Title
An exploration into attributional beliefs by persons with inflammatory bowel disease

Author
Lewis, M. Catherine

Publication Date
1987

AN EXPLORATION INTO ATTRIBUTIONAL BELIEFS BY PERSONS WITH INFLAMMATORY BOWEL DISEASE

by

M. Catherine Lewis

THESIS

Submitted in partial satisfaction of the requirements for the degree of

MASTER OF SCIENCE

in

NURSING

in the

GRADUATE DIVISION

of the

UNIVERSITY OF CALIFORNIA

San Francisco

[redacted]

Date University Librarian

Degree Conferred: January 4, 1987

ACKNOWLEDGEMENTS

I would like to extend many thanks to ...

- Caverly Whittemore, for fundamental support and confidence.

- My committee: Jeanie Kayser-Jones, for support and editing which has moved this paper toward a form which is as efficient and stylish as she is; Jeanne Hallburg, for her perceptive and thoughtful criticism and kindness in helping me learn this process; and Linda Chafetz, for support, criticism, and wit in seeing what's important.

- Others who could empathize from their experiences in working on big projects: Andy Yun, Karl Hunter, Susan Quaglietti, Dan O'Connor, Janine Gardner.

- Those who could give me access to subjects made the project run very smoothly: Terry McCarthy and Jane Fame ; the gastroenterologists; and Patti McCarthy and Monica Vitlar, whose actions towards protection of patient rights were exemplary.

- Other attributions and IBD researchers who contributed to the development of the study: Barbara Lowery, Shelley Taylor, and Gloria Joachim.

- Wendy Ullman-Duarte, for her sensitivity to my own and my potential subject's feelings.

- Tess Joseph, for accurate and fast transcribing of the tapes and for her interesting comments.

- Mark Hudes and Steve Paul, for making statistics something to look forward to.

- Betty Davies and Chuck Pitkofsky, for sharing what they know about qualitative analysis.

- Erica Heath, for typing (through pregnancy, bouts of wallpapering, and moving, even!), putting up with short turnaround time and invaluable advice on the protection of subject rights.

- My friend, Lynda, whose trials caused the questions to be asked and whose spirit keeps inspiring me.

- My brother Steve, for egging me on.

- The UCSF Century Club for financial and technical support and the Alberta Association of Registered Nurses for generous financial support and initiation to grant applications.

TABLE OF CONTENTS

I. INTRODUCTION 1

- A. Purpose 1
- B. Significance 1
  - 1. Clinical Significance
  - 2. Theoretical Significance

II. REVIEW OF THE LITERATURE 6

- A. Attribution Theory 6
- B. Attribution Theory in Illness Situations 6
- C. Nursing Research on Illness Attributions 8
- D. Nursing Research on IBD 10
- E. Attribution Theory in Helping Models 11
- F. Attributions and the Social Meanings of Illness. 12

III. METHODOLOGY 16

- A. Study Design 16
- B. Instrument 16
- C. Sampling Procedure and Setting 17
- D. Sample 18
- E. Data Analysis 20
  - 1. Qualititative analysis
  - 2. Quantitative analysis

IV. RESULTS 22

- A. Purpose 1: Attributions for the Cause of Illness 22
  - 1. Explanations of the Mechanisms. 23
    - a. Scientifically Inclined
    - b. Stress as Cause Explanations
    - c. I Don't Know Group
      - 1/ I Don't Know and Its Got Me Down
      - 2/ I Don't Know and It Doesn't Matter
  - 2. Meanings Explanations 30
    - a. The Role of God
    - b. Illness as Punishment
    - c. Illness as Part of a Larger Plan
    - d. It Just Happens
    - e. On Asking "Why Me?"
  - 3. Quantitative Results for Purpose 1 33
- B. Purpose 2: Reasons for the Course of Illness 35
  - 1. Quantitative Results
  - 2. Stress
    - a. Control of Stress
  - 3. Medications
  - 4. Diet and Exercise
  - 5. God

6. "Finding a Good Doctor"
7. Unpredictable, Unexplainable Episodes
C. Purpose 3: Perceptions of Others Attributions 45
1. Attributions of Significant Others
2. Health Care Professionals
D. Purpose 4: Effects of Attributions on Relationships . . 47
1. Significant Others
2. Health Care Professionals
3. Responsibility

V. DISCUSSION 54
A. Meaning of Results in Relation to Other Research 54
1. The Weiner Model of Attribution
2. Relationship Effects and the Brickman Model
a. Significant Others
b. Physicians
3. Attribution in Illness Situations
a. Meanings and Mechanisms
b. Stress as a Causal Explanation
c. The "I Don't Know" Response
d. Attributional Stances of Others
B. Limitations 64
1. Generalizability
2. Internal Validity
3. A Methodological Limitation
C. Directions for Future Research 67
D. Clinical Implications 68
1. Coping with Feelings Aroused by Attributions
2. Relationship Problems

VI SUMMARY 71

VII REFERENCES 74

VIII APPENDICES

\A. Interview Guide
Demographic Information Sheet

B. Information Sheet
Consent Form
Subject Debriefing Sheet

INTRODUCTION

"It should be encouraging for today's researchers to know that the answers they seek are all lying around, waiting for someone to take that one step further."

John R. Edwards
Member's Forum,
National Geographic
October, 1986.

Abstract

This study sought to learn from persons with inflammatory bowel disease (IBD) their attributions (causal explanations) for the cause and course of IBD, their perceptions of significant others' and health care professions attributions for IBD and how these attributions affect interpersonal relationships. Although research on illness attributions is increasing, little has been done on IBD, an illness which is interesting for attributional study since it is chronic, with high morbidity, of unknown etiology and uncertain course. An interview consisting of open and closed ended questions was used to study a convenience sample of 17 persons with Crohn's disease and ulcerative colitis. Subjects varied in age, severity of illness and length of time since diagnosis.

Subjects gave separate explanations for "how" the illness occurred, vs. "why" it happened (meanings). Fifty-nine percent felt IBD was caused by stress, 23% didn't know the cause and 18% gave "scientific" explanations. Of the 23% who lacked an explanation, half were troubled by this and half felt cause was a moot point. Ninety-four percent felt stress influenced the course of illness and defined stress in different ways. Other factors included medications, diet and exercise, having a good physician, and God. The unpredictability of IBD episodes was an important recurring theme. Respondents generally were not able to be specific about others' attributions and how these attributions affected interpersonal relationships. Three interaction patterns surrounding IBD were identified: interactions that were action oriented; attempts by others to change ill person's health habits; attempts by others to find quick solutions to the ill person's problems. Subjects felt responsible for managing their illness and felt comfortable with their cooperative roles with their gastroenterologists. They did not tend to blame themselves or feel blamed by others.

Results were discussed in terms of Weiner's attribution theory, the "helping models" of Brickman et al., and selected research findings. Methods used by subjects to cope with uncertainty were outlined. Results suggest a need for mutual clarification between providers and clients regarding their conceptions of responsibility for illness. Future research avenues include exploring lay conceptions of stress, the relationship of attribution and coping, identifying those at risk of inadequate coping, and the temporal aspects of attribution.

I. INTRODUCTION

Purpose

The overall purpose of this research project is to investigate the attributional perspective of persons with inflammatory bowel disease (IBD), and the impact of this perspective on the lives of these people. Attributions studies examine people's search for explanations of causes of life events. Attribution making, then, is defined as the process in which people ask and seek answers for questions such as "Why is this event (e.g., accident, achievement, illness) happening? Why is it happening to me?"

Specifically, the purpose of the research is to learn the following from persons with IBD:

1. their beliefs about why they have the illness,
2. their beliefs about reasons for the course of their illness (i.e., why they are or are not recovering from the disease),
3. their perceptions of the attributional stances of significant others and health professionals, and
4. how the stances of these others affect their relationships with them.

Significance

Inflammatory bowel disease (IBD) is a chronic illness of unknown cause. It is known for high rates of morbidity and for the difficulty associated with its control. Inflammatory bowel disease encompasses two similar chronic diseases, ulcerative colitis and Crohn's disease. Both are characterized by inflammation of the gastrointestinal tract causing bloody diarrhea, abdominal pain, fever, anorexia, nausea, vomiting and weight loss. Fistulas and abcesses can occur in Crohn's disease. Exacerbations and remissions of symptoms are characteristic of IBD.

Treatment is mainly tried through medication: sulfasalazine for mild to moderate disease, steroids in more severe cases, and occasionally, immunosuppressive agents (e.g., 6-MP) when steroids are not effective. Surgery is a last resort. Although colectomy is curative for ulcerative colitis, 50% of Crohn's patients may have recurrence in another section of the GI tract (Heitkemper & Martin, 1986). IBD affects as many as a half million Americans, generally in younger age groups (Mendeloff, 1985).

Attribution making has been found to occur in situations, such as chronic illness, which involve threat, uncertainty and unexpectedness (Wong & Weiner, 1980). IBD is a chronic illness which has an immense impact on the sufferer's life and involves a high degree of uncertainty. Thus, the attribution process, where persons seek reasons and causes for situations is likely to occur with IBD. Understanding the attribution process in IBD has clinical and theoretical importance.

Clinical Significance

The purpose of the study is to describe people's beliefs about why they have acquired IBD and to examine the effects of this causal thinking on interpersonal relationships. The study will potentially make a contribution to the clinical understanding of ill persons' responses (i.e., beliefs and attitudes) to chronic illness. Knowledge of these responses is important to effective nursing care of persons with IBD. A clear understanding of the client's beliefs about his problem is also required in order to create effective helping relationships (Brickman et al., 1982; Paterson & Zderad, 1976). Based on differing attributional beliefs, different models of helping may be operating for the ill person than for his family and/or health professionals, and may result in ineffective relationships. Little is known about the attributional beliefs of persons with IBD, since the problem has not been previously investigated.

Changes in today's health care beliefs and philosophies have important implications for the attributions made by persons affected by illness. Lay beliefs about the etiology of illness are currently influenced by the human potential, self care and holistic health movements which emphasize self responsibility for health. Examples of this emphasis are found in the work of Jampolsky (1979) and Cousins (1979). Jampolsky believes that negative feelings and illness are the result of perceptions of the world which are subject to personal control. Cousins advocates using positive attitudes in the treatment of illnesses.

Such approaches give a measure of perceived control in illness situations (Sontag, 1977). Ideas about control lead to beliefs about responsibility and sometimes to blame for illness. As Angell (1985) argues, these approaches can create an implied sense of personal failure or blame when illness develops or progresses. This study seeks to obtain information on beliefs about cause, control and responsiblity and whether these attributional beliefs lead to blaming in IBD.

The ambiguity caused by the present lack of scientific knowledge about the causation of IBD may also result in holding the ill person responsible. As Meyers states, "In caring for the patient newly diagnosed as having inflammatory bowel disease, one of the most frustrating issues for the nurse to deal with is [the unknown causes of IBD]" (1984, p. 4). In many lay and professional minds, IBD is often linked to emotional/psychological/personality causes, although there is yet to be any evidence for this etiological explanation (Hawkins, 1983; Korelitz, 1985). Furthermore, as Mendeloff (1985) says, "the old idea that IBD patients are the paradigms of psychosomatic illness has not been borne out." No other cause, however, has been positively identified. Promising fields in the search for a causative agent include microbiology, immunology and epidemiology (Janowitz, 1985). Emotional stress has been linked to disease exacerbation; a causal relationship, however, has not been established (Alpers, 1981; Korelitz, 1985). This study brings forth information on the effects of unknown disease etiology on attribution making, and on interpersonal relationships.

Theoretical Significance

This project is aimed at augmenting middle range theory related to the attribution process and the effects of attributions for chronic illness on interpersonal relationships. It examines the attribution process in a real life situation. Further, the project provides data related to the Brickman et al. (1982) models of helping by documenting the ill person's beliefs about responsibility for the problem as well as responsibility for the solution.

This study is also significant for its contribution to the sociological understanding of the sick role of chronic illness.

> "For which illnesses, and to what degree, are people likely to consider themselves responsible?" (Kassenbaum & Baumann, 1965:27)

When Kassenbaum and Baumann posed this question in 1965, they were questioning the applicability of Parsons' sick role model in explaining social roles in chronic illness.[1] The social expectations of the chronically ill were poorly defined at that time, and have remained ambiguous (Segall, 1977). Work in attributions contines to clarify social expectations of the chronically ill by describing conceptions about responsibility for illnesses and expectations for control of problems.

---

[1] Parsons' model stated that the ill person is not held responsible for his disease (although he is responsible to obtain and cooperate with competent technical help and to return to his normal social roles as quickly as possible). Kassebaum and Baumann found many limitations in Parson's model in chronic illness situations.

REVIEW OF THE LITERATURE

"As years went by, such verbal deposits would thicken."

John McPhee
Basin and Range, 1980.

