ABSTRACT. Non-compliance with medical advice is poorly understood. Most of the existing literature considers the problem only from the doctor's point of view. We undertook a diachronic, qualitative study of the illness experiences of 19 women to try to understand non-compliance from the patient's perspective. Three-fourths of our study group had ceased to follow their doctor's recommendations by four months post-diagnosis. Their non-compliance could not be explained by the fact that the women held understandings of their illnesses which were incongruent with their physicians'; nor were they unable to understand the diagnosis they received. A consideration of the roles that their diagnosis and treatments played in their daily lives proved more useful in explaining their failure to follow physicians' recommendations. Patients' use of treatments reflected their desire to control symptoms within the constraints of their daily routines.

INTRODUCTION

Non-compliance with medical advice is considered a major problem in health care. It is estimated that a third of all patients and half of chronically ill patients do not follow medical regimens (Marston 1970; Haynes 1979a; Epstein and Cluss 1982). Non-compliance is one of the least understood issues in health care. In spite of a veritable explosion of research and literature in recent years, studies on compliance have produced generally inconsistent, inconclusive or controversial results (Haynes et al. 1979), indicating that the predominant approach to the problem is not especially fruitful (Caplan et al. 1976; Chrisman 1977; Haynes 1979b; Ley 1979; Epstein and Cluss 1982; Pederson et al. 1984; Roter 1985).

Some of the problems with the compliance literature may be due in part to differing definitions of compliance among researchers and variations in its measurement. It is also possible that the confusion may stem from something much more basic. Compliance is usually defined as the extent to which patients' behavior coincides with medical advice (Haynes et al. 1979; Hulka 1979). This definition orients the researchers to assess patients' behavior from the physician's point of view, rather than from that of the patient.\(^1\)

When viewed from a biomedical perspective, actions which are not consistent with medical advice appear to be unwarranted (Stimson 1974; Good and Good 1981). They are judged in terms of physicians' authoritative knowledge, which assumes that doctors hold the only valid explanations of illness and advise the most appropriate behavior (Irwin and Jordan 1987; Jordan 1987). However, recent work suggests that exploring the meaning that the illness holds for
the patient is essential to understanding non-compliant behavior (Kleinman 1981). What appears as non-compliance within the health care system may be normative and logical within the constraints of day-to-day life (Stimson 1974; Stimson and Webb 1975; Chrisman 1977; West 1979; Chrisman and Kleinman 1983; Levy 1983; Conrad 1985).

We conducted a diachronic, qualitative study of the illness experiences of a group of women and found that many did not comply with medically recommended treatments over an extended period of time. To try to understand why this was so, we examined two factors which are commonly cited by physician-centered researchers as causes of non-compliance: inconsistency between doctors' and patients' explanations of illness, and patients' failure to understand the diagnosis and therapy. We found these factors inadequate in explaining non-compliance in this group. Our interest in a patient-oriented approach led us to explore the everyday contexts in which the women used their treatments. Our results show the women were primarily concerned with controlling their symptoms and that they were constrained by the demands of the life situations in which they employed treatments. A consideration of these factors led to more useful explanations of their behavior. The discussion that follows is designed to assess the relative value of considering a patient-centered versus a physician-centered perspective in comprehending non-compliance in this group.

**METHODS**

In order to assess change in peoples' understandings of their illnesses over time, a series of interviews was conducted with patients of four physicians who worked in two private practices in a major mid-western metropolitan area. One was a fairly traditional internists' practice, the other specialized in metabolic dysfunctions. During a 6-month period, every woman making an appointment for the first time at either of these clinics was asked by the receptionist if the researchers could call her before her initial appointment. People were asked to participate in the series of interviews if during the screening phone call they reported two or more of the following symptoms: anxiety, irritability, dizziness, headaches, confusion, fatigue, palpitation, abnormal appetite, or tremor. These symptoms were chosen with the intention of forming a sample of women experiencing very common, but non-specific and vague symptoms. We interviewed 19 women who consulted with these doctors, eight from the internists' office and eleven from the metabolic clinic.

The sample was limited to women to reduce the number of potentially confounding variables. Based on the researchers' observations and estimations by clinic staff the sample did not differ in any substantial way from the general populations of either clinic. The study group ranged in age from 19 to 64 years...
old, with a mean age of 38. Their education level ranged from 11th grade through postgraduate, with three years of college the mean. Their incomes ranged from less than $10,000 to over $50,000, and was typically between $30,000 and $40,000.

