VARIABLES ASSOCIATED WITH DIAGNOSTIC ERRORS 
OR DEFERRAL IN INDIVIDUALS 
WITH CHRONIC ILLNESSES

A Thesis

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by 
Lisa Lynn Conant, B. A.

*** *** ***

The Ohio State University

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Master's Examination Committee: 
Nancy Betz 
Samuel Osipow 
Pamela Highlen 

Approved by 

Adviser 
Department of Psychology
To My Parents
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VITA

May 7, 1969 . . . . . . . . . . . . Born - Dallas, Texas

1988 . . . . . . . . . . . . . . . . B.A. in Anthropology, The Ohio State University, Columbus, Ohio

1989 . . . . . . . . . . . . . . . . B.A. in Psychology, The Ohio State University, Columbus, Ohio

1989-1990 . . . . . . . . . . . . University Fellow, The Ohio State University, Columbus, Ohio

1990-Present . . . . . . . . . . Graduate Administrative Associate, The Ohio State University, Columbus, Ohio

FIELD OF STUDY

Major Field: Psychology

Studies in Counseling Psychology
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CHAPTER I

INTRODUCTION

When people become ill, they seek a physician who can determine what is wrong and how to treat the problem. Because the physician has been sanctioned by society as well as by some educational institution, patients hold certain expectations with regard to the accuracy of the physician's medical judgment. The patient, who is in a state of uncertainty, tends to trust the physician's assessment of the situation and to accept his or her suggestions regarding how to proceed. Several authors (Poser & Aisen, 1987; Rogers, 1983) have mentioned the necessity of a trusting doctor-patient relationship for the well-being of the patient. However, "the public's assumption that engaging a physician's services means an 'implied contract to diagnose properly and early' is in conflict with reality" (Neumann, 1985, p. 700). Medical science is inexact, and the medical diagnosis is not always correct. Many illnesses such as lupus and multiple sclerosis are extremely difficult to diagnose. Numerous individuals with these illnesses are either misdiagnosed as having an illness other than the one they actually have, told that their symptoms have no organic basis

- 1 -
(psychophysical misdiagnosis), or given no diagnosis for a prolonged period of time (deferred diagnosis).

Although a few researchers (Kassirer & Kopelman, 1989; Kutz, Garb, & Kuritzky, 1983) have investigated the nature and possible origins of diagnostic errors, the impact of diagnostic errors or deferral on the patients has remained essentially unexplored. Consequently, little information is available concerning what types of patient responses are most associated with these errors. However, on the basis of this author's communication with chronically ill individuals, anxiety, self-esteem, and patient satisfaction with physicians will be considered in relation to diagnostic errors or deferral.

Anxiety has frequently been associated with situations of uncertainty. Booth-Butterfield, Booth-Butterfield, and Koester (1988) reported that reduction in uncertainty was associated with a corresponding decrease in tension in groups of individuals. Bramwell and Whall (1986) also reported uncertainty as a source of anxiety for the wives of men who had suffered myocardial infarctions. Furthermore, Schag and Heinrich (1989) examined the amount and severity of anxiety experienced by cancer patients in a variety of medical situations. The situation that provoked significant anxiety in the highest percentage of individuals in this sample was that of waiting for test results. Therefore, one might also expect to see higher
levels of anxiety in the case of an individual who is still waiting for a diagnosis and, thus, in a state of uncertainty.

Anxiety has traditionally been divided into two types: state anxiety and trait anxiety. State anxiety refers to the transient situational experience of apprehension, worry, and autonomic arousal, whereas trait anxiety is considered to be a relatively stable characteristic of the individual (Chaplin, 1984; Spielberger, Gorsuch, Lushene, Vagg, & Jacobs, 1983). Because the anxiety described in the aforementioned studies is dependent on situational factors, it would appear to be the state form of anxiety. However, in cases of prolonged periods of uncertainty, it is possible that the anxiety experienced can become incorporated into the personality and appear as trait rather than state anxiety. In their study of acculturation experiences, Chataway and Berry (1989) concluded that the higher Trait Anxiety scores exhibited by Chinese students may in fact represent situational anxiety. Consequently, because many people must endure extended intervals of time without a diagnosis, diagnostic deferral could be related to heightened levels of trait rather than state anxiety.

Self-esteem involves the individual's evaluation of one's mental image of oneself. Walsh and Walsh (1989) defined self-esteem as people's estimates of their dignity
and worth as humans. Some researchers (Tweed, Shern, & Ciarlo, 1988; Walsh & Walsh, 1989) have reported a relationship between low self-esteem and physical disability. In addition, it seems possible that the stigma of being told that one's symptoms have no physical basis could be associated with a further decrement in self-esteem. In these cases, the patients begin to wonder if they are, indeed, "crazy." Individuals who have been given no diagnosis can also begin to question their own perception of their bodily states and their sanity. Swift (1987) suggested that the identification of individuals with an increased genetic risk of psychiatric disorders can result in injury to those individuals' self-esteem. Thus, the thought that one's symptoms are indicative of psychiatric rather than physical illness might tend to lower an individual's assessment of his or her self-worth and, therefore, his or her self-esteem.

In addition, diagnostic errors could possibly be related to patient satisfaction with physicians. Patient satisfaction involves the patient's personal appraisal of the physician. Consequently, it has a primary component that is based on the realities of the situation as well as a secondary component based on the patient's expectations (Ware, Snyder, Wright, & Davies, 1983). Intuitively, it would make sense for diagnostic errors of all types to be associated with lower levels of patient satisfaction.
Moreover, the lowest levels are expected with individuals who were incorrectly informed that their symptoms had no physical cause. Recommendations for psychiatric referral are often viewed by the patient as a personal injustice. This perception can lead to suspiciousness with regard to the physician's subsequent suggestions (Rogers, 1983).

This study involves the exploration of differences in anxiety, self-esteem, and patient satisfaction with physicians among groups of individuals who received a prompt, accurate diagnosis; those who were originally misdiagnosed as having a physical illness they did not have; those who were initially told that their symptoms had no organic cause; and those who have been given no diagnosis. The majority of the diagnosed participants in this study have either multiple sclerosis or lupus erythematosus. These illnesses were selected because of the diagnostic challenges they present and their consequent high rate of misdiagnosis or diagnostic deferral.

The hypotheses are as follows: (a) Trait and possibly state anxiety would be significantly higher in the group of participants who have no current diagnosis; (b) self-esteem would be significantly lower in the psychophysical misdiagnosis group and the no diagnosis group; (c) self-esteem would be lowest in the psychophysical misdiagnosis group; and (d) patient satisfaction with physicians would
be highest in the prompt, accurate diagnosis group and lowest in the psychophysical misdiagnosis group. If these relationships are supported, they would clearly indicate the necessity for further investigation of the diagnostic process. Rogers (1983) has stated that emotional distress can exacerbate both multiple sclerosis and lupus. Consequently, it is important to determine if emotional distress is associated with diagnostic errors or deferral. Moreover, for counselors working with clients who have experienced diagnostic errors or deferral, the elucidation of these relationships could facilitate the identification of issues that need to be addressed in counseling and the selection of appropriate intervention techniques. These hypothesized relationships could also be useful in recognizing potential problems before they exist, thereby providing the counselor with an opportunity to develop preventive measures.
CHAPTER II
LITERATURE REVIEW

Unfortunately, little research has been conducted concerning diagnostic errors or deferral, particularly with regard to multiple sclerosis or lupus erythematosus. Therefore, much of the literature reviewed in this section is based on informal, clinical observations. Background information on the two illnesses also is presented. Some speculations are discussed, and, where possible, empirical data are used to support these speculations; however, many remain to be substantiated. The information is presented in two sections. The first of these concerns the different types of diagnostic errors and deferral, and the second section pertains to the two chronic illnesses, multiple sclerosis and lupus erythematosus.

Diagnostic Errors and Deferral

Medical Diagnostic Errors. It is known that diagnostic errors do occur. Although some diagnostic errors are inevitable, many are not (Gowers, 1895). Regrettably, the reasons why these avoidable errors occur are still little understood. However, some researchers
have directed their efforts toward developing a better understanding of diagnostic errors in the hopes that this will lead to the discovery of ways to prevent them. Through the analysis of published patient histories along with transcripts of physicians' reasoning processes in response to these histories, Kassirer and Kopelman (1989) identified flaws in cognition throughout the diagnostic process. They reported cognitive errors in the production of diagnostic hypotheses, in the formation of a cognitive representation of the patient's problem, in the collection and processing of data, and in the substantiation of the diagnosis. A few "no-fault" errors, in which the nature of the patient's symptoms or the existence of a plausible alternative made the diagnosis extraordinarily difficult, were also noted. Errors in reasoning were frequently reported to have grave physical and emotional consequences.

