

SYMPTOM MONITORING AND USAGE IN
CHRONIC MENTAL ILLNESS

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ABSTRACT

The major purpose of this descriptive study was to determine whether clients with chronic mental illness were able to identify symptoms they associated with their illness and whether they took action based on their symptom experience. Secondly, the study (a) examined whether clients use feedback from a support person to identify when their symptoms were getting better or worse, (b) explored the clients' perception of the causes, duration, and consequences of their chronic mental illness, and (c) investigated whether clients had been told how to monitor the symptoms of their illness.

Thirty subjects, diagnosed with schizophrenia from an outpatient mental health clinic, participated in the study. The subjects were interviewed using a semistructured questionnaire. Twenty-seven of the subjects reported using symptoms as indicators of when their condition was getting worse. The majority of symptoms were neurotic or stress-related symptoms while only a small portion of these symptoms were psychotic in nature. All 30 subjects reported using symptoms as indicators of when their condition was getting better. Less than one-third of the subjects used feedback from a support person to assist them in telling when their illness was getting better

and/or worse.

Twenty-six subjects took action on symptoms used as indicators of their illness. Most of the actions were categorized in the active coping phase, a phase consisting of activities utilizing high energy, rather than the rest phase, a phase consisting of resting activities.

Only seven subjects stated they had been told how to monitor when their condition was getting better or worse. The majority of subjects attributed their illness to external factors and perceived their illness to affect numerous areas of their lives. Only slightly more than one-third of the subjects perceived their illness and their need for treatment as chronic.

Findings indicate that clients with chronic mental illness do use symptoms to monitor when their condition is getting better and/or worse and do take action on identified symptoms.

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TABLE OF CONTENTS

	Page
ABSTRACT	ii
ACKNOWLEDGEMENTS	iv
TABLE OF CONTENTS	v
LIST OF FIGURES	vii
LIST OF TABLES	viii
Chapter	
I. INTRODUCTION	1
Statement of the Problem	1
Review of the Literature	3
Chronic Mental Illness as a Concept ..	4
Research on Chronic Mental Illness and Symptoms	13
A Model of Self-Regulation	23
Components of Self-Regulation in Chronic Mental Illness	24
Purpose of the Present Investigation and Research Questions	27
II. METHOD	29
Design	29
Setting and Subjects	29
Measure	30
Chronic Mental Illness Symptom Interview (CMISI)	30
Procedure	31

Chapter	Page
III. RESULTS	32
Description of Subjects	32
Identification of Symptoms	33
Action on Symptoms	40
Cause, Consequences, and Duration of Illness	43
Monitoring of Illness	48
IV. DISCUSSION	49
REFERENCES	61
APPENDIX	
A. Chronic Mental Illness Symptom Interview .	66

LIST OF FIGURES

Figure		Page
1.	Components of self-regulation in chronic mental illness.	26

LIST OF TABLES

Table		Page
1.	Categories and Frequencies for Symptoms Used as Indicators of Condition Getting Worse	35
2.	Checklist Symptoms Reported Most Frequently by Subjects	38
3.	Checklist Symptoms Reported Least Frequently by Subjects	39
4.	Active Coping and Rest Phase Model	41
5.	Cause of Nervous Condition Checklist	44
6.	Consequences of Nervous Condition Checklist	45
7.	Perceived Duration of Illness and Treatment	46
8.	Distribution of the 18 Subjects Indicating Congruence between Perceived Duration of Their Illness and Perceived Duration of Their Treatment	48

CHAPTER I

Introduction

Statement of the Problem

Although an increased interest has been shown in assisting the chronically mentally ill, they continue to be stigmatized by society and are a group about whom even health professionals are dubious. Health professionals may play the role of attentive listener as clients tell their stories, but give minimal credence to their clients' subjective experiences. Attention is focused on medication side effects, adherence to treatment regimes, attendance at jobs, and/or family reports of behavior and daily functioning. While these are important criteria, it seems little value is placed on the clients' personal views of their illness. Health professionals may minimize and even devalue the clients' subjective experiences.

If the chronically mentally ill feel their stories are minimized or devalued by health professionals, they may minimize or stop their reports of subjective experiences. Health professionals would then no longer have access to the rich source of data that at one time was offered willingly. It is important that health professionals not only recognize the value of clients' subjective

experiences, but also integrate these experiences with other aspects of treatment.

Recent research by Leventhal, Meyer, and Nerenz (1980) indicated that clients' subjective experiences of their chronic physical illnesses were an intricate part of their responses to treatment regimes. More specifically, Leventhal and associates (1980) have shown particular interest in clients' reports of symptoms associated with their chronic illnesses. They reported the use of symptoms to be highly representative of how clients view their illnesses. For example, research with hypertensive clients revealed that although they believed hypertension to be asymptomatic for the general population, the clients, themselves, believed they could tell when their own blood pressure was elevated based on certain symptoms they were having (Leventhal, Meyer, & Nerenz, 1980).

In other studies involving clients with lymphoma and metastatic breast cancer, Leventhal and Nerenz (1981) found that clients responded to their illness in terms of how quickly tumors disappeared once treated with chemotherapy. Clients with tumors that disappeared quickly or completely were much more anxious than those who observed a gradual shrinkage of their tumors. In this particular group of clients, the presence and size of tumors were used as the representative signs of the disease condition.

Generally speaking, symptoms are useful to clients

because they serve as monitors of the disease process and treatment progress. The symptom is used as a cue which provides automatic and continuous feedback about one's condition and allows clients to determine their illness status.

Not only do symptoms allow clients to monitor their illness status, but they also influence clients to take specific actions in response to the symptom experience. O'Connell, Hamera, Knapp, Cassmeyer, Eaks, and Fox (1984), in their study of diabetics who used symptoms to monitor their blood glucose levels, found that the majority of subjects took action on symptoms used as signals of high blood glucose levels.

Thus far, Leventhal, Meyer, and Nerenz's (1980) and Leventhal and Nerenz's (1981) research has been applied to clients with chronic physical illnesses and related symptomatology. A logical extension of their framework is to clients with chronic mental illness. Therefore, the major purpose of the present study is to investigate whether the chronically mentally ill can identify symptoms they associate with their illness and whether they take action based on these symptoms.

Review of the Literature

The review of the literature begins with a general discussion regarding the concept of chronic mental illness;

this discussion will include definitions, properties, theoretical models, and explanations of chronic mental illness. The second section will summarize the various ways the symptoms of chronically mentally ill individuals with schizophrenia have been investigated. The study of symptoms in terms of diagnosis, prognosis, and the hierarchical model of personal illness will be presented. In addition, research focusing on clients' reports of their subjective symptom experiences will be discussed. The third section will discuss Leventhal, Nerenz, and Straus's (1980) model of self-regulation and how this has been applied to the study of chronic physical illness. Finally, a model of the components of self-regulation for chronic mental illness will be presented.

Chronic Mental Illness as a Concept

What is chronic mental illness? Who are the chronically mentally ill? Identified as a major health problem, "chronic mental illness is discussed, debated, and deplored, but rarely defined" (Krauss & Slavinsky, 1982, p. 3). In many institutions, the label of chronic mental illness seems to be determined by the length of time a particular client has contact with a particular institution. A popular diagnosis given the chronically mentally ill client, who has symptoms "persisting over a number of years without remission," is that of chronic

undifferentiated schizophrenia (Krauss & Slavinsky, 1982, p. 4). Furthermore, society in general seems to link chronic mental illness with schizophrenia.

Strauss and Glazer (1982), however, believe the idea of equating chronic mental illness to schizophrenia is changing. They stated: "In the past, chronicity in psychiatric disorder has also been equated more or less with the diagnosis of schizophrenia, but at least this unfortunate practice appears to be diminishing" (p. 207). Rather, they believe the chronically mentally ill are often viewed as a "homogenous group of people with a hopeless prognosis for which only limited treatment resources should be utilized" (p. 207). Strauss and Glazer (1982) further identified chronicity in terms of the following four dimensions:

- (1) chronicity of symptoms,
- (2) chronicity of dysfunction in occupational or relationship spheres,
- (3) chronicity of receiving treatment, and
- (4) the chronic attitude--a sense of hopelessness, of having given up, of having settled into being bizarre or disabled. (p. 208)

Over the years, essentially five theoretical models utilized in the definition and explanation of chronic mental illness have evolved. These five models are known as the medical, epidemiological, sociological, intrapsychic, and mythological models. The medical model focuses on the ills of the body and values physical interventions. This model has generated one of the most

effective interventions utilized by the health care system in the treatment of the chronically mentally ill, that being medication. The epidemiological model is similar to the medical model in that it, too, focuses on the ills of the body, is highly concerned with the incidence and prevalence of disease, and has been most valuable in acquainting health care professionals with the broad scope of the problem of chronic mental illness.

