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EVALUATION OF A PATIENT-EDUCATION, PSYCHOLOGICAL ASPECTS OF CHRONIC
DISEASE APPROACH TO CHRONIC OBSTRUCTIVE PULMONARY DISEASE: A PILOT STUDY

THE UNIVERSITY OF ARIZONA

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EVALUATION OF A PATIENT-EDUCATION,
PSYCHOLOGICAL ASPECTS OF CHRONIC DISEASE
APPROACH TO
CHRONIC OBSTRUCTIVE PULMONARY DISEASE:
A pilot study

by

R. Maurine Roach

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In Partial Fulfillment of the Requirements
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1983

STATEMENT BY AUTHOR

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PREFACE

Many patients who suffer from chronic lung disease will eventually relocate to a dry desert climate in an attempt to alleviate the health problems brought on by a damp, cold environment. Thus the percentage of patients with this disorder is disproportionately high in Tucson as compared with the other chronic diseases found here. St. Mary's Hospital Respiratory Therapy Department was interested in formulating a program that would be comprehensive in meeting the needs of these patients. Those people responsible for setting up the program were concerned that it not be simply another "breathing class", since there seemed to be an abundance of such information available in the community, and began looking at possibilities for an enlarged scope to what was offered. It was decided that the phrase "debilitation prevention" would be appropriate as a description for the goal of keeping the patients from getting worse, or at least slowing down the progress of the disease process. Another goal of the program was to be that of looking at the "whole patient" and providing investigation of psychological factors which are involved in the everyday problems of these patients in living with their disease. The medical counselor was thus invited to participate and formulate studies which might be helpful in

evaluating the efficacy of the program and presenting to the patients furthered awareness of the emotional components of chronic lung disease.

ACKNOWLEDGMENTS

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ABSTRACT

The author tested the assumption that a comprehensive patient-education, psychological aspects of chronic disease approach for patients with chronic obstructive pulmonary disease could be of value to the patient. Twenty-six class members were evaluated regarding their level of disease information before and after class instruction. These same patients were tested with twenty-one comparison subjects on four variables regarding disease information, health locus of control, psychosocial problems related to illness, and coping skills. Results of this study indicated significant improvement in knowledge for the class members and significant difference in health locus of control between the two groups. No differences were found in psychosocial problems related to illness or in general coping skills. A literature review was completed

CHAPTER 1

STATEMENT OF PROBLEM

Introduction

The need for treating the whole person instead of just the physical illness has come to the attention of many workers in the health-care field in recent years. One area where this need is especially felt is that of chronic obstructive pulmonary disease. COPD refers to a group of diseases that produce permanent impairment of lung function, with clinical characteristics of shortness of breath on exertion, cough and progressive disability, and is estimated to affect more than 1.5 million adults in the U.S. Nett and Petty, (1970) stated that COPD was at that time the second most common cause for disability under the Social Security System.

One of the primary problems with COPD is the "emotional straight jacket" imposed on the patient by the fear of dyspnea (difficulty in breathing) since any emotional response, from laughter to weeping, is likely to exacerbate the condition.

These physical conditions have been the subject of much literature and many programs addressed to the topics of improving the patient's stamina, exercise tolerance and

general reduction of symptoms. The area which has not been as well covered is that of combining a "respiratory therapy-patient education" program with a "psychological aspects of chronic disease" program in order to better cover all the needs of the COPD patient. Lessening the deterioration of the body will not appreciably improve the patient's life-style if the anxiety, frustration, flattened affect and many other emotional components are not recognized and dealt with. The current study was designed as an attempt to combine these two facets of COPD treatment.

Objectives of Study

The objectives of this patient-education, psychological aspects of chronic disease program were:

- (1) To increase the patient's information level regarding his disease.
- (2) To improve the patient's understanding of the psychological aspects of chronic disease.
- (3) To increase the patient's ability to control his disease both physically and emotionally.
- (4) To heighten the patient's awareness of his strengths and how to utilize these strengths in coping with his illness.
- (5) To evaluate the program for continuation or expansion as part of the services offered by the Respiratory Therapy Department.

Definition of Terms

COPD--Abbreviation for Chronic Obstructive Pulmonary Disease, including asthma, chronic bronchitis, emphysema, or other conditions which restrict the air-flow process through the lungs.

Dyspnea--Difficulty in breathing, either inspiration or expiration or, in some conditions, both.

FEV-1/FVC Ratio--Forced expiratory volume in one second over forced vital capacity. Pulmonary lab measurement of how much air the patient is able to move through the respiratory tract. For this study a ratio of less than 70 percent was required as substantiation of the diagnosis of COPD.

Research Hypotheses

Hypothesis 1. COPD Patients who participate in a patient-education, psychological aspects of chronic disease class will show a different level of information regarding their disease following the instruction as measured on the COPD Information Index, when compared to their pre-class scores on this same instrument.

Hypothesis 2. COPD Patients who participate in a patient-education, psychological aspects of chronic disease class will show a different level of information regarding their disease following the class, as measured on the COPD

Information Index, than a comparison group of similar patients who do not participate in the class.

Hypothesis 3. COPD patients who participate in a patient-education, psychological aspects of chronic disease class will show scores on the Health Locus of Control which differ from those of a comparison group of similar patients who do not participate in the class.

Hypothesis 4. COPD patients who participate in a patient-education, psychological aspects of chronic disease class will have scores on the Psychosocial Problems Inventory which differ from those of a comparison group of similar patients who do not participate in the class.

Hypothesis 5. COPD patients who participate in a patient-education, psychological aspects of chronic disease class will show scores on the Dudley Coping Scale which differ from those of a comparison group of similar patients who do not participate in the class.

Research Design

The first portion of this study was set up as a One-Group Pretest-Posttest Design utilizing the class members as the subjects. The independent variable (X) was the information given in class lectures regarding the physiology and anatomy of lung disease, the use of medication, and effective physiologic techniques for coping with shortness of breath. The pretest dependent variable (Y-1) was the

COPD Information Index given before the six-week class and the posttest dependent variable (Y-2) was the same test given to the same group at the end of the class. A t-test for significance of difference between means for the two sets of scores was done with significance level set at .01.

The remainder of the study was a Two-Group Static design utilizing the class members as one group (E) and a comparison group of similar patients not enrolled in the class as the other group (C). The independent variable (X) was the six weeks of class instruction and the dependent variable (Y) was the battery of tests given to each group. t-tests for significance of differences between means for the two groups were done for each of the four testing instruments used. The significance level was set at .01.

CHAPTER 2

RELATED LITERATURE

In order to see what has already been done in the different areas examined in this study, a rather extensive literature review was completed. Applicable portions of this material are presented in this section.

Comprehensive Programs

In examining the literature regarding chronic lung disease, the importance of a comprehensive program was stressed by Fishman and Petty (1971) when they stated their intervention was psychotherapeutic for a patient in the following ways:

(a) providing long-term emotional support to the patient through continuing social interaction with the staff, (b) by encouraging the patient to experience mastery over his chronic disease, and optimism about controlling it, through education and through the learning of specific medical techniques for dealing with it and (c) on the assumption that these techniques are effective, by enhancing the patient's feeling of emotional well-being as a response to his improved physical well-being. (pg 776)

One of their statistically significant findings was that of absolute improvement in patient-rated affective distress as determined by the Multiple Affect Adjective Checklist. This test was given at the beginning of the program and again at the year-end conclusion of the study.