**TABLE I**
Most Commonly Mentioned Reasons for Going to the Doctor

<table>
<thead>
<tr>
<th>Reasons</th>
<th>Times Mentioned*</th>
</tr>
</thead>
<tbody>
<tr>
<td>Headache</td>
<td>8</td>
</tr>
<tr>
<td>Fatigue</td>
<td>6</td>
</tr>
<tr>
<td>Dizzy/Lightheaded</td>
<td>5</td>
</tr>
<tr>
<td>Establish Contact with Doctor</td>
<td>5</td>
</tr>
<tr>
<td>Abdominal Pain/Distress</td>
<td>4</td>
</tr>
<tr>
<td>Hot Flashes</td>
<td>4</td>
</tr>
<tr>
<td>Possible Hypoglycemia</td>
<td>4</td>
</tr>
<tr>
<td>Overweight</td>
<td>4</td>
</tr>
<tr>
<td>Blood Pressure (High or Low)</td>
<td>3</td>
</tr>
<tr>
<td>Irritability/Stressed</td>
<td>3</td>
</tr>
</tbody>
</table>

* Because multiple reasons were often given, total > 19.

**TABLE II**
Diagnoses Reported by 4 Physicians for 19 Patients*

<table>
<thead>
<tr>
<th>Diagnosis</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Hypoglycemia</td>
<td>9</td>
</tr>
<tr>
<td>Allergy</td>
<td>6</td>
</tr>
<tr>
<td>Emotional Problems/Stress/Overwork</td>
<td>6</td>
</tr>
<tr>
<td>Thyroid Problems</td>
<td>5</td>
</tr>
<tr>
<td>Digestive Problems</td>
<td>5</td>
</tr>
<tr>
<td>Lack of Vitamins/Minerals</td>
<td>4</td>
</tr>
<tr>
<td>Infection</td>
<td>4</td>
</tr>
<tr>
<td>Pulmonary Obstruction</td>
<td>3</td>
</tr>
<tr>
<td>Climacteric Syndrome</td>
<td>2</td>
</tr>
<tr>
<td>Coronary Disease</td>
<td>2</td>
</tr>
<tr>
<td>Gallstones</td>
<td>1</td>
</tr>
</tbody>
</table>

* Because most patients received multiple diagnoses, total > 19.

The women sought medical assistance for a variety of reasons which primarily centered around such non-debilitating complaints as headache, fatigue, dizziness, abdominal distress, hot flashes, and weight gain (see Table I). The physicians' diagnoses were most often hypoglycemia, allergy, stress or overwork, thyroid problems and digestive problems (see Table II). The treatment most often recommended was diet change and vitamin supplementation (see Table III).

Each person was interviewed at five points in time. The first interview was about a week before the first consultation with the physician, the second about
| Patients Initials | MR | VC | SL | PK | YE | HT | WB | MM | CA | SM | TJ | SB | BK | SD | PP | DC | BD | BL | JV | Tot. |
|------------------|----|----|----|----|----|----|----|----|----|----|----|----|----|----|----|----|----|----|----|----|-----|
| Change of Diet   | x  | x  | x  | x  | x  | x  | x  | x  | x  | x  | x  | x  | x  | x  | x  | x  | x  | x  | x  | x   | 13  |
| Vitamins/Minerals| x  | x  | x  | x  | x  | x  | x  | x  | x  | x  | x  | x  | x  | x  | x  | x  | x  | x  | x  | x   | 12  |
| Antibiotics      | x  | x  | x  | x  | x  | x  | x  | x  | x  | x  | x  | x  | x  | x  | x  | x  | x  | x  | x  | x   | 4   |
| Quit Smoking     | x  | x  | x  | x  | x  | x  | x  | x  | x  | x  | x  | x  | x  | x  | x  | x  | x  | x  | x  | x   | 3   |
| Digestive Aids   | x  | x  | x  | x  | x  | x  | x  | x  | x  | x  | x  | x  | x  | x  | x  | x  | x  | x  | x  | x   | 3   |
| Reduce Stress    | x  | x  | x  | x  | x  | x  | x  | x  | x  | x  | x  | x  | x  | x  | x  | x  | x  | x  | x  | x   | 3   |
| Tranquilizers    | x  | x  | x  | x  | x  | x  | x  | x  | x  | x  | x  | x  | x  | x  | x  | x  | x  | x  | x  | x   | 2   |
| Surgery          | x  | x  | x  | x  | x  | x  | x  | x  | x  | x  | x  | x  | x  | x  | x  | x  | x  | x  | x  | x   | 2   |
| Allergy Inj.     | x  | x  | x  | x  | x  | x  | x  | x  | x  | x  | x  | x  | x  | x  | x  | x  | x  | x  | x  | x   | 1   |
| See Counselor    | x  | x  | x  | x  | x  | x  | x  | x  | x  | x  | x  | x  | x  | x  | x  | x  | x  | x  | x  | x   | 1   |
| Hygienic Regimen | x  | x  | x  | x  | x  | x  | x  | x  | x  | x  | x  | x  | x  | x  | x  | x  | x  | x  | x  | x   | 2   |
| Totals           | 2  | 2  | 2  | 2  | 1  | 3  | 2  | 1  | 3  | 2  | 5  | 3  | 3  | 3  | 3  | 2  | 2  | 3  | 1  | 2   |
two weeks after they received a diagnosis. Both of these were face-to-face
encounters, of one to three hours duration. Two short phone interviews were
also conducted with each person between the second and final face-to-face
interviews. The final interview was 14 to 16 weeks post-diagnosis and also was
between one and three hours long. The average time between the first and last
interviews was eighteen weeks (see Figures 1 and 2). All interviews were tape
recorded and transcribed.