The sociological model, having a social science base, is concerned with the ills of the group, rather than the ills of the individual. It focuses on social engineering and helps initiate change in institutional structures. The fourth model, the intrapsychic model, studies the individual rather than the group. It focuses on the ills of the mind and promotes the alteration of one's interpersonal environment by individual or group psychotherapy. Finally, the mythological model, an anti-science model, is one that proposes that the chronically mentally ill are simply individuals who choose to live their lives less conventionally and less rationally than the majority of individuals in society. This model has been the proponent of a more humanitarian approach in the treatment of the chronically mentally ill, one that includes patient advocacy and political and legal reform.

In light of the discussion above, Krauss and Slavinsky (1982) believe that the chronically mentally ill

should not be viewed from any one perspective. Rather, they believe it best to utilize an approach that integrates each of the five models into one that views chronic mental illness from a medical, epidemiological, sociological, intrapsychic, and mythological perspective.

Although numerous perspectives and explanations of chronic mental illness have been recognized, the lack of a universal definition defining chronic mental illness and who are the chronically mentally ill, makes it difficult to have an adequate understanding of this concept. Therefore, Krauss and Slavinski (1982) found it easier to explain the concept in terms of what chronic mental illness is not. They began by stating, it is not a diagnosis, not a diagnostic category, but an illness that encompasses all diagnostic categories.

Chronic mental illness is not unique to any specific age group. Children, teenagers, young adults, and the elderly may all develop chronic mental illness. "The fact that chronic illness is neither age specific nor clearly developmentally linked is one of the most difficult features affecting its prevention and diagnosis" (Krauss & Slavinski, 1982, p. 19). In addition, chronic mental illness is not an illness which may be attributed to any specific socioeconomic class. Although often stereotyped as a disease of the poverty stricken, both rich and poor alike suffer with this illness.

If chronic mental illness cannot be explained in terms of diagnosis, an age group, or a specific socio-economic class, how may one differentiate this illness from any other mental disorder? Krauss and Slavinski (1982) believe that "once a patient's difficulties have been categorized as 'mental illness,' of whatever variety, the illness can be considered chronic if four properties are found to be present" (p. 20). A chronic mental illness is: "severe, permanent, stigmatized, and contagious" (Krauss & Slavinski, 1982, p. 20).

Chronic mental illness is severe in the sense that it becomes an intolerable burden for both client and family alike, if professional intervention is not sought. Many individuals with chronic mental illness have symptoms which are not adequately controlled by medication or psychotherapy. Such symptoms as thought disorders may significantly impair the individual's ability to solve problems in day-to-day living. Changes in affect or disturbances in mood may hinder one's personal, social, and occupational relationships. The person may become so dysfunctional that a massive lifestyle change in the family unit becomes a necessity. Finally, the severity of impairment may become such that the only choice of a living situation becomes one of institutionalization.

Permanence is probably one of the strongest defining and diagnostic properties of chronic mental illness.

Although the illness is marked by periods of remission, the chronically mentally ill individual lives with the constant expectation that, given enough time or the right stressful event, the symptomatology of the illness will reappear. It seems this aspect of permanent mental illness is one that sets the individual apart from society for the rest of his/her life.

Society's response to permanent or chronic mental illness is often one of labeling or stigmatizing the individual. In fact, "the prevailing social attitude toward chronic psychiatric illness differs in quality from that toward acute illness in our society" (Krauss & Slavinski, 1982, p. 22). Society is more accepting of individuals with acute mental illness. Those individuals who suddenly cannot cope with the stress of everyday living are usually offered a great deal of sympathy and support from loved ones. Furthermore, once the crises have passed, these individuals may even be admired for having persevered and conquered their particular stressors.

The attitude toward chronic mental illness has been closely paralleled to that of a progressive or terminal physical illness. When individuals in both categories are first diagnosed, society responds by offering much support, much optimism, and vigorous treatment interventions. However, when these illnesses do not remit or even

lives to the care of this perennial child.

The contagiousness of chronic mental illness extends beyond the family of origin. Chronically mentally ill individuals who do leave their parents and have families of their own oftentimes put their own offspring at risk (Krauss & Slavinski, 1982). Liabilities in the form of "bad genes," environmental stressors, and/or separations from parents who are repeatedly hospitalized hardly offer children "sane" upbringings.

Finally, the contagiousness of the illness is felt by society. Because most chronically mentally ill individuals do not recover, caring for them becomes a tremendous financial burden. Families who do assume financial responsibility for these individuals are most often only able to do so temporarily, before they must resort to assistance from public funds. Society is then faced with the growing problem of taking care of the chronically mentally ill, be it in the form of community services, social rehabilitative services, and/or welfare.

While Krauss and Slavinsky (1982) have expanded the concept of chronic mental illness in an interesting way, the four properties, severe, permanent, stigmatized, and contagious, are difficult to operationalize and utilize for research purposes. Strauss and Glazer (1982) offered understanding of the concept of chronicity which is easier to operationalize. Chronicity is abstractly defined in

terms of: (a) chronicity of symptoms, (b) chronicity of dysfunction in occupational or relationship spheres, and (c) chronicity of receiving treatment. Although Strauss and Glazer (1982) do not equate chronic mental illness with schizophrenia, the diagnosis of schizophrenia most clearly meets their criteria. For example, chronicity of symptoms and of receiving treatment (Strauss & Glazer, 1982) are related to the DSM-III (1980) criteria that states that an individual with chronic schizophrenia must show specific signs of the illness for over two years. Secondly, chronicity of dysfunction in occupational or relationship spheres (Strauss & Glazer, 1982) is related in a similar fashion in the DSM-III (1980) that states that an individual with chronic schizophrenia demonstrates "deterioration from a previous level of functioning in such areas as work, social relations, and self-care" (p. 104). In addition, the DSM-III (1980) states that an individual must demonstrate onset of the "prodromal or active phase of the illness before age 45" (p. 106). Finally, the individual with chronic schizophrenia must be clearly distinguished from those individuals with an organic mental disorder or a disorder of mental retardation (DSM-III, 1980). Although other mental disorders such as major affective disorders and anxiety disorders may meet Strauss and Glazer's (1982) criteria for chronicity, the present study will limit the definition of

chronicity to include only subjects with the diagnosis of schizophrenia.

Research on Chronic Mental Illness and Symptoms

The concept of chronic mental illness is believed to encompass more than a diagnostic category; however, most researchers investigating chronic mental illness have focused on schizophrenia. A number of these researchers have specifically investigated symptoms associated with schizophrenia and have classified symptoms in a variety of ways. One method of classifying symptoms has been according to Schneider's first-rank symptoms (Carpenter, Strauss, & Muleh, 1973; Mellor, 1970, Taylor, 1972). These symptoms, utilized by Schneider for diagnosing schizophrenia, include auditory hallucinations, experiences of alienation and influence, through broadcasting, and delusional perceptions (Taylor, 1972). Carpenter, Strauss, and Muleh (1973), in their investigation of the frequency of first-rank symptoms in schizophrenia, found the presence of one or more first-rank symptoms in 53 (51%) of 103 schizophrenic inpatients. Mellor (1970), in a similar study, reported the presence of first-rank symptoms in 119 (72%) of 166 schizophrenic inpatients. Taylor (1972), however, upon examining the case records of 78 male inpatients with schizophrenia, found that only 28% had first-rank symptoms. Carpenter, Strauss, and Muleh (1973)

further found that first-rank symptoms do not occur exclusively in clients with schizophrenia. Investigators (Carpenter et al., 1973; Mellor, 1970; Taylor, 1972) also studied the relationship between the frequency of first-rank symptoms and the duration of illness, and reported conflicting findings. Taylor (1972) found that the majority of clients with poor prognoses (based in part on duration of illness and premorbid adjustment) also exhibited first-rank symptoms, while clients with good prognoses did not exhibit such symptoms. Mellor (1970), on the contrary, found that clients with first-rank symptoms had been hospitalized fewer times and had a shorter duration of illness than those clients without first-rank symptoms. Carpenter et al. (1973) investigated the relationship between the duration of hospitalizations and illness in both clients with and without first-rank symptoms and found that first-rank symptoms were not reflective of chronicity.

