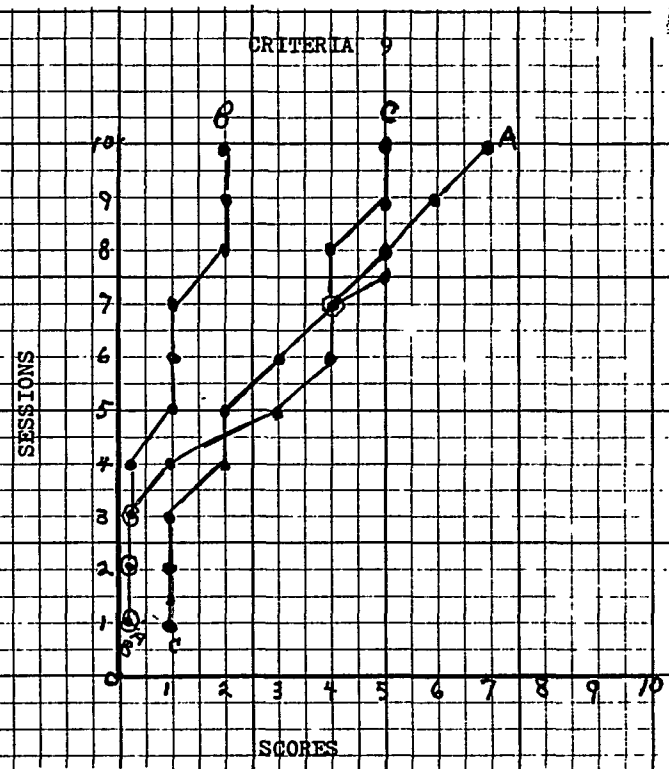


Fig. 31

Knows Need of Support from Family & Peers Aware of Self as a Resource Person

- A - Group 1
- B - Group 2
- C - Group 3

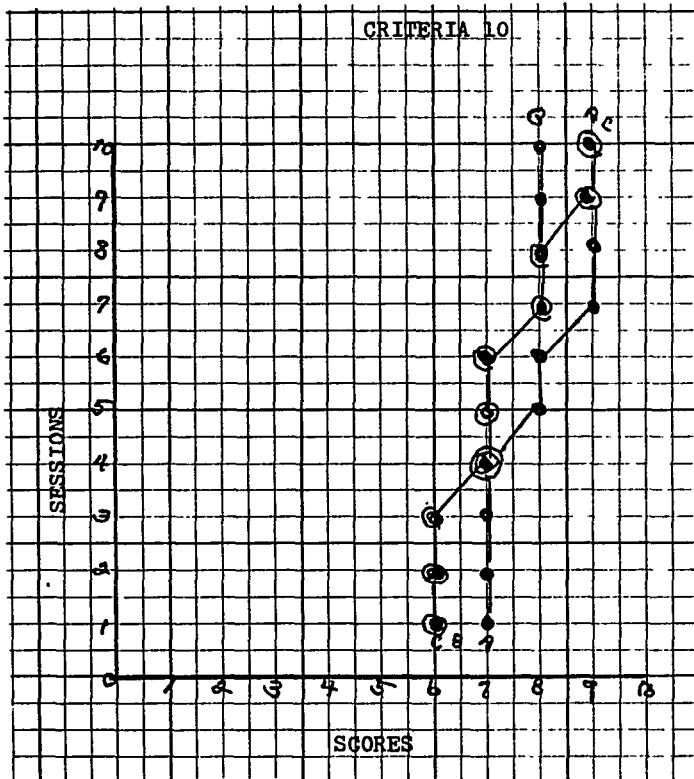


Fig. 32

Seeks Information About Diabetes

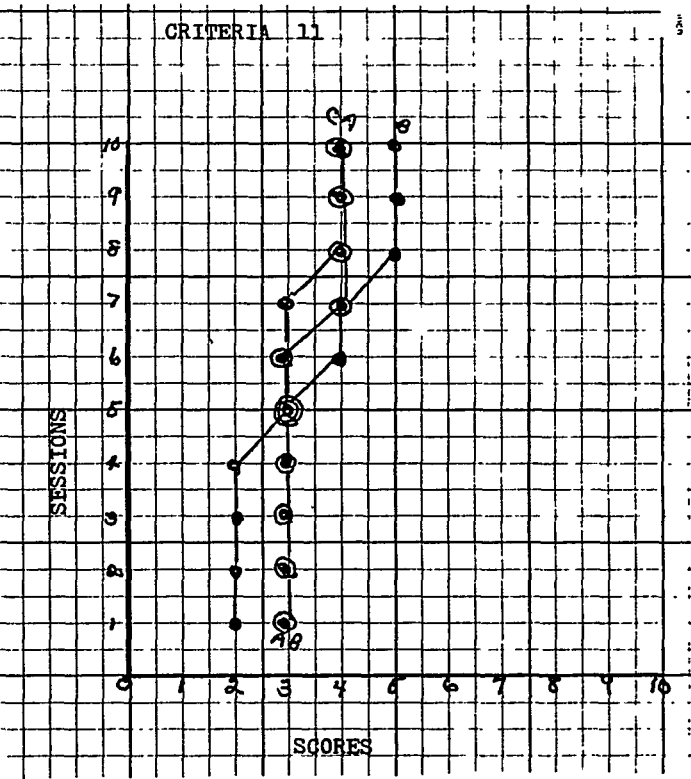


Fig. 33

Active in ADA and NYDA

- A - Group 1
- B - Group 2