They also found definite improvement in tolerance for walking and in maximum voluntary ventilation (MVV) on pulmonary function studies. Another positive finding was that of stabilization of physical symptoms in a disease process which would be expected to deteriorate over the one-year passage of time.

Another comprehensive program by Agle et al. (1973) tested the assumption that a comprehensive rehabilitation program could produce significant beneficial changes in patients with COPD and examined whether such changes correlated with physiologic or psychologic factors. Their results suggest that the degree of psychologic distress is not necessarily related to the degree of physical impairment. Many other factors seem to play a vital role in whether or not the patient improves in physical performance and lessens his psychological distress. Their program included these factors:

1. Progressive exercise leading to a decrease in unrealistic fear of activity and dyspnea.
2. Education in self-care leading to increased autonomy in the control of symptoms.
3. Staff attitudes that the patient is worth the effort.
4. The setting of realistic goals leading to improvement in self-esteem.
5. Monthly followup to consolidate gains.
6. Mutual support from the group interaction.
7. All those factors within the patient that lead to strong motivation." (pg 46)

Their results indicated that meaningful improvement in performance can occur in some patients. This change correlated positively with psychological factors but not with physiologic measures. Of particular importance in affecting positive change seemed to be the decrease of fear of dyspnea and feelings of increased autonomy in patient control of symptoms. Several factors from this study, especially numbers 1,2,4 & 6 have been modified and utilized in the present program.

Patient Education

The importance of patient education and information was evident in a study done by Posavac (1980) wherein he discusses the fact that the majority of patients today are being treated for chronic conditions that cannot be cured but must be lived with and coped with in the best way possible. Chronic patients are responsible for following the extended treatment regimens prescribed for their conditions, and must have the knowledge necessary to fulfill this self-care role and become the active participants in the management of their own disease process. Sexton (1980) states that the individual needs certain information in order to understand the illness and cope with the symptoms and associated disability, and that people must certainly know what to do and when and how to do it before they can take action.

Facilitating patient control of asthma was the topic of a study done by Maiman, et al. (1977) wherein their objective was to evaluate the efficacy of a series of educational and motivational interventions in reducing unnecessary visits to the emergency department by adult asthmatics. The material given the patient focused on (1) prevention and control of asthma attacks, (2) compliance with medication regimen and (3) increasing both the patient's belief in the benefit of following therapeutic regimens and ability to cope with asthma through self-care. This study showed statistically significant improvement in the patient's ability to manage his own disease after the self-care instruction was given.

Instruction designed to encourage self-confidence in coping with asthma attacks was the main purpose of a program designed by Green (1974) in which he found decreased use of hospital emergency services by people with asthma who took part in a small group discussion-decision program.

Green's results were used by Moldofsky, et al. (1979) in designing a video-tape educational program for people with asthma and he found results of the test on knowledge about asthma revealed that the experimental group who had seen the tape obtained a mean total score that was significantly higher than that of the control subjects who had not seen the tape. One interesting finding of this study was the lowered "knowledge" score for the experimental

group when re-tested 16 months later. At that time there was no significant difference between the two groups. Moldofsky discusses the probable causes for this loss of information as the failure to foster active involvement of the subject in the learning process and that the program could be improved by combining the videotape with small group discussions led by a medical or paramedical person.

Small group discussions were used in many of the 63 articles on patient education reviewed by Mazzuca (1982) in which he found that the average patient who received education with a behavioral emphasis demonstrated a physiologic response to therapy better than 78% of control patients. He stresses the importance of a behavioral rather than didactic emphasis as follows:

A patient education program conceived and designed to help patients cope with their unique self-management plan is much more likely to improve the course of chronic disease than is a standard presentation of medical facts and treatment rules which all hypertensives, or all diabetics or all asthmatics should know. (pg 528)

Black and Mitchell (1977) conducted a purely informational program consisting of an audiovisual instructional tape for COPD with a pre and post information test given to each patient. The mean score rose from 71% to 88%, a significant rise in knowledge of disease. The author did not examine whether or not this educational process influenced the patient's care by increasing compliance with prescribed treatment.

Locus of Control

The problem of compliance with doctor's orders and medication has been rather extensively studied, and one of the main factors to come forth is that of a patient who feels more "in control" of his illness will be more likely to comply than one who feels that what he does or does not do won't make any difference in the long-term outcome of his disease. Strickland (1975) did an extensive review of research on internal-external (I-E) locus of control expectancies and health attitudes and behaviors. Her definition of I-E is:

Simply stated, I-E refers to the degree to which an individual perceives the events that happen to him/her as dependent on his/her own behavior or as a result of luck, chance, fate, or powers beyond one's personal control and understanding. (pg 1192)

Results of research suggest that beliefs about internal versus external control are related in significant and even dramatic ways to health-related behavior. As early as 1962, Seeman and Evans found evidence that hospitalized patients with tuberculosis who were internal as assessed by an early I-E measure, with intelligence controlled, knew more about their disease than their matched external counterparts. The medical staff also rated internal patients higher in objective knowledge about tuberculosis than externals. In wards in which information was difficult to obtain, internal patients were significantly less satisfied with the flow of information than externals.

Wallston et al. (1976) have also found that internals who value their health are more likely than others to collect information about disease and health maintenance when alerted to possible hazards, such as hypertension. These findings suggest that individuals with internal rather than external expectancies are more likely to take action to improve their health habits, particularly when faced with evidence that needed changes may result in improved physical functioning. Therefore, Strickland (1978) concludes that internals, in contrast to externals, would be more sensitive to health messages, would have increased knowledge about health conditions, would attempt to improve physical functioning, and might even, through their own efforts, be less susceptible to physical and psychological dysfunction. Internals seem to be able to use specific information about their disease and treatment, whereas externals respond to general instructions.

Very little research seems to have been done linking I-E beliefs to specific physical illnesses. However, Ireland (1973) attempted to investigate participation in treatment in relation to I-E beliefs among pulmonary emphysema patients. Ratings were difficult to obtain and no clear findings emerged. He did find, however, that internal patients knew more about their disorder than externals, even with intelligence controlled.

Research on the I-E variable and the reporting of psychological and/or emotional problems seems to be more extensive than that on I-E and physical disorders. Felton & Kahana (1974) report that on a general level of overall functioning internal individuals, including the elderly, are significantly more likely to report themselves as content with their life situation than externals.

Internals are also more likely to enter a treatment program with expectations for improvement, and more able to assume responsibility for their difficulties and attempting to change. However, Nowicki, Bonner and Feather (1972) found internals to be more resistive to interventions they perceive as limiting their freedom or control, even when these treatments are shown to be beneficial to the health problem. Therapeutic programs seem to be most helpful when they can be based on the individual's own locus of control beliefs.