Several researchers have studied symptoms for other than diagnostic purposes. They have investigated the symptoms of schizophrenic clients in hopes of linking individual symptoms to a good or poor outcome. McCabe, Fowler, Cadoret, and Winokur (1972), in their study of 53 schizophrenic inpatients, investigated symptom differences between patients with good and poor prognoses. Good prognoses were based on satisfactory premorbid functioning and

acute onset (less than six months). Clients with good prognoses were more likely to exhibit the following symptoms: mania or depression, perceptual disorders, visual hallucinations, and confusion and were less likely to have a special combination of haptic and auditory hallucinations and affective blunting. In fact, affective blunting "differentiated the good and poor prognosis group at the $p < .05$ level" (McCabe et al., 1972, p. 61). The reliability of these findings is questionable due to the small sample sizes of each of the outcome groups.

Two other studies (Bland & Orn, 1980; Carpenter, Bartko, Strauss, & Hawk, 1978) reported findings similar to those of McCabe et al. (1972). Carpenter's et al. (1978) five-year follow-up study of 131 acute psychiatric inpatients, of which 61 were diagnosed with schizophrenia, revealed that only one symptom variable, "restricted affect," predicted poor outcome. In a second study, Bland and Orn (1980) investigated the relationship between presenting symptoms in 43 acute schizophrenic inpatients and their long-term outcome 14 years later. Findings revealed that several symptoms were related to a good and poor outcome, but the one finding that concurred with those of McCabe et al. (1972) and Carpenter et al. (1978) was the association of "inappropriate affect" to poor outcome. A limitation of Bland and Orn's (1980) study was that presenting symptoms were obtained from case records.

In contrast to these three studies, results of a two-year follow-up study of 185 acute schizophrenic inpatients revealed that affective symptoms did not have prognostic value in schizophrenia (Gift, Strauss, Kokes, Harder, & Ritzler, 1980). In addition, Carpenter et al. (1973), in their previously mentioned study of first-rank symptoms, found no relationship between the presence or absence of first-rank symptoms and outcome for clients with schizophrenia. Thus far, two approaches which researchers have taken in investigating symptoms have been reviewed, these being the study of symptoms for: (a) diagnosis and (b) prognosis. Other researchers have related symptoms to a hierarchical model of classes of personal illness as proposed by Foulds and Bedford (cited in Palmer, Ekisa, & Winbow, 1981). Palmer et al. (1981) defined the hierarchical model as follows:

(. . .) when symptoms are arranged in a hierarchy of classes according to their severity with respect to personal functioning, the more severe will occur only in the presence of the less severe, but not vice versa. Thus the most severe symptoms, Delusions of Disintegration (Class 4) will be found only when the subject also experiences Integrated Delusions (Class 3), Neurotic Symptoms (Class 2), and Dysthymic States (Class 1). (p. 209)

The two following studies, utilizing the Delusions-Symptoms-Sign Inventory (DSSI) to test this model, reported on the hierarchy patterns in chronically mentally ill clients. Bedford and Presly (1978), in their study of

33 chronic nonparanoid schizophrenic inpatients from two long-stay wards, found that 81% reported symptoms which complied with the hierarchy hypothesis. The investigators, however, reported a most atypical finding for a chronic population, in that over half (54%) of the distribution were allotted to the two least severe classes--Symptom Free (Class 0) and Dysthymic States (Class 1). The authors speculated whether these findings reflected "burnt out" clients who no longer experienced the more severe symptomatology of chronic mental illness, but were left with personal and social deficits (Bedford & Presly, 1978). Palmer and colleagues (1981) examined the patterns of self-reported symptoms in 103 chronic psychiatric clients (of which 88% were schizophrenic) from two inpatient wards and reported results similar to Bedford and Presly (1978). Seventy-five percent of the subjects responded according to the hierarchy hypothesis. Most of the subjects not responding according to the hierarchy hypothesis reported delusional symptoms (Classes 3 and 4), but as the authors had previously predicted, did not report neurotic (Class 2) symptoms. These subjects, compared to those who reported delusions and obeyed the hierarchy, were significantly older and had been hospitalized longer. It is speculative whether neurotic symptoms were ever present with these subjects or, if present, did the symptoms become less salient with chronicity?

These studies linking symptoms to diagnosis, outcome, and to a hierarchical model of illness provide little insight into the subjective meaning of symptoms for the chronically mentally ill. Unfortunately, only a few investigators have studied clients' reports of their subjective experiences (Chapman, 1966; Freedman & Chapman, 1973; Tucker, Harrow, Detre, & Hoffman, 1969) and these studies have been primarily limited to cognitive and/or perceptual experiences.

One such study by Chapman (1966), involved the investigation of symptomatic changes in the subjective experiences of 40 schizophrenic inpatients who were in the early stages of their illness. Because of the difficulty clients had in communicating their subjective experiences, Chapman (1966) modified his original structured interview format to one of asking the clients to project their experiences onto the investigator or "an imaginary third person" (p. 228). Subjective experiences were then categorized according to disturbances in speech, attention, memory, motility, perception, and thinking. Chapman (1966) summarized a list of presenting complaints and found that for individual clients, complaints were multiple. Compilation of results for the groups as a whole revealed that almost every type of neurotic symptom was experienced by clients in the early stages of their illness. Of particular interest was that intense anxiety

reactions were reported more frequently than depression. A detailed examination of the clients' subjective experiences revealed that a certain pattern did emerge, although it was not uniform. On the whole, clients did report disturbances in speech, attention, memory, motility, perception, and thinking. Chapman (1966) concluded "that these phenomena may be subjectively experienced long before signs of established disease appear overtly" (p. 249).

A few years after the Chapman (1966) study, Tucker and colleagues (1969) investigated the subjective perceptual experiences of 73 inpatients, 23 of which were schizophrenic, and 50 of which were nonschizophrenic. The Perceptual Experience Inventory was used to assess the perceptual experiences of clients during three time periods: (a) the time period exceeding one year prior to hospitalization (premorbid period), (b) the year prior to hospitalization (morbid period), and (c) the time period since hospitalization. Correlational analysis revealed that perceptual experiences thought to be characteristic of schizophrenic clients were: (a) not found in all schizophrenic clients, (b) also found in nonschizophrenic clients, and (c) not found in a higher proportion of schizophrenic versus nonschizophrenic clients. However, investigators did report a greater frequency of perceptual experiences in chronically anxious clients who were

externally oriented and attributed many of the events in their lives to fate.

Freedman and Chapman (1973) found that schizophrenic clients did differentiate from nonschizophrenic clients on the basis of subjective changes in cognitive and perceptual function. The authors, after administering a standardized interview schedule to 20 newly admitted schizophrenics and 20 nonschizophrenic clients (both inpatients and outpatients) concluded that schizophrenic clients, more frequently than nonschizophrenic clients, reported the following perceptual cognitive changes:

thought blocking which disrupts speech ($p < .02$), mental fatigue ($p < .05$), inability to focus attention ($p < .05$), attribution of impaired concentration to factors other than preoccupation ($p < .01$), language not understood ($p < .02$), more acute auditory perception ($p < .05$), and impaired perception of speech ($p = .05$). (p. 46)

Limitations of this study included small sample sizes and a heterogeneous sample.

In summarizing the previous studies, it is apparent that the study of symptoms has been approached in a variety of ways. Although investigators reported interesting findings, the methodologies of these studies have numerous limitations. First, many studies lacked homogeneous samples. Those that attempted to achieve homogeneity and claimed to have schizophrenic clients in their samples were based on DSM-II diagnostic criteria and/or other diagnostic methods (i.e., New Haven Schizophrenic

Index, Schneiderian First-Rank Symptoms, etc.). In other studies, it was not clear how the diagnosis of schizophrenia was made; thus, many studies did not utilize a systematic approach for diagnosing clients. Some studies had small sample sizes and no control groups. The majority of studies did not measure the clients' subjective experiences of their symptoms. Instead, symptoms were evaluated on the basis of retrospective data obtained from case records, self-report instruments, fixed symptom lists, and even by observers' clinical assessments of clients' behaviors.