The interviews consisted of both open-ended and fixed-response questions.
These questions focused on the patients' reasons for consulting the doctor, the
symptoms they were experiencing and their ideas about their cause, what
relieved or aggravated their symptoms, what treatments they pursued, the
women's thinking about the effect of treatments, and their sources of informa-
tion about their own condition and about health in general. In addition there
were questions about their daily routine, how that was affected by their
symptoms, and any changes in their lives over the interview period. The second
and last interviews also included questions about their impressions of the
physician and their understandings of the diagnoses and treatments recom-

Figure 1: Ideal Time-Line for Interview Scheduling.

Figure 2: Actual Time-line of Interviewing: Range and Mean of Time in Weeks.
mended. Most of the interviews were conducted in the women's homes, making some observations of their home lives possible.

In addition, the four physicians were also interviewed about each of their patients in our study, and their diagnoses and treatments for each. Medical chart information for each patient was reviewed after the last interview. Finally, one patient of each physician was accompanied by a researcher each time she consulted with the doctor or had related tests or procedures performed. These consultations were tape recorded and transcribed and careful observational notes were made of these interactions.

**TREATMENT COMPLIANCE OF THE STUDY GROUP**

The literature reflects wide variation in techniques used for measuring compliance. Although some studies use outcome as an indicator of compliance levels (see for example Becker et al. 1979), it is not generally considered an adequate measure since the condition may be self-limiting or the treatment ineffective. Most studies of compliance instead focus on pill-taking and compare what patients took with what physicians said they should have taken. Because researchers assume patients will not give adequate self-reports on compliance, more indirect means of assessing levels of compliance are often used. Pharmaceutical records of prescription refills and pill-counts (sometimes surreptitious) are the most commonly used indicators. The method considered most reliable is bio-assay, but this is rarely used since it is often too expensive or logistically impractical (Eraker et al. 1984).

All of these techniques focus on a single treatment modality, chosen *a priori* and based on the particular interests of the researchers. This, however, may not well represent the way treatment recommendations are actually made. In the group we followed, only two people were prescribed a single treatment, the rest received multiple instructions, averaging 2.3 treatments per person, and ranging as high as five separate recommendations in one case (see Table III). To comprehend the way treatment recommendations are perceived from the patient's perspective, it is necessary to consider the multiple concepts they are dealing with.

In the following analysis, a case-by-case approach of assessing compliance was taken in order to preserve the diversity and multiplicity of the women's treatment behaviors. These assessments were then aggregated to facilitate the following discussion. First, the medical chart of each patient was carefully reviewed, to determine what treatment was prescribed. Doctors were also interviewed about what they had recommended that each patient do. If applicable, this was supplemented by information from the clinics' staffs on instructions they gave patients, and by written information provided patients on
their particular condition and its treatment. A composite assessment of each person's compliance to recommended treatments was then made based on their responses to such open-ended questions as: "What did the doctor tell you to do?" "Are you able to do it?" "What have you been doing about your condition?" The responses to these questions were combined with information obtained during parts of the interviews about behavior (for example: "What's an average day look like for you?" and "Tell me what you've been doing to handle stressful situations lately."), and with observations of the women's behavior and their domestic environment during the interviews. The individual's focus in these responses determined which treatments we identified as central in the analysis of each case, rather than the physician's emphasis or the researcher's interest. For example, if a person had been told to take vitamins and to follow a diet, but focused exclusively on the vitamins in the interviews, her adherence to the vitamin regimen but not the diet would be emphasized in our assessment of her treatment behavior.

