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Wendy Jean Fielder

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AN EXPLORATORY STUDY TO DELINEATE PERSONAL
MEANING CATEGORIES OF CHRONIC PHYSICAL ILLNESS

By

Wendy Jean Fielder

A THESIS

Submitted to
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ABSTRACT

AN EXPLORATORY STUDY TO DELINEATE PERSONAL MEANING CATEGORIES OF CHRONIC PHYSICAL ILLNESS

By

Wendy Jean Fielder

One hundred fifty-three individuals with chronic lung disease or diabetes completed a 60 item questionnaire designed to measure illness perception. Factor analysis yielded five factors with good reliabilities. Correlations were carried out between these factors and various other demographic measures as well as with a measure of helpfulness of others developed in this study, and the Holmes and Rahe Social Readjustment Rating Scale. The factors were compared to those proposed and found in two other studies, and their relationship to coping strategies was discussed. Scale validation attempts and difficulties were discussed and suggestions for future study offered.

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INTRODUCTION

Facing the reality of having a chronic disease certainly ranks as one of the most stressful events a person can encounter during his lifetime. Aside from the possible life threatening implications, the very nature of a chronic ailment implies that a person has to re-evaluate the rest of his life in terms of the illness' effects. This may involve many changes; from day to day routines, lessening abilities to engage in activities, alterations in social relationships to changes in an individual's self concept. And when the disease is not only chronic but threatening to an individual's life itself, the person's concept of what his life will be, in terms of length and achievements, is drastically challenged. These stressful changes are also made even more difficult to deal with because, due to the disease involved, the person's strength and resources are being drained. So, not only is the situation difficult to face in itself, but a person's resources for dealing with stress are likely to be lower than at other times in his life.

Stress, and the individual's strategies for coping with it, have been topics of increased interest in recent years. What types of events are the most stressful, what environmental configurations increase the likelihood that an event

will be seen as stressful, how do personality characteristics affect the appraisal of, and subsequent coping with, stress, what behavioral, physiological and emotional reactions are common to all in stressful encounters and what ones are specific to certain individuals?

Generality vs. Specificity: Two Ways of Viewing Stress

There seem to be two main theoretical approaches to stress found in the literature. The first, illustrated best by the early work of Selye (1956), emphasizes the generality of response to all kinds of stress. His popular concept of a General Adaptation Syndrome (GAS) explains all forms of threat as activating this general defense. An individual is first in a state of alarm as the threat is recognized, then goes into a stage of resisting the threat, and finally, as the situation continues, the system reaches a point of exhaustion. A person in this final stage is likely to have undergone some type of tissue damage as a result of the struggle.

The well known Holmes and Rahe social readjustment scale is based upon the concept of a general reaction to stress. In this, major life changes are given point values according to the amount of stress they produce (in any person) and a total of above 200 is an indication that the individual's defensive resources are likely to be depleted, with the possibility of serious physical illness following.

The other approach to conceptualizing stress is that

of specificity. According to this viewpoint, different environmental demands will result in differential stress disorders, depending on the nature of the demand, the characteristics of the individual facing that demand, and the ways in which that individual attempts to cope with the situation (Lazarus, 1966). Both approaches have given us valuable insights into the components and reactions to stress, but as Lazarus states, "...I find the specificity arguments richer in the range of potential factors that might account for variations in the degree and type of somatic illness in different individuals and under different environmental conditions." (1974)

A concept that supports the idea that an individual plays an important role in determining his reaction to stress is that of threat being cognitively mediated. A study by Symington, Currie, Curran and Davidson (1955) showed that the physiological mechanisms of the GAS are not brought into play by an injured animal unless the organism is conscious during the injury. In other words, the activation of the GAS is psychologically determined, in that threat, or stress, is not reacted to without it being cognitively assessed as such. Theorists such as Ellis (1973) and Seligman (1975) also emphasize the causal chain as being from cognition to emotion, and not the other way around. Lazarus' major work on stress (1966) is based on the belief that cognitive appraisal of the situation leads to feelings of stress, anxiety and fear; and that this appraisal is necessary to mobilize coping responses.

This is not to say that these appraisals are necessarily rational or lead to particularly adaptive responses. Individuals' beliefs about the environment and themselves can run the gamut from being reasonable and reality oriented to delusional and fantasy based. It is to say that these appraisals of the situation will follow from these beliefs, and likewise be realistic and lead to reasonable responses, or be unrealistic and result in unadaptive and possibly even harmful coping reactions.

Threat and Its Appraisal

Threat is by definition an anticipated harm, which promises to hinder or prevent a personal goal. The more important the reaching of this goal is to a person, the more threat its demise presents. Some types of goals are more or less universal, e.g. good health and freedom from pain, and so reactions to threats of these goals will be somewhat similar for every person. Even so, some differences in response can be noted, and these relate to different coping mechanisms utilized by different individuals.

The two major factors that affect how a threat is appraised are the situational factors involved and the personality characteristics of the person doing the appraising (Lazarus, 1966). In considering the situational factors, one must first assess the balance of power between the harm producing stimuli and the individual's own resources to counteract the potential danger. If the person can muster the power to overcome the harm, the threat is substantially

reduced; likewise if it seems that the harm will occur regardless of personal efforts, the threat grows. The person's resources include his knowledge of the objective danger, his environmental supports in the form of his family and other interpersonal relationships, and his beliefs about his own power. In this last aspect, it is important to note that it is the person's belief about his abilities, more than his actual power, that is the vital factor.

One must also take into account the imminence of expected confrontation with harm. If it is expected far in the future, the magnitude of the threat it presents is likely to be much less than if it is more immediate. This can be seen in Mechanic's study of graduate students facing doctoral exams (1962). He found that the anxiety and preoccupation of the students with possible failure increased as the time for the exams grew closer. This can also be seen clearly in the attitudes found towards death in this country. Younger, healthier people rarely dwell on thoughts of their own deaths and therefore do not consider it much of a threat to their planned activities and goals for their lives. But as anyone who has visited an older, and/or quite ill person can see, death, and the threat it poses are much more immediate and great.

The appraisal of threat is also influenced by the ambiguity of clues about the anticipated harm. The more vague the danger seems, the less threat it will cause a person to feel, in general. However, ambiguous clues about harm allow personal idiosyncrasies to dominate the affective reaction.

That is, if a person is inclined to be pessimistic about his environment and his abilities to resist harm, even slight indications of harm can set this apparatus into motion. Likewise, a more optimistic personal outlook will allow an individual to overlook or minimize small possibilities of danger.

In the case of dealing with physical illness, aspects of the illness itself are important considerations in how the situation will be appraised. The seriousness of the disease, its location in the body, degree of reversability and extent to which personal efforts can change its course are all important variables. These variables must not only be viewed from their objective harm producing characteristics, but for the meaning they have to the person who is afflicted (Lipowski, 1970). As he states, "The more the impaired body part or function involves the individual's values, conflicts and sources of gratification, the more it challenges his coping resources".

This brings us to the personality factors that have an effect on how threat will be appraised. As mentioned above, threat is the potential harm that will be done to a motive or goal. In the individual, a threat is only as strong as the motive it endangers is important. These goals may be quite individualistic, or more culturally determined. Whatever their source, a great deal of the meaning of an illness to a person relates to the importance and meaning of the goal it threatens to cut short or alter. This can be clearly seen in the case of mastectomies. The Reach for

Recovery program instituted by the American Cancer Society, for instance, focuses heavily on the emotional meanings and consequences of losing a breast as well as on physiological recovery from such a trauma (Lasser, 1972).

Threat appraisal is also influenced by the individual's beliefs about his interaction with the environment. If he is inclined to see the environment as dangerous, hostile and untrustworthy he is more likely to appraise a threat as more serious than a person who has more positive trusting feelings about his surroundings and his ability to deal with them (Davids, 1956, Lazarus, 1966).

A final determinant of the way in which crises are viewed are personal characteristics of the individual, such as intelligence, educational level and general sophistication. These can have varied effects on appraisal, e.g. a person of lower intelligence may not recognize certain cues of threat and therefore not feel in danger, but he may also be less amenable to comforting efforts by others in his environment and so may feel more threatened than the objective situation calls for. By the same token, a person of high education may be able to control his fear through his knowledge of the situation, while another of comparable training may know almost too much about the possible complications and become overly worried. These factors, therefore, can not be examined in isolation from the other variables mentioned; importance of the goal in danger and the individual's concept of the friendly or unfriendly nature of the environment.

Methods of Coping; Minimization, Vigilant Focusing and Capitulation

The appraisal of threat is only the first step a person facing a crisis will take. Following a concept of the amount and type of danger one is in, one must then formulate a method of dealing with, or coping with, the situation.

Much has been written in recent years about the different methods of coping, their relative efficacy, and their effect on the adaptation of the individual to his situation. Different authors have titled methods differently, but one finds three major classifications emerging from most of the literature.