Psychosocial Factors

Of the many factors involved in treating the COPD patient, several authors feel that recognition of psychosocial considerations is essential in planning for long-term care. Dudley, et al. (1980) state:

Successful rehabilitation of the patient with chronic obstructive pulmonary diseases depends not only on treatment of the physical aspects in the disease, but also on improvement of the individual's ability to cope with his illness. The physician's

understanding of the psychosocial, as well as physiological, aspects of respiration is vitally important to the long-term adjustment and survival of the patient with emphysema, chronic bronchitis, and chronic asthma. (pg 413)

Psychosocial assets, from a compilation of several lists, include such qualities and conditions as congeniality, flexibility, reliability, good judgment, vital interest in life, self-esteem, not overly sensitive, acceptance of reality, feeling loved, belonging to a relationship or community, willingness to accept responsibility, adequate financial resources and housing. Patients with these assets seem to deal more effectively with the disease process. This may be, according to Rabkin (1976) because patients with a broader experience base are more able to adapt to situational changes and the more experience they have with a particular stressor the more probable it is that their present responses will be effective.

It appears that patients with many strong psychosocial assets are more responsive to rehabilitation efforts than are patients with few such assets, seem to protect themselves more efficiently from dangerous symptoms such as attacks of dyspnea, and carry out treatment programs more carefully and responsibly, according to Dudley, et al. (1980).

Pattison, et al. (1971) found that COPD patients with highly developed psychosocial assets exhibited positive

response to group psychotherapy and manifested effective interpersonal behaviors.

These interpersonal behaviors can have a profound effect on the progress of the COPD patient's disease. Any emotional strain may cause exacerbation of symptoms and even positive reactions such as laughter may bring on an episode of coughing. Because of this, the patients very frequently find it safer to live in an emotional "straight jacket". Dudley et al. (1973) observed that the patient can no longer become depressed, angry, or even happy because any significant emotional change leads to distressing symptoms, and Lester (1973) discusses the problem of COPD patients choosing a constricted "living space" which can be perceived in spatial or interpersonal terms such as withdrawal into the home and/or avoidance of social interaction with others. Increase in social interaction, along with recognition and use of the other available psychosocial assets, composed part of the objective of the present program.

The importance of high psychosocial assets is particularly stressed by DeAraujo (1972) in his discussion of the probability of early death in a group of patients with diffuse obstructive pulmonary disease being increased in the presence of low psychosocial assets. He found that patients with low adaptive ability and chronic disease lack the options for coping with change whereas patients with

high adaptive ability exhibit many different coping behaviors.

Coping Skills

The concept of coping with illness was discussed in a paper by Lipowski (1970) where he states, "One of the major inquiries about the state of being sick is how the individual copes with it, as well as the causes and consequences of his failure to cope." (pg 92) He refers to two definitions of coping, one by Lazarus (1966), that when we use the term "coping" we are referring to strategies for dealing with threat, and the other by Mechanic (1968), discussing the instrumental behaviors and problem-solving capacities of persons in meeting life demands and goals, including the application of skills, techniques and knowledge that a person has acquired. Lipowski sees these two views as differing in their emphasis and yet compatible. The first sees man as struggling with his environment, experiencing stress, conflict, threat, danger signals and defenses. The other view seems more adaptational, emphasizing tasks and challenges which man attempts to master by use of the resources at his command. The state of physical illness could utilize both views of coping, that of the stress from suffering and loss, and also as a set of adaptational tasks and challenges or goals to be mastered. Which choice the patient makes as he faces his illness

depends on a complex combination of past experiences which have formed the person's coping style and strategies.

Lipowski (1970) uses as his definition of coping "All cognitive and motor activities which a sick person employs to preserve his bodily and psychic integrity, to recover reversibly impaired function and compensate to the limit for any irreversible impairment." (pg 93) This definition takes into account the fact that in illness, the primary source of psychological stress lies within and not without the person's body boundaries. Thus, it both imposes tasks to be dealt with and impairs in some degree the person's capacity to meet life's demands and follow his goals. How he deals with this double-edged sword of the illness causing problems and the illness keeping him from solving problems will be determined by his coping style and strategies which he brings with him, and will reflect the patient's habitual methods of dealing with threatening and novel situations in general.

These habitual coping styles may be categorized, according to Lazarus (1969) as intrapsychic (cognitive) or direct action (behavioral). The former includes attempts to ignore or withdraw attention from the threat, minimize it and seek relief in fantasy. The latter style involves active preparation against harm.

In 1976, Moos and Tsu described several different coping skills used by patients in the adaptive tasks of

dealing with their illness. The first category consists of those skills based on denying or minimizing the seriousness of the disease and to accomplish this the patient may use projection, detachment, or isolate himself emotionally from the illness. These tactics may be useful for reduction of anxiety during the early stages of the disease since White (1974) states that high levels of fear may prevent the patient from learning the information essential to dealing with his disease, such as self-care procedures.

Seeking of information may also be used as a coping skill according to Moos (1976) wherein the patient attempts to use intellectual resources to combat physical problems. This may also help to restore the person's feeling of control and autonomy.

Relationship of Literature to Present Study

This rather extensive literature review was done to examine previous work performed in the same areas as those listed in "Objectives for present study" on page 2. The comprehensive programs (physical and psychological treatment combined) were included to see if, indeed, this approach could be deemed helpful to the patient. Since the studies show lessened physical deterioration and improvement on psychological tests, several factors from these programs were incorporated into the present research in an attempt to make participation more valuable to the patient.

The patient-education studies were examined with the idea of gaining insight regarding effective methods of increasing the patient's information level concerning his disease and his ability to deal with the illness both physically and emotionally. The need for group discussions was brought out in this section and used as part of the format for the present research.

In a further attempt to help the patient learn to control his disease both physically and emotionally, the locus of control studies and information were included in the literature review. Material drawn from the work of these researchers helped in understanding the differences in patients who see themselves as internal versus external in ability to cope with their illness. This information was used in the discussions regarding the psychologic aspects of chronic disease.

The studies regarding psychosocial factors of chronic disease were valuable in gathering material for use in helping the patient become more aware of his strengths in these areas. This awareness was used to help the patient learn methods of adapting to and living with his disease.

The final area of literature review, that of coping skills, was included to show what others have found regarding this psychological component to dealing with chronic disease. Strategies and skills used by others were

shared with the patients in the discussions on increasing the ability to cope physically and emotionally with COPD.

CHAPTER 3

METHODOLOGY

This chapter will explain the techniques used in conducting the present research, including subject selection and class procedures. The testing instruments used to evaluate the progress of the class members and to examine the differences in the groups are also described, including validity and reliability studies.

Subjects

The subjects (N-26) for this study were all the patients who registered for the "Debilitation Prevention" class sponsored by St. Mary's Hospital Respiratory Therapy Department from August through December, 1982. Patients were recruited by announcement in the newspaper, brochures placed in physicians' offices (Appendix A), newsletters to physicians suggesting they recommend the class, and posters placed in clinic lobbies, etc. A written prescription from the patient's primary physician was necessary for registration, in order to insure no conflict in the program and the patient's routine care.

The criteria for selection included a medically substantiated diagnosis of COPD, verified by pulmonary function studies showing FEV-1/FVC ratio of less than 70

percent. These did not need to be new studies, simply a record in the patient's history of these results and attested to by the physician in the written prescription for the class.

The ages of the class members ranged from 47 to 82 years with a mean of 66.3 and a median of 68. The male-female ratio for the class members was 14/12. All class participants indicated their race as "white" or "caucasian".