A more recent study by Herz and Melville (1980) has evaluated symptoms as perceived by the client. The authors administered a structured interview (based on the Psychiatric Status Schedule, Research Diagnostic Criteria, and clinical experience) to 145 chronic schizophrenic clients (diagnosis based on DSM-II) and 80 family informants. This sample consisted of two groups: (a) group A--99 outpatients in a relatively stable condition from two community mental health centers and 80 family members, and (b) group B--46 inpatients who recently had experienced an acute psychotic episode but were stable enough to participate in the interview. Approximately 70% of the clients from both groups A and B noticed a change in their thoughts, feelings, or behavior that led them to believe they were becoming sick and might

need hospitalization. Thirty percent of the clients reported no such changes. More family members (92.6%) noticed changes in the clients than did the clients themselves. In approximately 66% of the cases, both the client and the family member "agreed that there were early signs of decompensation, indicating a high level of concordance" (p. 802). Herz and Melville (1980) reported that symptoms which occurred for the first time or became worse during the prodromal period before hospitalization were similar for groups A and B ($r = .85$) and for group A family members ($r = .78$). "Becoming tense and nervous was the symptom reported by most patients in both groups" (p. 803). Symptoms mentioned most frequently were non-psychotic in nature such as eating less, trouble concentrating, trouble sleeping, depression, and seeing friends less. Psychotic symptoms mentioned most frequently were feelings of being talked about or laughed at and increased religious preoccupation. Another interesting result was that 60% of the group B clients identified loneliness as a symptom present when they were feeling well.

In response to the question, "What did you do about these changes when you realized they might become serious," nearly 50% of the clients stated they sought professional intervention and 60% of the family members stated they arranged for professional intervention for the client (Herz & Melville, 1980, p. 803). Twenty-six percent of

group A clients and about 33% of group B clients reported "that they did nothing" (p. 803). Finally, less than 4% of all clients took more medication when they noticed that symptoms were becoming more severe.

Herz and Melville (1980) were also interested in whether clients could identify anything that might have led to them becoming upset. Approximately 40% of the clients and family members stated they did not know or attributed the relapse to biological factors. Approximately 33% attributed the relapse to some stressful life event (i.e., marital problems, loss of job, etc.). Only 2% related their emotional problem to stopping their medication or not taking it as prescribed. In conclusion, Herz and Melville's (1980) findings do support that chronically mentally ill clients do associate symptoms with their disease condition.

A Model of Self-Regulation

Leventhal, Meyer, and Nerenz (1980) have proposed a model of self-regulation to explain how chronically physically ill individuals use symptoms in forming perceptions of their illness. The model is based on the following assumptions:

1. An individual is an "active self-regulating problem solver" (p. 10).
2. An individual defines or represents his/her

illness.

3. The individual's representation of his/her illness is based on personal perceptions shaped by mass media, social sources (i.e., family, friends, health care professionals, etc.), past illness experiences, and/or present symptom sensations.

Leventhal's et al. (1980) goals in the development of this model were to understand how people represent the illness threat and how they proceed to cope with this threat.

Leventhal and Nerenz (1983) viewed this regulatory system as "a feedback system comprised of a set of serially arranged components or stages (. . .)". The major components of this self-regulatory feedback system are the symptom experience, the interpretation of symptoms, the coping process which incorporates both objective and emotional factors, and monitoring of the effectiveness of coping mechanisms. Because this model has been applied meaningfully to clients with chronic physical illness, it is thought to have particular merit in this study of clients with chronic mental illness.

Components of Self-Regulation in Chronic Mental Illness

The following model of the components of self-regulation in chronic mental illness has been developed to explain how chronically mentally ill clients use symptoms as signals to assess whether they are getting

better or worse and whether they take actions based on these symptoms as shown in Figure 1 on page 26.

As presented schematically in Figure 1, this model begins by clients' automatically and unconsciously assessing their current status, and comparing this assessment to their standard of well-being. For symptoms to enter the clients' conscious awareness, it is believed that the symptoms must stand out and be discriminated from the usual standard of well-being (O'Connell et al., 1984). Symptoms related to chronic mental illness are detected when the clients experience changes in their standard of well-being and attribute these changes to their mental illness. In this model, all three of these components, standard of well-being, disease related symptoms, and coping with symptoms, may be dependent on feedback and resources from a support system.

According to Cassell (cited in Caplan, 1974), individuals become more susceptible to disease when they "are not receiving any evidence (feedback) that their actions are leading to desirable and/or anticipated consequences" (p. 1). In consideration of Cassell's central thesis, Caplan (1974) believed the harmful effects of absent or confusing feedback from the general population might be reduced if individuals are well-integrated into their own social network. It is this small social network which can provide them with consistent feedback

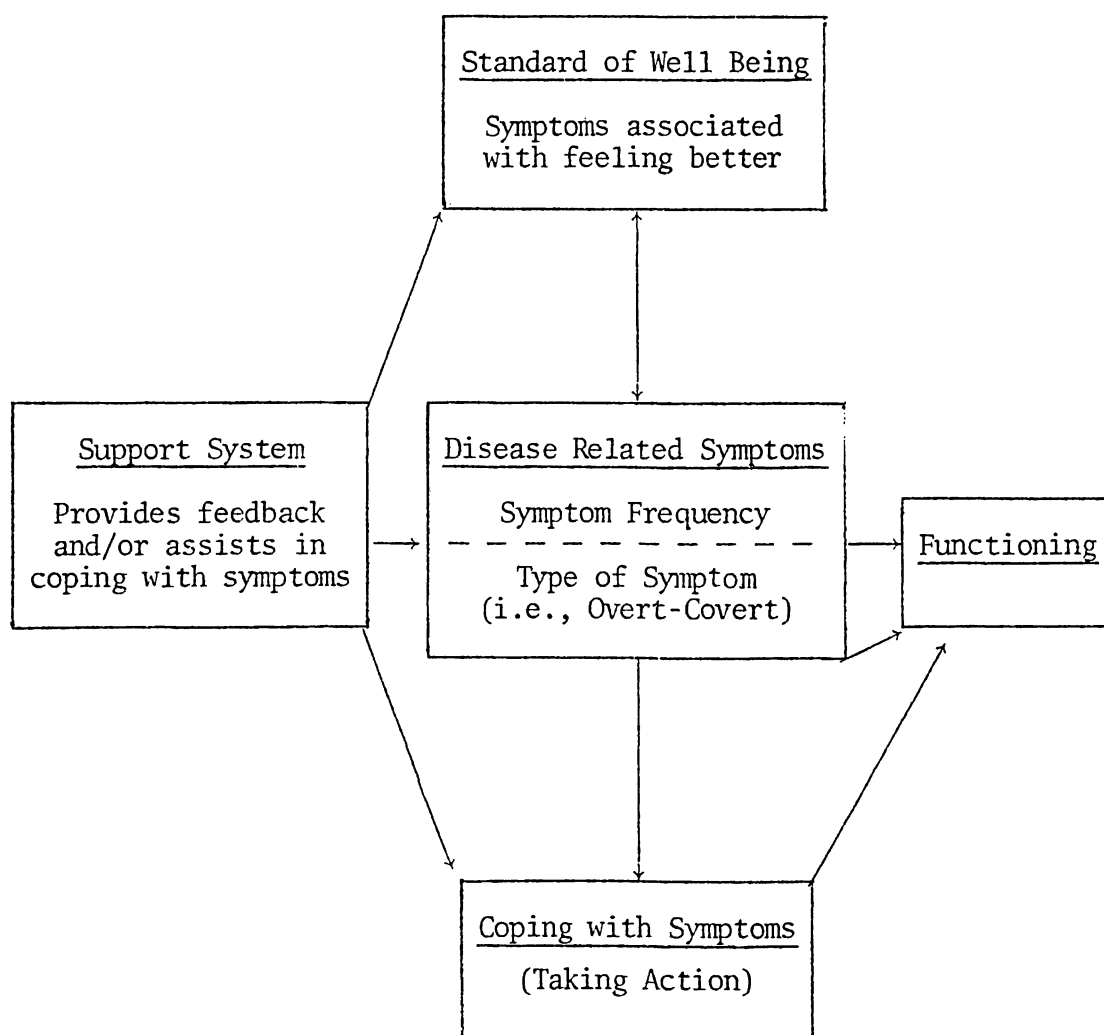


Figure 1. Components of self-regulation in chronic mental illness.

"of what is expected of them, supports and assistance with tasks, evaluations of their performance, and appropriate rewards" (p. 4). For example, with the chronically mentally ill clients, this consistent feedback might simply involve telling them how they are doing, or it might be in the form of more direct assistance, such as giving the clients their medication. Thus, feedback as conceptualized by Cassell (Caplan, 1974), is an important component in the model. This feedback directly influences the clients' standard of well-being, their perceptions of disease related symptoms, and how the clients cope with symptoms. These three components, in turn, all influence the clients' level of functioning.