Gruver and Freis (1957) also attempted to analyze the causes of diagnostic errors. They examined 64 cases of misdiagnosis as determined by autopsies and identified several possible factors contributing to the mistaken diagnoses. These included the inability to obtain an adequate medical history; failure to perform an indicated procedure; failure to explain a sign, symptom, or abnormal test result; failure to review the entire case occasionally; and a misleading "normal" test result. They concluded that the amendable errors did not appear to
result from a dearth of medical knowledge, but rather the mistakes seemed to be due to inadequacies in medical judgment, thoroughness, and mental alertness on the part of the physician.

Gowers (1895, p. 22) stated that "all diagnosis that rests on reasoning is a matter of probability." Often, a diagnosis is made on the basis of the physician's estimate of the probability that a patient exhibiting a certain set of symptoms has a specific illness. Dawes (1986) noted that people frequently base probability estimates on the extent to which characteristics are representative of certain schemas. Unfortunately, according to Dawes, the accessed schema is not always the most probable one. In representative thinking, schemas are accessed automatically by a characteristic or set of characteristics; however, the prevalence of the object represented by the schema is not. Thus, this type of thinking can lead to manifestly irrational probability estimates and, perhaps, to diagnostic errors.

*Psychophysical Misdiagnosis.* Psychophysical misdiagnosis occurs when a physician tells a patient that the patient's symptoms have no organic basis. This type of diagnostic error can be associated with a faulty reasoning process. Kutz, Garb, and Kuritzky (1983) discussed the factors involved in the incorrect diagnosis of physical
illness as psychiatric disorder. Their study was based solely on retrospective data and had an extremely small sample size, yet it did offer some interesting ideas about the origins of psychophysical misdiagnosis. They examined four cases histories in which peripheral neurological disorders were misdiagnosed as psychiatric disorders. Kutz et al. stated that the reasoning process followed by these physicians led from the initial lack of physical findings to the idea that there must not be a physical illness, ending with the conclusion that the illness must then be psychiatric. One major problem in this reasoning lies in equating the lack of physical findings with the absence of physical illness. The lack of physical findings simply means that there were no abnormal results on the specific tests that were run at certain examination times. This statement is not the same as saying that there is nothing to be found or that there is no physical illness.

Kutz et al. suggested that the physician's emotional reaction to the patient's perplexing condition may also contribute to the occurrence of psychophysical misdiagnosis. In most of these cases, the patient's symptoms are enigmatic and do not conform well to the physician's existing diagnostic schemata. Psychiatric referral allows the physician to alleviate the frustration arising from this incongruence and perhaps to punish the
patient for having these bewildering symptoms. Also, Carmichael (1985) and LeMaistre (1981) both discussed the propensity of some physicians to blame or focus their frustration on their patients rather than accept their own fallibility. Thus, the emotional attributes of the physician can affect the accuracy of the outcome of the diagnostic process. Unfortunately, these physician attributes can have devastating emotional and physical consequences for the patient.

Also, psychophysical misdiagnosis can occur because some medical illnesses can cause psychiatric symptoms. In a study of 658 psychiatric outpatients, Hall, Popkin, Devaul, Faillace, and Stickney (1978) reported physical illness causative of the psychiatric symptoms in 9.1% of the patients. Hall, Gardner, Stickney, Le Cann, and Popkin (1980) examined 100 patients in a clinical research ward. Forty-six percent of the patients had previously unidentified physical disorders that were thought to either cause or exacerbate the psychiatric symptoms. In a sample of 2,090 patients seen at a psychiatric clinic, Koranyi (1979) reported an incidence of causative physical illness of 18%. Furthermore, Koranyi found that non-psychiatric physicians had failed to identify a major physical disorder in 32% of the medically ill patients whom the physicians had referred to the clinic.
The results of these studies pose the question of why physical illnesses are so frequently missed by physicians. Johnson and Ananth (1986) suggested that many physicians are biased because of negative attitudes regarding psychiatric illness. This bias can lead physicians to overlook physical findings in patients who exhibit what appear to be psychiatric symptoms. Unfortunately, psychophysical misdiagnosis can not only substantially decrease the probability of amelioration of the patient's condition but also may contribute to a deterioration of his or her physical health (Hall et al., 1978).

**Diagnostic Deferral.** Diagnostic deferral can occur for two distinct reasons. First, the physician may be uncertain of the correct diagnosis. Almost 100 years ago, this problem and its emotional consequences for the patient were described by Gowers in a lecture presented at the National Hospital for the Paralyzed and Epileptic. Although his attitude was somewhat condescending toward his patients, some of Gowers' remarks are interesting and relevant here:

> The desire for a name is strangely strong in the case of the majority of patients. Unless their disease is designated, they go away unhappy, discontented, distrustful. 'But you have not told me what is the matter with me' is their parting plaint. What are you to do? In a very large number of cases, no recognised name can be given to the disease that does not involve more error than truth. (Gowers, 1895, p. 18)

Gowers suggested that physicians who find themselves in
these circumstances could provide the patient with a descriptive name for his or her problem. Giving patients a name for their attacker can be comforting.

Second, the communication of the diagnosis to the patient is often delayed because the physician chooses not to inform the patient of the diagnosis. Although some physicians decline to inform the patient because they believe that the complicated nature of medical knowledge renders the diagnosis meaningless to the layperson (Kalisch, 1975), many physicians decide not to disclose the diagnosis to the patient because they anticipate serious psychological repercussions such as fear and profound depression (Oken, 1961; Poser & Aisen, 1987). However, there is not much reliable evidence to support this view. Oken (1961) reported that only 6 out of 219 physicians could describe unequivocal cases of suicide from among their cancer patients. An investigation of the circumstances surrounding the suicides revealed that two of the patients who committed suicide had actually never been informed of their diagnoses. Furthermore, the reasons underlying most of the suicides were unclear, and, therefore, it is not possible to determine with complete certainty that the telling of the diagnosis directly precipitated all of the suicides. The same physicians could recall numerous instances in which the informed
patient appeared to "do well." Oken noted that much energy is expended attempting to determine whether the patient can handle being told the diagnosis, but the question of whether the patient can handle not being told is seldom raised.

Further evidence that informing the patient does not always lead to negative consequences comes from a study done by Gerle, Lunden, and Sandblom (1960). These authors studied 52 cancer patients who had not been told their diagnosis and 38 cancer patients who had been informed of their condition. They reported that the majority of the informed patients reacted favorably to the information, and that learning the diagnosis was often helpful to the patients. Only three completely negative reactions were observed in the group of patients who had been told by their surgeons that they had cancer. According to the social worker involved in the study, the group of 52 patients not told their diagnosis had more problems. These patients were described as "anxious and desperate because, despite increasing symptoms, they received no help from the hospital" (Gerle, Lunden, & Sandblom, 1960, p. 1215).

Moreover, the majority of patients want to know what is wrong with them. Dodge (1972) asked 139 patients to rate the importance of different types of medical information. The patients believed that it was very
important to be apprised of their diagnosis. In an effort to determine whether patients want to be told if they have cancer, Kelly and Friesen (1950) surveyed a group of 100 cancer patients and a group of 100 patients without cancer. In the cancer group, 89 people indicated that they preferred to be told their diagnosis, and 73 patients believed people in general should be told. Many of these patients thought that the unknown was more frightening than the knowledge that they had cancer. Eighty-two of the noncancer patients said they wanted to be informed in the event that cancer was discovered by their physicians.

When people are in pain, they know that something is wrong. Not knowing the cause of the pain can provoke anxiety because the individual does not know if the problem is disabling, fatal, or psychological. The latter possibility can be as terrifying as the first two because of the feeling that one can no longer trust one's own perceptions and because of the stigma mental illness carries with it in today's society. In this regard, Martin (1978, p. 794) remarked that "many people find some comfort in the knowledge that physicians can name their problem, that it is organic and, therefore, something for which they are not to be blamed, and that a society which cares for its own innocent victims will not abandon them."
Chronic Illnesses

Multiple Sclerosis. Multiple sclerosis is a chronic illness that affects the central nervous system. It is the most prevalent of the neurological illnesses, striking 58 out of 100,000 people in the United States (Scheinberg & Smith, 1987). Multiple sclerosis involves damage to the myelin sheath that insulates the nerve fibers of the brain and spinal cord. When the sheath is damaged, electrical current is allowed to leak out, which can severely impede or terminate the transmission of neural impulses. Moreover, at the site of the damage, other cells multiply, causing a hardening of the tissue (Whitaker, 1987).