One factor which may have been a deterrent in self-selection of subjects is the \$100 charge for the class, even though eighty percent of this was reimbursed by Medicare or other insurance coverage, and it did not have to be paid in advance.

No other factors were considered to be significant in the selection of subjects. The class members were given the option of participating in the study or not, and were assured their lack of filling out the forms would not affect their medical care or inclusion in the class activities in any way.

The comparison group (n=21) consisted of out-patients who were sent to the Pulmonary Function Lab by physician's prescription to be tested for respiratory flow. They were given a letter (Appendix B) explaining the study and asking for their participation, with assurance that lack of participation would not affect their medical care in any way. These patients were screened by the lab technician as

having never participated in a patient-education program for lung disease. Also, if the lab results for that patient showed FEV-1/FVC ratio of more than 70%, he/she was eliminated from the study and considered not to have a medically substantiated diagnosis of COPD.

Procedure

The class members (treatment group) attended six 2-hour sessions, one per week, for a total of 12 hours in class. The class was jointly conducted by a respiratory therapist and a medical counselor. Instruction was given in pulmonary anatomy and function as related to the breathing process, and improved self-care and management of the disease. The emotional problems associated with chronic lung disease were addressed as they applied to the various topics under discussion. For the fifth class, the entire session was devoted to a closer look at several types of problems including: psychological problems associated with loss of function, adaptation to illness, defense mechanisms used to avoid anxiety of illness, problems of daily living as a disabled person, disruption of interpersonal relationships, role-reversal, dependency problems, self-concept, conquering fear of crisis and adherence to medical regimen. The class included group discussion of these problems and how COPD patients might cope with them.

Special emphasis was given to the importance of the patient taking responsibility for the management of his/her own disease with lessened dependence on the medical professional. Another area stressed was that of utilizing available assets to meet the psychosocial problems inherent in living with COPD. The coping skills and styles which the patient had previously acquired were discussed as being applicable to the present condition.

The class members were given the COPD Information Index at the beginning of the first class session, along with the demographic information sheet (Appendix C). During the last class session, the sixth week, they were given the Information Index again along with the Health Locus of Control Scale, the Psychosocial Problems Inventory, and the Dudley Coping Scale (Appendix D).

The comparison group participation consisted only of filling out the demographic information and answering the questions on the four measurement instruments.

Instruments

COPD Information Index: The COPD Information Index was compiled by the respiratory therapist who co-lead the class. It consists of 15 questions with multiple-choice answers. The questions were prepared from the outline of material presented in the first five class sessions, three questions per lecture-discussion, with a possible score of

15. At this point there have been no reliability or validity procedures done on this instrument. It appears to have face validity as judged by two respiratory therapists who were not involved in teaching the class. It was compiled as a measure of what the patient knew about the disease before and after taking the class, and special care was taken to insure that the material in the Information Index was well covered and stressed in the lectures, thus creating content validity. The control group was given the I.I. to indicate their working level of knowledge of COPD as patients who had not, and were not currently, enrolled in a patient education program.

Health Locus of Control Scale: This scale was designed to answer the kind and extent of control a person thinks he/she has over his/her own state of health, and consists of eleven statements with a six-point Likert-type scale for responses. The total score for the instrument may range from 11 to 66. A high score denotes belief in a high degree of external health locus of control and a low score indicates belief in a high degree of internal locus of control.

The authors' (Wallston et al, 1976) rationale for development of this instrument was to provide specific information about the relationship between an individual's health behaviors and that person's belief about the locus of health control. They indicate that previous information

available about this relationship was inadequate because it had been derived from instruments whose measures were very general.

The main problem seen in using this instrument for the present study is that it was validated almost exclusively on college students, the vast majority of whom were 20-30 years of age and could not be considered comparable to the participants in the present study who had a mean age of 66.3 years. Another confounding factor is that of the validation groups being considered healthy, except for one group of 40 hospital outpatients who were known to be hypertensive. The present study consists only of medically verified chronic lung disease patients who might be expected to have different opinions on illness than those who were not disabled. One interesting result of the validation studies is that the hypertensive group did show a significantly higher (external) HLC score than the other groups of respondents.

Psychosocial Problems Inventory: The third instrument administered to both groups was a modified version of the Psychosocial Problems Inventory by Jacox and Stewart. The variables measured by this instrument are psychosocial problems that are associated with pain and illness. A psychosocial problem is conceptualized by Jacox and Stewart (1973) as something that is a source of distress to a person.

This Inventory is a 24 item self-administered instrument with the subject simply asked to circle the best response alternative--yes, occasionally, or no--depending on how he/she responds to the illness situation. The total score can range from 0 to 48 with the higher score denoting more psychosocial problems related to illness.

The underlying rationale for the development of this instrument lies in the concept of pain and illness being viewed as a bio-psycho-social phenomenon and associated with a variety of problems, some of which are measured by this inventory.

Reliability was tested with a split-half reliability of .84 computed for the Problems Inventory. The sample consisted of 102 hospital patients (31 short-term pain patients, 31 long-term pain patients, and 40 progressive pain patients).

Concurrent validity was tested by correlating the inventory scores with scores from other indices. The inventory correlated positively with the Neuroticism Scale of the Eysenck Personality Inventory ($r=0.43$, $p<.01$, $n=97$). It is also correlated negatively with the Health Self-Concept Scale ($r=.41$, $p<.01$, $n=97$).

The authors reported that face validity was considered good as judged by a panel of three instructors in psychiatric and medical-surgical nursing. These studies are considered applicable to the present population since they

were done entirely on hospitalized patients, who certainly would fit the "disabled" category. The only problem seen in this is that the patients in the present study were not themselves hospitalized at the time (although they have a history of past hospitalizations), and could possibly see themselves as having fewer problems since they were relatively mobile and functional at the time of testing. The authors state that further studies of reliability and validity should be done.

The Inventory was somewhat modified for this study by substituting the word "discomfort" (from lack of oxygen) for the word "pain" to make it more applicable to the lung disease population.

Coping Scale: The fourth and final instrument used in this study was the Coping Scale, a Dudley and Welke (1977) adaptation of part II of the Berle Index. The Coping Scale is a self-report instrument of coping ability which is defined as the person's ability to change environments to meet needs. On the Coping Scale, a score of above 80 represents excellent ability to deal with life, with a negative score the person would be considered deficient in the ability to deal with life. (Dudley & Sitzman 1979). Most people fall between the positive 40 and positive 80 range.

The Berle Index from which the Dudley Coping Scale was derived, was developed by Berle, et al (1952). In their

work they found a direct correlation between psychosocial assets and coping ability in studying patients with various chronic diseases. They isolated psychological and social variables associated with improvement or lack of improvement in these patients. Part II of the Index, which deals with the same categories as the Coping Scale, consists of items associated with the patient's family and interpersonal relationships as they are perceived by the patient.

The Coping Scale was used in this study to examine the difference, if any, in the scores of patients who were enrolled in the patient-education program and the comparison group. The problem inherent in using this scale is that it was not specifically designed to measure the "coping skills" taught in the patient-education class which made up this study. There was a certain amount of overlap with the same items as shown on the scale being on the discussion outline, but the discussions were much more comprehensive than the scale. The design would have been enhanced by developing a scale which had a better correlation with the items that were presented in class.