The first, and the one which has received the most attention, is denial. Cohen and Lazarus (1973), Lipowski (1970) and Kiely (1972) refer to this as minimization, or avoiding, Verwoerd (1972) as retreat from threat and suppression, and Hamburg, Hamburg and deGoza (1953) as constriction, but all are referring to a similar phenomenon. Minimization is perhaps the most inclusive of these terms and is characterized by "...a tendency to ignore, deny or rationalize personal significance of information input related to one's illness and its consequences" (Lipowski, 1970). This mechanism is most likely to be seen in the initial, emergency, phase of illness, and is very common and functional when displayed at the beginning (Hamburg et al., 1953, Visotsky, 1961).

Visotsky, Hamburg, Goss and Lebovits (1961) offer a

six part definition of the effectiveness of coping, and it would be well to keep this in mind when considering the effects of any attempt to deal with illness. Coping is effective when it serves one or more of the following functions; 1) keeping distress within manageable limits 2) enabling one to feel hope 3) maintaining a sense of personal worth 4) maintaining meaningful social relationships 5) enhancing prospects for physical recovery 6) enabling one to establish a satisfactory situation after maximum physical recovery has been reached.

One could look at denial, long perceived as a negative mechanism, in these terms. Work done with victims of cancer and cardiac illness has shown that denial can be quite effective and useful for the cardiac patient, and, in fact, tends to be fostered by the staff and hospital atmosphere (Hackett and Weisman, 1969). For the patient with a good chance of recovery, denial enables him to keep his distress at a minimum, generate hope for recovered functioning, which in turn enhances possibilities for a good recovery, and maintain a sense of personal worth and the quality of relationships with significant others. The picture is somewhat different, however, for those with an incurable illness.

Weisman and Hackett (1967) formulate the idea that the major function of denial is to preserve relationships with important others. Often, those close to a person are made so uncomfortable by a change in the relationship, i.e. the fact that one of them is dying, that they may be driven away

from closeness with that person. They hypothesize that the fear of abandonment, of isolation and loneliness, is greater among the dying than the fear of death itself. For this reason, many dying people will attempt to ignore the issue of death with those close to them, although they may make it clear to a relative stranger, e.g. a hospital aide, or a social worker, that they are well aware of their situation (Weisman, 1972). While this, on the one hand, will keep those close from being driven away, it, on the other, often increases the individual's loneliness in that he has no one close to him with whom to discuss the vital changes that are occurring within him. This may be likened to the disturbing sensation we are all familiar with; feeling alone in a crowd. This often leads to depression and feelings of extreme alienation, as the person may feel rejected as the individual he truly is; a person with a predictably short life span.

Minimization is but one way a person consistently deals with stress in his life. Another, also titled by Lipowski (1970), is vigilant focusing. These two forms of cognitive coping styles are, of course, on a continuum, with very few individuals falling on the extreme ends. However, there is some indication that, within limits, a person tends to use these mechanisms to the same degree in any stressful situation, of which dealing with a chronic illness is only one instance (Shneidman, 1963).

Vigilant focusing is characterized by obsessional, anxiety prone attention to the problem, with attempts at

mastery and understanding. It too falls, at times, in the effective coping category, and at others, not. When anxiety is moderate, for example, before surgery, the post operative prognosis is generally good, as the person has had a chance to do his "worrying work" in advance and come to terms with his situation (Janis, 1958). On the other hand, those that are extreme vigilant copers may be so caught up in the need to master situations, that they have extreme difficulty in accepting the necessary dependent position of illness and therefore, hinder their chances for recovery (Cohen and Lazarus, 1973).

The third major coping mechanism, capitulation, has not received quite the interest and study that the other two have had, but is an important variable none the less. Perhaps the most influential discussion of giving up is offered by Seligman (1975), who puts forth the idea that those who have become convinced of their powerlessness in altering their lives tend to give up. This phenomenon has been nicely distinguished from hopelessness by Schmale (1972). Helplessness, he says, is the feeling of powerlessness over the achievement of external sources of gratification. Hopelessness, while it may be generated by helplessness, is different in that it represents a person's inability to satisfy his own standards. Both are detrimental to recovery, or effective acceptance of the situation.

These mechanisms should not be confused with passivity in the service of letting the body rest and get better.

This type of passivity, which in the case of a curable illness, is temporary, is an adaptive response to the reality of decreased bodily energy. Capitulation should also be differentiated from what Weisman and Hackett (1961) refer to as a predilection to death. This occurs when death is seen as appropriate, desirable, and accompanied by little anxiety or depression. The instance of this is somewhat rare, but gives us a model of what may be fostered in the terminally ill in order to make their death more acceptable and anxiety free. Conflict is reduced, compatibility with the ego ideal is achieved, important relationships are continued or restored, with death representing the fulfillment of a wish.

Although these three mechanisms may continue for the duration of the illness, often the patient is able to move on from these towards recovery and/or acceptance. Visotsky et al. (1961) and Hamburg et al. (1953) have reported very interesting observations of the progress of polio and burn victims, respectively, and cite the aforementioned strategies of coping as emergency mechanisms for the most part. After the emergency phase has passed, they record the mechanisms that aid in recovery. Important among these are renewal of hope, sustaining family and other significant relationships, the use of humor, interaction with other patients and the community, the setting of intermediate goals, the restoration of self esteem, and the perceived ability, as functioning is beginning to be recovered, of being able to master some of the situation.

Personal Meanings of Illness

As mentioned above, a person's appraisal of threat results from many situational and personal variables. The same is true for the type of coping strategy an individual adopts in the face of threat; it is based on the personal meaning an illness or injury has to an individual (Lipowski, 1970). Lipowski details eight major categories this meaning may fall into which are prevalent in our culture.

The first is "illness as challenge". This meaning encourages active participation in coping and generally inspires adaptive behavior. In direct contrast to this is "illness as enemy", which, as the name implies, denotes attack, which leads to anxiety, fear and anger, and can promote the feelings of helplessness, desire to surrender, passivity, and in its extreme forms, blame towards others for "causing" the illness.

In a slightly different vein, there is "illness as punishment". This may be accompanied by depression, anger and anxiety and can represent the illness as just or unjust punishment. Some patients may come to the conclusion that they have now paid for their wrongdoings, and can face the rest of their lives with renewed hope and vigor. Others, who feel unjustly afflicted, are likely to show signs of deep depression.

A meaning especially related to our culture is "illness as weakness". This not only refers to physical weakness, but some flaw in moral character as well. This is likely to

lead to guilt feelings and the attempt to hide the fact of being ill.

A particularly dangerous meaning in terms of the ability to recover is "illness as relief". Some patients may discover that their illness gives them a welcome respite from responsibilities, and attempt to cling to their disabilities even when physiologically recovered. This phenomenon is akin to that of secondary gain in psychologically disturbed individuals. Although the symptoms may develop from many sources, the person discovers, "secondarily", that these same symptoms are giving him advantages and power he is reluctant to give up. This makes the treatment of these types of disturbances much more difficult, because removal of the symptoms also means removal of the gains a person is getting from them. Parsons and Fox (1952), in their classic discussion of illness in America, have taken the "illness as relief" idea one step further, saying that in many cases, the etiology of illness can be traced to the individual taking a "legitimate", culturally approved way out of his life pressures, by becoming ill.

Related to the relief patients may feel at being ill, is the meaning "illness as strategy". In this, the ill person may, through his dependence, attempt to manipulate those close to him. To the extent that this strategy is successful, this type of patient may also fight any improvement in his health.

A meaning that is especially vital to discover early on

in the illness process is "illness as irreparable loss or damage". This relates strongly to the excessive emphasis our society places on physical vitality in men, and physical attractiveness in women. A patient who believes that he or she has lost something vitally important which can never be restored or replaced is a good candidate for severe depression, and possibly attempts at suicide. Therefore, the early identification of this meaning may be necessary to save a patient's life.

The final meaning Lipowski lists is "illness as value". Whether one wishes to classify this as a "defence" or not, there are individuals who firmly believe that the experience of being ill has enabled them to deepen their personalities and has given them extra sensitivity to life. This is not a prevalent viewpoint in our society, but certainly enables the person who can believe this to develop a much more positive outlook on himself and his experience than many of the preceding meanings.

Experimental Work with Coping Styles

Some work has been done trying to link meanings and coping styles to observable differences in recovery rate and emotional reactions to illness and surgery. Janis' classic work on stress (1958) studied the connection between pre-operative defense mechanisms, or ways of coping, with post-operative reactions. He found that very low levels of pre-operative fear, or high degrees of denial, were

linked with poor recovery rates coupled with anger and resentment. He hypothesized that this was the result of lack of preparation for the ordeal, while those that had a medium level of pre-operative fear were able to do the "work of worrying" prior to their operations. This enabled them to take the frightening aspects of the experience and develop some reassuring attitudes which carried them through recovery with a minimum of emotional disturbance.