In order to make the diagnosis of multiple sclerosis, there must be two or more scars or lesions, primarily involving the white matter of the brain, and the possibility of other diseases that can cause similar damage must be eliminated. However, these criteria are not always easily met (Poser & Aisen, 1987). Furthermore, the bizarre and transient nature of many of the symptoms can complicate the diagnostic process. The most common symptoms of multiple sclerosis include fatigue, visual blurring or diplopia (double vision), difficulty walking, numbness or tingling in one or more limbs, and problems in bladder or bowel function (Poser & Aisen, 1987; Scheinberg & Smith, 1987). These symptoms can occur for reasons
other than multiple sclerosis. In addition, approximately two-thirds of all multiple sclerosis patients experience periods of exacerbation and remission. Both this ambiguity and the transient nature of these symptoms contribute to the difficulty of making a correct diagnosis (Poser & Aisen, 1987). In fact, for 60 patients at the Multiple Sclerosis Comprehensive Care Center of the Albert Einstein College of Medicine, Scheinberg et al. (1984) reported an average period of 43 months between the patient's first contact with a physician and the time at which the patient heard the diagnosis of multiple sclerosis.

Because many of the symptoms of multiple sclerosis are bizarre, erratic, and not easily objectively substantiated, patients with this disease are sometimes misdiagnosed as having psychiatric disorders, particularly hysterical conversion reactions (Matthews, 1985; Poser, 1984; Poser & Aisen, 1987). Skegg, Corwin, and Skegg (1988) explored the prevalence of psychophysical misdiagnosis in a group of 91 multiple sclerosis patients. Ten patients were referred to psychiatrists due to their symptoms, and eight of these patients were actually given psychiatric diagnoses before being correctly diagnosed with multiple sclerosis. These researchers suggested that such psychophysical misdiagnoses tend to increase the emotional discomfort of the patients.
Deferred diagnosis is also commonly found with multiple sclerosis. Many doctors are hesitant to tell patients the diagnosis for fear of causing depression (Gorman, Rudd, & Ebers, 1984; Poser & Aisen, 1987). Many physicians truly believe that most people do not wish to know the truth. Gorman, Rudd, and Ebers (1984) suggested that some doctors may not inform their patients of the diagnosis because the doctors feel inadequate due to the lack of effective treatment or because they want their patients to be dependent on them. Scheinberg et al. (1984) reported that 97.4% of a sample of 347 physicians said that they usually or always tell their patients the diagnosis. However, these physicians also mentioned a number of patient characteristics that might lead them to postpone informing the patient. These characteristics include the patient not asking to be told the diagnosis, the patient's lack of medical sophistication, and the patient's lack of a medical degree. Neither the proportion of patients exhibiting these characteristics nor the average length of delay were provided by the researchers. Nevertheless, it does seem clear that, although these physicians may believe that they promptly inform their patients of the diagnosis, they may often withhold the diagnosis altogether or use euphemistic terms. Unfortunately, people who are not informed of their
diagnosis experience decreasing faith in themselves, their perceptions, and their physicians (Gorman, Rudd, & Ebers, 1984), and the use of such terms as "demyelinating disease" or "possible" multiple sclerosis can prolong the period of anxiety the patient must endure (Poser & Aisen, 1987, p.41).

In a study described by Gorman, Rudd, and Ebers (1984), 100 multiple sclerosis patients and 35 family members or friends from the MS Research Clinic at University Hospital, London, Ontario were interviewed. The most salient factor for both groups was the length of time between the onset of symptoms and the time at which the diagnosis was heard. For many of these patients, this period of time was marked by marital strain, anguish, and increased smoking and drinking. None of the patients said that they did not want to be informed of the diagnosis. Furthermore, 52% of the patients and 62.9% of the relatives believed that physicians should tell their patients what they only suspect is the correct diagnosis. Thus, although physicians frequently display some reticence to inform their patients of the diagnosis, most patients and their close relatives want complete disclosure.

**Lupus Erythematosus.** Lupus erythematosus is an autoimmune disease that is more common than muscular dystrophy, leukemia, or multiple sclerosis (Nass, 1984), striking 1 in every 2000 individuals in the United
States (National Institute of Arthritis and Muskuloskeletal and Skin Diseases, 1986). It is thought that approximately 80% of those individuals afflicted with lupus are female (Phillips, 1984). There are primarily two types of lupus: discoid lupus erythematosus and systemic lupus erythematosus. In discoid lupus, crusty, patchy lesions appear on the skin. Systemic lupus also can entail skin problems, but, in addition, it involves multiple organ systems such as the heart, lungs, kidneys, and central nervous system. It results from the production of antibodies that attack the person's own connective tissues. The impact of systemic lupus on the individual can range from being relatively mild to being potentially fatal (Carr, 1986; Nass, 1984; Phillips, 1984).

The diagnosis of lupus is a difficult and complicated process. It is based on whether the patient displays at least 4 of 11 criteria (see Table 1) set forth by the Subcommittee for Systemic Lupus Erythematosus Criteria of the American Rheumatism Association Diagnostic and Therapeutic Criteria Committee (Tan et al., 1982). Unfortunately, there is no foolproof test that will either prove a diagnosis of lupus or eliminate it as a possibility (Carr, 1986; Nass, 1984; Schur, 1983). These tests sometimes fail to indicate the presence of lupus in an individual who actually has the illness, and a weak
Table 1. The 1982 revised criteria for classification of systemic lupus erythematosus*

<table>
<thead>
<tr>
<th>Criterion</th>
<th>Definition</th>
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<tr>
<td>Malar rash</td>
<td>Fixed erythema, flat or raised, over the malar eminences, tending to spare the nasolabial folds</td>
</tr>
<tr>
<td>Discoid rash</td>
<td>Erythematous raised patches with adherent keratotic scaling and follicular plugging; atrophic scarring may occur in older lesions</td>
</tr>
<tr>
<td>Photosensitivity</td>
<td>Skin rash as a result of unusual reaction to sunlight, by patient history or physician observation</td>
</tr>
<tr>
<td>Oral ulcers</td>
<td>Oral or nasopharyngeal ulceration, usually painless, observed by a physician</td>
</tr>
<tr>
<td>Arthritis</td>
<td>Nonerosive arthritis involving 2 or more peripheral joints, characterized by tenderness, swelling, or effusion</td>
</tr>
</tbody>
</table>
| Serositis       | a) Pleuritis—convincing history of pleuritic pain or rub heard by a physician or evidence of pleural effusion  
|                 | OR                                                                          |
|                 | b) Pericarditis—documented by ECG or rub or evidence of pericardial effusion  |
Table 1 (continued)

7. Renal Disorder  
   a) Persistent proteinuria greater than 0.5 grams per day or greater than 3+ if quantitation not performed  
   OR  
   b) Cellular casts—may be red cell, hemoglobin, granular, tubular, or mixed  

8. Neurologic disorder  
   a) Seizures—in the absence of offending drugs or known metabolic derangements; e.g., uremia, ketoacidosis, or electrolyte imbalance  
   OR  
   b) Psychosis—in the absence of offending drugs or known metabolic derangements, e.g., uremia, ketoacidosis, or electrolyte imbalance  

9. Hematologic disorder  
   a) Hemolytic anemia—with reticulocytosis  
   OR  
   b) Leukopenia—less than 4,000/mm3 total on 2 or more occasions  
   OR  
   c) Lymphopenia—less than 1,500/mm3 on 2 or more occasions  
   OR  
   d) Thrombocytopenia—less than 100,000/mm3 in the absence of offending drugs  

10. Immunologic disorder  
    a) Positive LE cell preparation
Table 1 (continued)

OR

b) Anti-DNA: antibody to native DNA in abnormal titer

OR

c) Anti-Sm: presence of antibody to Sm nuclear antigen

OR

d) False positive serologic test for syphilis known to be positive for at least 6 months and confirmed by Treponema pallidum immobilization or fluorescent treponemal antibody absorption test

11. Antinuclear antibody

An abnormal titer of antinuclear antibody by immunofluorescence or an equivalent assay at any point in time and in the absence of drugs known to be associated with "drug-induced lupus" syndrome

*The proposed classification is based on 11 criteria. For the purpose of identifying patients in clinical studies, a person shall be said to have systemic lupus erythematosus if any 4 or more of the 11 criteria are present, serially or simultaneously, during any interval of observation.