II. REVIEW OF THE LITERATURE

Attribution Theory

Several research approaches in social psychology including locus of control and self perception were united and defined in the mid-1960's under the label of attribution studies (Harvey & Weary, 1984). Although Harvey and Weary assert that there is no single unifying theory of attribution, the work of B. Weiner (most recently described in Wong and Weiner, 1981) has been widely used as a model for attributional analysis. The Weiner model postulates three dimensions of concern in the process of formulating an attribution. The first concern is the locus of causality: whether the event is caused by circumstances internal or external to the person. The second dimension is controllability: whether or not the event is subject to personal control. The third dimension of concern is stability: the likelihood that the cause will change (Wong & Weiner, 1981).

Wong and Weiner have found that in circumstances of unexpectedness, frustration and personal importance involving stress, that the attributional search takes place, mainly along the first two dimensions. People ask "Did I cause this?", and "Did I have any control over it?" They have found that the stability dimension is less salient in attribution making (1981).

Attribution Theory in Illness Situations

Until 1977, most studies examined attributions for achievement in laboratory situations. The limitation of these studies was that causal thinking has been shown to be more likely to occur in situations involving stress, frustration, unexpectedness and situations of great personal importance (Wong & Weiner, 1981).

In 1977, Bulman and Wortman began the study of attributions in "real world" situations by examining causes given by spinal cord injured persons for their misfortunes. They found that those who blamed themselves for the accident were the best "copers", as shown by hospital staff ratings. The investigators felt that these self-blamers were using attributions to maintain control over their situations by believing that their actions created the situation.

Since Bulman and Wortman pointed out the need for "real world" attributions research, studies on the attributions of illness have become more common in the social psychological literature. Nursing research has also begun to use attribution theory in examining human reactions to illness.

Baider and Sarell (1983) studied the causal attributions made by Israeli women with breast cancer. They used interviews in order to explore the influence of the subjects' ethnic and religious backgrounds on their beliefs about the cause of the illness, about what or who is to blame and about resources for help. They found that more traditional women tended to attribute their illnesses to emotional causes, God's will, or fate, and to take a more passive stance ("only God can help") regarding their role in the treatment of the diseases.

In another study on breast cancer, Taylor, Lichtman and Wood (1984) examined the correlation between attributional style, beliefs about control and adjustment to the disease. This well designed study tested several hypotheses. The investigators found, in contrast to Bulman and Wortman (1977), that no particular attribution style was related to successful coping, except that blaming another person was related to poorer coping. In their discussion of these findings, they speculated that making attributions for the occurrence of a one time traumatic event (i.e., spinal cord injury) may serve a different purpose in maintaining feelings of control than finding reasons for ongoing processes in the course of a chronic disease such as breast cancer. Another finding of this study was that 63% of significant others made attributions for the occurrence of the subject's cancer.

Witenberg et al. (1983) studied feelings of control and attributional style as predictors for coping and compliance in persons with end stage renal disease on hemodialysis. They found that those who had wondered about the reason for their illness but were unable to find an answer were rated as poorer copers and compliers. Of those who did find answers, specific attributions were not significantly related to coping or compliance ratings made by dialysis staff.

Koslowsky, Croog and LaVoie (1978) studied perceived causes of myocardial infarctions using a closed ended questionnaire. Nearly two-thirds of their respondents attributed personal causes for their MI's, and 58% felt they could have prevented their heart attacks.

Nursing Research on Illness Attributions

Rudy (1980) examined reasons for the illness event given by males with myocardial infarctions and their wives. The philosophical rationale she gave for the study related to man's search for meaning in events.

Rudy found spouses of MI patients were slightly more likely than the patients themselves to have a causal explanation for the MI. She found that approximately half of the MI patients changed their causal explanations between the acute and convalescent stages and that 18% of patients stated they "didn't know" the reason for the MI. Additionally, she found that medical risk factors (i.e., "professional causal explanations" such as smoking and obesity) did not generally emerge on open-ended questioning, but were rated as important by respondents in forced choice questions.

Ongoing research on the attribution process in illness situations has been conducted by a team at the University of Pennsylvania School of Nursing (Lowery, Jacobsen & Murphy, 1983; Lowery & Jacobsen, 1985). The team's 1983 research examined the frequency of causal thinking by arthritics and how this causal thinking may be connected to affect and to success in treatment outcomes. This study used the Weiner model (Wong & Weiner, 1981) as its theoretical base. Results disclosed that 85% of arthritics gave causal explanations for their disease. The researchers found that no particular attribution style could be linked to affect or treatment outcome except that those who did not have a causal explanation were more depressed, anxious and hostile than those who did.

Lowery and Jacobsen (1985) built on the arthritis study and altered the research questions and methodology slightly. This study gave more emphasis to causal explanations for the success or failure of treatment (according to the ill persons' own definitions of success and failure). They examined the relationship of these explanations to self-estimates of health status. They found that most persons rated their treatment as a success. Attributions for successful outcomes tended to be related to stable internal factors while failure outcomes were ascribed to external and uncontrollable factors. On the basis of their own and other's previous research, Lowery and Jacobsen conclude that persons who do not have a causal explanation for their health problem or feel there is no real reason for them having the problem tend to be "patients in trouble."

Nursing Research on IBD

Joachim and Milne (1985) used closed ended questionnaires to investigate the effect of IBD's on lifestyles. Respondents indicated that lifestyle areas most significantly affected by having IBD were their overall life satisfaction (42%) and various psychosomatic symptoms (low energy, 56%; depression 39%; nervousness, 36%; and insomnia, 32%). Relationships with family and friends were less affected by IBD, although 13% of the sample reported major illness-related interpersonal problems. The investigators concluded that their subjects felt themselves to be less affected by their illnesses than others felt them to be. The investigators explained these results in terms of adaptive mechanisms and the subjects' need to "feel normal."

Reif (1975) studied the strategies that people used to manage the effects of ulcerative colitis on their lives. Although her original study did not look specifically at attribution, Reif states that blaming of the patient seems to occur and that this may be due to the lack of clear connection between the disease treatment regimen and the outcomes of this regimen (Reif, 1985; personal communication).

Attribution Theory in Helping Models

Brickman et al. (1982) used attribution theory to construct a model to explain forms of helping behavior. They theorized that beliefs about "who is responsible" for the problem and for its solution are important in helping situations, such as in a nurse-client relationship. Responsibility for the problem, or "blame" in the Brickman group's terms, is linked to the internal/external dimensions of Weiner's model (Wong & Weiner, 1980). Brickman's group uses the word "control" to describe responsibility for the solution of the problem and links control to the stability-instability dimension of causes in the Weiner model.

Brickman et al. describe four possible combinations of high and low self responsibility for problem solution: the moral, compensatory, medical and enlightenment models. In the moral model, persons are held responsible for both the causes and the solutions to their problems. In the compensatory model, persons are not blamed for causing their problems, but are seen as able and responsible to solve them. The medical model assumes that persons are neither responsible for their problems (illnesses) nor their solutions (treatment). The enlightenment model holds persons responsible for their problems but not their solutions.

Brickman et al. suggest that ineffectiveness in helping may result from the use of different helping models by the parties in a help situation. Effective helping is undermined when conflicting expectations about actions to be taken occur. For example, a person with a chronic illness who wishes to make his own decisions in his care regimen (compensatory model) works with a physician who expects unquestioning adherence to his orders (medical model). Another example is a dyad where a physician uses a compensatory model expecting his patient to make lifestyle changes to improve her health, while the patient uses the medical model and desires a medication to cure the problem.

Attributions and the Social Meanings of Illness

Several current theologians, philosophers, psychologists and sociologists have addressed the area of responsibility for illness. Kushner (1981) sought to assist people who were facing tragedy and suffering to answer deep seated theological questions such as, "How can God let this happen to me?" This author, a rabbi, cites humanity's need to feel that the world makes sense and that there must be reasons for events which occur. He suggests that many people's views of the meanings of tragic events cause them to feel guilt ("I deserve this"), anger ("God is doing this to me"), or powerlessness ("This is part of God's plan, there's nothing I can do"). He then describes a different view of God in order to liberate his readers from the sense of a cruel, punishing or constantly testing God. He writes that God created the world "with a few rough edges" and that "sometimes there is no reason for things that happen." Kushner encourages his readers to use the comfort that comes from sharing in rituals and to seek God's inspiration in dealing with tragedy and suffering imposed by life.

Sontag (1977) explored social meanings or metaphors which have become attached to illness. Sontag's seminal book outlines historical and modern moral and characterological attributions of illness. She describes images used to describe victims of different illnesses (e.g., cancer patients as angry and repressed) and how these images have served to stigmatize ill persons. Sontag contends that our modern trend toward explaining events psychologically causes guilt by promoting the belief that cause and control of illness are in the hands of the ill person. She states that the reason for the tendency for psychologizing is to give a needed feeling of control over events. She points out the importance of differentiating between hypotheses which state that emotions cause disease and those which postulate that distress can lower immunity.

Lerner (1971) created a theory called the "just world theory" which incorporates the above described need to believe in an orderly world where all events have causes and reasons. Misfortune happening to an innocent victim is a threat to this belief, this sense of justice. When such a misfortune occurs, this theory goes, people tend to find reasons for the occurrence which restores a sense of justice; so that people deserve what they get. If justice cannot be restored by compensating the victim or punishing the inflictor of the suffering, then somehow the victim must be deserving of his fate. Lerner's work has been used as the basis of studies investigating a phenomenon called "blaming the victim" (e.g., Alexander, 1980).

Gruman and Sloan (1983) studied perceptions of ill persons using the just world theory as a theoretical base. In a lab situation, they found that with the exception of stomach cancer, the less ill persons were rated as more likeable than sicker persons. In explaining the cancer finding, Gruman and Sloan hypothesize that factors such as the etiology of an illness may play a part in the evaluation of a victim of that illness, i.e., that victims of a disease seen as not preventable would be derogated less. These findings give some support to the just world theory (illness victims are less attractive and thus more deserving of their fate). It seems, however, that the cancer finding is worth investigating in terms of responsibility for illness.

Taussig (1980) writes that modern science dichotomizes the objective view of disease etiology and treatment from subjective social meanings of illness, and ignores this subjective view. That is, medical science reduces disease to a mere physical phenomenon by focusing only on "how" an illness occurs (the objective view). He asserts that modern physicians are unable to help their patients come to terms with the "whys" of illness and to reach an understanding of the subjective, cultural significance of illness. Rather than relieving guilt about illness with this objective view, Taussig feels that health care systems create guilt in a different way by creating power differences between patients and health care providers.

However, persons may recombine subjective and objective factors to formulate their own hypothese of disease causation. Taussig (1980) describes the causal exploration made by a woman with polymyositis: she links her poverty, malnutrition and physical overwork with a hereditary factor, a possible bacteria (objective factors), and a belief that God gave her the illness so doctors could learn how to cure it (subjective significance).

Researchers have shown the importance of having a causal explanation in coping with illness (Bulman & Wortman, 1977; Witenberg et.al., 1983;

Lowery, Jacobsen & Murphy, 1983; Lowery & Jacobsen, 1985; Taylor, Lichtman & Wood, 1984). They have shown that persons may feel responsible for certain illnesses (e.g., Koslowsky et al, 1978). Little research has been done that specifically addresses attribution for illness of ambiguous etiology such as IBD. Research has not yet examined the effects of attributions on personal relationships in chronic illness situations.

METHODOLOGY

"Especially while learning, each movement should be thought out and performed carefully and deliberately. Experience develops the necessary efficiency of movement, which enables the proficient climber to move steadily, smoothly, and confidently."

Mountaineering: The Freedom of the Hills.
1982.

III. METHODOLOGY

Study Design

This exploratory study seeks to elicit and describe previously unexplored attitudes and beliefs of the study population (Wilson, 1985; Polit & Hungler, 1983). An interview was chosen to collect data for several reasons. So little is understood about attributions, especially in IBD, that the full range of responses is presently unknown. Thus, a questionnaire would gather limited and possibly invalid data. The complexity of attributional issues is best explored through face to face exchange. This style gives the investigator the opportunity to clarify or probe into certain responses (Wilson, 1985).

Instrument

The interview schedule included open and closed ended questions (See Appendix A). Open ended questions were designed to aid in discovering what is important to subjects in their own words. This type of question is most appropriate in this exploratory, descriptive research. Little is known about attributions in IBD and important insights may be missed by the sole use of focused, narrow questions. The interview was used as a guide rather than a standardized format since a flexible yet systematic outline was desired for the interview (Patton, 1980). The ordering and wording of questions remained standard for all interviews. However, different areas, such as family relationships, were sometimes highlighted in the discussions with different respondents.

In the study of attribution, many authors have noted that open and closed ended questions yield different types of attributional information. For example, different attributions may be given in response to open ended questions as opposed to closed (See Rudy, 1980). Structured questions may be less threatening, or can suggest a valid answer that the respondent may not have thought of or been able to articulate during the interview. Indeed, closed ended questions often disclose differences in attributional style between "success" and "failure" groups (Lowery & Jacobsen, 1985). For these reasons both types of questions were included in this interview.