Based on systematic comparisons of the doctors' recommendations and patients' reported behavior, we classified each person's compliance with treatment. As we look at these women, there is a continuum from highly compliant to highly non-compliant. There are not simply two discrete groups. However, to facilitate discussion we have reduced this continuum to three categories: non-compliant, somewhat compliant and compliant. People who never or only rarely followed the central treatment recommendations were classified as non-compliant, those who followed some of them only part of the time were classified as somewhat compliant, and those who followed most of the central treatment recommendations most of the time were classified as compliant. Using these criteria we judge that two thirds of the people in this study (66%) are non-compliant or only somewhat compliant at two weeks post-diagnosis. By 15 weeks post-diagnosis this proportion rises to three fourths (74%).

Commonly, diachronic studies of health behavior span periods of only two or three weeks. Our assessments of compliance at two and at fifteen weeks indicate that these short time periods may be inadequate. The women in this study showed a trend toward decreasing compliance as time since the diagnosis increased. How can we account for both the lack of compliance in this group and its change over time?

COMPLIANCE AND CONGRUENCE BETWEEN PATIENT AND PHYSICIAN EXPLANATIONS

It has been a nearly axiomatic finding in social research on compliance that compliance is greater when the physician's diagnosis coincides with the
patient's explanation for an illness, and conversely, that inconsistencies in doctor and patient explanations are correlated with non-compliance (Koos 1954; Bury and Woods 1979; Blumhagen 1980; Nations et al. 1985; Chrisman 1983). Our data indicate that this formulation may be overly simplistic, failing to consider the importance of stability or change over time.

We compared patients' explanations at the time of each interview with those of their doctors. Doctors' explanations were noted from interviews with them about each patient and from reviews of their notes in the medical charts. Women's explanations were drawn from their responses to a variety of questions asked during each interview such as: "What do you think is causing your problem?" "Did what the doctor says make sense to you?" "Do you agree with it?" "Have you changed your way of thinking about your condition?" Responses to these questions were combined with other comments on these topics people made during the interviews. Since doctors as well as patients employed multiple diagnoses, the emphasis each placed on a particular aspect of the explanation was taken into consideration. Each facet of the explanation the patients used at each point in time was compared with each aspect of the physician's diagnosis. Each woman was then classified as showing high, moderate or low levels of congruence.

Consistent with previous studies, we found that patients showed a marked shift toward congruence with their physicians between the pre-diagnosis interview and the interview two weeks after diagnosis (cf. Chrisman 1983). However, patients' and physicians' explanations tended to show less congruence over time. Though 56% were highly congruent with the physician two weeks after diagnosis, this drops to 36% who were highly congruent by the 15-week interview. (For further discussion of these trends see: Hunt, Jordan, and Irwin 1989) Thus we see that both congruence and compliance decrease over time for the group. But what, we may ask, is their relationship?

At two weeks post-diagnosis those who are utilizing explanations congruent with physicians’ are no more likely to comply with the prescribed treatments than those who are not. On the contrary, slightly more of those who have views consistent with the physicians are non-compliant or only somewhat compliant. By 15 weeks post-diagnosis, 56% of the study group were still at least moderately in agreement with the physician, but failed to comply well with treatment recommendations. Incongruence between the patients’ and the doctor's explanations seems inadequate to account for non-compliance in this group. What might explain the fact that these people were not following the prescribed treatments, even though they agreed with their physician’s explanation? Let us turn now to another commonly studied variable to try to understand their non-compliance.
COMPLIANCE AND THE PATIENT’S PERSPECTIVE

COMPLIANCE AND RECALL OF MEDICAL INFORMATION

The most commonly studied variable in studies of non-compliance is that of patients’ knowledge about the diagnosed disease and prescribed therapy. Haynes, Taylor and Sacket cover 40 such studies in their review of the compliance literature, reporting great inconsistency in the findings (1979). Most of the studies they review concern strategies to increase patient compliance. They focus on the relationship between compliance and the patient’s knowledge of the diagnosis and treatment. Contrary to expectation, many studies of longterm therapy have found that although patients’ knowledge may be improved through providing increased information, improved knowledge is not correlated with increased compliance (McKenney et al. 1973; Sacket et al. 1975). This anomalous observation is made less so when the meaning of medical information from the patient’s perspective is considered.