This chapter has thus explained the criteria for subject selection, the class procedures used, and the testing instruments employed for evaluation of the patients and the program itself.

CHAPTER 4

RESULTS

Since the underlying purpose of any research is to gather data, analyze it, and present it in such a manner as to support the efficacy of the project, this task will be attempted in the following chapter. A discussion of some unexpected findings is presented, as well as coverage of the limitations and possible expansion of the work.

Presentation of Data

In examining the results of testing in the class and control groups, the first instrument administered was the COPD Information Index. The class members were given this test before they received any instruction and again at the end of the class session, creating a pre and post-test situation. The results are shown on the following table.

| | <u>Pre-test</u> | <u>Post-test</u> | <u>t</u> | <u>p</u> | <u>df</u> |
|-------|-----------------|------------------|----------|----------|-----------|
| Class | 8.2 | 11.7 | 4.21 | .001 | 35 |

TABLE 1. PRE-POST INFORMATION INDEX

Mean scores for the two administrations of the I.I. to the class members showed a significant difference and thus the hypothesis that the class members would show different scores after the series of discussions as compared to their pre-class scores is accepted.

Results of testing the class members and the comparison group on the four measurements utilized are shown as follows:

| | <u>CLASS</u> | <u>COMP.</u> | <u>t</u> | <u>p</u> | <u>df</u> |
|--------------|--------------|--------------|----------|----------|-----------|
| Info. Index | 11.7 | 8.2 | 6.03 | .001 | 41 |
| H.L.C. | 36.8 | 29.9 | 3.08 | .01 | 44 |
| Psych. Prob. | 20.2 | 19.9 | | ns | |
| Coping Scale | 41.6 | 40.2 | | ns | |

TABLE 2. CLASS & COMPARISON-GROUP RESULTS

Mean scores on the I.I. for the comparison group, when compared to the post-test results for the class group, showed a significant difference, thus the second hypothesis, that the class members would show a different score after taking the class than the comparison group, is accepted. One interesting finding is that the mean score for the comparison group (8.2) was the same as the class group pre-test, showing a consistency of scores among people who have not taken the class.

In the Health Locus of Control there was a statistically significant difference between the mean scores of the class group and the comparison group. The third hypothesis, that of the two groups showing a difference in scores on the HLC, is accepted.

Results of testing on the Psychosocial Problems Inventory showed no significant difference between the means of the two groups. Thus the fourth hypothesis of a difference between the two groups is rejected.

The fifth hypothesis, that regarding difference in scores on the Dudley Coping Scale, is also rejected due to the finding of no significant difference between the mean scores of the two groups.

Discussion of Results

The findings in this study indicate several different relationships among COPD patients, patient education, and emotional components of the disease process. The very significant difference in the pre and post class mean scores on the Information Index indicates a measureable increase in their knowledge of the physiology and anatomy of their disease, along with medication and exercise tolerance information. These results are seen to support the statement by Green (1982) that "Health education influences patient behavior primarily through changes in knowledge,

attitudes, beliefs and perceptions and is expected to influence health behaviors."(pg 91)

One interesting finding in demographic comparison between the two groups which may have a bearing on the degree of information-seeking behavior is that of an average education level of 13.5 years (one and one-half years college) for the class members as compared to 11.5 years (one-half year short of high-school graduation) for the comparison group. Thus enrollment in the class may be seen as a continuation of information-seeking by these higher educated patients.

The significant difference in the class members' post-test knowledge of disease as compared to the comparison group is valuable in justifying the time and expense involved in conducting the program. If the patients who took the class learned more than they knew beforehand, and more than patients who did not take the class, then the instruction may be seen as being potentially helpful to them in managing their disease.

The most interesting finding in this study is that of a significant difference in perceived health locus of control between the two groups. The unexpected finding was that the comparison group had the higher scores, and for this instrument a high score denotes a higher level of internal control of disease. It appears, from this result, the comparison group who did not take the class see

themselves as being more able to manage their own disease and take responsibility for their health than those patients who enrolled in the class. The material in the literature review indicated the "internal" patients would be the ones who would seek further information, and take other active steps to manage their disease, whereas the "externals" would have more of an attitude that such things were not under their control, and thus why make the effort to do anything about it.

In reviewing the material by Wallston, et al (1976), the finding that the group of hypertensive patients in their validation studies (the only group of chronic disease patients included) showed a higher external score than any other group becomes more significant. Cromwell, et al. (1977) also found a group of 229 coronary patients to be more external than the controls. The statement by Felton (1974) cited earlier that elderly internals were more likely to report themselves as content with their life situation than elderly externals would be understandable in this situation in that those who were not content (externals) would be more likely to seek a change in their situation (enrolling in the class).

This researcher, from personal acquaintance with the members of the class, is inclined to agree with the statement by Wortman & Brehm (1975) in which they caution that an emphasis on personal causation may be dangerous when

individuals are faced with situations that are truly uncontrollable. These COPD patients have the disease, the damage is not reversible and it was found that during the discussion sessions the issue of possible personal causation of the illness and guilt for having gotten sick was a very complex one. If these patients viewed themselves as responsible for their condition (by refusing to give us cigarettes, etc.) the guilt became a possible limiting factor in their willingness to seek and use information. If, on the other hand, they could see the disease as "fate", "bad luck" or "life", and not under their causation or control, they appeared much more willing to learn what had happened to their lungs and what they could do now to keep it from getting worse. They were also, at this point, ready to become involved in learning emotional coping skills to assist them in the task of adaptation to chronic disease. In light of these observations, the finding of external locus of health control for this group is perhaps not so unexpected.

One interesting demographic finding related to locus of control was that the two members of the class who had the highest HLC scores (49 and 56), were the only two members of the class who were still smoking. They had been smoking for 48 and 55 years, compared to the class average of 38 years. This could indicate they did not feel they had internal control over their situation and could account for

their high external ratings. The lowest HLC score for a class member (13) was received by a patient who had smoked for 20 years and, interestingly, had an education level of 16 years compared to 12 years for both high HLC patients. There were eight other class members, however, who had 16+ years education and whose HCL scores ranged from 31 to 40. None of these patients had continued to smoke.

The fourth finding of no significant difference between the two groups in personal assessment of psychosocial problems associated with disease indicates that those who do not take the class see themselves as having no more disease-related concerns than the class members.

The last variable, that of Coping Scale scores for the two groups, also showed no significant difference and indicates the groups see themselves as equal in ability to deal with life's problems.

Limitations of Study

The most serious limitation of this study was the time frame under which it was conducted. The promotional materials had been distributed and registration for the first class begun before the researcher was invited to join the staff and asked to conduct the "Psychological Aspects of COPD" portion of the class. It was requested at that time that formal evaluation of the proceedings be conducted to determine benefits, if any, for those who took the class and

also to examine differences, if any, between patients who registered for the class and those who did not. This restriction of time available to create a research design and develop proper testing instruments is seen as the main limitation to the study.

The first portion of the research design, where the class members were given pre and post-class administrations of the Information Index, was limiting for several reasons. First, no comparison group was available of patients who took the same test separated by a six-week interval, but without class participation (the comparison group used was given the I.I. only once). Thus it is not possible to know if the change in scores between the pretest and posttest was brought about by the experimental condition, that of class participation, and not other extraneous variables. There is also the possibility of practice effect where the patients may have done better the second time even without any instruction or discussion during the six-week interval. Thus this portion of the study lacks internal validity in these areas.