Andrew (1970) worked with prospective surgery patients also, giving them information on their upcoming operations. She found that people with different customary coping styles (i.e. avoiders, sensitizers, which correspond to vigilant focusers, and neutrals) reacted differently to her "helpful" tactics, with only the neutrals being able to use the information to cut their recovery time.

In another study on surgery reactions, Cohen and Lazarus (1973) found that neutral and avoidant groups recovered the quickest, with vigilant focusers having the most difficulty. They theorized that vigilant copers are, by nature, people to whom mastery is important, and the dependent and helpless aspects of undergoing surgery were very difficult for them to accept. They also postulated that denial, or avoidance, is the most effective way of dealing with surgery, especially if the prognosis is good. This conclusion is at odds with that of Janis, and illustrates the relatively small degree of knowledge that is available in this area at the present time.

Using a different group of subjects, Bulman and Wortman

(1977) studied the reactions of accident victims who were now quadriplegic or paraplegic. They found that the best copers were those who blamed themselves for the accident, but at the same time felt that they could not have done anything to avoid it. They interpret these findings as indicating a need for an orderly and meaningful world, rather than a controllable one. It could also be seen as an effort on the part of the victim to reason that if it was his fault he would have the power to make it better somehow. This is reminiscent of a vigilant form of coping, of a person who feels somehow responsible for what happens to him, and consequently, responsible for his reactions to the event of being injured. The authors do warn, however, that these responses are those of people who were healthy one day, and permanently crippled the next, and these may differ significantly from the dynamics of people whose illnesses progress at a more gradual rate.

Another offshoot of the theorizing on meaning dimensions of illness are attempts to empirically document important dimensions of disease, by collecting responses to items about illness perception and then conducting factor analyses on the resulting data. Most of these studies have been conducted on patients with chronic pain (Pilowsky and Spence, 1975, Timmermans and Sternback, 1974), and while these are interesting, they have doubtful generalization to populations with illnesses that do not have the obvious psychosomatic components chronic pain does.

One series of studies has been done on patients in haemodialysis (Pritchard, 1974a, 1974b, 1974c) which lends some support to the meaning categories proposed by Lipowski. Pritchard found the following factors emerging from his study; disease seen as enemy vs. seen as a challenge, feeling self responsible vs. disease as unjust punishment, help appreciated vs. dependence resented, anger vs. depression, information desired vs. worry, fight vs. escape and a dimension of loss and failure. Unfortunately, this study was conducted on a very small group of patients, which casts extreme doubt on the validity of conducting a factor analysis, and therefore, on the factors identified.

Work in this area is obviously, however, of importance in the treatment of people with illnesses. If a method of identifying both the factors in disease meaning, and an individual's scores on those factors, can be devised, it could be possible to pinpoint early in treatment those high risk patients, as well as finding which methods of coping are the most effective for various types of illness. There is some indication that attempts to help patients cope effectively will have varying consequences depending upon the preferred coping mechanisms of the person involved, so that if his customary outlook could be identified early, the most effective method of reaching him to aid in speedy recovery could be used. The specific areas of an individual's concern could be located, and emphasis, therefore, could be concentrated on these aspects. Doctors have long noted that

different patients with the same prognosis have different rates of recovery and differing degrees of co-operation with therapy; this area of research could eventually give us an empirical method of identifying and helping those with less than optimal attitudes.

The current study proposes an initial attempt to identify the relevant factors of disease perception, using as a basis the questionnaire devised by Pritchard (with some modifications) and using a much larger population so that a factor analysis of the results will have a chance of resulting in some valid dimensions.

METHOD

Subjects

The subjects were patients who were participating in outpatient clinics for chronic disorders at two medical facilities in the Lansing area. These clinics required regular visits (anywhere from once a week to once every six months, depending on the patient's condition) during which time each patient met with his doctor and reviewed his progress, problems and any relevant medical tests that had been done. Subjects were asked about participating in the study when they made this regular visit, and questionnaires were generally completed in the waiting room, or other rooms made available by the clinic. Data were collected over a ten month period, during which time 238 people were approached about participating. They were informed of the voluntary nature of participating, assured of confidentiality regarding their responses and promised that general results of the study would be sent to the clinic where they could pick up a copy on a subsequent visit. One hundred fifty-three individuals completed the questionnaires, 36 declined participation, 45 took the materials home and did not return them, and four questionnaires were returned incomplete and therefore were not used. In these four cases, the materials were not completed because the subject was too ill to

continue. An attempt was made to approach everyone who met the criteria of having a chronic illness, so there would not be a biased selection procedure.

Of the completed questionnaires, 92 were from men and 61 were from women. The subjects covered a wide age range, from 20 years to 86 years with a mean of 55. All education levels were represented, the largest group being that with a high school diploma (43 individuals). Over 60% had a high school education or schooling beyond that level. (See Table 1.)

The subjects used in the present study, and in Pritchard's (1974b), the only other study to date to employ the Response to Illness Questionnaire, all had chronic illnesses, but the type of illness varied, and this may have had an impact on the results of both these studies. The subjects used by Pritchard were 14 (5 male, 9 female) patients with chronic renal failure, undergoing haemodialysis. No other demographic data was given, other than that six of these subjects had been seen by Pritchard for psychiatric consultation in the past. This is a type of illness and treatment that, one might surmise, is quite obvious in the day to day life of the patient, and which requires active monitoring and intervention, as well as, quite possibly, concern about further complications which might be life threatening.

The patients used in the current study were for the most part (86%) taken from a clinic population of persons with chronic lung disorders; emphysema, chronic bronchitis, chronic obstructive pulmonary disease, asthma, chronic

Table 1

Demographic Information

Male Subjects 92
 Female Subjects 61

N=153

<u>Diagnosis</u>	<u>Frequency</u>
Diabetes	21
Emphysema	63
COPD	25
Asthma	17
Chronic Bronchitis	24
Misc.	<u>3</u>
	153

<u>Educational Level</u>	<u>Frequency</u>
More than 4 years college	7
College degree	17
Partial college	21
High school degree	43
10th or 11th grade	16
7th, 8th, 9th grade	36
Less than 7 years schooling	4
Missing data	<u>9</u>
	153

shortness of breath and chronic respiratory infection. The remaining 21 subjects had diabetes. There was a large range in these patients as to how physically debilitating the illness was, how much it affected their lives and plans for the future, and how much time and effort had to be outlayed in maintaining and caring for their conditions. While some of the lung patients carried oxygen tanks with them at all times, most of them did not require equipment to keep them alive, unlike the haemodialysis patients. Also, the life threatening aspects of these illnesses had a greater range than those of Pritchard's patients, in that some of the older patients in the lung clinic sample had to be concerned about the increased rate of infections, while many of them and the younger patients did not have a reduced life expectancy due to the disease. This same range was evident in the diabetic patients, with those who had developed the disease earlier in life likely to develop more serious complications than those who had developed it later.

Because no demographic data was included in Pritchard's publication, one has no information as to the differences between these two populations in terms of length of illness, age and education level. There may also have been a difference in terms of voluntary participation, as several of Pritchard's patients had a previous association with him, and no data is given to indicate how many patients declined to participate.

Diagnosis

The subjects were drawn from a clinic for diabetics and a clinic concerned with chronic lung disease. No patient with cancer or a progressive fatal disease was included, as were none who had temporary disorders. Twenty-one subjects were gathered from the diabetes clinic and the remaining 132 subjects attended the chest clinic. Among the latter group, several diagnoses were included. The largest group was 64 people with emphysema, followed by 26 with chronic bronchitis, 25 with chronic obstructive pulmonary disease (COPD), 19 with asthma and three in a miscellaneous category (two with chronic shortness of breath and one with chronic respiratory infection). Across all groups, the average duration of the disease was 6.808 years, with a range of .75 years to 40 years.

Materials

The questionnaires consisted of several parts. The first part was concerned with demographic data; diagnosis, length of illness, whether or not the doctor had given the patient all the information he had desired, age, sex, education level and employment information (job of primary wage earner, or major source of support). The person was asked, if working, whether or not the illness had affected his or her job. The subject was also asked to rate his or her current feeling state (worse than usual, about average, or better than usual) at the beginning and end of the questionnaire. Several of these indices were not used in the final analysis, due to lack of variation (feeling state, information from doctor) or

insufficient numbers of respondents (employment information).

The next five questions dealt with the support systems available to the patient and the extent to which these had been found to be helpful during the illness. These asked the patient to rate on a five point scale, from very unhelpful to very helpful, his or her spouse, children, co-workers, and members of any clubs or religious organizations to which he or she belonged.

The next part of the questionnaire was the Social Readjustment Rating Scale (SRRS) developed by Holmes and Rahe (1967). This scale is reproduced in Appendix A. These instructions asked the patient to check any event listed which had taken place in the last two years of his life.

The final section of the questionnaire was a variation of the Response to Illness Questionnaire (RIQ) developed by Pritchard (1974a). This scale is shown in Appendix B. It consisted of 60 statements, each followed by five possible responses, ranging from strongly disagree to strongly agree.