- C - Group 3

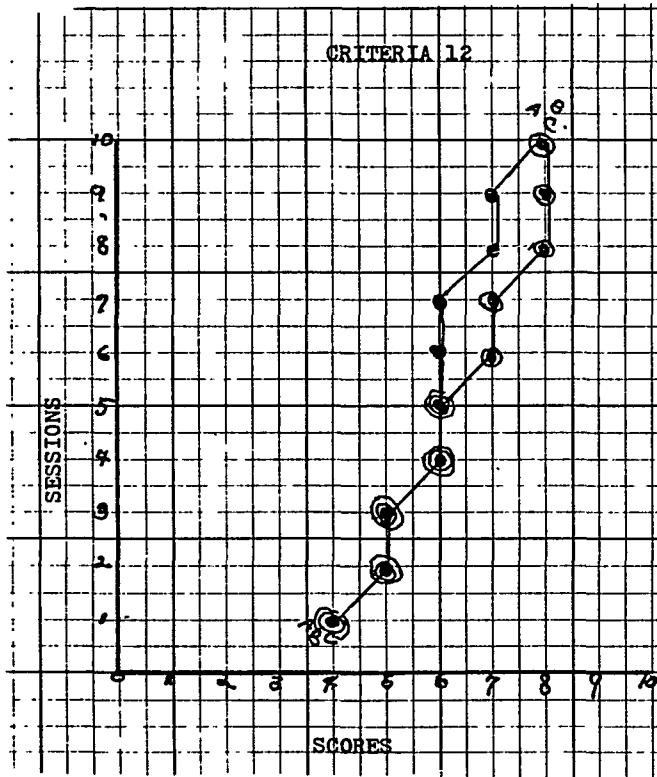


Fig. 34

Carries Sugar at All Times

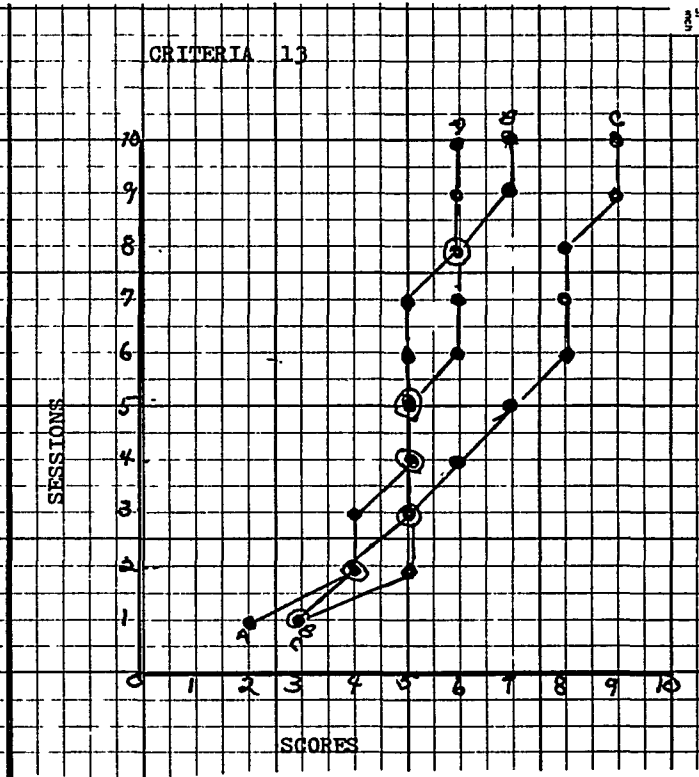


Fig. 35

Performs Special Foot Care

- A - Group 1
- B - Group 2
- C - Group 3

APPENDIX C4

The following are the calculations that were used in determining the tests of significance, which are illustrated in Figures 36, 37, and 38.