The second portion of the study wherein the class members and comparison group were evaluated on the other three instruments also has some design limitations. The basic problem is that since neither randomization nor matching were used to assign subjects to the experimental or comparison groups, we cannot assume the groups were

equivalent prior to the class presentation. They may have differed on certain relevant variables and it may be these differences rather than the class instruction that was responsible for the observed changes in the Information Index scores, and the difference in HLC scores between the two groups. This lack of control is not considered to be a problem with the Psychosocial Problems Inventory and the Coping Scale, since the two groups showed no significant difference in scores on these instruments.

Another limitation of the study is that it was conducted only with a COPD population and may not be representative of chronic disease patients generally. COPD is a progressively debilitating condition, and thus the majority of patients are older than the population as a whole by the time they become disabled. Also, the intense fear of dyspnea (a moment-by-moment life threatening condition) creates an anxiety level in COPD patients which one would not expect to find in other chronic diseases, such as diabetes or stabilized stroke.

The major operational limitation of the study is that of using testing instruments which were not specifically developed and perhaps not totally appropriate for this research. The Information Index was formulated by the respiratory therapist who taught the class, and it is felt it has content and face validity, but lack of factor

analysis, field testing, reliability studies and other validity measures is acknowledged.

The biggest problem with the Health Locus of Control Scale is that it was validated on younger and healthier subjects than the subjects of this study. It is only logical that young, healthy people would have rather different views of just how much control they could exert over their health status than those who were not only elderly but also afflicted with a condition that will get progressively worse and more life-threatening. The ideal situation would have been to develop a scale which was validated on a chronic-disease population

As mentioned earlier, the validation and reliability studies for the Psychosocial Problems Inventory were done on hospitalized patients and are considered to be appropriate for the present population.

The Dudley Coping Scale has limitations for use in the present study since it does not deal specifically with the psychological coping skills discussed in the class. As mentioned earlier, this scale measures general coping ability, and Dr. Dudley sees it as relating to the lung patient's ability to cope with his disease, but this researcher feels the results could have been measured more accurately with an instrument designed for use with this particular class. The illness related factors, adaptation tasks and coping skills and styles discussed in class were

much more specific than those measured on the Coping Scale. Further research could be done to include factor analysis of the items discussed in class and a more valid testing scale created. This would give more support to the value of participation in the class, since one of the stated purposes was to increase the patient's ability to "cope with his disease, both physically and emotionally".

Suggestions For Further Study

The most important continuation of this research would be the long-term followup of the patients who participated in the class. If they could be checked periodically for decreased hospitalization, compliance with medical regimen and increased ability to deal physically and emotionally with their disease and life in general, the worth of the program could be substantiated.

Another possible aspect for further investigation would be that of doing a comparison study with COPD patients and another chronic disease, such as heart problems, to see the similarities and differences between these populations and how they deal with chronic illness.

One more valuable area for study would be possible investigation regarding the effect of the chronic disease on the spouse and other family members. Spouses were included in the class discussions and separate sessions were held for the partners as a group, but no operational instruments were

used to examine statistically just how these people felt the disease had affected them and their relationship with the patient.

The entire field of counseling in a medical setting is seen as a virtually untapped area for investigation of pertinent theoretical assumptions and methodology which might prove to be most effective for this population.

In presenting and discussing the research results for this study, significant differences were found in the class members' knowledge of the lung disease process after having taken the class. These patients also scored higher on the I.I. after class participation than the comparison group. There were significant differences in mean scores between the two groups on the Health Locus of Control with the class members seeing themselves as more external than the comparison patients. No significant differences were found on the Psychosocial Problems Inventory or the Coping Scale.

APPENDIX A

PROMOTIONAL MATERIALS

ST. MARY'S TO OFFER SPECIAL COURSE FOR THOSE WITH CHRONIC LUNG DISEASE

The Respiratory Therapy Department of St. Mary's Hospital and Health Center will offer a six week course for patients with chronic obstructive pulmonary disease. The program, which will focus on the prevention of rapid debilitation rather than on rehabilitation, will begin on Sept. 21st, 1982. Each series of classes will accommodate eight to fourteen patients at a cost of \$100 per person which will go toward the costs of sponsoring this program. Eighty percent of the cost is reimbursable by Medicare and most other medical insurance plans. Entrance requirements include a written prescription from the patient's own physician.

The Debilitation Prevention curriculum will include:

Relaxation techniques

Graded exercise

Pulmonary anatomy and physiology

Improved self care and the emotional problems associated with chronic shortness of breath. Each patient will be visited once in his or her home to help identify individual or family problems.

Classes will be held from 7:00 to 9:00 p.m. once a week for six weeks. For further information concerning the program and patient enrollment contact St. Mary's Hospital and Health Center, 622-5833, Ext. 4130.

St. Mary's Hospital and Health Center Respiratory Therapy Department

Debilitation Prevention for Chronic Lung Patients

Phone: 622-5833 Ext.4130



Next Class: _____ Time: _____

Curriculum includes:

- **Relaxation Techniques**
- **Graded Exercise**
- **Pulmonary Anatomy and Physiology**
- **Improving Self-Care**
- **Coping with Continuous Shortness of Breath**
- **Discussion Group for Spouses**

Each patient will be visited once in his or her home to help identify individual or family problems.

Each series meets once a week for six weeks.

For further information and patient enrollment contact St. Mary's Hospital and Health Center.

APPENDIX B

LETTER TO COMPARISON GROUP

Dear Patient:

Attached are several questionnaires regarding health problems and information. We would appreciate your voluntary participation in filling out these forms.

The purposes and objectives of this study are to determine pulmonary outpatients' knowledge level, feelings about health control, feelings regarding health problems, and coping ability. The personal-demographic data sheet is to gather some basic information about you and your disease. We do not need your name since the study is anonymous.

The Information Index is to determine your general knowledge and understanding about your illness and its treatment; the Health Locus of Control assesses how much control a person has over his/her own state of health; the Psychosocial Problems Inventory measures problems associated with illness; and the Coping Scale refers to your ability to deal with a variety of types of stress.

If you are willing to participate, please use the time while you are waiting to be seen to fill out the papers. When you are done, return them to the therapist who gave them to you.

We appreciate your cooperation, but if you prefer not to participate, it will not affect your medical care in any way.

APPENDIX C

MATERIALS FOR FIRST MEETING

PERSONAL DEMOGRAPHIC DATAOUTPATIENT

AGE: _____

SEX: _____

RACE: _____

MARITAL STATUS: Single _____ Married _____ Separated _____
Divorced _____ Widowed _____ Other _____If married, how many years with the same
spouse? (even if now widowed or divorced) _____

Number of years formal education: _____

Usual occupation: _____

Current employment status: Retired _____ Unemployed _____

Sick Leave _____ Disabled _____

Work full time _____ part time _____

How long have you known that you have lung disease? _____

What is your primary lung problem? Asthma _____

Bronchitis _____

Emphysema _____

Other _____

Where do you receive your primary medical care?