Following these statements was a sentence inviting the patient to add any feelings about his or her illness that the 60 items had not covered.

The questionnaire was administered in this total form to 81 patients. The remaining 72 subjects completed only the RIQ, and indicated their age, sex, and education level.

RESULTS

Development of Measures

Helpfulness Scale. The five items which asked subjects to rate the helpfulness of people around them (spouse, children, fellow club members, fellow members of a religious congregation and if employed, co-workers) were correlated with each other. These correlations ranged from .2985 to .6878 and all were significant at the .001 level. The reliability (coefficient alpha) for these five items was found to be .79542. It was decided to treat these five items as a cohesive scale, and scale scores for individuals were calculated by adding up the responses on each of the items.

The Social Readjustment Rating Scale. The scale was scored according to the method described by Holmes and Rahe (1967). Each checked item was given the appropriate number of points according to the weighting system and these points were added together to compute the final score for each individual. The mean score for this sample was found to be 180.95, with a score range of 53 to 688, and a standard deviation of 95.82.

Response to Illness Questionnaire: Factor Analysis. A classical or common factor factor analysis was performed on the items in the RIQ. Squared multiple correlations were

used as initial communality estimates. Varimax orthogonal rotation was used throughout these procedures.

Use of the scree criterion suggested that seven or eight factors be rotated. The eight factor solution was chosen as the basis for further scale development, since it had the most conceptually meaningful factors. The last two factors in this solution were judged to be meaningless, and the items which composed these factors were dropped (#30, 38, 8, and 12) as were all items that had loaded less than .4 on their respective factors in the seven and eight factor solutions (#2, 4, 7, 15, 16, 20, 29, 33, 35, 36, 37, 43, 44, and 55). The remaining 42 items were refactored specifying the rotation of six factors. The items making up these six factors were further scrutinized by comparing the corrected item-total correlations for each item with the scale to which it belonged with its correlation with the other five scales. Any item which correlated higher with another scale than with the one of which it was a part was dropped from the scale (#52, 54, 10, 19, and 51).

The remaining 37 items were factor analyzed again specifying the rotation of six factors. Reliabilities (coefficient alpha) were calculated on these six factors and two items which lowered the reliabilities of their factors were dropped (#21 and 23).

Of these six remaining factors, the sixth consisted of only two items (#22 and 31) and had a reliability of .46517 and so was not used in any further analyses.

The items in the five remaining factors are listed in Table 2, and were interpreted in the following way. The first, a more general factor, contained 12 items relating to alienation from others, e.g. Others do not understand how being ill is for me, It makes me feel I am alone, My illness is worse than others realize; concern with the consequences of the illness, e.g. I feel threatened by it, I don't worry much about my illness (reflected), I feel depressed about it; and feelings of being depleted, e.g. I feel it indicates that I am inferior, My illness has taken something from me, It is a sign of weakness in me. The reliability of this factor was .87954 and it will be referred to as Alienation in the following.

The second factor was named Responsibility and contained seven items dealing with personal responsibility and participation in contracting the illness. Representative of this scale are items like; I feel I am in some way responsible for being ill, I must have done something to deserve it, and It is a punishment for something I have done. Reliability for this factor was found to be .83721.

Factor three was named Defeat and contained four items that dealt with loss of control over one's life and feelings of helplessness. Examples are: It defeats me and There is nothing I myself can do about my illness. The reliability found for this scale was .78064.

Fourth was a five item scale that dealt with increased dependence on others, resentment of this dependence, and

Table 2
Final Scales

Alienation

Others do not understand how being ill is for me
 I feel depressed about it
 I feel resentful about it
 I feel threatened by it
 I feel it indicates that I am inferior
 My illness is worse than others realize
 I feel frightened about it
 It makes me feel I am alone
 I feel angry about it
 I don't worry much about my illness (reflected)
 My illness has taken something from me
 It is a sign of weakness in me

Responsibility

I feel I am in some way responsible for being ill
 I must have done something to deserve it
 It is a punishment for something I have done
 I do not think there is anything I've done that explains why
 I've become ill (reflected)
 I cannot think of any reason having to do with me that explains
 why I should have it (reflected)
 This shows that I have somehow failed
 I feel guilty about it

Defeat

It defeats me
 There is nothing I myself can do about my illness
 I am defenseless against it
 Being ill has made me feel I have little control over what
 happens to me

Illness as Enemy

It makes me more dependent than I'm used to being
 I feel it is something that has come and attacked me
 My illness is like an enemy
 I resent the way it makes me dependent on others
 I feel I have to resist it

Table 2 (cont'd.)

Denial

It is a punishment which I do not deserve

It is wrong that I should have to suffer this

I feel it's like a dream; that it's not really happening to me

Others are responsible for it

viewing the illness as an attacking force that must be resisted. This included items like; I feel it is something that has come and attacked me, I feel I have to resist it, and I resent the way it makes me dependent on others. The reliability for this scale was .72181 and it was named Illness as Enemy.

The final, fifth scale contained four items dealing with the wrongness of having the illness, externalization of responsibility, and denial of the situation. These items were: It is a punishment which I do not deserve, It is wrong that I should have to suffer this, I feel it's like a dream; that it's not really happening to me, and Others are responsible for it. The reliability for this scale, called Denial, was .70277.

Scale scores for each subject on each scale were computed by adding the responses made by an individual to each item (ranging from strongly disagree = 1 to strongly agree = 5) on a scale.

The factor loadings for the items on the five factors are presented in Table 3.

A Pearson correlation coefficient was calculated for each scale with each other scale. These correlations ranged from .3458 between Denial and Illness as Enemy to .6860 between Illness as Enemy and Alienation. The correlations are presented in Table 4.

Table 3
Factor Loadings for the Final Items

<u>Item</u>	<u>Factor 1</u>	<u>Factor 2</u>	<u>Factor 3</u>	<u>Factor 4</u>	<u>Factor 5</u>
1	.42788	.13991	.08103	-.12276	.03106
5	.23226	.70106	.02199	.13633	-.02277
6	.13739	.14078	.04473	.32455	.52271
9	.39969	.34597	.21305	.19366	.21168
11	.25721	-.06240	-.02875	.25353	.60804
13	.71731	.08448	.05268	.06756	.11827
14	.62681	.22944	-.06539	.19450	.37248
17	.11440	.83388	.10343	.15973	.07113
18	.63060	.14897	-.05684	.41647	.07253
24	.35587	.08550	.35318	.42527	-.10430
25	.11023	-.03552	.16442	.62212	.26794
26	.28803	.15609	-.08351	.61875	.32690
27	.22931	.76074	.12449	.11863	.21399
28	.03557	-.54584	-.13227	.01260	.13955
32	.52130	.31969	.25830	.13967	.28915
34	.42921	.13025	.16458	.09179	.01442
39	.43201	.00531	.26678	.50019	.18010
40	.74770	-.02799	.02971	.09838	.03520
41	.65869	.10584	.24169	.13535	.15342
42	.62024	.10797	.10043	.19372	.27035
45	.03589	-.49933	.26801	.08848	.10043
46	.43869	.57561	.14419	.01694	.24696
47	.25208	-.06953	.15618	.05777	.60238
48	-.60349	-.02449	.23074	.07481	-.03971
49	.04624	.07466	.13452	-.03513	.45955
50	.51675	.10612	.52822	.09822	.05280
53	.45720	.49365	.22294	-.03687	.30020
56	-.09010	.02304	.69932	.06747	.13773
57	.20100	.22145	.68375	.04590	.15203
58	.35535	.09449	.57679	.12229	-.03901
59	.52500	.11501	.20002	.37317	.22092
60	.04725	.09590	.01964	.35284	.08682

Table 4

Intercorrelations for the Five Final Factors

	Alienation	Responsibility	Defeat	Illness as Enemy	Denial
Alienation	.87954*	.6539**	.5214	.6860	.5964
Responsibility		.83721	.4534	.5141	.4796
Defeat			.78064	.4434	.3458
Illness as Enemy				.72181	.5568
Denial					.70277

* Diagonal values are coefficients alpha

** All correlations are significant at the .001 level

Hypotheses Relating RIQ Factors to Other Measures

Three hypotheses were generated on the basis of the factors which were found. It was thought that there might be a significant relationship found between the scale Responsibility and the category of diagnosis; specifically that there would be a difference between the diabetic and chest clinic patients on this scale, with the chest clinic patients scoring higher. This hypothesis was based on the experimenter's observation that while many of the chest clinic subjects spontaneously expressed the belief that some of their actions, e.g. cigarette smoking and working in atmospherically hazardous jobs, were responsible for their current condition, none of the diabetic group mentioned this idea. These observations were based on both verbal comments made to the experimenter and on the written comments subjects were invited to make at the end of the RIQ.

It was also hypothesized that a significant negative correlation would be found between the level of helpfulness experienced and the scores found on the scale Alienation. If the factor Alienation did, as thought, measure some degree of social isolation and loneliness, it would follow that this would vary inversely with the level of helpfulness experienced by an individual, i.e. that if people felt helped by relatives and friends they would experience less loneliness and social alienation around the illness.