Purpose of the Present Investigation and Research Questions

The major purpose of the present investigation was to determine whether clients with chronic mental illness are able to identify symptoms they associate with their illness and whether they take action based on their symptom experience. Secondly, the study (a) determined whether clients use feedback from a support person to identify when their symptoms are getting better or worse, (b) explored the clients' perception of the causes, duration, and consequences of their chronic mental illness, and (c) investigated whether clients have

been told how to monitor the symptoms of their illness.

The specific research questions that were addressed were:

Do clients with chronic mental illness use symptoms to monitor when their illness is getting better and/or worse?

Do clients with chronic mental illness use feedback from a support person to tell when they are getting better and/or worse?

Do clients with chronic mental illness take action on the symptoms they identify as indicators of their illness?

Do clients with chronic mental illness get assistance from a support person in taking action in response to symptoms of their illness?

What do clients with chronic mental illness describe as the cause, duration, and consequences of their illness?

Are clients with chronic mental illness told how to monitor when their condition is getting better and/or worse?

CHAPTER II

Method

Design

This study was descriptive in nature and used a semistructured questionnaire to explore the components of the model of self-regulation for the chronically mentally ill.

Setting and Subjects

This study was conducted at a nonprofit community mental health center, which serves a one county catchment area of a midwest state. The community mental health center serves approximately 3,000 active clients, of which 600 clients are served by the Medical Re-evaluation Service. The Medical Re-evaluation Service, which is operated by two psychiatrists and three registered nurses, provides a variety of services such as medication evaluation and supervision, individual and family counseling, and/or financial counseling. Permission to conduct the study in this setting was obtained from the medical director of the mental health center.

Thirty subjects participated in the study. Subjects met the following selection criteria:

1. Primary diagnosis of schizophrenia or other psychotic disorder (schizoaffective disorder) based on DSM-III (1980).
2. Illness has prevailed for greater than a two-year period of time.
3. Onset of illness prior to age 45.
4. Age 18 to 65.
5. Living with family (i.e., spouse--blood relation) or significant other.
6. Client has the following abilities as judged by the principal investigator:
 - a. Oriented to time, place, and person.
 - b. Can stay with subject being discussed, making relevant comments to questions asked.
 - c. Behaviorally capable of sitting throughout the interview.

Measure

Chronic Mental Illness Symptom Interview (CMISI)

This questionnaire was developed from a questionnaire used in studying diabetes (O'Connell et al., 1984) and was adapted for chronic mental illness. The Chronic Mental Illness Symptom Interview (CMISI) contains 15 questions. Several questions addressed whether clients use symptoms as indicators of when their condition is getting better and/or worse. A 46-item checklist, developed from various

sources, was administered to subjects to elicit specific symptoms they associate with changes in their condition. Questions also investigated actions clients take in response to experiencing symptoms associated with their condition. Final questions investigated the clients' perceptions of the causes, consequences, and duration of their illness. The adapted questionnaire was piloted on approximately 10 subjects and revised to insure that items were easily comprehended by subjects and would elicit the kind of information that was being sought by the questionnaire. A complete copy of the Chronic Mental Illness Symptom Interview (CMISI) is found in Appendix A.

Procedure

Clients were screened by using the coding sheet in Appendix A. Those subjects who met the criteria were approached by the investigator at the mental health center on the day of their clinic appointment or in advance by telephone. Subjects were told that a study, investigating how clients view their mental health, their symptoms, and their need for treatment, was being conducted by a nurse. All 30 subjects voluntarily agreed to participate in this study. Subjects were interviewed in a private office at the mental health center with only the principal investigator present. The Chronic Mental Illness Symptom Interview (CMISI) took approximately 30 to 60 minutes to administer.

CHAPTER III

Results

Description of Subjects

The subjects for the study were 30 adult psychiatric clients from a community mental health center of a midwest state. All 30 subjects were diagnosed according to the DSM-III (1980). Sixteen (53.33%) subjects had been diagnosed with paranoid schizophrenia, 8 (26.66%) subjects with undifferentiated schizophrenia, and 6 (20%) with schizoaffective disorder. Of the estimated 600 clients who are served by the Medical Re-evaluation Service, approximately 40% are diagnosed with some form of schizophrenia. Approximately one-third of the subjects screened with schizophrenia were not eligible for study because they were not presently living with a spouse, blood relative, or significant other. All 30 (100%) of the subjects admitted to having a nervous or emotional problem and were being maintained on antipsychotic medication at the time of the interview. The duration of nervous or emotional problems ranged from 2.2 to 42 years with a mean duration of 15.67 years. All 30 subjects were oriented in all three spheres, made relevant comments to questions asked, and were behaviorally capable of sitting

throughout the interview. It was necessary to terminate the interview prior to completion with two subjects and therefore the data from these two subjects were not included in the data analyzed in this study. One of these two subjects denied having a nervous or emotional problem. The other subject was too disorganized to provide relevant and coherent answers to the questions asked.

Demographic information from the 30 subjects revealed that 15 (50%) of the subjects were women and 15 (50%) were men. The subjects ranged in age from 22 to 63 years with a mean age of 37.36 years. Eleven (36.66%) subjects were white and 19 (63.33%) were black. Only 4 (13.33%) were married, 23 (76.66%) were divorced or single, 2 (6.66%) were separated, and 1 (3.33%) was widowed. Twenty-eight (93.33%) subjects were living with a spouse, blood relative, or significant other, and 2 (6.66%) subjects lived in a group home. Subjects' most recent hospitalization ranged from less than one month to 15 years, with 19 (63.33%) subjects having been hospitalized within the last two years.

Identification of Symptoms

The first research question addressed was whether clients with chronic mental illness use symptoms to monitor when their illness is getting better and/or worse. Twenty-seven (90%) of the subjects reported that they could

tell when their nervous condition was getting worse, 2 (6.66%) reported they could not tell, and only 1 subject (3.33%) reported that he/she did not know. The 27 (90%) subjects who identified that they could tell when their nervous condition was getting worse were then asked, "How do you tell when your nervous condition is getting worse?" A total of 51 symptoms were reported. The majority of these were neurotic or stress-related symptoms (i.e., cannot eat/sleep, feel shakey, worry, etc.), while only a small portion of the symptoms offered were psychotic in nature (i.e., hear voices, etc.). Subjects' responses were coded into four symptom categories: (a) somatic, (b) affective, (c) motor, and (d) perceptual/cognitive. One response was not codable. Intercoder reliability was 88.23% (agreement in 45 of 51 responses). Consensus was reached by discussion between the two coders in the six cases of disagreement. The symptom categories were defined as follows:

Somatic Symptoms: Symptoms pertaining to the body and bodily processes;

Motor Symptoms: Symptoms involving movement of voluntary muscles, including verbal and nonverbal;

Perceptual/Cognitive Symptoms: Symptoms involving the process of obtaining, utilizing, and conceptualizing internal and external stimuli;

Affective Symptoms: Symptoms involving emotions,

feelings, or mood.

The frequency of symptoms coded into these four categories is shown in Table 1.

Table 1
Categories and Frequencies for Symptoms Used as
Indicators of Condition Getting Worse

Symptom Category	Frequency
<u>Somatic</u> (i.e., not sleeping and eating, headaches, heart starts racing, etc.)	16
<u>Motor</u> (i.e., start shaking, want to lie down and rest, etc.)	14
<u>Perceptual/Cognitive</u> (i.e., hear voices, start thinking wrong, start getting paranoid, etc.)	12
<u>Affective</u> (i.e., get to feeling bad, worrying, etc.)	9
TOTAL	51*

*11 subjects reported symptoms that were coded into more than one symptom category.

Of the 27 respondents, 11 subjects indicated symptoms that fell into more than one symptom category, thus explaining the greater number of responses than subjects. Subjects mentioned somatic and motor symptoms most frequently as

an indication of their condition getting worse. In fact, 10 of the 14 responses in the motor symptom category reflected an increase in motor function (i.e., "Get shakey." "Legs get jittery." "Get the twitches."). Subjects reported symptoms coded as affective least frequently.