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positive lupus reaction occasionally occurs in an individual not affected by lupus (Phillips, 1984). Also, lupus, like multiple sclerosis, is characterized by exacerbations and remissions, meaning the symptoms can come and go extemporaneously (Carr, 1986; Nass, 1984).

The symptoms of lupus often mimic those of other illnesses. For this reason, lupus has often been called "the great impersonator" (Carr, 1986, p.4). Consequently, individuals with lupus are frequently misdiagnosed as having other illnesses. Moreover, many of these symptoms such as fatigue, weakness, and pain are vague and subjective, thereby further complicating the diagnosis (McClary, Meyer, & Weitzman, 1955). All of these factors can extend the period of time between the onset of the illness and the time of diagnosis. Phillips (1984) stated that the average length of time to diagnosis was eight years. Also, in a sample of 120 lupus patients, Stein, Walters, Dillon, and Schulzer (1986) reported that an average of 4.4 years transpired between onset and diagnosis. The reason for this delay was often misdiagnosis.

Psychophysical misdiagnosis also is a problem for many lupus patients. Oftentimes, the patient's physical complaints are thought to be the result of a psychological rather than an organic disorder (Carr, 1986; Nass, 1984; Phillips, 1984). In the Stein et al. (1986) study, 24% of
the patients in the sample were initially told that there was no physical illness underlying their symptoms. As a result, many patients begin to believe that other people think they are hypochondriacs. Furthermore, the patients start to wonder if they are hypochondriacs. These doubts are stressful and can lead to a further exacerbation of the lupus (Nass, 1984).

Lupus patients must sometimes endure a delay in diagnosis because the physician is reluctant to make such a serious diagnosis without conclusive evidence (Nass, 1984; Rogers, 1983). However, it can take months or years before such evidence is obtained. Meanwhile, patients cannot learn to accept what they do not know they have. When the diagnosis is finally made, the individual often experiences a sense of relief (Nass, 1984; Phillips, 1984).

Thus, diagnostic errors and deferral do occur, and, with lupus and multiple sclerosis, they occur frequently. The purpose of the present study was to evaluate the relationship between certain patient response variables and diagnostic errors or deferral. Personal communication with chronically ill individuals and a review of the relevant literature have indicated that anxiety, self-esteem, and patient satisfaction with physicians may be associated with diagnostic errors and deferral. In this
study, these hypothesized relationships were systematically examined.
CHAPTER III

METHODS

Participants

The participants were recruited from the Mid Ohio Chapter of the Multiple Sclerosis Society and from the Marcy Zitron Chapter of the Lupus Foundation of America. An advertisement was placed in the local newsletters published by these organizations explaining the research and asking for participants (see Appendix A). Also, 23 participants were recruited from a support group meeting and a chapter meeting of the Lupus Foundation (see Appendix B). There are five groups of participants: (a) those who received a prompt, accurate diagnosis; (b) those who were originally misdiagnosed as having an illness other than the one they have; (c) those who were initially told that their symptoms did not have an organic basis; (d) those who experienced both types of misdiagnosis; and (e) those who have not received a diagnosis as yet. All participants volunteered to take part in the study.

Materials

The participants were asked to complete a packet containing several questionnaires. Appendix C contains all
of these questionnaires except the State-Trait Anxiety Inventory, which the author did not receive permission to reproduce. These scales are labeled in Appendix C but were not labeled for the participants. First, they were asked a few questions regarding background information about themselves and their medical histories. The responses to these questions were the basis for classifying the participants into the five groups. This questionnaire was followed by three other instruments: the State-Trait Anxiety Inventory, the Self-Esteem Questionnaire, and three scales from the Patient Satisfaction Questionnaire. The order of these last three questionnaires was counterbalanced in order to prevent responses given to a previous instrument consistently influencing responses to a subsequent instrument. Because participation is on a voluntary basis, only one inventory was selected for each variable. Otherwise, the length of the study might have discouraged many individuals from participating.

The State-Trait Anxiety Inventory Form Y (STAI).

This measure was used to assess both state and trait anxiety. The respondent is asked to indicate the extent to which each item reflects his or her feelings. The four possible responses are "not at all," "somewhat," "moderately so," and "very much so." For the anxiety-present items, these responses are weighted one, two,
three, and four points, respectively. These weights are reversed for anxiety-absent items. For each scale, total scores can range from 20 to 80 points, with higher scores indicating greater anxiety (Spielberger et al., 1983).

Research has indicated that the STAI is reasonably reliable. For samples of male and female working adults, high school and college students, and military recruits, the 20-item State-Anxiety scale has yielded internal consistency alphas ranging from .86 to .95. For the 20-item Trait-Anxiety scale, internal consistency alphas ranging from .89 to .91 were obtained. The State-Anxiety scale test-retest reliability correlations for a 60-day interval were much lower, ranging from .36 for a group of female high school students to .51 for a group of male high school students. However, these low figures are to be expected because the State-Anxiety scale is thought to be highly affected by situational variables. As expected, the Trait-Anxiety scale test-retest reliability coefficients for a 60-day interval were generally higher than those for the State-Anxiety scale, ranging from .65 for a group of female high school students to .68 for a group of male high school students (Spielberger et al., 1983).

The best evidence for the construct validity of the State-Anxiety scale arises from a study in which this scale was administered four times to 197 college students. The first administration took place under normal conditions.
Stressful conditions were created for two of the administrations, and a ten-minute relaxation training preceded the other administration. The average scores were lowest after the relaxation training and highest under the two stressful conditions. However, it is possible that the subjects were able to fake this anxiety in response to demand characteristics (Chaplin, 1984; Spielberger et al., 1983).

The evidence for the construct validity of the Trait-Anxiety scale is not as strong as that for the State-Anxiety scale (Chaplin, 1984). However, some support for the validity of the Trait-Anxiety scale can be found in the correlations between this scale and other measures of trait anxiety such as the Zuckerman Affect Adjective Checklist (AAACL), the IPAT Anxiety Scale (IPAT), and the Taylor Manifest Anxiety Scale (TMAS). For a sample of 126 college females, these correlations were .52, .75, and .80, respectively. The AAACL did not correlate highly with the IPAT or the TMAS either; therefore, the lower correlation ($r = .52$) between the AAACL and the Trait-Anxiety scale of the STAI can probably be attributed to the inadequacy of the AAACL as a measure of trait anxiety (Spielberger et al., 1983).

The comparison of the mean scores for groups of normal subjects with the mean scores for groups of
neuropsychiatric patients provides further evidence of the construct validity of the Trait-Anxiety scale. All of the neuropsychiatric groups for whom anxiety was an important symptom showed much higher Trait-Anxiety scores than the normal subject groups. The only neuropsychiatric group that did not display a substantially elevated mean score was the group of patients with character disorders. According to Spielberger et al. (1983), this fact can be viewed as evidence for the validity of the scale because the lack of anxiety is a defining characteristic of these disorders.

The Self-Esteem Questionnaire (SEQ). The SEQ is a 50-item, self-report measure found in an appendix of a drug education book by Cornacchia, Smith, & Bentel (1978). An individual responds to each item on the scale by indicating whether the item is "not true" (0), "somewhat true" (1), "largely true" (3), or "true"(4). To determine the overall score, the sum total of the odd numbered items is subtracted from the sum total of the even numbered items, yielding a score between -100 and +100. Higher scores indicate higher levels of self-esteem.

The SEQ does not seem to be significantly related to age, race, intelligence, or social position. Furthermore, for a ten-week interval, the SEQ yielded an $r$ of .76 in a sample of 38 psychology students. In a sample of 86 high
school students, an internal consistency alpha of .52 was obtained, indicating that, statistically, the SEQ is somewhat heterogeneous. Indeed, a factor analysis revealed three primary factors. The first of these was a general factor and accounted for 62% of the variance. Eleven percent of the variance was accounted for by a factor related to neurotic defensiveness, and the final factor, which accounted for 5% of the variance, was related to interpersonal proficiency (Domino & Blumberg, 1987).