The closed ended questions were based on Lowery and Jacobsen's (1985) Attributions Interview Schedule. As the instrument had not been tested on an IBD population, its validity in this situation could not be assumed. For example, it was not known at that point whether the tool's questions covered the range of causal explanations given by persons with IBD. As will be described in the Results and Discussion sections, results from open ended data collection, when compared to these closed ended results, showed that a major causal explanation, "stress", was omitted. Although Lowery and Jacobsen achieved high inter-rater reliability for recording and coding the data, other reliability scores were not available.

The interview guide was piloted on two subjects. With some revisions to the wording and order, the questions were found to be effective in bringing forth information pertinent to the study.

Sampling Procedure and Setting

Interviews were conducted with persons with inflammatory bowel disease receiving care at the UCSF Ambulatory Care Clinic (ACC) or from the private gastroenterologists at the UCSF Medical Center. Subjects were approached by the nurse practitioner or physician's secretary prior to their physician appointments and asked for permission to be interviewed. All of those approached consented to be interviewed. They were then contacted by telephone and an interview time and location was arranged. To be eligible, subjects needed to have a diagnosis of either Crohn's disease or ulcerative colitis, be 18 to 65 years of age, and speak English. Seventeen subjects composed this convenience sample from the patient registries at the GI ACC and private physician's offices.

Subjects were selected by a stratified procedure in order to gain a sample which reflects various lengths of time since illness onset, since attributions may change as the ill person gains experience with the illness. Every two weeks, the researcher went over upcoming IBD appointments for the ACC and private physicians with the nurse practitioner and secretaries, and decided which patients the practitioner and secretaries should approach, according to length of time since diagnosis.

Sample

The sample consisted of 17 study subjects, 9 females and 8 males. The subjects ranged in age from 18 to 62, with a mean age of 35.7 years and a standard deviation of 10.5 years. All subjects had completed high school, 3 had college diplomas, 5 had university baccalaureates, and 5 had post graduate degrees; 8 were employed full time, 4 part time and 5 were not employed at paying jobs (3 were on disability, 1 retired and 1 was a housewife). Nine subjects lived with their spouses, 4 lived alone and 4 lived with their parents, siblings or children.

There were 9 subjects with ulcerative colitis and 8 with Crohn's disease. The mean length of time since diagnosis was 11.4 years with a range of 6 months to 24 years. The frequency distribution of the time since diagnosis is shown in Table 1.

Table 1. Frequency distribution for length of time since subjects were diagnosed with IBD.

Length of time since diagnosis	n
Less than 5 years	4
5 - 10 years	6
11 - 20 years	4
More than 20 years	3

In an attempt to ascertain the seriousness of the subjects' illness, data were gathered on treatment and the frequency of IBD-related doctor and/or clinic visits. Table 2 shows the frequency distribution for type of treatment. As an indication of seriousness, prednisone (or 6-MP, an immunosuppressive drug) is given for cases which cannot be controlled by any other means. Table 3 shows the frequency distribution for the annual number of IBD related visits.

Table 2. Frequency distribution for type of IBD treatment received.

Treatment	n
None	3
Medication other than prednisone or 6-MP	3
Prednisone or 6-MP	8
Formerly prednisone or 6-MP	3

Table 3. Frequency distribution for number of IBD-related physician/clinic visits made annually.

Number of visits annually	n
More than 6	8
4 to 6	5
2 to 3	3
One	1

Interviews were held in a private conference room at the ACC in five cases, in a small room near the private physicians' offices in seven cases, in the subject's home in three cases and in the subject's office in two cases. Informed consent was obtained prior to each interview.

The interview took 45 minutes to two hours, averaging approximately one hour and were taped pending the interviewee's permission. The interviewer also took notes. The closed ended questionnaire was read to the respondents following the open ended interview. In a debriefing session following the interview, respondents were informed (or in most cases, reminded) that the causes of IBD are still uncertain.

Data Analysis

Qualitative Analysis

Analysis of qualitative data began in the data collection stage. Using the naturalistic method for field study (Glaser & Strauss, 1967; Schatzman & Strauss, 1973), the investigator examined interview notes and transcriptions and made observations as to possible emerging themes and categories.

The qualitative analysis of data also attempted to incorporate the analytical induction method as described by Wilson (1985, p. 413). This is a creative method which involved formulating categories and attempting to find explanations for the phenomena in question; in other words, theory generating research. In the inductive analysis, the researcher kept in mind the objectives of the study -- to elicit and describe patient beliefs about responsibility for disease causation and control, patient beliefs about attributions by others, and how the combination of these beliefs affect relationships.

Categorization and the search for themes began in the data gathering phase. New categories were created and old ones reformulated as cases emerged which did not fit the existing categories. Although a hypothetical explanation to cover all cases was not discovered, the application of attribution theory as an explanation of these cases is described in the Discussion chapter.

Quantitative Analysis

Descriptive statistics were used to supplement the qualitative analysis of data. The number of subjects falling into each response category was tabulated.

Data from closed ended questions were analyzed using frequencies and percentages for each of the twenty closed ended items to show the number of persons agreeing and disagreeing with each cause. To facilitate analysis, the scales had four points that eliminated the middle response to force the subject to choose between "not much of a cause" and "somewhat important cause". Formulating the questions this way, however, meant sacrificing finding the tendency for those subjects to choose middle ground.

Responses to each set of closed ended questions were compared to see whether subjects gave different reasons for having the illness than for the success or failure of illness control measures. Demographic variables were examined for significant relationships with attributions categories using Kendall's tau technique.

RESULTS

"Let us be as journalists, then. And, like all good journalists, we shall present our facts in an order that will satisfy the famous five W's: wow, whoopee, wahoo, why-not and whew."

Tom Robbins
Even Cowgirls Get the Blues, 1976.

"For a sixth 'w' - is this wise?"

Linda Chafetz
Feedback on final draft,
November, 1986

IV. RESULTS

Data will be presented according to the four stated purposes of the research. The four purposes were to learn the respondent's beliefs and perceptions as to (1) the cause of the illness, (2) reasons for the course of the illness, (3) other's attributional stances, and (4) the effects of these stances on interpersonal relationships. Qualitative data collected from the open-ended interview will be presented together with related quantitative data obtained by the closed ended questionnaire as it relates to each of the four sections.

Purpose 1: Attributions for the Cause of Illness

The first purpose of the research was to explore beliefs that persons held about the causes of IBD. In describing questions people ask about their illness, Taussig (1980) differentiates between the "how" questions, which describe the more immediate causes (e.g., bacterial agents, an accident), and the "why" questions pertaining to personal and social meanings of illness. This study also found that people formulate answers to both of these questions about the causes of IBD. Using a term quoted by one of the respondents, answers to the "how" questions will be called "mechanisms." The answers to the "why" questions will be termed "meanings explanations."

Data related to this first purpose will be presented in three segments. The first two segments will describe qualitative findings on the search for the mechanisms and the meanings of IBD. The categories of respondents beliefs about the immediate causes (mechanisms) will be described in the first segment, themes related to the meanings of IBD will be presented in the second segment. Quantitative data from the section of closed ended questions (CEQs) which relate to these qualitative data will then be presented in a third segment.

Explanations of the Mechanism

The interviews began with the following question:

> Most people who have Crohn's (or ulcerative colitis) develop some hunches as to how they got the disease. I wonder if you would mind sharing your beliefs with me, if you have any?

In response to this question, subjects tended to give their beliefs on how their IBD was caused (or express their confusion in this regard). Their replies fell into three general categories. These were the "scientifically-inclined" explanations, (3 subjects, 18%) the "stress as cause" explanations, (10 subjects, 59%) and "I don't know what caused it." (4 subjects, 23%) This section will separately examine the qualitative results for each of these categories and their subcategories.

It should be noted that some subjects reported changes in their beliefs over time. For example, one described his early search for a causal agent such as a virus before adopting an explanation involving responses to stress. Another describes a period of seeking causes before deciding that the cause did not matter.

Scientifically Inclined

Three respondents (18%) gave causal explanations based on medical research, although all three acknowledged that at present, medical science does not have an explanation for the causes of IBD. These respondents cited heredity as being linked to IBD (i.e., that people of the Jewish race were predisposed to IBD). Some felt a possible viral cause might someday be found, or that a factor such as long-term constipation might be implicated. These respondents did not see a strong link between stress or personality and the causes of IBD (although some felt stress might exacerbate the illness.)

The three respondents in this category described themselves as "scientifically inclined" persons. They had investigated the medical literature for information on their illness and quoted this literature in their responses to the questions.

These respondents were not the only ones who used medical literature as a source of information. People in other categories had also read medical literature but seemed to use it differently. The "scientifically inclined" persons gave a higher priority to medical literature and showed a stronger tendency to believe that a single physical mechanism had caused the IBD.

Although they had much faith in their gastroenterologists, the "scientifically inclined" respondents also used or considered using alternative therapists such as acupuncturists and stress management specialists. They generally discussed the use of alternative methods of treatment with their doctors. This use of alternative healing methods was to them a way of "covering the bases" and exploring all possibilities to regain health.

Stress-as-Cause Explanations

The majority of respondents (59%) felt that "stress" had played a part as a cause of their illness. These respondents, in contrast to respondents in the other categories, felt that physical and/or emotional stress "set off" the illness in some way. It should be noted that most respondents in this group believed that additional causal factors also played a part. Four felt they had a hereditary predilection, while another four felt their diet was also a factor in the development of IBD.

These respondents defined and described stress in particular ways. Some respondents described difficult events or periods such as family problems, a slumping stock market, or school pressures as stresses that caused IBD. Others defined stress as their reactions to these events (e.g., tension, anxiety, trauma, unhappiness). Lastly, some defined it as their outlook and reactions to life in general (e.g., being a "nervous type person" or not expressing feelings).

Respondents were unable to be specific as to the actual mechanism that converted stress into inflammatory bowel disease. Some felt that there was a "weak link" or vulnerability in their body system -- that is, that their intestine broke down or became vulnerable to disease under the pressure. Three respondents viewed IBD as a response to emotional repression and believed that feelings were converted into a physical problem.

The respondents who saw stress as an initial cause of IBD also saw it as a factor which influenced the course of the illness.

<u>"I don't know" Group</u>

The four respondents (23%) in the third category either have not sought causal explanations for their illness, have not been successful in their search, or feel that the cause does not matter. Respondents from other categories (especially the scientifically inclined) acknowledge that the cause is unknown to science, but believe in a "scientific" or "stress" explanation. Respondents from the "I don't know" category, however, are much more characterized by the lack of a causal explanation than subjects in the other two categories.

The "I don't know" category breaks down into two subcategories based on respondent's reactions to the fact that they do not know the cause of their IBD. One subcategory response can be described as "I don't know and it's got me down", the other as "I don't know but it doesn't matter."

<u>"I don't know and it's got me down"</u>. The two respondents in the first subcategory are characterized by a sense of confusion, frustration and helplessness about the IBD. These respondents describe a process of seeking causes and cures for the illness and not finding any answers. One subject said:

> "I've been to virtually every healer there is... I've just gone sort of full circle. I thought I had it figured out but I don't. I don't know why. I don't know why I have this illness."

This process has included seeking care from many different practitioners in the hope of regaining health. Among this list of practitioners are acupuncturists, biofeedback trainers; counsellors in psychosomatic illness; herbalists; "holistic" doctors who advocate vitamin therapy, resolving emotional conflicts, or nutritional approaches[2]; and traditional medical specialists (i.e., gastroenterologists).

---

[2] As one respondent put it, "Holistic physicians claim to take into consideration the whole person -- the mind, the body, the spirit and whatever is left over after that!"

Although one subject in this subcategory has maintained a long term relationship with his first gastroenterologist, these subjects have gone from practitioner to practitioner, but have found that "nothing helps." They gave various reasons for changing practitioners. Unhappiness with side effects of medications, unwillingness to undergo recommended surgery, desire for other options, lack of results from therapy and dissatisfaction with relationship with practitioners were reasons for seeking new healers.

These respondents are also frustrated with the illness itself. They are extremely frustrated by the sense that there is no pattern to the illness, and that it "has a life of it's own." They feel there is no explanation for what has happened to them and why the disease flares up when it does. A related source of frustration is the feeling that they are following all the rules and the disease still comes back.

These respondents also experience confusion as to the part emotions and attitudes play in the illness. They report that they have "negative attitudes" because of the illness. They wonder whether their attitudes made the disease worse and sometimes feel guilty about this. These respondents reported having difficulty maintaining hope, but wondered whether hope, or a "positive attitude" would improve their health anyway. They stated that even at times when they had positive attitudes, it did not seem to help. One respondent said, "IBD has been an obstacle for me, or maybe I just let it get in the way, or use it as an excuse. Maybe I'm just lazy." Another reported that his fear of embarrassment of incontinent bowel movements was stopping him from pursuing a performing arts career. He felt unfairly criticized by people who told him he was "over-reacting as far as fear goes."

The role of "stress" in the illness was another source of confusion for these respondents. One related stress to a characteristic personality type: "a stressful type person -- really high strung," and did not consider himself to be this way: "I've always been fairly composed." This respondent also noted that "stress" had so many different meanings that he did not understand it at all.