Subjects were also asked. "How do you tell when you are getting better?" All 30 subjects indicated they could tell when they were getting better. Twenty-four subjects gave more than one symptom as evidence of this. Fifteen subjects reported specific changes in behaviors or feelings (i.e., "I sit down more and I sleep better." "I'm outside all the time running." "I usually end up getting a job." "I feel cheerful." "I feel happy." "I'm calm." etc.). Eight subjects explained an improvement in their condition in terms of an absence or improvement of symptoms previously associated with getting worse (i.e., "I don't hear voices." "I'm not depressed." "My light-headedness goes away. . ." etc.). Six subjects stated they felt better in general (i.e., "I just feel better." "I just feel good all the time." "I can feel it within my system." etc.). One subject's response could not be categorized.

The symptoms subjects used as an indication of their condition getting worse were compared with the symptoms subjects used as an indication of their condition getting

better. Eighteen (60%) of the subjects offered symptom responses that showed some congruence between the symptoms they used to monitor when they were getting worse and when they were getting better (i.e., "Hear voices" / "do not hear voices." "Don't know what's going on around me" / "Become more in touch with surroundings and reality." etc.). Twelve (40%) of the subjects offered symptom responses that showed no congruence between the symptoms they used to monitor when they were getting worse and when they were getting better (i.e., "Start shaking; get the twitches" / "I start enjoying life." "Get shakey" / "become more lively and talk to people more." etc.).

In addition to the two open-ended questions utilized to address how subjects could tell if their condition was getting worse and/or better, a 46-item symptom checklist was administered to subjects. The number of symptoms reported by each subject ranged from 2 symptoms to 39, with the mean number of symptoms reported being 22.76, the median being 25, and the standard deviation 9.35. Symptoms reported most frequently (see Table 2 on page 38) were stress-related symptoms, while the symptoms least frequently endorsed (see Table 3 on page 39) were those associated with an acute schizophrenic exacerbation.

Table 2
 Checklist Symptoms Reported Most Frequently by Subjects
 (N = 30)

Symptom	Frequency
Nervousness/tenseness	26
Depression	24
Less active than usual	23
Greater than usual fatigue/no energy	22
Irritability	22
Trouble sleeping	21
Difficulty thinking or concentrating	20
Unable to get going (i.e., getting up/ getting where supposed to be)	20
Difficulty doing your work	19
Avoiding activities with others	19
Religious concerns	19
Hear voices/noises when no one is present	19
Feel people are talking or laughing about you	19
Moodiness	18
Do others tell you that your behavior is strange?	18
Someone trying to hurt you or a family member	18
Confusion	17
Having the same thoughts over and over	17
Trouble eating (too much or too little)	16
Speech problems	16
Harassment from others	16
Get special messages from newspaper, T.V., radio	16

Table 3
 Checklist Symptoms Reported Least Frequently by Subjects
 (N = 30)

Symptom	Frequency
Having trouble getting along with other people	4
Everyone around you seems dead	5
Cannot stop doing the same thing over and over	7
Feel like hurting others	8
Feel like you are not really here	8
Feel like hurting self	9
Being controlled by device (i.e., computer/ electrodes)	9

The second research question addressed was whether clients with chronic mental illness use feedback from a support person to tell when they are getting better and/or worse. Subjects were specifically asked if they, themselves, identified symptoms when their nervous condition gets worse or whether these symptoms were identified by someone else and pointed out to the subjects. Only four (13.33%) subjects reported that symptoms were identified by someone else and pointed out to them. Eighteen (60.0%) of the subjects identified symptoms themselves. Four (13.33%) subjects reported that symptoms were

identified by someone else. Five (16.66%) subjects reported both themselves and others as sources of identifying symptoms. The three (10.0%) subjects who did not identify symptoms indicating that their condition was getting worse were not asked this question.

Action on Symptoms

The next research question addressed was whether clients with chronic mental illness take action on the symptoms they identify as indicators of their illness. Twenty-six (86.66%) of the 30 subjects took some form of action on the symptoms they identified as indicators of their illness and 23 (88.46%) of the 26 subjects stated the action taken helped. The single most frequently taken action, as indicated by 11 (43.30%) subjects was seeking assistance from a physician and/or mental health center. Actions of subjects were categorized according to Stoyva and Anderson's (1982) coping-rest model (see Table 4 on page 41). The coping-rest model consists of two phases: (a) an active coping phase and (b) a rest phase. Each phase consists of physiological, behavioral, and experiential aspects as is shown in Table 4. The authors believe that individuals need to have strategies from both the active coping and the rest phase.

Subjects' responses, regarding the type of action(s)

taken when noticing symptoms, were coded into the four following categories: (a) only active coping, (b) only rest phase, (c) both active coping and rest phase, and (d) do nothing.

Table 4
Active Coping and Rest Phase Model

Active Coping	Rest Phase
<u>Physiological Aspects</u> (moderate to high arousal) (i.e., sympathetic nervous system)	<u>Physiological Aspects</u> (low arousal) (i.e., parasympathetic nervous system)
<u>Behavioral Aspects</u> (active) (i.e., wakefulness)	<u>Behavioral Aspects</u> (quiet, inactive) (i.e., sleep)
<u>Experiential Aspects</u> (verbal report) (sense of effort and/or strong emotions) (i.e., excitement, focused attention, mental effort)	<u>Experiential Aspects</u> (serenity, sense of ease) (i.e., relaxation, absence of striving)

Note. Adapted from "A Coping-Rest Model of Relaxation and Stress Management" by J. Stoyva and C. Anderson, 1982, Handbook of Stress--Theoretical and Clinical Aspects, p. 746. Copyright 1982 by The Free Press.

Intercoder reliability was 90% (agreement in 27 of 30 responses). Consensus was reached between the two coders in the three cases of disagreement. Sixteen (53.33%) subjects were assigned to only active coping. These subjects stated they self-initiated such actions as taking medication, praying, and/or self-rationalizing to cope with symptoms. Six (20%) subjects were assigned to only the rest phase and stated they took such actions as the following: "sleeps," "watch T.V.," and/or "go off and be by myself." Four (13.33%) subjects were assigned to both active coping and the rest phase. Four (13.33%) subjects stated they "did nothing" and were assigned to the do nothing category.

The fourth research question investigated was whether clients with chronic mental illness get assistance from a support person in taking action in response to symptoms of their illness. Only the four subjects who stated they took no action in response to symptoms of their illness were asked if someone else took action for them when symptoms were apparent. Of these 4 subjects, 3 (10%) stated someone else took action for them and 2 (6.66%) of the 3 subjects stated the action taken helped. One subject reported taking no action and having no one else take action; even so, taking no action was described as helpful as the symptoms usually went away with time.

Cause, Consequences, and Duration of Illness

The next research questions investigated what clients with chronic mental illness described as the cause, consequences, and duration of their illness. Subjects were specifically asked, "Why do you think you have this nervous condition?" Responses were coded into three categories: (a) external attribution, (b) self-attribution, and (c) unknown. Data for this question was missing on one subject; therefore, percentages are based on 29 subjects. Intercoder reliability was 96.55% (agreement in 28 of 29 responses) and the two coders reached consensus in the one case of disagreement. Nineteen (65.55%) of the subjects believe the cause of their illness to be explained by external factors (external attribution). Attributing one's illness to drugs, an injury, or fate are examples of responses of external attribution. Three (10.34%) subjects attributed their illness to self (self-attribution). Seven (24.13%) of the subjects simply stated they did not know why they have their nervous condition.

In addition to the open-ended question used to address what subjects believe to be the cause of their illness, the subjects were also asked to respond to a nine-item checklist (see Table 5 on page 44). Generally, subjects believe the source of their nervous condition to

be multicausal. Eighteen of the subjects mentioned stress as the cause of their illness. Seventeen of the subjects believe their illness to be inherited (i.e., "runs in the family") and 16 of the subjects attributed their illness to their home situation. Finally, 13 subjects attributed their illness to "other" causes (i.e., injuries/physical conditions, religion, termination of close relationships, etc.).

Table 5
Cause of Nervous Condition Checklist
(N = 30)

Cause	Frequency
Stress	18
Runs in my family	17
Home situation	16
Job situation	14
Something I've done in the past	14
Other	13
Change of life	10
Drinking or drug usage	8
Pregnancy	2

A nine-item checklist of consequences was administered to subjects to address how they perceived their emotional problems affecting areas of their lives (see Table 6).

Table 6
Consequences of Nervous Condition Checklist
(N = 30)

Area of Life	Frequency
Energy level	22
Work	22
Mood	20
Concentration	19
Memory	18
Sex drive	16
Physical health	13
Anything else	9
Resistance to minor illnesses	3

Most subjects endorsed more than one consequence. "Work" and "energy level" were the two most frequently endorsed categories. Nine of the subjects offered additional comments regarding what effect their illness has had on

their lives. Examples of some of these comments were:

"Sometimes you don't want to talk to people," "My social life," "My relationship with doctors," "It's caused me to smoke a lot and drink coffee," and "I feel I'm closer to God than I've ever been before."