The outcome of these tests support the data presented in the profile and the graphs, that a significant difference exists between the initial scores and those recorded at the final session.

These figures are included in Figures 14 and 15 as a reference for those persons reviewing the study and for anyone who might wish to analyse the data in more depth.

The computations for the analysis variance F ratio are illustrated in Fig. 39-40.

$$1) \quad t = \frac{\Sigma D}{\sqrt{\frac{N\Sigma D^2 - (\Sigma D)^2}{N-1}}} \quad N = 10$$

$$2) \quad t = \frac{-49}{\sqrt{\frac{10(201)^2 - (-40)^2}{10-1}}} = \frac{-49}{\sqrt{\frac{2010 - 2401}{9}}} =$$

$$\frac{-47}{\sqrt{\frac{-391}{9}}} = \frac{-49}{\sqrt{-43.4}} = \frac{-49}{\pm 6.58}$$

$$t = \pm 7.44$$

Fig. 36. t-Test Computation for Group 1

The numerical values for Group 1 can be observed on p. .
 The computed value of t with a = 0.05 and df = 9 is 7.44 .
 The tabulated value of t with a = 0.05 and df = 9 is 2.26
 The computed value of t is greater than the tabulated
 value; therefore, the null hypothesis is rejected.
 There is a significant difference between the pre and
 post scores in Group 1.

$$1) \quad \underline{t} = \frac{\Sigma D}{\sqrt{\frac{N \Sigma D^2 - (\Sigma D)^2}{N - 1}}} \quad N = 10$$

$$2) \quad \underline{t} = \frac{-47}{\sqrt{\frac{10(205) - 166^2}{9}}} = \frac{-47}{\sqrt{\frac{2050 - 2209}{9}}} =$$

$$\frac{-47}{\sqrt{\frac{-159}{9}}} = \frac{-47}{17.6} = 11.2$$

$$\underline{t} = 11.2$$

Fig. 37. \underline{t} -Test Computation for Group 2

The numerical values for Group 2 can be observed on p.

The computed value of t with $\underline{a} = 0.05$ and $\underline{df} = 9$, is 11.2.

The tabulated value of \underline{t} with $\underline{a} = 0.05$ and $\underline{df} = 9$, is 2.26.

The computed value of t is greater than the tabulated value; therefore, the null hypothesis is rejected.

There is a significant difference between the pre- and post scores in Group 2.

$$1) \quad \underline{t} = \frac{\Sigma D}{\sqrt{\frac{N\Sigma D^2 - (\Sigma D)^2}{N-1}}} \quad N = 10$$

$$2) \quad \underline{t} = \frac{-44}{\sqrt{\frac{10(166) - (-44)^2}{9}}} = \frac{-44}{\sqrt{\frac{1660 - 1936}{9}}} =$$

$$\frac{-44}{\sqrt{\frac{-276}{9}}} = \frac{-44}{30.6} = \frac{-44}{5.53}$$

$$\underline{t} = 7.95$$

Fig. 38. \underline{t} -Test Computation for Group 3

The numerical values for Group 3 can be observed on p.

The computed value of \underline{t} with $\underline{a} = 0.05$ and $\underline{df} = 7.95$.

The tabled value of \underline{t} with $\underline{a} = 0.05$ and $\underline{df} = 9$ is 2.26.

The computed value of t is greater than the tabled value, therefore, the null hypothesis is rejected.

There is a significant difference between the pre and post scores in Group 3.

$$1) \quad SS_t = \Sigma X^2 - \frac{(\Sigma X)^2}{N} = 1169 - \frac{36481}{30} = 1169 - 1216 = -47$$

$$SS_t = -47$$

$$2) \quad SS_B = \frac{(\Sigma X_1)^2}{N_1} + \frac{(\Sigma X_2)^2}{N_2} + \frac{(\Sigma X_3)^2}{N_3} - \frac{(\Sigma X)^2}{N} =$$

$$\frac{3600}{10} + \frac{3969}{10} + \frac{4624}{10} - \frac{36481}{30} =$$

$$1219.3 - 1216 = 3.3$$

$$SS_B = 3.3$$

$$3) \quad SS_w = SS_t - SS_B = -47 - 3.3 = -50.3$$

or

$$SS_w = \Sigma X_1 - \frac{(\Sigma X_1)^2}{N_1} + \Sigma X_2^2 - \frac{(\Sigma X_2)^2}{N_2} + \Sigma X_3^2 - \frac{(\Sigma X_3)^2}{N_3} =$$