The third hypothesis was that a significant positive correlation would be found between the amount of change

recorded on the Social Readjustment Rating Scale and the score on the scale of Defeat. The SRRS measures the amount of change, or potential stress, in a person's recent life. Holmes and Rahe (1967) have found that a score above 200 indicates that a person's defenses are likely to be depleted, leaving them open to illness. Selye's GAS theory (1956), in correspondence with Holmes and Rahe's ideas, postulates that after resistance to stress is depleted, the individual reaches a point of exhaustion and gives up. These are theories based on physical phenomena, and it was thought that it might follow that the physical exhaustion would be accompanied by emotional defeat, as measured by the Defeat scale developed in this study.

Results

Correlations of the Factor Scales with Helpfulness Scale and SRRS. The hypotheses concerning these correlations were not confirmed. The correlation between Alienation and Helpfulness was $-.0984$, not found to be significant at the .05 level in a one-tailed test. The correlation between the scores on the SRRS and the scores on Defeat was found to be $-.1721$, also not significant at the .05 level in a one-tailed test. The Helpfulness scale and the SRRS also did not show significant correlations with any of the other scales derived from the factor analysis (see Table 5).

Relationship of Diagnostic Categories and Factor Scales. One way analyses of variance were computed for each of the scales with the six categories of diagnosis. No significant

Table 5

Correlations of Factor Scales with SRRS, Helpfulness Scale, and Demographic Data*

	Duration (N = 78)	Age (N = 151)	Education (N = 144)	Sex (N = 153)	Affecting Job? (N = 32)	SRRS (N = 75)	Helpfulness (N = 78)
Alienation	.0651	-.1227	.0608	.0410	.3874***	.1326	-.0984**
Responsibility	-.0142	.0452	.1007	-.0558	.3871***	.0394	.0524
Defeat	.1122	.0987	.1701***	-.0949	.2182	-.1721**	.0731
Deny	.0877	-.0335	.0087	.0138	.2426	.0694	-.0062
Illness as Enemy	.0236	.1114	.0958	-.1156	.3413	-.0426	-.0097

* All significance tests are two-tailed except for those marked

** One-tailed significance tests

*** $p < .05$

F ratio was found for the scale Responsibility (DF of 5 and 147; F ratio = .4162; probability = .8369). While no other hypotheses about diagnostic categories were made, one was ANOVAs showed significant effects for the analyses involving the scales of Defeat and Illness as Enemy.

The F ratio for the ANOVA between Defeat and categories of diagnosis was 2.4119, with DF of 5 and 147, significant at the .05 level. Contrasting all means against all others using the Scheffe methods showed no significant differences.

The F value for the ANOVA between Illness as Enemy and the six diagnostic categories with DF of 5 and 147 was found to be 2.1760, significant at the .059 level. Again using the Scheffe method to contrast all means with all other means, no significant differences were found.

Correlations of the Factor Scales with the Demographic Data. The scores on the factors were correlated with the demographic items of duration of illness, age, level of education, sex, and the effect of the illness on the individual's job (see Table 5). Using two-tailed significance tests, positive correlations ($p < .05$) were found between the factor scales of Alienation and Responsibility, and the job of the individual being affected by the illness. A correlation ($p < .05$) was also found between the level of education and the factor scale of Defeat, with the scores on Defeat increasing as education level decreased.

Correlations of Demographic Data, Helpfulness Scale and SRRS with Items which were Rejected in RIQ Factor Analysis.

In an attempt to extract full information from the data set, the items which were dropped during the factor analysis were correlated with the demographic information, as well as with the Helpfulness scale and the SRRS. The correlation matrix and significant correlations are listed in Table 6.

Table 6

Correlations of Rejected Items from RIQ with Demographic Data, Helpfulness Scale, and SRRS¹

Item	Duration	Age	Education	Sex	Affecting Job?	SRRS	Helpfulness
2	.0188	.0792	.2332**	-.1743*	.1664	-.0336	.0196
3	.0003	.0444	.3317***	-.1365	.4317**	.0576	-.0409
4	-.0908	.0263	.1394	-.1102	.2577	.0009	-.0743
7	.2459*	-.0283	.1553	-.0175	-.2540	-.0354	.0185
8	-.1135	.1881*	.2328**	-.0732	.3220	-.3160**	-.0296
10	-.0675	.1505	.2621**	-.0365	.4721**	-.1873	-.1361
12	-.1057	.1229	.2118	-.1223	.1070	-.0522	.0834
15	.0791	.1467	.1457	-.2980***	.3659*	-.0832	-.0344
16	.0524	.0364	-.0726	.0582	.0374	.0666	-.0064
19	-.1100	.1472	.0248	-.2050**	-.2816	.0238	.1754*
20	.0599	.0373	.0662	-.1035	.4214*	-.0617	-.0739
21	-.3320	-.0120	-.0118	.0259	.0129	-.0236	-.0263
22	.0116	.1194	.1132	-.0939	.1806	-.1886	-.0024
23	.1227	.2113**	.1008	-.0379	.0553	-.1978	.0859
29	.0017	.2848***	.2085**	-.1828*	-.2420	-.1005	.0411
30	-.0036	.0495	-.0962	.0625	.3198	.2325*	.0347
31	-.1527	.1414*	.0652	-.1402	.1797	.1097	.1224
33	.1206	.2004*	.0703	-.2258**	.2866	.0477	.1093

¹All significance tests are two-tailed

*p < .05

**p < .01

***p < .001

Table 6 (cont'd.)

<u>Item</u>	<u>Duration</u>	<u>Age</u>	<u>Education</u>	<u>Sex</u>	<u>Affecting Job?</u>	<u>SRRS</u>	<u>Helpfulness</u>
35	.0051	-.2005*	-.2343**	.2390**	.1705	.3334**	-.0839
36	.1268	-.0710	.1189	-.0700	.1884	.0368	-.0053
37	.0231	-.0041	-.0898	.1659*	-.2405	.0115	-.1020
38	.1676**	-.0863	-.1091	.0777	-.3622*	.0673	.0128
43	.1506	.2391**	-.0713	-.0674*	.0000	-.2759*	.0350
44	.1265	.0357	-.1926*	-.0255	.1011	.1401	.1010
51	.0638	-.0362	-.0733	.0967	.2486	-.0782	-.1639*
52	.0571	.0527	-.0605	.0892	.2102	.1890	.0429
54	.0414	.0936	.0358	.0112	-.0419	-.1550	-.0725
55	-.0399	.1556	.0851	.0070	-.0590	.0963	.0138

DISCUSSION

The Response to Illness Questionnaire was administered to 153 medical patients, drawn from chronic care clinics for chest diseases and diabetes. This questionnaire was factor analyzed, resulting in five meaningful factors, with reliabilities ranging from .87954 to .70277. Correlations were carried out between these factors and various other demographic measures as well as with a helpfulness scale developed in this study, and the Holmes and Rahe Social Readjustment Rating Scale.

In the discussion, these factors will be compared to the theoretical dimensions proposed by Lipowski (1970) and to the factors found in the one other study using this scale done by Pritchard (1974b). Fairly close correspondence was found between the factors identified in this study and the dimensions proposed and found in the other two publications. The dimensions not found in this study which were represented in the other two will be discussed, and several hypotheses will be offered to account for their lack of representation in the current investigation.

The factors found in this study will be then compared with three major coping strategies; vigilant focusing, minimization, and capitulation. The possible consequences of

these various coping strategies with regard to illness will also be discussed.

The attempts to validate the factors will be described, and the problems with validating these factors discussed. Primary among these problems is the high intercorrelation of all the factors, leading to the suggestion that the items retained in this analysis tend to measure one broad aspect of illness perception, that being depression and discontentment.

Suggestions for further inquiry will be offered, among these being subject populations which might endorse items which measure the other, more "positive" outlook on illness. Correlations of the rejected items in this analysis with high education level and younger age indicate that these positive items are salient to some individuals, and in an expanded study, these dimensions might be represented.

Comparison with Lipowski's Meaning Categories: The Similarities. The illness meaning categories postulated by Lipowski in his 1970 theoretical article were substantiated to some degree by this study. Two of his meanings were found to be the central component in two of the factors found. These were Illness as Enemy and Illness as Punishment. Three of his other meaning categories; Illness as Weakness, Illness as Irreparable Loss, and Illness as Strategy were represented to some degree, and three categories were not represented in any of the factors found.

Illness as Enemy, a meaning which regards the illness as an invading force which should be fought, corresponds

closely to the factor named Illness as Enemy, which, in addition to the items relating closely to feeling attacked, also contained two items having to do with acknowledgement and resentment of the increased dependency resulting from being sick.