Compliance studies that focus on patient education usually look at what patients remember. They fail to assess the sense that patients make of medical information, how useful they find it, or how convincing it is when compared with their own ideas (Tuckett and Williams 1984). We found that people base their judgment about diagnosis and treatment on their own experience and their interpretations of their bodily sensations. Whether or not a patient follows a physician’s directions is not simply a matter of whether the patient can understand them but also a question of how those directions fit in with the rest of their thinking and their lives.

For example, P.K. is a person whose understanding of her diagnosis is good, but whose compliance is poor. She consulted with the doctor because of headache, double vision, stomach ache, lethargy, and tiredness. She thought her symptoms might be related to hypoglycemia and stress. The doctor confirmed her suspicions and recommended a change in diet and increased exercise. For about a month she followed the diet fairly well and said she felt much better. Two weeks after diagnosis she said: “Food has become the answer for everything.” However, at 17 weeks post-diagnosis, while her conception of her hypoglycemia and its treatment remained essentially unchanged and quite similar to that of the physician, she rarely adhered to the diet. She said she felt worse, but she was unable to stay on the diet because of the demands of her life as a graduate student and teacher. She found the treatment useful in dealing with specific instances of symptom onset, but too cumbersome to employ on a day-to-day basis.

W.B. provides another example of someone who understands the diagnosis well but does not comply. She sought medical assistance in order to explore the cause of hot flashes she had been experiencing several times daily. She suspected the cause was menopause, but was skeptical because she thought it unlikely at her age of 43. The doctor told her that she indeed was entering
menopause and prescribed a tranquilizer to relieve her symptoms. Prior to the first interview she had already begun to read a great deal about menopause and by the second interview her knowledge of the physiology and symptoms of the condition was quite extensive. However, she still had not filled the prescription by the time of the 15-week interview. She said she did not feel that she really needed medication since the symptoms would subside on their own. Furthermore, she was very hesitant to take tranquilizers because several years earlier she had been taking a similar medication for depression and had developed a dependency and some serious side effects. W.B.’s previous experience caused her to fear that taking the prescribed tranquilizer might cause more problems than it solved. Thus, her high degree of understanding did not translate into compliance.

Although failure to understand medical information cannot explain non-compliance in these particular cases, can it do so for the others in the group? To address this question we compared doctors’ diagnoses as reported in doctors’ interviews and in the medical records with patients’ responses at each interview to the question: “What did the doctor say was the problem?” Each aspect of the doctor’s diagnosis was compared with those in the patient’s report of what she understood the doctor to say. Since all diagnoses were multiple, the emphasis the doctor placed on each aspect was considered. Women who did not include all the major points of the doctor’s diagnosis in their responses were classified as inaccurate; those who included all the major facets, but with some discrepancy in their understanding, were classified as moderately accurate; and those who reported all the major points correctly were classified as accurate.7

The women were remarkably accurate in recalling the doctors’ diagnoses. Even at the time of the 15 week interview 95% (18) of the women’s reports were accurate or differed from their doctor’s in only minor ways.

The data show that even when our informants have a good understanding of the information provided by the physicians, they do not necessarily comply with prescribed treatments. Most of those who were non-compliant or only somewhat compliant at two weeks post-diagnosis were able to accurately report what the doctor said. Even at 15 weeks post-diagnosis, poorly compliant individuals are evenly divided between high accuracy and moderate to low accuracy. Given time, the women became less compliant, but no less accurate in remembering what the doctor said. In fact, at both points in time most of those reporting diagnoses accurately were not complying well with the recommended treatments. Clearly, factors other than the patient’s understanding of diagnoses account for non-compliance in this group.
Patients are portrayed as passive in many studies of their behavior and this is the case in most of the compliance literature. The ideal patient is often thought to be cooperative, acquiescent, obedient, passive and deferential. We have found that real patients are not passive recipients of recommendations, but are reflective actors who review information about health and illness and make decisions based on what makes sense given their experience of bodily changes, the framework of their prior knowledge, and the everyday life situation in which the illness is lived and the treatment used (see also Stimson and Webb 1975; Mathews 1983). They are active interpreters of medical information (see Hunt, Jordan and Irwin 1989; Irwin, Jordan n.d.).

Previous studies have shown that people continually reevaluate their explanation for their illness and its treatment as their experience unfolds and as they try to fit the explanation and treatment into their daily lives. Variations in experience will necessarily lead to varying degrees of compliance (Chisman and Kleinman 1983). Conrad (1985), for example, in studying compliance to medication for epilepsy found that patients modified their use of medication in ways which were meaningful in terms of their everyday lives. Patients' modifications allowed them to test the effect of the drug, to control their dependence on it, to reduce the stigmatization they experienced, and to accommodate the practical constraints on their use of the medication. Thus viewed from the patient's perspective, as self-regulation rather than as non-compliance, the modified treatment behavior becomes comprehensible. Conrad notes that patients are not passive, but rather are active agents, who interpret and modify prescribed regimens to create a "medication practice" which may differ slightly or markedly from that prescribed, but which acts as a vehicle for exerting control over illness.