To determine the validity of the SEQ, a study was undertaken in which six groups of college students thought to have different degrees of self-esteem were given the SEQ. These groups included student leaders, varsity athletes, introductory psychology students, counseling center clients, "problem" students, and students on academic probation. The difference among groups was highly significant (F=9.8, p<.001), with student leaders scoring highest (M=62.3, SD=5.7) and the last three groups scoring the lowest (Ms=46.3, 43.4, 41.4, SDs=5.1, 4.8, 5.4, respectively). Also, significant correlations were obtained between the SEQ and other measures of self-esteem such as the Rosenberg Self-Esteem Scale (r=.68), the Tennessee Self-Concept Scale (r=.73), and the Adjective Checklist Self-Confidence Scale (r=.51) providing some evidence for criterion-related validity (Domino & Blumberg, 1987).
The Patient Satisfaction Questionnaire (PSQ). The PSQ is a self-report measure that assesses patient satisfaction with overall medical care using a five-point Likert scale ranging from "Strongly Disagree" to "Strongly Agree". Higher scores are associated with greater satisfaction. Because this study is concerned specifically with patient satisfaction with physicians, only the Technical Quality, Interpersonal Manner, and Overall Satisfaction scales will be used.

The reliability of these scales appears to be reasonably good. For Doctor Conduct, which subsumes the Technical Quality and Interpersonal Manner scales, internal consistency coefficients ranging from .88 to .94 were obtained in four field tests. The test-retest reliability correlations were .78 and .82 for a six-week interval and .61 for a two-year interval. For Overall Satisfaction, internal consistency alphas ranged from .62 to .77 (Ware, Snyder, & Wright, 1976a).

Ware, Snyder, and Wright (1976a) constructed a multitrait-multimethod matrix in order to examine the convergent and discriminant validity of these scales. To determine the convergent validity, these researchers looked at the correlations between two measures of the same trait using different methods. They correlated the PSQ global scales with single-item satisfaction ratings that had both
belief and evaluative components. In the Sangamon County field test, the convergent validity coefficients for the PSQ Form II global scales of Humaneness and Quality were .62 and .50, respectively. However, because these PSQ scales were so strongly correlated ($r = .71$), Humaneness did not pass the heterotrait-monomethod test for discriminant validity. Thus, it is unclear whether the scales assessing the technical and interpersonal skills of physicians truly measure two distinct aspects with regard to patient satisfaction with quality of care (Ware, Snyder, Wright, & Davies, 1983).

Another strategy to explore the validity of the PSQ entailed the correlation of PSQ scale scores with answers to open-ended questions regarding recent health care experiences. These answers were coded according to the content area (humaneness, quality/competence, etc.) and feeling expressed (positive or negative). There were more negative comments than positive ones, resulting in a skewed distribution and attenuated correlations. In the Sangamon County field test, the significant correlations for humaneness ($r = .86$, $p < .001$) and for quality/competence ($r = .67$, $p < .001$) were taken as evidence for the convergent validity of these PSQ Form II scales. Moreover, answers pertaining to the humaneness of physicians were most highly correlated to the Humaneness Total ($r = .86$) and to
Consideration (r = .85), and comments regarding the quality or competence of physicians were most strongly related to the PSQ Quality/Competence Total scale (r = .67). Thus, the discriminant validity criterion was also satisfied.

Procedure

Individuals who were interested in participating sent their names and addresses in response to the advertisement. They then were sent the packet containing the questionnaires, along with a self-addressed, stamped envelope. The packet required approximately one hour to complete. Their return of the completed questionnaires was construed as consent. The names of the participants were not associated with their responses at any time.

Analysis

The participants were separated into five groups according to whether they had received a prompt, accurate diagnosis, a deferred diagnosis, a medical misdiagnosis, a psychophysical misdiagnosis, or both a medical and a psychophysical misdiagnosis. Due to the small sample sizes of the five groups, primarily non-parametric tests were used in the analysis of this data. For each hypothesis, the deferral or misdiagnosis groups were compared to the prompt, accurate diagnosis group using the median test. In the median test, the scores from the two groups being compared are divided into those above and those below the
combined median, and the resulting frequencies are placed in a 2x2 contingency table. The probability of finding that pattern of frequencies when the null hypothesis is true can then be calculated. These calculations are accomplished through the use of the Fisher exact test with samples under 20 and the chi-square test for 2x2 contingency tables with larger samples (Siegel & Castellan, 1988). One parametric statistic, the Pearson product moment correlation coefficient, was also used (Cohen & Cohen, 1983).

In order to control the familywise Type I error rate, the Bonferroni test was used (Keppel, 1982). The familywise alpha level was set at .11, and 11 tests were performed. Thus, the alpha level for each comparison was .01.
CHAPTER IV

RESULTS

Description of Sample

Of the 73 packets sent to chronically ill individuals, 60 were returned, yielding a response rate of 82%. Six of the respondents were not classifiable in terms of the five groups. These respondents either did not answer all of the questions required to classify them or they did not fall into any of the categories. In the latter case, the respondents had once had a deferred diagnosis but had since been diagnosed. Thus, the overall sample size was 54, with 10 people (18.5%) falling in the prompt accurate diagnosis category, 6 (11.1%) in the deferred diagnosis group, 18 (33.3%) in the medical misdiagnosis group, 8 (14.8%) in the psychophysical misdiagnosis category, and 12 (22.2%) in the combined misdiagnosis group.

All but five of the respondents were female, which was expected due to the fact that one of these illnesses, lupus, strikes many more women than men. Most of the respondents (72.3%) were either married or partnered. The remainder were divorced (11.1%), single (11.1%), or
widowed (5.6%). The ages of the respondents ranged from 24 to 75, with the average age being 41.5 years.

With regard to the illness histories of the respondents, 18 (38.3%) have multiple sclerosis, 28 (59.6%) have lupus, and 1 (2.1%) has another connective tissue disorder known as CREST syndrome. These respondents have been suffering from these illnesses for an average of 14.05 years. The average length of time between first requesting medical assistance and receiving the current diagnosis is 4.56 years. With the assumption that the time of the first symptom and the time of first requesting medical assistance roughly coincide, an estimate of the time since receiving the correct diagnosis can be calculated. Thus, the estimated average time since receiving the correct diagnosis is 9.13 years.

Comparison to Normative Data

With regard to anxiety and self-esteem, this sample of chronically ill individuals was also compared to groups of healthy adults tested in previous studies. The chronically ill sample exhibited significantly higher trait anxiety ($t=3.46$, $p<.01$) than the group of 451 female working adults who participated in a study by Spielberger et al. (1983). The self-esteem of the participants was 12.51 points below that of 23 female community adults tested by Domino and Blumberg (1987). However, those researchers did not supply
a standard deviation, and therefore a statistical test was not possible.

The Median Test

The results of the comparisons were somewhat surprising. There was no significant difference in state or trait anxiety between the deferral group and the prompt, accurate diagnosis group (p=.63, p=.12, respectively). There was also no difference between the two groups in levels of self-esteem (p>.99). However, the deferred diagnosis group did exhibit significantly lower levels of patient satisfaction with physicians than the accurate diagnosis group (p<.001). Table 2 shows the frequencies of scores above and below the median for these two groups on all of the variables.

Comparing the psychophysical misdiagnosis group with the accurate diagnosis group, no significant differences were found in either self-esteem (p=.64) or patient satisfaction with physicians (p=.64). The frequencies of scores above and below the median for these groups are given in Table 3. The medical misdiagnosis group did not differ from the prompt, accurate diagnosis group with regard to levels of patient satisfaction with physicians (X2(1)=0, p>.99). The frequencies of these scores are provided in Table 4. The combined misdiagnosis group also showed no significant differences in terms of self-esteem
(X2(1) = .05, p < .0) or patient satisfaction (X2(1) = .183, p < .70). Table 5 shows the frequencies of scores on either side of the median for these groups.