The other meaning that closely corresponds to the factors found in the present study was Lipowski's category of Illness as Punishment. In this category, the patient explains the illness as being related to some of his or her own actions. Lipowski includes in this meaning a patient's judgement about whether the illness is just or unjust. Statements about this judgement were not included in the factor labeled Responsibility, but items explaining the illness as a punishment and/or a responsibility of the patient were included. Combined with this feeling of responsibility was a feeling of guilt and failure. This factor seems to reflect beliefs that the person had, at one time at least, control over contracting the disease, and because he or she did not avoid it, or through his or her actions encouraged it; the resulting feelings are of failure and guilt.

There was also some correspondence between the factor of Denial and Lipowski's theorizing. In his explanation of the category Illness as Weakness, Lipowski states that while there is responsibility felt here also, the resulting affect is shame, and therefore attempts to hide the illness from others, or to escape the situation through denial are found. The factor labeled Denial contains, in addition to the denial

item, two items which express the idea that the illness is wrong, that the person should not have to suffer this. These two items could be seen as a denial of weakness, and the negative moral implications that accompany this perception of the cause of the illness. The fourth item in this factor puts the cause of the illness outside the individual, to others. This factor is not only the denial of the consequences, but the denial of the responsibility for the contraction of the disease. Lipowski states in his explanation of Illness as Enemy that "In its extreme pathological form this attitude may be frankly paranoid and others may be blamed for having caused or aggravated the illness." (1970) The factor labeled Denial then seems to have connections to illness seen as weakness, as well as to this specific consequence of illness seen as enemy. It may be that the meaning of illness as enemy is not felt merely on a continuum, from a little to a great deal, but that the upper limits of this meaning are actually of a different quality, perhaps a defense against feeling weak and out of control. Rather than admitting a belief of being out of control personally, the control is believed to be in others' hands and therefore, while the individual still lacks control, it is not seen as a personal failing, but as a punishment from without.

Lipowski's meaning of illness that he calls irreparable loss or damage seems fairly close in meaning to the factor of Defeat. In this outlook, the belief is that what has been lost is irreplaceable and the loss is felt to be overwhelming. While none of the items that addressed these feelings

specifically were retained in this analysis, the feelings that result from this belief, depression and resistance to rehabilitative assistance, are expressed in the items in Defeat. This factor expresses a hopeless outlook, in which the individual feels defenseless, defeated and without control over his or her life. It is not a long way from these feelings to depression and to beliefs that any rehabilitative measures are worthless and unlikely to lead to improvement.

The fifth factor found in the present study, called Alienation, is a more general factor, and contains components of several meaning categories. Most of the retained items which described feelings; depression, anger, resentment and fright, are in this factor and could apply to many of the meaning categories. Also contained in this factor are two items having to do with inferiority and weakness, which would apply to Illness as Weakness. Most of the other items have to do with being misunderstood and alone. These items do not correspond closely to any meaning category, but may have some connection with the Illness as Strategy meaning, which deals directly with the impact of the illness on the patient's relationship with others. For patients who score low on this factor, the illness may represent a successful attempt to gain more attention and involvement from others, which in turn could alleviate their feelings of being inferior and weak, as they do not perceive themselves as powerless in gaining or maintaining important relationships. At the opposite pole, feeling alone and misunderstood could exacerbate

the feelings of depression, resentment and fear.

Comparison with Lipowski's Meaning Categories: The Differences. While all the factors which resulted from this analysis correspond with variable closeness to the meaning categories proposed by Lipowski, three of his meanings were not represented to any degree in the present sample. These areas were those he labels illness as relief, illness as value, and illness as challenge. There are several plausible explanations as to why the items expressing these feelings did not load highly enough on a factor to be retained. The correlations between the demographics and the responses to the rejected items can help to account for this.

None of the items that characterize the illness as a relief from responsibilities or those that expressed direct gains from the illness were retained. It may be that the social undesirability of responding to these items in the affirmative prevented an accurate measurement of these perceptions.¹ It must also be recalled that Lipowski includes in this meaning category relief through unconscious strategies and unconscious resolutions of inter and intra personal conflicts. It is possible that this type of questionnaire would have difficulty in measuring these feelings in a direct way. It is also possible that the particular population used in this study generally disagreed with these items because of

¹ Inspection showed that the mean of each of these items fell below the average mean of all the items.

the organization of the clinic which they attend, resulting in a restriction of range.² Part of the objective of this clinic is to involve the family of the patient, and a family member attends all clinic visits with the patient whenever possible. This is to encourage family assistance in care, and to discourage the transmission of distorted information to the family from the patient. In other words, one of the objectives of this clinic is to prevent the patient from developing strategies with which to manipulate those around him or her, or to gain unduly by being ill.

In describing the view of illness as value, Lipowski states, "This belief is not prevalent in our hedonistic society. On the contrary, illness tends to have a negative value and everything is done to counteract it" (1970). It may very well be that because of this, the items having to do with seeing illness as a valuable experience, one that facilitates growth and understanding, may not have been salient items for this population. This is also a viewpoint that requires some perspective on the experience, as well as a propensity for abstract and philosophical thought, so the failure of these items to load highly on any factor may be related to the educational level of this population.³ For example, originally a semantic differential scale was planned, to be given along with the RIQ, but it was discovered very quickly

²Two out of the three items clearly related to relief through illness had variances that fell below the average variance of all the items.

³68% of the subjects had a high school education, or less.

that the level of abstraction involved in that kind of instrument was experienced as too confusing and vague for many of the subjects, even with extensive explanation.

The final meaning category, illness as challenge, was represented in this questionnaire by items having to do with seeing the illness as a problem to be tackled, as a challenge, and to this end, desiring all pertinent details and information about the illness process. Again, a restriction of range may have contributed to none of these items being retained.⁴ The first 81 subjects answered a question which asked if their doctor had told them all they wished to know about their illness, and of the 78 who responded to this question, only 6% (five individuals) answered no. It may be, too, that people participating in these clinics, which require regular attendance, are for the most part, those that are interested in complete information. It also may be that for this population, the words "challenge" and perhaps "tackle" were somewhat confusing, as the experimenter was asked to define many simpler words for subjects, such as "defeat" and "inferior." Again, these items may be found to be more meaningful to a better educated population. In addition, items which dealt with challenge and wanting to know details were positively correlated with education level; the higher the education, the greater the desire to know. This would be

⁴Four of five of these items had variances below the average variance of all the items. One was over one S.D. below and one item fell over two S.D.s below this average.

a quite understandable coping device for better educated individuals as their outlook would be likely to regard knowledge, information, and detailed understanding as methods of problem solving. In a population with a higher education level, therefore, there are several reasons to hypothesize that the challenge items would be retained.

There is also some evidence that age may have been a factor in the exclusion of the challenge items. Age was found to be significantly positively correlated with items expressing a desire not to know details, and a desire not to think about the illness. Age was also correlated with education, with the younger person more likely to have had more years of schooling. Both these subject variables suggest that the person most likely to endorse challenge and information seeking items may be the one who feels better equipped to deal with the illness, through youth and schooling.

Comparison with Pritchard's Empirically Obtained Factors:
The Similarities. One previous attempt has been made to factor analyze the RIQ to result in illness meaning categories (Pritchard, 1974b). There were 14 subjects undergoing haemodialysis for chronic renal failure in his study, and with this few subjects, the possibility of capitalizing on chance combinations of items should be kept in mind when examining these factors. Also, no reliability data was given so there is no indication of the stability of these factors in the population used. To complicate matters, the 22 variables Pritchard chose to use in his factor analysis were not all separate items.

Fourteen of these "variables" consisted of the sum of two items and his basis for creating these variables was subjective rather than empirical. Therefore, some of these combinations have even a lower chance of being replicated when the composition of factors is computed using each item as a separate variable.

In spite of these rather serious methodological problems, there is some correspondence between the factors found by Pritchard (see Table 7), and those which resulted from the current analysis. Four out of the seven factors identified in Pritchard's study have similar meanings to four of the five factors reported here.

The meaning which is clearly defined in both studies is Illness as Enemy. Three of the items are identical. The other two items in Pritchard's factor of this name were dropped from the current study because their factor loadings were less than .4. The items in this study which were not included in Pritchard's were two items which acknowledged the increased dependency and resentment of the same. The fact that there is such close correspondence between the two studies on this factor, in spite of the methodological problems mentioned above and the different populations used, is a strong support for this being a dependable, consistent and stable factor in illness perception.

The factor Pritchard named Helpless Loss is similar to the Defeat factor found in this inquiry. Both express a sense of helplessness in the face of the illness, and a sense

Table 7

Factors Identified by Pritchard

Hopeless Defeat

- I do not think others realize that because of it I cannot cope
- (with responsibilities
- I am worried that because of it I am not meeting my responsi-
- bilities as I should
- (I feel depressed about it
- (I feel miserable about it
- (I want to escape from it
- (I want to run away from it
- (I have to give in to it
- (It defeats me
- I resent the way it makes me dependent on others

Anxious Preoccupation vs. Denial

- I think a good deal about it
- (I feel anxious about it
- (I feel frightened about it
- (I am not told enough about it
- (I am kept too much in the dark about it

Outward Hostility

- (I cannot think of any reason to do with me why I should have it
- (I do not think there is any explanation on my part why it oc-
- cured
- (I feel angry about it
- (I feel resentful about it

Helpless Loss

- (I am defenseless against it
- (I do not think I can resist it
- (It has taken something from me
- (I will never be the same again because of it
- There is nothing I can do myself about it

(- Indicates that item above and below were combined and used as a single variable

Table 7 (cont'd.)