For the women in our study, self-regulation was also a major issue in their pursuit and interpretation of treatment. Most of those who were not complying with medical advice 15 weeks post-diagnosis had modified the prescribed treatment in ways that allowed them to control their symptoms. A frequent trend was for a person who initially followed the doctor's recommendations to modify the regimen in some way and continue to pursue a treatment that was somewhat idiosyncratic. These modified regimens often incorporated many of the doctor's recommendations but permitted the woman greater latitude. The women often viewed these modified regimens as, in principle, consistent with what the doctor had recommended. Another frequent pattern was for the person to be non-compliant unless they were bothered by symptoms, in which case they conscientiously pursued the prescribed treatments. These women reverted to their more normal behaviors when they felt well. Commonly, people who had modified their treatment practices expressed satisfaction with the diagnosis and treatment,
for they felt they had gained knowledge of how to control their conditions.

H.T.'s behavior is typical of people who fit this pattern. She had been experiencing periods of extreme fatigue, headaches, and facial pain. The doctor found she had hypoglycemia and calcium deficiency and recommended a regimen that included a change in diet, exercise, and vitamin supplements. At about two weeks post-diagnosis she was religiously following the doctor's recommendations. She said that she felt terrific. By 15 weeks post-diagnosis, however, she had gone back to her previous diet, stopped exercising and suspended the supplements. When she experienced symptoms, however, she would return to the prescribed treatments for a few days. Then when she felt better she would again return to her pre-consultation routines. She said she was very satisfied with the diagnosis and treatment since she now knew how to control the problem. The issue for her, and for many others in our study group, was not that they should be pursuing a certain treatment regimen in order to remain healthy. Rather they sought information they could use to restore themselves to a healthy state when they felt ill.

S.L. provides another example of modifying treatment to control symptoms. She is a 20-year old medical assistant who was experiencing recurrent urinary tract infections during the course of the study. The doctor, who prescribed antibiotics to treat the infections, told her she must finish the course of pills for them to be effective. Twice during the series of interviews she stopped taking the medication when her symptoms subsided. Upon suspending the first course she said: "I didn't take them and I felt good for a week ... I didn't take all of them, but it didn't matter. [When it came back] he just said to take more." After taking some of the second course of pills and again stopping when the symptoms subsided, she said: "I feel better now because of the medicine ... I still have some left. I'll take them if it starts up again." For her, relief of her symptoms was the only point of the treatment. She adjusted her use of the medication in a way that allowed her symptoms to subside, and she was satisfied with the results. Because the doctor had told her that hers was a case of recurrent infection, she said she expected to intermittently have to deal with her symptoms in this manner.

Most of the non-compliant patients in this study showed similar behavior. Treatment was not altogether abandoned, but only pursued when the symptoms were problematic.

**COMPLIANCE AND CHANGES IN DAILY ROUTINES**

In analyzing our data it becomes clear that compliance or non-compliance with treatment regimens are not a result of deliberate or explicit decision-making so much as actions arrived at in the course of living through everyday situations.
Patients may or may not hold constructions of their illness compatible with the physicians', and may or may not understand the diagnosis and treatment, but treatment actions always happen from moment to moment within the framework of the patient's day-to-day life.

The present analysis indicates that a major factor affecting levels of long-term compliance is how readily the treatment fits into the person's preexisting life. For most people we spoke with, as for H.T. in the above example, normal life routines tend to take precedence over treatment regimens, especially given time. This trend can be seen in virtually every case involved in this study. Nearly all those who were complying at a high level at 15 weeks post-diagnosis were pursuing treatments that were readily compatible with their everyday lives. For example, V.C. and Y.E. were both very carefully following prescribed diets at the time of the last interview. Both had been involved in dietary manipulation for a long time prior to their medical consultations, and dieting was thus already a habitual course of action for each of them. There were only two women who were moderately compliant with treatments that required them to make important changes in their daily routines: both had been diagnosed as having serious heart conditions.

Of the many individuals who were prescribed treatments which would require a long-term major change in their daily routines, none was highly compliant by the time of the last interview. For example, five people were prescribed strict changes in diet. All were women whose diets had been very erratic and heavily involved foods excluded from the recommended diets; all habitually skipped meals due to intensive work schedules and relied on high sugar or carbohydrate snacks through the day. They would usually eat only one meal a day, in the evening. This generally was a large one, often consisting of "fast food."