To investigate how chronically mentally ill clients described the duration of their illness, subjects were asked two closely related questions: (a) "How long do you think you will have this illness?" and (b) "How long do you think you will need to be in treatment for your problems?" Responses to both questions were coded into three categories: (a) chronic, (b) temporary or dependent on other variables, and (c) unknown (see Table 7).

Table 7
Perceived Duration of Illness and Treatment
(N = 30)

	Chronic		Temporary/Dependent on Other Factor		Unknown	
	<u>n</u>	%	<u>n</u>	%	<u>n</u>	%
Illness	11	36.66	11	36.66	8	26.66
Treatment	11	36.66	12	40.00	7	23.33

Intercoder reliability for both questions was 93.33% (agreement in 28 of 30 responses). Consensus was reached between the two coders in the four total cases of disagreement.

Such responses as "All my life." "Forever." or "Probably until I die" were typical for those subjects categorized as chronic. Subjects considered to perceive their illness and treatment as temporary or dependent on other factors offered such responses as, "Not very long." "Another four to five months." "Probably until my father dies." or "At least until I get a job or have some friends." Subjects categorized in the "unknown" category simply stated, "I don't know."

The number of subjects in the categories in Table 7 seemed evenly dispersed. A logical question is whether the same subjects who perceived the duration of their illness as chronic, temporary, or unknown, perceived the duration of their treatment the same. Responses of how clients perceived the duration of their illness and treatment were compared within subjects. A total of 18 (60%) subjects perceived the duration of their illness and the duration of their need for treatment the same (see Table 8). on page 48). Of the 18 subjects who were congruent, only 7 (23.33%) subjects perceived their illness and their need for treatment as chronic.

Table 8
 Distribution of the 18 Subjects Indicating Congruence
 between Perceived Duration of Their Illness and
 Perceived Duration of Their Treatment

Duration	Frequency	%
Chronic	7	23.33
Temporary/Dependent on Other Factors	7	23.33
Unknown	4	13.33
TOTAL	18	60

Monitoring of Illness

The final research question investigated whether clients with chronic mental illness are told how to monitor when their condition is getting better or worse. In response to the question, "Has anyone ever told you how to identify when you're getting better or worse?", seven (23.33%) subjects stated "yes" and 23 (76.66%) subjects stated "no."

CHAPTER IV

Discussion

This study focused on the symptom beliefs of chronic schizophrenic clients. Leventhal, Meyer, and Nerenz (1980) reported that symptoms are crucial to clients' perceptions of their illnesses and the actions they choose to cope with these illnesses. A model of the components of self-regulation, based on the work of Leventhal, Nerenz, and Straus (1980), was developed to explain how chronically mentally ill clients use symptoms to assess whether they are getting better or worse and whether they take actions based on these symptoms. Utilizing a semistructured questionnaire, symptom monitoring and usage were investigated in 30 subjects diagnosed with some form of schizophrenia according to the DSM-III (1980). Twenty-seven (90%) of the subjects reported using symptoms as indicators of when their condition was getting worse. The majority of symptoms were neurotic or stress-related symptoms, while only a small portion of these symptoms were psychotic in nature. A total of 51 symptoms were categorized into the four following areas: (a) somatic, (b) affective, (c) motor, and (d) perceptual/cognitive. Sixteen symptoms were categorized as somatic, 14 were motor, 12 were

perceptual/cognitive, and 9 were affective. Perhaps somatic and motor symptoms were mentioned with greater frequency because they are more concrete and/or more socially acceptable.

All 30 subjects responded to a 46-item symptom checklist. Again, the stress-related symptoms were endorsed more frequently than those symptoms generally associated with an acute schizophrenic exacerbation. All 30 subjects reported using symptoms as indicators of when their condition was getting better; these responses consisted of: (a) specific changes in behavior or feelings or (b) absence or improvement of symptoms previously associated with getting worse, or (c) statements of feeling better in general. Eighteen (60%) of the subjects offered symptom responses that showed some congruence between the symptoms they used to monitor when they were getting worse and when they were getting better. The majority of subjects, rather than relying on feedback from a support person to help monitor their illness, stated they identified symptoms indicating they were getting better and/or worse themselves. Action was taken on symptoms used as indicators of their illness by 26 (86.66%) of the 30 subjects. Actions taken were categorized into two phases: (a) the active coping phase and (b) the rest phase. Both phases consist of physiological, behavioral, and experiential elements. The elements of the

active coping phase include activities utilizing high energy, whereas the elements of the rest phase include quiet, relaxing activities. Most of the actions taken by subjects were categorized in the active coping phase rather than the rest phase. While the majority of subjects reported using symptoms to monitor their illness and taking action based on these symptoms, only seven (23.33%) stated that had been told how to monitor when their condition was getting better or worse.

Most of the subjects believed the source of their illness to be multicausal and the majority attributed their illness to external factors such as drugs or injuries. Subjects indicated that they perceived their illness to have an effect on numerous areas of their lives, with "work" and "energy level" being the areas indicated by most subjects. Slightly more than one-third of the subjects believed they will have their mental illness the rest of their lives, approximately one-third believed their illness to be temporary or dependent on other factors, and slightly less than one-third stated they did not know how long they would have their illness. These same findings were found in terms of how long subjects believed they would need treatment. Sixty percent of the subjects showed congruence between how long they thought they would have their illness and how long they thought they would need treatment. Interestingly, only

seven (23.33%) of these subjects viewed their illness and treatment as chronic.

The fact that almost all subjects use symptoms to monitor when their illness is getting better and/or worse seems to imply that mental health clients are using an implicit symptom belief system. This means that regardless of what mentally ill clients are told about their illness by health professionals, clients seem to have their own beliefs about symptoms and their association with illness. Furthermore, clients are taking action based on their symptoms. These may or may not be congruent with their treatment recommendations. A limitation of this study is that the reliability of the subjects' belief systems is unknown. A follow-up study with this sample might be helpful in determining how many of these subjects would report the same symptom indicators. It is also unknown at this point whether these are the symptoms clients use in daily life. It might be feasible to suggest that clients keep a diary of symptoms that indicate when their illness is getting better and/or worse to monitor whether symptom beliefs are actually used in daily life. It is interesting that approximately 40% of the subjects showed incongruence between the symptoms used to monitor when they were getting worse and the symptoms used to monitor when they were getting better. It is unclear what this means. Perhaps clients see a dichotomy

between symptoms associated with feeling better and symptoms associated with feeling worse. Future research might address the outcome of clients who see a dichotomy between symptoms associated with getting worse and better as compared to clients who show congruency between these symptoms.

It is noteworthy that clients diagnosed with schizophrenia reported neurotic or stress-related symptoms more often than psychotic symptoms. For example, the majority of subjects mentioned depression, trouble sleeping, and difficulty thinking or concentrating, all symptoms that the general population experience under stress. This finding was further supported by responses to the symptom checklist as the most frequently endorsed symptom was nervousness and tenseness. This finding was similar to those reported by Herz and Melville (1980) and Morell, Levine, and Perkins (1982). The fact that stress-related symptoms were reported more frequently than psychotic symptoms may indicate that as the duration of the illness increases, the subjects may have adjusted to or accepted the more severe symptoms; that is, their standard of well-being changes and, therefore, clients limit themselves to struggling with the stresses of everyday living. This indicates that clients' symptom beliefs may change as the duration of their illness increases and influences their standard of well-being. A longitudinal study might

compare acute and chronic schizophrenics to evaluate whether the report of the less severe symptoms is a function of change over time

Leventhal, Meyer, and Nerenz (1980) believe that an individual's representation of his/her illness is based, in part, on personal perceptions shaped by significant others; therefore, the frequency and type of feedback offered to subjects about their symptoms by significant others should influence their representation of their illness. Interestingly, every subject lived with a significant other, but less than one-third of the subjects used feedback from a support person to assist them in telling when their illness was getting better and/or worse. This may imply that family members (a) do not see the importance of offering feedback on symptoms, (b) simply ignore or do not mention the symptoms to the subjects, and/or (c) are not really aware of symptoms. For example, the symptom and lifestyle patterns of subjects may have become so well-integrated into the family system that they are no longer really noticed and therefore not commented on by family members. Family members may not be aware of clients' symptoms simply because clients choose to conceal their symptoms. Another implication may be that clients are getting feedback but (a) are not using feedback and, instead, are relying on their own symptom self-monitoring system, or (b) are not

willing to acknowledge the feedback they are getting or the dependency on that feedback. This might be supported by Herz and Melville (1980) who found that family members were more likely to notice early signs of relapse than the clients themselves. Since Cassell (cited in Caplan, 1974) linked confusing or absent feedback to an increased susceptibility to disease, further research exploring this postulate should investigate how family members give feedback and offer support to clients.