One common thread in the background of this confusion about stress was a feeling that if stress, emotions or attitude caused the problem, then the ill person was responsible for his own illness. One respondent described it as "the notion that... it's my inability to cope with certain things that brings on the illness." A feeling of guilt accompanied the feeling of responsibility: they felt "blamed" if the problem was caused by emotional conflict or inability to handle stress.

"I don't know but it doesn't matter". The two persons in this subcategory are notable for the belief that asking the "why" question is not important to them. One respondent summarized this attitude as, "I don't know how, and the why doesn't matter. [IBD] just got me, you know, and there is nothing I can do but go on from here."

These respondents came to this attitude through different processes. One said that she had never spent much time "analyzing why I have it or why it is flaring up now." Another had spent many years searching for the cause of the disease and a reason that it could have happened to him. He eventually came to the belief that he had to live with the disease, and that he would put his energy into guarding and making the most of his present health and into hoping for a cure.

Notable features of this group were their orientation to "taking care of the problem," and their acceptance of the illness and some of its uncontrollable aspects. These respondents showed much acceptance of the illness in their lives. One respondent said, "Crohn's is just something I've had and what I have I just have to deal with, and it's just part of life, like taking a shower every morning." This is not to say they are happy about the situation: "I'm making it sound less awful than it is... when I flare up, it's awful, really bad, and I don't like it, and the fissures and the cramps <u>hurt</u>, but you just have to deal with it." They had been forced to make room in their lives for IBD; for example, "spending about 3 hours a day, off and on, in the bathroom", with diarrhea and sitz baths.

In their adaptation to the disease these respondents learned there were certain things they could do to decrease the frequency and or intensity of flares, such as taking medications, following diet restrictions, and getting a lot of rest. However, they found they were unable to eliminate flares completely, that the disease "still picks it's own time to flare up." One respondent expressed how he coped with this uncertainty:

> "You have to take control, take responsibility and yet know that it's not going to work all the time -- expect that."

He added,

> "it's important to try and keep a good attitude. But, like I said, I know its impossible to do all the time, so those times when you don't have it, you don't. Just ride it out, but just try and have that good attitude."

These statements reflect a realization of the varying amount of control they have over the illness. They also reflect acceptance of self when things go wrong despite control measures, and when a positive attitude cannot always be maintained.

Using Kendall's tau, these four categories of open ended responses were statistically checked for relationships with the study's demographic variables of sex, "lives with whom", occupation, education, diagnosis, length of time since diagnosis, frequency of visits and type of treatment. No significant relationships were found between the response categories and demographic variables.

Meanings Explanations

Still relating to the first purpose of the study which is to illuminate subject's beliefs about the causes of IBD, this section will present the data obtained on the respondent's meanings explanations for IBD. These explanations could also be thought of as "reasons" (rather than causes) for IBD. As one subject put it, these are "ideas about how my disease fits into the big picture."

Subjects were not specifically asked in the open ended interview about the larger meaning they gave to their illness. However, 13 of 17 (76.5%) subjects discussed this aspect of IBD in their lives, often in response to closed ended questions related to religious/spiritual meanings of illness. These were the questions that asked if the development and course of IBD were due to God, and to luck. Also, respondents were asked to agree or disagree with the statement that there was "no real reason" for these things happening to them, "they just happened." Several themes emerged from these data including the role of God, illness as punishment, illness as part of a larger plan and illness as "just something that happens."

The Role of God

God's role in the causation of illness was discussed by several subjects. While some (17.7%) felt that God had some control over the fact that they had IBD, others (17.7%) firmly believed that God had nothing to do with it. The three subjects who elaborated on the belief that God did have something to do with an individual having IBD felt that there was a reason or plan in mind. This aspect of God's role will be discussed in the "Illness as part of a Larger Plan" section.

Other subjects (17,7%), on open ended questioning, expressed the belief that although they believed in God, God did not cause or allow the illness to happen. One subject said he didn't think that there was a "cause and effect between the Supreme Being and my poor little body." Another remarked that "God had more important things to do." Another, in response to the question asking "Was it because of God" that she had IBD, said, "No. I don't think God is stupid."

Illness as Punishment

Three respondents mentioned that at one point in time they believed that IBD, in some way, was a punishment. These feelings of being punished occurred as meanings explanations soon after developing IBD. These respondents all described the process of coming to terms with these feelings -- one subject stated that she had a realization: "What did I ever do that was that bad?" Others felt guilty and regretful for longer periods of time, where one described his thoughts as "What if's and what if's and what if's going through my mind." However these respondents say they are now more or less free from their past guilt feelings.

Illness as Part of a Larger Plan

Approximately one third of the respondents saw their illness as part of a larger plan for their lives or for the world. Some had understanding of the reason for this plan, such as Karma from past lives, or that God does things like this "to teach us lessons -- mine was to give up my speedy life, but I've been awfully stubborn and resentful about learning this lesson." Others said they did not have an understanding of the overall plan, but stated for example, "God has his reasons", or "these things are meant to be". One newly diagnosed subject poignantly described the importance of having a belief in a larger plan:

> "I'm not really into God, ... but I believe that I'm here for a reason, and if things happen to me, there's a reason. I don't know what it is, but it's like, it really helps me to tell myself that I have Crohn's because of some reason. I don't know what it is, but it was meant to be, and that I'm just going to have to live with it, kind of."

"It Just Happens"

Another theme which surfaced in interviews was the belief that IBD "just happens" and that there is no particular reason that it happened to one individual. Respondents who voiced this theme may or may not have had an explanation for how the disease occurs, but their explanation for why it happened to him/her in particular was that it was chance, luck, or as one subject comments, "a matter of statistics." Another respondent put it: "It [IBD] didn't pick on me because I'm J. It just got me. I'm a human being. It just got me."

On Asking, "Why me?"

It is interesting to examine respondents spontaneous comments on asking the "Why me?" question. When respondents spoke of asking themselves this question, they frequently brought up losses brought on by the illness (e.g., valued family activities) or troubling news (such as a colonoscopy report that showed increased disease).

Respondents view this questioning in various ways. Some saw it as a natural part of illness: "all of us with chronic illness ask that." Some accept the questioning as uncomfortable but "something you just have to go through." Others see this type of questioning as part of "dwelling" on the illness. They believe that it can get in the way of "getting on with life."

Quantitative Results for Purpose 1

The initial question on the closed ended questionnaire asked specifically about various beliefs about the causes of IBD. (see Appendix A) This question read, "Some people say, 'I got Crohn's disease/ulcerative colitis because . . .' Is that a cause in your case?" The subject rated each factor on a scale from 1 (not a cause) to 4 (very important cause). Table 4 shows the frequency distribution for responses to these CEQ's.

As can be seen from the frequency distribution, most causes suggested by the questions were not held as important by the subjects. The exceptions were "frame of mind" and "no real reason" which received more support as causes.

Table 4. Responses to interview question concerning the causes of IBD. The mean represents the average rating of importance given to each causal factor (a higher mean indicates more importance ascribed to the factor). n=17

Causal Factor	Rating of Importance in percentages				Mean Rating
	1	2	3	4	
	Not A Cause	Not Much of a Cause	Somewhat Important Cause	Very Important Cause	
a. Never taken care	47.0%	29.4	5.9	17.7	1.941
b. Not taking good care at time	52.9	23.5	5.9	17.7	1.882
c. Personality	35.3	23.5	23.5	17.7	2.235
d. Runs in the family	70.6	17.7	0	11.7	1.706
e. Bad habits	64.7	29.4	0	5.9	1.412
f. Unlucky	64.7	5.9	11.7	17.7	1.824
g. God	76.5	11.7	5.9	5.9	1.412
h. Frame of mind	17.7	23.5	23.5	35.3	2.765
i. Difficult to avoid	64.7	29.4	0	5.9	1.471
j. Other people	88.2	0	5.9	5.9	1.294
k. No real reason	23.5	5.9	11.8	58.8	3.059

Purpose 2: Reasons for the Course of Illness

The second purpose of the study was to learn what subjects believed were the reasons for the course of their illness. This section presents quantitative and qualitative data related to these beliefs. The quantitative data will be presented first in a separate section so that it can be discussed as it corresponds to data collected from the open ended interview.

Quantitative Results

In the closed ended section of the interview, the second set of questions asked respondents for their beliefs as to causes for the course of their illness. Respondents were asked to rate themselves as "doing well" or "not doing well" in terms of their IBD. Subjects were then read the following question: "Some people say 'I'm doing well (not doing well) with my Crohn's/ulcerative colitis because [causal factor].' Is that so in your case?" and asked to rate the importance of each causal factor. Table 5 gives the results of those who rated themselves as doing well while the results of whose who rated themselves as not doing well are shown in Table 6.

Table 5. Responses to interview question concerning the importance of various causal factors in the course of illness. Subjects rated themselves as doing well. Numbers indicate the percent of the sample who gave each rating. The mean represents the average rating given by the sample for each causal factor. n=12.

Causal Factor	Rating of Importance (in percentages)				Mean Rating
	1 Not A Cause	2 Not Much of a Cause	3 Somewhat Important Cause	4 Very Important Cause	
a. Try hard, pay attention to everything about health	16.7%	16.7	25.0	41.7*	2.917
b. Do what I should to manage illness	0	16.7	25.0	58.3	3.417
c. Disease is easy to control	83.3	8.3	8.3	0	1.250
d. Good MD advice	8.3	16.7	16.7	58.3	3.250
e. Type of body that responds	33.3	16.7	25.0	25.0	2.417
f. Others helping	41.7	16.7	0	41.7	2.417
g. God	58.3	16.7	8.3	16.7	1.833
h. Frame of mind	25.0	8.3	25.0	41.7	2.833
i. Drugs working	33.3	0	41.7	25.0	2.583
j. Lucky	50.0	8.3	33.3	8.3	2.000
k. No real reason, just happens	27.3	9.1	36.7	27.3**	2.636

* Total of percentages do not always equal 100% due to rounding errors.

** Data missing from one subject.

Table 6. Responses to interview question concerning the importance of various causal factors in the course of illness. Subjects rated themselves as not doing well. Numbers represent the percent of the sample who gave each rating. The mean represents the average rating given by the sample for each causal factor. n=5 .

Causal Factor	Rating of Importance (in percentages)				Mean Rating
	1 Not A Cause	2 Not Much of a Cause	3 Somewhat Important Cause	4 Very Important Cause	
a. Not trying hard enough, not paying attention to everything about health	20%	20	0	60	3.0
b. Don't do what I should to manage the illness	20	20	0	60	3.0
c. Disease is hard to control	20	20	40	20	2.6
d. Poor MD advice	80	0	0	20*	1.6
e. Type of body that doesn't respond well to treatment	60	40	0	0	1.4
f. Others not helping	20	20	40	20	2.6
g. God	60	20	20	0	1.6
h. Frame of mind	0	40	40	20	2.8
i. Drugs not working	40	0	60	0	2.2
j. Unlucky	60	20	20	0	1.6
k. No real reason	80	20	0	0	1.2

* Subject responded to this question as though she was doing well (i.e., "When I'm doing well it's because of good physician's advice.").

Subjects tended to give more than one causal factor for disease course in the open-ended section of the interview and these data did not fall into constellations of beliefs. Thus, rather than characterize subjects by their set of beliefs as in the previous section, it is more logical to present causal beliefs separately.

Many factors emerged as attributions for exacerbations and remissions of IBD. These factors included stress, medications, diet and exercise. God and "finding a good doctor" were also named as influencing the general course of the illness. A very striking observation, however, was the unpredictablity of disease episodes reported by respondents. These factors and observations will be reported below.

Stress

Whether or not they believed stress caused the illness in the first place, almost all respondents (16, 94%) felt stress played a role in the course of their IBD. Ten of these sixteen respondents stated that stress was an exacerbating factor in their illness. Three other subjects linked their improved condition to the better control of stressors. A "positive attitude" was named by one of these respondents as helping him to stay healthy, as well as helping him to cope with disease episodes when they occurred. Additionally, three subjects gave weak support to stress as a factor: as one said, "I'm not very sure that it is, but I can't rule it out."

Only one respondent (5.9%) did not link stress and illness episodes. He discussed his dissatisfaction with the concept of "stress." He felt that stress was related to a type of personality and described himself as a more easy going type. He thus could not understand how his rather severe IBD could be related to stress.

The closed ended questionnaire did not ask specifically about stress. The most closely related CEQ was whether respondents felt "frame of mind" was a cause for them doing well or not. Eleven (64.7%) subjects rated this factor as a somewhat or very important cause.

As will be discussed in a following section, subjects do not see stress as a factor that can account for all of the disease flares that they experience. Many related symptomatic episodes which occurred when they did not feel under stress. Others reported stressful periods, or constant stress in their lives which were not accompanied by flare ups of IBD.

Control of Stress

Although not asked specifically, there were striking differences noted as to some subject's apparent feelings of control over the stresses which they believed caused exacerbations of the IBD. Some respondents (29.4%) felt unable to change the stresses or their responses to them, while others (47.1%) felt that they could control the stress, and thus, their illness, to an extent.