The recommended diet for each of these women was to eat high protein foods in small frequent feedings and to avoid sugar and carbohydrates. All tried, with some success at first, to pursue the dietary changes. Only one, B.K., managed to comply through the second week post-diagnosis. None was compliant by 15 weeks post-diagnosis. All had reverted to some semblance of their initial eating pattern, citing the restrictions and demands of their jobs as reason for not being able to follow the doctor's recommendation.

They all felt they should be pursuing the prescribed diet, and said they would if they could do so while going on with the necessary routines of their lives. In these five cases, a treatment which could not be integrated readily into their normal routine was abandoned, in whole or in part, because it did not prove serviceable in terms of the person's everyday situation.

A rather striking example of an individual struggling to incorporate treatment recommendations into the requirements of her everyday life is seen in the case of S.M. She is a 58-year old woman who is married to a man who has suffered from severe mental problems for the past twenty years. Her life has been totally
absorbed with caring for her husband. "It's like having a child," she said, "day and night you have to watch him." Just before coming to one of the doctors involved in this study, she had been told by another doctor that she had a serious heart condition. She had been put on medication that she said made her very sleepy and caused severe, debilitating headaches. Because of her husband's need for constant attention, she felt she could not take the heart medication. After two days she completely stopped the medicine and rejected the idea that there was anything wrong with her heart. At her family's insistence, she sought another physician's opinion about her heart.

The second doctor (the one involved in this study) found nothing wrong with her heart, but told her that her main problem was the stress caused by caring for her husband. This, he said, was causing her physical problems. He recommended tranquilizers three times a day and also told her she needed surgery for gallstones.

At the two-week interview she said she "[couldn't] take the tranquilizers since you can't have two dopeys in the house." However, during a period when her husband was temporarily hospitalized for his mental problems, she had the gallbladder surgery. This treatment was more acceptable to her because she expected this to disable her only for a limited amount of time. Her family came to her temporary aid while she was recuperating. She later said: "I rushed the recovery because of my predicament." As soon as she was able to function at all, she resumed caring for her husband who was again at home.

S.M. rejected the heart medication and tranquilizers because she perceived them to require that she limit her usual level of activity - something she felt she was unable to do. The gallbladder surgery was more acceptable since it did not require a long-term role change. By the time of the 15-week interview she had begun to take the tranquilizer, but she had her own schedule for taking it so that she could control their impact on her life. She said: "If it gets rugged, I'll take it around 5:00. But it makes me a little dovey yet in the morning. I have to really limit it." In the case of S.M. we see how the suitability of a treatment is assessed in terms of its compatibility with the milieu in which it is to be employed. Now, we shall consider whether the incompatibility of treatment with the individuals' life routines accounts for non-compliance for the group as a whole.

The treatment recommendations for each case were reviewed and compared with the life-situation and pre-diagnostic habits reported by each person. We examined each woman's responses pre- and post-diagnosis to such questions as: "What have you been doing about your health?" "How does your condition affect your daily life?" "What's an average day look like for you?" "Have there been any changes in your daily routine?" These responses were supplemented by information the women provided about their life in general and the health history and background information they provided about their habits and lifestyle during both interviews and observations. This information provided the
background for classifying the prescribed treatments as requiring little change, moderate change or major change in the person's daily life.

We found a marked negative relationship between compliance and the amount of change treatment required: for the group as a whole, as the degree of difficulty of treatment increased compliance decreased. Fourteen weeks after diagnosis those whose treatment required little change were evenly divided between compliance and non-compliance. Of the five whose treatment required moderate change two were compliant at this time. Finally, of the eight whose treatment would have required that they make a major change in their lives, only one was compliant at two weeks post-diagnosis, and none was at 15 weeks. Clearly, for this group, long-term compliance requires that the treatment fit in with the person's life situation.

CONCLUSIONS

Most of the compliance literature is unilateral in that it takes the physician's perspective and fails to consider the views of patients in their own terms. Our data show that considering the context in which patients utilize diagnoses and treatments is important in understanding their health behavior, especially in the long run. To be able to utilize a diagnosis and its associated treatment in their day-to-day lives, patients must actively interpret them. Elsewhere, we have shown that people often modify a diagnosis in order to incorporate it into their pre-existing understandings about their illness (Hunt, Jordan and Irwin 1989).