Challenging Appraisal

- (I look on it as a challenge
- I think of it as a problem to be tackled
- I want to find out all I can about it

Illness as Enemy

- (It is like an enemy
- I feel it is something that has come and attacked me
- I appreciate the help and sympathy it has brought me
- (I must fight it
- I feel I have to resist it

Paranoid Withdrawal vs. Involvement

- It is worse than others realize
- (It is wrong that I should have to suffer this
- It is a punishment which I do not deserve
- It is something I must overcome myself (reflected)

that the illness has prevailed and the individual must give up in defeat. Two items match, a third found by Pritchard was included in his analysis because it was subjectively combined with one of these matching items into one of his variables. In addition, Pritchard's Helpless Loss includes feelings of being permanently and negatively changed because of the illness experience. While there are, then, a few items which do not appear in both factors, there is little doubt in the experimenter's mind, because of the content of the items, that these two factors are expressing the same meanings and feelings.

A third area which both studies tapped were feelings Pritchard titled Paranoid Withdrawal and this study called Denial. Both these factors contained items having to do with the unfairness of the illness. It seems, though, that the resulting additional feelings associated with unfairness were slightly different in the two studies. In Pritchard's, the unfairness was coupled with feeling powerless and misunderstood by others, as if the experience of developing an unexpected and seemingly unfair illness had seriously eroded the individual's faith in his or her own power to change and control his or her life. There is a somewhat different flavor to the Denial factor in the present study. In these results, included along with the unfairness items are an item that expresses a desire not to think about the illness, and an item placing the responsibility for the illness on others. This has a sense of, instead of admitting a personal lack of

control, making an attempt to place that control outside the individual. This may have been a consequence of the different populations involved in these two studies. Pritchard's subjects, in having to spend substantial amounts of time on dialysis machines may have not been able to externalize the situation, or ignore it, as much as the patients in the current study, whose illnesses did not require such a visible rehabilitation regime.

Finally, the reflection of Pritchard's factor Outward Hostility has some similarity to this study's factor named Responsibility. Pritchard associates this factor with the Just Punishment meaning suggested by Lipowski, which may make it more clear as to why it is also associated with Responsibility. The present factor Responsibility is, however, much more extensively defined than Pritchard's factor, and this may be due to the populations tested. Many of those included in the present study had a realistic basis for feeling responsible, citing cigarette smoking, living in polluted surroundings and working in atmospherically hazardous jobs. There is no indication that Pritchard's subjects had any identifiable actions that they could connect with the onset of their conditions. This factor, then, may be more stable and meaningful for populations to whom the concept of personal responsibility is most salient.

Comparison with Pritchard's Factors: The Differences.

Three of Pritchard's factors were not replicated to any degree by the current study. The first he named Hopeless Defeat, and

associated this with Lipowski's meaning category of weakness. As was indicated in the discussion of Lipowski's categories, the feelings that he associates with weakness were found to be distributed among several factors in this study, and the same is true for the items in this factor of Pritchard's. This Hopeless Defeat factor was the general factor found in Pritchard's study, and simply does not correspond closely to any one factor found in the current investigation.

The other two factors Pritchard found that were not included in the present study were those he titled Anxious Preoccupation vs. Denial and Challenging Appraisal. Both of these factors related closely to Lipowski's Illness as Challenge category, in that they included items directly labeling the illness as a challenge, a problem to be tackled (these two items were, however, used together as a variable) and many items concerned with information gathering and thinking. The possible explanations for why these types of items were not retained in the current inquiry were discussed above in the comparison with Lipowski's categories.

Summary. In spite of the above mentioned discrepancies in factors, and the very different types of patients and statistical reliabilities involved in these two studies, the similarities are striking. In fact, they are even more striking when one does keep in mind the many differences between the studies. Definite credence is lent to the questionnaire being used with different patient populations, and additional support is given (beyond the acceptable

reliabilities) to the stability of the majority of the factors found in the present study.

The Meaning of Illness and Coping Strategies

Deliniating the different meanings of chronic illness is merely an intellectual exercise unless this inquiry is taken as the first step in linking these meanings with coping strategies, with behaviors that directly affect the course and outcome of an illness. Some attempts to connect meaning categories with coping strategies will be described below.

Lipowski states, "It is the writer's thesis that coping strategies are directly related to the individual's personal meaning of and attitudes towards his illness, injury, or disability" (1970). Taking the meaning categories deliniated in this study, it may be useful to trace these back to the involved coping strategies they may represent or be part of.

The first major coping strategy of interest here is that of vigilant focusing (Lipowski, 1970). It may be remembered that this was described as involving obsessional, anxiety prone attention to the problem with the objective being understanding and mastery of the situation. There is a large range of intensity found in these types of feelings, and they may not always lead to effective coping or mastery. The two factors found in this study that seem to relate to this coping strategy are Illness as Enemy and Responsibility. Illness as Enemy seems to represent an extreme form of vigilant coping, one in which attention is clearly focused on the

illness, and the attempts at mastery are in the form of conscious resistance and counterattacks. It should be noted that this may not be an effective way of dealing with the illness, due to the inflexibility implied in these feelings. This may represent the mastery component of vigilance, while Responsibility seems more closely linked to the effort to understand the illness and its causes. A person who scores high on Responsibility would be someone who has actively explored what the illness might mean about him or her, and come to some conclusions about his or her levels of responsibility in contracting the illness, and consequently, to a greater personal understanding of the condition.

Another coping mechanism which has received a great deal of attention is denial, or to use a more inclusive term, minimization (Cohen and Lazarus, 1973; Lipowski, 1970; and Kiely, 1972). Involved in this are attempts to rationalize, ignore or deny the significance of the illness, its causes and its consequences. The factor Denial found in this study corresponds to this strategy, primarily in the rationalization expressed in the items. Most of the items that directly expressed denial or lack of awareness of the illness were not retained in this factor for reasons discussed above. However, it is plausible that a person scoring high on this factor, especially someone who has had the illness for some time (as denial is a common initial response to an injury or illness), would have trouble adhering to a rehabilitation schedule, and therefore might be a person to whom extra attention should be

paid by the helping professions. It should also be kept in mind, however, that this mechanism can be adaptive and useful in some conditions, like cardiac illness (Hackett and Weisman, 1969).

The final major coping mechanism is capitulation, which can be particularly harmful to the individual, as this way of viewing the illness can preclude adaptive acceptance of the condition or effective resistance. The factor Defeat closely corresponds to this coping strategy, expressing as it does the belief that the individual can do nothing about his or her illness, and on a more inclusive level, that the illness experience has resulted in a felt loss of control over many events in the person's life. This can be a particularly crucial set of beliefs in a chronic illness, where some level of constant attention and personal effort is required to keep the condition under control.

The Problems with Validity

Although there is fairly good theoretical support for the content of the factors found in this study, there is a less clear empirical base, in terms of validity. Although no concerted effort was made in this study to validate the dimensions found, the ANOVA performed between the factor Responsibility and the diagnostic categories and the correlation carried out between the Helpfulness scale and the factor Alienation, and between the factor Defeat and the SRRS, were a first step in this direction. The lack of significant

findings on these hypothesized combinations therefore, does not offer any positive evidence for the validity of these meaning dimensions, either the theoretical dimensions, or the ones found in practice through this investigation, but on the other hand, it seems far too soon to take these as an indication that no validity of such does exist.

Part of the difficulty in establishing significant and/or important relationships between any one of these factors and any other measure employed lies in the fact that all the factors were significantly and highly correlated with each other. This could be a by product of lack of precision in the measuring instrument, as very little empirical work has been performed on this scale up to now. It does seem clear that the items retained in this study are those that could be termed more "negative" ones, which, as discussed in relation to particular dimensions above, could be the result of those particular items being more salient to the population sampled, and/or a consequence of the greater variability of answers to these items.⁵

These intercorrelations of meaning categories may have the greatest part in explaining the lack of association found between the scale of Responsibility and the diagnostic categories. They may also partially explain the lack of connection between the scale of Alienation and the Helpfulness scale,

⁵The average variance of the retained items was 1.1962, as compared to the average variance of the rejected items, which was 1.0737.

as the factor named Alienation contained items which expressed other feelings. Also, since the Helpfulness scale was formed during this study, and has no validity data it is possible that, although reliable, it has little validity. The Social Readjustment Rating Scale also was not found to be significantly associated with any of the factors. This may be a function of its measuring, as explained in the introduction, a general factor of stress, assuming as it does that the value of stress will affect different people in the same ways. It is possible, however, that the specificity theory of stress has more application in this instance, so that two different individuals who scored the same amount of change in their lives actually see this in different ways, and it has a different impact on their outlook on themselves and their illnesses. If this is the case, it would not be surprising that the SRRS would not correlate highly with measures of meaning of illness, as the stress assessment would differ from person to person.