The respondents in the first subgroup saw stress or their reactions to it as unchangeable for different reasons. Three (17.7%) felt their current job and family situations were stressful but they could not change these situations at present. Two others (11.7%) felt that their reactions to stressful work and family events were part of their basic personality -- "That's just the way I am."

The other subgroup felt some control over the stresses that they felt were making them ill. They reported methods such as assertiveness and improved communications, keeping a positive attitude, and walking away from stressful or frustrating situations as useful in dealing with stress. Typically, these people stated that they learned these techniques as a result of having IBD. Many felt that the diagnosis of IBD was a turning point for them and had made changes because of it.

It is important to note that these people do not feel they have ultimate control over the illness. As mentioned previously, most have had unexplainable disease flareups. However, as one respondent described the type of control he had, "You can't control it to the nth degree, but you can moderate it. It's like steering an ocean liner -- you can't make a U turn, it's a gradual, slow turning around."

Medications

Medications were named as a factor in two ways. Seven subjects (41.2%) felt that medications were improving their condition. Five others (29.4%) felt that medications were either having no effect or worsening the problem. Those who felt medications (e.g., Prednisone) were not affecting their IBD were disappointed and mystified, especially when these medications had helped them in the past. Of those who felt that medications were a negative factor, some related allergy or side effects that caused them to be sicker than they originally were. It should be noted that even the subjects who felt the medications were helping had concerns about side effects.

In the closed ended questionnaire, subjects were asked whether "drugs working" was a factor in doing well (or, if not doing well, whether drugs not working was a factor). Eleven subjects (65%) rated drugs as a somewhat or very important factor in their doing well or not.

Diet and Exercise

Diet and exercise were named as factors in the illness course in particular ways. Certain foods were named by respondents as causing problems. Five subjects (29.4%) reported that milk and dairy products aggravated their IBD, while three reported intolerance of spicy foods and/or roughage. Some noted that in general, increased eating led to increased bowel activity. One newly diagnosed respondent felt diet had no effect on the illness.

Three respondents (17.7%) noted that with regular exercise, their IBD seemed to be generally under better control. One of these, however, stated that he had learned that during an acute attack he had to "play it by ear as far as exercise goes": sometimes exercise worsened the symptoms.

Diet and exercise were not specifically covered by the closed ended questionnaire. The question regarding attention to general health somewhat relates to regular exercise, but less so to diet in the sense that these subjects meant (i.e., avoiding problematic foods rather than in a "general health" sense of maintaining a nutritious diet). Eleven subjects (65%) felt that trying hard and paying attention to all aspects of health was a somewhat or very important factor. Another CEQ, possibly more related to diet in the sense that the subjects meant it, was the importance of "doing what I should to manage the disease." Twelve subjects (71%) felt that this was a somewhat or very important factor.

God

God was felt as an influence on the course of IBD by some respondents, generally the same ones who mentioned God's role as a "meaning explanation" for developing IBD. In fact, the correlation between the two CEQ's that related to God was significant at the p .005 level. That is, subjects ascribed the same importance to God as a causal factor in the disease course as to God as a cause for illness in the first place.

Subjects who discussed God's influence on the course of their IBD (and this mainly occurred with closed ended questioning) usually felt He had a positive influence, or at least helped them cope with living with IBD. In discussing remissions, one subject remarked, "Dear old God, He sometimes gives me a reprieve."

Results to the CEQ that asked whether subjects felt their illness course was "because of God" indicated that only 3 subjects, (25% of those doing well) felt God was a somewhat or a very important cause. Four of those not doing well indicated that God was not a cause in their not doing well. Thus, it seems that subjects who are not doing well do not blame God for this occurence.

"Finding a Good Doctor"

In the open ended interview, three subjects (17.7%) gave direct credit to their physicians for the improved status of their IBD. Several other subjects, in different parts of the interview, alluded to the importance of the help they recieved from their present gastroenterologists. These subjects discussed the process of seeing several physicians that they were unhappy with until they found one who could help them. They said that there were several differences between their present physicians and previous ones. These differences included the present physician's belief that the illness was not "in their head", their better knowledge of current therapy, the cooperation between physician and patient, and fewer uncomfortable tests.

In the CEQ data, physician's advice emerged quite strongly as an important factor in the course of IBD. Nine subjects (75% of those doing well) rated this advice as a somewhat or very important cause for doing well with IBD. Also, all of those who were not doing well said that physician's advice was not a cause for this occurrence. That is, these patients do not blame their physicians for an unfavorable course of illness.

Unpredictable, Unexplainable Episodes

As has been alluded to earlier, most subjects related experiences with IBD flare ups which they were unable to link to a cause. Commonly expressed themes were: "I never know when it's going to flare up", "I can't figure out why one day I'm fine and then it flares up all of a sudden," "I can't see what I do different that causes a flare," "the illness has a mind of it's own" and "it decides when it will go into remission." This unpredictability and uncontrollability is one of the most frustrating and, indeed, frightening aspects of IBD.

Despite attention to diet, following medication regimens with troublesome side effects, and avoiding stress, the disease can still flare up. Frustration is a frequent reaction to unpredictability and uncontrollability. As one subject put it: "I follow all the rules and it doesn't improve the colitis."

A lack of an explanation or of predictability can cause fear which erodes self confidence. It seems to some that "this thing [IBD] has a life of its own." Not knowing when an episode of diarrhea will occur is nerve wracking for many.

A less uncomfortable reaction to unpredictability reported by one subject was feeling mystified. He had infrequent attacks of IBD although he said he was under constant stress. When an attack occurs, he said, "I'm baffled. I'm really baffled by the whole thing."

The results of closed ended questions concerning the difficulty of controlling the illness, as well as the "no real reason" question seem relevant to this aspect of the illness. Subjects were asked if they felt that they were doing well or not because the illness was easy (difficult) to control. Eleven of the twelve subjects who were doing well indicated that ease of control was not much of a cause for their doing well. Most also added that "this is <u>not</u> an easy disease to control." Sixty percent of those not doing well said that the difficulty of controlling the illness was a somewhat or very important factor in this occurrence.

Subjects were asked if they agreed that there was no real reason for them doing well, it just happens." Four respondents rated "no real reason" as a somewhat or very important cause for doing well. None of those not doing well agreed that "no real reason" was a cause for not doing well. Several of the respondents in the first group commented along the lines of "there must be a reason for flares--I don't know what it is all the time, but there _is_ a reason." When referring strictly to doing well, however, seven subjects agreed that there was no real reason for this occurrence.

Purpose 3: Perceptions of Others Attributions

The third objective of the study was to learn how people with IBD perceive the attributions for their illness by significant others (spouses, family and friends) and health care professionals. This section will present these findings, all of which were obtained as part of the open ended interview.

Attributions of Significant Others

The most striking finding in this regard is the observation that subjects in general report little knowledge of others' attributions. In fact, six subjects (35.3%) stated that they had never discussed this question with their significant others. When subjects told the interviewer about another's attributional beliefs, they often prefaced remarks with, "I think."

The rather speculative information from the subjects had a few patterns. Seven subjects (41.2%) felt that their significant others thought stress was a major factor affecting the illness. Four subjects (23.5%) reported that their significant other was just as puzzled as they were about causes. Four (23.5%) reported other's beliefs that diet caused flares, while three (17.7%) stated that others believed heredity was a factor. Allergies and viruses were cited as causal beliefs by two subjects (11.7%). One subject felt that his mother, a very religious woman, believed that IBD was his punishment (although, he says, "she never actually said so.")

Interesting information emerged when the researcher had the opportunity to ask two significant others directly (a father and a husband) about their attributional beliefs. These two had definite beliefs about factors involved with IBD. The father felt that a stressful life event (parent's divorce) had brought on the illness and also that allergy was related. His daughter said that they had never discussed it and she did not want to discuss it with him in the interview. The husband felt that his wife's diet was a factor which caused flare ups of IBD.

Health Care Professionals

Subjects had had little contact with nurses except three who had hospitalization experience. Thus, this section will generally address perceptions of physician's attributional beliefs.

As with perceptions of significant others' beliefs, respondents tended to be somewhat indefinite as to their physician's illness attributions. Five (29.4%) reported that they had never discussed the causes of IBD with their doctor. Respondents generally discussed the causes of IBD with their physicians soon after diagnosis. If their present physician was also the diagnosing physician (as was true in seven cases) respondents tended to have a clearer view of the physician's attributional beliefs.

The more specific information the subjects were able to give included the following perceived beliefs. Diet as an important cause or (mainly) treatment for IBD were cited as physician beliefs by eight subjects, and stress as a cause or aggravator by five subjects (29.4%). One subject reported beliefs of "holistic" physicians as including emotional conflicts as a cause for IBD.

A trend here was that subjects generally felt the physician's beliefs were the same as their own. Nine subjects (52.9%) agreed with their physicians attributions. (Two of these felt that neither they nor their physician was very sure of the cause). Subjects tended to emphasize causal factors which they believed in common with their physicians and in some cases, different patients of the same doctor gave differing accounts of the physician's beliefs.

In the three cases where causal disagreement occurred, the subjects felt that stress or conflict was a chief factor while, they believed, their physician emphasized a physical cause.

Purpose 4: Effects of Attributions on Relationships

The fourth objective of the study was to examine how attribution making affected relationships between persons with IBD and their significant others and health care professionals. Generally, it was found that most subjects did not seem to rate attributions as the key issue in dealing with family, friends, or health care professionals about their IBD. This section will present results on relationships with each of these two groups separately.

Significant Others

Three interview questions asked about how family and friends beliefs about the causes and course of IBD affected the respondent's relationships with them. Respondents were also asked whether others ever blamed them for IBD.

Most subjects were unable to identify immediate ways that others' attributional beliefs affected relationships. They were able to relate more obvious ways that IBD was a problem, such as situations where others did not understand problems such as fear, fatigue, pain, shame or frustration of living with IBD. On closer examination of the interviews, however, data emerge on how attributions of blame and responsibility affect relationships. The interactions surrounding these formed three general patterns.

The first interaction pattern treated attributions as a non-issue. Problems were simply dealt with. For example, one respondent described travelling in Asia with one of his friends where IBD was part of the daily schedule for these two. The friend accepted that the person with IBD needed a certain amount of time, as he put it, "to get his shit together" every morning. Another example is a wife whose accepting attitude combined with gentle challenges enabled her husband to conquer his fears about living a normal life with IBD.

All participants in this type of interaction seemed to look at IBD in the same way: IBD creates problems that must be dealt with, and responsibility for the creation of the problem is not important in the situation. Both parties participate in their own ways in the management of the problem, however.

The second type of interaction involved another person wanting the ill person to behave in a particular way in order to avoid illness. For example, many respondents said that their spouses wanted them to change their diets, decrease their stressful activities or get more rest. One respondent said that her friends got more vocal about her "partying" when they saw how sick she could get as a result. Respondents in these situations tended to resist the desired change, giving reasons such as necessity to go on working hard, or not believing that such change would make a difference in their condition.

The third type of interaction involved a search for and/or suggestions for a quicker solution to the problem by the "other" in the situation. One respondent described his "well meaning friends":

> "They seem to be real puzzled about this "no cure' thing. It just does not sink into their heads that there is not cure for it. [They say:] 'Can't some doctor do something for it? Maybe you ought to look into this cure I read in the paper...'
>
> "They read about the thousands of diseases in the world and 99% of them are, in some way or another, curable. That's why they have a hard time. 'Are you sure there's no cure?' 'Nope, there is no cure.' I don't know why they refuse to believe there is no cure. The only way to understand it is to go through it. I say to myself 'Well, the reason you [the others] don't understand it is because you don't have it. And you don't have something wrong with you for which there is no cure.' That's very frustrating, you know."

Another respondent reflected this same feeling.

> "People want there to be an easy way out. Like my sister thinks that if I was put on a vegetarian diet, I would never have any more problems. I just shake my head and say, 'You don't understand.'"

Health Care Professionals

As with relationships with family and friends, attributions do not seem to have much surface impact on relationships with physicians. Most respondents stated that beliefs about the cause and course of IBD had little effect on their relationships with their doctors. Many subjects (12, 70.6%) remarked on the openness and trust they felt in their relationships with their current gastroenterologists. Even in three cases where the physician's perceived attributions for cause were different than the subject's, comments by the subjects indicated that differences in attribution did not interfere with the relationship.

Some subjects reported past experiences with physicians who believed they should see psychiatrists, or that IBD had an emotional origin. They were offended by these apparent physician attributions. Another subject reported that when he was diagnosed with IBD at age 16, the gastroenterologist told him that he must remember that, except for the IBD, he was "completely normal." He felt very reassured by this perspective.

It must be noted that subjects named many factors as important in physician-patient relationships. Among these factors were physician characteristics including openness, knowledgeableness, and perceived lack of judgemental attitude by the physician. Another very important factor was the perception that the doctor got results in treating the illness.