Private physician _____

Clinic _____

Hospital outpatient _____

Other _____

Do you smoke now? _____

Have you smoked in the past? _____

If "yes", how many years? _____

and how many packs per day _____

Have you ever attended classes to learn about your lungs and
lung disease? _____

If "yes" when did you attend? _____

and where were the classes? _____

COPD INFORMATION INDEX

1. Good breathing techniques are important to:
 - A. Help increase the amount of oxygen available to your blood stream
 - B. Help eliminate the carbon dioxide from your blood stream
 - C. Insure a regular heart beat
 - D. A & B
 - E. All of the above

2. What is the diaphragm?
 - A. Major muscle of ventilation
 - B. Another name for the windpipe
 - C. A sac surrounding the heart

3. What is the purpose of the bronchial tubes?
 - A. To direct food and liquid from the mouth to the stomach
 - B. To direct air from the windpipe to the alveoli and back
 - C. To secrete mucus that carries debris from the lungs to the mouth
 - D. B and C
 - E. None of the above

4. The tiny air sacs deep in the lungs are called:
 - A. Bronchioles
 - B. Alveoli (Alveolus)
 - C. Arteries

5. Chronic Bronchitis is a condition in which:
 - A. The walls of the air sacs are destroyed, making them larger and less efficient
 - B. The muscles of the bronchial tubes spasm when irritated
 - C. There is a chronic swelling of the bronchial tube lining making the hollow portion of the tube narrower

6. Emphysema is:
 - A. The walls of the air sacs are destroyed making them larger and less efficient
 - B. The muscles of the bronchial tubes spasm when irritated
 - C. There is a chronic swelling of the bronchial tube lining making the hollow portion of the tube narrower

7. The best time for postural drainage and percussion is:
 - A. About noon once you are breathing better
 - B. In the morning when the largest amounts of pulmonary secretions have accumulated in your chest
 - C. Only when you are short of breath

8. Medication for your breathing (Prednisone, Theodur, Breathine, etc.) are usually best taken:
 - A. With meals
 - B. On an empty stomach
 - C. Before a short rest

9. When walking up a flight of stairs, you should:
 - A. Take a deep breath and ascend the stairs as quickly as possible
 - B. Ascend slowly inhaling and exhaling at each step
 - C. Ascend slowly remembering to exhale for twice as long as you inhale, stopping to rest as needed.

10. If you feel an attack of shortness of breath coming on you should:
 - A. Sit up and lean forward slightly preferably on a supporting object
 - B. Walk around a little trying to breathe more rapidly
 - C. Try to exhale rapidly so you will have more time to inhale

11. The right _____ and the left _____ are the two top chambers of the heart.
 - A. Ventricle
 - B. Atrium
 - C. Alveolus

12. Veins are the vessels that carry blood _____.
 - A. To the heart
 - B. Away from the heart
 - C. To just the lower extremities

13. Arteries are the vessels that carry blood _____.
 - A. To the heart
 - B. Away from the heart
 - C. To just the upper extremities

14. The blood in the arteries is bright red because
 - A. It contains oxygen
 - B. It does not contain oxygen
 - C. It contains carbon dioxide

15. The purpose of breathing exercise is:
 - A. To strengthen your back muscles
 - B. To make you more physically fit
 - C. To make you better able to handle episodes of shortness of breath.

APPENDIX D

TESTING INSTRUMENTS

HEALTH LOCUS OF CONTROL SCALE:

52

THIS IS A QUESTIONNAIRE TO DETERMINE THE WAY IN WHICH DIFFERENT PEOPLE VIEW CERTAIN IMPORTANT HEALTH-RELATED ISSUES. EACH ITEM IS A BELIEF STATEMENT WITH WHICH YOU MAY AGREE OR DISAGREE. BESIDE EACH STATEMENT IS A SCALE WHICH RANGES FROM "STRONGLY DISAGREE" (1) TO "STRONGLY AGREE" (6).

FOR EACH ITEM YOU ARE TO CIRCLE THE NUMBER THAT REPRESENTS THE EXTENT TO WHICH YOU DISAGREE OR AGREE WITH THE STATEMENT. PLEASE CIRCLE ONLY ONE NUMBER. THIS IS A MEASURE OF YOUR PERSONAL BELIEFS; THERE ARE NO RIGHT OR WRONG ANSWERS. TRY TO RESPOND TO EACH ITEM INDEPENDENTLY WHEN MAKING YOUR CHOICE; DO NOT BE INFLUENCED BY YOUR PREVIOUS CHOICES.

| | STRONGLY DISAGREE | MODERATELY DISAGREE | SLIGHTLY DISAGREE | SLIGHTLY AGREE | MODERATELY AGREE | STRONGLY AGREE |
|--|-------------------|---------------------|-------------------|----------------|------------------|----------------|
| 1. IF I TAKE CARE OF MYSELF, I CAN AVOID ILLNESS. | 1 | 2 | 3 | 4 | 5 | 6 |
| 2. WHENEVER I GET SICK IT IS BECAUSE OF SOMETHING I HAVE DONE OR NOT DONE. | 1 | 2 | 3 | 4 | 5 | 6 |
| 3. GOOD HEALTH IS LARGELY A MATTER OF GOOD LUCK. | 1 | 2 | 3 | 4 | 5 | 6 |
| 4. NO MATTER WHAT I DO, IF I AM GOING TO GET SICK I WILL GET SICK. | 1 | 2 | 3 | 4 | 5 | 6 |
| 5. MOST PEOPLE DO NOT REALIZE THE EXTENT TO WHICH THEIR ILLNESSES ARE CONTROLLED BY ACCIDENTAL HAPPENINGS. | 1 | 2 | 3 | 4 | 5 | 6 |
| 6. I CAN ONLY DO WHAT MY DOCTOR TELLS ME TO DO. | 1 | 2 | 3 | 4 | 5 | 6 |
| 7. THERE ARE SO MANY STRANGE DISEASES AROUND, THAT YOU CAN NEVER KNOW HOW OR WHEN YOU MIGHT PICK ONE UP. | 1 | 2 | 3 | 4 | 5 | 6 |
| 8. WHEN I FEEL ILL, I KNOW IT IS BECAUSE I HAVE NOT BEEN GETTING THE PROPER EXERCISE OR EATING RIGHT. | 1 | 2 | 3 | 4 | 5 | 6 |
| 9. PEOPLE WHO NEVER GET SICK ARE JUST PLAIN LUCKY. | 1 | 2 | 3 | 4 | 5 | 6 |
| 10. PEOPLES' ILL HEALTH RESULTS FROM THEIR OWN CARELESSNESS. | 1 | 2 | 3 | 4 | 5 | 6 |
| 11. I AM DIRECTLY RESPONSIBLE FOR MY HEALTH. | 1 | 2 | 3 | 4 | 5 | 6 |

PSYCHOSOCIAL PROBLEMS INVENTORY

53

WE KNOW THAT ILLNESS MAKES NEW PROBLEMS AND ADDS TO OLD PROBLEMS. HERE IS A LIST OF DIFFICULTIES REPORTED BY PEOPLE AS BEING CONNECTED TO THEIR ILLNESS. SOME OF THESE PROBLEMS ARE STATED BY ALMOST EVERYONE AS PART OF BEING ILL; OTHER PROBLEMS ARE EXPERIENCED BY ONLY A FEW. BY LEARNING MORE ABOUT HOW PEOPLE'S ILLNESS AND PAIN BOTHER THEM, HEALTH PERSONNEL WILL BE BETTER ABLE TO HELP.