Symptom frequency, the type of symptoms, and feedback from a support system are all factors thought to have an influence on the actions clients take to cope with their illness. Twenty-six (86.66%) of the subjects all took some type of action. Comparing the actions subjects took in this study to the actions taken by subjects in the Herz and Melville (1980) study revealed that: (a) 30% of the subjects sought professional intervention as compared to 50% of the subjects in Herz and Melville's investigation, (b) 13.3% of the subjects stated they did nothing as compared to Herz and Melville's report of 26% and 33% of subjects who stated they did nothing in groups A and B, respectively. The different percentages in the present study and Herz and Melville's (1980) might be attributed to differences in samples. For instance, fewer subjects in the present investigation sought professional help and did nothing when noticing they were getting sick,

assistance clients get from support systems in taking action when noticing symptoms; a limitation of this study was that only subjects who reported "doing nothing" were asked if someone else took action for them when symptoms were noticed. It may provide a broader data base to ask this of all subjects.

A finding similar to Herz and Melville (1980) was that most of the subjects reported the cause of their illness to be related to external events. This suggests that clients feel they have little control over their illness and may assume a "that's the way it is" attitude. These external attributions may have been strengthened by the health care system itself. Clients are often given messages that they do not have the ability to take control of their lives, and in subtle ways, are encouraged to become dependent on the health care system.

Subjects generally perceived their illness affecting numerous areas of their lives. The fact that one subject spontaneously mentioned feeling "Closer to God than I've ever been before" implied that all subjects did not consider the effects of their illness to be negative. Data on perceived consequences of illness were limited to a nine-item checklist. The open-ended question in the interview protocol was not clear to subjects and the responses could not be analyzed. A future study needs to allow subjects to respond more spontaneously.

It is interesting that in a sample of schizophrenic subjects, all considered to have a chronic mental illness, that only slightly more than one-third of the subjects perceived their illness and their need for treatment as chronic. This is a surprising finding which may be representative of other schizophrenic populations or may be a function of the small sample size used in the present study ($N = 30$).

It is noteworthy that while 27 (90%) subjects used symptoms to monitor when their illness was getting worse, and all 30 (100%) subjects used symptoms to monitor when their illness was getting better, that only 7 (23.33%) subjects reported that someone had told them how to monitor when they are getting better or worse. These results may imply that health professionals do not really consider clients' reports of subjective experiences important and, thus, have not introduced clients to the idea of monitoring their symptoms, but even so, clients continue to maintain an implicit symptom belief system. It is apparent that health professionals need to give more credence to clients' symptom reports.

Obviously, a great deal of research is necessary before clients' reports of symptoms can be used to guide interventions. Further research should investigate the accuracy of symptoms reported by chronically mentally ill clients, the types and the effectiveness of actions taken

by clients to cope with their symptoms and, finally, whether clients who accurately report symptoms and utilize effective actions have a better outcome. Findings from this type of study may lay the groundwork for the development of future client and family teaching programs.

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APPENDIX

APPENDIX A

CHRONIC MENTAL ILLNESS SYMPTOM INTERVIEW

9. Physical problems or diseases:

Questionnaire

1. Do you have a nervous/stress-related problem?

If yes, what do you call this problem?

If "no," generally people who come here for treatment have been diagnosed as having a nervous/mental problem. What is your thinking on that? (Stop interview if client still says "no" to this question.)

2. About how long have you had nervous/emotional problems?

3. I'm going to ask you to think back to when you first suspected something was not quite right with you or your life. When your problems first began, did you suspect you were having problems with your thinking/ nerves?

- a. _____yes
b. _____no
c. _____don't know

If yes,

- 3.1 What led you to think that?

4. What was your reason for seeking help?

5. Do you think you can tell when your nervous condition is getting worse? (Signs, symptoms)

- a. _____yes
b. _____no
c. _____don't know

If you don't know,

- 5.1 Did you ever think you could tell?

- a. _____no
b. _____never
c. _____yes. Why don't you think so now?

If no or never,

- 5.2 Has it ever happened that someone else has pointed out that you're getting worse?

If yes,

- 5.3 How do (did) you tell when your nervous condition is getting worse?

- 5.4 Do you identify this yourself or does someone else, at times, point this out to you?

6. Here are some (additional) signs that other people have told us they use to tell if there are changes in their thoughts or behaviors. (See below)

- ___ ___ 1. Difficulty doing your work.
- ___ ___ 2. Greater than usual fatigue/no energy.
- ___ ___ 3. Headache.
- ___ ___ 4. Irritability.
- ___ ___ 5. Lapse in memory.
- ___ ___ 6. Difficulty thinking or concentrating.
- ___ ___ 7. Moodiness.
- ___ ___ 8. Nervousness/Tenseness.
- ___ ___ 9. Do others tell you that your behavior is strange?
- ___ ___ 10. Heart pounding.
- ___ ___ 11. Speech problems.
- ___ ___ 12. Unable to get going (getting up/getting where you're supposed to be).
- ___ ___ 13. Trouble eating (too much or too little).
- ___ ___ 14. Sexual concerns.
- ___ ___ 15. Have special mental powers.
- ___ ___ 16. Something controlling or putting thoughts in head.
- ___ ___ 17. Someone trying to hurt you or a family member.
- ___ ___ 18. Depression.
- ___ ___ 19. Confusion.
- ___ ___ 20. Trouble talking so that people understand you.
- ___ ___ 21. Feel that there is a pressure in your head.

- ___ ___ 22. Being controlled by a device (computer; electrodes).
- ___ ___ 23. People are talking or laughing about you.
- ___ ___ 24. Avoiding activities with others.
- ___ ___ 25. Feel like something terrible or strange is happening to your body.
- ___ ___ 26. Things look funny or unusual.
- ___ ___ 27. Everyone around you seems dead.
- ___ ___ 28. Trouble sleeping (too much or too little).
- ___ ___ 29. Nightmares.
- ___ ___ 30. Less active than usual.
- ___ ___ 31. More active than usual.
- ___ ___ 32. Legal problems or trouble with police.
- ___ ___ 33. Harassment from others.
- ___ ___ 34. Feel like hurting self.
- ___ ___ 35. Feel like hurting others.
- ___ ___ 36. Having the same thoughts over and over.
- ___ ___ 37. Having trouble getting along with other people.
- ___ ___ 38. Cannot stop doing the same thing over and over.
- ___ ___ 39. Everyone can hear your thoughts.
- ___ ___ 40. Feel like you are not really here.
- ___ ___ 41. Get special messages from newspaper, TV, radio.
- ___ ___ 42. See things that others do not see.
- ___ ___ 43. Religious concerns.
- ___ ___ 44. Feel you are losing control of your thoughts/feelings.
- ___ ___ 45. Hear voices/noises when no one present.
- ___ ___ 46. Other (specify)_____.

- 7 Which of the signs that you have just mentioned do you pay most attention to as an indication your thinking is becoming disordered or your behavior unusual for you?
8. What do you do when you notice _____?
Symptom
- 8.1 If respondent says they do nothing, ask:
Does someone take action for you when noticing this?
9. Does that help?
10. Has anyone ever told you how to identify when you're getting better or worse?
- a. _____yes. How?
- b. _____no
- 10.1 If yes, Who?
11. How do you tell when you're getting better?

12. Why do you think you have this "nervous condition?"

Some people think it's due to:

- runs in my family.
- home situation.
- job situation.
- stress (specify)_____.
- something I've done in the past.
- drinking or drug usage.
- change of life (specify)_____.
- pregnancy.
- other.

12.1 What is the most important reason?
(put asterisk *)

13. Do you think your emotional problems and the treatment have affected any areas of your life?

13.1 Some people have said their emotional problems have affected the following areas. Is this true for you?

- physical health.
- work.
- energy level.
- sex drive.
- memory.
- mood.
- concentration.
- your resistance to minor illnesses (e.g., colds, flu).
- anything else.

14. How long do you think you will have this illness?

15. How long do you think you will need to be in treatment for your problems?