Responsibility

Respondents were asked whom they felt was responsible for the control of this chronic health problem. Only one subject thought IBD was a completely controllable problem. Most subjects (11, 65%) felt that they had either all or the majority of the responsibility for controllable aspects of the disease. Aspects that subjects felt responsible for included: carrying out regimens such as medications, enemas, sitz baths (named by 8 respondents); moderating stress (3 respondents); finding a physician and keeping him informed (2 respondents); and learning about the illness (2 respondents). One respondent said she believed IBD was controllable and it was all up to her to make the decision to go to yoga class or see a psychiatrist to control her nervousness which would bring the disease under control. She stated that "if the disease got bad enough," she would take these measures.

Most also felt that they shared a portion of the responsibilty for control with their physicians. Two felt physicians were important during flareups. Three felt that they themselves generally knew what to do (based on experience or reading) but consulted their physicians for guidance, knowledge or new treatments. Three felt that the physician's role was to present alternatives and it was the patient's responsiblity to make the decisions about therapy.

Two subjects (11.7%) felt that there was nothing they themselves had done or could do to control their illness: that if any control could eventually be achieved it would be done by doctors or scientists in their labs who discovered a cure.

Three subjects (17.7%) stated that fate and luck were also slight factors in the control of IBD. Another felt one could not control one's environment (e.g., job situation) which was a chief causative factor (although he said, one can change one's responses to the environment). Another made a similar comment about the interpersonal environment one lives in.

Related to the concept of responsibility is blame, either by self or by others. Subjects were asked whether they blamed themselves for having IBD. Most subjects (82.3%) answered that no, they did not blame themselves, and had some rationale for this. These rationales included a belief that external circumstances (stressors) caused the IBD or that they could not have helped their response. As one respondent said, "it was natural for me to react the way I did [with tension and nervousness] -- all the other kids had the same problems." Another could not see anything she had done to cause it. One respondent summed up her attitude as, "It was not something I had control over -- this is <u>not</u> my choice."

One subject said he occasionally blamed himself. He thought his IBD had been caused by physical and emotional stress and stated "sometimes... if I'd done things different, made other choices," he might have avoided IBD. Two blamed themselves for aggravating their own stress and not taking time to relax, which they felt worsened their symptoms.

When asked if others blamed them for having IBD, fifteen subjects (88.2%) responded "no". Some were surprised at the thought as reflected by the comment: "Why would anyone blame me?" Another said, "People see illness as something you just get." It is interesting to note that this latter subject herself believed that IBD was a part of God's lessons for her. She also said later that people would blame her for aggravating her symptoms if she did this by acts under her own control (e.g. drinking champagne). One subject said that people do not blame her for having IBD, but feels that they would blame her if she had bulemia (which, she says, people sometimes think, due to her current state of underweight).

The two respondents who answered affirmatively had different explanations. One gave a tenative "yes" answer and stated that she sometimes thought her husband thought she aggravated her own stress. The other respondent felt that a holistic doctor who felt emotional conflicts were at the root of IBD was blaming him for this. He said he felt more comfortable with physicians who paid more attention to the actual symptoms he was having.

DISCUSSION

> "Good information is hard to get. Doing something with it is even harder."
>
> Luke Skywalker

V. DISCUSSION

Meaning of Results in Relationship to other Research

The first section of this chapter will discuss the results of the present study in comparison with other attributions research that has been done. The results will be examined with respect to the Weiner model, the Brickman models of helping and coping and other illness attribution research.

The present study reaffirms past research that attribution making does occur in situations such as IBD which involve threat and uncertainty. Sixteen subjects (94%) were able to describe their attributions or their attribution making process (although some were not able to find a causal answer).

The Weiner Model of Attribution

The attributions made by the subjects can be analyzed according to the dimensions of the Weiner model (Wong & Weiner, 1981) using the same method as Lowery, Jacobsen, and Murphy, (1983); and Lowery and Jacobsen, (1985). The dimensions of the Wiener model were: internality/externality ("Did I cause this?"); controllability ("Could I control it?"); and stability ("Is it likely to change?"). These research projects utilized a panel of experts to analyze responses according to these dimensions by giving a rating of one to three on each dimension. In their reports, they described characteristic responses for the categories. Using these descriptions, the results of the present study can be analyzed and compared to the University of Pennsylvania results.

The first study done by Lowery, Jacobsen and Murphy (1983) focused on attributions for the cause of arthritis. The researchers found that the majority of causal explanations fit into three categories. Most subjects gave causes that were external, uncontrollable and stable. The second most frequent set of causes were internal, controllable, and of intermediate stability. The next most frequent were internal, uncontrollable and stable. Table 7 compares Lowery, Jacobsen and Murphy's results with the results of the present study.

Table 7. Comparison of results of two studies, categorized according to the dimensions of Weiner's model of attributions.

Categories of Causes	Lowery, Jacobsen and Murphy, 1983			Lewis, 1986		
	n*	%	Example	n*	%	Example
External Uncontrollable Stable	19	40	"Lord's will" "Old age" "Its going to happen no matter what"	6	46	Extremely stressful events (e.g., poor stock market, family relationships.) Possible virus
Internal Controllable Intermediate Stability	8	17	"Didn't take care of myself" "Abused my body" "Working in all kinds of weather"	3	23	Responses to tension "Being a nervous type person."
Internal Uncontrollable Stable	7	14	Heredity	2	15	Heredity
Intermediate Uncontrollable Intermediate Stability				2	15	Respondents placed themselves in stressful situations (college) which made them vulnerable to developing IBD
Other	13	27	Not described			

* n's do not include subjects from either study who were unable to give a cause.

It can be seen from this table that results from both studies were very similar. It is interesting to note that the causal explanations given by subjects in the present study tended to be more "mechanistic" (that is, more concerned with immediate causal agents) than those of the Pennsylvania subjects. As will be discussed, this tendency toward explanations which give immediate causes may be an artifact of the study design.

The second study (Lowery & Jacobsen, 1985) which emphasized causal explanations for the course of chronic illness (arthritis, diabetes or hypertension) is more difficult to compare to the present study. Subjects in the present study tended to give multiple causal explanations for the course of their illness, while Lowery and Jacobsen elicited a single explanation from each respondent. However, a tally can be made of the number of times certain causes were mentioned in open ended responses as improving or worsening the illness. The reader is cautioned, however, that respondents put different "weights" on each cause: this tally does not indicate the perceived importance of each cause. Table 8 shows the results of this tally.

Table 8. Tally of number of times internal and external factors were mentioned as contributing to control/non control of IBD. Note that subjects often gave multiple factors so totals equal more than study "n".

Locus of Control	Factor Named as Contributing to Control of IBD	# of Times Mentioned	Factor Named as Contributing to Non-Control of IBD	# of Times Mentioned
Internal	Handling Stress	4	Not Handling Stress	3
	Positive attitude	3	Non compliance (diet)	1
	Compliance with diet/exercise	2		
	Working with MD	2		
	TOTAL	11	TOTAL	4
External	Medications Working	4	Medications not working	8
			Stress from external situations	3
	TOTAL	4	TOTAL	11

As in the Pennsylvania study, success tended to be attributed internally, while failure is attributed externally. It is interesting to note that in neither study did subjects attribute a poor illness outcome to the external factors of God, luck or physicians. This finding reaffirms other attributions studies (Harvey & Weary, 1984).

These open ended findings somewhat conflict with the closed ended responses from those who rated themselves as not doing well. Factors which emerged most strongly for not doing well (see Table 6) were not trying hard enough, not doing what I should to manage the illness, frame of mind, the disease being hard to control, others not helping and drugs not working. The first three factors are generally seen as internally controlled: thus it would seem that these subjects do attribute failure internally. Extreme caution must be used in interpreting these results, however, due to the wording of the questions (See Limitations section) and the scant sample size (n=5).

Relationship Effects and the Brickman Model

The findings regarding interactions surrounding illness attributions were interesting in light of Brickman's helping models (1983). The following subsections will relate Brickman's models to the three identified interaction patters with significant others, and to the findings regarding physician interactions.

Significant Others

The first interaction pattern was an action oriented, non-causal approach which skirts the issue of responsibility and instead focuses on problem solution. In this interaction pattern, attributions were a non-issue. It would be safe to say that persons with IBD are not blamed in this type of interaction, since blame or responsibility is not seen as relevant to the situation. It is implied that both parties cooperate (or at least not interfere) with executing care measures. It is possible that attributions have been previously examined and agreement reached either explicitly or implicitly.

In the second interaction pattern, others desired the ill person to behave in certain ways in order to increase health and thus move toward solving the problem. In this situation, it is more clear that the ill person is expected to take responsibility for the problem solution. Since the ill person was generally not blamed for creating the problem, but was seen by others as having some responsiblity for it's solution, Brickman's compensatory model would seem to be the one used by significant others in this situation. As noted, subjects sometimes resisted making changes toward problem solution. This does not necessarily mean that the person does not feel he or she has responsibility for his or her health, merely that he or she is not willing to act in ways that would increase their chances at health.

The third type of interaction, where others were unable to accept the chronicity and incurability of the illness, seemed to imply that these others felt that doctors should come up with the solution to the problem. There is frustration for these subjects, but it does not seem to come from a clash of helping models. It may be that these others are reacting to feelings of helplessness and a wish that they could do something for the ill person. Sontag describes our present times as "an era in which medicine's central premise is that all diseases can be cured" (1977, p.5). The comments of the respondents reflect their frustrating position: they have painfully learned that this premise is unfounded and must face other's pressure resulting from naivety.

Physicians

The fact that subjects were generally not sure about their physician's beliefs about the causes of IBD has several explanations. First, could be explanations similar to lack of knowledge of significant others attributions. Second, it could be that since the etiology of IBD is unknown to science the physicians simply did not reflect any attributional beliefs to their patients. Third, the physician-patient interactions may have been chiefly centered on symptoms, problems, and therapy thus avoiding issues of causation. These latter two explanations imply a more objective physician view of illness, and a traditional medical model where patients are not responsible for their illness.

Subjects reported that they had a large proportion of responsiblity in controlling or managing their IBD and that their physicians allowed them this responsibility and control. Thus, it would seem that agreement on responsibility for problem solution was reached and that both parties are using a compensatory model (helpee is not responsible for the problem but is responsible for the solution). This has aided in creating smooth cooperative relationships.

The subject who felt blamed by the holistic physician may have been experiencing a clash in helping models. He felt the physician was holding him responsibile for his IBD (possibly a moral model of the patient was also responsible for solving his problems) and was more comfortable with the traditional medical model where the patient was not responsible for the illness.

Attribution in Illness Situations

This section will compare the results of various aspects of the present study with results obtained by other illness attributions research.

Meanings and Mechanisms

Other studies (Lowery, Jacobsen & Murphy, 1983; Lowery & Jacobsen, 1985; Bulman & Wortman, 1977; Koslowsky et al. 1978; Witenberg et al, 1983) have created nominal categories to describe attributions in illness situations. Most of these sets of categories combine mechanistic and meanings explanations. The present study found that persons tend to separate explanations for meanings from explanations of cause, or "mechanism". This finding backs Taussig's assertion that people look for subjective and objective meaning in illness (1980). The fact that subjects tended to respond by naming possible causal agents also gives some support to Taussig's claim that illness has beome objectified (i.e., that subjective meanings are discounted) by Western medicine.

This finding may be partially due to the wording of the interview questions. Other studies have asked subjects if they have asked themselves "Why me?". This question may evoke more meaning-related responses than the question used in the present study: "Do you have any beliefs as to what caused your IBD?"

Stress as a Causal Explanation

In spite of what the medical literature says about stress and IBD etiology, it is interesting that stress emerged as a strongly perceived as a causal factor in the present study. It seems that many people associated the development of IBD with a stressful period in their lives. This association could be the result of retrospection and a need to make sense out of an unexpected event. Or, as Sontag (1977) would suggest, persons might be looking for a feeling of control of a situation through their attributions. It could be that these lay persons are ahead of medical research in their intuitive understanding of the interaction of stress and illness. Perhaps the field of immunology will reveal ways in which the body becomes prone to illness during times of stress (e.g., by changes in the T-cell helper-supressor ratio).

Taylor, Lichtman and Wood (1984) in their study of breast cancer obtained results to open ended questions that pertained mainly to mechanistic causes of illness. It is interesting to note that this study is the only other illness attributions study in which respondents named "stress" as a major cause of their illness.

The "I don't know" Response

Subjects in other illness attribution studies (Lowery, Jacobsen & Murphy, 1983; Lowery & Jacobsen, 1985; Bulman & Wortman, 1977; Koslowsky et al., 1978; Witenberg et al., 1983; Taylor, Lichtman & Wood, 1984) gave "don't know" responses in 5-22% of cases. This study obtained a 23.6% "don't know" rate (in the open ended interview). This rather high rate may be a factor of the small sample size or could be related to the nature of IBD. Since the medical causes of IBD are unknown, with few good leads discovered as yet, people with IBD may be less likely than people with other illnesses to have a firm idea of the cause.

It is also interesting to compare the results for the "no reason" question from the Lowery and Jacobsen (1985) study with the results of the present study. In their study, 27% of subjects agreed that there was no real reason for their illness. The present study showed 70.6% agreement with this statement (see Table 4).