In this paper we have sought to show that viewing patients as active participants in their own treatment facilitates understanding their health-related behavior. Those we interviewed generated ways of understanding and acting upon their health conditions compatible with their everyday needs and experiences. This permitted them to incorporate their interpretation of their illness and its treatment into their everyday lives. What appears to be contradictory or illogical health behavior becomes more understandable by taking this into consideration. In contrast with the findings of much of the compliance literature, non-compliance in our study group could not be explained by patients' failure to understand their diagnosis, or by disagreement with their physicians over the diagnosis. These women's use of treatments instead reflects their desire to control their symptoms within the constraints of their daily routines.

We do not know the extent to which our findings are generalizable to other populations because of our small sample size and its exclusion of people with severe or disabling symptoms. Conventional wisdom would suggest that in cases where symptoms are severe or disabling compliance would be greater. However, extensive previous research does not support this expectation. In a comprehensive review of the compliance literature Haynes (1979b) reported that studies
most often find no correlation between symptom severity and compliance. Moreover, compliance may decline rather than increase with greater number of symptoms. There is some evidence that greater degrees of disability may be associated with increased compliance, but studies suggest this may be due to the increased supervision which often accompanies disability. Our data would lead us to expect that people with severe or disabling symptoms would also evolve treatment practices compatible with their life situations to the extent that they are able to influence the content and course of their treatment.

The findings for our study group are clear. For these women the issue in health behavior is not compliance, but controlling symptoms with treatments they can live with. They strive to fit the diagnoses and treatments into their everyday routines in ways which would allow them to feel better while not making drastic changes in their life situations. Thus, the relevant question to consider in trying to understand non-compliance is whether or not the patient can make the diagnosis and treatment useful. To be of any real value the treatment for an illness must be usable. It must be capable of addressing illness as it occurs in the context of everyday life.

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COMPLIANCE AND THE PATIENT'S PERSPECTIVE

NOTES

1 There has been some increasing effort in compliance research to take patients' perceptions into account by using the Health Belief Model (HBM). (For reviews of this method see: Becker et al. 1979; Janz and Becker 1984.) However, this approach still amounts to measuring patients' perceptions in terms of the physician's diagnostic category (the disease), rather than the patient's own explanations. The HBM considers patients' conceptualizations and decision-making only to the extent that they relate to the diagnosis at hand. It thus fails to consider patients' understandings of their condition independent of that of the physician.

2 The rate of refusal at this stage is unknown since the receptionists failed to keep records. We estimate that about 70% agreed to be called. Of the 29 women asked by the researchers to participate in the study 23 (80%) agreed. Four of these women did not consult a physician and therefore are excluded from this analysis.

3 These symptoms were chosen because they are the most commonly mentioned in the hypoglycemia literature. The medical diagnosis of hypoglycemia has been the subject of a great deal of controversy. Some doctors diagnose it regularly and others believe it to be a fallacious disease category and never diagnose it (Hunt 1985). One of our original foci was to see what differences there were in the illness experience of people with similar symptoms who were diagnosed as hypoglycemic and those who were not. We found however that few people sought medical consultation primarily for these symptoms. Instead they were seeking treatment for a variety of problems, of which these symptoms were a sub-set. We came to realize that our focus upon hypoglycemia and its symptoms had been too narrow. Early in the research we broadened our focus in the interviews to examine the full range of symptoms and diagnoses the women were dealing with.

4 For the sake of simplicity the patients of the two clinics will not be distinguished in the following discussion. It should be noted, however, that there are some systematic differences in the kinds of diagnoses and treatments recommended in each clinic. Preliminary analysis shows no straightforward relationship between compliance and clinic, but that the differences between the clinics may be influencing the compliance rates in some complex ways. The implications of these differences are of some interest, but lie beyond the scope of this paper.

5 One person was unavailable for several of the interviews. For this reason N=19 for the first and last interviews, and N=18 for the two-week and the phone interviews.

6 The rate of non-compliance in this group is rather high when compared to the 30% to 50% found by most other researchers. Our sample is too small to allow us to account for this difference; further research would be necessary to pursue this question. Some possible reasons for this higher rate are: 1) The length of time our study involves is considerably longer than is common in compliance research. 2) The treatments prescribed those in our sample often involved more demanding behavior changes, such as altering diet, than the simple pill-taking behavior usually studied in compliance research. 3) Our qualitative method may result in a closer scrutiny of patient behavior than the more usual quantitative methods of compliance research.

7 These comparisons are based on what the physicians reported they had told patients. We have no way of knowing what was actually said, except for the few cases in which patient-physician interactions were actually observed. Based on those observations, we believe the physicians' report of what they said to be fairly accurate.
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