$$344 - 360 + 405 - 396.9 + 420 - 462.4 = -16 + 8.1 + -42.4$$

$$= -50.3$$

Fig. 39. Computation of the F Ratio

$$4) \quad MS_B = \frac{SS_B}{df_B} = \frac{3.3}{2} = 1.65$$

$$MS_W = \frac{SS_W}{df_W} = \frac{-50.3}{27} = -1.8$$

$$F = \frac{MS_B}{MS_W} = \frac{1.65}{-1.8} = -.91$$

$$K = 3$$

$$df_B = K - 1 = 2$$

$$N = 30$$

$$df_W = N - K = 27$$

Fig. 40. Computation of F Ratio (cont'd)

The numerical values can be seen on p.

The computed value of F with $\alpha = 0.05$, $df_B = 2$ and $df_W = 27$ is $-.91$

The tabled value of F with $\alpha = 0.05$ and $df = 2$, and df_W of 27 is 3.35.

The computed value of F is less than the tabled value, therefore, the null hypothesis can be retained.

There is no significant difference between the pre scores means of all three groups.

APPENDIX C5

All programs sponsored by the New York Diabetes Affiliate must submit a self response from clients that are participating in the program. This provides a subjective perspective of the client's view of the outcome. See Table 24, the questionnaire, and a summary of the responses obtained from the clients. The responses reflect the value of the program to the individual members of the group. This information should be of value to the educator when establishing criteria for future programs involving similar participants.

Knowles, in his 1980 edition of The Modern Practice in Adult Education supports the value of the informal evaluations in addition to the formal educator controlled program evaluations.

We can use these natural and powerful evaluations to improve our programs and our accountability, if we recognize that they exist and relate more imaginatively than we have been doing. It is a good way to help adults involved in the program (including ourselves) mature, grow and increase their power and control over their experiences. What is critical in effectively using informal evaluations, however, is to recognize their existence, their varied nature, their control and influence over future decisions, and therefore their importance. We should make it obvious to participants that we recognize their informal judgements and expect their feedback.¹

M. Knowles, The Modern Practice of Adult Education (New York Assoc. Press, 1980). p. 350.



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TABLE 24

CLIENT EVALUATION FORM

Title of Program _____

1. How did you first learn about the program?

NYDA News Friends
Local Newspaper Posters

2. What is your age group?

Under 20 Under 40 Under 60
Under 30 Under 50 Under 70

3. Are you Male _____ Female _____

4. Did you come

Alone _____ With a Friend _____
With Spouse _____ With a Relative _____

5. What did you like most about the program?

6. What did you like least about the program?

7. What will you do different as a result of this program?

8. What topic would you like to learn more about in future programs?

9. Are you presently

On insulin _____ Oral medication _____

Diet control _____

10. Are you presently a member of NYDA?

Which chapter? _____

Comments

This form is used for all programs sponsored by NYDA.

Chairman of the Board, THOMAS P. STRAUS; President, F. XAVIER PI-SUNYER, M.D.; President-Elect, STANLEY MIRSKY, M.D.;
Vice President, REYNOLD CORRADO; Vice President, ROBERT MATZ, M.D.; Secretary, IDA KLAUS;
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A copy of NYDA's report as filed with the New York State Board of Social Welfare is available from the Board Office Towers, Empire State Plaza, Albany, N.Y. 12223 or from the New York Diabetes Affiliate, Inc

Client Evaluation

This evaluation is based on the standard New York Diabetes Affiliate Evaluation form:

What was liked most

1. Everything clear and understandable
2. Free to ask any questions
3. Questions always answered
4. I am less afraid and anxious
5. I feel that I can do something
6. Better understanding of diabetes process
7. Have better idea what I should do.

What was liked least

1. That I did not have this sooner
2. That MD does not recommend attendance
3. The time is inconvenient--must make meal adjustments
4. Not advertised enough
5. Ten sessions not enough--they should continue as needed.

50% of clients attended with husband or wife

30% of clients attended with friends

10% of clients attended with children

10% of clients attended alone--used group as support or made friends with a member of the group and used them for support.

What one thing will be different as a result of these sessions?

1. Will wear ID badge
2. Will take better care of feet
3. Will take better care of eyes
4. Will try to prevent infections
5. Will ask MD more questions
6. Will attend more seminars
7. Will always carry some form of sugar
8. Will tell other diabetics about the group
9. Will join a local diabetes group for support

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