The conclusions of Witenberg et al. (1983) and Lowery and Jacobsen (1985) that persons without a causal explanation for their health problem or who feel that there is no real reason for them having the problem tend to be "patients in trouble" is very relevant to this study. With such high rates of these responses in the present study, one must ask whether persons with IBD have more difficulty. Is this finding an artifact of the sample size? Is this response adaptive in any way for people with IBD? Could it be that these patients have been labelled as having psychological problems and are reacting against the label? It would seem that these subjects who were troubled by the lack of a causal explanation might be those that Lowery and Jacobsen identified as patients at risk.

Attributional Stances of Others

In light of the finding that subjects were unsure of others causal explanations it is interesting to note that two other studies have shown that the attributions are made by a large majority of significant others (Taylor, Lichtman, & Wood, 1984; Rudy, 1980). In two cases where others attributions were directly obtained by serendipity, it was seen that others made attributions for IBD. Thus, it would seem that although attributions might be made by significant others, the attributions are not well communicated among these subjects and their significant others.

There are several possible explanations for this occurrence. It could be that attributions are implicit in situations and are not usually explicitly discussed. Also, these issues may be difficult to discuss since attributing cause to certain factors might easily be taken as blaming, which may explain one subject's reluctance to discuss her father's attributions. Frustration or conflict may result when others feel that the ill person is not taking as much responsibility as he or she could in improving their condition. Failure of illness control mechanisms may also result in blaming the ill persons since there might be no obvious cause of the failure. Another explanation is that agreement or lack of focus on attributional issues provides a more action oriented cooperative approach to the problems of IBD.

Limitations

Generalizability

Three factors related to sampling procedures limit the external validity of this study. The first limitation is the fact that the population from which the sample was drawn may be a subpopulation which is different from the whole population of persons with IBD. The study subjects were patients being seen by gastroenterologists in a leading medical center. Many IBD patients get medical care from general practitioners, internists, proctologists or other medical personnel. Others may have "quit" the traditional medical care system completely and seek care from alternative healers.

The type of health care practitioner being seen by the subjects in this study may affect the results in two ways. It can be seen in the data that levels of satisfaction and patient involvement differ from care situation to care situation. Patients in the setting sampled by this study may be more or less satisfied and/or involved than patients in other health care settings. Moreover, attributions which patients make are probably somewhat related to information they receive from their physicians. Therefore, physician attitudes and knowledge about IBD are likely to have an impact on patient beliefs about IBD. If the population sampled in this study is under the care of more knowledgeable physicians, it is possibly a more knowledgeable population.

The second limitation involves the sampling protocol. A non-randomized convenience sample was used. It is possible that the most cooperative, most articulate patients were selected by the nurse practitioner and secretaries. The fact that no refusals occurred may indicate that a "pre-selection " process may have taken place. The researcher sought to avoid this by discussing the possibility with those assisting in recruiting subjects and by going over the upcoming appointments with secretaries and attempting to choose subjects on the basis of demographic variables. This was not always possible with the nurse practitioner. She occasionally informed the researcher that she "had a real nice potential subject who will probably tell a lot."

Thirdly, generalizability is limited by the small size of the sample. A larger sample would decrease the chances of error and increase the chances of covering all attributional explanations given by IBD patients. A larger sample would facilitate the use of statistics in quantitatively analyzing the data.

Internal Validity

Certain threats to the study's internal validity exist because of problems with the study instrument. As previously mentioned, the wording of the open-ended questionnaire may have tended to elicit responses more related to the mechanisms than the meanings of IBD. It would appear that the tool was not sensitive enough to draw out the deeper meanings of illness. Stress, a causative factor which emerged as very important on open ended questioning was not included in the closed ended ratings section of the interview. As well, the CEQ's related to "doing well" and "not doing well" but did not translate well from one situation to the other.

Alterations to the questionnaire would first be to add a question relating to "Why me?" This could gather more information on the meanings of illness. Secondly, the CEQ's could be amended to include stress as a factor in the etiology and course of IBD. It would be important to differentiate between external and internal views of stress as cause. Questions could be worded, "I developed Crohn's/ulcerative colitis because of stressful circumstances" and "...because of nervous tension in reaction to stress." Thirdly, respondents should be asked standardized questions in order to eliminate the "doing well/not doing well" problem. Questions could be worded either, "My Crohn's/UC improves because of . . ." or "My Crohn's/UC deteriorates because of...". Possibly, respondents could be asked both sets of questions in order to obtain differences in attributions for "success" and "failure" illness outcomes. This would involve a long series of CEQ's, however.

A Methodological Limitation

The outside imposition of an interpretation of the internality/externality of responses is another threat to the validity of the study. For example, "having a good doctor" may be interpreted as an external cause for the course of the illness. One subject in this study, however, felt that it was the patient's responsiblity to "find and cooperate with a good doctor."

One solution to this problem is to ask the subjects to give their own interpretation of the internal or external control of a cause (see

Russell, 1982). This was attempted in the piloting of the closed ended questionnaire but was found to be unwieldy and confusing to the respondents. Further work should be done on developing a tool that avoids this problem.

Directions for Future Research

Information uncovered in this study gives indications for development of future research questions. One direction for development is the role of the perceptions of stress in illness behavior. Since stress is becoming a pervasive concept in looking at health today, it seems important that we know as much as possible about the layman's understandings of stress as a causative and/or complicating factor in illness. There seems to be much confusion over what stress is, and the individual's role in creating and handling stress. The relationship between stress as a causal factor in illness and self-blame or guilt should be investigated. Research on attributions and coping should continue. As other research has pointed out, persons who do not have beliefs about the cause of their illness generally do not cope as well. This study found this to be partially true -- some respondents reported extreme frustration and difficulty because of the unknown causes of IBD. Research could be done to identify those at risk for these problems. A line of questioning that might be fruitful is: Does the lack of a causal explanation cause helplessness and hopelessness or does it merely accompany this constellation of feelings? Do attributions express personality traits?

If one assumes that persons can feel some control over illness events through their attributions, then it is important to examine the effects of this perceived control. Does this make a difference in coping? illness recovery? affect? No research has been done related to these questions in IBD

The role of attitude was mentioned by some subjects. It would be interesting to know if any attitudes were related to severity of illness and to successful coping. For example, do persons with a positive attitude make better recoveries from IBD?

This study turned up some indications that attribution may be a process with different phases. A long range study might look at attribution making and its effects at different phases of the illness (e.g., initial diagnosis, flares, remissions, tests, surgery).

A few factors related to successful physician-IBD patient relationships were identified. Future research could explore these factors in more depth.

Clinical Implications

Information learned from the subjects in this study can be applied to practice and thus be used to help others in the same situations. The findings have implications for client-professional relationships as well as for interventions which may aid coping with IBD as outlined below.

Coping with Feelings Aroused by Attribution

Subjects in the study have discussed feelings they have experienced related to attributions in the course of their IBD. Some have also shared methods they have learned to cope with these feelings.

The feeling that "there must be a reason" for this event can be important especially in early phases of the illness. For some people, that reason is that the illness is punishment. This belief can add much guilt to an already painful situation. Clients can be encouraged to ventilate these feelings or to talk to others with similar experiences (e.g, through the National Foundation for Ileitis and Colitis). Many people have discovered through time that they are no different from other people who do not have IBD, and do not "deserve" what they've got. Sharing this realization may help others going through the same process. Suggesting that clients read books such as Kushner's, When Bad things Happen to Good People, or Sontag's, Illness as Metaphor, may also be helpful in assisting people to examine different perspectives on the meaning of illness.

Clients should be taught to be sensitive to what aggravates their condition and be encouraged to make healthy lifestyle choices. However, the unpredictability and unexplainability of IBD is something that persons with IBD and their families should be prepared for in order to avoid blaming when symptoms flare up. As one subject said, "be prepared to accept that the illness may pick its own time to flare up." A positive attitude helps, but is not always possible to maintain: "when you don't have it, you don't. Just try and ride it out." A realistic acceptance of self through the ups and downs of IBD is vital in coping with the illness.

Relationship Problems

Sharing insights into relationships gained in this study may be helpful to persons experiencing problems with others surrounding IBD. For example, other people may not accept the current limited state of medical knowledge about IBD and seek a quick solution for the ill person's problem. This may be merely frustrating for some who have learned through experience that there are not, as yet, any easy answers. For others who desperately seek a cure, the continual discouragement encountered by cure-seeking can be devastating. An understanding attitude as well as client and public education may help to alleviate some of this problem. Professional education is also important in this regard so that we can assure clients that as much as possible is being done for them.

The subjects in this study have told us that attributions have an impact on relationships between health care professionals and their clients. When professionals discuss such concepts as "stress" with their clients, they must be sensitive to different meanings people give this concept. The client's feelings regarding the meanings he applies to stress and his own role in the illness should be assessed. Professionals must be aware that some people feel responsible or blamed if it is implied that stress or emotional conflict is the cause or a contributing factor in IBD. The difference between being able to make changes that improve health and being responsible for illness must be made clear to clients.

Health care professionals should examine their own "just world" theories. Does the professional's need to see justice in the world cause him or her to believe subconsciously that some people deserve to have IBD? Beliefs such as the existence of an "IBD personality" may be related to just world theories.

SUMMARY

VI. SUMMARY

The first objective of this study was to learn about the beliefs of people with IBD's concerning why they have the illness. It was learned that persons tend to give separate explanations for the mechanisms that cause the illness (e.g., virus, stress) and for the meanings that IBD has in their lives (e.g., lesson from God, Karma).

The mechanisms explanations could be categorized according to their content. 59% of subjects believed stress was the cause. These persons defined stress as either a situation or their reaction to events. 18% termed themselves "scientifically inclined" and gave causes which they felt reflected medical literature. 23% did not know what caused the IBD and for some in this group, not knowing the cause was a weighty problem. It is possible these are "at risk" patients (Lowery & Jacobsen, 1985). For the others in this group, the cause was a moot point, and they were more concerned with dealing with present problems caused by the illness.

Related to meanings explanations, 17.7% felt God had a larger plan in mind when He allowed them to develop IBD. Another 17.7% said that although they believed in God, God did not cause them to be sick. A theme which emerged in the interview but most strongly on closed ended questioning was that "it just happens" (70.6% rated this as somewhat or very important.)

People do not tend to blame themselves for having IBD. Some, (17.7%) however, reported past feelings (now resolved) that IBD was a punishment for some transgression. Some others felt that if they took control of the stress in their lives, their illness would improve. These are possible sources of self-blame, or may reflect a need for perceived control (see Bulman and Wortman, 1977).

Regarding the second objective of the study, to learn what factors people believe influence the course of IBD, 94% of subjects felt stress was a factor in the course of the illness. Some felt more control over this stress than others. Other factors included the efficacy or inefficacy of medications, self care practices such as diet and exercise, God's influence, and assistance from physicians. The unpredictability of exacerbations was also a strong theme in the interviews. Thus, the causes for the occurrence of symptoms are perceived to be different than the original causes of the illness. It appears that people feel some control over the course of the illness, a finding similar to other illness attribution studies. However, they are often baffled and frustrated when the illness progresses despite their control measures.

The third and fourth objectives of the study were to discover the ill person's perceptions of the attributional stances of significant others and health care professionals and how the stances of these others affect their relationship with them. The data showed that subjects were generally vague about the attributions of their families and friends and several possible explanations for this finding were given. A few patterns of interaction were identified: action oriented, where attributions were not an issue; urging the person with IBD to be more responsible; and search by others for a quick solution. The pattern of urging the ill person to be more responsible gave some support to Brickman's models of helping (1982).

Some subjects were able to be specific about their physician's IBD attributions, others were not. The sample generally reported cooperative relationships with their present physicians. Although this finding could be an due to the sample studied, it seems to reflect a good fit between the helping models of both parties. Although attributions are of some importance in physician patient relationships, whether or not attributions are the most important factor in relationships is open to further research.

REFERENCES

REFERENCES

Alexander, C.S. (1980). Responsible victim: Nurses perceptions of victims of rape. Journal of Health and Social Behavior, 21, 22-33.

Alpers, D.H. (1982). Psychiatric illness and inflammatory bowel disease. In Inflammatory Bowel Disease. D. Rachmilewitz (ed) Boston: Martinus Nijhoff Publishers.

Angell, M. (1985). Disease as a reflection of the psyche. New England Journal of Medicine, 312:1570-1572.

Baider, L. & Sarell, M. (1983). Perceptions and causal attribu-tions of Israeli women with breast cancer concerning their illness; The effects of ethnicity and religiosity. Psychotherapy and Psychosomatics, 39, 136-143.

Brickman, P., Rabinowitz, V.C., Karuza, J., Coates, D. Cohn, E., & Kidder, L. (1982). Models of helping and coping. American Psychologist, 37, 368-384.

Bulman, R.J., & Wortman, C.B. (1977). Attributions of blame and coping in the "Real World": Severe accident victims react to their lot. Journal of Personality and Social Psychology, 35, 351-363.