Correlational Data

In order to determine whether the length of time since receiving the correct diagnosis was related to the levels of self-esteem or patient satisfaction exhibited by the respondents, Pearson product moment correlation coefficients were calculated. The correlation between self-esteem and time since correct diagnosis was not only negligible but also negative (r = -.03, p = .85). The correlation between patient satisfaction with physicians and the estimated time since correct diagnosis was positive and slightly stronger but still statistically insignificant (r = .14, p = .35). Thus, the length of time since diagnosis does not appear to be a strong factor in unexpectedly high levels of self-esteem or patient satisfaction.
Table 2. Comparison of the deferred diagnosis group with the prompt, accurate diagnosis group on all variables

<table>
<thead>
<tr>
<th>Group</th>
<th>Deferred</th>
<th>Accurate</th>
<th>Combination</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>STATE ANXIETY</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Placement Above Around the Median Below</td>
<td>2</td>
<td>5</td>
<td>7</td>
</tr>
<tr>
<td>Total</td>
<td>6</td>
<td>10</td>
<td>16</td>
</tr>
<tr>
<td>p=.63</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>TRAIT ANXIETY</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Placement Above Around the Median Below</td>
<td>1</td>
<td>6</td>
<td>7</td>
</tr>
<tr>
<td>Total</td>
<td>6</td>
<td>9</td>
<td>15</td>
</tr>
<tr>
<td>p=.12</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>SELF-ESTEEM</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Placement Above Around the Median Below</td>
<td>3</td>
<td>5</td>
<td>8</td>
</tr>
<tr>
<td>Total</td>
<td>6</td>
<td>10</td>
<td>16</td>
</tr>
<tr>
<td>p&gt;.99</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>PATIENT SATISFACTION WITH PHYSICIANS</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Placement Above Around the Median Below</td>
<td>0</td>
<td>8</td>
<td>8</td>
</tr>
<tr>
<td>Total</td>
<td>6</td>
<td>10</td>
<td>16</td>
</tr>
<tr>
<td>p&lt;.001</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Table 3. Comparison of the psychophysical misdiagnosis group and the prompt, accurate diagnosis group on self-esteem and patient satisfaction with physicians

<table>
<thead>
<tr>
<th>Group</th>
<th>Psychophysical</th>
<th>Accurate</th>
<th>Combination</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>SELF-ESTEEM</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Placement Above</td>
<td>5</td>
<td>4</td>
<td>9</td>
</tr>
<tr>
<td>Around the Median</td>
<td>3</td>
<td>6</td>
<td>9</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td>8</td>
<td>10</td>
<td>18</td>
</tr>
<tr>
<td>p=.64</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Group</th>
<th>Psychophysical</th>
<th>Accurate</th>
<th>Combination</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>PATIENT SATISFACTION WITH PHYSICIANS</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Placement Above</td>
<td>5</td>
<td>4</td>
<td>9</td>
</tr>
<tr>
<td>Around the Median</td>
<td>3</td>
<td>6</td>
<td>9</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td>8</td>
<td>10</td>
<td>18</td>
</tr>
<tr>
<td>p=.64</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Table 4. Comparison of the medical misdiagnosis group with the prompt, accurate diagnosis group on patient satisfaction with physicians

<table>
<thead>
<tr>
<th>Group</th>
<th>Misdiagnosis</th>
<th>Accurate</th>
<th>Combination</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>PATIENT SATISFACTION WITH PHYSICIANS</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Placement Above</td>
<td>9</td>
<td>5</td>
<td>14</td>
</tr>
<tr>
<td>Around the Median</td>
<td>9</td>
<td>5</td>
<td>14</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td>18</td>
<td>10</td>
<td>28</td>
</tr>
<tr>
<td>$\chi^2(1)=0$, p&gt;.99</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Table 5. Comparison of the combined misdiagnosis group with the prompt, accurate diagnosis group on self-esteem and patient satisfaction with physicians

<table>
<thead>
<tr>
<th>Group</th>
<th>Combined</th>
<th>Accurate</th>
<th>Combination</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>SELF-ESTEEM</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Placement Above</td>
<td>5</td>
<td>5</td>
<td>10</td>
</tr>
<tr>
<td>Around the Median Below</td>
<td>6</td>
<td>5</td>
<td>11</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td>11</td>
<td>10</td>
<td>21</td>
</tr>
<tr>
<td>$X^2(1) = .05, p &lt; .00$</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>PATIENT SATISFACTION WITH PHYSICIANS</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Placement Above</td>
<td>5</td>
<td>6</td>
<td>11</td>
</tr>
<tr>
<td>Around the Median Below</td>
<td>7</td>
<td>4</td>
<td>11</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td>12</td>
<td>10</td>
<td>22</td>
</tr>
<tr>
<td>$X^2(1) = .183, p &lt; .70$</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
CHAPTER V

DISCUSSION

The results of the study were unexpected. Only one of the hypotheses received any support. This support arose from the finding that the group of individuals still awaiting a diagnosis were significantly less satisfied with physicians than the group who received prompt, accurate diagnoses.

The test of the trait anxiety in the diagnostic deferral and the prompt, accurate diagnosis groups was associated with a relatively low probability (p=.12). Perhaps with a larger sample size, the result would have been significant. Moreover, because the overall sample showed significantly greater trait anxiety than a group of healthy adults, differentiating two groups within the sample in terms of trait anxiety may have been more difficult.

No significant relationships were found between misdiagnosis and patient satisfaction. Perhaps because these individuals had later been correctly diagnosed by physicians, they had found physicians that they trusted, respected, and with whom they were satisfied. The length
of time since receiving this correct diagnosis did not appear to be a major factor in the development of that satisfaction.

Nonetheless, it is surprising that these individuals attitudes are still remarkably positive. Possibly this belief in physicians performs a psychological function by protecting the patients from continually doubting the physician's judgment. It may allow them to trust the person who is vitally important to their survival.

There were also no significant relationships between self-esteem and psychophysical misdiagnosis. One possible explanation is based on the length of time since the correct diagnosis was made. When the individuals' self-perceptions were shown to have objective validity, they may have gradually recovered their self-esteem. However, the lack of a significant correlation between the estimated time since receiving the correct diagnosis and self-esteem as well as the absence of a significant relationship between self-esteem and diagnostic deferral do not support this explanation.

Another possible explanation stems from the cross-cultural anthropological work of Arrien (1989) with regard to self-esteem. She concluded that self-esteem is comprised of three components: self-love, self-respect, and self-trust. When individuals are told that the symptoms they are experiencing have no objective reality, they may
suffer a decrement in their ability to trust their own self-perceptions without losing the ability to love or respect themselves. Thus, it is possible that one aspect of self-esteem, self-trust, is affected by psychophysical misdiagnosis without causing a decrease in overall self-esteem.

**Limitations**

The primary limitation of this study was the nature of the sample. First, the sample was extremely small. A larger sample would have allowed the use of parametric statistical procedures and increased the power of these procedures.

Second, this study was retrospective. For most of the participants the misdiagnosis occurred and was corrected several years ago. Thus, they have had a considerable length of time to recover from the experience.

Furthermore, the participants were all volunteers. Borden and Abbott (1988) have indicated that studies involving volunteers may generate results that do not apply to the population of interest. In this study, volunteer bias could have contributed to the significant relationship between diagnostic deferral and lower patient satisfaction with physicians. Perhaps the individuals who were less satisfied with their physicians were more motivated to participate in the study.
Finally, some demographic variables were not included in the study. The severity of the symptoms and the race of each participant were not assessed. Thus, the representativeness of the sample and the generalizability of the study are unknown.

**Implications**

Although there were not significant results on those measures of self-esteem or anxiety, several of the comments made by the participants indicated a high level of discomfort spawned by the experience of psychophysiological misdiagnosis or diagnostic deferral. For example, when the physician told her she was physically fine, one participant, later diagnosed with lupus, wrote, "I doubted myself -- I thought -- wow maybe I'm crazy -- maybe I do imagine the pain." Another participant who does not yet have a diagnosis was tested for depression. She said, "I resented that, and it took all I had to try and stay positive." A third participant who has multiple sclerosis almost committed suicide after being told her symptoms were hysterical not physical.

Consequently, it is still important from a psychological as well as a medical standpoint to consider ways of improving diagnostic accuracy. To accomplish this enhanced accuracy, Dawes, Faust, and Meehl (1989) propose a greater use of actuarial methods in the diagnostic process.
This suggestion is based on a review of the studies comparing clinical and actuarial methods, the vast majority of which support the superiority of actuarial approaches.

There are several explanations for these findings. First, for a particular data set, actuarial methods, unlike clinical ones, will always give rise to the same conclusion. Furthermore, with actuarial procedures, variables influence the conclusion according to their true predictive abilities and association with the criterion of interest, whereas people often find it difficult to discriminate valid from invalid variables. This difficulty can lead to the formation of false beliefs, which is then augmented by the human propensity to pay greater attention to data consistent with one's hypotheses and disregard conflicting evidence. Mistakes can also arise from the human tendency to ignore base rates, or prevalence data. Thus, the development and use of actuarial procedures for making diagnoses could significantly improve the accuracy of these diagnoses.