In looking at the correlations between demographic data and the factor scales, it was found that if a person's job had been affected by the illness, that person was significantly more likely to score higher on Alienation and on Responsibility. The positive correlations of this item with the other factors were not significant, but definite trends were found. This may be related to the previously mentioned observation that the items retained in these factors were primarily "negative" ones, measuring discontent, depression,

and dissatisfaction with the situation. That these correlate highly with problems on the job due to the illness is another support for the factors measuring something significant, albeit similar from one factor to another.

Additional support for the Defeat factor measuring that concept is found in the significant correlation found between this factor and the level of education, with persons scoring higher on Defeat as their education level decreases. This could relate to the resources a person feels he can muster to deal with the illness; as these resources, in the form of education, decrease, he is likely to feel more helpless in the face of an illness. This could be the opposite side of the coin to the correlation between higher education and endorsement of the challenge items discussed previously.

It might be noted that no significant relationship was found between the sex of the individual and any of the factors. This would support the concept that the factors are measuring something related to subject characteristics other than sex.

The problem of good criterion variables has to be considered in this area of research. When we are assuming that coping strategies are directly related to the behaviors of the patient, we are making a statement about the importance of identifying these strategies, in an effort to provide better care, and to predict the behavior that has relevance to the illness process. The difficulty arises when one tries to clearly define the behaviors that are adaptive and maladaptive, and this seems to vary depending on the illness

considered. Once the behaviors have been identified, there is the additional problem of operationalizing these behaviors so they can be accurately measured. This seems especially hard when dealing with illnesses which are not usually fatal, so the degrees of adaptive coping are just that, a matter of degrees, and nothing concrete like life or death. Also to be considered are other inter-patient variables which could affect the progress and seriousness of the disease, like age or previous illnesses.

Future Directions

In spite of the criterion variable problem, there are possibilities for future exploration of this area. In a more long term validation study, one might be interested in trying to link these meaning factors to some measure of relapse, like admittance to the hospital, demonstrable deterioration in physical status, or contraction of other physical ailments. Since the variable of adaptive coping is often a subjective judgement, one might want to seriously consider developing reliable scales of this, tapping the judgements of medical personnel and/or the family. Aside from the subjective nature of these measures, however, one has the difficulty of validating a meaning scale with a level of coping scale, which in turn would have to be validated using some kind of stable behavioral measure. It seems clear that a vital area of exploration for the future involves establishing these measurable behavioral aspects of illness maintenance

or recovery, for only using these could a scale be adequately validated, and therefore, of use in identifying those individuals who are most likely to have difficulty in coping with an illness.

Future work on this scale might also include giving it to individuals with other diseases, both chronic and more time limited. It may be that certain of the meanings of illness would be more salient to a population with a non-chronic condition and this could only be determined by giving these items to such a population. A more extensive data base would also go a long way to furthering the reliability data on any of the scales, as well as determining which are stable across populations, and which have variable applicability. A greater population with higher education level, and of younger age, could also give information on items which were dropped in the current analysis, and give a better indication of whether or not these would be salient to a different population.

Conclusion

This was an exploratory study, an attempt to discover if there were identifiable meaning and illness perception categories, on which there would be variable scoring by different individuals. There is certainly the indication from this inquiry that this is so, and it remains the task of future explorations to discover if these categories can be expanded and new categories added, as well as to establish empirical links to observable and measurable behaviors which affect

recovery from, and/or adequate maintenance of, illness. This could add not only to the general information about the process of recovery, and the emotional components of physical illness, but give health care professionals a tool with which to identify problem patients early on in the illness process, when the chances of effective intervention are the greatest.

APPENDICES

APPENDIX A

Social Readjustment Rating Scale

Here is a list of things that happen in people's lives.
Please check any of the events that have happened to you in
the last two years.

- ☐ Death of a spouse
- ☐ Divorce
- ☐ Marital separation
- ☐ Jail term
- ☐ Death of close family member
- ☐ Personal injury or illness
- ☐ Marriage
- ☐ Fired at work
- ☐ Marital reconciliation
- ☐ Retirement
- ☐ Change in health of family member
- ☐ Pregnancy
- ☐ Sex difficulties
- ☐ Gain of new family member (e.g., through birth, adoption, parent moving in, etc.)
- ☐ Business readjustment (e.g., merger, reorganization, bankruptcy, etc.)
- ☐ Change in financial state (e.g., a lot worse off or a lot better off than usual)
- ☐ Death of a close friend
- ☐ Change to a different line of work
- ☐ Change in number of arguments with spouse (e.g., either a lot more or a lot less than usual regarding childrearing, personal habits, etc.)
- ☐ Mortgage over \$10,000 (e.g., purchasing a home, business, etc.)
- ☐ Foreclosure of mortgage or loan
- ☐ Change in responsibilities at work (e.g., promotion, demotion, lateral transfer)
- ☐ Son or daughter leaving home (e.g., marriage, attending college, etc.)
- ☐ Trouble with in-laws
- ☐ Outstanding personal achievement
- ☐ Wife begin or stop work
- ☐ Begin or end school
- ☐ Change in living conditions (e.g., building a new home, remodeling, deterioration of home or neighborhood)

APPENDIX A (cont'd.)

- ___ Revision of personal habits (e.g., dress, manners, associations, etc.)
- ___ Trouble with boss
- ___ Change in work hours or conditions
- ___ Change in residence
- ___ Change in schools
- ___ Change in recreation
- ___ Change in church activities (e.g., a lot more or a lot less than usual)
- ___ Change in social activities (e.g., clubs, dancing, movies, visiting, etc.)
- ___ Mortgage or loan less than \$10,000 (e.g., purchasing a car, T.V., freezer, etc.)
- ___ Change in sleeping habits (e.g., a lot more or a lot less sleep, or change in part of day when asleep)
- ___ Change in number of family get-togethers (e.g., a lot more or a lot less than usual)
- ___ Change in eating habits (e.g., a lot more or a lot less food intake, or very different meal hours or surroundings)
- ___ Vacation
- ___ Christmas
- ___ Minor violations of law (e.g., traffic tickets, jaywalking, disturbing the peace, etc.)

APPENDIX B

Response to Illness Questionnaire

1. Others do not understand how being ill is for me.
2. It is a real threat to my health.
3. I feel miserable about it.
4. It threatens to change my life in ways I don't like.
5. I feel I am in some way responsible for being ill.
6. It is a punishment which I do not deserve.
7. I do not like others knowing about it.
8. I am not told enough about my illness.
9. It is a sign of weakness in me.
10. Because of my illness I feel I cannot cope with my responsibilities.
11. It is wrong that I should have to suffer this.
12. It is hard for my family and friends to refuse me things because of it.
13. I feel depressed about it.
14. I feel resentful about it.
15. I have to give in to it.
16. I think of my illness as a problem to be tackled.
17. I must have done something to deserve it.
18. I feel threatened by it.
19. Being ill has brought me closer to my family and friends.
20. I do not think I can resist it.
21. Having it has made me more aware of some of the good things in my life.
22. It is kind of a relief not to have to do some of the things being ill prevents me from doing.
23. I would rather not think about it and when these thoughts come to mind I push them away.
24. It makes me more dependent than I'm used to being.
25. I feel it is something that has come and attacked me.
26. My illness is like an enemy.
27. It is a punishment for something I have done.
28. I do not think there is anything I've done that explains why I've become ill.
29. I don't want to know any details of it.
30. It is something I must overcome myself.
31. My illness has given me some control over those close to me.
32. I feel it indicates that I am inferior.
33. I have lost some things through this that I can never get back.
34. My illness is worse than others realize.

APPENDIX B (cont'd.)

35. I want to find out all I can about it.
36. I feel ashamed of it.
37. I feel I can accept my illness and go on from there.
38. It is not as serious as others make out.
39. I resent the way it makes me dependent on others.
40. I feel frightened about it.
41. It makes me feel I am alone.
42. I feel angry about it.
43. I appreciate the help and sympathy my illness has brought me.
44. I look on it as a challenge.
45. I cannot think of any reason having to do with me that explains why I should have it.
46. This shows that I have somehow failed.
47. I feel it's like a dream; that it's not really happening to me.
48. I don't worry much about my illness.
49. Others are responsible for it.
50. It defeats me.
51. I feel like running away from it.
52. I have learned something from being ill.
53. I feel guilty about it.
54. I want to escape from it.
55. I must fight it.
56. There is nothing I myself can do about my illness.
57. I am defenseless against it.
58. Being ill has made me feel I have little control over what happens to me.
59. My illness has taken something from me.
60. I feel I have to resist it.

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