Cousins, N. (1979). Anatomy of an Illness as Perceived by the Patient. New York:Grace W.W. Norton.

Glaser, B. G., & Strauss, A. L. (1967). The discovery of grounded theory: Strategies for qualitative research. New York: Aldine Publishing Co.

Gruman, J. C. and Sloan, R. P. (1983). Disease as justice: Perceptions of the victims of physical illness. Basic and Applied Social Psychology, 4,39-46.

Harvey, J.H., & Weary, G. (1984). Current issues in attribution theory and research. Annual Review of Psychology, 35, 427-459.

Hawkins, C. (1983). Psychological problems and the management of patients with inflammatory bowel disease. In Inflammatory Bowel Diseases. R.N. Allen (ed.) London: Churchill, Livingstone.

Heitkemper, M. & Martin, D. (1986). Infectious and inflammatory gastrointestinal disorders. In Medical-Surgical Nursing: Pathophysiological Concepts. Patrick, M.L. et al (eds.) Philadelphia. J.B. Lippincott.

Jampolsky, G. G. (1979) Love is Letting Go of Fear. Millbrae, CA: Celestial Arts.

Janowitz, H.D. (1985) Research frontiers in IBD. in Inflammatory Bowel Disease: Experience and Controversy. B. I. Korelitz and N. Sohn (eds). New York: Grune & Stratton.

Joachim, G. & Milne, B. (1985). The effects of inflammatory bowel disease on lifestyle. The Canadian Nurse, 81(10);38,40.

Kassenbaum, G. G. & Baumann, B. O. (1965). Dimensions of the sick role in chronic illness. Journal of Health and Human Behavior, 6, 16-27.

Korelitz, B.I. (1985). General Observations on IBD. in Inflammatory Bowel Disease: Experience and Controversy. B. I. Korelitz and N. Sohn (eds). New York: Grune & Stratton.

Koslowsky, M., Croog, S. H., & LaVoie, L. (1978). Perceptions of the etiology of illness: Causal attributions in a heart patient population. Perceptual and Motor Skills, 47, 475-485.

Kushner, Harold S. (1981). When Bad Things Happen to Good People. New York: Schocken Books.

Lerner, M. J. (1971). Observers evaluation of a victim: Justice, guilt and veridical perception. Journal of Personality and Social Psychology, 20;127-135.

Lichtman, R. B., Taylor, S. E., & Wood, J. V. (1985). Research on the chronically ill: Conceptual and methodological perspectives. In J. Singer & A. Baum (eds.) Advances in Environmental Psychology, 5;43-74.

Lowery, B. J., Jacobsen, B. S., & Murphy, B. B. (1983). An exploratory investigation of causal thinking of arthritics. Nursing Research, 32, 157-162.

Lowery, B. J., & Jacobsen, B. S. (1985). Attributional analysis of chronic illness outcomes. Nursing Research, 34, 82-88.

Mendeloff, A. I. (1985) Changes in the epidemiology of IBD: Implications for the Future. in Inflammatory Bowel Disease: Experience and Controversy. B. I. Korelitz and N. Sohn (eds). New York:Grune & Stratton.

Meyers, S. A. (1984). Overview of inflammatory bowel disease. Nursing Clinics of North America, 19,3-10.

Paterson, I.G., & Zderad, L.T. (1976). Humanistic Nursing. New York: J. Wiley & Sons.

Patton, M. Q., (1980). Qualitative Evaluation Methods. Ch.7 Qualitative interviewing. Beverly Hills: Sage Pub.

Polit, D. F. & Hungler, B. P. (1983) Nursing Research: Principles and Methods. (2nd ed.). Philadelphia:J.B. Lippincott.

Rief, L. (1975). Ulcerative colitis: Strategies for managing life. In Chronic illness and the quality of life. by Strauss, A. L. & Glaser, B. G., St. Louis: C. V. Mosby Co.

Rief, L. (1985). Personal Communication, September.

Rudy, E. B. (1980). Patient's and spouse's causal explanations for myocardial infarction. Nursing Research, 29; 352-356.

Russell, D. (1982). The causal dimension scale: A measure of how individuals perceive causes. Journal of Personality and Social Psychology, 42;1137-1145.

Schatzman, L., & Strauss, A.L. (1973). Field Research: Strategies for a natural sociology. Englewood Cliffs, N.J.:Prentice Hall, Inc.

Segall, A. (1976). The sick role concept: Understanding illness behavior. Journal of Health and Social Behavior, 17, 163-170.

Sontag, S. (1978). Illness as Metaphor. New York: Vintage Books.

Taussig, M. T. (1980). Reification and the consciousness of the patient. Social Science and Medicine 148;3-13.

Taylor, S. E., Lichtman, R. R., & Wood, J. V. (1984). Attributions beliefs about control and adjustment to breast cancer. _Journal of Personality and Social Psychology_, _46_, 489-502.

Witenberg, S. J., Blanchard, E. B., Suls, J., Tenned, H., McCoy, G., & McGoldrick, M. D. (1983). Perceptions of control and causality as predictors of compliance and coping in hemodialysis. _Basic and Applied Social Psychology_, _4_, 319- 336.

Wilson, H.S. (1985). _Research in Nursing_. Menlo Park, CA: Addison Wesley.

Wong, P. T. P., & Weiner, B. (1981). When people ask "Why" questions; and the heuristics of attributional search. _Journal of Personality and Social Psychology_, _40_, 650-663.

APPENDICES

APPENDIX A

Interview Guide
Demographic Information Sheet

INTERVIEW GUIDE

1. **Most people who have Crohn's or ulcerative colitis (UC) develop some hunches as to how they got the disease. I wonder if you would mind sharing your beliefs with me if you have any?**

   Is it important to you that a cause be identified?

2. **Do others, like your family or friends, have beliefs about the cause of Crohn's/UC?**

   What are their ideas/hunches?

   Do you agree with their ideas?

   What effect does this have on your relationship with that person?

   Do your health care givers (doctors and nurss) have ideas similar to or different from yours? Could you explain?

   How does this affect your relationship with them?

   Are there some professionals that are different than others?

3. **How are you doing with your Chrohn's/UC? (How is your condition?)**

   Do you ever ask yourself why your condition is improving/deteriorating/stable? Could you share some of your hunches with me?

   Do you ever ask yourself why your treatment is working or not?

4. **Do others, like your family or friends, have ideas or hunches? about the why your Crohn's/UC is doing well or not?**

   What are their beliefs/hunches?

   Do you agree with their beliefs?

   What effect does this have on your relationship with that person?

   Do you think your health care givers have beliefs about why your treatment is working or not?

   How does this affect your relationship with them?

5. **Would you say you ever blame yourself for the disease? Do others ever blame you?**

6. **Who has ultimate reponsibility for the control of this chronic health problem?**

   Who should have ultimate responsibilty for this control?

   Who can control it? (e.g., you, physician, God, chance)

7. **Anything else you'd like to talk about?**

8. **So, you think you got Crohn's/UC because of ____. On a scale of one to 4 (SHOW CARD) we might rate that then as an important cause in your case.**

Now, other people have answered the same questions and some answered differently. I would like you to listen to the causes they gave and rate on this same scale of one to 4, how much each of the following causes applies in your case.

Not A Cause	Not Much Of A Cause	Somewhat Important Cause	Very Important Cause

a. Some people say, "I got Crohn's/UC because I have NEVER taken very good care of my body." Is that a cause in your case?

1 2 3 4

b. Some people say, "I got Crohn's/UC because I wasn't taking very good care of my body at the time I contracted the disease." Is that a cause in your case?

1 2 3 4

c. Some people say, "I got Crohn's/UC because of my personality, (.e.g., I push myself) etc." Is that a cause in your case?"

1 2 3 4

d. Some people say, "I got Crohn's/UC because it runs in my family." Is that a cause in your case?

1 2 3 4

e. Some people say, "I got Crohn's/UC because of bad habits such as smoking, drinking, overeating." Is that a cause in your case?

1 2 3 4

f. Some people say, "I got Crohn's/UC because I was unlucky." Is that a cause in your case?

1 2 3 4

g. Some people say, "I got Crohn's/UC because of God." Is that a cause in your case?

1 2 3 4

h. Some people say, "I got Crohn's/UC because of my frame of mind (emotions or moods) at the time I contracted the disease." Is that a cause in your case?

1 2 3 4

i. Some people say, "I got Crohn's/UC because it a difficult disease to avoid." Is that a cause in your case?

1 2 3 4

j. Some people say, "It's someone else's fault that I got Crohn's/UC." Is that a cause in your case?

1 2 3 4

If Yes, Who? How come?

k. Some people say "There is no reason for Crohn's/UC happening to them. It's just something that happens." Is this true in your case?

1 2 3 4

9. Remember when I asked you about your beliefs as to why your condition was improving, deteriorating or stable? Other people have answered this question too, and again they have given different answers. I'd like you to listen again to the reasons they gave and rate how much of a cause it is in your case.

a. Some people say I'm doing well with my Crohn's/UC because I try hard to be healthy in every way. I really pay attention to everything about my health. Is that so in your case?

1 2 3 4

b. Some people say, "I'm doing well with my Crohn's/UC because I do what I should to manage the illness." Is that so in your case?

1 2 3 4

c. Some people say, "I'm doing well with my Crohn's/UC because it's a fairly easy illness to control." Is that so in your case?"

1 2 3 4

d. Some people say, "I'm doing well with my Crohn's/UC because I get good advice from my doctor." Is that so in your case?

1 2 3 4

e. Some people say, "I'm doing well with my Crohn's/UC because I have the type of body that responds well to treatment." Is that so in your case?

1 2 3 4

f. Some people say, "I'm doing well with my Crohn's/UC because of other people helping." Is that so in your case?

1 2 3 4

Who? How?

g. Some people say, "It's because of God that I'm doing well with my Crohn's/UC." Is that so in your case?

1 2 3 4

h. Some people say, "I'm doing well with my Crohn's/UC because of my frame of mind (emotions or moods)." Is that so in your case?

1 2 3 4

i. Some people say, "I'm doing well with my Crohn's/UC because the drugs are making me better." Is that so in your case?

1 2 3 4

j. Some people say, "I'm doing well with my Crohn's/UC because I am lucky." Is that so in your case?

1 2 3 4

k. Some people that there is no real reason why they are doing well. It's just happening. Is this true in your case?

1 2 3 4

_________ Identifier

DEMOGRAPHIC DATA

Age__________

Sex__________

Lives with Whom?____________________

Education ____________________

Occupation ____________________

CHART DATA:

Diagnosis ____________________

When diagnosed? ____________________

Time between presentation and diagnosis? ________________

Frequency of clinic visits?________________

Treatment____

____

____

APPENDIX B

Information Sheet
Consent Form
Subject Debriefing Sheet

CONSENT TO BE A RESEARCH SUBJECT

My name is Cathy Lewis. I am a nurse and am working on my master's thesis. My research interest is chronic illness and my thesis will be on the beliefs held by people who have Crohn's Disease or ulcerative colitis. It is my hope that if nurses have more information, they will be better able to help their patients.

I would like to invite you to participate in my study. To do so will mean an interview of about one hour. Ideally it will be in a quiet place in the clinic before or after an appointment. The interview will be about your beliefs and there might be questions that could make you uncomfortable. If so, please feel free to skip those questions.

An hour interview might be difficult so if, at any time, you wish to take a break, please let me know and we can stop.

The information from this interview is anonymous. Your name or any identifying details will not appear anywhere in my notes or in the report. Tapes will be stored in my files and erased at the completion of the study.

If you have any questions about participation or wish further information later, please feel free to contact me about the study through the School of Nursing at 476-4280.

Of course, being in this or any study is voluntary. ;I would appreciate your participation but you should feel free to refuse or to withdraw at any point should you wish to do so. Your participation in this study will not affect your care at UCSF.

****

I have read this consent form and agree to be interviewed.

Signature

Date

For YOUR information...

I've asked you a lot of questions about your beliefs about the causes of Crohn's/UC. I would like to finish off our talk by giving you back some information. It is important that you know or remember that scientists are still not sure what causes Crohn's/UC. The causes are obscure and seem very complex. It may be that many factors act together to make a person vulnerable to inflammatory bowel disease. Exposure to environmental agents or infectious agents such as virus or bacteria and the possibility of Crohn's/UC being an "auto-immune" disease are causes which are being investigated. None of these causes have been established with any certainty.

Stress is something that many lay people suspect as causing Crohn's/UC, but it has never been definitely shown as a cause. Stress *can* cause flare-ups to be more severe, however. We do know that the disease itself causes stress and this added stress causes problems of its own. Sometimes its hard to tell if stress is a cause or an effect of illness.

Hopefully, we will continue to gain more and more knowledge about the causes of inflammatory bowel disease. You have been very helpful in helping me learn how people deal with these unknowns. Your participation in this study will help nurses learn about what it's like to have Crohn's/UC, and about what the illness means in a person's life. With better knowledge, we will be able to provide more understanding care.

Thank you very much.