Finally, although misdiagnosis and diagnostic deferral do not appear to be related to anxiety or low self-esteem, they have caused some emotional distress. Since emotional distress can exacerbate both multiple sclerosis and lupus (Rogers, 1983), it is important to explore the use of actuarial procedures to enhance diagnostic accuracy. Furthermore, counselors working with
clients who have experienced diagnostic delay or errors need to be aware that this experience can lead to emotional distress. As a result of this awareness, possible problems could be recognized before they exist, thereby providing the counselor with an opportunity to develop preventive measures.

**Directions for Future Research**

In the past, there has been little empirical research regarding psychological variables associated with misdiagnosis and diagnostic deferral. Consequently, it is important for more research to be conducted in this area. One possibility to explore is the potential relationship between psychophysical misdiagnosis and self-trust. An instrument specifically measuring self-trust might reflect a difference not evident with a measure of overall self-esteem.

Also, in future research efforts, greater control of the length of time since receiving the correct diagnosis could maximize the possibility of discovering the existing effects. The researcher could endeavor to recruit participants as soon as possible after their misdiagnoses were corrected. When the experience is still fresh, some psychological correlates not found in the current study might be in evidence.
APPENDIX A

THE RECRUITMENT ADVERTISEMENTS
Hi. My name is Lisa Conant. I’m a graduate student at the Ohio State University, working with Professor Nancy Betz of the Psychology Department. I’d like to ask for your assistance to learn more about some of the feelings and attitudes associated with diagnostic errors. By increasing the amount of information and awareness about diagnostic errors and illnesses such as multiple sclerosis, I believe that we can help others who have these illnesses and have been incorrectly diagnosed.

To participate, you need to be 18 years or older. One of the following should also be true of you:

1. You received a prompt, correct diagnosis;
2. You were first misdiagnosed as having an illness other than multiple sclerosis;
3. You were first told that your symptoms did not have a physical cause; or
4. You have not been given a diagnosis yet.

Over the summer, I’ll send each participant a packet containing a few questionnaires to fill out, with a self-addressed, stamped envelope. This packet should take less than an hour to complete. All of the responses will be anonymous. Names and addresses will only be used to mail out the forms.

If you’re interested in participating, please either call me or fill out the attached coupon and send it to

Lisa Conant
2369 Williams Street, Apt. E
Columbus, OH 43202
614/291-9371

Yes—I would like to participate in this study.

NAME ____________________________
ADDRESS __________________________
CITY ______________________ STATE ____ ZIP ______
PHONE NUMBER (OPTIONAL) ________

College of Social and Behavioral Sciences
Hi. My name is Lisa Conant. I'm a graduate student at the Ohio State University, working with Professor Nancy Betz of the Psychology Department. I'd like to ask for your assistance to learn more about some of the feelings and attitudes associated with diagnostic errors. By increasing the amount of information and awareness about diagnostic errors and illnesses such as lupus, I believe that we can help others who have these illnesses and have been incorrectly diagnosed.

To participate, it's only necessary that you be 18 years or older and that one of the following statements be true for you:

1. You received a prompt, accurate diagnosis;
2. You were initially misdiagnosed as having an illness other than lupus;
3. You were originally told that your symptoms did not have a physical cause; or
4. You have not been given a diagnosis yet.

Over the summer, I will send each participant a packet containing a few questionnaires to fill out along with a self-addressed, stamped envelope. This packet should take less than an hour to complete and all of the responses will be anonymous. Names and addresses will only be used to mail out the forms.

If you are interested in participating, please either call me or fill out the attached coupon and send it to

Lisa Conant
2169 Williams Street, Apt. E
Columbus, OH 43202
614/291-9371

Yes--I would like to participate in this study.

NAME_____________________________________________________________

ADDRESS__________________________________________________________

CITY__________________________ STATE_______ ZIP_____

PHONE NUMBER (OPTIONAL)________________________________________
APPENDIX B

THE RECRUITMENT SCRIPT
Hi. My name is Lisa Conant, and I am a graduate student at the Ohio State University. I am working with Professor Nancy Betz of the Psychology Department. I am here to request your assistance to learn more about some of the feelings and attitudes associated with diagnostic errors. By increasing the amount of information and awareness about diagnostic errors and illnesses such as lupus, I believe that we can help others who have chronic illnesses and were incorrectly diagnosed. Please write your name and address on this notepad if you are interested in participating, are over the age of 18, and one of the following statements is true for you: (1) You received a prompt, accurate diagnosis; (2) you were initially misdiagnosed as having an illness other than lupus; (3) you were originally told that your symptoms did not have a physical cause; or (4) you have not been given a diagnosis as yet. Over the summer, I will send you a packet containing a few questionnaires to fill out along with a self-addressed, stamped envelope. The packet should take less than an hour to complete and all of your responses will be anonymous. Your name and address will only be used to mail out the forms. They will not be included in my thesis nor will they ever be associated with your responses to the questionnaires.
APPENDIX C

THE PACKET
August 7, 1990

Dear Participant,

Thank you for agreeing to participate in my research on diagnostic errors or delay, which I am doing under the direction of Dr. Nancy Betz of the Department of Psychology. In response to your show of interest, I have enclosed a few questionnaires regarding your medical history, feelings, and attitudes. Please read the instructions carefully and try to answer every question on the front and back of each page. Do not write your name on any of the materials. When you have completed these questionnaires, please return them to me in the enclosed envelope. If you have any questions or wish to find out the results of the study, call me at 291-9371. Thank you again for your participation.

Sincerely,

Lisa Conant
Graduate Associate
Department of Psychology
291-9371

Dr. Nancy Betz
Professor
Department of Psychology
104 Townshend Hall
614/292-4166

THE OHIO STATE UNIVERSITY
Department of Psychology
142 Townshend Hall
2915 Neil Avenue Mall
Columbus, OH 43210-1225

College of Social and Behavioral Sciences
Age: ___

Sex: ___

Marital Status: _________

Do you have a current diagnosis? Yes__No__If yes, what is it? If no, please describe briefly.

How long has it been since you experienced your first symptoms?

How much time elapsed between the time you first requested medical assistance and the time at which you received your current diagnosis?

Were you ever misdiagnosed as having another physical illness? Yes__No__If yes, please describe briefly.

Were you ever told that you were not physically ill (that "it's all in your head")? Yes__No__If yes, please describe briefly.

Has there been someone in your life who has been particularly supportive throughout the course of your illness? If so, what relationship is this person to you (spouse, mother, brother, etc.)?
THE SELF-ESTEEM QUESTIONNAIRE

Reply to the following statements, using this scale:

0 -- not true
3 -- largely true
1 -- somewhat true
4 -- true

<table>
<thead>
<tr>
<th>SCORE</th>
<th>STATEMENT OF PRESENT CONDITION OR ACTION</th>
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<tbody>
<tr>
<td></td>
<td>1. I usually feel inferior to others.</td>
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<td></td>
<td>2. I normally feel warm and happy toward myself.</td>
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<td></td>
<td>3. I often feel inadequate to handle new situations.</td>
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<td></td>
<td>4. I usually feel warm and friendly toward all I contact.</td>
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<tr>
<td></td>
<td>5. I habitually condemn myself for my mistakes and shortcomings.</td>
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<td></td>
<td>6. I am free of shame, blame, guilt, and remorse.</td>
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<td></td>
<td>7. I have a driving need to prove my worth and excellence.</td>
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<td></td>
<td>8. I have great enjoyment and zest for living.</td>
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<td></td>
<td>9. I am much concerned about what others think and say of me.</td>
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<td></td>
<td>10. I can let others be &quot;wrong&quot; without attempting to correct them.</td>
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<tr>
<td></td>
<td>11. I have a strong need for recognition and approval.</td>
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<td></td>
<td>12. I am usually free of emotional turmoil, conflict, and frustration.</td>
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<td></td>
<td>13. Losing normally causes me to feel resentful and &quot;less than.&quot;</td>
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<tr>
<td></td>
<td>15. I am prone to condemn others and often wish them punished.</td>
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<td></td>
<td>16. I normally do my own thinking and make my own decisions.</td>
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<td></td>
<td>17. I often defer to others on account of their wealth or prestige.</td>
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<td></td>
<td>18. I willingly take responsibility for the consequences of my actions.</td>
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<td></td>
<td>19. I am inclined to exaggerate and lie to maintain a self-image.</td>
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<tr>
<td></td>
<td>20. I am free to give precedence to my own needs and desires.</td>
</tr>
<tr>
<td></td>
<td>21. I tend to belittle my own talents, possessions, and achievements.</td>
</tr>
<tr>
<td></td>
<td>22. I am free to speak up for my own opinions and convictions.</td>
</tr>
<tr>
<td></td>
<td>23. I habitually deny, alibi, justify, or rationalize my mistakes and defeats.</td>
</tr>
</tbody>
</table>
24. I am usually poised and comfortable among strangers.
25. I am very often critical and belittling of others.
26. I am free to express love, anger, hostility, resentment, joy, etc.
27. I feel vulnerable to others' opinions, comments, and attitudes.
28. I rarely experience jealousy, envy, or suspicion.
29. I am a "professional people pleaser."
30. I am not prejudiced toward racial, ethnic, or religious groups.
31. I am fearful of exposing my "real self."
32. I am normally friendly, considerate, and generous with others.
33. I often blame others for my handicaps, problems, and mistakes.
34. I rarely feel uncomfortable, lonely, and isolated when alone.
35. I am a compulsive "perfectionist."
36. I accept compliments and gifts without embarrassment or obligation.
37. I am often compulsive about eating, smoking, talking, or drinking.
38. I am appreciative of others' achievements and ideas.
39. I often shun new endeavors because of fear of mistakes or failure.
40. I make and keep friends without trying.
41. I am often embarrassed by the actions of my family or friends.
42. I readily admit my mistakes, shortcomings, and defeats.
43. I experience a strong need to defend my acts, opinions, and beliefs.
44. I take disagreement and refusal without feeling "put down" or rejected.
45. I have an intense need for confirmation and agreement.
46. I am eagerly open to new ideas and proposals.
47. I customarily judge my self-worth by comparison with others.
48. I am free to think any thoughts that come into my mind.
49. I frequently boast about myself, my possessions, and my achievements.
50. I accept my own authority and do so as I, myself, see fit.
*Project Promise, Washoe County School District, Reno, Nevada.

THE PATIENT SATISFACTION QUESTIONNAIRE

DIRECTIONS:
On the next few pages, you will find statements about different aspects of medical care. We would like to know whether you agree or disagree with each statement so that we can learn which things people think are good and which are bad. Try to think about the care you are now getting as you respond to each statement. When you cannot respond to a statement from your own experience, respond to what you would expect on the basis of the other medical care you now get. For each statement, we want to know how much you agree or disagree with what is said. There are no right or wrong answers. We just want to know your opinion. Again, we want you to know that your answers will not be revealed to anyone.

The following example will help you to answer these statements.

Example: Suppose one of the statements was, "Ambulance service is too expensive."

If you Strongly Disagree that "Ambulance service is too expensive," then you would place your mark like this:

Ambulance service is too expensive.

:____________________:____________________:
Strongly Agree Uncertain Disagree Strongly Agree

If you Strongly Agree, Agree, Disagree, or are Uncertain, that "Ambulance service is too expensive," then you would put your mark above the word(s) which come closest to saying what you think.

IMPORTANT:

(1) Place your mark in the middle of the spaces provided.

:____________________:____________________:
THIS NOT THIS

(2) Be sure you answer each statement -- do not leave any out.

(3) Never put more than one mark for a single statement.

Mark the items fairly quickly. Do not worry or puzzle over individual items. It is your first impressions, the immediate thoughts or feelings about the item that are important. On the other hand, please do not be careless, because we want your true feelings.
1. I'm very satisfied with the medical care I receive.
   Strongly Agree Uncertain Disagree Strongly Disagree

2. Doctors ask what foods patients eat and explain why certain foods are best.
   Strongly Agree Uncertain Disagree Strongly Disagree

3. Doctors are very careful to check everything when examining their patients.
   Strongly Agree Uncertain Disagree Strongly Disagree

4. I think my doctor's office has everything needed to provide complete medical care.
   Strongly Agree Uncertain Disagree Strongly Disagree

5. Most people receive medical care that could be better.
   Strongly Agree Uncertain Disagree Strongly Disagree

6. Most people are not encouraged to get a yearly exam when they go for medical care.
   Strongly Agree Uncertain Disagree Strongly Disagree

7. Doctors always treat their patients with respect.
   Strongly Agree Uncertain Disagree Strongly Disagree

8. Doctors don't advise patients about ways to avoid illness or injury.
   Strongly Agree Uncertain Disagree Strongly Disagree

9. Doctors never recommend surgery (an operation) unless there is no other way to solve the problem.
   Strongly Agree Uncertain Disagree Strongly Disagree
10. Doctors hardly ever explain the patient's medical problems to him.

   : Strongly Agree  Uncertain  Disagree  Strongly Agree

11. Doctors always do their best to keep the patient from worrying.

   : Strongly Agree  Uncertain  Disagree  Strongly Disagree

12. Doctors aren't as thorough as they should be.

   : Strongly Agree  Uncertain  Disagree  Strongly Disagree

13. Doctors always avoid unnecessary expenses.

   : Strongly Agree  Uncertain  Disagree  Strongly Disagree

14. Most people are encouraged to get a yearly exam when they go for medical care.

   : Strongly Agree  Uncertain  Disagree  Strongly Disagree

15. Sometimes doctors make the patient feel foolish.

   : Strongly Agree  Uncertain  Disagree  Strongly Disagree

16. My doctor's office lacks some things needed to provide complete medical care.

   : Strongly Agree  Uncertain  Disagree  Strongly Disagree

17. The care I have received from doctors in the last few years is just about perfect.

   : Strongly Agree  Uncertain  Disagree  Strongly Disagree

18. Sometimes doctors take unnecessary risks in treating their patients.

   : Strongly Agree  Uncertain  Disagree  Strongly Disagree
19. Doctors are very thorough.

| Strongly Agree | Uncertain | Disagree | Strongly Agree | Disagree |

20. The medical problems I've had in the past are ignored when I seek care for a new medical problem.

| Strongly Agree | Uncertain | Disagree | Strongly Agree | Disagree |

21. Doctors never expose their patients to unnecessary risk.

| Strongly Agree | Uncertain | Disagree | Strongly Agree | Disagree |

22. Doctors respect their patient's feelings.

| Strongly Agree | Uncertain | Disagree | Strongly Agree | Disagree |

23. There are things about the medical care I receive that could be better.

| Strongly Agree | Uncertain | Disagree | Strongly Agree | Disagree |

24. When I seek care for a new medical problem, they always check up on the problems I've had before.

| Strongly Agree | Uncertain | Disagree | Strongly Agree | Disagree |

25. Doctors seldom explain why they order lab tests and x-rays.

| Strongly Agree | Uncertain | Disagree | Strongly Agree | Disagree |

26. Doctors cause people to worry a lot because they don't explain medical problems to patients.

| Strongly Agree | Uncertain | Disagree | Strongly Agree | Disagree |

27. Sometimes doctors cause their patients unnecessary medical expenses.

| Strongly Agree | Uncertain | Disagree | Strongly Agree | Disagree |
APPENDIX D

PERMISSION TO USE THE SEQ
2367 Williams St. Apt. E  
Columbus, OH 43202  
June 20, 1990  JUN 25 1990

Dear Ms. Broderick,

I am a graduate student in Counseling Psychology at the Ohio State University and am currently preparing to conduct research for my Master's thesis. In this regard, I am requesting permission to use and reproduce the self-esteem inventory printed in the back (pp. 305–306) of the 1978 edition of Drugs in the Classroom by Cornacchia, Smith, and Bentel. I would like to use this inventory to explore the relationship between diagnostic errors and self-esteem in chronically ill individuals. This written request is a follow-up to a phone call made on June 20. Thank you for your time and consideration.

Sincerely,

[Signature]

Lisa Conant

6/26/90

Permission granted for above request. Please include the following credit line as a footnote (in addition to the existing footnote to the source):


[Signature]

Anastasia Broderick, Manager  
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St. Louis, MO 63146
LIST OF REFERENCES

Arrien, A. (Speaker). (1989). Healing all our relationships. [2 tape set cassette recording]. Angeles Arrien, P. O. Box 2077, Sausalito, CA 94966 (415-331-5050).