INSTRUCTIONS: FOR EACH OF THE FOLLOWING STATEMENTS, PLEASE CIRCLE "YES" IF IT DESCRIBES HOW YOUR ILLNESS USUALLY MAKES YOU FEEL AND "NO" IF IT DOES NOT. IF YOUR DISABILITY AND ILLNESS MAKE YOU FEEL THIS WAY OCCASIONALLY, CIRCLE "OCCAS'Y". THERE ARE NO RIGHT OR WRONG ANSWERS.

- | | | | |
|--|-----|---------|----|
| 1. WOULD LIKE MORE CONTACT WITH OTHERS. | YES | OCCAS'Y | NO |
| 2. WORRY ABOUT DUTIES AND BURDENS AT HOME. | YES | OCCAS'Y | NO |
| 3. FEEL DISCOURAGED MORE EASILY. | YES | OCCAS'Y | NO |
| 4. HAVE TO LEAN ON OTHERS TOO MUCH. | YES | OCCAS'Y | NO |
| 5. FEEL INSECURE ABOUT HAVING A GOOD INCOME | YES | OCCAS'Y | NO |
| 6. FEAR MAY NOT BE ABLE TO GET RELIEF FROM DISCOMFORT. | YES | OCCAS'Y | NO |
| 7. FEEL LONESOME. | YES | OCCAS'Y | NO |
| 8. FEEL UNSURE ABOUT FUTURE HOME LIFE | YES | OCCAS'Y | NO |
| 9. SEEM TO HAVE GIVEN UP. | YES | OCCAS'Y | NO |
| 10. FEEL BADLY WHEN OTHERS HAVE TO DO SO MUCH FOR ME. | YES | OCCAS'Y | NO |
| 11. LOSE CONFIDENCE IN ABILITY TO DO MEANINGFUL THINGS. | YES | OCCAS'Y | NO |
| 12. FEAR HAVING MORE DISCOMFORT OR DISABILITY LATER. | YES | OCCAS'Y | NO |
| 13. FEEL ISOLATED FROM OTHERS. | YES | OCCAS'Y | NO |
| 14. FEEL AM NOT ABLE TO DO ENOUGH FOR FAMILY. | YES | OCCAS'Y | NO |
| 15. FEEL THERE IS NO HOPE. | YES | OCCAS'Y | NO |
| 16. WOULD LIKE TO BE MORE INDEPENDENT. | YES | OCCAS'Y | NO |
| 17. FEAR NOT BEING ABLE TO CONTINUE WITH USUAL WORK OR ACTIVITIES. | YES | OCCAS'Y | NO |
| 18. FEAR LACK OF OXYGEN MAY AFFECT MIND. | YES | OCCAS'Y | NO |
| 19. SPEND TOO MUCH TIME ALONE. | YES | OCCAS'Y | NO |

PROBLEMS INVENTORY: (CONTINUED)

| | | | | |
|-----|---|-----|---------|----|
| 20. | WORRY ABOUT HOW WELL FAMILY IS GETTING ALONG. | YES | OCCAS'Y | NO |
| 21. | FIND IT HARDER TO FACE LIFE. | YES | OCCAS'Y | NO |
| 22. | FEEL BADLY ABOUT ASKING FOR HELP WHEN NEEDED. | YES | OCCAS'Y | NO |
| 23. | CANNOT BE SURE ABOUT FUTURE WORK OR ACTIVITY LEVELS. | YES | OCCAS'Y | NO |
| 24. | FEAR MAY NOT HAVE ENOUGH COURAGE TO STAND DISCOMFORT. | YES | OCCAS'Y | NO |

COPING SCALE:

55

FOR EACH QUESTION, CIRCLE "YES" OR "NO" TO INDICATE YOUR ANSWER. GIVE "YES" OR "NO" IF AT ALL POSSIBLE. IF YOU FEEL THAT YOU DO NOT KNOW THE ANSWER, OR IF IT IS ONE-HALF "YES" AND ONE-HALF "NO", CIRCLE BOTH "YES" AND "NO". THERE ARE NO RIGHT OR WRONG ANSWERS.

1. DO PEOPLE WHO KNOW YOU WELL THINK YOU GET UPSET EASILY? YES NO
2. DO PEOPLE WHO KNOW YOU WELL THINK YOU ARE STUBBORN? YES NO
3. DO PEOPLE WHO KNOW YOU WELL THINK YOU UNDERSTAND OTHER PEOPLE'S POINTS OF VIEW AND ACCEPT THEM THE WAY THEY ARE? YES NO
4. DO PEOPLE WHO KNOW YOU WELL THINK THAT WHEN YOU GET MAD YOU GET OVER IT QUICKLY? YES NO
5. DO PEOPLE WHO KNOW YOU WELL THINK THAT YOU OVERCOME PROBLEMS EASILY? YES NO
6. DO PEOPLE WHO KNOW YOU WELL THINK YOU ARE RELIABLE AND RESPONSIBLE IN MEETING YOUR FINANCIAL OBLIGATIONS? YES NO
7. DO PEOPLE WHO KNOW YOU WELL THINK YOU HAVE CONTINUED TO MATURE AND GROW EMOTIONALLY AS YOU HAVE GOTTEN OLDER? YES NO
8. DO YOU THINK THE WAY YOU ADJUST TO LIFE CAN CONTRIBUTE TO GETTING SICK? YES NO
9. DO YOU THINK THAT CHANGING YOUR LIFE IN SOME WAY MIGHT MAKE IT EASIER TO GET WELL ONCE YOU GET SICK? YES NO
10. IF YOU ARE SICK AND ARE TOLD TO TREAT YOURSELF WITH SOMETHING THAT YOU DO NOT UNDERSTAND AND IS DIFFICULT, BUT WHICH NO ONE WILL KNOW ABOUT IF YOU DO NOT DO IT, WOULD YOU DO IT? YES NO

PART B:

1. DO YOU HAVE GOOD HEALTH? YES NO
2. DO YOU THINK YOU HAD A SATISFYING RELIGIOUS EDUCATION? YES NO
3. DO YOU THINK YOUR FATHER WAS SUPPORTIVE AND UNDERSTANDING? YES NO
4. DO YOU THINK YOUR MOTHER WAS SUPPORTIVE AND UNDERSTANDING? YES NO

COPING SCALE (CONTINUED)

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|-----|---|-----|----|
| 5. | DO YOU THINK THOSE CLOSE TO YOU PROVIDE THE EMOTIONAL SUPPORT YOU NEED? | YES | NO |
| 6. | DO YOU THINK HOUSING IS A PROBLEM? | YES | NO |
| 7. | ARE YOU (OR WERE YOU) SATISFIED WITH YOUR OCCUPATION? | YES | NO |
| 8. | ARE YOU (OR WERE YOU) SATISFIED WITH YOUR WORKING CONDITIONS? | YES | NO |
| 9. | IS YOUR INCOME SATISFACTORY? | YES | NO |
| 10. | HAVE YOU SET GOALS FOR THE FUTURE THAT SATISFY YOU AND ARE REALISTIC? | YES | NO |

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